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Abstract

The current study reviews practice patterns of birth and children's hospitals who provide feeding assessment, parent education, and follow-up to parents of newborns with cleft lip/palate. The intent of the study was to determine whether any formal standard of care exists regarding management of early feeding issues for newborns with cleft lip/palate. A complete survey consisting of care related to newborns with cleft lip/palate was sent to approximately 300 cleft palate teams recognized by the American Cleft PalateCraniofacial Association. The online surveys were completed by 33 international cleft palate teams. Results indicated that birth hospitals and cleft palate teams lack a standard of care and even specific patterns of care. Results of the study suggest a need to improve quality of care across birth hospitals and cleft palate teams. There appears to be a great need for guidelines and standards based on current research upon which to model their practices.

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Dedicated to my dad and mom
for their faithful love, support, and encouragement,
and for always reminding me that with God, nothing is impossible.

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Chapter I – Introduction

Cleft lip and/or palate is the most common congenital craniofacial malformation affecting one in every 700 live births (Mitchell & Wood, 2000; American Cleft Palate Craniofacial Association, 2003). There are several different types of clefts that can occur during development. Infants can have an incomplete cleft of the lip (unilateral/bilateral), and this may have little or no effect on feeding. The second type of cleft is a complete cleft of the lip and primary palate (unilateral/bilateral). The third type of cleft is an incomplete cleft palate, and the final type is a complete cleft palate. Infants may also have any combination of these different types of clefts (Kummer, 2001).

Issues related to feeding will vary depending on the type and severity of the cleft (Kummer, 2001). Feeding problems that will typically occur with cleft lip/palate are poor oral intake and lengthy feeding times resulting from poor sucking, nasal regurgitation, choking, gagging, and excessive air intake (Clarren, Anderson, & Wolf, 1987). More severe problems involve difficulty maintaining airway protection and poor weight gain which may necessitate an additional surgical procedure to establish enteral feeding (Kummer, 2001).

Given the feeding and subsequent growth issues of the infant with cleft palate, parents are confronted with difficult emotional and care issues at the time of birth. The infant's birth hospital is where the parents have the first opportunity to receive information regarding the care and feeding of their infant with cleft lip/palate. Whether or not the birth hospital nursery can provide specialized care may be influenced in part by the levels of neonatal care that it provides. Nurseries are ranked by levels depending on the types of services that can be provided. In a Level 1 newborn nursery, they are prepared to care for healthy term newborns who are physiologically stable. Level 2 nurseries have medical professionals who are capable of caring for infants who have physiologic immaturity and may require brief periods of ventilation. Level 3 nurseries are prepared to provide comprehensive care for infants who are less the 28 weeks gestation and can provide access on-site to a full range of pediatric subspecialty professionals including services for children with cardiovascular conditions. (Stark, 2002)

Feeding intervention is one of the primary concerns for the new parents, however, there is little research regarding the type of support and help that parents receive in the birth hospital and/or with the cleft palate team (Oliver & Jones, 1997). While medical organizations and associations recognize the importance of these issues, few specifics are available that indicate which healthcare professional has the lead role in feeding intervention and what the expected standard of care is exist (American Cleft PalateCraniofacial Association, 2000). In the American Cleft Palate - Craniofacial Association's document, "Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Anomalies", they state that it is the responsibility of the nurse to monitor nutrition and weight gain and provide educational programs for hospital personnel and primary care providers regarding feeding in the first few weeks of life, preferably the first few days (American Cleft Palate-Craniofacial Association, 2000).

The American Speech and Hearing Association (ASHA) has also outlined knowledge and skills expected of speech-language pathologists in regards to swallowing and/or feeding disorders. For working with the pediatric population, ASHA states that speech-language pathologists should be able to demonstrate understanding of etiologies, nutritional knowledge, be aware of risks for aspiration, be able to provide instrumental assessment, and carry out treatment for these disorders (ASHA, 2001). While these general skills are all necessary for treating patients with swallowing disorders and feeding problems, more specific information is necessary. While specific facilities and cleft palate teams have standards of care for feeding at their facility, a best practice standard of care across all facilities is lacking. Given the incidence and prevalence of cleft lip/palate and related health issues, it is imperative to understand how current practices affect care. This would include variations of the present level of care, as well as, what an ideal standard of care or best practice might be. The cleft lip/palate population has unique feeding issues, and so for professionals to be able to provide the best service, there is a great need for increased knowledge, widespread publication of this knowledge, and then adaptation of present practices based on new evidence and information. Since no clear statement of best practice or recommended standard of care exists, the purpose of the present study is to determine what, if any, standard of care exists across facilities for infants with cleft lip/palate in regards to feeding.

The results of this research will attempt to answer the following specific questions:

1. Is there a uniform standard of care or best practices provided by hospital nursery staffs and cleft palate teams regarding feeding issues of the infant with cleft lip/palate of any type?
2. Do practice patterns differ by hospital size, location, and/or nursery level?

3. Is there a uniform standard of care provided by cleft palate teams?
4. What are the strengths of teams at present in caring for infants with cleft lip and/or palate?
5. What do teams identify as weaknesses or obstacles to providing optimal care for infants with cleft lip and/or palate?

Chapter II- The Review of the Literature

Quality of Care and Best Practices:

There has been a recent movement in medicine to put greater emphasis on quality of care and to offer strategies to help medical organizations improve care. The Institute of Medicine recently defined quality as "those health services for individuals and populations [that] increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (Eagle, Garson, Beller, & Sennett, 2003, 196). Though medical professionals strive to improve care, intentions alone do not cause change. Medical professionals must be able to self-reflect, evaluate current practice, and change their practices based on research and evidence. Though great achievements and improvements have been made, the public recognizes that despite these positive strides, quality of care can and should be improved (McNeil, 2001). Because it is a broad and variably defined issue, there is limited research on what constitutes "quality of care". In fact, clinical care can only be improved when the evidence base for a particular population is strengthened and expanded (Fernandopulle, Ferris, Epstein, McNeil, Newhouse, Pisano, & Blumenthal, 2003). For quality to improve across all populations, there is a need for specialized societies and organizations to expand the research in their specific areas and build the clinical leadership necessary to support the changes and implementation of the evidence-based practice (Eagle et al., 2003).

Cleft Lip and/or Palate and Related Issues:

Cleft lip/palate is one of the most common congenital anomalies, affecting one in every 700 live births (Mitchell & Wood, 2000; American Cleft Palate Craniofacial Association, 2003). Given the large numbers and health concerns of newborns with cleft lip/palate, it should follow that best practice standards would be well established for this population. In fact, this is not documented. The diagnosis of cleft lip/palate involves not only the physical challenges but myriad family and feeding care issues as well. When a newborn is diagnosed with cleft lip and/or palate, the parents immediately go through a period of shock, grief, denial, anger, and great anxiety (Young, O'Riordan, Goldstein, & Robin, 2001). In the midst of trying to cope with their own feelings and fears, the parents must comprehend and apply complex information on how to provide care for their child. A primary concern for parents of an infant with cleft lip and/or palate is how to successfully feed their child (Young et al., 2001). The initial care of these newborns "focuses on problems associated with feeding and weight gain" and emphasizes intervention to attain healthy growth (Balasubrahmanyam, Scherer, Martin, & Michal, 1998, 146).

Feeding can be a problem for many newborns, but there are specific and unique issues that affect the population with cleft lip/palate. These include poor oral intake, poor suction, lengthy feeding times, nasal regurgitation, choking, gagging, and excessive air intake that are a result of structural abnormalities (Clarren, Anderson, & Wolf, 1987). The more severe problems involve difficulty maintaining airway protection and poor weight gain which may require that the child undergo an additional surgical procedure to establish enteral feeding (Kummer, 2001).

Feeding and Swallowing in Infants:

Normal swallowing is often described as four different phases: the oral preparatory, oral, pharyngeal, and esophageal. The oral preparatory phase begins with the intake of food into the oral cavity and the formation of the bolus. In infants, bolus formation is minimal because of the thin liquid texture that infants take, and this phase is generally considered to be when the infant latches on to the nipple. Lip closure is also needed during this phase to prevent liquid from spilling out of the mouth and the bolus is held in the oral cavity, preventing any premature spillage into the pharynx. (Arvedson & Brodsky, 2002)

In the oral phase, the tongue begins to manipulate the bolus and propel it in a posterior direction toward the pharynx. Elevation of the soft palate also occurs during this phase preventing nasal regurgitation. As the food is propelled toward the base of the tongue, the pharyngeal swallow is triggered. (Arvedson & Brodsky, 2002)

The pharyngeal phase begins with the voluntary initiation of the swallow and continues with the opening of the upper esophageal sphincter (UES). As the food is propelled into the pharynx by the tongue, respiration ceases. Laryngeal elevation and anterior movement of the hyoid bone bring the larynx under the base of the tongue which in turn causes the epiglottis to retrovert directing food into the pyriform sinuses. From the pyriform sinuses, the food moves into the UES opening just as the airway should be completely protected by the complete adduction of the true and false vocal folds. (Arvedson & Brodsky, 2002)

Finally, there is the esophageal phase which consists of the peristaltic wave which is an autonomic function. This peristaltic wave carries the bolus through the esophagus and ends when the food passes into the gastroesophageal junction into the stomach. (Arvedson & Brodsky, 2002)

Typical infant feeding is often thought about as two different tasks: suckling, the action that draws the milk into the mouth, and swallowing, which moves the milk from the oral cavity through the pharynx to the stomach (Clarren et al., 1987). During the oral phase of swallowing, when infants feed from a nipple, they first suck from the nipple by repeatedly pumping the tongue to express milk with each pump of the tongue. To accomplish this motion, the infant uses the hard palate to help stabilize the nipple, allowing the tongue to pump. Each pump expresses milk which gathers in the valleculae until an adequate sized bolus has collected there. When a certain volume is achieved, the pharyngeal swallow triggers. As the pharygeal swallow triggers, the tongue base directs the food into the pharynx, and the epiglottis retroverts to provide laryngeal protection. At this point the tongue base retracts and the pharyngeal walls contract creating increased pharyngeal pressure. The pharygeal walls continue to contract creating increased pressure in a downward wave, which causes the movement of the bolus into the esophagus (Logemann, 1998).

Infants who have a cleft lip/palate typically experience difficulty with the oral phase of the swallow while the pharyngeal and esophageal phases are less affected (Clarren et al., 1987). The structural abnormalities of the oral cavity cause feeding problems in the oral phase. Depending on the severity of the cleft, the infant may have difficulty compressing the nipple against the hard palate and be unable to create negative intraoral pressure to allow milk to be drawn in.

Infants utilize different techniques when feeding depending on whether they are being breast or bottle-fed. When typically developing infants are breastfeeding, they use negative intraoral pressure to position and stabilize the nipple, and then they use the tongue and palate to strip the milk from the breast. When bottlefeeding though, they rely more on their gums to stabilize the nipple and create negative intraoral pressure to pull milk from the bottle (Clarren et al., 1987). Since successful breastfeeding is more dependent upon the infant using the tongue and palate to stabilize and compress the nipple, this method may be difficult or impossible for some infants with cleft lip/palate.

In typically developing children, the hard palate and velum serve as a protective barrier between the oral and nasal cavities, but in infants with clefts, this barrier may be reduced or absent resulting in nasal regurgitation (Kummer, 2001). This can cause discomfort for the infant and can "affect the coordination of breathing and feeding" (Kummer 2001). The combination of these issues can cause problems with airway protection because of the disorganization of the movements and timing in the oral cavity.

Even though the structural abnormalities for infants with cleft lip/palate often negatively impact the oral preparatory and oral phases of swallowing, there are feeding methods that make oral feeding possible for infants with cleft lip/palate. Some general guidelines such as upright positioning, neutral midline posture, and monitoring flow rate may prevent discomfort, create less work for the infant to get the liquid and to slow the flow. (Arvedson & Brodsky, 2002) Another general guideline is to limit feeding time to 20-30 minutes and feed more frequently so that the parent and child do not become frustrated and exhausted at one time. Bottles have also been modified in different ways to overcome some of the problems that infants with cleft lip/palate face. Some modifications that are often made to bottles is softer nipples, longer nipples, variable flow rate nipples, and flexible plastic squeeze bottles. Some commonly used bottles in the United States that each have a different combination of these modifications are: Mead-Johnson, Haberman Feeder, Ross, and Pigeon. Other products are also available but are used less often. All of these modifications have aided in making oral feeding less frustrating and more beneficial for the infant with cleft lip/palate. (Arvedson & Brodsky, 2002)

Apart from the direct problems associated with feeding these infants, there can be secondary problems, such as, poor weight gain, excessive energy expenditure during feeding, lengthy feeding times, discomfort with feeding, and stressful feeding interactions between the infant and caretaker (Carlisle, 1998). These issues not only affect the newborn, but they also have an impact on the parents and family. It is important that professionals validate and recognize that the concerns of the mother are real and very urgent (Curtin, 1990). The reason for parents' concern is the growth, nutrition, and health of their baby, but other issues exist.

Parents, especially mothers, deal with multiple losses when their newborn is diagnosed with a serious medical condition. In the case of cleft lip/palate, mothers are dealing with the loss of that bonding time during feeding, especially if they are expecting to breastfeed. Even those mothers who do not plan to breastfeed probably expect feeding to be a time of bonding between the mother and child, but instead feeding is often a time of stress and frustration. To help alleviate and deal with many of these concerns and problems, it is important to have a professional educated in feeding newborns with cleft lip/palate immediately involved in the intervention.

Standard of Care:

Considering the prevalence of feeding problems, the significant impact of the feeding problems, and the concerns of parents of these infants, it is important that professionals evaluate present care for this population, identify barriers, and devise strategies to improve care. In a recent survey examining the concerns of parents of a newborn with cleft lip/palate, the top stated concerns included feeding methods and home management of feeding. In this same study, approximately 95-97%of parents thought it was critical to discuss bottle-feeding difficulties and to have a demonstration of breast and bottle-feeding (Young et al., 2001). Parents also wanted to know about special nipples and feeders that were available for their children. Only 55% of those surveyed recalled that the professional responsible for feeding intervention actually demonstrated feeding, and only 69% perceived that the professional discussed feeding difficulties and how to deal with them (Young et al., 2001). Though some concerns were addressed and education was given at the birth hospital, many unanswered questions, concerns, and dissatisfaction regarding services remained.

Oliver and Jones (1997) documented that parental concerns regarding feeding did not end when the parents left the hospital. In this study, 84% of parents surveyed expressed concern about their child's feeding when they went home from the hospital (Oliver and Jones, 1997). Oliver and Jones (1997) reported that parents felt that they received support but needed more practical help for daily life.

In a study by Young et al. (2001), one parent documented her frustrations and concerns about feeding intervention:

> "My main problem was feeding the baby. I really needed help with that. No one on staff was well trained in that area. We left the hospital 2 days later and I know he was not feeding correctly. Twenty-four hours after we got home he was hospitalized for dehydration. Mothers need to be taught how to feed these children before they are sent home."
> (Young et al., 2001, 57).

Not only do studies show that parents are frustrated by the types of intervention they receive, but some studies show that parents are frustrated with the timing of services. Parents felt they needed earlier intervention from the team as earlier intervention provides help to families when their needs are greatest and helps them adapt in the first few months of life (Pelchat, Bisson, Ricard, Perreault, and Bouchard, 1999).

Other studies, such as this one by Grow and Lehman (2002) provide some insight as to why parents have frustrations with the feeding intervention they receive. Grow and Lehman found that 56% of institutions, including primary care physicians, family practice, internal medicine and pediatric specialties, had no guidelines for caring for children with cleft when they are initially diagnosed (Grow and Lehman, 2002). The studies examining parental concerns underscore the need to improve the standard of care for these infants.

The Need for Specific Feeding Guidelines

In 1619, Fabricus of Aquapendente noted that infants with cleft palate were unable to feed, and therefore many died of malnutrition (Jones, 1988). Over the past three centuries, great improvements in feeding methods have been developed to avoid such devastating results of clefting in children. The parents are reliant upon the recommendations and counsel of professionals to help them establish which feeding technique is most beneficial and effective for their child. Care for infants with cleft lip and/or palate has improved over time, but the literature documenting parental concerns suggests additional changes are needed. Care and feeding of the infant with cleft lip/palate should be guided by sound evidence based practices. Though professional societies have offered general hospital and team care, there is an apparent need for more research to develop specific and consistent guidelines for these infants and their families.

Current Challenges

One of the current challenges to improving care is a lack of evidence regarding appropriate recommendations and interventions. Variability among cleft palate teams and birth hospitals provides an opportunity to learn from institutions and study how successful they are, what makes their interventions successful, and investigate how other teams can learn from each other and employ successful interventions with their own patients (Fernandopulle et al., 2003). After gathering the evidence and information, the next challenge is how to select best practice methods, how to motivate professionals for change based on new evidence when they may already be experiencing some degree of success. Apart from the challenge of motivating professionals to change their current ideologies, there are the ongoing challenges of training healthcare providers every time new evidence impacts practice, the cost of continuing education, and the necessity for regular evaluation and assessment of practice and identification of future research needs (Fernandopulle et al., 2003).

The goal of this research is to gain new knowledge that can be applied to improve the lives of infants with cleft lip/palate. Research is the foundation upon which practices and interventions must be built because "uninformed action carries the risk of inefficiency and perhaps even harm"

(Fernandopulle et al., 2003). Current practice is already improving lives, but it requires ongoing research and education to provide even better services to the infants with cleft lip/palate and their families.

Chapter III - Methodology

Type of Study

This was a descriptive study that utilized a survey instrument that was developed to gather information regarding feeding evaluation, intervention, and follow-up care for newborns with cleft lip and/or palate.

Subjects

The population originally consisted of approximately 300 national and international cleft palate and craniofacial teams, but only 33 teams completed the survey. All of the centers that were surveyed are operating under the guidelines of the American Cleft Palate and Craniofacial Association.

It was intended for the surveys to be completed by the clinical leaders/coordinators of each center. The coordinators' and clinical leaders' professional roles on the team varied among centers and included nurses, physicians, speech-language pathologists, dental hygienists, and administrators.

Procedure

The survey and project was sent to the American Cleft Palate and Craniofacial Association's National Headquarters for approval. Then, the coordinators of all the cleft palate and craniofacial centers were identified using the American Cleft Palate and Craniofacial Association's 2003-2004 Directory. After identifying the coordinator, an e-mail cover letter and direct link to a web-based survey was sent to each coordinator discussing the nature and purpose of the study. Consent was based on the individual's willingness to complete and return the survey.

It was requested that the coordinators complete the survey and return it within two weeks of receipt. Two weeks after the due date for the initial survey, a second e-mail reminding them about the survey and another link to the survey was sent out to the coordinators who had not yet responded. In order to maximize the responses for the study, multiple modes of communication were used. Some cleft palate teams listed in the directory did not have e-mail addresses listed, and so phone calls were made to some teams to try to find an alternate means for the team to complete the survey. So, for those teams that requested to be a part of the study, some surveys were mailed and faxed.

Instrument

The survey was designed primarily by the principal investigator, and the committee served as a panel of experts in the field to modify and clarify the survey. The survey consisted of 32 questions, including multiple choice, checklists, and open-ended responses. Survey questions were derived from the reviewed literature and experts.

Questions for the survey were created to identify who provides the feeding intervention at the birth hospital, who provides the feeding intervention on the cleft palate team, when most families first visit the team, what feeding methods are being recommended, the presence and type of education given to the parents, and what type of follow-up is being done with the family following the initial intervention by the team.

Protection of Subjects

This research study was reviewed by the University of Cincinnati and Children's Hospital Medical Center Institutional Review Board and by the American Cleft Palate Craniofacial Association for the protection of human rights and for usefulness to clinical practice.

Potential Risk/Consent

The study included minimal risk and no direct benefit to participants. All participation was voluntary. Return of the survey indicated implied consent.

Procedures and Time Frame

Once the Cincinnati Children's Hospital Medical Center and the University of Cincinnati Institutional Review Boards approved the study, a copy of the cover letter and the questionnaires was sent to each Cleft Palate Center.

Analysis of Data

Descriptive and summary statistics were used as the method for data collection. The responses to each question were tallied, and the number of times that each answer was obtained was also documented. Descriptive statistics were also used to summarize the data collected from the open-ended questions. The information collected was subject to correlation analysis, specifically in the areas of geographic location, size of team, and size of geographic area covered by the team.

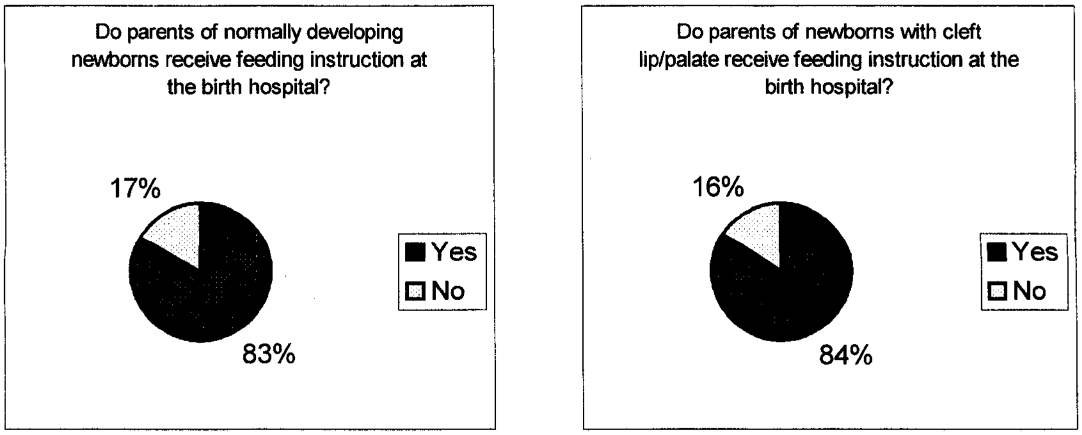
Chapter IV - Results

The following results were found based on the six questions that this research was intended to answer.

1. Is there a uniform standard of care or best practices provided by hospital nursery staffs and cleft palate teams regarding feeding issues of the infant with cleft lip/palate of any type?

Survey questions 9, 14, 15, 16, and 17 were intended to answer the first research question of this research. Question 9 asked the question: is feeding instruction provided to parents of normally developing newborns and newborns with cleft lip/palate at the birth hospital? Between 83-84% of those surveyed believe that parents of newborns do receive feeding instruction at the birth hospital, as shown on the following charts.

Figure 1: Do parents receive feeding instruction at the birth hospital?



In answer to question 9, the figures below demonstrate the distribution of professionals who provide feeding instruction at the birth hospital as reported by cleft palate teams.

Figure 2: Distribution of Professionals Providing Feeding Instruction at the Birth Hospital to Normally Developing Newborns

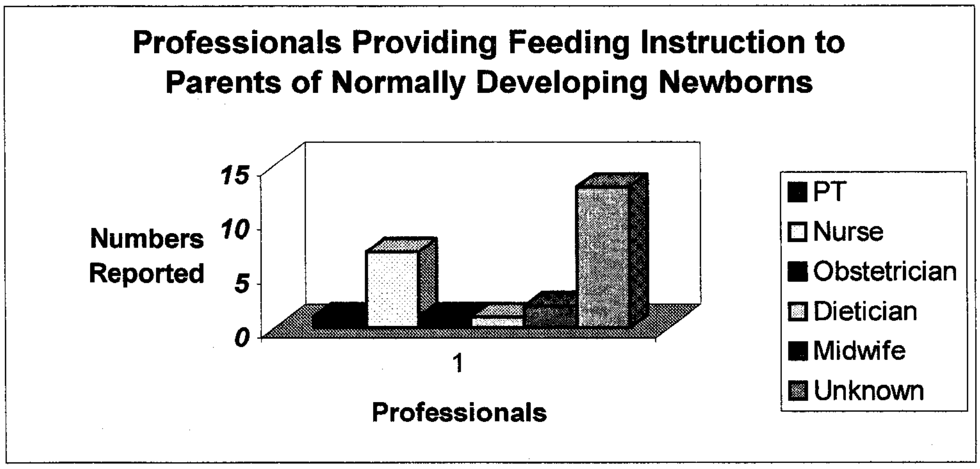
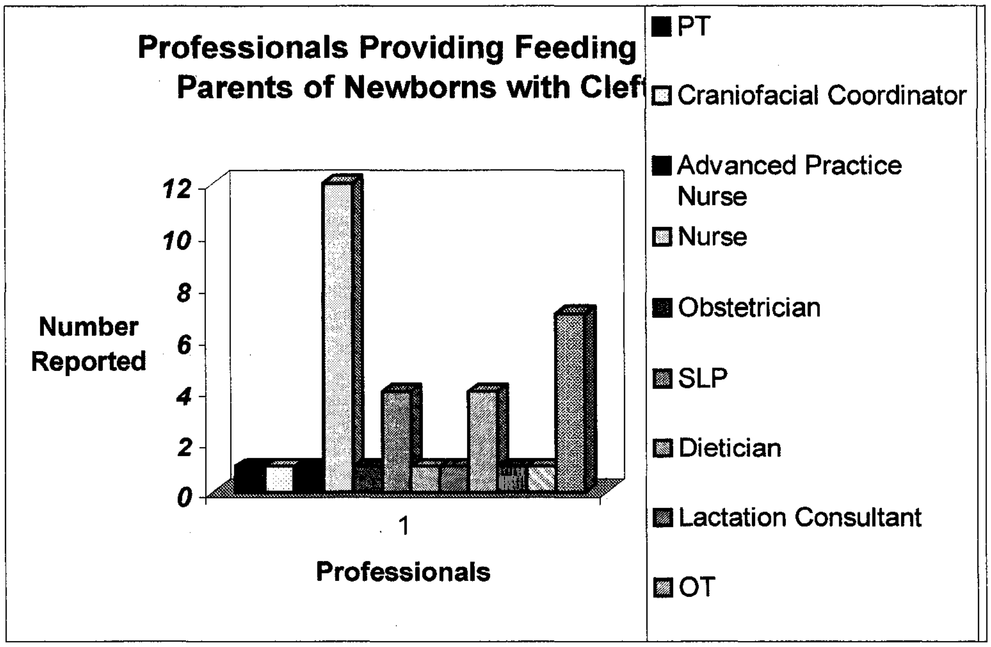


Figure 3: Distribution of Professionals Providing Feeding Instruction at the Birth Hospital to Newborns with Cleft Lip/Palate



Questions 15, 16, and 17 asked teams to provide scaled responses to statements about the care and feeding intervention that birth hospitals provide to families of newborns with cleft lip/palate. Following is a list of statements scaled by 29 of the teams. The remaining 4 teams did not respond to this section.

Figure 4: Sufficiency of Information Provided at the Birth Hospital

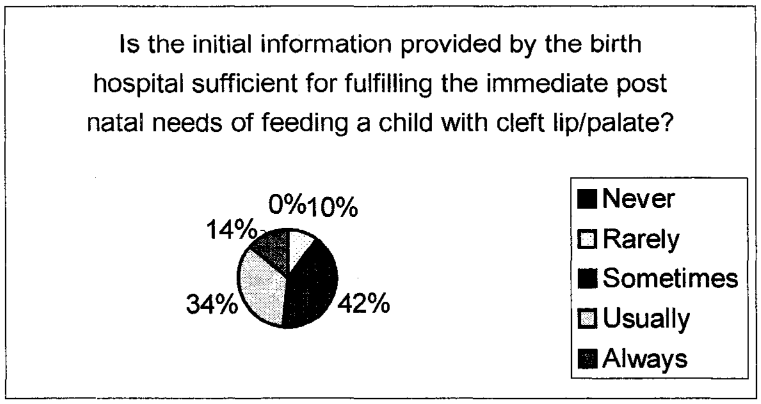


Figure 5: Parent Satisfaction with Instruction at the Birth Hospital

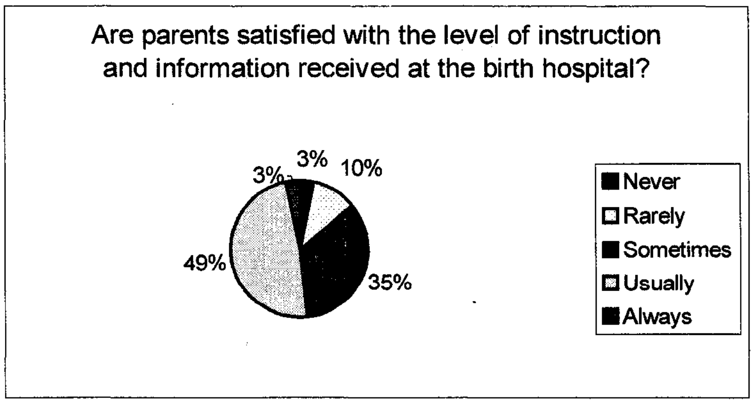
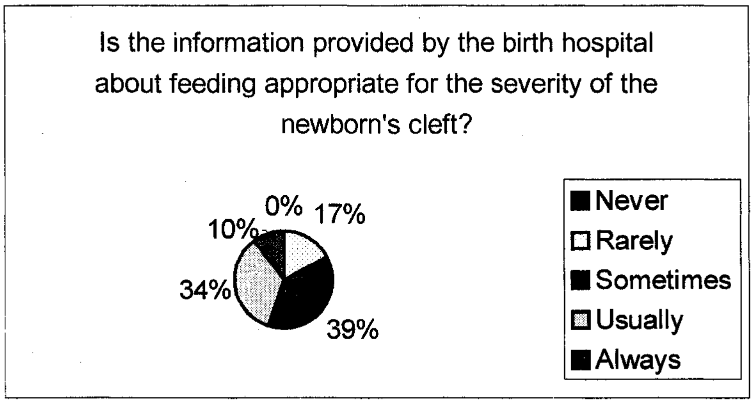


Figure 6: Appropriateness of Feeding Information by the Birth Hospital



The first purpose of this research was to determine if a uniform standard of care or best practices provided by hospital nursery staffs and cleft palate teams regarding feeding issues of the infant with cleft lip/palate of any type exists. The results of this section indicate that at present, no standard of care exists in birth hospitals.

2. Do practice patterns differ by hospital size, location, and/or nursery level?

There were differences between teams in these various categories, however, it was not possible to note patterns based on these factors secondary to insufficient information. It was not possible to evaluate patterns based on hospital size, location and nursery level because of limited information reported. This may be a result of the survey instrument or lack of clarity regarding some of those questions. Other factors were impacted by the limited distribution of teams in these areas. Information was collected regarding the professional composition of the various teams. Table 1 shows the distribution of professional members for the 27 teams that responded to this question.

Table 1: Professionals Composing Teams

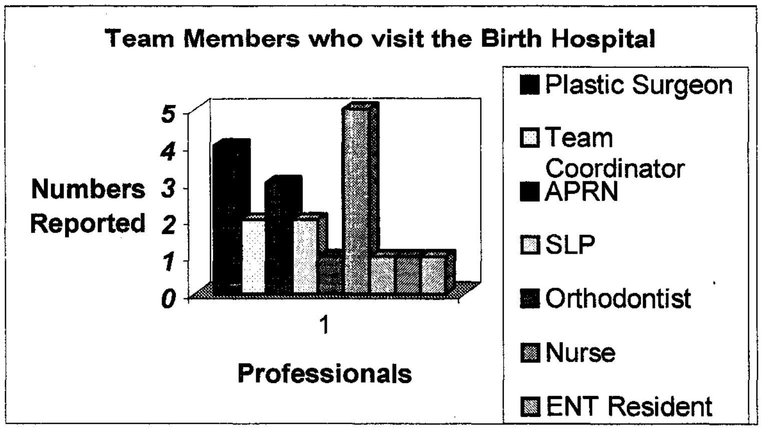
Professional	Number of Teams	Average Number/Team
Advanced Practice Nurse	17	2
Audiologist	13	2
Clinical Geneticist	10	1
Dentist	23	2
ENT	23	2

Genetic Counselor	9	1
Neurosurgeon	9	1
Nutritionist	7	1
Occupational Therapist	5	2
Opthamologist	6	1
Oral Surgeon	20	1
Pediatrician	14	1
Plastic Surgeon	23	2
Psychologist	9	1
Social Worker	16	1
SLP	27	2
Staff Nurse	6	2
Orthodontist	22	3
Prosthodontist	2	1
Anesthesiologist	1	1
Radiologist	2	1
Parent Advocate	1	1
Neonatologist	1	1
Orthopedics	1	1
Service Coordinator	1	1
Patient Care Coordinator	1	1
Public Health	1	1
Dental Hygienist	1	1

3. Is there a uniform standard of care provided by cleft palate teams?

On the survey, 17 questions were asked about the evaluation, intervention, and care provided by cleft palate teams to determine whether there is currently a pattern of care or if there are any consistencies among teams. Question 10 asked whether or not those teams that are not in the birth hospital go to the birth hospital for initial feeding evaluation and intervention for the newborns with cleft lip/palate. Of the 25 teams who answered this question, 44% stated that it is not standard practice for the whole team to travel to birth hospitals for feeding evaluation and intervention. The other 56% reported that traveling to birth hospitals is part of their standard practice. A wide range (range = 5-100%; mean = 55%) of visits to referrals was reported by the teams that are available to travel to surrounding/referring birth hospitals. Professionals conducting the visits included: plastic surgeon, team coordinator, advanced practice nurse, speech-language pathologist, orthodontist, nurse, ENT resident, occupation therapist, and doctor. Figure 7 shows the distribution of professionals conducting initial visits.

Figure 7: Professionals Conducting Visits at the Birth Hospital



Respondents indicated that children are often transferred from the birth hospital to a hospital with a specialized team to better meet the needs of the child. Question 11 asked about the percentage of children who are transferred to the hospital with a specialized team; when and why they are transferred. Responses (n = 24) indicated 24 percent (range = 0-100%)of infants are transferred. Close to fifty percent (n = 11) of those teams reported the newborns transferred within 2 to 4 days after birth. A small percentage of respondents reported (n = 4) reported babies were transferred on the first day of life, and three teams reported transfers occur at greater than four days of life. The reasons for transfet are displayed in table 2.

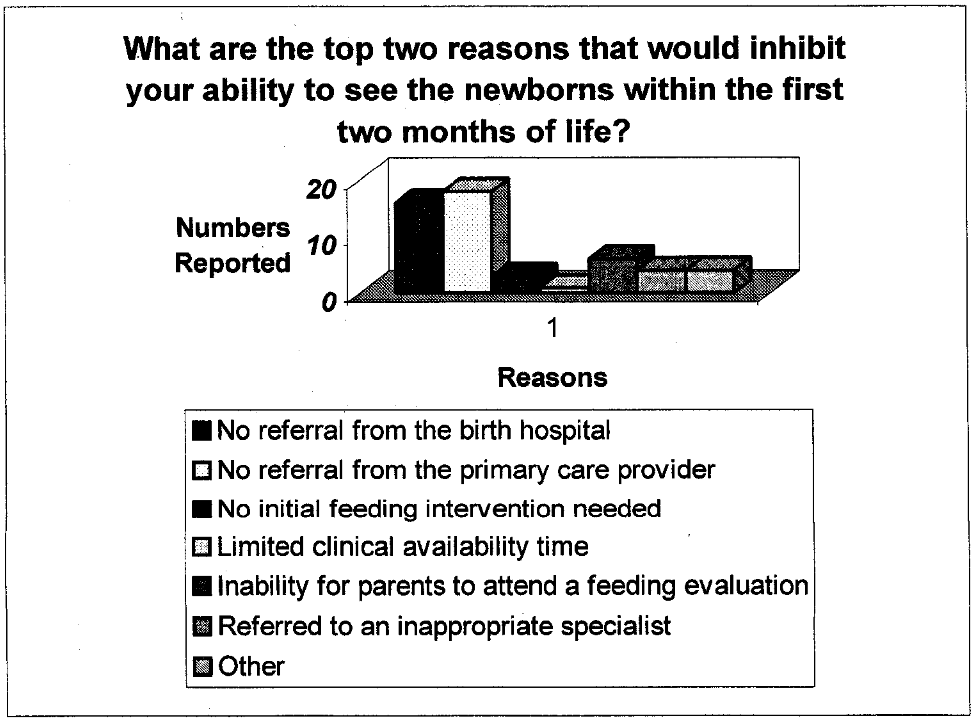
Table 2:
Primary Reasons Newborns are Transferred
From the Birth Hospital

Airway Management	7
Feeding/Nutrition Management	5

Coordination of Care	4
Standard Protocol	2
Complicated Syndromic/ Clefting Issues	2
Fear of the Unknown	1
Birth Hospital	1
Other Medical Concerns	2

Respondents also indicated key reasons why newborns are not seen within the first two months of life. These are depicted in figure 8.

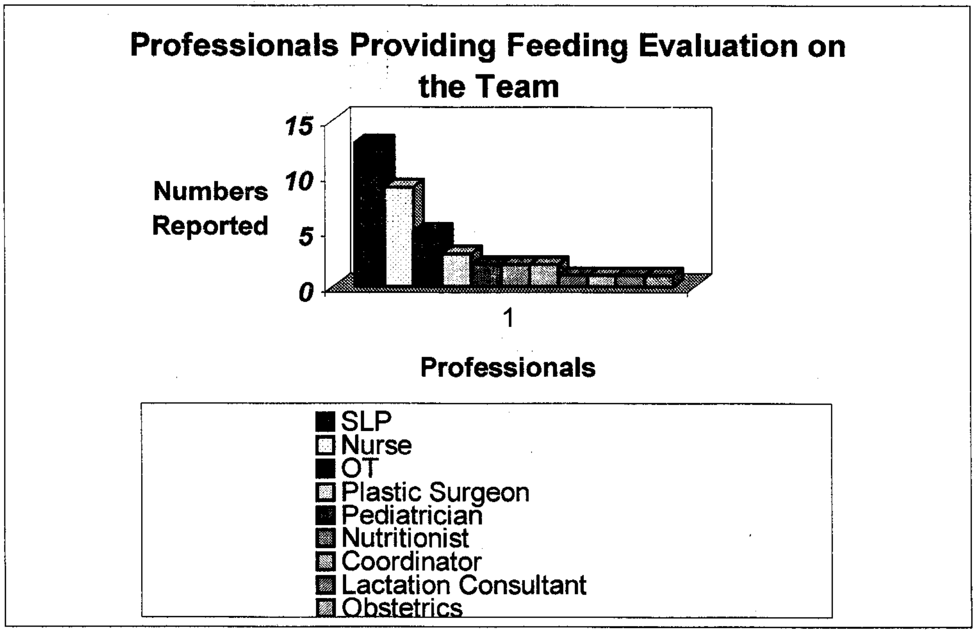
Figure 8: Top Two Reasons Preventing the Newborn from being seen in the first two months of life



Four teams responded to this question with the response "other", and one of those teams stated that infants are always seen within the first two months of life.

Respondents also provided information about the initial team evaluation and intervention with the newborn. In question 20 teams were asked who provides the feeding evaluation/intervention on the team? Responses are indicated in figure 9.

Figure 9: Professional Providing Feeding Evaluation



In question 22 respondents ranked how often the following methods are used in the evaluation process: parent reports, instrumental, observation, and clinical evaluation. The scale used to rank was: always, usually, sometimes, rarely, and never. One respondent provided additional information stating that data intake regarding feeding is collected prior to evaluation. The figures below demonstrate how each respondent ranked the team's use of these methods.

Figure 10: Clinical Evaluation

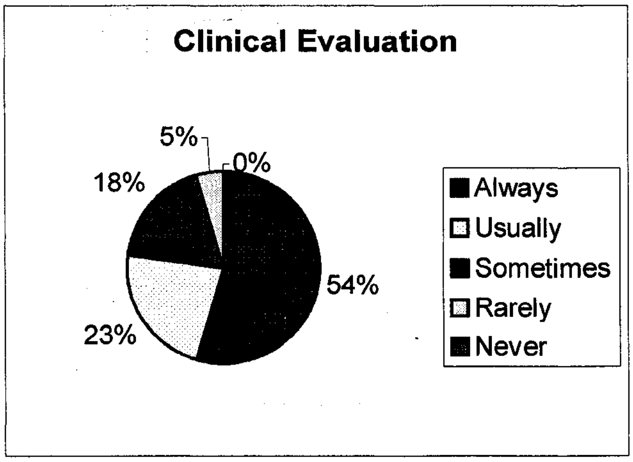


Figure 11: Parent Reports

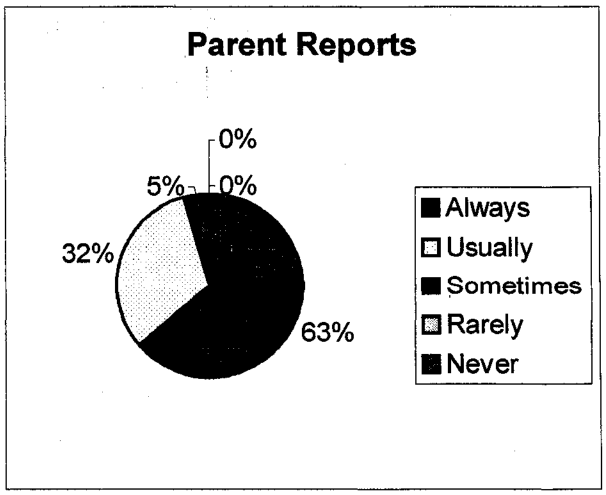


Figure 12: Observation

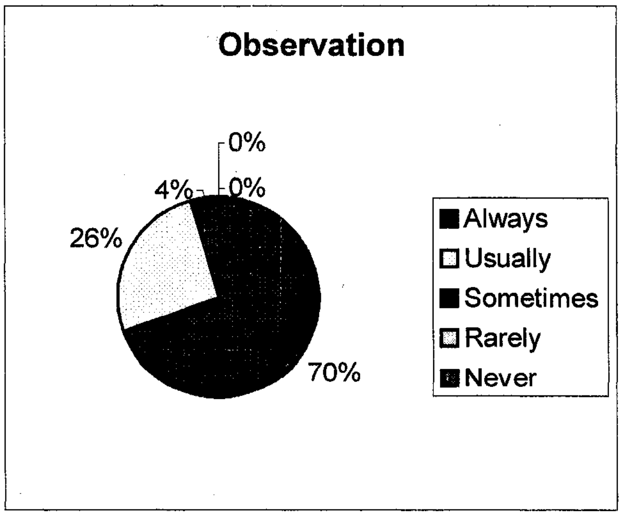
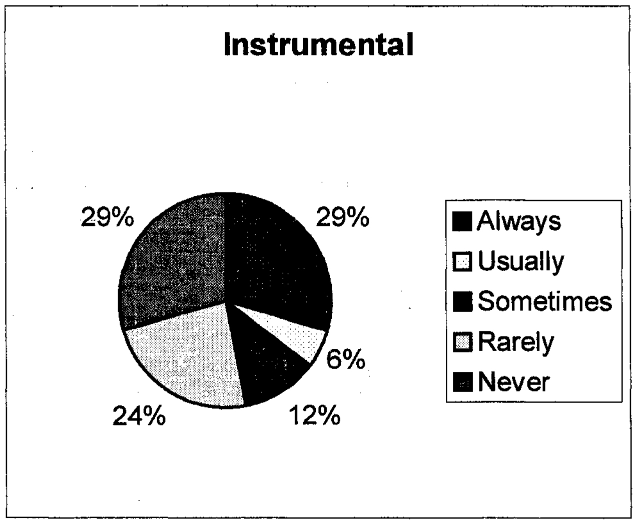


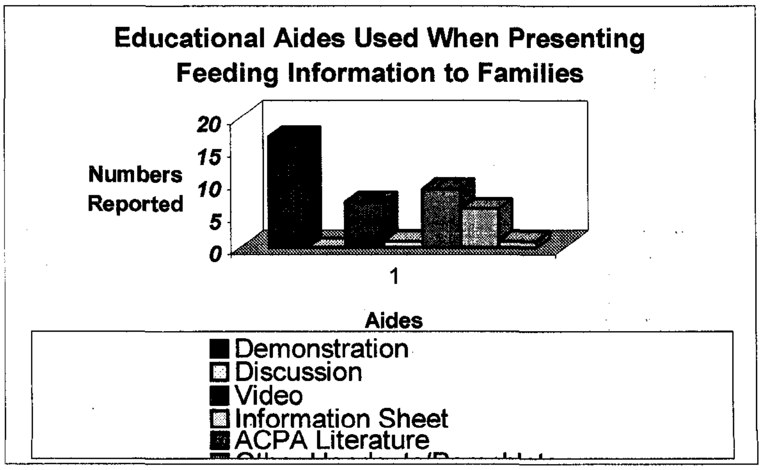
Figure 13: Instrumental



Question 23 asked if teams have a standard protocol that is used for evaluating the feeding session and providing information to the family. The results indicated that 57% do have a standard protocol, and 43% do not have a standard protocol. Respondents who reported having a standard protocol were asked to describe it. The most common answers included general feeding recommendations (e.g.. positioning, pacing, feeding) are explained, a standard set of questions are asked of parents regarding the child's feeding history, teaching use of a specific feeding method, and conducting a feeding and oral-motor evaluation, and trialing different feeding methods.

The survey also asked teams in an open-ended format to describe the educational aides used to present feeding information to families. Several teams reported using multiple educational aides. The number of responses for each method is evidenced in the figure below.

Figure 14: Educational Aides



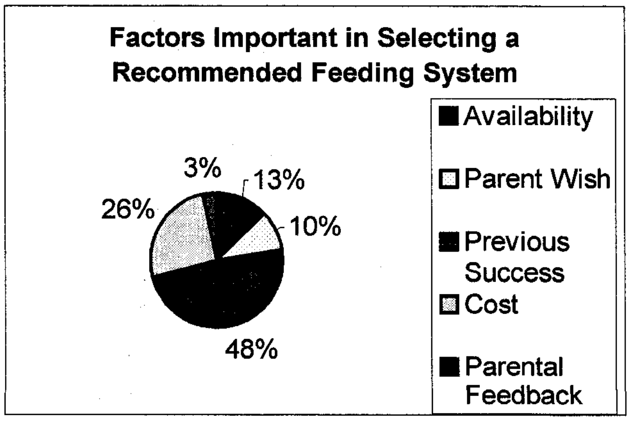
Question 25 asked whether teams recommend a specific feeding method. Twenty-nine teams reported recommending certain feeding systems, and four teams responded that they do not make specific recommendations. Respondents were asked to indicate how often they recommend the following feeding systems (Ross, Haberman, Mead-Johnson, and Pigeon) and were given the opportunity to list any other recommended systems. The other systems reported included Dr. Brown, breast-feeding, and a slit normal nipple. In the following table, the frequency of each response, the range of percentage use, and the average percent for each feeding method is listed.

Table 3: Recommended Feeding Systems Among Teams

FEEDING SYSTEM	***FREQUENCY OF RESPONSE***	***AVERAGE***	***RANGE OF PERCENTAGES***
Ross	2	22.5%	20-25%
Haberman	22	48.26%	5-100%
Mead Johnson	17	66.8%	10-100%
Pigeon	7	17.43%	1-40%
Dr. Brown	2	7%	5-9%
Breast Feeding	1	100%	100%
Slit Normal Nipple	1	100%	100%

Given that feeding success and individual considerations are the primary factors for those teams that recommend a particular feeding method, teams were asked what the next most important factor is in determining the recommendation. This question was asked in a multiple-choice format with the following factors as answers: availability, parent wish, previous success, or cost. Teams were also given the option of entering another reason that might be an important factor for them in recommending a system. Only one team entered a separate factor and that was parental feedback. Some teams also listed more than one factor, but their responses were still included in the results. The chart below shows the factors that are most important in determining feeding system recommendations.

Figure 15: Factors in Selecting a Feeding System



Questions 26-29 asked teams to scale the following comments regarding their approach to parents, consistency of care between cleft palate teams and birth hospitals, and success and support for parents with their feeding intervention during the initial meeting and evaluation. The results to these questions are displayed in the following figures.

Figure 16: Parent Knowledge

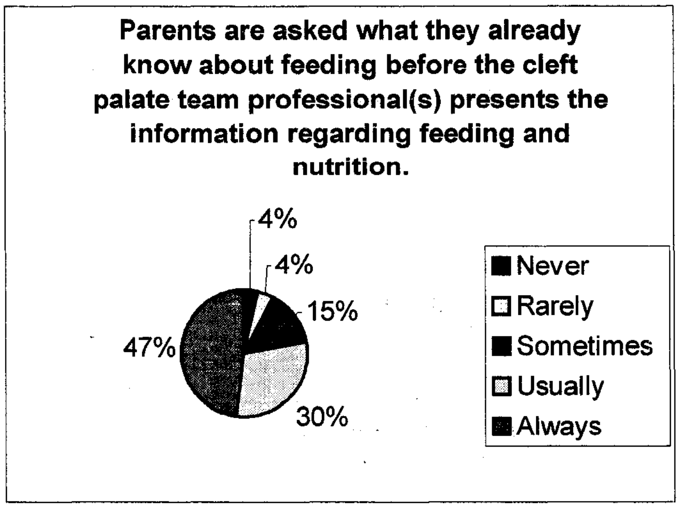


Figure 17: Parent Input

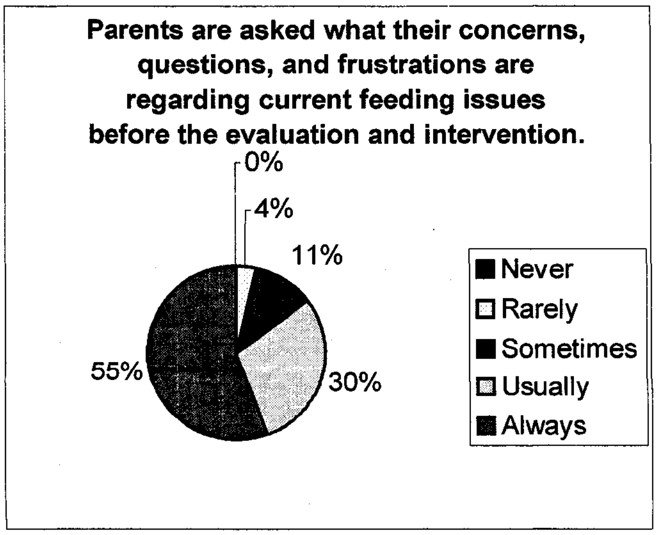


Figure 18: Consistency of Recommendations

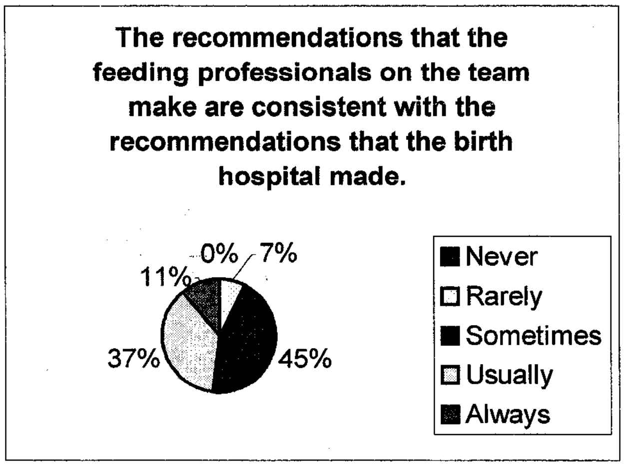
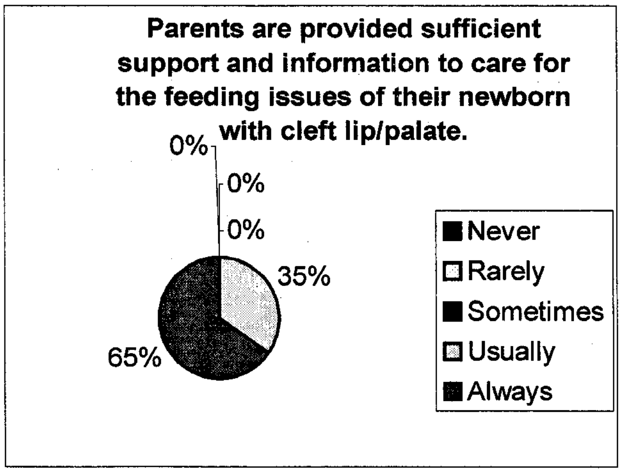
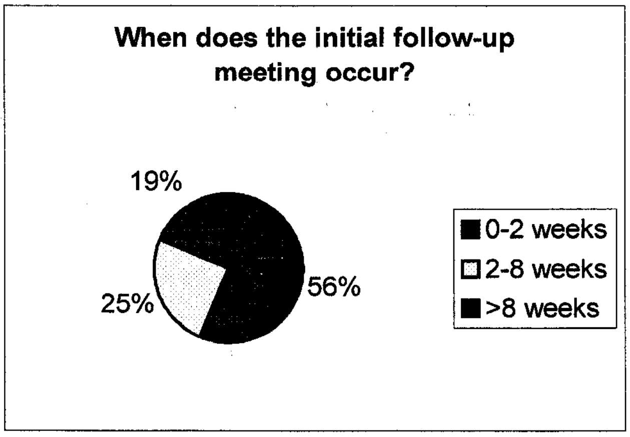


Figure 19: Parent Support



Question 30 asked teams when the initial follow-up occurs and what the purpose of the follow-up is. The results of this question are displayed in the figure below.

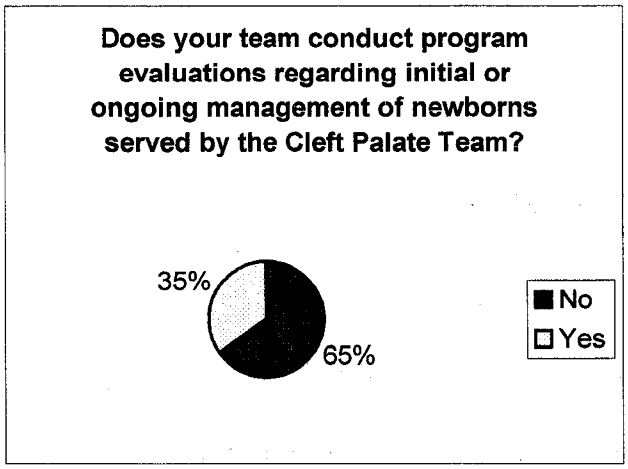
Figure 20: Initial Follow-up



This question was asked in an open-ended format, and some teams did not respond with quantitative answers but instead stated that it depends on a variety of factors, including the type and severity of the cleft and the significance of the issues the family is facing. The teams were also asked about the purpose of this follow-up, and a variety of answers were received with the main sampling including issues related evaluating the success of feeding, monitoring weight gain, dealing with issues and questions as they arise for parents, evaluating and planning for surgery, and developing a treatment plan for the child.

Question 31 asked whether teams conduct program evaluations regarding initial or ongoing management of newborns served by the Cleft Palate Team. The results are displayed in the figure below.

Figure 21: Program Evaluations



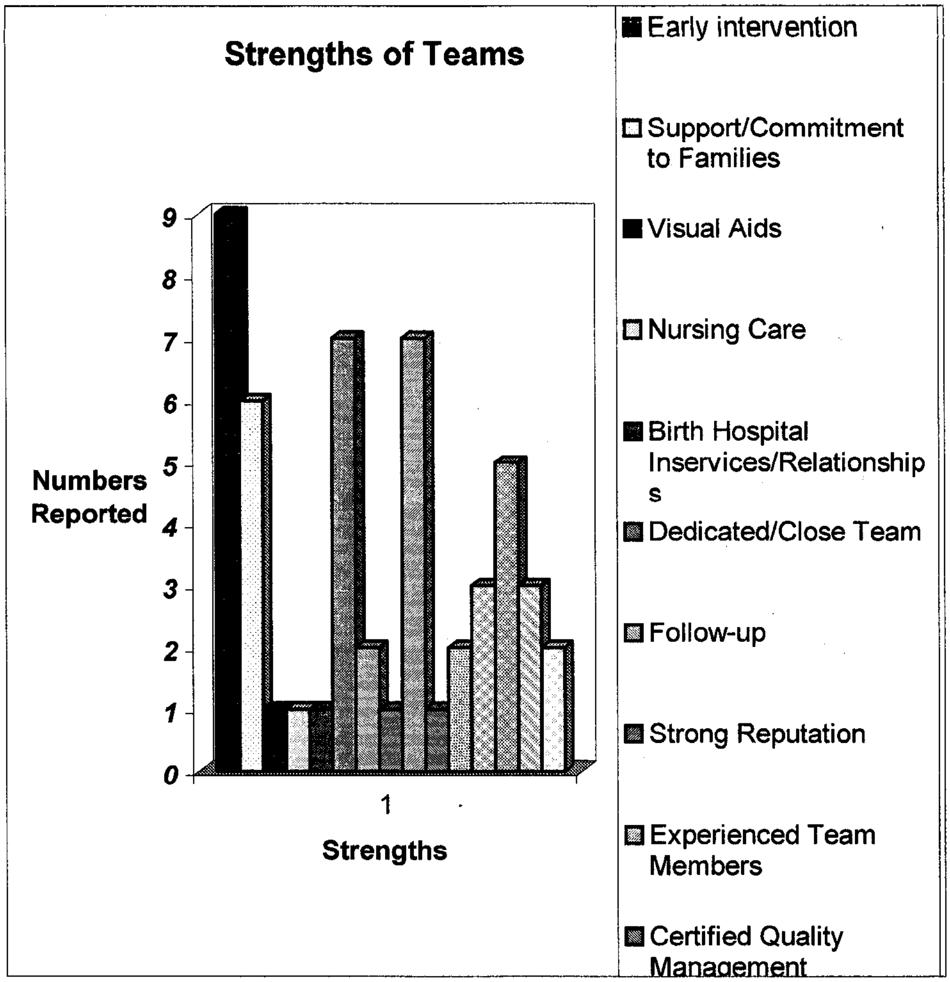
Those teams that stated that they do conduct evaluations were also asked to describe their evaluation process. A sampling of the answers given was surveys completed by families, reviewing cases at established intervals, conferencing with other teams, previously using the Cleft Foundation's Outcomes Registry, and reviewing for quality improvement.

The third purpose of this research was to determine if there is a uniform standard of care among cleft palate teams. Similar to the findings regarding birth hospitals, the results indicated that no uniform standard of care exists among cleft palate teams.

4. What are the strengths of teams at present in caring for infants with cleft lip/palate?

This question was asked of teams in an open-ended manner to allow for teams to provide unique and spontaneous responses, and then these responses were categorized. Twenty-nine teams elected to answer this question, and many provided multiple strengths that their team possesses. The figure below lists the response categories, and the frequency of these responses.

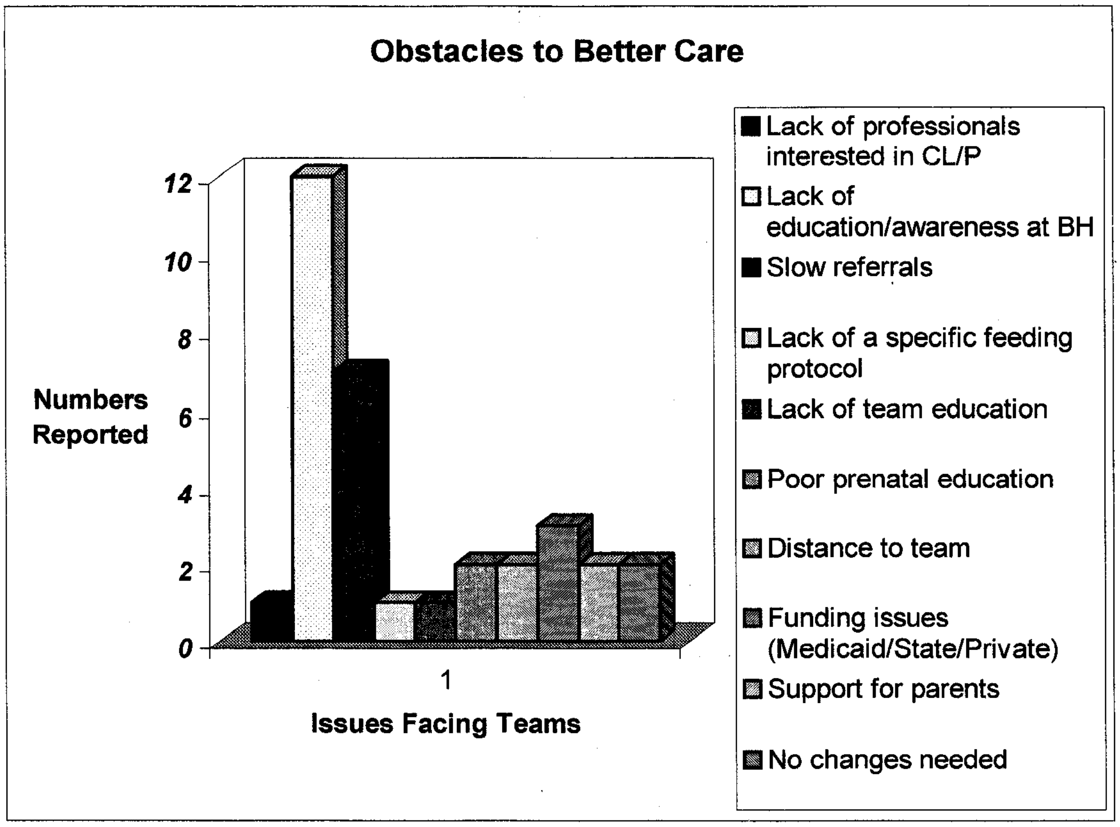
Figure 22: Strengths



5. What do teams identify as weaknesses or obstacles to providing optimal care for infants with cleft lip and palate?

This question was also asked in an open-ended manner so that teams could independently name what they believed to be weaknesses and obstacles. Please see the figure below.

Figure 23: Weaknesses/Obstacles



Chapter V – Discussion

The current study was designed to examine whether standards or patterns of care exist at birth hospitals and on cleft palate teams, how patterns of care differed, and identify the strengths and weaknesses of cleft palate teams. Results provided a variety of descriptions of current practice at the birth hospitals and on the cleft palate teams. This chapter will discuss the limitations of the study, the conclusions that can be drawn from the results, and the potential for future research and developments regarding a standard of care for infants with cleft lip/palate.

1. Is there a uniform standard of care or best practices provided by hospital nursery staffs and cleft palate teams regarding feeding issues of the infant with cleft lip/palate of any type?

This question was asked to determine if a standard of care existed across facilities and professional teams providing services to infants with cleft lip/palate. Based on the diversity of responses received, there are variable standards of care. Several questions on the survey targeted this topic, including whether parents of children with and without cleft receive feeding instruction at the hospital; the primary reason that children with cleft lip/palate are directly admitted to specialized hospitals with cleft palate teams; and scaled statements regarding the quality of services that the birth hospital provides.

While approximately 83-84% of respondents agreed that parents of newborns receive feeding instructions, the remaining 16-17% of parents go through the feeding process without feeding instructions and without the support of feeding professionals (e.g. nurses, SLPs etc.). Most parents of typically developing newborns may learn to adjust and figure out feeding on their own, but for the parents of newborns with cleft lip/palate, the structural abnormality of the cleft prevents most children in this particular population from being able to compensate without the help of adaptive techniques and bottles. The diverse range of health professionals reported to provide feeding intervention suggests the lack of a standard approach to feeding across birth hospitals. Based on the current survey, it is estimated that at least 14 different professions with varying levels of education are responsible for providing feeding education to families of newborns with cleft lip/palate. This suggests that parents are receiving inconsistent recommendations and information about feeding.

A common concern for newborns with cleft lip/palate is nutrition and growth. A study by Richard (1994) documented slower weight gain in children with cleft lip/palate. In another study, poor weight gain has been attributed to feeding difficulty and the mother's distress in feeding (Harris, 1993). However, other researchers contend that feeding difficulty does not account for the differences in growth, and if parents receive specific instruction in appropriate feeding techniques, then infants with cleft lip/palate can have weights in and above the 50th percentile (Felix-Schollaart, Hoeksma, and Prahl-Anderson, 1992; Richard, 1994). This data suggest that professionals with specialized training and current knowledge regarding feeding could improve weight and nutrition issues in some infants with cleft lip/palate. In the current study, specially trained professionals were not reported to be consistently providing intervention. By consistently using professionals with specialized feeding education at the birth hospital and on the teams, this could hopefully minimize the poor weight gain and nutrition that is currently affecting many infants in this population.

Overall cleft palate teams rated birth hospital feeding intervention and education as average. Approximately 40-50% of respondents stated that some hospitals usually or always make the right feeding recommendations and provide services with which parents are satisfied. If at least 50% of recommendations are inconsistently appropriate and satisfactory to parents, then at least 50% of infants are potentially not receiving optimal care and nutrition. It is unacceptable for only 50% to be receiving consistently appropriate care. This indicates the need for change.

One of the potential biases of the current study is that cleft palate teams evaluated the care provided by birth hospitals. Birth hospitals were not direct participants and so did not have the opportunity to provide their own input. Some birth hospitals may conduct their own program evaluations and have a different opinion about the level of satisfaction and the level of care that they provide. Future research might include a direct survey of birth hospitals to study how they evaluate and assess their own feeding evaluation and intervention services.

The first purpose of this research was to determine if there is a uniform standard of care or best practices provided by hospital nursery staffs and cleft palate teams regarding feeding issues of the infant with cleft lip/palate of any type. Some of the responses that answered this question included: an estimated 15% of infants with cleft lip/palate still do not receive feeding intervention at the birth hospital, a variety of professionals are responsible for providing feeding evaluation and education at the birth hospital, and the inconsistent satisfaction rate of parents. The responses of those surveyed suggest that there is no standard in terms of initial care and education for families at the birth hospital.

2. Do practice patterns differ by hospital size, location, and/or nursery level?

Teams responded with a variety of different ideas and methods of practice, but there appeared to be no consistent differences among teams based on hospital size, location, and/or nursery level. This research intended to compare urban versus rural patterns of care by cleft palate teams, but only urban-based teams/hospitals to the surveys. Another study might target those teams in rural settings and study their practices in serving infants with cleft lip/palate and see how they rank the birth hospitals in the rural areas regarding feeding intervention with this population.

Several international teams participated in the current study, and similar to the American teams, no practice patterns were noted. The international teams also appeared more willing to identify obstacles to care and state their needs for more current information regarding feeding evaluation and intervention for the population with cleft lip/palate. International teams are also regionalized, unlike teams in the United States, meaning that most countries only have one or two recognized teams with cleft palate specialists. Future studies may consider investigating how the geographic location, distances from patients, and limited specialists affects the philosophies and quality of care provided by teams in a variety of international locations.

Even though various practices were noted among teams, there appeared to be no patterns to the differences. Practice patterns were not identified based on hospital size, location, or nursery level.

3. Is there a uniform standard of care provided by cleft palate teams?

Similar to feeding evaluation and intervention at the birth hospitals as suggested in the current study, there appeared to be no consistent pattern among teams in regards to feeding evaluation and intervention. Like birth hospitals, there are a variety of professionals who evaluate feeding and provide interventions. This means that families are receiving various advice, recommendations, and interventions. The healthcare professionals providing the intervention and information have varying levels of education and approach feeding from different perspectives.

Teams also have different approaches for evaluating feeding. Most teams report varying levels of consistency when using observation, clinical evaluation, and parent reports to develop a treatment plan. For example, the same number of teams reported always using instrumental evaluation (29%), as never using (29%) instrumental evaluation. Those teams who are not consistently using instrumental evaluation may benefit from the current practices of other teams in using objective data as part of their evaluation. Three teams stated that one of their primary obstacles to care is funding issues, such as insurance and medicaid. Currently there is a growing emphasis on documentation and objective data to justify insurance reimbursement, so those teams who do not currently use instrumental evaluation might benefit from discussing with other teams the benefits of objective data in evaluation. Also, it might warrant investigation as to why teams reported only sometimes or rarely using parent reports or a clinical evaluation as part of their overall evaluation process. By only using parent reports and clinical evaluation sometimes, the team appears to be suggesting the parent reports and clinical evaluation are only significant sometimes. Supporting families and providing care and feeding education is more than identifying the problem and giving a professional solution. It is imperative that parents be asked their concerns and that their concerns be listened to and addressed, not glossed over as unimportant. The public has recently begun to recognize that despite great gains in medicine, there is a need to improve quality of care (McNeil, 2001). Care does not only involve offering a solution to a problem, but supporting and addressing the needs and concerns of families and patients.

Another area of concern revealed in the current study was that 65% of respondents reported that they do not conduct program evaluations concerning initial and ongoing management of their cases. If teams do not evaluate their care, then it is questionable that they are identifying weaknesses and areas for improvement and even more questionable that they are attempting improvement. Evaluation is time-consuming and is not always a comfortable process, but it identifies weaknesses and problems in the system that merit change. It is the beginning of the process of improvement. Improvement occurs once areas of weakness are identified. Medical professionals should regularly evaluate cases and determine if they are providing care that is anchored in current professional knowledge (Eagle, Garson, Beller, and Sennett, 2003).

4. What are the strengths of teams at present in caring for infants with cleft lip/ palate?

Respondents indicated that teams are collaborating in order that they might provide outstanding and individualized services to children and families of children with cleft lip/palate. Several strengths were identified, indicating that most teams desire to provide excellent care. Identifying strengths of teams will serve as a model and help other well-intended teams realize their goals of improving patient care (Fernandopulle et al., 2003).

The strength most commonly identified was that respondents feel the members of their team are committed to serving the population with cleft lip/palate and their families. The overall dedication expressed by the respondents is one of the more encouraging results of this survey. Many researchers and medical professionals have in the years 2002-2003 written perspective papers regarding the Institute of Medicine's 2001 report, *Crossing the Quality Chasm.* One of the overriding themes in these papers has been that embracing patient-care is an important and powerful message to patients, families, and the public (Fernandopulle et al., 2003). The expressed commitment of teams implies that they are committed to working hard and are willing to make changes to better serve this population.

Teams also report they are developing strong relationships with birth hospitals and are providing more education and in-services to the staff there. This is starting point for what might be an ongoing process of education at birth hospitals. The current study indicates that there is a need for more research to investigate what birth hospital staffs need to know and be able to do in order that they might provide the appropriate education and intervention to families of newborns with cleft lip/palate during the first few days of life. The strengths identified in these surveys show that there is a strong commitment to excellent service.

5. What do teams identify as weaknesses or obstacles to providing optimal care for infants with cleft lip/palate?

A variety of obstacles to providing optimal care was identified by teams, but some concerns were noted to be beyond the control of the team. Some issues, such as the distance that some patients must travel to the team, will always be a problem and therefore cannot be resolved by the team. Another problem some teams identified was financial/medicaid issues. Issues such as these require professional advocacy and political involvement. Unfortunately though, medical professionals once again are not able to directly control and fix these problems. Professionals understand that there are always going to be problems, and so the key is to identify the ones that teams have the power to change. The two most commonly identified weaknesses were poor education at the birth hospitals and slow referrals from primary care providers and birth hospitals. These are issues that can be improved. One team suggested that the lack of a standard of care is the obstacle, and while this was listed as a separate weakness than the others, they are closely related. The creation of a standard of care or recommended guidelines may be the solution to the varying levels of education, intervention, and care that families and patients receive.

Limitations:

The primary limitation of the current study regards whether or not this study contains a representative sample. The factors affecting the valid representation of the sample include uneven distribution of teams and limited respondents. The surveys were completed by 33 teams, which are approximately 13% of potential participants. The sample could be skewed in two directions. Depending on whether the sample includes teams that tend to be proactive in care or teams that take less initiative, the results could be skewed in a more positive or negative direction. Another limitation of the study is the insufficient information regarding the focus of the teams. The focus of the teams, whether it be surgical or pediatric, affects intervention, education, timing of care, and other aspects of care. Future research might focus on the philosophies of teams and how this affects their care.

Conclusions

The responses to these surveys show that at present, a standard of care is lacking in birth hospitals and on cleft palate teams. A standard of care would outline to professionals at birth hospitals how to evaluate and educate families. It would also educate the professionals themselves and create a resource to help answer questions about feeding techniques and methods that might help families through those first few days of life. A standard of care for teams would provide support for those teams who are geographically separated from other teams and are unable to participate in educational opportunities that might be more readily available to others. For those teams who are already providing excellent services, it would provide support and reassurance that the services they are providing are evidence-based. For those teams who are trying but need more guidance, it would more clearly define roles and responsibilities. For all teams, it would provide a resource that is founded on current professional knowledge and details the specific roles and responsibilities of team members, and a model for the optimal care that can be provided to those newborns and their families who are reliant upon the feeding education, intervention, and support that the cleft palate teams provide. The establishment of a standard of care is only the beginning of the process of improving services. Further research and the development of a standard will not ensure quality care, it will only serve as part of the answer. Quality care is and will always necessitate professionals being committed to always doing the right thing. A standard of care will serve as way of helping healthcare professionals do the right thing and provide optimal care more effectively.

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Feeding Intervention for the Newborn with Cleft Lip/Palate: A Survey

I. General Demographic Information

1. Please indicate all disciplines and the numbers represented on your Cleft Palate Team.

___ Advanced Practice Nurse
(List specialty) ______________
___Audiologist
___Clinical Geneticist
___Coordinator
(List discipline)______________
___Dentist
___ENT
___Genetic Counselor
___Neurosurgeon
___ Nutritionist
___Other ____________________

___ Occupational Therapist
___ Opthamologist
___ Oral Surgeon
___ Orthodontist
___ Pediatrician
___ Plastic Surgeon
___ Prostodontist
___ Psychologist
___ Social Worker
___Speech Pathologist
___Staff Nurse

2. What is the discipline of the director of your team? ____________________________

3. What is the discipline and position of the person completing this survey?

____

4. Are you a birth hospital? ___Yes ___No

5. Approximately how many patients with cleft lip and/or palate are served at your center annually?

________New Patients ________Established Patients

6. What is the (percentage estimate) geographic radius of your referral/patient base?

___ Less than 25 miles ___26-50 miles ___51-100 miles

___Greater than 100 miles

II: Birth Hospital Experience- *The following questions relate to the infant and family's experiences at the birth hospital. Please answer to the best of your ability.*

7. What is the number of referring hospitals to your team? ____________________

8. Are the majority of referrals from level 1 and 2 or level 3 nurseries?

___Levels 1 and 2 ___Level 3

9. Do most parents and patients receive one-on-one feeding evaluation, education, and intervention at the birth hospital? If yes, who provides these services?

a. Normal Newborn	b. Newborn with Cleft Lip and/or Palate
___No	___No
___Yes __________________	___Yes ______________________
___Unknown	___Unknown

10. If you are not the birth hospital, is it standard practice for your team members to go to the birth hospital for feeding evaluation and intervention?

____No

____Yes (If yes, please answer parts a, b, c, and d.)

a. In your best estimate, what percentage of newborns with cleft lip and/or palate at hospitals in your region do you visit at the birth hospital? _____%

b. Who on the team goes to the birth hospital?

____

c. How far do you typically travel (in miles)?

____

d. Are the referrals to your team based on severity of the cleft? ___Yes ___No

11. What percentage of infants with cleft lip and/or palate in your region are directly transferred from the birth hospital to your facility? _____%

12. If infants are transferred, on what day of life are they typically transferred?

___Day 1 ___Days 2-4 ___Greater than 4 days

13. What is the primary reason for a direct admission to your facility? (Only mark one.)

_____Feeding/Nutrition Management _____Airway Management

_____General Protocol _____Coordination of Care

_____Other (please specify)____

14. The intervention and education about feeding and feeding options that parents receive at the birth hospitals in your region are . . . (Please give estimated percentages.)

___1 ___2 ___3 ___4 ___5

Poor Average Excellent

15. Is the initial information provided by the birth hospital sufficient for fulfilling the immediate post natal needs of feeding a child with cleft lip and/or palate?

1 2 3 4 5 N/A

Never Rarely Sometimes Usually Always

16. Are parents satisfied with the level of instruction and information received at the birth hospital?

1 2 3 4 5 N/A

Never Rarely Sometimes Usually Always

17. Is the information provided by the birth hospital about feeding appropriate for the severity of the newborn's cleft?

1 2 3 4 5 N/A

Never Rarely Sometimes Usually Always

III. Cleft Palate Team Experience - The following questions relate to the services provided by your specialty hospital or cleft palate team.

18. How soon after birth do infants and patients typically see a member of the cleft palate team? (If you choose more than one category, please give the percentage that applies to each.)

___1-3 Days ___3-7 Days ___7-14 Days ___15-30 Days
___4-6 Weeks ___6-8 Weeks ___Greater than 8 weeks

19. How soon after birth do parents receive the initial feeding instruction from the cleft palate team? (If you choose more than one category, please give the percentage that applies to each.)

___1-3 Days ___3-7 Days ___7-14 Days ___15-30 Days

___4-6 Weeks ___6-8 Weeks ___Greater than 8 weeks

20. What are the top two reasons that would inhibit your ability to see the babies within the first two months of life?

___No referral from the birth hospital

___No referral from the primary care provider

___No initial feeding intervention needed

___Limited clinical availability time

___Inability for parents to attend a feeding evaluation (i.e. transportation problems,

financial limitations)

___Referred to an inappropriate specialist

___Other____

IV. Feeding Evaluation and Intervention on the Cleft Palate Team

21. Who provides the feeding evaluation/intervention?

____

22. How is feeding evaluated? Please select any/all that apply, using the following scale: 1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always.

_____Parent reports _____Instrumental

_____Observation _____Other (please specify)

_____Clinical Evaluation

23. Does the team have a standard protocol that is used to evaluate the feeding session and provide information back to the family?

___Yes ____No

(If yes, please describe.)

____

____

____

____

24. What, if any, educational aides are utilized when presenting information to patients and families regarding feeding? (i.e.- videos, posters, illustrations, demonstrations, etc.) Please be specific.

____

____

25. Is it your standard practice to recommend a specific feeding system?

___Yes ____No

a. If yes, excluding feeding success and individual considerations, what is the next primary factor that determines the recommendation?

___Availability ___Parent Wish

___Previous Success ___Cost

___Other ______________________________

b. What feeding system do you recommend? Please give an estimated percentage.

___Ross Feeder

___Mead-Johnson

___Haberman

___Pigeon

___Other____________________________

For the following statements, please circle the appropriate answer.

26. Parents are asked what they already know about feeding before the cleft palate team professional(s) presents the information regarding feeding and nutrition.

1	2	3	4	5
Never	Rarely	Sometimes	Usually	Always

27. Parents are asked what their concerns, questions, and frustrations are regarding current feeding issues before the evaluation and intervention.

1	2	3	4	5
Never	Rarely	Sometimes	Usually	Always

28. The recommendations that the feeding professional on the team makes are consistent with the recommendations that the birth hospital made.

1	2	3	4	5
Never	Rarely	Sometimes	Usually	Always

29. Parents are provided sufficient support and information to care for the feeding issues of their newborn with cleft lip and/or palate.

1	2	3	4	5

Never Rarely Sometimes Usually Always

V. Follow-up

30. When does the initial follow-up meeting occur, and what is the purpose(s)?

____

____

31. Does your team conduct program evaluations regarding initial or ongoing management of newborns served by the Cleft Palate Team?

___No

___Yes (If yes, what are the methods you use to evaluate your effectiveness?)

____

____

____

32. What are some of the strengths of your team that help to best serve the newborn with cleft lip and/or palate?

____

____

____

____

33. What changes are needed to improve care for the newborn with cleft lip and/or palate in the future or what are hindrances at present to providing better care for newborn with cleft lip and/or palate?

____

____

____

____

Thank you for taking the time to complete this survey.