THE INFORMATION EXCHANGE BETWEEN
PARENTS OF CHILDREN WITH CLEFT LIP AND PALATE AND
MEMBERS OF THE CRANIOFACIAL TEAM

by

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For the degree of Master of Arts

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*We also certify that written approval has been obtained for any proprietary material contained therein.
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List of Abbreviations

**ASHA:** American Speech-Language-Hearing Association

**CLP:** Cleft Lip and/or Palate

**FTT:** Failure to Thrive

**PEPC:** Parent Experiences of Paediatric Care

**SLP:** Speech Language Pathologist

**SPSS:** The Statistical Package for the Social Sciences
The Information Exchange Between Parents of Children with Cleft Lip and Palate and Members of the Craniofacial Team

Abstract

by

LINDSAY ANN KODRAMAZ

The purpose of this study was to expand on previous research that focused on what information parents felt was critical to know about their child with cleft lip and palate (CLP) and to create a more detailed understanding of the exchange of information regarding feeding and swallowing that exists between parents of children with CLP and members of the craniofacial team. Questionnaires were distributed to parents of children with CLP and to craniofacial team members during craniofacial clinic at a hospital in northeast Ohio. Responses to the questionnaires were then analyzed using analytical software. Results of the study found that parents wished they received more information about specific topics related to feeding and swallowing, craniofacial team members agreed with parents about what information was most important to know about feeding and swallowing, and despite the fact that craniofacial team members reported specific information about feeding and swallowing was important to know, parents reported that they did not get, or would have like more, information on these topics.
Introduction

A cleft lip is defined as the “separation of the two sides of the lip” and often includes the upper jaw and/or upper gum (Cleft Palate Foundation, 2007). A cleft palate is defined as “an opening in the roof of the mouth in which the two sides of the palate did not fuse, or join together, as the unborn baby was developing” (Cleft Palate Foundation, 2007). Clefts of the lip and palate can occur unilaterally (on one side) or bilaterally (on both sides) (Cleft Palate Foundation, 2007). The American Speech-Language-Hearing Association reported that clefts occur in approximately 1 in 700 live births and more than 5,000 babies are born with a cleft lip and/or palate (CLP) each year in the United States (Grames, 2008).

Problems Associated with Feeding and Swallowing

Infants and children with CLP are at risk for feeding difficulties due to malformed anatomy and the changes that occur in swallow function. Infants with cleft lip may have difficulties forming a seal on the nipple and infants with cleft palate may have difficulties generating enough coordination for a suck. In either case, the infant may not be able to successfully draw milk from a nipple or breast (Mitchell & Wood, 2000; Robin et al., 2006). Because of this difficulty, the infant may consume excessive amounts of air, which can lead to burping and nasal regurgitation (Mitchell & Wood, 2000). Other feeding problems noted with children with CLP include bolus organization, retention of the bolus in the mouth before swallow initiation, swallow initiation, coughing, choking and gagging on fluids, and discomfort (Reid, 2004). Because of feeding difficulties, infants with CLP can expend high levels of energy while attempting to feed which can then lead
to longer feeding times and fatigue before consumption of adequate nutrition (Mitchell & Wood, 2000; Robin et al., 2006). This results in a cascade of other problems including poor weight gain, poor growth (as measured by height and weight), and a possibility of failure to thrive (FTT) (Beaumont, 2008; Felix-Schollart, Hoeksma, & Prahl-Andersen, 1992; Mitchell & Wood, 2000; Robin et al., 2006).

Feeding difficulties can result not only in poor physical health of the infant or child with CLP, but can result in mental and emotional health concerns for the parents as well. A study by Johansson and Ringsberg (2004) looked at parents' experiences of having a child with CLP. The study also reported that stress was evident in mothers regardless of whether they breast-fed or used a breast pump (Johansson & Ringsberg, 2004). The study quoted one mother who said, “Feeding him was very difficult. It could take an hour to give him 30 mL. It took ages, at first, to use the pump and to feed him. I felt I was under a lot of pressure, that I must get him to feed” (Johansson & Ringsberg, 2004, p.169).

A study by Trulsson and Klingberg (2003) described parents' experiences of daily living with a child with a severe orofacial handicap and found that almost all families were dealing with existential anxiety, a term that originated from “the fear of losing the child owing to major nutritional problems caused by the child's severe disability” (Trulsson & Klingberg, 2003, p.21). The study stated that nutrition problems affected the families in such a way that every day was a struggle to feed the child enough as to prevent starvation (Trulsson & Klingberg, 2003). The parents reported that the main concerns were nutritional problems and communication issues. While this article studied
populations with more severe, life-threatening conditions such as Rett syndrome, Cri du chat syndrome, and Angelmann syndrome, it still embodied the idea that the primary concern of the parents was to assure their child was surviving and that the child was being fed through any means necessary (Trulsson & Klingberg, 2003).

Another common issue that families with a child with CLP have is a disruption between parent and child bonding (Mitchell & Wood, 2000) that is often facilitated during the feeding experience. When parents feel as though they cannot feed their child in a way that ensures safety and adequate nutrition, they become overwhelmed and discouraged and begin to associate feeding with a negative experience.

Results of Feeding Problems

Infants with isolated cleft lip had similar weights as children without CLP (Beaumont, 2008). However, children with cleft lip and palate were smaller than children without CLP and children with isolated cleft palate were significantly smaller than children without CLP, indicating that they experience greater difficulties with eating and maintaining adequate nutrition (Beaumont, 2008). Therefore, children with clefts of the palate are at greater risk for becoming FTT than children without CLP or children with cleft lip only as a result of the heightened risk of feeding concerns associated with cleft palate (Beaumont, 2008).

A correlation was found between children with CLP and the rate of FTT (Pandya & Boorman, 2001). Children who were undergoing primary lip and palate repairs were carefully monitored for signs of FTT and found that the rate of FTT was 32% for unilateral cleft lip and palate, 38% for bilateral cleft lip and palate, and 49% for cleft
palate. Following the collection of data, changes were implemented to lower the rate of FTT. One change included providing a feeding-support nurse to supervise and monitor patients at risk for FTT. Data collected after the changes were applied found that the rate of FTT decreased, concluding that the changes were effective (Pandya & Boorman, 2001).

FTT not only affects the child's growth development, it can lead to a delay in surgical procedures, as well (Robin et al., 2006). If the child does not gain enough weight, surgery will be delayed until the child has gained adequate weight. This can create a vicious cycle because without repairs, the child may continue to experience difficulties with eating, and difficulties with eating can prevent growth development. Therefore, it is critical that parents be educated on how to feed their child in the most effective way possible.

Feeding Interventions: Nipples, Bottles, and Devices

Given the anatomical and physiological differences caused by CLP, external supports are often needed so that a child with CLP can effectively feed (Reid, 2004). Research indicates that there are effective ways to feed a child with CLP. Methods that can be used to improve feeding include assisted feeding devices, support, nutrition monitoring, and parent education. While there has been limited scientific investigation into feeding techniques and supports for infants with CLP, the available research should be considered best practice at this time (Reid, 2004).

Mizuno, Ueda, Kani, and Kawamura (2002) reported that a type-P nipple, which has a wider and longer shaft than a standard nipple and is designed for infants with CLP,
results in higher expression/compression pressure than a standard nipple. When the specialized nipple was combined with lactation education, feeding time was reduced and volume intake was increased, resulting in overall more effective feeding for the infant with CLP. Additionally, Savion and Huband (2005) suggest that the use of a feeding obturator may reduce stress on behalf of the parents and child and may encourage weight gain. Taken together, these studies support the idea that the use of supportive feeding devices and education can ultimately support a more normal pattern of growth for the infant with CLP and reduce the variety of difficulties often associated with feeding a child with CLP.

Shaw, Bannister, and Roberts (1999) compared the effectiveness of squeezable and rigid feeding bottles for children with CLP. The study followed 101 infants with CLP for one year with random assignment to one of the feeding techniques. The study concluded that there were similar outcomes regarding nude weight, crown-heel length, and occipito-frontal circumference across groups. However, the study reported that there was a beneficial effect on head circumference and weight in the assisted feeding group, or the group using the squeezable bottle, providing evidence that assisted feeding improves growth in children with CLP. The authors also stated that assistance from a specialist health visitor service for feeding assessment and counseling can be clinically helpful and cost effective based on the use of additional outside supports who assessed and counseled the families in the study (Shaw et al., 1999).

Two types of feeding devices have been proven beneficial to reduce feeding time, decrease vomiting, and improve weight gain. The first was a “gravity-flow” nipple that
attaches to a squeezable plastic bottle and utilizes the same concept as a bulb syringe method. (Martin, 1983). The “gravity-flow” nipple is placed into the back of the mouth and the bottle is squeezed to dispense the formula onto the back of the tongue. The second assisted feeding device discussed was the Haberman feeder (Campbell & Tremouth, 1987). The design of the Haberman feeder allows the child to compress the teat alone while sucking instead of compressing air inside the bottle (Campbell & Tremouth, 1987). The study found that children with CLP fed faster and more easily with the Haberman feeder, there was less vomiting, weight gain was adequate, and parents preferred the Haberman feeder (Campbell & Tremouth, 1987), further supporting the notion that feeding for infants with CLP can be conducted in a more safe and effective way when feeding devices are provided to parents.

*Role of Craniofacial Team Members*

The craniofacial team is a multidisciplinary team of medical and allied health professionals that, together, address the wide array of health and developmental concerns that arise in the care and rehabilitation process of a child born with CLP (Robin et al., 2006). Members of the craniofacial team can include a clinic director, clinic coordinator, audiologist, craniofacial surgeon, geneticist, neurosurgeon, nurses, occupational therapist, orthodontist, otorhinolaryngologist, pediatrician, pediatric anesthesiologist, pediatric dentist, prosthodontist, pediatric radiologist, physical therapist, plastic surgeon, speech language pathologist (SLP), and surgeon's assistant (Robin et al., 2006). The members of the team often gather on a single day, often referred to as a “craniofacial clinic,” to collectively meet so that parents can have all of their needs and/or concerns addressed in
one day, without having to attend numerous medical appointments. This model is not only efficient for families, it is also beneficial to the craniofacial team members as it allows all working on the team to be familiar with the child with CLP and to conduct open conversations regarding treatment options as a team.

The role of the SLP on a craniofacial team, aside from assessing speech and language disorders, includes knowing the physiology and neurophysiology of a swallow, knowing etiologies that may result in feeding or swallowing issues, knowing the reason for adequate nutrition and the result of inadequate nutrition, and recognizing signs and symptoms of problems with feeding and swallowing (American Speech-Language-Hearing Association, 2001). Together with the other members of the craniofacial team, the SLP assists with the assessment, intervention, and education of feeding and swallowing issues so that the families receive the best possible care. These duties are in addition to the tasks that the SLP already accomplishes on a regular basis including identifying individuals at risk for feeding and swallowing problems, conducting necessary examinations that assess feeding and swallowing, providing treatment, and providing education, counseling, and training to family members (American Speech-Language-Hearing Association, 2001).

*Information Delivery and Information Seeking*

While there are many available techniques and devices used to assist with feeding, and the research indicates increase in effectiveness of feeding when used, parents are not always informed of these options. For example, questionnaire data gathered by Byrnes, Berk, Cooper, and Marazita (2003) found that parents of children with CLP wanted the
informing health professionals to be more sensitive, empathetic, and to provide a frank discussion of other possible associated conditions with CLP. Specific parent comments regarding feeding included that a parent was not shown how to feed her child until she got to the Cleft Palate Center. A second parent reported receiving inconsistent information in that she was told she could breastfeed by her pediatrician, but the lactation consultant told her she could not. She noted that this information was given only one hour before discharge (Byrnes et al., 2003).

While parents most trust information given to them by their health care practitioner (Wainstein, Sterling-Levis, Baker, Taitz, & Brydon, 2006), they will seek out alternative sources when they do not receive information that they perceive to be adequate. One such source is the Internet and parents find this to be one of their preferred sources (D’Alessandro, Kreiter, Kinzer, & Peterson, 2004; Khoo, Bolt, Babl, Jury, & Goldman, 2008). Khoo et al. (2008) reported that parents felt the Internet provided knowledge and assisted them with understanding a condition, despite the fact that information found on the Internet can be unreliable. The authors reported that parents seek information more often from ‘Google’ than from other websites that contain “known and authoritative” sources of health information, such as hospital websites. However, parents reported a greater trust in a hospital-based website compared to a search engine such as Google. Given the parental reports of a higher level of trust in a hospital-based website, parents reported that they would respond favorably to credible websites being directly suggested by their health care team (Khoo et al., 2008). While the Internet is clearly an important tool for information access, information should also be available in
print form so that a lack of computer access does not limit a family's ability to gain essential information regarding their child's condition (Blackburn & Read, 2005). Outside of information gained through health care sources and the Internet, Johansson and Ringsberg (2004) found that parents felt it was important to meet other parents of children with CLP as a way to exchange thoughts and practical advice.

One study used survey research to determine that the top three sources of information about health, in rank order, were health care providers, Internet/web sites, and friends and co-workers. Other sources of health-related information included (in order of frequency of use) family members, magazines, newspapers, television, general word of mouth, librarian/library, and other (D'Alessandro et al., 2004). To summarize, parents place the greatest trust in their health care professionals and frequently seek out these professionals for information. When these individuals are not available, they will go to alternate sources, such as the Internet, despite having less trust in these sources. Ultimately, parents would prefer speaking to health care professionals to receive information or having these professionals recommend trusted resources on-line.

Previous Research: What Information Parents Want

A study by Young, O'Riordan, Goldstein, and Robin (2001) reflected the previously reported information in that it asked parents questions about the issues they dealt with regarding their child with CLP and found feeding to be a top priority. The purpose of the study was to determine what information parents of children with CLP wanted to specifically hear on their child's first day of life, to distinguish this information from that which could be heard at a later time, and to evaluate whether informers met
these parents' needs. The authors ultimate goal was to uncover ways that the parent-informer interaction could be more effective in conveying information, lowering anxiety, and enabling earlier bonding.

To achieve this, Young et al. (2001) provided parents of children with isolated CLP a questionnaire to complete that asked questions about diagnosis, education, prognosis, management and treatment, home management, and psychosocial issues. Each question contained two components – one that asked whether the parent recalled receiving specific information from the informer during the child's first day of life and the second asked the parent to rank how “critical” it was for them to hear the information at that time. The study found that the topics that were most important to parents pertained to feeding methods and home management. However, it appeared that the information that parents felt was most critical was perceived by the parents to not have been delivered to them (Young et al., 2001).

As previously stated, there are problems associated with feeding and swallowing in children with CLP, there are ways to improve the feeding process through the help of assistive devices, and parents seek out information about ways to better this process through various resources, including the craniofacial team. The purpose of the present study is to expand on the study conducted by Young et al. (2001), to examine the information the parents are receiving and the craniofacial team is providing, and to create a more detailed understanding of the exchange of information regarding feeding and swallowing that exists between parents of children with CLP and members of the craniofacial team. The specific aims of this exploratory study are to identify what
information about feeding and swallowing parents of children with CLP reported they were given by the craniofacial team, to identify what information about feeding and swallowing the craniofacial team reports they are giving to parents of children with CLP, and to determine if a discrepancy exists between the information about feeding and swallowing that the parents perceive they are getting and the information about feeding and swallowing that the craniofacial team reports they are giving.
Method

Participants

Parents of children with CLP were approached by the researcher during craniofacial clinic conducted at an area hospital and were asked to complete the study questionnaire. The target population was biological parents of children with CLP under the age of six, but the study population included both biological and internationally adopted children with CLP under the age of eleven. All parents of children with CLP were considered potential respondents regardless of their children’s co-morbid disorders or genetic conditions. The target study recruitment was 40 respondents, given significant results with that sample size in similar studies (Young et al., 2001). Data collection occurred over an eight week period and the total number (N) of questionnaires collected during that time was 36 (N=36).

All members of the craniofacial team at the study site were also approached and asked to participate. A total of ten team members were given questionnaires with all team members returning the questionnaires to the researcher either in person or via mail.

The study was approved by the participating hospital's Institutional Review Board. Completion of the questionnaire served as study consent.

Materials

Parent questionnaire

The creation of the parent questionnaire was based on previous research that focused on what information parents felt was critical to know about their child with CLP (Young et al., 2001) and general principles of health care information sharing and seeking
The questions were created to help improve communication between parents and the craniofacial team and to educate professionals about the most effective means of communication. The questions included open-ended responses, closed responses (e.g. 'yes,' 'no,' and 'not sure'), and five point Likert scale statements (which ranged from 'strongly agree' to 'strongly disagree') that asked about the parents' experiences with feeding their child with CLP and their initial meeting with the craniofacial team. The visit with the craniofacial team was defined as the meeting with the professionals that occurred a few weeks after the child's birth. Some of the open-ended questions were reworded as closed-ended questions to support consistency among parental responses. Questions were written as both positive and negative statements in an aim to make parental responses consistent among the Likert scale statements. (See Appendix A).

Table 1

<table>
<thead>
<tr>
<th>Question Number</th>
<th>Purpose and Justification of Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>To identify if the speech language pathologist played a role in the experience of sharing information regarding feeding and swallowing with the parents of children with CLP.</td>
</tr>
<tr>
<td>2</td>
<td>To identify what specific information the parents wanted to know regarding feeding and swallowing as a way to expand on the Young et al. (2001) finding.</td>
</tr>
<tr>
<td>3, 4, 14</td>
<td>To find out where parents went to find information about feeding and swallowing and who parents went to as a</td>
</tr>
</tbody>
</table>
To determine if parents received a demonstration of feeding and how they received this demonstration.

To determine if parents were given the opportunity to ask questions during their initial meeting with the craniofacial team and if the parents took this opportunity to ask questions concerning feeding and swallowing.

To determine what information about feeding and swallowing the parents felt was important, but never received.

To understand parents' opinions about the information sharing experience. These questions were derived from the Parent Experiences of Paediatric Care (PEPC) Questionnaire. A study by Garratt, Bjertnaes, and Barlinn (2006) focused on the reliability and validity of the PEPC Questionnaire and concluded that there was sufficient evidence to support internal consistency, test-retest reliability, and validity (Garratt et al., 2006).

To differentiate the knowledge of the craniofacial team versus the craniofacial team's ability to share the information about feeding and swallowing at a level the parents can understand.

To aid in finding out what information the parents received about feeding and swallowing and in what area the parents felt they could use more information about feeding and swallowing.
**Craniofacial team questionnaire**

The craniofacial team questionnaire was created to reflect the same themes that are present in the parent questionnaire, with a focus on the team member's perception of information exchange instead of from the parents' perspective. The questions included open-ended responses, closed responses (e.g. 'yes' and 'no'), and five point Likert scale statements (which ranged from 'strongly agree' to 'strongly disagree') (See Appendix B).

Table 2

Craniofacial Team Questionnaire

<table>
<thead>
<tr>
<th>Question Number</th>
<th>Purpose and Justification of Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>To determine the role of the craniofacial team member.</td>
</tr>
<tr>
<td>2</td>
<td>To determine approximately how much time the craniofacial team members spend discussing issues related to feeding and swallowing.</td>
</tr>
<tr>
<td>3</td>
<td>To understand what the craniofacial team members felt was most important to know about feeding and swallowing and, therefore, assume that what the team members felt was most important to know was discussed during the initial visit with the parents.</td>
</tr>
<tr>
<td>4</td>
<td>To see if members of the craniofacial team provide the parents with written information about feeding and swallowing.</td>
</tr>
<tr>
<td>5</td>
<td>To see what questions parents are asking and what questions the craniofacial team members are answering, assuming that the team members answer the questions that parents ask.</td>
</tr>
</tbody>
</table>
To determine how the craniofacial team members helped instruct parents understand how to feed their children.

To understand where parents go and who parents go to when they need more information about feeding and swallowing, based on what the craniofacial team members observe.

To see what information about feeding and swallowing the craniofacial team members give to the parents and where they send the parents to get additional information about feeding and swallowing.

To gain information about how prepared the craniofacial team members are to discuss the topic of feeding and swallowing and whether or not they feel they have adequate time to provide the parents with information about feeding and swallowing.

**Procedures**

After receiving approval from the Akron Children's Institutional Review Board, questionnaires were distributed and collected during craniofacial clinic at Akron Children's Hospital in Akron, Ohio. Data was gathered from May 2009 – June 2009. The parents and craniofacial team members were informed of the purpose of the exploratory study and completion of the questionnaire was considered study consent. One CLP parent support group meeting was also attended by the investigator at Akron Children's Hospital as a way to collect additional questionnaires from parents.
Data Analysis

The questionnaires were then reviewed and the responses to the questions were analyzed using qualitative measures. To determine the results of the first two specific aims, the responses to the closed-ended and open-ended questions on both the parent and craniofacial team questionnaires were coded so that each response correlated with a number. For example, all 'yes' responses were designated the number one and all 'no' responses were designated a zero. Closed-ended questions that were answered 'not sure' were designated a number two. These numbers were then calculated to determine frequencies using descriptive statistics from the SPSS Version 17 analytical software. The open-ended responses were transcribed and grouped into themes. Two raters then investigated the themes until consensus was achieved. Themes for specific aim one included: additional problems associated with CLP; adequate nutrition; bottles/nipples; cleaning/hygiene for lip and palate; complications with feeding; how to feed or position the child; information about specialized bottles and feeders; pain; presence of cleft; preventing aspiration; preventing emesis (i.e. spit-up); relationship between cleft and breastfeeding; signs, symptoms, and causes of feeding difficulties; specialized bottles and feeders; and using medical devices. Themes for specific aim two included: breastfeeding; equipment/specialized devices (e.g. bottles and feeders); feeding techniques; nutrition; seeking additional resources; and warning signs of feeding difficulties.

Responses to the questions then received a one if the theme was present and a zero if the theme was not a part of the parent's response. Frequencies of responses were then calculated using SPSS Version 17. Likert scale responses were coded based on the five
point scale ranging from strongly disagree (one) to strongly agree (five). All parent responses were entered into the database and frequencies were calculated using SPSS Version 17.

The open-ended responses used from specific aims one and two were used to determine the results of specific aim three. The themes of the parent responses were then matched to the themes of the craniofacial team responses, where applicable. Those that were matched included themes about breastfeeding, specialized bottles and feeders/specialized devices, and complications with feeding/warning signs. These results were then analyzed using both descriptive statistics and t-tests from the SPSS Version 17 analytical software as a way to determine if there was a discrepancy between the information shared between the craniofacial team and the parents.
Results

Thirty-six parents of children with CLP completed the parent questionnaires. Data from all completed questionnaires was used in the study. The parent group consisted of 27 biological mothers (75%), 6 biological fathers (16.7%), 2 adoptive mothers (5.6%), and one biological grandmother (2.8%). The ages of the parents ranged from 19-52 years, with a mean age of 32 years (SD = 8 years). The children with CLP in the study included 21 males (61.8%) and 13 females (38.2%). Their ages ranged from seven days old-11 years old, with an average age of 37 months (SD = 29 months). Additional diagnoses or syndromes included one child (2.8%) with autism spectrum disorder. In the study sample 36.4% of parents knew that their child had a CLP prior to the birth. Parents who reported their children had difficulties with feeding totaled 45.5%, almost half of the questionnaire respondents.

Based on calculations from the Four Factor Index of Social Status by A.B. Hollingshead (Hollingshead, 1975), the scores to calculate socioeconomic status ranged from 9-59.5, with a mean score of 39. The parent group consisted of a socioeconomically diverse sample, ranging from unskilled workers/unemployed persons at the poverty level to professional workers classified as upper middle class. Most of the parents fell within the area of skilled, non-professional workers with a middle class income. The parents' education levels ranged from the eighth grade to a doctorate level.
### Table 3
Demographic Information

<table>
<thead>
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<th></th>
<th>Number</th>
<th>Percentage</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parents</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mothers</td>
<td>27</td>
<td>75%</td>
<td>-</td>
</tr>
<tr>
<td>Fathers</td>
<td>6</td>
<td>16.7%</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>8.4%</td>
<td>-</td>
</tr>
<tr>
<td><strong>Children</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>21</td>
<td>61.8%</td>
<td>-</td>
</tr>
<tr>
<td>Females</td>
<td>13</td>
<td>38.2%</td>
<td>-</td>
</tr>
<tr>
<td><strong>Style of Feeding</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bottle</td>
<td>25</td>
<td>78.1%</td>
<td>-</td>
</tr>
<tr>
<td>Breast</td>
<td>2</td>
<td>6.3%</td>
<td>-</td>
</tr>
<tr>
<td>Both</td>
<td>2</td>
<td>6.3%</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>9.4%</td>
<td>-</td>
</tr>
<tr>
<td><strong>Type of Cleft</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleft Lip</td>
<td>4</td>
<td>13.8%</td>
<td>-</td>
</tr>
<tr>
<td>Cleft Palate</td>
<td>3</td>
<td>10.3%</td>
<td>-</td>
</tr>
<tr>
<td>Cleft Lip and Palate</td>
<td>16</td>
<td>55.1%</td>
<td>-</td>
</tr>
<tr>
<td>Submucous</td>
<td>3</td>
<td>10.3%</td>
<td>-</td>
</tr>
<tr>
<td>Soft Palate</td>
<td>2</td>
<td>6.9%</td>
<td>-</td>
</tr>
<tr>
<td>Midline Facial Cleft</td>
<td>1</td>
<td>3.4%</td>
<td>-</td>
</tr>
<tr>
<td><strong>Additional Diagnoses</strong></td>
<td>1</td>
<td>2.8%</td>
<td>-</td>
</tr>
<tr>
<td>Hospitals</td>
<td>19</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Socioeconomic Status</td>
<td>-</td>
<td>-</td>
<td>39</td>
</tr>
</tbody>
</table>

Ten members of the craniofacial team completed the team questionnaires. These included two plastic surgeons, two speech-language pathologists (SLP), one audiologist, one craniofacial patient intake/service coordinator, one registered nurse/craniofacial team nurse, one orthodontist, one otorhinolaryngologist, and one social work supervisor.

**Specific Aim 1**

As noted above, 45.5% of respondents indicated that their child with CLP had feeding difficulties. Only 6.8% of respondents recalled discussing feeding and
swallowing issues with an SLP. This indicates that a greater number of parents experienced problems with feeding and swallowing than those who discussed the issue with an SLP.

The number of respondents who reported asking questions during their initial visit with the craniofacial team was 60.6%. Common questions asked during the initial visit included the signs, symptoms, and causes of feeding and swallowing difficulties (19.4%), how to feed (11.1%), information about nutrition and consumption amount (11.1%), information about bottles and nipples (8.3%), information about cleaning and hygiene (2.8%), information about pain (2.8%), and additional problems the child may have (2.8%).

Figure 1

Common Questions Parents Ask
The top three issues related to feeding and swallowing that parents reported were most important during the first few weeks of life included adequate nutrition (27.8%), specialized bottles and feeders (25%), and how to feed/position the child (22.9%). Additional responses included preventing aspiration (13.9%), preventing emesis or spit-up (11.1%), and using medical devices (5.6%).

Parents were given a checklist within the questionnaire as a way to identify the type of information received from the craniofacial team during their initial visit. Most parents reported receiving information about potential difficulties with feeding and swallowing (75%), how to feed with a bottle (69.4%), special nipples and feeders (58.3%), and a reference list of the craniofacial team members (55.6%). Only 38.9% reported receiving information about support groups. Even fewer parents (36.1%) recalled receiving a video or DVD about feeding and swallowing. Finally, 25% of parents recalled receiving information for a website about feeding and swallowing issues and only 13.9% of parents recalled being given information about breastfeeding.
Figure 2

Information from Parent Checklist
Respondents who recalled and reported being told or shown how to feed (either through demonstration, explanation, video, etc.) totaled 65.6%. The majority of the parents reported that they were shown how to feed by a demonstration (44.4%) or video (30.6%). Fewer parents reported that they were told how to feed via a verbal explanation (13.9%). Only one parent recalled being able to practice feeding before the birth, but because this occurred prior to the birth of the child, the instruction was not provided by the craniofacial team.

Figure 3

How Parents Received Instructions About Feeding
A vast majority of respondents agreed or strongly agreed that the information about feeding and swallowing given by the craniofacial team was “enough” (combined total of 86.2%) and was “easy to understand” (combined total of 82.1%). Respondents disagreed or strongly disagreed that the same information was “too much” (combined total of 92.0%), “not enough” (combined total of 72.0%), and “hard to understand” (combined total of 84.6%). This indicates that parents reported they did not receive too much information and that they found the information about feeding and swallowing to be understandable.

Table 4

Opinions of Parents About Information Received from the Craniofacial Team

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Agree Somewhat/Disagree Somewhat</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enough</td>
<td>34.5%</td>
<td>51.7%</td>
<td>13.8%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Not enough</td>
<td>0%</td>
<td>8%</td>
<td>2%</td>
<td>36%</td>
<td>36%</td>
</tr>
<tr>
<td>Too much</td>
<td>0%</td>
<td>0%</td>
<td>8%</td>
<td>48%</td>
<td>44%</td>
</tr>
<tr>
<td>Easy</td>
<td>25%</td>
<td>57.1%</td>
<td>14.3%</td>
<td>3.6%</td>
<td>0%</td>
</tr>
<tr>
<td>Hard</td>
<td>0%</td>
<td>3.8%</td>
<td>11.5%</td>
<td>50%</td>
<td>34.6%</td>
</tr>
</tbody>
</table>
Those who disagreed or strongly disagreed that they were overwhelmed by information about feeding and swallowing given by the craniofacial team totaled 63.4% of respondents.

Figure 4

Parents' Opinions About Being Overwhelmed by Information

Parents responded with a variety of answers to the open-ended question, “Looking back to the first weeks after your child was born, what do you wish you knew about feeding and swallowing?” The various answers were categorized into themes, which included presence of cleft (8.3%), specialized bottles and feeders (8.3%), complications with feeding (5.6%), and the relationship between the cleft and breastfeeding (5.6%).
When parents were asked to rank on a five point Likert scale whether they wished they had received more information in the areas of breastfeeding, feeding with a bottle, special nipples/feeders, feeding difficulties, feeding techniques, and support groups, they responded with varying answers. Approximately one-third of parents were not strongly interested in breastfeeding information (31.6% strongly disagree), but almost half of the parents wished they had received more information about bottle feeding (40%). Parents also reported a high level of interest in receiving information about feeding difficulties (44%), feeding techniques (42.3%), and special nipples and feeders (36%). Parents reported mixed opinions regarding support group information with 26.1% indicating they would have liked more information (agreed) and 21.7% indicating that they did not have a strong interest in the information (strongly disagreed).

Table 5

<table>
<thead>
<tr>
<th>What Parents Want More Information About</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Agree Somewhat/Disagree Somewhat</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breastfeeding</td>
<td>21.1%</td>
<td>21.1%</td>
<td>10.5%</td>
<td>15.8%</td>
<td>31.6%</td>
</tr>
<tr>
<td>Feeding with bottle</td>
<td>8%</td>
<td>40%</td>
<td>20%</td>
<td>24%</td>
<td>8%</td>
</tr>
<tr>
<td>Special nipples/ feeders</td>
<td>16%</td>
<td>36%</td>
<td>16%</td>
<td>20%</td>
<td>12%</td>
</tr>
<tr>
<td>Feeding difficulties</td>
<td>8%</td>
<td>44%</td>
<td>12%</td>
<td>28%</td>
<td>8%</td>
</tr>
<tr>
<td>Feeding techniques</td>
<td>11.5%</td>
<td>42.3%</td>
<td>19.2%</td>
<td>15.4%</td>
<td>11.5%</td>
</tr>
<tr>
<td>Support groups</td>
<td>17.4%</td>
<td>26.1%</td>
<td>17.4%</td>
<td>17.4%</td>
<td>21.7%</td>
</tr>
</tbody>
</table>
When asked in an open-ended format about *where* parents went for additional information about feeding and swallowing, most parents responded with the Internet (41.7%), pediatrician/nurses (33.3%), or craniofacial clinic (19.4%). Other sources of information included hospital/health clinic (13.9%), books/movies (8.3%), library (5.6%), friends/family (5.6%), Help Me Grow (2.8%), and other (2.8%).

Figure 5

Where Parents Went for Additional Information
When asked in another open-ended question about *who* parents went to for additional information about feeding and swallowing, many parents responded with similar answers to the *where* including three primary sources of doctors/nurses (72.2%), craniofacial clinic (22.2%), and hospital/health clinic (13.9%). Additional resources included friends/family (11.1%), social worker/adoption agency (2.8%), Help Me Grow (2.8%), parenting group/support group (2.8%), and listserves (2.8%).

Figure 6

Who Parents Went to for More Information

<table>
<thead>
<tr>
<th>Resource</th>
<th>Percentage of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors/Nurses</td>
<td>72.2%</td>
</tr>
<tr>
<td>Craniofacial Clinic</td>
<td>22.2%</td>
</tr>
<tr>
<td>Hospital/Health Clinic</td>
<td>13.9%</td>
</tr>
<tr>
<td>Friends/Family</td>
<td>11.1%</td>
</tr>
<tr>
<td>Social Worker/Adoption Agency</td>
<td>2.8%</td>
</tr>
<tr>
<td>Help Me Grow</td>
<td>2.8%</td>
</tr>
<tr>
<td>Parenting Group/Support Group</td>
<td>2.8%</td>
</tr>
<tr>
<td>Listserves</td>
<td>2.8%</td>
</tr>
</tbody>
</table>
When asked to provide specific information about additional resources ranging from one meaning strongly disagree to five meaning strongly agree, most parents (40.7%) agreed they went to the Internet for supplemental information about feeding and swallowing. Some parents (32%) agreed that they went to the craniofacial team for additional information and almost half of the parents (48%) agreed somewhat/disagreed somewhat that they went to the craniofacial team for further information about feeding and swallowing. When it came to asking friends and family members for information, the same number of parents of children with CLP agreed somewhat and disagreed somewhat (30.8%) as those parents who disagreed (30.8%) that they utilized their friends and family as resources. Over half of the parents (59.3%) strongly disagreed that they went to the library to seek information about feeding and swallowing.

Table 6

<table>
<thead>
<tr>
<th>Additional Sources of Information</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Agree Somewhat/Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLP Team</td>
<td>0%</td>
<td>32%</td>
<td>48%</td>
<td>20%</td>
<td>0%</td>
</tr>
<tr>
<td>Friends/family</td>
<td>0%</td>
<td>11.5%</td>
<td>30.8%</td>
<td>30.8%</td>
<td>26.9%</td>
</tr>
<tr>
<td>Internet</td>
<td>0%</td>
<td>40.7%</td>
<td>29.6%</td>
<td>11.1%</td>
<td>18.5%</td>
</tr>
<tr>
<td>Library</td>
<td>0%</td>
<td>7.4%</td>
<td>14.8%</td>
<td>18.5%</td>
<td>59.3%</td>
</tr>
</tbody>
</table>
Specific Aim 2

Nine out of ten team respondents (90%) reported that parents asked questions about feeding and swallowing during their initial visit. The only craniofacial team member that reported parents do not ask questions was the speech-language pathologist. However, the other speech-language pathologist on the team reported that parents do ask questions about feeding and swallowing. In an open-ended format, craniofacial team members responded that parents ask questions pertaining to warning signs of feeding and swallowing difficulties (40%), special equipment and devices for feeding (40%), nutrition (30%), and breastfeeding (10%).

Figure 7

Questions Parents Ask the Craniofacial Team
In an open-ended format, the craniofacial team was asked what they thought was most important for parents to know about feeding and swallowing. Their top three responses included seeking additional resources (50%), knowing the warning signs of feeding difficulties (50%), and understanding about adequate nutrition (40%). Additional topics included feeding techniques (30%), special devices (10%), and breastfeeding (10%).

Figure 8
Information the Craniofacial Team Thinks is Most Important to Know
When asked whether or not the team members provided parents with written information, 40% of respondents said “yes.” The team members that reported providing this information included the craniofacial patient intake/service coordinator, plastic surgeons, and registered nurse/craniofacial team nurse.

Craniofacial team members were given a checklist and asked to identify what additional information/sources of information they gave to the parents during craniofacial clinic. The most common response was 'other,' where six out of ten team members (60%) listed information about other professional referrals, including their contact information. Five out of ten team members (50%) reported giving their phone number. Other resources provided by the team to parents included support group information (30%) and a website containing information about feeding and swallowing (20%).

Figure 9
Additional Information Craniofacial Team Provides
Craniofacial team members who reported that they personally provided feeding instructions to parents were the craniofacial patient intake/service coordinator, plastic surgeon, and registered nurse/craniofacial team nurse. These methods included demonstration (20%), verbal explanation (20%), and/or observation with instruction (10%). A total of 40% of craniofacial team members reported that parents were given instructions on how to feed via video.

Figure 10

How Craniofacial Team Members Give Instructions About Feeding
Specific Aim 3

A small percentage of the parents (19.5%) reported that they wished they knew information about one or more of the following topics during their child's first few weeks of life: specialized bottles and feeders, complications with feeding, and the link between the cleft and breastfeeding. A majority of the craniofacial team members (70%) reported that the same topics were the most important to know about feeding and swallowing in the early days of life. It was assumed that because the craniofacial team members felt this information was important to know, the team members shared this information with the parents of children with CLP. However, because a select group of parents reported that they wished they knew this information about feeding and swallowing, it indicates that they were not provided this information, did not recall receiving the information, or the information was not salient. This resulted in a significant difference between what parents wished they knew about feeding and swallowing ($t[36] = p = .017$) and the information the craniofacial team members felt was most important for the parents to know about feeding and swallowing ($t[10] = p = .001$).

Specifically, additional t-tests were conducted to identify more specific areas of discrepancy between specific topics that parents wished they knew about during the first few weeks of life and the specific topics the craniofacial team members reported were most important to know. There was no significance between the subject of breastfeeding ($t[36,10] = .103, p = .872$) or specialized feeding devices ($t[36, 10] = .103, p = .872$). The topic of complications with feeding was calculated to be highly significant ($t[36, 10] = 36.010, p = .000$), with the craniofacial team members not indicating this as one of their
highest priorities.

The information from the craniofacial team member checklist indicated that half of the craniofacial team members (50%) gave their phone number or contact information to the parents of children with CLP during their first visit. Only just over half of the parents of children with CLP (55.6%) recalled receiving contact information from the craniofacial team during their initial visit.

Three of the craniofacial team members (30%) reported giving information about cleft lip and palate support groups, indicating that the parents should have received this information from multiple sources. However, only slightly over one-third of the parents surveyed (38.9%) reported getting information during their initial visit.

The number of craniofacial team members who reported supplying the parents with a website containing information about feeding and swallowing was 20% or two craniofacial team members. Only a small percentage of parents (25%) recalled receiving information for a website about feeding and swallowing, indicating that when only a few team members provide the parents with information about feeding and swallowing, merely a small number of parents recall receiving this information.

The craniofacial team reported that feeding instruction was provided by multiple team members, with 30% of the team stating that they personally discussed feeding. However, parental report indicated that only 65.6% of the sample recalled receiving feeding instruction in some form. Upon comparison, a greater percentage of craniofacial team members (40%) reported that an instructional video was shown during the initial craniofacial team meeting, while a small number of parents (30.6%) recalled watching a
video about feeding and swallowing. Incidentally, 20% of team members reported showing parents how to feed through a hands-on demonstration and 44.4% of parents reported that they received their feeding instruction through a hands-on demonstration.
Discussion

The results of this study support the finding of the Young et al. (2001) study indicating that parents indeed desire information about feeding and swallowing and that it is a topic of major concern for families.

Specific Aim 1

Based on the results, a larger percentage of parents reported experiencing feeding and swallowing problems than those who recalled discussing these issues with the SLP at the craniofacial clinic. At the facility used in the study, SLPs were not the primary resource for information about feeding and swallowing, despite American Speech-Language-Hearing Association practice guidelines in the area of CLP (American Speech-Language-Hearing Association, 2001). While the primary source of information about feeding and swallowing did not come from the SLP, parents at this site reported receiving this information but primarily from alternate sources, such as the nurse and plastic surgeon. Given the nature of professional practice of providing clinical services in a team, the initial source of information is not the main concern, rather that each member of the team contributes specific expertise. Because ASHA professional practice guidelines (American Speech-Language-Hearing Association, 2001) include assessing, treating, and educating the families about issues related to feeding and swallowing, it is within the role of the SLP on the craniofacial team to provide these services to families and to reinforce, repeat, and confirm the information that may have been presented to them by another member of the team.

Consistent with the literature (Trulsson & Klingberg, 2003), most parents in this
study had concerns about adequate nutrition. There parents reported a desire to gain specific information that would improve comfort and efficiency of feeding. This included information about specialized bottles and feeders and appropriate positioning during feeding. Consistent with the areas that parents identified as important, parents reported that they wished they had received additional information on specialized nipples, bottles, and feeders, complications associated with feeding, information focused on bottle feeding, and general feeding techniques. One might therefore infer that because parents wished they had received more information on these topics, the information they were provided did not adequately address the scope of their concerns. One contributing factor to the above inconsistency may be that craniofacial teams are not doing enough in terms of how systematically they present information. Parents did not always report receiving similar information from the craniofacial team. More than half of parents recalled receiving information about difficulties with feeding and swallowing, feeding with a bottle, and special nipples and feeders. However, information on these topics was discussed with no more than 75% of the parent sample, indicating that at least 25% of parents did not receive or do not remember receiving this information. It may be that the parents did not recall receiving it, received it but did not read it or understand it, did not receive the information multiple times, or were not ready to handle the information that was presented to them. Parents may also have had different recollections of information they received because the method of presenting information could have changed over time or the craniofacial team members themselves could have been different throughout the years, both of which could have contributed to the differing responses of parents.
When people do not feel they received adequate information, there can be a cascading effect in that they will seek additional resources to satisfy their desire for information. Similar to previous research (D'Alessandro et al., 2004; Khoo et al., 2008), most parents in this study used the Internet as a source of additional health related information. Because Internet content can vary in terms of credibility, parents may receive misleading information which could serve to heighten anxiety or concern. Because parents view health care professionals as the most trusted source of information (Wainstein et al., 2006), it is the role of the craniofacial team, which should include the SLP in some capacity, to provide the parents with more information about feeding and swallowing during their craniofacial visit or to offer alternate, reliable sources where parents can go if they have additional questions.

Parents indicated both that they would like additional information and that they would be likely to seek other sources to provide informational support. Therefore, it is not surprising that parents generally reported that they did not feel overwhelmed by the information that was provided by the craniofacial team. The majority of parents agreed or strongly agreed that the information they received was easy to understand and felt that the amount of information provided was adequate and appropriate. Though minimal, an equal number of parents ranked the information about feeding and swallowing as not easy to understand and as hard to understand. Comprehension of the information about feeding and swallowing may have been related to the parents' education level or socioeconomic status, though the correlation was not calculated in this study. The study can therefore draw the conclusion that parents appear receptive to trying to understand complex
material as it relates to improving their child's health. Clinical professionals can capitalize on this willingness by providing expanded information in areas that parents are especially interested.

Specific Aim 2

The information craniofacial team members deemed as most important should be the information that is discussed with families at length and by various team members. When providing clinical services, professionals have to make a determination regarding what specific information is the most important to cover in detail with families. With a complex disorder, such as CLP, there are a multitude of topics to address with families ranging from medical care, development, and behavioral intervention options. By asking the craniofacial team members what information they felt was most important, it can be assumed that the identified topics then became the focus of their conversations with families. In this study, the topics that the craniofacial team members identified as important to know included information about warning signs of feeding difficulties, adequate nutrition, feeding techniques, special devices, and breastfeeding. Because parents did not recall receiving information on these topics or reported that they would have liked to receive more information, it should be the role of craniofacial team members in the future to repeat the perceived important information to the parents of children with CLP so that they hear the information multiple times and have a higher likelihood of remembering what information they received.

While the craniofacial team is a vital source of information, the members of the team understand that parents will need to seek additional resources outside of the team.
Furthermore, team members must be willing to provide parents with contact information for the appropriate professionals. As a clinician, it is important to have access to both the various professionals and the outside resources that contain the necessary information parents want and need as a way to bridge the communication gap between parents and the craniofacial team.

Specific Aim 3

The parents reported that they did not have knowledge of the information that the craniofacial team members regarded as most important to know, indicating that there is a communication gap between the two samples. The most significant discrepancy existed in that despite professionals stating the importance of providing information about feeding and swallowing, parents consistently reported that they did not get, or would have liked more, information on this topic. There are multiple explanations for this other than the idea that the team is not providing enough information. It is also quite possible that parents may not recall receiving this information, may have received it but did not understand it, or may not have been ready to handle the information that was presented to them. Additionally, craniofacial team members most likely have differed throughout the years, parents' education levels may effect their comprehension of the material about feeding and swallowing, and parents of children with clefts that are less severe may not have received as much information or the same information as parents of children who had more severe clefts. For example, information about complications with feeding was one topic that both the craniofacial team members identified as most important and that the parents reported they wish they would have known more about. It is possible that
because of the variety of problems that can arise associated with feeding children with CLP it is not reasonable to discuss all case scenarios with all parents, especially if the child is not experiencing problems with feeding or has problems that are relatively minor compared to other children. Because the parents' individual problems with feeding were not specifically addressed, parents may state that they were not provided adequate information by the craniofacial team. It is also possible that the individual scenario was addressed but that the information was presented in a way that was difficult for the parents to understand, especially if the parent has a lower education level. As one craniofacial team member reported to this researcher, “we... probably need a feeding pamphlet that is less technical than the one we provide – with more parent friendly instruction.”

As questionnaire results concluded, information about feeding instructions parents received that was more hands-on was indicated to be recalled more often than information presented in a verbal or written format. Consistent with the Young et al. (2001) study, just more than half of the parent sample recalled receiving instructions about feeding, with most recalling a demonstration. This number is relatively low considering how many craniofacial team members reported giving instructions on how to feed. Therefore, more craniofacial team members reported giving instructions on feeding than the number of parents who recalled receiving instructions about feeding. It is unknown why more parents did not recall receiving a feeding instruction. It may have been because some children did not attend their first craniofacial clinic at the same location as the study took place, some children did not attend craniofacial clinic as an
infant and went later in life (as with many children with submucous clefts), or some children did not have problems with feeding and the craniofacial team did not think it was necessary to give feeding instruction if it did not appear to be needed. Regardless, all parents should receive instruction on how to feed their child, especially if the child has or is at risk for having anatomical and physiological differences. If demonstration is the most efficient way to provide information, as concluded in this study and supported in the literature (Mcgowan & Graham, 2009), craniofacial team members, and specifically SLPs, in the future should provide parents of children with CLP with a demonstration of feeding techniques. Encouraging the SLP to provide parents with a feeding demonstration enhances the role of the SLP in feeding and swallowing, a professional practice supported by ASHA guidelines (American Speech-Language-Hearing Association, 2001).

Additionally, craniofacial teams in the future should provide parents with information presented in multiple formats and from multiple reliable sources as a way to reinforce and confirm information about feeding and swallowing.

Additional areas of discrepancy existed between the information the craniofacial team provided and the information the parents received, which further reinforces that there are a variety of contributing reasons and further supports the need for multiple repetitions and resources of information. As concluded in the Blackburn and Read (2005) study, though the Internet may be an important source for information access, information should also be accessible in print form so that those who do not have access to a computer are not limited to receiving the same information. As a specific example, a folder of information is given to parents at their first craniofacial clinic visit which
contains the names of the members of the craniofacial team and the phone number of the craniofacial clinic. Despite this information clearly being accessible, only half of the craniofacial team members reported that they gave contact information to parents, and just over half of the parents recalled receiving this information. One reason for this disconnect could be that the written information provided in the folder does not contain the contact information of each individual team member, but rather a general departmental number. Parents, however, may find it particularly beneficial to have individual professional contacts for when they need very specific questions answered. One such role of SLPs in the future could be to provide parents with contact information and external resources, such as websites, so that parents feel their concerns have been addressed when they ask questions about feeding and swallowing issues. As a way to reduce the number of parents who do not recall receiving specific information about feeding and swallowing, it should be the role of the craniofacial team members in the future, including the SLP, to reinforce, repeat, and confirm the information that was given to the parents during the initial craniofacial clinic meeting.
Conclusions

The results of this study highlight that parents of children with CLP had very specific concerns regarding feeding and swallowing, including feeding with a bottle, feeding difficulties, feeding techniques, and special nipples and feeders. While these issues were clearly considered by the craniofacial team to be an area of importance and there was some level of communication of feeding and swallowing material to parents by team members, a large number of parents did not recall receiving this information. This finding indicates a need for change in terms of how information is presented to families and also highlights the possibility of an enhanced role of the SLP on the craniofacial team in the future.

Limitations of the study were that there was no question that specifically asked if the craniofacial team members discussed the information they reported as important to know with the parents of children with CLP. The assumption was made that the craniofacial team members would discuss information they felt was important to know with the parents, but they were not given the opportunity to report whether or not they had discussed this information with the parents.

Additionally, there was a small number of participants who completed questionnaires. Even fewer of the participants experienced feeding and swallowing difficulties with their child with CLP. Because there was such a small sample size, the responses may not be representative of a larger sample of parents. Also, parents who did not experience problems with feeding and swallowing may not have desired more information about feeding and swallowing, which could have affected the results of the
study. The parents' education levels, the child's type of cleft, the child's age, and the child's birth hospital may all have had an effect on the results of the study, as well. Parents with lower education levels may have been more likely to report having difficulties with understanding the information about feeding and swallowing that was presented to them. Children with clefts that were not as severe may not have experienced feeding difficulties, thus indicating that there wasn't as much of a need for information about feeding and swallowing. Parents of children with CLP who were older may have met with a different craniofacial team than the team that completed the questionnaires, which could be a cause of differing responses from parents and why some parents reported wanting more information and others did not. Additionally, some team members may not have been present at all craniofacial clinics. Therefore, parents may not have received specific information about feeding and swallowing because the appropriate professional was not available to provide the parents with information. All of the parents in the study were required to recall information from the past and the results of the study were dependent on parents' memories. Parents of children with CLP who were six years old were required to recall information from over five years ago. It is unlikely that all of the parents accurately recalled what information they received and who they received it from. Finally, children in the study were born at various hospitals in Ohio and the surrounding states. These children may have attended their first craniofacial clinic at a different hospital than the one used in the study. Therefore, the information that parents recalled receiving may have been from a different hospital and may have been the reason that the parents' responses did not correlate with the responses from the craniofacial team.
In the future, it would be beneficial to gain a more in-depth understanding of what information about feeding and swallowing each of the craniofacial team members provide to parents. The current study asked the team members what they thought was most important for the parents of children with CLP to know about feeding and swallowing, but the study did not provide an opportunity for team members to outline the particular component or components they individually discussed with families. It would also be beneficial to ask the craniofacial team members their opinions about the information that they do share with parents regarding feeding and swallowing. Based on the response from the one team member, it appears as though the craniofacial team could feel as though the information about feeding and swallowing that they provide may be too complex. Despite parents denying a feeling of being overwhelmed by the information provided, the complexity of the material may be a contributing factor to the parents' inability to remember the information they were given. Information could be refocused with a more parent-friendly framework, which could be an additional area of research.

It would also be beneficial in future studies to note parents attitudes about participating in the research process, as their attitude could skew their responses and the results of the research. Finally, a larger sample size including multiple craniofacial clinic locations would allow the researcher to access a more diverse sample and to gain a greater understanding of the communication exchange between the craniofacial team and parents of children with CLP. Even though the target sample size was achieved in this study, there were multiple families that did not experience difficulties with feeding and swallowing or who did not attend craniofacial clinic for the first year of the child's life.
While the questionnaire responses of these families were greatly appreciated, a more narrow sample including only those who had feeding problems may be a source of more focused information. Attending a variety of craniofacial clinics across multiple hospitals would allow for an examination of the differences in communication styles among clinics and assist in determining which clinic provides information about feeding and swallowing to the parents in the most effective manner.
Appendix A

Parent Survey for Children with Cleft Lip and/or Palate

Please answer the following questions about your experiences with feeding your child with a cleft lip and/or palate. Please feel free to give as much information and as many details as you would like. By responding to this questionnaire, you are consenting to participate in the study. Your responses will remain confidential. You are free to answer as much of the questionnaire that you are comfortable with. Should you choose to not participate in the study, you may discontinue completion of the questionnaire at any point.

1. Did you discuss your child's feeding and swallowing issues with a speech pathologist? *(please circle one)*
   - YES
   - NO
   - NOT SURE

2. During your child's first few weeks of life, what was most important for you to know about feeding and swallowing?

3. **Where** did you go if you needed more information about feeding and swallowing? *(for example: call line, library, magazines, Internet, etc.)*

4. **Who** did you go to if you needed more information about feeding and swallowing? *(for example: doctor, friends, co-workers, health clinic, etc.)*
5. Did someone show you how to feed your child during your first meeting with the cleft lip/palate team? (The cleft lip/palate team are the professionals you went to see a few weeks after your child was born.)

(please circle one)

YES
NO
NOT SURE

If yes, how? (for example: demonstration, video, explanation, etc.)

6. During your first meeting with the cleft lip/palate team, were you able to ask questions about feeding/swallowing concerns?

(please circle one)

YES
NO
NOT SURE

7. During your first meeting with the cleft lip/palate team, did you ask any questions about feeding/swallowing concerns?

(please circle one)

YES
NO
NOT SURE

If yes, what questions did you ask?

8. Looking back to the first weeks after your child was born, what do you wish you knew about feeding/swallowing?
Please respond to the following statements about the information given to you about your child's cleft lip and/or palate. Please answer each question strongly disagree (1), disagree (2), agree somewhat and disagree somewhat (3), agree (4), and strongly agree (5). Some statements may not apply to you. If the statement does not apply, check does not apply. Some statements have a comment section where you can add details to your response.

The members of the cleft lip/palate team are the professionals you went to see a few weeks after your child was born.

9. “The information about feeding/swallowing that I received from the cleft lip/palate team...”
   a. was enough information. 1 2 3 4 5
   b. was too much. 1 2 3 4 5
   c. was not enough. 1 2 3 4 5
   d. was hard to understand. 1 2 3 4 5
   e. was easy to understand. 1 2 3 4 5

10. “When I look back to when I first learned about my child’s condition, I wish I got more information about...”
    a. breastfeeding my child. 1 2 3 4 5
    b. feeding my child with a bottle. 1 2 3 4 5
    c. special nipples/feeders. 1 2 3 4 5
    d. feeding difficulties (with breast and/or bottle). 1 2 3 4 5
    e. feeding techniques. 1 2 3 4 5
    f. feeding support groups. 1 2 3 4 5
    g. other. 1 2 3 4 5

If other, please explain:
11. *I was often overwhelmed by the information about feeding/swallowing that I got from the cleft lip/palate team.*

Comment:

12. *The information about feeding/swallowing that I got from the cleft lip/palate team was helpful.*

Comment:

Please let us know what you remember about your child's cleft lip/palate team.

13. "*My cleft lip/palate team...*"
   
   a. knew a lot about feeding/swallowing.
      
      
      
      
      
      
   b. explained information about feeding/swallowing clearly.
      
      
      
      
      
      
   c. understood my concerns about feeding/swallowing.
      
      
      
      
      
      
Please answer the following questions by circling never (1), rarely (2), sometimes (3), and often (4). Some statements may not apply to you. If the statement does not apply, check does not apply. There is also a comment section where you can add details to your response.

14. “When I needed more information about feeding my child, I went to the following sources...”

   a. the cleft lip/palate team.  1  2  3  4
   b. a friend or family member.  1  2  3  4
   c. the Internet.  1  2  3  4
   d. the library.  1  2  3  4

Comment:

Please place an X next to each item that you received during your initial meeting with the cleft lip/palate team.

____ information about the difficulties with feeding and swallowing
____ information about how to breastfeed your child
____ information about feeding your child with a bottle
____ information about special nipples and feeders for children with cleft lip and/or palate
____ information about feeding or cleft lip and/or palate support groups
____ a list of the people on the cleft lip/palate team and a way to contact them
____ a video or dvd with information about feeding and swallowing
____ a recommendation for a website that has information about feeding and swallowing
In this final section, please provide information to help us understand more about you and your child.

15. What is your relationship to your child?  
(please circle one)  
MOTHER          FATHER

16. What is your child's gender?  
(please circle one)  
FEMALE          MALE

17. What is your age?

18. What is your child's age?

19. My child was born at:  
   hospital (name: __________________________)  
   home  
   other __________________________

20. Did you have any prior experience with cleft lip and/or palate?  
(please circle one)  
YES          NO  
If yes, please explain:

21. Did you know that your child had a cleft lip and/or palate before he/she was born?  
(please circle one)  
YES          NO          NOT SURE
22. What type of cleft does your child have?

23. In addition to the cleft, does your child have any other medical diagnosis?

24. Did you bottle feed, breastfeed, or both?

25. Did you have any problems with feeding your child?  
   *(please circle one)*

   YES  NO

   If yes, please explain:

26. Highest level of education mother completed:

27. Highest level of education father completed:

28. Mother's occupation:

29. Father's occupation:

   **THANK YOU** for all of your help!
Appendix B

Craniofacial Team Questionnaire

Please answer the following questions regarding your specific role on the craniofacial team and the information that you share with parents of children with cleft lip and/or palate. By responding to this questionnaire, you are consenting to participate in the study. Your responses will remain confidential. You are free to answer as much of the questionnaire that you are comfortable with. Should you choose to not participate in the study, you may discontinue completion of the questionnaire at any point.

1. What is your profession?

2. During your initial visit with the parents of a child with cleft lip and/or palate, approximately how much time do you spend talking to the parents about feeding/swallowing?

3. In your experience, during a child's first few weeks of life, what is most important for the parents to know about feeding/swallowing?

4. Do you provide the parents with written information about feeding/swallowing? *(please circle one)*

   YES    NO

5. Do parents ask questions about feeding/swallowing?

   YES    NO

Please provide examples of common questions that parents frequently ask about feeding/swallowing:
6. Do you show parents how to feed their child?

YES       NO

If yes, how? (for example: demonstration, video, explanation, etc.)

7. Do parents come armed with information about feeding/swallowing from other sources?

YES       NO

If yes, please provide examples of the other sources:

8. If parents want additional information about feeding/swallowing, do you provide them with any of the following:

Circle all that apply:

your email address

your phone number

hospital website

other website(s) (please specify) ________________________________

support group information

emergency call number

other (please specify) ________________________________
In the final section, please rate the following statements that relate to how you feel about the delivery of information to the parents of children with cleft lip and/or palate. Please answer each question strongly disagree (1), disagree (2), agree somewhat and disagree somewhat (3), agree (4), and strongly agree (5).

9. “In general, I feel I…”

a. am equipped to discuss feeding concerns with the parents of my patients.  
   1                 2                   3                      4                5

b. have enough time to give all of the information about feeding/swallowing that I need to give.  
   1                 2                   3                      4                5

c. don’t have enough time to give all of the information about feeding/swallowing that I need to give.  
   1                 2                   3                      4                5

THANK YOU for all of your help!
Works Cited


