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Caregiver Experiences of Feeding Instruction for Infants Born With Cleft Lip and/or Palate

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Abstract

Purpose: The purpose of this pilot study was to attempt to describe how feeding education was provided to a group of caregivers of infants with cleft lip and/or palate and how they viewed the feeding experience. **Method:** Participants (n=5) were recruited from two Facebook support groups, *Cleft Lip and Palate Support Group* and *Cleft Mom Support*. The data were collected using Qualtrics™ software. The questionnaire consisted of eight demographic questions and seven topic-specific questions. The demographic questions included the exclusion and inclusion criteria. The participants of this study were required to be an English-speaking parent or a caregiver of a child under one year of age with non-syndromic cleft lip and/or palate. While six participants qualified, only five continued on to complete the topic-specific questions. **Results:** Four of five participants reported receiving feeding education from a speech-language pathologist, and all reported being provided follow-up care in regard to feeding. Three out of five participants mentioned the use of specific bottles in regard to the feeding education they were provided. Three out of five participants also described using Facebook support groups to acquire additional feeding information. **Conclusion:** This study helps to clarify the importance of speech-language pathologists' role in cranio-facial teams as providers of feeding therapy to infants born with cleft lip and/or palate.

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ABSTRACT

Purpose: The purpose of this pilot study was to attempt to describe how feeding education was provided to a group of caregivers of infants with cleft lip and/or palate and how they viewed the feeding experience. **Method:** Participants (n=5) were recruited from two Facebook support groups, *Cleft Lip and Palate Support Group :*)* and *Cleft Mom Support*. The data were collected using Qualtrics™ software. The questionnaire consisted of eight demographic questions and seven topic-specific questions. The demographic questions included the exclusion and inclusion criteria. The participants of this study were required to be an English-speaking parent or a caregiver of a child under one year of age with non-syndromic cleft lip and/or palate. While six participants qualified, only five continued on to complete the topic-specific questions. **Results:** Four of five participants reported receiving feeding education from a speech-language pathologist, and all reported being provided follow-up care in regard to feeding. Three out of five participants mentioned the use of specific bottles in regard to the feeding education they were provided. Three out of five participants also described using Facebook support groups to acquire additional feeding information. **Conclusion:** This study helps to clarify the importance of speech-language pathologists' role in cranio-facial teams as providers of feeding therapy to infants born with cleft lip and/or palate.

Keywords: cleft lip, cleft palate, pediatric feeding, caregiver education

INTRODUCTION

Cleft lip and/or palate is the second most common congenital malformation.[1] These orofacial (i.e., relating to the mouth and face) anomalies occur in the womb. In the case of cleft lip, the lips fail to fuse together, while in the case of cleft palate, the palatal shelves fail to fuse as they should. Cleft palates appear either in the velum or in the hard palate, negatively impacting oral musculature.[2] Additionally, a cleft palate can be complete, meaning that it spans the entire length of the primary and secondary palate, or incomplete, which spans only through the secondary palate. These anomalies often co-occur with 46% of orofacial clefts including both the cleft lip and palate.[3]

While some researchers have examined the feeding intervention methods for infants born with cleft lip and/or palate, few have focused on the feeding education or personal experiences and perspectives of parents as they navigated through the process of learning to feed their infant. Parents' perspectives are worth understanding due to their impact on family life. The family environment, particularly the mother's well-being and health, both physical and mental, is a significant factor in the quality of life for a child born with cleft lip and palate.[4] When parents have a child with cleft lip and/or palate there are factors they must adjust to mentally and physically beyond simply the visual differences of the cleft. Some of these factors include difficulty with feeding, failure to thrive, and the stress that accompanies these aspects.

Feeding an infant with cleft lip and/or palate comes with a unique challenge due to the lack of intraoral negative pressure which makes sucking and swallowing more difficult, causing a decrease in volume intake by the infant.[5] The extent of clefting can affect respiratory health potentially causing issues with airway protection during the swallow. The infant's feeding and swallowing skills may be impaired, characterized by inefficient oral feeding skills along with poor airway protection ability during swallowing.[6] For infants with cleft palates and more structural issues, cranial nerve abnormalities and neuromotor issues may further complicate feeding during the oral phase.[6] There are interventions and feeding techniques available to parents of infants with cleft lip and/or palate, such as the use of the previously mentioned specialized bottles, different pacing strategies, and specific facilitation procedures.[7] These interventions, if taught effectively and thoroughly to parents, could help train caregivers to overcome the unique challenges in feeding their infants.

Infants with cleft lip and/or palate can fail to grow and gain weight at a normal rate because of their extensive feeding problems, such as nasal regurgitation, fatigue, choking, excessive air intake with inadequate milk intake, and insufficient suction.[8] Infant weight, both maintaining and gaining, is a consistent goal for medical professionals and parents. A risk of not feeding problems for infants of this population include failure to thrive (FTT), which is described as inadequate physical growth in terms of weight gain or height, and it is diagnosed when a child is below the 10th percentile for either marker.[9] The importance of caregiver education relative to FTT was indicated by Baylis et al. who found that when such targeted interventions (such as improving feeding equipment and access, providing standardized caregiver feeding education as well as targeted education to cleft lip and palate team members, encouraging contact with caregivers between visits and tracking infant follow up, and increasing access to dietician/nutrition services) were used, there was a substantial decrease in the percentage of infants with cleft lip and/or palate that exhibited FTT.[10]

Martin and Greatrex-White found a correlation between infant weight gain and the mothers' low self-perceptions.[11] They found that mothers whose infants have severe clefts leading to difficulties in feeding and deficiencies in weight can experience severe depression.[11] Feeding infants with cleft lip and/or palate can be not only a physically taxing experience on the parents with the varied feeding techniques and difficulties, but also emotionally and mentally taxing. If parents of children with cleft lip and/or palate find feeding times to be a source of extreme stress, it is possible that they are not being provided sufficient medical training in how to best take care of their infant.

Martin and Greatrex-White analyzed the impact of various feeding methods and attention to family needs on infant weight and maternal self-esteem with the aim of helping medical practitioners provide better care for families of infants with cleft lip and palate.[11] For example, they noted that a prompt visit from a designated and trained cleft palate team was judged to be essential to support and teach parents feeding methods.[11] Per the American Cleft Palate-Craniofacial Association, members of a cleft palate team should include a patient care coordinator, professionals from the speech-language pathology, surgical, and orthodontics specialties, as well as professionals in the disciplines of psychology, social work, audiology, genetics, general and pediatric dentistry, otolaryngology and pediatrics/primary care.[12] On this team, the speech-language pathologist, orthodontist, prosthodontist, and registered dietician work together closely to promote effective feeding and nutrition for the infant.[13] Although considered integral members of the cleft palate team, speech-language pathologists (SLPs) often do not have sufficient training in feeding methods, which can result in ineffective training and intervention for infants born with cleft lip and palate.[14] Parents' negative experiences with feeding their infants may be indirectly caused by insufficient feeding instruction and education.

Caregivers' perspectives and needs in the area of feeding education and experience are significant and too often overlooked. There is a paucity of recent research that studies the postnatal feeding experiences of parents of children with cleft lip and palate in a qualitative design. The purpose of this pilot study was to try to learn what kinds of feeding education was provided to a select group of caregivers of this population and how they viewed the experience.

LITERATURE REVIEW

Feeding Education Provided

Feeding challenges of infants with cleft lip and/or palate can be heightened by a lack of sufficient education and training in appropriate intervention strategies. Attia found that of 100 parents studied, only 37 knew from prenatal screening with ultrasonography that their child would be born with a cleft.[5] Further, of those 27, only 46% confirmed that they received adequate feeding education before their child's birth.[5] This highlights that those parents felt the education provided by medical teams was insufficient and wanting, even when given adequate time to prepare. Similarly, Young et al. determined that 40% of caregivers thought they were not adequately taught how to face the feeding challenges brought on by their child's diagnosis and only 55% were given brief demonstrations on different feeding interventions.[15] One parent in the Young et al. study specifically highlighted the lack feeding education, stating:

> *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.*[15]

The inadequate feeding instruction was not only a source of frustration for the parent but may have jeopardized the health of the infant.[15] Parents should have access to appropriate training and education in feeding their infants with cleft lip and/or palate. In a study by Snyder and Ruscello,18 of the 26 parents experienced extended feeding times.[7] Of the 26 parents in the study, 96% of their infants with cleft lip and/or palate presented with more than one feeding issue, such as poor suck, difficulty latching on the nipple, reflux, and extended feeding periods.[7] Specific bottles were one of the most problematic area reported by parents.[7] Half of parents reported they had to try two different or more kinds of specialty bottles to find one that was successful with their infant with cleft lip and/or palate.[7] Twenty-one of the parents were taught to use a specialized bottle or nipple by the hospital, and four of the parents sought out the specialized bottle on the Internet.[7] The bottles provided to the parents, however, were only 50% successful with feeding.[7] Forty percent of parents found different bottles that were more successful on the internet and 44% from their physician or local hospital with the remainder of parents acquiring bottles from a local store.[7] At birth, 20 parents were provided with the *Haberman Feeder* or the *Mead Johnson Cleft Palate Nurser* by the hospital, and only one parent was given the *Dr. Brown's™ Specialty Feeding System*.[7] Forty-four percent of parents reported the most success with the *Dr. Brown's™ Specialty Feeding System*.[7] Snyder and Ruscello's study indicated the importance of parents being provided education on the different feeding methods available to them, as this is a significant aspect of feeding education.[7]

Wijekoon, Herath, and Mahendran studied 101 mothers of children with cleft lip and/or palate.[1] Because the knowledge of mothers is an important component in feeding infants with clefts and supporting their nutritional status, these researchers aimed to assess the awareness mothers had on the feeding and growth of their infants.[1] Contrary to some of the previously mentioned studies, Wijekoon, Herath, and Mahendran concluded that over half the mothers felt that they had a higher knowledge of factors related to feeding and the growth of their infant with cleft. In fact, they found that 80% of mothers felt aware of factors specifically relating to the growth and development of their child.[1] They also found that 73% of the mothers expressed receiving advice and training via demonstration as essential for successfully feeding their infants with cleft lip and/or palate.[1]

Researchers Thompson et al. assessed the impacts that prenatal consultations with a multidisciplinary cleft team had on infants with cleft lip with or without cleft palate in a retrospective case study.[16] They compared those infants who had received prenatal consultations with a pediatric otolaryngology team to those that did not during the years 2005-2019.[16] Results showed that early hospitalization durations decreased by over 6 days for those that had received prenatal consultation.[16] The infants' cleft lip repair also occurred almost two weeks earlier for those infants' whose mothers had received prenatal consultation.[16] Finally, it was found that fewer clinic visits with a speech-language pathologist were required for feeding difficulties for those who had prenatal consultations.[16] Unplanned visits with a speech-language pathologist for feeding difficulties increased by 8.6% for infants who had not received prenatal consultation.[16] This led Thompson et al. to suggest that prenatal education and consultation improve patient clinical outcomes for this population, and multidisciplinary teams should prioritize prenatal consultation as a crucial part of patient care.[16]

Sources of Feeding Education

Wijekoon, Herath, and Mahendran found that most families received feeding education from either doctors, nurses, staff, and/or midwives.[1] Similarly, Snyder and Ruscello found that 61% of parents of infants with cleft lip and/or palate received feeding information from a nurse and/or a lactation consultant, 12% from a physician, 8% from a nutritionist, 4% did not remember, and 15% reported receiving no instruction.[7] Fifty percent of the parents in this study did not feel prepared to feed their infant, and felt it was necessary to seek out additional feeding education from either the Internet, books, or other medical clinics.[7]

In the previously mentioned study by Attia, it was found that when parents were informed of the cleft diagnosis, 91% of parents investigated feeding methods prior to the birth of their infant.[5] Attia found that when these parents were asked where they received support and help for education in cleft care, 35.6% stated the Internet as a primary source, with surgeons, pediatricians, other parents of children with clefts, gynecologists, and orthodontists comprising the balance.[5]

Because the Internet was a source for so many, an effort was made to determine how families searched the web. That led the authors to a study by Çınar, Boztepe, and Özgür who looked at the way parents of infants with cleft lip and/or palate use the internet through the means of social media for gathering information.[17] Çınar, Boztepe, and Özgür reviewed and analyzed posts in 8 different Facebook groups and determined that over 50% of the posts had a central theme of “requesting information” for a variety of topics, including feeding.[17] Questions such as, “Is it difficult to feed your infant after surgery,” and “How did you feed your baby?” were cited.[17] Interestingly, Çınar, Boztepe, and Özgür shared that the second most common theme was “seeking support,” which serves to highlight the stress that many of these parents feel.[17] Their results suggest that parent education is wanted and needed to support children with cleft lip and/or palate.

Parental Experiences Regarding Feeding

While accepting a child’s diagnosis of a health condition is never easy for parents, some studies highlighted that the stress associated with feeding infants with cleft lip and/or palate may only be exacerbated by parental dissatisfaction with neonatal care. Costa et al. sought to better understand the experiences of parents with the aim of improving care for infants with cleft lip and palate.[18] Only 50% of parents felt they had received the right amount of information regarding their child’s cleft and many felt dissatisfied with the care they were given.[18] Costa et al. found that the parents who received a delayed diagnosis (made more than 24 hours after birth) were particularly physically and emotionally exhausted. Even when the diagnosis was made, the appropriate feeding equipment was often not immediately available.[18] This study suggests that the stress of parents during feeding time is linked with the quality of care provided by health professionals.

Poor feeding education can have a negative effect on the feeding experience for parents of children born with cleft lip and palate. Jeffery and Boorman studied parent satisfaction with cleft lip and palate services.[19] They found that 33% of parents felt they either did not have enough knowledge about their children’s clefts and treatments or no knowledge at all.[19] Conversely, 96% of parents in this study also reported that they were either satisfied or very satisfied with the level of care that they received.[19] The noticeable percentage of parents who felt a deficit with the feeding instruction provided to them is significant.[19] These studies suggest a connection between parent satisfaction and adequate feeding instruction.

Parents are an important member of the team when a child is born with cleft lip and/or palate. Researchers Knapke et al. examined parent perspectives on effective interventions and their suggestions for health care professionals.[20] After interviewing 17 parents, they found that most said they were satisfied with the care they had received.[20] In addition, most said that helpful interventions included information about what surgeries to expect and before and after surgery pictures of other children.[20] Reassurances, information about their child’s development, and simple repetition of information was helpful.[20] Parents in this study reported difficulty with feeding.[20] One parent suggested that feeding tips and calorie conversions should be provided in writing and others wished that the craniofacial team had provided more information on feeding and/or nursing problems with warnings about the challenges associated with feeding their infants post-surgery.[20] Specific suggestions from parents regarding feeding included: give parents more than one box of bottles, be more sensitive when telling parents that they will not be able to breastfeed, provide more information about feeding/nursing difficulty following surgery, and educate lactation consultants, nurses, and residents about cleft lip and/or palate.[20] While the parents in that study may have been satisfied with their experience overall, they still believed there was room for improvement in health care professionals with improving the parental experience when feeding an infant with cleft lip and/or palate.[20]

Based on the review of the literature, this study sought to identify the feeding education that was provided to caregivers of infants with cleft lip and/or palate. How those caregivers viewed the feeding experience was also examined.

METHOD

Design

The questionnaire used in this study was developed by the principal investigator with the guidance of a faculty committee member. A qualitative approach was used to allow researchers to understand the unique experiences of participants. Using this approach, themes and findings emerged with careful analysis.[21] Following a search of relevant literature, questions were developed in order to delve more deeply into the thoughts and perspectives of parents of children with cleft lip and/or palate. The demographic portion consisted of eight questions; two of which contained the inclusion and exclusion material. The inclusion and exclusion questions determined whether the child of the parent was currently under one year of age, and if the child's cleft was associated with a syndrome. The other six demographic questions gave a more detailed picture of the respondents completing the questionnaire. The topic questions were short answer in order to give the participants the ability to type as much or as little as they desired into a text box. The questionnaire was given electronically to participants using the Qualtrics™ software, an online company that enables researchers to design surveys, questionnaires, and analyze data effectively and efficiently.[22] A unique link was generated that, when clicked, guided participants directly to the online questionnaire. Participants were able to complete the questionnaire from a mobile device or a computer.

Participants

Participants were recruited through the social media platform, *Facebook*. Posts were published in two *Facebook* groups opened for parents and caregivers of children with cleft lip and palate, *Cleft Lip and Palate Support Group :*)* and *Cleft Mom Support*. *Cleft Lip and Palate Support Group :*)* is a support group for families or anyone who has been affected by a cleft lip and/or palate. It has members from all over the world seeking support from one another during their journeys. *Cleft Mom Support* is a private cleft lip and/or palate support group for those who identify as a cleft parent, adoptive cleft parent, cleft guardian, cleft grandparents, and those pregnant (expecting a child with a cleft). The participants of the study were required to be an English-speaking parent or a caregiver of a child under one year of age with non-syndromic cleft lip and/or palate.

Procedure

Researchers were granted permission to post the link to the online questionnaire in the Facebook group *Cleft Lip and Palate Support Group :*).* An administrator of the group published a post in *Cleft Mom Support* on behalf of researchers due to the more private nature of the support group. The Facebook posts consisted of a detailed written description of the research, which included the purpose and procedure of the study. The approved IRB consent form was included in the post. Each participants' willful completion of the study implied their consent. The participants were made aware that their anonymity would be maintained and that at any time during the study they could withdraw without penalty. The participant data was collected via Qualtrics™, and the participants were given the opportunity to type detailed responses to topic questions. The data and participant responses were analyzed for common or recurring themes which in turn composed the majority of the discussion in this thesis.

Analysis

A qualitative, grounded theory method was used in this study as it is best suited for researchers studying participants' thoughts and perspectives and it allows for a comprehensive and descriptive insight into phenomena.[23] A grounded theory approach is a specific qualitative method of data collection wherein researchers collect information using semi-structured methods, such as the questionnaire with open-ended and short answer questions, to develop theory from participant responses.[24] Manual open coding, which is a specific way of coding used in grounded theory approaches, was used with an inductive method to analyze data and determine underlying similarities in participants' responses. Open coding is a technique for analyzing data. This allows for researchers to identify distinct concepts and themes for categorization. An inductive approach to research aims to generate theory from collected data.[25] The manual open coding method used to analyze data collected from the questionnaire enabled researchers to closely analyze participant responses for commonalities by hand. First, researchers extensively reviewed relevant qualitative literature to determine similarities and recurrences among parents' responses that previous studies found. From that review the researchers found that the internet was often a supplemental source of feeding education for caregivers and that bottles played an important part in feeding training. These helped to assist researchers in determining keywords and topics. Researchers then determined key words and topics from the relevant literature, such as "internet," "bottle," and topics related to feeding education. These selected keywords and topics were used as "codes" to be searched for in participants' responses. The codes and the rationale for the selected codes for each question are listed in Table 2. Next, researchers read each response from participants. Responses were analyzed to determine if the selected codes were present or not present. Finally, researchers reported the findings of codes present or not present to exhibit commonalities, or lack thereof, across participants' response. This use of open coding as an analytic technique allowed researchers to take qualitative data and sort it into manageable and meaningful segments.[26] Braun and Clarke's phases of thematic analysis were used as guidance in the manual coding process.[27] Researchers first reviewed and familiarized themselves with the data collected from participants. Next, the data was manually coded and searched for recurring themes by looking for commonalities, such as the use of similar phrases, topics, or words within the responses for each question. The commonalities guided the creation of the subheadings. They were reviewed before being named and produced in this final report.

Table 1. Codes and Rationales

Question from Questionnaire	Codes Chosen and Rationales	Codes: Word, Topic, Concept
"What education, if any, is your medical center offering you on different methods, bottles, and techniques for feeding your infant?"	Rationale for "Bottle": Specialized bottles are a piece of feeding equipment that caregivers are trained with to feed an infant with cleft lip and/or palate. Rationale for "Method": Different methods, such as pacing strategies and shorter feeding times, are often part of the feeding education that caregivers receive. Rationale for "Technique": There are various techniques, such as different feeding positions, that can be part of the feeding education that parents receive.	Bottle Method Technique
"What type of service provider (doctor, nurse, SLP, etc.) is providing you that education?"	Rationale for "SLP/Speech": Speech-language pathologists play a significant part of feeding education for caregivers on an interprofessional team. Rationale for "Doctor": Medical Doctors play a significant part of the feeding education for caregivers on an interprofessional team. Rationale for "Nurse": Nurses play a significant part of the feeding education for caregivers on an interprofessional team	SLP/Speech Doctor Nurse
"Do you rely on your service providers for information on feeding your infant, or do you use online resources as a supplement? If so, what online resources do you use?"	Rationale for "Internet": The internet was often listed as a source of supplemental feeding education by parents in the studies reviewed as part of this project. Rationale for "Facebook/Names of Facebook groups": Because the participants were recruited from Facebook support groups, it was felt likely by researchers that Facebook would be named as a specific source of feeding education.	Internet Facebook/Names of Facebook groups
"Do you find any aspects of the feeding stressful? If so, what do you find to be the most stressful?"	Rationale for "feed/feeding": Feeding times can be a source of stress to caregivers due to the unique challenges posed by the cleft lip and/or palate. Rationale for "bottle:" Bottles can play a part in whether feeding periods feel successful or stressful to caregivers depending on their success with the bottle. Rationale for "positive indications of stressful periods/aspects": In order to better understand the experiences of caregivers, stressful aspects of feeding were searched for.	Feed/feeding Bottle Positive indications of stressful periods/aspects
"Do you find any particular aspect of feeding more successful than another? If so, please explain."	Rationale for "feed/feeding": Feeding times can be positive for caregivers if a part of feeding times were found to be successful. Rationale for "bottle:" Bottles can play a part in whether feeding periods feel successful or stressful to caregivers depending on their success with the bottle. Rationale for "positive indications of successful periods/aspects": In order to better understand the experiences of caregivers, successful aspects of feeding were searched for.	Feed/feeding Bottle Positive indications of successful periods/aspects
"Have you received any follow-up medical care or instruction (in regard to feeding and swallowing) and which	Rationale for "SLP/Speech": Speech-language pathologists are part of the interprofessional team that educate caregivers on feeding, and follow-up care is a component of feeding education.	SLP/Speech Positive indications of follow-up care.

Question from Questionnaire	Codes Chosen and Rationales	Codes: Word, Topic, Concept
providers are working with you for that?”	Rationale for “positive indications of follow-up care”: Follow-up care, as a part of feeding education, is an important component in order to address caregiver concerns and ensure that the feeding training caregivers receive is effective.	
“Is there anything additional you would like to share about your experiences with feeding your child?”	Rationale for “feed/feeding”: Participants were asked to expand on their feeding experiences in order to offer further qualitative information not touched on in previous questions. Rationale for “bottle:” Bottles are an important aspect of feeding an infant with cleft lip and/or palate.	Feed/feeding Bottle

RESULTS

The results presented seek to shed light on the study’s main research question: How do caregivers of infants born with cleft lip and/or palate view the feeding experience based on the feeding instruction provided. The questionnaire results are sorted in the order of questions that the participants received.

Table 2 provides the participants’ responses from the demographic portion of the questionnaire. A total of 12 participants began the questionnaire, but only six of those participants met the inclusion criteria. Five of those six participants completed the questionnaire beyond the demographic portion. All six participants who completed the demographic portion described themselves as mothers. Four of the children were described as males, one as female, and one parent did not respond to the question regarding gender. Additionally, four of the children were described as Caucasian/white by their mother, one as South Asian, and one parent did not respond. Four of the children had cleft lip and palate and two had cleft palate. Two mothers were from the North region and two were from the West region. Five mothers confirmed they receive care from a specialized cleft and craniofacial center, and one did not respond to the question.

Table 2. Participant Demographic Data

Question	Results (n=6)
How would you describe yourself?	
Mom	6
Dad	0
Caregiver	0
What gender best describes your child?	
Male	4
Female	1
Declined to answer	1
What race best describes your child?	
White/Caucasian	4
South Asian	1
Declined to answer	1
What kind of cleft does your child have?	
Cleft lip	0
Cleft palate	2
Cleft lip and palate	4
Which region best describes the part of the country where your child receives services?	
North	2
West	2
Declined to answer	2
Are you receiving care from a specialized cleft and craniofacial clinic?	
Yes	4
Declined to answer	1

Table 3 provides a list of the topic questions from the questionnaire, the codes chosen for analysis, and the number of participants who did and did not present with the codes in their responses.

Table 3. Data Analysis

Question from Questionnaire	Codes Chosen for Each Question: Word, Topic, Concept	Number of Participants Who Presented With Code in Their Response (n=5)	Number of Participants Who Did Not Present With Code in Their Response (n=5)
"What education, if any, is your medical center offering you on different methods, bottles, and techniques for feeding your infant?"	Bottle Method Technique	3 0 0	2 5 5
"What type of service provider (doctor, nurse, SLP, etc.) is providing you that education?"	SLP/Speech Doctor Nurse	4 3 2	1 2 3
"Do you rely on your service providers for information on feeding your infant, or do you use online resources as a supplement? If so, what online resources do you use?"	Internet Facebook/Names of Facebook groups	0 3	5 2
"Do you find any aspects of the feeding stressful? If so, what do you find to be the most stressful?"	Feed/feeding Bottle Positive indications of stressful periods/aspects	2 1 4	3 4 1
"Do you find any particular aspect of feeding more successful than another? If so, please explain."	Feed/feeding Bottle Positive indications of successful periods/aspects	1 3 5	4 2 0
"Have you received any follow-up medical care or instruction (in regard to feeding and swallowing) and which providers are working with you for that?"	SLP/Speech Positive indications of follow-up care.	3 5	2 0
"Is there anything additional you would like to share about your experiences with feeding your child?"	Feed/feeding Bottle	2 1	3 4

Bottle Training

In question one, participants in the questionnaire were asked "What education, if any, is your medical center offering you on different methods, bottles, and techniques for feeding your infant?" Findings exhibited that 3/5 parents presented with the "Bottle" code in their response while 2/5 did not present with "Bottle" code in their response. Zero parents presented with the codes "Method" or "Technique" in their response. Two participants did not describe specific education they received. Two of the five participants referenced the use of specific bottles in answer to the question, the *Haberman* bottle and the *Dr. Brown*'s™ bottle. One mother responded that "Our cleft team recommended *Dr. Brown's*™ bottles. We have a speech pathologist on the cleft team that has watched my husband and I feed my son and told us that she could help if he was struggling. He's never struggled with eating." Another mother wrote about the training provided with feeding, stating "The hospital has a feeding team that helps us. Also, we have a private speech specialist and an occupational therapist (OT) specialist. The first week when we were in NICU (neonatal intensive care unit) we all worked together on different bottles to find the one that works best for him." One mother's comment stood out from the rest in her reference to the use of social media and other mothers as a source of education, saying she had "Lots of information but I had already figured most of it out from Facebook and other moms with cleft children." Interestingly, although not stated in answer to the first question, this caregiver later used the word “bottle,” specifically, *Dr. Brown’s*™ bottle, when describing a successful aspect of feeding times.

The Role of Speech-Language Pathology

In question two, participants were asked “What type of service provider (doctor, nurse, SLP, etc.) is providing you that education?” Findings exhibited that 4/5 participants presented with the “SLP/Speech” code in their response while 1/5 did not present with the “SLP/Speech” code in their response. Additionally, 3/5 participants presented with the “doctor” code in their response while 2/5 did not. Lastly, 2/5 participants presented with the “nurse” code in their response while 3/5 did not present with the code “nurse” in their response. One participant described their service provider only as a “cleft palate specialist.” An additional service provider listed by a participant included a dietician. One mother went into great detail and listed the service providers offering feeding education: “Cranial team, OT specialist, 2 speech specialist(s), and his primary doctor, ear nose and throat (doctor), neurologist. . .” Table 3 exhibits the sources reported by participants and the percentage of times it appeared in participant responses:

Table 4. Sources of Feeding Education

Question	Results (n=5)
What type of service provider (doctor, nurse, SLP, etc. is providing you that education?	
Speech-language pathologist	4
Doctor	2
Nurse	2
Occupational therapist	1
Cranial team	1
Cleft-palate specialist	1
Dietician	1

The Role of the Internet

In question three, participants were asked “Do you rely on your service providers for information on feeding your infant, or do you use online resources as a supplement? If so, what online resources do you use?” Findings exhibited that 3/5 parents presented with the “Facebook/names of Facebook groups” code in their response while 2/5 did not present with the “Facebook/names of Facebook groups” code in their response. Zero parents presented with the code “Internet” in their response. Two participants specifically referenced *Cleft Mom Support,* and the other participant said more broadly, “Cleft support group on Facebook.” One participant stated that “Just my providers” were used for feeding education. An additional participant described using family as a source of information due to the hereditary aspect of cleft lip and/or palate in this case, “My husband’s parents are a good resource when we aren’t able to ask the doctors (he was born with a cleft lip and palate).”

Stressful Feeding Times

In order to expand on how parents view the feeding experience, participants were asked in question four, “Do you find any aspects of the feeding stressful? If so, what do you find to be the most stressful?”. Findings were that 2/5 parents presented with the “feed/feeding” code in their response while 2/5 did not present with the “feed/feeding” code in their response. Additionally, 1/5 participants presented with the “bottle” code in their response while 4/5 did not present with the “bottle” code in their response. Lastly, findings showed that 4/5 participants presented with the “positive indications of stressful periods/aspects” code in their response while 1/5 did not. One mother said that “I exclusively pump for my daughter. It’s exhausting pumping around the clock. Otherwise, she takes the milk without difficulty from the Dr Brown’s™ specialty bottles.” Another participant described her primary difficulty as “Learning how to initiate feeds without baby crying.” For one mother, difficulty with feeding was resolved within the first few months. The fifth participant described feeding her child solids as the most stressful aspect with ensuing gagging, and food coming out of the infant’s nose.

Successful Strategies

In question five, participants were asked “Do you find any particular aspect of feeding more successful than another? If so, please explain.” Findings exhibited that 1/5 parents presented with the “feed/feeding” code in their response while 4/5 did not present with the “feed/feeding” code in their response. Additionally, 3/5 participants presented with the “bottle” code in their response while 2/5 did not present with the “bottle” code in their response. Lastly, findings showed that 5/5 participants presented with the “positive indications of successful periods/aspects” code in their response. One parent said, “Works better to feed him in a quiet room.” While two participants stated success with bottles in general, one mother went into detail about the types of bottles and foods that offered success, saying “Using *Dr. Brown*’s™ bottles than *Haberman* after 3 months. Pureed foods than finger foods.” One mother said that her son is a “really good eater,” and another mother said that her daughter “takes the bottle well.”

Provision of Follow-up Care

Caregivers of infants with cleft lip and/or palate ideally receive feeding education upon learning of their child's diagnosis, shortly after their infant's birth, and with follow-up care. Follow-up care is important to answer any caregiver concerns and to ensure that the feeding education caregivers received is effective. In questions six, participants were asked, "Have you received any follow-up medical care or instruction (in regard to feeding and swallowing) and which providers are working with you for that?" Findings exhibited that 3/5 parents presented with the "SLP/speech" code in their response while 2/5 did not present with the "SLP/speech" code in their response. Findings showed that 5/5 participants presented with the "positive indications of follow-up care" code in their response. Two responses did not indicate what provider they received their follow-up feeding instruction from. Of the parents that went into more detail with their response, one parent wrote that she received "Weekly visits with SLP, and Dietician." Another parent described the need for follow-up feeding instruction due to the difficulty her daughter had with progressing to solid foods, stating "My daughter went for a feeding evaluation since she is not taking solids. We went to a SLP from a different clinic for the help."

Additional Experiences

In order to give participants an opportunity to offer further qualitative information not touched on in earlier questions, participants were asked in the final question "Is there anything additional you would like to share about your experiences with feeding your child?" Only two participants offered additional information, both related to feeding. Findings exhibited that 2/5 parents presented with the "feed/feeding" code in their response while 2/5 did not present with the "feed/feeding" code in their response. Additionally, 1/5 participants presented with the "bottle" code in their response while 4/5 did not present with the "bottle" code in their response. One participant wrote that what helped with feeding included "Positioning (the infant) upright. After a certain time trying a different level of *Dr. Brown*'s™ nipple." Another mother went into great detail about a stressful aspect of feeding, specifically, the lack of feeding knowledge among the medical team, stating that "The hospital doctors and nurses didn't spot it right and away, and once they did, they were not very knowledgeable on how/what I could do to feed her. I had to try and figure it out on my own."

DISCUSSION

The purpose of this study was to gain an understanding of feeding education provided to a select group of caregivers of infants with cleft lip and/or palate and how the caregivers view the feeding experience. Manual open coding of the questionnaire responses helped to determine the kind of feeding education caregivers received, including the source of the feeding education, and the successes and difficulties they felt towards feedings. Questions 1, 2, 3, and 6 on the questionnaire were designed to help answer the portion of the primary research question targeting the feeding instruction the caregivers were provided. Questions 4 and 5 invited participants to describe aspects of feeding that were more successful or stressful, and question 7 provided as an opportunity for caregivers to expand and touch on any topic related to feeding that was not directly targeted with the researchers' main questions. While the caregivers had a variety of experiences, there were many consistent responses among them, such as the involvement of SLPs with feeding education, feeding success being tied to the use of specific bottles, and the use of online resources as a supplement to feeding education from service providers.

Findings

Four of the parents specifically referenced that one of the service providers giving them feeding education was an SLP and one said that it was a "cleft palate specialist." That four of the parents received feeding education from an SLP suggests that SLPs play a significant role in the feeding education of cleft lip and/or palate infants. SLPs' timely identification of feeding difficulties and the following intervention and feeding modifications provided to families with feeding instruction is considered essential for feeding success.[6] Additionally, a SLP is an integral member of the interdisciplinary cleft lip and palate team and acts as a feeding and swallowing specialist.[13] According to the American Speech-Language-Hearing Association, the scope of an SLP encompasses all aspects of swallowing, including feeding behaviors and issues.[28] A SLP completes tasks such as assessing the feeding and swallowing skills of the infant, providing recommendations for specific feeding devices and therapeutic techniques, determining the need for instrumental assessment or specialist referrals, and aiding in coordination of care with other providers.[29] Thus, it was not surprising when one parent stated that, although doctors and nurses were involved in providing feeding education, it was "mainly SLP(s)."

In order to further understand how caregivers viewed the feeding experience, participants were asked about aspects of feedings that they considered to be successful or stressful. The use and training with bottles were mentioned by three of the caregivers as an important part of the feeding education they were given by service providers, and caregivers referenced bottles as being an important part of their feeding success. While there are a variety of specialized bottles for infants with cleft lip and/or palate, only two were specifically mentioned by participants. Three of the participants mentioned service providers recommending and training them to successfully use *Dr. Brown's*™ bottles. One parent wrote that, while *Dr. Brown's*™ was used successfully for the first 3 months of feeding, they switched to using the *Haberman Feeder*™ (now called the Medela SpecialNeeds™ feeder); however, the participant did not state why the switch was made. Neither of these bottles, which contain one-way valves to isolate milk in the teat, have shown significant differences in terms of infant weight/calorie gain, complications or feeding time outcomes in a recent study comparing the two bottles.[30] That three of the caregivers in this survey particularly mentioned a positive experience with *Dr. Brown's*™ bottles correlates well to the previously mentioned statistic by Snyder and Ruscello who reported that 44% of parents in their study had the most success feeding their infant with the *Dr. Brown's*™ bottle.[7] Similarly, the study by Attia looking at the feeding challenges of infants with cleft lip and/or palate, found that 53.9% of participants used conventional bottles, with 25% using *Dr. Brown's*™ bottles and 20.1% using the Medela SpecialNeeds™ feeder.[5] The emphasis placed on bottles as an important part of the feeding education caregivers received and their connection to successful feedings indicates the important role that bottles play in the feeding training and education offered by service providers.

Three of the participants stated that they use online resources as a supplement to feeding education from service providers. All three specifically referenced the online resource as being a Facebook group, which is unsurprising due to participants being recruited from Facebook. The development of Facebook support groups for rare pediatric diseases has significantly increased since the website's creation, and cleft lip and palate groups make up 1.5% of them; 93 out of 6398 rare pediatric disease support groups found on Facebook were related to cleft lip and palate.[31] The finding that three of the participants use online resources for additional feeding information aligns well to the previously referenced study by Snyder and Ruscello, who found that 50% of caregivers sought out feeding information from additional sources such as the internet.[7] The finding in this study also correlates well with the study completed by Attia found that 35.6% of caregivers used the Internet as a primary source of education in caring for the infants rather than service providers.[5] While ideally the internet and social media groups should be used as supplemental information and not as a replacement for education from service providers, the availability and easy access to the Internet makes it unsurprising that caregivers would refer it for additional education.

When asked for additional comments, one participant gave a detailed response highlighting the lack of knowledge that service providers had in regard to feeding when her infant was born with a cleft palate which had gone unnoticed on ultrasounds and how she was compelled to learn how to do it on her own. The lack of adequate feeding education and training among service providers is not an uncommon theme and has been a source of frustration for caregivers of the population before, as referenced in the studies done by Young et al., Costa et al., and Lindberg and Berglund.[15, 18, 6] However, in this study, none of the other participants expressed displeasure or dissatisfaction with the feeding education or knowledge provided by medical professionals, suggesting that it was not a source of frustration for them.

Implications

The current study sought to learn what kinds of feeding education was provided to a select group of caregivers of this population and how they viewed the experience. The education for caregivers of infants born with cleft lip and/or palate can be critical to success during feeding. SLPs (who play a large part in providing feeding education, bottle recommendations, and feeding techniques to caregivers) should be properly trained in providing that education. Due to the emphasis placed on bottles in the responses of questionnaire participants in this study, SLPs and service providers may wish to ensure that they have sufficient knowledge on the various kinds of bottles available when providing feeding education and training to caregivers. As previously mentioned, insufficient knowledge and training of SLPs can result in ineffective intervention for infants of this population.[14] Communication and collaboration between SLPs and other service providers on the cleft palate team is crucial when caring for the infant and their family in order to adequately address feeding challenges.[29] Educating parents in feeding interventions is helpful and important in supporting the feeding needs of infants with cleft lip and/or palate.[5] In order to adequately support families during the feeding process, emphasis should be placed on training the SLPs involved in cleft lip and/or palate care to ensure their knowledge and training is sufficient and effective. Most importantly, there should be future studies to help providers learn how to educate families.

Strengths and Limitations

Strengths of the present study include involving caregivers and their perspectives in the study of feeding education for infants with cleft lip and/or palate. Parents are an important part of the cleft team, and their perspectives on feeding education and their feelings towards feedings should be emphasized, especially since the quality of life for an infant with cleft lip and/or palate is tied to the family environment.[4] Suggestions that caregivers understand the importance of receiving feeding education, and those caregivers are motivated seek out feeding education, whether it be from a SLP, service provider, or the Internet can be inferred from this small study.

There are several limitations in this study that should be noted. First, participants were recruited from only two caregiver and parent-oriented Facebook support groups, *Cleft Lip and Palate Support Group :*) :*)* and *Cleft Mom Support*, thus limiting the reach of caregivers used in the study to those who use social media and those who are members of the groups. This limitation is problematic because it limited the number of participants, was exclusionary and did not involve the views of caregivers without access to these groups. While researchers were given permission to directly post in *Cleft Lip and Palate Support Group :*) :*)*, they were not able to directly post in *Cleft Mom Support* due to the private nature of the group. A group administrator posted on behalf of the researchers, and researchers were not able to view, manage, or edit the post directly. This was a significant limitation because researchers could not control how the post was phrased or presented to the group. Additionally, due to the electronic format of the questionnaire, participants were restricted to those who had technological devices such as computers or phones with Internet access.

The study was limited in its size with only five participants. A larger number would give researchers a broader, more definitive perspective. The five participants were mothers; thus, perspectives of fathers and other caregivers are not represented in this study. Limited racial and ethnic diversity was also noted making it difficult to generalize the results of the study as it excludes other populations.

Future Directions

If this pilot study was developed into a full research project, a sufficient number of subjects should be sought in order to make definitive statements about findings. Future studies would benefit by expanding the availability of the questionnaire to participants beyond those in specific social media support groups, such as seeking out caregivers who attend local clinics. Ideally, participants should be made up of other caregivers, including fathers. The perspectives of fathers were not present in the current study, and as a parent they have a significant role in the family environment and feeding of their infants. Including the perspectives of other caregivers would ensure more valid data. Additionally, if researchers wished to duplicate the study, strategies should be used to ensure that participants give more detailed and thoughtful responses to questions. Doing so would provide greater insight into the feeding education caregivers received and their perspectives on the feeding experience.

Conclusion

This pilot study serves to clarify the importance of speech-language pathologists' role in cranio-facial teams as providers of feeding therapy to infants born with cleft lip and/or palate. It contributes to the field of speech-language pathology by giving more definition in the SLPs role in cleft lip and/or palate feeding education, and it sets the base for understanding their responsibility in providing feeding intervention on an interprofessional cranio-facial team. SLPs should continue to research effective and successful methods of feeding intervention for infants born with cleft lip and/or palate, remembering to include the perspectives and thoughts of caregivers when designing goals for therapeutic intervention since their input and collaboration is key to successful feeding.

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APPENDIX

Questionnaire

I have been informed of the purposes, procedures, risks and benefits of this study. I have had the opportunity to have all my questions answered and I have been informed that my participation is completely voluntary. By continuing on and completing and submitting the survey, I am indicating consent to serve as a participant in this research, that I am a parent or primary caregiver of a child under 12 months of age with cleft lip and/or palate, and that I am at least 18 years of age.

D1. How would you describe yourself?

- ○ Mother
- ○ Father

- ○ Caregiver

D2. Is your child under one year of age?

- ○ Yes
- ○ No

D3. What gender best describes your child?

D4. What race best describes your child?

D5. Does your child have a syndrome associated with their cleft?

- ○ Yes
- ○ No

D6. What kind of cleft does your child have?

- ○ Cleft Lip
- ○ Cleft Palate
- ○ Cleft Lip and Cleft Palate

D7. Which region best describes the part of the country where your child receives services?

- ○ North
- ○ South
- ○ West
- ○ Midwest
- ○ South

D8. Are you receiving care from a specialized cleft and craniofacial clinic?

- ○ Yes
- ○ No

Please answer the following questions openly and truthfully. Be as expansive or concise as you wish with open ended questions, if you prefer not to answer you may skip the question.

Q1. What education, if any, is your medical center offering you on different methods, bottles, and techniques for feeding your infant?

Q2. What type of service provider (doctor, nurse, SLP, etc.) is providing you that education?

Q3. Do you rely solely on your service providers for information on feeding your infant, or do you use online resources as a supplement? If so, what online resources do you use?

Q4. Do you find any aspects of the feeding stressful? If so, what do you find to be the most stressful?

Q5. Do you find any particular aspect of feeding more successful than another? If so, please explain.

Q6. Have you received any follow-up medical care or instruction (in regard to feeding and swallowing) and which providers are working with you for that?

Q7. Is there anything additional you would like to share about your experiences with feeding your child?