UNIVERSITY OF CINCINNATI

Date: August 11, 2004

I, Sara Courtice Rankin, hereby submit this work as part of the requirements for the degree of: Master of Science in: Medical Genetics

It is entitled:
Parental Perspectives of Children born with Cleft Lip and/or Palate:
A Qualitative Assessment of Concerns, Satisfaction and Suggestions for Healthcare Improvements and Interventions

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Parental Perspectives of Children Born with Cleft Lip and/or Palate: A Qualitative Assessment of Concerns, Satisfaction and Suggestions for Healthcare Improvements and Interventions

A thesis submitted to the

Division of Research and Advanced Studies
of the University of Cincinnati

in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

Genetic Counseling Program
in the Department of Analytical and Diagnostic Sciences
of the College of Allied Health Sciences
2004

by:
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Abstract

Cleft lip and/or palate is the fourth most common birth defect and requires a great deal of medical intervention from healthcare professionals. Little has been published describing parental experiences and satisfaction related to the care of their child born with a cleft. This study characterizes parental concerns and stresses during the first year of their children’s lives and clarifies what parents expect from the healthcare professionals who care for their children. Qualitative interviews were completed with seventeen parents of children under the age of one who were born with cleft lip and/or palate and who have been treated by members of a comprehensive craniofacial center at a Midwest pediatric hospital. Among the concerns and stressors that parents shared were the following: stress of surgeries before and after the procedure(s), difficulty with feeding, and the social and cosmetic implications for their child. All participants (100%) were satisfied with their children’s care. Interventions that parents identified as effective included repetition of information, showing pictures of other children (before and after surgery), and anticipatory guidance about surgeries and their children’s development. Despite the high level of satisfaction, parents expressed that they want healthcare professionals to use more written and visual information, to have more contact with other parents of children born with clefts, and would like healthcare professionals outside the Craniofacial Center to be more knowledgeable about cleft lip and/or palate. These recommended interventions need to be considered not only for families who have a child born with a cleft but also families who have children born with other birth defects.
Acknowledgements

The author is grateful to the Research Advisory Committee chair Howard Saal, M.D. and to committee members Tricia Bender, RN, MSN, Cindy Prows, RN, MSN, and Janet Schultz, Ph.D for their guidance. The author also acknowledges Iris Sageser of the Craniofacial Center at Cincinnati Children’s Hospital Medical Center for providing background information and data, and the parents who offered their time and thoughtfulness to participate in this study.
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Introduction

According to the American Cleft Palate-Craniofacial Association (2000), of every 750 live births, one child is born with a cleft lip and/or palate (CL/CP) making this the fourth most common congenital anomaly. Treatment of this condition is well-established and involves multiple surgeries, various therapies and other healthcare interventions (Edmonson and Reinbartsen, 1998). When a child is born with an orofacial cleft, parents are usually shocked and must adjust not only to the condition itself but also to the treatment process that follows (Dolger-Hafner et al., 1997; Riski, 1991). The list of specialists that a child might need to see can become overwhelming. The purpose of this study was to determine specific sources of parental concern and stress during the first year of the treatment process, to assess needs and whether needs were being met by a multidisciplinary craniofacial team and to summarize parents’ suggestions for improving the care provided to their families.

Based on information provided by the Cleft Palate Foundation (2004), over 200 craniofacial centers exist in the United States to improve coordination of care from multiple specialists. The members of craniofacial teams strive to identify and address the information and service needs of these families in a synchronized fashion. Specifically at the craniofacial center where this study was performed, families are most often referred at the time of diagnosis; both pre and postnatal. The family may be referred directly to the Craniofacial Center or to a specific department; most often Plastic Surgery or Genetics. Whether the first interaction is before or shortly after birth, the focus is on educating and empowering the family with information about the condition. Information shared with families usually includes feeding tips and description of surgeries. Particular attention is paid to the psychosocial parameters and stressors exist for each individual family. During the first visit with the infant, a physical exam is also performed to
look for associated anomalies. Parents and patients are referred as needed to care providers within the craniofacial team and return for follow-up as directed. Appointments with individual specialties/specialists continue until the patient is approximately three years of age, at which point they begin to see the expanded craniofacial team at each visit. Depending on the timing of diagnosis, expecting or new parents are also invited early on in their interaction with the craniofacial center to attend an Infant and Toddler Education meeting where they are oriented to the craniofacial team and have an opportunity to hear from parents of older children and specialists who are members of the team.

Parents of children with disabilities or chronic illnesses have been surveyed to determine their needs, concerns and stress. Results from a study by Horner et al. (1987) of parents of children with CL/CP and other diagnoses indicated that program service needs include help with the financial burden of having a child with a birth defect, recreation for the child, child care, and counseling options for the family and parents. An investigation by Young (2001) examined what information parents feel they need and desire when being informed after delivery that their newborn has a cleft. The results showed that parents wanted the informer to be sure to cover topics such as feeding methods and home management. Parents responded that subjects such as etiology and repair of the cleft could wait until follow-up visits. Results from a study in England showed that parents of young adults who were born with a cleft were generally no longer concerned by the repair process but were concerned about and wanted information regarding potential social and emotional implications (Noar, 1991). A paper summarizing three extensive parent interviews suggests that young parents and parents whose children have more severe clefts experience more stress (Riski, 1991). The authors also state that those parents who are familiar with clefting and those whose children have less severe clefts adjust more easily and
experience less stress. A study by Andrews-Casal et al. (1998) revealed that having a family history of cleft lip with or without cleft palate did not significantly influence the level of stress of parents of a child born with a non-syndromic cleft(s). Lastly, a recent qualitative study performed in Sweden attempted to capture parents’ experiences (Johansson and Ringsberg, 2004). Parents of children under the age of 5 shared that they had been worried about topics such as speech problems, appearance issues, surgeries and heredity.

Information about parent satisfaction with services and treatment is critical for the continuing evolution of craniofacial care. Professionals have presumed that by using a team based approach in which not only medical but also psychosocial concerns are addressed, patient and parent satisfaction and treatment outcome will be enhanced (Strauss and Broder, 1985). A few studies have examined parent satisfaction with their children’s CL/CP related care. A study done in Germany examined the information and support given to parents by medical staff (Dolger-Hafner et al., 1997). Most parents were satisfied with the amount of information they received but some indicated that the information did not aid in their coping. Results from a satisfaction study by Jeffery and Boorman (2001) in England concluded that most parents were satisfied with the clinic services. One-third, however, wanted to be more involved in their child’s treatment. Another 33% expressed they needed more information about CL/CP. An aforementioned study assessed patient and parent satisfaction (Noar, 1991). Results showed that parents and patients were generally happy with the results of treatment. Much of the literature related to satisfaction has been done in the United Kingdom or in Europe, where the parameters of care for children born with clefts are different from what is common in the United States. Recently, a satisfaction survey was performed at this study’s center in which 85% of responses
from parents of children who are seen by the craniofacial team (>3 years of age) were favorable (Sageser and Schultz, 2001).

Parents have expressed often that they want to be involved in the care of their children. Pannbacker and Scheuerle (1993) published results from a study that evaluated parental attitudes about being involved in their child’s treatment of cleft palate. In this study, 36% of parents wished for more participation in their children’s treatment decisions and a large percentage (65%) thought that their help was only slightly effective or ineffective. Professionals have noted the benefits of parental involvement and, in fact, are encouraged by the American Cleft Palate Association to, “actively solicit family participation and collaboration in treatment planning” (2000).

To further involve parents in the treatment process and to increase satisfaction, it is important to assess what interventions healthcare professionals utilize and which are viewed as effective. Some studies suggest that to increase parental retention of information and to promote the process of coping, professionals should give parents information early in the course of treatment and in multiple sessions (Dolger-Hafner et al., 1997; Broder and Trier, 1985). In addition, these studies suggest that parents feel that it is the role of the healthcare professionals to provide emotional support. Similarly, in the study by Johansson and Ringsberg (2004), parents shared that they thought a psychologist should be available to families and that the professionals in the maternity ward need to be more knowledgeable about the condition at hand. Furthermore, it has been suggested that formal letters should become standard of care following evaluation in clinic (Broder and Trier, 1985). Although the current literature gives professionals some tools to use to meet the needs of families, this study aims to expand our knowledge of effective
interventions and allows parents the opportunity to suggest additional techniques to the craniofacial team.
Methods

Study Design and Participants

Approval for this study was obtained from Cincinnati Children’s Hospital Medical Center and the University of Cincinnati institutional review boards. Potential participants were identified through existing patient databases of CL/CP patients at the medical center. A continuous sample was used including all willing parents of children less than 1 year of age who are patients in the Craniofacial Center. Eligible parents of children born with cleft lip and/or palate from their first visit to the child’s 1st birthday were sent a letter that described the study and explained that the families would receive a phone call at home inviting them to participate. A postage paid envelope and reply card was included with each letter that, if returned, allowed the parents to decline phone contact and involvement in the study. The postcard contained space for the parent’s name and signature and two check boxes stating that they would either be willing to learn more about participating in the study or would like to decline participation. Each family who did not return the postcard within two weeks was then called by the principal investigator. Prior to the phone call, the principal investigator performed a limited chart review to obtain demographic data about the child and family. Any previous information gathered from the charts of patients whose parents declined participation was discarded in accordance with HIPAA regulations. For those willing to participate, verbal consent was obtained over the phone and recorded.

The subjects in this study were the parents and primary caretakers of children (<12 months of age) who were followed in the craniofacial center. Only one parent from each home was eligible to participate. Inclusion criteria stated that participants must be parents of children who were born with a cleft lip and/or palate from their first visit to the clinic through one year of
age. Those who were excluded from participating included parents of children who had already had their first birthday at the time of initial contact and parents of children with clefts secondary to syndromes or associations. The exceptions to this rule were that patients with Stickler syndrome or Van der Woude syndrome were included since clefting is initially the primary concern in these patients.

The Craniofacial Center sees about 70-80 new patients with cleft lip and/or palate each year (I. Sageser, personal communication, June, 2004). In this study, thirty-three families were eligible and were sent invitations to participate. Four parents returned the reply card indicating that they were willing to learn more about participation and were subsequently called and gave verbal consent. Thirteen additional participants were called and reached by phone and gave verbal consent. Two parents indicated they did not want to be contacted by return of the reply card and one family declined participation over the phone. The remaining thirteen families could not be reached by phone.

Instrumentation

After reviewing many different established assessment tools (Goodstein, 1960; Miller et al., 1999; Rawlins et al., 1990) it was determined that an interview guide needed to be created to meet the objectives of this project. The interview guide included both closed-ended demographic questions and open-ended questions to allow the parents to respond freely about their experiences (Appendix B). Demographic information was obtained from the databases, the patient’s chart and/or the parents themselves. Parents were then asked free association questions about their past and current experiences with their child and in clinic with craniofacial team members. Follow-up question probes were used to obtain details the parents might not have
offered in response to the initial open-ended questions. A team of experts including the director of the Craniofacial Center, a psychologist with expertise in the field and two clinical nurse specialists who also have extensive experience in the craniofacial clinic helped to tailor the interview guide to fit the specific aims of this investigation of CL/CP and care of patients at CCHMC.

Data Collection and analysis

All 17 telephone interviews were conducted by the primary author between March and June of 2004. Verbal consent to participate was obtained from each participant and was audiotaped and documented by the interviewer. The interviews ranged from 20-60 minutes in length. All interviews were audiotaped. All responses were transcribed verbatim with the names and other personal health information removed.

Transcribed interviews were analyzed using a modified version of the constant comparative method to elicit categories from the open-response questions (Maykut and Morehouse, 1999). Folioview, a text management program, was utilized to organize the responses and facilitate data processing. To increase reliability, an independent examiner reviewed a sample of 8 transcripts and developed a list of themes. These themes were not reviewed until the author completed initial analysis of the entire data set. The author’s categories aligned closely (approximately 90% agreement) with the basic themes identified by the independent examiner. Once categories were identified, they were reviewed, discussed and agreed upon with the co-authors. Descriptive statistics were used to summarize the close-ended questions.
Results

Participants

Seventeen parents participated in the interview. The participants included 15 (88%) biological mothers and 2 (12%) biological fathers. The mean age of the participants was 30.9 years (range 18-41). The median age was 33 years and the standard deviation was 7.4. Eight of the participants had affected daughters and nine had affected sons. The average age of their children was 6.8 months of age (range 1.5 -12 months of age) at the time of the interview. Diagnoses of the participants’ children included 3 (18%) with cleft palate only, 6 (35%) with cleft lip only and 8 (47%) with both cleft lip and cleft palate. Ten (59%) of the participants learned of their child’s cleft at birth while 7 (41%) had received the diagnosis prenatally. These and other participant demographics are summarized in Table 1.

The participants’ children had been to appointments with many different specialists who are members of the craniofacial team. All of the families had seen plastic surgery, 16 had been to Genetics, 10 to ENT/Otolaryngology, 5 to Dentistry and 3 to Audiology.

Thirteen families could not be reached by phone. The average age of the mothers in this group was 25.3 years which is younger than that of the participant population. The majority (54%) had children with cleft lip only, which differs from the participants in which the majority (65%) had palate involvement. This was the first child for 5 (38%) of the non-responders compared with this being the first-born for only 18% of the responders. Also of note, only 3 (23%) had children that were diagnosed prenatally compared with 41% of those included in the study. The average distance of the non-responders from the medical center was 32.65 miles.
Parental Experiences

During the first part of the interview, parents were asked what it has been like to have a child with a cleft. During this portion of interviews, participants were asked open-ended questions related to their experiences with their children, their initial reaction to the diagnosis of their children’s cleft, what had been particularly concerning or difficult during the first months of their children’s life and what advice they might give to other parents in their situation. After analyzing all of the responses about the aforementioned parental experiences, two major categories were identified. The first category addresses difficulties or challenges that parents identify that they face/faced (including surgery, feeding and the unknown) and the second category focuses on the evolution of the parental perspective.

A stressful first year: Parental Challenges and Concerns

The hard part has been the surgeries

Many parents shared that the most concerning or stressful factor has been the anticipation of surgery. A participant shared in reference to her son’s surgeries, “his life has sort of been broken up into three month increments.” The most stressful component for her was “the anxiety of knowing what was coming.” Similarly, another parent shares,

When you get closer to the surgery dates, you get more stressed. Because there’s an unknown there that you don’t know. I guess you just kind of count down the days until she can get that over with. Get through the hospital stay and get back home and get on with your life.
While summarizing her experiences, one mother states, “he’s my greatest joy and my greatest sadness. The sadness is not for me but for him. Knowing that he has to go through surgeries and that he has difficulties that he will [have to] overcome.” The same parent also comments, “I feel like I’m constantly preparing for the next step.”

Parents also shared that one of the most difficult components of the surgery process was the first moments they saw their baby after the procedure. A parent shared, “the only thing they really can’t prepare you for is what your child’s going to look like. You go into the recovery room after surgery and that’s not something they can really prep you for.” Similarly, another parent shared her initial reaction, “seeing him lay there, blood coming from his mouth. It was a little rough.” Many parents agreed that, “the hardest thing was seeing [their child] in pain.”

Other parents were stressed by and/or wanted more information about what would happen after surgery. Parents wanted to know or wish they had known how their child would feed and/or nurse following surgery. A parent who had not yet experienced her child’s first surgery shared, “the surgeries he’s going to have to go through. That’s the worst part.” She worried, “is he going to have trouble eating? Like after his surgeries, is he going to have trouble and what is it going to be like after his surgeries…the pain and stuff.” Another mother shared that,

After the surgery, I was um, I was excited, I was scared because I didn’t know how much she could handle. They tell you that they can go back to eating pretty much regular but I wasn’t really sure how much she could handle at that time.

Other parents commented that they had been given the impression that, after surgery, their child would feed or nurse normally and, as one mother stated, that “was a little bit of a misrepresentation.” On this topic, a mother shared that,
Because (she) was born with just the cleft lip, I nursed her. And I know the craniofacial team does not deal with people that nurse very much because you can’t nurse a child with cleft palate. Which I understand, however, because of that, I really felt like I didn’t get an accurate understanding of how (she) would be for the next month nursing (after surgery). It was very difficult for her to nurse after the surgery.

*It’s not like feeding other babies*

Difficulties feeding or breastfeeding was stressful for many participants. In particular, many shared that, from the start, they wanted or needed more information and guidance about how to feed their baby. An experienced mother shared her sentiments stating that, “you really have to learn to feed babies all over again.” To further illustrate this challenge, one mother reported she left the birth hospital feeling like she was, “running blind-sighted” because “no one there knew how to feed him….I didn’t know whether I was doing it right…because I had no one to really show me.”

Several participants were concerned with their child’s initial weight loss due to feeding difficulties. One mother shared her concerns,

I still obsess over what he eats and doesn’t eat. I think that was just ingrained when he was born that I had to watch his weight so closely those first two months. That’s just stuck with me. And I worry, will he be heavy enough for the next surgery or will he lose that weight again?

Another source of stress mentioned by parents was the time required to feed the baby. For example, one mother shared that, “by the time I got him fed, it was time to feed him again.” Another parent elaborates saying,
It’s been kind of time consuming and a little difficult at times because a baby with a cleft palate doesn’t eat like other babies. You have to take a lot of time and a lot of energy. When you’re supposed to be doing something else, you’ve got to drop doing the other things to take a lot longer time to feed and stuff like that.

Those who had hoped to breastfeed faced additional challenges. A few of the parents who had a child with cleft palate with or without cleft lip shared that even after the baby was born, the lactation consultants and other professionals at the birth hospital told them that breastfeeding was a viable option. A parent shared that, “part of the stress of it was, the hospital where I delivered didn’t understand that he didn’t have the ability to nurse. So, for two whole days, they were trying to get him to latch on.” Other parents commented on the psychological stress of not being able to breastfeed, “it hurt me, I guess mentally because I really wanted to be able to do that [breastfeed] for her.”

*The unknown is stressful*

A large proportion of the parents shared their concerns about their child’s future. Various topics were discussed including potential medical and cosmetic issues.

In terms of medical concerns, many parents worried that their child may have issues requiring more treatment or therapy. “I think my concerns are really more the long term,” one parent said, “you know, speech problems, stuff like that.” Another participant noted concern by saying,

Since the first day the doctor saw him he’s been talking about risks he can have later. Like he will develop hearing problems, speech problems and stuff. I was just praying for
my child not to go through that. So far, he looks fine. I go day by day and hopefully nothing like that will happen.

Other parents expressed concern about potential dental issues wondering things such as, “I’m really wanting to know what those teeth are going to look like where the hole is.”

Many of the parents wondered if/how the cleft(s) would impact social aspects of their child’s life due to the visibility of the cleft(s). For example, a parent shared, “I’m concerned that (the child) will be self conscious about it.” Similarly another parent, “was afraid (the child) would go through a lot of problems in growing up. I was afraid he’d be made fun of and all of that.” A handful of the parents who had daughters shared that they felt the cosmetic issues and therefore social implications will be more difficult given the child’s gender. “Why does a little girl have to have something on her face?” one parent asked. Another participant commented,

I knew I was having a girl. When she told me that day, she has a cleft lip…that made it twice as bad. I have two sons with perfect faces. Even my OB said “It is harder…guys can just grow a mustache.” And I was like, yes, I know that. It was very difficult.

Parental Perspectives: An emotional rollercoaster

An imperfect child: What now?

At the time of diagnosis (whether pre or post natal), all of the participants recalled an initial reaction that was unenthusiastic in tone. The vast majority of the parental reactions aligned closely with the term dysphoria which has been described in previous literature as “a mixture of sorrow and depression, fear and anger, search for reasons, feelings of guilt (oneself and partner), overprotection and social withdrawal.”
The most prevalent reaction mentioned by parents was a sense of shock or being stunned. One parent shared that she, “was probably in shock for a couple of weeks at least” and that she “probably wasn’t even processing what was going on.”

Other parents shared that they were scared or afraid of what the cleft(s) might mean for their child. In particular, a parent says she was, “scared to death” because she was “unaware of the cleft lip and thought that something was really wrong with her.” Another mother admitted, “I was afraid I was going to hurt her.” Overall, these parents worried that they would not know how to or be able to take care of their baby.

Some parents also felt like the cleft was their fault because they felt that the cleft had been inherited or that they had done something wrong. A mother described her husband’s reaction as, “he was crying and feeling like we did something wrong, like something happened to the baby.” Similarly, another parent shared that since they had had a cleft, “there was a lot of guilt that you passed this trait onto your child.”

Other parents shared that they experienced a sense of devastation. One mother shared, “Devastated, I was absolutely devastated. That’s the only way to describe it. I couldn’t even control myself….I was out of control. It was so unbelievable.”

Of those who were informed before birth of the cleft, most were glad to have the information but there were also parents with mixed emotions. Some parents felt that the prenatal diagnosis allowed time to adjust and educate themselves, “I guess when we first found out, it was pretty devastating. But, we did a lot of research on it so when he came, we were pretty prepared. And actually, it’s not been as hard as I thought.” In a related comment, another parent professes, “I was a little disappointed…As soon as I found out, I called (the doctor’s office) and started making arrangements. So I was glad I found out early.” Yet, other parents reported distress due
to knowing ahead of time. “We were concerned that maybe she wouldn’t just have a (cleft) lip but it would be a lip and palate,” a parent notes, “they couldn’t tell us for sure at that time.”

Parents who learned of the cleft(s) at birth think they would have been better off if they had known earlier. A mother shared, “I was having a hard time…Looking back on it, I almost wish we’d known prenatally.”

Other reactions that participants in this study mentioned included: denial, disappointment, sadness, concern or worry, nervousness, anger, feeling sorry for the child, ignorance, horrified, and wonder about how the cleft happened.

*It’s going to be a normal baby: A lot of things are a whole lot worse*

Throughout the interviews, parents commented on their current perspective or feelings related to their child’s cleft(s). Their sentiments differed greatly from their initial reaction to the diagnosis. Parents shared that as they got to know their children, they saw their children as normal or like other children. When discussing her rapid emotional transformation one mother shared,

I was horrified. My OB/GYN told me as soon as his face came out. I just remember looking down through my legs. Then they left us in the room with him for an hour, just me and dad and (baby). After that hour, we were completely fine. Like this is our baby, we love him and we’ll be fine. This can be fixed.

Although all parents’ perspective didn’t change in as quickly as an hour, they shared that life had become easier and their outlook had become more positive.
Yes, it’s a defect, a birth defect that we’ll deal with for many years. But, it gets easier all the time. Compared to when he was first born, it almost feels normal. We’re almost to the point where we can say that it’s very close to being normal.

Many parents of children with cleft lip w/ or w/o cleft palate commented that they had grown so used to and fond of their child’s appearance or “crooked smile” that they went through a period of mourning when their child had to go in for corrective surgery. A mother speaks of her daughter, “by the time you had her surgery, you’re so used to the way she looks that you think, why does she even have to have the surgery? Why can’t she just stay the way she is?”

Participants also recognized that children can be born with many birth defects or health problems that are much more serious than clefting. Commenting on her perspective, a parent shares that this experience has been,

Very eye-opening. I guess it has made me more acceptable of other children born with birth defect. And more sympathetic to what other parents have to go through. Actually it made us thankful that our son was only born with, I hate to say cosmetic problems but his wasn’t life threatening at all. We were grateful that it was something that was fixable. Another parent stated, “Compared to another child with a handicap, I would take a child with a cleft any day.”

This category is further supported by the responses participants offered when asked what advice they would give to a friend who found out they were going to have a baby with a cleft lip and/or palate (the same type as the given participant’s child). Most frequently, parents shared that they wanted the expecting mother to know that although there would be challenges, the cleft is fixable and that things will not be as difficult as she imagines.
Craniofacial Center Services

Satisfaction

After sharing about their experience as parents, participants were asked to describe their experiences with the healthcare team, their level of satisfaction and their suggestions for improvement. Overall, the parents were satisfied with their experiences with the craniofacial team members and with their child’s care. All (100%) participants stated that they were satisfied with the services they had received. Specifically, many parents described that they were “very satisfied” with the services and other parents described their satisfaction as “excellent”. Other noteworthy descriptions included, “On a 1-10 scale, I would say a 9 ½” and “It’s been A+.” Although not specifically asked this question, parents who had been through the first or more than one of their child’s surgeries commented that they were satisfied with the surgery outcome.

Some parents mentioned different techniques or interventions that the craniofacial team members implemented that were particularly helpful. Specifically, parents appreciated repetition of information, seeing pictures of other children (before and after surgery), anticipatory guidance about how to deal with people staring, about the surgical procedure and about follow-up surgeries, and reassurance and information about their child’s cognitive and social development.

Suggestions to healthcare providers

Parents were asked to offer ways in which the craniofacial team could better serve them and their families. Several suggestions were made.

Some of the parents wanted the Craniofacial Team to create and distribute more pamphlets and other written information. The parents who wanted more written information had different ideas about the focus of the materials. One mother shared, “I think I would like to have
a pamphlet sent. To find out what it’s actually caused from and stuff.” Another participant stated that in regard to her difficulty with feeding and getting the correct amount of calories it would have been helpful to have, “the calorie conversions and some feeding (tips) in writing.”

As previously mentioned, parents also want more education about CL/CP for lactation consultants, nurses and residents at the birth and treatment hospitals. At various times during their experience, several parents thought that certain healthcare personnel needed more education or training. As one mother shared her experience with the nurses and lactation consultants in the birth hospital she stated, “I would go back to (the birth hospital) and say, you know what guys, we have something called the internet. Figure it out, go look it up.” Another parent suggested that the nurses who cared for their child, “didn’t seem to know a lot about what (the surgeon) wanted post surgery.” Two parents also commented that the residents that they had been seen by or who they contacted after surgery did not seem adequately knowledgeable about CL/CP. Many of these parents suggested that an online resource for information (feeding info, surgery follow-up care, etc.) might be valuable.

Seven of the parents had been to the aforementioned quarterly Infant and Toddler Education meeting. This meeting typically involves a group of parents sitting in a room while different professionals explain their roles and provide some anticipatory guidance and health information specific to their specialty area. Some participants had suggestions about what changes should be made. One parent shared that he would like the meetings to be more frequent and on more varied topics. Another parent suggested that the meeting would have been more helpful for her if she would have attended prenatally because, “before is when I really needed more information and when I was really searching for more information.” While another wished that the meeting were more specific to her child’s diagnosis and issues.
Parents also suggested that the team establish more parent-to-parent contact and communication. One mother suggested that support be added to the treatment process by establishing a parent-to-parent network. She shared, “Having support, someone besides your spouse or yourself is a lot of help. Someone that’s been through it…another parent, you could call that would be more than happy to take this family under their wing.” Another parent suggested that an information booklet by parents, for parents, would be valuable. She shares, 

They could make a parent information booklet that parents actually sit down and provide information, provide strategies, provide different ways of feeding your child...Everybody I’ve talked to has different ways of doing what they need to do and how they need to do it.

Another suggestion noted by parents was to try to improve coordination of information between specialties or departments. “I think it is a little fragmented” a parent shared, “Where one person doesn’t know what the other person is doing or telling us. Sometimes, I have gotten mixed information.” This parent suggested that it would be helpful to meet with the whole team at once instead of in separate appointments.

As mentioned in the discussion of parental comments about feeding difficulty, some parents would like the Craniofacial Team to provide more information about feeding and/or nursing difficulty following surgery. They wished they had been given warning about the difficulties children can have feeding after surgery and more information about the time frame involved in this readjustment.

The suggestions listed here and other parents’ suggestions are summarized in Table 5.
Discussion

The responses characterized the parental experience during their child’s first year of life. The most universal concern was anticipation of surgeries. Bottle or breast feeding difficulties and their children’s future medical or social issues were also frequently cited as concerns by parents at this stage. The primary concerns of these parents have similarities and differences from the priorities of parents of newborn infants (Young, 2001) and the parents of young adults (Noar, 1991). Parents of newborns want information about feeding and home management while parents of young adults are most concerned with social implications related to their child’s cleft(s). It seems that, during the first year, although parents concerned with feeding and are beginning to consider the future implications of the cleft(s), surgery causes the most stress. The results reported here show similarities to concerns cited by parents who were recently interviewed in Sweden (Johansson and Ringsberg, 2004). The parents in that study were most concerned with speech, appearance, upcoming surgery and heritability. The study population in Sweden had children up to five years of age, which may account for the more frequent mention of speech implications and appearance, but there may also be a cultural component in play. Healthcare providers can use this information to further guide their interactions with families in the United States who have children under the age of one born with clefts. By providing more information and support related to surgery and the other concerns that were mentioned, parents may feel more empowered and knowledgeable and therefore, less stressed.

Results from this study support that although parents initially have a difficult reaction to learning of their child’s cleft(s), they quickly adjust. The majority of the parents (64.7%) shared that, even as early as the first months, their child was seen as normal or close to normal. Their specific concerns about the implications of the cleft may persist, but stress related to the cleft
decreases as they get to know their child and a routine is established. Professionals may choose to share with families that other parents often remark that, at some point within the first year, their lives will begin to feel more normal than abnormal. Professionals may also use this opportunity to help parents network with other families who have had experience with surgeries, feeding issues and other challenges. Education about and exposure to the experience of other parents can serve as a valuable tool in meeting the psychosocial needs of families.

Overall, participants in this study were satisfied with the services provided to them through the members of the craniofacial team. This information supports the aforementioned professional preference for a team-based approach that stresses both medical and psychosocial care (Strauss and Broder, 1985). Moreover, the results of our study give insight about parental satisfaction in a multidisciplinary treatment center in the United States medical system. Parents in the US seem to be as or possibly more satisfied than those in Europe (Dolger-Hafner, 1997) or the United Kingdom (Noar, 1991; Jeffery and Boorman, 2001). When asked what they would like improved to better meet their needs parents shared that they would like more written materials, more education for healthcare professionals outside the craniofacial team, more contact with other parents, more accurate information about post-surgical feeding difficulties and better consistency and coordination of information between the individual departments. The suggestions are reasonable and realistically attainable and as craniofacial team care becomes more established and begins to evolve, they represent the next level in the hierarchy of patient/family care. In sum, given the participant feedback, this study’s craniofacial team can be assured that essentially all of the families they serve are satisfied with their services (Sageser, 2001) but that improvements can be made to better serve the families with younger children.
Some of the participants’ suggestions, such as more education for healthcare professionals, overlap with findings from the study by Johansson and Ringsberg (2004). As those authors state, the findings from studies such as these can serve as part of the education for health professionals that is currently lacking. To further address this issue, birth and treatment hospitals should implement education about and training regarding the care of patients with orofacial clefts. Perhaps, as participants mentioned, create an online resource that addresses etiology of clefting, surgeries and post-surgery care, feeding limitations and tips and other crucial information. Alternatively, craniofacial teams or the hospitals themselves could develop care standards in a written form that would accompany the baby through the steps of the treatment process. By training healthcare professionals who are likely to care for children with clefts, treatment can be implemented earlier and more effectively. Future research should be designed to assess the knowledge and skill level of the healthcare professionals that come in contact with these families: specifically nurses, lactation consultants and residents. The data will facilitate further inquiry about specific deficits and allow birth and treatment hospitals to begin to develop appropriate standards.

There are several specific strengths of this study. First, the scope of this investigation is unique in that this is the first to concentrate on the first year of life and also capture a balance of perspectives from parents who learned of the cleft prenatally and at birth. The perspective of many of the parents can be summarized by the statement of one mother, “it is a stressful first year. I just keep thinking that it’s going to get easier each year but the first year has been tough.” Educating professionals who will interact with these families early on about the particular concerns and stressors of these families and how to best address their stress can potentially
decrease parental anxiety and improve the treatment environment. Second, given that the study population was recalling experiences within a year, the potential for recall bias is minimized. Lastly, the results of this study can be generally used to guide professionals with families who have children born with indications other than cleft lip and/or palate. As noted by Noar (1991), families who have a child born with a variety of birth defects can have similar reactions, concerns and needs. Although the responses reported here are specific to families who are dealing with the issues related to clefting, the themes are applicable to many other families.

Certain parameters of this study may be viewed as limitations. For instance, the findings noted here cannot be generalized to the parents of older children with CL/CP. It is known that beyond the first year and throughout the lifespan, familial perspectives change (Noar, 1991). Health professionals must continually check in with families regarding their evolving concerns. Also, the participants may not have been reflective of the general population of children with cleft(s) under the age of one. As noted in the results, there may be a difference in age, diagnosis and prior experience with parenting. It may be possible that the participants were more likely to be older more experienced parents who have children with more palate involvement. Without more information about the non-responders and those who declined participation, comparison with the participants is not possible. Also, as with any qualitative research, the findings can be reported as inferences and can be invaluable in developing future research inquiries but caution must be taken when generalizing the results. Even more, given the qualitative nature of this investigation, direct comparisons cannot be made between parents with varying circumstances. Future studies should involve investigation into whether there are significant differences in parental experiences based on variables such as the specific type of cleft(s) (i.e.- CL vs. CP vs.
CL&P) or the time of diagnosis (pre vs. post natal). A follow-up to this study which will be quantitative in focus is currently being developed.

This study helps to clarify the experiences and perspectives of parents of children born with a cleft lip and/or palate at one regional pediatric medical center. Although, at this point, the results of this study cannot be directly extrapolated to other craniofacial centers, the themes that have been identified can be recognized as potentially universal. The authors suggest that similar studies in other craniofacial centers may also yield valuable information about parental concerns and suggestions for improvement. In particular, the qualitative, open-response approach utilized in this study allowed parents to share openly and expand upon their thoughts and ideas, which would not have been feasible with a more prescribed, quantitative-type survey. Giving parents the opportunity to express their concerns and offer their propositions for enhancing their experiences with the healthcare professionals that care for their children is an effective way to make the parents an instrumental part of craniofacial team.
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Appendix A

Dear Parent,

It is our understanding that your baby was born with a cleft lip and/or palate. We are looking for ways to improve how we care for children born with these conditions and their families. We would like to hear from you about your experiences with your child’s cleft and your experiences with the Craniofacial Team at Cincinnati Children’s Hospital Medical Center.

Although a cleft can be repaired with surgery, babies that are born with this condition will have to see many specialists during treatment to make sure they are getting the best care. At Cincinnati Children’s Hospital Medical Center, a team of professionals will be involved in your child’s care. The Craniofacial Center at CCHMC follows children through each stage of treatment, usually beginning after birth and continuing through adolescence. The Craniofacial Center at CCHMC is composed of a team of specialists representing many different departments and divisions. Newborn infants and babies such as yours may initially only see certain members of the team who are important to their early care (such as Genetics, Plastic Surgery, Dentistry and ENT). Beginning at age 3-4, regular Craniofacial Team evaluations include all of the members of the team continue until treatment is complete. The members of the team hope that they can meet the information and service needs of you and your family.

We need your help. We are asking for your participation in a study at CCHMC. The purpose of the study is to interview parents like yourself to determine the causes of stress and the needs that you have during the first year of treatment of your child’s cleft and to assess whether your needs are being met by the craniofacial team. The study involves participating in a telephone interview. You will be called within the next month and asked if you are willing to participate.

If you agree to be involved, you will then be asked questions about your experiences with your child and the Craniofacial Center team members. The interview should take approximately 20-45 minutes, depending on your responses. All of your responses during the interview will remain confidential. If you decide to take part in the research study, you are free to withdraw at any time. Leaving the study will not result in any penalty or loss of benefits to you.

Your participation in this study is completely voluntary. You may choose either to take part or not take part in this research study. Your decision whether or not to participate will not result in any penalty or loss of benefits to you and the standard medical care for your child’s condition will remain available to you. If you do not want to participate in this study, please return the enclosed postage-paid postcard with your name and signature. Returning the postcard within two weeks ensures that you will not be called.

Thank you for your help. If you have any questions or concerns about the study, please call the principal investigator, Sara Rankin, at 513-636-5840.

Sincerely,

Howard Saal, M.D.  Patricia Bender, R.N, M.S.N.  Sara Rankin
Clinical Geneticist  Clinical Nurse Specialist  Graduate Student
Division of Human Genetics  Division of Human Genetics
Appendix B

Perspectives of Parents of Children Born with Cleft Lip/Palate: A Qualitative Assessment of Stress and Needs.

Interview Guide

Introduction/Verbal Consent:
“Hi, my name is _________ and I am calling to follow up on a letter that was sent to you about participating in a study for Cincinnati Children’s Hospital Medical Center. Did you receive this letter?_____ (If not, give them info from letter including purpose, goals, incentive, confidentiality. If they did receive the letter than read the following summary). As the letter states, we are asking for your participation in a study that involves interviews with parents of children who were born with a cleft lip and or palate. Are you interested in learning more about participating in this study?_____ (If not than thank them for considering this opportunity and end the phone call.) This study is being done for research purposes. Although this study will not have direct benefit to you or your family, the results will be used to assess and potentially improve the care that is provided to families like yours in the future. Participation is completely voluntary. If you choose not to participate, your decision will not interfere with the care of your child. Should you agree to participate, this study involves a telephone interview during which you will be asked questions about what it is like to have a baby with a cleft and your experiences with the Craniofacial Team at CCHMC. All of your responses will be confidential. Responses will be recorded to make sure we accurately represent parent responses but the tapes will be erased after all of the data is collected. Are you willing to participate?_____ Is this a good time to talk? (If not, then agree on a day and time to call back). The interview should take between 20-45 minutes. If at any time you feel uncomfortable, you can let me know and I will stop the tape recorder. Do you feel comfortable proceeding with the interview?”____

“In the letter, there was a description of the Craniofacial center and the healthcare team involved with children who are born with clefts. Would you like me to describe this again now? (If so, read info from letter to subject). Throughout this interview, I will be referring to the Craniofacial team. This includes any healthcare professionals that are affiliated with the Craniofacial Center at CCHMC. Please let me know if you need clarification at any time.”

Demographics:
“I would like to start by reviewing some information that is present in ____’s chart. Please update or correct the information as I go along.” (Most items obtained prior to interview by chart review.)

1. 1. Your baby is a _____ month old _________ (female/ male).

2. Your baby has a cleft _____ (lip/ palate/ or both).

3. (Palate and/ or lip) Surgery (was performed/ is scheduled/ will be scheduled) when your child (is/was) ____ (months or weeks).

4. You live in ______ (KY, OH, or IN).
5. Your child’s ethnicity is described as _______.

6. What members of the CFC team (specialists) have had appointments w/ _______?
   Include list in case the parents don’t know exactly.
   
   ____ Genetics ____ Craniofacial Surgery ____ Prosthodontics
   ____ Plastic Surgery ____ Neurosurgery ____ Psychology
   ____ Dentistry ____ Oral Surgery ____ Speech Pathology
   ____ ENT ____ Orthodontics
   ____ Audiology ____ Otolaryngology

7. What is your relationship to _________ (the baby)? (Biological mother/father, foster 
   mother/father, adoptive mother/father)

8. How old are you?_____

9. How many children do you have?_____ Is this child the 1st, 2nd, 3rd, etc.?_____

10. Who else lives in your home with the child? Both parents? Other relatives or children?

11. Who takes care of the baby the most?_______ Who else helps take care of the 
   baby?_______ Is the baby in daycare?________

12. At the time of birth, How would you have described the severity of your child’s cleft? 
   (minor, moderate, severe)________

13. When did you find out your child had a cleft?

14. Before this child, were you familiar with cleft lip/ palate? How?

Qualitative:
“Thank you for sharing all of this information. I will now ask you some questions about your 
experiences with your child, the cleft itself and the CFC health professionals you have been 
seeing so far. Please respond as openly as possible. If at any time you need a question repeated 
or clarified, let me know.”

Concerns/ Stress:
15. What has it been like for you to have a baby with a cleft?

   Prompts:
   ▪ What were you feeling and what thoughts do you remember having after delivery? (In 
     other words, could you please describe your reaction to your child’s cleft (if diagnosed 
     postnatally)?)
   ▪ Please tell me about your first week at home with ____. Please describe a happy time 
     you had during those initial days. Was there a time during that first week when you 
     felt particularly stressed or overwhelmed? If so, please describe that time for me.
   ▪ What are your days like now? How would you describe your current stress level?
   ▪ What has been most concerning or difficult about your child’s cleft?
- If a friend of yours found out she was pregnant with a child who had a cleft lip, what would you tell her to help her prepare for the birth of her child?

Interventions:
16. Could you please describe your experiences with (above mentioned CFC members) so far?
   Prompts:
   - What happens during your appointments?
   - How well have your questions and concerns been addressed by the member(s) of the Craniofacial Team?
   - What type of information is discussed at your clinic visits with member(s) of the Craniofacial Team?

17. I am interested in your suggestions about how information about your child’s cleft provided by Craniofacial Team member(s) could be made easier to understand and/or more helpful.

18. What could the Craniofacial team members do better to address your questions and concerns?

19. Have you attended or are you planning to attend the Infant and Toddler meeting? If so, did you find this helpful? Why or why not?

Needs/ Satisfaction:
20. What do you need from (the above mentioned CFC members)?
   Prompts:
   - What information do you feel is most important to discuss with the Craniofacial team member(s)?
   - Do you have any needs that have not been met by the Craniofacial Team member(s)?

21. Are you satisfied with your child’s care? Please describe why
   Prompts:
   - How would you describe your overall satisfaction with your child’s care from the Craniofacial Team member(s)?
   - What would make your experiences with the Craniofacial Team member(s) better?

“We are finished with the question and answer portion of the interview. Thank you for your taking your time to participate in this study. Do you have anything else that you would like to share about being a parent of a child born with a cleft or about CFC? (Pause for response) “Again, I thank you for your time. Would you like a copy of the results of this study when it is completed? (Yes/ No). If you have any additional questions about the study, you can contact me at 513-535-5840. Goodbye”
Appendix C

Table 1. Participant demographics

<table>
<thead>
<tr>
<th>Category</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total participants</td>
<td>17</td>
</tr>
<tr>
<td>Average Age of Participant (years)</td>
<td>30.9</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>7.4</td>
</tr>
<tr>
<td>Median Age of Participant (years)</td>
<td>33</td>
</tr>
<tr>
<td>Average Age of Child (months)</td>
<td>6.8</td>
</tr>
<tr>
<td>Average distance from medical center (miles)</td>
<td>65.5</td>
</tr>
<tr>
<td>Relationship to child</td>
<td></td>
</tr>
<tr>
<td>Biological mother</td>
<td>15 (88%)</td>
</tr>
<tr>
<td>Biological father</td>
<td>2 (12%)</td>
</tr>
<tr>
<td>Gender of child</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8 (47%)</td>
</tr>
<tr>
<td>Male</td>
<td>9 (53%)</td>
</tr>
<tr>
<td>Ethnicity of Child</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>15 (88%)</td>
</tr>
<tr>
<td>North African/ Mediterranean</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>Cuban American</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>Diagnosis of child</td>
<td></td>
</tr>
<tr>
<td>Cleft Lip and Cleft Palate</td>
<td>8 (47%)</td>
</tr>
<tr>
<td>Cleft Lip only</td>
<td>6 (35%)</td>
</tr>
<tr>
<td>Cleft Palate only</td>
<td>3 (18%)</td>
</tr>
<tr>
<td>Time of diagnosis</td>
<td></td>
</tr>
<tr>
<td>Prenatal</td>
<td>7 (41%)</td>
</tr>
<tr>
<td>Postnatal</td>
<td>10 (59%)</td>
</tr>
<tr>
<td>Family history of CL and/or CP</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5 (29%)</td>
</tr>
<tr>
<td>No</td>
<td>12 (71%)</td>
</tr>
<tr>
<td>Familiarity with CL and/or CP</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>7 (41%)</td>
</tr>
<tr>
<td>Little – Some</td>
<td>7 (41%)</td>
</tr>
<tr>
<td>Much</td>
<td>3 (18%)</td>
</tr>
<tr>
<td>Birth Order of Child</td>
<td></td>
</tr>
<tr>
<td>First born</td>
<td>3 (18%)</td>
</tr>
<tr>
<td>Not first born</td>
<td>14 (82%)</td>
</tr>
<tr>
<td>Severity of Cleft (as reported by participant)</td>
<td></td>
</tr>
<tr>
<td>Minor</td>
<td>8 (47%)</td>
</tr>
<tr>
<td>Moderate</td>
<td>3 (18%)</td>
</tr>
<tr>
<td>Severe</td>
<td>6 (35%)</td>
</tr>
<tr>
<td>Surgery status</td>
<td></td>
</tr>
<tr>
<td>Has had at least 1</td>
<td>12 (71%)</td>
</tr>
<tr>
<td>Has not had surgery yet</td>
<td>5 (29%)</td>
</tr>
</tbody>
</table>
Appendix C (Continued)

Table 2: Parent’s Stated *Main* Concerns and Stressors

Anticipation of Surgery/Surgeries (6)  
Feeding Difficulties  
  Difficulties with bottle or inability to Breastfeed (5)  
  Infant Weight Loss (2)  
Future Issues  
  Cosmetic Issues/ Outcome of surgery (2)  
  Development/ future healthcare needs (1)  
People Staring (2)  
Getting Good Care (1)  
Relationship with siblings (1)

Table 3: Parental Concerns and Stressors Overall

Anticipation of surgery /Cosmetic outcome of surgery (12)  
Attempting to breastfeed/ Difficulties with feeding / Weight loss (10)  
Future Issues  
  Child’s development and/or future therapeutic needs (4)  
  Cleft had occurred in a daughter rather than a son (3)  
  Dental implications from the cleft(s) (2)  
Transportation to and from the multiple doctor’s appointments  
People Staring  
Getting Good Care  
Relationship with siblings
**Table 4. Advice for a parent expecting a child with CL and/or CP**

Emphasize that it is fixable (4)
Tell her that it will not be as bad/ hard as she thinks (4)
Warn of breastfeeding challenges/ feeding difficulties (4)
Contact/ meet with professionals early (3)
Discuss how to deal with people staring and asking questions (2)
Show pictures of their own baby (2)
Stay away from internet (2)
Take things one day at a time (2)
Warn of surprise of seeing baby for 1st time (2)
Other advice (1 each):
  - Tell her it will be overwhelming
  - Read a lot to prepare
  - Prepare yourself emotionally
  - Tell her she’ll get through it
  - Look at your baby as being unique
  - Help is available and don’t be ashamed to ask
  - Be patient
  - Don’t be disappointed
  - Warn her that there will be a lot of doctor’s appointments
**Appendix C (Continued)**

**Table 5: Parents’ Suggestions to the Craniofacial Team**

<table>
<thead>
<tr>
<th>Suggestions</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Create and distribute more pamphlets and other written information</td>
<td>(4)</td>
</tr>
<tr>
<td>Educate lactation consultants, nurses and residents about CL/CP</td>
<td>(4)</td>
</tr>
<tr>
<td>Make changes to Infant and Toddler meetings</td>
<td>(3/7)</td>
</tr>
<tr>
<td>Establish more parent-to-parent contact/communication</td>
<td>(2)</td>
</tr>
<tr>
<td>Provide more information about feeding/nursing difficulty following surgery</td>
<td>(2)</td>
</tr>
<tr>
<td>Improve coordination between departments</td>
<td>(2)</td>
</tr>
<tr>
<td>Other parents’ suggestions included (1 each):</td>
<td></td>
</tr>
<tr>
<td>Allow (lip) surgery to be done earlier to decrease the issues related to</td>
<td></td>
</tr>
<tr>
<td>development of hand/eye coordination</td>
<td></td>
</tr>
<tr>
<td>Use a model to explain how the cleft occurred and how it will be repaired</td>
<td></td>
</tr>
<tr>
<td>Be more sensitive when telling parents that they will not be able to breastfeed</td>
<td></td>
</tr>
<tr>
<td>Give parents more than one box of bottles</td>
<td></td>
</tr>
<tr>
<td>Do not alarm parents with small details related to their child’s deviation from growth charts and normal development</td>
<td></td>
</tr>
</tbody>
</table>