

Experiences of Couples Having a Young Child with Cleft Lip and/or Palate, Comparing

Prenatal and Postnatal Diagnosis Groups:

A Phenomenological Study

A Thesis

Submitted to the Faculty

of

Drexel University

by

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in partial fulfillment of the

requirements for the degree

of

Doctor of Philosophy

May 2014

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DEDICATIONS

To the people who remained by my side, in my thoughts, and in my heart throughout this process:

- “Zeytins”: I hope that I was able to give voice to the experiences that each of you had throughout this study. You all were great sources of inspiration.
- Can Saydam: You are my “port of call,,” my “secure base..” Sen benim hayat şansısın.
- Handan Oktar: You showed me the real virtues in life. I miss you always.
- Fehime Öztemir: Thank you for teaching my mom how to feed me. You did both of us a huge favor!

“İt Ulur Kervan Yürür”

- Anonymous

ACKNOWLEDGEMENTS

Couple and family therapists believe that relationships matter. In fact, close relationships can provide us with safety, strength, and courage to go out into the world, grow, and become whom we dream to be. There are many people in my life who were a source of safety, strength, and courage and who made it possible for me to conduct this dissertation study.

Working with Dr. Maureen Davey as my mentor and dissertation chair was the best thing that happened to me in my doctoral program. For the last 4 years, I never felt lost because Dr. Davey was always there to guide me. She provided me with opportunities that I could only dream of; she made me a better researcher, teacher, writer. I am and will always be grateful for her presence in my life. I also owe so much of my growth to Dr. Harry Aponte, who gave me unconditional support and loving guidance. He helped me see human beings and relationships in a different way, highlighting our humanness and potential for growth in the presence of adversity.

My gratitude also goes to my committee members Dr. Kathleen Fisher, Dr. Canice Crerand, and Dr. Erica Wilkins, all of whom have been patient and supportive as I learned how to conduct my own study. They provided me with suggestions and steady guidance to improve the quality of my study. I have been so fortunate and lucky to be able to work with professionals who are so knowledgeable, responsive, and caring.

My luck in finding exceptional people by my side continued as I met Dr. Ting Liu. She became a mentor and a friend to me. I owe so much of my growth as a novice Emotionally Focused therapist to her. She made me think and dream much bigger.

I am also grateful for the friendships that I developed throughout the Drexel University doctoral program over the last 4 years. Alba Nino, Karni Kissil, Florina Apolinar Claudio, and

Laura Lynch became my colleagues, but more importantly my family at Drexel. They constantly motivated me to think more deeply and helped me grow as a person both personally and professionally. Emre Yetkin, Ceren Özek, and Başak Doyan opened my eyes to different parts of Philadelphia and even encouraged me to really like this city that was so different from my home in Turkey.

And when I failed in my attempts to like Philadelphia, Ceren Zeytinoğlu, Alaattin Özbaş, and Jülide Orhon opened up their homes to me when I needed to become centered and balanced again, taking a break from the rigors of graduate school. They helped me stay connected to my other self, the self that keeps me away from fully becoming a workaholic and a hopeless nerd. Yudum Akyıl also became a role model and an inspiration for me throughout my PhD program. She led the way for me to follow.

When I moved back home last summer (2013) to analyze my data and write my dissertation, I once again felt the love and support of colleagues, friends, and family. Selda Özen and Memet Özek were the best bosses ever. They encouraged me to keep going and allowed me to prioritize my dissertation above everything else. Muattar, Candan, and Esra Saydam provided me with continuous logistical support.

Finally and most importantly, I would like to thank the three people who provided me with unconditional love and support. They were the people who dropped everything to help me whenever I needed them:

Can Saydam, you are the person I always hoped to partner with, but I never thought you actually existed! Thank you for encouraging me to prioritize this dissertation above our relationship, for being there during my emotional breakdowns, and for staying by my side when I could not bear myself. Thank you for being an amazing partner in life.

And Mom and Dad, thank you for believing in my dreams. Without you, none of this would have been possible.

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Abstract

Experiences of Couples Having a Young Child with Cleft Lip and/or Palate, Comparing Prenatal and Postnatal Diagnosis Groups:
A Phenomenological Study
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This study was designed to describe the experiences of *both* mothers and fathers who are currently caring for an infant (12 months old) or young child (up to 4 years old) who was born with cleft lip and/or palate (CL/P). The biopsychosocial approach, the Resiliency Model of Family Stress, Adjustment, and Adaptation, and transcendental phenomenology guided this study. A convenience sample consisted of 17 couples (10 prenatal and 7 postnatal) who previously volunteered for an ongoing longitudinal quantitative study at the Children's Hospital of Philadelphia [PI: Dr. Canice E. Crerand, PhD (2008). Psychosocial adjustment in parents of infants with cleft lip and/or palate: The impact of prenatal versus postnatal diagnosis].

Couples completed a consent form, a demographic self-report survey, and the Revised Dyadic Adjustment Scale and then participated in in-depth interviews. The timing of the CLP diagnosis, the birth, and the initial stages after birth were reported as the most challenging periods for both prenatal and postnatal couples, unless their children still had ongoing developmental delays. The initial stages immediately following the birth were reported as more stressful for the postnatal diagnosis group because they had no time to prepare. Course of treatment, feeding, and social stigma were reported as major sources of stress for all 17 couples.

Findings suggest that, regardless of the timing of the diagnosis, couples could benefit from (1) health professional's calm demeanor when first delivering the CL/P diagnosis, because it affects how parents perceive the CL/P, which later determines how they cope and problem

solve; (2) an initial information session with both parents at the time of the diagnosis; (3) peer support from other couples to reduce their feelings of isolation; (4) help from health professionals to alleviate any self-blame, especially for the mothers; and (5) help for couples who are more distressed at diagnosis and especially during the first year after birth, such as regular screening and referrals for couple-based interventions to promote secure attachment and better coping. Finally, future research should include more racially and economically diverse samples of couples to develop culturally sensitive intervention programs.

CHAPTER 1: INTRODUCTION

1.1 Prevalence of Cleft Lip and/or Palate

Orofacial clefts including cleft lip with or without palate and cleft palate without cleft lip are among the most common congenital anomalies in the United States. Cleft lip with or without palate impacts 1 in every 940 (10.63 per 10,000) live births, whereas 1 in every 1574 (6.35 per 10,000) babies are born with cleft palate without cleft lip (Parker et al., 2010). The prevalence of orofacial clefts varies by race, occurring most frequently among Asians and Native Americans, followed by Whites and Hispanics; it occurs least frequently among African Americans (Banales, 2009; Wilkins-Haug, 2012). Cleft lip with or without palate is more common among males, whereas cleft palate is more common in females (Wilkins-Haug, 2012).

1.2 Etiology

Clefts are classified as cleft lip (CL), cleft palate (CP), and cleft lip palate (CLP). Both CL and CP can occur unilaterally or bilaterally as well as be complete or incomplete. A complete cleft of the lip includes the entire upper lip and continues up into the nose through the nostril sill and up into the incisive foramen, which is the beginning of the hard palate behind the incisive teeth (Figure 1.1). An incomplete CL is a vertical indentation or a notch on the upper lip. CP is classified on the basis of its inclusion of the primary and secondary palates. Primary palate includes the part preceding the incisive foramen; the secondary palate refers to the roof of the mouth involving both the hard and soft palates. A complete CP involves both the primary and the secondary palates. An incomplete CP is usually a gap in the roof of the mouth (Figure 1.1). The least severe type of CP is submucous cleft palate, which refers to an incorrect positioning or a

deficiency of the palate muscles that often involves a cleft in the uvula, which is the small fleshy tissue that hangs at the back of the soft palate. Clefts are classified as unilateral or bilateral on the basis of whether they are located on one or both sides of the cleft lip and/or palate. CLPs involve a cleft in both the lip and in the palate (Friedman, Wang & Milczuk, 2010).

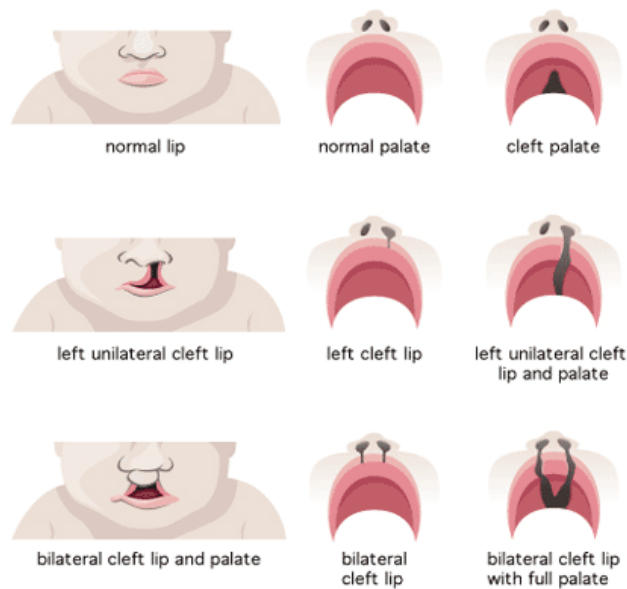


Figure 1.1. Different Types of Clefts

(Reprinted from Cleft Lip and Palate, In *Brenner Children's Hospital*, n.d., Retrieved October 28, 2012 from <http://www.brennerchildrens.org/KidsHealth/Parents/Doctors-and-Hospitals/Surgical-Conditions/Cleft-Lip-and-Palate.htm>)

Even though a definitive cause of CL/P is unknown, researchers have discovered that CL/P develop between the fifth and twelfth weeks of neonatal development (Conrad, Richman, Nopoulos & Dailey, 2009; Friedman, Wang, & Milczuk, 2010). At the end of the fourth week in utero, neural crest cells, which form the brain and facial tissue, become differentiated from the neural tube to form the facial structure. During the fifth

and sixth weeks of embryonic development, these tissues start growing to develop the frontal face, cheeks, lower lip, and chin. Clefts occur if there is a problem with the fusion of these tissues and the fusion that forms the lip. The primary and secondary palates and the uvula end by the twelfth week of embryonic development (Friedman, Wang & Milczuk, 2010; Mavroudi, Rekapoulou, Papadopulos, & Papadopulos, 2007).

Although there is no definitive cause for the development of CL/P, chromosomes, genes, proteins, and the environment as well as spontaneous genetic mutation all play a role in the development of clefts in utero (Conrad, Richman, Nopoulos, & Dailey, 2009). The probability of clefts occurring in monozygotic twins is 40% to 60% (Friedman, Wang, & Milczuk, 2010). If neither parent was born with clefts, the chance of cleft lip with or without palate occurring in a sibling when another sibling was previously born with this condition is approximately 4%. These chances increase to 7% to 10 % for a third sibling if the other two siblings are born with cleft lip with or without palate. If one of the parents has a cleft, the likelihood that a child will be born with CLP or with an isolated CP is 3.2% to 6.8%, respectively. If one parent and one child are both affected by clefts, the next child has approximately a 15.8% chance of having CL or CP and a 14.9% chance of having CP (Friedman, Wang, & Milczuk, 2010; Suslak & Desposito, 1988). These findings suggest that both genetic and environmental factors affect the development of clefts in utero.

In terms of environmental factors, maternal cigarette smoking, paternal smoking as well as passive smoking before and during pregnancy are significantly associated with developing a CL/P in utero. The risk of a baby developing cleft increases with the amount of exposure to cigarette smoke (Chung, Kowalski, Kim, & Buchman, 2000; Khoury et al,

1987; Leiby, Tan, & Brown, 2010; Li, Liu, Ye, Zang, Zheng, & Ben, 2010; Zhang, Jiao, Mao, & Xue, 2010).

Zhang, Mao and Xue (2010), for example, investigated the association between maternal and paternal cigarette smoking before and during pregnancy and the chance of a baby developing a CL/P. They compared 304 babies diagnosed with cleft with 453 unaffected control babies and assessed parents' patterns of smoking both 6 months before and 3 months after conception. The researchers reported that CL/P were more likely to occur if the mother was smoking 1 to 10 cigarettes per day *before* pregnancy.

Researchers adjusted for vaginal bleeding, abdominal pain, baby's sex, maternal age, and educational level when investigating the impact of maternal smoking on the baby's cleft. Maternal cigarette smoking during the first trimester was significantly associated with an increased risk of a baby developing a CL/P.

Using the 1996 US Natality database, Chung, Kowalski, Kim and Buchman (2000) examined CL/P cases from 46 states; they reviewed 2207 cases in which the babies were born with cleft/palate and 4414 case control babies born with no congenital defects. The covariates were maternal age, educational level, race, and maternal medical conditions. After controlling for these covariates, they reported that maternal cigarette smoking during pregnancy was significantly associated with having a child with CP; as the number of cigarettes smoked per day increased (1-10 cigarettes versus 11-20 versus more than 21), the likelihood of cleft occurrence also increased. Being non-Black, having less than a high school education, or having diabetes or pregnancy-related hypertension were other salient risk factors for offspring developing cleft lip/palate. There were no significant differences between the two groups regarding the timing of prenatal care.

Increased maternal age and having more than a high school education significantly decreased the risk of having a baby born with cleft lip/palate.

Paternal smoking at both light and moderate levels *before* pregnancy was also significantly associated with the occurrence of all types of cleft in babies, especially cleft lip/palate. Passive smoking in this study was operationalized as environmental tobacco exposure (ETS). ETS at lower levels was defined as less than 2 hours/day, whereas medium levels were defined as 2 to 6 hours/day. Furthermore, researchers reported a strong and significant association between medium levels of paternal smoking a month before pregnancy until the end of the first trimester and the occurrence of clefts in utero. Light ETS 1 month before pregnancy and during the first trimester was more likely to lead to CL; heavy ETS (more than 7 hours/day) during the same period was significantly associated with CP. Increases in maternal age and high school levels of education were significantly associated with decreased risks of having a baby born with CL/P.

Li et al. (2010) also reported a significant association between maternal passive smoking and the occurrence of cleft lip with or without palate. They compared 88 cleft cases with 651 healthy controls with no major external birth defects. They also controlled for infant's sex, season of conception, resident county, maternal age, maternal education, maternal occupation, number of the mother's pregnancies, number of times the mother gave birth, history of birth defects in previous pregnancies, flu or fever in early pregnancy, and use of periconception folic acid. Between 1 month before and 2 months after conception, the mother's passive smoking was significantly associated with the development of CL/P in utero. The levels of smoking exposure through passive smoking or secondhand smoke were classified as at least one cigarette one to six times per week

and more than six times per week. The researchers reported a positive dose-response association, indicating that, as the frequency of exposure to smoking (secondhand smoke) increased, so did the cleft risk, especially for male offspring.

Lebby, Tan and Brown (2010) examined secondary data from The National Center for Health Statistics (2005) and reported that the mothers of children born with oral clefts were more likely to be non-Hispanic white, to smoke, and to have pregnancy-associated hypertension. Smoking was significantly associated with having a child born with cleft across all racial/ethnic groups, whereas pregnancy-associated hypertension was a risk factor for only non-Hispanic whites. The researchers suggested that clefts are not prevalent in some racial groups such as African Americans because of inheritance factors, whereas smoking and hypertension are modifiable environmental factors.

In addition to smoking and secondhand smoke exposure, having an unplanned pregnancy was another significant risk factor for having a baby born with cleft. For example, a mother who smoked and who had an unplanned pregnancy was three times more likely to have a child born with cleft compared to a mother who did not smoke and who had a planned pregnancy (Mossey, Davies & Little, 2007). Factors associated with pregnancy planning, however, were not fully examined in this study; more definitive conclusions are still uncertain. Even though CL/P occurs more frequently in Whites compared to Blacks and Hispanics living in the United States, the number of cleft cases are significantly increasing among Blacks who were living in New Orleans after Hurricane Katrina (Goenjian, Chiu, Alexander, Hilaire, & Moses, 2011). The authors suggest that felt maternal stress, stress-related substance use, and exposure to

environmental teratogens (e.g., Hurricane Katrina induced environmental changes) such as radioactivity during pregnancy may be the causes of this significant increase.

Wallace, Arellano and Gruner (2011) investigated the impact of maternal stress in the formation of nonsyndromic CL/P. They hypothesized that increased maternal stress would significantly affect the distribution of blood flow to the fetus, changing in utero physiology and embryonic development. When the stress hormone cortisol was given to pregnant mice, it significantly increased the chances of the baby mice being born with cleft (Boseley, 2000). Including 43 participants from different parts of the country to control for environment, Wallace, Arellano and Gruner (2011) then examined mothers' stress levels during the time of conception and 2 months later. The researchers also investigated maternal alcohol and tobacco use; medications and supplements taken; maternal age, height, and weight as well as cleft history in the family. Mothers were grouped into three categories on the basis of their stress level: (1) traumatic stress, (2) elevated stress, and (3) no stress. Occurrence of clefts was more frequent in the traumatic stress group followed by the elevated stress group, which suggests a possible impact of maternal stress (e.g., increased levels of maternal cortisol levels) on in utero cleft formation.

Goenjian, Chiu, Alexander, Hilaire and Moses (2011) suggested that maternal alcohol consumption before or during pregnancy is another possible risk factor for the development of CL/P in utero. Shaw and Lammer (1999) investigated this possibility using a population-based sample living in California. They included 731 oral cleft cases who were born between 1987 and 1989 and compared them to 734 nonmalformed cases. The authors assessed mothers' alcohol consumption 1 month before and 3 months after

conception. They adjusted their statistical analyses for maternal smoking, race, education, and vitamin use. Mothers who consumed five or more drinks on a weekly or more frequent basis were significantly more likely to give birth to infants with cleft lip with or without palate and with additional anomalies or known syndromes; however, none of these infants had symptoms of fetal alcohol syndrome.

Using data from the National Birth Defects Prevention Study, Romitti et al. (2007) included participants from 8 U.S. states (Arkansas, California, Iowa, Massachusetts, New Jersey, New York, Texas, and Georgia). The authors evaluated the number of live births, fetal deaths, and elective terminations. They asked about maternal alcohol consumption 1 month before and 3 months after conception. The occurrence of CP was significantly associated with the maternal consumption of distilled spirits even though the association was not strong. The association was stronger for mothers who did not take folic acid during their pregnancies.

Cech, Burau and Walston (2007) investigated the effect of exposure to radioactive teratogens and the occurrence of clefts in utero. They used a sample from Harris County, Texas where elevated levels of radium and radon in tap water were found in certain geographic areas. Examining the incidence of CP and CL based on zip codes, the authors reported that in regions with more elevated levels of radium, the incidence of cleft was 2.7 times higher compared to areas with nonelevated levels. The incidence of cleft increased by 1.5 times in areas with elevated levels of radon compared to areas with nonelevated levels, again suggesting a strong environmental cause of cleft development in utero.

1.3 Treatment and Prognosis

Babies who are born with CL/P need ongoing surgical, dental, and speech treatment. They also need assistance with feeding, particularly at the time of birth. School-aged children with CL/P may also experience learning disabilities, which would require additional support.

1.3.1 Surgical Procedures

The treatment of CL/P can include multiple surgical procedures typically starting from the first month of life. For this reason, it is ideal that the cleft treatment be conducted by a collaborative team of health care professionals. Mavroudi, Rekopoulou, Papadopoulos and Papadopoulos (2007) suggest that a cleft management center should have the following health care professionals: “radiologist, anesthesiologist, geneticist, plastic surgeon, maxillofacial surgeon, social worker, speech therapist, neurologist, neurosurgeon, nursing staff, orthodontist, pediatrician, pedodontist, prosthodontist, psychiatrist, psychologist and Ear-Nose-Throat (ENT) Specialist” (p. 115).

Clefts can be repaired with one surgery or up to four surgeries may be required. Most cleft cases (71.1%) are repaired with two surgeries (Mavroudi et al., 2007). The goal of these surgeries is to repair the muscles in the lip and/or palate so that the baby can have appropriate movement and function (Slator et al., 2010). Ideally, the first surgery is conducted between the 1st and 3rd months of life to close the lip; the next surgery takes place at approximately 12 months to close the palate (Lockhart, 2003). Some surgeons repair the lip within 48 hours after the child’s birth so that there will not be any more hospitalizations and parents can leave the hospital with a healthy-looking baby. Other surgeons believe that the parents need more time to adjust to the congenital condition,

especially those in the postnatal diagnosis group. Some surgeons also believe that the period right after the birth is crucial for mother-child bonding and health attachment, so they prefer to wait at least 1 month to do the first surgery. Generally, surgeons perform the lip surgery if the baby is “at least 10 weeks old, weighs 10 pounds and has a hemoglobin level of 10 g/dL” (Friedman, Wang & Milczuk, 2010, p. 2667).

In cases of unilateral CL, if the lip is not repaired correctly, the repaired side of the lip will be shorter. Nasal deformity is another complication that can occur if the septum is deviated to the noncleft side. For cases of bilateral CL, the tip of the nose may be flat, the nose could be wide, and the columella, the lower part of the nose, can be short. Palatal fistula, gap in the palate, is a complication that can occur when the cleft in the palate is not repaired correctly, which can lead to speech and feeding difficulties (Padwa & Mulliken, 2003).

Palatoplasty (palate repair) should take place no later than at 18 months. The time of the palate repair is still controversial in cleft treatment. Early repair, before the first year of life, can lead to a dramatic decrease in articulation errors in the child’s speech. Additionally, children who go through the palate repair before 18 months are less likely to have hypernasal speech and articulation errors and tend not to require an additional surgery to correct their speech. Even though prior research results support an early palate repair to prevent speech difficulties, palate surgery may have a negative impact on facial growth. Therefore, some surgeons prefer to repair the soft palate first and to wait for the hard palate repair. Despite this concern, researchers who compared the results of these two types of surgical techniques were unable to find a significant difference in facial growth (Friedman, Wang, & Milczuk, 2010).

If there is severe nasal distortion that affects a child's breathing, an early rhinoplasty can be done when the palate is being repaired. Children with cleft, however, need a rhinoplasty and nasal septum repair once their facial growth is completed. This type of surgery is usually conducted during late adolescence or in early adulthood (Lockhart, 2003; Mavroudi et al., 2007).

1.3.2 Dental Treatment

Children who have clefts often need dental treatment, which starts at approximately age 6, since they commonly have missing, small, malformed, and misaligned teeth (Lockhart, 2003; Suslak & Desposito, 1988). In some cases of CL/P, there is also a gap in the upper gum. This gap is usually repaired when the child is 8 to 10 years old. The gap in the upper gum is filled with bone tissue collected elsewhere in the body, typically from the hip, so that the secondary teeth can grow through this new bone tissue. For this reason, a bone graft is often conducted before the permanent canine teeth emerge. The bone graft makes the orthodontic treatment easier and fills up the baseline of the nose (Slator et al., 2010). In some cases, canine eruption may not occur spontaneously, which will require further orthodontic treatment (Padwa & Mulliken, 2003).

Children born with cleft may also have a smaller upper jaw, although the reason for this is not yet known. The upper jaw should be moved forward with a surgical procedure because it can affect facial appearance and the lower teeth might be in front of the top teeth. If the upper jaw location is not severe, it can more easily be corrected with orthodontic treatment (e.g., braces). More severe cases require additional surgery, which

tends to take place after the child's facial growth is completed, during late adolescence and in early adulthood (Lockhart, 2003; Slator et al., 2010).

1.3.3 Feeding, Speech, and Language Treatment

In addition to ongoing surgeries to repair the lip and palate, feeding, speech, and language difficulties are the main concerns of families coping with CL/P. Approximately half of the children born with CL/P need interventions for speech and language difficulties. Feeding difficulties at birth is also a common struggle for parents and their offspring born with clefts. Co-occurring syndromes as well as less well-defined anomalies such as learning disabilities are also possible among children born with cleft (Lockhart, 2003).

Feeding babies born with clefts is one of the biggest sources of anxiety for mothers at the time of birth (Zeytinoglu & Davey, 2012). Because of the gap in the baby's lip and/or palate, the baby is more likely to suck in air rather than milk even if she/he has a sufficient sucking reflex at birth. A variety of items are available that parents can use to feed their babies, such as, "soft squeezable bottles, latex teats, scoop feeders and nasogastric tubes" (Cole, Tomlinson, Slator, & Reading, 2010, p. 157). Nurses should be knowledgeable enough to help parents feed their babies to ensure weight gain and to prevent the parent and baby from getting fatigued during regular feedings (Cole, Tomlinson, Slator, & Reading, 2010). Mothers frequently report that the maternity ward nurses are not always knowledgeable about how to help them, which contributes to their anxiety about feeding their babies (Zeytinoglu & Davey, 2012).

Even though the milk from breast-feeding will not be enough to sufficiently feed the baby born with CL/P, mothers who want to breast-feed can still place the baby on

their breasts to have close skin contact and to stimulate lactation. Babies may develop ulcers in the septum (e.g., the septum divides the walls of the nostrils) when the bottle's teat rubs on it, which can lead to bleeding in this area and discomfort for the babies. If this happens, it is best to switch to a scoop feeder (Figure 2.1) until the ulcer heals. Cooled-down boiled water can also be given to the baby after each feeding to clean the inside of the mouth. If the lip gets sore because of the feeding, moisturizing cream can be administered to soothe the lip (Cole, Tomlinson, Slator, & Reading, 2010).



Figure 2.1. Scoop Feeder

(Reprinted from Clapa Shop Feeding Equipment, In *Cleft Lip and Palate Association*, n.d., Retrieved January 28, 2013 from http://shop.clapa.com/feeding_equipment.php)

Bessell et al. (2011) reviewed five randomized controlled trial studies on effective feeding interventions for babies born with CL/P. Among babies who had the surgery for cleft lip, those who were breast-fed gained more weight than those who were spoon-fed 6 weeks after the surgery; however, the sample size for this study was relatively small (N=40). Results from the two randomized controlled trials designed to compare the effects of rigid bottles and more flexible baby bottles, feedings with squeezable/flexible bottles were easier because rigid bottles had to be modified more frequently, e.g.,

opening up more holes on the teat. For example, because of these modifications, 6 babies were switched to squeezable bottles during the two randomized control trial studies.

Paliobei, Psifidis and Anagnostopoulos (2005) suggested that children born with CL/P could have speech problems because of hearing loss. When babies are born with cleft, their hearing is tested immediately in the hospital. Three in every one thousand babies born with CL/P are diagnosed with a significant hearing loss at the time of birth (Cleft Palate Foundation, 2008). Mavroudi et al. (2007) suggested that all children should have auditory check-ups beginning in the first 3 months of life and should continue to do so until they are at least 6 years old. Paliobei, Psifidis and Anagnostopoulos (2005) stated that the cleft palate may negatively affect hearing because repeated otitis media or infection of the middle ear tends to occur because of a gap between the oral and nasal cavities. When the palate does not function properly because of the cleft between the oral and nasal cavities, the function of the Eustachian tube, which connects the nose to the middle ear, can be decreased. The result is blockage of the middle ear and otitis media, an inflammation of the middle ear often associated with hearing loss (Lockhart, 2003; Shah & Wong, 1980).

Possible speech defects for children born with CP are “hypernasality, hyponasality, audible nasal air emission, consonant production error and voice disorders” (Rullo, Di Maggio, Festa, & Mazzarella, 2009, p. 641). Paliobei et al. (2005) evaluated the hearing and speech abilities of 42 children born with unilateral and bilateral CLP as well as CP. The children had a palatoplasty between 18 and 24 months of age and had not yet received speech therapy. The authors reported that in the cases of mild and moderate

hearing loss, hypernasality and compensatory articulation were present. Compensatory articulation occurs when a child produces sounds from the back of his/her mouth.

Hamming, Finkelstein and Sidman (2008) similarly reported that children with CP also have velopharyngeal insufficiency, a disorder that causes air to escape from the nose to the mouth and often leads to hoarseness in speech. Velopharyngeal insufficiency tends to resolve itself as the child gets older and has speech therapy, whereas hoarseness tends to remain the same. Rullo et al. (2009) evaluated the speech quality of 68 children between the ages of 5 and 8, born with cleft palate, after the CP surgery. Approximately 6% of the children had severe nasality, nasal air escape, pharyngeal friction leading to an additional sound produced before speech, and glottal stop, a consonant produced when the vocal cords are closed, leading to poor intelligibility. Approximately 38% of the children exhibited mild nasality and nasal air escape and normal intelligibility; approximately 56% of the children had normal speech. Children's social background, especially parents' efforts to improve their child's speech by involving them early in speech therapy had a significant and positive impact on their speech development (Rullo, Di Maggio, Festa, & Mazzarella, 2009).

Pamplona and Ysunza (2000) reported that having a mother who was an active participant in the speech therapy process with children who have complete unilateral CP after the surgery significantly improves language development. Forty-one mothers were recruited for the study sample. Their children were between the ages of 3 and 5 and did not have a velopharyngeal insufficiency or postoperative fistulae. The children all had normal hearing and moderate language delay. Twenty-one children and their mothers were included in the experimental group, and 20 children were in the control group.

Children in both groups had speech therapy 3 hours a week for a year. In the experimental group, the mothers also participated in the speech therapy. When the mothers were active participants in the speech therapy group along with the speech therapist and their children, the children made more significant gains from the speech therapy. Additionally, the mother's interactional style became more nurturing rather than directive (Pamplona & Ysunza, 2000; Pamplona, Ysunza, & Jimenez-Murat, 2001). Scherer, D'Antonio and McGahey (2008) emphasized that the mothers of children born with cleft lip/palate can be taught during early interventions, which can improve the number of words, variety of words, and mean length of utterances a child uses. This early intervention with mothers could also significantly decrease the number of consonant production errors, which refers to not being able to pronounce certain consonants. Even though there were some gains from the early intervention for children born with cleft, their speech capacity did not exceed those children who were not born with cleft.

Associated anomalies and syndromes can co-occur with CP with or without CL. The frequency of this co-occurrence is controversial, with some studies reporting 25% or less, and some reporting between 45% and 70% (Harville, Wilcox, Lie, Abyholm, & Vindenes, 2007). The most frequently associated anomalies with CP are Pierre Robin sequence and velocardiofacial syndrome (Friedman, Wang and Milczuk, 2010). Pierre Robin sequence and velocardiofacial syndrome occur in the facial region and affect primarily the oral function and appearance but also vital functions such as swallowing and breathing (Friedman, Wang and Milczuk, 2010).

1.3.4 Cognitive Functioning

Children born with clefts often struggle with basic reading skills, phonological memory, and reading fluency compared to their peers who were not born with a cleft (Collett, Stott-Miller, Kapp-Simon, Cunningham & Speltz, 2009). Conrad, Richman, Nopoulos and Dailey (2009) evaluated the neurological functioning of a sample of children born with clefts and a demographically matched control group in a cross-sectional study. They reported that the group of children with cleft performed significantly worse on verbal skill measures and verbal memory measures but not on the perceptual and nonverbal measures in the Wechsler IQ and NEPSY assessments. They did not find any statistically significant differences in the executive cognitive functioning between the experimental (children born with CL/P) and the control groups of children.

Difficulties with verbal labeling and reading disabilities are more common among children born with clefts. In their cross-sectional study, Richman, Wilgenbusch and Hall (2005) investigated if certain memory deficiencies (e.g., visual versus verbal) contribute to the development of reading disabilities among children born with CL/P. Their findings suggest that children born with CL/P tend to have more difficulty labeling objects verbally when material is presented visually, which can lead to reading disorders. The authors emphasized that associations between deficits in visual memory and reading disorders are also prevalent among children born without clefts. Yet, it is important to remember that hearing problems may also account for some of the reading difficulties that children born with CL/P often experience (Collett, Stott-Miller, Kapp-Simon, Cunningham & Speltz, 2009).

1.4 Research Questions and Aims

Most researchers have investigated the impact of the timing of the CL/P diagnosis (prenatal versus postnatal) with only one parent (primarily mothers) in their samples. To fill this gap, this phenomenological study was designed to describe the experiences of both parents who have an infant or young child who was born with CL/P. Unlike earlier studies that included only one parent, this study was designed to better understand how the timing of the cleft diagnosis (prenatal versus postnatal) affects both mothers and fathers, using a dyadic approach. Although prior CL/P studies have investigated the differences between prenatal and postnatal diagnosis groups of parents at the time of the diagnosis or soon after the child's birth, this study included parents with infants or children up to 4 years of age who were born with CL/P to determine if the timing of the diagnosis has a long-term effect. Two theoretical frameworks guided the development of this study: the biopsychosocial (BPS) model (Engel, 1977a) and the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993). These two frameworks are summarized below. A more thorough description is presented in Chapter 2.

1.5 Theoretical Frameworks

1.5.1 Biopsychosocial Model

Engel's (1977, 1980) BPS model describes the importance of considering the multiple systems that individuals are nested in while being treated for medical conditions by focusing on the biological, psychological, and social domains. Engel believed that coping with a disease or a disability is a systemic, hierarchical phenomenon that has a bidirectional influence on patients' psychological, relational, and community domains.

Engel (1977) proposed this new systemic model as an alternative to the more reductionistic biomedical model and stated that a “disease” comprises not only somatic, chemical, and physical phenomena but also has behavioral, psychological, social, and cultural dimensions.

Engel (1977, 1980) recommended relying on patients’ own descriptions (e.g., illness narratives) of their physical, behavioral, psychological, and relational issues and asking about and evaluating the patient’s current life and living conditions to understand the onset and the course of the illness, disability, or disease. This systemic model additionally advocates changing the patient’s role in the treatment process, making him/her an active collaborator rather than a passive recipient of medical care. According to the BPS model, patients should be encouraged to explore their experiences (cognitions, feelings, coping), share their illness narratives with their providers and be part of the treatment process. It is therefore essential for clinicians to engage in more open dialogue with their patients throughout treatment and to garner family and social support to help, for example, couples better cope and care for a baby born with CL/P (Engel, 1997).

1.5.2 Resilience Model of Family Stress, Adjustment, and Adaptation

The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993) also informed the development of this dissertation study because unlike BPS, it attends to salient factors that influence how families adjust and adapt to a condition like CL/P over time. McCubbin and McCubbin (1993) identified myriad factors that can affect how an individual, couple, or family adjusts to an external stressor, like a baby either prenatally or postnatally diagnosed with CL/P: (1) the family’s vulnerability; (2) established patterns of functioning; (3) resistance resources; (4) appraisal of the

stressor; and (5) problem solving and coping strategies, which in turn determine if an individual, couple, or family is effectively coping and adapting to a stressor, which can either result in *maladjustment* (crisis) and lead to crises or to *bonadjustment* (growth) (McCubbin & McCubbin, 1993).

When an individual, couple, or family becomes *maladjusted* while facing a crisis or stressor like CL/P in an offspring, this event marks the beginning of the adaptation phase that families experience in order to restore the stability of the family.

Bonadaptation requires the family to cope and adapt to the stressor at the individual, family, and community levels. Factors that play an important role during this adaptation phase, which is similar to the adjustment phase, are the pileup of demands, newly established patterns of functioning, family type, family resources, social support, family appraisal, and problem-solving and coping mechanisms. The Resiliency Model of Family Stress, Adjustment, and Adaptation was chosen because it describes the variables that play a salient role in how couples whose offspring are diagnosed either prenatally or postnatally adjust and adapt over time to CL/P.

1.6 Prenatal Versus Postnatal Diagnosis of CL/P

Shock is the most common feeling reported by parents at the time of the diagnosis in both prenatal (diagnosis in utero) and postnatal (diagnosis at birth) diagnosis groups (Johansson and Ringsberg, 2003; Nusbaum et al., 2008). Parents also report a mixture of feelings including grief about the cleft condition and delight about the new baby (Johansson and Ringsberg, 2003; Nelson, Kirk, Caress, & Glenny, 2012). Parents in both groups described searching for a possible cause of the cleft in their child (Nusbaum et al., 2008). Parents who received a postnatal diagnosis questioned why the condition was not

diagnosed prenatally, despite the in utero ultrasound examinations. Overall, parents who received a prenatal diagnosis were satisfied with the timing of the diagnosis and reported that it gave them more time to prepare for the birth, cope, adjust, accept the CL/P diagnosis, and find appropriate resources and supports. The disadvantages reported by this prenatal diagnosis group of parents were not being able to enjoy the pregnancy period, the anxiety, and the anticipatory stress it caused them and their families (Davalbhakta & Hall, 2000; Kutenberger, Ohmer, & Polska, 2010; Matthews, Cohen, Viglione, & Brown, 1998; Nusbaum et al., 2008).

1.7 Impact on Couples and Parents

Research studies that have examined parents' concerns; how parents cope with the multiple surgeries; the impact of CL/P on family functioning; parent-child attachment; parents' marital relationship; parenting stress; parents' social life and support systems; and parents' psychosocial adjustment are reviewed in this section. Most CL/P studies have not investigated the timing of the diagnosis (in utero or at birth) and have included only one parent (mothers) in their samples, which are two salient research gaps in the CL/P literature that this study addresses.

Parents primarily report concerns about self-blame, feeding, speech and neurological functioning, and multiple surgeries. Self-blame is a frequently reported experience regardless of the timing of the diagnosis. Parents describe questioning what caused the cleft in their offspring and feeling guilty when their reactions to the cleft diagnosis are further explored (Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz, & Saal, 2010; Nelson, O'Leary, & Weinman, 2009; Nusbaum et al., 2008). Furthermore, mothers often report struggling with how to feed their child, especially right

after birth. They described feeling the pressure of having to breastfeed, in particular from the nurses in the maternity ward, and stated that this pressure made them feel even more anxious (Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz, & Saal, 2010). Moreover, the parents reported feeling anxious about their children's speech development, noting that it is important for children to be able to communicate with other children so that they can be accepted by their peers. Parents also shared concerns about their children's appearance, especially for their female offspring. Forthcoming surgeries and heredity were the two areas that the parents were most concerned about. Parents also described concerns about their child's appearance, especially because of the negative reactions they received from others (Johansson & Ringsberg; Nelson, Kirk, Caress, & Glenny, 2012). Additionally, parents noted their need for the health care professionals to discuss the possibility of learning disabilities and cognitive deficits, suggesting that the possibility of their child having impaired neurological functioning is a major concern among the parents (Byrnes, Berk, Cooper, & Marazita, 2003).

Parents reported having conflicting emotions about the treatment of their child's cleft, especially the many years of intrusive surgeries. Although they wanted their children to have the multiple surgeries to improve their physical functioning as well as their appearance, they worried about their child's emotional well-being because of the distress and discomfort that the surgeries caused (Nelson, Kirk, Caress, & Glenny, 2012). Johansson and Ringsberg (2003) described common concerns reported by parents regarding their children's surgeries, such as anesthesia, risk of infections, and unsuccessful outcomes. Most parents reported being satisfied with the results of the operations and the positive comments that they received from other people who saw their

babies after the surgery. Some parents preferred not to be actively involved in decisions about their child's treatment, even though family involvement can actually be helpful in the treatment process (Pannbacker & Scheuerle, 1991).

Parents described struggling with their children's experiences of serious emotional difficulties, even suicidal thoughts, while coping with their appearances and with outsiders' reactions to them. Parents also described their failed attempts to find effective professional services to help them better cope with these emotional and social strains. To ensure improvement in their child's appearance and to reduce social stigmatization, parents often encouraged their children to comply with any available invasive treatments (e.g., surgery) in order to improve their appearances and psychosocial functioning (Nelson, Kirk, Caress, & Glenny, 2012). Kramer, Baethge, Sinikovic and Schliephake (2007) investigated the family impact of raising a child with CL/P in the following five domains: (1) financial, (2) social, (3) personal, (4) coping strategies, and (5) concerns of siblings. Both diagnosis (pre vs. post-natal) groups reported similar levels of impact in four of these domains; however, there was a significant increase on social impact for the prenatal diagnosis group. Specifically, the total impact score, which included the impact scores for all five domains, was positively associated with the overall results of treatment: When the families were more satisfied with their child's cleft treatment, they reported lower impact of the cleft condition on their family. The negative social impact on the family was reduced over time as the aesthetic result (e.g., facial surgeries and dental work) of the child's treatment improved.

Some researchers have reported that CL/P affects the mother-child attachment negatively. They found that mothers of infants born with CL/P were less likely to have

secure attachment representations and more likely to have disengaged attachment representations compared to the control group of mothers with healthy babies. Additionally, mothers who have infants born with CL/P tend to experience more post-traumatic symptoms compared to the control group (Despars et al., 2011). Other researchers reported that CL/P did not have a significant effect on the mother-child attachment (Murray et al., 2008; Speltz, Endriga, Fisher, & Mason, 1997).

When asked about their marital relationship, parents reported that, because they were trying to care for their children born with CL/P, they frequently forgot about each other and that some marital “misunderstandings” that took place during this time caused them to withdraw from each other (Pelchat, Lefebvre, Proulx, & Reidy, 2004). Marital stress was significantly associated with fathers’ insensitivity toward their children born with clefts but not for mothers. Fathers who reported less marital stress were more sensitive toward their children born with clefts (Pelchat, Bisson, Bois, & Saucier, 2003).

Parenting stress during the child’s infancy significantly predicted the child’s psychosocial adjustment, social skills, and parent’s evaluation of the child’s social skills and parents’ use of social support (Krueckberg and Kapp-Simon, 1993; Pope, Tillman and Snyder, 2005). Social support is important for families who have a child born with a craniofacial anomaly; however, parents often report having less social support and less satisfaction with the sources of support available to them. This finding could be because of the demanding care that their child needs, which takes away time and financial resources to garner social support from family, friends, and the community. Satisfaction with the sources of social support decreased as the severity of the child’s deformities increased. Satisfaction ratings also decreased as the social competence of the child

decreased (Benson, Gross, Messer, Kellum, & Passmore, 1991). Additionally, parents tended to report discomfort, anxiety, and rejection during their social experiences because of the “differences” their children have and how outsiders reacted to their children. Mothers reported an increased level of sensitivity to outsider reactions because of negative experiences. Negative outsider reactions to their children and lack of time and financial resources were noted as hindrances for garnering more social support, which also affects the couple’s social life. Parents described different reactions from people around them, ranging from approaching the child with a positive attitude, providing emotional support to the parents, acting neutral, trying to console the parents, to keeping their distance (Johansson & Ringsberg, 2003; Nelson, Glenny, Kirk, & Caress, 2011).

Coping with the reactions of friends, family, health professionals, and the public is often difficult for parents, especially during the child’s infancy. Parents often report feeling stigmatized as a family and report feeling that their friends and family did not know how to act around their child. As the parents struggled with their child’s differences, reactions from important friends and family increased their emotional discomfort. Parents, especially mothers, described the reactions of the outside public as painful and upsetting and often tried to hide their child’s cleft, withdrawing socially and not disclosing the diagnosis to close friends and family in order to avoid their negative reactions (Nelson, Kirk, Caress, & Glenny, 2012).

A balance between the demands of the child’s situation and coping resources is needed to achieve positive parental adjustment to CL/P (Baker, Owens, Stern, & Willmot, 2009). A supportive extended family network, availability of ongoing social support, and financial support are all resources that can help parents better cope and

adjust to their child's condition (Baker, Owens, Stern, & Willmot, 2009; Broder, 2001). Furthermore, parents can seek out pro-social organizations (e.g., support groups), effective schools, and supportive teachers to support themselves and their children (Broder, 2001). Approach-oriented coping strategies such as active problem solving and using social support significantly reduced the impact of CL/P on the family. Parents who used problem solving for coping and who had more people available to them were more positively adjusted to CL/P. Parents who reported having fewer confidants and who used more avoidance coping strategies reported increased distress and more negative effects on their families. Additionally, families who had younger children with additional medical problems reported experiencing the most negative impact of CL/P on their families (Baker et al., 2009). Mothers reported more parenting stress and lower levels of adaptation compared to fathers because they felt restricted in their parental roles as the primary caregivers of the children (Pelchat et al., 1999).

Parents reported appreciating having access to an intervention program designed to help them adapt to CL/P in their offspring. It gave them the opportunity to express their fears and worries, to understand their reactions, and to feeling less lonely during this tough time as new parents (Pelchat et al., 1999). Most parents noted that being able to talk more openly about the situation and to share their feelings reduced self-blame and anxiety. The intervention was also effective on the individual-cognitive level because it helped parents better understand their children's CL/P condition and their needs; however, it was not effective for helping parents understand the cause of the condition or for correcting any misinformation that they were given regarding their child's CL/P. In terms of extended family or other support services, parents reported appreciating help

exploring available resources, especially how to contact other parents whose children have the same conditions. Finally, parents reporting appreciating receiving the written materials and hoping that these psychoeducational materials would be available in all hospitals (Pelchat et al., 1999).

1.8 Impact on Children

In preparation for this study, I reviewed publications on the impact of CL/P on children between the ages of 0 to 4. The extant research studies in this age group were focused primarily on parents' reports. Timing of the diagnosis was not investigated in any of the studies, and these studies included reports from only one parent. Children were in the normal clinical range for withdrawn behavior and were less likely to engage in externalizing behavior or have problematic functioning. Starting with age 4, boys were more likely to experience problems within the clinical range in areas of thought, attention and social problems as well as total competence and academic competence in school, however, they were also less likely to have externalizing behavior or somatic problems. Starting at age 4, parents reported that girls had more social and attention problems within the clinical range and in others areas of scholastic competence. According to the parents, girls were also less likely to have externalizing behavior and somatic problems (Pope & Snyder, 2005).

1.9 Primary and Secondary Aims and Summary of Methods

This phenomenological study was designed to describe the experiences of mothers and fathers who have an infant or young child who was born with CL/P. Unlike earlier studies that included primarily mothers, this study was designed to better understand the experiences of both parents. Additionally, it was designed to explore how

the timing of the cleft diagnosis (prenatal versus postnatal) affects mothers and fathers, using a dyadic approach by interviewing the parents separately and then together as a couple. This study is also unique because a secondary aim is to understand if the timing of the diagnosis has a long-term effect by recruiting parents with offspring who are infants up to 4 years of age who were born with CL/P.

To fill this gap, I conducted a secondary phenomenological qualitative analysis with a convenience sample of couples who were recruited from an ongoing longitudinal quantitative CL/P study at CHOP (PI: Dr. Canice E. Crerand, Ph.D. “Psychosocial adjustment in parents of infants with cleft lip and/or palate: The impact of prenatal versus postnatal diagnosis”). I used *transcendental phenomenology* (Moustakas, 1994), the primary goal of which is to discover the *meanings* and *essences* of the phenomena being studied. Transcendental phenomenology focuses on how these phenomena are understood by the participants themselves by describing the themes that emerged from participants’ stories and experiences. It includes the following steps:

- **Epoche** is ongoing process that the researcher engages in to become aware of and set aside his/her knowledge, understanding, assumptions, and judgment of the phenomena that she/he intends to study. This process allows the researcher to become more aware of the representation of the phenomena in his/her consciousness and to accept the new information with an open consciousness without prior commitments and restraints. Epoche requires the researcher to concentrate and to allow himself/herself to be transparent and to have access to all his/her biases, assumptions, and judgments in order to examine the subject with an open consciousness and a new set of eyes (Moustakas, 1994). Epoche can be

achieved through (1) understanding one's self-location as a researcher (Chapter 4) and (2) writing reflective memos throughout the research process (Daly, 2007).

- **Phenomenological reduction** includes (1) bracketing and (2) horizontalization. Bracketing is conducted in two ways: (1) placing the researcher's previous knowledge, understanding, assumptions, and judgments in brackets and (2) placing the researched phenomena in brackets, eliminating the others parts of the participants' told experiences (Gearing, 2004). Through horizontalization, horizons of the researched phenomena emerge from the shared experiences, and each of these horizons is of equal value. Following horizontalization, horizons are grouped into *themes* to form a coherent description to explain the essence of the phenomena (in this study, the experiences of parents who are raising a young child with CL/P). During the process of phenomenological reduction, conventional content analysis is used to extract major themes and horizons.
- **Imaginative variation** refers to attaching possible meanings to the horizons using different frames of reference and producing a structural description of the phenomena (Moustakas, 1994). For this study, the frames of reference are the BPS model (Engel, 1977) and the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993).
- **Synthesis** offers a unified explanation that includes the complete structural descriptions of the essences and meanings attached to the phenomena.

1.10 Sampling Frame and Procedure

Couples were recruited from an existing research study sample in CHOP's Division of Plastic and Reconstructive Surgery, which was being conducted by the PI,

Dr. Canice Crerand. For this study, the goal was to include up to 20 couples (approximately 10 couples coping with a prenatal diagnosis of CL, CP or CLP and up to 10 couples coping with a postnatal diagnosis of CL, CP or CLP, pending saturation) until saturation was reached. Saturation occurs when the researcher can no longer extract new information from the data (Creswell, 2007). A nonprobabilistic sampling strategy was used to recruit a convenience clinical sample of couples at (CHOP) who were part of the original study.

Couples were asked to volunteer for a one-time, semi-structured, in-depth interview (first with mothers separately, then with fathers separately, and finally with couples in a conjoint interview) to examine their experiences of parenting an infant or a young child diagnosed with CL/P. Mothers and fathers first completed a demographic self-report survey and the Revised Dyadic Adjustment Scale (RDAS: Busby et al., 1995). The final study sample included 17 couples: 10 in the prenatal diagnosis group and 7 in the postnatal diagnosis group. Ten mothers and 10 fathers from the prenatal diagnosis group and 6 mothers and 5 fathers from the postnatal diagnosis group returned their surveys. One couple and one father from a couple dyad in the postnatal diagnosis group did not return the surveys. Before the telephone interview, they informed the researcher that they had read and signed the consent form and completed the two surveys. When the researcher did not receive the surveys for 2 weeks, she contacted them again by phone, leaving voice messages to remind them to send back the surveys. However, the research team never received the surveys.

The mean relationship length for couples in the prenatal diagnosis group was 11.41 years and 11.06 years for those in the postnatal diagnosis group. The mean length

of marriage was 7.8 years for the prenatal group and 6.9 for the postnatal group. On average, prenatal mothers were 39 and postnatal mothers were 34.7 years old. The mean ages for the fathers in the prenatal and postnatal diagnosis groups were 41.20 and 34.4 years, respectively. Nine mothers and 8 fathers were White; in the prenatal diagnosis group, one mother and two fathers were Asian. In the postnatal diagnosis group, 10 parents identified themselves as White, and one parent identified herself as “other.” Nine of the mothers and 8 of the fathers had completed college or graduate school. In the prenatal group, 7 of the mothers and 10 of the fathers worked full time. Of the 6 mothers and 5 fathers who returned their surveys, 3 of the mothers and 3 of the fathers had completed college or graduate school; two mothers and four fathers worked full time. The relationship length of the couples was similar across groups even though the couples in the prenatal group were married for a slightly longer time. The mothers and fathers in the prenatal group were older than the mothers and fathers in the postnatal group. More couples in the prenatal diagnosis group had higher levels of education and were working full time. Half of the couples in both groups had two children and half of them had one child. All couples in both groups had only one child between the ages of 1 and 4 years who was born with cleft. RDAS scores indicated that, on average, all of the couples in the prenatal group were in the clinically nondistressed range and all of the couples in the postnatal diagnosis group were in the clinically distressed range.

All interviews were transcribed verbatim; the transcriptions were analyzed using conventional content analysis (Hsieh & Shannon, 2005) to identify frequent and notable themes. During the second stage of analysis, the findings were examined using the BPS

model (Engel, 1977) and the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993).

1.11 Trustworthiness

The following three strategies were used to increase the trustworthiness of this qualitative study (Lincoln & Guba, 1985): (1) triangulation, (2) peer debriefing, and (3) member checking. Findings from this phenomenological study were triangulated as follows: (1) the relational distress measure (RDAS); (2) multiple coders; and (3) triangulation of the individual data with the couple data of mothers and fathers. Member checking was also used to increase the credibility of the research findings. After completing the data analysis, the researcher contacted all couples via e-mail and asked if the themes that emerged captured their experiences. All of the steps and procedures that led to the final research findings were documented with a clear audit trail and memos. A more detailed description of the methods and the strategies used to increase trustworthiness is found in Chapter 3.

CHAPTER 2: THEORETICAL FRAMEWORKS AND LITERATURE REVIEW

2.1 Prevalence of Prenatal versus Postnatal Diagnosis of Cleft Lip/Palate (CL/P)

In the United States, an ultrasound examination is typically conducted on all pregnant women at the end of their first trimester or during the beginning of their second trimester. The prenatal diagnosis of a CL/P is possible at this time (Matthews, Cohen, Viglione, & Brown, 1998). Savoldelli, Schmid and Schitzel (1982) reported that the prenatal diagnosis of bilateral cleft lip palate through roentgenographic images was first described during the late 1960s and the prenatal diagnosis of abnormalities through ultrasound was first discussed in the early 1980s. Prenatal diagnosis has been possible since the early 1980s with the development of two-dimensional (2D) ultrasound. Christ and Meininger (1981) demonstrated the efficacy of using real-time 2D ultrasound images for prenatal cleft diagnosis. After the development of 3D ultrasound in 1987, prenatal CL/P diagnosis became even more common and accurate, especially during the second trimester (Johnson, Honein, Hobbs, Rasmussen and the Birth Defects Study, 2009).

The accuracy of prenatal CL/P diagnoses has improved steadily over the last few decades. Johnson, Honein, Hobbs, Rasmussen, and the National Birth Defects Study (2009) conducted a study with 2,289 mothers from 10 U.S. states: Arkansas, California, Georgia, Iowa, Massachusetts, New Jersey, New York, North Carolina, Texas, and Utah. The mothers gave birth between 1998 and 2004. Approximately 20% of Hispanic mothers, 28% of non-Hispanic Black mothers, 32% of Asian mothers, 32% of White mothers, and 36% of Native American mothers received a prenatal diagnosis. Almost 24% of mothers who received a prenatal diagnosis had household incomes lower than \$40,000 whereas almost 40% of mothers who received a prenatal diagnosis had

household incomes of \$40,000 or more, suggesting that higher income was associated with a greater likelihood of receiving a prenatal diagnosis. Four hundred and thirty-four (18.9%) of the mothers in this study reported that they received a prenatal diagnosis of orofacial cleft (e.g., cleft lip, cleft palate, cleft lip palate). One third of the CLP and one fifth of the CL cases received a prenatal diagnosis; only 0.3% of the CP cases were diagnosed prenatally (Johnson et al., 2009).

Similar to the situation in the United States, mothers in the United Kingdom routinely have an ultrasound examination at 20 weeks gestation. Shaikh, Mercer, Sohan, Kyle and Soothill (2001) examined 8 years of ultrasound data and discovered that, of 130 cases of cleft lip with or without palate, only 23 (17.7%) were diagnosed prenatally. The severity of the cleft, however, was misdiagnosed in 8 of the 23 cases. Similar to Johnson's (2009) findings, the frequency of CP detection was low (8%) in this study. Two of the 23 cases chose pregnancy termination. In another study conducted in the United Kingdom, 30% of the cleft cases received a prenatal diagnosis: 38% of the CL cases and 8% of the CP cases were diagnosed prenatally, usually between the 19th and 21st weeks of pregnancy (Davalbhakta & Hall, 2000).

Baumler et al. (2011) evaluated the results of the 2D and 3D ultrasound scans used to diagnose cleft cases prenatally. The fetuses were referred for further examination once they received unilateral or bilateral CL diagnosis from a 2D scan in the middle of the third trimester. The researchers then used both 2D and 3D ultrasound examinations to diagnose cleft lip with or without palate or alveolus. Their predictions were correct in 77 of 79 cases. Two cases were cleft lip with cleft alveolus rather than with cleft palate. This finding is important because, in this study, all of the CL/P cases were correctly

diagnosed; in the past, diagnosing CP was more difficult (Davalbhakta & Hall, 2000; Johnson et al., 2009).

The prenatal diagnosis of CL/P is possible during the first trimester (Martinez-Ten et al., 2012). Researchers have correctly diagnosed 100% of cleft lip cases with the cleft in the primary palate and 86% of cases with the cleft in secondary cleft palate using an offline analysis of 3D ultrasound scans. The researchers suggest that the diagnosis of CP is more feasible in the first trimester because of the developmental stage and the position of the infant. Using data from the National Birth Defects Study, Johnson et al. (2009) reported several factors that are significant predictors of the prevalence and feasibility of prenatal cleft diagnoses: study site, household income, type of cleft, prepregnancy body mass index (BMI), presence of multiple defects, and the year of infant's birth.

The percentages of prenatal cleft diagnoses increased from 22.8% in 1998 to 33.9% in 2004. This finding implies that the prevalence and accuracy of prenatal diagnoses have been increasing steadily over the years. Prenatal cleft diagnosis was also more common among infants who had other defects in addition to the cleft, although this finding was not statistically significant (Johnson et al, 2009). Cleft severity is also another predicting factor of having an accurate prenatal CL/P diagnosis. Evaluating 13 prenatal diagnoses of cleft cases out of 80 cleft referrals, Matthews, Cohen, Viglione and Brown (1998) discovered that bilateral clefts comprised most of the prenatal diagnosis cases; however, this finding was not supported by other studies (Johnson et al., 2009; Robbins et al., 2010).

Geographic location is another significant determinant of the prevalence of prenatal cleft diagnosis: 13.9% of the cleft cases were diagnosed prenatally in California whereas this percentage increased to 52.7% in Massachusetts. The authors hypothesized that this significant geographic difference might be because of the differences in ultrasound examination styles in the different states and a tendency to focus on parts of the fetus other than the face (Johnson et al., 2009). Household income is another significant predictor. For example, it is more common for mothers who had household incomes of \$40,000 or more to receive a prenatal diagnosis. This finding is not surprising because higher-income mothers tend to have better access to more sophisticated and expensive prenatal care and prenatal ultrasound services (Johnson et al., 2009). Similarly, Robbins et al. (2010) reported that having a household income of \$60,000 or more was a significant predictor of having a prenatal diagnosis, even though ethnicity and the type of insurance were not.

Additionally, mothers who have diabetes, a lower pre-pregnancy body mass index, or an unwanted pregnancy have an increased chance of receiving a prenatal cleft diagnosis. The authors suggested that diabetes is a risk factor for birth defects, which can lead to a more thorough prenatal ultrasound examination and an increase in the percentage of prenatal cleft diagnoses in this group of mothers. Additionally, mothers might have had a more thorough ultrasound examination if they were not expecting the child and had not been cautious about their health behaviors before learning about the pregnancy. Finally, being obese or overweight can make the ultrasound visualization much more difficult and consequently tougher to accurately diagnose clefts in utero (Johnson et al, 2009).

These results suggest that the prenatal diagnosis of CL/P has been steadily increasing in the United States, even though most parents still continue to receive a postnatal diagnosis. Factors such as the clinic site, geographic location, household income, type of cleft, prepregnancy BMI, presence of multiple defects, and the year of the infant's birth make the prenatal diagnosis more prevalent and feasible even though the misdiagnosis of clefts in utero or their severity still exists. Currently, MRI imaging after the first trimester is more often used because of its higher quality of resolution and ability to overcome obstacles such as maternal obesity and fetal position (Wang, Shan, Zhao, Zhu, & Zhang, 2011).

2.2 Theoretical Frameworks

2.2.1 Biopsychosocial Model

The BPS model (Engel, 1977, 1980) emphasizes the importance of considering the multiple systems that individuals are nested in when treating medical conditions and considering the biological, psychological, and social domains. Even though a disease may start at the cellular level in a patient's body, it ultimately has a bidirectional influence on patients' psychological, relational, and community domains (Figure 2.2). (Engel, 1980).

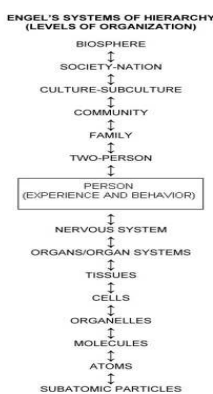


Figure 1. George Engel's hierarchy of natural systems (1980).

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Figure 2.2. Engel's Systems of Hierarchy

(Reprinted from University of North Texas Digital Library, Retrieved February 9th, 2013 from <http://digital.library.unt.edu/ark:/67531/metadc68013/m1/79/>)

Engel (1977) proposed this systemic model as an alternative to the more reductionistic biomedical model and stated that a “disease” comprises not only somatic, chemical, and physical phenomena but also has behavioral, psychological, social, and cultural dimensions. The BPS model is based on six assumptions. First, one must consider the psychological, social, and cultural factors that interact with the biological factors for all illnesses, disabilities, and diseases. One of the advantages of the BPS model is that it highlights the importance of understanding the psychological, relational, and societal barriers that ill patients cope with and of assessing these domains by designing holistic treatments that attend to the multiple domains that affect all patients coping with illness.

Second, one should develop a scientifically rational approach for understanding behavioral and psychosocial information and linking this information to biochemical data

gathered from patients. Engel (1977, 1980) also recommended relying on the patients' own descriptions (e.g., patients' and families' illness narratives) of their physical, behavioral, psychological, and relational issues. Third, it is important to ask about and evaluate the patient's current life and living conditions in order to best understand the onset and course of the illness, disability, or disease. Fourth, one should ascertain when patients began viewing themselves as sick and when they were first viewed by others as sick because this information can help providers obtain a clear picture about the course of the disease or illness. Engel (1977) suggested that viewing oneself as sick has both psychological effects and social consequences. Fifth, one should focus on the psychological (e.g., depression) and social (e.g., lack of social support in the family) variables that can slow patients' recoveries when the biochemical treatment is not fully effective. Finally, it is important to develop a strong, trusting relationship between physicians and patients because the quality of this relationship can lead to better treatment retention and adherence and to more positive clinical outcomes.

This systemic model also advocates changing the patient's role in the treatment process, making him/her an active collaborator rather than a passive recipient of medical care. According to the BPS approach, patients should be encouraged to examine their own experiences, share their illness narratives with their providers, and be part of the treatment process. It is therefore essential for clinicians to engage in more open dialogues with patients throughout treatment (Engel, 1997). Because the BPS model highlights the importance of *relationships* among the different systems (e.g., patient-clinician, patient-family members/community members, clinician-clinician, health care system-

community, clinician-self), Suchman (2005) describes the BPS model as *relationship-centered care*.

McDaniel (1995) also suggested that biological, psychological, and social factors act together and bi-directionally influence patients' lives in multiple ways; therefore, all biological problems have psychosocial effects, and all psychosocial problems have biological consequences. For this reason, collaboration between physical and mental health care providers is crucial for understanding patients' concerns and their environment and including the patient's family in treatment (McDaniel, 1995; Zeytinoglu & Davey, 2012). Both medical and mental health providers have skills and knowledge that they can offer each other to more holistically treatment patients and their families.

Influenced by the BPS model, Ross (2000) developed a guide for a BPS formulation of patients' medical conditions that evaluates the biological, psychological, and social problems of the patient over time (past and present) and helps to formulate solutions for the future. He asserts that this approach will help providers gain a deeper understanding of patients' conditions and also facilitates the formulation of more family-centered treatment goals for the future. Similar to Ross (2000), Huysse et al. (2001) offer the INTERMED grid as a BPS formulation. The grid includes (1) biological, (2) psychological, (3) social and (4) health care systems. The grid allows one to evaluate the patient's condition in terms of history, current state, and prognosis. Providers first do a structured interview to gather information about patients' past and current physical and emotional issues, social supports, and relational issues. Then, physicians and mental health clinicians who have provided and who are now providing treatment meet to discuss the prognosis and optimal holistic treatment plan. The BPS model has recently

been incorporated into medical school educational curriculum, and its use is becoming more frequent. The Accreditation Council for Graduate Medical Education also recommends that physicians become more skilled in interpersonal communication skills and systems-based thinking (Frankel & Quill, 2005).

I chose the BPS model to examine the experiences of couples coping with a child diagnosed either prenatally or postnatally with CL/P because the BPS model has been used in other studies with couples coping with other conditions such as Parkinson's disease, depressive symptoms in pregnancy, high-risk neonates, and premature ejaculation (Blanchard, Hodgson, Gunn, Jesse, & White, 2009; Hodgson, Garcia, & Tyndall, 2004; Mrdjenovich, Bischof, Menichello, 2004; Placencia & McCullough, 2012).

For example, Mrdjenovich, Bischof and Menichello (2004) advocated using a BPS approach to treat premature ejaculation, to describe the biological, psychological, and social factors that can affect the etiology of this condition, and then to recommend treatments for each of these dimensions. For example, taking an antidepressant medication is a biologically oriented treatment frequently offered for premature ejaculation. This biological method of treatment may, in turn, affect patients negatively, depending on their views about taking psychotropic medications, or positively, because the medication can reduce their performance anxiety. If a more psychologically oriented treatment is needed, patients may receive individual therapy to overcome personal difficulties and performance anxiety. Finally, a socially oriented intervention may include both the patient and his partner in order to resolve any interactional patterns that lead to

the onset of premature ejaculation and to explore their beliefs about sexuality and consider the use of different sexual activities to promote intimacy.

Palencia and McCullough (2012) also suggested a BPS-based counseling approach for parents caring for high-risk newborn children. Physically, parents report experiencing migraine headaches, heart disease, and cancer more frequently than the national average. Family functioning and stress, caregiving demands, and the child's behavior affected their health conditions. Parents of high-risk newborns also reported more substance use, worse sleep, less exercise, poorer nutrition, less relaxation, and lower vitality. Psychologically, these parents reported posttraumatic stress disorder (PTSD) and depressive symptoms. Socially, parents had lower levels of education and income and higher levels of unemployment. Couples' relationships were also strained. Because parents reported lower functioning in the biological, psychological, and social dimensions, the authors advocated a BPS-based treatment approach for parents caring for high-risk newborn children.

Hodgson, Garcia and Tyndall (2004) interviewed 10 couples coping with Parkinson's disease in a partner and examined the BPS-spiritual impact of this condition on the couples. The couples described their relationship at the time of the diagnosis; the impact of the disease on their relationship, self, and others; their experiences trying to find different medical providers so they could receive a multidisciplinary model of care; and possible strategies for coping as a couple. It is evident in this study that Parkinson's disease affects the couples' lives physically, psychologically, and socially, as proposed by the BPS-spiritual model.

Blanchard, Hodgson, Gunn, Jesse and White (2009) conducted a phenomenological study with couples coping with depressive symptoms during pregnancy. The authors used a BPS-spiritual framework and described how the biological causes of symptoms can lead to systemic effects on couples. The spiritual dimension was more recently added to the BPS model to emphasize the spiritual orientation of patients and how they cope with illness (Hodgson, Lamson, Reese, 2007). The researchers interviewed 7 couples. Thematic clusters yielded the following themes: (1) challenges and stressors for both partners; (2) the impact of the pregnancy on the mood states of both partners ; (3) relationship dynamics that influence the female partner's depression; (4) the impact of pregnancy and mood states on relationship dynamics; and (5) use of external support. This study clearly highlights the relational aspect of a health condition and how it impacts both partners.

Similarly to the medical conditions described above, raising a child born with CL/P affects the lives of individuals, couples, and families coping with this condition (Zeytinoglu & Davey, 2012). Engel's BPS model (1977, 1980) informs this phenomenological study by emphasizing the links between a medical condition in a child and the quality of the parents' relationship. I explored the experiences of parents who are currently raising a child born with CL/P (prenatal diagnosis compared to postnatal diagnosis) to better understand the psychological and social dimensions of this condition. Engel (1977) stated that there are multiple relationships that play a salient role in the experience of any illness. The primary aim of this phenomenological study is to describe the experiences of a sample of parents who are caring for a child born with CL/P and how it affects their relationship. Although the BPS model guided my focus on the medical,

psychological, and social domains among couples coping with a child born with CL/P, it does not specify how couples cope and adapt to such a stressor, which is why the second theory, the Resiliency Model of Family Stress (McCubbin & McCubbin, 1993), was chosen to inform the design of this study.

2.2.2 Resiliency Model of Family Stress, Adjustment, and Adaptation

The development of the Resiliency Model of Family Stress, Adjustment, and Adaptation was influenced by Reuben Hill's Family Stress Theory (Hill, 1949). Hill examined how families react differently and the processes they go through to adjust to a stressor or crisis. In Hill's model, the balance of family resources in relation to the perception of stressors is the critical factor that can influence how a family adjusts to a stressor and the chances that a family will go into crisis because of that stressor (Robinson, 1997). McCubbin and Patterson (McCubbin & Patterson, 1983) developed the Double ABCX Model from the Family Stress Theory (Hill, 1949). This model includes additional factors that can affect how families adapt to stressors, such as the pileup of additional stressors, new and existing resources, the family's perceptions of the stressor, and coping strategies (Robinson, 1997, p 17).

The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) is based on these two earlier theories and includes additional factors that can affect how families adjust and adapt to stress. McCubbin and McCubbin (1993) identified two phases that families navigate when they are coping with a stressor: (1) *adjustment* and (2) *adaptation*. They described different mechanisms and resources that families tend to use while adjusting and adapting to stressors like the prenatal or postnatal diagnosis of CL/P in offspring. The authors identified the following factors that affect a

family's ability to adjust to an external stressor like CL/P: (1) the family's vulnerability; (2) established patterns of functioning; (3) resistance resources; (4) appraisal of the stressor; and (5) problem solving and coping strategies.

Stressors based on the demands placed on the family's resources and abilities can affect the relationship among its members; the family's relationship with outside systems like school and work; and the family's goals, values, and patterns of functioning.

Stressors can also affect the family for shorter or longer periods of time, depending on their severity. A family's vulnerability can be assessed by examining the pileup of demands that the stressor causes such as increased social isolation and financial debt as well as demands on families when the stressor first occurs in the family life cycle. The family's vulnerability differs, depending on the timing of the diagnosis. For example, when a couple receives a postnatal CL/P diagnosis, the family needs to adjust to the diagnosis while trying to figure out how to care for a newborn. In contrast, when a couple receives a prenatal diagnosis, they have more time to adjust to the CL/P diagnosis and can make plans ahead of time for caring for their child and for ongoing CL/P treatment.

A family's social and material resources, such as more open communication and/or financial stability, are considered strengths that a couple or family can use to cope with a stressor like CL/P. When the family has more time to overcome the initial shock and adjust to the stressor, they in turn have more time to reduce their anxiety, discuss their options, and arrange their financial resources. A family's appraisal of the stressor refers to how the family approaches the stressor in terms of its significance and the significance of related struggles. After having a child diagnosed with CL/P, parents can determine their approach toward the child's condition. Because a prenatal diagnosis gives

the family more time to prepare and to adjust, it might lead the family to have a more optimistic approach toward the stressor. Problem solving and coping strategies refer to the family's ability to divide the stressor into manageable parts and to deal with each part proactively by communicating openly with each other about their problem-solving strategies.

Coping refers to the family's efforts to maintain the family members' well-being and emotional stability. For example, some couples who have children born with CL/P could manage the situation better by dividing the stressor into manageable parts such as feeding difficulties and upcoming surgeries. They can also participate in other activities to release stress and to increase leisure time spent together as a couple. How a couple uses such factors determines whether a couple is coping with the stressor. Some stressors result in *maladjustment* or crises. Stressors that do not lead to crises in the family can result in *bonadjustment* or growth (McCubbin & McCubbin, 1993). *Bonadjustment* occurs when the family is able to navigate a stressor with ease by making adjustments in the family system. For example, couples who have children born with CL/P who received a postnatal diagnosis may ask for help from extended family members. They may contact other families who have gone through the same stressor to learn about different treatment options and the prognosis, which could help them better adjust to the CL/P. *Maladjustment* to the stressor requires the family to reorganize its roles, rules, priorities, and patterns of functioning in order to overcome the crisis. Family crisis occurs when instability and chaos emerge. For example, a couple may avoid communicating with each other as they go through their own, separate emotional upheavals. This reaction could happen with couples, regardless of the timing of the CL/P diagnosis.

When a family becomes *maladjusted* while facing a crisis or stressor like CL/P in an offspring, they experience the beginning of the adaptation phase that helps restore stability to the family. *Bonadaptation* requires the family to adapt to the stressor at the individual, family, and community levels. For this study, bonadaptation means that the physical and emotional well-beings of both partners are not compromised; they are satisfied with their marital relationship; and they are able to keep their connection to the community, such as continuing to be employed and to be involved in outside social activities.

Some factors that play an important role during this phase are the pileup of demands; newly established patterns of functioning; family type; family resources; social support; family appraisal; and problem-solving and coping mechanisms. The pileup of demands involves the stressor and any associated family struggles over a period of time; normative transitions that family members traverse over time such as family life cycle changes; residual family strains that existed prior to the stressor such as the unemployment of a family member; contextual difficulties such as dealing with medical agencies; consequences of the family's attempts to cope such as repressed anger or feelings of resentment; ambiguities regarding family rules, roles, and responsibilities; and guidelines on how to resolve a crisis. For a couple coping with a child born with CL/P, the child's treatments continue until young adulthood and involve multiple family life cycle stages (e.g., infancy, childhood, adolescence, and young adulthood). Parents need to adjust to the demands of the different treatments as well as to the demands of the life cycle stages. Couples who receive a prenatal CL/P diagnosis will be able to begin

adjusting to the stressor before entering the life cycle stage of having a newborn child at home.

According to the Resiliency Model of Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993), families can develop new patterns of functioning in order to adapt to an external stressor such as new rules for carrying out household responsibilities. For example, the couple who is caring for a child born with CL/P may create a new regimen for household responsibilities, so that one partner does not feel overwhelmed. The level of cohesion in a family can range from disengaged to enmeshed, and the level of adaptability may range from chaotic to rigid. For example, a couple who is raising a child born with CL/P may be rigid in their roles, which prevents them from making the necessary changes in household responsibilities; or they could be disengaged and have a difficult time communicating to each other about their own needs.

Family resources include family strengths and adaptive coping strategies both at the individual and family levels. Families may rely on individual members, their family unit, and the community as resources. Each member of the family has his or her own personal resources such as education, sense of humor, personality, intelligence, and self-esteem. The bond between the family members and their ability to deal with hardships are considered family resources. Social support describes the support that a family receives from friends, the religious community, school, and work place. The resources that the family has are identified as the family's strengths.

Coping strategies refer to open communication and maintaining family routines. A couple coping with raising a child born with CL/P would, for example, continue to have their "date nights" as part of their couple routine. They may use their own personal

resources such as humor or a positive outlook/personality to cope with this stressor. Social support includes any kind of outside social support that a family may draw from, such as nonprofit organizations on CL/P; extended family members; churches; and hospital groups for parents coping with CL/P. Family appraisal describes the family's perceptions regarding their ability to manage a stressor as well as the meaning they attach to the stressor. Problem solving and coping behavior describe efforts to reduce the intensity and number of stressors by looking for additional resources, changing their approach to the stressor, and managing ongoing difficulties. Couples can view having a child with CL/P, for example, as an opportunity to make their relationship stronger or as a punishment from God (McCubbin & McCubbin, 1993). If a family cannot adapt to a stressful situation like a CL/P diagnosis in a child, then *maladaptation* will occur. The family will be in a chaotic state that prevents the personal growth of its members (Robinson, 1997). An example would be one of the partners being hospitalized for depression.

McCubbin, McCubbin, Thompson, Han and Allen (1997) described the following ten factors that promote resiliency in families: (1) problem-solving communication; (2) equality; (3) spirituality; (4) flexibility; (5) truthfulness; (6) hope; (7) family hardiness; (8) family time and routines; (9) social support; and (10) health. Problem-solving communication describes how family members communicate in supportive and caring ways to reach a solution rather than, for example, yelling and blaming each other. Equality among family members promotes self-reliance and independence among all members, which in turn is positively associated with the family's adjustment and adaptation. Spirituality helps families give deeper meaning and sometimes even

justification for the stressor. Faith can give people a different perspective around looking at life's struggles as well as reasons to remain optimistic.

Flexibility refers to being able to change the rules, roles, and life styles in order to adapt to a stressor. Truthfulness among family members as well as from the agencies and providers who are helping the family cope with the stressor is essential so that the family has a direction and a plan that ultimately lead to adaptation to the stressor. Maintaining hope is vital for families so they can maintain their strength and continue to cope with the stressor. Family hardiness refers to the family's shared commitment to dealing with the stressor and viewing themselves as having control over it. Continuing to maintain family routines is important for the family to promote connectedness among its members. Finally, receiving social support and maintaining the physical and emotional health of family members are additional factors that are crucial for promoting resilience in families who are coping with a stressor.

Few research studies have been conducted with couples coping with ill or disabled children using the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993). Doucette and Pinelli (2004), however, conducted a longitudinal quantitative study with parents of children who were placed in the neonatal intensive care unit (NICU). They collected data from 71 couples on family coping, resources, strains, and family adjustment at two time points: (1) right after the child's birth and (2) 18 to 24 months later. They found that family coping scores improved for both parents and that family adjustment scores improved for fathers, but declined for mothers. The family resource scale scores declined for both parents over time. Fathers' scores on mastery and the health subscales improved over time whereas the

mothers' scores on these two subscales significantly decreased over time. Couples' resources decreased over time even though their coping strategies increased over time. Common coping strategies used by these parents included accessing social support, mobilizing the family to receive and to accept help, looking for spiritual support, reframing, and passive appraisal. The use of these coping strategies increased significantly over time. Mothers reported improved family adjustment at the 18th to 24th month assessment whereas fathers reported a decline in family adjustment.

Frain et al. (2007) identified how rehabilitation counselors can help families coping with a disability. The authors suggest that helping the family identify existing resources and educating the family about the rehabilitation process, procedures, and realistic time frames for each treatment procedure are crucial. To help couples and families prepare, adapt, and cope with the intrusive medical procedures their children with CL/P will require, it is vital to inform them about the treatments that will be needed, such as ongoing surgical procedures, dental treatment, and speech therapy during different developmental stages of the child's life. Providers can also help families to identify questions that they would like to ask service providers; role play how to ask these questions; and inform the families about the existing service providers (Frain et al., 2007). Parents of children with CL/P can also benefit from this type of service because identifying the questions and role playing how to ask them can give them more control over their ongoing medical visits and reduce their anxiety and stress levels. It is necessary for providers to understand that stress is a natural response to adapting to a disability or congenital medical condition like CL/P and that stress responses are likely to increase during the first year of being diagnosed with a disability (Frain et al., 2007). When a

child is born with CL/P, the first year is also very stressful because of issues with feeding, surgeries, and trying to adjust, cope, and adapt to a congenital condition like CL/P in a baby.

The Resiliency Model of Family Stress, Adjustment, and Adaptation informs this study by asking about and considering salient factors that can play an important role in the couple's adjustment and adaptation while raising a child born with CL/P.

2.2.3 Congruencies and Tensions between the Models

The two theories that guide this qualitative dissertation, the BPS model (Engel, 1977) and the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993), share many similarities. They also have differences that, when negotiated, help to more fully address the gap in the CL/P literature related to the experiences of couples coping with prenatal versus postnatal CL/P diagnosis.

Walsh (2002) suggested that a family resiliency approach is based on a biopsychosocial framework because it approaches family problems and solutions by involving individuals, families, and other social systems. A family resiliency approach is also grounded in the premise that medical problems affect patients on individual, relational, and social levels. Even though the symptoms are biologically based, they are informed by social and cultural factors. For this reason, both theories are congruent because they share a systems framework in their approach to coping with an illness.

The two theories additionally highlight different ways of thinking about the multiple systems, which makes them complementary. BPS (Engel, 1977) focuses on the patient as an individual and views the family as another system of which the individual is a part of. The Resiliency Model of Family Stress, Adjustment, and Adaptation

(McCubbin & McCubbin, 1993) identifies the illness as a stressor that the family is coping with and focuses on how the family adapts and copes with the stressor. In the Resiliency Model, the family is the identified patient rather than the individual. For couples who receive a prenatal diagnosis of CL/P in an offspring, this approach is very helpful because the couple is the identified patient before the child is born. The BPS approach suggests that patients are nested in multiple systems, for example, psychological, social, and cultural systems (Engel, 1977). The Resiliency Model of Family Stress, Adjustment, and Adaptation is congruent with BPS in this regard; the former describes the key factors that affect a patient's life from a family or relational perspective.

Both models highlight the importance of relationship-centered care. BPS states that there could be relational barriers that the patient faces while coping with an illness. The Resiliency Model describes the relational barriers that occur within the patient's family and offers ways to cope with and adapt to these relational barriers to promote family resilience and to optimally adjust to a stressor such as prenatal or postnatal diagnosis of CL/P in a child (McCubbin & McCubbin, 1993). Both theories have a developmental perspective. BPS considers the patient's history and assesses for the social, biological, and cultural components that contributed to the present symptoms; it then proposes treatments and solutions for the future. Similarly, the Resiliency Model focuses on the adaptation processes as well as the family life cycle changes that occur as the family adjusts to an illness or condition like CL/P. BPS (Engel, 1977) provides the lens that I looked through when describing the experiences of couples raising a child with CL/P. The Resiliency Model of Family Stress, Adjustment, and Adaptation helped me

focus on the specific factors, coping mechanisms, and adaptation that couples experience when coping with a prenatal or postnatal diagnosis of CL/P in their offspring.

2.3 Critical Analysis of the Literature

This section summarizes findings from several bodies of literature to more fully describe the experiences of couples coping with a prenatal versus a postnatal CL/P diagnosis and who have children from a few months of age to 4 years of age. First, I provide a brief description of the experiences of mothers and fathers who received a prenatal diagnosis of CL/P in their offspring compared to those who received a postnatal diagnosis. Then, I present a review of the literature describing the common concerns of parents. I also consider how the parents' self-blame and their worries about the child's feeding, speech, appearance, and neurological functioning enhance understanding of parents' concerns about their children born with CL/P. A summary of research studies describing the psychosocial functioning of the child, the couples/parents, and the family as well as their adjustment to the diagnosis is also presented. This section concludes with a summary of the gaps in the literature that this study was designed to address.

2.3.1 Couples Learning about CL/P (Prenatal vs. Postnatal Diagnosis)

Nusbaum et al. (2008) conducted a qualitative study to examine parents' experiences of receiving a cleft diagnosis prenatally compared to postnatally. Parents in both groups revealed similarities dominant themes, regardless of the timing of the diagnosis (in utero vs. at birth). Findings also suggest that there are unique themes specific to parents who received the diagnosis prenatally. Parents in both groups reported feelings of shock when their child was diagnosed with CL/P. Parents in the postnatal diagnosis group questioned why the condition was not diagnosed prenatally, despite the

in utero ultrasound examinations. Parents in both groups described searching for a possible cause of the CL/P in their child. Parents who had a history of cleft in their families primarily attributed the CL/P condition to genetics. Parents who did not have a family history discussed what happened during the pregnancy to find a possible environmental cause of the CL/P.

Nelson, Kirk, Caress and Glenny (2012) reported that, regardless of the timing of the diagnosis, parents reported a mixture of feelings including grief about the cleft condition and delight about the new baby. They questioned the labels associated with normality, perfection, and difference and were reluctant to label their child as “abnormal” because of the cleft condition, even though they were disappointed about the CL/P diagnosis.

Overall, parents in the prenatal diagnosis group in the study of Nusbaum et al. (2008) were satisfied with the timing of the diagnosis and reported that it gave them an advantage before the birth for coping, adjusting, and accepting the CL/P diagnosis and gave them time to find the appropriate resources and supports. Parents reported using religion to cope with the prenatal CL/P diagnosis. They stated that they had the time to prepare themselves and their families for the birth of the baby and to read about required surgeries, feeding difficulties, parenting strategies and other possible challenges to ensure optimal care for their child. The prenatal diagnosis group of parents reported that the disadvantages were not being able to enjoy the pregnancy period and the anticipatory stress it caused for both them and their families. No families in this study considered terminating the pregnancy (Nusbaum et al., 2008).

Some parents in the postnatal diagnosis group shared that they would have been more anxious during the pregnancy if they received the CL/P diagnosis prenatally. Other parents, however, thought that it would have been useful to have had the opportunity to adjust *before* the birth of the baby. Additionally, parents in the postnatal group noted that knowing the diagnosis prenatally could have helped them better prepare themselves financially, emotionally, and medically (Nusbaum et al., 2008).

Parents in both groups also described the need for parent-to-parent support at the time of the CL/P diagnosis because they reported struggling with accepting the condition as a “disability.” Parents expressed dissatisfaction with the way they received the health information regardless of the timing of CL/P diagnosis. They wanted more written information and referrals to a cleft or craniofacial medical center. Parents in the prenatal diagnosis group wanted to receive this information before the birth of their child, whereas parents in the postnatal diagnosis group wanted it in a more timely fashion, right after the birth of the baby (Nusbaum et al., 2008).

Dissatisfaction with the quality of the information provided at the time of diagnosis and suggestions for improvement are prevalent topics in the extant CL/P literature (Byrnes, Berk, Cooper, & Marazita, 2003; Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz, & Saal, 2010; Robbins et al., 2010). Robbins and colleagues (2010) noted that mothers who received a prenatal diagnosis reported needing more information regarding “feeding challenges, prognosis, access to specialty care, and appropriate timing for the surgery” (p. 479). Mothers also wanted more direct linkages to peer-to-peer support groups and more knowledgeable, sympathetic, and supportive approaches to care from the medical staff.

Matthews, Cohen, Viglione and Brown (1998) surveyed nine families about their experiences receiving a prenatal cleft diagnosis. Of these **nine** families, six received the cleft diagnosis from the physician who supervised the ultrasound, and three received the diagnosis from an obstetrician. One third of the families reported they were given adequate information. Four families were informed about the CL/P diagnosis but were not provided with further information. Most families in this study were able to consult with the cleft team *before* the birth of their child and felt they were adequately informed about the cleft treatment. They were also shown photos of other children before and after their CL/P operations. Almost all families found this helpful and reported that it made the adjustment easier for them. The families also said that they would seek a prenatal ultrasound examination during their next pregnancy and that the existence of this kind of examination is a determining factor for them to consider in future pregnancies.

Some medical professionals that provided prenatal counseling for CL/P after the diagnosis examined the effectiveness of this type of prenatal counseling (Kuttenberger, Ohmer, & Polska, 2010; Davalbhakta & Hall, 2000; Matthews, Cohen, Viglione, & Brown, 1998). In three studies, similar to the findings of Nusbaum et al. (2008), most parents reported that the prenatal diagnosis made it possible for them to better prepare themselves psychologically and gave them more time to educate themselves about the condition. In contrast, some parents said that they would have preferred not knowing ahead of time, because it created a lot of anxiety for the rest of the pregnancy and prevented them from enjoying being pregnant (Kuttenberger, Ohmer, & Polska, 2010; Davalbhakta & Hall, 2000; Matthews, Cohen, Viglione, & Brown, 1998). In one study, 3 of 30 mothers terminated their pregnancies after the CL/P diagnosis. It is important to

note that in this study two of the terminated fetuses had additional abnormalities to the cleft. One mother decided to terminate her pregnancy because of the prenatal diagnosis of bilateral CL/P. Two families considered termination but changed their minds after prenatal counseling (Davalbhakta & Hall, 2000).

For parents who receive a cleft diagnosis at birth (postnatally), researchers have emphasized that, because of the overwhelming and complex feelings that parents often experience after the delivery of their babies, mothers might ask questions repeatedly because of their anxiety and uncertainty about how to best care for their babies. Medical staff in the delivery unit should listen carefully to parents' concerns, giving them sufficient time to talk, cry, or just be silent. Showing before and after photos of other children born with clefts and talking to the parents of other children born with CL/P have all been described as helpful strategies by other parents who are raising babies born with clefts (Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz & Saal, 2010; Lockhart, 2003; Ripley, Kallaus & McDermott, 1965).

Exploring parents' experiences of having a child born with a CL/P, Johansson and Ringsberg (2003) reported parents' mixed feelings of happiness, despair, and guilt upon seeing their babies for the first time after they received the postnatal CL/P diagnosis. Shock was often reported among parents, especially in the postnatal CL/P diagnosis group. A few participants who received a prenatal diagnosis were also included in this study. They reported that they were shocked at the time of the diagnosis but had more time to overcome the crisis period and to better prepare themselves because it was diagnosed in utero. Parents in this study were worried about the appearance of their children and speech problems but did not view CL/P as a handicap, which is similar to

the findings of Nusbaum et al. (2008). The authors described parents' experiences with the hospital staff and noted their lack of knowledge about CL/P and about how to support parents at this vulnerable time.

Mothers who learned about the diagnosis of CL/P at birth (postnatally) consistently reported more anxiety when information was withheld, when there was a delay in seeing their baby after the birth, and when they first received information about the CL/P. Therefore, it is important to give information about CL/P and the recommended medical procedures right after the baby is delivered. It is also important for nurses to have accurate information about CL/P and to be trained to share it with parents in an empathic, detailed, and clear way. Parents most often described the need for health care professionals to be in control of the conversation, to show their feelings, to be authentic, and to provide parents with many opportunities to express their concerns in order to help parents feel more confident about caring for their babies at home. Some parents also discussed the importance of learning about the possibilities of mental retardation and learning disabilities as well as the risk of cleft in future pregnancies (Byrnes, Berk, Cooper, & Marazita, 2003; Collett & Speltz, 2007).

The intensity of emotions may differ between the two types diagnosis groups (pre- vs. postnatal), which could affect parents' receptiveness to the information provided by the health care team. Davalbhakta and Hall (2000) compared parents' satisfaction with prenatal compared to postnatal counseling for CL/P. Of 90 parents who were counseled, 12 parents reported that the counseling session was confusing; only 11 of 90 received postnatal counseling. For 7 parents, postnatal counseling sessions took place either on the day of the birth or on the day after the birth. Four of the 7 parents reported that they were

overwhelmed with the amount of information provided by the medical team. Nine-two percent of parents who received prenatal counseling thought it was helpful and helped them better understand the extent and implications of CL/P. These parents were also more receptive to counseling and more clearly understood the responsibilities of the different cleft team members providing care.

2.3.2 Common Parental Concerns and Stressors

Both international and U.S. research studies are included in this review because more studies have been conducted outside of the United States. The studies are described in terms of methods, sample size, and demographics; constructs studied; and measures used. I targeted studies in which the study samples included children and/or parents of children between the ages of 1 and 4 because this is the target age group of children diagnosed with CL/P for this dissertation study. Overall, most studies do not provide information about the timing of the diagnosis (pre- vs. postnatal) and the demographic description of samples in many studies was sparse. Common concerns that parents described were self-blame, feeding and speech problems, and neurological functioning.

2.3.2.1 Self-Blame

Parents often described questioning what caused the cleft in their offspring and feeling guilty when their reactions to the cleft diagnosis were examined (Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz, & Saal, 2010; Nelson, O'Leary, & Weinman, 2009; Nusbaum et al., 2008). Nusbaum et al. (2008) noted that searching for the cause of the cleft condition and trying to make sense of it are common experiences among all parents, regardless of the timing of the CL/P diagnosis. Parents initially explored their family histories for cleft occurrences. If they were not able to find any,

parents, especially the mothers, usually resorted to self-blame because they had had an MRI examination or smoked during the early stages of their pregnancies.

Nelson, O'Leary and Weinman (2009) investigated parents' reactions using casual attribution theory. Casual attributions describe how individuals make sense of a health threat. Attributions can be classified as blaming others, self-blame, chance, and environmental causes. According to this theory, people are more likely to first consider external factors before resorting to self-blame. Forty-two sets of parents of 12- to 24-month-old babies diagnosed with C/LP were recruited for this study (Nelson et al., 2009) and their casual beliefs were investigated. The researchers did not ask parents about the timing of the cleft diagnosis (pre- vs. postnatal). Diet, alcohol consumption, use of medication, and own behaviors during pregnancy were all categorized as self-blame. Parents who resorted to self-blame were all women. Not taking their folic acid, consuming sugary sodas (e.g., coke) and candy, drinking alcohol before learning about the pregnancy, and vegetarian diets were some of the reported reasons for self-blame among these mothers. The authors stated that parents who blamed themselves tended to report higher anxiety and more perceived stress compared to parents who made more external attributions (e.g., blaming others, chance, and environmental causes).

Knapke, Bender, Prows, Schultz and Saal (2010) interviewed 17 parents (15 mothers and 2 fathers) to explore the quality of health information they received about their children born with CL/P. Most parents in this study were White. The children were aged 1.5 to 12 months. Ten parents received the diagnosis postnatally and 7 received the diagnosis prenatally. The authors noted that some parents emphasized that they preferred more written information describing the causes of cleft. Even though the authors did not

provide an explanation regarding the reasons for this request, it is possible that parents wanted written information to reduce their feelings of self-blame.

Johansson and Ringsberg (2003) examined parents' reactions to having a child born with CL/P. Most parents included in this study received the CL/P diagnosis postnatally, and some received it prenatally. Most parents reported feeling guilt and despair, but the authors did not further explore these feelings in their study.

2.3.2.2 Feeding, Speech, Appearance, and Neurological Functioning

Few studies examined parents' concerns about their child's speech and neurological functioning; however, the mothers in some studies did report struggling with how to feed their child, especially right after birth (Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz, & Saal, 2010).

Sweden, Johansson and Ringsberg (2003) interviewed 20 families (20 mothers and 12 fathers) about having a child born with CL/P. The children were between the ages of 1.5 months and 5 years. The authors reported that only a few of the parents received the diagnosis prenatally, but the authors did not fully describe the exact timing of the CL/P diagnosis for the entire study sample. Most parents reported feeling anxious about their children's speech, noting that it is important for children to be able to communicate with other children so they can be accepted by their peers. Parents also reported concerns about their children's appearance, especially for the girls. Forthcoming surgeries and heredity were the two areas that the parents were most concerned about.

Parents included in the study of Knapke et al. (2010) emphasized the need for lactation consultants and nurses to be more knowledgeable about how to feed a baby born with CL/P, especially because this information is easily accessible through the Internet.

Some parents additionally said that not being able to breastfeed might be a sensitive issue for some parents; therefore, health care professionals should be careful when conveying this type of information. Ringsberg and Johansson (2003) described parents' experiences of nurses insisting on breastfeeding, even though many parents had difficulty, and some were unable to breastfeed because of their children's cleft condition. Mothers had to instead use breast pumps, which was difficult for many mothers. Parents reported that not being able to breastfeed caused them stress because of the nurses' stated preference that they breastfeed their babies.

Parents also reported concerns about their child's appearance, especially because of the negative reactions they received from others (Johansson & Ringsberg; Nelson, Kirk, Caress, & Glenny, 2012). In their qualitative study, described below, Nelson, Kirk, Caress and Glenny (2012) examined parents' experiences as they cared for their children who had ongoing cleft treatment. Parents reported conflicting emotions about realizing their child's visible difference when seeing their child's face in a mirror or from a stranger's point of view. They reported concern about judgments from outsiders regarding their children's appearance.

Parents who volunteered for Johansson and Ringsberg (2003)'s study reported they noticed people staring, staying, looking away, and making negative comments about their children. Parents said that some people were even reluctant or scared to see the baby's face. When they did see the baby, some made hurtful negative or unenthusiastic remarks about its appearance.

Few studies have examined neurological functioning as a concern for parents. Yet, in the United States, most parents (66%) noted their need for health care

professionals to discuss the possibilities of mental retardation and learning disabilities. This finding suggests that the possibility of their child having impaired neurological functioning is also a concern of parents even though the authors did not provide any explanation for this finding (Byrnes, Berk, Cooper, & Marazita, 2003). This study is described in more detail in section 2.3.1

2.3.3 How Parents Cope with Multiple Surgeries

In their research study on parents' experiences caring for a child during cleft treatment, Nelson, Kirk, Caress and Glenny (2012) described parents' conflicting emotions about their child's cleft treatment, especially the many years of intrusive surgeries. Although they wanted their child to have the multiple surgeries in order to improve his or her physical functioning and appearance, they worried about their child's emotional well-being because of the distress and discomfort that the surgeries caused. This parental conflict reached its peak right before the surgeries; however, parents reported concealing their feelings and worries in order to stay strong for their child at this tough time. After the surgeries, parents reported their distress upon seeing their child bleeding, swelling, and experiencing nausea and sometimes infections because of the surgical procedures.

Parents were often worried about the emotional well-being of their child and stated that it would be less stressful for them to go through the surgeries themselves rather than seeing their child go through them. Uncertainty about the length of the treatment for CL/P caused emotional tension among the parents, who often described feelings of freedom and relief when there were gaps in the treatment process. Even though some children were diagnosed prenatally, the extent of the child's defect was

often not accurately assessed in utero. Additionally, the uncertainty about the outcomes of the cleft treatment was stressful for parents. They tried to resolve and manage this stress by following the treatment protocols as closely as possible.

Johansson and Ringsberg (2003) described common concerns reported by parents regarding their children's surgeries, such as anesthesia, risk of infection, and unsuccessful outcomes. Most parents reported feeling content with the result of the operations and the positive comments they received from other people after seeing their babies post-operation.

Pannbacker and Scheuerle (1991) investigated U.S. parents' attitudes toward involvement in their child's cleft treatment decisions by conducting a cross-sectional survey study. Their sample included 42 parents from Pennsylvania, Minnesota, Florida, and Louisiana. The authors did not report the gender or demographics of the parents who completed the survey. Most parents had children between the ages of 3 and 5 or 10 and older who were born with CL/P and lived in two-parent homes (79%).

Eighty-nine percent of parents received treatment from a collaborative health care team; 85% were satisfied with the treatment. Ninety percent of the parents believed that they had extensive knowledge about their children's treatment, but 79% still wanted to know more. Ninety-one percent of the parents reported that they had participated in all treatment decisions, but 36% wanted more involvement. Sixty-five percent of the parents evaluated their help as either not effective or slightly effective. Eighty-nine percent of the parents wanted to participate in support programs for CL/P treatment.

The authors also noted that not all of the parents wanted to be actively involved in decisions about their child's treatment, even though family involvement can facilitate the

treatment process. The researchers pointed out the need for exploring parents' current roles in their children's treatment process.

2.3.4 Parenting Stress

Parenting stress and its association with the psychosocial functioning of children born with CL/P are other important factors that researchers have examined (Krueckberg & Kapp-Simon, 1993; Pope, Tillman, & Snyder, 2005). Using retrospective clinical chart reviews, Pope, Tillman and Snyder (2005) assessed parenting stress in 47 US mothers who had children with craniofacial anomalies at 24 months of age and again at 46 months using the short version of the Parenting Stress Index. The toddlers' psychosocial adjustment at 46 months of age was evaluated using the Child Behavior Checklist. In the study sample, of 30 children born with CL/P, 77% were White, 6% were Asian, 11% were Hispanic, and 6% reported their ethnicity as "other" or did not report it at all. Most patients lived in New York City. The timing of the children's diagnosis (prenatal vs. postnatal) was not reported in this study.

The researchers reported that even though mothers' parenting stress at both 24 and 46 months after the birth was similar to that of the original sample used to develop the parenting stress instrument, most parents in this study reported clinical levels of parenting distress at both 24 and 46 months after the birth. Results from using the Child Behavior Checklist suggest that children with craniofacial anomalies scored lower on internalizing and externalizing subscales as well as on the total checklist compared to the normative sample. Additionally, the percentage of children with clinical levels of problems was similar to that of the norm group. The researchers noted that, when age, gender, and race were controlled, parenting stress during the child's infancy (24 months)

significantly predicted the toddler's psychosocial adjustment at 46 months. The researchers also reported that parenting stress was stable over time and that there was a significant association between parenting stress at 24 months and at 46 months. However, parenting stress at 46 months significantly affected the psychosocial adjustment of toddlers more than the parenting stress at 24 months. The children of parents whose parenting stress was persistent over time (at both 24 and 46 months) scored significantly worse on both subscales as well as on the total scale even though the scores were still in the healthy range.

Krueckberg and Kapp-Simon (1993) evaluated parenting stress, parenting style, and social support networks for preschool children with craniofacial anomalies to examine how they affected the children's social skills. The study sample included 52 preschool children with craniofacial anomalies and their families: 30 in the experimental group (22 in a Head Start program and 8 not in school) and 22 in the control group. Eighteen children in the experimental group were diagnosed with CL/P. Fifteen parents of children in the experimental group and 17 parents of children in the control group were either married or cohabitating. The researchers did not report the gender and race of the parent or the children participating in this study.

The parents completed the Parenting Stress Index to assess their parenting stress; the modified Block Child Rearing Practices Report to capture their parenting styles; and the Four Factor Index of Social Status to evaluate their socioeconomic status. The parents also completed a Social Skills Questionnaire to determine the level of social skills in their children. The children's social skills were also evaluated using facial encoding and decoding tasks and the enactive social knowledge interview. For facial encoding, children

expressed one of the five primary emotions: (1) happiness, (2) sadness, (3) anger, (4) fear, and (5) surprise; their facial expressions were photographed. The photographs were then shown to four graduate students who identified the emotions of the children. The number of graduate students correctly identifying the emotion that the child expressed facially determined the score that the child received for the task. For facial encoding, the children were told stories about emotional situations, and the emotion expressed in the stories was clearly stated. The researchers then showed photographs to the children and asked them to identify the emotions presented in the story. Male children were shown male photos, and female children were shown female photos. During the enactive social interview, the researchers described hypothetical social situations and the children were asked to respond with toys and puppets. Their enactments were rated for friendliness and assertiveness (Krueckberg and Kapp-Simon, 1993).

There were no significant differences between groups regarding age, socioeconomic status, and the time spent in school. Parents of children with craniofacial anomalies evaluated their social support networks as more helpful and tended to use more nurturing parenting styles. According to the results of this study, parenting stress affected the child's social skills and the parents' evaluation of the child's social skills.

2.3.5 Psychosocial Functioning of the Children

In their US study, Pope and Snyder (2005) used retrospective clinical chart reviews to assess the psychosocial functioning of children born with craniofacial anomalies. Their sample included 724 children between the ages of 2 and 18. Three hundred and five of these children were born with CL/P. The timing of the diagnosis was not assessed. Parents were asked to complete the Child Behavior Checklist to report on

their children's psychosocial functioning. This scale assesses anxious-depressed, withdrawn, aggressive, and destructive behaviors as well as sleep problems and somatic problems for children between the ages of 2 and 3 years. For children between the ages of 4 and 18 years, the scale assesses internalizing and externalizing problems, focusing on anxious-depressed, withdrawn, and aggressive behaviors; delinquency; somatic problems; attention problems; thought problems; social problems; and sex problems. Five hundred twenty-four mothers and 101 fathers completed the checklist on their children. Parental information on 24 parents was missing; in 75 of the scales, the caregiver status was listed as "other." The authors reported that the demographics of the sample were not available but that the study was conducted primarily with a sample from New York City and included people from different socioeconomic levels. The authors reported that the racial makeup of the sample was predominantly White but that it also included African Americans, Hispanics, and Asians. The parents completing the surveys all spoke English as a first language.

For the purpose of this study, I have reported only the findings on children aged 2 to 3 and 4 to 11 years because of the target age of the children in my study (a few months to age 4). Children between the ages of 2 and three years were in the healthy clinical range for withdrawn behavior and were less likely to engage in externalizing behaviors or to have problematic functioning within the clinical range. For children between the ages of 4 and 11, boys were more likely to experience problems within the clinical range in areas of thought, attention, and social problems as well as total competence and competence in school and extracurricular activities; however, they were less likely to have externalizing behavior or somatic problems. Girls between the ages of 4 and 11 who

were born with craniofacial anomalies had more social and attention problems within the clinical range and in other areas of competence. They were also less likely to have externalizing behaviors and somatic problems. The authors hypothesized that attention problems can be the result of learning disabilities, which are diagnosed more frequently in children born with craniofacial anomalies. The authors reported that the decreased likelihood of somatic complaints may be linked to parents' interpretations of the aches and pains caused by the children's condition.

2.3.6 Parent-Child Attachment

Some researchers have used an attachment theoretical framework to evaluate the psychosocial functioning of mothers and its effects on the quality of the mother-child relationship and on the child's psychosocial functioning (Despars et al., 2011; Murray et al., 2008; Speltz, Endriga, Fisher, & Mason, 1997; Speltz, Greenberg, Endriga, & Galbreath, 1994). For example, in their theoretical paper, Speltz, Greenberg, Endriga and Galbreath (1994) suggested that the psychological functioning of children born with craniofacial anomalies is negatively affected because of the possible difficulties in mother-child attachment styles. The authors hypothesized that the development of the attachment during the first year of life between children born with craniofacial anomalies and their parents can be negatively affected by additional stressors such as intrusive surgeries, feeding problems, and parents' possible negative reactions to the child's appearance. The authors further hypothesized that attachment issues can negatively affect children's speech and language development and their ability to be independent.

In Switzerland, Despars et al. (2011) investigated the attachment representations of mothers who had a child born with CL/P and compared their findings to those from a

control group of mothers whose children were healthy during the first year of the child's life. The researchers additionally assessed for PTSD symptoms and their associations with the complexity of the child's cleft. The experimental group included 22 mother-child dyads; the control group included 36 mother-child dyads. The authors did not report the demographics of their sample. Neither did the authors report the timing of the cleft diagnosis but noted that mothers of both prenatally and postnatally diagnosed infants were included in the study sample.

They assessed the mothers' attachment representations using the Working Model of the Child Interview. The results were categorized as balanced, disengaged, or distorted. The balanced representation was classified as secure attachment whereas disengaged and distorted were classified as insecure attachment styles. Posttraumatic symptoms were evaluated using the Impact of Event Scale, which examines an individual's experiences of avoidance and intrusion. Examples of avoidance symptoms are unresponsiveness or avoidance of feelings, situations, or ideas; examples of intrusion symptoms are nightmares and intrusive thoughts (Despars et al., 2011).

Despars et al. (2011) reported that mothers of infants born with CL/P were less likely to have secure attachment representations and more likely to have disengaged attachment representations compared to the control group of mothers with healthy babies. Additionally, mothers who had infants born with CL/P tended to experience more posttraumatic symptoms compared to the control group; however, mothers who had lower levels of PTSD symptoms were more likely to have disengaged attachment representations compared to mothers who reported higher levels of PTSD and to the control group. Mothers who had higher levels of PTSD were more likely to have

balanced or distorted attachment representations, which indicates significant emotional involvement with their children. The authors explain this unexpected finding by suggesting that mothers might be experiencing fewer PTSD symptoms because they tended to be more disengaged during interactions with their children (Despars et al., 2011).

In the United States, Speltz, Endriga, Fisher and Mason (1997) investigated the attachment styles of infants who were born with CL/P and compared their results to those of healthy infants. Again, the timing of the infants' cleft diagnosis was not reported. The researchers studied infants' attachment at 3 months and 12 months in order to identify key factors that affect the infants' attachment styles, whether these factors are stable over time, and if there are significant differences between the two groups of infants. A total of 115 mother-infant dyads were included in the study sample: 24 infants had cleft lip palate; 27 had cleft palate; and 64 were not affected. The healthy infants and their mothers served as the control group and were matched by infant's age, gender, socioeconomic status, birth order, and parental marital status. At 3 months, none of the infants in this study had had their first surgeries. The demographic profile of the sample was 86% White, 3.5% African American, 3.5% Asian, 1% Hispanic, and 6% multiracial (Speltz, Endriga, Fisher, & Mason, 1997).

The researchers evaluated the infants, their mothers, and the family/social context. Infant evaluations included the Bayley Scales of Infant Development, Infant Behavior Questionnaire, and facial attractiveness rating. Mothers' evaluations included the Mental Health Index and the Parenting Stress Index. The researchers evaluated the family and social context using the Dyadic Adjustment Scale (DAS), the Family Environment Scale,

and a self-report Questionnaire on Social Support. The attachment assessment was conducted using the Strange Situation Experiment (Ainsworth & Wittig, 1969), (Speltz, Endriga, Fisher, & Mason, 1997).

The researchers reported no significant differences between the attachment styles of the two groups of infants. In the cleft group, male infants were less likely by more than half to be insecurely attached and there was a low partial correlation between the Bayley's mental development subscale index and insecure attachment. Mothers' parenting stress index depression scores were also significantly correlated with insecure attachment. As the mothers' depression scores increased, their children were more likely to be insecurely attached. Strikingly, the mother's Mental Health Index Positive Well-being subscale was also correlated with insecure attachment, indicating that as a mother's positive well-being scores increased, children were more likely to be insecurely attached. The authors hypothesized that this unexpected finding might be because the Parenting Stress Index focuses on how parents feel about their parenting, whereas the Positive Well-being subscale focuses on global mental health. Family and social contextual variables included the parents' marital relationship and parents' perception of the family's social environment. The Dyadic Adjustment Scale (DAS) and Family Environment Scale were used for this assessment. These domains did not have a significant effect on the insecure attachment of the infants. , Infants who were rated as less attractive on the facial attractiveness scale were more likely to be securely attached. The authors hypothesized that this is because of the possible increase in mothers' nurturing attitudes toward "unattractive" infants because mothers perceived their babies as more vulnerable (Speltz, Endriga, Fisher, & Mason, 1997).

In Canada, researchers conducted a cross-sectional quantitative study to investigate the factors associated with parental sensitivity (Pelchat, Bisson, Bois, & Saucier, 2003). The researchers evaluated (1) early relational antecedents (parenting experiences of the parents themselves); (2) marital distress; (3) parenting stress; (4) socioeconomic status; and (5) the infant's gender and disability. The study sample included 117 18-month-old toddlers and their parents (116 mothers and 84 fathers). The sample included mothers and fathers of toddlers born with CL/P and Down syndrome and toddlers with no disabilities. The researchers did not report the timing of the diagnosis (pre- vs. postnatal). The researchers administered the Parent/Caregiver Involvement Scale for parental sensitivity; the Parental Bonding Instrument for early relational antecedents; the Parenting Stress Index for parenting stress; the IDESPQ14 for depression; and an unvalidated, newly developed survey that included four questions that assessed marital stress and parents' reports of family income and education for socioeconomic status. The researchers did not report the name of this particular assessment in their article.

The researchers reported that mothers with higher family incomes and more education tended to feel more restricted in their parenting roles and tended to display more sensitivity toward their children. Single mothers were less sensitive toward their children. Higher family income and education were also significant factors contributing to more parental sensitivity displayed by the fathers. Lower levels of marital stress, having experienced less control from his own parents, lower levels of stress regarding the adaptability and acceptance of the child was also significantly associated with more sensitivity displayed by the fathers. Fathers of children who were born with Down syndrome tended to display less sensitivity toward their children compared to fathers of

children with CL/P or nondisabled children. There were no significant differences between the sensitivity displayed by the fathers in the CL/P and the nondisability group of children (Pelchat, Bisson, Bois, & Saucier, 2003).

In the United Kingdom, Murray et al. (2008) conducted a longitudinal study to evaluate if the timing of the lip repair was significantly associated with the quality of the mother-infant attachment and infant development. They evaluated attachment style and cognitive and behavior problems among infants who had neonatal lip surgery and among infants who had lip surgery at 3 to 4 months after birth and at 2, 6, and 12 months. They also recruited a control group of children born without CL/P to compare their results.

The researchers recruited 100 infants for the control group and 103 infants for the experimental group. Among the infants in the experimental group, 48 had the lip repair neonatally; the remaining 55 infants had it at 3 to 4 months. At the 18-month assessment, 96 infants in the control group and 94 infants in the experimental group remained in the study. The experimental group included 45 infants who had an early repair and 49 infants who had a later repair. Twenty-three infants who had an early repair were diagnosed prenatally, whereas 13 infants in the later repair group were diagnosed prenatally. The authors did not provide a demographic profile of the sample except for socioeconomic status. Half of the early and late repair groups and 55% of the control group were middle/upper class; the remaining participants were in the lower class.

The researchers investigated mother-infant interactions through videotaped sessions of the mother and child interacting at 2, 6, 12, and 18 months. The researchers evaluated cognitive development and behavioral problems at 18 months. To assess for cognitive development, the researchers used the mental development index of the Bayley

Scales of Infant Development Attachment was evaluated by conducting the Strange Situation Experiment. The mothers completed a behavioral screening questionnaire to assess their toddlers' behavioral problems. Finally, mothers were interviewed using the Structured Clinical Interview to assess for a DSM IV diagnosis; they also completed a questionnaire evaluating their experiences with professional support from the surgical team (Murray et al., 2008).

There were no significant differences between the three groups of children regarding the quality of the mother-infant attachment and behavior problems at 6 months and at 12 months, even though the late repair group tended to score lower on the cognitive functioning measures. At the 2-month assessment, however, mothers from the later repair group were less positively involved with their infants and looked at them less often compared to the mothers of the other two groups of children. Severely disfigured infants also looked at their mothers less often. Findings from this study suggest that mothers' responsiveness to their infants at 2 months mediated the cognitive functioning of the infant at 12 months of age. The relationship between the measures of maternal sensitivity at the 6th and 12th months also predicted the infant's cognitive development at 18th months. Prenatal diagnosis did not significantly impact the infants' scores on any of the variables.

2.3.7 Impact on Couple's Marital Relationship

No research has focused primarily on the marital relationship of a couple who have a child born with CL/P. The couple's marital relationship has been explored in the literature in relation to parenting stress (Krueckeberg & Kapp-Simon, 1993; Pope, Tillman, & Snyder, 2005), maternal functioning (Speltz, Arnsden, & Clarren, 1990),

parental sensitivity (Pelchat, Bisson, Bois, & Saucier, 2003), adaptation (Pelchat et al., 1999; Pelchat, Lefebvre, Proulx, & Reidy, 2004), and attachment (Speltz, Endriga, Fisher, & Mason, 1997). The marital relationship is typically evaluated by using one subscale in the assessment packet. I have already reviewed the sampling approach and methods of most of the prior studies (Krueckeberg & Kapp-Simon, 1993; Pelchat et al., 1999; Pelchat, Bisson, Bois, & Saucier, 2003; Pelchat, Lefebvre, Proulx, & Reidy, 2004; Pope, Tillman, & Snyder, 2005; Speltz, Endriga, Fisher, & Mason, 1997). For this reason, only the results describing marital satisfaction are summarized here.

Krueckeberg and Kapp-Simon (1993) examined the spousal relationship by administering the Parenting Stress Index; they did not report any significant differences between the parents of children with and without craniofacial anomalies. Pope, Tillman and Snyder (2005) and Pelchat et al. (1999) also used the Parenting Stress Index but did not report any findings regarding the quality of the couples' relationships.

Speltz, Endriga, Fisher and Mason (1997) evaluated the marital relationship using the Spousal Relations subscale of the Parenting Stress Index and the DAS. The researchers assessed the family/social context domain by combining the results of these measures to assess the marital relationship and the families' reports on social isolation, support, family environment, and socioeconomic status. Family/context domain did not predict attachment insecurity in infants with cleft.

Pelchat, Bisson, Bois and Saucier (2003) investigated marital stress among couples using an newer, unvalidated scale that included the following four statements about their relationships: "(1) In the last six months, I had difficulties to accept that my spouse expresses anger toward our family situation; (2) In the last six months, I had

difficulties to accept that my spouse expresses sadness towards our family situation; (3) In the last six months, fights are more frequent between my spouse and me; and (4) In the last six months, we do not have any more activities together” (Pelchat, Bisson, Bois, Saucier, 2003, p 36). Marital stress was significantly associated with fathers’ insensitivity toward the children born with clefts. Fathers who reported less marital stress were more sensitive toward their children born with clefts.

Pelchat, Lefebvre, Proulx and Reidy (2004) evaluated parents’ satisfaction with the impact their intervention program had on their marital relationship. Parents reported that, as they were trying to care for their children born with CL/P, they forgot about each other. Some “misunderstandings” took place during this stressful time that caused them to withdraw from each other. For this reason, discussing these issues with the nurse was very helpful for them. The parents stated that the intervention was very helpful because they were able to discuss their worries about shared parental responsibilities and how it affected their marital satisfaction.

Speltz, Armsden and Clarren (1990) evaluated the effect of having a child born with a craniofacial birth defect on maternal functioning post-infancy. For the experimental group, the sample included 33 children between the ages of 1 and 3 with CLP, CP, or sagittal synostosis (premature closing of the soft spot on the top of a baby's head) and their mothers. Twenty-three of these children were born with CLP or cleft CP. The control group included 22 mothers and their children who were matched with the experimental group for the age of the child and the mother, socioeconomic status, child’s sex, and the parents’ relationship status (single versus two-parent). The authors did not report the timing of the diagnosis (pre- vs. postnatal).

The researchers evaluated the marital relationship using the Locke-Wallace Marital Adjustment Scale. This scale assesses the marital relationship in terms of leisure time that the couple spends together, displays of affection between the couple, finances, and decision making. Mothers who have children born with craniofacial anomalies reported lower marital adjustment. The authors suggested that this adjustment scale assesses the disagreement level in the relationship between the couple but not their satisfaction or general happiness. There were no significant differences in the happiness rating between the experimental and control groups; therefore, the lower scores could be an indication of increased levels of verbal conflict.

2.3.8 Family Functioning

Some international and U.S. researchers have examined the effects of raising a child born with CL/P on family functioning, focusing primarily on parents' reports (Kramer, Baethge, Sinikovic, & Schliephake, 2007; Nelson, Kirk, Caress, & Glenny, 2012). Nelson, Kirk, Caress and Glenny (2012) interviewed 27 families whose children were between 20 weeks and 21 years of age and who were born with different types of cleft in the United Kingdom. The researchers conducted qualitative interviews with the parents (8 couples, 3 fathers and 16 mothers individually). A total sample of 24 mothers and 11 fathers was included in their study. Thirty-one parents were White, two were Indian, and two were Pakistani. The authors did not report the timing (pre- vs. postnatal) of the cleft diagnosis. Parents described their experiences caring for a child born with CL/P. They noted that their children often experienced serious emotional difficulties, even suicidal thoughts, while coping with concerns about their appearance and outsiders' reactions. Parents additionally described their failed attempts to find effective

professional services to help them better cope with these emotional and social stressors. To ensure improvement of their child's appearance and to reduce social stigmatization, parents encouraged their children to comply with any available and often invasive treatments (e.g., surgery) in order to improve their appearance and psychosocial functioning.

In Germany, Kramer, Baethge, Sinikovic and Schliephake (2007) compared the impact of having a young child between the ages of 6 and 24 months born with CL/P on the quality of life of families on the basis of the timing of the CL/P diagnosis (pre- vs. postnatal). The researchers asked a convenience sample of parents to complete self-report questionnaires together as a couple. Their study included 130 families, of which 24% received a prenatal diagnosis. The demographics profile of this sample was not reported except for the mean ages for the mothers and fathers at the time of birth. The mean age was 28.5 years for the mothers and 30.6 years for the fathers. Family impact was evaluated using the following dimensions: (1) financial, (2) social, (3) personal, (4) coping strategies, and (5) concerns of siblings. Higher scores indicated more impact. The authors reported that most parents reported experiencing a lower impact on the five family dimensions; however, coping skills and personal impact were the dimensions most significantly affected by the CL/P diagnosis. Financial impact and concerns for siblings were the least significant for these couples.

Coping and mastery strategy questions included asking parents if they analyzed problems together as a family, if they were stronger as a family because of this experience, and if they were able to treat their child as a normal child. The timing of the diagnosis had a significant effect only on the social impact scores; families receiving a

prenatal diagnosis reported a higher social impact. The authors hypothesized that this increase could be related to the prolonged social pressure parents might have started to feel *before* the birth of their child because they knew about the diagnosis of cleft prenatally. Even though the authors did not fully explain this finding, it is likely that they are describing parental social pressure about the disclosure of the child's CL/P diagnosis to others.

The parents rated the results of treatment using a scale that ranged from 1 to 6 (1 indicated very good and 6 indicated very poor) based on their perceptions. Specifically, the total impact score, which included the impact scores for all five family dimensions, was positively associated with the overall results of treatment and with the results of speech treatment and negatively associated with the mother's age.

Families reported experiencing significantly more impact on all 5 dimensions when the general treatment results deteriorated. Younger mothers were more negatively affected by their child's cleft condition. The authors additionally reported a positive association between the social impact that the cleft diagnosis had on the family and the aesthetic result of the cleft treatment. The social impact on the family was more negative when the results of the aesthetic treatment were poor. The negative social impact on the family was reduced as the aesthetic result of the child's treatment improved. Finally, personal impact was measured by asking parents about wanting to have more children, feeling supported throughout child rearing, experiencing doubts about parenting, and worrying about the child's future. The personal impact was also positively associated with the general result of treatment; the course of treatment; and the results of speech-related treatment, breastfeeding, and quality of the initial consultation. Better results in

these treatment areas reduced the personal impact the child's condition had on the parents (Kramer, Baethge, Sinikovic and Schliephake, 2007).

2.3.9 Sources of Family Social Support and Effect on Parents' Social Life

I describe the different sources of family social support and the impact of the child's condition on parents' social life together because prior studies suggest that these two factors are bidirectional. Parents most often describe reactions that they received from close friends and family as an indicator of social support, which directly affects their social lives. The exceptions to this are reactions from individuals who are not friends or family members and the engagement in social activities, which is highlighted throughout this section.

Social support is an important resource that can decrease stress and increase emotional well-being for individuals and families coping with CL/P. Benson, Gross, Messer, Kellum, and Passmore (1991) compared the social support networks available to families who have a child born with a craniofacial anomaly to those available to parents of healthy children. The researchers recruited 36 children between the ages of 1 month and 5 years with craniofacial deformities and their primary caretakers and 36 children without any physical or behavioral problems and their primary caretakers. They compared the availability of social support and satisfaction with the social support networks of the two groups. Most children with craniofacial deformities (80.6%) were born with CL/P. In both groups of children, most primary caretakers included in the study were mothers: 89% for the craniofacial group and 83% for the control group. There were fathers in both groups: 5.5% for the craniofacial group and 11.3% for the control group.

The remaining primary caregivers defined their parental role as “other.” The timing of the diagnosis was not investigated or reported.

Primary caregivers were interviewed regarding their own family background, demographics, their children’s developmental history, and existing physical and psychological issues. They also completed The Social Support Questionnaire-Revised and The Revised Denver Developmental Screening Test. The children’s attractiveness was also evaluated by independent evaluators using the children’s photographs.

The two groups of parents had no significant demographic differences regarding marital status, age and race, birth order of the target child, and the family member participating in the study; however, the parents of children in the nonaffected group had higher standards of living.

The families who had a child born with a craniofacial anomaly had less social support and reported less satisfaction with the sources of support available to them. The authors stated that this could be because the demanding care required by the child takes time and financial resources from outside social activities. Satisfaction with the sources of social support significantly decreased as the severity of the child’s deformities increased. Parents’ satisfaction ratings also decreased as the social competence of the child decreased. The authors hypothesized that this result could be due to the negative evaluations of the child’s behavior by other adults (Benson, Gross, Messer, Kellum, & Passmore, 1991). Nelson, Glenny, Kirk and Caress (2011) emphasized that, on the basis of their review of the literature, parents tended to report more discomfort, anxiety, and rejection during their social experiences because of the “differences” their children have compared to other children. Mothers additionally reported increased levels of sensitivity

to outsiders' reactions because of prior negative experiences. In these two studies, outsider reactions and the lack of time and financial resources were highlighted as areas that hindered the level of social support, which also negatively affects the quality of the couple's social life.

Parents who participated in the Johansson and Ringsberg (2003) study reported both positive and negative reactions from the people around them after the birth of their child. Relatives and close friends of these parents tended to approach the child in a positive way and provided emotional support to the parents. Some people acted neutrally, which the parents perceived as a lack of interest. Others tried to console the parents by showing support and stating that the baby would eventually be fine, which was frustrating for many parents because they heard the same reassurance repeatedly. Some kept their distance, which was hurtful for parents because they perceived it as denying the arrival of their new baby.

Nelson, Kirk, Caress and Glenny (2012) suggested that coping with the reactions of friends, family, health professionals, and the public is often difficult for parents, especially during the child's infancy. Parents often reported feeling stigmatized as a family and felt that their friends and family did not know how to act around their child. As the parents struggled with their child's physical differences, reactions from important friends and family increased their emotional discomfort. Parents, especially mothers, also described the reactions of the outside public as painful and upsetting and often tried to hide their child's cleft, withdrawing socially and not disclosing the diagnosis to close friends or family in order to avoid these negative reactions. Parents were also worried

about their child's possible experiences of social rejection as the child gets older, especially in relation to finding a marital partner or employment.

2.3.10 Adjustment to Prenatal versus Postnatal Diagnosis of CL/P

Individual, familial, and extrafamilial factors all play a salient role in how couples and families adjust to chronic pediatric conditions like CL/P. It is important to study effective family management strategies including open family communication, cohesion, competence, and adaptive coping skills to understand how couples adjust to their child's CL/P. It is necessary to have caring, consistent parents, who themselves are well-adjusted to the cleft condition, to ensure the child's emotional well-being. A supportive extended family network and the availability of social support and socioeconomic resources are important extrafamilial factors to consider (Baker, Owens, Stern, & Willmot, 2009; Broder, 2001). Overall, there should be a balance between the demands of the child's CL/P condition and coping resources (Baker et al., 2009). Broder (2001) emphasized that it is important that the parents seek out pro-social organizations, effective schools, and supportive teachers to help support their child.

In the United Kingdom, Baker et al. (2009) investigated the social support and coping strategies used by parents of a child born with CL/P and the effects on the family's adjustment and distress. Participants were parents of children and young adults between the ages of 0 and 18. One hundred and three parents volunteered for this study: 86 were mothers and 17 were fathers. The parents were divided into three groups based on the ages of their children: (1) 0 to 6 years; (2) 7 to 12 years; and (3) 13 to 18 years. The timing of the diagnosis was not investigated or reported in this study. The Coping Response Inventory was used to investigate coping strategies; the Interpersonal Support

Evaluation List-Short Form was used to assess social support; the Stress-Related Growth Scale was used to determine adjustment; the General Health Questionnaire was used to assess psychological distress; and the Family Impact Scale was used to measure family stress (Baker et al., 2009).

Approach-oriented coping strategies and the availability of social support significantly reduced the negative effects of CL/P on the family. Parents who used active problem solving for coping and who had more people available to them were more positively adjusted to CL/P. Parents who had fewer confidants and who used more avoidance coping strategies (e.g., denial) reported significantly more distress and more negative impact on the family. Additionally, families who had younger children with additional medical problems reported experiencing the most negative family impact because of the pileup of stressors (Baker et al., 2009).

Canadian researchers explored the adaptation of parents to their 6-month-old child's disability by comparing the parents of children born with congenital heart disease, CL/P, and Down syndrome with parents of nondisabled children (Pelchat et al., 1999). The sample included 72 parents, both mothers and fathers. Nineteen of the parents had a child born with CL/P, 16 had a child with Down syndrome, 18 had a child with congenital heart disease; 19 parents who did not have a child with a disability were included in the control group. Most mothers and half of the fathers had university or college educations, and most families were middle or upper class. Parents reported their perceptions of stress when parenting their child, experiences of parenting stress, and psychological distress. The Stress Appraisal Measure was used to assess parents' perceptions of stress; the Parenting Stress Index was used to capture parenting stress; and

the Psychological Distress Index of Quebec Health Survey was used to evaluate psychological distress in the parents.

Results from this study suggest that each group of parents experienced greater levels of parenting stress and lower levels of adaptation compared to the parents of nondisabled children, even though the results were not significant for the CL/P group of parents. Yet, parents of children born with Down syndrome and congenital heart disease were more threatened by the disability of their children, found it more stressful and uncontrollable, and had more difficulty accepting their children. Furthermore, mothers reported more parenting stress and lower levels of adaptation compared to fathers because they felt restricted in their parenting roles as the primary caregivers of their children (Pelchat et al., 1999).

Canadian researchers also implemented an early family prevention program for parents who recently gave birth to a baby with CLP or Down syndrome to help them with their adaptation. They did a program evaluation and assessed parents' satisfaction with the program on individual, parental marital, extended family, and support network levels (Pelchat, Lefebvre, Proulx, & Reidy, 2004).

This couple early intervention program includes 6 to 8 meetings with the nurse and the couple. Two to three of these meetings occur in the hospital and begin a few hours after the birth of the baby. During the first meeting, the nurse can be with the physician to inform the parents about their children's condition for the first time or can come in a few hours after the parents first learn about the child's diagnosis. This intervention was developed to (1) normalize parents' reactions; (2) increase resources for

adaptation; (3) increase self-awareness and competencies; and (4) facilitate mutual support between parents, extended family, and other services.

Forty-seven couples (N=94 individuals) participated in the early intervention program. The nurses gave both parents the satisfaction questionnaire during their last meeting and collected it a week later. In total, 76 questionnaires were collected; 72 parents (36 couples) participated. Of these 76 parents, 19 mothers and 18 fathers had children born with CLP. Almost half of the parents were 35 years of age or older and had post-high school schooling or university level educations. The satisfaction questionnaire assessed parents' satisfaction with the early intervention program on multiple domains: individual, marital, parental, extended family/other support systems, and printed material. Individual domains were assessed on cognitive and emotional components in order to examine the program's impact on the individual on these two different levels.

The program helped the parents most on the individual-emotional level. The parents reported appreciating the opportunity to express their fears and worries, to understand their reactions, and to feeling less lonely during this tough time as new parents. They reported that being able to talk openly about the situation and their feelings reduced their self-blame and anxiety. The early intervention program was also effective on the individual-cognitive level, because it seemed to help parents better understand their children's condition and their needs; however, it was not effective for helping the parents understand the cause of the condition or for correcting any misinformation that they were given regarding their child's congenital condition. The early intervention program was also helpful on the marital level, though not as helpful as it was at the individual level. Parents reported appreciating help exploring available resources and

better understanding them, especially how to contact other parents whose children have the same condition. Yet parents stated that they did not really worry about their extended family's reactions or support; therefore, they did not need help in this area. Finally, parents reported appreciating receiving the written materials and benefitting from them and hoped that these types of materials would be available in all hospitals for new parents.

2.3.11 Summary of Gaps in the Literature

Several gaps exist regarding the experiences of couples coping with a prenatal compared to a postnatal diagnosis of CL/P in their children. The first gap is the lack of inclusion of *both parents* in research studies, because most prior studies were conducted only with mothers (Baker et al., 2009; Benson, Gross, Messer, Kellum, & Passmore, 1991; Despars et al., 2011; Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz, & Saal, 2010; Krueckberg & Kapp-Simon, 1993; Murray et al., 2008; Nelson, Kirk, Caress, & Glenny, 2012; Nusbaum et al., 2008; Pope & Snyder, 2005; Pope, Tillman, & Snyder, 2005; Speltz, Arnsden and Clarren, 1990; Speltz, Endriga, Fisher, & Mason, 1997).

In the field of mental health in general and in that of CFT in particular, attention has been given to assessing the views of both partners using a dyadic or relational approach. Yet, the extant literature on CL/P has focused primarily on the perspective of one parent (the mother). Little attention has been given to the couple's perspective and in particular how the child's condition affects the quality of the couple's relationship. This phenomenological study focused on the experiences of couples who have an infant or young child (up to age 4) who was born with CL/P.

The second gap is investigation of the timing of the cleft diagnosis. Both prenatal and postnatal diagnosis of CL/P is now standard clinical practice in the United States (Baker et al., 2009; Benson, Gross, Messer, Kellum, & Passmore, 1991; Despars et al., 2011; Johansson & Ringsberg, 2003; Krueckberg & Kapp-Simon, 1993; Murray et al., 2008; Nelson, O'Leary, & Weinman, 2009; Pelchat et al., 1999; Pelchat, Bisson, Bois, & Saucier, 2003; Pelchat, Lefebvre, Proulx and Reidy, 2004; Pope & Snyder, 2005; Pope, Tillman, & Snyder, 2005; Speltz, Armsden and Clarren, 1990; Speltz, Endriga, Fisher, & Mason, 1997). Investigating the impact of the timing of the diagnosis on parents' reactions and functioning is now studied more frequently; however, few studies have examined the impact of the timing of the diagnosis as the child gets older. This phenomenological study compared the effects of the timing of the diagnosis (in utero or at birth) on the experiences of couples who have an infant or young child born with CL/P.

I used the BPS theory (Engel, 1977) and Resiliency of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) to design this phenomenological study of couples coping with children born with CL/P. These two frameworks informed the research questions and interview guide by highlighting the importance of taking into consideration multiple systems while coping with a congenital condition like CL/P in an offspring. BPS additionally emphasizes the importance of considering the psychological and social dimensions of the illness. The Resiliency Model of Stress, Adjustment, and Adaptation views the couple or family rather than the individual as the identified patient. Both theories also view coping with a congenital condition like CL/P as a developmental process that requires adaptation and coping over time. For this reason, the targeted sample was couples who were recruited from an ongoing study at CHOP. I focused on

their experiences (psychological and social) of having an infant or young child who was born with CL/P and the long-term effects of the timing of the CL/P diagnosis (pre- vs. postnatal).

CHAPTER 3: METHODS

I conducted a secondary phenomenological qualitative analysis with the qualitative couple data from an ongoing longitudinal quantitative study at CHOP (PI: Dr. Canice E. Crerand, Ph.D.). The original study is called the “Psychosocial adjustment in parents of infants with cleft lip and/or palate: The impact of prenatal versus postnatal diagnosis” and was funded by The Women's Committee of The Children's Hospital of Philadelphia (Crerand, 2008).

Prenatal diagnosis is becoming more frequent in medical facilities even though most cleft cases are still diagnosed at birth (Jones, 2002). Parents report experiencing shock, anxiety, guilt, anger, grief, and sadness when they learn about their child’s cleft condition regardless of the timing of the diagnosis (Pope, 1999; Leuthner, et al., 2003; Skari, et al., 2006; Statham, et al., 2000). Parents who received a prenatal diagnosis report psychological distress at the time of the diagnosis; however, their distress tends to decrease after their child’s birth (Brosig, et al., 2007; Davalbhakta & Hall, 2000; Johnson & Sandy, 2003; Leuthner, et al., 2003; Statham, et al., 2000). This change may be due to the additional time that parents who receive the diagnosis prenatally have to adjust psychologically. Davalbhakta and Hall (2000) similarly reported that parents who participated in their study stated that receiving a prenatal diagnosis allowed them to better prepare themselves psychologically until the time of birth. The researchers of the ongoing study at CHOP similarly hypothesized that the timing of the child’s cleft diagnosis may affect the psychological adjustment of both parents after the birth of their child (Crerand, 2008).

This ongoing original study (PI: Dr. Canice Crerand at CHOP) has two primary aims. The first aim is to assess and to compare the effects of the timing of the diagnosis (pre- versus postnatal) on the psychosocial adjustment of the mothers of infants who were born with CL/P. The assessment is made at their initial consultation, which takes place shortly after the infant's birth for the postnatal group and shortly after the diagnosis in utero for the prenatal group. The second aim is to explore differences in psychosocial adjustment and parenting distress between the two groups of parents (mothers and fathers) at baseline and again at 12 months after the infant's initial consultation at CHOP. The researchers hypothesize that mothers in the prenatal diagnosis group will report better psychosocial adjustment both at the initial consultation and at the 12th month follow-up compared to the mothers in the postnatal diagnosis group. Additionally, the researchers are exploring changes in the psychosocial adjustment among mothers in the prenatal diagnosis group between two data points (baseline and 12-month follow-up) and assessing the gender differences in psychosocial adjustment (mothers versus fathers) in both (pre- and postnatal) diagnosis groups.

The CHOP researchers are conducting an ongoing prospective, two-group cohort quantitative study that primarily targets the mothers. The fathers, whose participation was optional, were asked to complete self-report surveys at their initial consultation and at the 12-month follow-up. Each parent was given a \$15 gift certificate to thank them for their time and effort. The inclusion criteria for this ongoing study are:

- Biological mothers of fetuses/infants who were born with CL/P who are aged 18 years and older. Biological fathers aged 18 and over are asked to participate only if the mother of their child agrees to participate so that the researchers can explore

gender differences. Mothers can participate regardless of the father's decision.

Parents do not need to be married in order to participate.

- Informed consent is obtained (Crerand, 2008).

The exclusion criteria for this study are:

- Inability to read and/or understand English.
- Presence of a cognitive or physical disability that would impair the parent's ability to complete self-report questionnaires at the data collections.
- Having an infant who is diagnosed with other significant health problems (e.g., heart defects) in addition to the cleft condition (Crerand, 2008).

The researchers plan to recruit 36 mothers in each diagnosis group. The study measures include (1) a demographic questionnaire; (2) perceived severity and satisfaction ratings of their child's condition and appearance after surgery; (3) Brief Symptom Inventory; 4) Perceived Stress Scale; 5) Parenting Stress Index; and 6) State-Trait Anxiety Inventory.

This follow-up qualitative study will use transcendental phenomenology (Moustakas, 1994) to explore and compare the experiences of couples (pre- vs. postnatal diagnosis) coping with CL/P in an offspring. In the following section, this method is referred to as phenomenology.

3.1 Aims

Most researchers who investigated the impact of the CL/P diagnosis conducted their studies at the time of the diagnosis (prenatal versus postnatal) and included only one parent (mothers) in their study samples. Although previous studies have focused on the multiple systems in which families are nested and have explored different factors

affecting the adjustment and adaptation of couples and families to a child born with CL/P, there is still little research that intentionally recruited both parents (dyadic approach) and investigated the long-term impact of the timing of the CL/P diagnosis.

To fill this gap, the primary aim of this study was to gain a better understanding of the experiences of parents who are currently parenting an infant or young child (up to age 4) who was born with CL/P. Unlike earlier studies that included only one parent in their study samples, this study examined both parents' experiences using a dyadic approach. The secondary aim of this study was to examine differences between the experiences of parents who received prenatal versus postnatal diagnosis of CL/P. Earlier studies have investigated the differences in parents' experiences between prenatal and postnatal diagnosis groups primarily at the time of the diagnosis or soon after the child's birth. This study was designed to understand if the timing of the diagnosis had a long-term effect on the experiences of parents regarding how they cope, adjust, and adapt to their child's condition. The ages of the children whose parents were targeted ranged from a few months old to 4 years old. These two aims were operationalized using specific open-ended questions and probes in the semi-structured interview guide (Appendix D) and were directly informed by the two theoretical frameworks used to design this phenomenological study, the BPS approach (Engel, 1977) and the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993).

3.2 Method

The method used in this archival qualitative study was *transcendental phenomenology* (Moustakas, 1994). Phenomenology was influenced by the ideas of Edmund Husserl, who considered personal consciousness as the only source of

information to best understand a phenomenon (Groenewald, 2004). The main goal in a phenomenological approach is to discover the *meanings* and *essences* of the phenomena being studied by focusing on how these phenomena are understood in the participant's consciousness by describing the themes that emerged from the participants' stories or narratives. Essence is defined as "the structure of essential meanings that explicates a phenomenon of interest" (Dahlberg, 2006, pp 11). Therefore, the primary aim for a phenomenological researcher is to understand the meanings attached to a particular situation through the participants' comprehensive and rich descriptions (Moustakas, 1994). Phenomenology has premises similar to the two organizing frameworks used to develop this dissertation study, BPS theory (Engel, 1977) and the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993).

In BPS theory, Engel (1980) stated that the patient is the most important source of information in describing his/her inner experiences of the illness. Weston (2005) similarly said that, "Illness, on the other hand, is a unique experience of the person who feels ill – the thoughts, the feelings, and the behavior of a particular individual at a particular time and place; it is expressed in terms of phenomenology and the language of the lifeworld" (p. 389). During this process, the physician has access to the patient's inner world and tries to understand it by eliciting the patient's illness narrative. For this reason, it is important for the clinician to adopt a communication style that encourages narration rather than being interrogative. Emphasizing the importance of understanding a patient's inner experiences by relying on verbal reporting leads to greater trust toward the health professional and better knowledge of a medical issue rather than defensiveness from patients. These principles are also shared with phenomenology (Moustakas, 1994).

In their Model of Family Stress, Adjustment, and Adaptation, McCubbin and McCubbin (1993) similarly noted that each family's way of responding to and dealing with a stressor like a CL/P diagnosis in an offspring will be different because it is determined by a couple's adjustment and adaptation to CL/P in their baby. The authors suggested that the following key factors could affect this process: (1) family vulnerability, (2) social support, and (3) family appraisal. It is important to examine the experiences of family members to more fully understand what makes some families cope or adapt better than others. Phenomenology focuses on how individuals experience a particular phenomenon such as CL/P. In my interview guide (Appendix D), I asked couples how they have adapted to and coped with having an infant or young child born with CL/P. This phenomenological approach was chosen to help me better understand couples' in-depth experiences and the meanings they attached to these key factors.

Creswell (2007) also noted that phenomenological research is most suitable for understanding people's shared experiences of a particular phenomenon. This study was designed to understand the shared experiences of parents who are currently caring for an infant or young child diagnosed with CL/P either prenatally or postnatally. Dahl and Boss (2005) state that the use of phenomenology as a research method in couple and family therapy research allows the researcher to better understand the multiple perspectives held by different family members who are experiencing the same phenomenon. For this reason, it is important to include more than one member of the family (e.g., both parents in this dissertation study) to better understand the dyad, which directly informed the design of this study by including both members of the couple (mothers and fathers) to

understand the experiences of parents who are raising a young child who was diagnosed with CL/P.

3.3 Participants and Sampling Method

Participants were recruited from an existing research study being conducted at the Division of Plastic and Reconstructive Surgery at CHOP by the PI Dr. Canice Crerand. When the data collection began for this dissertation study in the spring of 2013, the existing sample for the CHOP study had a total of 105 participants, which included 73 participants in the prenatal group and 32 in the postnatal group. There were 41 mothers and 32 fathers in the prenatal group and 19 mothers and 13 fathers in the postnatal group. Most parents were White, had high school or college educations, and worked full time. The demographic profiles of the full sample are described in Tables 3.1 to 3.3.

Table 3.1 Demographic Characteristics of the Full Sample

Demographic Variable	Sampling Frame	
	N	%
Gender		
Male	45	42.9
Female	60	57.1
Total	105	100
Race		
Asian	9	8.6
African American/Black	3	2.9
Hispanic	3	2.9
White	65	61.9
Other	2	1.9
Unknown	23	21.9
Total	105	100
Education		
Eighth grade or less	1	0.9
Some high school	3	2.8
High school graduate	15	14.2
Some college	9	8.5

College graduate	25	23.6
Graduate degree	21	19.8
Missing	32	30.2
Total	105	100

Table 3.2. Demographic Characteristics of the Full Prenatal Diagnosis Group Sample

Demographic Variable	Sampling Frame	
	N	%
Gender		
Male	32	43.8
Female	41	56.2
Total	73	100
Race		
Asian	7	9.6
African American/Black	3	4.1
Hispanic	3	4.1
White	48	65.7
Other	1	1.4
Unknown	11	15.1
Total	73	100
Education		
High school graduate	9	12.3
Some college	7	9.6
College graduate	11	15.1
Graduate degree	11	15.1
Missing	35	47.9
Total	73	100
Occupation		
Full time	43	58.9
Part time	9	12.3
Unemployed	7	9.6
Disabled	1	1.4
Homemaker	2	2.7
Missing	11	15.1
Total	73	100

Table 3.3 Demographic Characteristics of the Full Postnatal Diagnosis Group Sample

Demographic Variable	Sampling Frame	
	N	%
Gender		
Male	13	40.6
Female	19	59.4
Total	32	100
Race		
Asian	2	6.3
White	17	53.1
Other	1	3.1
Unknown	12	37.5
Total	32	100
Education		
Some high school	3	9.4
High school graduate	3	9.4
Some college	1	3.1
College graduate	6	18.75
Graduate degree	6	18.75
Missing	13	40.6
Total	32	100
Occupation		
Full time	10	31.2
Part time	3	9.4
Unemployed	1	3.1
Homemaker	6	18.8
Missing	12	37.5
Total	32	100

The prenatal diagnosis group had more participants (n=73) than the postnatal diagnosis group (n=32). This difference is expected because conducting a 3D ultrasound at the 20th week of pregnancy has become a regular procedure for most health care providers. With this new, improved technology, clefts, mostly cleft lip and cleft lip palate, are more often diagnosed prenatally.

The two diagnosis groups differed on some demographic characteristics. The prenatal diagnosis group had a higher percentage of participants who identified as White

(65.7%) or Asian (9.6%) and more participants who worked full time (58.9%). The postnatal diagnosis group had a higher percentage of participants who completed college or graduate school (37.5%) compared to the prenatal group (30.2%).

3.4 Sampling Strategy

A nonprobabilistic sampling strategy was used by recruiting a convenience clinical sample of couples who were part of the original study described above. The inclusion criteria for this follow-up phenomenological archival study were:

- Two biological parents of a child diagnosed with CL/P aged 18 years and older. Parents should be in an intimate partner relationship, cohabitating or married at the time of the interview.
- Informed consent for participation in the study obtained

The exclusion criteria for this study were:

- Inability to read and/or understand English.
- Presence of a cognitive or physical disability that would impair the parents' ability to complete self-report surveys and interviews.
- The infant having been diagnosed with other significant health problems (e.g., heart defects) in addition to the cleft condition.

3.5 Institutional Review Board Approval and Procedures for Recruitment

After I received institutional review board approval from CHOP and Drexel (Appendix F and Appendix G), I mailed recruitment letters to possible participants. To avoid recruiting participants in an invasive or coercive manner, I mailed a recruitment letter describing the follow-up qualitative research study and providing recipients with the researchers' (PI: Dr. Crerand and Doctoral Student: Senem Zeytinoglu) contact

information (Appendix B) and a stamped refusal postcard to 61 participants who fit the inclusion/exclusion criteria from Dr. Crerand's ongoing study. I asked couples to mail back the refusal postcard within 2 weeks if they did not want to be contacted about this study. In this manner, couples who were interested in volunteering for the one-time qualitative interview were afforded the opportunity to volunteer without any undue coercion.

I only received one refusal postcard at the end of the 2 weeks. Next, I made phone calls to couples who did not return the refusal postcard. At this time, 15 couples either declined to participate or their phone lines were cut off. Seven of these couples were from the postnatal diagnosis group, and eight were from the prenatal diagnosis group. One couple in the postnatal diagnosis group declined to participate after the two measures (demographic survey and RDAS) were sent to them because they found the questions too personal. Another couple from the postnatal diagnosis group agreed to participate at first but later declined because the husband changed his mind at the last minute. Finally, I started interviewing one couple from the prenatal diagnosis group and learned in the middle of the interview that their child also had Down syndrome. Therefore, I had to remove the couple from my sample because of the exclusion criterion that I only interview couples who have children with isolated clefts.

After 2 months of data collection during the spring of 2013, I had 10 couples in the prenatal diagnosis group and four couples in the postnatal diagnosis group. Next, I sent an additional letter to the remaining seven couples in the postnatal diagnosis group explaining my need for additional participants. Dr. Canice Crerand contacted them a week later asking if they would like to volunteer for the study; three of the seven

postnatal couples accepted. Therefore, my final sample included 10 couples in the prenatal group and 7 couples in the postnatal group. I reached saturation after I interviewed the seventh couple in the prenatal diagnosis group and after the sixth couple in the postnatal diagnosis group but completed all interviews with interested couples.

3.6 Data Collection

Data were collected using (1) in-depth semi-structured interviews (father and mother separately, then as a couple) (Appendix D); (2) a self-report demographic survey (Appendix C); and (3) the RDAS (Busby, Christensen, Crane, & Larson, 1995) (Appendix E).

3.6.1 In-depth Semi-structured Interviews

Semi-structured interviews (Appendix D) were conducted with couples who had young children (ages 1 to 4 years old) born with CL/P to better understand their experiences. The interviews were scheduled during the initial screening phone call and took place at a convenient time and place for the couples. Face-to-face interviews occurred whenever possible, but I offered couples the option of a phone or an Internet-based interview when in-person interviews were not possible. Three interviews were conducted face to face: Two couples were from the prenatal diagnosis group and the other couple was from the postnatal group. One couple from the prenatal diagnosis group wanted to be interviewed via the Internet. The remaining 13 interviews, 7 from the prenatal diagnosis group and 6 from the postnatal diagnosis group, were conducted over the telephone. All interviews followed the same interview guide, were audiotaped, and then were transcribed verbatim (Appendix D, interview guide). The interviewer took detailed memos during and after each interview to record impressions that could not be

captured by the audiotape (e.g., facial expressions, body language). The interviews, notes, and memos were then transcribed verbatim and coded as qualitative data.

If I conducted the interview in person, I explained the consent form and then obtained written informed consent from both parents (Appendix A). Then the participants individually completed the demographic survey (Appendix C) and the RDAS (Appendix E) and handed them to me. If the interview was conducted over the phone or via a Web-based conferencing system, the consent form and the surveys were mailed to the participants before the interview. At the time of the interview, the researcher asked participants to review and sign the consent form if they had not done so. The researcher also asked the participants to complete the surveys and mail them to the researcher as soon as possible if they had not already done so. Then, the researcher conducted a semi-structured interview in the following sequence: (1) both partners together to orient them to the interview process; (2) each partner separately to ask about his or her experiences of having a young child born with CL/P; (3) both partners together as a dyad to understand their experiences of having a young child born with CL/P.

The average length of the interviews for both groups was 90 minutes. Thirty minutes was scheduled for each partner and 30 minutes for the couple interview. When one partner was interviewed, the other one took a break and left the room where the interview took place. All interviews were audiotaped and transcribed verbatim by a transcriptionist. Couples used pseudonyms throughout their interviews to preserve anonymity. One couple and one father from a couple in the postnatal diagnosis group did not return the demographic and RDAS surveys. Before the interview, they informed the researcher that they had read and signed the consent form and completed the two surveys.

When I did not receive the surveys for 2 weeks, I contacted them again by phone, leaving voice messages to remind them to send back the surveys. Although the research team never received the two surveys, they did receive the signed consent forms.

3.6.2 Demographic Survey

Each member of the couple separately completed a demographic self-report questionnaire that included contextual information such as length of relationship, relationship status, cohabitation status, age, education level, occupation, number of children, history of psychological and psychiatric treatment, and participation in support groups. The answers were used to understand the social location and medical and psychological background of the couple. This demographic questionnaire was identical to the one collected for Dr. Crerand's larger study; however, specific questions whose responses could not have changed with time (e.g., race, ethnicity, family cleft history) were eliminated to avoid redundancy (Appendix C).

3.6.3 Demographic Description of the Sample

Ten couples in the prenatal diagnosis group and five couples in the postnatal diagnosis group returned their surveys. Each of the 10 couples in the prenatal diagnosis group were married and living together, whereas five of the seven couples in the postnatal diagnosis group were married and living together (Table 3.5). One couple in the postnatal group reported that they were living together but were on the verge of a breakup. The length of the relationship of couples in the prenatal diagnosis group ranged from 6 years and 3 months to 25 years; the mean relationship length was 11.41. All couples in the prenatal diagnosis group were married and lived together at the time of the interview. The length of marriage ranged from 3 years 8 months to 18 years and 6

months. Half of the couples in the prenatal diagnosis group had two children and half had one child. All couples in the prenatal diagnosis group had only one child born with cleft. The ages of the mothers in the prenatal diagnosis group ranged from 32 to 45 years (mean age, 39 years). The ages of the fathers in the prenatal diagnosis group ranged from 30 to 52 years (mean age, 41.20 years). Nine of 10 mothers and 8 of 10 fathers had college or graduate degrees. All fathers in the prenatal group were employed full time; seven mothers in the prenatal group were employed full time, one mother was employed part time, and two mothers were homemakers (Table 3.4). None of the fathers reported receiving psychological or psychiatric help during the last 12 months. One mother reported receiving psychiatric help and two mothers reported previously participating in support groups.

In the postnatal diagnosis group, of the seven couples who participated in the study, six mothers and five fathers returned the demographic and RDAS surveys. The length of the relationships of couples in the postnatal group ranged from 5 to 18.5 years (Table 3.5). The mean relationship length for couples in the postnatal diagnosis group was 11.06. The ages of the mothers in the postnatal group ranged from 23 to 41 years (mean age, 34.3 years). The ages of the fathers in the postnatal group ranged from 24 to 43 years (mean age, 34.4 years). Three of six mothers and three of five fathers completed college and/or graduate school. Four of five fathers and two of six mothers were employed full time. Two mothers and one father were employed part time and two mothers were homemakers. One father and one mother reported receiving psychological help during the last 12 months. Four couples had two children and three couples had one. Even though one of the couples did not return the surveys, they mentioned during their

interview that they had two children. All couples in the postnatal group reported having only one child with cleft.

Participants in both diagnosis groups were predominantly White. Therefore, the demographic profile of the diagnosis groups did not differ based on race. However, it did differ on participants' level of education and work status. Of the 20 individuals (both mothers and fathers) in the prenatal diagnosis group, 17 had completed college or graduate school. In contrast, of the 11 postnatal participants who returned their demographic surveys, 6 had college or graduate degrees. Furthermore, 7 of 10 couples from the prenatal diagnosis group reported that both partners worked full time whereas four fathers and two mothers in the postnatal group worked full time. For participants in the postnatal diagnosis group, the lower level of education and less access to financial resources could lead to additional stress as they cared for their children born with cleft. Additionally, receiving the diagnosis postnatally may have prevented them from preparing financially for the additional expense of caring for a child born with cleft. For this reason, they may be at a disadvantage compared to those in the prenatal diagnosis group. Demographic descriptions of the final sample for both diagnosis groups are described in Tables 3.4 and 3.5.

Table 3.4. Demographic Characteristics of the Prenatal Diagnosis Group

Demographic Variable	Sampling Frame	
	N	%
Gender		
Male	10	50
Female	10	50
Total	20	100
Race		
Asian	2	10
White	18	90

Total	20	100
Education		
High school graduate	2	10
Some college	1	5
College graduate	6	30
Graduate degree	11	55
Total	20	100
Occupation		
Full time	17	85
Part time	1	5
Homemaker	2	10
Total	20	100

Table 3.5. Demographic Characteristics of the Postnatal Diagnosis Group

Demographic Variable	Sampling Frame	
	N	%
Gender		
Male	7	50
Female	7	50
Total	14	
Race		
White	10	71.43
Other	1	7.14
Missing	3	21.43
Total	14	100
Education		
High school graduate	2	14.3
Some college	3	21.43
College graduate	3	21.43
Graduate degree	3	21.43
Missing	3	21.43
Total	14	100
Occupation		
Full time	6	42.3
Part time	3	21.43
Homemaker	2	14.3
Missing	3	21.43
Total	14	100

3.6.4 Revised Dyadic Adjustment Scale

Each member of the couple was asked to complete the *Revised Dyadic Adjustment Scale* (RDAS; Busby, Christensen, Crane, & Larson, 1995) (Appendix E). The RDAS is a brief, self-report questionnaire that includes 14 items designed to assess relationship adjustment using a 6-point Likert scale (except for Question 11, which uses a 5-point Likert scale). The RDAS includes the following subscales: (1) consensus, (2) satisfaction, and (3) cohesion. The consensus subscale includes six questions that assess the level of agreement or disagreement between intimate partners on topics such as affection, decision making, and values. The satisfaction subscale assesses the stability and conflict in a couple's relationship. Finally, the cohesion subscale assesses the frequency of shared activities and discussion between the couple (Busby et al., 1995). The researcher used the results of this scale to triangulate the qualitative data (Appendix E).

The RDAS has solid construct validity for both first order and second order factor analyses with robust loadings. When tested with both distressed and nondistressed couples, the RDAS has demonstrated a similar factor structure (Busby et al., 1995); the correlation coefficient between the RDAS and DAS is 0.97. The correlation coefficient between the RDAS and a widely used marital adjustment test, the Lock-Wallace Marital Adjustment Test (MAT) is 0.68. The criterion validity for RDAS was also investigated and the accuracy of classification rates was 86% and 74% for nondistressed and distressed couple respectively. Furthermore, analysis suggests discriminant coefficients of 0.34, 0.55, and 0.32 for consensus, satisfaction, and cohesion scales respectively. The RDAS has a Cronbach's alpha of 0.90, establishing the internal consistency and has a Guttman split-half reliability coefficient of 0.94. Possible RDAS scores can range from 0

to 69, with higher scores indicating higher levels of relationship adjustment. The clinical cutoff score for the total RDAS is 45 and scores of between 32 and 45 indicate moderate distress, whereas scores lower than 32 indicate severe distress (Busby, et al., 1995).

3.7 Procedure

Data collection began after CHOP's institutional review board approved this phenomenological dissertation study (Appendix F), and a cooperative agreement was established with Drexel's institutional review board (Appendix G). The existing sample in Dr. Crerand's larger study was reviewed, and letters (Appendix B) were mailed to 61 couples who fit the dissertation study inclusion and exclusion criteria: 20 from the postnatal diagnosis group and 41 from the prenatal diagnosis group. Only one couple returned the postcard indicating that they did not want to participate in the study. Two weeks later, I contacted the remaining 60 couples by phone. The dissertation study was explained and the informed consent form was briefly reviewed during the initial phone call.

Fifteen couples either declined to participate or could not be reached because their phone numbers had changed or been disconnected. Seven of these couples were from the postnatal diagnosis group and eight were in the prenatal diagnosis group. One couple in the postnatal diagnosis group declined to participate after the two self-report measures were mailed to them because they found the questions too personal. Another couple dropped out at the last minute because the husband was reluctant to participate in the interview. After two months of data collection in the spring of 2013, I had 10 couples in the prenatal diagnosis group and 4 couples in the postnatal diagnosis group. I sent another letter to the remaining seven couples in the postnatal diagnosis group explaining my need

for additional participants. Dr. Canice Crerand then contacted them a week later asking for their participation. Three of the seven postnatal couples accepted. After saturation was reached, my final sample included 10 couples in the prenatal group and 7 couples in the postnatal group.

If the couple decided to volunteer for this study, we agreed on a convenient time and place and scheduled the one-time qualitative interview. If the couple stated that they preferred a phone or a Web conferencing system-based interview, the PI mailed them an information packet about the study. This packet included (1) informed consent form (Appendix A); (2) the interview guide (Appendix D); (3) the self-report demographic survey (Appendix C); and (4) the RDAS (Appendix E). The participants were also informed about the compensation they would receive for their voluntary participation (\$20 gift card for each parent). Fourteen of 17 couples preferred the phone- or Web-based conferencing system interview. With face-to-face interviews, the consent form was signed on the day of the interview before the actual interview began. Then the demographic survey and RDAS were administered in person to both parents separately. The interviews that were conducted over the telephone or via a Web-based conferencing system did not take place until the signed consent form was mailed back to the researcher. Strict confidentiality of the participants' identities was maintained by using pseudonyms and removing all identifiers of the participants and for any third parties mentioned during the interviews.

3.8 Data Analysis

MAXQDA (2010) is the data analysis software that was used to organize and analyze the couples' qualitative data. I first analyzed the individual (mother vs. father)

interviews for each diagnosis group (prenatal and postnatal) by coding common themes that emerged among mothers and fathers and considered possible differences between the two gender groups and the two types of CL/P diagnoses (pre- vs. postnatal). I then analyzed the couple interviews for the prenatal and postnatal groups and focused on the commonalities and differences between their experiences. I also wrote case summaries for each couple to understand their stories in depth, to triangulate their individual interviews with the couple interview, and to check if the dominant themes emerged in each couple's individual story.

All interviews were audiotaped with a digital audio recorder and then transcribed verbatim by a professional transcription service. The recorded interviews were stored as electronic audio files in a password-protected computer that was accessible only to the researcher, the PI of the original larger study (Dr. Canice Crerand), and the dissertation chair at Drexel University (Dr. Maureen Davey). Additional copies of the interviews were stored in a password-protected back-up drive as well as in a password-protected computer at CHOP. The transcription of the interviews and the descriptive data gathered from the demographic survey and the relational distress measure (RDAS) were stored in a similar fashion. All data were qualitatively analyzed following phenomenological data analysis described in the next section.

3.8.1 Epoche

In phenomenological research, *epoche* describes the ongoing process that the researcher engages in to become more aware of and to set aside his/her knowledge, understanding, assumptions, and judgments about the phenomena that s/he intends to study. This process allows the researcher to become more aware of the representation of

the phenomena in his/her consciousness and accept the new information with a more open consciousness without prior commitments and restraints. Epoche requires the researcher to concentrate and allow himself/herself to be transparent by having access to all his/her biases, assumptions, and judgments in order to examine the phenomena with an open consciousness and a new set of eyes (Moustakas, 1994). Epoche can be achieved through (1) understanding self-location as a researcher (Chapter 4) and (2) writing reflexive memos throughout the research process (Daly, 2007).

Daly (2007) refers to this reflexive process as self-positioning and suggests that it starts with the formulation of the research questions and should continue throughout the data collection, analysis, and interpretation phases. Examining and describing one's location of self as a researcher at the beginning stage of understanding reveals what biases and views the researcher brings to a phenomenological research project and the phenomena being studied. For this reason, in Chapter 4, I described my own experiences, values, beliefs, and judgments regarding couples raising a young child born with CL/P. I also describe my own social location (e.g., gender, social class, ethnicity, race), my professional training, and what I expected to find based on my review of the cleft literature to consider how these might have affected my analysis of the data. Throughout data collection, analysis, and the interpretation phases, I continued to write memos to describe what I saw, heard, thought, and experienced so I could examine my own biases, assumptions, and judgments as they emerged in my consciousness. In Chapter 5, I describe how my views stayed the same and/or changed after conducting this study.

3.8.2 Phenomenological Reduction

Phenomenological reduction includes (1) bracketing and (2) horizontalization. Throughout this process, I described what I heard, saw, and experienced without the restraints of my previous knowledge, understanding, assumptions, and judgment. The first step, *bracketing*, was conducted in by (1) placing my previous knowledge, understanding, assumptions, and judgments in brackets and (2) placing the researched phenomenon in brackets, eliminating the other parts of the participants' told experiences (Gearing, 2004). Through horizontalization, horizons of the researched phenomena would emerge from the told experiences; each of these horizons hold an equal value (Moustakas, 1994). Following horizontalization, I grouped the horizons into *themes* and developed a coherent description using the horizons and the themes to explain the essence of the phenomena (for this dissertation study, the experiences of parents who are raising a young child born with CL/P diagnosed either pre- or postnatally).

During the process of phenomenological reduction, I applied conventional content analysis to extract themes and horizons. Hsieh and Shannon (2005) explained that conventional content analysis is ideal for describing a phenomenon, particularly when existing literature and/or theory on the targeted phenomenon is scarce. For this type of analysis, the researcher is expected to engage herself/himself in the data to develop new insights about the phenomenon without having preconceived judgments. With this goal in mind, the researcher first reads all of the transcripts several times, extracts words that describe the key ideas, and then writes down his/her first impressions and thoughts generated from immersing him-/herself in the raw data. Next, the researcher organizes key ideas into codes, groups the related codes into meaning categories, and organizes the

group codes into clusters. When the codes, categories, and clusters are formed, the researcher identifies each of them using the data and describes them in relation to one another (Hsieh & Shannon, 2005). Dahl and Boss (2005) emphasize that when labeling the codes, categories, and clusters generated from participants' everyday expressions, it is crucial to use psychological language that captures the phenomenon being studied.

3.8.3 Imaginative Variation

Through imaginative variation, the goal is to attach possible meanings to the horizons using different frames of reference in order to produce a structural description of the phenomenon (Moustakas, 1994). The two frames of reference that were used in this phenomenological study to understand the themes that emerged from the data and to formulate structural descriptions are BPS theory (Engel, 1977) and Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993). These two organizing theories helped me make sense of the themes that emerged, in particular how multiple systems affect couples' experiences and how some resiliency factors were more salient regarding how they coped and adapted to having a child born with CL/P.

3.8.4 Synthesis

During the final step of the phenomenological research process, the researcher provides a unified explanation of the phenomenon(a). This explanation includes the complete structural descriptions of the essences and meanings attached to the phenomenon(a), which are derived from the previous processes at a given time and place and from the point of view of the researcher (Moustakas, 1994).

3.8.5 Trustworthiness

Lincoln and Guba (1985) stated that trustworthiness determines if the findings from a research study are worth the audience's attention. They described four areas that researchers should take into consideration to ensure trustworthiness of the qualitative findings.

3.8.5.1 Credibility

Credibility is achieved by using additional measures to increase the probability that findings from a qualitative research study are believable or credible. I used the following techniques to ensure the credibility of the findings that emerged: (1) triangulation, (2) peer debriefing, and (3) member checking. Triangulation refers to the verification of qualitative findings through different sources such as other data collection modalities, theories, or investigators (Lincoln & Guba, 1985). The findings from this phenomenological study were triangulated as follows: (1) using the relational distress measure (RDAS); (2) sending representative data and codes that emerged to my dissertation chair (M. Davey) and committee member (K. Fisher) to confirm the major themes; and (3) triangulating mothers' and fathers' individual data with their couple data. The RDAS was a secondary source for increasing the credibility of the findings describing the couple's experiences.

Lincoln and Guba (1985) defined peer debriefing as explaining the research process to a "disinterested peer" who plays the "devil's advocate" by exploring and challenging the researcher's biases, meanings, and explanations. The researcher becomes aware of his/her own process, clarifies those of his/her emotions that can possibly affect his/her judgment in some way, and has the chance to consult about hypotheses that may

be emerging. The debriefer challenges the researcher about his/her hypotheses, which gives the researcher a chance for further exploration, possible revision of the hypotheses, and for planning the next steps. Lincoln and Guba (1985) asserted that the debriefer should not be junior or senior to the researcher and should be someone who will take his/her job of playing the devil's advocate seriously. In this phenomenological research study, the debriefer was the PI's peer, another doctoral student who was working on her dissertation during the same time and conducting a phenomenological research study. The PI trusts the debriefer's knowledge on the phenomenological research process as well as her ability to play the devil's advocate.

Member checking was another method used to increase the credibility of the research findings (Lincoln & Guba, 1985). Once the analysis was completed, I contacted all of the participants (n=17 couples) via e-mail and asked them if the themes generated from the data captured their experiences. This process gave the participants an opportunity to provide feedback to the researcher (Dahl & Boss, 2005). I received 2 of 17 responses back, confirming the findings of the study. However, I did note in the body of the e-mail that if I did not hear back from the 17 couples in 2 weeks, I would assume they were in agreement with the codes that emerged. After waiting 2 weeks, I sent an additional reminder.

3.8.5.2 Transferability

Transferability refers to the applicability of the research findings to other contexts or to the same context at a different time. One can assess the applicability on the basis of the similarities between the population and context of this research study and the qualities of the population and the context that the findings are expected to apply to (Lincoln &

Guba, 1985). Accordingly, to give other researchers an opportunity to assess the transferability of the research findings, it was my goal to clearly describe the demographic profile of the participants and of the contexts in which the interviews took place. This detailed description will help third parties to make informed judgments about the similarity of the contexts and the possibility of transferring such findings (Lincoln and Guba, 1985).

3.8.5.3 Dependability

Lincoln and Guba (1985) state that ensuring credibility may be sufficient for ensuring dependability; however, they also described possible techniques that can increase the dependability of the results. Inquiry audit was the technique used in this research study. An “auditor” examined the research process and the findings of the research study to ensure its accuracy. My dissertation chair (Dr. Maureen Davey) and one of my committee members (Dr. Kathleen Fisher) audited the research methods and the codes that emerged.

3.8.5.4 Confirmability

An inquiry audit is not possible without an audit trail. An audit trail, a technique for establishing confirmability, is composed of records kept during each step of data collection and analysis. These records include raw data of the interviews (electronic files); field notes, survey results, data reduction, and analysis trails; products; data reconstruction and synthesis trails and products; reflexive memos; notes on the trustworthiness process; and notes on the theoretical frameworks (Lincoln & Guba, 1985). For this research study, all of the steps leading to the research findings were carefully detailed, and the documentation was available for examination at any time.

3.9 Limitations

The participants in this archival dissertation study were recruited from an ongoing larger study sample at CHOP. The parents who participated in the larger study (who at the time of the interview had children born with CL/P who were now 1-4 years old) were contacted to ask about their participation in this follow-up qualitative study. The sample of couples is English speaking and predominantly White, middle to upper class. All participants had an equal chance of participating as long as they fit the original study's inclusion and exclusion criteria. For this reason, one of the limitations of this study is the lack of economic and sociodemographic diversity because of the homogenous privileged demographic profile of the participant pool at CHOP.

The primary aim of this study was to describe the experiences of couples (both mothers and fathers) who are currently raising a young child who was diagnosed prenatally or postnatally with CL/P. The inclusion and exclusion criteria required that participants be the biological parents of the child, at least 18 years old, able to speak English, and not currently suffering from any cognitive or physical disability that would hinder the completion of the surveys and interviews. Parents of children with other significant health problems were excluded from this study. Consequently, another limitation of this study is that the findings may not be applicable to couples who do not fit these specific inclusion criteria.

3.10 Obstacles

When I first began this research study, I encountered a number of obstacles. First, I expected it to be more difficult to recruit participants for the postnatal diagnosis group because there were fewer postnatal participants in the original sample. Additionally,

because of the demographic profile of the original study sample (e.g., predominantly White, higher educational and socioeconomic status), I expected to have difficulty recruiting minority couples. Furthermore, I knew that I would be significantly impacted by my own experiences growing up with a cleft so I wrote memos about and bracketed my own biases throughout the study.

As expected, I did struggle recruiting participants for my study, specifically the postnatal diagnosis group and a diverse sample of couples. When I completed the interviews with participants who contacted me after the first recruitment letter was mailed out and I made the follow-up phone call, I had 10 couples in the prenatal diagnosis group and only 4 couples in the postnatal diagnosis group. Dr. Davey advised me that I needed more participants for my postnatal diagnosis group to ensure I reached saturation for both diagnosis groups. So I prepared a second letter explaining my need for more participants whose children were diagnosed with CL/P after birth (Appendix B). I asked couples to contact me within a week via e-mail or phone if they were interested in participating, but I did not receive any responses. At this point, I talked to Dr. Canice Crerand, who kindly agreed to call participants in her original sample whose children were diagnosed postnatally to ask again if they would like to volunteer for my study. She was able to obtain approval from three more postnatal couples. As a result, my final sample includes 10 couples from the prenatal diagnosis group and 7 couples from the postnatal diagnosis group; I reached saturation for both diagnosis groups with this final sample of 17 couples.

Because most participants in the original study sample were White, had a college or graduate degree, and worked full time, I struggled to recruit a racially and economically diverse sample. I noticed that it was easier to recruit participants who did

not complete college or work full time, but it was difficult to recruit racial and/or ethnic minorities. I looked for minority participants in the larger study sample, which was stored in CHOP's secure database and reached out to them. In addition to the biracial couples (White-Asian) I was able to recruit, I contacted one African American, one Asian, and one Indian family; all of these couples had received their child's diagnosis postnatally. Additionally, I contacted one Latino family who received a prenatal diagnosis.

When I contacted the African American family, the grandmother answered the telephone and I asked if the mother could contact me. The grandmother informed me that she would tell the mother about the study, but the father was not in their lives. The father in the Asian family told me to contact his wife for "such things" because he was too busy to participate. Finally, the Indian family agreed to participate in my study, so I mailed them the consent form and two surveys, which they mailed back. However, the husband changed his mind about participating in my study on the day the interview was scheduled. When I interviewed the Latino family in person, I learned that their son was also born with Down syndrome (an exclusion criteria for my study). Because the original study sample at CHOP was only supposed to include families whose children were born with isolated cleft, it never occurred to me that I should screen for it before the interview was scheduled. I learned an important lesson and made sure I screened for additional anomalies before each interview.

I found myself having a reaction to some of the comments couples made about children who are born with cleft in other countries or their emphasis on their children being "perfect." I found myself getting frustrated with the assumptions they made about people in the other countries because I was born with cleft in Turkey. I also had a

difficult time with parents who put so much emphasis on their child being “perfect” because I believe this can have a negative effect, causing the child to struggle with feelings of inadequacy. However, I was familiar with this experience since my clients also made these types of statements that triggered me as a therapist. I learned not to be consumed by my own reactions, not to judge them, noting my feelings and reactions in memos after conducting each interview. Furthermore, I became accustomed to pushing myself to explore each person’s reactions and statements; trying to make sense of what they were saying so I could better understand their experiences; and bracketing my own reactions.

I encountered some unanticipated obstacles. For months, I struggled to get institutional review board approval at CHOP. I submitted the application package in November, 2013 and did not receive final approval until April 2014, 5 months later. I had to revise my application four times before obtaining final approval. Dr. Crerand, who was the PI at CHOP, was invaluable and helped me navigate the institutional review board. She informed me that the difficulties occurred because the reviewers on the institutional review board were not familiar with qualitative research.

As I was collecting my data, some participants behaved in ways that I did not expect. Some fathers had dismissive attitudes during the interviews, making comments like, “Let’s get it over with,” “I’m fading,” “I hope this was it.” I reminded myself that they were taking time out of their busy schedules to conduct this interview. Some couples agreed to be interviewed and then never answered their phone at the time of the scheduled interview. Finally, one couple in the postnatal diagnosis group agreed to participate but then dropped out when they received the surveys and the consent form.

The wife informed me that they found the questions too personal. I was surprised because the husband was a psychiatrist and the wife was a psychologist, so I thought they would be more familiar with these types of personal questions about themselves and their relationship.

As noted by Moustakas (1994), a phenomenological researcher has to consistently and thoroughly work on being aware of any preconceptions, previous ideas, and memories related to the studied phenomenon(a) in order to bracket them and set them temporarily aside. The next chapter describes my location as the researcher, which is an important part of this first stage in the phenomenological process.

CHAPTER 4: LOCATION OF THE RESEARCHER

One of the epistemological assumptions of phenomenology is that the researcher is not separate from the phenomena under study (Dahl & Boss, 2005). This premise is even more meaningful for this study because the researcher is also an individual who was diagnosed with CLP as a newborn.

4.1 Personal Location

I am a 30-year-old White, upper-middle class, heterosexual female who was born and raised in Turkey. I am coupled and have been in a relationship with my partner for 2 and a half years. I am the oldest child in my family and was born prematurely with a cleft lip palate. My parents did not know prenatally that I was going to be born with a cleft lip palate; my mother found out at birth (postnatal diagnosis). She told me that the doctor broke the news to her by saying that I would have difficulty eating because of the cleft. She stated that he was very calm when he talked to her, so she did not get too anxious. She asked the doctor to check my neurological functioning; apparently, the doctor told her that I was above average. He decided not to even place me in an incubator because I was a very active premature baby.

Because my birth was earlier than expected, my father could not be at the hospital when I was born. So my mother had to go through the initial shock of having a baby born with cleft lip palate without him by her side; however, my maternal grandmother was with her. My mother's family described how well she took the news. When family members arrived to visit my mother in the hospital, she already had her lipstick on. I think that has been my mother's attitude toward my cleft lip palate; she always presents my condition like it never affected her, but deep inside, I feel that this is not the truth. I

think it was very difficult for my mother in the first months of my life, especially because of my feeding difficulties and my ongoing surgeries as well as my family's focus on physical appearance.

My mother initially had a lot of trouble feeding me. When I was born, the nurses told her she would not be able to breastfeed because of my cleft lip palate. So they tied her breasts to help her milk dry up. My mother told me that this was very hard for her physically and emotionally. She had to feed me with formula, which was very difficult because I threw up all the time. The doctors told her that if she was not able feed me, I could die. My father told me this created a lot of anxiety in my mother. She became so obsessed with feeding me and taking care of me that my father remembers she forgot to change the bed sheets for three months (Why he did not change the bed sheets himself is something that I have yet to ask him.) My maternal grandmother was the one who fed and took care of me in the first months of my life and stayed with my parents for 40 days to make sure that they had the help they needed. That is why my father gave me a middle name to honor my material grandmother, "Fehime."

I had my first surgery when I was 3 months old. My parents took me to Germany for this first surgery because my mother read a book on cleft lip palate and learned that there was a famous cleft surgeon in Germany. My parents did not have enough money to pay for the surgery at that time so my father asked my mother's father, who is well-off, for a loan. My grandfather refused to loan them the money saying that my operation was my father's responsibility because we were a separate family. So my father had to pawn his own car to pay for my first surgery.

By the age of 19, I had had six surgeries for my nose, lips, and teeth as well as dental treatment that lasted for almost 10 years. During my adolescence, I remember looking in the mirror and thinking how ugly I was and that no man would ever want me or love me because of my physical appearance. I always chose to become best friends with the people that I was in love with because it was safer for me to not risk the rejection. It is still hard for me to believe when a man finds me attractive, because I never believe I am pretty enough for any man. As an example, my ex-boyfriend's mother refused to meet with me and forbade him to marry me because of the fear that our children would have cleft-lip palates.

Throughout my life, I received implicit and explicit messages from my family, friends, and outsiders about my physical appearance being related to my self-worth as a woman. For example, family members emphasized how much prettier I became after each surgery, which implied that I was not pretty *before* the surgical procedure. Furthermore, they emphasized how I would be even prettier after my next surgery. When I was growing up, strangers often asked me questions about my facial features and made fun of my "facial deformities," my nasal speech, and my inability to pronounce certain letters correctly. I learned that answering questions about my scars, surgeries, and dental treatments was a part of my life that I needed to accept (Carneiro, Zeytinoglu, Hort, & Wilkins, 2013).

My cleft impacted my relationship with my parents and with my younger sister. It is hard for me to talk to my mother about how my cleft impacted her because she denies that she was ever affected by it. When I talk to her, she says that she never made a big deal out of it and always tried to do the best she could to raise me well. She says that she

is so happy that I was not born with any mental disabilities. Yet, I think that she was concerned about my physical appearance at some point because she told me stories about how her brother commented on how beautiful I would become one day.

I know that my mother loves me very much, but I also believe that a part of her resented me. I think it was especially difficult for her as a first-time mother to feed me and take care of me during my many surgeries. I experienced her as being viciously hostile toward me when I was growing up. The day before one of my surgeries, she told me that I destroyed our family emotionally and economically. As I was growing up, my father was my confidante and my protector. If my mother was trying to force feed me (she was obsessed about feeding me), he would eat my portion in secret. If my mother was yelling at me, he would come to my defense. I lived in this triangle between my two parents until recently (it has been hard for me to differentiate). Yet, whenever I had surgeries, my mother was the one who took care of me, gave me my medications, and cleaned around my stitches while my father disappeared for most of the day. I attributed this to my dad's discomfort dealing with medical issues when his loved ones are in physical pain.

My paternal uncle's son was also born with CLP, which for me confirmed that I inherited the gene from my father's side. My mother told me that she was glad that my cousin was born with CLP because people blamed her after my birth, and his condition proved that it was not her fault. I think my father blamed himself; he told me on several occasions that my cleft was his fault.

My parents struggled with many of the treatment decisions; my mother always wanted me to get the surgeries in the United States and my father, in Turkey. I decided to

have my surgeries in my home country at that time because I felt more comfortable and probably because I trusted my father's decisions more than my mother's. However, I had two of my last surgeries when I was 18 and 19 in the United States because my doctor in Turkey turned out to be a fraud who did not know how to correctly repair clefts. I realized this too late. My sister was left at home in Turkey with my aunt when I had my surgeries in the United States. She remembers this time vividly, especially how scared she was on September 11, 2001 because we were in New York for my surgery. I actually had my surgery on September 10. My sister recently told me that she felt she always had to be the obedient, accommodating daughter because of my ongoing cleft-related health issues. My sister and I also had a strained relationship because everybody noted how beautiful she was, which made me feel insecure. It was especially difficult when people made explicit comments about how much more beautiful she is compared to me. I explained to my sister that my discomfort is about me so that she would not feel guilty about her good looks; it is a conversation that we are still openly having with each other.

My cleft significantly affected all of my family relationships and my self-esteem. It also impacted my parents' relationship and my sister's relationship with my parents, which illustrates the systemic impact of a congenital condition like cleft on family members, parents, and siblings. I know that everyone's story is different. I went through my struggles in a different country, culture, and time period. For this reason, I tried to keep my biases in check by constantly writing memos and working closely with my dissertation chair and committee members to more fully capture couple's experiences coping with a child born with CL/P.

4.2 Professional Training

I am a fourth year doctoral student in Drexel University's couple and family therapy program. Our program focuses on self-of-the therapist issues, cultural sensitivity, helping underserved populations, and social justice. I received my master's degree in psychological counseling at Teachers College, Columbia University in New York City. I decided to pursue a doctoral degree in couple and family therapy because I am a systemic provider and believe it is crucial for mental health professionals to take the individual's social and personal contexts into consideration when providing treatment. I believe that interpersonal relationships are essential to everyone's well-being, especially during personal crises or times of stressful. This view is congruent with my commitment to strengthening secure attachments when providing care to individuals, couples, and families. According to attachment theory (Bowlby, 1980), having a secure base in life allows individuals to regulate their own emotions and better cope with outside stressors. When I interviewed the 17 couples in this study, I was probing to understand if they could rely on their partners and support each other. In my own therapeutic practice with couples, I use Emotionally Focused Couple Therapy (EFT; Johnson, 1996). This model was developed to ascertain the underlying dynamics of couple's interactions. For this reason, during the interviews I probed to understand each partner's primary feelings and their impact on the couple's dynamic. The challenge was to draw the line between therapy and research and refrain from intervening to help to improve their relationships. Instead, I focused on understanding their current relational dynamic and experiences parenting a child born with CL/P.

During my training in the doctoral program, I had the privilege of teaching a class on the Person-of-the-Therapist Training (POTT) model (Aponte & Winter, 2000). This model encourages therapists in training to connect with their clients' pain by relating to it on the basis of the therapists' own life experiences and their own woundedness. It also encourages therapists to have mastery over their own personal issues so that they are able to differentiate between their own experiences and their clients' issues in therapy. The POTT model influenced how I conducted the interviews because, at times, I had to use my own experience as a person who grew up with CLP to better connect with participants' stories.

Finally, I trained to use Eye Movement Desensitization Reprocessing (EMDR) (Shapiro, 1989). This model emphasizes understanding the core beliefs and messages that individuals attach to stressful experiences. Because having a child born with CL/P often causes distress in both the parent(s) and in couples, my goal was to understand the core beliefs that couples attached to this experience.

4.3 How the Literature Review Informs Self of Researcher

Mothers tended to report feelings of self-blame, shock, and grief as well as joy of having a new baby with CL/P (Johansson & Ringsberg, 2003; Nusbaum et al., 2007). Yet mothers reported questioning why the CL/P happened, often blaming themselves (Nelson, O'Leary & Weinman, 2009). This experience can lead to parents questioning their own beliefs about what is healthy and normal (Johansson & Ringsberg, 2003).

Parents who received a prenatal diagnosis reported having more time to adjust to their child's diagnosis, to choose a course of treatment, and to find resources and social support. They also reported using religion and spirituality as coping mechanisms. Yet

some parents were not happy with the prenatal diagnosis; they described not being able to enjoy the pregnancy because they were anxious about their child's in utero condition. Parents who received the diagnosis at the time of birth reported that they would have preferred knowing prenatally so they could have had more time to prepare physically, emotionally, and financially. Other parents felt it was better not to know prenatally because the diagnosis could have increased their anxiety during pregnancy (Davalbhakta & Hall, 2000; Nelson, Glenny, Kirk & Caress, 2011; Nusbaum et al., 2007).

Overall, parents (primarily mothers) in published studies stated that they found it helpful to receive parent-to-parent support, for example, seeing photos of other children who were born with CL/P before and after their operations, and to receive information about how to raise a child with cleft. Prior literature also suggests that health professionals should be patient and give parents who received the diagnosis at birth enough time to ask questions and express their feelings. They should not withhold any information; they should stay in control of the conversation when educating the parents on cleft and connect with their experiences in an authentic way (Knapke, Bender, Prows & Shultz, 2010; Robbins et al., 2010).

Parents reported worrying about feeding, upcoming surgeries, speech problems, physical appearance, bullying, learning disabilities, and mental retardation (Johansson & Ringsberg, 2003; Nusbaum et al., 2007). They struggled deciding whether or not their children should receive more surgeries to improve their physical appearances; at the same time, they worried about possible distress additional surgeries would cause for their children. The parents also worried about the anesthesia, possible infections, and surgical outcomes (Nelson, Kirk, Caress & Glenny, 2012).

Parents' sensitivity to their child's CL/P condition improved as the level of income and education increased. Marital distress was less if the father was sensitive to the child's condition. Still, some misunderstandings were reported to occur in couples as they raised the child that caused them to withdraw from each other. Couples did not experience significant marital distress when raising their children with cleft (Pelchat, Lefebvre, Proulx & Reidy, 2004).

Parents struggled with issues of social support, which negatively impacted their level of stress and emotional well-being. Parents in both diagnosis groups reported feelings of discomfort, anxiety, and rejection in response to the reactions of outsiders that led them to withdraw socially. Active problem solving and having people to support them led to better adjustment for parents (Baker, Owens, Stern & Willmot, 2009; Nelson, Kirk, Caress & Glenny, 2012).

I kept these important findings from the literature in mind when conducting my interviews. It was important for me to refrain from making assumptions from the existing literature and to keep an open mind to participants' experiences. So I wrote memos after each interview to explain my impressions of participants' experiences. I continued to write memos during the coding phase, to document the rationale behind creating the codes, and to bracket my assumptions. I also wrote a case summary for each couple (n=17) to check if the same themes reported in my results frequently emerged in the individual case summaries. This process also helped me to triangulate the findings of the individual partner interviews with the couple interviews and to provide a rationale and time sequence for how the dominant themes emerged.

CHAPTER 5: RESULTS

The Moustakas (1994) 4-step data analysis plan described in Chapter 4 directly informed this chapter's structure for summarizing the qualitative findings. After reviewing the interviews with the individual mothers, individual fathers, and couples for each diagnosis group, I organized the qualitative results into the following sections: (1) interview summaries; (2) prenatal diagnosis group, interviews with mothers; (3) prenatal diagnosis group, interviews with fathers; (4) prenatal diagnosis group, interviews with couples; (5) prenatal diagnosis group, comparison of interviews with mothers and fathers; (6) postnatal diagnosis group, interviews with mothers; (7) postnatal diagnosis group, interviews with fathers; (8) postnatal diagnosis group, interviews with couples; and (9) postnatal diagnosis group, comparison of interviews with mothers and fathers. Table 5.1 summarizes how the data analysis plan corresponds to the sections in this chapter. During each step of the data analysis, a specific type of interview (e.g., father, mother, or couple) was targeted and became the primary unit of analysis. Each step of the analysis contributed to a specific section in this chapter.

Table 5-1. Qualitative Results Sections and Units of Data Analysis

Step	Data Analysis Groups	Primary Unit of Analysis	Chapter Section
1	Individual and couple interview for each case	Interviews with mother, father, couple for each case	5.3 Interview Summaries
2	Prenatal diagnosis group: individual interviews with mothers	Interviews with mothers in the prenatal diagnosis group	5.4 Prenatal diagnosis group, mothers: dominant and subdominant themes
3	Prenatal diagnosis group: individual interviews with fathers	Interviews with fathers in the prenatal diagnosis group	5.5 Prenatal diagnosis group, fathers: dominant and

			subdominant themes
4	Prenatal diagnosis group: interviews with couples	Interviews with couples in the prenatal diagnosis group	5.6 Prenatal diagnosis group, couples: dominant and subdominant themes
5	Postnatal diagnosis group: individual interviews with mothers	Interviews with mothers in the postnatal diagnosis group	5.8 Postnatal diagnosis group, mothers: dominant and subdominant themes
6	Postnatal diagnosis group: individual interviews with fathers	Interviews with fathers in the postnatal diagnosis group	5.9 Postnatal diagnosis group, fathers: dominant and subdominant themes
7	Postnatal diagnosis group: interviews with couples	Interviews with couples in the postnatal diagnosis group	5.10 Postnatal diagnosis group, couples: dominant and subdominant themes
8	Analysis within the couples: Comparing mothers and fathers in the prenatal group	All interviews in the prenatal diagnosis group	5.7 Prenatal diagnosis group, mothers vs. fathers: Comparison of findings
9	Analysis within the couples: Comparing mothers and fathers in the postnatal group	All interviews in the postnatal diagnosis group	5.11 Postnatal diagnosis group, mothers vs. fathers: Comparison of findings

5.1 RDAS Statistical Results

Of the 17 couples (10 in the prenatal diagnosis group, 7 in the postnatal diagnosis group) interviewed for this study, 15 couples returned their RDAS scales and demographic surveys (10 from the prenatal diagnosis group, 5 from the postnatal diagnosis group). One mother from the postnatal diagnosis group mailed back her RDAS scale. Therefore, the couple analyses for the RDAS were conducted on 15 of the 17 couples. Comparing the results of the mothers across groups, the sample included 16 mothers (10 in the prenatal diagnosis group, 6 in the postnatal diagnosis group). Additionally, the sample of fathers included 10 fathers who received the diagnosis

prenatally and 5 who received the diagnosis postnatally. Table 5.2 summarizes the RDAS results for the prenatal diagnosis group and Table 5.3 summarizes the findings for the postnatal diagnosis group.

Table 5.2. RDAS Scores of Couples in the Prenatal Diagnosis Group	Total RDAS	RDAS Diff	Couple Avg RDAS	Consensus	Satisfaction	Cohesion	Distress Level
PreCouple 1 Mother	49	-10	54	23	15	11	Nondistressed
PreCouple 1 Father	59			27	18	14	
PreCouple 2 Mother	48	-3	49.5	27	16	5	Nondistressed
PreCouple 2 Father	51			23	16	12	
PreCouple 3 Mother	57	4	55	26	16	15	Nondistressed
Pre Couple 3 Father	53			24	15	14	
PreCouple 4 Mother	49	2	48	24	15	10	Distressed
PreCouple 4 Father	47			24	15	8	
PreCouple 5 Mother	53	-1	53.5	24	17	12	Nondistressed
PreCouple 5 Father	54			24	16	14	
PreCouple 6 Mother	59	3	57.5	27	18	14	Nondistressed
PreCouple 6 Father	56			25	18	13	
PreCouple 7 Mother	55	15	47.5	25	14	16	Distressed
PreCouple 7 Father	40			22	12	6	
PreCouple 8 Mother	59	-3	60.5	24	18	17	Nondistressed
PreCouple 8 Father	62			26	18	18	
PreCouple 9 Mother	55	-2	56	27	16	12	Non- distressed
PreCouple 9 Father	57			24	18	15	

PreCouple 10 Mother	52	-1	52,5	24	16	12	Non- distressed
PreCouple 10 Father	53			26	15	12	
Mean	53.4	4,4	53.4	24.8	16.1	12.5	
Standard deviation	5.14	4.53	4.18	1.51	1.62	3.35	

Pre = Prenatal diagnosis group

Table 5.3. RDAS Scores of Couples in the Postnatal Diagnosis Group

Couple	Total RDAS	RDAS Diff	Couple Avg RDAS	Consensus	Satisfaction	Cohesion	Distress Level
PostCouple 1 Mother	57	1	56.5	24	16	14	Non- distressed
PostCouple 1 Father	56			28	16	12	
PostCouple 2 Mother	45	3	43.5	22	10	13	Distressed
PostCouple 2 Father	42			19	10	12	
PostCouple 3 Mother	42	-7	45.5	21	12	9	Distressed
PostCouple 3 Father	49			23	15	11	
PostCouple 4 Mother	39	9	34.5	14	14	11	Distressed
PostCouple 4 Father	30			12	11	7	
PostCouple 5 Mother	26	-16	34	16	8	2	Distressed
PostCouple 5 Father	42			23	14	5	
Mean	42.8	7.2	42.8	20.6	12.8	9.4	
Standard deviation	9.90	5.85	9.24	4.87	3.12	3.66	

Post = Postnatal diagnosis group

5.1.1 Couple Distress Level and RDAS Score Differences Across Diagnosis Groups

Busby et al. (1995) noted that the distress cutoff scores for RDAS total score and the three subscales are as follows: total = 48; consensus=22; satisfaction=14; and cohesion=11. As illustrated in Table 5.3, the average individual RDAS score and the average couple RDAS score (\bar{x} =53.4) for the prenatal diagnosis group were both above

the total cutoff score. On average, each parent and couple who participated in this study from the prenatal diagnosis group could be categorized in the nondistressed clinical range. According to Table 5.3, the mean consensus (\bar{x} =24.8), satisfaction (\bar{x} =16.1) and cohesion (\bar{x} =12.5) scores for the prenatal diagnosis groups were also well above the distress cutoff scores. In the prenatal diagnosis group, two couples, Couple 4 and Couple 7, scored at or below the distress cutoff score, 48.

In the postnatal diagnosis group, four of the five couples fell within the clinically distressed range. Table 5.3 shows the RDAS score summaries of the participants in the postnatal group. The average individual RDAS score and the average couple score (\bar{x} =42.8) were both below the cutoff score of 48, which indicates that, on average, couples in the postnatal diagnosis group were clinically distressed in their relationship. The mean consensus (\bar{x} =20.6), satisfaction (\bar{x} =12.8) and cohesion (\bar{x} =9.4) scores (Table 5.3) were also below the RDAS subscale cutoff scores stated by Busby et al. (1995).

The mean RDAS score of the mothers in the prenatal diagnosis group (\bar{x} =53.6) was above the cutoff score; the mean RDAS score of the mothers in the postnatal diagnosis group was below it (\bar{x} =42) (Table 5.4). The mean scores for the consensus, satisfaction, and cohesion subscales were also above the RDAS cutoff scores for the prenatal group (\bar{x} = 25.1; \bar{x} =16.1; \bar{x} =12.4, respectively) and below them for the postnatal diagnosis group (\bar{x} = 20.5, \bar{x} =12.8, \bar{x} = 8.7, respectively).

Table 5.4. Means of RDAS Scores of Mothers in Both Diagnosis Groups

RDAS Scale	Participant Type	Mean
Total	PreMothers	53.6

	PostMothers	42.0
Consensus	PreMothers	25.1
	PostMothers	20.5
Satisfaction	PreMothers	16.1
	PostMothers	12.8
Cohesion	PreMothers	12.4
	PostMothers	8.7

PreMothers = mothers in the prenatal diagnosis group;
PostMothers = mothers in the postnatal diagnosis group

Similarly, the fathers' scores also suggested significant differences between the two groups (Table 5.5). The mean RDAS scores of the fathers in the prenatal diagnosis group were in the clinically nondistressed range for both the total score and the three subscales whereas the fathers in the postnatal diagnosis group were in the clinically distressed range.

Table 5.5 Means of RDAS Scores of Fathers in Both Diagnosis Groups

RDAS Scale	Participant Type	Mean
Total RDAS	PreFathers	53.2
	PostFathers	43.8
Consensus	PreFathers	24.5
	PostFathers	21.0
Satisfaction	PreFathers	16.1
	PostFathers	13.2
Cohesion	PreFathers	12.7
	PostFathers	9.6

PreFathers = fathers in the prenatal diagnosis group;
PostFathers = fathers in the postnatal diagnosis group

Independent sample *t* tests were then conducted to examine if there were any statistically significant differences between the RDAS scores of the mothers, fathers, and couples in the prenatal diagnosis group compared to those in the postnatal diagnosis group. There were 10 mothers, 10 fathers, and 10 couples in the prenatal diagnosis group and 6 mothers, 5 fathers, and 5 couples in the postnatal diagnosis group. Statistical significance was set at the standard $p \leq .05$. There was a statistically significant difference between RDAS total scores of couples based on the time of diagnosis [$t(13) = 3.125, p = 0.008$]. The couples in the prenatal group had higher scores on all subscales as well as on the total score [$t(9.703) = 2.404, p = 0.038$], [$t(11.488) = 3.140, p = 0.009$], [$t(28) = 2.320, p = 0.028$].

When independent sample *t* tests were conducted to assess for differences between the mothers in the prenatal diagnosis group and mothers in the postnatal diagnosis group, mothers in the prenatal group had higher scores than the mothers in the postnatal group; the difference between the scores was statistically significant for the total RDAS score [$t(14) = 3.296, p = 0.005$], but not for cohesion [$t(14) = 1.974, p = 0.068$], consensus [$t(5.570) = 2.206, p = 0.073$], and satisfaction subscales [$t(5.78) = 2.142, p = 0.078$].

The fathers in the prenatal diagnosis group had higher total RDAS scores [$t(13) = 2.299, p = 0.039$] and satisfaction subscale scores [$t(13) = 2.430, p = 0.030$] than the fathers in the postnatal diagnosis group; the differences were statistically significant. Even though the fathers in the prenatal diagnosis group had higher scores, no statistically significant differences were found between consensus and cohesion subscales across

fathers' scores in the two diagnosis groups [$t(4.26) = 1.293, p = 0.262$; $t(13) = 1.638, p = 0.125$].

The average difference in the total RDAS scores between members of the same couple in the prenatal diagnosis group was 4.4. Couple 7 had largest couple difference score, with a difference of 15; Couples 5 and 10 had the smallest difference score, with a difference of 1. In the postnatal diagnosis group, the average difference between the couples' total scores was 7.2. The largest difference of 16 was reported by Couple 5 and the smallest difference of 1 was reported by Couple 1. The RDAS validation study of Busby et al. (1995) did not provide any mean scores or RDAS score differences between members of the couple. Even though the mean difference score of the prenatal diagnosis group was lower, suggesting that couples in this group agreed more with each other on the quality of their relationship, the score differences across two diagnosis groups were not statistically significant [$t(13) = -1.028, p=0.332$].

5.1.2 Within-Couple RDAS Score Differences

5.1.2.1 Comparison of Mothers and Fathers in the Prenatal Diagnosis Group

Small differences were observed between the RDAS scores of mothers and fathers in the prenatal diagnosis group: Mothers' scores were slightly higher than fathers' scores (Table 5.6). The total scores and the subscale scores were all above the clinical distress cutoff levels. There were no statistically significant differences between the total scores [$t(18) = 0.169, p=0.867$], consensus subscale scores [$t(18) = 0.885, p=0.388$], satisfaction subscale scores [$t(18) = 0.000, p=1$], and cohesion subscale scores [$t(18) = -0.194, p=0.848$] of mothers and fathers from the prenatal diagnosis group.

Table 5.6. Summary of Mean RDAS Scores of Mothers and Fathers in the Prenatal Diagnosis Group

	Total	Consensus	Satisfaction	Cohesion
PreMothers	53.6	25.1	16.1	12.4
PreFathers	53.2	24.5	16.1	12.7

PreMothers = mothers in the prenatal diagnosis group; PreFathers = fathers in the prenatal diagnosis group

5.1.2.2 Comparison of Mothers and Fathers in the Postnatal Diagnosis Group

Postnatal fathers' scores were slightly higher than mothers' scores for all categories (Table 5.7). All total and subscale scores were below the clinical distress cutoff levels. There were no statistically significant differences between the RDAS [$t(9) = -0.302, p = 0.770$], consensus subscale [$t(9) = -0.152, p = 0.883$], satisfaction subscale [$t(9) = -0.190, p = 0.854$], and cohesion subscale [$t(9) = -0.408, p = 0.693$] scores of mothers and fathers in the postnatal diagnosis group.

Table 5.7 Summary of Means of RDAS Scores of Mothers and Fathers in the Postnatal Diagnosis Group

	Total	Consensus	Satisfaction	Cohesion
PostMothers	42.0	20.5	12.8	8.7
PostFathers	43.8	21.0	13.2	9.6

PostMothers = mothers in the postnatal diagnosis group; PostFathers = fathers in the postnatal diagnosis group

5.1.3 RDAS Statistical Results Summary

The statistical analysis of the parents' RDAS scores revealed some interesting trends. First, it suggested that individual and couple scores of participants in the prenatal diagnosis group were higher than those of participants in the postnatal diagnosis group. In fact, the results suggest that, on average, the scores of both individuals and couples in the

prenatal diagnosis group were above the clinical distress cutoff range, indicating nondistress whereas average scores of individuals and couples in the postnatal diagnosis group were within the clinically distressed range. The differences between the total score and all three subscale scores across the two diagnosis groups were statistically significant. This result provides important information about the couples' relationships in the context of the phenomenological analysis.

The differences between RDAS total scores of the mothers in the prenatal diagnosis group and those in the postnatal diagnosis group were statistically significant, with prenatal mothers significantly less distressed than postnatal mothers. Similarly, the differences between the total RDAS and satisfaction subscale scores of the fathers in the two diagnosis groups were also statistically significant, with postnatal fathers significantly more distressed than prenatal fathers. These findings suggest that parents in the prenatal group have more positive views of their relationship than parents in the postnatal group.

When the mean RDAS scores of mothers and fathers within the couple dyad were compared, no statistically significant differences were found for either group. In fact, the individual scores of parents in the couple dyad were similar. This finding implies that, on average, each partner in the couple dyad has similar views of their relationship. Nevertheless, each couple's similarities and differences on the RDAS scores are examined and explained in the following section.

5.2 Within-Couple Analysis: Couples' Case Studies

The couples' case studies served three purposes: (1) to fully understand the specific experiences of the 17 couples who participated in this study; (2) to triangulate the

data from the individual interviews of the parents with that from the couple interviews to determine if there were aspects of their experiences that they did not want to share when they were interviewed together; (3) to demonstrate how I reached saturation by describing the frequently occurring dominant themes as well as the new themes in the “Personal Reactions” section after each case study. When writing up the case studies, I highlighted frequent themes that emerged for each couple. I focused on what each partner reported when explaining the timing of the CL/P diagnosis, their initial feelings and concerns, sources of stress, their child’s current functioning, impact of cleft on their relationship, decision-making process about parenting and treatment, roles and responsibilities, their views of cleft, and lessons learned from the experience. I also shared my researcher reflections to illustrate the bracketing process that I used during the interviews and data analysis and to explain how the couples affected me as a researcher.

Table 5.8 provides an overview of the 17 couples. Each participant was given a pseudonym and a participant code to protect her/his confidentiality. The table is organized by the order of the ID number assigned to the couple in the original research study conducted at CHOP. Table 5.8 also describes the length of the interview and the child’s age and diagnosis in order to provide some context for the interview and for the couple’s experience.

The couple case studies are organized under (1) demographics, (2) couple’s story, (3) RDAS summary, and (4) researcher reflections.

Table 5.8. Couples’ Pseudonyms, Diagnosis Group, Length of the Interview, Child’s Age, and Diagnosis

Participant Code	Participant Pseudonym	Time of the	Length of the	Child’s Gender	Child’s Age at	Child’s Diagnosis
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		Diagnosis	Interview, minutes		Interview	
1M	Jane	Prenatal	M: 45	Male	2	Cleft lip
1F	Mitch	Prenatal	F: 38 C: 39 Total: 122			
2M	Vader	Prenatal	M: 34	Male	4	Cleft lip
2F	Darth	Prenatal	F: 23 C: 22 Total: 79			palate
3M	Rachel	Prenatal	M: 19	Male	1	Cleft lip
3F	Francis	Prenatal	F: 22 C: 24 Total: 65			palate
4M	Zoe	Prenatal	M: 36	Male	3	Cleft lip
4F	Bob	Prenatal	F: 19 C: 27 Total: 82			palate
5M	Mary	Prenatal	M: 42	Male	3	Cleft lip
5F	Frank	Prenatal	F: 36 C: 34 Total: 112			palate
6M	Laurie	Prenatal	M: 35	Male	3	Cleft lip
6F	Bill	Prenatal	F: 19 C: 29 Total: 73			palate
7M	Rebecca	Prenatal	M: 30	Male	2	Cleft lip
7F	Ben	Prenatal	F: 34 C: 38 Total: 102			
8M	Mo	Prenatal	M: 34	Female	2	Cleft lip
8F	Chip	Prenatal	F: 27 C: 61 Total: 122			palate
9M	Abby	Prenatal	M: 33	Female	2	Cleft lip
9F	Murray	Prenatal	F: 31 C: 28 Total: 92			palate
10M	Elizabeth	Prenatal	M: 30	Female	2	Cleft lip
10F	Joe	Prenatal	F: 22 C: 40 Total: 92			palate
11M	Pam	Postnatal	M: 32	Male	4.5	Cleft lip
11F	Paul	Postnatal	F: 15 C: 22 Total: 69			

12M	Ann	Postnatal	M: 18	Female	3	Cleft palate
12F	Eric	Postnatal	F: 12			
			C: 18			
			Total: 48			
13M	Diane	Postnatal	M: 61	Female	2	Cleft palate
13F	Jack	Postnatal	F: 39			
			C: 50			
			Total: 150			
14M	Jill	Postnatal	M: 14	Female	2	Cleft lip
14F	Larry	Postnatal	F: 29			palate
			C: 26			
			Total: 69			
15M	Minnie	Postnatal	M: 39	Female	2	Cleft palate
15F	Junior	Postnatal	F: 47			
			C: 59			
			Total: 145			
16M	Sarah	Postnatal	M: 35	Male	3	Cleft lip
16F	Brandon	Postnatal	F: 17			
			C: 36			
			Total: 88			
17M	Gayle	Postnatal	M: 63	Female	2	Cleft palate
17F	Joey	Postnatal	F: 12			
			C: 20			
			Total: 93			

5.2.1 Length of the Interviews

The in-depth phenomenological interviews were conducted individually with each parent separately and then with the couple. Because most couples had at least one partner working full time and half of the couples had more than one child at home, it was difficult to schedule the interviews, especially with fathers and the couples. I had difficulty going more in depth with some parents because they reported either being occupied or tired. Some parents became defensive if I wanted to explore certain aspects of their experience more deeply. The interviews also got shorter as I reached saturation, which was after the eighth interview in the prenatal group and after the sixth interview in the postnatal group. The interviews of the prenatal group lasted an average of 95.1

minutes (range, 65-122 minutes) (Table 5.8). On average, the mothers' interviews lasted 30.4 minutes (range, 19-45 minutes) whereas the fathers' interviews averaged 27.1 minutes (range, 19- 38 minutes). The shortest couple interview in the prenatal group was 22 minutes and the longest was 61. The average time spent on the interviews of the prenatal diagnosis couples was 34.2 minutes. I spent an average of 95.57 minutes interviewing the parents in the postnatal diagnosis group. The shortest interview was 48 minutes and the longest was 145 minutes. The mothers' interviews lasted an average of 37.43 minutes (range, 14-64 minutes) whereas the mean length for the fathers' interviews was 24.43 minutes (range, 12-47 minutes). The shortest time spent on the couples' interview was 18 minutes and the longest time was 59 minutes. On average, I spent 33 minutes interviewing the couples in the postnatal group.

Many factors may have played a role in the fathers' interviews being shorter than the mothers' interviews. First, more fathers in both groups were working full time. I had to conduct the interviews either in the evenings or on the weekends to accommodate their schedules. When I conducted the interviews during the evening, some fathers reported being tired. When I conducted the interviews on weekends, I was taking time away from their leisure activities. Also, social and neurological research indicates that women tend to remember more and be more verbal than men (Brizendine, 2006). Fathers often reported that they did not remember the details of the events, so their descriptions of both their past and current experiences were not as rich as those of the women participating in this study. Furthermore, fathers reported having the soothing role in their relationships, trying to stay strong for their wives. For this reason, it might have been difficult for them

to express their experiences in detail during the interviews when I tried to understand their feelings and concerns.

5.2.2 Child's Gender, Age, and Diagnosis

In the prenatal diagnosis group, 8 of 10 couples had children who were born with CL/P. Two of the children were born with cleft lip. Seven of the children were boys and three were girls. The children's ages ranged between 1 and 4 years. In the postnatal diagnosis group, four of the seven couples had a child with cleft palate; two had children with cleft lip; and one couple had a child with cleft lip palate. Five of the children were girls and two were boys. The youngest child in the postnatal group was 2 years and the oldest was 4.5.

5.3 Interview Summaries

5.3.1 Interview # 1: Diane and Jack

Demographics: Diane and Jack were together for 18.5 years, lived together for 10, and had been married for 5.5. Diane was a 41-year-old special education teacher and Jack was a 43-year-old project manager. They both went to graduate school. They were both White. Their daughter was born with cleft palate diagnosed postnatally. Jack was the only father in the postnatal diagnosis group who had psychological counseling in the last year. I interviewed this couple in person at their home.

Couple's Story: The couple received the diagnosis of their daughter 2 days after her birth when Diane had trouble breastfeeding. Their daughter was born 4 weeks prematurely, so initially the hospital staff thought Diane was having difficulty because her milk supply was not in yet. When her difficulties continued, the night nurse became suspicious and requested a pediatric consultation. As a result of pediatric consultation,

their daughter was diagnosed with cleft in her soft palate. Diane reported that initially she was not worried because it was very difficult for them to get pregnant and they had expected to face significant health issues in their child.

Diane and Jack had been through fertility treatments for 2 years and were on the verge of starting the in vitro fertilization treatment when Diane became pregnant naturally. Throughout the pregnancy, she had been extremely worried about miscarrying or the child being born with Down syndrome. Therefore, the cleft did not seem like a significant issue for her. For Diane, the most difficult part about having a child born with cleft palate was not being able to breastfeed her. She said that she felt “guilty” and “robbed” because she was so set on breastfeeding before the birth. For this reason, she decided to pump and feed their daughter breast milk. Because her supply was not in yet, they needed to supplement the breast milk with formula for the first 3 weeks. Jack fed their daughter with formula because Diane had a difficult time adjusting to the idea that they needed to give their daughter formula. The couple committed to a feeding schedule whereby Diane pumped and fed the baby during the night and Jack fed her during the day. Jack worked from home at this time.

Jack stated that his main issue with the cleft was wrestling with the possibility of the fertility treatments causing the cleft, even though he knew that fertility treatments were probably the reason that they were able to conceive. Diane also questioned the cause of the cleft and thought that it was probably related to her taking progesterone to prevent her from miscarrying. She stated that she did not regret taking it. Jack was also worried about their daughter being low on the growth charts, possible social stigma, and speech delays that the child could experience because of the cleft. The couple stated their

reluctance to have another child because of their worry about the cleft being caused by the fertility treatments. The possibility of the next child having cleft was an issue that they thought about when they talked about having a second baby together.

The couple's worst experience related to the cleft was when their child experienced complications after surgery. She had difficulty breathing on her own after the surgery and had to be reintubated. She stayed in the pediatric intensive care unit for some time. The couple stated that they were so scared of losing their daughter that, at that time, any worries about their child having cleft seemed insignificant. Overall, the couple seemed very happy with the care and support they received from the treatment team. However, they stated that no one explained to them about the complications that could happen after the surgery.

The couple stated that going through the experience of raising a child with cleft made their relationship stronger. They learned how to act as a team when it came to parenting. They also learned that they could count and depend on each other.

The couple viewed cleft as a fixable issue that would be a small part of their daughter's life. Considering the other health issues that could have happened, they felt grateful that their child had cleft. However, they also reported worrying about her development. They described doing research about multiple developmental issues that could possibly co-occur with cleft palate such as constitutional growth delay and cystic fibrosis, especially because their daughter was relatively small in height and weight. They listened to their doctors, did research, and talked about the next approach to treatment. They talked about hypothetical situations that could happen and how they would handle them. In terms of parenting, Diane and Jack said that they were on the same page when it

came to the fundamental issues and would debate about the details. For example, they both wanted their daughter to learn another language, but they were not sure if it should be German or French. They had separate roles and responsibilities when it came to parenting and were content with them; however, Diane stated that she would like Jack to be more helpful with the house chores.

The couple noted that it was important to do research and learn about cleft, have access to a good treatment team, and know people who would support them. They said that the cleft was “not there anymore, but it’s always there,” indicating that even though it was still in the back of their minds, it did not hold a significant place in their lives, especially since the tough days were over and their daughter was “emerging into normalcy.”

RDAS Summary: Diane and Jack scored as a distressed couple according to the average of their total RDAS scores (45.5). Diane had a RDAS score of 42, which was below the postnatal sample mean (42.8) for the postnatal diagnosis group, below the mean score for mothers in the postnatal diagnosis group, and below the cutoff score (48). Jack’s total RDAS score (49) was above the sample mean and distress cutoff. The difference in the couple’s RDAS scores (7) was close to the sample mean (7.2). Diane’s consensus subscale was slightly above the sample mean (20.6), but below the cutoff score (22). Her cohesion (9) and satisfaction (12) subscale scores were below the sample mean (9.4; 12.8). Jack’s consensus (23), satisfaction (15), and cohesion (11) subscale scores were all above the cutoff scores, the sample mean for the postnatal diagnosis group, and the sample mean for the fathers in the postnatal diagnosis group. Diane’s relatively higher

consensus score suggested that she felt better about their level of agreement on important matters, which she also reported during the interview.

The differences in the total RDAS, cohesion subscale, and consensus subscale scores are noteworthy because the couple expressed a high level of congruence during the interview. They reported that going through the fertility treatments before they had their daughter was hard on their relationship. Additionally, Diane said that Jack commuted 6 to 7 hours a day for work, so it was difficult for him to help her with the household chores. For this reason, the couple was in the process of relocating.

Personal Reactions: This interview was the first one I conducted. The couple was identified as part of the prenatal diagnosis group in CHOP's database. When I found out at the beginning of the interview that they had received the diagnosis after birth, I was relieved because I had fewer participants in the postnatal diagnosis group to begin with and was worried about getting a sufficient number of couples in the postnatal group.

This first couple had a lovely home in South Philadelphia and was very welcoming, which made me feel at ease. They were very verbal and explained their experiences in depth. After the interview, I revised my interview guide by adding the question; "Is cleft a concern for your next child?"

I was surprised that the father was so focused on exploring the reasons for the cleft and blaming himself because the research suggested that mothers more often blamed themselves. I secretly wondered if a part of him was blaming his wife for the cleft, even though this seemed to not be true.

Jack and Diane talked about their daughter's growth and how they were concerned about her height. Even though height is a significant concern for any parent

whose child struggles with growth, they stated that they were particularly concerned because of the cleft. I felt they were constantly waiting for another disaster to occur. This reaction made me think about my mother's generalized anxiety disorder and how she constantly worried that I was not eating enough.

Diane wanted to breastfeed her child so badly that she described the formula as "evil." Because she could not feed her child with the formula, Jack had to do it. When she realized that their daughter "was not turning green," she was able to do it herself too. This statement is exaggerated, which signifies how strongly Diane felt about the negative impact of formula on her child's well-being. She almost felt that formula would poison her baby and make her "turn green." I could not understand why she was so reactive to formula, but I could not explore this reaction in more depth because I was worried about sounding judgmental. At the back of my mind, I thought that I was always fed with formula and I turned out fine. Diane said that she wanted that bonding experience breastfeeding her baby. This statement made me think about my relationship with my mother. She had told me that the nurses had to tie her breasts so that her breast milk would disappear, which was a painful experience for her. I wondered if she resented me for that.

Jack and Diane also spoke about worrying that the CLP could be severe and that they could be in the middle of nowhere, which made me sad to realize the struggles that I had to endure. They seemed very privileged.

5.3.2 Interview # 2: Frank and Mary

Demographics: Mary and Frank had been together for 13 years and had been married for 10 years. They had lived together for 2 years before getting married. Mary

was 41 years old and worked full time in human resources. Frank was 46 and worked in sales. The couple had two sons; their second one was born with CLP. Their son with cleft was 3 years old. The couple received a prenatal diagnosis. Mary and Frank preferred to be interviewed over the telephone.

The Couple's Story: Frank and Mary had three miscarriages before Mary became pregnant with their second child. She was monitored closely, because her pregnancy was considered high risk. During a routine ultrasound, the doctor told her that the fetus had CLP and trisomy 18 (Edwards syndrome). Trisomy 18 is more prevalent among children of older mothers. It is a chromosomal disorder that develops in utero. A large percentage of babies born with trisomy 18 are stillborn or die within the first year of life. Trisomy 18 can lead to congenital malformations that cause developmental and motor disabilities that independent living in older children and adults. It can also co-occur with conditions such as spina bifida, cleft, and congenital heart defect (Carey, 2012).

Mary was alone at the time she received the diagnosis. She told Frank over the telephone, and they visited the same doctor for the second time on the same day so that Frank could hear the doctor's explanation. During the interview, Frank did not mention his absence when his wife first received the news, although Mary remembered this detail clearly.

During their individual interviews, the couple both talked about the doctor's demeanor; how he delivered the news without emotion and hinted that they could abort the baby before he conducted any further testing. Mary and Frank were both Catholics; abortion was not an option for them. Even though they had an amniocentesis done at the clinic where they received the diagnosis, they decided to transfer to CHOP for additional

testing because they did not like the doctor's demeanor and approach. They praised the level of care and consultation they received at CHOP. After further testing, the possibility of additional syndromes was ruled out, and their baby was diagnosed with isolated cleft lip and palate. Both Frank and Mary reported relief and happiness when they heard about the isolated cleft diagnosis.

Frank's initial concerns were about the possibility of repair, outcome of the surgery, feeding, and speech. He praised CHOP's supportive program whereby parents are put in contact with other parents who have been through the same experiences. He described this as helpful because other parents talked about their concerns and provided helpful information about raising a child born with CLP. For example, Mary discussed learning invaluable information about insurance coverage, which helped them financially. Mary also joined an online support group for parents who have a child born with cleft to obtain information and support.

When talking about the initial stages, both Frank and Mary described the nasal alveolar molding (NAM) device as a blessing and a curse. They said it was a blessing because it decreases the width of the cleft through the application of constant pressure to the area, thus reducing the number of surgeries their child had to endure. It also created an artificial palate, which made feeding their child much easier. Yet they also described the NAM as a source of stress because it was very difficult to constantly do the tapings correctly. They also had to attend frequent doctor appointments at CHOP so they could adjust the NAM device. They eventually had to put their son through his first surgery earlier than anticipated because their dog ate the NAM when they had taken it out and put it on the kitchen counter.

Frank said that he currently had no concerns about CLP; he described it as being on the back burner in their lives. The only concern that he could identify was the upcoming treatments that their child would receive. However, toward the end of the interview, he also mentioned his son's satisfaction with his own appearance and worried about bullying that he might experience. Mary identified their son's speech as a current concern because of his difficulty pronouncing certain words. He had received speech therapy and improved, but she wanted him to be evaluated again.

Both Frank and Mary were glad that they received a prenatal diagnosis because it gave them more time to (1) figure out the treatment; (2) learn about how to feed their child; (3) obtain the Haberman bottles for feeding; (4) inform family members, including their older son; and (5) prepare emotionally. Mary described being prepared in terms of learning about what awaited them but not being prepared for actually "doing it."

Frank described being very happy for the first month of his son's life. This period was different for Mary: She discussed the first month of her son's life as being stressful because she was trying to figure out how to feed him and how to secure the NAM device. Mary said that Frank had to go back to work right after the birth so she was the one waking up for the feedings and worried about "doing them right." She talked about getting a lot of help from her mother at this time, especially when Mary had to go back to work. Their social life was impacted because they did not feel comfortable leaving their son with anybody because of the feedings and the NAM device, especially when Mary's mother was not available. Later on, she did not feel comfortable with the NAM device because their son had learned how to pull it off. Mary did say that it became easier with time and that she realized her own strength through this experience.

The NAM device is an orthodontic appliance that babies with cleft lip and palate wear a couple of weeks after birth. It was designed to decrease the width of the cleft by applying pressure through tapings on both sides of the lip and palate (Figure 5.1).



Figure 5.1. NAM Device

Both Mary and Frank described the impact of their son's postoperative physical appearance when they described his first surgery. They felt that their child looked "older" because he was swollen. Frank described that it felt like their son went through the trauma of a surgery, "his innocence was kind of gone." Mary identified anesthesia as one of her concerns before the surgery. She also talked about missing the child's cleft after the surgery since that was the way she had met him and had gotten used to it. Frank and Mary both described feeling grateful that this was what they had to deal with since it was fixable. Mary, at times, even felt guilty for feeling bad.

Neither parent knew what may have caused their child's cleft but had ideas about possible causes. Frank spoke about his wife's age and processed foods as possible reasons. He was ambivalent about the theory of processed foods because cleft also occurred in "third world" countries. Mary, on the other hand, blamed herself and

wondered if her drinking when she thought that she could not get pregnant because of her previous miscarriages had caused the cleft. She stated that the fact that clefts did not have a definitive cause was helpful because it helped her to let go of any self-blame.

Learning about cleft was helpful for Mary, especially before her son's birth, because she felt more in control and empowered. Frank also talked about the importance of doing research, learning about cleft, and keeping his emotions "in check." He stated that it was difficult to talk without crying and worrying about the baby all the time. During this time, he needed to keep his emotions "in check" so he could soothe Mary. He had to remind himself that their son was not going to remember any of this.

Mary identified Frank as the person who was "reeling her back in" so she could feel better. Frank believed that this was also helpful for him because it served as a distraction from focusing on his own emotions and worries. The couple emphasized the importance of updating each other about their feelings and moods so that misunderstandings did not occur. They identified this process of checking in with each other as an opportunity to evaluate their relationship and shared that if they were able to get through this, then they could get through anything.

They emphasized the importance of learning about cleft and choosing a good treatment team because they closely followed the doctors' advice. Mary was the one primarily in charge of the clinical issues, such as hospital appointments. When it came to parenting, they reported having a united front; they have open discussions about any problems they experience and talk about how to solve them. Currently, they do not talk much about cleft, except before their son's upcoming treatments.

RDAS Summary: The couple's average RDAS score was 53.5, well above the clinical distress cutoff (48), which placed them in the nondistressed category. Mary's score was 53 and Frank's score was 54. Their RDAS score difference of 1 was the lowest in the prenatal diagnosis sample, suggesting they see their relationship similarly. The couple did not have any major differences in their subscale scores. Their consensus subscale scores were identical, indicating that the couple agreed on how frequently they agree on the important issues. Their consensus score of 24 was slightly below the mean consensus score for the prenatal diagnosis group (24.8). Mary's consensus score was also slightly below the sample mean for mothers in the prenatal diagnosis group (25.1), whereas Jack's consensus score (24) was slightly below the average score for fathers in the prenatal diagnosis group (24.8). Their satisfaction subscale scores (M: 17; F: 16) were similar. Mary's score was above the average compared to the prenatal diagnosis sample mean (16.1) and prenatal group mothers' mean (16.1). Frank scored at the mean for each group. Frank's cohesion subscale score (14) was two points higher than Mary's score (12). Frank's score was above the mean for the prenatal diagnosis sample (12.4) and the prenatal fathers group (12.7). However, Mary's consensus scores were slightly below the mean. The couple seemed to have slightly different perceptions on their sense of closeness and participation in shared activities.

Personal Reactions: This interview was the second one that I conducted and my first for the prenatal diagnosis group. It was also the first interview that I conducted over the phone. I started the interview by interviewing the father. It felt very different from the previous interview because Jack, the previous father, was very talkative and openly shared information. It was somewhat frustrating to interview Frank because I felt that he

was more reserved and gave quick, one-word answers as if he wanted the interview to be over quickly. I questioned if this was because I was interviewing him over the phone.

As I came to know the couple better, I understood that Frank was a person who takes pride in being strong and rational. He talked a lot about “keeping his emotions in check” during the interview when discussing the way he coped with his son’s cleft diagnosis. On the basis of my knowledge of Emotionally Focused Couples Therapy (EFT), I questioned whether his insistence on “keeping his emotions in check” was genuine. I wondered if this was his true self or if he was acting this way because he is the “male” who needed to support his wife and felt it was his role to prevent her from becoming overwhelmed with her emotions. I confirmed this view as I continued to interview him and he talked about “not walking around crying and worrying about the baby 24/7” as a challenge during this time. I realized how sensitive and emotional he actually was. I felt sorry for him and for men in general because this was the role assigned to them. Part of me wanted to intervene, but I knew that I could not do that because this was a research interview, not therapy.

Another issue I was hesitant to explore further was Frank not being there the first time Mary received the news about the possibility of a genetic syndrome. He did not mention this; I learned about it during my individual interview with Mary. I wondered if he felt guilty because he was not with Mary and worried that I would judge him for leaving his wife alone at a doctor’s visit.

After this interview, I noticed how important the health professional’s demeanor and clinical style is when delivering tough news to couples. Previous literature on CLP describes the importance of the health professional’s warm and engaging style in the

context of delivering a postnatal diagnosis to couples, but this was the first time I noticed that it was possibly also important for a prenatal diagnosis. Another reoccurring experience I heard from many couples, like Mary and Frank, is receiving further testing and second opinions to rule out the possibility of additional syndromes. Parents' initial concerns seem to focus on worries about the diagnosis of additional syndromes.

I was surprised that the doctor hinted at abortion. When I was developing the interview guide, I had a question about abortion; however, Dr. Crerand informed me that it would be difficult for the CHOP institutional review board to approve this question because it is a sensitive, loaded topic. Therefore, I was surprised that the doctor presented that as an option without knowing the couple's background (Catholic). When Frank spoke highly of the possibility of connecting with other parents who have been through the same experience, I was glad that I had a question in my interview guide about meeting with other parents for support. I felt relieved that I was covering a topic that parents found important and helpful.

This interview was the first during which I heard about the NAM device. I asked Frank to explain it to me and initially felt bad because I did not know about it. I thought that it was best to ask rather than to act like I knew what the NAM was. I had never used the NAM and wondered if it could have reduced the number of surgeries I had to go through when I was younger.

This couple, the first of those who received the diagnosis prenatally that I interviewed, described being happy about receiving the diagnosis prenatally. It gave them time to prepare, figure out the course of treatment, learn about feeding, and get Haberman bottles. Furthermore, they were able to better prepare themselves emotionally, thereby

reducing feelings of shock and surprise they would have experienced if they first found out at their son's birth.

Frank mentioned that cleft was "on the back burner." Another couple, Diane and Jack, also mentioned that it was not a dominant topic. However, I could really see that Frank and Mary were moving forward without waiting for the next possible crisis to occur. The constant worry and anxiety were not there for this couple. I wondered if this was related to them receiving a prenatal diagnosis and having a longer period of time to prepare and to adjust.

Mary fed their son formula, which was not a big issue for her. She also stated that she had fed their previous child with formula. I felt relief thinking that there are other people out there who had experiences similar to mine, other children who were fed formula. She talked about getting help from her mother with the feeding, which is the same thing that my mother did. I was surprised by the similarities between how my Turkish family took care of a child with cleft and how an American family dealt with it. I was also surprised because I would have expected the husband to take a more active role in doing the household chores and childrearing tasks because less constricted gender roles are encouraged in American culture. I was happy that there were similarities between my Turkish family and an American family; it eased my frustration with my father for not being there to help my mother and me.

The way that this couple described their child's surgery was emotional for me. Especially emotional was Frank's description of feeling that his son has gotten "older" and "wiser" and "his innocence was kind of gone" because of the trauma of the surgery he had gone through. Then, Frank said, "Maybe I got older" to describe the impact of the

surgery on him. I never thought about going through a surgery at a young age as a trauma that makes you grow up quickly or lose your innocence. His remarks also helped me understand the impact of “post-operational appearance” on the parents. It was surprising for me when the mother described “missing the child’s cleft,” because I expected that the mothers looked forward to the child’s changed appearance, the “new look.”

The possible cause of cleft is always a sensitive topic because I worry about seeming judgmental. When Frank mentioned Mary’s older age as a possible cause, I raised my eyebrows, but I did not feel that he was blaming his wife. Mary talked about blaming herself and feeling relieved that there was no definitive cause for her son’s CLP. I remembered Dr. Crerand talking about the lack of a definitive cause for cleft during my proposal defense and asking me to report that in my dissertation proposal. I now understood how valuable it is for parents to know that. I also noticed “self-blame” as a recurring theme when the issue of possible causes came up.

A common theme during this couple’s interview was feelings of gratitude and concern. They spoke about being concerned about their child’s well-being but also about being grateful that cleft is a fixable issue. Diana and Jack also mentioned this theme.

Their privilege was apparent throughout the interview: They were White and middle class; they had access to care at CHOP; they had health insurance coverage for their expenses; and they had a speech therapist come to the house. When they stated that they could easily recognize when an older person had cleft because medicine was not always as advanced, I became sad and wondered if they knew about me. I thought that if they knew, they would not have said that; doing an interview on the phone kept my own CLP hidden. I had a similar experience with Diane and Jack when they stated that their

experience would have been different if they were not living in the United States. I similarly wondered if they noticed my cleft or my accent.

5.3.3 Interview # 3: Vader and Darth

Demographics: Darth (husband) and Vader (wife) had been married and living together for 7 years. They had been in a relationship for 8 years. Vader was a 42-year-old teacher. Darth was a 38-year-old letter carrier with the US Postal Service. Darth was White and Vader was Asian. The couple had a 4-year-old son born with CLP. The couple received the diagnosis prenatally. Vader reported that they also have two “nonhuman” children, meaning their pets. The couple chose to be interviewed over the Internet.

The Couple’s Story: Darth and Vader learned about their child’s diagnosis when they were at an obstetric-gynecologic clinic that specializes in high-risk pregnancies. The doctor informed them about the cleft diagnoses and asked them if they wanted to terminate the pregnancy. He stated that he had never heard anybody who wanted to terminate because of a cleft but still presented the couple with the option. This decision was difficult for Vader because she did not have extensive knowledge about cleft and got scared when her doctor mentioned the possibility of abortion. After learning about clefts and the possibility of treatment, she was angry at the way in which the doctor had brought up the option of abortion. She stated that he made it seem like a serious problem when it was something that could be repaired through surgery.

When he describing hearing about the diagnosis, Darth spoke about how the ultrasound technician commented on the severity of their son’s cleft, saying, “It looks like a big one.” Darth was worried about the severity of the cleft, especially its impact on the child’s neurological functioning and development. Darth stated that, from the

ultrasound picture, it looked like half of his son's head was missing! He cautioned other parents to be skeptical of the ultrasound pictures because when their son was born, his cleft was actually very small.

Darth discussed how they were initially worried about severity of the cleft and about the possibility of additional issues that could impact their son's neurological functioning and development. He mentioned how they researched the different levels of severities online and how they contacted people, both in person and on line, who had been through it. This knowledge reduced their concerns somewhat, but they still waited for the child to be born and to have certain tests to make sure that the cleft was isolated. He stated that he remained was anxious about developmental issues until their son grew up and was developmentally on track. Vader did not mention any of these experiences during her individual interview. She described being "fine" throughout the pregnancy.

For Vader, the main issue after her son's birth was feeding. She fed her son formula on the pediatrician's advice because Vader was taking an anticonvulsive medication for her epileptic seizures. For this reason, she felt comfortable formula-feeding her son even though the lactation consultant in the hospital pressured her to breastfeed. She had difficulty feeding her son because he could not suck easily due to the cleft palate and quickly became tired. Vader described being concerned about "doing it right" and not knowing if it was her fault that her son did not eat much. "Doing it right" was a frequently occurring theme when it came to the feedings. Darth agreed that feeding issues while caring for a child with cleft were different from those involved with caring for any other child.

Vader felt relieved after their son's first surgery because his cleft was repaired. After the surgery, he had to wear stents that were stitched to his nose for a while. She talked about feeling bad for him because he knocked the stents out a couple of times, and Vader was worried that he was in pain. Darth was also worried about their son being in pain and discomfort after the surgery because he wore arm braces to prevent him from touching his face.

Vader's concern at the time of the interview was about their son's teeth and appearance. She described him as having a bad cross bite and a crooked nose. Darth's current concern was the pain that their son might have to endure during the upcoming surgeries.

The couple was content about receiving the diagnosis prenatally. Darth seemed to be happier with the timing of the CLP diagnosis than Vader. Darth considered being able to figure out what was going to happen, searching for information about cleft on line, participating in online groups to learn about people's experiences, seeing before and after surgery photos of other children, and preparing emotionally to be positive aspects of receiving the prenatal diagnosis. Vader mentioned being able to prepare other people as an asset. The couple informed other people, mostly their family, once they learned about their child's cleft diagnosis and encouraged them to do their own research to understand that it was "not a big deal."

, The couple identified Vader's seizure medication as a possible cause for cleft. She learned about the side effects of the medication after their son was born and was frustrated with the doctor because he had not informed her earlier nor had he adjusted her dosage. Darth also mentioned Vader's medication as well as genetic background as

possible causes because she was Asian. Cleft is a concern for their next child because Vader continues to take the medication.

Both parties identified cleft as a fixable cosmetic issue. They both reported feeling grateful that their son had a treatable health problem. During their couple interview, Darth and Vader advised other parents to look for signs of additional anomalies to make sure that their child was developmentally on track. They also highlighted the importance of having a good insurance plan to cover treatment in an equipped facility. They mentioned that some parents had to take out loans to pay for their child's treatment because the treatment procedures were so expensive.

At the time of the CLP diagnosis, the couple both researched cleft on their own. They spoke to other people who had been through the same experience. Darth stated that it was helpful meeting with other parents, but it was not necessary because he could find a lot of information on the Internet. Vader emphasized that talking with another parent was helpful if the severities of the children's clefts were similar. The previous interview couple had also pointed this out.

They spoke to the doctors about treatment and followed their advice. They took turns taking their son to doctor's appointments depending on the flexibility of their work schedules. They no longer talked frequently about cleft except to mention the upcoming appointments and treatments. They stated that the experience of raising a child with cleft did not have a negative impact on their relationship.

RDAS Summary: Darth and Vader's average RDAS score was 49.5, placing them just above the clinical cutoff (48) in the nondistressed category. Vader's score (48) was 3 points lower than Darth's score (51) and was at the distress cutoff. Their RDAS

score difference of 3 put them below the sample average of couples' differences (4.4). The couple scored identically (16) on the satisfaction subscale, which is above the distress cutoff score and at the sample mean. Vader's cohesion subscale score (5) was the lowest in the sample, below the distress cutoff score, and below the sample mean for the prenatal diagnosis group and the prenatal mothers' group. Darth's cohesion subscale score was 7 points higher (12) than Vader's and was slightly below the sample average for the prenatal diagnosis group and for the prenatal fathers' group. Darth's consensus subscale score (24) was 3 points lower than Vader's subscale score (27) and was below the average of the prenatal diagnosis sample (24.8). In keeping with these differences in the cohesion and consensus subscales, Vader felt that their level of closeness and of shared activities was significantly lower, and Darth felt their agreement on important issues was lower.

Personal Reactions: Darth and Vader were the third couple I interviewed, the second couple from the prenatal diagnosis group. This interview was by far by my most frustrating because initially I could not figure out how to have an audio conference on the Web-based conferencing system. I could tell that Vader was becoming frustrated with me because I was taking a long time trying to figure it out.

When we first started the Web-based conferencing system interview, I felt that she was very guarded and did not remember much when I asked her questions. I could not decide if this was because she did not feel comfortable sharing her experiences or because it was a long time ago. The couple has the oldest child in the prenatal diagnosis sample (4 years old), so it is possible that she was unable to remember clearly details from 4 years ago. Additionally, she told me that she was taking seizure medication,

which made me think that there could be a neurological reason why she did not remember certain things.

At one point during the interview, she questioned my position at CHOP because I did not know their surgeon and I referred to the surgeon as a man when in reality she was a woman. She seemed suspicious of me. I tried not to become defensive and tried to explain the miscommunication. I had forgotten that they had not received the initial letter that I sent out. She contacted me to volunteer for the study after receiving the voice message I left on her phone. I explained the study on the phone and provided her with the consent forms, which she mailed back to me. I wondered if she had forgotten about that too. I had to constantly encourage her to answer the interview questions and to give her examples of what other people had said to make her share her experiences. I did not know if that was the right way to conduct an interview.

Vader was the third mother I interviewed who tried to get pregnant later in life. The other two mothers spoke about having miscarriages before they had their children. I wondered if difficulty conceiving or being older has any connection to a child developing cleft in utero. Vader spoke about the doctor's demeanor and the way he brought up abortion. This couple was the second one in the prenatal diagnosis group to discuss the doctor's demeanor and the doctor presenting them with the possibility of abortion.

Darth, the husband, was much more verbal than Vader. They both said that cleft was a cosmetic condition and that families should do research to learn more about it. The importance of gathering information is a general theme that frequently came up in my interviews. So far, all the couples I had interviewed emphasized the importance of gathering information and learning about what it means for a child to have cleft.

Vader's main struggle during the initial stages was feeding. She talked about the lactation consultant pushing for breastfeeding. I wondered if this was a good idea, especially given the fact that she was taking anticonvulsive medication. She was the second mother in my study sample who mentioned that the lactation consultant pressured her to breastfeed. I wondered about the psychological impact this pressure would have on a mother, especially if, like Vader, she were not able to breastfeed because of the medication she was taking.

Vader is Asian and Darth talked about the possibility of his wife's racial background being a cause for cleft. It is true that clefts are more prevalent in Asians. Both Darth and Vader identified Vader's seizure medication as a possible cause. I wanted to explore this suggestion because the other parents I interviewed frequently reported feelings of self-blame. She said she was annoyed that the doctor had not warned her and had not adjusted the dosage of her medication when she was pregnant. I felt that she was becoming defensive when I asked about her feelings and wondered if this was because she was trying to cover up her self-blame.

I wondered if her feelings of guilt were the reason she spoke of her experiences as not being stressful and of CLP as trivial. I decided that this response could also come from my bias that raising a child with CLP is a stressful process. I reminded myself to bracket my beliefs and biases.

When Vader mentioned that their son wore stents in his nose after surgery, it resonated with me because I also wore stents after one of my surgeries. However, I was 14 years old at the time; as a teenager, my biggest worry about wearing them was my appearance and the questions, looks, and comments that I was going to have to endure. I

wondered if the couple also worried about the social stigma that the child could be exposed to because of the stents. However, they did not describe any such worries.

During the interview, I felt that they were making fun of my questions, which suggested that they were not focused on the important areas that needed to be covered. I also questioned the value of my questions, wondering if they did not capture the crucial areas of concern to couples raising a child born with CLP. I also wondered if the disconnect between the couple and me was because I was conducting the interview via the Web.

I struggled with determining how deeply I should go in making a distinction between therapy and interviewing for research. I also felt that this family was very aware of their privilege because they talked about insurance coverage and about how some people are not able to pay for the surgeries. I wondered if this attitude was related to their social class, racial background, and disability status because Vader has epileptic seizures.

5.3.4 Interview # 4: Minnie and Junior

Demographics: Minnie and Junior had been together for 10 years. They had been married and living together for 5 years according to Junior and 6 years according to Minnie. She was 30 years old and Junior was 32 years old. They were both college graduates. Minnie was a homemaker and Junior worked full time as an instrument and control technician. Both Minnie and Junior were White. The couple had two daughters and the oldest, who is 2 years old, had cleft palate. The couple received the diagnosis after her birth. Minnie reported struggling with postpartum depression and receiving psychological and psychiatric help in the last year. She had also been struggling with depression before her pregnancy and birth. The couple was interviewed over the phone.

The Couple's Story: Minnie and Junior tried to conceive for 3 years until Minnie finally became pregnant. She was seeing a high-risk specialist because she had gestational diabetes during her pregnancy. She asked for a 3D ultrasound from this doctor but could not obtain it. Her daughter's birth was difficult for Minnie; the doctor had to perform an episiotomy. After her daughter's birth, she had trouble breastfeeding her daughter. The baby cried a lot. When the baby cried, Minnie realized that something was different about her daughter's mouth. She notified the nurses on staff, her husband, and the pediatrician, but was ignored. The nurses and the pediatrician told her that her daughter was fine. Minnie said that she "did not want to create any problems when there weren't any" so she did not question the issue further. However, she still had trouble breastfeeding and had to feed her daughter with syringes. The family was discharged from the hospital and sent home.

The lactation consultant came to Minnie and Junior's home to assist them with the feeding and told Minnie that her daughter was having trouble breastfeeding because Minnie had inverted nipples. She expressed feeling blamed by the lactation consultant. Eventually their daughter had to be readmitted to the hospital because of failure to thrive. During her daughter's second stay at the hospital, Minnie reported that the nurses continued to blame her daughter's difficulties with nursing on Minnie's breast milk. One of the nurses even grabbed her breast and shoved it into her daughter's mouth. Finally, the night nurse suspected cleft palate and called in another pediatrician for consultation. The pediatrician diagnosed their daughter with cleft palate.

In his individual interview, Junior did not mention that he had ignored Minnie's initial concerns. He did confirm that their daughter had to be readmitted to the hospital a

couple of days after they were discharged because of failure to thrive. He was surprised that the first pediatrician did not give them the cleft diagnosis even though he examined her. Junior agreed that Minnie had a difficult time trying to feed their daughter; she tried multiple ways such as pumping and trying to feed her using regular bottles, which did not work.

Minnie was initially scared that she had to put her baby through surgery at such a young age. She was also scared that Junior would leave her because he had decided not to marry one of his former girlfriends because she had a lot of health problems and Junior did not want their children to inherit health issues. This former girlfriend was still in their lives and refused to refer to Minnie as Junior's wife until they had children. Junior said he was not well informed about cleft palate and only wondered if it was repairable. Additionally, he was concerned about its impact on their daughter's feeding and speech.

During the initial stages after her daughter was born, Minnie was recovering from giving birth and had to take sitz baths. She did not feel supported by Junior; she reported that he often criticized her for spending a lot of time taking the baths.

The period after the first cleft surgery was difficult for both Minnie and Junior. Both had a difficult time with their daughter's postoperative look. They talked about seeing blood coming out of her mouth, which was difficult. Junior also mentioned the arm restraints that she had to wear, which were uncomfortable for her and upsetting for Junior. This period was also difficult for their relationship.

Junior's concerns at the time of the interview involved speech since their daughter's speech regressed significantly after the surgery. She had started to say a few words before the surgery; after the surgery, it was difficult to get her to say "yes" or "no."

She also refused to put anything in her mouth, including the bottles, after the surgery. Junior suspected that it was psychological. He stated that their daughter was receiving early intervention for her speech twice a week.

The couple wished they had known about the diagnosis prenatally because they could have been better prepared. They stated that they could have gotten the Haberman bottles and chosen a hospital equipped to care for a child born with cleft. Feeding was an initial challenge for the couple since the hospital did not have Haberman bottles, and the staff had to order the bottles from another hospital. When the bottles came in, one of the nipples got torn because the couple did not know how to use it. Once the couple figured out how to use the Haberman bottles, feeding became a lot easier. The feeding became even easier when Minnie gave up pumping and switched to formula. She did talk about feeling guilty for switching to formula because there was pressure to breastfeed during the classes she took throughout her pregnancy.

Minnie talked about additional challenges she experienced after birth and as she raised her daughter. Her mother passed away before she gave birth, so she felt very lonely. She reported having a conflicted relationship with her mother-in-law and not feeling supported by her. She often felt alone while taking care of her daughter. She sought support on the Internet and learned about cleft through online support groups. Minnie stated not knowing what caused her daughter's cleft and says, "I hope it was not something I did." She talked about eating shellfish and drinking alcohol before knowing that she was pregnant.

The couple had another daughter about a year after their first daughter. Junior checked her palate himself to make sure that there was no cleft palate. Minnie talked

about packing a “special bottle” for the hospital just in case. Their concern for the next child developing a cleft was apparent.

The couple reported having a difficult time in their relationship throughout this time. Minnie said that the tension was there even before their daughter was born, but “cleft brought everything out.” She identified communicating and working as a team as some of the challenges they went through. Junior, on the other hand, talked about learning how to put things into perspective; he found that some issues he worried about proved to be minor compared to what they had been through.

It was primarily Minnie’s responsibility to feed their daughter when she was pumping. When she switched to feeding her daughter formula, they could take turns. Minnie said that the household chores were not divided fairly. She acknowledged that her husband works full time but talked about feeling his resentment when she asked him for help.

The couple needed to educate other people about what cleft palate meant since it was not visible. Minnie talked about hearing hurtful comments from her family, but overall, the couple was grateful when they saw more severe cases of cleft in the hospital. She stated that it was helpful to talk with another parent who had a child with cleft if the severities were similar. Otherwise, she felt guilty for complaining. Junior said that it could be helpful to talk with another parent, but he also felt well informed by the doctors and the pamphlets.

At the time of their interview, their daughter was experiencing speech difficulties and developmental delays. She had a difficult time being around other children because she struggled with expressing herself, which led to temper tantrums and conflicts with

other children. Minnie described how their daughter's behavioral problems sometimes affected their social life; they were hesitant about going out. Junior stated that having kids impacted their social life, not necessarily their daughter's difficulties. Minnie described being assertive about getting early intervention to improve her daughter's speech because the doctors alerted her to the fact that her daughter's palate muscles may need to be examined and that she could need another surgery if her speech did not improve.

RDAS Summary: Junior's total RDAS score was 42, whereas Minnie had the lowest RDAS score in the entire sample at 26, suggesting she was distressed about the relationship. The difference of 16 in their RDAS scores was the highest difference between partners, illustrating divergent views of their relationship. Their average RDAS score of 34 was the lowest average couple score and within the distressed range. Junior's consensus subscale score of 23 was above the sample average for the postnatal group (20.6) and for the sample average of fathers in the postnatal group (21). Minnie's consensus subscale score was 16 and below the sample average for the postnatal diagnosis group and the sample average of mothers in the postnatal diagnosis group. The difference of 7 between their consensus subscale scores suggested that they had different views about their agreement on important matters in their relationship. Their satisfaction scores were also very different; Junior's was 14 and Minnie's was 8. Junior's score was above the average for the postnatal diagnosis group (12.8) and for the fathers' subsample (13.2). Minnie's was below the average for both the postnatal sample and the mothers' subsample (12.8). The smallest difference was between each partner's cohesion scores. Minnie scored 2 and Junior scored 5. Both scores were below the average for the

postnatal diagnosis group (8.7 for the mothers, 9.6 for the fathers). In addition, Minnie's consensus, satisfaction, and cohesion subscale scores were the lowest among the mothers in the whole sample. Junior's cohesion score was the lowest among the fathers in the whole sample. As was evident from their RDAS reports, Minnie and Junior agreed that their relationship was distressed. Yet Minnie reported that her relationship satisfaction, closeness, and participation in shared activities were much lower compared to Junior's perspective. As described in the couple's story, Minnie resented Junior for not being there for her throughout the experience of raising a child with cleft. Thus, Minnie's lower subscale scores seem to reflect her interview descriptions.

Personal Reactions: This interview was the fourth one I conducted and the second for the postnatal diagnosis group. I interviewed the husband first. I could not decide if he was reserved or distracted. I felt like I had to pull the words out of his mouth and wondered why. Is it because men are not as verbal as women? Do they need more help to express their thoughts and feelings? I realized that my background in EFT and POTT really impacted the way I conducted the interviews. I tried to understand core feelings of the individuals and couples, which is part of my EFT training. I also used a lot of my own experience and the information I gathered from my interviews to connect and try to understand my participants. When I made an assumption on the basis of my own previous knowledge, I checked in with the participant to see if my statement described their experience correctly.

Junior seemed upset about their daughter's difficulty with speech and her change of behavior after her surgery; he felt these behaviors resulted from a negative psychological impact of the surgery. He seemed very concerned about his daughter's

health. He talked about staying with his daughter overnight at the hospital. I perceived him as a concerned and attentive father who wanted to be there for his daughter. I noticed that I always expect men to be less involved, especially because of my own experiences with my father. So, I was touched and impressed with this dad. I was surprised by my own reaction because it was to be expected that he felt bad about seeing his daughter in pain! When he described that he saw her with blood coming out of her mouth after the cleft palate surgery, it sounded like he was about to cry. I was surprised about his emotional reaction because he seemed very guarded throughout the interview to the point where he could come off as dismissive.

Minnie's interview was very different. She actually cried throughout the interview. This interview was my first experience with an interviewee who cried. I did not know what to do at first: My therapist self told me to comfort her and help her self-soothe; my researcher self told me that this was not the place for that. So, I tried to validate her feelings and continued to ask my questions.

Listening to Minnie's story, I felt very angry and sad. She was the second mother in postnatal diagnosis sample who received a late diagnosis for her daughter's cleft palate. I realized that diagnosis both before and after birth is much more difficult with cleft palate because it is not always visible. The way that Minnie described being treated at the hospital broke my heart. It was especially infuriating to hear the way the hospital staff continued to ignore her concerns and to blame her for the feeding difficulties. I was surprised that this kind of neglectful medical treatment existed in the United States.

Minnie and Junior were the second couple from the postnatal diagnosis group that I interviewed. Like the first couple, they discussed complications after surgery. The first

couple, Diane and Jack, described problems with breathing after the first surgery. Minnie and Junior stated that their daughter's speech regressed significantly after surgery and she refused to have anything put in her mouth such as the bottle. In this case, the impact seemed more psychological.

Minnie talked about Junior being in love with another woman. He did not marry the other woman because she had a lot of health issues and Junior was worried that their children would inherit these health issues. Now that their daughter was born with cleft, Minnie talked about blaming herself. I also felt that she was worried that Junior regretted marrying her.

I also become jealous of my boyfriend's former girlfriends so I could relate to her feelings. I did not know if I should have pointed out the helplessness she felt or if that would make her feel more agitated? I did not say anything in response because I was scared. I felt angry toward Junior. Minnie talked about Junior's mother and how she tried to come between Minnie and her daughter. She described her husband as siding with his mother. This point reminded me of Turkish mothers-in-law. I was surprised that the same dynamic occurred in America.

I think it is important to have boundaries in a couple's relationship and to have a husband who is capable of setting appropriate boundaries with his family. I felt very sad for Minnie because she felt so alone. She was currently being treated for depression and sounded very lonely. I wondered if that was why she cried throughout the interview, because she did not really have a lot of people to discuss these issues with. Additionally, I wondered if their daughter was not speaking not only because of the impact of the

surgery but also because of the marital problems between her parents or having had a sibling at such a young age.

During the couple interview, their daughter did not stop screaming, which was annoying. I knew not to say anything because they were actually doing me a favor by taking time from their busy schedules to do the interview. I was nervous that the transcriptionist was not going to understand what they were saying because of the screaming in the background. Their daughter had minor developmental delays and she could not speak, so I wondered if that was why she screamed so much. I wondered what I would do if my child had developmental delays in addition to a cleft.

Minnie's self-blame was apparent during the interview because she blamed herself for "causing the cleft." She also blamed herself for not advocating enough to receive a comprehensive examination of her daughter when she was having difficulties with breastfeeding. Unfortunately, nobody listened to her at that time. I thought of my mother, who is a very anxious person, and of how nobody listens to her because she seems anxious all the time. I wondered if Minnie had the same effect on other people and that was why nobody listened to her, even though her concerns were valid. During their couple interview, she was careful about what she was saying, which made me sad because it seemed that she was editing and censoring what she shared in front of her husband in order to keep her marriage intact but that she actually felt very alone in her marriage.

Some themes recurred during the four interviews. Feeding and speech were a common concern for parents. The couples also had a difficult time with their child's postoperative appearance and worried about their next child having cleft. All couples

interviewed so far used the Internet as a resource, which helped them most of the time but sometimes added to their concerns. Like the previous couples, this couple was grateful that cleft is a fixable issue. They felt that it would be helpful to speak with other parents at that time.

5.3.5 Interview # 5: Rebecca and Ben

Demographics: Rebecca (38 years old) and Ben (33 years old) reported the length of their relationship differently. They had been in a relationship for 6 years and 3 months and had lived together for 6.5 years because they were roommates first. Rebecca reported that they had been married for 4 years. Rebecca was White and Ben was Asian. They both completed graduate school and worked full time at the same company. Rebecca was the director of research and Ben was a research consultant. The couple had two sons. Their oldest son was 2 years old and was born with cleft lip. Their younger son was 7 months old. They did not receive any psychological help over the last year. The interview was conducted at the couple's home.

The Couple's Story: Rebecca and Ben were together at the time of the prenatal diagnosis. During their 20-week ultrasound visit, the technician claimed that she was not getting good pictures of their son's face so she asked them to come back. Both Rebecca and Ben suspected the cleft but were not sure until the doctor delivered the news. At the time of the prenatal diagnosis, Rebecca described Ben as being very supportive and comforting toward her. Both Rebecca's and Ben's first concern was their son's appearance and social stigma. Rebecca stated that since "the first thing people see is a person's face," people could judge her son by the way he looked. Ben also described similar concerns about people judging their son because of his appearance. Ben

mentioned going through a similar experience growing up, looking different because he was an Asian living in Florida.

The couple had additional testing to make sure this was an isolated issue. Once they found out that there were no additional syndromes, they felt grateful. Rebecca then informed everybody that their son was going to be born with a cleft. She posted the news on Facebook. She did not want this to be a topic that people discussed “under their breath.” Ben noted that once they learned about the diagnosis of the cleft, they were able to educate their families and prepare them before he was born. Ben, however, stated that delivering the news about cleft took the pure joy out of delivering the news about their baby.

Rebecca did not know what caused their son’s cleft. Yet she was the first mother that I interviewed who did not describe blaming herself. Ben talked about reading that clefts were more common among children of biracial couples, especially when one partner was Asian and the other was White. Ben said that his parents wondered if God could have put his hand there when the fetus was developing, which caused the cleft to form. Ben explained to them that he did not think that was the reason.

This child was their first. Rebecca’s labor was long and she had to have an episiotomy. She lost a lot of blood. For this reason, the health of the mother and the baby were Ben’s first concerns at the time of his son’s birth. Rebecca wanted to learn about the severity of their son’s cleft. When I asked about their experiences right after their son’s birth, both partners had bitter looks on their faces. Rebecca reported having trouble breastfeeding her son after birth. It was not because of the cleft lip but because he had jaundice and had to receive phototherapy. During this time, he was fed with bottles,

which was why he did not want to be breastfed afterward. Rebecca said this was difficult for her because she had always wanted to breastfeed her babies. She felt inadequate because her son “rejected her breasts.” She had to pump, supplement the breast milk with formula, and use the bottle to feed her child, which was difficult for her. Their son also had eczema, and she did not know what that was. She felt stressed because he cried constantly and scratched himself until he bled. As a result, she experienced postpartum depression and took antidepressants for a short period after his birth.

Ben described the initial stages after birth as “emotionally scarring.” He was not prepared for the long, difficult labor and the stress that occurred in their household. He had to go back to work 2 weeks later. At first it was difficult for the couple to manage their roles and responsibilities. For this reason, after their second son was born, they prepared a list of chores and divided them fairly between them. Cleft was also a concern for their second child. They asked for a 3D ultrasound to check if he had cleft too, but he did not.

The couple talked about their son’s cleft becoming “endearing” after a time. They had photos taken of their son before the surgery because they “did not want to forget the way they met him.” Before the surgery, Ben was concerned about complications related to anesthesia and the psychological impact of the surgery on their son. During the surgery, the couple became anxious when it took longer than anticipated and when they did not get frequent updates. After the surgery, seeing their child’s swollen face with stitches and bandages was challenging. Ben wondered if the baby was in pain. However, they were also grateful when they compared the lack of severity of his cleft with that of other children they saw in the waiting room.

The couple talked about the support they provided for each other throughout this process. Ben supported Rebecca emotionally, soothing her and calming her down when she became scared or upset. Rebecca provided practical support to Ben by doing the research, learning about cleft and the treatment path, picking out specialists, and making all of the appointments. They made decisions about treatment by talking to doctors, asking questions, and then having discussions with each other. The initial stages were challenging for their relationship, but it became easier over time. They talked about giving up the idea of having the “perfect” child and realizing that “there is no such a thing as ‘perfect’ when you are a parent.” The couple agreed that even though they might have experienced problems in other areas of their lives, when the issue was their child, they were able to put their other problems aside and support each other.

RDAS Summary: The couple’s average RDAS score was 47.5, the lowest couple score in the prenatal diagnosis group, putting them just below the distress cutoff score, indicating mild distress in their relationship. Rebecca’s total score was 55, whereas Ben’s was 40. Ben had the lowest total and subscale scores among all of the fathers in the prenatal diagnosis group (consensus = 22, satisfaction = 12, cohesion = 6). The difference between their total scores (15) was the highest difference between partners in the prenatal diagnosis group. This dyadic score difference suggests that Ben had a much lower relationship satisfaction level than Rebecca. Her consensus subscale score (25) was at the mean for the prenatal diagnosis group (24.8) and the mothers’ subgroup (25.1). Her satisfaction subscale score (14) was just below the mean for both groups (prenatal diagnosis group = 16.1, mothers’ subgroup = 16.1). Rebecca’s cohesion subscale score (16) was the second highest in the prenatal diagnosis group whereas Ben’s was the lowest

(6). This finding indicates that the couple has very different perspectives on their relationship, mostly around their shared activities.

Personal Reactions: Rebecca's and Ben's interview was the fifth couple interview I conducted and the third one in the prenatal diagnosis group. When I arrived at their house, I was impressed by their neighborhood. It was clear that they were from a higher class. There was an elementary school right across from their house, which made me think, "How convenient!" I was jealous because I had been feeling that I was trying to multitask and was overwhelmed at times finishing the data collection for my dissertation before flying home to Turkey.

Rebecca answered the door. I was relieved that she was not surprised to see me because I had forgotten to confirm the date and time of our interview the previous day. Ben was also at home. They are a biracial couple, which made me think about my former boyfriend, who was also Asian. Rebecca seemed to be the one who had more power in their relationship. It seemed that Ben was following her lead during the most of the interview.

Rebecca also looked older than Ben, which made me think about my former boyfriend's previous girlfriend, who was much older than he was. Even though I tried to acknowledge that and keep it out of my mind, I still found myself thinking about it at times during the interview. When Ben stated that cleft occurred more frequently in children of biracial couples who are White and Asian, I thought about Lawrence's mother and how she did not want me to marry him because I was born with cleft and our children could inherit it.

Rebecca and Ben seemed a lot more relaxed than the previous couple, Minnie and Junior, which made me feel at ease during the interview. I was surprised by the untidiness of their living room and wondered if this was because they were juggling the parenting of two young children while working full time. Rebecca and Ben both did research in their full-time jobs, so I felt the need to provide more details about my research study. It felt as though Rebecca was evaluating my research design and my performance when I conducted the interview. She even stated that a sample of 20 couples was not a lot! I explained that I was more interested in people's stories. I noticed that I was getting somewhat defensive.

A recurring theme in their interview was concerns around appearance and social stigma. I had been hearing about this concern often from the parents I had already interviewed. Another frequently mentioned experience was being both concerned and grateful at the same time. This feeling of gratefulness was a recurring theme in parents' experiences, especially when they put everything in perspective and compared their children with others who had more severe clefts or more serious health issues.

The prenatal couples I interviewed so far talked about the importance of gathering information, learning about what cleft is and how it would be repaired, and developing a treatment plan before birth. They reported primarily using online resources such as Web sites and online support groups. They also received support by talking to other parents virtually online. Furthermore, they described being prepared emotionally and being spared the shock and the surprise. As they learned more about what cleft entailed, they were able to inform and educate other people around them, for example family members

and friends. These were the unique aspects mentioned about receiving the prenatal diagnosis.

Couples mentioned the impact of being a first-time parent and learning how to parent. They said that, no matter how much they prepared, they were only able to prepare conceptually. “Doing it” was a different thing. Additionally, parents described their reactions to the postoperative appearance of their child y and concerns about the child being in pain.

5.3.6 Interview # 6: Abby and Murray

Demographics: Abby and Murray had been together for 25 years and were married for 18.5. The couple was White. Abby was a 41-year-old, stay-at-home mother with a graduate degree; Murray was a 43-year-old physics/astronomy teacher with a graduate degree. Abby used to work as a teacher until they had their daughter. The couple had a 2-year-old daughter who was born with CLP. They received the diagnosis before she was born. I conducted the interview with the couple over the phone.

The Couple’s Story: Abby and Murray tried to conceive for 8 years and were told that they had a 1% chance of getting pregnant so they gave up trying. Two years later, Abby became pregnant naturally. At the 20-week ultrasound examination, Abby and Murray found out they were going to have a girl and that she was going to have cleft lip and possibly cleft palate. Both partners described that the cleft diagnosis took the “pure joy” out of learning about the sex of the baby. They were referred to CHOP and had intensive testing to find out the extent and severity of their daughter’s cleft. They received an isolated cleft lip and palate diagnosis. The couple was together at the time of the prenatal diagnosis and Abby described that it was good to feel his support.

Additionally, Abby stated that they had been together for a very long time and had a good partnership so she believed that they were going to work through it together.

At the time of the prenatal cleft diagnosis, Abby and Murray were both concerned about feeding the baby. Abby was also concerned about the NAM device and Murray was concerned about the number of surgeries their daughter would have to go through as well as the impact of cleft on her physical appearance. The prenatal diagnosis affected the pregnancy positively because they were able to do research, learn about cleft, buy Haberman bottles, plan the treatment path, grieve the loss of the “perfect child,” and prepare and educate their families before their daughter was born. They had a friend who had recently had a child born with cleft lip, and they talked with her for guidance. They highlighted the importance of doing research and learning more about cleft because having more information reduced the “fear of the unknown.” Murray was more “matter of fact” about letting people know about their daughter’s diagnosis whereas Abby became more emotional and thought more about how people would perceive her daughter.

The couple described the initial stages after birth as very difficult because of the feeding issues and taping the NAM device. Abby had to pump and supplement her breast milk with formula and did so for 6.5 months. She described the experience as “horrible” and “exhausting” because of the lack of sleep. She stated that she wanted to give her daughter breast milk because she learned it was the best food for newborns and did not want to deprive her daughter of the benefits of breast milk, given that “she was already coming into this world with a deficit.” Taping the NAM device was also hard. Abby talked about not taking her daughter out in public until her first surgery was completed

and her visible difference was corrected. She wanted to protect her daughter from people's reactions. During the initial stages after birth, it was difficult for Murray to see his wife under stressed; she had to pump her milk and feed their daughter, do the tapings, go to the doctor for readjustments of the NAM device, and basically go without any sleep. He had to go back to work so she handled these responsibilities by herself. Even when he was at home, he could not help with the pumping and felt "helpless."

After the lip surgery, Murray stated that because of the post-operative appearance of their daughter, he could not understand the impact of the surgery on their daughter's appearance. It took some time for the facial swelling to disappear, and they were then able to see the difference. Abby and Murray talked about being content with the way their daughter looked after the first surgery. Abby was able to take her daughter out after the surgery now that "her appearance was normal" and she would not be exposed to social stigma. A major stressor related to the lip surgery was that fact that her daughter was no longer wearing the NAM. The NAM created an artificial palate, so, without it, Abby had to relearn how to feed her daughter with the Haberman bottles. It was very difficult in the beginning because the baby refused to eat but became used to it eventually.

Another stressor for the couple during the initial stages was the cleft palate surgery because of the pain they witnessed their daughter experiencing. Murray described how the pain medication did not show its effect for a while so their daughter had to be placed in the pediatric intensive care unit.

Abby thought that environmental causes led to their daughter's cleft. She attributed it primarily to genetically modified organisms and pesticides. She also stated that she did not take prenatal vitamins before and during the initial stages of her

pregnancy because she was told that she was not going to be able to conceive. She thought that her age could also be a factor, but she did not blame herself.

The couple emphasized that they had a very strong foundation in their relationship because they had been together a long time. This situation was the first real challenge they experienced in their relationship, and they were able to get through it. They talked about the importance of being in agreement about how they would solve the problems throughout this process. It was a challenge when they had divergent views on how to do things. Another challenge was not being able to spend time alone as a couple because their lives revolved around their daughter. They stated that, having a child, not necessarily having a child with cleft, negatively impacted their social life.

At the time of the cleft diagnosis, the couple both researched it. They divvied up the responsibilities equally after the birth. However, once Murray had to go back to work, Abby had to do more, especially the feedings, tapings, and making the doctors' appointments. Murray helped when he was home. They made decisions about treatment by listening to the doctors and having discussions with each other. At the time of the interview, they only talked about cleft when a doctor's appointment was coming up. Murray described his satisfaction with the treatment they received at CHOP, especially the sequencing of appointments, the team approach to treatment, and the long-term tracking of their daughter's progress.

RDAS Summary: The couple's average RDAS score was 56, well above the clinical distress cutoff (48), which placed them in the nondistressed category. Abby's score (55) was above the average of the prenatal diagnosis group sample (53.4) and the mothers' subsample (53.6), whereas Murray's score (57) was above the average for the

prenatal diagnosis sample (53.4) and fathers subsample (53.2). Their RDAS score difference of 2 was the second lowest difference score in the sample, suggesting they had similar views of their relationship. On their consensus subscale, Abby's score was 3 points higher indicating that she felt they had slightly more agreement on issues than Murray did. Murray's consensus score (24) was slightly below the mean for the prenatal diagnosis sample (24.8) and fathers' subsample (24.5). Abby's satisfaction score (16) was at the mean for the prenatal diagnosis group and the mothers' subsample. It was also 2 points lower than Murray's score (18). Murray was slightly more satisfied in their relationship than Abby. Murray's cohesion subscale score (15) was also higher (better) than Abby's score (12). The couple seemed to have slightly different perceptions of closeness and participation in shared activities. The couple had been together for 25 years and indicated that they have been best friends. However, Abby quit her job after their daughter was born. She did talk about her husband not being able to do as much around the house and with parenting because he had to work. The couple also talked about longing for time alone with each other since they had their baby. The findings may signal that even though Abby believes that they agree on important issues, she does think that they do not participate in shared activities as much as they used to.

Personal Reactions: Abby and Murray were the 6th couple interviewed and the 4th interview for the prenatal diagnosis group. I had a pleasant time interviewing this family because they were ready and enthusiastic for the interview, unlike some of the other couples who agreed to the interview and then did not pick up their phones at the scheduled time. I felt very comfortable throughout the interview. It was clear that this couple was still very affectionate toward each other. Listening to their story, I missed my

boyfriend who was in Turkey and missed being a couple. I hoped that after 18 years of marriage we could be like Abby and Murray.

I learned that Abby became a stay-at-home mother after having their daughter and was a little annoyed about that. She also talked about doing most of the work around the house when her husband was at work, although Murray did more when he was home. As she said this, I felt that she was somewhat embarrassed about it. I could not decide how I felt about putting one's career on hold to take care of a baby.

The couple talked about their daughter being a miracle baby; she came after 8 years of trying and after a long period of fertility treatments. Abby eventually became pregnant naturally! This experience of having a difficult time conceiving was common in my sample. Their story made me tear up—I felt for them. I thought that a couple who seemed to be so happy in their relationship deserved a child. However, the couple did talk about the adjustments that they needed to make in their lives after they had their baby. I liked that they did not describe a perfect picture about being a new parent.

Most of the people that I interviewed were mothers who became pregnant in their late 30s, which made me think about a link between cleft and mother's age. However, the literature does not report a correlation between the mother's age and the child developing a cleft.

The couple talked about some of the more common themes that emerged in previous interviews. All couples, especially in the prenatal group, described going through intensive testing to determine the severity of the cleft. They described preparing “practically” by doing their research, learning about cleft, buying the “special bottles” to feed their baby, grieving the loss of the “perfect child,” figuring out the treatment path,

preparing people who are close to them to meet their child, and educating them on cleft. They stated that, at the time of birth and during the initial stages, having a child born with cleft affected their experiences as new parents taking care of a helpless newborn. All couples agreed that it was harder than having an “average newborn.”

All couples talked about issues with feeding, the NAM device and the tapings, and the lack of sleep. Most of their concerns were about the next treatments and surgeries and whether their child would experience any ongoing difficulties and/or developmental delays. Before surgery, the possibility of complications related to anesthesia was also a common concern. After surgery, the couples described feeling relieved but also being sad because of their child’s swollen “post-op appearance.” They could not understand the full impact on their child’s appearance because of the “post-op appearance.” This experience was described as stressful and challenging for parents during the initial stages and up to 1 year, but they did not report ongoing stress if their child did not have any long-term difficulties or developmental delays.

All couples emphasized the importance of being on the same team, supporting each other throughout the process, and relying on the strength of their relationship. Abby and Murray were the first couple who talked about missing each other because they were unable to have any time alone with each other. Additionally, Abby’s hesitance in taking her daughter outside prior to her first lip surgery in order to protect her from the reactions of other people was a new theme that emerged in this interview. She was also the first parent to talk about the cleft palate surgery as being more difficult than the lip surgery.

5.3.7 Interview # 7: Jane and Mitch

Demographics: Jane (36 years old) and Mitch (43 years old) had been together for 7 years and 11 months. They were married 6 years ago and lived together for 1 year prior to their marriage. Jane was an attorney and Mitch worked in law enforcement; they both worked full time. Both members of the couple are White. Jane had a graduate degree and Mitch had a college degree. The couple had two sons, the oldest of which was 2 years old. He was diagnosed with cleft lip in utero. The couple was interviewed over the phone.

The Couple's Story: Jane and Mitch found out about their son's cleft during the 20th- week ultrasound visit. The midwife informed them that their son was going to be born with cleft lip but was not certain if he also had cleft palate. When they asked for additional ultrasounds, the nurse dismissed them by saying that was not necessary since there was nothing they could do about it. However, she also put them in touch with the Maternal Fetal Medicine High Risk Practice where they had genetic testing and received the isolated cleft lip diagnosis.

When Jane and Mitch learned about the diagnosis, Jane was very concerned about Mitch's reaction and wanted to soothe him. She immediately said, "Oh, those babies they do fine. They just need to use a special bottle." During the interview, she mentioned that Mitch was very worried about raising a child with a chronic illness or disability even before Jane became pregnant. For this reason, Jane was very concerned about his reaction. She also thought that it was her responsibility to take care of Mitch because it was "her body" and "her pregnancy." She wanted to stay strong for Mitch and let him know that she could "handle this," so she reassured him that they could continue her

pregnancy. Additionally, Jane wanted to be there when Mitch researched the diagnosis on the Internet and read about the “worst-case scenario.” She stated that she knew Mitch was going to be upset but that he was not going to share his feelings with anybody. So she wanted to support him and give him the opportunity to cry and be upset.

Mitch did not talk about this relational dynamic in his individual interview. However, he admitted that he was very worried about additional syndromes even after receiving the isolated cleft lip diagnosis. He continued to question the accuracy of the tests throughout his wife’s pregnancy. He described researching cleft on the Internet and preparing himself for the “worst-case scenario.” His concern about their son’s appearance was secondary to his worry about the additional anomalies.

Jane was concerned about the feeding, especially not knowing if the palate was involved. She planned to breastfeed, so the possibility of her not being able to do so was difficult for her. When she learned about the diagnosis, she called her mother and cried.

Jane let people know about the diagnosis via email, explaining the situation and requesting that people not ask any questions until they were ready to talk about it. People were respectful, except for Mitch’s parents, who asked intrusive questions and used the term “harelip.”

Describing his thoughts and feelings at the time of his son’s birth, Mitch talked about being relieved that it was only cleft lip, a cosmetic issue. He was initially worried about outsiders’ reactions toward his son. It was a long and difficult labor for Jane, but she was relieved that their son did not have additional difficulties. She had difficulty breastfeeding at the time of birth, which was not because of the cleft but because the baby

had a tight frenulum of the tongue. Frenulum of the tongue is the flesh that connects the floor of the mouth to the tongue.

Even though the couple had a difficult experience coping with the cleft diagnosis throughout the pregnancy, they were both glad that they received the diagnosis prenatally. They were able to educate themselves about cleft, learn about feeding, have a plan, grieve the loss of a “perfect” child, and were spared the shock. After their son’s birth, Jane was on maternity leave and Mitch went back to work. Therefore, Jane took the lead in caring for their son. She described worries about “doing it right.”

Mitch was relieved after the first surgery. He talked about questioning the timing of his son’s first surgery and wondering if they could have waited a little longer so that their son would not need another surgery. Jane described having a more difficult time after the surgery, especially when she saw their son with bandages and stitches. He cried because of the pain and Jane had difficulty feeding him.

When I interviewed them, their concerns centered on their son’s appearance, any social stigma he might experience, and his upcoming surgery. Jane described being concerned about the pain and the psychological impact that their son could experience after the surgery, given that he was now old enough (2 years) to remember the experience. However, she also acknowledged that she felt grateful that his condition was fixable.

Jane and Mitch agreed that this was the first significant challenge they navigated together as a couple and had a chance to evaluate their partnership throughout this process. Mitch shared his belief that if they could get through this, they can get through

anything. Jane was also content that they were able to get through this experience together.

For Jane, the biggest challenge was deciding whether or not they wanted an abortion because there was a risk that their child would have a severe cleft as well as additional anomalies. Mitch stated that the challenges were not feeling the pure joy of having a new baby, adjusting to the idea of their son having a cleft, and immediately having to plan his course of treatment. The cleft was also a concern for their second child so they had the nuchal screening and further testing, which eventually ruled out the possibility of cleft. Nuchal screening is a pregnancy scan that is conducted at the 12th week to diagnose any possible fetal abnormalities.

They shared that they no longer talked about cleft other than to discuss the timing of the upcoming surgery. They decided to tell their son about cleft before the second surgery. They thought that it was beneficial to talk with another parent if the severities were similar. Now that they had been through this experience, Jane acted as a resource for other parents when they called her for advice.

RDAS Summary: The couple's average RDAS score was 54, placing them in the nondistressed category. Mitch's total score was 59, the second highest among the fathers in the sample; Jane's total score was 49, the second lowest among the mothers in the sample. With a difference of 10 in their total scores, this couple had the second highest score difference in the prenatal diagnosis sample behind Rebecca and Ben. This high dyadic score difference suggested that Jane had a much lower relationship satisfaction level than Mitch, which may also be associated with her having the caretaker role in the relationship. Mitch's subscale scores of consensus (27), satisfaction (18), and cohesion

(14) were well below the mean for the prenatal diagnosis group and the fathers' subsample. Jane's subscale scores were slightly below the mean for the prenatal diagnosis group and the mothers' subsample. The differences between each partner's consensus, satisfaction, and cohesion subscale scores were high, indicating diverging views of their relationship.

Personal Reactions: Jane and Mitch were the 5th couple I interviewed from the prenatal diagnosis group. I realized during this interview that I was not as enthusiastic about hearing their story because I felt like I was hearing the same thing. I started by interviewing Mitch. I felt his defensiveness at times, but I had experienced this defensiveness with some of the other fathers so I was not surprised. I remembered what Dr. Fisher said about just listening to how they make sense of their experiences, so I let him be. I realized that this approach made him relax.

I realized that during previous interviews, I was trying to connect the participants' experiences to the data that I previously collected, probably because I was worried about not reaching saturation. However, I understood that the goal was to hear a range of experiences and that it was acceptable if they were not saying the same thing every time. I also realized my struggle during the interviews stemmed from my secret wish that they would reach an epiphany about their feelings and concerns at the time, looking back on their experiences. I wanted them to be able to tease out their feelings with all the complexities, describing both the negative and the positive. During this interview, I decided to acknowledge this secret wish and tried to let it go because I did not want to put words in people's mouths or direct them in the direction that I wanted them to go. This time, I allowed the interviewees to speak more about their experiences without

interference. I only asked questions if I was confused about an issue they were explaining.

Both partners, especially Jane, were very verbal; she described her experiences clearly. Throughout this experience, Mitch was the one who had been anxious and Jane supported and soothed him. I could also feel the love toward Jane in Mitch's voice. She said that at the time of the cleft diagnosis, she had to be the support system for him because she knew that he often worried. She seemed to treat Mitch like a little child that she needed to comfort, but somehow I was really touched by that. I liked that women could be strong and be there for their partners because in prior interviews I heard about how the husbands provided emotional support for their wives during this process. I was content that there were cases where the roles were reversed. I think this response is related to my EFT experience: I noted that the men felt just as sad, helpless, and scared as the women even though they tried to hide it and stay strong. Their main issue as a couple was Mitch worrying about additional syndromes even when they received the isolated cleft diagnosis after the amniocentesis was completed. This response was strange for me, but I acknowledged my belief and bracketed it. During the interview, Mitch used a touching statement about "becoming a father before birth" because of the preparation he needed to do to prepare for the cleft treatment and buying the necessary equipment to take care of a child with cleft. I felt that this was a great description of the fathers' experiences in my sample.

In this case, it was clear that Mitch was the anxious type; he questioned me about audiotaping and confidentiality before starting his individual interview. I provided the necessary information and tried to assure him. I realized that I was taking on the caretaker

role like Jane does. However, I learned that he worked in law enforcement and served as a detective. Therefore, it was natural for him to be more suspicious than other parents in my sample.

As I was reading the transcript for the interview, I was surprised at how different my reaction was compared to my reactions right after I had conducted the previous interviews. I found myself being annoyed with Mitch for not supporting Jane. I pictured him as ruining the pregnancy for her. I felt that she needed to keep her fears and frustrations to herself throughout the pregnancy to keep Mitch calm so that they could have this baby. I wondered if Jane resented Mitch and if that was why her RDAS score was much lower than his.

Like other parents, Jane and Mitch talked about going through intensive testing to find out the severity and identify additional anomalies. They did research, learned about cleft, focused on feeding, grieved the loss of the “perfect child,” and figured out the treatment path. They stated that, at the time of birth and during the initial stages, the experience of having a child with cleft was muddled with having a newborn. They were concerned about an upcoming surgery. After their child’s first surgery, they felt relieved but also sad that their child experienced pain. Similar to the previous couples, Jane and Mitch talked about evaluating their partnership throughout this process.

Even though some doctors had mentioned it, couples considering abortion was a theme that did not come up in the previous interviews. Usually couples felt relieved once they receive the isolated cleft diagnosis. Mitch was the first parent who highlighted “staying off the WebMD” especially before having a definite diagnosis. He also was the first parent who mentioned preparing himself for the worst-case scenario. I thought about

how the couples mentioned gathering information about cleft to feel more in control of the situation. During this interview, I noticed the other side of the coin-- the anxiety of the parents actually increased. I wonder where the line lies in terms of how much research one should do.

5.3.8 Interview # 8: Mo and Chip

Demographics: Mo and Chip had been together for 7 years and were married for 3 years and 8 months of those years. Mo was a reading specialist/teacher with a graduate degree, and Chip was a physics laboratory technician with a college degree. They both worked full time. Mo was 45 years old and Chip was 50 years old. They were both White. They had a 2-year-old daughter who was born with cleft lip. They learned the diagnosis prenatally. Mo and Chip were the 8th couple I interviewed and the 6th couple in the prenatal diagnosis group. I interviewed the couple over the phone.

The Couple's Story: Mo and Chip learned during an ultrasound visit that their daughter was going to be born with CLP. Mo described her initial feeling as devastated and Chip, as catastrophic. Mo was glad that Chip was there because they were able to hear the news together and discuss what they heard afterward. Throughout the pregnancy, they continued to receive news about possible health problems that their daughter might face such as potential stomach or kidney problems. For this reason, they were scared throughout the pregnancy, but "they handled it together" as Mo states.

At the time of the diagnosis, Both Mo and Chip were concerned about additional anomalies, appearance, and social stigma. Additionally, Mo was worried about feeding. Chip had a childhood friend who was born with CLP in the 1970s. He remembered this friend as being significantly disfigured, which contributed to his worries about their

daughter's appearance. Mo's worry about appearance was related to her professional background as a teacher. She was familiar with the social stigma that children had to endure so she was concerned that her daughter was going to be bullied due to her visible differences. Because the possibility of additional health problems was not eliminated until birth, the couple worried about additional anomalies. Furthermore, Mo was worried about her daughter's survival. She stated, "Many children born with cleft lip palate don't make it." Mo and Chip had a frank conversation about abortion and decided not to do it because they are both Catholic and "don't think like that."

Throughout the pregnancy, Mo and Chip prepared themselves by contacting CLP organizations and asking for information. They even got a DVD on how to feed a child who was born with cleft. They also got in touch with CHOP through one of these organizations and attended childbirth classes.

At the time of birth, the intensive care unit staff was on call in case there was an emergency regarding the health of their daughter, but it turned out to be unnecessary. Their daughter was born with isolated cleft lip palate without additional health issues. After birth, Mo was worried about feeding and possible breathing difficulties for her daughter. Her worries eased as she came to trust the treatment team and believed that their daughter was in good hands.

After the birth, Mo went on maternity leave and Chip took off 2 weeks from work. Mo's initial concerns were making sure that their daughter was eating properly and gaining weight. The baby was also wearing the NAM device, so Mo and Chip worked cooperatively to make sure that tapings were done regularly. After Chip went back to work, Mo continued to take their daughter for regular appointments to adjust the NAM

device. When their doctor emphasized the importance of the NAM device, the couple saw it as a way of “molding their daughter’s face.” They were adamant about doing it. Chip took it upon himself to make sure that enough tapes were stocked and cut, ready to be used.

Mo continued to worry about breathing, especially because her daughter was wearing an appliance in her nose and mouth. She thought, “What if it shifts?” The couple had an angel monitor and a video monitor in their child’s room. Mo stated that they were so worried about their daughter initially that it put them both on guard to prevent any possible danger that could occur such as death.

The couple did not describe raising a child with cleft to be as stressful as they thought it would be. Mo said that, especially after they learned that there were no additional anomalies and no permanent disfigurement, cleft became “just a cosmetic problem.” Yet, there were times when it was stressful such as when their daughter suffered a skin infection due to the tapings and when they witnessed blood coming out of her mouth after her palate surgery. For the couple, seeing their daughter in pain was the primary cause of stress.

When hypothesizing about a cause for their daughter’s cleft, the couple stated that they did not know of a specific cause but shared three ideas. They both underlined a possible genetic cause. Mo shared in her individual interview that her husband was adopted so it was possible that cleft existed in his genetic roots. She also stated that she had a mammogram before she knew about her pregnancy and the radiation she had may have caused her daughter’s cleft. Chip highlighted that their older age may have led to their daughter developing a cleft in utero. The couple talked about possible causes but

they decided that it was not helpful or necessary to blame each other and instead to focus on taking care of their daughter.

During the couple interview, Mo frequently emphasized the importance of having her husband by her side during every doctor's appointment. When taking care of their baby, the couple was able to depend on each other and give each other a break when they needed it. Mo described Chip as being more in control of his feelings. He was able to soothe her when she was overwhelmed with anxiety. The couple shared that, because of these experiences, their relationship had gotten stronger. They stated that "they can get through anything." There were also challenges, especially when they were not on the same page, such as on how to do the tapings when their daughter was suffering from a skin infection.

Throughout this process, educating themselves on cleft was important, but providing emotional support to each other after they learned about the diagnosis was their primary focus. The couple shared that there were times, after learning about the diagnosis, that they just "had to hug one another and tell each other that it was going to be okay."

When we talked, they did not have any major concerns except for upcoming surgeries and residual issues around appearance and orthodontics. They also would like to have their daughter evaluated for speech even though she was not displaying any significant developmental delays. When making decisions about treatment, they talked to the doctors and then discussed the issue with each other. They also shared the parenting responsibilities equally once Mo also returned to work.

The couple stated that they did not talk about cleft often since the difficult stages were over. They discussed the child's current issues and upcoming treatments. They planned to tell their daughter about her cleft once she asked about it. They did not want to make her self-conscious by highlighting the issue until she asks. They viewed cleft as a cosmetic problem and felt grateful that it is treatable.

RDAS Summary: Mo and Chip's combined average RDAS score was 60.5, the highest couple RDAS score in the sample. Mo's score (59) was the highest score among the mothers' scores in the whole sample and Chip's score (62) was the highest score among the fathers' scores in the sample. The difference of 3 in their individual scores was below the prenatal diagnosis group's average difference of 4.4. The couple was above average in all RDAS subscales as well, and there were only minor differences between their individual subscale scores. Chip scored the highest in the sample among the fathers in all subscales whereas Mo scored the highest among the mothers on satisfaction and cohesion subscales. Chip's scores on the consensus (26) and cohesion (18) subscales were slightly higher than Mo's (cohesion: 24, consensus: 17). Their satisfaction scores of 18 were identical. As seen from these results, Chip believed that they agreed on important matters in their relationship and engaged in activities slightly more than Mo did.

Personal Reactions: This was my 6th interview for the prenatal diagnosis group. I was not surprised that Mo and Chip had a high, positive RDAS score. I was really impressed by the way they explained how they supported each other throughout this process. When they talked about how they just had to hug one another and tell each other that everything was going to be okay, I found myself tearing up. There were no other couples in my sample who described supporting each other this way. More couples talked

about their practical preparation in terms of learning about cleft and how to take care of a child with cleft. This couple also described the importance of being there for one another during vulnerable times to take care of their relationship, especially for the women.

Based on my knowledge of EFT, I am aware of the impact of attachment injuries that can occur in a couple's relationship during a pregnancy. Women are especially vulnerable at this time. For this reason, I understood why Mo frequently stated how her husband "never left her side" throughout the interview. From the interviews I conducted so far, I realized that raising a child with cleft is a tough experience for parents, especially during the initial stages after birth and right after learning about the diagnosis. This observation was true for both diagnosis groups in my sample. The most commonly reported stressors were feeding difficulties and surgeries. This stress continued if the child had ongoing issues.

When describing the stressors, I have to acknowledge that participants in my sample were primarily from privileged backgrounds. They could afford the treatment needed for cleft and had supportive partners and families. I wondered if the same levels of adjustment and adaptation could occur in families who have limited resources for putting their child through the necessary treatments and who have a limited support network to help them take care of their child. During my interview with Chip, he described meeting a "single mother" who was probably a "waitress" in the waiting room at CHOP. He talked about how she could not make her child wear the NAM device as frequently as Mo and Chip did. He said, "She was really kind of neglecting her responsibility, and I just remember that one lady. In the end she was just not really looking out for her child's condition. I wanted to be like the exact opposite. I could not do enough." Part of me was really disappointed by his statement. I noticed myself feeling

angry at the way he was looking down on this single mother without knowing what she had to endure to take care of her child with cleft. This statement made me think about the limitations of my sample.

Additionally, I was surprised when Mo said she was worried about her daughter's survival before birth. Initially, I attributed her worry to the possibility of additional anomalies. However, when she said, "You hear so many stories of children who have bilateral cleft lip and palate who don't make it," I was confused. I have never read about the possibility of death in children with cleft. Therefore, I found myself wondering if her concerns were legitimate. However, I did not want to question the legitimacy of her concerns because I was afraid of sounding judgmental. She also stated that she worried about her daughter's breathing after birth to the point that she got an angel monitor *and* a video monitor. She was the first parent in my sample who talked about breathing concerns. Therefore, I felt the need to question the rationale behind her concern. When she talked about the NAM device shifting and blocking her child's breathing, I understood the level of anxiety Mo experienced during the initial stages. I felt that she was hypervigilant, constantly thinking about possible dangers and trying to prevent them from happening. I checked in with her regarding my assumptions and she confirmed that this was how she felt at that time.

5.3.9 Interview # 9: Pam and Paul

Demographics: Pam and Paul were White and had been married for 10 years. According to Pam, they had been together for 12 years and 6 months. Pam was 35 years old and Paul was 36. Pam had a college degree and worked part-time as a registered nurse. Paul had a graduate degree and worked full time as an optometrist. The couple had

two children; their older child was born with cleft lip. He was 4.5 years old. The couple received the diagnosis postnatally. I conducted the interview with the couple over the phone.

The Couple's Story: Paul and Pam learned that their son was born with cleft lip right after Pam gave birth. She described being shocked because she had been through the 3D ultrasound examinations but was not informed of a cleft. However, the doctor comforted her by saying, "Oh, it's very minor. They usually do a surgery for this and it's not a big deal anymore." Her husband was also with her at her son's birth, which made her feel more "secure." Paul talked about being sad, worried, and confused when he first heard the diagnosis. He was not familiar with clefts and did not know "what it meant" if a baby had a cleft lip. Pam's first concerns were surgery and feeding. She had planned to breastfeed her baby and did not know if cleft would be a hindrance. Paul was also concerned about the surgery and its outcome. He said that his worry about the surgery was because he did not want his son to be bullied because of an apparent visible difference. He also talked about cleft being a setback regarding experiencing the joy of having a new baby and being first-time parents.

Pam was anxious during the initial stages after birth. She said that her son's cleft added an additional layer of anxiety to the typical anxiety of learning how to take care of a newborn. She was hesitant to take her baby out in public because she worried about outsiders' reactions. Additionally, she worried about her son having to go through surgeries at such a young age. Paul agreed that the surgeries were the most significant source of stress during this time. Their son had to go through two surgeries, one when he was 3 months old and another one when he was 3 years old.

For Pam, it was especially difficult to “hand her child off to strangers” before the surgery. She kept telling herself that “everything was going to be fine” and that she was “doing the right thing.” She questioned if it was worth putting their son through a surgery for a “cosmetic” issue. However, she accepted that it was necessary because of the importance of physical appearance “in this day and age.” For Paul, his main concern before the surgeries was anesthesia. The couple struggled when they were deciding to schedule their son for a second surgery, which was a lip revision. This time, it was more challenging for them to decide because this surgery was being done to “make him perfect.” They wanted to get it done before their son started school to prevent him from being bullied by his peers. The couple described being concerned about possible social stigma that their son could experience because of his cleft scar. They wondered about the effects of such experiences on him as a young child and later as an adolescent and an adult.

Both partners stated that they did not know what caused their son’s cleft. When asked about whether they would have preferred a prenatal diagnosis, Paul said that he would not have wanted to know before his son’s birth because he would have started worrying earlier. Pam was ambivalent about the timing of the cleft diagnosis; she said she could not have done anything about it before his birth, but then acknowledged that perhaps she could have researched it and been more prepared to see him with the cleft at birth. Additionally, with her second pregnancy, she had ultrasound examinations to see if cleft occurred in her second child. Even though cleft was a concern with their second child, it did not stop them from becoming pregnant again, and the second child was not born with a cleft.

Like most couples I interviewed, Pam and Paul highlighted the importance of teamwork when taking care of a child with cleft. They said that, even though surgeries added an additional layer of stress to their lives, this experience did not negatively affect their relationship. They held onto traditional gender roles at the time of their son's birth. Paul took 2 weeks off after his son's birth and then returned to work while Pam took 3 months off from work. Pam's responsibilities included taking care of doctors' appointments and the household tasks whereas Paul's responsibility was managing the finances. Their roles have remained the same.

The couple had friends whose child was born with cleft lip 4 years ago, and they used this family as a resource. It eased their concerns to see the appearance of this child after the surgeries. Pam and Paul also got advice from this family regarding the doctors they should see.

Pam and Paul told their son that he had a cleft lip before he had his second surgery at the age of 3. They showed him a picture of himself before he was born and told him that he was born with a cleft lip. His reaction was "Oh!," which was very minor compared to what they expected. They stated that they were actually more nervous than their son when they were telling the story. Their son, on the other hand, was more concerned about the intravenous tube that he was going to have before the surgery.

RDAS Summary: Pam and Paul had the highest RDAS score in the postnatal diagnosis group sample, suggesting the least amount of relational distress. Pam had an individual RDAS score of 57 and Paul had a score of 56. The couple's RDAS score was 56.5, which was well above the mean RDAS score for the couples in the postnatal diagnosis group (42.8). Each partner's individual score was well above the mean scores

for the mothers (42) and the fathers (43.8) in the postnatal diagnosis group. The difference between their scores was 1, which was well below the average difference score of couples in the postnatal diagnosis group (7.2). Overall, this couple was in the clinically nondistressed category. Their subscale scores were also above the clinical distress cutoff of RDAS subscales and mean subscale scores of the postnatal diagnosis group. Pam's consensus subscale score was 24 and Paul's was 28. The difference of 4 points between their consensus subscale scores suggested that Paul believed that they agreed on the important matters regarding their relationship more than Pam did. Their partner satisfaction subscale scores were identical whereas Pam's cohesion subscale score (14) was only 2 points higher than Paul's score (12). These findings indicated that Pam believed that they participated in shared activities more frequently than Paul did.

Personal Reactions: Pam and Paul were the 3rd couple from the postnatal diagnosis group that I interviewed and the 9th interview. I was beginning to get nervous because there was a significant difference in the number of couples I interviewed between the two diagnosis groups. I wondered if I was ever going to be able to interview enough couples from the postnatal diagnosis group to reach saturation, given that the original sample was much smaller.

Compared to the previous couple I interviewed from the postnatal diagnosis group, Minnie and Junior, this couple felt like a breath of fresh air. They also did not seem to have the constant anxiety that Diane and Jack had about their son's health. Their way of questioning the necessity of the surgeries was not a common theme from previous interviews. They talked openly about the pros and cons with each other, because they felt that cleft lip surgery was more of a cosmetic procedure. However, they still opted for the

first and second surgeries. I realized two things: For the parents, the possibility of their child being bullied was a significant concern. Their worry about his physical appearance was to prevent their child from being a target among his peers, as parents frequently stated, “We live in a visual world.”

Paul and Pam were the first couple I interviewed who told their son that he was born with cleft (at the age of 3, before his second surgery). I thought this was because their son was one of the oldest children in my sample at the time of the interview (4.5 years old). It made sense because most of the couples talked about telling their children when they were old enough to understand the cleft. I found myself having a negative reaction when parents shared that they did not want to tell their child about cleft because s/he might end up thinking that something was wrong with her/him. I believe this approach comes from the parents’ own fears and shame. I think it is a child’s right to learn what s/he was born with and the experience s/he went through. I believe that if parents hide these experiences from their child, it diminishes their experiences of strength and resilience and transforms it into a source of shame.

5.3.10 Interview # 10: Sarah and Brandon

Demographics: Only Sarah mailed back her two surveys. For this reason, only her surveys were evaluated. Sarah was a 41-year-old sales administrator. She had completed some college. She and Brandon had been in a relationship for 7 years and 4 months; they had been living together for 5 years and married for 4. Sarah did not report receiving any psychological or psychiatric help. They had a 3-year-old son who was diagnosed with cleft lip after birth. I conducted their interview over the phone.

The Couple's Story: Sarah described learning about her son's cleft as "traumatic." She had a cesarean delivery because the baby was breach. Her husband, Brandon, was with her. However, after her son's birth, the doctor and her husband left the room to get their son cleaned up and weighed. At this time, because the doctors were doing her stitches to complete the cesarean delivery, a "woman" who did not identify herself told her that her son was born with cleft. Sarah said that she was being operated on and all alone when she received the news about her son's cleft. She was "flabbergasted." She later found out that this person was the pediatrician who worked in the operating room that day. She complained to the doctor about this provider's demeanor. Brandon later comforted Sarah about the diagnosis. He said to her, "We will get him fixed. He will look perfect."

At the time of their son's cleft diagnosis, both parents' first thought was "what did I do wrong?!" Sarah felt that she failed her husband and her son because she was the one carrying the baby. Her guilt was exacerbated because her husband was a former model and she gave birth to a child with a visible difference. Sarah stated that she had been born with a cleft in her earlobe, which made her wonder if this was a factor in her son's cleft. The doctors did not find this relevant. Brandon believes that the umbilical cord got wrapped around their child in utero and was on his son's lip, causing the cleft.

Sarah's immediate concern was her son's physical appearance and the social stigma that he could experience. She was worried that people were not going to look at him and see a "perfect" baby, since his lip was not "perfect." She wanted to learn when he could go through the surgery so that his appearance would be corrected as early as possible. Similarly, Brandon wondered how soon their son could go through the surgery

and hoped that he could do so before he started school. After their son's birth, the couple was very happy that they had a baby. The only struggle Sarah identified was losing her father soon after their son was born.

The couple reported that the surgery was stressful for them. Before the first surgery, the hardest part was "handing him off to the strangers." Sarah talked about being concerned about complications because of the anesthesia. She found comfort in the anesthesiologist's demeanor and statement, "I will treat him like my own child." After the surgery, seeing their child in pain, swollen, and with stitches was challenging for both parents. For Brandon, it was also difficult seeing his wife in distress. Yet, the couple identified feeling grateful that their son's condition was minor compared to that of the other children they saw at the hospital.

Even though Sarah was worried about her son's physical appearance and the social stigma he could face, she said she would not have put her child through the surgery if they were "living in a different society." Sarah expressed concern about the possible bullying her son might experience because he has a scar and excess skin around his lip.

This couple did not have a strong preference for a prenatal diagnosis. Sarah stated that it would have been helpful if she had known prior to her son's birth, because she could have prepared herself emotionally to see her son with a cleft. Brandon said that he could have been better prepared financially to handle the cost of the surgeries.

When their son was born, Brandon was switching careers and was self-employed. They had to rely on Sarah's health insurance, which did provide extensive coverage. The couple struggled financially because they had hospital bills for both the cesarean delivery and the cleft surgeries in addition to expenses related to taking care of a new baby. Still,

they were determined to get the best care possible for their son. Going through these financial struggles was challenging for their relationship, and they continually “get frustrated easily over money.” Despite their financial struggles, the couple said that they were both on the same page regarding getting the best treatment for their son, which helped them work as a team and stay strong as a couple.

During the interview, the couple had different views on some issues. First, they had different views about roles and responsibilities in their relationship. They had traditional gender roles, where Sarah took care of the household tasks and the child rearing while Brandon supported the family financially. Sarah shared her resentment against her husband for not being as involved in child rearing. Brandon identified himself as the disciplinarian in the family as part of his role as a father. The couple also disagreed about whether their son had a difficult time making friends. Brandon did not think so whereas Sarah talked about him being shy and playing alone in the playground. Finally, Brandon was hesitant about telling their son that he had a cleft. He did not want their son to think of himself as defective, whereas Sarah planned on telling him when he got older.

RDAS Summary: Sarah’s individual RDAS score was 43, placing her in the clinically distressed range. Her score was just above the mean score for mothers in the postnatal group (42). Her consensus subscale score was 22, which was at the clinical distress cutoff score for the consensus scale. Her satisfaction subscale score (15) was just above the cutoff score (14) and the sample mean for the mothers in the postnatal group. Her cohesion subscale score (6) was below the cutoff score (11) and the sample mean for the postnatal mothers (8.7). During the interview Sarah described herself as being resentful about the traditional gender roles the couple had in their relationship when it

came to child rearing. I expected her low score on the cohesion subscale, which indicates the shared roles and responsibilities.

Personal Reactions: Sarah and Brandon were the 4th couple I interviewed in the postnatal diagnosis group. I realized that Sarah really took the time to convince her husband to participate in this interview, which I greatly appreciated. As I started talking to her, I had a feeling that she was lonely in her marriage and life but I could not pinpoint the exact reason. I decided to make a mental note of it and continue with my interview. Sarah and Brandon's son was born with cleft lip and was diagnosed postnatally, which was surprising for me because usually cleft lip can be seen with a 3D examination. Throughout their interview, a few things made me react to this family that were based on my own assumptions.

First, this marriage was the husband's second; and he had an 11-year-old daughter from a previous marriage. I do not remember if Sarah explicitly said it but I immediately felt that she was perhaps his mistress before his first marriage ended. Then, I found out that he was a model before he changed careers, which made me perceive him as self-centered. Later in the interview, when Sarah described doing more of the child rearing and household tasks, Brandon got angry and belittled her for the lack of authority she had over their son. I was shocked that he spoke to her in a demeaning way in front of me. I found myself becoming anxious and tried to soothe his anger by asking questions about his role as a father.

Sarah described feeling guilty that her son was born with a visual difference because her husband was a former model. It felt like she was apologizing to him for not being able to pass on his good looks to their son. When she talked about her self-blame,

Brandon said, “He is still our son, he’s still the best.” It was intriguing for me that he never considered his part in their child developing a cleft in utero. It never occurred to him that it might have come from his genes.

This interview was the first one in which a couple mentioned going through financial difficulties to put their child through surgery. I was surprised that none of the couples thus far had talked about the cost of the surgery because the financial burden I caused my parents was always at the back of my mind when I was having my surgeries. In fact, a day before one of my surgeries, my mother told me that I had “destroyed them emotionally and financially,” which had confirmed my beliefs about being a financial burden on my parents. Therefore, I was surprised that financial struggles caused by the treatment were never mentioned in any of the other interviews.

5.3.11 Interview # 11: Laurie and Bill

Demographics: Laurie and Bill had been together for 12 years. According to Laurie, they had been living together for 7 years and married for 6. They were both 30 years old and White. Laurie was a speech pathologist with a graduate degree. Bill was a Web developer with a college degree; they both worked full time. The couple had a 3-year-old son who was born with cleft lip. Laurie was also born with CLP. The couple learned of their son’s cleft diagnosis prenatally. Laurie reported that she received counseling in the last year. She also participated in the Yahoo support groups on CLP. I interviewed the couple over the telephone.

The Couple’s Story: Laurie and Bill struggled with conceiving and Laurie had several miscarriages. They were informed of their son’s cleft diagnosis at an ultrasound examination. The technician checked for cleft in their baby because Laurie was born with

CLP. Laurie and Bill were together when they learned of the cleft diagnosis and both reported feeling sad. They tried to comfort each other. Laurie was familiar with the process because she had been through it herself. She provided Bill with information about cleft and its treatment. Bill comforted Laurie by saying that “it could have been much worse.” During their interview, Laurie said, “I had the fear and Bill had the mystery.” What made Laurie sad and scared was recalling the pain she had to endure going through multiple surgeries. She also had to answer other children’s blunt and invasive questions about “what is wrong with her lip.” Additionally, Laurie talked about feeling guilty because she was the one who “gave it to him, hands down.” When describing the time of the cleft diagnosis, Bill said he was sad because he could not take the “glamorous and easy road” that parents whose children are born healthy are able to take.

The couple was glad that they received the diagnosis prenatally because they were able to go through additional testing and learned that it was an isolated cleft, which is easier to treat. They met with a surgeon before their son’s birth and learned about the course of treatment. They were also able to mentally prepare their families. For Bill, the biggest challenge was “bracing people”; telling them about the cleft diagnosis, answering their questions and easing their concerns. He identified this process as “annoying” and “tiresome.” Informing other people was a source of concern for Laurie too, as she shared feeling especially nervous telling her in-laws because she was the one who passed the cleft to their son. She stated that they were very understanding once she told them. During his individual interview, Bill said something to contradict this, stating that he was upset with his father because he had an apologetic tone when he was telling other people that his grandchild was going to be born with cleft.

Aside from the reaction of her in-laws, Laurie's initial concern was the extent and severity of her son's cleft. At the time of his birth, their son was also diagnosed with cleft in his soft palate. Then, their biggest concern was feeding him. Laurie had planned on breastfeeding; instead she had to pump, supplement breast milk with formula, and use normal bottles to feed her son. Feeding this way was difficult for her because she was unable to experience bonding through breastfeeding. Additionally, pumping was hard and time consuming for her. She felt that if she had been able to breastfeed, her experience would have been more "natural" and "complete." Bill's initial concern was feeding; he wondered if their son was in pain every time he ate because of the cleft. Additionally, he was worried about outsiders' reactions because of his son's visible difference. He was thinking that they were not going to see a "handsome baby boy." Furthermore, he questioned how much pain his son was going to be in at the time of the surgeries. At the interview, the couple shared being worried about the upcoming surgeries; Laurie wondered if he was going to need an additional cosmetic surgery and Bill was concerned about the bone graft procedure that he might need in the future.

The first surgery was challenging for the couple. Before the surgery, Laurie was anxious about her son receiving anesthesia and how he was going to look after the surgery. She stated that her son looked like a new kid after the first surgery was completed. She was happy that he was going to have an easier time feeding. Yet initially she missed his cleft because she was so used to it. Bill did not agree with her statement; he never missed the cleft. He felt that his son looked as "he was supposed to look" after the surgery.

When asked about what may have caused their son's cleft, the couple explained that they had extensive genetic testing because of the miscarriages they had had. Laurie did not carry the genetic marker for cleft even though clefts occurred in her family. The genetic testing results indicated that she had a chromosome deficiency, which made it difficult for her body to absorb folic acid. Both Laurie and Bill believed that this deficiency led to their child's cleft.

The couple shared that this process was another challenge that they went through "without turning on each other." They talked about "being at different stages of processing at different times." When one was angry, the other partner was upset. Laurie stated that it usually takes her longer to "process things." In this case, she wanted to talk about it when Bill was not yet ready. So, they had to learn how to be patient with each other. Another challenge for the couple was worrying about the reactions of others and clearing up the assumptions they had about their son. It helped that they were on the same page about how they viewed cleft.

RDAS Summary: The couple had an RDAS total score of 57.5. Laurie's individual score was 59, and Bill's individual score was 56. Their scores suggested that they were a clinically nondistressed couple. Their individual and total scores were all above the means of the prenatal diagnosis group and of the mothers' and fathers' subsamples. Laurie's subscales scores (consensus= 27, satisfaction=18, cohesion=14) were all above the distress cutoff scores and sample means. Bill's subscale scores (consensus= 25, satisfaction=18, cohesion=13) were also above the distress cutoff scores and sample means. The couple's score difference was 3, which was below the mean for score differences (4.4) in the prenatal diagnosis group. Overall, the couple did not report

relational distress in any of the areas examined by the RDAS. Their reports indicated that the couple had divergent views on how much they agreed on important decisions in their relationship.

Personal Reactions: Laurie and Bill were the 7th couple I interviewed in the prenatal diagnosis group. Unlike the earlier interviewees, Laurie had been born with CLP. Therefore, I felt comfortable disclosing that I was also born with CLP. This family was the first one with whom I shared this information. I do not know how it affected the interview. I questioned the appropriate approach for disclosing this personal information. Because one of my peers who also did a phenomenological study on a topic with which she has a personal experience (e.g., experiences of immigrant therapists in the United States), agreed to serve as my “peer-debriefer,” I consulted with her about this issue. She told me to do whatever feels comfortable but make sure to keep detailed memos.

The reason that I did not disclose it in earlier interviews was because none of my participants asked about it. Part of me questioned if they secretly wanted to ask if I also had a cleft at birth. I thought about how to handle disclosing personal information in the therapy setting. I do not disclose any personal information unless my client asks me about it. Therefore, I decided to wait until participants asked me to share this information with them. I wanted participants to share their own stories and I did not want to take the focus away from their stories. There were times when I was glad I did not share my own experiences with cleft because some of my participants made statements about being grateful for being in the United States and near CHOP compared to having a child with cleft in a third-world country. I felt that they would not have been able to share this information with me if they had known I was also born with cleft in Turkey. However,

because of my accent and speaking English as a second language, I shared with all of my participants that I was from a different country in case I was unclear or difficult to understand, giving them permission to ask for clarification about the questions in the semi-structured interview guide.

Laurie had studied to become a speech pathologist because of her own experiences with cleft and speech issues, which made it easier for me to relate to her. She said that she was already knowledgeable about cleft and the course of treatment. This knowledge was both a blessing and a curse: Because she had extensive information about cleft, she had a better understanding of what her son was going to go through during the multiple surgeries, treatment, and possible bullying from his peers because of his physical appearance. During the interview, she was more open to talking about her own experiences compared to her husband. Part of me felt that having a child born with cleft became a source of shame for the father. He talked about being tired of “bracing people” and trying “not to make a big deal out of it.” He especially had trouble with his own father because of his demeanor when explaining to people that his grandson was going to be born with cleft. I wondered if the diagnosis caused tension between Laurie and Bill’s families. Laurie talked about being concerned about the reaction of her in-laws but stated later that they were supportive. I also wondered if Bill had to protect his son as well as his wife from outsiders’ reactions throughout this process.

Two fathers I had previously interviewed, Bill and Brandon, were hesitant to talk to their children about the cleft. Their fears were that their sons would start seeing themselves as “defective.” Interestingly, both children were male so, I wondered if the

fathers' fears stemmed from their children thinking of themselves as "less of a man" and perhaps "defective."

After interviewing this couple, I noticed that I always take the possibility of my child being born with cleft very lightly. I think to myself that it would not be a significant problem because I am familiar with the treatment path as well as with successful treatment teams. I know a lot more about the topic than my parents knew when they had me. Even though I think of the surgeries I went through as a financial burden on my father, I tend to downplay the emotional and physical burden of going through seven surgeries. This attitude leads me to think that it wouldn't be a "big deal" if my child were born with cleft. However, through my interviews, I become aware of the multiple dimensions of raising a child with cleft.

5.3.12 Interview # 12: Elizabeth and Joe

Demographics: Elizabeth and Joe had been together for 7.5 years. They had been living together for 5 years and married for 4 years. Elizabeth was a 36-year-old health care consultant. Joe was 40 years old and did marketing for a living. Elizabeth completed graduate school and Joe was a college graduate. Elizabeth was White and Joe was Asian. They had a 2-year-old daughter who was born with CLP that was diagnosed prenatally. They were interviewed over the telephone because they lived in California.

The Couple's Story: Elizabeth received the cleft diagnosis during the 20-week ultrasound examination and was referred for amniocentesis. For this reason, at the time of the CLP diagnosis, the couple was very concerned about additional syndromes. Both partners described being worried, but Joe took on the role of soothing Elizabeth at the time of the CLP diagnosis, assuring her that they would do whatever they needed to do

for their baby and everything would be fine. After receiving the isolated cleft diagnosis, they reported feeling better.

The couple visited three hospitals to get different opinions about the course of treatment. They learned about CLP and developed a plan about what they would do once the baby was born. They highlighted the positive impact of receiving the diagnosis prenatally because it gave them time to prepare both emotionally and practically.

They did a great deal of research about cleft on the Internet prior to the birth, which at times made the couple more concerned and anxious. Joe described being worried about their child's physical appearance and Elizabeth was worried about speech development. They were both worried about social stigma.

After the birth, Elizabeth and Joe had no concerns left related to the cleft. Their concerns focused more on being new parents and taking care of a baby for the first time. Initially, they stated in the interview that their experiences were not so different from those of other new parents, but then they talked about how having a baby born with cleft was "more stressful than not having a baby with cleft." Elizabeth described pumping breast milk to feed their daughter, doing the tapings for the NAM device, and making many trips to Philadelphia for doctor's appointments as difficult during the first few months. She shared how she refrained from joining the new moms groups because she felt that other mothers would not be able to relate to her experience. They both agreed that everything became easier after the first CLP surgery. At the time of the interview, their main concern was about the upcoming treatments related to cleft.

Both Elizabeth and Joe agreed that their "positive experience" as a couple increased their belief in their partnership. Joe said that, after going through the first year

of having a baby, he did not respect anyone more than he respected his wife. Elizabeth added that this experience reminded her why she married Joe in the first place. They both highlighted the importance of teamwork—the other person being there to help when one partner needed a break. The only challenge they described during this process was deciding on a treatment team. They initially disagreed and argued about where their daughter should be treated, but eventually they worked it out.

Given her professional expertise in health care, Elizabeth took on the role of searching for hospitals and making medical appointments. Elizabeth also pumped breast milk, but the couple split the feedings and diaper changes. At the time of the interview, they did not have defined roles and responsibilities; instead they tag-teamed as necessary. However, Elizabeth still made the appointments and Joe was the main financial provider.

They agreed that dealing with the CLP treatment became easier once they chose the treatment team. They listened to the doctors to decide on the next steps and asked the right questions. They shared their own experiences with their parents, both the aspects they liked and disliked. They also discussed hypothetical scenarios they could experience with their daughter ahead of time and talked about how they would act. They noted the importance of not being judgmental if one of them did something that the other did not approve of.

When we spoke, their daughter did not have any problems because of the cleft. They described how they taught their daughter to massage her scar every morning with sunscreen, but they had not yet told her about the cleft. The couple stated that they were very proud of their daughter for being so strong. Regarding the cleft, they were grateful

because after seeing what other children are dealing with while in the hospital, they realized it was important to keep things in perspective.

RDAS Summary: Elizabeth's total RDAS score was 52 and Joe's total RDAS score was 53, suggesting that this couple was satisfied with their relationship. The difference of only 1 point between their RDAS scores was the lowest difference in the sample, illustrating similar views of their marital relationship. Elizabeth's total score and her satisfaction (16), cohesion (12), and consensus (24) subscale scores were above the cutoff points but below the sample mean for the prenatal diagnosis group and prenatal mothers' group. Joe's consensus subscale score (26) was the highest among the prenatal fathers. His total score (53), satisfaction subscale score (15), and cohesion subscale score (12) were slightly below the sample mean for the prenatal diagnosis group and prenatal fathers group. The couple had identical scores on the cohesion subscale. Joe scored higher on the consensus subscale whereas Elizabeth scored higher on the satisfaction subscale. The RDAS results suggest that Joe felt they agreed more on important matters whereas Rebecca felt more stability and less conflict. Both had the same opinion about the amount of time they spent on shared activities.

Personal Reactions: This couple was the 8th one I interviewed whose child was diagnosed prenatally; I felt that I had reached thematic saturation after this interview for the prenatal diagnosis group. The couple were currently living in California so I was very excited that they were interested enough to participate in my study via phone. The couple gave me the impression that they had a strong, stable relationship. They both talked throughout the interview about the value and respect they had toward their partner. Initially, I envied the way they spoke so highly of their daughter, praising her for her

strength given that I had never felt as if my parents took pride in me for being able to cope with such a long course of treatment. I always felt that arranging for the multiple operations and treatments was a burden for my parents both emotionally and financially.

Two aspects of what they shared created a reaction in me when I started reading their interview during the data analysis phase. First, when talking about the impact of the prenatal diagnosis on the pregnancy, Joe mentioned the additional appointments they needed to go to “causing extra work.” I wondered if he resented this “extra work.” I wondered if the fact that Elizabeth did not mention the additional appointments when talking about the impact of the prenatal diagnosis on her pregnancy was because Joe as the father was perhaps not as connected to the fetus and the pregnancy as the mother.

Elizabeth mentioned that she was the one searching for doctors and making appointments throughout her pregnancy because she worked in health care and was “the pregnant one.” It seemed odd to me because she described being pregnant as an individual experience and responsibility. I wondered if this perspective was connected to some of her feelings of self-blame because she also talked about questioning her role in her child developing a cleft in utero, thinking it was the couple of glasses of wine she drank or the warm bath she took before knowing she was pregnant.

5.3.13 Interview # 13: Rachel and Francis

Demographics: The couple had been together for 13 years; they lived together for 10 years and had been married for 9 years. They were both White. They both had college degrees. Rachel was a homemaker and Francis was a financial advisor. He was employed full time. The couple had two children, a daughter and a son. Their son, who

was a year old, was born with cleft lip. They learned about the diagnosis before his birth. I interviewed the couple in person at CHOP.

The Couple's Story: Rachel and Francis found out that their child was going to be born with CLP when they had the integrated testing at the 20th week of the pregnancy. They were initially shocked. They were not familiar with CLP except for the commercials of Smile Train they had seen on television. Rachel stated that it was “heartbreaking” to hear the cleft diagnosis and she felt that she “failed at protecting her baby.” Accepting that they were not going to have a “perfect child” was difficult for Rachel. The couple had additional testing to find out if it was an isolated cleft lip and palate. It was a relief that their baby did not have any additional anomalies.

They both wanted the birth to come more quickly. After the possibility of additional anomalies was ruled out, Francis was worried about the severity of the cleft whereas Rachel was worried about other people's reactions to their child. She wondered how people were going to view him, how their daughter was going to view him, how their families were going to view him. Rachel identified Francis as her “rock” during these stages. Francis stated that he was very worried about his wife and her reaction to the diagnosis. He stated that Rachel could not look at a picture of a baby with cleft until 2 weeks before the birth. He was worried that Rachel was going to reject the baby. The couple described becoming more reserved throughout their pregnancy because they did not want to answer questions about their baby's diagnosis.

In contrast to Francis' fears, when describing the birth, Rachel said, “First time my eyes laid on him, I knew everything was okay. My husband brought him over, brought him around, and I laid my eyes on him and he was perfect. Anything and

everything that I was feeling went out the door.” Francis was really happy that his wife accepted their baby. However, the couple continued to face challenges after birth.

Initially, they experienced difficulties because the hospital staff was not familiar with how to feed a baby born with a cleft. Their son had colic and reflux, which made it difficult for him to sleep. Rachel continued to worry about how the cleft was going to affect him both physically and emotionally. After the first surgery, the couple was very happy. Rachel stated that his reflux and colic dissipated; he became more relaxed and slept better. The couple reported that they no longer had any concerns.

The most challenging part of raising a child born with cleft for Rachel and Francis was people’s reactions to the cleft diagnosis and to their son. When they let people know about the diagnosis, some of them said, “Don’t worry, they will fix him right up!” It felt dismissive to the couple. They appreciated genuine concern more. Additionally, when their son was born, they received a range of reactions from people. People staring, asked their children not to look, asked intrusive questions, or complemented the visual appearance of their son in an excessive manner. People’s reactions were not something they were prepared for, so it became challenging to go out in public with their son. Rachel described that she still struggled with self-blame, feeling that she was the one who caused the cleft to develop. She kept going back to the time she was on antibiotics because of a dermatological problem before knowing she was pregnant.

The couple reported being able to depend on each other. They said their priorities were the same, which made it easier to cope with the experience. They agreed that nothing was more important than their family, primarily their children. They paid attention to prioritizing their son’s treatments as well as spending alone time with their

daughter. They identified the challenge for their relationship as not being able to spend time alone with each other. They were hoping that this was going to become possible soon since their son's surgeries had been completed.

During this time, Rachel was the one primarily taking care of the children, communicating with the doctors and scheduling appointments. Francis was the "chauffeur" and the "part-time psychologist" providing emotional support to Rachel. He was also the family's financial provider. Both Rachel and Francis were heavily involved in their children's lives; they stated that they mostly agreed on the "major stuff" and they used "trial and error" for the minor issues.

By the time of the interview, cleft was not a topic that they discussed often with each other, with family, or with others. They usually talked about the cleft when there was an appointment scheduled or when people asked about how his treatment was going. They focused more on being a resource for other parents and giving back to the cleft community.

RDAS Summary: The couple's RDAS score was 55, placing them in the clinically nondistressed group. Their total score was above the mean for the RDAS couple scores prenatal diagnosis group (53.4). Rachel's individual RDAS score was 57, which was above the mean score for the mothers in the prenatal diagnosis group (53.6). Francis's individual score was 54, just above the mean score for the fathers in the prenatal diagnosis group (53.2). Their score difference of 4 was just below the mean for score differences in the prenatal group (4.4). The couples subscale scores did not indicate any clinical distress in the areas of consensus, satisfaction, and cohesion. There were small differences between the couple's subscale scores. Rachel scored 26 in her

consensus subscale whereas Francis scored 24. Rachel's satisfaction (16) and cohesion subscale (15) scores were each one point higher than Francis's satisfaction (15) and cohesion scores (14). Through the experience of raising a child with cleft, Francis seemed to be the partner who provided emotional support for his wife. During the interview, it seemed that this process was draining at times for Francis. Therefore, I was not surprised that he scored slightly lower than Rachel in RDAS.

Personal Reactions: The interview with Rachel and Francis was the 9th in the prenatal diagnosis group. Francis was the most open and sharing father that I interviewed in the study. He said that he was really enthusiastic about this interview because he never had a chance to talk about his experience in depth. Also, he was the first parent in my sample who asked me what made me interested in this topic. I explained that I was also born with a cleft. I was surprised when he told me that he could not tell. I had had an operation long ago with the medical expertise available at that time; compared to people who have the operation today, my scar is more visible. Part of me was sad that he could not tell because I love my scar and I wished that it were more visible.

Francis emphasized the importance of giving back to the cleft community. He recently participated in a money-raising event for CLP. I perceive being able to serve as a resource for other people as a sign of adaptation after a crisis situation. Rachel, however, seemed still to struggle with self-blame. She talked about her fear of their son being born with additional anomalies and she cried frequently in the interview. I also found myself tearing up listening to her. I wondered if that was appropriate. I thought about what would have been appropriate in a therapy setting. I decided that it was acceptable as long as I did not cry earlier and/or harder than my participant.

I noticed after this interview that I was not hearing any new information. Most couples identified the same concerns and same lessons learned. However, some couples emphasized one concern having the most significant impact. For example, some couples, such as Rachel and Francis, were upset about the social stigma they experienced and consequently withdrew from people especially during the initial stages after birth.

At this time, I was still struggling to find more participants for my postnatal diagnosis group. I continued to make phone calls to the prospective participants from the original sample. Two other couples seemed interested in the study but later dropped out. One couple said she found the survey questions too personal. I assumed she was referring to the questions in the RDAS about sexual relations. I was surprised because the mother in this couple was a psychological counselor and the father was a psychiatrist. I expected them to be more enthusiastic about research in the field of psychology and more open minded about answering questions. I tried to explain the rules of confidentiality to the mother one more time, but she stated that she was still not interested.

Another couple from the postnatal group agreed to participate but dropped out on the day of the interview because the father did not want to participate. I checked in with the mother about their participation multiple times before the interview. She confirmed each time that they wanted to participate. Therefore, I sent them the consent form and the surveys. They confirmed that they mailed them back to me. Finally, on the day of the interview, the mother told me that her husband had changed his mind. I was angry because they had many opportunities to drop out of the study but waited until the last minute to drop out. However, this experience is also a part of doing a research study. It is time consuming for participants, which can affect their willingness to volunteer.

5.3.14 Interview # 14: Zoe and Bob

Demographics: Zoe and Bob had been together for 15 years; they lived together for 11 years and had been married for 10. They were both White. Zoe was a graphic designer with a college degree. Bob was a woodworker who completed some college. They both work full time. The couple had two children, a daughter and a son. Their son, the couple's second child, was born with CLP. He was 3 years old at the time of the interview. Their daughter was 18 months when their son was born. Zoe reported participating in online groups from CHOP and Cleft Advocate. The couple received the cleft lip diagnosis prenatally and the cleft palate diagnosis at the time of birth. I interviewed Zoe and Bob over the telephone.

The Couple's Story: Zoe was alone when she found out that her son was going to be born with cleft lip. She stated that it was the only ultrasound visit she attended alone in both of her pregnancies. She was upset by the "loss of the perfect child." Her initial fear was that her son was going to be teased at school because of the cleft. After leaving the doctor's office, she immediately called her husband, crying.

In his individual interview, Bob stated that he was with his wife when they found out about the diagnosis. He said he did not know what cleft was, so he did not think of it as a "huge issue." Zoe agreed that when Bob heard the diagnosis, he was more concerned about her and felt guilty that he was not in the doctor's office with her. The couple wanted to have additional ultrasound examinations to understand the severity of the cleft. However, they were not able to do so due to the position of their baby.

The prenatal diagnosis affected Zoe's pregnancy negatively: She worried excessively because she did not know the severity of the cleft or about the existence of

co-occurring syndromes, how to take care of a baby with cleft, and the cost of the operations. She checked with her insurance provider and learned that the insurance would not cover any medical appointments until birth. Therefore, she was unable to obtain information from CHOP regarding how to care for a baby born with cleft prior to the birth. Even though she could have talked to CHOP staff on the telephone and received some information, at the time she did not know about this possibility. She had to rely on information she found on the Internet. Additionally, she did not know what the insurance would cover regarding her son's treatment and surgeries. Bob was also worried about the severity of the cleft and stated that he did not want his son to live with a facial deformity.

At the time of their son's birth, the couple learned that he also had cleft palate. Zoe said that she was not surprised and had anticipated this because she knew that there were different levels of severity. The challenge at the time of the birth was the hospital not being familiar with how to feed a baby born with cleft. Learning how to feed her baby was hard for Zoe since the baby stopped breathing a couple of times while he was being fed. During their hospital stay, he had to be fed with a tube. When Zoe and Bob brought their son home, Zoe was concerned about "feeding her baby right." She fed the baby formula and felt bad about it because there was "too much out there glamorizing the breastfeeding." However, her pediatrician comforted her by saying that formula provided the same nutrients. Bob, on the other hand, stated that he was initially frightened because of the severity of his son's cleft. He thought about the course of treatment and whether they would be able to close such a wide cleft.

The first few months were the hardest for the couple because of adjustments to feeding, the NAM device, and going through the surgeries. Bob was happy that their son

adjusted to both the Haberman bottles and the NAM. Zoe shared that she was still grieving the “loss of the perfect child.” She did the tapings for the NAM and admitted that she was putting too much pressure on herself to “do it right.” Using the NAM was stressful for her, but she said she “would do it again in a heartbeat” because she saw the improvement in her son’s cleft. Feedings also became easier once she found the right bottles and nipples.

When she took her son out in public, one person asked her, “What’s wrong with him?” Zoe guarded her son after that incident; she often did not take him out because she did not want to hear insensitive comments from people. She thought that these were the types of questions her son was going to answer throughout his life, so she wanted to protect him when she could. The couple also found it “disheartening” when people they knew downplayed the significance of the cleft and the struggle it took to take care of their baby.

Before the first surgery, both parents were concerned about the anesthesia. It was difficult for Zoe to “hand him off to strangers,” but she trusted the CHOP treatment team, which eased her concerns. After the first surgery, the couple was happy that it was behind them. Zoe had a hard time seeing her son in pain after the first surgery. Bob admitted that he missed the cleft a little bit since her son’s smile “shrunk” after the first surgery.

The couple was glad they received the diagnosis prenatally because they were able to talk to the treatment team, come up with course of treatment, prepare emotionally, and were spared the shock. Both parents agreed that the first few months after his birth were hard but that now “he is just another boy” and the cleft did not impact his personality. During this process, Bob emphasized the importance of being patient.

This experience encouraged Bob to realize that his wife was stronger than he thought. Zoe also realized how resilient and strong she could be. They both were able to handle challenges when they worked together as a team. Bob and Zoe said that they were able to become a team when the issue was about their children. Zoe identified Bob as her “rock” during this process, providing emotional support. She was the one primarily responsible for the feedings and the tapings for the NAM, but Bob was there for the initial appointments for the NAM until she felt comfortable going by herself. He also soothed her when she got anxious about feeding their baby “right.”

RDAS Summary: Zoe and Bob were the second couple in the prenatal diagnosis group, besides Ben and Rebecca, who were clinically distressed based on their RDAS couple score. Their couple scores were at the clinical distress cutoff score of 48. Zoe’s individual score was 49 and Bob’s was 47. The couple scored above the cutoff scores for both consensus and satisfaction subscales. They had identical consensus (24) and satisfaction (15) scores. However, Zoe scored 10 in her cohesion subscale score whereas Bob scored 8, both of which were below the cutoff score. During their interview, Bob talked about his guilt about not being able to help Zoe with child rearing and household chores. Zoe agreed but understood it was because he carried most of the financial responsibility. Therefore, I expected the couple to score lower on the cohesion subscale. I also expected Bob to score lower in the cohesion subscale because of his guilt.

Personal Reactions: After interviewing Zoe and Bob, my interviews for the prenatal diagnosis group were finished because I had reached saturation in the previous prenatal interview. Overall, I had 10 interviews. Initially, I had believed them to be a couple from the postnatal group but later learned that they had received the cleft lip

diagnosis prenatally. At their son's birth, they found out that the baby also had cleft palate. However, I thought that this still classified them as a prenatal couple.

Even though my interviews for the prenatal diagnosis group were completed, I still had only four couples in my postnatal diagnosis group and was not sure that I had reached saturation for the postnatal group.

Bob stated that he was with Zoe when she received the cleft diagnosis whereas Zoe said that he was not there. She also talked about her husband feeling guilty about that, so I assumed that there was a reason he withheld this information. His guilt about not being able to do enough around the house to help his wife with child rearing and household chores became apparent during the couple interview.

Because Bob and Zoe were the last couple I interviewed for the prenatal diagnosis group, I wanted to reflect on the recurring themes. I also wanted to mention the new experiences I heard when I interviewed Bob and Zoe.

Zoe and Bob was the second couple in my sample who received the cleft lip diagnosis prenatally but learned about the cleft palate after their child's birth. Laurie and Bill also learned about their child's cleft palate postnatally. Zoe was not surprised because she knew there were different levels of cleft severity and that it was possible there could also be a cleft in their son's palate. She was worried about not being able to breastfeed him. However, her pediatrician's demeanor comforted her. The pediatrician reassured her that the formulas included the same nutrients as breast milk. I found this empathic demeanor of the health care provider beneficial for the emotional well-being of the mother because most mothers in my sample described feeling guilty about not being

able to breastfeed due to the glorification of and pressure to breastfeed by some of health care professionals.

Like other couples, Bob and Zoe described grieving the loss of the perfect child. They wanted to receive additional testing to find out about the co-occurring anomalies and severity. They were worried about the social stigma their son would experience. They were glad that they received the diagnosis prenatally because they were able to prepare emotionally and practically, but the prenatal diagnosis also caused Zoe to worry throughout her pregnancy. During the initial stages after birth, NAM, feeding, and surgery were the sources of stress the couple went through. Similar to the other mothers in the sample, Zoe emphasized that she wanted to “do it right.” Additionally, she talked about the comments and questions she encountered when she took her baby out. Other mothers reported having this experience before their children had their lip surgery. When asked about the impact of this experience on their relationship, Zoe and Bob emphasized being a team in going through the challenges. Zoe identified Bob as her “rock” during this process. The couple also spoke about financial concerns. They were the second couple in my sample who spoke of financial struggles related to cleft. The other couple, Sarah and Brandon, was in the postnatal diagnosis group. Zoe mentioned not knowing about the extent of her insurance coverage initially and then finding out that the insurance did not cover any visits before birth. For this reason, she could not speak to any professionals before she gave birth. She did not know that it was possible to receive information over the phone.

5.3.15 Interview # 15: Gayle and Joey

Demographics and RDAS Summary: Gayle and Joey were the only couple in my sample who did not return their demographic surveys and the relational distress measures. They informed me each time I checked in with them that they put the measures in the mail. However, the research team at CHOP never received their surveys, so I am unable to demographically describe them fully or report their RDAS scores. I conducted a telephone interview. Additionally, it was not possible for me to access their information through the CHOP database because the database includes detailed information about the children rather than the parents. However, from the CHOP database I learned that they were married. During their interviews, they stated that they had two children. Gayle was looking for a job.

The Couple's Story: Gayle was in a car accident two days before she was due to give birth, which triggered her labor early. Complications with normal delivery led her to have a cesarean delivery. After the child's birth, the doctor informed her that her daughter was born with cleft palate. She did not know what cleft palate was; she was only familiar with cleft lip. She told Joey herself since he was not with her at the time of her child's birth. Joey stated that he was shocked when he heard about the cleft palate diagnosis. He was stressed because "everything was snowballing"; the car accident, early labor, and cleft palate. However, he was happy that it was not cleft lip because he had seen children with cleft lip on commercials, which made his "blood run cold." Gayle described being really anxious when she found out about the cleft diagnosis because she had to pay extra attention to feeding her baby. Both Joey and Gayle were also worried about the first surgery.

Gayle had a difficult time feeding their daughter with the Haberman bottles initially, so Joey fed the baby. Gayle said that her daughter became more attached to Joey because he was the one who first fed her. Feeding their daughter was the biggest challenge for Gayle and Joey before the first surgery because the food came out of their daughter's nose and she threw up a lot. She also stopped breathing a few times when she was being fed. Additionally, special feeder bottles were expensive, and both Joey and Gayle were out of work at the time. Gayle noted that they were prepared for a baby, but not necessarily for a baby with a cleft. They had their family's support when providing care for their daughter. After the first surgery, the couple felt relieved because their daughter made it through the surgery and was on her way to recovery. Her feeding issues dissipated and she stopped throwing up.

For Gayle, their daughter's weight was an ongoing concern. She talked about being worried because her daughter was very thin. Speech was a concern for both Gayle and Joey because their daughter had speech difficulties and could not yet say her vowels. Gayle and Joey had to guess what she wanted to say as she pointed. If they were not able to guess correctly, she would lie on the floor and bang her head. She was receiving speech therapy, but she had to stop when her evaluation showed that she was not eligible for services; her speech delay was not significant enough to qualify for services. Gayle emphasized the importance of patience when trying to help her daughter communicate. Throughout this process, Gayle said it was important for her to remind herself that her daughter had cleft, which made her life more difficult and gave her less freedom.

When their daughter was born, the couple realized that her chin was too small. They alerted the doctors, who told the couple that they were going to keep the chin under

observation as the child matured. She might need surgery when she is 18. Another concern the couple had was the possibility of surgery on her chin in addition to orthodontic issues.

Joey believed that the medication Gayle took to quit smoking led to their daughter's cleft. Gayle said that she did not know what caused it but could not help thinking that it might have been something that she did. She believed that a prenatal diagnosis could have helped her become more knowledgeable about cleft. However, she would still have kept the baby. She believed that "God does not give anybody more than they can handle." Joey was glad that he did not know beforehand because he would have been more worried and stressed throughout the pregnancy.

The couple believed that this experience brought them closer to each other. They became a team while taking care of their daughter and did it in shifts. They did not want to leave their daughter with strangers because she had stopped breathing twice while feeding. Additionally, they did not want to place the burden of taking care of their daughter on anybody else. Therefore, they spent more time as a family doing movie nights and "snack nights" with their daughter and two other children. They believed that this was a way that the experience of cleft brought them together.

The couple listened to their doctors when making decisions about treatment. They had confidence in their treatment team. They believed that it was important to "take it day by day" and to refrain from focusing on hypothetical scenarios, which would increase their anxiety. They got their support from their families, God, and other parents who have children with cleft. They emphasized the importance of connecting with other parents

who have been through this experience by using online support groups to receive advice and information.

Personal Reactions: Gayle and Joey were the fifth couple I interviewed in the postnatal diagnosis group. I interviewed the mother, the father, and the couple on three different days. They were one of the hardest parents to track down and schedule an interview with. Gayle was very talkative; she answered every question in depth even when it meant that she was providing additional information. Joey was taking care of their daughter at the time of the interview. I learned that their daughter became very attached to Joey since he was the one who fed her right after she was born. The couple explained that this was why their daughter had difficulty being separated from Joey right now. I wondered what they were doing when he had to go to work. At the time of Joey's interview, their daughter was screaming and crying in a separate room, but I could hear her. Part of me felt guilty that I was taking Joey away from her. I asked Joey if he wanted to do the interview at a different time. He told me that he preferred to "get it over with." I found that this did not impact me negatively since I was used to fathers seeing the interview as an ordeal.

When Gayle and Joey mentioned their daughter's chin being too small, I was immediately alarmed because I knew that it could indicate additional anomalies. In that case, I had to remove them from my sample. I was afraid of this possibility because I was in desperate need of participants in my postnatal diagnosis group. Therefore, I checked in with the parents again to see if she was diagnosed with any other anomalies. They stated this was not the case. Additionally, I checked in with the research team at CHOP and learned that her diagnosis was bilateral cleft palate. I was relieved.

I was surprised when Joey said that he was happy their daughter was not born with cleft lip because the sight of it “makes his blood run cold.” He was the second parent in my postnatal diagnosis group, after Minnie, who shared being happy about his daughter having cleft palate rather than cleft lip. I was surprised because I know that cleft palate rather than cleft lip is associated with additional anomalies. Also, it is harder to feed a child with cleft palate, and they are more likely to have problems with speech. I wondered if they had the same knowledge that I have about the comparisons between cleft lip and cleft palate. Furthermore, it gave me an idea about how important appearance is for people living in our society, even if it is at the cost of reduced functioning.

Throughout their interview, I heard themes similar to those I heard from other parents in the postnatal diagnosis group. Gayle and Joey were the third couple in the postnatal diagnosis group who reported that their child had problems with speech. I felt that their struggles were similar to those of Minnie and Junior, who also talked about having to play the “guessing game” with their daughter to figure out what she wanted. Both couples described their daughters as becoming frustrated to the point that they started to hurt themselves when the parents were unable to figure out what the children wanted. Joey seemed especially overwhelmed with this situation. At the time of their couple interview, I learned that they were not going to continue with speech therapy because they were told that their daughter’s speech delay was not severe enough. Gayle felt this was a positive development whereas I was suspicious because they had described their daughter’s speech as a significant problem in their daily lives. I thought of this new development as them not being eligible for speech therapy anymore even though they

needed it. However, I did not want to rain on their parade and kept that information to myself.

Both Joey and Gayle described “taking it day by day” and not worrying about “hypothetical scenarios” to manage their anxiety. I thought of this as a helpful approach that any family or person who is dealing with the “fear of unknown” could use.

Gayle’s concern about her daughter’s eating and weight reminded me of my own mother. I was also a child who threw up often, especially when I was younger. I was born with cleft lip and palate, so I probably also had food coming out of my nose when I was fed. I was told and had seen in pictures that I was a skinny baby. I heard stories about how, right after I threw up, my mother would prepare the same meal and force me to eat it. Growing up, she continued to be obsessed with what and how much I ate. I remember us having a fight every morning when she was forcing me to have breakfast. She was furious if I did not eat enough. It was a traumatizing experience. I still cannot eat breakfast right after I wake up. She also continues to perceive me as “very skinny” even when I am not. Sometimes, I find myself wondering if there is a part of her brain that distorts the image she sees of my body.

5.3.16 Interview # 16: Jill and Larry

Demographics: Jill and Larry had been together for 12 years and 9 months. They got married and started living together 9 years ago. Jill was a 36-year-old waitress and Larry was a 37-year-old forklift operator. They were both college graduates. Larry worked full time and Jill worked part time. They had two daughters. Their younger daughter, who was 2, was born with CLP. Their older daughter was 4 when her sister was

born. The couple received the diagnosis postnatally. I interviewed the couple over the telephone.

The Couple's Story: Jill and Larry found out that their daughter was born with CLP after Jill gave birth. Jill said that the doctor did not bring her daughter to her right after the delivery. The doctor asked them if they were familiar with CLP and told them that their daughter was born with it. Jill's initial thought was "What did I do wrong?" The doctor comforted her by saying that she did not do anything wrong. Jill was also trying to figure out the course of treatment to "fix" the cleft. Larry confirmed this and said that Jill was initially very anxious but calmed down when the doctors provided them with information about the treatment. Yet she was still worried about feeding, speech, and social stigma. Larry already knew that a surgery existed for this condition from the commercials of Smile Train he saw on television. Therefore, even though he was "a little shocked," he was not "distracted." Jill was also more worried about their daughter's appearance than she "let on." Larry said it did not bother him because "she was still beautiful" to him. Jill did not mention being bothered by her daughter's initial appearance during her individual interview.

The first few months were hard for the couple because their daughter had reflux and colic. She was not sleeping through the night and was constantly crying. Jill felt bad that she was not able to breastfeed her daughter because she had breastfed her older child. She felt that she could have given her daughter better nutrients with breast milk, but it was difficult and time consuming to pump and feed her daughter, so she decided on feeding her formula. Yet it was challenging to find a formula that she felt comfortable eating. Additionally, they struggled with finding the right bottle and nipple. Another

challenge was the tapings for the NAM. Keeping the NAM in their daughter's mouth, doing the tapings right, and making it to the doctor's appointments were challenging. Jill was the one who took their daughter to the doctor and she said it was difficult to take time off from work for the appointments. Struggling with feeding, reflux, and colic as well as the NAM caused a significant amount of stress in their lives; Jill went back to the hospital with stress-induced cardiac issues 2 weeks after giving birth. This period was also challenging for the couple's relationship; they were both frustrated with their daughter. Because they could not take it out on their daughter, they directed their frustration toward each other. Once they found the right formula and she started sleeping through the night, taking care of her became easier.

Jill stated that she had no concerns before their daughter's first surgery, whereas Larry identified possible complications and the outcome of the surgery as some of his worries. After the surgery, Larry was content with the changed appearance of their daughter. Jill said it did not matter—she was beautiful before and after the surgery. Their opinion of her did not change.

The couple was concerned about their daughter's speech because she was still receiving speech therapy. Larry was also concerned about social stigma and its social impact on their child. He stated that she might have to go through another surgery in the future, which was worrisome. He also got tired of explaining his daughter's condition to people.

When asked if they would have liked to receive a prenatal diagnosis, the couple emphasized that even though they had the ultrasound examinations, they were not informed before the birth. Jill said that a prenatal diagnosis could have helped them to do

research about cleft and prepare. However, it would not have made a difference as to whether they would have the baby or not. She stated that they “would not have put their child on the side of the road like people in other countries do.” Larry agreed that they would have been familiar with cleft and prepared rather than “taking the crash course” as they were trying to take care of a baby with cleft.

Larry and Jill stated that they learned to depend on each other throughout this process and realized the strength in themselves and each other. Larry identified Jill as the person who was doing most of the care since she was at home during the day. He was the one helping out in the evenings and providing emotional support. He highlighted the importance of checking in with each other, talking about issues that were bothering one partner, and giving each other nights off when one needed a break. Larry talked about learning the importance of taking a step back, understanding his priorities, and being there for their children. He admitted that there were times he felt that they neglected their older daughter because they were so focused on taking care of their daughter with cleft. He realized that this was having a negative impact on their daughter and started paying more attention to her feelings. The challenging part was keeping calm and focused when trying to get through each day. They also had to endure questions and stares from both children and adults when they were out. They became used to answering people’s questions.

At the time of the interview, the couple was no longer spending much time talking about cleft. They would update people on where they were in their treatment path. Larry stated that he did not want to provide a lot of details, which can overwhelm people and lead them to think about cleft as more significant than it actually is. He worried that this

might cause other people to pity them. Thus, he provided a basic explanation to people when they asked. The couple did not talk about cleft with each other anymore either, unless something came up on television or the Internet that reminded them of their experience. If it did, they would think back and talk about what they had been through.

RDAS Summary: Jill and Larry's couple RDAS score was 34.5, indicating that they were in the clinically distressed category. Jill had an individual score of 39 and Larry had an individual score of 30. Their individual scores were below the distress cutoff score of 48, illustrating clinical distress. Larry had the lowest father score and Jill had the second lowest mother score in the postnatal diagnosis group. Their score difference of 9 was the second highest score difference after Minnie and Junior's and was higher than the average score difference of the couples in the postnatal group (7.2). Their total RDAS score and individual scores were all below the postnatal groups' means for the couple (42.8), mother (42), and father (43.8) scores. Jill and Larry had the lowest consensus subscale scores in the postnatal group. Jill's score was 14 and Larry's was 12. Furthermore, Jill had a satisfaction subscale score of 14 and Larry's was 11. The couple had the largest score difference in the cohesion subscale, in which Jill's was 11 and Larry's was 7. Larry had the lowest cohesion subscale score in the postnatal group. I attributed the lack of cohesion in their relationship to their social class. In families in which both parents work to make ends meet and arrange their work schedules according to the chores they have to do, it is difficult for them to find time for each other and to do activities together that they both enjoy. Additionally, since Jill was the partner in this couple who hesitated to show her vulnerabilities, I was not surprised that she rated their relationship higher than Larry did.

Personal Reactions: Jill and Larry were the sixth couple I interviewed for my postnatal diagnosis group. I conducted this interview in three days; first, I interviewed Jill, then Larry, and then I conducted the couple interview. Even this process gave me the impression that they had hectic schedules.

I conducted Jill's interview during the day. It was frustrating because she was very guarded during the interview. She stated that she experienced so much distress during the initial stages that she had to go to the hospital because of stress-induced cardiac issues. She did say that feeding was a big challenge for her. However, when I wanted to explore that more deeply, she denied that it was challenging at all. I felt that she was trying to give short, dry answers to my questions. I questioned if this was related to her desire to come off as "strong." Therefore, I was glad that I was also going to have the opportunity to interview Larry. I was hoping to get a more in depth description of their experience from him.

Larry was indeed more open and sharing than Jill. He described their experience when receiving the postnatal diagnosis in much more depth than Jill did. He said that Jill was more bothered by her daughter's appearance than she let on. Additionally, she was very anxious about the treatment path until she talked to the doctors. Jill did state that she was concerned about the treatment path, but she did not provide details about the extent of her reaction. She said she felt relieved when the doctor said she did not do anything to cause her daughter's cleft. Part of me felt dubious about her getting over her self-blame that easily. My suspicion might have stemmed from the number of mothers in my sample who struggled with self-blame.

I also found myself having a strong reaction when Jill stated that there are many parents in other countries who “put their children on the side of the road” because they are born with cleft. I was once again happy that I did not share my cleft status with my participants because it could prevent them from talking without restrictions. However, I also felt frustrated when Americans passed judgment about people living in countries that they would not even know how to locate on a map. I think, with time, I learned to attribute these comments to their ignorance.

Listening to Jill and Larry, I did not notice any new themes emerging from their interview except when Larry talked about her older daughter being jealous when they were focused on taking care of the one with cleft. I felt that this was an important issue that none of the couples I had previously interviewed had mentioned. I do remember my sister once describing a similar experience of having to stay in the background as I was going through my surgeries. I do believe in the importance of spending alone time with the other child so that he or she would not feel jealous. Rachel and Francis described doing this with their daughter. Francis had talked about taking a day off from work as being acceptable if his children needed him. However, there is an apparent class difference between the two couples. I wonder how easy it would be to take time away from their work schedules for both Larry and Jill so that they could spend time with their daughter.

5.3.17 Interview # 17: Ann and Eric

Demographics: Ann was 23 and Eric was 24 years old. Ann stated that she was a stay-at-home mom and Eric worked part time. The couple was White. He did not report his occupation on the demographic survey. Ann and Eric had been together for 5 years.

At the time of the interview, they informed me that for the past month they had been in the process of separating but were still living together “part-time.” The couple had one daughter who is 3. She was born with cleft palate. I conducted the interview on the telephone.

The Couple’s Story: When Ann gave birth to their daughter at a local community hospital, the hospital staff noticed that she was not breathing right away. She was then transferred to the intensive care unit and was taken to CHOP. Ann and Eric went to the hospital the next morning and found out that she was born with cleft palate. Eric was upset and started to cry. He worried about his daughter having breathing problems. Ann was scared too; she did not know if cleft palate was a permanent disability or if it was fixable. Being with Eric reduced Ann’s distress because she did not feel alone. Eric stated that it was his duty as a father to be there for Ann and his child.

Their daughter stayed in the NICU at CHOP for 3 weeks. She was fed with a feeding tube and monitored for sleep apnea. Ann stated that she knew her daughter was in good hands at CHOP, which made this process easier. Ann fed her daughter with breast milk when she was at CHOP. She switched to formula when the couple brought their daughter home. Ann stated that she had planned to breastfeed before birth, but it was not difficult for her to switch to formula. It was more difficult to feed their child through a tube even after they took her home because they were afraid that their daughter was going to pull the tube out. Before they left the hospital, they took CPR classes because their daughter had sleep apnea. Additionally, the hospital staff at CHOP taught Ann and Eric how to put the tube back in case their daughter pulled it out. Ann was too scared, so

Eric did it. He was also scared about hurting his daughter. For the couple, the most challenging part of this experience was feeding.

Their daughter had her surgery when she was 15 months old. Ann was concerned because she was “too young.” Both Eric and Ann were worried about the anesthesia, possible complications, and the results of the surgery. Eric said he “just did not want them to damage the cleft any worse than it was.” After the surgery, they were saddened by the postoperative appearance of their daughter because she was swollen and had restrainers on so she could not touch her face.

Their daughter started receiving speech and physical therapy when she was 9 months old. The therapists came to the house for 2 years. At the time of the interview, she did not have any developmental issues or trouble making friends. Ann stated that she was prepared to have a baby but not a baby with cleft palate. Yet the couple described that raising a child with cleft palate was not stressful except for the first few months.

When asked if they would have liked to receive the diagnosis prenatally, the couple stated that they had had the ultrasound examinations but that they “were not looking for cleft.” Ann would have preferred to know, but Eric said it would not have mattered; he was still going to do his duties as a father. Ann did not know what caused it; Eric thought that it was Ann’s poor eating habits and lack of exercise.

The couple was having problems in their relationship when their daughter was born, but they stated that this experience brought them closer. They had to be civil with each other for their daughter’s sake because now the problem was not about them but about their daughter. The car rides to the hospital when their daughter was staying at CHOP were difficult because they lasted about an hour, and it was “a lot of time to bring

up arguments.” After they brought their daughter home, both Ann and Eric were at home with her for 2 months. They shared the responsibilities and tag-teamed with each other. At the time of the interview, Ann was not working, so she was with her daughter during the day and Eric was with her in the evenings and on weekends.

They told me that cleft palate was no longer “an everyday discussion” in their relationship. They mostly listened to the doctors about treatment issues and took their advice. They had a mutual agreement that “whatever needs to be done, will be done.” They were also on the same page about parenting most of the time. When they disagreed, they debated it until they came to an agreement. They no longer talked about cleft palate with their families as they did in the beginning during their initial struggles. They were hesitant about sharing with outsiders, but if they needed to explain it, they highlighted that it was fixable and that it was not visual and was not a significant issue that would impact her for the rest of her life

RDAS Summary: Ann and Eric’s total RDAS score was 43.5. Ann’s individual score was 45 and Eric’s was 42. Their individual and couple scores indicated that the couple was clinically distressed. This result was expected because they reported that they were in the process of separating. What was surprising was that, even though they were separating, they scored higher than two of the other couples in the postnatal diagnosis group. Their score difference of 3 was below the mean score of the group (7.2). Ann’s subscale scores for the consensus, satisfaction, and cohesion subscale scores were 22, 10, and 13 respectively. Her consensus subscale was at the distress cutoff whereas her satisfaction subscale score was just below the cutoff score of 14. Her cohesion subscale score was above the distress cutoff (11). Larry’s consensus (19) and satisfaction (10)

subscale scores were below the distress cutoffs, but his cohesion subscale score of 12 was above the cutoff score as well. In cohesion, the both partners scored higher than the average cohesion score for mothers and fathers in the postnatal diagnosis group.

Personal Reactions: Ann and Eric were the last couple that I interviewed for my dissertation study and the seventh couple in the postnatal diagnosis group. It was extremely difficult to reach them. I interviewed Ann, and it took me a month to get in touch with Eric to conduct his individual interview as well as their couple interview. At one point during my struggles to get in touch with him through Ann, she said she was sorry, but he was “irresponsible,” so I figured that their relationship was not on solid ground. Ann and Eric were the only couple in my sample who were not married. They were also the only couple who was in the process of separating at the time of the interview. Additionally, they were the only couple below the age of 30. For this reason, I was curious how their experiences would compare to those of the other couples.

I was struck by how Eric described being there for his wife at the time of birth and taking care of their daughter as his “duties” as a father. The other fathers did not use this terminology when describing their experiences of taking care of their children. I wondered if it related back to Ann and Eric having problems in their relationship. I wondered if a part of him resented that he had to do so much. I questioned if “marriage” promotes the emotional connection that fathers have for their children because in my therapeutic practice, I meet with many fathers who do not fulfill their responsibilities as a parent, especially when they are not married to the mothers.

When Ann and Eric’s daughter was born, she had difficulty breathing, she had to be transferred to CHOP, and she had to stay in the NICU at CHOP for 3 weeks. This

experience was a new one that none of the other couples had reported. I questioned if their daughter had additional anomalies because this interview was the only one in which I heard about breathing restrictions in a baby with cleft palate. I asked Ann if there were additional anomalies involved, but she denied it. I conducted a literature search and found that sleep apnea can co-occur with nonsyndromic cleft palate. Additionally, their daughter had to be fed with a feeding tube, which was similar to Zoe and Bob's son. However, the duration of Ann and Eric's experience with the feeding tube was much longer, increasing their level of stress around it. They continued to feed their daughter with the tube even when they brought her home. When Eric described how he was the one who learned how to put the tube down his daughter's throat and stayed at home with her for 2 months, I realized that he was more involved than some of the fathers in my study who were at home for 2 weeks with their wives and went back to work. The feeding was mostly the responsibility of the mothers and the fathers provided emotional support during this process, trying to ease their wives' anxieties. Part of me appreciated Eric for being more involved practically.

Another new experience I heard when I interviewed this couple was their daughter being in the NICU for 3 weeks. The couple mentioned that it was due to the breathing restrictions their daughter was having as well as the necessity for the feeding tube. I wanted to question this further because I did not want to create an additional anxiety in them by saying that most children in my sample did not stay in the NICU for 3 weeks. I realized that I would have been more suspicious toward this decision if their daughter had been staying at any hospital other than CHOP, because in my interviews I have heard many parents complaining about hospital staff not being knowledgeable about

how to care for a child with cleft. However, since they were at CHOP, I figured that the hospital staff wanted to bring their daughter's sleep apnea and feeding under control. I also wondered if the hospital staff was hesitant to send their daughter home because the couple seemed to be unknowledgeable about cleft. Initially, they described not even knowing if it was fixable.

Ann and Eric shared many experiences with other couples interviewed for this study. They described feeding as the biggest challenge similar to many other couples even if there were differences in the way that the children were being fed. They shared the same concerns as other parents regarding the surgery, such as being concerned about the outcome of surgery, anesthesia, and possible complications before the surgery and being saddened by their daughter's postoperative appearance after the surgery. They stated that the initial stages of taking care of their daughter with cleft palate were challenging but that they were no longer stressed. Thus, cleft palate was no longer a topic that they talked about frequently. When they explained it to other people, they highlighted that it is fixable and that it is not a significant issue that would impact her for life. Like other parents whose children were born with cleft palate, they also educated people about different types of clefts and how their daughter has the cleft in her palate, which is not visible.

They made decisions about treatment by listening to the doctors and having discussions on the basis of what they said. Similar to other couples, they agreed that they would provide all the treatments necessary for their daughter. Even if they were having issues, Ann and Eric emphasized that this experience brought them closer. They could be

having problems in their relationship, but it did not stop them from becoming a team for the sake of their daughter.

5.4 Prenatal Diagnosis Group, Mothers: Dominant and Subdominant Themes

Mothers in the prenatal diagnosis group described their experiences raising a child with cleft and focused on the following four time periods: (1) prenatal diagnosis, (2) birth, (3) initial stages after birth, and (4) current situation. Prenatal mothers also reflected on their experiences raising a child born with cleft. The dominant themes summarizing the experiences of the 10 prenatal mothers are organized into the following five categories: (1) prenatal diagnosis, (2) having the baby, (3) initial stages, (4) current situation, and (5) raising a child with cleft. Within each of these five dominant themes, 20 subthemes emerged that capture specific aspects of their experiences. An analysis of these subthemes is provided with illustrative quotes from mothers in the prenatal diagnosis group. An overview of the 5 dominant themes and 20 subthemes is provided in Table 5.9. I defined a theme as “dominant” if more than half of the participants in the sampling unit mentioned it. In this section, six or more mothers mentioned the dominant themes (of the 10 prenatal mothers interviewed). To inform the reader of the frequency of specific themes mentioned by mothers in the prenatal diagnosis group and the number of mothers who mentioned them, I included the “theme frequency” section in Table 5.9. Finally, representative (anonymous) quotes are provided to illustrate each subtheme.

Table 5.9. Dominant Themes of Mothers in the Prenatal Diagnosis Group

Level	Themes	Theme Frequency/Prenatal Mothers' Quotes in this Chapter
100	Dominant Theme: Prenatal Diagnosis	321 total segments: All prenatal mothers

101	Process of finding out	76 segments: All prenatal mothers Prenatal mother quotes: Laurie, Rebecca, Jane, Vader, Elizabeth
102	Initial feelings	41 segments: All prenatal mothers Prenatal mother quotes: Elizabeth, Zoe, Mo
103	Initial concerns	82 segments: 9 of 10 prenatal mothers Prenatal mother quotes: Rebecca, Mo, Mary
104	Couple's process	28 segments: 9 of 10 prenatal mothers Prenatal mother quotes: Rebecca, Zoe, Jane
105	Impact on pregnancy	14 segments: 6 of 10 prenatal mothers Prenatal mother quotes: Rachel, Mo
106	Informing	32 segments: All prenatal mothers Prenatal mother quotes: Rebecca, Jane, Mary, Laurie, Rachel, Elizabeth
107	Opinions on the prenatal diagnosis	31 segments: All prenatal mothers Prenatal mother quotes: Abby, Zoe
200	Dominant Theme: Having the Baby	118 segments: All prenatal mothers
201	Pregnancy and birth	13 segments: 6 of 10 mothers Prenatal mother quotes: Rachel, Zoe
202	Preparedness	65 segments: All prenatal mothers Prenatal mother quotes: Jane, Mary, Zoe
203	Concerns	14 segments: 8 of 10 prenatal mothers Prenatal mother quotes: Mo, Zoe, Rebecca
300	Dominant Theme: Initial Stages	140 segments: All prenatal mothers
301	Feeding	22 segments: 8 of 10 prenatal mothers
302	Surgery	90 segments: All prenatal mothers
400	Dominant Theme: Current Situation	44 segments: 9 of 10 prenatal mothers
401	Treatment	8 segments: 6 of 10 prenatal mothers Prenatal mother quotes: Rebecca, Laurie
402	Child's functioning	12 segments: 7 of 10 prenatal mothers Prenatal Mother Quotes: Rebecca, Vader
403	Concerns	24 segments: 8 of 10 prenatal mothers Prenatal mother quotes: Elizabeth, Mo, Jane
500	Dominant Theme: Raising a Child with Cleft	183 segments: All prenatal mothers
501	Sources of stress	40 segments: All prenatal mothers Prenatal mother quotes: Abby, Zoe, Elizabeth

502	Challenges	23 segments: All prenatal mothers Prenatal mother quotes: Rebecca
503	Reasons for cleft	21 segments: All prenatal mothers Prenatal mother quotes: Mo, Rachel, Mary
504	Lessons learned	45 segments: All prenatal mothers Prenatal mother quotes: Rebecca, Mary, Mo, Jane, Laurie
505	View of the child with cleft	30 segments: All prenatal mothers Prenatal mother quotes: Vader, Elizabeth

5.4.1 Dominant Theme: Prenatal Diagnosis

The first dominant theme, prenatal diagnosis, describes the experiences of mothers when they first heard about their child's cleft diagnosis during the ultrasound examination. The first three questions in my interview guide (Appendix D) focus on learning how the mothers first found out about their child's cleft and on their initial thoughts, feelings, and concerns. All 10 mothers described their experiences at the time of the diagnosis in 321 segments. This dominant theme was then divided further into the following seven subthemes: (1) process of finding out, (2) initial feelings, (3) initial concerns, (4) opinions regarding the prenatal diagnosis, (5) impact on pregnancy, (6) couple's process, and (7) informing others.

5.4.1.1 Subtheme: Process of Finding Out

The process of finding out subtheme describes mothers' reactions when they first received the cleft diagnosis in utero. Mothers shared their reactions during the ultrasound examination and their impressions of the doctor's demeanor as she/he delivered the diagnosis. As described in Table 5.9, this subtheme appeared 76 times in the descriptions of all 10 mothers in the prenatal diagnosis group.

Most mothers received the diagnosis at the 20th week ultrasound examination, when an ultrasound technician conducted the examination. Mothers reported that usually the ultrasound technician suspected something first and then alerted the doctor or the midwife who later shared the diagnosis with them. Seven received the diagnosis immediately; two mothers, Rebecca and Rachel, had to wait because the doctor was not at the clinic or because they had to go through an additional ultrasound examination because the first one was not clear enough to make a definitive diagnosis of cleft.

Rebecca shared the following:

The ultrasound tech was saying she didn't get a good shot of his face and to come back in a couple of weeks. I didn't think anything was wrong. It didn't even cross my mind at first that anything could be wrong; I just thought she couldn't see it. But then as it got closer, I started thinking maybe something is wrong and the only thing I thought it could be was cleft. Then when we did go back for the follow up ultrasound, they kept focusing on it.

When I asked her how she suspected it was cleft, she told me it was because the technician kept focusing on the baby's face in the previous ultrasound examination. However, the technician did not say anything because she was not sure. Rebecca's experience illustrates the importance of the health care professional's demeanor when providing the diagnosis to parents. One mother, Mary, received a trisomy 18 diagnosis initially, had additional testing, and found out that her daughter had an isolated cleft lip palate. Rachel had to wait 7 hours before the ultrasound technician spoke with the doctor and the doctor called them to share the news. Mothers were referred for additional testing after they received the cleft diagnosis in order to rule out any co-occurring anomalies.

Laurie, who was also born with CLP herself, was one of the parents who received the diagnosis immediately and was referred to further testing. She explained:

When I was pregnant with my son they did basically a screening at the first ultrasound, at the screening ultrasound where they are looking at all the structures to see if it is intact. At that point we did see that he had a cleft lip, a unilateral cleft lip, and then we were referred to CHOP for their fetal program.

Unlike the nine other mothers in my sample, Laurie used medical terms when describing how she received the cleft diagnosis. She was keenly aware that it was the ultrasound examination that providers checked to see if “all the structures were intact.” Additionally, she was the only mother in my sample who used the medical term “unilateral cleft lip.” I thought this was because she had extensive knowledge about how cleft was diagnosed and about its different formations because of her own experiences. Similar to other mothers in my sample who were not born with cleft themselves, she was referred for additional testing to find out the severity of the cleft and the possibility of additional syndromes.

Four mothers in my sample reported being negatively impacted by the health professional’s demeanor at the time of the cleft diagnosis. It was helpful for them if the doctor first explained the diagnosis in a calm and nurturing way, helping to soothe parents’ concerns and anxiety. It was upsetting for parents if the doctor was dismissive of their concerns. Jane talked about the reaction of the nurse when she and her husband asked to receive more ultrasound examinations to determine the severity of their son’s cleft. She shared:

One of the things that has always stood out to me and I've held against particular physician, that the nurse practitioner who was on staff that day when my doctor was not available; I remember - you know, we were obviously pretty shocked at the diagnosis. I remember Mitch asking, "Well, will we have other ultrasounds as the baby gets bigger and as the baby develops to really get a sense is it just the lip, is it the lip and palette, and how extensive is it," to know. She was very dismissive and said "Well there's nothing you can do about it, so I don't see any reason why we would do that," and she sort of closed the door on it. Two mothers diagnosed prenatally described how their doctors talked about abortion as an option after giving them the cleft diagnosis. Vader expressed her reaction to the way her doctor gave her the news:

Well, he scared me at first because he's like, "Well, you know, your son has a cleft. I don't know if you want to terminate. I've never heard of anybody wanting to terminate." Actually, I can't believe he said that to me. I was very upset afterwards, after the whole shock of him saying that, like oh my God, this is what I have to decide on. Even if the doctor did later say that he did not know of anybody who wanted to terminate a pregnancy because of a cleft diagnosis, even mentioning abortion as an option gave a false impression to Vader about the seriousness of her son's cleft. She stated that she was angry when she learned more about cleft and learned that it was fixable with surgery and treatment. On the contrary, Mary shared that doctors initially diagnosed her baby with trisomy 18. He told her that he found problems in her baby's heart and brain, in addition to diagnosing the baby with cleft. Mary described being distraught hearing this news. However, after having additional testing at CHOP, trisomy 18 was ruled out and the baby was only diagnosed with cleft.

Regardless of the doctor's demeanor when first delivering the cleft diagnosis, mothers did think about the severity of the cleft and considered the possibility of co-occurring syndromes. Most doctors referred mothers for additional ultrasound examinations and testing to learn about the extent of the cleft. They had multiple screenings and tests that they would not otherwise have had to learn if their child's cleft was isolated. Describing the additional procedures she had, Elizabeth said;

We got an ultrasound that was a high resolution one it sort of took an hour. It was forever and they checked everything, and then we had to get a fetal cardiac echo, had to meet with a genetic counselor, but the results of all those things was that they felt the baby was fine and this was an isolated issue. Then we began to feel a little bit better. When mothers learned that their child had an isolated cleft, they usually felt relieved and grateful. They thought about so many other health conditions that their child might have had and began viewing the cleft as a "cosmetic" and a "fixable" problem. One mother felt angry because her doctor described it as a more serious condition and suggested an abortion at the time of the diagnosis. Four mothers, however, still continued to worry about the additional syndromes, thinking that they could never be sure until the baby was born.

They also continued to worry about the severity of the cleft. They asked to receive additional ultrasounds to find out more about the severity. For example, Jane wanted to learn if her son had cleft palate in addition to the cleft lip. She described going through additional ultrasounds to find out about the severity:

We persisted and we had other ultrasounds, and we had an ultrasound where the doctor and the tech were trying to figure out if they could visualize the palate. That was

very reassuring when they thought they could do that. They thought they could see teeth buds and in a full row, but that was very reassuring and so that just let us plan and it certainly gave us time to adjust the idea. Knowing the extent of the cleft provided Jane with a sense of security. She said that she could just get ready for her son being born with cleft lip. This statement suggests the different level of care needed when a baby is born with cleft palate and cleft lip because it requires additional surgeries and more challenges with feeding and speech. At the time of the cleft diagnosis, mothers were going through a roller coaster of emotions.

5.4.1.2 Subtheme: Initial Feelings

Mothers who received the diagnosis prenatally reported that at the time of the diagnosis they felt upset and scared. Some mothers described feelings of shock, worry, and self-blame. As shown in Table 5.9, 9 of 10 mothers shared these feelings in 41 segments. The feeling “upset” includes a mixture of sadness, worry, and anger. Eight mothers in the prenatal diagnosis group described feeling upset. When they found out about the cleft diagnosis, most did not have extensive information about cleft and consequently did not know what to expect. Elizabeth said:

We were definitely upset, we didn't know what it meant, I think then when they said we had to have an amnio because clefts are associated with other issues, and I think that was what was more worrying to us. It made it seem like a bigger deal; frankly we didn't know that much about cleft. So I was definitely upset, it wasn't inconsolable but I cried a lot, we were trying to process it, that sort of thing. Mothers also talked about being upset because of the loss of the “perfect child.”

For example, Zoe said; “I was pretty upset. You know, you want that perfect child.” When asked about what made her upset about not having the “perfect child,” she expressed her frustration and said, “There’s going to be something wrong here, and we’re going to need to deal with that.”

Six mothers described being scared when they first heard about the cleft diagnosis. The main sources of their fears were concerns about their child being disfigured, social stigma that she/he might experience, not knowing the severity of the cleft, and co-occurring syndromes. The most prominent source of fear was different for each mother, but they all they talked about being fearful about the “unknown.” As Mo stated, “You didn’t know what was in store. You know what I mean?”

5.4.1.3 Subtheme: Initial Concerns

The “unknown” was the most commonly reported concern. The other main sources of concern were feeding, surgery, additional anomalies, severity, the child’s appearance after the surgeries, and social stigma she/he might endure as a result of the appearance. Nine of 10 mothers spoke about their concerns; the initial concerns subtheme included 82 segments. Seven mothers mentioned their child’s appearance and the social stigma she/he might face both as a baby and in the future. For example, Rebecca said, “You know I said to my husband, “I don’t want him to get made fun of by other kids,” and that was the biggest thing to initially get over.” Similar to Rebecca, Mo was concerned about the reactions of other children toward her daughter: “When we first heard of the diagnosis, well, I’m a teacher, and it was the kind of thing where you thought to yourself: Does my child have to endure the teasing of other children?”

Feeding was the second most frequently mentioned concern, described by five mothers, especially after the mothers researched cleft and found out that feeding was a significant challenge for other mothers after birth. For example, Mary said;

Is he going to eat enough? I mean, because we did a lot of research when I was pregnant. We had a lot of time to kind of prepare ourselves for what we could expect. I went on and I joined a parents group on www.babycenter.com and I got a lot of information from that from other moms who had kids with cleft. I think I really had as good of an idea as I could what I could expect. The main theme seemed to be the eating. So my biggest concern was he going to eat enough? [sic]

As mothers learned about cleft, they also came to the realization that they would not be able to breastfeed their children and instead would need to pump their milk and use the special feeder bottles for feeding. The mothers were concerned about their children would adjust to the bottles. Abby expressed her initial concerns about feeding as follows:

Your instinct is to want to feed your child, your baby, and that was my greatest worry when we found out about this, you know, how were we going to get her to feed and was she going to be able take to a special bottle? And obviously, we knew that breastfeeding – I would have to pump instead. So there were a lot of factors that went into it ahead of time.

In addition to the feeding, appearance, and social stigma, four mothers were concerned about additional syndromes, severity, surgery, insurance coverage, dental issues, speech, survival, care, family reactions, and impact on the child. Mothers worried about the number of surgeries it would take to treat their children's clefts. They were upset that

their children were going to have to endure pain during the surgeries. One mother also considered the costs of the surgeries and whether their insurance would cover them. Mothers were aware that surgery was not the only treatment for the cleft; the children would also have to receive treatment for speech issues and dental problems. They did not know how the course of treatment and coping with a visible difference would impact their children. They also did not know whether their families would accept their children. During their interviews, the mothers frequently described going through this process with their husbands.

5.4.1.4 Subtheme: Couple's Process

Nine mothers described the process they went through at the time of the diagnosis with their husbands, which was mentioned in 28 segments (Table 5.9). Eight mothers were with their husbands when they learned about their child's diagnosis. They identified their husbands as a source of support at the time of the diagnosis. The mothers also noted that it was good to have their husbands by their sides, because they were able to hear the news together, process it, and ask questions. Rebecca explained, "I was very happy that he was there with me. I started crying, he comforted me, and we got to hear the information together and ask questions at the same time."

For one couple, Jane and Mitch, the roles were reversed: The mother had to be the source of support for her husband when they first learned the diagnosis. Jane tried to provide comfort by framing the condition as more cosmetic and trivial. She knew that her husband had fears about having children with health issues even before the pregnancy, so when she described the moment they found out about the child's cleft, she said,

I think I immediately was worried. Mitch and I looked to see and I didn't know if he knew what it was and I said, I think she started describing it and I said something quickly like "Oh, those babies they do fine. They just need to use a special bottle."

If their husbands were not there at the time of the cleft diagnosis, the mothers had to inform them later about the cleft. Two mothers initially reported that their husbands were more concerned about them learning the diagnosis alone than about the cleft. They apologized and tried to provide comfort and reassurance. As Zoe described,

He was apologetic that I was there by myself. He was more concerned about my upsetness. I think I was more concerned about the cleft than he ever was. I think he was one of the people who said to me, "It's okay. It'll be okay. They do amazing things these days. They can fix that. This is a problem that can be fixed."

Mary was the other mother who was not with her husband at the time of the diagnosis; her doctor also suggested that their baby could be born with trisomy 18. She stated that she had to come back for a second appointment during the same day with her husband so that the doctor could explain the news to him. She said that she did not remember the details of the conversation she had with the doctor because she was so shocked and upset.

Two mothers discussed the possibility of abortion with their husbands. They had this conversation by themselves in private after receiving the diagnosis. The mothers explained that they decided to not go through with an abortion, either because of their religion or because they had been trying to conceive for a long time.

5.4.1.5 Subtheme: Impact on Pregnancy

Mothers reported experiencing a variety of feelings and thoughts throughout their pregnancies because they knew about the cleft diagnosis before the birth. Six of 10 mothers spoke about their experiences during the pregnancy in 14 segments. Mothers continued to be concerned about severity of the cleft, feeding challenges, and additional anomalies throughout their pregnancies. They wanted the birth “to come quicker” so they could know what they were dealing with. Even if they had information about the severity and the type of cleft, they still felt worried that there was something “more” so they still had to deal with the “unknown” until the baby was born. As Rachel explained,

We wanted the birth to come quicker. We wanted to definitely move it along quicker just to be sure that he or she was going to be okay. Other than having the cleft lip and palate, just that he or she would be okay and be a healthy baby.

Laurie also spoke about looking forward to the birth of her baby. She was a speech pathologist so she wanted to hold the baby and check the lip and palate herself to see how severe the condition was.

For two mothers, waiting for the birth was more challenging because they were informed that test results indicated that their babies could experience additional health problems. One of these mothers, Mo, said;

Every time I went for an ultrasound there was something else, whether it was a small stomach or whether it was a bowel problem. The very last ultrasound that we had we discovered that she was okay, but then they said, no, she had a kidney problem. So it was one of those things where you really didn't know what was

going to happen at the birth, and I was really scared throughout the entire time but handled it along with my husband.

In contrast, Elizabeth said that she knew her baby was “fine,” because she had been monitored closely throughout her pregnancy and been through many additional tests.

Feeding was another issue that created stress in the mothers throughout their pregnancies. If breastfeeding their babies were important for mothers, they continued to question if their babies also had cleft palate. One mother explained that she entered a Babies R Us store when she was pregnant and had to leave the store crying because the first section of the store had the feeding equipment. She remembered thinking to herself that she could never use any of these bottles because she would have to feed her baby differently from other parents.

Finally, mothers continued to worry about disfigurement. It took some more time to adjust to the idea that their child was going to look different from other children. Rachel explained that she took her time looking at the pictures of children with clefts. She went through different emotions and tried to focus on the belief that they could still have another baby so she prepared the room, picked out the furniture and bought the clothes. The best way for her to prepare herself emotionally was to remind herself that they were having a baby regardless of the cleft diagnosis.

5.4.1.6 Subtheme: Informing Others

When the mothers received the cleft diagnosis, they informed the people close to them. All 10 mothers explained how they informed other people about the diagnosis in 32 segments. They wanted to “prepare” their families beforehand so there would be no “surprises” at the time of the birth. Mothers usually called close family members such as

their parents soon after they received the diagnosis. Because they did not have extensive information about cleft, it was challenging for mothers to contain their own feelings when they delivered the news to others. For the other members of the family, they waited until they received more information about the severity and extent of their child's cleft.

Mothers described different ways of communicating this information. For three mothers, it was challenging to deliver the news to everybody in person so they did it via e-mail.

For example, Elizabeth said;

I told my parents over the phone, and of course I didn't know what I didn't know then, so that was hard because my mom completely over reacted. But then by the time I told everyone else in my family I did it via email. I had done basic research, I had gotten the amino. I can't remember if we waited for amino results or not, but I knew what we were dealing with and could make sure that they understood that it wasn't a big deal.

Because most families were not familiar with cleft, the mothers had to play the educator role as they shared the news with them. Delivery of the news started a "learning process for everybody." As Rachel pointed out,

We—actually we all kind of learned about it together because nobody, you know, from what we knew of it, it wasn't in the family. This was the first time, so we all – it was a learning process for everybody; the different Web sites, speaking with all the doctors and nurses who are extremely knowledgeable about it. It did. We were able to explain it to family and friends and they were able to look further and ask questions and research more about it as much or as little as they wanted to.

In addition to being educated about cleft beforehand, some parents noted that it was important to prepare their families emotionally. For this reason, it was helpful to receive the diagnosis before the birth. Laurie described, “It was great because everybody was prepared, there was no surprises [sic]. I think it’s one of those things you kind of process it, it’s good to process it before you have to face it I think.” If mothers had another child at home, they made sure to inform the sibling about cleft to prepare him/her for the visual differences that she/he would witness in his/her sibling. Mary showed pictures of babies with cleft and emphasized that having cleft did not cause any pain for the babies. She said;

We would pull up pictures online and say these are kids with cleft and this is what they look like and this is what your brother is going to look like. So that helped as well. It helps with the older sibling so that they’re not afraid or think that they’re hurt, that they’re in pain or anything like that.

Five mothers reported that they received positive reactions from their family members. They did their own research and informed the couple about stories of people who completed the cleft treatment successfully. One mother, Jane, had to deal with intrusive questions and degrading remarks from her family even though she and her husband had expressly stated that they did not want to talk about it. As she shared:

Really, the only people who said anything that made me angry, but I think it’s because we don’t always see things eye to eye, were my in-laws. One didn’t do a very good job of respecting our wish at the beginning that we not talk about it on Christmas. I remember being asked immediately about the amniocentesis I had, and I just remember being annoyed and saying, “We expressly told you we didn’t

want to talk about it, and I don't want to talk about it today." Then I think they used the word harelip, and that really bothered me.

Like Jane, other mothers had a difficult time sharing the news before they found out that there were no co-occurring syndromes. They wanted to wait until they received the results of the genetic tests before they told others, both inside and outside the family. Jane described e-mailing their friends before they found out about the results of the genetic tests and asking them to give the couple space before "they were ready to talk about it."

On the other hand, one mother, Rebecca, wanted to share the news with people outside of their families, such as friends and co-workers "right then and there" once she received the isolated cleft diagnosis. It was important for her that the cleft diagnosis was "out in the open" and was not something that people "whispered about under their breath." Rebecca emphasized:

I would say that I wanted it to be known right then and there. I wanted everyone to know, because I didn't want it to be like something people whispered about. You know what I mean, that people had to tell each other under hushed breath. I made sure everyone that I talked to knew that I was having a baby with a cleft because I wanted it to be out there in the open. Because I wasn't trying to hide it.

People outside of the family also described advancements in the medical field and the "amazing things the doctors can do these days." Mothers in the prenatal diagnosis group highlighted the importance of preparation both for themselves and for their families. They also described being worried about the child throughout the pregnancy.

5.4.1.7 Subtheme: Opinions on the Prenatal Diagnosis

All 10 mothers shared their opinions about the prenatal diagnosis (Table 5.9). There were 31 segments capturing their experiences. Even though three mothers mentioned that they wished they did not know about the cleft diagnosis before their babies were born because it increased their worries and prevented them from having a “happy go lucky pregnancy,” all 10 mothers were happy that they knew before the birth. They were able to prepare both emotionally and practically before they gave birth. They described the value of emotional preparation because they were able to process the information before rather than after birth when their “hormones are crazy” and they lacked sleep.

Additionally, six mothers explained that it could have been “shocking” for them to see their children with cleft when they were expecting a “perfect child.” Once they learned about it, they were able to do their research and learn more about what they would be dealing with, which made them feel more in control of the situation. With time, they were able to process their feelings about the diagnosis, grieve the loss of the “perfect child,” and get excited again about having a newborn. As Abby said,

I had the time to grieve it and didn't have to deal with a newborn all at the same time and my hormones were not all out of whack, you know, at the time. So I just think it's so, so critical that people find out ahead of time. I don't know what we would have done if we hadn't because it was the best thing to happen to us

Additionally, mothers were able to prepare “practically” for having a child with cleft. They were able to learn what cleft entailed and whether their children's clefts were isolated. Because they were able to talk to multiple treatment teams and pick their

preferred surgeon, they had information and a treatment plan when their babies were born. For example, when asked about her opinions regarding the prenatal diagnosis, Zoe expressed, “We were able to choose a doctor already; kind of have a plan. That’s kind of important for me. When something is wrong, I need to plan to fix it.”

5.4.2 Dominant Theme: Having the Baby

The second dominant theme, *having the baby*, describes the experiences of prenatal mothers when they gave birth to their babies with cleft. Question 4 in my interview guide (Appendix D) focused on the mothers’ experiences at the time of birth. The goal of the question was to understand if the mothers felt “prepared” to have a baby. The dominant theme included explanations from all 10 mothers from 118 segments. The dominant theme of having the baby was then divided into three subthemes: (1) pregnancy and birth; (2) preparedness; and (3) concerns.

5.4.2.1 Subtheme: Pregnancy and Birth

Six of 10 mothers described their experiences during pregnancy and birth in 13 segments. Four mothers in the prenatal diagnosis group had difficulty conceiving before they became pregnant with their child born with cleft. Some had had several miscarriages; some had tried to become pregnant for a long time and were even told that they were not going to be able to conceive. For this reason, they were really excited to finally have a new baby, regardless of the cleft. For example, Abby said, “I mean, she was such a miracle baby to begin with that we were just so elated to be able to have her. So I think that helped because we were so grateful it helped ease the stress of everything.”

When their babies were born, mothers described being relieved that they were finally able to hold their babies, check out the severity of the cleft, and determine the occurrence of additional syndromes for themselves. Rachel, who had a difficult time adjusting to the idea of her son being born with cleft, explained that her worries “went out the door” when she first saw her son. She said,

First time my eyes laid on him, I knew everything was okay. My husband brought him over, brought him around, and I laid my eyes on him and he was perfect. Anything and everything that I was feeling went out the door.

This experience was surprising for Rachel because she could not look at a picture of a child with cleft until 2 weeks before she gave birth.

5.4.2.2 Subtheme: Being Prepared

When asked if they felt prepared to have a baby at the time of birth, most mothers described being prepared to care for a child with cleft even though there were still some aspects they did not feel prepared for. This subtheme included 65 segments, and all 10 mothers spoke about being prepared (Table 5.9). They stated that they were able to process their feelings about having a child with cleft, grieve the loss of the “perfect child,” and figure out the treatment plan. They felt more “in control” of the situation at the time of birth. Throughout the rest of their pregnancies, they became more knowledgeable about taking care of a baby with cleft, especially about the feeding. Jane said, “We had selected our teams that would do his repair and knew which hospital we were going to go with. I had read a fair amount about feeding a child with a cleft and about potentially breastfeeding a child with a cleft.” Mothers signed up for online

mothers' support groups to learn what they can expect when raising a child with cleft and received advice from the other mothers who had been through the experience.

No matter how much they tried to prepare before the birth, there were some aspects that mothers did not feel prepared for when they gave birth. Two mothers stated that they did not feel prepared for actually "doing it." They were able to prepare conceptually about how to take care of a baby born with cleft, but they needed to adjust to it on a day-to-day basis. Mary explained, "I don't think you really know until you're in the thick of it, until the baby's here."

Mothers noted that cleft "changed the reality of what it means to have a newborn." There were additional stressors such as the surgeries and the social stigma that the mothers experienced when they took their children out that they were not prepared for. Zoe described a stranger approaching her and asking, "What's wrong with him?." She stated that it was "heartbreaking for a new mom to hear." She also did not want her son to hear it so, she ended up often guarding him from strangers after that incident..

5.4.2.3 Subtheme: Concerns

Eight mothers explained their concerns at the time of birth in 14 segments. The main concern most mothers had at the time of birth was feeding. First, they wanted to know if they would be able to breastfeed their babies. Mothers could not breastfeed because of the cleft. Therefore, they needed to use the Haberman bottles to feed their babies. They stated that it was a "learning process" to adjust to the bottles. One mother, Mo, had to stay in the hospital longer so that she and her husband could get used to feeding their child with special feeder bottles. She said, "We did have another extra day in the hospital because she wasn't eating enough, they felt like, at first. But I think that

was just a case of me getting used to the way of feeding her.” Additionally, they sometimes needed to try out different bottles and nipple sizes to find which one “worked” for their baby. The feeding was also difficult because it was slower compared to feeding a child without a cleft. The babies would often get tired and give up during the feeding process, which worried the mothers, who wondered if their babies were getting enough nutrition.

Mothers described the importance of going to a hospital that is equipped to care for a child with cleft. It was difficult for the mothers if the staff did not know how to feed their babies. Zoe described when her son was born, hospital staff did not have experience with feeding a baby with cleft so “they had to figure it out first” before they taught Zoe and her husband. In Zoe’s case, her son also stopped breathing several times while she was feeding him, which frightened her. He needed to be fed with a tube until Zoe and her husband figured out how to feed him with the bottles. However, she described still being afraid that he would stop breathing.

In addition to the feeding, two mothers were concerned about the severity of the cleft, the child’s ability to breathe, the impact of the cleft on the child, and the child’s general health at the time of birth. Rebecca remembered asking, “How does his lip look?” as soon as she delivered her son. She stated, “It looked like it was relatively small but you don’t know if it’s going to go all the way up into the nose or, you know.” Because cleft involves the mouth and nose, Mo was worried about breathing. She wanted to make sure that her daughter did not need extra oxygen and that “she was breathing okay.” Thinking about the social stigma that her son might have to endure, Rachel described being worried about the psychological and physical impact of the cleft on her son. She

remembered wondering about the “challenges he was going to face in life” right after she gave birth.

5.4.3 Dominant Theme: Initial Stages

The third dominant theme, *initial stages*, described the experiences of mothers during the first year of their children’s lives. Questions 4 and 5 in my interview guide (Appendix D) focused on the mother’s experiences during the first month of her child’s life as well as at the time of surgery. All 10 prenatal mothers described their experiences during the initial stages in 140 segments. This dominant theme was then divided into 2 subthemes: (a) feeding and (b) surgery.

5.4.3.1 Subtheme: Feeding

During the initial stages of their babies’ lives, mothers struggled with feeding. Eight mothers described struggling with feeding in 22 segments. Their main struggle was not being able to breastfeed their children because of the cleft whereas some identified other issues. For example, Rebecca talked about her son having jaundice after birth and receiving phototherapy. He was fed with bottles during this time and consequently did not want to be breastfed later. Rebecca said she felt “inadequate” because her son “rejected her breasts.” It was even more frustrating for Rebecca when people tried to comfort her by saying it was probably because of the cleft because she knew that was not the case.

Mothers who could not breastfeed had to adjust to using the bottles. Seven had to use the special feeder bottles; one mother used the “normal bottles” by adjusting the nipple size. Mothers who were using the special feeder bottles emphasized that they

“wanted to do it right.” They wanted their babies to get enough nutrition and gain weight. For example, Mo said,

During the first month I guess we were a little unnerved because of making sure she was eating properly and taking her to the pediatrician, making sure she was gaining weight. She was a little slow in gaining her weight, but there wasn't any time that she was in any kind of danger; but as a new mother you're nervous with that.

They also tried different bottles and nipple sizes so their babies could eat better. They described it as a “matter of finding what worked” and then “it got easier.” Aside from learning it themselves, they also taught other people who were caring for the baby how to use the bottles. Additionally, one mother emphasized that NAM was helpful in making feedings easier because it created an “artificial palate” for the baby.

Mothers had to make a decision about whether they would like to pump and give their children breast milk or feed their children formula. For 5 mothers, this was not a hard decision to make. They expressed that they were primarily concerned about their children getting enough nutrition. They had an easier time with it if they had fed their previous children formula. Mary said, “My firstborn was formula fed as well so I don't think – my plan was to formula feed so there was none of that oh, I can't breastfeed, you know.” For the mothers who were planning on breastfeeding before the birth or if they breastfed their previous child, making this decision was more difficult. They felt guilty. Zoe stated, “I had a little guilt. I felt bad that I was able to give my daughter the breastfeeding experience and not him.” Mothers expressed that “there is so much out there describing the benefits of breastfeeding.” They felt that their experience was not

“complete” because they could not provide their children with the same level of nutrients and the experience of bonding. It was helpful for the mothers if their pediatrician did not glorify breastfeeding.

Three mothers wanted to pump their breast milk, especially during the initial stages of their child’s life. They described the experience as “horrible” because it was “challenging” and “exhausting.” It affected their sleep because they had to wake up multiple times at night since they had to pump before each time they fed the baby. They could not get as much “production” as they could if they were breastfeeding. They needed to supplement it with formula. The process was stressful for the mothers, but they still wanted to continue because they learned through their “research” that breastfeeding was better for the baby. Abby said;

Yes, because with everything that I’ve researched, that would be the best for her and she was already coming into this world with a deficit. We certainly wanted to give her the best that we possibly could and I knew that that would give her the past antibodies and the most nutrition to protect her against illnesses.

Lastly, mothers’ experiences were even more difficult if the baby had colic or reflux. They had to cope with these conditions in addition to learning how to feed their children with cleft.

5.4.3.2 Subtheme: Surgery

All 10 mothers shared their experiences at the time of surgery in 90 segments. Lip surgery usually took place around the third month whereas mothers had to wait for almost a year for the palate surgery. Before the surgery, anesthesia was a primary concern for mothers. They worried about their babies having a negative reaction to anesthesia given

that they were going to receive it for the first time at such a young age. One mother even described being more concerned about the anesthesia than the actual procedure before the lip surgery because “it’s a cosmetic procedure.”

Mothers wondered about the surgery outcome and how much their babies’ appearance was going to improve. They stated that they were looking forward to the surgery so that the cleft would be “fixed.” One mother, Mary, had mixed feelings about the cleft being fixed. She was looking forward to the child’s changed appearance but also felt sad that her child was going to look different from the way she “met him” when he was born. She said, “I was crying because he was going to look so different because I’d gotten so used to how he looked and I fell in love with him that way and I thought oh my Gosh, he’s going to look so different.”

Mothers were also anxious for the baby to have the surgery because they would have an easier time feeding. For example, Laurie said, “I think we were – I mean we were very anxious to get it done. I remember really looking forward to it. Because I knew that it was going to help him with his eating and things like that, so we were very excited for it.” On the other hand, it was especially challenging for parents to “hand their children off to a stranger,” relinquishing control and protection. Having confidence in their doctor reduced their anxiety before the surgery. It also eased their concerns if they saw their children in a happy mood. Elizabeth described, “She was like cooing and giggling when they carried her in because she was happy and not scared. If she had been scared I would have been scared. It was like, yeah she was fine, and she was literally giggling.” Additionally, Abby spoke about having an easier time sending her daughter to the palate surgery because she had a good experience with the lip surgery. During the interviews,

mothers shared funny anecdotes about their surgery experiences. Mary talked about how they had to have the surgery a month and half early because their dog ate the NAM device! They needed to change surgeons and have their surgery early than anticipated.

One mother, Rebecca, described being anxious while her child was going through the surgery. She stated that she was calm initially while she was waiting for her son to come out of surgery. She was told that the surgery would take 45 minutes. When it took longer than anticipated and she did not receive an update about her child's condition for a long time, she started getting anxious. She emphasized that mothers should be informed about the actual length of time the baby would be away even though the actual procedure only takes 45 minutes.

When mothers saw their babies for the first time after the first surgery, they had mixed feelings. They described being "happy" and "relieved" that the surgery was over and successful: The cleft was repaired! They felt that they put a "big hurdle" behind them. One mother mentioned being happy they were not going to have to "deal with the NAM anymore." Yet, three mothers felt sad to see their children in pain and also "missed the cleft" deep inside.

Mothers thought that the surgery made a "huge difference" in their child's appearance. One mother, Elizabeth, did not recognize her own child because she looked so different! She said,

Partly it was — I mean I didn't recognize her when I first saw her. You're like, "oh my gosh she looks so different." You love your kid with the cleft, it didn't bother me it at all that she had it, but it's just different to see her without it.

The good outcome was a relief for mothers because it reduced the possibility of their children experiencing social stigma due to a visible difference. They were also relieved that they no longer had to think about other people's reactions when they took their baby out. Even though most of the mothers identified the NAM device as a source of stress, they were also grateful for it because they believed that it improved the surgery outcome dramatically. Mothers mentioned how they continued to see improvements in their children's appearance over time. Rebecca stated,

I took a picture like 10 days after the surgery and I couldn't believe already how great it looked. There was a little scar there at the time, but it was little, and so we were amazed at how good a job they can do these days with that.

Even less emotional mothers were "amazed" by their child's changed appearance. Some reported "missing the cleft" because that was the way they had met their children, and they had gotten used to seeing them with. Laurie said, "Just because we were so used to seeing his cleft and then he got it closed. You know, he looked so different and we didn't realize it, but we actually missed it I think a little bit." One mother talked about taking many pictures of her child before the cleft surgery because she viewed cleft as part of who her son was. The mothers emphasized that they did not want to forget the way they met their children and wanted to keep memories of it since they were not going to see the cleft anymore.

The initial period after the surgery was also difficult for the parents because of the children's postoperative appearance. One mother, Mary, thought that her child "looked older" because of the swelling after surgery. She described seeing her son after the surgery as;

He looked like he had been through something. That's the best way I could describe it. You're going, "Oh, he just looks like he's been through the ringer."

He looked like he aged overnight. And I think it was more appearance-wise probably because he was swollen. He was swollen from the surgery and his face looked bigger and you're just going he's too tiny to have gone through this. But he did. He looked older.

It was "heartbreaking" for Mary to see her son in such a position. She stated that her son looked like he went through something that he should not have gone through at the time. Rebecca also mentioned that her son's nose looked "piggy" because of the swelling, and it did not feel like he was her child. She was not expecting the swelling on his nose; she thought that it could be on his lip. The postoperative appearance was more difficult for the mothers whose children had palate surgery; some of them described bleeding in their children's mouths. In general, mothers agreed that it was stressful to see their babies "bandaged, bloodied, stitched." They thought that their children were "too tiny" to deal with the stitches and the pain. The pain that their children were going to be in was a concern for the parents throughout the surgery experience. After the surgery, Mary described thinking, "You go how much pain is he going to be in when he wakes up? Is what they're giving him enough to manage his pain to the point where he's not miserable?"

After the surgery, four mothers had to relearn how to feed their children. Some had a difficult time initially because their children were in pain. It was an additional struggle for some mothers when their children no longer had to wear the NAM device,

“fake palate,” which made it easier for them to use the bottles. Abby talked about her experience trying to feed her daughter after surgery:

So for her to use a bottle with that palate actually was easier for her. So that was extremely difficult to get her to feed and she would not feed. The very week, after the initial lip surgery, that was the worst because she just would not take the bottle. We literally were hours away from determining, like the end of the week, I thought she was going to be dehydrated and we were going to have to take her back to the hospital.

Trying to feed their children after the surgery was a more stressful experience for the parents if the hospital staff was not helpful in assisting them. After the mothers passed through the initial stages, the feeding became easier because their children were able to eat solid foods.

Three mothers discussed going through a short recovery period, stating that the children healed quickly even though it was still challenging to see their children in pain. Jane talked about her whole family struggling with “massaging” her son’s scar after the surgery because he was crying because of the pain. She emphasized that she had to “call in a meeting with them” to explain what was needed so that her son would not have to deal with a visible scar in the future. However, it was still very difficult for her:

So I would just count I guess to sort of give myself something to do or so I didn’t have to hear him as much. I literally would count to 90, and I would say, “We’re almost done; we’ve got 30 seconds to go. Let’s get through it.”

Mothers stated that there were positive changes in both theirs and their children’s lives after the surgeries. As Elizabeth said, “Once we got past the first surgery our stress

level dropped significantly. Once we got passed the second surgery it was like completely gone.” Rachel talked about her son being more “relaxed” and “sleeping better” after the surgery. The doctors also cleaned out her son’s ear tubes during the surgery so he was able to hear better. She understood that his demeanor changed in the positive direction because she “was finally able to take a shower, a 5-minute shower instead a 3-minute shower.”

5.4.4 Dominant Theme: Current Situation

The fourth dominant theme, *current situation*, described the mothers’ opinions about their children’s current functioning, the results of their surgeries, and upcoming treatments as well as their concerns at the time of the interviews determined from the answers they provided for Question 3 in my interview guide (Appendix D). All 10 mothers reported on their children’s current situation in 44 segments. This dominant theme was then divided into three subthemes: (1) treatment, (2) functioning, and (3) concerns.

5.4.4.1 Subtheme: Treatment

Six mothers explained their opinions about the results of the surgeries and the upcoming treatments in 8 segments. They talked about the surgeries being successful and being satisfied with their children’s appearance. Rebecca described how people commented on her son’s postsurgical appearance. She said,

I just was at a family party this weekend and people tell me all the time you would never, never know now if someone didn’t tell you had a cleft lip. And he’s only two, so he’s not old. I think that the surgery was great.

However, two mothers still expected their children to have additional surgeries to improve their appearances. They planned to listen to their doctors' recommendations regarding the timing of the surgery. Another upcoming surgery that the mothers talked about was the bone graft surgery. They were not certain that it was going to be necessary. They were waiting to hear the doctors' comments based on roentographic results. Laurie explained, "I am just waiting to see bone graft wise if that needs to be happening for him. They still don't know because he is so young and we haven't had any x-rays."

5.4.4.2 Subtheme: Functioning

Seven mothers described their children's functioning in 12 segments. When discussing their children's current functioning, most mothers commented on their children's speech and shared that their children did not have speech problems. They believed that their children's speech improved after they had their surgeries. Two mothers were concerned about their children having a nasal tone and were waiting for their yearly evaluations to have more definitive information about their children's speech development.

One mother described having early intervention representatives come into their homes for speech therapy. Two mothers stated that they could use the early intervention services if their children ever experienced speech problems. Additionally, mothers talked about the possibility of their children experiencing dental issues. For some, this was not the case even though they were told that it was possible. For example, Rebecca shared, "The doctor also told me a few times that his teeth might not come in properly, and so that was a concern for a while, but they're all there now. So I guess I don't have to worry about that anymore, from what I understand." Two mothers stated that their children

might need orthodontic treatment in the future. Vader was one of these mothers. She said, “I’m a little worried about his teeth. They’re very crooked. He has a very bad cross bite (crooked teeth). I’m just hoping that something can be done.” In general, mothers in the prenatal diagnosis group did not describe any issues with their children’s hearing and development.

5.4.4.3 Subtheme: Concerns

Eight mothers spoke about their current concerns in 24 segments. They pointed out multiple sources of current concern such as upcoming treatments, appearance, social stigma, speech, orthodontics, and genetic disposition. Five mothers indicated that their children were likely to go through additional surgeries and treatments. Summing up all the possible surgeries, Elizabeth said, “She’s got the bone graft one, that’s the big one. Then she’ll probably have some small cosmetic ones, and then they did talk about how she’ll probably get a rhinoplasty, a nose job when she is a teenager.” Mothers reported that it would be concerning any time their children needed to go through surgery. Mothers’ concerns were mostly about their children being in pain as a result of the surgeries. They also worried about telling their children that they had gone through a surgery and their reactions to it. They also said that the thought of their children going through a surgery was no longer as worrying for them as it was in the beginning. When talking about the upcoming treatments, Mo highlighted, “I don’t feel as upset about it as I did in the beginning. You know what I mean? I feel like now we can handle whatever comes our way because I feel like the toughest stuff is actually behind us.”

Even though most mothers emphasized being content with the surgical outcome, their child’s appearance was still a concern for four mothers. They planned to get

revisions because they thought that their children's faces were not as symmetrical as they should have been or that their noses looked crooked. It was important for the mothers to know how well the doctors could "fix" the appearance and to make sure that everything possible was done to improve their children's appearance. The primary reason for the mothers' concerns about appearance was the possibility of social stigma. For instance, Jane talked about wanting to "time the surgeries well" so that her son "has the best recovery he can have and the least social awareness of it." She stated that they "want to get ahead of it before there's any teasing or questions or why do you look different or negative statements that he has to hear." Elizabeth, too, explained that she still worried about her daughter "being a girl with cleft" because "people are mean."

Jane's worry was more centered on her son's speech. She had called in the Early Intervention team to her house before but stopped it because she did not think her son was benefiting from it. Once the speech therapist stopped coming, her son's speech improved. She plans to use Early Intervention personnel for speech therapy when her child turns 3 to help him with his pronunciation. Rebecca worried about her son's genetic disposition to having a child with cleft. She talked about this being her only lingering concern.

5.4.5 Dominant Theme: Raising a Child with Cleft

The last dominant theme, raising a child with cleft, describes mothers' views about the process of raising a child with cleft. When answering questions 7, 8, 12, 13, and 14 in my interview guide (Appendix D), mothers talked about their sources of stress, challenges, and lessons learned as they looked back on their experience of raising a child with cleft. They also explained their current views of the cleft and their child as well as their ideas

about possible factors that led to their children developing clefts in utero. All 10 mothers explained their experiences in 183 segments. The dominant theme of raising a child with cleft was divided into five subthemes: (1) sources of stress; (2) challenges; (3) advice/lessons learned; (4) reasons for cleft; and (5) view of the child and cleft.

5.4.5.1 Subtheme: Sources of Stress

All mothers shared their sources of stress as they reflected on the experiences of raising a child with cleft in 40 segments. When asked about their sources of stress, mothers stated that they went through most of the major stressors during the initial stages of their babies' lives. Mothers who had children with cleft lip and palate explained that their stress levels went down drastically once their children had the second surgery. If the children only had cleft lip, mothers started having an easier time after the lip surgery was completed. During the initial stages, the primary stressors were feeding, the NAM device, and the surgeries. Additionally, the mothers described being stressed about lacking sleep, appliance complications, and additional health issues.

Five mothers described feeding as stressful. There were many factors that made the feedings stressful for the mothers. They described pumping as a stressful experience. Abby explained:

And me having to pump exclusively because I had to do that and then feed her. There were literally times where I'm pumping and trying to hold her at the same time because my husband did have to go back to work eventually. I had to do it by myself and that was definitely more difficult than just having an average newborn.

Additionally, mothers had to teach other people who were taking care of the children how to use the special feeder bottles. They had a hard time teaching because they were not completely certain about how to do it in the first place. The feedings were harder if the child had additional health issues such as colic or reflux. The feedings themselves became a stressor because it was difficult to feed and console the baby. The mothers wondered if colic and reflux were indicative of a deeper issue. Some mothers were stressed about feeding the children once the doctors took off the NAM device because the children no longer had the artificial palate.

The NAM device was a significant source of stress for four mothers during the initial stages. Even though the mothers described NAM as a primary factor in the success of the surgery and in the easiness of feeding, they also agreed that the tapings and the regular trips to the hospital to get the NAM adjusted were definitely stressful. They had to change the tapes for the NAM multiple times a day and had to attend doctor's appointments for readjustment biweekly. Initially, it was hard for the mothers because they were afraid of ripping their babies' skin during the repeated tapings. As the children got older, they were able to pull the NAM device out of their noses, which irritated their skin. It was difficult to do the tapings on an irritated skin because the mothers did not know if they were hurting their children. Still, they wanted to do it correctly to improve the surgical outcome. Even though the process was difficult, the mothers realized the benefit of the NAM after the surgery. Zoe stated, "As much – as difficult as it was dealing with the NAM, seeing the results, I would do it again in a heartbeat."

Surgery was another stressor that the mothers had to cope with during the initial stages of their children's lives. They were mostly concerned about the child being too

young to go through surgery and receiving anesthesia as well as the pain that they witnessed their children experiencing after the surgery. In some cases, the children had to wear nose stents after the surgeries that were stitched to their noses. One of the mothers described worrying about it when the child took it out of his nose even though it was still stitched. She was afraid that her child was in pain.

Most mothers did not identify significant stressors at the time of the interview. Vader said that it was stressful attending the full-day evaluations at CHOP because it was a long commute. For Mary, talking to her son about an upcoming surgery was stressful. Three mothers noted that this process was not as stressful for them as they thought it would be. There were times that it was stressful, but they would not consider it as an overall significant stressor and not a major issue in their lives. As Elizabeth explains, “I honestly, I don’t think about it. It’s just part of who she is; it really is just a thing for me now.”

5.4.5.2 Subtheme: Challenges

Nine mothers spoke about the challenges they experienced raising a child with cleft in 23 segments. The most noteworthy challenge, described by three mothers, was the social stigma they experienced when they took their children out in public. It was difficult seeing people staring at them, whispering to each other, pointing at their children, and giving their children strange looks. The mothers stated that they would have preferred strangers asking about their children’s condition rather than acting like there was something wrong with them.

Mothers shared that they not only got these uncomfortable reactions from strangers but also from close friends and family. For Rebecca, it was especially

frustrating when her friends told their children to be quiet when the children asked about the cleft. She preferred the cleft to be “out in the open.” She said,

Even if the mom was trying to set him up, I would make sure that I answered the kid so that the mom would hear. It’s okay, I’m answering the question. He’s going to ask. Kids are going to ask and kids are going to notice. Let’s not pretend it’s not there.”

One mother talked about family members asking intrusive questions about the cleft and using offensive descriptions such as “harelip” just after the mother received the cleft diagnosis.

For three mothers, the initial stage was the most challenging period. Some identified the “initial stages” as the first month and some, as the first 4 months up until the first surgery. The challenging part included feeding their children, teaching other people how to feed their children, adjusting to different styles of feeding before and after the NAM device, the surgery, and the NAM. Two mothers said that the most challenging time was when they first learned about the cleft diagnosis but they did not know the level of severity. During that time, they also had to grieve the loss of the perfect child.

To cope with these challenges, mothers emphasized the importance of learning about cleft and understanding what they were up against. They questioned the concept of perfection and asked themselves, “Whose kid is perfect?” To manage outsiders’ reactions, they described the importance of being open about cleft, being comfortable, and not being ashamed so that people could talk about it and ask questions. Rebecca shared:

What happens in situations like that is if people would've saw that my son had a cleft lip and I didn't mention anything, they wouldn't ask me directly right.

They'd ask my friend, "Oh I didn't know what happened. Did she know? Is it going to be fixed," etc. and then misinformation gets passed. I would make the advice to just be open with people. Don't try to hide it or be ashamed of it. I mean it is what it is.

5.4.5.3 Subtheme: Reasons

All 10 mothers talked about the reasons they attributed to their children developing a cleft in utero in 21 segments. Five mothers talked about not knowing what caused their children's clefts. They initially tried to find an answer to this question but could not. They eventually accepted that there was no way of knowing what exactly caused the cleft because it was a "roll of dice." They said that it was crucial not to blame themselves or their partners. Mo said, "I don't blame either parent for any of it because I say to myself, we are so blessed in having our daughter."

The fact that there is no definitive cause for cleft was for a relief for the mothers, but they still considered what may have caused their children's clefts. One mother was told that she was not going to be able to conceive, so she was *not* taking prenatal vitamins when she got pregnant and thought that could be a factor. One mother was being treated for epilepsy and was taking anticonvulsive medication at the time. The doctor later informed her that this could be a cause for the cleft. Another mother blamed environmental pesticides and stated that she has been eating organic food since then. One mother in my sample was born with CLP herself. She noted that clefts occurred sporadically in her family. However, she and her husband had genetic testing before she

got pregnant because they had difficulty conceiving; they learned that she was not carrying the gene for cleft. What they did find, however, was that she had a chromosome deficiency that affected her ability to metabolize and absorb folic acid. Her mother also had the same condition. So she believed that this why her child was born with cleft.

Even if there was no definitive cause, four mothers continued to struggle with feelings of self-blame because they were not able to protect their children. As Rachel described, “I just – from day one and even now like I’m still believing—I feel like the fault is on me.” Mothers kept thinking about the first few months of their pregnancies and wondered what they could have done wrong. One thought it was the antibiotic she used before knowing that she was pregnant; another thought it was the glass of wine she drank; and another one thought it was the warm baths she took. Eventually some realized that it was not beneficial for them or their children to keep dwelling on the cause of the cleft and accepted that it was just “bad luck.” Mary explained:

And really, to be honest, I had to kind of force myself to say no matter what caused it, this is what it is and it’s one of those things you have to tell yourself you can’t change. Whether you think it’s your fault or not, you can’t change what it is so it’s not doing anybody any good. It’s not doing me any good. It’s not doing him any good to wonder how it happened or to obsess over how it happened or what I could or couldn’t have done differently.

5.4.5.4 Subtheme: Lessons Learned

All 10 mothers described lessons learned throughout this process in 40 segments.

Mothers described two salient aspects: (1) learning about cleft and (2) keeping things in perspective. They shared that the “unknown” was scary for them and that they needed

more information so they felt more in control and could move forward with their lives as new mothers. Especially after receiving the prenatal diagnosis, they wanted to learn as much as they could to figure out how they were going to manage their children's clefts. They talked to other people who were more knowledgeable about cleft, such as nurses, doctors, and other parents who had been through the same process with their children. They looked at "before and after pictures" of children who had cleft to see how their appearances changed after having the surgery. The Internet was a primary source of information. Rebecca mentioned,

I guess what I did, which was helpful to me, is I went on Babycenter.com, and there's a cleft palate group there and a lot of people post before and after pictures. I looked at a ton of those. Those made me feel good because I looked to see people who were in the same situation as me, you know, what their kid looked like before.

As they learned more, their stress levels and their "fear of the unknown" dissipated because they felt more empowered. For example, Mary advised:

Learn as much as you can about it because it does give you a sense of empowerment to know what you're up against. Even though you don't really know, like I said, until you're in the thick of it, it definitely does help you to become informed. And I think that's with anything in life. Anything that you're not sure about, the more you know and the more you learn, the more you feel empowered to deal with it and deal with it effectively.

At the same time, mothers also acknowledged that they "did not know what they were going to deal with until they were in the thick of it." However, it was helpful to identify

what they were going to need help with. Feeding was one of these salient issues for all mothers; they thought it was helpful learning about it and bought the special feeder bottles before their babies were born.

Even though having a child born with a cleft was stressful and challenging for all 10 prenatal mothers, they emphasized the importance of “keeping things in perspective.” They learned to categorize the stressors, deciding to worry about what they could control and letting go of what they could not control. Observing other children at the hospital helped to put their concerns into perspective. Mothers described feeling grateful as they witnessed the experiences of other children who had more severe health issues and more severe clefts. For example, Mo described her experiences staying with her daughter in the hospital after her surgery.

Because I mean CHOP makes you realize when you see all the parents and the children going in and out of there, and we had two stays in the hospital with our daughter. We both stayed with our daughter, which I think is outstanding for CHOP to do that; they allow parents to stay with their children. I think that’s great. But we just said that there are some of these children who aren’t coming out ever. Some of these children here are going to die, and our daughter’s not.

You know what I mean?

Mothers also talked about their doctors encouraging them to “keep things in perspective” as they described the cleft as a “fixable” and a “cosmetic” issue. For example, Jane shared that when they worried about the cleft, their doctor told her and her husband: “There are so many things that can go wrong when you’re creating life. You got one that’s fixable.”

Laurie, who was born with cleft herself and had surgeries many years ago, mentioned being grateful for the medical advances because she could see the differences between her experiences and those of her son. When asked about the “pearls of wisdom” she could give to another mother she said:

I think I would just make sure they knew of what my experience was, how different it is today and to be thankful for that. Because my son won't have to go through – again, his cleft is different than mine, but he really won't have to go through as many surgeries as I did. I think that is something to be grateful for now, that you don't have to be as scared because they handle it so much more differently now.

Looking back on their experiences raising a child with cleft, mothers advised that, “It got easier with time.” Mothers explained that this process made them realize their own resilience and helped them solidify their couple relationships. They stated that they ended up doing things that they never thought they could do. They described the importance of keeping their relationship as a couple strong during this process, because their partners were a main source of support. This experience allowed them to experience “another layer of parenting” with their children. Some stated that it made them feel “special” to be present for their children as they had their surgeries and to be the first person to comfort them when they came out of their surgeries. Mothers said that “time heals” and that now as they look back, “it's all a blur.”

Three mothers advised more about the practical aspects. They said that it was important to get a good treatment team and to inform and educate family members including their older children about cleft and to prepare them for meeting their children

with cleft. When asked about their pearls of wisdom for other parents in general, mothers described being really happy about having children regardless of the cleft but advised that others parents understand that “they could never know what they were going to get.”

5.4.5.5 Subtheme: View of the Child and Cleft

All 10 prenatal mothers discussed their views of cleft and their children in 30 segments. Mothers described their children in a positive way, highlighting their favorable qualities. They were very proud of their children for being strong and brave throughout this process. Some pointed out that their children were confident and personable and hoped that these qualities would make their lives easier as they coped with a visible difference. They shared that their children were the true survivors because they went through more than the mothers went through. Overall, for the mothers, cleft was a “fixable issue.” As Vader said, “it was something that a surgery could take care of.” Additionally, it was a “cosmetic” issue and therefore not a “huge problem.” At the same time, some mothers acknowledged, “no one would want to have a child with cleft.” When their children were initially diagnosed, they did not know that it was common in the United States and thought that it occurred mostly in third-world countries. Mothers did not think of cleft as something that defined their children, but it was part of who they were. Raising a child with cleft was different from raising a child without a cleft. As Elizabeth said, it “changed the reality of what it is like to have a newborn.”

5.5 Prenatal Diagnosis Group, Fathers: Dominant and Subdominant Themes

Similar to the 10 prenatal mothers, findings from the 10 prenatal fathers focused on the following four time periods: (1) prenatal diagnosis; (2) birth; (3) initial stages after birth; and (4) current situation. Fathers’ reflections on the general process were included

in the fifth dominant theme: raising a child with cleft. As a result, the interviews conducted with the fathers were grouped into the following five dominant themes: (1) prenatal diagnosis; (2) having the baby; (3) initial stages; (4) current situation; and (5) raising a child with cleft. Within these five dominant themes, 22 subthemes emerged. In the next section, I describe each subtheme and illustrate them with anonymous quotes from fathers. Table 5.10 contains an overview of the 5 dominant themes and 19 subthemes. To inform the reader about the frequency of the themes and the number of fathers who mentioned them, I included the “theme frequency” section in Table 5.10.

Table 5.10. Dominant Themes of Fathers in the Prenatal Diagnosis Group

Level	Themes	Theme Frequency/Prenatal Fathers' Quotes in this Chapter
100	Dominant Theme: Prenatal Diagnosis	246 Total Segments: All prenatal fathers
101	Process of finding out	48 segments: All prenatal fathers Prenatal father quotes: Mitch, Chip, Ben
102	Initial concerns	58 segments: All prenatal fathers Prenatal father quotes: DARTH, Ben
103	Initial feelings	16 segments: 9 of 10 prenatal fathers Prenatal father quotes: Chip, DARTH
104	Couple's process	11 segments: 7 of 10 prenatal fathers Prenatal father quotes: Joe, Murray
105	Informing	25 segments: 9 of 10 prenatal fathers Prenatal father quotes: Ben, Bill
106	Impact on pregnancy	33 segments: All prenatal

		fathers Prenatal father quotes: Murray, Ben
107	Opinions on the prenatal diagnosis	29 segments: All prenatal fathers Prenatal father quotes:
200	Dominant Theme: Having the Baby	100 segments: All prenatal mothers
201	Preparedness	52 segments: All prenatal fathers Prenatal father quotes: Chip, Mitch, Ben
202	Reactions to the baby	13 segments: 6 of 10 prenatal fathers Prenatal father quotes: Mitch, Darth, Bob
203	Concerns	15 segments: 9 of 10 prenatal fathers Prenatal father quotes: Francis, Darth, Chip
300	Dominant Theme: Initial Stages	138 segments: All prenatal fathers
301	Taking care of a baby with cleft	43 segments: 9 of 10 prenatal fathers Prenatal father quotes: Mitch, Murray, Frank
302	Feelings	13 segments: 9 of 10 prenatal fathers Prenatal father quotes: Bill
303	Surgery	78 segments: All prenatal fathers Prenatal father quotes: Joe, Darth, Chip, Murray, Bob, Bill
400	Dominant Theme: Current Situation	28 segments: All prenatal fathers
401	Concerns	17 segments: 9 of 10 prenatal fathers Prenatal father quotes: Mitch, Ben
500	Dominant Theme: Raising a Child with Cleft	170 segments: All prenatal fathers
501	Sources of stress	19 segments: 9 of 10 prenatal fathers Prenatal father quotes: Francis, Bill

502	Challenges	14 segments: 9 of 10 prenatal fathers Prenatal father quotes: Mitch, Murray, Bill, Frank
503	Reasons for cleft	13 segments: All prenatal fathers Prenatal father quotes: Frank
504	View of the child with cleft	40 segments: 9 of 10 prenatal fathers Prenatal father quotes: Ben, Darth
505	Lessons learned	54 segments: All prenatal fathers Prenatal father quotes: Frank, Francis, Bob, Ben

5.5.1 Dominant Theme: Prenatal Diagnosis

The first dominant theme, *prenatal diagnosis*, describes the reactions and experiences of the fathers in the prenatal diagnosis group when they first learned about their children's cleft. All fathers described their experiences at the time of the diagnosis in 246 segments. There were many similarities between the dominant themes of the mothers and fathers in the prenatal diagnosis group. As the fathers explained their experiences, they often shared stories similar to those their wives shared, so overall major differences between them did not emerge. However, interviewing the fathers allowed me to capture more specific details about their own process, giving me a fuller picture of the unique experiences of the fathers in the prenatal diagnosis group. For this reason, the dominant theme of prenatal diagnosis yielded the same seven dominant themes that emerged from the interviews with the mothers in the prenatal diagnosis group: (1) process of finding out; (2) initial concerns; (3) feelings; (4) opinions regarding the

prenatal diagnosis; (5) impact on pregnancy; (6) couple's process; and (7) informing others.

5.5.1.1 Subtheme: Process of Finding Out

All 10 fathers in the prenatal diagnosis group described how they first found out about their children's cleft. This subtheme included 48 segments. These fathers confirmed the mothers' descriptions about first finding out about the cleft through a 3D ultrasound examination. Yet fathers did not provide as much detail about the specifics of the ultrasound examination as the mothers did, which might be due to gender differences, communication styles, and the fact that mothers were pregnant and had the ultrasound while most fathers were present during this examination. When mothers described the ultrasound examination, most described specific details, for example, who conducted the ultrasound examination, his/her demeanor when she/he noticed the cleft, events before and during the examination, and the individual who actually delivered the diagnosis. Fathers gave more direct practical descriptions, without specific details. For example, Mitch said, "We had an ultrasound done and the tech saw something in the ultrasound and alerted us to the fact that our son had a cleft." Some fathers like Chip remembered how they first noticed the cleft. When asked about the timing of the diagnosis, he said, "It was through ultrasound that they spotted that there was a dark area where the lip is where it should've not been dark, which signified that that tissue had not developed."

Some fathers did describe the demeanor of doctors who first delivered the cleft diagnosis like their wives did, or how they had to come for a second visit, or had to wait for hours before the doctor evaluated the ultrasound picture and finally delivered the cleft diagnosis. For example, Francis acknowledged that he and his wife visited a high-risk

specialist just to find out “if the pregnancy was going well” who first diagnosed their son’s cleft. Ben, who shared that they had to come for a second visit, provided his own rationale for it: “My suspicion is they saw something then, but they weren’t sure and they wanted to confirm it with the doctor first, so they asked us to come back when the doctor was going to be back in.” A few fathers shared more details about the accompanying events during the examination such as learning about their baby’s gender or referrals they received after first learning about the cleft.

Fathers explained that there were many “unknowns” that contributed to their concerns, which were exacerbated by their doctors’ reactions. In Frank’s case, the doctor initially diagnosed their baby with trisomy 18 in utero and suggested that they could think about having an abortion. After going through additional testing at CHOP, the couple later received the cleft diagnosis and found out their baby did not have trisomy 18. Frank was relieved, but he was still upset about the doctor’s demeanor, stating that the most infuriating aspect of this experience was that their doctor did not suggest that they get additional tests or a second opinion but immediately suggested they consider an abortion.

Not knowing the severity of their child’s cleft was a difficult experience for many fathers. Some were concerned if they did not know if the palate was involved. Darth reported being scared of the ultrasound picture because he thought it looked like “half of his head was missing” and the doctor said that the cleft “looked like a big one.”

5.5.1.2 Subtheme: Initial Concerns

All 10 prenatal fathers described their initial concerns in 58 segments. Fathers primarily reported being worried at the time of the diagnosis because there were so many aspects of the cleft they did not yet understand. They had many unanswered questions,

for example, the possibility of repair, severity of the cleft, feeding difficulties that the baby was likely to experience, co-occurring syndromes, speech problems, social stigma, the psychological impact on their children, appearance issues, surgery outcome, and breathing issues. It was impossible to eliminate all of these concerns until the time of the birth. Yet there were some aspects such as the possibility of repair that fathers were able to learn more about before the birth.

The possibility of additional syndromes was of most concern among the 10 prenatal fathers. They shared that the cleft was not a “huge concern” since it was more of a “cosmetic” issue. For fathers, it was more important to know if their children would be able to function “like a normal child.” As Darth noted “It’s whether it’s going to be so severe to the point where he can’t function like a normal child could. Pretty much is this going to be in the brain to the point where he’s born and he can’t do anything?” Severity of the cleft was another concern because in some cases, before the birth, the doctors were not sure if the baby had cleft palate in addition to the cleft lip. Even though all 10 fathers reported that their children had additional testing to rule out any co-occurring syndromes and to understand the level of severity, some continued to worry until their children were born.

Fathers were also concerned about their children experiencing social stigma because of their visible differences. They wondered if the cleft was going to impact their children’s appearance even after the surgeries and lead to bullying at school. Some fathers who had been through similar childhood experiences of being “different” worried about the psychological impact of bullying on their children. For example, when asked about his concerns at the time of the diagnosis, Ben said,

I guess just psychological problems, mostly. Not so much being different, having to deal with being different as a kid. It's something, at least for me is something that I know I had something that I had to deal with. I grew up in the south in Florida; an Asian kid. It's not very common. So I know there was something challenging that I had to deal with and I knew this was a more pronounced physical manifestation than even I had – even my hair color and everything. Because this was physically something that was not normal for any other kid. That was my biggest concern. Fathers explained that since they did not have extensive knowledge about cleft, after the possibility of co-occurring syndromes was ruled out, they viewed it as more of a cosmetic problem and worried about their children's appearance and social stigma. They did start worrying about feeding and speech after they learned more about the cleft and wondered how their babies were going to be able to eat and talk. Some stated that initially they were not sure if the baby was going to be in pain every time she/he ate. Finally, fathers were concerned about the necessary surgeries and when they should be done. They wanted to have a plan ready before their children were born.

5.5.1.3 Subtheme: Initial Feelings

Nine of 10 fathers talked about their feelings at the time of the diagnosis in 16 segments. Fathers described being worried, shocked, and sad at the time of the cleft diagnosis; the most frequently reported feeling was worry. They worried about the overall health and development of their children as well as the severity of the cleft. Some fathers were sad at the time of the diagnosis because they realized they were not going to be able to take the “glamorous easy road” while raising their children. Chip reported that he felt it was “catastrophic” when he received the cleft diagnosis because, when he was

young, he knew someone who had a cleft. He remembered the visible disfigurement of this person and did not want that for his own child. Darth shared that the ultrasound picture made the cleft seem much worse than it actually turned out to be. However, looking at the ultrasound picture and thinking that it looked like “half of his head was missing,” he worried if the cleft would go “further than cosmetic, whether it goes into the brain.” This experience was also shocking for most fathers. They were not expecting the diagnosis. Some of them learned the sex of their baby at the same appointment. So what they thought should be a “joyous occasion” turned out to be a “deflating” experience.

5.5.1.4 Subtheme: Opinions about the Prenatal Diagnosis

Even though fathers in the prenatal diagnosis group did talk about increased stress and worry during the pregnancy, most were glad they received the diagnosis prenatally because it gave them more time to prepare both practically and emotionally. They were able to have additional testing, rule out some of the accompanying issues, and get an idea about the severity of the cleft. They had more time to do research; learn about cleft; talk to other parents both in real life and virtually; read other posts and testimonies online; and see pictures of other children born with cleft. They were able to learn about feeding issues and to buy the special bottles, evaluate different options for treatment, and with their wives develop a course of treatment. As Ben said,

But also I can think about even beyond that first sight of him, what’s my plan to make sure that everything is taken care of for him. I can I start developing that plan for him so I can reduce the impact for him both physically and developmentally wise moving forward. It helped me ground things into a plan, basically.

They were also able to better prepare financially because treatment for a child with cleft treatment can be expensive. As they learned more about cleft, they also prepared themselves emotionally. They shared that it was helpful to look at pictures of other children with cleft to spare them the shock at the time of birth. As Francis noted, “I was able to look at kids that were born with cleft and to see the different spectrums and the variations of it.” Some stated that they prepared themselves for the worst-case scenario regarding anomalies and severity of the cleft. The part that was still challenging was not being able to do anything to prevent their child from being born with cleft, no matter how much preparation they did in advance.

5.5.1.5 Subtheme: Couple’s Process

All 10 fathers stated they were with their partners at the time of the diagnosis, yet two mothers said that they were alone. Seven fathers out of 10 in the prenatal diagnosis group described the process they went through with their partner when they learned the diagnosis in 11 segments. Fathers said it was really helpful that they were with their partners at the time of the diagnosis because they were able to comfort each other. For example, Joe said that he and his partner viewed the situation differently, which helped to calm each other down. He said:

On my end I think my wife was able to comfort me because she — she kind of works in an adjacent field where she works with doctors and hospitals and I think she understand better than I did or do. Having a cleft in a country with well-developed medical industry is not as serious as maybe I would have thought without her. So I think she was able to comfort me in that way and I think that I

was able to comfort her in that we are still having a baby. We were all obviously really excited about it and just being there for each other helped out.

In some cases, mothers were more upset than the fathers at the time of the diagnosis so the fathers took on a soothing role. Fathers also noted the doctor's demeanor and described appreciating when doctors focused more on their partners' reactions and took the time to comfort them. Yet fathers described having the same reactions to the cleft diagnosis as their wives. Fathers shared that they initially were not familiar with clefts so they wanted to learn more and come up with a plan to "fix" it. Murray explained,

And, you know, what kind of surgeries were going to be necessary and when?

And my wife is kind of, too, but I'm much more this way of okay, here's the problem. What's the solution? How do we solve it? What's the plan? So it was more like okay, the cards have been dealt, what's the plan from here?

Since fathers were focused on what was necessary to "fix" this problem, some felt that they "thrust into fatherhood immediately."

5.5.1.6 Subtheme: Informing

Similar to the mothers, fathers described preparing their families to meet their children *before* they were born. They did not want their families to be shocked or surprised at the time of birth because they were expecting a "perfect baby." Fathers emphasized that they wanted to prepare their families for what they were going to "see" once they first met the newborns. So they showed their families pictures of other children who had clefts. They also thought that this would be an opportunity for family members to do their own research and learn more about cleft. Some fathers informed their families

by sharing more information about the accompanying issues their babies could have; others discussed the cleft as not being “a big deal.” The fathers explained that as they received more information about their children’s diagnosis, they continued to inform and educate family members throughout the pregnancy. Some fathers’ families were familiar with cleft because they worked in the medical field, so they did not have intense reactions to the prenatal cleft diagnosis. However, some family members had reactions that were stressful for the fathers, such as asking questions about the baby having additional syndromes or the cause of the cleft. For example, Ben said:

Although some people will ask questions, which I’m very much open to the questions, especially with my parents; “Do you think God kind of put his hand in there and kind of pulled it apart?” You know stuff like that. Obviously, that’s out of ignorance, so you just try to answer it and say, “No, I don’t think that’s the case.”

Some family members had more intense reactions such as being scared of the pictures they were shown or being negative about the situation as they explained it to other people. Bill, for example, had a difficult time with his father’s reaction to the cleft condition:

I guess the only part would’ve been that my father is just retarded in some aspects of that stuff. So it just kind of made me angry that mentally, he just doesn’t comprehend things that well. So he just pisses me off with some of his comments. Like just maybe some of the ways he would describe things with other people in stuff. I could tell he wouldn’t really understand that it’s not that the child would be imperfect or something, it’s just – I don’t know. That he kind of

has to feel like he needs to almost apologize if he's explaining to somebody else about his grandson or something.

His father's reaction was challenging for Bill because his wife was also born with cleft lip and palate.

5.5.1.7 Subtheme: Impact on Pregnancy

All 10 fathers in the prenatal diagnosis group described their impressions of the cleft's impact on the pregnancies in 33 segments. Cleft diagnosis "took the pure joy away" from the pregnancy for some of the fathers. The fathers emphasized that they were still excited about the birth of their children. For some it was their first child and for others it was a "miracle baby" that was conceived after a long period of trying and fertility treatment. However, knowing about the cleft diagnosis prenatally increased their worries and stress during the pregnancy. They were anxious because they did not know "what it meant" to have a baby born with a cleft. Therefore, they started doing online research about cleft, which increased their worries because they came across the "worst-case scenarios." They started wondering if their children had the additional issues noted on the Web sites. Murray described the impact of the Internet searches on his own worries:

You start looking on the Internet and you see everything. Things that are very scary and things that make you extra nervous and so those things probably make you worry probably more so, definitely more than I am after the baby was born and after all the procedures she's had.

For fathers, it was more challenging if medical staff could not answer all of their questions about the severity of the cleft and additional syndromes; the staff often told

them that they had to wait until their babies were born to know for sure. For this reason, they believed that they needed to prepare themselves for the worst-case scenario.

Suddenly they became more cognizant of all possible things that could go wrong when expecting a child. Ben was one of the fathers who struggled with these worries: “What else could go wrong, what other risks are there, what risks are associated with the cleft lip? So it made me a lot more aware of the child’s development in the womb, for sure.” For this reason, they wanted the birth to come faster so that they could see and interact with their children. Some fathers stated that the prenatal diagnosis led to them doing “extra work” during the pregnancy because they needed to attend additional appointments for further testing.

Finally, it was challenging to keep informing people about the cleft every time they talked about the pregnancy. They felt that they always had to let people know about the cleft and prepare them. Some mentioned that it was tiring to constantly “brace” people, especially their family members, as they delivered the news about the cleft. Some fathers said they became more reserved because they were not yet ready to talk about the cleft.

5.5.2 Dominant Theme: Having the Baby

The second dominant theme, *having the baby*, describes the experiences of the fathers in the prenatal diagnosis group when their children were born. Question #4 in my interview guide (Appendix D) asked about the father’s experiences at the time of the birth. All 10 fathers described their experiences of having a baby in 100 segments. The dominant theme of having the baby was divided into the following three subthemes: (1) preparedness; (2) reaction to the baby; and (3) concerns.

5.5.2.1 Subtheme: Preparedness

Like the mothers in the prenatal diagnosis group, the fathers talked about having additional time to prepare practically and emotionally for the birth of their children. All 10 fathers in the prenatal diagnosis group described in 52 segments how they prepared. At the time of birth, fathers were knowledgeable about cleft care and treatment so there were no surprises. Furthermore, they knew about the worst-case scenarios and specific issues a child with cleft could face. They were able to go onto cleft Web sites, read people's testimonies, or talk directly with people and see pictures of other children born with cleft before and after the surgery. These experiences were comforting for fathers. For example, Chip said, "We went through a whole battery of pictures of people that were born with all kinds of severe and not so severe clefts and, obviously, the results are really, really good. And so we were pretty confident that was going to be the case." In addition to learning more about cleft, fathers felt prepared about the course of treatment. They met with the doctors who would be in charge of their children's treatment and bought special feeder bottles.

At an emotional level, fathers felt it was helpful knowing before the birth what they might cope with in the future, such as the treatment and surgeries. They were able to process their emotions *before* the birth and put the situation into perspective. They thought about other health issues their children could have had and felt grateful. Fathers also emphasized that it was helpful to know beforehand to spare any shock they could have experienced in the delivery room because birth was already an "emotionally charged," life-changing moment.

Some fathers got emotionally prepared by getting themselves ready to cope with the “worst-case scenario,” especially because of the information available on the Internet. For example, Mitch stated, “I think it would’ve been shock, surprise visually because you never anticipate that. But, I think knowing allows you to do the research and gather sometimes, horrific information that prepares you or makes you think of issues that are reality when he is born.” As Mitch shared, it was important for fathers to be prepared to “see” a baby with a cleft, in addition to being emotionally prepared to care for a child with cleft. They shared that it could have been “traumatic” to see the cleft at the time of birth, they could have “freaked out.”

Additionally, fathers described being prepared to welcome a new baby. They prepared their babies’ rooms and took classes to learn how to care for a baby born with a cleft. Most fathers said that they had children later in life so they felt more certain that they would be able to take care of a child born with cleft.

Still, the fathers felt there were some aspects that they were not prepared for at the time of birth. Most were related not to cleft but to becoming a father. Only one father mentioned not being ready for the outsiders’ comments they could receive when they took their baby out in public. For seven of the 10 fathers, this was their first child so they found that they were not fully prepared to take care of a child. They were not prepared for their wives having a difficult labor and the stress in the household during the initial stages after birth. Ben described the initial stages after his child’s birth as “emotionally scarring” and shared that:

One of the other things I guess I could tell you that I wasn’t prepared for was the amount of just stress in the household, like I would say the first three months. I

always tell people this, the first three months once the baby's born, it's so stressful in the house because just your wife is physically not at 100%. But then also, hormones are raging. I wasn't prepared for that.

Some fathers said that their lives completely changed after their children were born because they did not have as much free time to do activities as a couple.

5.5.2.2 Subtheme: Reactions to the Baby

Six of 10 prenatal fathers described reactions to their babies when they first saw them in 13 segments. Most fathers had a positive reaction to their newborns. Mitch, who continued to worry about the possibility of additional syndromes until the time of birth, expressed feeling relieved. He said:

Then once he was born and seeing him and experiencing him it was not, I felt like I probably worried too much, but I didn't know to worry less because I never experienced that. I didn't have that education or I didn't know what to expect, so I expect the worst and then when he was born it was "Okay, we can certainly deal with this. It's not a big issue."

Darth, who worried about the severity of his child's cleft because of the ultrasound picture, also shared that when he saw his child for the first time, he thought, "That's not too bad." He was relieved. One father said that their baby still looked "beautiful," even with the cleft; another admitted being "frightened" by the child's cleft. Bob said initially he was scared of his son's cleft. He shared, "My first thought when I saw him was, 'Don't worry, buddy, we'll fix you up.'" For one father, cleft was "not even the top thing" at the time of birth. They were just happy to meet their babies for the first time. Finally, one father noted that his son received positive reactions not only from

him but also from the whole family. Even though most prenatal fathers who received the diagnosis prenatally felt relief on meeting their children for the first time, they still had concerns.

5.5.2.3 Subtheme: Concerns

Nine prenatal fathers out of 10 described their concerns in 15 segments. Their concerns included (1) feeding, (2) social stigma, (3) appearance, (4) possibility of repair, (5) child's development, (6) surgery, and (7) parenting. Concerns about feeding emerged at the time of birth if the hospital staff did not have adequate information regarding how to feed a baby born with cleft. Francis shared, "Feeding was very important; absolutely. My wife obviously couldn't breastfeed because he had a very wide cleft, and we had the bottles but none of those nurses had ever dealt with a cleft lip and palate kid before." Feeding also became an issue when the two babies were diagnosed at the time of birth with cleft palate in addition to the cleft lip. Fathers were relieved that their babies were not born with any additional anomalies that could cause developmental issues, even though a few still wanted to wait and see. Darth was one of the fathers who said,

Hearing, speech, just basic motor skills, everything is like working the way he wants it to work and the way it's supposed to work. So it's mostly a waiting game. It's just you just wait it out and hope everything comes back with the tests that he goes to a lot.

Bob stated that his son's cleft was more severe than he had expected from what he saw on the ultrasound scan so he questioned whether it could be repaired. He said that he was afraid his son "would not be a good looking kid." Some started thinking about the next steps right after their children were born. For example, Chip said, "We knew she

was healthy besides that, so my concerns were just doing what we had to do to prepare her for her surgery and doing the best we could for her.”

Social stigma was another concern expressed by five prenatal fathers. They wondered how strangers would react to their children when they went outside. One father worried that his wife might have difficulty accepting their child. Finally, two fathers said they did not have any concerns about the cleft at the time of birth and that their concerns shifted either to the usual parenting issues or to the health of the baby and the mother.

5.5.3 Dominant Theme: Initial Stages

The third dominant theme, *initial stages*, describes the experiences during the first year of their children’s lives of fathers who received the diagnosis prenatally. Questions 4 and 5 in my interview guide (Appendix D) asked the fathers about their experiences during the first month of their children’s lives and at the time of the first surgery. All 10 prenatal fathers described their experiences in 138 segments. The dominant theme of initial stages was then divided into three subthemes: (1) taking care of a baby with cleft, (2) feelings, and (3) surgery.

5.5.3.1 Subtheme: Taking Care of a Baby with Cleft

Nine fathers described their experiences taking care of a baby born with cleft in nine segments. They said that the “bodily instinct” kicked in and they were really happy about being a father; it was fun to hold their babies and be with them. The cleft did not change their love for their babies, even though it took time for some fathers to get used to seeing the cleft. Five fathers who had two children compared their experiences of taking care of a baby with and without a cleft. They thought that the main difference between taking care of the two children was the cleft surgery. Mitch explained:

Compared to our second son, you know, now I can have something to compare it to. I mean it was joyous and it wasn't really any issues. You know we had different things we had to do. Get him checked and you know, the initial surgery. I think it was 3 or 4 months, so other than that, which you wouldn't expect to have a newborn and have to have a surgery and go through that. I mean it was obviously a trying experience, but it was no, you know regrets or lack of love or anything like that. I mean it's our son.

In contrast, the first-time fathers identified parenthood as an all "encompassing" experience. Taking care of the baby took "every part of their lives." They talked about being sleep deprived and, for some, not being prepared for the stress in the household and walking on eggshells at home.

They wanted to help their wives as they struggled with recovering from birth, taking care of the babies, and making sure their babies were eating well. Three fathers wanted to see if their babies were able to breastfeed or to adjust to the special feeder bottles and were relieved when the babies eventually adjusted. None of the mothers was able to breastfeed, but all of them pumped their milk and fed it to their children. It was challenging for fathers to see their wives stressed, especially when it was because they had to pump their breast milk instead of breastfeeding their child. As Murray shared, "Happy wife, happy life, and she wasn't necessarily happy at the time, so that was stressful for me, too." He felt inadequate when he could not help with the feedings, since his wife had to pump the breast milk multiple times a day.

Some fathers took on the responsibility of doing the tapings for NAM. For example, Frank said,

“After we met with that doctor we had to go through taping an appliance to her face, have it on there 24 hours a day. I just kind of thought that that was my one way of trying to make her life better as a result of the cleft. That was my one way of me helping her through it.”

5.5.3.2 Subtheme: Feelings

Nine fathers described their feelings during the initial stages of raising a child with cleft in 13 segments. The fathers primarily described being happy and joyous because their babies were healthy, except for the cleft, and eventually able to feed. They were relieved that having a child with cleft was not as bad as they thought it would be before the birth. They described seeing something of themselves in their babies and rediscovering different aspects of their babies every day. Bill was one of the fathers who really enjoyed becoming a first-time father during the initial stages. He said,

I guess the first month you couldn't tell, but as he got older it was a lot more fun because you could see little pieces of us coming out in him. The first month was just kind of like a joyous thing. We're battling sleep and trying to get sleep, but it was always fun to hold him and kind of be with him. It was cool, like a new toy.

In contrast, some fathers felt consumed by the experience of taking care of a baby and helpless at times when they could not help their wives. Some described feeling scared that they were not going to be able to improve their child's physical appearance as the result of the surgery. The time of the surgery was another salient experience during the initial stages.

5.5.3.3 Subtheme: Surgery

All 10 fathers who received the diagnosis prenatally shared the experiences of their children's first surgeries in 78 segments. Before the surgery, fathers had myriad concerns. They were concerned about the child receiving anesthesia and wondered if he or she would have an adverse reaction or experience other complications during the surgery. They worried about how their children's appearance was going to change , after the first surgery. For example, Joe said, "It was nerve racking up until the cosmetic surgery because we didn't know what she looked like or how well they would be able to repair that lip." They wanted their children to look good enough to avoid any social stigma. As Darth said,

The main thing is once we found out he has a cleft and you find out he's doing okay, you just want to make sure that he looks good enough to the point where he feels comfortable and doesn't feel strange or people looking at him or something. They also wondered if the surgery would impact their children psychologically and if they would later remember this experience. They did not want their children to be in pain after the surgery. For fathers, trusting the treatment team and being comfortable with course of treatment reduced their levels of stress before that first surgery. It was also helpful if their children were content and peaceful before the surgery.

After the surgery, the fathers were concerned about their children's pain and distress. Some thought that the recovery period was very challenging; for others, it was faster than they expected. Fathers wondered about the psychological impact of the surgery on their children. Chip said that his son looked "older" to him after the first surgery, as if he has been through a trauma. He said,

You feel like he's gone through some trauma like he'd changed in some way because he felt older to me. I think when you put a baby in an operation you feel like he's been through a trauma so now his innocence is kind of gone.

Most fathers were content with the changed appearances of their children. They were relieved that the first surgery changed their children's appearance positively. Some shared that they could not initially see its full effect and had to wait for the swelling to go down. After a few medical appointments in which the staff removed the stitches and the bandages, they were able to see the results more clearly. Murray explained:

And then the one time I came home and my wife had taken her to the doctor and she said, "Here's your new daughter." She had the bandages removed and I was like Oh my Gosh. It looked unbelievable. She looked so different after the first surgery but it was amazing to see how the surgery turned out.

One father said that even though his son's appearance changed, he still looked like a child with cleft because that was the way "God created him," but it was still good to see him "actually smile." Like the mothers who received the diagnosis prenatally, one father said that he initially missed seeing his child with cleft. Talking about his son's changed physical appearance, Bob said, "I was a little upset that his smile shrunk. Well, when he had a gap in his lip when he smiled, it was ear to ear. And afterwards, it wasn't quite as wide." The mother from one couple, Bill and Laurie, said that both she and her husband missed seeing the cleft initially. Laurie herself was born with CLP. However, in his individual interview, Bill said that he actually did not miss the cleft and thought that their son "looked like he was supposed to look" after the surgery. So, unlike his wife who

was also born with a cleft, he was glad that he would not have to protect his son from the outsiders' reactions anymore. He said:

I heard Laurie say she spoke for both us and said that she thought both of us missed it. I disagree. I felt like he was the way he was supposed to be. I felt that he would be happier that way. I didn't want people to see him as like something — people making judgment and seeing him differently before it was corrected. I felt like after it was corrected that it would only be better for him as he got older. He wouldn't be treated differently.

If their children also had cleft palate, some fathers shifted their focus to the next surgery in which the palate would be corrected. However, fathers reported that the hospital experiences made them feel grateful. They talked about seeing other children with more severe health conditions or more severe clefts, which put things into perspective for them.

5.5.4 Dominant Theme: Current Situation

The fourth dominant theme, *current situation*, describes the concerns raising a child born with cleft that the fathers expressed at the time of the interview. Question 3 in my interview guide (Appendix D) asks fathers about their current concerns. All fathers described the process of currently raising a child between the ages of 1 and 4 with cleft in 28 segments. The dominant theme had one subtheme: *current concerns*.

Fathers described the following two main concerns: (1) upcoming treatments and (2) social stigma. This subtheme included 17 segments from 9 of the 10 fathers who received the diagnosis prenatally. Some children needed to go through additional cosmetic revisions of their lips, and some were going to receive a bone graft when they

were 7 years old. Fathers were primarily concerned about the pain their children could experience because of the surgeries. Fathers who were told that their children needed additional cosmetic surgeries for lip revision questioned the timing of the previous surgery and wondered if the additional surgery would not have been necessary if they waited a little longer. As Mitch said:

I feel maybe sometime if we waited we wouldn't have to have a second surgery. So if he was able to develop a little bit more and have a little bit more to work with his lips because his lips obviously were so small at the age; I think it was 3 or 4 months when he had it. But maybe if we let him develop to 6 months or whatever, the doctor would have had a little more to work with and it would have been a little more perfect or what have you.

Fathers hoped that, after going through the reconstructive surgeries, their children would not be targeted by their peers because of visible differences. They wanted their children to fit in socially and to not be “shy.” Some worried that the surgery scar could make them more of a target, especially if combined with other visual differences. For example, Ben said:

I guess developmentally he's a little smaller, but it's not necessarily a concern. Maybe he's a little behind there, so we're a little concerned that he might be a bigger target for a little bullying and stuff like that. That's crossed my mind a few times, but that's more so because of his stature versus... And maybe if there's any scar left in his lip, that makes him an easier target, or the combination of the two, but that's really it.

5.5.5 Dominant Theme: Raising a Child with Cleft

The fifth and last dominant theme of fathers receiving a prenatal diagnosis, *raising a child with cleft*, describes fathers' impressions about the process of raising a child with cleft (questions 7, 8, 12, 13 and 14 in my interview guide; Appendix D). Fathers talked about their sources of stress, their challenges, and lessons learned as they reflected on their experiences. They also described their views at the time of the interview of the cleft and of their child and possible factors that led to their children developing clefts. All 10 prenatal fathers described their experiences in 170 segments, which were divided into the following 5 subthemes: (1) sources of stress, (2) challenges, (3) advice/lessons learned, (4d) reasons for cleft, and (5) view of the child and cleft.

5.5.5.1 Subtheme: Sources of Stress

Similar to the sources of stress of their wives, fathers also experienced stress during the initial stages after their children's birth. Nine fathers described their sources of stress in 19 segments, which included: (1) NAM device, (2) surgery, (3) feeding, (4) doctors' appointments, (5) seeing their children in pain, (6) seeing their wives stressed, (7) social stigma, and (8) fears of the unknown.

Fathers described the challenges of using the NAM device, for example, having to keep it on all the time even after their children grew up and learned how to pull it off on their own. They also described the stress of doing the tapings regularly even when the children's skin was irritated, attending the appointments for the orthodontist to adjust the NAM, positioning the NAM correctly, and dealing with the social stigma when they took their children out wearing the NAM. Describing the different reactions he got from outsiders, Francis shared:

Then also part of the impact of people looking at your child differently or people making silly or stupid comments. I'll give you an example of one of the extremes; a lot of people look at the baby and then quick look away. If their kids look at the baby, they're like, "Don't look. Don't look." So he was taped up and then a tube up his nose and all that stuff. On the flip side of that is if somebody wanted to see the baby and noticed that he looked a little bit different and blew it completely out of proportion. We had one guy, "Oh, my, god. He's the cutest" – you're full of shit – "Oh, my, god." Calling his wife from across the store. "You've got to see this baby." It's like, really?!

Even though it was challenging, fathers wanted to be hypervigilant about their children wearing the NAM because they were told that it could impact the outcome of surgery. The surgery was another source of stress for fathers. Waiting for the surgeries, wondering about the outcome before the surgery, and seeing their children in pain after the surgery were all described as stressful for fathers. They found themselves counting down the weeks before the surgeries and experiencing distress about possible complications and the outcome. For some, the palate surgery was more difficult than the lip surgery because their children experienced more pain. They described as stressful removing the NAM device and adjusting to a new way of feeding their children after the lip surgery. Furthermore, the fathers said that they needed to go to regular doctors' appointments, which sometimes included procedures that caused pain for their children, such as changing their ear tubes. It was also stressful for the fathers to wait with their babies to see the doctor. At times, they had a difficult time soothing their babies when the babies were frustrated because of being tired or in pain. Bill explained,

Every session we had been to, it was a nice three hour ordeal or waiting and sitting in a room for an hour and half trying to figure out something to do with him. Usually by the time he would be seen it was always, by that point he was always at the end of his happy time.

It was also hard for fathers to see their wives stressed. Yet, some fathers expressed that the hardest part was waiting for their babies to be born because they did not know what they were going to deal with; however, once the baby was born, everything got easier.

5.5.5.2 Subtheme: Challenges

Nine fathers out of 10 described the challenges of raising a child with cleft. Similar to their sources of stress, most identified the initial stages as the most challenging. The NAM device, surgeries, finding the best treatment team, feeding, and meeting family members for the first time were identified as initially challenging. Ongoing challenges included, keeping their anxiety in check and preparing people.

Fathers described the NAM device as challenging when they first started using it because they were not used to it and their babies were not happy about having it on. However, as time passed, using the NAM device became easier and a routine. The surgery was another challenge for the fathers. Some fathers shared that the challenge of the surgery was unique to them because not all fathers who have newborns have to think about putting their 3-month-old babies through surgery. Mitch said,

I guess, you know, having to have the birth of a new baby; having to worry about having a surgery shortly after birth. Rather than just enjoying the birth. Having you know in the back of your head, “Okay how are we going to deal with this,

when we're going to deal with this, seeing specialists," and all that rather just changing diapers.

They were worried about possible complications before the surgery. The situation became more stressful if the surgery took longer than expected. The challenge after surgery was taking care of the baby and trying to ease their child's pain. For example, Murray said,

Just seeing her in pain and not being able to do anything. I mean, I was there and I was comforting her and holding her and singing to her. But just seeing her in pain, like any parent or loved one, you don't want to see anyone in pain and how can you help that not happen?

Some fathers said that initially it was difficult to pick a surgeon because there were many hospitals in the area and the surgeons were using different treatment methods. Once they chose their hospital (CHOP), it also took some time for them to trust their treatment team. In the beginning the fathers shared that helping their babies adjust to the special feeder bottles was another challenge.

One father reported an ongoing struggle with outsiders' comments and questions. It was frustrating for him to keep talking about cleft to "brace" outsiders. Bill explained,

Honestly, I would just say the biggest problem is just having to kind of feel like that you need to brace everyone else. Like I said before, you're constantly talking about it and constantly being forced to bring it up. Instead of being able to just deal with it and let it go, you feel like it's the topic every time.

For another father, Frank, it was sometimes difficult to soothe his own anxiety about the impact this process could have on his child. He said,

And then the emotional, I wouldn't call it a challenge, but it's an emotional challenge of trying to not walk around crying, worrying about the baby 24/7. Just understanding that when he grows up, he's not going to remember any of this, he's not going to have any memory of it, so he'll be okay.

5.5.5.3 Subtheme: Reasons for Cleft

All 10 prenatal fathers described the reasons they attributed to their children being born with a cleft in 13 segments. Most fathers shared that they did not know what caused their children's clefts. They stated that, on the basis of the research they did on their own and the conversations they had with the doctors, they could not find definitive cause for the cleft. Some decided to stop thinking about a possible cause. Frank was one of these fathers, "I didn't really worry about why just because that's not my nature. I try to ignore the things that I have no control over. I try to worry about the stuff I do have control over."

Nevertheless, the fathers still pondered the causes of their children's cleft. They identified race, ethnicity, medications used, vitamin deficiency, lack of folic acid, genetics, and age as possible reasons for the cleft. Two fathers who were in a biracial relationship (White-Asian) said that race/ethnicity could be a possible cause. However, they did not express any feelings of self-blame related to this disposition. One father talked about his wife taking epilepsy medication while she was pregnant, which might have led to the cleft. Another father said that his wife was not taking prenatal vitamins at the time because they were told that they were not going to be able to conceive a child.

Yet another father stated that he was adopted and he and his wife were older parents so these factors could have led to their child developing a cleft. He said,

I was adopted, so I don't know if there's any medical history from me having any cleft/lip palates in my family. I was born with, I guess you'd call it a genetic defect myself, a different one. I was born with hernias and undescended testicles, which was corrected, so I just didn't know if there was something in my family genes that may have contributed to it.

5.5.5.4 Subtheme: View of the Child and Cleft

Nine fathers shared their views of their children and the cleft in 40 segments. Almost all the fathers described their children positively. They stated that they experienced their children as fun, healthy, happy, smart, bright, beautiful, and strong. They emphasized that they did not see their children as being deficient in any way. Three fathers said that the cleft did not change their love for their children. Ben said, "Even when he was born and even when we saw the cleft before it was fixed, it even became something endearing to us. Because he or she is your kid and there's no way you're not going to love your kid." Even though some described the cleft becoming "endearing," some did see it as a "deformity," as something that needed to be fixed. One father stated that, other than the cleft, his son was a "normal kid."

Fathers viewed cleft as a "fixable" and a "cosmetic" issue. For them, cleft was a minor issue compared to all the other issues their children could have faced. Some thought of it as a common issue whereas others stated that it was "uncommon but well-addressed." Some fathers knew that it was common in "third-world countries." In general, fathers agreed that cleft was a treatable issue in the United States. As the fathers

who received a prenatal diagnosis looked back on their experience, they did not think that having a child born with cleft was that different from having a child without a cleft, except for the feeding. For example, Darth said, “There’s not really much stuff you need when you have a child with cleft. It’s just the same stuff. You just have to feed him slightly differently, and everything else is pretty much the same.”

5.5.5.5 Subtheme: Lessons Learned

Throughout this process, all 10 prenatal fathers talked about learning many lessons about being a parent and being the father of a child with cleft. The subtheme of lessons learned included 54 segments. Looking back on their experience of raising a child with cleft, fathers learned that cleft is more of a cosmetic issue. However, it still affected the feeding and caused additional stress because of the surgeries. The fathers felt that raising a child with cleft was challenging in the first few months but got easier after the surgery and after feedings improved.

Fathers described the importance of getting a second opinion when they first received the prenatal cleft diagnosis and choosing a hospital equipped to do the prenatal testing. Frank, whose baby was initially mistakenly diagnosed with trisomy 18 in utero at another hospital, said,

Clearly there’s a difference between hospitals because like I said, I don’t think the other hospitals we could have dealt with didn’t even have the equipment that a hospital that specializes in prenatal issues would have clearly. You know what I mean? That was clear when we were there. It’s a big advantage to put people more at ease.

Reflecting back on the prenatal ultrasound picture they received, Darth warned other parents that the picture could be misleading. The fathers emphasized that before the birth, learning more about cleft reduced their stress and gave them more time to prepare emotionally, practically, medically, and financially. However, it would have been more helpful to get the information from their doctors rather than from the Internet since Web sites can be misleading. Joe said,

I would just advise them to limit the amount getting information from third party sources over the internet and have as much trust in their doctor and the stuff that their telling them and to have more dialogue with their doctors more so than trying to find information themselves.

When their babies were born, fathers stated that it was important for them to pick a treatment team whom they could trust. Francis said,

Make sure that you are 100 percent confident in your medical professionals. Go out and meet – if you go somewhere and you're not comfortable with them, go somewhere else. I don't care if it's in the United States. I don't care if it's in Germany. I don't care if it's in Russia or Australia. Just find the best place that you're most comfortable.

As their children grew older, some fathers continued to monitor their children's development to make sure there were not any developmental delays.

The fathers expressed that they learned to put things into perspective and to be grateful that cleft was all they were dealing with. Yet they also shared that it was important to get the best possible results since "this world is a visual world." Fathers described the importance of patience. Sometimes, it was difficult for them to remain

patient because they wanted the treatment to conclude as quickly as possible. As Bob expressed, “I don’t know, perhaps I’m a typical male. I just wanted to fix things. It can’t happen that quickly.” Finally, they wanted other parents to know that they were not alone.

This experience taught fathers that being a parent is a big responsibility, that “it is not a walk in the park.” It is never the “perfect” experience you dream it to be. Still, it is worth it. Ben shared:

I guess one of the biggest things was when you have a kid, the only thing you can think about is like having this Gerber baby, right, this perfect baby. But it really helped me prepare for – and that’s probably not going to happen. Even if you do have the perfect Gerber baby in terms of physical perfection, having a kid is not perfect. You’re going to have issues. So for me, it helped kind of accelerate that maturity in my understanding of what being a parent is, right. Things aren’t going to be perfect. It’s how you deal with it.

Some fathers also mentioned the importance of patience when they were talking about being a parent. They described fatherhood as a “learning experience” and said, “It’s not the end of the world if you make a mistake. They are not breakable.”

5.6 Prenatal Diagnosis Group, Couples: Dominant and Subdominant Themes

After I completed the individual interviews of mothers and fathers, I interviewed them as a couple. Questions 12 to 26 in my interview guide asked about the impact on their relationship of raising a child born with cleft. Furthermore, I wanted to explore how they talked about cleft with each other, with other people, and with their older children. I also wanted to understand the ongoing functioning of the children through their parents’

eyes. The couple interviews gave me the opportunity to triangulate the individual interviews with the couple interview to obtain a deeper understanding of their experiences. The findings from the interviews of the 10 prenatal couples yielded the following dominant themes: (1) couple's relationship, (2) about the experience, (3) child's functioning, and (4) talking about cleft. Within these four dominant themes, 18 subthemes emerged that captured the couples' experiences. Table 5.11 lists the dominant themes and subthemes. To inform the reader about the frequency of themes and the number of prenatal couples who mentioned them, I included the "theme frequency" section in Table 5.11. The following section contains quotes from the couples to illustrate each subtheme.

Table 5.11. Dominant Themes of Couples in the Prenatal Diagnosis Group

Level	Themes	Theme Frequency/Prenatal Couples' Quotes in this Chapter
100	Dominant Theme: Couple's Relationship	295 Total Segments: All prenatal couples
101	Impact on couple's relationship	38 segments: All prenatal couples Prenatal couple quotes: Mo&Chip, Rebecca&Ben, Jane
102	Rules and responsibilities	43 segments: All prenatal couples Prenatal couple quotes: Jane&Mitch, Abby&Murray, Mo&Chip, Bob&Zoe
103	Decision making	57 segments: 9 of 10 prenatal couples Prenatal couple quotes: Darth&Vader, Francis&Rachel, Jane&Mitch, Joe&Elizabeth
104	Challenge for the relationship	23 segments: All prenatal couples Prenatal couple quotes: Jane&Mitch, Mo&Chip, Rebecca&Ben
105	Impact on couple's social life	18 segments: All prenatal couples Prenatal Couple Quotes: Abby&Murray, Rachel&Francis,
106	Sources of support	78 segments: All prenatal couples Prenatal couple quotes: Rachel&Francis,

107	Concerns	Chip, Darth&Vader 18 segments: 6 of 10 prenatal couples Prenatal couple quotes: Joe&Elizabeth, Jane
200	Dominant theme: About the Experience	34 segments: 9 of 10 prenatal couples
201	Lessons learned	26 segments: 8 of 10 prenatal couples Prenatal couple quotes: Mitch, Rachel&Francis, Mary&Frank
300	Dominant Theme: Child's Functioning	74 segments: All prenatal couples
301	Appearance concerns	10 segments: 9 of 10 prenatal couples Prenatal couple quotes: Elizabeth&Joe, Laurie
302	Social functioning	10 Segments: All prenatal couples Prenatal couple quotes: Mary&Frank
303	Speech	10 segments: All prenatal couples Prenatal couple quotes: Bob, Mo
304	Development	11 segments: All prenatal couples Prenatal couple quotes: Elizabeth, Laurie
305	View of the child with cleft	25 segments: 9 of 10 prenatal couples Prenatal couple quotes: Darth, Chip
400	Dominant Theme: Talking About Cleft	208 segments: All prenatal couples
401	Talking about cleft as a couple	26 segments: All prenatal couples Prenatal couple quotes: Darth&Vader, Mo
402	Talking about cleft with family	39 segments: All prenatal couples Prenatal couple quotes: Bob&Zoe, Mo
403	Talking about cleft with their children	40 segments: All prenatal couples Prenatal couple quotes: Laurie, Mo&Chip
404	Talking about cleft with others	56 segments: All prenatal couples Prenatal couple quotes: Bob&Zoe, Rebecca
405	Talking with another parent	47 segments: All prenatal couples Prenatal couple quotes: Francis, Darth, Mary, Bob, Elizabeth

5.6.1 Dominant Theme: Couple's Relationship

The first dominant theme, *couple's relationship*, describes the impact of raising a child born with cleft on the couple's relationship. Questions 14, 15, 19, 20, 21, 22, and 25 in the interview guide (Appendix D) focused on understanding how couples negotiated decision making, roles and responsibilities, challenges, the impact of this experience on their social life, and their sources of support. All 10 couples described the impact of this experience on their relationship in 295 segments. The dominant theme was further divided into seven subthemes: (1) positive impact on couple's relationship, (2) roles and responsibilities, (3) decision making, (4) challenge for the relationship, (5) impact on couple's social life, (6) sources of support, and (7) concerns.

5.6.1.1 Subtheme: Impact on Couple's Relationship

All 10 couples in the prenatal diagnosis group described the positive impact this process had on their relationship in 38 segments. Couples shared that the experience of raising a child born with cleft made their relationship stronger and increased their faith in their partnership. Together they were able to work together as a team and support each other. For two couples, this was the biggest challenge they had ever faced in their relationship and they were happy they overcame it without turning on each other.

In four couples, fathers provided emotional support for the mothers and the mothers supported the fathers by doing research on cleft, sharing what they learned, figuring out the treatment approach, and scheduling the medical appointments. Some mothers described their husbands as their "rock" during this time, the person who was always there for them during the emotionally challenging times. As an example, doing the tapings for the NAM device was one of the tasks where Mo and Chip worked together

as a team. They described some stressful times throughout this process when Chip had to support Mo emotionally and help her stay calm. They both shared:

Chip: If I was really tired and the baby needed to have some taping done to her face, it took the two of us to apply the taping and appliance to the baby. If one of us was tired and the other one wasn't, you really had to focus when you were doing that in order to put it on correctly. We would need to sit her up more straight or hold the baby tighter or something. We worked with each other.

Mo: Yeah, to piggyback on that, we had a moment in [orthodontist's] office where [our daughter] was actually getting fitted for the appliance. I was so emotionally upset by it that I actually just slinked back in the corner and just cried the whole time she was having it happen because, as I say, it sounded like she was going to choke; but she wasn't in any danger or anything like that. My husband and I had a conversation in the car later, and he said, "You really can't do that. You really can't do that for the sake of your daughter." Really, it made me stronger because in the future hospital visits and the future experiences that we had, I had to do things that I thought I could never do and would never do. I did them in a strong manner. My husband is very calm. He has a very calm demeanor. I have a tendency to be the more upset one, I guess, with all of that pattern, but he made me stronger. That was something that, I think, it was tough for me at first. I realize the importance of it now.

For one prenatal couple, Jane and Mitch, the roles were reversed. The mothers provided the emotional support for the fathers, especially at the time of the diagnosis. Jane, who took on the "caretaker role" for her husband, said; "I think there are different

challenges that you face as a couple and as parents, and probably your roles change.

There are places where I think one of you will be stronger than the other.”

Ben and Rebecca were one of the couples who had complimentary ways of providing support for each other, specifically at the time of the cleft diagnosis. They said:

Rebecca: Well, I guess I felt really supported when we were going through it, by you. When we first heard the information, I was really upset at the moment and I felt you were really supportive. When we were in the waiting room and stuff, I felt you were really supportive during that stressful time for me.

Ben: I think I was saying this when I was first talking to her about helping me cope with the idea of having a cleft baby and understanding what that meant. I think what was really helpful – part of my ability to cope with that was actually a lot of the work you did researching it, looking into it, what is meant, what were the therapy options for the baby.

Five couples explained that this experience led them to evaluate their partnership and remember why they married each other in the first place. For example, two couples agreed about the course of treatment and worked together as a team. They realized that their priorities were the same; they were able to put their relationship struggles aside and work together for the benefit of their children. One couple stated that their ability to communicate improved under stress. This process helped another couple recognize their own strengths as well as those of their partners. Nine couples agreed that if they were able to get through this, as a couple they could “get through anything.”

5.6.1.2 Subtheme: Roles and Responsibilities

All 10 couples described how they negotiated their roles and responsibilities at the time of the cleft diagnosis, throughout the pregnancy, at the time of birth, and on an ongoing basis in 43 segments. At the time of the diagnosis and throughout the pregnancy, mothers were the ones who primarily did the research, evaluated the providers, and scheduled appointments, especially if they were already working in the health field. In some cases, both mothers and fathers did the research and “compared notes.” One mother (Bill and Laurie) was herself born with CLP and was a speech pathologist. She stated that she took on more of the “educator role” for her husband at the time of the diagnosis and during the pregnancy because of her previous experiences.

Couples additionally became a source of emotional support for each other by hugging one another or giving each other space as needed to self-soothe. Chip said, Educating ourselves was the second-most. First-most was making sure that we were both okay because when she was first diagnosed it was just a profound sadness because you just want to protect your child. There were just a number of days following the diagnosis where you just had to hug one another and just let each other know that it was going to be okay.

In five cases, prenatal fathers took on the comforter role. The roles were reversed in one couple (Jane and Mitch), because Mitch was worried throughout the pregnancy. They shared:

Jane: I think I took on a caretaker role for Mitch. I was worried about his reaction and his dealing with it. I think I put my dealing with it second to helping him deal with the news.

Mitch: I don't know if I would describe a role for me. I mean it was just trying to be a concerned parent and to educate myself and try and figure out what we were in for and how to handle it and overcome it and deal with it and a host of emotions, which I don't know how it would describe a role, but just trying to figure all that out and come to an understanding after you get by the why me and why us and dealing with it.

At the time of the birth, fathers were by the mothers' sides because they wanted to ensure they were doing well after the labor and that the hospital staff was attentive to their babies. All fathers were initially at home when the couples took the baby home. However, they had to get back to work earlier than the mothers. For this reason, all 10 mothers became the primary caregiver while fathers made sure that the "bills were paid" and the "financial resources were available" for care and treatment. They also continued to provide emotional support for the mothers. The mothers did the breast milk pumping, feeding, diaper changing, tapings, making doctors' appointments for the NAM device, and figuring out next steps for treatment. During the individual and couple interviews, both mothers and fathers who received the diagnosis prenatally agreed that fathers shared the responsibilities of child rearing when they were at home in the evenings and on the weekends; couples tag-teamed during these times. For example. Abby shared:

I was fortunate to have him home longer than most fathers that have to go back to work. But once he had to do that in August then more of the responsibility fell to me. And as far as taking her, because I would have to take her to all of the appointments to get her appliance readjusted and taped. But when he was home, it was 50/50.

For one couple, this situation created a challenge because the father wanted “a break” when he got home or complained that the house was messy.

The only responsibility that fathers could not share was pumping breast milk. In two cases, fathers and mothers took on specific responsibilities, such as making sure that the tapes were stocked and cut for the NAM device. Chip was one of these fathers:

My wife was not working for a year and a half after the baby was born, so she was busy just doing the normal mommy things. I was working, but in addition I really tried to get good at taping because that was the one way that I could help her. I just tried to get really proficient at it. In fact, thinking back, she had to be retaped three or four times a day, I think. So I was always making sure that she was well-stocked and the tapes were cut and ready to be applied because they had to be cut a certain way. So that was my job entirely. I took that role. But when she was taped, it required both of our attention.

One mother said that her husband wanted to be as involved as she was during the doctors’ appointments. Scheduling the appointments was at times challenging because they conflicted with her husband’s work schedules, but they found a way to arrange the appointments so that he could be more involved. One mother shared that her husband was there for the initial appointments until she felt more comfortable doing it on her own.

Five couples shared that they planned to continue to “tag team.” If the mothers are not working, they carry out child-rearing and household tasks but share responsibilities “50-50” with their husbands in the evenings and on the weekends. For eight couples, the way they carried out roles and responsibilities regarding parenting have not changed since the birth of their child. For two couples the fathers became more involved over

time. Jane and Mitch explained how they share ongoing child-rearing responsibilities and how it was different from what they did at the time of their child's birth:

Jane: I was going to say now we're much more 50/50, I think, whereas when we have a newborn, which we've been through twice, I'm much more in the lead on that process. Certainly, when we had our firstborn, who was the child with the cleft, I babysat and I spent a lot of time with babies on my own growing up or with friends' children. I'd read a lot, and I wanted to be the decision maker on those things. I think now we have a very balanced approach to caregiving, so our roles are, I think, a little bit different in terms of our schedule and things.

Mitch: Everything is just less defined. I think it just comes more natural.

Initially, it was like okay, you're going to do this; I'm going to do that. Now there's no discussion in who's doing what. It just kind of happens.

On the other hand, two couples had a more defined way of sharing the responsibilities of child rearing. Each parent either had specific responsibilities or they shared caregiving and household tasks by dividing the day in half. For example, Mo and Chip negotiated their work schedules so that Chip took care of their daughter in the morning when Mo went to work. Their daughter went to day care in the afternoon when Chip went to work; Mo picked her up on her way home from work in the late afternoon and then spent time with her until Chip came home in the evenings. The couple shared caregiving and household tasks in the evening, suggesting a more egalitarian relationship. Rebecca and Ben preferred to make a list of the shared responsibilities and then decide which one each would do each week.

Two couples took on more traditional gender roles in which the husband went to work and paid the bills and the wife took care of all household tasks and child rearing. No mothers in the prenatal diagnosis group identified this more traditional marriage as being a problem for them. However, one father felt guilty because his wife was doing “more than her share.” During the conversation about roles and responsibilities, they shared:

Bob: Like I said, Zoe does most of the work. I’m there when I can be and I do my best to be there when I have to be.

Zoe: That’s the time, and the rest of the time he’s working to provide for his family. That’s a big part of it, too. I like him home, but what he’s doing is pretty important, too.

Bob: Yeah, I’d rather be home, though.

Zoe: I know.

5.6.1.3 Subtheme: Decision Making

All 10 couples who received the diagnosis prenatally described how they made decisions about parenting and the course of treatment in 57 segments. They talked about listening to the doctors and asking questions to get more information. They stated that their treatment team provided them with a treatment plan and schedule, which reduced feelings of anxiety. For example, Darth shared:

Darth: It was pretty much just we talked to CHOP and to the people there and they’d plan out all the stuff for you. You pretty much just wasted time and then show up. That’s pretty much it.

Interviewer: Okay. That must have been a relief to know that.

Darth: Yeah, once you find out everything, you're given pretty much a schedule. It's like, right, we're going to do this at this age and this at this age. You mainly just bring him there and that's it.

One couple interviewed different treatment teams and then chose the one they felt most comfortable. Both mothers and fathers in the group who received the prenatal diagnosis were in agreement about getting the best treatment for their babies. The couples evaluated the different approaches to treatment, along with their advantages and disadvantages. They considered the treatment outcome, risks, rewards, logistics, timing, and well-being of all family members when making decisions about the course of treatment. Initially, couples needed to decide if they were going to make their babies wear the NAM device. This decision was difficult because they had to attend weekly doctors' appointments. However, since they were told that the results could save their children an additional surgery, they decided to use the NAM device. As Francis said, "I don't even know that we talked about that for more than two minutes because once she said that it would save him a surgery, we said we don't care if we have to drive out daily, we'd do it." They also needed to figure out the logistics such as finding a babysitter for their older children and taking time off from work.

The second important decision was about the timing of the surgeries. For the first surgery, some couples chose to put their children through it as soon as possible (approximately 3 month of age). One couple decided to wait for 3 more months because of advice they got from their doctors. Another couple decided to do the cosmetic revision before the child started school to prevent bullying from peers. Jane and Mitch, who are trying to decide on the timing for their son's second lip surgery, said:

Jane: People were telling us you could put off the surgery forever or till he's 16 or till 15 or till when he asks for it. I think we both wanted to just give him the best start, and we just talked about it. We're already in pretty good agreement, especially in regards to the age of the youngest child who had asked us about it. I think given that he's our oldest, we don't come into too much contact with kids who are meeting him for the first time who don't already know. So anyway, given that age factor, I think it was easy for us both to try to focus on the time before he goes to kindergarten.

Interviewer: Okay. What about you, Mitch? What's your opinion?

Mitch: It's just similar to what Jane said. We came to that agreement.

Prenatal couples said that cleft was not a factor in how they made parenting decisions. They cared for their children with cleft like they would parent any other child. They tried to first listen to each other when they disagreed about parenting practices. They discussed hypothetical situations and how they would react to them if they occurred. Bill and Laurie made parenting decisions using trial and error; they learned from their mistakes. For example, they realized that they should both be involved in parenting so Bill started to take a more active role at home. Couples shared that if one of them made a mistake, it was important to talk about it openly and not get reactive. Some couples shared that they were already on the same page regarding shared parenting practices. As Joe and Elizabeth described:

Joe: I don't know, I feel like we're muddling through but we were kind of on the same page before we had a kid that it doesn't feel like there has ever been any conflict. I definitely don't think we have sat down and documented all of our

polices. I don't even think that is possible, quite honestly, that when you have a kid.

Elizabeth: I think there are a few things that we agree whole heartedly on that we try to stick to and then the rest, you know, we — I think we have a similar enough outlook on life that we rarely have where one person does something that really bothers them. And if it does really bother them, then we talk about it.

When they were not on the same page, they usually tried to “pick their battles” if one of them felt more strongly about an issue.

5.6.1.4 Subtheme: Challenges for the Relationship

Even though all couples described working as a team and supporting each other, they also experienced challenges; all 10 prenatal couples described the challenges in 23 segments. Deciding at the time of the diagnosis if they should have an amniocentesis or abortion was challenging for couples. It was risky to receive the amniocentesis because there was a chance of losing the baby. Yet, they were not sure if their child had additional syndromes that could become a lifelong burden. Jane and Mitch had a challenging time deciding. Jane said:

We'd missed the window for a CVS, so the question was, do you want to have an amniocentesis? Originally, I was afraid to do it. What if we lost the pregnancy? I think Mitch was concerned about that too. If you had the test for me and we lose the pregnancy because we had the test, will you ever be able to forgive me? For me it was if we don't do the test and we have a very sick baby that you might've wanted to not have, how will you ever forgive me?

Throughout the pregnancy, it was also difficult keeping their emotions in check. The cleft diagnosis took the “pure joy” away from having a baby, which was challenging. They also had to prepare themselves for taking care of their children emotionally, practically, and financially. For example, Darth described finding the right insurance to cover their child’s treatment as a challenge.

When the couples had their children, they continued to go through challenges. They all described the first month as challenging, especially if they were first-time parents. They needed to learn how to take care of the baby, pump milk, and make many doctors’ appointments. These responsibilities were especially challenging for fathers if they were working full time. They described having difficulty lightening their wives’ workloads at home.

Making decisions about treatment was challenging for couples if they had different opinions about how to proceed. One couple had a difficult time picking a treatment team because each partner liked a different group of providers. It was also challenging to do the tapings for the NAM device when there was an infection on their children’s skin. They had different opinions about how the infection should be treated and whether to continue the tapings. Mo and Chip had difficulty with the NAM. Mo shared:

There were some moments that as a couple were a little tense, not bad tense but just a little tense, like she was getting an infection on her skin. It was just a little bit of a tumultuous time for the both of us, you know what I mean? Because we were upset at the fact that the skin issue was happening and how to clear it up. I had one idea, and he might have had another idea. There were times maybe we

didn't always agree on how her skin should be remedied, but we finally came to terms with all that; but it was a little tough with that kind of stuff, you know what I mean?

Putting their child through surgery was the most challenging treatment-related experience; Rebecca and Ben described the surgery as the biggest "cleft-related challenge." They were worried about possible complications and became more anxious when the surgery took longer than they expected. After the surgery, it was difficult to see their child in pain and to realize the positive changes in their appearances because of the swelling. Ben said:

I guess the biggest challenge, now that I think back on it that was cleft-related, it was the day of the surgery, both in terms of when we said goodbye to the baby and hoping everything was going to be okay and nothing went wrong with the surgery. When things went a little longer than expected, but then also after the surgery when everything was swollen and it wasn't looking like what we thought it would. We imagined a perfectly healed baby at that time. That was challenging, for us, to deal with. Because again, we probably had unrealistic expectations, so we had to deal with that. Then also dealing with the idea that the baby is in pain and having to deal with that pain, and having to share that burden between the two of us.

In addition to having a child with cleft, having a child in general was challenging for two couples because they were not able to spend as much time with each other anymore. They stated that their priorities changed when they had children; their lives started to revolve around their children and parenting. They tried to catch up on their

work when they were not taking care of their children and missed each other. For some couples, however, this process was not challenging at all because they found themselves being on the same page about parenting, even more so than in any other areas of their lives.

5.6.1.5 Subtheme: Impact on Social Life

All 10 couples who received the diagnosis prenatally described the impact of raising a child with cleft on their social lives in 18 segments. Four couples said having a child with cleft did not necessarily impact their social lives because they “could not take a 3-month-old baby out anyway.” However, four couples shared that having children in general negatively affected their social lives. They had less time, less freedom, and fewer financial resources to socialize outside of the home. As Abby and Murray shared:

Abby: Just having a toddler affects our social life. It has nothing to do with the cleft, but yeah, having a kid...

Interviewer: Impacts your social life, yeah.

Murray: Yeah, and whoever tells you otherwise, he’s a liar.

Abby: But as far as impacting our social life with her preexisting condition, no.

Murray: No.

Three couples said that the cleft impacted their social life during the initial stages, before their children had the lip surgery. They stated that they did not feel comfortable leaving their children with other people because of how they had to be fed. It was difficult teaching others how to feed their children, and most did not feel comfortable taking on that additional responsibility. In addition to the feedings, couples worried about their children removing the NAM device and the babysitters not knowing how to put it

back on, so they preferred to stay home the first month after their babies were born and did not really miss socializing.

Some mothers said they initially kept to themselves because they did not want to share their experiences with other mothers who did not have children born with cleft. They refrained from joining new mothers' groups because they did not feel other mothers could relate to their experiences regarding breast pumping, feeding, and using the NAM. Elizabeth shared:

Elizabeth: I would say in the first, looking back on it as a new mom, I probably, I know I did not socialize as much as a lot of new moms did, because I had a hard time relating to them because what I was going through was different.

Interviewer: Would you say a little bit more about that, in what ways did you feel different?

Elizabeth: I couldn't breastfeed; I had to pump all the time. We had the NAM device and the taping. I just felt like we were having somewhat the same experience, and now when I look back on it, even when I talk to my friends, parts of my experience are the same, and parts of my experience they can never understand. It's just the way that it is. Yeah, so I don't know, I just definitely think that, I didn't want to go to a new Mom's group with a bunch of strangers. I did once and I didn't enjoy it, like they were all having one experience and I was having a different one, so I didn't relate to them as much, that's all.

Three couples experienced negative reactions, questions, comments, and stares when they took their children out in public, which led them to avoid going out until their children had the lip repair surgery. Francis and Rachel received negative reactions from

their friends when they let them know about the cleft diagnosis. They explained that their friends did not know how to react and “disappeared.” For this reason, this couple became very particular about who visited them in the hospital at the time of birth. They were in the process of adjusting to the situation themselves and did not want to experience any negative reactions from others. They shared:

Francis: We actually wouldn't even let certain people come visit him at the hospital when he was born. We were still figuring it out for ourselves. We weren't ready to explain it.

Rachel: Given the fact that we definitely learned a lot about our family and friends through this experience; we didn't know how they were going to react. And at the time, we weren't able – we couldn't control their reaction. And this was all still brand new to us and we had to worry about us.

Francis: Us; not them.

Rachel: And find our own peace with this.

Two couples experienced the looks and the stares from outsiders but were not affected. One couple talked about establishing new friendships at this challenging time. They started spending more time with people who previously supported them or met new parents because of their children.

5.6.1.6 Subtheme: Sources of Support

All 10 couples who received the prenatal diagnosis identified multiple sources of support throughout this process in 78 segments. They described getting their support primarily from each other, their families, and their friends. Couples shared that they supported each other by having open conversations about the cleft, comforting each other

by highlighting the positive experiences, helping each other navigate the treatment and feedings, being there for each other during the doctors' appointments and surgeries, hugging each other, and giving each other free time as needed. The couples explained that the way they supported each other changed as their partner's needs changed. For example, Rachel and Francis said:

Interviewer: How do you support each other?

Rachel: Communication.

Francis: Sometimes it's just hugging.

Rachel: The unspoken; emotional, like you said, a hug.

Francis: Sometimes it's giving the other one some space.

Couples also received support from their families. Some family members babysat when couples were at work or took care of older siblings when couples needed to take their babies to doctors' appointments. Some family members learned how to feed the children and provided emotional support by being there and giving tips for taking care of a baby. For some couples, seeing their family members accepting their children was a source of emotional support. One couple stated that not all family members treated their children "like a normal child," but still wanted to be involved.

Friends were another source of support, especially if they had children at the same age. Couples described their friends visiting, embracing their children as they would embrace any other child, lending a sympathetic ear, and even bringing over meals at stressful times when they did not have time to cook. It was important knowing that their friends were there to help them if needed. In addition to friends, their co-workers and neighbors provided support. They identified feeling their support when receiving words

of encouragement and prayer cards. Some co-workers supported the couples by sharing information they had about cleft and putting them in contact with other parents who had children with cleft. Chip said, “I could think of a lady at work who I really only have limited contact with, but she kept sending me, whether it was a prayer card or whether it was information about the cleft or hooking me up with another parent that she wanted me to talk to who had this same problem with her child.” Some couples shared that their companies also believed in “work-life balance” and provided them with good health insurance. For one couple, church was a source of support. They stated that their church community supported them by showing their concern and willingness to help.

Mothers in particular identified getting support from their moms’ groups by organizing playdates and nights out as well as having speakers come in to talk about certain topics. For the mothers, having a caring and compassionate obstetrician/gynecologist was helpful even if she/he did not have any previous experience with delivering a baby with cleft. If they knew people in the medical field or were seeing certain doctors regularly, couples used them as a source of support and information.

Furthermore, they identified their treatment team at CHOP as a significant source of support. They said that they were able to ask questions and get them answered quickly. They had close relationships with the staff and the doctors and shared that they “did not feel like a number to anybody.” The CHOP staff also put them in contact with other parents who had been through the same experiences and invited them to the annual picnics where they could meet other parents. This experience was beneficial for couples because it reduced their feelings of isolation. Additionally, couples used cleft-specific Web sites and online groups as other sources of assurance that they were not alone. They

received information about the process by talking to other parents and reading information online. One of the couples even picked their surgeon using suggestions they received from other parents online.

Couples emphasized that they did not necessarily need any more support. Darth and Vader shared that they did not need support at this time. They said; “It’s not a big deal to the point where we’re worried about stuff really, so we’re not really concerned too much about it. He has a cleft. That’s pretty much it.”

5.6.1.7 Subtheme: Concerns

Six couples out of 10 continued to share their concerns during the couples’ interview, which included 18 segments. Three couples identified cleft being a concern for their next child. Three couples said that they were not planning to have more children for reasons that were unrelated to the possibility of cleft. All couples agreed that cleft alone was not a factor in their decision not to have more children. However, Joe and Elizabeth did share this concern:

Joe: I guess slightly, slightly, slightly, I guess more than not, because you know we are aware what a cleft is now, maybe it would be slightly on the back of your mind.

Elizabeth: Yeah, I did read somewhere for my part, that there is slight correlation with not enough folic acid in kids with cleft, so I have been taking vitamins that have folic acid so if we have another baby, then I know for a fact that I have done my part on that. If I were to get pregnant maybe that would change, because then it would be a reality, but right now it is not. It does not dominate my mind when I think about potentially having another child.

Joe: Yeah, I agree.

Elizabeth: I am sure if we become pregnant again, it would probably become more prominent, but right now it isn't.

Two couples already had a child after they gave birth to the child with cleft. The children with cleft were both 2 years old at the time of the interviews. Even though cleft was a concern for the parents, it did not prevent them from trying to conceive again. However, they wanted to get more information as early as possible. For example, they had the nuchal test (sonographic prenatal ultrasound to help identify higher chances for chromosomal conditions) on the 12th week of the pregnancy instead of waiting for the 3D ultrasound at the 20th week. They did not share the news about their pregnancies with anyone before they found out that the fetus did not have any significant health issues. For example, the results of Jane and Mitch's nuchal test were positive so they had additional testing. They stated that they could not have known about the risk for Down's syndrome if they had not asked for additional testing because of their concerns about cleft.

The additional tests eventually ruled out the possibility of Down syndrome, but the couple felt that they were having a similar experience in their second pregnancy. Jane said, "So it felt like sort of déjà vu again because we were like, really? Just think, people go through pregnancies all the time with nothing, and here we have our second pregnancy and we have this big scare."

All the couples agreed that they no longer had "huge concerns". Some had concerns not related to the cleft, such as having a college fund ready for their children. However, four parents shared that they still had slight concerns about their children's appearance, possibility of bullying, and speech.

5.6.2 Dominant Theme: About the Experience

The second dominant theme, *about the experience*, describes couples' reflections about their experience. When answering questions 12 and 13 in my interview guide (Appendix D), they talked about lessons learned and the advice they would give other parents of children with cleft. Nine out of 10 couples described their experiences in 34 segments. One subtheme, *lessons learned*, emerged from this dominant theme.

Eight out of 10 couples shared lessons they learned throughout this process in 26 segments. Most couples reiterated what they expressed during their individual interviews as lessons they have learned. For this reason, this subtheme provided a source of triangulation for the individual interviews. As in the individual interviews, couples described the importance of doing research and getting educated about cleft. At the same time, they also cautioned other parents for "staying off the WebMD," especially if they did not have a definitive diagnosis prenatally. Mitch said:

I would say that every situation is very unique, so just to stay off of Web M.D. and the internet. Ask those questions to the doctors you're dealing with. I think that outside information leads to added stress that may or may not be there. So obviously if they tell you yes, you have cleft lip and palate, then you can research that. But if it's open-ended and you don't know, a lot of that information is a lot of what-ifs and it tends to add to the stress.

Couples did describe the importance of knowing about the severity of the cleft, getting additional testing done to receive a more definitive diagnosis, and choosing an experienced treatment team. Some couples also suggested continuing to observe their child's development as he/she matures. The couples said the prenatal diagnosis impacted

them positively. It gave them time to grieve the loss of the perfect child and to develop a plan about how to cope with the cleft before their child was born. The couples identified cleft as more of a “cosmetic” and “manageable” issue. Some couples even described this process as a “good experience.” Reflecting on their experience, Francis and Rachel said:

Francis: And the experience has been – it’s been challenging at times, but it’s also been incredibly rewarding at times.

Rachel: Every challenge that we’ve gotten over is another....

Francis: Is a victory.

When asked about lessons learned, one couple continued to highlight the importance of open communication and “having somebody to lean on.” They shared:

Mary: I think sometimes, as the woman, I think I would get sometimes like I’m the one carrying the baby and I’m the one that knows this is going on in my body. I think that’s in general. I think there’s sometimes a, “I know more than you because it’s me and it’s my body and the baby’s in my body.” So when I say, “Stay on the same page,” I mean try not to – my husband is very good at reeling me back in when I need to be. Meaning, I tend to get more stressed than he does. So I think staying on the same page is very important so if someone is having a hard day, it’s very important to let the other one reel you back in.

Interviewer: Okay. So whatever kind of feelings that you’re having, it is important to let the other person know rather than make it ambiguous or going through it on your own?

Mary: Exactly.

Interviewer: Frank, would you say the same thing or any other things that you would like to add?

Frank: No, I agree, same thing. That's just how it is with ours. It could be reversed, obviously, the emotion could be reversed. But just have somebody to lean on.

5.6.3 Dominant Theme: Child's Functioning

The third dominant theme, *child's functioning*, describes couples' views of their children's overall functioning. Question 22 in my interview guide (Appendix D) asked the couples about their children's concerns about their appearance, social functioning, speech problems, and development. All 10 couples described their children's situation in 74 segments. This dominant theme was then divided into the following subthemes: (1) appearance concerns, (2) social functioning, (3) speech, (4) development, and (5) view of the child with cleft.

5.6.3.1 Subtheme: Appearance Concerns

Nine of the 10 couples described their children's concerns about their appearance in 10 segments. None of the couples reported that their child was concerned about his or her appearance because he or she was too young to be attuned to this issue. Three couples noted that their children were not aware of their own clefts, and two couples gave their children some hints about the cleft. For example, Joe and Elizabeth taught their daughter to put sunscreen on her scar and massage it every morning. However, Elizabeth stated that her daughter did not seem to think of her scar as a visible difference. She said, "It's part of her morning routine, we have a routine where we massage the scar, put on face lotion and then put on sunscreen. She thinks it's part of her routine; I don't think she

knows that other kids probably don't have that in their routine." Another mother, Laurie, who had CLP herself, stated that her son was not aware of his scar but that he pointed to her scar. She said, "I don't know if he is aware of it on himself, but he's pointed out on me twice that mommy has a boo-boo. I don't think, he thinks himself; he thinks he's like every other kid."

5.6.3.2 Subtheme: Social Functioning

All 10 couples shared their observations about their children's social functioning in 10 segments. None of the couples described their children having any trouble making friends. Some couples stated that their children had already started day care and were socializing well with other children. Some children were shy in the beginning during the adjustment phase, but they adapted to the situation. As Frank and Mary shared:

Mary: I mean, he's only in school twice a week. Aside from that initial shyness, separation anxiety in the beginning, he's been fine.

Interviewer: Frank, what do you think?

Frank: Same thing. He's perfectly normal and he fits right in with the crowd and does his thing and he's fine.

Two couples said that their children became more social once they started day care. For example, Mary said, "She's been there since November—we're very happy and so is she. She has a nice little group of friends there that she plays with. We're grateful for that. I'm very pleased with how social she has become since the day care situation."

5.6.3.3 Subtheme: Speech

All 10 couples talked about their children's speech in 10 segments. Most couples shared that their children did not currently have any speech problems. The couples

observed their children's speech carefully, because cleft can cause problems in speech development. They also compared their children's speech to that of other children at the same age who were not born with clefts. Some couples did note that their children seemed to have problems initially but that their speech had improved as they got older and listened to other people speak. Bob stated, "Actually, in the last six months or so, I'm kind of amazed at how much his speech has improved and that's just from him mimicking us and his sister."

Three couples identified minor issues with pronunciation and putting words together. If their children had speech issues, couples either had them evaluated by a speech therapist or plan to do so in the future. Mo said, "We actually are having her evaluated by a speech therapist. The pediatrician said she was fine. He said it's totally optional as to whether or not you think she needs a speech therapist. Some words that she says are a little off, but I wouldn't say that it's a huge concern."

5.6.3.4 Subtheme: Development

All 10 couples described their children's development in 11 segments. None of them described their children having problems with cognitive development. One couple shared that their child seemed more advanced than her peers. Elizabeth said, "Actually her preschool teacher and the day care teachers are saying, because she's not 2, she's 22 months right now, that she could move up to the 2-year-old class if they had space."

Two couples noted that their children were small compared to their peers but still in the developmentally appropriate range. As Laurie stated, "He's always been on the low end of height and weight, but not outside of where they want him to be. But it's never been a concern." Even though this was not a concern for Laurie, it was a minor concern

for some parents because they believed that this could make their children a target for bullying, especially combined with the cleft scar.

5.6.3.5 Subtheme: View of the Child with Cleft

Nine out of 10 couples shared their views of their children and the cleft in 25 segments. They said that their children were “normal,” “average toddlers,” and “not different from anybody else.” One father, Darth said, “Nothing’s wrong with him right now, so you don’t even think about it. It’s not even there really.” They stated that other people also commented on their children’s appearance and how they could not even tell they had clefts. As parents, they also sometimes forgot that their children had clefts because “it is not in their radar anymore.” Some couples admired their children’s strengths and were grateful for who they are.

The couples described cleft as more of a cosmetic and manageable issue that was no longer part of their lives. Chip said, “Initially, it’s all you think about, and afterwards you don’t think about it.”

5.6.4 Dominant Theme: Talking About Cleft

The last dominant theme was *talking about cleft*. Questions 18 and 23 in my interview guide (Appendix D) asked couples to describe how they currently talk about cleft with each other, their family members, their children, and people outside of their families. The couples also shared their opinions about meeting others parents who have a child with cleft. All couples in the prenatal diagnosis group discussed how they talk about cleft in 208 segments. The dominant theme of talking about cleft was divided into the following subthemes: (1) talking about cleft as a couple, (2) talking about cleft with

family, (3) talking about cleft with their children, (4) talking about cleft with others, and (5) talking about cleft with other parents.

5.6.4.1 Subtheme: Talking About Cleft as a Couple

All couples shared how they talked about cleft with each other in 26 segments. Cleft was no longer an issue that they discussed regularly, even though they addressed it frequently during the initial stages. Darth and Vader shared:

Interviewer: How do you talk about cleft lip/palate among yourselves?

Vader: We really haven't.

Darth: Yeah, we really don't. Once you get that first surgery, you immediately talk about it once you have to go for the surgery, I guess, or hey, next week's the surgery. That's pretty much it.

Couples also talked about the cleft when they needed to choose a new treatment team because they were relocating. Furthermore, if their children had residual issues such as dental or speech problems, couples talked about how they could resolve them. They also commented on the positive developments they saw in their children regarding their speech or appearance. For example, Mo stated; "Her teeth maybe were a little bit of a concern for us too because she has a couple teeth that are a little out of line. I guess that's more the conversation we might be having now, not meaning today in particular but in general: What do you think they're going to do with her mouth?" Couples noted that they took pride in their children because of their strength and resilience. Some couples did not bring up the cleft in conversations with each other until someone commented on their children's appearance or asked about the next step in treatment.

5.6.4.2 Subtheme: Talking about Cleft with Family

All 10 couples described how they talked about the cleft with their family members in 39 segments. Couples stated that they no longer talked about cleft with family except to give them information about the next steps in treatment. In the beginning, they talked about it more frequently because they were educating family members about the cleft. Initially, talking about it with family members was not easy for parents; they built up to it as they increased their comfort level with discussing the issue. They also educated their older children and prepared them for welcoming a sibling born with cleft. Bob and Zoe explained that they informed their older child by telling him that her brother will be born with a “cut.” They shared:

We told her that he had a cut. I had read or talked to someone who gave that advice to just explain it. She was a year and a half at the time. She wasn't old enough to understand at all. So we just said he was born with a boo-boo, and the doctor was going to sew it up for him. And I don't think we even discussed that initially. I don't even think she was old enough to see or to know that he was any different than any other baby.

Other couples agreed that their older children did not ask questions about the cleft, even when they came to doctors' appointments with the family.

They stated that they no longer felt the need to talk about the cleft since “everything is fine.” If they had family members who were health professionals, they would occasionally continue to discuss their children's development. For instance, Mo said, “We used to talk about it a whole lot, but now it doesn't come up as much. My one niece is a speech pathologist, so occasionally I talk to her about it when she comes over.” The couples explained that their families checked in with them after surgeries to see how

they were doing. They sometimes commented on the child's development and appearance saying they "can't even tell" she/he had a cleft. Couples shared that it was unpleasant for them when their family members asked them questions for which they did not have answers, such as the impact of this process on their children or if the timing of the surgery was appropriate. Some couples said that they did not talk about it unless someone in their family asked them about it.

5.6.4.3 Subtheme: Talking About Cleft with Their Children

All 10 couples described how they explained to their children that they were born with a cleft. This subtheme included 40 segments. At the time of the interview, none of the couples had informed their children about their cleft condition, but most had plans to explain the cleft in the future. They believed that their children were too young to have this conversation. Still, some started giving hints to their children about the cleft, even though they did not talk about it openly. For example, Laurie, who was born with a cleft, described an interaction she had with her son:

Laurie: No, we don't really make it a big deal because it's not something we have to deal with right now. He says, I have a boo-boo on my lip. I do tell him that you have one too, and I say you are just like mommy.

Interviewer: And how does he react to that?

Laurie: I think he thinks it's pretty cool, he's like, "Okay." You know he's just turning three, so everything is okay with him as long as mommy or daddy has it. That's the furthest we have really talked to him about it.

One family encouraged the child to put sunscreen on her scar every day so the child was aware that she had a scar even though she was not clear about the reason for it.

Most couples did not plan to hide anything from their children and would treat them as “normal children.” One couple said that their child was “not getting any breaks as a result of it.” Some couples stated that they planned to get advice from a child life specialist before telling their children about the cleft.

One couple said that their children did not ask about the cleft even when they saw pictures of themselves before they had the surgery. Another couple was advised to tell their children when they asked about the cleft. They said:

Mo: No, no, we really haven't done that. My husband talked to one of his doctors about it, and he said we really probably shouldn't bring it up unless she asks us.

Chip: No, we haven't spoken with her about it at all. In fact, Mo did bring up the point of a doctor that I have. He's a neurologist that I see. I mentioned it to him, and he said if you don't bring it up, then she won't even notice it. It's when people accentuate her condition that she could become self-conscious about it. I mean that's advice that was given to me by a medical doctor, and up to this point I've just gone with that.

Another couple believed that they should talk about the cleft with their child before he had his next surgery. They worried about their child's reaction because he was worried about being in a hospital and getting shots. The father stated that he could explain the cleft to his son by talking about the dry skin on his lip that he picks and telling him that the doctors would correct his lip so he does not need to pick at it any more. One couple in the study said that they would eventually tell their child because he has a risk of passing the cleft on to his own children.

Two parents were hesitant to talk about it with their children, even in the future. They did not want their children to think they had a problem and were different from others. They worried about the negative impact this awareness would have on their children, so they did not talk about the cleft in front of their children. During the interview, it was difficult for one couple to discuss this topic since each parent had a different idea about they should proceed.

5.6.4.4 Subtheme: Talking about Cleft with Others

All couples shared how they talked about cleft with people outside of their families in 56 segments. They shared the information with other people when they first received the diagnosis to spare them the shock at the time of birth. For four couples, it took time to share the news with friends so at first they shared it only with their families.

Couples received different reactions from people outside of their families. It was not helpful for the couples when others downplayed the seriousness of the issue and said, “They can fix that.” When discussing their experience of telling others about the diagnosis, Bob and Zoe said:

Bob: It seemed to be a little bit more important to us than to most.

Interviewer: You felt like they were downplaying it?

Bob: Well, yes, in a sense.

Zoe: I agree; as a parent it’s a struggle and everyone wants to reassure you that it will be okay. And in a sense, the reassurance is nice, but it’s also a struggle that we have to deal with.

However, couples also did not appreciate dramatic reactions such as “Oh my! Oh my!” They stated that they would have preferred genuine concern and questions.

When some couples were sharing the cleft diagnosis with others, they noted that it does not impact the child's intelligence. Most couples agreed that having to tell people about the cleft diagnosis when talking about pregnancy was challenging for them. It "took the wind out of the sails." It was easier if they had another friend who also had a child with cleft. Furthermore, if they received positive reactions from the first people they told, it became easier to tell the others. Two couples used e-mail or social media sites such as Facebook to deliver the news, especially if it was tough explaining it to everybody in person. Two couples shared the news and the ultrasound pictures with people they knew in the medical field to get their professional opinions.

After their child's birth, Rebecca and Ben were adamant about providing the right information to other people. They did not want to hide it and got upset when other people made it a "taboo issue" to discuss. They shared an incident they experienced at their workplace. They said that, after their child's birth, the human resources department mass e-mailed people working in the company about the birth of their son. However, the person who sent out the e-mails did not include information about the cleft, even though Rebecca asked her to before she gave birth. This oversight made Rebecca very upset:

I was crying because I was so mad. So I wrote back and I said, "Actually here's the paragraph I sent, and I pasted in my paragraph – I put every single person's name. I think at that time there was maybe 90 people in the company. I just clicked on every person's name in the company, because at that point it was blocked and you couldn't send an all company email; only she could send an all company email. So I clicked on every person's name in the company, so they all

got my version. I was so upset that she removed that part as if we shouldn't talk about it.

At the time of the interviews, the topic of cleft rarely came up in conversations with others. One father stated that he usually downplayed the significance of the cleft when talking about it with others. People sometimes asked about upcoming surgeries and provided support at the time of the surgery or made positive comments about their children's appearance. They shared the news with the day care providers if their children were going to day care. Sometimes, couples also shared their stories with other people if they wanted to or as a resource for other parents who were also raising children born with a cleft.

5.6.4.5 Subtheme: Talking About Cleft With Another Parent

All couples in the prenatal diagnosis group shared their opinions about talking with another parent who had a child with cleft. This subtheme includes 47 segments. Most couples believed that talking with another parent was very helpful for the following reasons: (1) getting information and (2) receiving emotional support.

Couples stated that it was helpful talking to another parent. They noted that it helped to reduce feelings of isolation and provided other parents with external validation. They shared that even though their doctors were knowledgeable about the treatment, they could not necessarily help them with the emotional aspects. Francis shared, "Talking to doctors; as good as these doctors may be they still never went through the actual emotional dynamic of having a child born with a cleft. They never went through the sleepless nights with their spouse. They never went through – their wife randomly

crying.” Additionally, couples said that other parents reassured them that their children were going to be fine and told them what to expect over time.

It was also an opportunity for couples to observe other children and better understand what awaits their child in the future. Darth said:

I guess it’s good to talk to people who have had this situation, so to put other parents’ minds at ease. You know, you have no idea what it’s even all about, and you’re just thinking a cleft is the end of the world for the child. I guess it’s good to talk to other people just to see what their experience was at a point where the child’s condition was from that and get an idea from that.

Parents who have been through the experience could share how they coped with issues such as dealing with the pain their child experienced the night after the surgery or helping their child adjust to the Haberman bottles.

Even if they did not meet other parents in person, some couples used online boards to connect to other parents. It was helpful getting their questions answered and seeing the pictures of other children who had been through the surgeries. Couples shared that they received invaluable information from the online groups, such as the availability of medical assistance and the name of a good surgeon. They give back by serving as online resources for other parents. Mary said, “I’ve had a couple of people contact me through Facebook who knew what we had gone through, who knew somebody who was going to have a baby with cleft and said, “Will you talk to them?” And I said, “Absolutely.””

Some couples had the opportunity to meet with other parents in the waiting rooms at the hospital when they took their children for doctors’ appointments or at the picnics

that CHOP organizes. Couples identified these times as helpful because they saw, once again, that they were not the only ones going through this experience. A few couples talked on the telephone with other parents that their friends or the hospital staff put them in contact with. One father, Bob, knew someone who was born with cleft. He talked to him and understood the importance of family support:

Bob: I met with an individual who was born with a more severe cleft and that was reassuring that he had a tougher time than I know my son did. And his family wasn't as supportive as my son's is.

Interviewer: And that was helpful to you how; to meet with him?-

Bob: It reassured me that I was – or my family was going to be more supportive to my son and be there for him going through all of these surgeries and what not where his family lacked in that department.

Other couples did not feel that meeting other parents was a necessity because they could get a lot of information on line. A few couples shared that it was helpful meeting with another parent if the severity of their children's clefts were similar. They stated that if the other parent had a child with a more severe cleft, they might feel embarrassed complaining about their experiences because their child's cleft was less severe, and the information they received may not be applicable to their situation. When asked about her experiences talking to other parents, Elizabeth said, "I think the only thing I would change is perhaps to have talked to a parent who had a kid with a pretty similar cleft to do. I had a coworker's son, he had a much milder cleft than my daughter did, so I wanted to relate to him, but I kept seeing, ours was worse so it's not really the same."

5.7 Prenatal Diagnosis Group, Mothers Versus Fathers: Comparison of Findings

Mothers and fathers provided similar descriptions about their experiences raising a child born with CLP. However, mothers provided more details when talking about their experiences. At the time of the diagnosis, 8 of 10 mothers who received the diagnosis prenatally stated that their husbands were with them, even though all 10 fathers said that they were with their wives at the time of diagnosis. One mother explained that her husband felt guilty about not being with her when she first learned about the cleft diagnosis. Four mothers blamed themselves for the baby developing a cleft in utero, whereas none of the fathers did. Both mothers and fathers emphasized the importance of the doctor's demeanor when delivering the cleft diagnosis. At the time of the diagnosis, both mothers and fathers were worried about the possibility of co-occurring syndromes, the severity of the cleft, and social stigma. Mothers seemed more worried about the feedings compared to the fathers, although both expressed concerns. One mother reported concerns about how they were going to afford the cleft treatment and another mother was concerned about reactions from her family, whereas none of the fathers were worried about reactions from family members. Fathers more often took on the supportive role for their wives/partners. The roles were switched in only one of the 10 couples.

The mothers primarily managed the practical aspects such as doing research, evaluating the providers, finding treatment teams, and scheduling appointments. Most fathers said that the cleft diagnosis took away the "pure joy" from the pregnancy whereas the mothers reported apprehension and wanted the birth to come quickly after receiving the CLP diagnosis to see what they needed to do to take care of their child. One prenatal couple described going through continuous monitoring and additional tests throughout their pregnancy.

At the time of birth, both mothers and fathers were concerned about the feedings. The mothers' main struggle was trying to feed their children by pumping breast milk and using the special feeder bottles. They also had to adjust to not being able to breastfeed, which was a challenging process. Most fathers described being happy and joyous during the initial stages after the birth. Their "bodily instincts" just kicked in, and they reported enjoying being fathers to their children. Most went back to work a few weeks after their wives/partners gave birth. Most mothers were the primary caretakers of their children; they fed them, taped the NAM device, and made the medical appointments. Most prenatal fathers helped when they were at home in the evenings and on the weekends and also accompanied their wives to the doctors' appointments.

Before the first surgery, both the mothers and the fathers were worried about complications from the anesthesia and the outcome of the surgery. The mothers hoped that the feedings would get easier after the surgery. It was difficult for the mothers to "hand their children off to strangers." One mother worried that her child's appearance was going to change significantly. After the first surgery, both mothers and fathers were worried about seeing their child in pain, bleeding, swollen, and having stitches, intravenous lines, and restraints. More mothers than fathers reported initially missing their children's clefts. One mother reported that both she and her husband missed the cleft, even though the father denied feeling this way during his interview and said after the surgery, his son looked as "he was meant to look."

When talking about their situations at the time of the interviews, the mothers provided many more details about their children's past treatments, ongoing functioning, and their concerns at the moment, whereas the fathers only spoke about their concerns.

Both mothers and fathers were worried about upcoming treatments and social stigma. Additionally, mothers were worried about speech development and genetic disposition of their next child to be born with a cleft.

Looking back on their experiences, both mothers and fathers described feedings, surgeries, and using the NAM devices as challenging. More mothers than fathers mentioned challenges coping with the fear of social stigma engendered by the questions, stares, and reactions they received before their children had the first surgery. Both mothers and fathers agreed that the initial stages were the most challenging and that caring for their child with clefts became easier with time. One father talked about soothing his own anxiety and not worrying about his child all the time, whereas another father described bracing people as an ongoing challenge. For the fathers, seeing their wives/partners stressed was another challenge. At times, they felt helpless.

Mothers and fathers described similar factors as possible causes for the cleft; however, more fathers reported older maternal age as a factor. Different from the fathers, some mothers reported feelings of self-blame because they were the ones who carried their children. When describing lessons learned, the mothers described learning about cleft from doctors, nurses, and other parents, keeping everything in perspective, and being grateful that cleft is fixable. The fathers described the following two main stressors: (1) feeding and (2) the surgery. One father stated that prenatal ultrasound pictures could be misleading. Both mothers and fathers believed that choosing a good treatment team and trusting them were very important. The fathers also advised that parents choose a hospital equipped for handling the birth of a child born with cleft.

Both mothers and fathers in the prenatal diagnosis group viewed their children positively and considered cleft to be a “fixable” and “cosmetic” issue. Fathers emphasized that the cleft did not change their feelings toward their children, whereas mothers stated that cleft significantly changed the experience of having a newborn and, for some, being a first-time mother.

When asked about their opinions of receiving the diagnosis of CL/P before or after the birth, both mothers and fathers agreed that, although the prenatal diagnosis did increase their feelings of worry and stress during the pregnancy, they were still happy they found out before giving birth. The prenatal diagnosis gave them more time to prepare emotionally and practically. One father reported that it also gave him time to prepare financially. Fathers mentioned that they prepared themselves for the worst-case scenario. The hardest part about knowing was that, even though they had time to prepare themselves, they could not change the fact that it was coming.

5.8 Postnatal Diagnosis Group, Mothers: Dominant and Subdominant Themes

Mothers in the postnatal diagnosis group described their experiences raising a child with cleft and focused on the following three periods: (1) birth and postnatal diagnosis, (2) initial stages after birth, and (3) current situation. Additionally, the mothers reflected back on their experiences of raising a child with cleft. The dominant themes summarizing the experiences of postnatal mothers are (1) birth and postnatal diagnosis, (2) initial stages, (3) current situation, and (4) raising a child with cleft. Within these 4 dominant themes, 18 subthemes emerged that capture the more specific aspects of their experiences. An analysis of these subthemes is provided using illustrative quotes from the mothers in the postnatal diagnosis group. An overview of the 4 dominant and 18

subthemes is shown in Table 5.12. Again, I defined a theme as “dominant” if more than half of the participants in the sampling unit mentioned it. Dominant themes had to be mentioned by four or more mothers (of the 7 mothers interviewed). To inform the reader of the frequency of specific themes mentioned by mothers in the postnatal diagnosis group and the number of mothers who mentioned them, I included the “theme frequency” section in Table 5.12. Finally, each subtheme is illustrated using representative (anonymous) quotes.

Table 5.12. Dominant Themes of Mothers in the Postnatal Diagnosis Group

Level	Themes	Theme Frequency/Postnatal Mothers' Quotes in this Chapter
100	Dominant Theme: Birth and Postnatal Diagnosis	109 Total Segments: All postnatal mothers
101	Pregnancy and birth	25 segments: All postnatal mothers Postnatal mother quotes: Minnie, Sarah
102	Delivery of the diagnosis	25 segments: All postnatal mothers Postnatal mother quotes: Jill, Sarah, Pam, Minnie
103	Initial feelings and thoughts	20 segments: All postnatal mothers Postnatal mother quotes: Sarah, Diane, Minnie
104	Initial concerns	23 segments: All postnatal mothers Postnatal mother quotes: Diane, Sarah
105	Preparedness	7 segments: 6 of 7 postnatal mothers Postnatal mother quotes: Diane, Ann
200	Dominant theme: Initial Stages	179 segments: All postnatal mothers
201	Being a first time mom	7 segments: 4 of 7 postnatal mothers Postnatal mother quotes: Pam, Minnie
202	First month	14 segments: 5 of 7 postnatal mothers Postnatal mother quotes: Diane, Ann
203	Feeding	34 segments: 6 of 7 postnatal mothers Postnatal mother quotes: Diane, Gayle, Jill
204	Surgery	73 segments: All postnatal mothers

205	Concerns	Postnatal mother quotes: Pam, Sarah, Diane, Gayle 39 segments: All prenatal mothers Postnatal mother quotes: Diane, Gayle, Pam
300	Dominant Theme: Current Situation	24 segments: All prenatal mothers
301	Treatments and current functioning	12 segments: 4 of 7 prenatal mothers Postnatal mother quotes: Gayle
302	Current concerns	12 segments: 6 of 7 prenatal mothers Postnatal mother quotes: Pam, Gayle
400	Dominant Theme: Raising a Child with Cleft	166 segments: All postnatal mothers
401	Challenges and stressors	34 segments: All postnatal mothers Postnatal mother quotes: Pam, Jill, Ann, Gayle
402	Impact on relationship	35 segments: 4 of 7 postnatal mothers Postnatal mother quotes: Minnie, Gayle
403	Lessons learned	58 segments: All postnatal mothers Postnatal mother quotes: Gayle, Ann
404	Reasons for cleft	16 segments: 6 of 7 postnatal mothers Postnatal mother quotes: Ann, Gayle
405	View of the child with cleft	21 segments: 6 of 7 postnatal mothers Postnatal mother quotes: Diane, Sarah, Ann, Gayle
406	Preference for prenatal diagnosis	12 segments: All postnatal mothers Postnatal mother quotes: Sarah, Jill

5.8.1 Dominant Theme: Birth and Postnatal Diagnosis

The first dominant theme, *birth and postnatal diagnosis*, describes the experiences of mothers in the postnatal diagnosis group at the time of birth and when they first received the cleft diagnosis. The first four questions in my interview guide (Appendix D) asked how mothers first learned about their child's cleft, their initial thoughts, feelings, concerns, and how prepared they were at the time of birth. All seven mothers in the postnatal diagnosis group reported their experiences in 109 segments. The dominant theme of *birth and postnatal diagnosis* was then further divided into the

following subthemes: (1) pregnancy and birth; (2) delivery of the diagnosis; (3) initial feelings and thoughts; (4) initial concerns; and (5) preparedness.

5.8.1.1 Subtheme: Pregnancy and Birth

All seven mothers who received the diagnosis postnatally shared their experiences during their pregnancies and at the time of birth, before they first received the cleft diagnosis, in 25 segments. One mother, Diane, had fertility treatments for 2 years before she was able to conceive. Because of her past experiences she said that she was “convinced” she was going to have a miscarriage during the first trimester; in the second trimester, she was “almost sure” that the baby was going to have Down’s syndrome. Another mother, Minnie, moved into a new house while she was pregnant. She stated that she had to pack all by herself because her husband did not help. Additionally, she had gestational type 2 diabetes during her pregnancy and had to see a high-risk specialist. During the interview, she stated that she had asked for a 3D ultrasound from the high-risk specialist but was “ignored.” She said, “I kept asking, and I asked for this 3-D ultrasound because I wanted to make sure my baby was okay. They wouldn’t give it to me.” After her daughter, who was born with cleft and diagnosed postnatally, Minnie had a second child and states that she was also unable to obtain a 3D ultrasound during that second pregnancy. In contrast, Sarah stated that she had a “model pregnancy” and shared that, “I never had morning sickness, every visit was great, everything was wonderful, I didn’t put on too much weight, so it was just a really – I loved being pregnant.” During their pregnancies, some of the mothers had 3D ultrasounds examinations but still did not receive a cleft diagnosis prenatally.

The time of birth was stressful for some mothers in the postnatal diagnosis group because they either had to have a cesarean delivery or had a long or unexpected labor. For example, Gayle was in a car accident 2 days before she was expected to give birth and as a result had to receive an emergency cesarean delivery. Sarah had to have a cesarean delivery because her baby was breech. In Minnie's case, the baby "got stuck" in the birth canal and she had an episiotomy. Diane gave birth to her daughter a month early, whereas Pam was in labor for 24 hours.

5.8.1.2 Subtheme: Delivery of the Diagnosis

All seven mothers described their baby's cleft diagnosis in 25 segments. Four mothers received the diagnosis in the delivery room shortly after giving birth. Jill remembered that the doctor did not immediately show her the baby. She said, "She was born via C-Section and they didn't show her to me right away and it didn't occur to me. Usually they'll lift her up, show her through the curtain, and they didn't do that. So I didn't think anything of it." Sarah also remembered seeing her son for the first time in the delivery room but did not notice his cleft at first. She said,

I heard him crying and they just cleaned him up a bit and then they showed him to me and it was wonderful and I was just overwhelmed. My husband showed him to me, but they showed him to me very quickly and I just saw perfection and I never even noticed it because it wasn't detected on any of my ultrasounds.

The mothers who learned about the cleft diagnosis in the delivery room received it either from their obstetrician/gynecologist or their pediatrician. Sarah described the way she found out as "traumatic." She was alone in the operation room because her husband had

left with the doctor to have their baby “weighed and measured.” At this time, a staff member told her that her baby was born with cleft lip. Sarah described how she felt:

She’s like, “Hi Sarah,” she goes, “I just want you to know that your son,” she had examined him, “your son is doing fine.” She goes, “He’s healthy and he’s a good weight, blah, blah, blah, blah, blah, but,” and remember, I don’t even know – she just came out of nowhere and she goes, “I just need you to know that he was born with a cleft lip and blah, blah, blah, blah, blah, and he’s definitely going to require surgery. He’s definitely going to need plastic surgery, but you’re very lucky because there are wonderful hospitals. You live close to a lot of really great hospitals that will be able to handle this, blah, blah, blah, blah, blah.” I was in shock and I was, you know, I was clearly medicated and on whatever drugs going through my system for the actual C-Section. My husband wasn’t there. The baby wasn’t there and I was floored. So that actually was very, very traumatic for me and I still get upset about it to this day. To this day, I don’t even know who this person was.

Sarah shared that she complained to her doctor about this person’s demeanor at her initial visit and told the doctor that this was supposed to be the happiest day of her life and this person “spoiled it a little.”

In contrast to Sarah’s experience, two mothers said that the way their doctors delivered the diagnosis made them feel calm and at ease. Pam said, “The pediatrician that was in the room said, “Oh, it’s very minor. They usually do a surgery for this and it’s not a big deal anymore.” So my initial thought was, oh my Gosh, there’s something wrong with him, and then I was relieved that it was just that.”

Some mothers could not receive the CLP diagnosis right after the birth. In Ann's case, the doctors noticed that her daughter "was not breathing right away" when she was born. So her baby was transferred to CHOP, and Ann learned that her daughter had a cleft palate when she arrived at the hospital the next day. Furthermore, two mothers learned that their children were born with cleft palate after first experiencing feeding difficulties. The nurses on staff became suspicious and ordered a consultation with the pediatrician on staff. In Minnie's case, the baby had to be readmitted to the hospital because she had failure to thrive. The hospital staff did not realize that there was a cleft, even though Minnie was having feeding difficulties and told the nurses and the doctors that "her baby's mouth looked different." She stated that both her husband and the hospital staff ignored her. The nurses and the lactation consultant blamed her for not being able to feed her baby. Minnie shared:

Then we were eventually feeding her with syringes in the hospital, and this was before we got discharged after me having her. When we got home they sent a person to the house. She was supposed to be a lactation consultant. She was not very helpful at all, and basically the whole time everybody was making it like it was my fault. I was doing something wrong. They go, "You have inverted nipples," and da, da, da. Basically, all me, so I started feeling like really rotten.

Eventually Minnie's baby was readmitted to the hospital and the night nurse diagnosed her cleft. Two mothers were not with their partners when they first received the cleft diagnosis. They had to call and tell their partners about it. They stated that their partners were confused because they did not know what cleft was. The five mothers who

were with their partners when they received the diagnosis reported that it was helpful having them there for support even though they still felt scared and concerned.

5.8.1.3 Subtheme: Initial Feelings and Thoughts

All seven mothers shared their initial feelings and thoughts at the time of the diagnosis in 20 segments. They reported feelings of shock, sadness, frustration, anxiety, and self-blame. They were also confused because they did not understand what cleft was. It was especially shocking for the mothers if t no one was with them when they first learned about the diagnosis or had not been diagnosed prenatally despite having had ultrasound examinations. Mothers described feelings of self-blame and wondered “what they did wrong.” Sarah remembered thinking, “How could this have happened? You know, how could this have happened? I thought I was doing everything correctly.” Mothers usually reflected back on their pregnancies and tried to find a cause for their children’s cleft. For example, Diane had to take progesterone during her pregnancy to prevent a miscarriage. She remembered reading that there was a risk of cleft palate on the medication bottle. She described her initial thoughts as:

Then I’m having a conversation with myself that, “I shouldn’t have taken the progesterone, I shouldn’t have taken the progesterone, I shouldn’t have taken the progesterone.” Then I was like, “Well, if I hadn’t taken the progesterone, I might not even have my child.” So I made a compromise with myself, like “It was a small price to pay. I have a child. I carried her almost to term and I didn’t lose her. Because I had 8 levels of progesterone and I was supposed to have 25.

Another mother was comforted by the doctor who told her that “she did not do anything wrong.” One mother could not recall anything she did wrong during her

pregnancy but remembered that she was born with a cleft in her earlobe. She believed that this anomaly might have been the cause, even though the doctor did not agree and reassured her.

The mothers who received the postnatal diagnosis were also afraid of the unknown and of putting their children through surgery. They did not know where to go for help. Five were first-time mothers, so it was especially scary for them. One mother, Minnie, was worried that her husband was going to leave her because she gave birth to a child with cleft. She was keenly aware that her husband had refused to marry his previous girlfriend because she had many health issues and he did not want their children to inherit those issues. Minnie believed that her husband was still in love with his previous girlfriend, so when their daughter was born with cleft palate she thought, “I was just like, okay, so I just found out that he loves another woman, and now our baby has a cleft. Is he going to leave me?”

The mothers reported feelings of sadness and anxiety. They were anxious about the feedings and the first surgery. One mother was frustrated when she learned that her son was born with cleft lip after she has been in labor for a whole day. She thought to herself that she finally had him and now she had to deal with this obstacle. Most mothers were confused because they did not know what cleft entailed or where they could go for help. A few mothers described being relieved when their child was born with cleft lip. One mother was relieved that the palate was not involved because “that could get serious.” Mothers who had children born with cleft palate were relieved that the lip was not involved because of appearance concerns. One mother described feeling guilty afterward for feeling relieved.

5.8.1.4 Subtheme: Initial Concerns

All seven mothers described their initial concerns in 23 segments. The two primary concerns were feeding and surgery. Feeding was a major concern, especially if mothers had planned on breastfeeding their children and especially if they had breastfed their previous child. Even if they pumped their milk, they had to supplement it with formula, which was upsetting for one mother, who said,

I didn't really much care about the cleft palate, I really just cared about the nursing. I was trying to get her fed. All I cared about was getting her fed and my entire pregnancy and before, I knew I wanted to nurse, so I felt like I wasn't able to give her from me because she was early, and my supply, and all of that was going on.

Four mothers were concerned that their children had to have the first surgery "at such a young age." They initially did not know when the surgery would happen and how long it would take to complete. They wanted their children to have the surgery as soon as possible but at the same time worried about its impact.

Additionally, mothers were concerned about severity, appearance, speech, learning disabilities, and underlying genetic issues. One mother wanted to make sure the cleft was fixable. Two mothers reported that their concern about physical appearance was related to how other people were going to view their children both as babies and children and in the future as adults. Sarah, one of the mothers who reported being concerned about physical appearance, said, "When they see, you know, he is a beautiful baby and then they see that his lip's not perfect. They're not looking at the baby. They're looking at the lip." Jill stated that she remembered scenes from Operation Smile commercials when

she heard about cleft, which increased her concerns about her child's physical appearance and the severity of the cleft. Diane, who became concerned about the underlying genetic issues, described waiting in fear for the genetic counseling report. She said, "I became Dr. Google, in figuring out all the other things. I was trying to figure out all the other things that might be wrong. You know, I'm not a doctor, but I was waiting for that report." Luckily, her daughter's cleft was isolated and not associated with any other underlying genetic issues.

5.8.1.5 Subtheme: Preparedness

Six of seven mothers shared how prepared or unprepared they felt at the time of their child's birth. Mothers felt prepared to have children, but most stated that they did not feel prepared for certain aspects of the experience. For example, two mothers who had their babies prematurely shared that they were not ready to have their children on that day. Diane, who gave birth a month earlier than expected said,

I didn't get to nest, her room wasn't ready. None of her clothes – like none of her little onesies were washed. We didn't even have the right size because we didn't know she was going to be premature. Everything on our registry was like for newborn and not preemie.

Some mothers were becoming parents for the first time, so even though they felt prepared, it was also a learning experience for them because they were "doing it" for the first time. Two mothers noted that they were ready for a new baby but not ready for baby with cleft. For example, Ann said, "I was prepared for the baby to come, but I wasn't prepared for a cleft palate."

5.8.2 Dominant Theme: Initial Stages

The second dominant theme, *initial stages*, describes the experiences of mothers during the first year of their children's lives. Questions 5 and 6 in my interview guide (Appendix D) asked about the mothers' experiences during the first month of their children's lives and during the first surgery. All seven mothers who received a postnatal diagnosis described their experiences during the initial stages in 179 segments. This dominant theme was further divided into five subthemes: (1) being a first-time mother; (2) first month, (3) feeding, (4) surgery, and (5) concerns.

5.8.2.1 Subtheme: Being a First-Time Mother

Four of seven mothers shared what it was like being first-time mothers; 3 mothers had an older child at the time of the birth. They described a myriad of feelings such as happiness, loneliness, confusion, anxiety, and sadness. One mother said that she was happy about "finally being a mother." These four first-time mothers described mixed feelings, such as anxiety about the child's development, concerns about their health, and sadness because they were experiencing "baby blues." Pam said, "I was a first time mom so I felt like I had to watch him all of the time and that feeling like, you know, I couldn't put him down or that he wasn't going to wake up. I had to keep checking on him." Another mother, Minnie, said that she felt confused and lonely because she had lost her own mother right before she had her daughter, so she did not have anyone to go to for advice and her husband was not helpful. She said, "It's just this is my first child. I didn't know what was going on. I didn't have my mom to talk to. Anytime I tried to talk to him I just got brushed off."

5.8.2.2 Subtheme: First Month

Five of seven postnatal mothers talked about what they experienced during the first month in 14 segments. Mothers described how they tried to figure out how to feed their babies born with cleft while at the same time recovering from giving birth. Because most mothers had had cesarean deliveries, they described having cramps in their lower bodies. Minnie, who had an episiotomy, had to do sitz baths and cope with bleeding and pain. Diane stated that she was exhausted and did not remember the first month clearly. Mothers who decided to pump and feed their children had to adjust to pumping, which was often difficult. Diane described her initial struggle with pumping:

The first month was super hard; super, super hard to make myself keep doing it. It's not like I'm living in Africa and my kid is going to die if I can't nurse my child. I knew there was an easy option sitting there that I could just say, "I'm done with this. I'm done." It was mentally so hard to refuse to do that.

In contrast, Ann's daughter was at CHOP for 3 weeks right after she was born and was fed with a tube. She found comfort in trusting the hospital staff, and said,

I was somewhat stressed, but for the most part I was pretty happy because she was in good hands at CHOP. I mean I was confident in what they do and what they told me. I felt comfortable with her being at CHOP, and I felt like everything would've been fine.

5.8.2.3 Subtheme: Feeding

Six of seven mothers who received a postnatal diagnosis described their experiences feeding their children during the initial stages in 34 segments. Most mothers were upset that they were not able to breastfeed, especially if they had planned to

breastfeed during their pregnancies and if they had breastfed their previous child. They wanted to breastfeed because they believed it provided their babies with better nutrients and more opportunities for mother-infant attachment. Diane described feeling “guilty” and “robbed” for not being able to breastfeed. She said, “I couldn’t feed my daughter, I couldn’t breast feed her and I really wanted to. I felt like we wouldn’t bond, you know.” She did “skin on skin” contact to enhance her attachment to her daughter and attended breastfeeding support sessions at the hospital. She decided to pump her milk and give her daughter breast milk. However, she had to supplement it with formula because her “supply was not in yet” because her daughter was born a month early.

Pumping was a difficult experience for most mothers, especially because they had to pump right before they fed their babies. Some mothers made the decision with their partners to pump breast milk and asked their partners to help them with the feedings. Diane described the feeding routine with her husband, Jack:

I pumped all night and slept most of the day. So I was pumping every two hours for 24 hours. Jack would feed her and do the overnight. She would wake up at like 11:30, so I would go to bed. So he slept, and then when I went to bed and he took over, he was basically up with her all night. He was like working the night shift and I was doing the day shift.

Diane shared that she learned how to pump everywhere but also felt judged by other mothers when they nursed their babies in front of her. She said,

The nursing thing was like a constant reminder and I felt judged because everywhere I went women would just nurse their babies and I always had to get a bottle out. But I made sure it was the Medela [breastfeeding] bottle with the

yellow. Then, I guess, Lanisoh used to make a bottle that said, “My mommy’s milk.”

She was able to pump and feed her daughter for 9 months. After her daughter had the first surgery, her doctor asked Diane if she would like to try breastfeeding, but by this time she was more comfortable with pumping so she did not want to switch to breastfeeding. Minnie said that she quit breastfeeding after a month because it was too difficult, but felt guilty about quitting because the professionals who led her prenatal classes had “pushed for breastfeeding.” She felt that she was feeding her daughter “junk food.” Another mother, Ann, said that she fed her daughter breast milk in the hospital through a feeding tube and switched to formula at home but did not feel guilty about switching to baby formula.

Two mothers explained that even though they were sad about not being able to breastfeed, their primary concern was giving their babies enough nutrition. Jill said,

I breastfed my oldest daughter not exclusively, but I wanted to do more with [my daughter]. But I was not able to and I was just more worried about how she was going to eat and I didn’t care where it came from.

In the beginning, Jill struggled with finding the right bottle and the right formula for her daughter. Additionally, her daughter had reflux, which made feeding her much more difficult. In fact, Jill was hospitalized because of stress-induced cardiac issues 2 weeks after her baby’s birth.

It was difficult for the mothers to see food coming out of their children’s noses and watching them throw up. They wondered if their newborns were gaining enough weight. Gayle said, “It’s hard to see your child, you know, throw up or when she eats it

just constantly comes out of her nose. Do you know what I mean? Sometimes I would think is she even getting anything?” As they watched baby formula or breast milk coming out of their children’s noses, mothers wondered if this was causing them pain or discomfort. They preferred to give their children breast milk rather than formula because they believed it had a smoother texture (more watery) and was less painful to swallow. It was scary for the mothers if their children stopped breathing during the feedings. They decided that they could not leave their children with anyone after these types of experiences because they did not want other people to have that kind of burden. Mothers described feeding their children as a “learning process” because they needed to find the right bottle and/or learn to use the breast pump. If their children had reflux or colic, the learning process was even more stressful because they also needed to find the “right formula.” Feeding continued to be an issue for one mother because her daughter did not like formula or breast milk and had difficulty switching to solid foods.

5.8.2.4 Subtheme: Surgery

All seven mothers described how they felt during their children’s first surgery in 73 segments. They described feeling sad and nervous before the surgery. One mother stated that she felt prepared because she knew it was coming. Another mother hoped that the feedings would become easier after the first surgery. The most challenging aspect before the surgery for the mothers was “handing their children off to strangers.” They had to relinquish control of their children and had to trust that the doctors knew what they were doing. Two mothers described questioning if they were “doing the right thing” since it was more of a “cosmetic surgery.” For example, Pam said,

Like am I doing the right thing because it's – I think because it's just a cleft lip but it was only a cosmetic procedure. But in this day and age you wouldn't not have your child have it repaired, you know what I mean? So I guess just questioning are we doing the right thing like by doing this even though not doing it – I wouldn't not do it. You know what I mean?

Mothers were also concerned about the anesthesia and surgical complications. At that time, the health professional's caring demeanor was described as comforting for the mothers. For example, Sarah noted how the anesthesiologist talked to them and took her son to the operating room himself. She said,

The anesthesiologist did say something very comforting. He was, you know, I guess, I'm not sure how old he was but he had grandchildren. He has grandchildren, I guess, and he said, "Just know one thing," he goes, "When I'm in there with him, I'm going to treat him like he's my own, my own grandchild." So that did help us.

One mother talked about being unaware of the possible complications before the surgery. She had been communicating with the doctors before the surgery about rescheduling because her daughter had an ear infection. Yet she did not remember her doctors explaining all of the possible complications that could happen during the surgery. Another mother shared that the doctors gave her daughter a "liquid form of Valium" before the surgery, which was helpful because her baby did not experience "separation anxiety."

Some parents described being nervous and "*pacing a lot*" during the surgery. They did not leave the waiting room area so that the doctors could find them "in case

something happened.” One mother said she kept “looking at the door, waiting for the news.” Another mother said that waiting was “nerve-racking” but that the surgery went “pretty fast.”

After the surgery, five of seven mothers were relieved that it was over and that they had completed the “first step on the road to recovery.” However, it was difficult seeing their babies so swollen and in pain, with the stitches, intravenous lines, and restraints. Some had a hard time consoling and feeding their babies after the surgery. One mother said that her daughter was bleeding and oozing more than the other children, so she had to be taken to PICU. This event was stressful for the mother, especially because her husband forced her out of the PICU because she was pregnant at the time. This mother also described having a difficult time when she stayed at the hospital overnight with her daughter because the people she was sharing the room with “smelled” and kept leaving their baby alone, so their baby did not stop crying.

Another mother, Diane, stated that her daughter had a complication during the surgery and the doctors had to re-intubate her. They also had a difficult time extubating her after the surgery because they had a hard time getting her heart rate under control. For this reason, they had to place her baby in the PICU for 4 days. Diane described how she felt while sitting in the waiting room:

“I was just like lying in the waiting room, waiting for her to be brought up to go to her room and just like, “How can I undo this? Can I go back in time? I want to go back in time and I don’t want to have the surgery. I just want to take her home. I just want to take her home...I just want to take her home...I just want

this to be over.” I was telling Jack, “Go get her, go get her, go get her. I want to go home.””

Most mothers shared the positive changes they noticed after the first surgery. One said her daughter started using the pacifier and “making more sounds.” They commented on their children’s changed appearance. Gayle said,

And when we got to see her after that she was just, you know, she was still a little out of it but the first time we looked at her mouth we were like, “Wow.” Do you know what I mean? There was nothing there before and now there is a roof of her mouth.

Another mother, Jill, said her daughter looked beautiful after the surgery but that she was also beautiful before the surgery. She emphasized, however, that the surgery did not change their opinion of her.

5.8.2.5 Subtheme: Concerns

All seven mothers who received a postnatal diagnosis described their concerns during the initial stages in 39 segments. The three cleft-related concerns were (1) surgery, (2) feeding, and (3) outsider reactions. Feeding became a concern for postnatal mothers when they watched food coming out of their children’s noses, when they had to use a feeding tube, when their babies stopped breathing in the middle of the feedings, when the babies had difficulty gaining weight, when the mothers were introducing different foods to their children, and if their children had additional feeding-related problems such as reflux or colic. The mothers were concerned about introducing different types of food to their children because they were afraid that the food would “get stuck.” Diane shared, “Then I started introducing foods and then that was a concern. Like I don’t want anything

to get stuck. I was very scared to feed her any kind of – she had cereal. Like we put cereal in the bottles, but I was scared to give her any real solid food until after her surgery.”

Surgery and outsiders’ reactions were also common concerns during the initial stages. Mothers had to cope with the constant questions and stares from outsiders; they had to explain their children’s condition repeatedly to outsiders. Additionally, mothers were worried about their children having speech delays. They acknowledged that they became very protective of their children. Two mothers worried about their children dying, became hypervigilant, and monitored them all the time. Gayle said that her daughter sometimes stopped breathing during feedings, so she did not want to send her to day care. She said,

I didn’t want to leave her with anybody because there were two incidents where she had, I don’t want to say stopped breathing, but it did happen twice when, I think, the first was when she was three months old. She just was gasping for air so they did admit her down at Children’s and we were there for a couple of days just for observation.

One mother said that she kept watching her child’s development to make sure that “there was nothing else going on.” She wanted to be certain that her child was “developmentally on track.”

Another mother, Pam, shared that she watched her child all the time when he was sleeping because she did not know if he was going to wake up. She admitted that part of her anxiety was normal for a first-time parent but that part of it was related to the cleft. She said: “I did have those anxieties, which I think some of that is normal being a new parent, but I think, also, I was a little anxious, like more anxious after the delivery than I

should have been if you know what I mean.” Two children could not keep their pacifiers in their mouths because of the cleft palate, which negatively impacted their sleep. One child’s “days and nights were switched” because she was premature. These issues were challenging for the mothers because they also could not sleep.

Finally, two postnatal mothers lost a loved one during their pregnancies or right after giving birth. This experience of loss and grief was difficult because they needed to cope with the grief in addition to taking care of a baby born with cleft. One mother, Minnie, said that she felt lonely and did not know what to do because she did not have her mother by her side. She stated that her husband was not supportive, so she had to do research and figure out the cleft and how to care for her newborn on her own.

5.8.3 Dominant Theme: Current Situation

The third dominant theme, *current situation*, describes the observations of the mothers who received a postnatal diagnosis of their children’s ongoing functioning and the outcomes of the surgeries. Furthermore, it provides information about the children’s upcoming treatments and the mothers’ concerns at the time of the interviews. Question 3 in my interview guide (Appendix D) asked mothers about their ongoing concerns, which led the mothers to explain their opinions about the outcomes of their children’s surgeries and current functioning, and concluded with descriptions of their current concerns. All seven mothers described their children’s functioning in 24 segments. This dominant theme of *current situation* was further divided into the following two subthemes: (1) *treatments and current state of functioning*, and (2) *current concerns*.

5.8.3.1 Subtheme: Treatments and Current State of Functioning

In addition to the surgeries required to treat their children's clefts, mothers described treatments their children had received and will receive in the future. They also described their children's current functioning. This subtheme includes 12 segments. Speech problems were common among the children in the postnatal diagnosis group. Three children had speech delays and difficulty with pronunciation. Mothers stated that their children were receiving speech therapy. Their children's speech delays were stressful because the children had temper tantrums when they could not express themselves clearly. For example, Gayle said, "She gets frustrated a lot and I told her therapist at one point, she would lie on the floor and bang her head." An additional challenge for this mother was trying to figure out what her daughter wanted when she cried. She had to play the "guessing game" with her daughter and shared:

We'll guess, like is this what you're asking for? Is this what you're asking for? But it gets to a point where she'll point if she wants a Popsicle. It's at the point now where we know even though she's not saying Popsicle, but how she says it, we know that's what she means. And she'll actually walk into the kitchen and point to the freezer. So it's kind of like a big help because then we know, okay, we can't quite understand yet what she's saying, but she knows where it's at and she's basically guiding us.

Ann stated that as part of early intervention/prevention, her daughter had been receiving speech and physical therapy for a year and a half. The speech therapist told her that her daughter was now developmentally on track. Diane said that her daughter had

tubes inserted in her ears and gets replacements when they fall out. One mother noted that her child no longer has any feeding problems.

5.8.3.2 Subtheme: Current Concerns

Six of seven mothers described their current concerns in 12 segments. Two mothers stated that they did not have any current concerns. Two mothers reported social stigma as a concern. They said that even though their children had the surgeries, they were still anxious about them being bullied because of their visible physical differences. Pam said, “I think my only concern now is what he’s going to think of it down the road because it isn’t perfect, so my only concern is he going to get teased?” These two mothers said that their children might have to go through additional surgeries to improve their physical appearance. Upcoming surgeries were not a concern for these 2 mothers since they felt the surgeries could prevent their children from being bullied. However, another mother said that her daughter might have to have an additional surgery when she is 17 or 18 because her chin is “too small.” She was worried about the impact of the surgery on her daughter since she would be old enough to remember the experience. This same mother also questioned if the cleft “healed correctly” after the surgery because her daughter still had fluid coming out of her nose at times when she vomited or drooled a lot. She said:

Before the cleft was fixed was when they vomit or anything it would come through the nose, which occasionally she does have some leakage through her nose, and not really that much. And I mean it’s rare anymore, but there’s a lot of drooling still, which I had asked the pediatrician just to check her cleft to make sure everything was healed right. And he just said, “Some kids just are droolers.”

Mothers were also concerned about their next child being born with a cleft. They stated that this would not stop them from becoming pregnant again but it would be “at the back of their mind” and they would “pay close attention to the ultrasound.” One mother was concerned about her child’s weight and speech delays.

5.8.4 Dominant Theme: Raising a Child With Cleft

The fourth and last dominant theme for postnatal mothers, *raising a child with cleft*, describes the mothers’ views about the process of raising a child with cleft. In answering questions 7, 8, 10, 12, 13, and 14 in my interview guide (Appendix D), the mothers described their sources of stress, challenges, and lessons learned as they looked back on the experience of raising a child with cleft. They noted whether they would have preferred receiving the cleft diagnosis prior to giving birth. They also described their current views of the cleft and their child and what factors might have led to their children developing clefts in utero. All seven mothers explained their experiences in 166 segments. This dominant theme was then divided into six subthemes: (1) challenges and stressors, (2) impact on relationships, (3) lessons learned, (4) reasons for cleft, (5) view of the child with cleft, and (6) preference for prenatal diagnosis.

5.8.4.1 Subtheme: Challenges and Stressors

Looking back at their experience, all seven mothers who received a postnatal diagnosis identified the biggest challenges and stressors in 34 segments. The two major sources of stress identified were (1) treatment and (2) feeding. Mothers experienced distress putting their children through surgery at such a young age (approximately 1 month old). They were concerned about the surgical complications and anesthesia. Witnessing their children in pain was another source of stress. One mother whose child

had a surgical complication described it as “the worst experience of her life.” Another mother, Pam, said that she had a difficult time deciding to pursue the second surgery because it was more of a “cosmetic procedure.” She said,

That was hard just making that decision but we knew that it was coming and that we’d eventually have to do it. We decided so I think between us I think that was challenging trying to make a decision on when to do it considering it was elective and cosmetic.

Pam said that they decided to have the surgery done before her son started school because they worried about bullying from peers. The doctor also said that her baby needed to be old enough so that there would be more tissue to work with. The NAM device was another challenge for mothers. Jill, for example, shared that it was hard to make her daughter wear the NAM and kept adjusting it to the right position. She said,

Trying to keep it in her mouth without taking it out of her mouth and keeping the teeth and having it in there correctly and making sure I did it right because every time we went to the doctor it was never the way it was supposed to be.

Feeding was another challenge for mothers. They could not nurse, so they had to pump in order to feed their children and the feedings took a long time. For example, Ann said, “It took about a half hour for her to drink three ounces.” When the children ate, the mothers wanted to make sure formula or breast milk was going into their stomachs and not coming out of their noses. One mother switched to formula after a month of trying to breast feed because pumping was too difficult. She said this decision was stressful because she felt guilty. Even if the mothers fed their children breast milk, they still had to use the special feeder bottles. Gayle noted that special feeder bottles were expensive and

that they were not financially prepared since they did not know about the diagnosis prenatally. She said, “We struggled through a lot because her dad was not working at the time and, you know, the bottles were very expensive.”

Speech and social stigma were additional sources of stress. Gayle described the importance of managing her own frustration when her daughter experienced problems expressing herself and Gayle had difficulty understanding what her daughter was trying to say. She said it was important to remember that this situation was not her daughter’s fault. Sarah said that she resented the stares that her son received from other people. She was concerned about the social stigma her son could experience in the future. The fear of the unknown was frightening for the mothers because they did not know what the future would be like for their children.

Reflecting back on her experiences, Diane identified lack of sleep during the first few months as a significant challenge. She said that her daughter’s days and nights were switched, and they could not understand the reason in the beginning. The baby started sleeping better a month later.

5.8.4.2 Subtheme: Impact on Relationships

Four of 7 mothers described in 25 segments how this experience affected their relationships with their partners and with their children. Minnie shared that her husband sided with his mother throughout this experience and ignored her concerns. She and her mother-in-law had experienced problems before, but Minnie said, “Cleft brought everything out.” According to Minnie, her mother-in-law “kept taking her daughter from her arms” and she “did not get to bond with her daughter.” She said that even the staff at CHOP thought that her mother-in-law was the mother because of her daughter’s reaction

every time she saw her grandmother. When Minnie tried to talk to her husband, he brushed her off. Minnie said: “Then he wouldn’t even talk to me. He was like talking to his mom, and anything I said was nothing. Anything she said was right. It was like I was just there to produce breast milk. That’s it.”

In contrast to Minnie’s experiences, Diane and Pam described how helpful their husbands were to them. For example, Diane and Jack decided to commit to a feeding plan whereby Diane pumped her milk and fed their daughter at night and Jack fed her during the day. Diane said, “It was like a commitment that we made together. We were going to give her breast milk and this is what it means.” Pam also described her husband getting up in the middle of the night and helping her with the feedings.

Diane said that she had a relationship with her pump rather than with her baby. For this reason, she tried to compensate by “baby wearing,” carrying the baby in a cloth carrier. She did not know if the lack of nursing negatively affected her relationship with her baby, but when she recalls this time, she remembers wanting to be able to say she did everything she could to attach to her baby securely.

Because Gayle’s daughter stopped breathing during some of the feedings, she did not want to leave her with strangers. This situation was difficult for her and her because they could not go anywhere without their children. She explained,

So now it’s hard for us. If we walk out the door, she’ll scream and cry and throw a fit because she’s not used to being left with people. Do you know what I mean? She was just with us like at least up until for the first year-and-a-half of her life. Do you know what I mean?

5.8.4.3 Subtheme: Lessons Learned

All seven mothers who received a postnatal diagnosis described the lessons they learned in 48 segments. Mothers primarily shared that cleft is a fixable issue. One mother, Jill, wanted other mothers to know that they did not do anything wrong and that their children would not remember this experience. Diane similarly shared that this situation would be a very small and temporary part of her daughter's life. In contrast, Gale said that children born with cleft go through a different experience compared to children born without cleft. She said, "A child that's not born with a cleft, I don't want to say they have more freedom, but they don't have as many difficulties as a child that is born with a cleft." For this reason, it was important to be patient with your children. She was referring to delays in her daughter's speech development. Ann agreed that the experience with a child born with a cleft is different, especially for the first few months. She said, "It probably would've been her first few months. She, I think, needed more care than a kid without a cleft palate."

Regarding diagnosing a cleft, Minnie emphasized that mothers should go "with their gut" and insist on obtaining additional consultations if the hospital staff does not listen to their concerns. She also suggested that mothers should push for a 3D ultrasound examinations when they are pregnant. Finally, she said it was important to find a good cleft treatment team and to interview the pediatrician to find out if he or she had ever treated a child born with cleft.

Mothers emphasized the importance of learning about cleft through support groups, looking on line at Web sites, and taking pictures of the child before and after the surgery in order to see the improvements. Furthermore, mothers noted that resources are

always available to help families cope with cleft. Ann stated that the CPR classes she took at the hospital to cope with her child's sleep apnea were very helpful.

The mothers also learned lessons about being a parent. They learned that once they became mothers, their children were their main priority and "nothing was about them anymore." As mothers, they learned that they would do anything for their children without feeling any resentment.

5.8.4.4 Subtheme: Reasons for Cleft

Six of seven postnatal mothers shared their ideas about what could have caused their children's clefts in 16 segments. Four mothers said that they did not know the definitive cause, but most shared their own ideas. Three mothers examined their family histories to find out if anybody was born with a cleft but could not find anyone. Sarah remembered that she was born with a cleft in her ear lobe. Ann was told that smoking could cause it, but she was not a smoker. Ruling out smoking and genetic background as possible reasons, she said; "I have no idea honestly. They told me smoking can cause it, but I'm not a smoker. So I honestly have no idea what would've caused it. Nobody on either side of our family, we don't know anyone in our family that had a cleft, so I have not a clue."

Mothers had their own theories about what could have caused the cleft. Diane thought it could be progesterone, the medication she took to prevent her from miscarrying. She had to take progesterone between the 5th and 12th weeks of her pregnancy because she had struggled with getting pregnant and received fertility treatments for 2 years before conceiving. As a result, she did not want to risk losing her baby once she finally conceived, so she took progesterone even though she knew that

there was a risk of cleft palate. Once she found out about the cleft diagnosis at the birth, she also remembered that not knowing she was pregnant, she had drunk alcohol on Mother's Day, which was the fourth week of her pregnancy. Similarly, Minnie said that prior to becoming aware of her pregnancy, she had eaten a lot of shellfish and drunk alcohol while her mother was dying.

Two mothers reported feelings of self-blame. They wondered if there was anything they could have done to prevent the cleft. Gayle said, "That kind of thought is always in the back of your mind like is there something that we could have done to prevent this? Do you know what I mean?"

5.8.4.5 View of the Child With Cleft

Six of seven mothers talked about their current views of their children and the cleft in 21 segments. Mothers described cleft as a "fixable," "manageable," and "minor" issue compared to other health issues their children could have experienced, so they felt grateful. Sarah described cleft as an "upside down heart." Diane shared what her doctor told her that made her feel less anxious: "My doctor told me, and this is what I clung to a lot. He said, 'This is going to be a very small part of your daughter's childhood.' So it's something that is not permanent."

Three mothers noted that, at the time of the interviews, their children were not any different from other children in terms of their physical appearance and development. Mothers emphasized that their children were "beautiful." They said that they could not tell that the children had clefts most of the time when they look at them. For example, Sarah said, "When I look at him, I don't see – I guess sometimes I do see it because I'll look for it but I don't even see it on him." Ann expressed that outsiders could not tell that

her daughter was born with cleft palate as well. She shared, “Nothing seemed different about her. People didn’t know she had a cleft. They couldn’t tell the difference. She was doing everything like pretty much right on target.”

However, Ann did stress that there were differences between her daughter and other children without clefts during the initial stages. She said, “It probably would’ve been her first few months. She, I think, needed more care than a kid without a cleft palate.” Diane and Gayle similarly shared that the experiences are different for both children and parents. Diane said, “I think people who are born with children with congenital defects or special needs is just a different journey than people who just pop out a healthy child.” Additionally, Gale noted that children born without a cleft have more “freedom” compared to children born with a cleft, but every child deserves the same love. She said,

God puts every child on this earth for a reason, you know, some with birth defects and some without, and every child is the same. Every child deserves the same love. Every child deserves the same future, whether they’re born with a birth defect or not.

5.8.4.6 Subtheme: Preference for Prenatal Diagnosis

When asked if they would have preferred knowing about the cleft diagnosis prenatally, all seven mothers shared their opinions in 12 segments. Six mothers said that they would have preferred to have known about the cleft *before* the birth because they could have been more prepared both practically and emotionally. For instance, they would have purchased and learned how to use the special bottles, figured out how to take

care of their children, and developed a treatment plan with their providers before the birth. For example, Diane said,

I was like drugged, hurting, C-section. It's a lot to deal with right then and you're exhausted. And I'm making phone calls, I'm making appointments with Plastics, I'm making appointments with nutrition consultants, I'm making appointments and I'm like three days out.

Furthermore, the mothers stated that if they had known prior to their child's birth, they would have been better prepared to "see" their newborns for the first time and would not have been so shocked.

Sarah noted that reviewing her ultrasound pictures now, she could "see" the cleft in the scans even though the doctors never told her. She said, "There is a picture, actually, that I have of him. I can't remember how many weeks I was maybe, I don't know, 22, 26, 28 weeks, and when we look at it now, we swear that we can tell in the picture."

All seven mothers also said that knowing about the diagnosis prior to the birth would also have made them more anxious during the pregnancy. For example, Pam was ambivalent about preferring to know before her baby's birth. Although she thought it would have been helpful because she could have researched cleft and prepared herself emotionally, she also felt that knowing ahead of time would have increased her feelings of anxiety during the pregnancy. Still, she opted to know if her baby had cleft in utero for her second pregnancy. Gayle and Jill both said that knowing would have prepared them better, but it would not have impacted their decision as to whether or not keep the baby. For this reason, Jill thought knowing prenatally would not have made a difference for her. She said, "It's not like we're not going to want her because she has it. I know in other

countries they dump them off at the side of the road because they have it. We're not like that.”

5.9 Postnatal Diagnosis Group, Fathers: Dominant and Subdominant Themes

Fathers in the postnatal diagnosis group described their experiences raising a child born with a cleft and focused on the following time periods: (1) birth and postnatal diagnosis, (2) initial stages after birth, and (3) current situation. Furthermore, these fathers also reflected on their experiences raising a child with cleft. The dominant themes summarizing the experiences of the seven fathers who received the diagnosis postnatally are organized as follows: (1) birth and postnatal diagnosis, (2) initial stages, (3) current situation, and (4) raising a child with cleft. Within these four dominant themes, 13 subthemes emerged that capture the more specific aspects of their experiences. An analysis of these subthemes is provided using illustrative quotes from the fathers in the postnatal diagnosis group. Table 5.13 contains an overview of the 4 dominant and 13 subthemes.

Table 5.13. Dominant Themes of the Fathers in the Postnatal Diagnosis Group

Level	Themes	Theme Frequency/Postnatal Fathers' Quotes in this Chapter
100	Dominant Theme: Birth and Postnatal Diagnosis	126 Total Segments: All postnatal fathers
101	Delivery of the diagnosis	34 segments: All postnatal fathers Postnatal father quotes: Larry, Junior
102	Initial feelings and thoughts	31 segments: All postnatal fathers Postnatal father quotes: Jack, Joey
103	Concerns	24 segments: 6 of 7 postnatal fathers Postnatal father quotes: Paul, Brandon
104	Being with the partner	10 segments: 4 of 7 postnatal fathers Postnatal father quotes: Larry, Brandon
105	Preparedness	8 segments: All postnatal fathers Postnatal father quotes: Junior

200	Dominant Theme: Initial Stages	50 segments: All postnatal fathers
201	Challenges	17 Segments: 4 of 7 postnatal fathers Postnatal father quotes: Joey, Junior
202	Surgery	30 segments: All postnatal fathers Postnatal father quotes: Eric, Brandon, Junior
300	Dominant Theme: Current Situation	22 segments: All postnatal fathers
203	Current concerns	21 segments: All postnatal fathers postnatal father quotes: Junior
300	Dominant Theme: Raising a Child with Cleft	119 segments: All postnatal fathers
301	Challenges and stressors	26 segments: All postnatal fathers Postnatal father quotes: Jack, Larry
302	Lessons learned	33 segments: All postnatal fathers Postnatal father quotes: Jack, Brandon, Paul
303	Reasons for cleft	17 segments: All postnatal fathers Postnatal father quotes: Larry, Brandon
301	View of the child with cleft	21 segments: 4 of 7 postnatal fathers Postnatal father quotes: Jack, Larry
305	Preference for prenatal diagnosis	9 segments: All postnatal fathers Postnatal father quotes: Eric, Jack

5.9.1 Dominant Theme: Birth and Postnatal Diagnosis

The first dominant theme, *birth and postnatal diagnosis*, describes the experiences of the fathers who first received the postnatal diagnosis at the time of birth. The first four questions in my interview guide (Appendix D) asked fathers how they first found out about their child's cleft diagnosis; their initial thoughts, feelings, concerns; and how prepared they felt at their baby's birth. All seven fathers described their experiences at the time of birth and postnatal diagnosis in 126 segments. The dominant theme of *birth and postnatal diagnosis* was divided into five subthemes: (1) delivery of the diagnosis,

(2) initial feelings and thoughts, (3) concerns, (4) being with the partner, and (5) preparedness.

5.9.1.1 Subtheme: Delivery of the Diagnosis

All seven fathers in the postnatal group described how they first received the cleft diagnosis at the time of birth in 34 segments. Four fathers learned about the cleft diagnosis in the delivery room, right after their wives gave birth. Confirming what his wife said, Larry said that the doctor covered their son's cleft right after his birth and asked them if they were aware of what a cleft is. Larry thought their doctor covered up the cleft because he did not want it to be the couple's first view of their newborn. Two fathers, Brandon and Paul, said that the doctor comforted them as s/he delivered the diagnosis by telling them that cleft is a fixable issue. Brandon said that the way he first learned of the diagnosis was very different from how his wife did because she was informed by a person whom she did not know, while she was being stitched up after the cesarean delivery. Brandon was upset about how his wife first heard about the diagnosis. Paul identified the moment of the cleft diagnosis as nerve wracking because he was already overwhelmed from watching his wife going through a cesarean delivery. He shared,

For me, the whole experience in the OR was pretty nerve-wracking just watching my wife being sedated and the C-section and all of the nurses doing their thing and the anesthesiologist, all of that was nerve-wracking enough and then the doctor handing me this little baby and said he had a cleft lip.

Eric said that he found out about the cleft at the hospital after his daughter was born even though his partner, Ann, shared that they found out the next day after their daughter was transferred to the CHOP NICU because she had breathing difficulties.

Another father, Joey, also shared a different version from his wife. He said that he found out about the cleft diagnosis the next day when his wife called him. Yet she shared that she realized that their daughter's chin was small, opened her mouth, and first noticed the cleft at the birth. Two fathers, Jack and Junior, received the cleft diagnosis days later, after their wives had difficulty feeding their children. Jack stated that he learned about the diagnosis 2 days later. The doctors initially thought that his daughter had a tight frenulum but then noticed she was born with a cleft. Additionally, the doctor informed them that their daughter was low on the growth charts. Diane did not mention this was information when telling her version of how she received the cleft diagnosis. She also said that she was the one who called Jack and told him, in contrast to Jack sharing that the doctors told him of the diagnosis.

Junior stated that he first heard the cleft diagnosis after his baby was readmitted to the hospital because his daughter had failure to thrive because of feeding difficulties due to the cleft. The pediatrician did not initially notice the cleft even though he examined her, likely because this was the first case of cleft the hospital had ever treated. Junior said,

I mean, the pediatrician, like I said, said that she's perfect and didn't discover that. Then you get readmitted for failure to thrive, so that was painful, realizing after the fact that you're not able to feed your child.

In his individual interview, he confirmed his wife's account of requesting a further examination after birth because their daughter's "mouth looked different" and getting brushed off and blamed by hospital staff.

5.9.1.2 Subtheme: Initial Feelings and Thoughts

All seven fathers described their initial feelings and thoughts upon receiving the cleft diagnosis in 31 segments. They identified a variety of feelings including anxiety, guilt, shock, and sadness. They were confused and worried because they did not know what cleft was, what it entailed, and if it could be easily fixed. They wanted to make sure that their children would be "okay." One father, Jack, said he was anxious because he did not know how cleft would impact his daughter in terms of feeding issues and speech development. Another father, Joey, was shocked and confused because he did not know that there was a cleft palate; he only knew about cleft lip. Similarly, Paul stated that he was shocked because he was not expecting it, because his older child was not born with cleft palate or a cleft lip.

Two fathers said they had feelings of self-blame, questioning what they could have done differently and what they might have done wrong. Similar to his wife, Brandon wondered what they did wrong. Unlike his wife, Jack questioned the impact of the fertility treatments his wife went through and wondered if that led to their child developing cleft. He said,

What did we do wrong and should we have done something differently. I guess like in the back of your head, when you're going through all the fertility treatments, you're sort of doing like a mini-risk analysis.

Four fathers said they also tried to take a more positive attitude about the cleft diagnosis. Jack was happy to finally have a child. Brandon reassured himself by reminding himself that his son was in good hands and God was watching over him. Joey was glad his daughter had cleft palate not cleft lip. He said, “The only thing, I hate to say it, I was just glad it wasn’t the lip. It was the inside the roof of the mouth because I see the commercials with the kids with the lips and that just makes my blood run cold.” Joey and Larry both shared that they were glad cleft, which was fixable compared to other more serious health issues, was the only problem their children had.

5.9.1.3 Subtheme: Concerns

Six of seven fathers described their initial concerns about the cleft in 24 segments. Social stigma and the treatment plan were their two major concerns. Four fathers described worrying about the questions and the reactions their children could receive from other children in the future. Larry said, “Were kids going to make fun of her? And always having to explain to people, not so much adults, but kids when they see her, of course they’re going to ask what’s wrong with her mouth.” The fathers who were worried about social stigma all shared that, “kids were mean” and they did not want their children to experience social problems because of bullying from peers.

Three fathers worried about their children’s treatment plan and the next steps. They wanted to make sure the cleft was repairable, understand the surgery, whether there was any possibility of complications, and what the outcome of the surgery would be. Paul stated that this was on their minds from the first moment he and his wife held their newborn son. He said,

I think the first time we were holding our baby we were already wondering when he was going to have to go in for surgery. And I guess those aren't normal thoughts you have when you have a healthy baby. You're not wondering when he has to go back in for surgery. I think we started thinking about that as soon as we got the baby.

Brandon wanted to learn when the surgery would take place and wanted to protect his son from being bullied. He said,

How to proceed; what the next step would be as far as do we have surgery right away? Do we wait six months, a year, two years before he's able to get surgery? I just wanted to make sure he wasn't going to go through this during his early stages of school and things of that nature with the cleft lip in place, you know, I didn't want him to be made fun of.

Two fathers were worried about their children's development and wondered if they were going to be "normal." They worried that their children would struggle with learning disabilities, speech delays, or issues with social functioning. Eric, whose daughter experienced breathing difficulties at birth, wondered if they would be permanent. Junior was worried about how his daughter would adjust to the special feeder bottles, and Jack was concerned about his daughter's height and weight because she had been born prematurely.

5.9.1.4 Subtheme: Being With the Partner

Four fathers described in 10 segments what it was like being with their partners at the time of the diagnosis. Eric, the only father in the postnatal diagnosis group who was not married to the mother of his child, stated that it was his "duty" as the father to be

there. Both Brandon and Larry tried to be the “strong one” and comforted their wives at the time of the cleft diagnosis. Larry noted that, initially, his wife was bothered by the cleft more than she let on. She was very worried until the doctors explained that it is a fixable issue. Describing his role at that time, Larry said,

I was just there to lend her support. I just tried to be the strong one to just help her realize that we’ll get through this. It’s not going to change. She’s still your baby.

It’s a very simple thing to fix and I just tried to be the emotional support for her.

Brandon tried to soothe his wife after she first learned about the diagnosis from an unfamiliar staff member at the hospital while she was being stitched up during her cesarean delivery. Brandon reassured his wife and told her, “He’s going to be all right. We’ll get him all fixed up and he’s going to look perfect.” He stated that he was calmer than his wife because he knew that cleft was “fixable, deep down inside.” Paul described what it was like to hold their son together for the first time. He said that it was a “joyful moment” because they had their “first son” and he was healthy. However, they were both “taken aback by the lip” and wondered about the next steps to have it treated.

5.9.1.5 Subtheme: Preparedness

All seven fathers discussed in eight segments how they felt about being prepared to care for their newborns. All fathers shared that they felt prepared to welcome a new baby. They knew that the baby was coming; they were prepared emotionally and financially, especially because most had scheduled cesarean deliveries. Jack shared that since they had been receiving fertility treatments for 2 years, he had been waiting to have a child “for the longest time.” Larry stated that he was familiar with the process of taking care of a newborn because he had an older child, so he felt ready. Even though Junior did

not have any other children, he did learn how to take care of children by talking to other people and going to prenatal classes with his wife. Similar to his wife, he did mention that they moved right before his wife gave birth and his family helped with their move.

He said,

We had a lot of stuff going on because she was born and then like maybe two weeks later we moved from an apartment to a house. So certainly that weekend there was a lot going on. But I mean we had a lot of family helping, so we moved in relatively quickly. We didn't have that much stuff anyway.

However, he did not discuss his attitude about the move in the same way his wife did.

Minnie said that he was not helpful to her as she was packing for the move and was dismissive saying that she did not need to rush because they had a long time ahead.

Yet, Junior and Joey said that they were not prepared for some of the difficulties that cleft caused. For example, Junior said, "I guess because she had the cleft palate or whatnot, but she wasn't really big on pacifiers either because I guess the sucking motion just was harder for her." This was hard for Junior because his daughter had trouble sleeping without the pacifier.

5.9.2 Dominant Theme: Initial Stages

The second dominant theme, *initial stages*, describes the experiences of the fathers during the first year of their children's lives. Questions 5 and 6 in my interview guide (Appendix D) asked fathers to describe their experiences during the first month of their children's lives and at the time of surgery. All seven fathers shared in 50 segments their experiences during the initial stages after the birth. This dominant theme was further divided into two subthemes: (1) initial challenges and (2) surgery.

5.9.2.1 Subtheme: Initial Challenges

Four fathers described in 17 segments the challenges they went through during the initial stages after the birth. Fathers identified feeding as the main challenge. Using the special feeder bottles and making sure they were feeding their children “right” was difficult for fathers. In Junior’s case, their baby was the first cleft case at the hospital, so staff did not have the proper bottles; the bottles had to be ordered from another hospital. Consequently, they had to feed their newborn with syringes while waiting for the special bottles to arrive. Junior said that even when the proper bottles arrived, neither the hospital staff nor they were familiar with how to use the bottles. The nipple of one of the bottles tore as they were trying to feed their daughter, which they did not realize initially.

Describing this incident, Junior said,

All the sudden she’s hungry; you’re trying to feed her, and then it’s in her mouth but it’s starting to pour out. So then I was under the impression at first that oh, maybe she’s not hungry, but then she is hungry. It was until a few attempts like that that I realized okay, the nipple split. Then we had to go through the process of finding the order form just to order the nipples.

Junior shared that once they learned how to use the bottles, feeding became much easier. His wife switched to formula after pumping her milk for a few months because pumping was very time consuming; Junior was then able to become more involved in the feedings.

Eric’s daughter was at CHOP for 3 weeks after her birth and was fed with a feeding tube. Before they were discharged, the hospital staff taught Eric and Ann how to put the feeding tube down their daughter’s throat, which was scary for Ann, so Eric learned how to do it. He said it was challenging for him too because he did not know if he

was hurting his daughter. For Joey, it was difficult seeing his daughter throw up after the feedings. He said, “It was hard feeding her because every time she would take the bottle she would throw up, but it wouldn’t come out of her mouth. It would come out of her nose. You feel helpless. You feel real helpless.”

For Larry, the challenge with feedings was finding the right milk and formula for his daughter because she “did not like any.” They struggled for 3 to 4 months until they found a formula that she liked. At the same time, they were using the NAM device, which was an additional challenge. During this time, their daughter had difficulty sleeping and cried constantly. Junior’s daughter also had trouble sleeping because she could not keep the pacifier in her mouth. Additionally, Larry acknowledged that they were so focused on taking care of their daughter with cleft that they were unable to spare much attention to their older child.

5.9.2.2 Subtheme: Surgery

All seven fathers shared in 30 segments their experiences during the first cleft surgery. Before the surgery, fathers were worried about complications, anesthesia, and pain after surgery. Similar to the mothers in the postnatal diagnosis group, it was difficult for the fathers to “hand their children over” before the surgery. Two fathers said they wondered if the doctors were going to be able to fix the cleft. For example, Eric said, “I just didn’t want them to damage the cleft any worse than it was. I didn’t want them to mess up at all.” Confirming what his wife said, Brandon said that he was worried about possible complications from the anesthesia. He shared:

That part to me was the toughest part of the whole thing for me when they took him away from us. When he had to go to anesthesia and we were playing around

in the waiting room and stuff like that. And then the anesthesiologist comes in and, “Okay, it’s time,” and when they took him from us, not knowing if we were ever going to see him again. That was the big question mark. That was the scariest part for me.

His wife, Sarah, explained that the anesthesiologist came and picked their son up himself and stated that he would treat him like his own grandson, which was comforting for Sarah. Brandon did not share this same story. Additionally, Larry wondered about the level of pain his daughter would experience after the surgery.

After the first surgery, it was difficult for the fathers to see their children with stitches, restraints, and swelling, especially if they considered the surgery a “quick fix.” Brandon described seeing his son after the surgery for the very first time and said:

He was a little banged up. I didn’t expect that much swelling and just when you see a little infant there with wires hooked up to him, and these things on his arms, and he can’t move, and he’s got no clue what is going on. I couldn’t tell if he was feeling pain or what he was actually thinking. I know he was thinking something but I just couldn’t tell.

Other fathers also commented on how hard it was seeing their children in pain after the first surgery. For example, Junior saw blood coming out of his daughter’s mouth after the palate surgery and said, “It was just different from coddling her and making sure nothing happens to her, then all of a sudden to feel like that.”

The recovery period was also stressful for fathers, especially if their children had complications. Larry said that the staff could not discharge his daughter on time because they had difficulty keeping her blood pressure under control. Jack’s daughter had a

“laryngeal spasm” and stopped breathing when they extubated her after the surgery, so she needed to be placed in the PICU. Junior noted that his daughter became more “docile” after the surgery. Fathers said they had to take their children for follow-up appointments 2 to 4 weeks later so that their doctors could evaluate the outcome and assess if another surgery was needed.

According to the fathers, their children experienced positive and negative changes after the surgery. On the positive side, some babies learned how to suck and stopped throwing up. Fathers whose children did not have complications were glad that the surgery went well even though one father, Paul, stated that he immediately started thinking about the next surgery. On the negative side, in Junior’s case, his daughter’s speech regressed after the surgery and she did not want to put anything in her mouth.

Junior said,

She was starting to say a few words before the surgery happened, and then it was like she stopped. Once the surgery happened she stopped. But at that same time before the surgery she was on bottles. After the surgery she was done with bottles. She didn’t want anything like that in her mouth, I guess, is what it seemed like. She kind of like also, I don’t know if I’d say regressed, but it was like starting over again with trying to have her speak and everything like that.

5.9.3 Dominant Theme: Current Situation

The third dominant theme, *current situation*, describes the postnatal fathers’ current concerns about and observations on their children’s functioning. Question 3 in my interview guide (Appendix D) asked the fathers about their current concerns. All seven

fathers described their concerns in 22 segments. The following subtheme emerged: current concerns.

All seven fathers in the postnatal diagnosis group described in 21 segments current concerns about their children's development, functioning, and treatment plan. Fathers' current concerns were related to speech, social stigma, upcoming treatments, development, impact of the surgery, and the next child having cleft. Three fathers in the sample, Joey, Junior, and Larry, had children who were still experiencing speech delays and were in speech therapy. Joey's daughter was not saying her vowels, which made it hard for her to communicate her needs. Joey stressed that his daughter was not able to tell him what was bothering her, so they had to play guessing games. Similarly, Junior's daughter had difficulty communicating her needs because she stopped speaking after the surgery. She was about 10 months old when she had her palate surgery and she had just started to say a few words before the surgery. After the surgery, she regressed. She frequently had temper tantrums because she was unable to express herself. Junior could not decide if this was because of the psychological impact of the surgery or a cleft-related issue. He said,

But there's just the sheer fact that she's not communicating, or sometimes it's hard to know if she's refusing to communicate, if she's being stubborn, I guess, I don't know, or if she's just choosing not to with that kind of thing. Because just simple yes and no and other verbal skills that she does have, it'd be nice to not have her have to point or have a tantrum. So it's just hard to imagine where she would be if maybe that wasn't the case with the cleft.

Unlike Joey, Junior stated that they began refusing to play the guessing game in order to encourage their child to communicate directly with them. When describing their daughters' current speech problems, both fathers said that their children did not have any problems with neurofunctioning. Larry also stated that his daughter was having speech problems and wondered if the speech problems would make his daughter a target for social stigma.

Like Larry, other fathers were concerned about social stigma because of the visible differences in their children. They wondered if their children would be teased by peers and if it would negatively impact their self-esteem. Additionally, fathers were concerned about the upcoming surgeries. Paul and Brandon said that their daughters could require additional cosmetic surgical procedures. Joey's daughter was likely to receive surgery on her chin once she turned 18. He also said that ear tubes had been inserted in his daughter's ears and that this was a concern for him. Eric was concerned about a non-cleft-related surgery; his daughter might need a tonsillectomy sometime in the future. Finally, Jack was concerned about his next child being born with a cleft and about his daughter's height and weight. He said that he did not know if the cleft would be more severe and syndromic in the next child, so he was considering those possibilities when considering having another child. He was still concerned about his daughter's development because she was still low on the growth charts.

5.9.4 Dominant Theme: Raising a Child With Cleft

The fourth and last dominant theme, *raising a child with cleft*, describes the views of the fathers who received a postnatal diagnosis about the process of raising a child with cleft. When answering questions 7, 8, 10, 12, 13, and 14 in my interview guide

(Appendix D), fathers described their sources of stress, challenges, and lessons learned as they looked back on the experience of raising a child with cleft. They described if they would have liked to receive the cleft diagnosis prior to the birth. They also explained their current views on cleft and their child and their ideas about possible factors that led to their children developing clefts in utero. All seven fathers described their experiences in 119 segments. The dominant theme of raising a child with cleft was further divided into the following subthemes: (1) challenges and stressors, (2) lessons learned, (3) reasons for cleft, (4) view of the child with cleft, and (5) preference for prenatal diagnosis.

5.9.4.1 Subthemes: Challenges and Stressors

All seven fathers in the postnatal diagnosis group described in 26 segments personal challenges raising a child with cleft. Challenges concerned feeding and treatment during the initial stages, residual issues (e.g., speech delays and the ear tubes), and outsiders' current reactions to their children. Using the special feeder bottles and the feeding tube were two major challenges. Like the mothers, they also shared that it was hard to do the tapings for the NAM device, cope with the complications after surgery, find the financial resources to pay for the surgery, plan the timing of the next surgery, and witness their wives/partners being so distressed. Larry said that when he and his wife were trying to do the tapings for their daughter's NAM device the biggest challenge was keeping calm and focused. Jack described how his immediate concerns changed once there was a complication after the surgery. He said, "It makes my whole initial thing about, 'Oh well, the social impact of her...' I mean you can throw all that out the

window when you're sitting in the NICU for five days hoping she's going to pull through."

The fathers reported coping with their children's residual issues, such as speech delays and ear tubes. It was also frustrating to keep explaining to outsiders about the cleft. Even though the fathers reported navigating the most stressful times (e.g., initial shock receiving cleft diagnosis at birth, first surgery), they still had some fears about the future. For example, Larry said, "It's stressful just wondering what's going to happen with her through her life. Like I said, with the speech therapy and I don't know if she's – I know she's going to need another surgery at some point."

5.9.4.2 Subtheme: Lessons Learned

All seven fathers in the postnatal diagnosis group described in 33 segments the lessons they learned while raising a child born with cleft as well as the advice they would share with other parents. Fathers noted the importance of exploring the treatment options, choosing the best treatment team available, and trusting the treatment team, which eases the parents' distress. For example, Jack said, "I think this would be a much different interview if we were in some other city that didn't have access to the resources that we're fortunate to have here." He said that CHOP provided them with invaluable resources for the surgical treatment and other aspects. Junior, who had a frustrating experience at the first hospital they went to, also emphasized the importance of choosing a hospital equipped for cleft treatment. For Brandon, it was crucial to prepare himself financially to obtain the best treatment available:

We made sure our priorities were set straight because financially we had to come up with some of the funds to pay for the surgeries because our insurance wasn't

the best at the time. But now they're excellent. But, yeah, more the financial part of it was the issue for us because it was back, to back, to back, to back. I wanted to make sure it was done early on in the stages while he was still little.

According to Joey and Junior, it was important to listen carefully to the doctors but also to remember that surgery is not a "quick fix" for cleft. There was a long recovery period and possible complications and negative changes after surgery.

When asked about their advice for other parents, both Eric and Brandon said that even though the process was initially stressful, routines do go back to "normal" eventually. For practical purposes, Joey said it was helpful teaching other people how to feed the baby and to order extra nipples because they tear so easily.

The fathers came to new realizations about themselves and their families. Larry emphasized the importance of asking for and receiving support from other parents, patients, and people around them. Patience was crucial for parents to cope with their children's difficulties. It was also important to remember that the situation was not about them but about their children. Jack stressed letting go of the self-blame as soon as possible and not dwelling on what they could have done wrong to cause the cleft. Both Jack and Paul said they were thankful that their children had a "minor" fixable issue. Paul realized that he and his wife were able to handle a lot more than he had thought possible, which in turn brought them closer together as a couple.

Reflecting back on the experience, Larry noticed the impact it had on his older daughter. He admitted that they were not able to pay as much attention to her. He shared that he was now trying to make his older daughter understand why they spent less time

with her and use the patience he learned from taking care of his daughter with cleft with his older daughter.

This process was also helpful for Larry and Paul, who learned more about their wives/partners. Larry learned about the importance of checking in with his wife to see if something was bothering her, asking her what she heard during doctors' appointments, and giving each other respite when needed. Paul realized that it was important to have a strong foundation in a relationship before having children. He said;

Make sure you're in a good relationship. Make sure you're secure with, I guess, financially secure and have a job and have a good wife and have family support because, you know, once the kids starts coming, it, you know, gets a little chaotic here. I think it's something you have to have a good relationship before you start planning and learn some patience, which is not my forte.

5.9.4.3 Subtheme: Reasons for Cleft

All seven fathers in the postnatal diagnosis group described in 17 segments the possible causes of their children's clefts. Four fathers said they did not know the cause of their children's clefts; five had some ideas. Paul thought it could be genetics and bad luck. Eric said he believed that it was caused by his partner's poor eating habits and lack of exercise. According to Joey, it could have been caused by the medication his wife took to quit smoking. Jack thought it was because of the fertility treatments his wife went through or the mothers' older age. Brandon suggested that it could be the position of the umbilical cord in utero. He said,

The only thing I thought of at first was that the umbilical cord got wrapped around and was stationary on the front of his lip. That was my thought. I didn't know if that was possible. I didn't know if it was or not. I wasn't sure.

When they first found out at the time of the diagnosis, two fathers, Jack and Larry, experienced feelings of self-blame, wondering what they could have done differently during the pregnancy. Larry said, "At first when it happened, I went through a lot of that. I was trying to think was there something I did? Is there some kind of medical history? Is there anything that could have caused it?"

5.9.4.4 Subtheme: View of the Child With Cleft

Four fathers shared in 21 segments their views of cleft and their children. They described cleft as a minor issue and felt "blessed" that this was what they were dealing with. It did not change the love they had for their children. For example, Jack said, "If she had three arms and 10 legs, I wouldn't care; I would've loved her just the same." Yet, it was not something they had wished for their children. As Larry said, "I kind of just wish sometimes she didn't have it, she wasn't born with it, obviously." Regarding physical appearance, most parents were happy with the outcome of the surgery. They thought their children looked "great." Jack stated that it was scary when he saw it on television, because of the level of severity and felt grateful that his daughter's cleft was not too severe.

5.9.4.5 Subtheme: Preference for Prenatal Diagnosis

All seven fathers in the postnatal diagnosis group described in 9 segments their preference for the timing of the cleft diagnosis. Two fathers openly stated that they would have preferred knowing about the cleft prenatally whereas 2 said they would not have

wanted to know. Three fathers stated that it would not have made a difference. For Junior, Brandon, and Larry, it would have been helpful to have known prior to the birth so that they could have prepared better rather than getting a “crash course” in cleft after the birth. All seven fathers noted that their wives had ultrasound examinations during their pregnancies, but the clefts were not discovered. Junior’s wife denied having the 3D ultrasound during pregnancy. She said that she asked for ultrasound examinations but was ignored. Junior stated that if he had known beforehand, he could have chosen a hospital that was more prepared and would have purchased the bottles and learned how to use them before his child’s birth. Brandon said they could have been better prepared financially. Both Joey and Paul stated that knowing before the birth would have increased their stress level during pregnancy. Joey emphasized that cleft was not something you could actually prepare for.

For Eric and Jack, it would not have made a difference if they had known earlier. They stated that they would still have kept the baby and treated him/her the same. Eric said, “I would treat her the same anyway. I would just have to fulfill my duties as a father to do what I’ve got to do.” Unlike his wife, Jack was not sure if he would have wanted to know about the diagnosis prenatally. He stated that, since they had been waiting for a child for a long time, abortion was not an option even if they knew about cleft. He said,

We didn’t find out about anything. We went into this and we weren’t going to have an abortion, no matter how bad things got. It was going to be what it was going to be kind of thing and we knew that going in.

5.10 Postnatal Diagnosis Group, Couples: Dominant and Subdominant Themes

After I completed individual interviews with the mothers and the fathers, I interviewed the parents in the postnatal diagnosis group as couples. Questions 12 to 26 asked couples how the cleft affected their relationships and how they talk about cleft as a couple, with other people, and with their children. I also wanted to understand the current functioning of their children. The couple interviews helped me triangulate the individual interviews and tease out a more coherent narrative of their experiences. The findings of the couples in the postnatal diagnosis group yielded the following dominant themes: (1) the couple's relationship, (2) about the experience, (3) child's functioning, and (4) talking about cleft. Seventeen subthemes emerged that captured the specific experiences of these couples. A description of each subtheme is provided using illustrative quotes from the couples in the postnatal diagnosis group. Table 5.14 contains an overview of the dominant themes and subthemes. To inform the reader about the frequency of specific themes mentioned by the couples in the postnatal diagnosis group and the number of couples who mentioned them, I included the "theme frequency" section in Table 5.14. Additionally, the same section provides information on the couples' quotes used in this section to describe each subtheme.

Table 5.14. Dominant Themes of Couples in the Postnatal Diagnosis Group

Level	Themes	Theme Frequency/Postnatal Couples' Quotes in this Chapter
100	Dominant Theme: Couple's Relationship	108 total segments: All postnatal couples
101	Impact on couple's relationship	17 segments: 6 of 7 postnatal couples Postnatal couple quotes: Jack&Diane, Ann&Eric
102	Roles and responsibilities	20 segments: All postnatal couples Postnatal couple quotes: Sarah&Brandon

103	Decision making	17 segments: All postnatal couples Postnatal couple quotes: Larry, Diane, Junior
104	Challenge for the relationship	17 segments: All postnatal couples Postnatal couple quotes: Brandon&Sarah, Ann&Eric
105	Impact on couple's social life	6 segments: 6 of 7 postnatal couples Postnatal couple quotes: Gayle, Minnie&Junior
106	Sources of support	30 segments: All postnatal couples Postnatal couple quotes: Pam&Paul
200	Dominant theme: About the Experience	41 segments: 6 of 7 postnatal couples
201	Lessons learned	21 segments: 5 of 7 postnatal couples Postnatal couple quotes: Minnie
202	Other reflections	10 segments: 4 of 7 postnatal couples Postnatal couple quotes: Diane, Sarah
300	Dominant Theme: Child's Functioning	43 segments: All postnatal couples
301	Appearance concerns	5 segments: 5 of 7 postnatal couples Postnatal Couple quotes: Diane
302	Social skills	8 segments: All postnatal couples Postnatal couple quotes: Minnie, Sarah
303	Speech	16 segments: All postnatal couples Postnatal couple quotes: Ann, Junior
304	Development	6 Segments: 6 of 7 postnatal couples Postnatal couple quotes: Minnie
400	Dominant Theme: Talking About Cleft	208 segments: All postnatal couples
401	Talking about cleft as a couple	29 segments: All postnatal couples Postnatal couple quotes: Diane, Gayle
402	Talking about cleft as a family	27 segments: All postnatal couples Postnatal couple quotes: Eric, Joey, Minnie
403	Talking to the child about cleft	21 segments: All postnatal couples Postnatal couple quotes: Diane, Pam&Paul
404	Talking about cleft with others	50 segments: All postnatal couples Postnatal couple quotes: Larry, Sarah, Jill
405	Talking with another parent	18 segments: All postnatal couples Postnatal couple quotes: Ann&Eric, Paul

5.10.1 Dominant Theme: the Couple's Relationship

The first dominant theme, *the couple's relationship*, describes the impact that raising a child with cleft had on the couples' relationships. Questions 13, 14, 15, 19, and 24 in my interview guide (Appendix D) asked couples how they negotiated the decision-making process; what were their roles and responsibilities throughout the process; what challenges they went through; the impact of this experience on their social life; and their sources of support. All seven couples described in 108 segments the impact of this experience on their relationship. This dominant theme was then further divided into six subthemes: (1) impact on the couple's relationship, (2) roles and responsibilities, (3) decision making, (4) challenges for the relationship, (5) impact on the couple's social life, and (6) sources of support.

5.10.1.1 Subtheme: Impact on the Couple's Relationship

Six of seven couples described in 17 segments how raising a child with cleft affected their relationships. All couples noted that this process made their relationship stronger and increased their faith in their partnerships. Jill and Larry stated that they learned how to depend on each other because they had more reason to rely on each other, especially during the first year. Their relationship became stronger as a result. Brandon and Sarah also shared that this process made their relationship stronger. Sarah said that she noticed how they were on the same page regarding how to proceed with the cleft treatment without even having a discussion. Similarly, Paul and Pam felt they were able to work well together as a team during this process. Raising a child with cleft made them realize that they could handle more challenges than they thought. Diane and Jack also felt that they could handle more challenges than they had thought and could work together in

the best interests of their daughter. Even if they had disagreements, couples described that having a solid foundation helped them overcome such disagreements and when “things are at their worst, people are at their best.” Diane and Jack talked about the feeding plan they agreed on for their daughter:

Diane: We made a joint decision because her days and nights were flipped and I was about three weeks into pumping and I said to him, “Jack, we either are going to commit to this or we’re going to start feeding her formula.” I want her to have breast milk. If you want her to have breast milk, this is what we’re going to have to do.

Jack: Nothing formal, but we mapped out a little game plan of this is how it’s going to go. Because I mean a lot of commitment, the lion’s share, was on your hand waking up.

Diane: But I couldn’t have done both.

Since coping with the complications their daughter suffered after her surgery, Diane and Jack have had the opportunity to see themselves and their relationship in a positive way. Diane realized that in the initial moments of crisis, both she and Jack felt “useless” to each other. After they had time to process how best to work as a team, they were “fine”.

Similarly, Gayle and Joey thought that the process made their relationship stronger and made them feel more connected to each other. They emphasized that, even though they were not prepared for the cleft, they worked through the process together. Because they could not leave their daughter with strangers because of feeding difficulties, they spent more time as a family with their children, which brought them closer together.

Finally, Ann and Eric agreed that this process made them feel closer to each other, even though they were going through a difficult time in their relationship. They were the only couple in my sample who was not married and who reported being on the verge of separating. However, describing the impact of raising a child with cleft on their relationship, they said;

Ann: It helped our relationship because it just brought us together because there was like a bigger issue than just our own personal issues.

Interviewer: Okay. How did these issues bring you together?

Eric: It's important for me and her to stay civil with each other for our daughter's sake.

5.10.1.2 Subtheme: Roles and Responsibilities

All 7 postnatal couples described roles and responsibilities at the time of birth as well as currently in 20 segments. Couples either tag-teamed, divided up the responsibilities, or had traditional gender roles. At the time of birth, Diane stated that since her daughter was born prematurely and she had a tough labor, Jack was the one who went home and got the house ready. During the initial stages after birth, five fathers were very involved with feeding their children. For example, Joey did the feedings most of the time since his wife did not feel comfortable using the special feeder bottles. Junior became much more involved with feedings once his wife switched to using formula. Two couples stated that they tag-teamed the feedings and child care with their partners. On the other hand, two couples upheld traditional gender roles. Pam stated that Paul took only a couple of days off from work before going back to work, so she was the primary caregiver for their son. Similarly, Sarah took care of their son while Brandon was

working. However, in their case, Sarah did state that she would have liked her husband to be more involved, which made Brandon defensive. They said:

Sarah: I took care of the baby all of the time and my husband didn't change too many diapers or give too many baths. I was constantly with the baby. I got up in the middle of the night all of the time. He slept through the night peacefully and got up for work and went to work in the morning.

Brandon: I worked 12-hour days too, every single day, being self-employed, so it was kind of tough.

As time passed, couples in the postnatal diagnosis group continued to share child-rearing responsibilities or to uphold the traditional gender roles they had at the time of birth. For two couples, the mothers were primarily responsible for taking care of the children during the day; the fathers became more involved in the evenings and on weekends. One couple stated that they tag-teamed taking care of the same responsibilities. For one couple, each partner had specific child-rearing responsibilities. Another couple, Minnie and Junior, disagreed about their roles and responsibilities. Junior stated that they tag-teamed, whereas Minnie said she was the one taking care of the household chores and child rearing, which got overwhelming.

Two couples continued to perform their traditional gender roles for child rearing; the mothers primarily took care of the household chores and child rearing while the fathers provided financially for the family. During the interview, Sarah continued to emphasize that she was still the person responsible for taking care of their son:

So I come home from work and I'm with him and sometimes my husband doesn't get home until eight o'clock at night let's say. And then, you know, it's

bedtime. And then in the morning our son wakes up and then my husband goes to work so he doesn't spend too much time with him. He does and he doesn't.

Brandon asserted that he was the “disciplinary person” in the family and that this was his role in child rearing. He said, “I’m actually the disciplinary person in our family so my son listens when I say things versus not listening when she says things.”

5.10.1.3 Subtheme: Decision Making

All seven couples explained in 17 segments how they made decisions as a couple about parenting and treatment. When discussing how they made decisions about parenting, five couples stated that they had open discussions or debates. One couple said that they usually agreed about approaches to parenting. One couple disagreed about how they decide about parenting.

Paul and Pam stated that when they have disagreements about parenting, they openly discuss it, but Pam makes the final decisions. The remaining four couples said that they debate and make compromises to reach a final decision. For example, Larry said;

Larry: Basically, the same way we did after as far as treatment with the cleft, we just, you know – we each have opinions on things and we disagree. But again, we just come up with a compromise, if that’s the best course, we’ll have an exchange of ideas and then we’ll just do what we think is best and what we’re both comfortable with.

Interviewer: If you are not on the same page, in terms of parenting, who has the last word?

Larry: It varies between us. It’s not like an always one. It’s either one of us in any given situation.

Jack and Diane said that when they disagree, they usually have the same priorities but different perspectives on how to approach things. Diane said,

I want her to go to a French school. He wants her to go to a German school. We both want her to go learn a different language. It's what language is she going to learn. It's like that kind of stuff. It's not like this is going to change the future history of the planet.

Saran and Brandon shared that they are usually on the same page about parenting except for discipline. Brandon finds Sarah "too soft." They acknowledged that it is not their beliefs and priorities about parenting that differ but their parenting styles. In Ann and Eric's case, Ann said that they are usually on the same page about parenting, whereas Eric stated that they debate.

As to decisions about the cleft treatment, four couples said they listen primarily to the doctors and follow their recommendations. The couples noted that they were assigned a doctor at the beginning and felt "comfortable" since s/he never said anything that they disagreed with. Two couples acknowledged that they follow the doctors' advice since they "know the best." Gayle and Joey shared that they "put things in the doctor's hands, God's hands really." Two couples stated that they also do their own research and discuss what they find with the doctors. At times, the doctor introduces different treatment options to couples who then discuss these options both at the doctor's office and at home. At the doctor's office, they have the opportunity to ask additional questions to form a better understanding of the treatment. If they forget, they e mail the nurses their questions when they go home.

Minnie and Junior met with the doctor three times before the surgery to have their questions answered. Junior described the conversations they had with their doctor: “One of the questions was like how she was going to perform the surgery. She drew a picture, so it was like something we were questioning that we got answered before we left.”

Finally, Diane and Jack shared that they discuss “hypothetical scenarios” about possible challenges they could experience during their daughter’s treatment and make plans about how they would approach it. Diane said,

I was flipping out about her height. He was flipping out about her height. We were both flipping out together and it didn’t matter how many times the pediatrician told us to relax about it, we were still freaking out. So we talked to each about well if it’s this, what are we going to do? And if it’s that, what are we going to do?

5.10.1.4 Subtheme: Challenges for the Relationship

All seven couples in the postnatal diagnosis group described in 17 segments the challenges they experienced while raising their children with cleft. Two couples noted that putting their children through the first surgery was stressful and a challenge to their relationship. For Larry and Jill, it was difficult not to take their frustrations out on each other while trying to do the NAM tapings and taking care of their child, who was often agitated because of colic. It was especially challenging when one of them felt that s/he was doing more than the other. Minnie stated that it was difficult for her and Junior to communicate and work together as a team. Feeding their daughter with the special bottles was challenging for Gayle and Junior. Diane and Jack emphasized that letting go of the self-blame and dwelling on what may have caused their daughter’s cleft was difficult for

them at first. For Brandon and Sarah, making sure that the financial resources were in place for their son's treatment was a challenge:

Sarah: I think that at the time of the surgery, we just were not in the same financial situation. My husband was self-employed. I was working, but we were on my insurance and my insurance, even though it was good, it was very expensive to have a family plan on our insurance. I was out on maternity leave for three months and that was very stressful as was having a newborn. I wasn't nursing. We had diapers. We had formula. We had hospital bills; my hospital bills. And then we had my son's hospital bills. That was very challenging.

Sarah: But Brandon, please interject if you would like.

Brandon: No, you're absolutely correct. For us, timing was just completely off.

They explained that, in order to afford the treatment, they had to cut back and make financial adjustments until they paid off the hospital bills. This situation was difficult for their relationship because they got "frustrated quickly over money." For Ann and Eric, driving back and forth to the hospital when their daughter was in the NICU at CHOP was difficult:

Eric: Probably driving back and forth to the hospital.

Ann: I mean, they were long rides, up to one hour.

Interviewer: What was the challenging thing about the rides for your relationship?

Ann: Just because there was like a lot of time to bring up a lot of arguments and stuff like that.

5.10.1.5 Subtheme: Impact on the Couple's Social Life

Six of seven couples in the postnatal diagnosis group described in 6 segments the impact on their social lives of having a child with cleft. Five couples denied that this experience affected their social lives. Gayle and Joey explained that they did not feel comfortable leaving their daughter with anybody else because she stopped breathing several times while being fed. For this reason, they did not want to put the responsibility of taking care of their daughter on anybody else. Because their daughter was not used to her parents not being with her, she threw temper tantrums when they left her with babysitters or other family members. Gayle shared that one time they had to return from their cousin's wedding because she was so distressed. However, even when they were asked how the experience of having a child with cleft impacted their social life, she answered:

I would say no, and to be honest with you, because we're not the type of couple that just goes out, you know what I mean. Like, "Who wants to babysit because we need a night out?" We basically just do things as a family. We sit in and we do movie night, we do snack night, so really as far as us socially going out, we really didn't do that before the kids so it really didn't make any difference to us.

Minnie and Junior, who have two children, disagreed about how their social lives changed. Their daughter, who was born with cleft, has speech delays, which causes her to have temper tantrums because she cannot clearly express herself. Therefore, when asked about the social impact of cleft, Minnie said, "It's definitely more stressful going out because we never really know what they're going to do." According to Junior, the changes in their social lives were not related to having a child with cleft, but having

children in general. He said, “I think having kids in general does impact your social life. The sheer fact that [our daughter] has these issues with the speech and then having had the surgery, I don’t think that really changes anything.”

5.10.1.6 Subtheme: Sources of Support

All seven couples in the postnatal diagnosis group identified in 30 segments their sources of social support. Couples received support primarily from each other, their families, and their friends. For example, Paul and Pam said:

Paul: I guess just being a family, just being there, nothing in particular, you know, like the first surgery my mother-in-law came down with us for the first surgery just to be there with us in the waiting room. The second surgery, I forget who, they took care of the baby for us so we could go down to surgery. So just being there as a family, helping us out logistically with child care and, you know, all that sort of stuff and then just being there.

Pam: Yeah, we have supportive families and we’re very close with both sides of our family.

The remaining six couples also described how both their immediate and extended families have been there for them emotionally and practically, listening when they needed someone to talk to and helping them when they needed assistance taking care of their children. Only Minnie mentioned that her own father understood her “sometimes.”

Four couples described receiving support from each other both emotionally and practically. For example, Diane and Jack negotiated a feeding plan for their daughter. They could rely on each other as a team to care for their children. Four couples identified

their friends as a source of support, especially close friends who have children of the same age.

CHOP was identified as a source of support, because the staff provided team treatment and early intervention information for their children. One mother said that she received support from her psychological counselor and her antidepressants. Another mother described her “Epping Group,” which is a support group for mothers who are exclusively pumping to feed their children, as a source of support. Finally, one mother, Sarah, identified her spirituality as a source of support. She said, “I always remember my mom telling me growing up as a child that God does not give you anything that you cannot handle.”

5.10.2 Dominant Theme: About the Experience

The second dominant theme, *about the experience*, describes couples’ reflections about the experience as they look back on it. When answering questions 12 and 13 in my interview guide (Appendix D), couples talked about the lessons they had learned and the advice they would give to other parents who are raising children born with cleft. Seven couples shared their experiences in 41 segments. Two subthemes emerged: (1) lessons learned and (2) other reflections.

5.10.2.1 Subtheme: Lessons Learned

Five of seven couples described in 21 segments the lessons they learned while raising a child with cleft. Five couples said that this experience taught them to put things into perspective. Larry and Jill realized their main priorities in life, which was being there for their children. For Jack and Diane, stressors such as relocating and buying a new house were not nearly as significant as having a sick child in the PICU. Similar to Jack

and Diane, Junior also realized that the things he used to worry about were minor compared to dealing with health issues in a newborn. Furthermore, three couples shared realizing how much of a minor issue cleft was compared to more severe health problems their child could have been dealing with. The couples stated that they are grateful because it was a “fixable” and “cosmetic” issue.

Couples also shared gaining practical knowledge such as learning about how to work with providers, contacting cleft-related support systems, and finding the best treatment team available. They complimented their CHOP treatment teams. They also advised other parents to make sure to ask that the doctor look not only for cleft lip but also for cleft palate in the ultrasound scans and to give birth in a hospital that has experience caring for a child born with cleft. For example, Minnie and Junior said:

Minnie: Even if the hospital had the bottles there, that would be helpful because it almost takes a day or two just to get them in. In the meantime, your baby’s not having an easy time eating.

Interviewer: Yeah. Is there anything that Junior would add to this?

Junior: No, that was the big thing. But I guess being new parents, your pediatrician knows what they’re doing. When they send you home with what they’ve termed the perfect child and you find out later—The pediatrician also should’ve caught the cleft palate of course.

5.10.2.2 Subtheme: Other Reflections

Four couples shared in 10 segments additional reflections about how this experience affected them. As a couple, they confirmed certain aspects that they discussed during their individual interviews. For example, Diane and Jack discussed the fertility

treatments as a possible cause for the cleft. When Jack shared his doubts about fertility treatment being the cause, Diane acknowledged she obtained that information from reading the literature. However, she emphasized that they got pregnant naturally, not with the fertility treatments, so she thought it could have been caused by the progesterone she took to prevent miscarriage. She also emphasized that she never blamed herself. She said; “Why would I blame myself for anything? It would probably for like getting smashed the day before Mother’s Day because I was so depressed, you know, and thinking was the alcohol – I never thought, oh, it’s his sperm.” Discussing their experiences raising a child with cleft, Diane and Jack shared that the cleft was a focal point in their lives during the initial stages, but not as much anymore. “It’s not there, but it’s always there.” For example, they continue to read articles on cleft palate to “prepare” for the next “thing” that can happen.

Two couples in the postnatal diagnosis sample experienced complications or negative experiences after their children had the first surgery. Jack and Diane shared that they would have liked to have been more informed about the possible complications before the surgery so that they could “prepare for it.” They also questioned themselves and wondered if they should have waited until their child was older to have the first surgery. They did not want to wait because they did not want her to experience speech delays or be negatively affected because she would have been more aware. Junior and Minnie also talked about how their daughter refused to put bottles in her mouth and even drink milk after the first surgery. She started to have difficulties with eating. In contrast, Gayle and Joey stated that their experience was much easier compared to what they read on line about other people’s experiences.

Finally, Sarah said during the couple interview that she felt guilty about giving birth to a child with cleft because her husband is a former model. She stated that she felt guilty because she was the one who carried the child. The couple said:

Sarah: I think that my feelings regarding our son's diagnosis were a little different than my husband's because he took it as, okay, this is what it is and this is how we're going handle it. Me, you know I think I explained this to you earlier, I still feel like I failed the baby. And I also kind of feel like I failed my husband even though, like I was explaining to you, I knew I was pregnant early on, I mean, before it was even confirmed and I did everything I could, you know, to do everything, who knows, every now and then I'll second guess myself like maybe I should have eaten organically. Maybe I should have done this. I don't know. My husband's a former model and then here I am. I give birth to a child who has a cleft lip.

Brandon: He's still our child. He's still [child's name]. He's still the best so there's not going to be any question.

5.10.3 Dominant Theme: Child's Functioning

The third dominant theme, *child's functioning*, describes the couples' opinions about their children's functioning and their views of their children at the time of the interviews. Question 22 in my interview guide (Appendix D) asked couples about their current views about their children's appearance, social functioning, speech problems, and development. All seven couples described their children's current situation in 43 segments. This dominant theme was then divided into four subthemes: (1) concerns about appearance, (2) social skills, (3) speech, and (4) development.

5.10.3.1 Subtheme: Concerns About Appearance

Five of seven couples who received the diagnosis postnatally discussed in five segments whether their children had concerns about their physical appearance. All five couples stated that their children did not have any concerns about their physical appearance, especially because they were very young and had not yet been told about the cleft. Diane said:

I don't even think she understands or comprehends that. She does this with the little skirt, but that's the first evidence that she even is aware of having preferences, like clothing preferences. She fell on her nose last April, last May, almost a year ago. It was a brush burn and it wouldn't heal and wouldn't heal and wouldn't heal, and I was rubbing Vitamin E, and I was rubbing kid's Mederma, and I was like freaking out. She wasn't like knowing that there's something wrong with my nose, like I see that there's a thing on my nose.

5.10.3.2 Subtheme: Social Skills

All seven couples described their children's current social functioning in eight segments. Five couples stated that their children did not have any problems making friends even though they were shy at times. Paul and Pam stated that their son took his time warming up to people when he first met them, especially when he is with his parents. However, he is social at day care and does not have problems making friends. During the interview, Diane emphasized that she did not want to label her daughter as "shy" but shared that her daughter was having difficulty with transitions, especially now as she was transitioning to a higher grade. However, she still has friends in her day care. Also, she is shyer around adults.

Two couples stated that their children have difficulty in social situations. Minnie explained that their daughter sometimes had difficulties playing with other children because she could not express herself clearly because of her speech delays. She tried constantly to hug and kiss other children, which created problems when other children did not want to be kissed. Minnie described the difficulties her daughter was currently going through:

The kids her age she doesn't play well with because she can't talk and express herself very well and she gets physical. Then I've been working with her to stop, but she'll hit and push and pull and kind of beat the other kids up a little bit.

Minnie said that her daughter did better with boys and older children.

Sarah and Brandon did not agree about their son's behavior in social situations. Brandon did not think their son was having any problems making friends but did share that his son was initially shy but then became "your best friend" when he warmed up to you. However, Sarah explained that even though he was doing well socially in his day care, he usually played alone in the playground. She said, "He goes down the slides, and he plays with the balls, and does this and does that, and he's just running around. But he doesn't really engage with other children. But he does do it at times." This behavior was is not a current concern for Sarah but she stated that she was "keeping an eye on it."

5.10.3.3 Subtheme: Speech

All seven couples described their children's current speech development in 16 segments. Four parents said that their children had either received speech therapy in the past, were receiving speech therapy currently, or would do so in the future. Jill and Larry said that their daughter was receiving speech therapy right now, whereas Ann and Eric's

daughter had received speech therapy in the past. When asked about their daughter's speech, Ann said, "I can't really tell now because she's still only three, but her speech therapist said it looks like she'll be fine." At the time of the interview, Gayle and Joey's daughter was receiving speech therapy and had another evaluation. At this most recent evaluation, her level of delay was not severe enough to be eligible for speech therapy services. The couple was happy about the news and stated that they would wait until their daughter turns 3 to take further action.

Minnie and Junior were waiting for the "paperwork to go through" for their daughter to begin speech therapy. They were also trying different ways to encourage their daughter to talk, such as playing the guessing game. Explaining the game, Junior said,

You play the game of when she points at something that she wants, whether it's graham crackers and just a whole bunch of other stuff, grabbing all the other stuff, hoping that she'll say something, I guess, at this point or say yes or no or whatnot.

According to Junior, the guessing game was not effective because their daughter got frustrated that they did not understand her and would hit herself in the face. Minnie said that they are also trying to use sign language with their daughter, but it was not effective because she "picks one sign for everything." The early intervention staff recommended that the couple put their daughter into a school for speech delays. However, Minnie was afraid that their daughter was going to regress further. She wanted her to be in an environment where she would have to push herself to do better. Throughout the interview, Minnie highlighted that their daughter had speech delays, but she was "incredibly intelligent."

5.10.3.4 Subtheme: Development

Six of seven couples described their children's development in six segments. Four couples shared that their children did not currently have any speech or language delays, whereas two couples identified some delays in development. Sarah stated that their son was "taking his time with the potty training." However, the doctor was not concerned because their son was 3.5 years old. Minnie stated that their daughter's developmental delays were more severe before she started receiving early intervention, but she quickly caught up but still has some delays. Describing the current issues, Minnie said,

She definitely chooses to play with things that don't involve talking or interactions like that. She'll pat the doll babies on the back and rock them, but she doesn't make them babble. She doesn't take two dolls and make them babble at each other.

The couple bought more dolls to improve their daughter's play.

5.10.4 Dominant Theme: Talking About Cleft

The fourth dominant theme was *talking about cleft*. Questions 18 and 23 in my interview guide (Appendix D) asked couples to describe how they currently talked about cleft with each other, their family members, their children, and people outside of their families. The couples also shared their opinions about meeting another parent who has a child with cleft. All couples in the postnatal diagnosis group discussed in 146 segments how they currently talked about cleft. This dominant theme was then divided into five subthemes: (1) talking about cleft as a couple, (2) talking about cleft with family, (3)

talking about cleft with their children, (4) talking about cleft with others, and (5) talking about cleft with other parents.

5.10.4.1 Subtheme: Talking About Cleft as a Couple

All seven couples in the postnatal diagnosis group described in 29 segments how they currently talked about cleft. All couples shared that they did not currently talk about cleft as much as they did in the first year. Couples explained that they discussed it if there were upcoming doctor appointments or surgeries and residual problems related to cleft. Additionally, six of seven postnatal couples talked about the possibility of their next child being born with a cleft. In general, couples emphasized that cleft was not a topic of everyday conversation since “it’s not a concern” anymore. Gayle and Joey stated that they were waiting until the next appointment, which would take place when their daughter turned 2.5 years old. Gayle said,

We try not to put ourselves under any stress that doesn’t need to be there, thinking the worst. Like, “Okay, what if this is going to happen,” or “What if she’s going to need this?” It’s basically now just wait until we see the team of specialists and then take it from there.

Couples also talked about the possibility of their children receiving another surgery or how to deal with any residual issues, such as speech delays. Sometimes couples worried about possible problems that could occur in the future. For example, Diane and Jack describe,

But like dental... She didn’t have a cleft palate and a hard palate so we didn’t really have anything concerned about with dental but it was a question that we

asked the dentist. Like we're always curious if something that she's experiencing... if it could lead to something else, you know.

For the couples, cleft was not a "game changer" regarding their decision to have another child. However, it was still a concern. For Paul and Pam, cleft was a concern "at the back of their minds" but did not stop them from having a second child. Yet, they wanted additional testing to rule out a cleft diagnosis for their second baby. Similarly, for Jack and Diane, cleft was a concern for them when they thought about having another child. They noted that now that they were older compared to when they had their daughter, they were nervous about more severe problems that can co-occur with cleft rather than the cleft itself. However, this did not stop them from actively trying to have a second child. Gayle and Joey decided not to have another child for reasons that were not related to worries about cleft. Gayle stated that she had complications during her last labor, so their decision not to have more children was related to her health and their financial situation. The couple stated that they could afford to have another child at this time. When talking about the possibility of their next child being born with cleft, Sarah and Brandon disagreed. Sarah stated that it would be a slight concern for her whereas Brandon said that it would not be any concern for him.

The couples also described talking about cleft when someone asked them about it, when they met other parents who have a child with cleft, when they commented about their child's appearance to each other, or when they saw or read something about cleft. These situations led them to talk about what they have been through and any concerns for the future.

5.10.4.2 Subtheme: Talking About Cleft With Family

All seven couples discussed in 27 segments how they currently talked about cleft with family members. Couples did not often talk about cleft with their families compared to the first year. Eric shared, “We would discuss a lot of stuff when she was first born, but now she’s fine. She’s normal. There’s nothing wrong at all.” They initially had to educate and inform people about their children’s cleft and answer their questions. Furthermore, couples asked their family members if there was anyone born with cleft in their families to determine if there was a genetic link. In the beginning, couples had to explain to their older children about cleft. Three couples had older children. In Gayle and Joey’s case, their older daughter asked them why her sister was born with a cleft. Joey described his answer,

I didn’t have the answers for her. The only answer I could give to my oldest daughter was, the doctor recommended mommy for her to take special medicine, for her to stop smoking and the medicine could have made [daughter’s] mouth not form right.

Jill and Larry stated that, even though their older daughter never asked about it, she was aware that her sister had been through surgeries because “something was wrong with her mouth when she was born.” Similarly, Brandon’s older daughter from his first marriage never asked Saran and Brandon about the cleft. They said;

Sarah: And you know what? When she met her brother, she didn’t see it.

Brandon: Nope.

Sarah: She saw a little baby with perfection.

Brandon: Yep.

Sarah and Brandon also explained that they did not want other children and Brandon's ex-wife to know about their son's cleft because of the negative reactions and comments they could receive.

Family members continued to ask if there were any upcoming surgeries or provided positive comments about the child's appearance. In Jack and Diane's case, family members were very happy that they "finally have a child." The only couple in the postnatal diagnosis group who received negative comments from family members was Minnie and Junior. Minnie talked about how her aunts did not want her to bring her daughter to her grandfather's funeral until "she is fixed." Minnie had to explain that her daughter's cleft was in the palate and was not visible to outsiders. Additionally, she stated that she felt the need to defend her choices to family members regarding putting her daughter in speech therapy. She said:

I guess sometimes when she's having, on both sides of our family, an issue, they'll say, "Oh, is it because of the cleft palate?" or, "Why are you doing that?" On both sides I find with the early intervention and the speech therapy, "Why are you doing that? She'll talk when she's going to talk." Well, because when we were talking with [doctor] she said if she is not meeting her milestones, be aggressive with it, get her the early intervention because sometimes the children do need another surgery because maybe something didn't connect the way it should.

Similar to Minnie and Junior, other families who had children with cleft palate needed to explain to their family members that their children's clefts are not visible.

5.10.4.3 Subtheme: Talking about Cleft with Their Children

All seven couples shared how they currently talked about cleft with their children. Six couples stated that they did not talk about it currently because their children were “too young” to know whereas one couple already talked about it. Three couples described how they planned to tell their children about it in the future. Ann and Eric were thinking about doing it when their daughter is in kindergarten or starting first grade. Jill and Larry were planning to inform their daughter about her future treatment. Diane and Jack were planning to explain to their daughter that she could not nurse because of her cleft and introduce her to the doctors who operated on her. They had videos and pictures of her cleft and the treatment. Diane explained,

We videoed when she was getting better, you know, a couple of days after she was getting better. But, you know, we tried to get a picture. We tried to get a picture of the hole so we could say this is what it looked like and you were repaired. I want her to know and see because it's part of who she is.

They wanted to make sure that their daughter was aware of the cleft when she started school so that she could answer other children's questions.

Sarah and Brandon had different views about whether they should tell their son he was born with a cleft in the future. Sarah believed that they should tell their son in the future whereas Brandon did not want to tell him. He believed that if he knew and explained it to other children, the children would tease his son, causing him to believe there was something wrong with him.

Paul and Pam had similar concerns before they told their son that he was born with cleft. The doctor suggested that they should tell their son before he received his lip

revision. He stated that their son should know a few days before the surgery. It should not be a long time before the surgery to prevent him from dwelling on it or “just before he gets into the car.” Before Paul and Pam told their son, they collected his baby pictures to show him and downloaded a book from the Internet about having cleft surgery. Paul and Pam stated that their son looked at his baby pictures as they explained it to him and pointed at his cleft saying that he had a “boo-boo” on his lip. When asked about their son’s reaction, Paul and Pam said;

Pam: I don’t remember him having a reaction.

Paul: Yeah, he wasn’t really – maybe like a little curious, maybe, just kind of maybe like a little look of kind of puzzlement on his face but that was it. Then it was kind of like, “Good night. See you in the morning.” That whole conversation was probably a lot more stressful on Pam and me than on the baby.

The couple explained that their son was more concerned about the intravenous lines and the needles than about the surgery and the cleft.

5.10.4.4 Subtheme: Talking About Cleft With Others

All seven couples in the postnatal diagnosis group explained in 50 segments how they currently talked to other people outside of their families about cleft. Most couples assumed an educator’s role, letting people know how cleft occurs and how it can affect their child. For example, when asked about how he informed other people about cleft, Larry said,

I just usually tell people there’s a gap in the top of her mouth that runs to her lip, just under her nose and it didn’t fuse together and simple surgery or a series of surgeries to correct it. When I explain it, I just try to keep it as simple as possible.

I don't try to overwhelm people with details and information unless they really want to know.

Similar to Larry, other couples expressed that they usually provided people with basic explanation without going into detail. They highlighted that it was a fixable problem and that the children needed to have surgery.

The couples whose children were born with cleft palate only described explaining to others that their children's clefts were not visible because most people associated cleft with cleft lip, so they often became confused. Junior explained that he usually downplayed the severity of his daughter's cleft by saying that it was only a cleft in the soft palate and that people could not tell just looking at her. Ironically, Brandon downplayed the severity by saying that his son only had a cleft on his lip, not on his palate, so it is "cosmetic" and "superficial." Both Sarah and Brandon explained that they did not freely "offer" people information about their son's cleft unless they are asked about it. Sarah said, "Because we just kind of feel like why? He looks great. Unless they ask, a lot of times we don't offer. To certain people we might but not normally. Am I right about that?" Two couples stressed that they shared more details with people who have children with cleft or who want to know about their experiences. Diane and Jack noted that they felt a "kinship" with other parents who have gone through the same experience.

Couples received a myriad of reactions from outsiders to their children's clefts. Some people were understanding and did not "make a big deal out of it." They shared with outsiders that cleft is fixable. Outsiders commented on their children's appearance by saying they looked "normal" or "perfect" and "you can't even tell." Others, primarily

children, stared and asked intrusive questions, especially before the first surgery. For example, Jill and Larry said, “We got the stares all the time. Everybody who is not too familiar with or just had never seen it in person, or not, I guess expecting – I don’t know. We were used to all the stares. Kids would stare and ask what was wrong with her mouth.” Even though they explained cleft to both adults and children when asked, they sometimes got tired of explaining. Larry described his frustration and shared,

I had no problem talking about it, it just got a little annoying having to always talk about it. It seemed like so many people asked questions, and it’s not their fault. I mean they were curious, but there were times when I almost felt like just let us be. I didn’t feel like I always should have to explain.

5.10.4.5 Subtheme: Talking about Cleft with Other Parents

All seven couples in the postnatal diagnosis group described in 18 segments how they felt about meeting other parents who have a child with cleft. Six couples thought it would be helpful. Couples felt that talking with other parents reduced their feelings of isolation and reminded them that they were not the only ones going through this experience. The other parents were a source of information about what to expect, so they could be better prepared and learn about how to deal with certain difficulties. They could also compare the development of their children with that of the children of other parents. Minnie stated that it would be helpful if the severities were similar, so she would not feel guilty complaining. Junior thought that meeting with another parent was helpful, but parents could also obtain sufficient information from the pamphlets and doctors.

Ann and Eric did not believe that it was necessary to meet with another parent:

Ann: I don't know. I guess it depends on the individual. Maybe they feel like they would want to talk with somebody who's been through it already. I don't know. Maybe if it was like a cleft lip, something more physical, it might be a little bit more traumatizing and the parents would want to see somebody. But I don't think it's anything significant that you would need to seek help or something.

Interviewer: Okay. What about you, Eric? What do you think? Should parents meet with another parent who has had a child born with cleft?

Eric: Yeah, I think if the individual feels they need to, it would be nice for them to get information. But it's all up to the person. It's what they want.

Paul and Pam shared that they already had a friend whose child was born with cleft lip a few years ago. They said,

I mean, fortunately for us, one of my pretty good friends had a child with cleft lip who is about four or five years older than our son. So I remember probably within that first two or three weeks, you know, I spoke with him and my wife spoke with his wife and they sort of gave us their experience, which I found that to be very helpful and kind of put me at ease.

Aside from reducing their anxiety, talking to their friends was helpful because they were able to get the name of their surgeon and other helpful tips such as which hotel they stayed in when they went to Philadelphia for the surgery. Looking at their friend's child, Pam and Paul were able to understand what their son would look like after the surgery. Diane had a friend in her online Epping Group who had a child with cleft and gave her tips about what to expect.

5.11 Postnatal Diagnosis Group, Mothers Versus Fathers: Comparison of Findings

Mothers and fathers in the postnatal diagnosis group shared similar experiences throughout the process of raising a child with cleft. Most fathers were not with their partners when they first received the cleft diagnosis. They then tried to soothe and comfort their partners by framing cleft as a fixable issue even though they were concerned themselves. Mothers were more concerned about feeding and putting their children through surgery when they first heard about the diagnosis and fathers were concerned about social stigma and figuring out the treatment path.

During the initial stages, mothers were recovering from giving birth. They had difficulty not being able to breastfeed and trying to pump their milk. Some mothers were first-time parents so they checked on their children often to make sure that they were healthy. Fathers wanted to make sure that the children were eating “right,” either with the bottles or with the feeding tube. Mothers and fathers had similar thoughts and feelings during the surgery process and currently shared the same concerns. Even though both mothers and fathers identified feeding as a challenge, fathers were more concerned about their children adjusting to the special feeder bottles whereas mothers were more concerned about not being able to breastfeed.

Mothers and fathers had their own ideas around what may have caused their children’s clefts, but two fathers put the responsibility more on the mothers. One father stated that it could be his partner’s “poor eating habits and lack of exercise.” This couple was in the process of separating even though they were still living together. Another father told their older child that the medication that the mother used for quitting smoking caused her sibling’s cleft.

When asked about the lessons they learned from this process, partners identified similar issues such as letting go of self-blame and choosing a hospital that had experience dealing with children born with cleft. Both mothers and fathers described the initial stages as difficult. Fathers highlighted picking a good treatment team and trusting it as well as the importance of checking in with their wives and giving each other night offs as needed. Mothers emphasized the importance of patience. They also advised other parents to insist on getting a 3D ultrasound scan.

More mothers than fathers wanted to know about the diagnosis prenatally. Few mothers and fathers stressed that it would not have caused them to have abortion or abandon their babies. They agreed that they would have been prepared emotionally and financially. One father in the postnatal diagnosis group stated that he would have been prepared financially.

5.12 Member Checking

After the individual and couple interviews were analyzed using content analysis, drafts of the findings of individual and couple interviews were e-mailed to each couple for member checking. I asked study participants the following: (1) if the findings from the individual and couple interviews were accurate descriptions of their experiences; (2) if there was anything missing or inaccurate; and (3) if there was anything that surprised them. Three weeks later, I sent all study participants reminder e-mail stating that if I did not hear from them then I would assume they were comfortable with the findings. Two of the 17 couples, both from the prenatal diagnosis group, responded and noted what an important study this was for them. Mo and Chip stated, “Thanks so much for doing this

study! We enjoyed participating in it.” Rachel and Francis wrote, “We were so glad to be a part of this study. All of this information seems to be very accurate. Thank you.”

CHAPTER 6: DISCUSSION

The purpose of this phenomenological dissertation study was to describe the experiences of mothers and fathers who were caring for a young child (ages 1-4 years) born with CL/P by comparing two diagnosis groups: prenatal and postnatal. Unlike earlier studies that included only one parent (primarily mothers) (Black, Giroto, Chapman, & Oppenheimer, 2009; Johnson, Honein, Hobbs, Rasmussen, & National Birth Defects Prevention Study, 2009; Klein, Pope, Getahun, & Thompson, 2006; Murray et al., 2008; Speltz, Endriga, Fisher, & Mason, 2009) or predominantly mothers (Chuacharoen, Ritthagol, Hunsrisakhun, & Nilmanat, 2009; Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz, & Saal, 2010; Nusbaum *et al.*, 2008; Pelchat, Bisson, Bois & Saucier, 2003), this qualitative study used a dyadic research approach to better understand the experiences of *both mothers and fathers* by exploring how the timing of the cleft diagnosis (prenatal versus postnatal) affected them individually and as a couple

Prior studies of CL/P (Davalbhakta & Hall, 2000; Knapke, Bender, Prows, Schultz, & Saal, 2010; Kramer, Baethge, Sinikovic, & Schliephake, 2008; Kuttengerger, Ohmer, Polska, 2010; Matthew, Cohen, Viglione, & Brown, 1998; Nusbaum *et al.*, 2008; Shaikh, Mercer, Sohan, Kyle, & Soothill, 2001) examined the differences between prenatal and postnatal diagnosis groups of parents at the time of the diagnosis or soon after the child's birth. This study is different because a secondary aim was to determine if the timing of the diagnosis had long-term effects by recruiting parents with offspring born with CL/P who were 1 to 4 years old at the time of the interviews. The BPS approach (Engel, 1977), the Resiliency Model of Family Stress, Adjustment, and

Adaptation (McCubbin & McCubbin, 1993), and transcendental phenomenology (Moustakas, 1994) were used to understand the experiences of a convenience sample of 17 couples (10 prenatal and 7 postnatal) who had previously volunteered for an ongoing longitudinal quantitative study at CHOP (PI: Dr. Canice E. Crerand, Ph.D.).

The following main themes emerged from interviews with the mothers and fathers in the prenatal diagnosis group: (1) prenatal diagnosis, (2) having the baby, (3) initial stages, (4) current situation, and (5) raising a child with cleft. The following main themes emerged from the interviews with mothers and the fathers in the postnatal diagnosis group: (1) postnatal diagnosis, (2) initial stages, (3) current situation, and (4) raising a child with cleft. The following main themes emerged from interviews with the couples in *both* the prenatal and postnatal groups: (1) couple's relationship, (2) child's functioning, (3) talking about cleft, and (4) about the experience.

6.1 Biopsychosocial Approach and Resiliency Model

The BPS approach (Engel, 1977) was influenced by general systems theory (Bertalanffy, 1968) because the main premise is that each system in the body is part of a higher system, starting from a microscopic cell in the body to the larger society that an individual is part of. Therefore, coping with a disease or a disability is a systemic, hierarchical phenomenon that has bidirectional influences on the patient's psychological, relational, and community domains. Engel (1977) proposed this new systemic model as an alternative to the more reductionistic biomedical model and stated that a disease not only comprises somatic, chemical, and physical phenomena but also has behavioral, psychological, social, and cultural dimensions. For this reason, Engel (1977) recommended that providers listen carefully to their patients' stories about the illness and

encourage them to be active collaborators in treatment rather than passive recipients of medical care.

Cleft is a congenital birth defect that begins at the cellular level, forming in utero between the 5th and 12th weeks of embryonic development when the facial tissue forming the face of a fetus does not merge correctly, leading to a defect around the mouth and nose areas. Cleft impacts the functioning of a baby on an individual level (physically and emotionally), often causing difficulties with feeding, hearing, speech, and orthodontic development. It also creates a visible physical difference in the child, often impacting the psychological (self-esteem) and social domains (outsider's reactions, peer relationships). Both the prior literature (Baker, Owens, Stern, & Willmot, 2009; Chuacharoen, Ritthagol, Hunsrisakhun, & Nilmanat, 2009; Johansson & Ringsberg, 2003; Kapp-Simon, 2004; Knapke, Bender, Prows, Schultz, & Saal, 2010; Nelson, O'Leary, & Weinman, 2009; Nusbaum *et al.*, 2008; Pelchat, Bisson, Bois & Saucier, 2003; Pelchat, *et al.*, 1999) and findings from this study suggest that a child's cleft significantly affects the physical, psychological, and social domains of the parents caring for that child.

Because individuals are nested in larger systems such as their families, the diagnosis of cleft in a child can significantly impact parents, especially during the first year when more acute care is needed (e.g., feeding, surgery, and treatment). Most parents in this study also described concerns about reactions from outsiders to their children (social domain) and how in the first few months it was difficult to go out socially because (1) they were concerned about the negative reactions they could experience because of their children's visible difference; (2) they could not trust other people to feed their children because they required special feeder bottles and for some because their child

stopped breathing during feedings. Parents in both the prenatal and postnatal diagnosis groups reported increased level of stress, sadness, worry, and fears about the future. The parents of children in the postnatal diagnosis group described a higher level of stress during the initial stages and more relational distress at the time of the interview compared to parents in the prenatal diagnosis group.

For this reason, it is important for health care providers to regularly screen, partner, engage, and collaborate with parents at diagnosis and throughout treatment to help them cope with challenges with feeding, treatment, and social stigma.

Even though the BPS approach (Engel, 1977) suggests that the treatment team should actively collaborate with families and, in this case, parents, it does not specify what couples need to better adjust to this type of stressor. For this reason, the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) was used to further explain the study findings.

The couples' demographic information, relational distress, and descriptions of their experiences help to elucidate how having a child born with CL/P affected them both individually and relationally. According to the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993), the stressors that couples encounter can be normative or non-normative. Normative/developmental stressors are typical stressors that couples frequently experience such as having a new baby and becoming first-time parents. In contrast, non-normative stressors are not typical for families such as having a child born with cleft. Furthermore, stressors can be isolated, occurring one at a time, or cumulative, occurring collectively. Cumulative stressors increase demands on couples, making the adjustment more challenging. McCubbin and

McCubbin (1993) identified various factors that can affect how an individual, couple, or family adjusts to an external stressor like a baby born with CL/P, such as (1) the family's vulnerability, (2) established patterns of functioning, (3) resistance resources, (4) appraisal of the stressor, and (5) problem-solving and coping strategies.

A couple's vulnerability is determined by considering the existing biological, ecological, social, and psychosocial factors that make a couple more susceptible to stressors. For example, lack of financial resources, preexisting issues in a couple's relationship, or psychological problems in one member of the couple can make a couple more vulnerable to distress.

Established patterns of functioning refer to the existing communication patterns in a couple and the flexibility of the partners in changing their roles and rules when faced with a crisis, such as fathers helping the mothers take care of their babies born with cleft.

Resistance resources refer to sources of support, appraisal of the stressor, and problem-solving and coping strategies. Sources of support can be both social and material, such as having supportive family members who help parents care for their children, having a supportive treatment team, or having a stable job to help couples pay for the expensive treatments.

Appraisal of the stressor describes how a couple perceives that particular stressor. Depending on their views of the stressor, partners may be optimistic and assertive or pessimistic and overwhelmed in dealing with that stressor. Applying this concept to this study, a couple's appraisal of the cleft can affect how they view the experience: Cleft is either a cosmetic issue that is treatable or a life-long issue that will negatively affect their child.

Finally, *problem solving and coping* describe the strategies that a couple uses to cope with a stressor, such as choosing an equipped hospital with an experienced CLP treatment team; being proactive by doing research on cleft; or seeking specialized CLP services. These factors determine if an individual, couple, or family is able to cope and adapt to a stressor, which can either result in *maladjustment* (crisis) or to *bonadjustment* (growth) (McCubbin, McCubbin, Thompson, Han & Allen, 1997; McCubbin & McCubbin, 1993; Williams & Williams, 2005).

6.2 Summary of Main Findings

6.2.1 Comparison of Findings: Mothers in the Prenatal Versus Postnatal Diagnosis Group

In this section, I compare and contrast (1) the social and relational context of the mothers in both diagnosis groups; (2) their experiences over time; and (3) their views about the process of raising a child with cleft palate.

6.2.1.1 Social and Relational Context

The demographic information provided by the mothers in both diagnostic groups helps us better understand their experiences because it provides a social context for their experiences (length of their relationship, ages, and socioeconomic status) and helps us understand resources available to them, individually, relationally, and financially. In the prenatal diagnosis group, the 10 mothers' ages ranged from 32 to 45 years (mean age, 39). Nine of 10 mothers had college or graduate degrees. Seven mothers in the prenatal diagnosis group were employed full time at the time of the interview; one was employed part time; and two were homemakers. One mother reported receiving psychiatric help and two mothers reported previously participating in support groups.

In the postnatal diagnosis group, the ages of the six mothers who returned their demographic surveys (of 7 postnatal mothers interviewed), ranged from 23 to 41 years (mean age, 34.3). Three of six mothers completed college and/or graduate school and two of six mothers were employed full time at the time of the interview. Two mothers were employed part time and two mothers were homemakers. One mother reported receiving psychological and psychiatric help during the last 12 months.

More mothers in the prenatal diagnosis group had higher levels of education and worked full time. Therefore, it is likely that these mothers had more financial resources because they had higher household income. Better financial resources provide the possibility of obtaining additional resources. Frain et al. (2007) suggested that a family's financial resources are an important factor that can help them in a crisis, such as having a baby born with cleft.

Especially during the first year, taking care of a child with cleft is more costly than taking care of an unaffected child. Cassell, Meyer and Daniels (2008) reported that the mean expenditure for a Medicaid-enrolled child with cleft was \$ 22,642 in the first year of life compared to only \$ 3,900 for an unaffected child. For the privately insured population, the difference in health care costs between the cleft and the unaffected children was also large. Between 2000 and 2004, the mean costs for caring for children with cleft younger than age 10 were 8 times higher than those for the unaffected population (Boulet, Grosse, Honein, & Correa-Villasenor, 2009). Furthermore, cleft is a condition that requires multidisciplinary treatment throughout a child's life. In some cases, the treatments are considered not "medically necessary" by some insurance companies. For example, Medicaid coverage of treatments taking place after the first year

is a significant issue for both children and adults with CL/P. Although primary repair services are medically necessary, orthodontic care and permanent dentistry, including braces and other services that improve appearance may not be covered (United Healthcare, 2012). Habal (2001) emphasizes that these regulations impact the affected individuals negatively because they prevent the children's access to regular orthodontic treatment and speech therapy. Children covered by Medicaid have more difficulty obtaining dental care and report less satisfaction with the dental care provided compared to privately insured children. Privately insured children were more likely to receive regular dental check-ups every 6 to 12 months and less likely to be denied treatment compared to publicly insured children (Becker et al, 2009).

The quality of a couple's relationship can also be a resource for mothers who are raising a child with cleft. The RDAS captures the quality of a couple's relationship. When I compared the scores of the mothers in the prenatal and postnatal diagnosis groups, the mean RDAS scores of the prenatal mothers ($\bar{x}=53.6$) was above the cutoff score (healthier), whereas the mean score of postnatal mothers was below it ($\bar{x}=42$). The mean scores for consensus, satisfaction, and cohesion subscales were also above the RDAS cutoff scores for the prenatal group ($\bar{x}= 25.1$; $\bar{x}=16.1$; $\bar{x}=12.4$, respectively) and below the cutoff scores for the postnatal diagnosis group ($\bar{x}= 20.5$, $\bar{x}=12.8$, $\bar{x}= 8.7$, respectively). The mothers in the prenatal diagnosis group reported significantly lower levels of relationship distress. However, it is important to note that relationship distress may not have been caused by raising a child with cleft but may instead describe the couple's established patterns of functioning before this experience or could have resulted from other stressors that couples are currently going through, such as financial problems.

Because the RDAS data were collected at one point in time, one cannot infer any direct causality between the timing of the diagnosis of the cleft and relational distress.

6.2.1.2 Pregnancy, Birth, and Cleft Diagnosis

At the beginning of the interviews, the mothers in the prenatal diagnosis group shared that they had additional testing and ultrasound examinations after receiving the cleft diagnosis to rule out any additional syndromes and to find out more about the severity of their children's clefts. Nelson, Kirk, Caress and Glennly (2012) also described the severity of the cleft as a significant concern for parents whose children were diagnosed prenatally because of limitations in prenatal scanning techniques. For example, one mother screened prenatally had to go through continuous monitoring throughout her pregnancy. Another mother initially received an incorrect diagnosis and received additional testing before she received a definitive diagnosis of an isolated cleft.

According to the BPS approach (Engel, 1977), a cleft diagnosis received prenatally and the additional testing impacted mothers emotionally throughout their pregnancies. The demeanor of the health professional was important at this time. One mother in the prenatal diagnosis group, Mary, stated that the doctor mistakenly diagnosed her baby in utero with trisomy 18 and immediately suggested an abortion without recommending further testing. Her husband recommended that they go to an equipped hospital for a more comprehensive evaluation where the baby was later correctly diagnosed with an isolated CLP. Mary explained that she "could not get out of the bed for 3 days" when she the provider first told her the trisomy 18 diagnosis. Even when the mothers diagnosed prenatally were not given a diagnosis for additional syndromes, they still wanted the birth to come more quickly so that they could meet their children and

better understand the extent of their clefts. They described feeling worried, stressed, and apprehensive throughout their pregnancies until they could see and hold their children for the first time.

Mothers in the postnatal diagnosis group also described stressful events during their pregnancies, such as moving from one house to another, fear of losing their babies, or concerns about their children being born with Down syndrome, but these concerns were not cleft related because their children were diagnosed at birth. The mother who was worried about losing her baby or that the baby would have Down syndrome, Diane, had fertility treatments for 2 years before becoming pregnant. For this reason, she was hypervigilant about her baby's health throughout the pregnancy. Two mothers in the postnatal diagnosis group, Minnie and Sarah, lost their parents either during the pregnancy or shortly after their child's birth, so they had to cope with the additional stressor of taking care of their parent or grieving the loss of their parent while pregnant.

Mothers in the postnatal diagnosis group said that they had ultrasound examinations during their pregnancies but that the clefts were not detected in utero. One mother said that she asked her high-risk specialist for a 3D ultrasound when she was pregnant, but she was "ignored." In the postnatal diagnosis group, four children had CP, two had CL, and one had CLP whereas eight children had CLP and 2 children had CL in the prenatal diagnosis group. Johnson et al. (2009) explained that CLP is more commonly diagnosed in utero than CL or CP. One in three cases (33%) of CLP and one in five cases (20%) of CL are diagnosed in utero whereas only 0.3% of CP cases are diagnosed prenatally.

Household income is another significant predictor; for example, it is more common for families who have household incomes of \$40,000 or more to receive a prenatal diagnosis. This finding is not surprising because families with higher incomes tend to have better access to more sophisticated and expensive prenatal care and prenatal ultrasound technology (Johnson et al., 2009). In a study on the prevalence and experience of receiving a prenatal diagnosis, Robbins et al. (2010) found that having a household income of \$60,000 or more was a significant predictor of having a prenatal diagnosis and that ethnicity and type of insurance were not salient predictors. For this reason, it is possible that couples in the prenatal diagnosis group received the diagnosis prior to birth because, on average, they had higher incomes compared to the postnatal group of couples. Our current health care system may have left the couples in the postnatal diagnosis group at a disadvantage for in utero diagnosis and treatment. Furthermore, the financial burden of treatment may be more significant for the couples in the postnatal diagnosis group, which added to their relational distress.

When they received the cleft diagnosis, mothers in both groups experienced similar feelings: They were happy about finally having a baby but at the same time reported feelings of shock, fear, anxiety, sadness, and self-blame because of the cleft diagnosis. Mixed feelings of happiness, shock, grief, anger, worry, and guilt are commonly reported by mothers at the time of the cleft diagnosis (Johansson & Ringsberg, 2003; Nelson, Kirk, & Glenny, 2012; Nusbaum *et al.*, 2008). In this study, 5 of 10 mothers in the prenatal diagnosis group and 3 of 7 mothers in the postnatal group reported experiencing difficulties conceiving and were happy that they were finally having a baby, regardless of the cleft diagnosis.

One mother in the postnatal diagnosis group was worried that her husband would leave her because she had given birth to a baby with a cleft. She knew that her husband did not marry his former girlfriend because he was concerned about the health issues their children could inherit because of her genetic background. For this reason, this mother was afraid that her husband might leave her after learning about the cleft diagnosis, implying an insecure attachment. This statement illustrates the importance of the preexisting patterns in a couple's relationship that can make a family more vulnerable to maladaptation when a baby is born with cleft (McCubbin, McCubbin, Thompson, Han & Allen, 1997). This finding also highlights the need for the couples to be screened for relational distress before receiving the diagnosis so the mental health professionals can gain a better understanding of the impact of having a child with cleft on the couple's relationship.

At the time of the cleft diagnosis, neither the mothers in the prenatal diagnosis group nor those in the postnatal diagnosis understood what cleft was except for one mother in the prenatal diagnosis group who was born with CLP herself. Mothers in both diagnosis groups wanted to know where to go for help. Because the 17 mothers reported feelings of anxiety and confusion at the time of the diagnosis, it was important for their treatment team to provide accessible information and counseling at this sensitive time. As suggested by the BPS model (Engel, 1980), mothers should receive information not only about the diagnosis but also about the course of treatment. Health care professionals should provide information in a calm and reassuring way, reminding them that the child's cleft is not the mother's fault. Matthew, Cohen, Viglione and Brown (1998) stated that, in

their study, all families who received prenatal counseling after the cleft diagnosis found it helpful, and most of them consulted with a cleft team before their child's birth.

For mothers in the postnatal diagnosis group, Byrnes, Berk, Cooper and Marazita (2003) suggested that health care professionals stay in control of the conversation; show genuine concern; give parents an opportunity to talk and express their feelings; try to comfort the parents; provide more information about the association between clefts, intellectual disability, and learning disabilities; and provide referrals to other parents in similar situations so that they feel less isolated.

In the prenatal diagnosis group, mothers' initial worries were about social stigma, disfigurement, and feeding whereas in the postnatal diagnosis group, mothers were primarily worried about feeding and the first surgery. It is understandable that mothers in the postnatal diagnosis group were first concerned about feeding and surgery because these are the most immediate needs of their children, whereas mothers in the prenatal diagnosis group were more focused on social issues, probably because they had more time to prepare for raising a child born with cleft. Yet, mothers in both diagnosis groups had multiple concerns at the time of the diagnosis, which suggests it is important that the treatment team provide them with psychoeducation and counseling in addition to preparing them for the course of treatment. Kuttenger, Ohmer, and Polska (2006) suggested that counseling should be conducted by a warm, empathic, sensitive provider who is well-informed. They reported that the family's psychological stress was not adequately addressed during the initial consultation. This finding is compatible with the emphasis of the BPS model (Engel, 1980) on the importance of bringing the

couple/family into the initial consultation to help them express their worries and concerns and self-soothe.

More mothers in the prenatal diagnosis group were worried about the severity of the cleft and additional syndromes compared to mothers in the postnatal diagnosis group. This finding is expected because mothers in the postnatal diagnosis group did not have to wait to see the extent of cleft at the time of birth whereas the mothers in the prenatal diagnosis group had months while still pregnant to worry about what their child would look like and the severity of the cleft. Mothers in the postnatal diagnosis groups were able to hold their children at the time of the cleft diagnosis and check out the severity for themselves. Yet, one mother in the postnatal diagnosis group was very anxious while waiting for the results of the genetic testing.

In the postnatal diagnosis group, mothers complained that hospital staff seemed to blame them when they experienced feeding difficulties rather than checking for a possible cause for the problems. Mothers in both diagnosis groups felt more comfortable if their doctors assuaged their concerns by describing the cleft as fixable and telling them they did not do anything wrong. This response is understandable because many couples in this study had fertility treatments and/or miscarriages before finally having their children. For this reason, it was helpful for them to frame cleft as a fixable issue because they had had to cope for a long time with the possibility of not having children.

Mothers in this study confirmed results from prior studies that suggested that the demeanor of the health care professional is very important for their emotional well-being and how they perceive having a child with cleft. McCubbin and McCubbin (1991) similarly suggested that how a family perceives a stressor plays an important role in how

they cope with it. If couples perceive the stressor of CL/P as overwhelming, they can become immobilized and have difficulty moving forward. Mothers in both diagnosis groups said that the demeanor of their doctor while delivering the cleft diagnosis significantly impacted their views of the cleft, reduced their feelings of self-blame, and affected how they coped with it.

Like the experiences of the 17 mothers in this study, Johansson and Ringsberg (2003) suggested that mothers who receive the diagnosis prenatally have more time to prepare and process their initial feelings regarding having a child with cleft. In particular, they have more time to grieve the loss of the perfect child. Nusbaum et al. (2008) stated that parents who get the diagnosis prenatally are able to prepare their family members; learn about feeding issues, surgeries, and the course of treatment; and talk to their treatment team. For example, Frain et al. (2007) described the importance of preparation and being knowledgeable about the course of treatment so parents can better adjust to CL/P. They noted that surprises are the most challenging part of caring for a child with a health problem. For this reason, it is invaluable for couples to be well-informed about the course of treatment so that they can feel more in control. This knowledge acts as a resource for parents, because their fears of the unknown tend to dissipate as they receive more information and feel more empowered regarding options for treatment and expected outcomes. According to McCubbin et al. (1997), having a sense of control can protect families against having a prolonged crisis when faced with a stressor.

Mothers in the prenatal diagnosis group reported feeling more in control compared to postnatal mothers. They reported that they had more time to prepare both practically and emotionally on learning the diagnosis. They were able to process their

initial emotions before the birth, learn about cleft, figure out the course of treatment, obtain the special feeder bottles for feeding, learn to use the NAM device, and have more time to prepare their family members and friends. They joined online support groups and looked at before- and after-surgery pictures of other children born with a cleft. They also showed these pictures to their family members to better prepare them for seeing their babies for the first time. Looking at before- and after-surgery pictures of other children born with cleft has been reported as helpful by parents throughout the literature (Knapke, Bender, Prows, Schultz & Saal, 2010; Matthews, Cohen, Viglione, & Brown, 1998). According to the literature, parents also expressed their need for written information and pamphlets. None of the parents in this study reported this, possibly because of the existence of cleft-specific Web sites and online support groups.

The mothers in the prenatal diagnosis groups were, however, not prepared for some aspects such as actually taking care of the baby, outsiders' reactions, and putting their children through the surgeries. Coping with outsiders' reactions is an important part of prenatal and postnatal mothers' experiences. Most mothers interviewed for this study said they were impacted negatively by people's reactions, especially before their children had their first surgery. Two mothers in the prenatal diagnosis group said that they became more reserved during the initial stages after birth because of the social stigma. Engel (1977, 1980) suggested that coping with a disease or a disability is a systemic and hierarchical phenomenon that has a bidirectional influence on patients' psychological, relational, and community domains. The social stigma that the mothers reported experiencing provides an example of the bidirectional social impact of having a child with cleft.

Mothers in the postnatal diagnosis group did not have time to prepare like the prenatal mothers did. Having a new baby is a normative stressor that many couples go through and have time to prepare for. However, having a child born with cleft is a non-normative stressor that is not typical for families to experience. The mothers in the postnatal diagnosis group had multiple stressors and more demands to manage at the time of birth compared to the mothers who received the diagnosis prenatally. Thus, it is understandable that the mothers in the postnatal diagnosis group did not have time to prepare for taking care of a child with cleft; most stated that they were only prepared for having a new baby. Yet only two of seven mothers in the postnatal diagnosis group specifically stated that they were not prepared for a child born with cleft.

Eight of 10 prenatal mothers said they were with their partners when they received the cleft diagnosis prenatally; the other two mothers had supportive partners who comforted them after the mothers shared the news. The mothers in the prenatal diagnosis group had the opportunity to be with their partners throughout the delivery and after, possibly because the partners were already aware of the child's condition and they did not want to leave their wives alone at the time of birth.

Most mothers in the postnatal diagnosis group were either not with their partners when they learned about the diagnosis or they were too emotional and upset to fully experience their partner's supportive presence at the birth. Two of these mothers delivered earlier than expected; two mothers were with their partners, but they stated that they were so consumed by their feelings of shock, worry, and sadness that they did not feel their partner's presence; and two mothers were already having difficulties in their relationships at the time of birth. Only one mother stated that she felt more secure having

her husband with her at the birth and diagnosis of cleft. Compared to the mothers in the prenatal diagnosis group, mothers in the postnatal diagnosis group had more preexisting challenges and issues in their relationships. For example, one mother in the postnatal diagnosis group, Minnie, who experienced a late cleft diagnosis, stated that her husband “brushed her off” even though she said repeatedly that she was unable to feed her baby and that her baby’s mouth “looks different.” Because of the delayed diagnosis, their baby had to be readmitted to the hospital for failure to thrive.

6.2.1.3 Initial Stages

As in prior studies (Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz, & Saal, 2010; Nusbaum et al., 2008), feeding was a stressor for both groups of mothers during the initial stages after birth. It is important for the treatment team to understand that this is a common stressor and to provide families with emotional and practical support for feeding during the initial stages. For example, Knapke, Bender, Prows, Schultz and Saal (2010) suggested that not being able to breastfeed might be a sensitive issue for some mothers, so health care professionals should be careful when conveying that information.

Mothers in the prenatal diagnosis group initially wanted to try to breastfeed. If they could not do it, then they had to adjust to special feeder bottles as soon as possible and “do it right.” These mothers had more resources to deal with this stressor because they were already aware of the possibility of not being able to breastfeed because of the cleft. Compared to the mothers in the postnatal diagnosis group, they had more time to accept not being able to breastfeed and to learn alternative ways to feed their children.

For example, some of these mothers had already purchased the special feeder bottles before the birth.

The mothers in the postnatal diagnosis group had to process their feelings about not being able to breastfeed their children right after the birth. It was more devastating for them because they did not have the additional time to prepare and were tired from the labor and delivery. Their initial challenge was deciding between pumping and feeding their children breast milk or feeding their children formula. They worried about mother-infant attachment and wanted to give their children “better nutrients” with the breast milk. The pressure to breastfeed and the negative impact of not being able to do so may have been exacerbated by the attitude of the health care professionals in the United States who tend to glorify breastfeeding. Therefore, it is important to consider the societal pressures on mothers to breastfeed. The mothers in the study whose obstetrician/gynecologist did not strongly encourage breastfeeding and the mothers who formula-fed their previous children were not impacted by not being able to breastfeed.

One mother in the postnatal diagnosis group had a difficult time finding the right bottle and formula for her daughter because the daughter had colic and reflux. Another mother in the postnatal diagnosis group was hospitalized for 2 weeks after her daughter’s birth for stress-induced cardiac issues. The health professional’s demeanor was important at this time because mothers who receive the diagnosis postnatally tended to feel more comfortable using formula if their pediatricians did not glorify breastfeeding. Lactation consultants in the treatment teams can help the mothers learn how to pump, how to use the bottle, and which bottle and formula to use. Thus it is important for treatment teams to be wary of their comments because they can negatively impact the psychological

functioning of the mother by increasing her feelings of self-blame. A health professional's demeanor also helps mothers with their perceptions of the problem. As Williams and Williams (2005) suggested, positive problem appraisal can help people better adjust to and cope with a stressor like CL/P.

In both diagnosis groups, there were children who were initially fed with a feeding tube or who had difficulty breathing during the feedings. These situations were especially stressful for the mothers because they worried about their child's life (Chuacharoen, Ritthagol, Hunsrisakhun, & Nilmanat, 2009). Johansson and Ringsberg (2003) stated that pumping can be a challenge because it is very time consuming.

Mothers' concerns about anesthesia and complications before the surgery have been reported in prior studies (Johansson & Ringsberg, 2003; Nelson, Kirk, Caress & Glenny, 2012). Mothers in both diagnosis groups were concerned about anesthesia, complications, and seeing their children in pain. Even though "handing their children over to strangers" was difficult for mothers in both groups, more mothers in the postnatal diagnosis group reported it as a significant challenge, likely because they had less time to mentally prepare themselves for the course of treatment. After the first surgery, mothers in both groups were relieved that it was over, even though it was difficult seeing their children in pain, swollen, and with stitches, intravenous lines, and restraints. Overall, they reported being happy with their child's improved physical appearance.

Three prenatal mothers in the prenatal diagnosis group stated that at first they missed their child's cleft because that was how they first met and bonded with their child. Nelson, Kirk and Glenny (2012) similarly reported that some mothers were ambivalent *before* their child received the first surgery because they had started seeing the cleft as a

unique part of their child but were then happy about the improved physical appearance. However, “missing the children’s clefts after the surgery” was a new finding reported by mothers in this study. In the prenatal diagnosis group, some mothers took pictures of their children before they had the first surgery. After surgery, care was reported as stressful for mothers in both groups. However, two mothers in the postnatal diagnosis group experienced additional unexpected complications after the surgery, which significantly increased their levels of stress.

The BPS approach emphasizes that patients should be active members of the treatment team rather than passive recipients of care (Engel, 1980). The first surgery is a major anticipated stressor for mothers in both diagnosis groups during the initial stages after birth. Thus, it is crucial that the treatment team include mothers when planning the first surgery. Some mothers said that trusting their treatment team helped to reduce their feelings of worry and concern prior to the first surgery. Therefore, it is likely helpful for members of the surgical team to interact with the family in person before the first surgery, to explain the procedure, and to answer their questions. One mother in the postnatal diagnosis group stated that the anesthesiologist himself came to pick up her son for surgery and comforted her. This gesture helped her to better manage her anxiety during the actual surgery. Additionally, the treatment team can prepare the mothers for their child’s postoperative appearance and the recovery period by providing them with information and increasing their sense of control.

6.2.1.4 Current Situation

Mothers in the prenatal diagnosis group did not describe any current significant issues. However, two of the mothers reported minor delays in their children’s speech and

were waiting for their annual evaluations to consider additional speech therapy. One mother stated that her child received early intervention and it helped. Two mothers said that their children are likely to receive orthodontic treatment in the future.

In contrast, three of seven mothers in the postnatal diagnosis group reported that their children currently had significant speech delays and were either in speech therapy or early intervention. Two mothers described delays in their children's speech that led their children to have frequent temper tantrums because they were unable to express themselves clearly. One mother stated that her child currently had ear tubes. Two of three children who were currently experiencing speech and developmental delays were born with cleft palate. Conrad, Richman, Nopoulos and Dailey (2009) suggested that individuals with clefts tend to have lower verbal IQ scores. Among the cleft groups, cleft palate was the diagnosis that impacted the verbal functioning the most.

In this study, the child's current issues were the most significant factor that prevented mothers from adjusting to the stressor. If the child was currently experiencing delays in speech or development, mothers continued to experience ongoing stress. All three mothers in the postnatal diagnosis group used active problem-solving strategies such as bringing in early intervention staff and speech therapy. Baker et al. (2009) stated that having approach-oriented coping strategies such as active problem-solving strategies reduces the impact of cleft on families. They also emphasized the need for an extended family network and ongoing social and financial support. These three mothers reported that an extended family network and financial support were missing in their lives. One mother said that her family criticized her for participating in speech therapy and early intervention, while another postnatal mother said she had ongoing financial struggles and

shared that her daughter would no longer receive speech therapy because her delay was not severe enough to be eligible for free services.

Mothers in both diagnosis groups identified upcoming surgeries as a current concern; however, they were not as worried as they were prior to the first surgery. In the prenatal diagnosis group, mothers were more worried about speech development, orthodontic treatment, and genetic disposition. In the postnatal diagnosis group, mothers were more worried about children gaining weight, speech development, and drooling.

6.2.1.5 Raising a Child With Cleft

Looking back on their experiences, mothers in both diagnosis groups reported that the initial stages after birth were the most challenging and stressful, especially the feedings and deciding about the course of treatment. Pumping breast milk was also a shared stressor for both groups. Mothers in both groups also said feedings took a long time. In the prenatal diagnosis group, one mother talked about teaching other people how to use the special feeder bottles, and another mother described as challenging feeding her child who had colic and reflux.

In the postnatal diagnosis group, it was challenging for mothers to watch the milk/formula coming out of their children's noses and to afford the special feeder bottles, because the bottles are expensive and the postnatal mothers did not have the additional time to prepare. Compared to the prenatal diagnosis group, a higher percentage of mothers in the postnatal diagnosis group reported struggling to afford the ongoing CL/P treatment and care that affected their adjustment.

Putting their children through the first surgery and using the NAM devices were stressors shared by both groups of mothers. Mothers in both groups were worried about

their children going through surgeries at such a young age (approximately 3 months old), side effects from the anesthesia, and seeing their children in pain. Mothers in both groups reported struggling with the NAM device, especially “doing it right.” Mothers in the prenatal diagnosis group also identified the weekly appointments as a challenge. Mothers in both groups described social stigma (outsiders’ reactions to their children) as a significant source of stress. Understanding the specific challenges mothers experience can help to inform the development of interventions discussed in section 6.4.

Five of 10 mothers in the prenatal diagnosis group and four of seven mothers in the postnatal diagnosis group did not know what caused their children’s clefts but had some ideas. For mothers in the prenatal diagnosis group, not taking prenatal vitamins, medication used while pregnant, environmental pesticides, and chromosome deficiency were described as possible causes. In the postnatal diagnosis group, mothers mentioned genetics, medication used during their pregnancies, drinking alcohol, and eating shellfish as possible causes. Four of 10 mothers in the prenatal diagnosis group and two of seven mothers in the postnatal diagnosis group reported feelings of self-blame. Based on the literature, self-blame and wondering about the cause of cleft are common experiences for mothers when they give birth to a child with cleft. Mothers initially searched for a genetic cause. However, when they could not find one, they reflected back on their pregnancies and wondered what they could have done to cause the cleft. Self-blame should be addressed because prior research reports that it has a negative impact on mothers’ emotional well-being and adjustment (Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz, & Saal, 2010; Nusbaum et al. 2008).

As mothers in both groups reflected back on the lessons learned, mothers in the prenatal diagnosis group emphasized that it was helpful to learn about cleft from experienced health care professionals, parents who have been through it themselves, and the Internet. Furthermore, these mothers talked about the importance of keeping things in perspective, categorizing stressors in terms of significance, and letting go of what one cannot control. They reported that being able to observe other children born with cleft at the hospital helped them view the cleft as “fixable.” They also described the importance of choosing an experienced CL/P treatment team whom they could trust and preparing their families *before the birth* to reduce any feelings of shock and surprise.

Mothers in the postnatal diagnosis group also described cleft as a fixable issue and emphasized the importance of learning about cleft. They wanted to let other parents know that there are resources to help them. These mothers additionally advised other parents that they should insist on getting a 3D ultrasound scan during their pregnancies and not blame themselves for the cleft.

Having more knowledge about a stressor brings a sense of control and possibility for adjustment (Frain et al., 2007). When faced with a stressor, the perception of the individual is crucial because it helps to determine how that individual will cope with it. For this reason, McCubbin and McCubbin (1991) described family appraisal as a crucial factor for adjustment. Mothers in both diagnosis groups were able to tap into their own and their partners’ resilience and strength as they learned about cleft and began to perceive it as “fixable” and treatable.

Mothers in both groups whose children were currently not experiencing any difficulties stated that the initial stages were the most difficult. Mothers whose children

were currently experiencing developmental and speech delays (more postnatal mothers in this sample) stated that children with cleft may go through a different journey and parents need to be patient. In the prenatal diagnosis group, mothers said that becoming a parent is a “roll of the dice” because “you don’t know what you will get” whereas in the postnatal diagnosis group, mothers said that once you become a parent, “nothing is about you anymore.”

Mothers in the prenatal diagnosis groups currently described their children as “strong,” “brave,” and “personable” and cleft as “cosmetic” and “fixable.” They acknowledged that “no one would like to have a child born with cleft,” and that it is more common in the United States than they originally believed. In the postnatal diagnosis group, mothers also described the cleft as a “fixable,” “manageable,” and a “minor” issue. One mother said that her child was “beautiful” regardless of the cleft. If their children were not experiencing any current problems, mothers in both groups agreed that cleft was now a small part of their children’s lives.

Even though three mothers in the postnatal diagnosis group stated that receiving the cleft diagnosis in utero increased their worries during their pregnancies, all 10 mothers were happy that they knew about the CLP before the birth, because it gave them more time to prepare both emotionally and practically. Two of these mothers considered termination, spoke about it with their partners, and then decided against it.

Six of seven mothers in the postnatal diagnosis group said they wished they had known about the cleft prenatally so that they could have learned about cleft treatment when they were not recovering from giving birth at the same time. Two mothers from the postnatal diagnosis group stated that they would not have considered aborting their

babies, even if they had known about the cleft diagnosis prenatally. Nusbaum et al. (2008) noted that even though parents stated that prenatal diagnosis improved their levels of stress throughout their pregnancies, none of them considered pregnancy terminations. All 10 mothers in the prenatal diagnosis group stated that they were content with knowing prenatally whereas mothers in the postnatal group reported mixed feelings.

6.2.2 Comparison of Findings: Fathers in the Prenatal Versus Postnatal Diagnosis Group

I first compare and contrast the findings from the fathers in both diagnosis groups as to social and relational context, specific time periods, and their reflections about the process of raising child with cleft palate. The experiences of mothers and fathers in both diagnosis groups were similar, yet they provided a fuller picture of their experiences.

6.2.2.1 Social and Relational Context

In the prenatal diagnosis group, fathers' ages ranged from 30 to 52 years (mean age, 41.20 years). Eight of 10 fathers had college or graduate degrees. All of the fathers were employed full time. None of the fathers in the prenatal diagnosis group reported receiving psychological or psychiatric help during the last 12 months.

In the postnatal diagnosis group, based on the reports of the five fathers who returned their survey packages (out of 7 postnatal fathers interviewed), the fathers' ages ranged from 24 to 43 years (mean age, 34.4 years). Three of five fathers completed college and/or graduate school. Four of five fathers were employed full time. One father was employed part time. Similar to the mothers groups, there were differences between the fathers' education and employment status in the diagnosis group. Fathers in the prenatal diagnosis group likely had higher household incomes because more fathers reported working full time and had higher levels of education. As mentioned earlier,

better financial resources can be a protective factor for prolonged crisis because it can lead to better adjustment and access to resources (Frain et al., 2007; McCubbin, McCubbin, Thompson, Han & Allen, 1997).

The mean RDAS scores of the fathers in the prenatal diagnosis group were in the clinically nondistressed range for the total score ($\bar{x}= 53.2$) as well as for the consensus, satisfaction, and cohesion subscales ($\bar{x}= 24.5$; $\bar{x}=16.1$; $\bar{x}=12.7$ respectively); the fathers in the postnatal diagnosis group were in the clinically distressed range for total score ($\bar{x}= 43.8$) and all 3 subscales ($\bar{x}= 21$; $\bar{x}=13.2$; $\bar{x}=9.6$, respectively). Similar to the mothers, the fathers in the prenatal diagnosis group were more likely to use their partners and relationships as a resource compared to the fathers in the postnatal group, who reported more relationship distress.

6.2.2.2 Pregnancy, Birth, and Cleft Diagnosis

The descriptions of the fathers from both diagnosis groups of their experiences raising a child with cleft contain differences and similarities. All 10 husbands in the prenatal group stated that they were with their wives when they first received the cleft diagnosis at the ultrasound appointment even though two prenatal mothers said that their husbands were not with them at the time of the diagnosis; perhaps these two fathers felt guilty for not being there. Eight of 10 prenatal fathers received the diagnosis during the ultrasound visit, and one father received a possible trisomy 18 diagnosis in addition to the cleft diagnosis. It was later confirmed that his child only had an isolated cleft lip palate and did not have trisomy 18. The remaining two prenatal fathers had to wait or have additional ultrasound examinations to receive a definitive cleft diagnosis.

In the postnatal diagnosis group, three of seven fathers received the diagnosis right after the birth, and four fathers received the cleft diagnosis 1 day later. One of seven postnatal fathers reported that his wife called him whereas the rest of the fathers said the doctor told them directly.

Fathers in both diagnosis groups reported experiencing feelings of anxiety, worry, sadness, and shock. In the postnatal group, fathers questioned what they might have done wrong to cause the cleft. This finding was surprising because fathers experiencing self-blame has not been reported in previous studies. Prior literature primarily reported mothers feeling guilt about their child's cleft diagnosis and searching for possible causes (Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz, & Saal, 2010; Nusbaum et al. 2008). These findings suggest that hospital staff should attend to fathers and ask about their feelings to address their views about the possible causes of cleft.

Fathers in the prenatal group stated that the cleft diagnosis turned a joyous occasion into a deflating one, confirming the psychological impact of a medical diagnosis in a child for fathers (Engel, 1977). These fathers' initial worries were about the severity of the cleft and co-occurring syndromes. After going through additional testing and ultrasound scans, most fathers in the prenatal diagnosis group were relieved. A few fathers continued to worry until the birth. Most research studies have been conducted with mothers, whose initial concerns focus on feeding (Johansson & Ringsberg, 2003; Knapke, Bender, Prows, Schultz, & Saal, 2010; Nusbaum et al., 2008). In contrast, most of fathers in the prenatal diagnosis group were concerned about the severity of their child's cleft and additional syndromes.

Most fathers in the postnatal group did not know what cleft was when they first received the cleft diagnosis. When working with families who are coping with a health issue in their children, health care professionals should keep in mind that the fear of the unknown is the most challenging stressor. It is essential that treatment teams provide sufficient knowledge about the health issue and the expected course of treatment. Being informed is an important resource for families throughout the process (Williams & Williams, 2005). Hospital staff more often includes the mothers when sharing information about cleft and the course of treatment, especially in the maternity ward. According to the findings, it is also important to provide the same information to the fathers in person. In fact, some fathers reported that when they found out more about cleft, they were able to see the silver lining, such as finally having a child, the cleft being fixable, and, for some, the palate not being involved. One father in the postnatal diagnosis group talked about knowing that God was watching over his son. The ability of the fathers to reframe this stressor and to see the silver lining in the cleft diagnosis adds to the body of literature on cleft. McCubbin and McCubbin (1993) also suggested that using spirituality as a resource and having a more optimistic perception of the stressor lead to better coping and adjustment.

At the time of the cleft diagnosis, the most common concerns for prenatal fathers were (1) social stigma, (2) appearance, (3) cleft severity, and (4) co-occurring syndromes. At the time of birth, they were primarily concerned about (1) feeding, (2) physical appearance, and (3) social stigma. For the postnatal diagnosis group, the most common concerns at the birth were (1) social stigma and (2) the treatment plan. These differences were expected because, similar to the mothers, fathers in the postnatal diagnosis group

focused more on the immediate concerns at the time of birth. The fact that fathers reported worrying about the social impact of having a child with cleft at the time of the diagnosis is an important indicator of the social impact of an illness. As stated earlier, Engel (1980) emphasized that an illness may start at a cellular level, but it becomes part of a much bigger system, including the community.

Nine of 10 prenatal fathers assumed the role of comforter for their wives at the time of the diagnosis. In the postnatal diagnosis group, only three of seven fathers stated that they tried to be strong and give their wives support at the time of diagnosis. One father in the postnatal diagnosis group who was on the verge of separating from his partner said that it was his “duty” to be there. Another postnatal father was with his wife, but he did not mention acting as a support system for his wife, and his wife stated that her husband was “clinging onto his mother” and leaving her alone throughout the process. This couple was already vulnerable to dysfunction at the time of the diagnosis because they could not serve as a support system for each other. Two of seven fathers who received the news postnatally stated that they were not with their wives at the time of the diagnosis (at the birth) because their children arrived earlier than anticipated.

Fathers in the prenatal diagnosis group reported that the prenatal diagnosis took away the pure joy of telling others about their babies and increased their levels of stress because (1) they did not know what cleft was and had to prepare themselves for the worst-case scenario because the doctor was unable to provide more definitive answers in some cases; and (2) they were tired of answering questions about cleft and preparing people. According to the few studies with fathers, they did report preparing themselves for the worst-case scenario while parents in general were tired of answering questions

about their children's clefts (Nelson, Kirk, Caress & Glenny, 2012; Nusbaum *et al.* 2008). Fathers' descriptions of the two sources of stress they had at the time of the diagnosis indicate what treatment teams should attend to during the initial counseling sessions with parents. In addition to providing information about the cleft and the course of treatment, treatment teams can provide helpful techniques to deal with outsider reactions.

Nusbaum *et al.* (2008) explained that a prenatal diagnosis can give parents time to inform their families and other people about their child's cleft diagnosis. Similarly, fathers in the prenatal diagnosis group stated that they had more time to prepare and inform their families about the cleft diagnosis before the birth. In fact, they took on the role of educator and showed pictures of children born with cleft to their close friends and family members. They also encouraged their families to do their own research about cleft. Similar to Johansson and Ringsberg (2003)'s findings on mothers' experiences, some of the reactions they received from family members were upsetting for the prenatal fathers, such as being scared when shown pictures of other babies with clefts or people showing pity toward them about the cleft, which bothered them.

At the time of birth, like the mothers in the prenatal diagnosis group, the fathers felt more prepared compared to the fathers in the postnatal diagnosis group because they had time to learn about how to care for a child with cleft and the expected course of treatment. They had a chance to ask their doctors many questions and to talk to other parents who had children born with cleft. They were also able to buy the special feeder bottles ahead of time and prepare the nursery. Emotionally, they had more time to process their initial feelings and prepare themselves to "see" a baby with cleft. A few fathers in

the prenatal diagnosis group stated that they were able to prepare themselves for the worst-case scenario. However, they were not prepared for a difficult labor or stress in the household right after the birth or for how their lives would change after having children. Even though having a new baby is a normative stressor (Williams & Williams, 2005), prenatal fathers explained that they were not prepared for all of the challenges that come with having a new child born with cleft. They might have been ready to become a parent conceptually, but they did not fully know what they were getting into.

All fathers in the postnatal group explained that they were ready to have children at the time of birth both emotionally and financially. However, two of seven of these fathers stated that they were not ready to care for a baby with cleft and that it significantly impacted them emotionally, practically, and financially. One father specifically stated that “things started going downhill” after the cleft diagnosis.

6.2.2.3 Initial Stages

Fathers in the prenatal diagnosis group described feelings of happiness and joy during the initial stages after the birth. They said that their bodily instincts of being a father immediately kicked in. They monitored their children’s feedings and helped with the NAM tapings. The fathers who became a parent for the first time also stated that they had to learn how to be a father. It was enjoyable for them to get to know and “rediscover themselves” in their children. One father explained that it was a unique experience seeing aspects of himself coming out in his child.

Fathers in the postnatal diagnosis group initially had to figure out how to care for their children and understand the course of treatment for CL/P. They stated that the initial stages after birth were difficult until they adjusted to caring for a child with cleft and

planned the course of treatment. For this reason, their reported stress levels were higher than those of the fathers in the prenatal diagnosis group. Frain et al. (2007) stated that stress in the initial stages when adjusting to any illness or disability is expected; however, anxiety and stress can eventually fade away with time and coping with the stressor.

Similar to fathers in the prenatal diagnosis group, those in the postnatal diagnosis group wanted to make sure their children were eating enough and gaining weight. They struggled initially if the hospital did not have the special feeder bottles, if the child had to be fed with a tube, or if they could not find the right formula for their child. Additionally, they reported that doing the tapings for the NAM device was difficult.

Before the first surgery, like the prenatal and postnatal mothers, fathers in both groups worried about side effects from the anesthesia, outcome of the surgery, and the children being in pain after surgery. Fathers in the postnatal diagnosis group were also concerned about complications whereas the fathers in the prenatal group were more worried about the psychological impact of the surgery on their child. Nelson et al. (2012) pointed out that parents are in the difficult position of being excited about the surgical outcome and at the same time worrying about the possible complications and impact of the surgery on the child. After the surgery, it was difficult for fathers in both groups to see their children with stitches, in pain, bloody, and swollen. They were, however, happy with the outcome. One father in the prenatal group reported missing his child's cleft. This finding is new, which is surprising, because most mothers and fathers wanted the cleft "fixed" as soon as possible, and they waited for the outcome with anticipation.

The treatment team can use this time to be a resource for the parents. They can explain to parents what to expect before and after the surgery, for example, possible

complications, the child's postoperative appearance, and the recovery period. It is helpful if this information is provided to both parents both in writing and in person. This information can help to soothe parents' anxiety and make them feel more in control. Because surgery is one of the most significant concerns for parents, it is also important for them to have realistic expectations about the process.

Three of seven fathers in the postnatal diagnosis group reported that their children had complications after their first surgeries, which they said was especially challenging for them. One father expressed that all his worries about the child's social functioning "went out the window" when his child's life was at stake. The fathers in the postnatal diagnosis group also noted positive changes in their children after the surgery. For example, one child started to suck better and stopped throwing up during the feedings.

6.2.2.4 Current Situation

Fathers in the prenatal diagnosis group reported having the following worries at the time of the interview: (1) social stigma and (2) upcoming treatments. They were worried that their children would experience bullying because of their visible facial differences. They reported that their children would likely have additional cosmetic surgeries, and they were concerned about the pain they would experience after these operations. Nelson, Kirk, Caress and Glenny (2012) stated that, even though parents wanted their children to go through all the treatment procedures, they were ambivalent about the child receiving additional surgeries. Although the surgeries can improve children's visible differences and prevent them from being stigmatized by their peers, parents worried about the treatments causing their children further discomfort and

distress. The parents also reported worrying that, as their children got older, they were more likely to be aware of the pain and the surgery process in general.

The fathers in the postnatal diagnosis group reported concerns about speech, social stigma, upcoming treatments, and development. Three of seven children in the postnatal diagnosis group were currently in speech therapy, and two children had significant speech delays so that fathers had to play the “guessing game,” in which they tried to guess what the children wanted by asking them to point at it or pointing it out for them. One stated that he tried to point to other things even though he knew that his daughter was not asking for it, hoping that she would be frustrated enough to say the word. Instead, his daughter had temper tantrums and started hitting herself. The father explained that he was not sure if the speech delay was caused by the cleft or by the psychological impact of going through surgery because his daughter’s speech regressed significantly after her surgery. This father’s confusion about the cause of his daughter’s speech delay emphasizes the importance of including a mental health professional in the cleft treatment team.

One of the children in the postnatal diagnosis group will need surgery on her chin when she grows older, and her father was very concerned about the pain. Another father was concerned about the current height and weight of his child, because she was low on the growth charts. The children’s ongoing difficulties prevented some of the fathers from moving on to the adjustment phase. The couples whose children were having ongoing difficulties with speech and development also had lower RDAS scores. A new contribution to the literature is the fact that fathers in both diagnosis groups were

concerned about their next child having a cleft even though this concern was not a “game changer” in their decision to have more children.

6.2.2.5 Raising a Child With Cleft

Fathers in both diagnosis groups described the first months after birth as the most challenging and stressful, especially the feeding and treatment. The fathers in the postnatal diagnosis group reported that using the special feeder bottles and the feeding tube was challenging; adjusting to feeding with the NAM device was a challenge for fathers in both diagnosis groups. Fathers in both groups identified the surgery and the NAM device as sources of stress. Mothers and fathers in both diagnosis groups described the NAM device as a significant stressor during the treatment process. They also stated that it helped improve the outcome of the surgery. For this reason, it would be helpful to provide parents with more information about the NAM device and the possible challenges that can occur while using it, such as skin infections. Such information could help parents better prepare for the upcoming challenges and help them understand how to deal with possible challenges while using the NAM device.

Surgery was reported as stressful for the fathers in the prenatal diagnosis group because they worried about the outcome and about seeing their children in pain. In contrast, fathers in the postnatal group worried more about surgical complications. Furthermore, fear of the unknown, finding the best treatment team, picking a surgeon, and introducing the child to their family members were challenging for the fathers in the prenatal diagnosis group, and outsider reactions were reported as the most challenging for the fathers in the postnatal diagnosis group. It is possible that having the “best” treatment team was a source of hope for the fathers in the prenatal diagnosis group. More fathers in

the postnatal diagnosis group were first at hospitals that were not equipped for treatment of cleft, which is a necessary factor for adjustment. As stated previously, it is crucial that the treatment team provide the fathers with techniques for dealing with outsider reactions.

The fathers in the prenatal diagnosis group reported that soothing their own feelings of anxiety about what the future may bring and comforting people about their children's development and functioning were the two challenges they faced.. Even though their children were currently functioning well overall, some fathers still worried about challenges their children might face in the future. They also had to answer outsider's questions about their children's functioning.

Fathers in the postnatal diagnosis group stated that dealing with their children's current developmental and speech delays gave them the greatest stress. In this study, fathers reported anxiety and distress because of their fear of the unknown, regardless of their children's current functioning; fathers whose children were experiencing delays in development and speech reported more current stress. It would be helpful for the members of the treatment team to assess the anxiety and stress levels of fathers as indicated and refer them to individual, family, or group therapy.

Most fathers in both diagnosis groups did not know what caused their children's clefts. However, fathers in both groups had some ideas. Fathers in the prenatal diagnosis group suggested race, medication used, lack of folic acid, not taking prenatal vitamins, genetics, and older maternal age as possible factors. Three couples in the prenatal diagnosis group were biracial. Two fathers and one mother were Asian. Both fathers said that their Asian race could be a cause for cleft. The husband of the Asian mother stated that his wife's epilepsy medication and possibly her race could be factors. When asked if

he held her responsible for the cleft, the husband stated that if she did not take the medication, it would be more dangerous for both her and the child, so he did not blame her for the cleft.

According to fathers in the postnatal diagnosis group, cleft could be caused by their partner's poor eating habits and lack of exercise, position of the umbilical cord in utero, medication used, genetics, and bad luck. One father in the postnatal diagnosis group seem to attribute blame to his partner in an obvious manner. However, it is important to remind the reader that this couple was on the verge of a separation at the time of the interview. Another father in the postnatal diagnosis group stated that he told his other daughter that the doctor recommended a medication for her mother to take, which caused her sister's cleft. Even though he put the obvious blame on the doctor, it is possible that he holds his wife partly responsible for the cleft.

Two of seven fathers in the postnatal diagnosis group reported feelings of self-blame. One father felt guilty because they were going through fertility treatments and he believed that the treatment was the cause of cleft. Another father said; "What did we do wrong that could have caused it?" In both cases, fathers seemed to experience concerns about how their own behavior could have caused the cleft. However, it is possible that they placed more of the responsibility on their wives because they were the ones who carried the children. During the initial meeting with couples, the treatment team should clearly state that there is no definitive cause for cleft and reduce any feelings of self-blame. Furthermore, fathers overtly or covertly placing blame on mothers is not adaptive either for the couple's relationship or the emotional well-being of the mother. It is crucial to explore this dynamic with all couples. Placing blame could be indicative of their

established patterns of functioning, and couples who demonstrate this dynamic could benefit from a couple's support group.

Fathers in both diagnosis groups viewed the cleft as a cosmetic and fixable issue. They believed that cleft was treatable in the United States, which demonstrates their positive appraisal of the problem and of the US health care system. They emphasized that it did not change their love for their children.

Fathers in both groups emphasized the importance of choosing a hospital equipped to handle the birth of a child with cleft, exploring different treatment options, picking a good treatment team, trusting the treatment team, and listening to the doctors. Fathers in both groups said that their treatment teams were a significant resource. They explained that part of why they felt comfortable with their treatment team was because team members had warm, empathic approaches. One father said that the team had a "holistic" approach, addressing the challenges they face both medically and psychologically. Another father valued that they could address the team members by their first names and did not feel that they were "just a number." Fathers' descriptions confirm what was proposed by the BPS approach (Engel, 1980), that health care teams should address the different domains of the illness (e.g., biological, psychological, and social), not just the biomedical. Fathers in both groups agreed that the first months after birth were the hardest but that overall it became easier over time.

Fathers in the prenatal diagnosis group described the feedings and the first surgery as the two most salient challenges and emphasized that ultrasound scans can be misleading. Fathers were grateful that cleft was a fixable, cosmetic issue. Throughout this experience, they learned the importance of patience and that nothing is "perfect" once

one becomes a parent. Questioning perfection is a common experience for the parents in this study, especially after they first grieved the “loss of the perfect child” and started to perceive the issue differently.

Fathers in the postnatal diagnosis group described the importance of finding a good support system. They learned that cleft is a process that requires patience and ongoing treatment. This realization was important because most fathers said that patience was a characteristic that they needed to learn. At this challenging time, they developed their inner strength and coped by learning how to be patient. Their experiences are an important example of the growth that can take place after a sudden crisis like postnatal diagnosis of cleft.

Even though the prenatal diagnosis increased the worry and stress in fathers during the pregnancy, they were able to prepare emotionally, practically, and financially compared to the postnatal fathers. They had additional testing, researched, learned about cleft, and saw pictures of other children born with cleft. One father even prepared himself for the “worst-case scenario.” Yet prenatal fathers described that it was difficult knowing ahead of time that “it” was coming and that they could not stop it. Parents in other studies also said that they preferred to know about the diagnosis prenatally, even though it increased their levels of stress during the pregnancy (Davalbhakta & Hall, 2000; Matthew, Cohen, Viglione & Brown, 1998; Nusbaum et al., 2008)

In contrast, only two of seven fathers who found out about the diagnosis at birth stated that they wished they had known about the cleft prenatally so they could have had more time to prepare. They could have chosen a different hospital and prepared themselves financially. It is likely that these two fathers felt that a prenatal diagnosis

would have given them the chance to arrange their finances and decreased their level of stress both at the time of birth and during the initial stages. Three of seven fathers in the postnatal diagnosis group said that it would not have made a difference if they had known ahead of time. Two fathers said that they would not have aborted the babies if they had known about the diagnosis prenatally. Two fathers said that they preferred not knowing ahead of time because they would have started to worry much earlier.

6.2.3 Comparison of Findings: Couples in the Prenatal Versus Postnatal Diagnosis Group

In this section, I compare the relational context of the couples in both groups; compare and contrast the experiences of couples in the two diagnosis groups; and compare their descriptions of how raising a child with cleft impacted their relationship and the lessons they learned throughout the process. In the couple interviews, the parents confirmed points that they had discussed in their individual interviews. Couple interviews also provided an opportunity to better understand their relational dynamics and to triangulate the individual interviews.

6.2.3.1 Relational Context

All 10 couples in the prenatal diagnosis group and five of seven in the postnatal diagnosis group returned their surveys. All prenatal couples were married and living together, whereas six of the seven postnatal couples were married and living together. One couple in the postnatal diagnosis group did not return their surveys, but I concluded that they were married since the CHOP database indicated that they shared the same last name. Another couple in the postnatal diagnosis group reported that they were living together but were on the verge of breaking up. The relationship length of couples in the prenatal diagnosis group ranged from 6.30 to 25 years (mean, 11.41 years). They were

married for 3.75 years to 18.5 years. The length of the relationships of couples in the postnatal diagnosis group ranged from 5 to 18.5 years (mean, 11.06 years). On average, couples in both diagnosis groups had similar relationship lengths. In the prenatal diagnosis group, half of the couples had one child and half had two. In the postnatal diagnosis group, four couples had two children and three had one child. All couples had only one child born with cleft.

There was a statistically significant difference between the RDAS total scores of couples in the two different diagnosis groups. Couples in the prenatal group had higher (better) scores on all subscales as well as the total score. The average couple RDAS score as well as the subscale scores for the prenatal diagnosis group was above the total cutoff score. The average couple score and the subscale scores for the postnatal diagnosis group was below the cutoff score, which indicates that, on average, couples in the postnatal diagnosis group were clinically distressed in their relationship. Because the couples in the prenatal diagnosis group had on average higher levels of relationship satisfaction, it is possible that they could better use their relationship as a source of support and had healthier patterns of functioning at the time of the interviews.

6.2.3.2 Roles and Responsibilities

All 10 fathers in the prenatal diagnosis group initially stayed home after the birth but returned to work within 2 weeks on average. One father did not work for the first 3 months because he was a teacher and the schools were closed. The mothers in the prenatal diagnosis group were the primary caregivers: They fed the children, did the NAM tapings, and made the appointments. Eight of the fathers in the prenatal diagnosis group helped when they were at home in the evenings and on the weekends. Couples in

the prenatal diagnosis group either tag-teamed or had specific responsibilities in terms of child rearing. Yet, in most cases, fathers in the prenatal diagnosis group were the sources of emotional support and provided financially for the family.

Two couples in the prenatal diagnosis group held more traditional roles: The mothers took care of the children and did the household chores; the fathers provided financially for the family. Even though all fathers in the prenatal diagnosis group worked during the day and all of the mothers in the prenatal diagnosis group were the primary caregivers, all mothers in the prenatal diagnosis group stated that their husbands were with them when they needed them, especially during the surgeries and the doctors' appointments. These mothers reported viewing their husbands as a source of support during this experience, which likely decreased their vulnerability to relationship stress. Similarly, Pelchat, Bisson, Bois and Saucier (2003) suggested that marital stress of couples who are raising a child with cleft is significantly associated with fathers' sensitivity toward their children with cleft.

In the postnatal diagnosis group, five of seven couples either tag-teamed or divided the responsibilities. More fathers than mothers in the postnatal diagnosis group were working, so the fathers contributed to child rearing when they were at home. Furthermore, two couples in the postnatal group held more traditional gender roles. However, in contrast to those in the prenatal diagnosis group, two mothers in the postnatal diagnosis group stated that they felt resentful toward their husbands for not being as involved in the child rearing and household chores. In one case, the couple's relationship had been in distress before they had their child, so they were confronted with the cleft-related stressor when their relationship was already vulnerable. The mother in

this couple had the lowest RDAS score in the study, and the father's score was in the distressed range. In another interview, a mother in the postnatal diagnosis group shared that she was resentful toward her husband because he did not help her take care of the baby during the initial stages. She stated that he did not currently help her. During the couple interview, the father became defensive and described a lack of adequate financial resources during the initial stages after birth. He said that he was changing careers at the time of the birth and was trying to provide financially for the family. Additionally, he criticized the mother's child rearing by stating that she was not strict enough.

This dynamic is an example of the stress that a lack of adequate financial resources can have on a couple caring for a baby born with cleft, which can affect how couples cope with the stressor. Furthermore, this interaction between the couple was surprising because they had expressed that this experience had impacted their relationship positively; they were on the same page about how to cope with it even though the mother's RDAS score was in the distressed range. It is possible that they experienced ongoing conflicts regarding child rearing and division of responsibilities but agreed on the course of cleft treatment for their child. Nevertheless, their way of criticizing each other in front of me suggested some preexisting relational patterns that could negatively affect how they coped with a child diagnosed postnatally with cleft.

6.2.3.3 Decision Making

Couples in the prenatal diagnosis group stated that they listened to their doctors' advice when making decisions about the treatment. Together, they evaluated the different options for treatment such as the NAM device or the timing of the first surgery by having open discussions and asking their doctors lots of questions. One couple in the prenatal

group said they had already been given a course of treatment before the birth, so they just followed it. Another prenatal couple stated that they investigated different courses of treatment and asked their doctors lots of questions.

In the postnatal diagnosis group, couples also reported listening to their doctors. They stated that they felt comfortable with their doctors; therefore, it was easy for them to follow their advice. When they met with the doctors, they asked lots of questions and would then discuss what they heard with each other either at the doctor's office or at home. At times, they e-mailed the nurses additional questions. One couple discussed hypothetical scenarios about future problems and planned how they would respond together as a couple. This couple described being constantly hypervigilant about the future, hypothesizing about possible challenges and making plans about how to overcome them. They wanted to be proactive about problem solving and have a plan with the solution, even before the problem occurred. For them, having a plan made them feel more in control of the situation and prevented them from experiencing a crisis. Their hypervigilance could be in reaction to receiving the diagnosis postnatally; they may have been determined to prepare themselves for the next unexpected crisis.

The fact that couples in both diagnosis groups stated that they listened to their doctors when making decisions about the treatment is a good example of how using a BPS approach (Engel, 1980) is crucial. During their interviews, couples often described the comfort they felt working with their treatment team because of their responsiveness. For them, the treatment team was a support system that they used throughout this experience. The demeanor of the members in the treatment team was described as an important resource for couples in the postnatal diagnosis group because they did not have

the same opportunity to prepare as the prenatal couples did and needed more guidance and support during the initial stages.

Couples in both groups said they openly negotiated the best parenting approach for their child. One couple in the prenatal diagnosis group discussed hypothetical scenarios beforehand and planned how they would respond. Another couple said they tried different parenting strategies to see what worked. Two couples stated that they were in agreement about parenting whereas one stated that they picked their battles.

In the postnatal diagnosis group, couples discussed, debated, and made compromises. One father said that he was the “disciplinary person” in the family because his wife was not firm enough. Another couple disagreed about how they made decisions: The mother said they were on the same page most of the time but the father said they debated. A mother in the postnatal diagnosis group explained that it was hard for them to make decisions about parenting as a couple because her husband’s mother constantly interfered in their child rearing and made decisions for them, ignoring her comments. The mother shared that her husband sided with his mother, leaving her feeling alone and not supported by her husband. These two postnatal couples’ statements describing how they made decisions about parenting captured their established patterns of functioning. These results were not surprising because one of these couples and one postnatal mother scored within the distressed range on their RDAS measures.

6.2.3.4 Challenges

Couples in both groups reported experiencing challenges. For the couples in the prenatal diagnosis group, deciding whether to have amniocentesis to find out about co-occurring syndromes and considering the possibility of an abortion were initial

challenges. Nusbaum et al. (2008) reported that none of the parents in their study considered abortion after learning about the diagnosis prenatally. However, in this study, two couples in the prenatal diagnosis group described having “frank” conversations about the possibility of having an abortion. Davalbhakta and Hall (2000) stated that two parents in their study considered abortion when they first heard about the cleft diagnosis but changed their minds after receiving information about cleft.

The couples in the prenatal diagnosis group stated that the cleft diagnosis took the “pure joy” out of the pregnancy period. Furthermore, the medical diagnosis impacted their individual and relational functioning at times when taking care of their children. Sometimes it was difficult keeping their emotions regulated. When their children were born, pumping breast milk and using the NAM devices were additional challenges for couples in the prenatal diagnosis group. Pumping was difficult for the mothers and seeing their wives stressed was challenging for the fathers. Using the NAM device caused stress in the couples’ relationships when the child’s skin was irritated and they still had to continue the tapings. Each partner in both diagnosis groups had different ideas regarding how to do the tapings. One couple in the prenatal diagnosis group stated that the only time they argued during this time was when each partner liked a different treatment team. One couple in the prenatal diagnosis group stated that they did not experience any challenges raising a child with cleft.

In the postnatal diagnosis group, couples also stated that putting their children through surgery and using the NAM devices were challenging. Using the NAM device was difficult because they were trying to do the tapings “right.” Similar to the prenatal couples, one couple in the postnatal diagnosis group expressed that they had a difficult

time deciding on what to do when their child had a skin infection due to NAM. Surgery was hard, especially when their children had complications after the surgery. Like the couples in the prenatal diagnosis group, feeding was a challenge for couples in the postnatal diagnosis group, especially because they had to adjust quickly to the special feeder bottles. Additionally, two postnatal mothers decided to pump their milk and feed it to their children, which was challenging. Seeing their wives stressed about the pumping was difficult for the fathers.

Once their wives switched to feeding their children formula, the fathers in the postnatal diagnosis group were able to help more. Feeding became even more challenging for these couples if the child had colic because of the additional stressor. One couple explained that it was difficult for them not to take the frustrations they felt toward their child out on each other when their child was constantly crying and had difficulty eating because of the colic. One postnatal couple said that letting go of their self-blame regarding what caused the cleft was difficult. One mother in the postnatal diagnosis group reported feelings of self-blame “giving birth to a child with cleft lip” because her husband was a model. Because self-blame, feeding, surgery, and using the NAM are common stressors that parents faced both individually and as couples when caring for a child with cleft, it is important for treatment teams to design interventions for helping the couples through these challenges. Another couple described that working as a team and communicating became a challenge because they were already experiencing problems in their relationship before the cleft diagnosis, but having a child with cleft was an additional stressor. As stated before, their preexisting patterns of functioning made them more susceptible to issues when faced with an additional stressor.

6.2.3.5 Impact on Social Life

When discussing the impact of having a child with cleft on their social lives, four couples in the prenatal group and one parent in the postnatal group said that having children negatively impacted their social life rather than the cleft itself. In fact, most couples in both groups stated that cleft by itself did not negatively impact their social lives.

One parent in the postnatal diagnosis group mentioned that it was difficult to go out with her child because she has temper tantrums because of her speech delay. One couple in the postnatal diagnosis group said that they were hesitant to leave their daughter with anyone because she had stopped breathing a couple of times during the feedings. Their daughter got used to having her parents with her all the time so she has temper tantrums once they leave. There were times they had to return from an outing because their daughter was crying uncontrollably. However, they denied that this impacted their social life because they did not go out often before having a child with cleft. Even though this couple stated that having a child with cleft did not impact their social life, it is possible that the cleft condition created stressors related to feeding and development that prevented the couple from socializing. Benson, Gross, Messer, Kellum, and Passmore (1991) reported that parents of children with craniofacial anomalies tend to underreport their children's difficulties. It is probable this couple is underreporting the impact on their social lives of having a child with cleft.

Some couples in the prenatal diagnosis group, however, did describe the negative impact of having a child with cleft had on their social lives. They discussed receiving negative reactions from outsiders, including questions and stares, which made them

hesitant to take their babies out in public. They also did not want to leave their babies at home because other people did not know how to feed their children or do the tapings for the NAM device. One mother stated that she did not want to join new-moms' groups because she did not think that mothers who did not have a child born with cleft could relate to her experiences. One prenatal couple described her friends disappearing during their pregnancy because they did not know how to react to the cleft diagnosis. However, they also established new friendships with people who were supportive during this process. Investigating the quality of life in families of children with cleft, Kramer, Baethge, Sinikovic and Schliephake (2007) found that parents whose children were diagnosed prenatally experienced more social impact, probably because they had to cope with people's reactions both during their pregnancies and after birth. Furthermore, because more children with cleft lip are diagnosed prenatally than children with cleft palate, the parents experience a higher social impact because their children's clefts are visible.

Couples in the postnatal diagnosis group who have children with CL and CLP also mentioned negative reactions from outsiders, especially children, including questions, intrusive comments, and stares. One mother emphasized that she resented the comments and the stares whereas another mother noticed them but trained herself not to care. One father said that he was tired of answering questions about his child's cleft and wished that people would "let them be." Four children in the postnatal diagnosis group were born with CP; therefore, their clefts were not visible. In most cases, outsiders did not realize that the children were born with clefts. However, the family of one couple asked the mother not to bring her child to an event until she was "fixed." The mother had

to explain that her child's cleft is in the palate so it is not visible. Additionally, she described her and her husband's family as being critical of her for bringing in early intervention staff to help her child with the speech delays. The family members expressed that early intervention was not necessary and the child "will talk eventually." These experiences highlight this mother's lack of family support, making her more vulnerable to psychological distress (Baker, Owens, Stern & Willmot, 2009).

Parents in previous studies have similarly stated that they experienced negative reactions from their friends, families, and people in public, which made them conceal their children's clefts or withdraw socially (Johansson & Ringsberg, 2003; Nelson, Kirk, Glenny and Caress, 2012). Throughout this study, parents described social stigmatization mostly from the public, both individually and as a couple. Social stigmatization is another important area to address during initial counseling.

6.2.3.6 Sources of Support

Couples in both diagnosis groups identified each other, their friends, and families as sources of support. The couples in the prenatal diagnosis group said that they supported each other by having open conversations about cleft, attending doctors' appointments together, hugging each other, and giving each other respite. Similarly, couples in the postnatal diagnosis group talked about helping each other when caring for their children, checking in with each other, and giving each other respite as needed. The family members of the couples in the prenatal diagnosis group supported them by learning how to feed their children and by providing tips on parenting.

The couples in the postnatal diagnosis group said their family members supported them by coming to help at the time of the surgery and with child care. Couples in both

diagnosis groups received support from their friends, especially if they had children who were the same age. Additionally, couples in the prenatal diagnosis group received support from their co-workers, church, neighbors, work place, doctors, hospital, and cleft-related Web sites. One parent in the postnatal diagnosis group stated feeling supported by her spirituality. Another parent mentioned her counselor and antidepressant as her support systems.

Overall, couples in the prenatal diagnosis group identified more sources of support than the couples in the postnatal diagnosis group. McCubbin, McCubbin, Thompson, Han and Allen (1997) identified community support, friendship support, neighborhood support, intrafamily mutual support, sense of control, and spouse commitment to the lifestyle of the work/occupation as the sources of support that Caucasian families use that protect them against crisis. Couples in the prenatal diagnosis group had more resources because they were able to inform their friends, neighbors, and co-workers of their children's clefts before the children were born and received primarily positive reactions.

6.2.3.7 Children's Current Functioning

Couples in the prenatal diagnosis group did not report any significant current issues in their children's social functioning, development, or speech. Two of 10 couples said their children were shy around strangers but that attending day care helped them to become more social. Three of 10 prenatal couples reported minor issues with speech development in terms of pronunciation and putting words together. One couple had called in early intervention speech counselors and the child's speech had improved. One couple

explained that their child was developmentally advanced whereas two couples said that their children were smaller in height and weight compared to other children.

More couples in the postnatal diagnosis group reported current problems with their children's functioning. Four of seven children diagnosed postnatally had current speech problems, and two children were in speech therapy at the time of the interview. One child was going to start speech therapy soon. Two children had significant speech delays, so they used sign language or their parents tried to understand what they were trying to say from their gestures. The children diagnosed postnatally had temper tantrums because they were not able to express themselves. Speech delays also caused one child to have problems in social functioning because she struggled communicating with peers. One mother said that her son usually preferred to play alone. One child in the group diagnosed postnatally was receiving early intervention and another child had problems with toilet training at the age of 3.

Raising a child who was experiencing ongoing difficulties was a significant source of stress for couples. If their children were developmentally on track, couples stated that the cleft was currently on the back burner, but if the child was still experiencing issues, the couples actively tried to work on it such as arranging early intervention for speech problems. According to Baker, Owens, Stern and Willmot (2009), using active problem solving to cope with stressors is associated with greater adjustment. Yet, dealing with residual issues was a determinant of ongoing stress in the family. Parents in this study reported similar experiences both in their individual and couple interviews. As stated in the BPS model (Engel, 1980), ongoing health issues and disabilities in their children continue to affect a couple psychologically and socially.

Additionally, these issues increase the pileup of demands on a couple, which in return can increase their relational distress.

Couples in both diagnosis groups stated that their children were too young to have concerns about their appearance. However, prior studies suggest that children with craniofacial anomalies do develop appearance concerns as they grow older because of bullying at school (Bemmels et al., 2013; Nelson, Kirk, Caress & Glenney, 2012).

6.2.3.8 Talking About Cleft

Couples in both groups reported that, at the time of the interviews, they no longer spent much time talking about the cleft unless there was an upcoming doctor's appointment or surgical procedure. They also described how to resolve cleft-related residual issues, such as speech problems. Couples in the prenatal diagnosis group said that they discussed positive developments in their children's functioning, such as how well his/her speech was coming along. They also discussed the subject when they had to choose a new treatment team because they were moving to a new place. In the postnatal diagnosis group, couples either discussed hypothetical situations that could arise because of the cleft or talked about their experiences, what they have been through, and their fears and concerns for the future. They also discussed how they could solve the residual issues such as speech delays. This dynamic between the couple complements the suggestions of the BPS model, because the disability in their children impacted the parents' relationship and taught them to use open communication as a resource.

Couples in both diagnosis groups no longer talked about cleft as often with their families. They discussed it more in the beginning because they were trying to adjust to the new stressor. As Frain et al. (2007) noted, families reported experiencing anxiety and

stress for the first year. Couples in both groups explained the cleft to older siblings, and all couples reported being concerned about their future children being born with cleft but it was not a “game changer.” Some of the couples who did have another child had additional testing to rule out cleft. In the prenatal diagnosis group, couples talked to their families about cleft when family members checked in after the children’s surgeries or when they commented on their children’s appearance.

None of the couples in the prenatal diagnosis group had talked to their children about the cleft because they were “too young,” though two of the families gave hints to their children about their cleft-related scars. Most of the couples planned to share the cleft diagnosis with their children when they are older and better able to understand. One couple stated that they did not plan to say anything until their child asks them questions about it. Another couple planned to first get advice from a child life specialist before talking to their child. Two parents were hesitant to talk about it with their children because they did not want their children to think that there is something wrong with them. Because the timing of this discussion is a concern for some parents, members of the treatment team should provide sufficient information to families on the best ways to inform children about their condition. How the discussion is handled is especially important as children grow older and become more aware of the surgeries and treatments.

Most couples (6 of 7) in the postnatal diagnosis group had not yet told their children about the cleft because they were “too young.” However, most of these couples planned to tell their children when they were old enough by either explaining the course of treatment or showing them videos and pictures of themselves. One parent was hesitant to tell his child and one couple had already shared the cleft diagnosis with their child

before he had his cosmetic revision surgery. The child's reaction was not as intense as the parents had imagined. He was mostly concerned about the intravenous line and the needle rather than the surgery itself. Because the concerns of the parents and the children differ before the surgery, it is important to identify the family as the patient because the health issue has an impact on multiple systems including the family. Furthermore, it is also important to consider the child's age when designing interventions.

Couples in both diagnosis groups talked about cleft with people outside of their families when they first shared the diagnosis with them. For those in the prenatal diagnosis group, it was not helpful if their friends downplayed the significance of the issue by saying that cleft was fixable. They agreed that having to share the cleft diagnosis during the pregnancy "took the winds out of their sails." If they received positive reactions from people, it became much easier to tell others. Some parents in both diagnosis groups stated that they downplayed the severity of the cleft when talking to other people, which signified that the fear of social stigma was an ongoing stressor for the couples.

All couples except for one in the postnatal diagnosis group stated that they are open about explaining their children's condition to other people. Because four couples in the postnatal diagnosis group had children born with cleft palate, they had to explain and educate other people that their children's clefts were not visible. One couple whose child was born with cleft lip stated that they did not offer the information unless somebody asks. One couple in the postnatal diagnosis group whose child was born with CLP said that they were open about answering people's questions, but they got tired of constantly having to explain the cleft to people and answer their questions.

Most couples in both diagnosis groups reported that talking with another parent who had a child born with cleft was helpful in reducing feelings of isolation, learning what to expect, and getting advice on how to handle challenges, all of which serve as emotional and practical resources, making the parents feel more in control. Prior studies also documented parents' desire to connect with other parents raising a child with cleft (Knapke, Bender, Prows, Schultz, & Saal, 2010; Nusbaum *et al.* 2008). A few couples explained that they would like to meet with another parent who has a child with cleft if the severities of the children's cleft were similar. A few couples said that it was not a must to meet with another parent since they were already able to obtain information from the doctors, online groups, and informational pamphlets. Couples in the prenatal diagnosis group stated that meeting with another parent would be helpful in getting reassurance from other parents that their children "will be fine," providing them with hope, which is a significant resource for adjustment. In the postnatal diagnosis group, couples thought it would be helpful to compare the development and functioning of the children because delays in development and speech were the common stressors in the postnatal group.

6.2.4 How the Timing of the Diagnosis Affected the Couple's Relationship

Even though the RDAS scores of the couples showed significant differences, couples in both diagnosis groups agreed that, overall, the experience of raising a child with cleft made their relationship stronger and increased their faith in their partnerships. They were able to work together and to support each other.

In the prenatal diagnosis group, 2 of 10 couples explained that this was the biggest challenge they had been through and that they overcame it without turning

against each other. One couple was happy that they were able to improve their communication while under stress. Two couples explained that that they were on the same page regarding how to proceed with treatment, which made their adjustment easier. In four of 10 prenatal couples, fathers provided emotional support for the mothers, and the mothers supported the fathers by doing research on cleft, sharing what they learned, figuring out the treatment approach, and scheduling the medical appointments. Some mothers described their husbands as their “*rock*” during this time, the person who was always there for them during the emotionally challenging times. Nine couples in the prenatal diagnosis group stated that if they were able to get through this as a couple they could “get through anything.”

Even though the couples in the postnatal diagnosis group also stated that this experience made their relationship stronger, there were differences in how they described their relationship. One couple, Ann and Eric, were on the verge of separating at the time of the interview. They did state that this experience actually brought them closer together because they had to put their issues aside and focus on the well-being of their daughter. This response suggests that this couple did have issues before having their child with cleft and that, even though this experience impacted them positively, it did not resolve their preexisting relational issues. However, they were able to cope with the stressor regardless of the vulnerability of their relationship at the time. During their interview, they explained that raising a child with cleft was only different for them during the initial stages after birth when their daughter was in the NICU at CHOP for 3 weeks. They agreed that the only part that was different from any other child was the feeding since she had to be fed with a tube. They did not perceive cleft as an overwhelming stressor, which

could be a protective factor for them in this experience. Yet, they were in the process of separating at the time of the interview, which would explain their low RDAS scores.

Another mother from the postnatal diagnosis group stated in her individual interview that she and her husband were experiencing problems before the birth, but “cleft brought everything out” and exacerbated their problems. Additionally, their daughter had speech and developmental delays at the time of the interview. This couple was the only one in the postnatal diagnosis group who did not state that this experience made their relationship stronger. During their couple interview, the mother stated that working as a team and communicating were the challenges she experienced in their relationship during this process. The father did state that other stressors seemed minor compared to having a child with speech delays. Their statements were significant because they were at a vulnerable stage in their relationship and had exhibited dysfunctional patterns of functioning even before having a child with cleft.

Another couple stated that this experience made their relationship stronger and helped them become a team even though their RDAS scores were in the distressed range. Yet, they had difficulty arranging the interview because each partner worked at different times of the day. The mother explained that it was difficult to arrange a couple interview because they worked different shifts and focused on child care once they were at home together. Therefore, I wondered if this was a factor impacting the cohesion in their relationship. I also wondered if socioeconomic status could be another factor because they had fewer material resources.

Another couple in the postnatal diagnosis group stated that they were usually in agreement regarding their child’s treatment. However, they had a heated discussion

during the interview about the husband not contributing to the house chores, and they did not seem to be in agreement about telling their child about his cleft. Only the mother returned her relational distress measure in this study, and her RDAS score was in the distress range.

Another couple in the postnatal diagnosis group stated that they had fertility treatments for 2 years before having a child and that it was challenging for their relationship. The wife identified this experience as “when things are at their worst, people are at their best.” Additionally, the husband was working in a different state and commuting 6 hours a day. The couple was on the verge of relocation during the interview, and the wife stated that not having him home during the week was challenging for their relationship.

I believe that it is important to consider the additional stressors outside of the cleft that could impact the couple’s RDAS scores. As stated previously, most couples were not struggling at the time of the interviews unless their children had ongoing delays in speech and development. Therefore, it is likely that couples in the postnatal diagnosis group were experiencing relationship distress because of their children’s delays in speech and development rather than because of the timing of the diagnosis. It is necessary for health professionals to understand the couple’s social context, existence of cumulative stressors, established patterns of functioning, and as current stressors to have a better explanation for their relational distress.

6.2.5 How Couples Adapted Over Time and Lessons Learned

When describing their adjustment to having a child with cleft, couples in both diagnosis groups said that they relied on their sources of support, increased their control

over the situation by learning about the cleft and its treatment, and changed their appraisal of the stressor by keeping things in perspective.

Couples in the postnatal diagnosis group did not have as much time as the couples in the prenatal group to research and learn about cleft. However, they still shared the importance of finding the right treatment team, learning how to work with the providers, and finding the best treatment team available. For them, gaining knowledge about the treatment path and finding a treatment team they could trust acted as resources against the stressor. Additionally, they stated that they came to frame cleft as a “fixable” and “cosmetic” issue. As their appraisal of the stressor changed, they felt more empowered to cope with upcoming challenges. One couple described having a different perspective about everyday stressors because they do not “compare to having a sick child in the PICU.”

One couple in the postnatal diagnosis group had severe ongoing stress in their relationship. The mother had the lowest RDAS score in the postnatal diagnosis group. During the interview, the father said that he had developed a different perspective on the struggles he experienced in life whereas the mother stated that she did not learn anything new about her relationship. This statement signified the existence of stressors in their relationship prior to having a child with cleft. This couple advised other parents to ask the doctor to look for a cleft palate in addition to the cleft lip and to find a hospital equipped to handle a child with cleft. For this mother, the demeanor of the hospital staff was traumatizing since they blamed her for not being able to feed her child and discharged her without diagnosing the cleft. This fact underlines the importance of the BPS approach to patient care.

Parents in the prenatal diagnosis group also highlighted the importance of gaining control over the stressor by trying to learn the extent of the cleft and the existence of additional syndromes before birth. They also described doing research and learning about cleft. Yet, one couple learned to “stay off the WebMD” because it increased their anxiety at times. They decided to ask their doctor instead. All of the couples were happy that they received the diagnosis prenatally because it gave them an opportunity to grieve the loss of the perfect child, learn about cleft, and develop a treatment plan. At the time of birth, they felt in control of the situation and had the resources to deal with the stressor. Some couples even described the process of raising a child with cleft as a “good experience.” Similar to the postnatal diagnosis group, the couples in the prenatal group perceived cleft as a “cosmetic” and “manageable” problem, especially compared to the other significant health problems they saw children having. For them, seeing the other children at the hospital changed the appraisal of the problem and put things into perspective. Additionally, one couple highlighted the value of being able to communicate under stress because it allowed them to be a source of support for one another.

6.3 Contributions to CLP Research

Studies conducted with parents of children who are born with cleft have primarily included individual parents (mothers) in their samples. This phenomenological study filled a major research gap by eliciting detailed, first-person descriptions about how couples experienced prenatal or postnatal diagnosis of their children with CLP. Additionally, this study included multiple perspectives from both mothers and fathers to expand our understanding of the relational effects of having a baby born with CLP. The findings help us understand how couples cope with cleft by describing the similarities

and differences between the experiences of mothers and fathers. The results indicated that mothers and fathers have similar experiences, even though some differences emerged, for example, mothers reported more stress about feeding and fathers often acted as a source of emotional support for mothers. Most couples said that the experience of raising a child with cleft impacted their relationship positively even though there were significant differences between their RDAS scores. This finding indicates that couple and family researchers should assess a couple's established patterns of functioning before they started raising a child with cleft.

This research study also compared the experiences of couples who are raising a child with cleft in relation to the timing of the diagnosis. Even though couples in the postnatal diagnosis group reported slightly more stress at the time of birth and during the initial stages, couples in both diagnosis groups adjusted to raising a child with cleft if the child no longer had ongoing issues. In this study, three children in the postnatal diagnosis group still had speech delays whereas none of the children in the prenatal diagnosis group had delays in functioning. This difference might be due to the fact that more children in the postnatal diagnosis group were diagnosed with cleft palate because more children with cleft palate suffer from delays in verbal functioning (Conrad, Richman, Nopoulos & Dailey, 2009).

Furthermore, this research study is one of the first to examine the family resiliency factors that can contribute to a couple's ability to cope with cleft. The findings suggest that a couple's vulnerability, established patterns of functioning, resources, and problem appraisal are important factors contributing to their adjustment. This observation

could act as a pathway for other clinicians who aim to investigate the factors that contribute to family adjustment and adaptation.

6.4 Clinical Implications

The findings of this study have clinical implications for pediatricians, obstetricians, gynecologists, and the treatment teams in pediatric reconstructive surgery units of hospitals as well as for mental health professionals who work with children and families coping with cleft. The descriptions of couples raising a child with cleft suggest that, regardless of timing of the diagnosis, the initial stages after the diagnosis and birth are the most challenging periods for parents and for some, beyond that time period, if their children have ongoing developmental delays. Parents' experiences highlight the importance of the demeanor of the health care professional when first delivering the CLP diagnosis, because how parents perceive the issue later determines their approach for coping and problem solving.

The initial information session conducted with parents of children diagnosed with cleft at the time of the diagnosis should include information describing what cleft entails. The session should include both parents because fathers described being anxious and stressed at the time of the diagnosis and because couples said they encountered challenges because of lack of information about the course of treatment.

The health care professional should inform couples about the course of treatment, how to do the tapings for the NAM device, surgeries, and how to do the feedings. The couples should have the option of contacting other parents to reduce their feelings of isolation and to provide an additional source of support. The health care professional

should also reduce any self-blame for the cleft, especially among mothers, but also for the fathers.

Health care professionals should be wary about suggesting abortion too quickly when first delivering the CLP diagnosis prenatally. It is important to recommend further testing to identify the extent of the cleft and the existence of co-occurring syndromes before presenting abortion as an option. Health care professionals should deliver the diagnosis and the possible prognosis in detail, allowing the families to process the information and evaluate their options.

Because many of the couples reported high levels of anxiety and stress at the time of the diagnosis, it might be difficult for the health care professional to contain the couples' anxiety and deliver all of the necessary information. Medical professionals should develop guidelines for how to deliver the initial diagnosis and conduct information sessions without overwhelming couples and being more attuned to their stress levels. If they follow this guide, they can more effectively inform couples about cleft, the course of treatment, the prognosis, and how to care for their children over time. It should also include information around the specific concerns that parents have, depending on the timing of the diagnosis. These guidelines can assist health care professionals to be more attuned and sensitive to couples' stress and anxiety when delivering the information.

This study also provides a better understanding the specific concerns parents have, depending on the timing of the diagnosis. Couples who received the information prenatally had time to process their initial feelings and educate themselves about cleft and the course of treatment before their babies were born. For this reason, these couples felt

more prepared to care for their children. In comparison, the parents in the postnatal diagnosis group suddenly faced feelings of shock and confusion at the birth of their child. Hospital staff and treatment teams should be prepared to help couples based on the timing of the cleft diagnosis. Providers in the maternity ward can provide relevant information related to ongoing care, and the mental health professionals can help to lessen the parents' anxiety so they can better hear and understand the information provided. The mental health professionals should meet more often with parents who were informed of the diagnosis postnatally because they will likely need more assistance to process their initial feelings.

Mothers who received the diagnosis prenatally reported being concerned primarily about the social stigma and feeding, whereas the fathers who received the information prenatally reported more concerns about the severity of the cleft, the possibility of co-occurring syndromes, and social stigma. Mothers in the postnatal diagnosis group were most concerned about feeding and the first surgery whereas fathers in the same group were most worried about the treatment and social stigma. Furthermore, couples who had children with cleft lip were naturally more worried about social stigma than couples who had children with cleft palate. It is important for treatment teams to provide information, referrals, and counseling for couples designed to meet their specific concerns. Social stigma is a frequently expressed concern for the parents of children with cleft lip, both at the time of birth and as their children prepare to enter primary school. The mental health professional in the treatment team can inform the parents about ways of coping with social stigma toward themselves and their children. Furthermore, the

mental health professional can educate the parents on how to behave toward their children to help them deal with social stigma in the future.

At the time of the diagnosis, it is highly recommended that couples be referred to a meeting with the mental health professional on staff so they can be screened for preexisting individual and relational distress. It is important to assess the couple's level of vulnerability, existing patterns of functioning, resources, problem-solving mechanisms, and appraisal of the stressor to help them better adjust to raising a baby born with cleft, as suggested by the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993). Identifying existing resources and problem-solving mechanisms can help the couples to realize their own strengths and instill them with hope. Exploring the couples' resources would also help them to mobilize the already existing resources they have, such as family and social support. The parents who have preexisting distress should be referred for individual, group, or couples' counseling to manage their stress and anxiety and to learn how to support each other during this process.

Couples could be referred to a couples' support group to improve their relationship and to help them become a resource for one another during this stressful time. The couples who had existing conflicts and high relational distress before their children's diagnosis or birth may be in need of interventions more targeted to improving their romantic relationship. This could be a vital period for the couple to come together and work as a team, even if they were experiencing problems prior to the cleft diagnosis. The "Hold Me Tight" (HMT) Couple Intervention Program (Johnson, 2009) is a type of support group that couples can benefit from at this time.

Emotionally Focused Therapy (EFT) (Johnson & Greenberg, 1985) guided the development of the “Hold Me Tight” (HMT) program. This structured, short-term (8 sessions) program was developed to help couples repair and enrich their relationship in a small-group setting. The eight sessions include reviewing psychoeducation materials; watching and discussing video training segments; and participating in dyadic experiential exercises to address the stressors the couples are experiencing in their relationships. The program’s primary goal is to promote partners’ emotional bonds and encourage more secure attachment to each other. Seeing each other as an emotional support system could help these parents soothe their own anxiety and better regulate their own emotions (Clothier, et al., 2002; Dandeneau & Johnson, 1994; Dessaulles, 1991; Johnson & Greenberg, 1985a, 1985b; Johnson & Talitman, 1997; Walker, Johnson, Manion, & Cloutier, 1996).

Parents who do not have preexisting stress in their lives can still benefit from preventive counseling programs. It is important to include both mothers and fathers in these programs because, to date, most interventions have targeted only mothers. Both parents can be informed about helpful ways to cope with raising a child with cleft. For example, the participants in this study frequently noted that keeping a positive attitude and focusing on the child rather than on their own anxiety helped them.

Parents continue to describe challenges during the first year related to the surgeries, using the NAM device, the feedings, and social stigma. As suggested by the BPS model (Engel, 1977), it is important to provide couples with ongoing psychoeducation on how to cope with these stressors. Increasing their control over the situation by explaining the process, talking about the possible challenges they may face

during the initial year, and normalizing their concerns would help the parents soothe their own anxiety and regulate their own emotions when raising their children. As indicated, mental health professionals on the treatment team can also provide parents with continuous resources and counseling for anxiety and stress management.

The results of this study indicate that there are gender differences regarding how parents cope with having a child with cleft. Men value practical coping skills such as learning about the cleft and its treatment whereas women need space to talk about their feelings and concerns. For this reason, fathers may appear to be less impacted by their children's conditions. It is helpful for the mental health professionals to remember that trying to "fix" the problem by figuring out and planning the treatment path is a coping mechanism for managing stress and anxiety for the fathers. Mental health professionals can suggest practical coping mechanisms to the fathers to help them with stress management rather than only sharing their feelings and concerns. For the couples' counselors, it is important to frame the differences in the way men and women cope with the stressor.

According to the findings of this study, the first surgery (when the baby is 3 months) is an especially challenging time for both parents. Parents in both diagnosis groups described being concerned about complications and anesthesia as well as not being prepared for their children's postoperative appearance and difficulties in the recovery period. Parents whose children are likely to receive surgical revisions in the future for improving their physical appearance reported experiencing inner conflict about putting their children through additional surgeries at the expense of the possible psychological impact. It is important for the treatment teams to establish a psychological

preparation program in their units and to include both families and children in their program. For families who may not be able to participate in the preparation programs in person, hospitals can offer online education and support groups. Online programs can make the services more accessible for low income families by precluding the need to pay for transportation or to take time away from work. Hospitals can design programs that can allow higher income families to donate their unused special feeder bottles to low income families.

Justus et al. (2006) reported that their surgical preparation program for children and families includes a pediatric surgery nurse practitioner, a registered nurse, a mental health professional, and a child life specialist. The team provides an intervention that includes psychoeducation, play therapy, and supportive counseling. The primary goal is to familiarize both the children and families with the hospital setting and staff, identify and reduce concerns of both parents and children before the surgery, and put families in contact with other families to increase sources of support and increase their repertoire of problem-solving skills. This type of prevention program can offer support to parents who are preparing their children for surgery. Parents can also learn about healthier and developmentally appropriate ways to inform their children about cleft, and parents' concerns can be assessed after the surgery to inform the treatment team. Parents frequently said that they did not need to tell their children about their clefts since they look "perfect" now. Because secrecy brings shame, the team can prepare a structured intervention on how to inform the child about his or her cleft, such as reading a children's book about cleft as a family. It is important for the child to be knowledgeable about a health condition that he may need to cope with throughout his life (i.e., orthodontic

treatment, speech therapy, surgeries). Plus, it would be helpful to explore the parents' need to describe their child as "perfect" because this attitude is likely to create unrealistic expectations for the child. As the child becomes more informed about his/her condition and grows up with realistic ideas about the way he/she looks, he/she can be better equipped to cope with trauma.

6.5 Limitations

This qualitative study was designed to understand participants' perceptions at one point in time, 1 to 4 years after couples had a baby born with CL/P. Parents described their experiences in four time periods: (1) at diagnosis (either prenatally or postnatal), (2) birth, (3) during the initial stages after birth, and (4) currently. They also shared their reflections on the experience of raising a child with cleft. It would have been helpful to prospectively assess couples' relationships and functioning throughout this time period using the same relational distress measure (RDAS). In future studies it will be helpful to assess their relationship distress at the time of the diagnosis, the birth, and during the initial stages to understand how raising a child with cleft impacted their relationship over time and not just retrospectively. It will also be helpful to examine their existing patterns of functioning and vulnerability before they started caring for their children. This information will provide a more realistic picture of the impact of this process on their relationship in real time. However, because this was a retrospective qualitative study, this approach was not possible.

Although a purposeful and criterion-based sampling strategy was used in this study, participants still self-selected to be interviewed for the study. There may have been a sampling bias in which only couples who had more positive experiences raising a child

with CLP chose to participate. However, it is important to note that three families in the postnatal diagnosis group had ongoing stress in their families because of their children's developmental delays, which did not necessarily make their experiences positive. Yet couples in both diagnosis groups stated that they had a "positive experience" overall.

The couples also provided retrospective descriptions of their experiences regarding the timing of the diagnosis, birth, and initial stages. Therefore, it is possible that they did not accurately remember some parts of the process such as specific incidences, feelings, and concerns. To overcome this limitation, I interviewed each parent individually before interviewing the couple together, so that I could get a more systemic understanding of their experiences. Overall, mothers in both diagnosis groups provided more details about their experiences. Fathers' interviews gave me the opportunity to triangulate the mothers' interviews and to have access to details that the mothers did not provide. At times, the individual interviews enabled me to see the couple's relationship in a different way because they shared details about their relationship that they might have been reluctant to share with me in front of each other, especially if they were in distress at the time of the interview.

The sample of couples was not diverse because the original CHOP study sample was not diverse. The original study had 105 participants; 65 participants were White and 46 participants had college or graduate degrees. However, during the data collection phase, I tried to contact participants from minority groups. As noted earlier, one African American family stated that the father was no longer at home, so I could not interview them since I was targeting both mothers and fathers for my study. One Indian couple initially agreed to participate, but the father dropped out at the last minute. I scheduled an

interview with a Latino couple and found out at the beginning of the interview that their child had Down syndrome in addition to the cleft. For this reason, I had to exclude them from my sample. Yet I interviewed three biracial couples in which two fathers and one mother were Asian. This demographic is expected since cleft occurs primarily in Asians followed by Whites. Yet, it is crucial for subsequent studies to have more diverse samples to understand the experiences of minorities who have children with cleft.

Because of the small, nonrepresentative sample, the findings from this study cannot be generalized to the population level. The participants' in-depth descriptions of their experiences may, however, provide important insight into how mothers and fathers from the two the diagnosis groups navigate raising a baby and even a young child up to 4 years old born with cleft. Finally, there are also multiple potential interpretations of qualitative data. The extensive bracketing process before, during, and after data collection hopefully limited this researcher's bias. The couples' perspectives and the triangulation of the data with my dissertation chair and the existing literature also add credibility to the findings.

6.6 Recommendations for Future Research

Future research on couples raising a child with cleft should focus on interviewing couples who have become more distressed as they raise their children, especially during the initial stages when they are dealing with multiple stressors. For example, the relationship distress of couples can be measured as a baseline at the time of the diagnosis for both diagnosis groups and then measured again at the end of the first year. The couples who become more distressed throughout the process can be interviewed to understand the specific challenges they face in their relationships. This approach would

also give the researchers an opportunity to describe the specific challenges each diagnosis group experiences in their relationship.

The results of this research study suggest that couples whose children experience ongoing problems will have a different experience from that of couples whose children do not have any residual issues. Therefore, future studies should be designed to understand couples' experiences as they deal with their children's developmental and speech delays. It would also be helpful to assess if there are any differences between the functioning of children who are diagnosed postnatally and those diagnosed prenatally. More studies are needed to understand the impact of the type of cleft (cleft lip, cleft palate, or cleft lip palate) on a child's functioning because two of three children who were experiencing delays in development and speech were born with cleft palate.

Furthermore, there is a dearth of diverse samples in the cleft literature. It is vital to understand the experiences of minority couples who are raising a child with cleft. One of the participants in my sample highlighted that he could relate to what his son might experience in the future due to his visible difference because he grew up as an Asian boy in Florida. His statement made me think about minority couples' concerns about their children experiencing social stigma because of their visible differences *and* their racial background. Additionally, it is important to understand their coping mechanisms, problem appraisal skills, and resources to better help minority families cope with cleft.

Finally, this study included both the fathers' and the couples' perspectives. More studies, both qualitative and quantitative, conducted with fathers and couples are needed to understand the experiences of couples/families raising a child with cleft.

6.7 Reflections: Final Self of the Researcher

Throughout this study, I discovered new things about myself. The bracketing process was a compass throughout the data collection and analysis phases. Even though I thought that I had extensive knowledge about cleft because I had been through it as a child in Turkey, there were certain experiences that parents described that I could not relate to. I realized that I could not relate to all of their experiences because while I had to deal with having a cleft myself, I was never the *parent* of a child with cleft.

Starting from the first interview, it was a challenge for me to understand mothers' strong desires to breastfeed their children and their glorification of breastfeeding by extolling the better nutrients it provides babies and emphasizing its positive effect on the mother-child attachment. Some mothers still seemed so upset about not being able to breastfeed their children that I wanted to ease their pain and tell them that I was never breastfed and I turned out fine! When I took a step back and realized that my reaction stemmed from my desire to ease their pain, I tried to empathize with their experiences as mothers who live in a culture that glorifies breastfeeding.

At the beginning of the interviews, another struggle that I had was when parents did not reach a new realization regarding their experiences. For example, if they talked only about the positive aspects of their experiences, I wanted them to talk about the negative aspects. I tried to guide them through my probes to make connections between their experiences and current functioning or between their core beliefs and behavior at the time. I had the nagging thought that my participants were not sharing genuine thoughts and feelings and that they were somehow in denial. I think this belief stems from my experiences as a therapist: When my participants told me that the process was not as

traumatic for them or that it no longer impacted them, I had a hard time believing them. On the other hand, when a participant described the experience as very traumatic, I wanted to take away his/her pain. As I moved forward in the process, I realized that I had to let go of my own expectations and listen to what my participants were sharing. Making the distinction between doing qualitative research and doing therapy was a lesson I learned during this process.

My participants also helped me see myself in a different way. As they described their children as “brave,” “strong” and “beautiful,” I questioned my own qualities and wondered if those descriptions could apply to me too. Part of me was impressed with the way they described their children and highlighted that this process was harder on their children than on them. Part of me was jealous. I appreciated it when some of the parents stated that it was important to take a step back and remember that this experience was not about them but about their children because the children are the ones who suffer most.

At times, the statements of my participants made me frustrated, especially when they made comments about children who are born with cleft in other countries. I realized that their knowledge of children with cleft in other countries was limited to the scenes in Smile Train commercials. Reminding myself of this helped to ease my frustration. I also realized that they took pride in the way they take care of their children even though it was a long struggle for them, especially in the initial stages. This realization helped me empathize with the parents and soothed my feelings of anger.

I also had difficulty when parents continuously described their children as “perfect.” Because I believe that perfection is an illusion and that everyone has flaws, I was frustrated with the façade they were trying to create regarding themselves and their

children. To manage my own reaction, I thought of the times that I tried to create a façade of perfection for myself and remembered how much of it stemmed from my own anxiety in life. As a consequence, I was able to create a different meaning for their behavior.

6.8 Conclusions

The timing of the CLP diagnosis, birth, and initial stages after birth were reported as the most challenging time periods for couples in both the prenatal and postnatal diagnosis groups unless their children still had ongoing developmental delays. Overall, the initial stages immediately following the birth were reported as more stressful for the postnatal diagnosis group because they had no time to prepare. Course of treatment, feeding, and social stigma were reported as major sources of stress for all 17 couples. Findings suggest that regardless of the diagnosis group, couples could benefit from (1) health professional's calm demeanor when first delivering the CLP diagnosis because it affects how parents perceive the CLP, which later determines how they cope and problem solve; (2) an initial information session with both parents at the time of the diagnosis (e.g., describing the course of treatment; the NAM device, surgeries, and feeding); (3) peer support from other couples to reduce their feelings of isolation ; (4) health professionals should help to alleviate any self-blame, especially for the mothers; and (5) couples who are more distressed at diagnosis and especially during the first year after birth should be regularly screened and referred for couple-based interventions like Hold Me Tight to promote secure attachment and better coping. Finally, future research should include more racially and economically diverse samples of couples to develop culturally sensitive intervention programs.

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APPENDIX A: INFORMED CONSENT FORM AND HIPAA AUTHORIZATION

Study Title: Experiences of Couples Having a Young Child with Cleft Lip and/or Palate Diagnosed Prenatally versus Postnatally: A Phenomenological Study

Version Date: March 8, 2013

You and your partner may be eligible to take part in a research study. This form gives you important information about the study. It describes the purpose of this research study, and the risks and possible benefits of participating.

If there is anything in this form you do not understand, please ask questions. Please take your time. You do not have to take part in this study if you do not want to. If you take part, you can leave the study at any time.

Why are you being asked to take part in this study?

You are being invited to take part in this research study because you are the parent of a child who has a cleft lip and/or palate and have already agreed to participate in the research study, "Psychosocial adjustment in parents of infants with cleft lip and/or palate: the impact of prenatal versus postnatal diagnosis." We are asking you to participate so that we can learn more about parents' thoughts and feelings about having a young child with cleft lip and/or palate.

What is the purpose of this research study?

The purpose of this research study is to examine the experiences of parents having a young child with cleft lip and/or palate. Results of this study may help us to target and

develop interventions that will potentially improve outcomes for both parents and children.

How many people will take part?

About 20 couples at CHOP will take part in the study.

What is involved in the study?

Parents will be asked to complete a demographic survey, a relational measure and a semi-structured interview about your experiences of having a young child with cleft lip and/or palate.

How long will you be in this study?

If you agree to take part, your participation will take up to 2 hours.

Study Procedures

Surveys/Questionnaires: You will be asked to complete a demographic questionnaire that includes some questions about yourself, such as age, gender, years of education and medical history. You will also be asked to complete a relational measure about your relationship with your partner.

Semi-structured Interview: You will be asked to participate in a semi-structured interview first by yourself then with your partner. The interview will include questions about your thoughts and feelings regarding having a young child with cleft lip and/or palate. The interview will last up to 2 hours. The interviews will preferably take place in person, but can also take place via web or phone. The interviews will be audiotaped and will be transcribed by a professional transcription service. We will not include any identifiable information in the interviews such as your names.

Visit Schedule

You and your partner will meet with a person from the research team once, at a scheduled time and place to complete the questionnaires and the interview. The visit will take about 2 hours. You, your partner and the interviewer will agree on a suitable time and place for the visit. If the interview is being conducted via web or phone, the questionnaires and the informed consent will be sent to you and your partner for you to sign the consent and fill out the questionnaires and mail them back to the research team before the interview.

After we have completed all of our interviews, we will summarize the themes that parents have identified. We will email you the findings to review through a secure email mechanism and ask you to provide us with feedback.

What are the risks of this study?

Taking part in a research study involves inconveniences and risks. If you have any questions about any of the possible risks listed below, you should talk to your study doctor or your regular doctor.

While in this study, you are at risk for the following side effects:

Risks associated with surveys and questionnaires:

There are no physical risks but you might experience momentary embarrassment or discomfort. You do not have to answer any questions that make you too uncomfortable.

If your responses suggest that you may be in need of additional support or counseling, Dr. Canice Crerand will discuss referral options with you. She will work with you to locate an appropriate provider.

Risks associated with breach of privacy and confidentiality:

As with any study involving collection of data, there is the possibility of a breach of confidentiality. Every precaution will be taken to secure participants' personal

information to ensure confidentiality. At the time of participation, each participant will be assigned a study identification number. This number will be used on data collection forms and in the database instead of names and other private information. Furthermore, each participant will pick an alias to use during the interview in order to further protect your privacy. A separate list will be maintained that will link each participant's name to the study identification number and their alias for future reference and communication. All data (raw and electronic) will be kept in secure offices and on secure, password-protected computers.

Are there any benefits to taking part in this study?

There will be no direct benefit to you from taking part in this study. The knowledge gained from this study may help us to understand the thoughts, feelings, and concerns that parents of children with cleft conditions may have. We hope to use this information to help other families in the future.

Do you need to give your consent in order to participate?

If you decide to participate in this study, you must sign this form. A copy will be given to you to keep as a record. Please consider the study time commitments and responsibilities as a research subject when making your decision about participating in this study

What happens if you decide not to take part in this study?

Participation in this study is voluntary. You do not have to take part in order to receive care at CHOP.

If you decide not to take part or if you change your mind later there will be no penalties or loss of any benefits to which you are otherwise entitled.

Can you stop your participation in the study early?

You can stop being in the study at any time. You do not have to give a reason.

What about privacy, authorization for use of Personal Health Information (PHI) and confidentiality?

As part of this research, health information about you will be collected. This will include information from the interviews and surveys, which are performed only for this research study. We will do our best to keep your personal information private and confidential.

However, we cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law.

The results of this study may be shown at meetings or published in journals to inform other doctors and health professionals. We will keep your identity private in any publication or presentation about the study.

People and organizations that may inspect and/or copy your research records to conduct this research, assure the quality of the data and to analyze the data include:

Members of the research team at CHOP and Drexel University;

CHOP staff who are directly or indirectly involved in your care;

People who oversee or evaluate research and care activities at CHOP;

People from agencies and organizations that perform independent accreditation and/or oversight of research; such as the Department of Health and Human Services, Office for Human Research Protections;

Fingers4Hire professional transcription company

By law, CHOP is required to protect your health information. The research staff will only allow access to your health information to the groups listed above. By signing this

document, you are authorizing CHOP to use and/or release your health information for this research. Some of the organizations listed above may not be required to protect your information under Federal privacy laws. If permitted by law, they may be allowed to share it with others without your permission.

There is no set time for destroying the information that will be collected for this study.

The audiotapes of the interviews will be destroyed as soon as possible after the completion of the study. Your permission to use and share the information and data from this study will continue until the research study ends and will not expire. Researchers continue to analyze data for many years and it is not possible to know when they will be completely done.

Can you change your mind about the use of personal information?

You may change your mind and withdraw your permission to use and disclose your health information at any time. To take back your permission, you must tell the investigator in writing.

Dr. Canice Crerand

The Children's Hospital of Philadelphia

Division of Plastic Surgery

34th Street and Civic Center Blvd.

Philadelphia, PA 19104

In the letter, state that you changed your mind and do not want any more of your health information collected. The personal information that has been collected already will be used if necessary for the research. No new information will be collected. If you withdraw

your permission to use your personal health information, you will be withdrawn from the study.

Financial Information

Will there be any costs to you?

There will be no additional costs to you from taking part in this study.

Will you be paid for taking part in this study?

Yes. You will each receive \$20 to thank you for your time and effort after the interview is completed.

Who is funding this research study?

The Division of Plastic Surgery at The Children's Hospital of Philadelphia is funding this research.

What if you have questions about the study?

If you have questions about the study, call the study doctor, Dr. Canice Crerand at 267-426-2279. You may also talk to your own doctor if you have questions or concerns.

The Institutional Review Board (IRB) at The Children's Hospital of Philadelphia has reviewed and approved this study. The IRB looks at research studies like these and makes sure your rights and welfare are protected. You can talk to a person from this group if you have questions about your rights as someone taking part in a research study. You can call the IRB Office at 215-590-2830 if you have questions or complaints about the study.

Consent to Take Part in this Research Study and Authorization to Disclose Health
Information

The research study and consent form have been explained to you by:

Person Obtaining Consent

Signature of Person Obtaining Consent

Date:

By signing this form, you are indicating that you have had your questions answered, you agree to take part in this research study and you are legally authorized to consent to your participation. You are also agreeing to let CHOP use and share your health information as explained above. If you don't agree to our collecting, using and sharing your health information, you cannot participate in this study.

Name of Subject (mother)

Signature of Subject (mother)

Date

Name of Subject (father)

Signature of Subject (father)

Date

Name of Subject (father)

Signature of Subject (father)

Date

APPENDIX B: RECRUITMENT LETTER AND REFUSAL POSTCARD

34th Street & Civic Center Boulevard.
Philadelphia, PA 19104

Announcement of Upcoming Research Study

Date

Dear Parents:

My name is Dr Canice Crerand, and I am the psychologist in Division of Plastic Surgery at Children's Hospital of Philadelphia. I am sending you this letter because you have participated in one of my research studies called, **“Psychosocial adjustment in parents of infants with cleft lip and/or palate: the impact of prenatal versus postnatal diagnosis”**). I am conducting a related research study with a doctoral student names Senem Zeytinoglu from the Couples and Family Therapy Program at Drexel University in order to better understand the experiences of parents who have a young child with cleft lip and/or palate.

I am inviting both of you, as a couple, to participate in an interview. I am interested in learning about your experiences, thoughts and feelings as a couple who have a young child with cleft lip and/or palate so that better interventions can be developed to help families like you. Your experiences would be a guide for other couples and families who have children with cleft lip and/or palate.

If you choose to participate, we will schedule the interview at a convenient time for both of you. The interviews can take place in person, via Webinar/WebEx or phone based on your convenience.

The interview would take up to two hours to complete. You will be interviewed individually and as a couple regarding your experiences of having a young child with cleft lip and/or palate. You would also complete a demographic survey and a questionnaire.

All responses will be kept confidential and participation in this study will be at no cost to you. Within two weeks of receiving this letter, we will contact you by phone to give you more information about the research study. We respect your privacy. If you do not wish to be contacted, please sign the enclosed postcard and return it to the research study team, or if you prefer, call the study investigators at the numbers below within two weeks. If you do not return this postcard, it means you are allowing the study staff to call you with more information; it does NOT mean you are volunteering for the study. Your child's care will not be affected by your decision to participate or not participate in this study. If you have any questions, please feel free to contact the study investigators, Dr. Canice Crerand (crerand@email.chop.edu or 267-426-2279) and/or Senem Zeytinoglu (zeytinoglu@email.chop.edu or 646-593-1247).

Thank you for your time.

Sincerely,

Dr Canice Crerand
Psychologist, Division of Plastic Surgery

Senem Zeytinoglu
Doctoral student, Drexel University



34th Street & Civic Center Boulevard.
Philadelphia, PA 19104

Calling for Participation

June 26th, 2013

Dear Parents,

My name is Dr Canice Crerand, and I am a psychologist in Division of Plastic Surgery at Children's Hospital of Philadelphia. I am sending you this letter because you have participated in one of my research studies called "**Psychosocial adjustment in parents of infants with cleft lip and/or palate: the impact of prenatal versus postnatal diagnosis.**" I am conducting a related research study with a doctoral student named Senem Zeytinoglu from the Couples and Family Therapy Program at Drexel University in order to better understand the experiences of couples who have a young child with cleft lip and/or palate.

Currently, we are in need of more participants whose **children were diagnosed with cleft lip and/or palate at the time of birth.** This is to understand the unique experiences, thoughts and feelings of couples who received a postnatal diagnosis so that better interventions can be developed for families like yours. Your experiences would be a guide for other couples and families who learned about their child's cleft at the time of (or after) birth.

If you choose to participate, we will schedule the interview at a convenient time for both of you. The interviews can take place during evening hours as well as on the weekends. The interviews can take place in person, via Webinar/WebEx or phone based on your convenience.

The interview would take up to two hours to complete. You will be interviewed individually and as a couple regarding your experiences of having a young child with cleft lip and/or palate. You would also complete a demographic survey and a questionnaire.

All responses will be kept confidential and participation in this study will be at no cost to you. You will be compensated for participating in this study.

Please contact Senem Zeytinoglu (zeytinoglus@email.chop.edu or 646-593-1247) **before July 5th, 2013** if you would be willing to participate in our research study. Your child's care will not be affected by your decision to participate or not participate in this study. If you have any questions, please feel free to contact the study investigators, Dr. Canice Crerand (crerand@email.chop.edu or 267-426-2279) and/or Senem Zeytinoglu (zeytinoglus@email.chop.edu or 646-593-1247).

Thank you for your time.

Sincerely,

Dr Canice Crerand

Senem Zeytinoglu

Psychologist, Division of Plastic Surgery

Doctoral student, Drexel University

Toy Story When Toy Story was released on November 20, 1995, traditional hand-drawn animation was still the dominant medium for feature animated films. Toy Story, the world's first full-length computer-animated film, took computer-generated animation to a new technological and artistic level. It also introduced characters and stories from contemporary life rather than from fairy tales and legends.

ID #



Dr. Cavice Czerand
 The Children's Hospital
 of Philadelphia
 Division of Plastic
 Surgery
 Wood Ambulatory Care
 Building, 1st Floor
 34th and Civic Center
 Blvd. Philadelphia, PA
 19104

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APPENDIX C: DEMOGRAPHIC SURVEY

Parent Demographic Questionnaire

Subject ID number: _____

1. What is your highest level of education:

8th grade or less Some high school
 High school graduate Some college
 College graduate Graduate degree (Masters degree, PhD, MD, JD, etc)

2. Occupation: _____

3. Employment status:

Currently I am: employed full-time (40 hours/week or more)
 employed part-time (less than 40 hours/week)
 unemployed
 disabled
 retired
 homemaker

4. How long have been in a relationship with your partner? _____ (years)
 _____ (months)

5. Do you and your partner live together? Yes No

If Yes, for how long? _____

6. Are you and your partner married? Yes No

If Yes, for how long? _____

7. What is your current age: _____ years

8. How many children do you have? _____

9. How many children do you have with a cleft lip and/or palate? _____

10. In the past 12 months, have you sought psychological treatment (e.g., counseling) for any reason? Yes No

11. In the past 12 months, have you sought any psychiatric treatment (e.g., medications such as antidepressants, anti-anxiety medications)? Yes No

12. In the past 12 months, have you sought any type of counseling to specifically help you cope with your child's condition? Yes No

13. In the past 12 months, have you joined any support groups (e.g., on-line or face-to-face groups) to help you cope with your child's condition? Yes No

If yes, tell us what kind of support group you participated in and how frequently you attended/participated:

APPENDIX D: INTERVIEW GUIDE

Interview Guide

Individual Question = I

Couple Questions = C

Individual and Couple Questions = I and C

- 1) Tell me the story of how you found out about your child's cleft (I)

Prompt: Who informed you of [child]'s cleft and what were you thinking/feeling when you heard of the diagnosis?

If prenatal diagnosis: How did the prenatal diagnosis affect the rest of the pregnancy?

If one had to tell the other: How did you tell your significant other?

- 2) Was she/he born with other health problems in addition to the cleft? (I)
- 3) What were your concerns then? What are your concerns now? (I)
- 4) How prepared were you in general for your baby's arrival at the time of birth? (I)
- 5) Describe your (thoughts) feelings during the first month of [child]'s life. (I)
- 6) Describe your (thoughts) feelings after [child] had his/ her first surgery performed. (I)
- 7) Has this experience of having a child with CLP been stressful for you? (I)
- 8) People have many ideas about what causes a cleft lip. What are your thoughts about what may have caused your child's cleft lip? (I)
- 9) Do you believe that prenatal diagnosis made the adjustment to [child]'s diagnosis of cleft lip easier than if the diagnosis were given at the time of birth? How? (Asked of prenatal participants only) (I)
- 10) Would you have preferred to know prenatally? (Postnatal participants only) (I)
- 11) How did having a prenatal diagnosis help you explain to your family that your baby would be born with a cleft lip? (Asked of prenatal participants only) (I)

- 12) If you were talking to someone as a parent, what would advise them? (I and C)
- 13) What did you learn from your experience that was most helpful to you? (I and C)
- 14) What was the biggest challenge for you in this process? (I and C)

- 15) What were the roles or responsibilities that you and your husband (wife) took on surrounding the time of your child's diagnosis? How were decisions made for your family at that time? (C)
- 16) Did you tell friends in addition to family members about the cleft before your child was born? (Prenatal only) (C)

- 17) How did you explain your child's condition to people after birth? (Post-natal only)
(C)
- 18) Should parents meet with another parent who has had a child born with a cleft? (C)
- 19) How do the two of you manage the care of your child? (C)
- 20) How did this experience impact your relationship?
- 21) How do you arrive at decisions regarding a) treatment b) parenting? (C)
- 22) Does your child have trouble with a) making friends b) appearance concerns c) speech
d) development? How do you deal with it? Does this impact your social life?(C)
- 23) How do you talk about cleft lip palate a) among yourselves b) within your family c)
to other people (C)
- 24) How are you talking to your child about CLP? (C)
- 25) Where do you get your support from? (C)
- 26) Is there anything else important that you think we should know about your
experience? (C)

**APPENDIX F: CHILDREN'S HOSPITAL OF PHILADELPHIA
INSTITUTIONAL REVIEW BOARD APPROVAL LETTER**

Date: Tue Apr 2 08:27:25 EDT 2013

To: Canice Crerand

CC: Senem Zeytinoglu

From: Mark Schreiner, M.D., Chair, Committees for the Protection of Human Subjects

Re: IRB# [IRB 12-009685](#), **Protocol Title:** Experiences of Couples Having a Young Child with Cleft Lip and/or Palate, Comparing Prenatal and Postnatal Diagnosis Groups: A Phenomenological Study

Sponsor: The Children's Hospital of Philadelphia (CHOP)

IRB SUBMISSION: NOTICE OF IRB APPROVAL

Approval Date: 4/1/2013

Expiration Date: 3/31/2014

Approved Document(s):

- Protocol (dated 3/8/13)
- Consent Form (dated 3/8/13)
- Recruitment Letter (dated 3/8/13)
- Please refer to this protocol workspace in eIRB to identify the materials reviewed by the IRB. The IRB considered all of the submitted documents when the research was approved.

Performance Sites:

- CHOP and affiliated sites

Number of Approved Subjects:

- CHOP Sites: 30 total subjects

Thank you for submitting the above-named study. A member of the CHOP IRB reviewed and approved the study via expedited review with the following determinations:

- Expedited Category: 45 CFR 46.110, Categories 5, 6, & 7

Please note the following conditions for conducting this study:

1. **REPORTABLE EVENTS:** On-site reportable events, such as serious adverse events, protocol deviations/violations, unanticipated problems involving risk to subjects or others, and non-compliance that occurs in relation to this study, must be reported to the IRB in a timely manner, as outlined in IRB SOP 408. Please refer to the following page on the IRB's website for information about reportable events: <https://intranet.research.chop.edu/display/cmtirb/Reportable+Events>.
2. **RENEWAL (Continuing Review/Progress Reports):** Approval is valid until the expiration date for your protocol shown above. The IRB must review and approve all human subject research studies at intervals appropriate to the degree of risk, but not less than once per year, as required by 45 CFR 46 / 21 CFR 50, 56. To avoid lapses in study approval and suspension of study procedures, please submit the application for continuing review at least 45 days before the expiration date for your protocol. This will provide the IRB will sufficient time to review your study. As a courtesy, the IRB will send you a reminder; however, it is your responsibility to ensure that you submit the continuing review application on time.
3. **CONSENT FORM:** The approved, date-stamped informed consent document is available in the eIRB study workspace to print out.
4. **CHANGES/AMENDMENTS/MODIFICATIONS/REVISIONS:** You must obtain IRB review and approval under 45 CFR 46 / 21 CFR 50, 56 if you change any aspect of this study, including but not limited to study procedures, consent form(s), co-investigator, study staff, advertisements, protocol document or procedures, investigator drug brochure or accrual goals. Implementation of these changes cannot occur until you receive the IRB Approval notice.
5. **COMPLETION OF STUDY:** Notify the IRB when your study is completed. Neither study closure by the sponsor nor the investigator removes your obligation for submitting a timely continuing review or a final report.
6. **INVESTIGATOR RESPONSIBILITIES:** Please refer to the following page on the IRB's website for information and guidance on the responsibilities of

investigators who conduct human subjects research at CHOP:

<https://intranet.research.chop.edu/display/cmtirb/Investigator+Responsibilities>.

Thank you for your cooperation in protecting human research subjects.

DHHS Federal Wide Assurance Identifier: FWA0000459

***** This memorandum constitutes official CHOP IRB correspondence. *****

APPENDIX G: DREXEL COOPERATIVE AGREEMENT



APPROVAL OF PROTOCOL

April 18, 2013

Maureen Davey, Ph.D.
Couples and Family Therapy
Mailstop: 905

Dear Dr. Davey,

On April 18, 2013 the IRB reviewed the following protocol:

Type of Review:	Initial
Title:	Experiences of Couples Having a Young Child with Cleft Lip and/or Palate, Comparing Prenatal and Postnatal Diagnosis Groups: A Phenomenological Study
Investigator:	Maureen Davey, Ph.D.
IRB ID:	1304001978
Funding:	Internal
Grant Title:	None
Grant ID:	None
IND, IDE or HDE:	None
Documents Reviewed:	Application and Approval Documents from The Children's Hospital of Philadelphia (CHOP) and the executed Authorization Agreement

Approved Conditions Met

Please Note: The Drexel University IRB has a reliance on the IRB of The Children's Hospital of Philadelphia (CHOP). The protocol has been approved by The Children's Hospital of Philadelphia (CHOP) IRB, along with the consent form to be used. All continuing reviews should be handled by The Children's Hospital of Philadelphia (CHOP) with copies of all correspondence being submitted to Drexel University

The IRB approved the protocol from April 18, 2013 to March 31, 2014 inclusive. Before March 31, 2014 or within 30 days of study close, whichever is earlier, you are to submit a completed Continuing Review Progress Report and required attachments to request continuing approval or closure.

If continuing review approval is not granted before the expiration date of March 31, 2014 approval of this protocol expires on that date.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL.

Sincerely,


Danyelle S. Gibson

Curriculum Vitae Senem Zeytinoglu

Education

- 2014 PhD, Drexel University, Philadelphia, Pennsylvania, Couple and Family Therapy
- 2008 MA, MEd, Columbia University, Teachers College, New York,
Counseling Psychology
- 2005 BA, Koc University, Istanbul, Turkey, Psychology

Selected Publications

Zeytinoglu, S., & Davey, M. (2012). It's a Privilege to Smile: The Impact of Cleft Lip Palate on Families. *Families, Systems, and Health, 30*(3), 265-277.

Davey, M., **Zeytinoglu, S.**, & Lynch, L. Integrating Theory and Research (Chapter 3). In Miller, R. & Johnson, L. (Eds) (2012). *Advanced Methods in Family Therapy Research: A Focus on Validity and Change*. Routledge Press.

Zeytinoglu, S., Akyil, Y., & Kissil, K. Supervising Foreign-Born Clinicians in the United States: A Clinical Guide. In Bean, R.A., Davis, S., & Davey, M (Eds) (Due to publisher August, 2013). *Clinical Supervision Activities for Increasing Competence and Self-Awareness*. Wiley Press, Inc.

Selected Conference Presentations

Zeytinoglu, S. (October 2013). Experiences of Couples Having a Young Child with Cleft, Comparing Prenatal versus Postnatal Groups: A Phenomenological Study. Accepted for Brief Presentation at European Family Therapy Association Conference (EFTA), Istanbul, Turkey.

Zeytinoglu, S. (June 2013). Experiences of Couples Having a Young Child with Cleft, Comparing Prenatal versus Postnatal Groups: A Phenomenological Study Preliminary Findings. Poster Presentation at American Family Therapy Association Conference (AFTA), Chicago, Illinois.

Zeytinoglu, S. (February 2013). Supervising Foreign-born Therapists in the United States. Lecture Presentation at International Family Therapy Conference (IFTA), Orlando, Florida.