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Fathers of Children Born With Cleft Lip and Palate: Impact of the Timing of Diagnosis

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Introduction: Cleft lip and/or palate (CL/P) affects not just the child born with the condition but also the child's parents. Prior research has been primarily cross-sectional, quantitative, and focused on mothers' emotional, social, and care experiences. Fathers' experiences have been neglected despite the important role fathers have in their child's well-being and development. The purpose of this study was to examine how the timing of a child's diagnosis (prenatal vs. postnatal) affects how fathers cope and adapt. ***Method:*** We conducted a descriptive qualitative study with a convenience sample of 17 fathers and used thematic content analysis to code the interviews. The sample included 10 fathers who received a prenatal diagnosis and 7 who received a postnatal diagnosis. ***Results:*** The following 4 major themes emerged: (a) first hearing the diagnosis, (b) taking care of a baby with cleft, (c) future concerns, and (d) reflections. Course of treatment, feeding, and social stigma were reported as major sources of stress for all fathers. ***Discussion:*** All fathers should be routinely assessed by CL/P treatment teams and included in support services. Some fathers whose babies were diagnosed at birth experienced self-blame, suggesting the importance of screening this group of fathers for distress at birth. Findings underscore the importance of family centered approaches to care that include both mothers and fathers in treatment planning, interventions, and future research.

Keywords: cleft lip and palate, father's experiences, prenatal diagnosis, qualitative

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Orofacial clefts including cleft lip with or without cleft palate are among the most common congenital anomalies in the United States (Parker et al., 2010). Children are treated by multidisciplinary teams of specialists at birth and continuing through early adulthood (American Cleft Palate Craniofacial Association, 2009). Surgeries to repair the lip and palate are first performed in early infancy and continue through adolescence and young adulthood. Children with craniofacial conditions are at risk for low self-esteem, learning disabilities, depression, social anxiety, and negative social reactions from others because of facial disfigurements and speech deficits (American Cleft Palate Craniofacial Association, 2009).

Cleft lip and/or palate (CL/P) affects not just the child but also parents (Zeytinoglu & Davey, 2012). Prior research has been cross-sectional, quantitative, and with mothers (Baker, Owens, Stern, & Willmot, 2009; Despars et al., 2011; Nelson, Kirk, Caress, & Glenny, 2012; Nus-

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baum et al., 2008; Stock & Rumsey, 2015). Fathers have been neglected despite their important role in children's development (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). Although a prenatal diagnosis is more common because of improved technology (Maarse et al., 2010), many babies are still diagnosed at or soon after birth (Jones, 2002).

Studying the impact of the timing of diagnosis is important because distress can affect how parents attach to their infants; poor attachment is potentially detrimental to later psychological functioning among children born with CL/P. (Fox, Nordquist, Billen, & Savoca, 2015; Pope, Tillman, & Snyder, 2005; Speltz, Armsden, & Clarren, 1990). A better understanding of how the timing of diagnosis affects both mothers and fathers could lead to the development of more family centered approaches to pediatric care (Zvara, Schoppe-Sullivan, & Dush, 2013).

Although few have examined fathers' experiences (Gassling et al., 2014; Pelchat, Bisson, Bois, & Saucier, 2003), an exception is a recent qualitative study with 15 British fathers caring for children born with CL/P (Stock & Rumsey, 2015). The authors reported fathers were at risk for distress, especially during the first year; however, the timing of diagnosis was not assessed in this study. To address these gaps, we conducted a descriptive qualitative study with 17 fathers of young children (1 to 4 years old) born with CL/P who were recruited from an ongoing larger study in a northeastern urban children's hospital in the United States.

Method

Researchers' Characteristics

The lead researcher (first author) is a licensed couple and family therapist who was born prematurely and diagnosed with CL/P at birth. She was a couple and family therapy (CFT) doctoral candidate when interviews were conducted; this article was derived from her dissertation study. The second author conducts clinical research with families coping with illness. The third author is a clinical psychologist, who works with families coping with CL/P, and the fourth author is nurse who works with families coping with disabilities.

Sample

Participants were recruited from a larger quantitative study examining parental distress and timing of CL/P diagnosis at a Northeastern urban children's hospital. When data collection began in Spring 2013, the larger study included 105 participants (73 parents who received a prenatal diagnosis, and 32 parents who learned of their child's diagnosis at birth). We used a convenience sampling strategy (nonprobability sampling technique where participants are selected because of their convenient accessibility) to recruit fathers from this sample. The first author sent a letter describing the study to fathers in the larger sample with a stamped postcard to mail back if they did not want to be contacted; two fathers returned postcards. Seventeen fathers agreed to participate (10 with a prenatal diagnosis and 7 with a postnatal diagnosis).

Children were between 1 and 4 years old, and all had CL/P without any additional health problems. Nine out of 10 fathers who received a diagnosis prenatally were White and between 30 to 52 years old. Five had college or graduate school degrees, 4 attended some college, and 1 was a high school graduate; all were employed full-time and married to their partners with a mean relationship length of 11 years. None reported receiving psychological or psychiatric help during the previous 12 months; all had one child born with CL/P. Eight fathers had children born with isolated cleft lip palate and two with isolated cleft lip.

Seven fathers whose children were diagnosed at birth were interviewed; however, only 5 returned their demographic surveys; they were White, and their ages ranged between 24 to 43 years old. Two completed college or graduate school, 1 attended some college, and 1 was a high school graduate. Four were employed full-time, and 1 was employed part-time. All but 1 was married with a mean relationship length of 11.4 years. One father received psychological help in the last 12 months. Five fathers had children born with isolated cleft palate, and 2 had children born with isolated cleft lip.

Data Collection

The Institutional Review Boards at the Children's Hospital of Philadelphia and Drexel Uni-

versity approved this study. After fathers provided informed consent and completed a demographic questionnaire, a semistructured interview was conducted. Face-to-face interviews occurred whenever possible; fathers had the option of a telephone or web-based interview. Interviews lasted between 25 to 50 min. Each father received a $20 gift card after completing the interview. Two fathers were interviewed in-person, 1 was interviewed over the Internet, and 14 were interviewed on the telephone. Interviews were audiotaped and transcribed verbatim.

Fathers used pseudonyms to ensure anonymity. The first author conducted interviews and kept memos after each interview, summarizing what fathers discussed and personal reactions. Interviews followed a semistructured interview guide (see Table 1) that focused on timing of the diagnosis, birth experience, first year of life, family reactions, and relationships.

Data Analysis

Thematic conventional content analysis (Braun & Clarke, 2006) was used to analyze the data. Audiotaped interviews and memos were transcribed verbatim. MAXQDA (2010) software was used to organize codes, categories, and themes that emerged from text segments (Braun & Clarke, 2006). Major themes were described by more than half of fathers. Data were analyzed independently by three researchers (first, second, and fourth authors) and again as a team. When disagreements occurred, the team discussed them until consensus was reached.

Credibility

During member checking, an e-mail summarizing findings was sent to fathers (Creswell, 2013). Two out of 17 fathers reported themes capturing their experiences. Other methods to establish credibility included prolonged engagement with the data and maintaining an independent audit trail (i.e., description of the research steps taken).

Findings

The following four major themes emerged: (a) first hearing the diagnosis, (b) taking care of a baby with cleft, (c) future concerns, and (d) reflections. In the next section, themes are described and illustrated with anonymous quotes using pseudonyms fathers chose.

Theme One: First Hearing the Diagnosis

Fathers in both groups reported feeling shocked, worried, and sad upon first hearing the diagnosis. They worried about CL/P repair, impact on feeding, speech, neurological functioning, severity, surgeries, appearance, and social stigma. Despite this, most fathers said CL/P was not a "huge concern" because it was more of a "cosmetic" issue.

Table 1
Semistructured Interview Guide for Fathers

1. Tell me the story of how you found out about your child's cleft. Was she/he born with other health problems in addition to the cleft?
2. What were your concerns then? What are your concerns now?
3. How prepared were you in general for your baby's arrival at the time of birth?
4. Describe your (thoughts) feelings during the first month of [child]'s life.
5. Describe your (thoughts) feelings after [child] had his/her first surgery performed.
6. Has this experience of having a child with CL/P been stressful for you?
7. People have many ideas about what causes a cleft lip. What are your thoughts about what may have caused your child's cleft lip? 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 participants with prenatal diagnosis only.)
8. Would you have preferred to know prenatally? (Asked of participants with postnatal diagnosis only.) How did having a prenatal diagnosis help you explain to your family that your baby would be born with a cleft lip? (Asked of participants with prenatal diagnosis only.)
9. If you were talking to someone as a parent, what would you advise him or her? What did you learn from your experience that was most helpful to you?
10. What was the biggest challenge for you in this process?

Note. CL/P = cleft lip and/or palate.

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Fathers who received a prenatal diagnosis experienced more distress if medical providers could not fully answer questions. They were also concerned about other syndromes, severity of CL/P, children's appearance, and social stigma.

Most fathers who received a prenatal diagnosis said providers' demeanor and accuracy while delivering the diagnosis affected them. Frank said the doctor initially misdiagnosed his baby with Trisomy 18 and encouraged an abortion. After going through additional testing, his child was correctly diagnosed with CL/P:

> . . . he didn't offer us any explanation . . . he was about as closed to questioning as anybody I have dealt with.

Fathers of children diagnosed with CL/P at birth also described the importance of providers' demeanor, especially when first seeing their babies. Larry said, "She was a Caesarean section . . . when the doctor pulled the baby out, she covered her up right away because she didn't want our first view of the baby to be that."

Five out of seven children diagnosed at birth were born with isolated cleft palate, which can be difficult to diagnose at birth. Consequently, two fathers had to wait for their children to be correctly diagnosed. Junior said,

> We had been discharged . . . she got readmitted because of failure to thrive. It was after being readmitted that the night nurse . . . noticed something . . . a couple days after delivery they finally realized what it was, but we had been sent home.

Fathers in the postnatal diagnosis group worried more about social stigma and treatment. Larry said, "Were kids going to make fun of her . . . kids when they see her . . . they're going to ask what's wrong with her mouth." Thus, these fathers wanted to learn about treatment options to prevent their children from experiencing social stigma. Brandon said,

> How to proceed; what the next step would be as far as do we have surgery right away? Do we wait 6 months, a year, 2 years before he's able to get surgery? I just wanted to make sure he was not going to go through this during his early stages of school . . . I didn't want him to be made fun of.

A minor finding was that 2 fathers in the postnatal diagnosis group experienced self-blame. Jack's wife went through several years of fertility treatments: ". . . in the back of your head, when you're going through all the fertility treatments, you're . . . doing . . . a mini-risk analysis."

Fathers in the postnatal diagnosis group seemed to have more positive attitudes, despite being surprised by the CL/P diagnosis. One father said he was happy to finally have a child; another said his son was in good hands and God was protecting him; and another was happy CL/P was only in the palate, and not the lip so it was less visible.

Theme Two: Taking Care of a Baby With Cleft Lip or Palate

All fathers reported "bodily instincts" kicked in after the birth. Darth said,

> I was relieved to find out it was so small. The doctors did a bunch of tests on him right away . . . they can tell how far the cleft went . . . everything was going to be pretty much fine.

Fathers in both groups reported CL/P did not change love for their babies, even though it took time to adjust. Ben, whose child was diagnosed before birth, said,

> . . . when he was born and even when we saw the cleft before it was fixed, it . . . 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.

Concerns about feeding emerged for all fathers, especially if hospital staff was not trained for CL/P care. All fathers were concerned about children receiving anesthesia during surgery; they did not want their children experiencing pain. Brandon said,

> 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 scariest part for me.

Trusting the treatment team reduced fathers' levels of stress. It was also reassuring if their children seemed content before the surgery. Most fathers were happy with the changed physical appearances of their children. Bill thought his son "looked like he was supposed to look" after the surgery.

In addition to learning more about CL/P, fathers whose babies were diagnosed prenatally felt more prepared for treatment. Before the birth, they met the treatment team and bought special feeder bottles. They had time to avoid feeling shocked and surprised in the delivery room.

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Learning how to use special feeder bottles was especially difficult for fathers whose children were diagnosed at birth. Junior said that his baby was the first CL/P case at the hospital; bottles had to be ordered. Consequently, he had to feed his newborn with syringes. When bottles arrived, hospital staff did not know how to use them.

Fathers who received a diagnosis at birth said they were prepared to welcome their babies. Paul said, "I think we were very prepared. I mean we both had established careers and we had a home and financially we were secure."

Theme Three: Future Concerns

Fathers in both groups were concerned about upcoming surgeries and social stigma. Fathers whose children were diagnosed before birth hoped that after going through surgery their children would not be bullied because of visible differences. Some worried surgical scars would make them a target, especially if combined with other differences. Ben, whose child received a prenatal diagnosis said,

> I guess developmentally he's a little smaller . . . so we're a little concerned he might be a bigger target for a little bullying . . . And if there's any scar left in his lip, that makes him an easier target.

Fathers whose children were diagnosed at birth were more concerned about children's delayed speech and neurological development. Joey's daughter was not saying her vowels yet, making it hard to communicate. Junior's daughter's speech regressed after CL/P surgery: He said,

> . . . she's not communicating . . . sometimes it's hard to know if she's refusing to communicate, if she's being stubborn . . . or if she's just choosing not to. . . . just simple yes and no . . . it'd be nice to not have her have to point or have a tantrum.

Theme Four: Reflections

All fathers learned how to put things into perspective and were grateful that CL/P was all they were dealing with. It was important to get the best possible results because "this world is a visual world." All fathers described learning how to be patient and to trust the treatment team. Francis said, "Make sure that you are 100 percent confident in your medical professionals. . . . if you go somewhere and you're not comfortable with them, go somewhere else." Sometimes, it was difficult because they wanted treatment to be completed as quickly as possible. Bob said, "I don't know, perhaps I'm a typical male. I just wanted to fix things. It can't happen that quickly." Even so, fathers in both groups were happy with outcomes of treatment.

Fathers whose children were diagnosed before birth described the importance of getting a second opinion and choosing a hospital equipped for CL/P care. They reported this experience taught them that being a parent is a big responsibility. It is never the "perfect" experience you dreamed it would be, but is worth it.

The fathers who learned about the diagnosis at birth described new realizations about themselves and their families, especially asking for and receiving support from others. Although initially stressful because of the lack of time to prepare, 2 fathers said, "things go back to normal eventually".

Larry and Paul learned more about their partners. Larry learned about the importance of checking in with his wife to determine whether something was bothering her, asking what she learned at doctors' appointments, and giving each other respite when needed. Paul realized it is important to have a strong relationship before having children:

> Make sure you're in a good relationship. Make sure . . . financially secure and have a job and have a good wife and have family support because, you know, once the kids start coming, it . . . gets a little chaotic. . . .

Discussion

This descriptive qualitative study extended the literature by examining how timing of a child's CL/P diagnosis affects fathers. Fathers in both groups reported experiencing personal growth as a parent, illustrating positive coping and resiliency. They gained new perspectives about health, parenting, and relationships. Fathers tended to view CL/P as cosmetic and fixable in the United States, illustrating a positive appraisal of the problem and the American health care system. Our findings also suggest that there are similarities and differences among fathers raising a child with CL/P that are based on timing of the diagnosis.

Similar to mothers in prior studies, fathers in both groups reported feelings of shock, worry,

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and sadness when they first learned about the CL/P diagnosis (Johansson & Ringsberg, 2004). A minor finding was that 2 fathers whose children were diagnosed at birth reported self-blame and wondered if they did something to cause CL/P. Although self-blame has been reported by mothers in both diagnosis groups (Baker et al., 2009; Davalbhakta & Hall, 2000; Knapke et al., 2010; Nelson, O'Leary, & Weinman, 2009), fathers experiencing self-blame has not been reported in previous studies.

Fathers in both groups described the importance of health care providers' demeanor and accuracy; it either eased or exacerbated stress. Stock and Rumsey (2015) also reported that hospital staff's lack of knowledge about CL/P can be stressful for fathers. Social stigma and upcoming treatments were two salient current concerns for all fathers. Stock and Rumsey (2015) similarly reported that social stigma is a common concern among fathers.

Fathers whose children were diagnosed before birth worried more about neurological functioning and severity of cleft. The fathers whose children were diagnosed at birth additionally reported worrying about delays in speech and development, which is not uncommon among children born with CL/P. In our sample, three out of seven children diagnosed at birth with cleft palate were in speech therapy and two had significant speech delays. Conrad, Richman, Nopoulos, and Dailey (2009) reported children with cleft palate are more likely to experience delays in neurological functioning compared with children with any other type of cleft. Recommended that health care providers delivering the diagnosis also provide psychoeducation about the possibility of their children having learning disabilities in the future.

Similar to studies with mothers, fathers in both groups reported that the first months after birth was the hardest; however, it became easier over time. Fathers also said being patient while navigating the treatment regimen in the first year was helpful, which is similar to findings reported by fathers in the recent study by Stock and Rumsey (2015). Fathers' experiences are an important example of growth that can take place after an expected (prenatal CL/P diagnosis) or sudden (postnatal CL/P diagnosis) crisis (McCubbin & McCubbin, 1993).

Limitations

Fathers in this study were predominantly White, most had college or graduate degrees, were married to their partners, and worked full-time; our sample lacked racial and socioeconomic diversity. Most interviews occurred on the telephone, which prevented a consideration of participants' body language and facial expressions. Yet, as Phares, Lopez, Fields, Kamboukos, and Duhig (2005) noted, engaging fathers in research can be challenging because of work and family commitments, and conducting interviews on the telephone or using the web can be an effective strategy for including fathers in health-related research. Additionally, only 2 fathers responded to the member-checking procedure. It is possible that fathers were busy with work and taking care of their children.

Implications

Future research should examine the experiences of fathers, coping strategies, problem appraisal, and resources (Fox et al., 2015; Zvara et al., 2013). Future studies should include diverse samples and prospective studies to more fully examine how parental adjustment is associated with child and family adjustment to CL/P.

On the basis of our findings, we recommend providing families with referrals based on timing of the diagnosis and developmental trajectories. Course of treatment, feeding, and social stigma were major sources of stress for all fathers. All providers can offer anticipatory guidance regarding how to address social stigmatization; for example, providers can help parents practice a brief explanation about their child's condition when asked about their child's appearance or in response to staring. They can also be informed that modeling appropriate responses to questions from others can help them to teach their child how to answer CL/P-related questions with confidence. Finally, fathers can be informed of the availability of behavioral health providers should their child encounter future teasing or bullying and how they can monitor and address any teasing as soon as it occurs.

Some fathers discussed the lack of information about CL/P in maternity wards, leading to a delayed diagnosis for the postnatal diagnosis group and difficulty feeding their children. All

nurses and doctors in maternity units should receive CL/P training.

Regardless of when a diagnosis is made, our findings suggest that fathers could benefit from (a) health care providers' calm demeanor when first delivering the CL/P diagnosis because it affects how parents perceive the CL/P, cope, and problem solve; (b) a consultation with a behavioral health provider to process emotional reactions, promote use of adaptive coping skills, and address concerns about social stigmatization and the psychological impact of CL/P; and (c) family-centered approaches to treatment that include ongoing support from the team and other parents of children with CL/P.

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