

Mothers' Reflections on Raising a Child With a Craniofacial Anomaly

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Objective: To conduct a qualitative evaluation of parenting among families with school-aged and young adolescent children with craniofacial anomalies (CFAs).

Methods: Interview responses were obtained from nine mothers of children ages 9 to 14 years old with CFAs. Mothers were asked to describe their perceptions of their children, their children's special needs because of CFAs, and their parenting strategies. Narratives were coded into categories, including maternal concerns and worries, children's strengths, proactive maternal behaviors, and role of CFAs in the families' lives.

Results and Conclusions: Mothers' responses indicated concern and protectiveness because of the challenges of having a CFA, as well as parenting strategies intended to promote autonomy and positive social and emotional adjustment.

KEY WORDS: *adolescents, children, craniofacial anomalies, parenting, psychosocial adjustment*

The psychosocial well being of children with craniofacial anomalies (CFAs) has received fairly extensive attention in the research literature, demonstrating generally good adjustment but with heightened risk for internalizing problems and social difficulties (Endriga and Kapp-Simon, 1999). Despite evidence from normative groups that parenting can prevent or alleviate psychosocial problems (e.g., Galambos et al., 2003), there is little research on parenting of children with CFAs, and much of it is focused on infants and young children (Speltz et al., 1995).

Understanding the range of parenting for school-aged and adolescent children with CFAs is important because this age group is expected to increase in autonomy, forging positive relationships outside the family in preparation for adulthood. Parental behaviors and attitudes may assist in this process. Existing studies on this group provide scattered information about quality of parenting. Several studies have described parenting that may be problematic, including a tendency for parents to overprotect, discourage autonomy, and be more permissive and tolerant of behavior problems (Richman and Harper, 1978; Tobiasen and Hiebert, 1984; Pillemer and Cook, 1989; Benson et al., 1991). Parents of children with

CFAs have also been described as less accepting of their children and more anxious about their children's futures (Branley and Clifford, 1979). One study described positive parenting strategies that were associated with better social outcomes for preadolescents with CFAs, including active encouragement and management of children's interactions with peers. Another study (Pope and Ward, 1997) also identified parental attitudes (i.e., excessive worry) that were associated with worse social outcomes.

It is difficult to interpret differences in parenting between CFA and normative families without a broader understanding of how these families function. In particular, we must consider that atypical parenting, in comparison with normative groups, is not necessarily maladaptive but may constitute a responsive and sensitive approach to a child's specific needs (Speltz et al., 1995). Fully understanding parenting choices requires knowing the context in which these decisions were made. Parents' perceptions of their children's strengths and weaknesses, perspectives on their children's specialized needs because of having a CFA, ideas about their role in helping their children overcome challenges, and the impact on family life of having a child with a CFA are all part of this context.

The purpose of this study was to conduct a qualitative evaluation of parenting among families with school-aged and young adolescent children with CFAs. Our method involved examining narratives of interviews with mothers in order to provide a rich, textured account of mothers' views of their parenting experiences. We anticipate that this narrative study can contribute to future hypotheses for empirical study while enhancing the understanding among professionals who work with these families. The study offers a glimpse into the hearts

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and minds of mothers as they work to find ways to provide for their children's ordinary and extraordinary needs.

METHODS

Participants

Participants were nine mothers of children (four boys, five girls) aged 9 to 14 years old (mean age = 11). Children's diagnoses included cleft lip and palate ($n = 4$; 1 with hypertelorism and hydrocephalus), hemifacial microsomia ($n = 3$; 2 with microtia), Apert syndrome ($n = 1$), and achondroplasia (short-limbed dwarfism) ($n = 1$). Ethnicity of all participants was Caucasian, and all were from middle to upper-middle socioeconomic status.

Procedure

Mothers were recruited by sending letters to the membership of a regional support organization for individuals with CFAs and their families. Volunteers were interviewed in their homes. This study reports on a subset of information gathered as part of a larger study. This study was approved by the Institutional Review Board of the medical center where the children were patients. Participating mothers provided written informed consent.

Maternal Interview

The maternal interview was developed to allow mothers to speak freely about their perceptions of their children with CFAs and of their thoughts about parenting. A standard set of questions was asked (see Appendix), and probes were used to encourage complete answers to the questions.

Data Analysis

Audiotapes were transcribed verbatim and categories were created to examine ways in which mothers thought about their children. Transcripts were read in their entirety by two independent coders (E.G. and J.T.), and coding categories were developed in consultation with the first author (T.K.). The data were analyzed based on a modification of the coding system described in Krueger (1994). This inductive approach involves several steps, similar to guidelines recommended by others in the qualitative research field (e.g., Vaughn et al., 1996). First, a preliminary set of analytic coding categories based on theory and a review of all transcripts was established. Applying an "open coding" strategy is recommended (Padgett, 1998) for use with an inductive method to best capture the themes among participants and not be limited by *a priori* categories. In line with this, appropriate maternal quotes were identified within categories to further define themes. Agreed-upon categories (maternal worries and concerns, maternal perceptions of children's strengths and positive attributes, and the role of CFAs in the children's and families' lives) were then used as the

TABLE 1 Coding Categories and Subcategories

Maternal worries and concern	
●	Physical/medical/safety—Concerns about how surgeries or procedures interfere with the child's or family's life and concerns about the child's physical safety. Interferences can be added stress, pain, and suffering of the child or the way the medical issues impose on or change the family's life (e.g., going to the doctor may make it hard for the family to do other things). Safety includes physical injury (e.g., head injury) or being protective of the child more generally (e.g., not letting the child do things alone that the mother may let a sibling do).
●	Social exclusion/teasing/reaction of others—Concerns about the child being left out of activities in the classroom by peers or social or occupational groups and other concerns about rejection, teasing from peers, or general reactions of people (e.g., staring).
●	Forming social relationships—Concerns about the child's ability to form positive relationships with peers or others because of the CFA and related disabilities.
●	Emotional well being—Concerns related to the child's self-esteem and psychological well being.
Maternal perception of children's strengths and positive attributes	
●	Sociability/peer relationships—Positive statements about the child's relationships with peers and others or relating in general. These statements are often about peers, but they can be more general about the child being social or well liked.
●	Determination/perseverance—Seeing the child as determined, persistent, or driven in achieving goals or working to overcome challenges. This includes particular examples as well as more general descriptions (e.g., "She is very driven").
Maternal proactive behaviors	
●	School related—Actions the mother takes to support the child's success at school. This includes speaking to the child about school issues, meeting with teachers and school personnel, and seeking appropriate school placements.
●	Social/peers—Actions the mother takes to help the child succeed with peers or in the general social domain. This includes facilitating playdates, encouraging the child to seek out peers, enrolling the child in activities with other children, helping the child through negative peer experiences, and boosting the child's self-esteem.
●	Encouraging independence/letting go—Actions the mother takes to support the child's independence, either proactively or in response to a child's request.
Role of CFA in child's or family's life—Statements about how the CFA defines the child and family or how it fits into the child's life. These are often broad or general statements about how having a CFA affects the child's life, at least from the mother's point of view. These can include statements about how a mother handles the CFA in her own life.	

organizational framework for coding all transcripts. Within each broader code, subcategories emerged from the data and were agreed upon by the coders (Table 1). Once this framework was established, two coders reviewed each transcript independently for reliability purposes. Coders organized quotes into the theme categories and then met to compare their codes. The first author read over all coding decisions, and coding discrepancies were discussed to agreement among the first author and the two coders. Reliability was above 80% for all codes.

RESULTS

This study was exploratory, a first step in understanding how mothers think about their children with CFAs. The results described below look first at how mothers view their children's strengths, challenges, and vulnerabilities in the context of having CFAs. Next, we report on maternal actions taken to address

each child's unique needs at home, at school, and in the social world. Finally, each mother articulated how her child's CFA has been incorporated into the child's and family's lives.

Maternal Concerns and Worries

All mothers expressed worries about at least one aspect of their child or their child's life because of the CFA, including physical well being, being teased or excluded from social activities, and the child's emotional health.

Physical and Medical Safety

Every mother reported concerns about her child's physical safety, usually because of the CFA, related medical problems, or surgeries and medical procedures interfering with the child's and family's lives.

The many surgeries children with CFAs experience lead to maternal worries about the children's physical and psychological well being. One mother expressed a commonly conveyed worry regarding the risks of surgery and whether to opt for an elective surgery:

I just feel like there's no surgery that's worth it if it's elective, if God forbid something horrible happens. So I'd rather him be like he is and have the face he has.

Another mother, whose daughter has a bilateral cleft lip and palate, orbital hypertelorism, and hydrocephalus, worried that the intrusiveness of multiple and frequent surgeries and medical appointments would have a negative effect on her daughter's emotional health:

Our bodies are the most private things about us. Because of the obvious nature of [the CFA], there's no hiding it, no privacy.

Another commonly expressed concern was of the child getting hurt while participating in typical child activities:

When she has her . . . soccer practice. . . I'm the only parent that stays the whole time. . . Just in case something happens, I'm there. I'm a little more overprotective with her. . . Oh, if she ever gets hit in the face with something, I would die, I think. . . To have to go through mouth surgery again.

Just 'cause he could get hurt more. . . He loses his balance, he goes under, he's not a good swimmer. So, it's just, you have to be more aware.

Heightened protectiveness is a theme that was expressed by many of the mothers. One mother said:

I pay a great deal of attention to his physical health just 'cause, you know, I'm aware there's so many things that we really have to watch carefully.

Exclusion and Teasing

All mothers expressed concern about their children being left out of activities in the classroom or with peers or excluded by social or occupational groups, whether their children were actively excluded or physically incapable of participating. Other concerns about rejection included teasing from peers or general reactions of strangers or others (i.e., teachers) to their children. A mother whose son has a cleft lip and palate said:

It was terrible. He would call kids, they wouldn't return his call. . . So we went through all of fourth grade not being invited to birthday parties, nothing. I mean no play-dates.

Even for children who are doing well with peers, mothers expressed concerns about the future, especially as adolescence approached:

I see the tendency of these girls to put so much emphasis on looks. . . They read magazines, they do their nails. And I'm thinking. . . all it would take would be for one kid to latch on to this and then it could really turn things around in a very bad way for her.

Dating. I do worry about that. . . I think there's definitely someone out there for her, but I do think that. . . it would take a probably pretty extraordinary teenage boy to overlook [her CFA].

The mother of a son expressed similar concerns regarding physical appearance hindering his future:

Will he get a chance to be an attorney 'cause he looks different?. . . If there's two people going for this one job is this gonna be something that he can't help, that can't be changed?

In particular, mothers of boys discussed concerns about their sons being left out of peer groups. This was often related to the boys' lack of abilities to play sports. Even when the boy played a sport, it was often at a lower skill level than his peers, or he played on the team but was not accepted fully into the group. This raises special concerns for boys, who tend to form large social groups during these years, often based on sports. The mother of the boy with Apert syndrome noted:

They're just faster than him, quicker. So it's hard. . . They wanna do their thing and he can't keep up. So he usually stays with a lot of younger kids.

Many mothers expressed concern that their children would be teased, because, as one mother said, "They're just an easier target." Mothers discussed worries about school and social situations with peers as well as the stresses of being in public and handling the stares or taunts of strangers. The mother of

a child with Apert syndrome described the stress of protecting against the taunting of others:

A trip to the ball game. Usually it's really fun, and he has a great time. . . But. . . you could get someone really mean two rows away from you and some people are really. . . cruel. I'm not talking little kids who don't know what they're saying. . . I mean adults.

Four of the mothers expressed entering a new school as a cause for concern. A child who is new is vulnerable to being teased as a newcomer who looks different. As her child was entering middle school, one mother said:

[I am worried about her] just finding a pool of potential friends. . . who are going to get by the way she looks.

Emotional Well Being

Perhaps the strongest concern for mothers was their children's emotional health. As one mother said:

I'm very concerned with his emotional health. . . I realize that it's so important that he feel good about himself.

Interestingly, a common theme was a fear that the child was internalizing negative emotions. Several mothers wondered what they could do to help their children express emotions successfully, and four mothers worried whether their children were emotionally intact, even when the children gave every appearance of being well adjusted. For example, a mother of a boy with hemifacial microsomia wondered:

Is there anything I should be looking for? . . . He doesn't really discuss it and he must internalize something. I mean, everybody looks in the mirror every day.

The mother of a child with cleft lip and palate expressed similar concerns:

It really doesn't bother him if people stare and say things. . . which sometimes worries me because I think he keeps a lot inside. He just doesn't say it.

In summary, mothers expressed a range of concerns about their children, from physical injury to social exclusion. Many of these worries involve social acceptance, whether it is their children being welcomed and included by peers now or being successful in the career world later. In all these concerns, mothers voiced the reality that having children whose medical conditions cannot be hidden intrudes on their children's privacy and makes them vulnerable to discrimination in myriad ways.

Children's Strengths

Mothers spoke eloquently about their children's strengths, particularly about positive attributes that helped a child overcome challenges or limitations attributed to a CFA. Two main themes emerged in this area: (1) determination and perseverance and (2) social adeptness.

Determination and Perseverance

Six of the nine mothers discussed their children's determination and perseverance in overcoming challenges and limitations attributed to CFAs. These characteristics were often illustrated through physical activities. A mother described her 10-year-old daughter's determination to do several activities despite physical limitations:

When she wanted to learn how to do the monkey bars. Her physical therapist called us and told us [the child] really wants to do this. So every day, for maybe 6 weeks to 2 months. . . she and my husband went to the park and did the hand-over-hand thing. She has a minimum of 2 years gross motor skill delay. . . She learned, she did it independently twice, she got a blister, and that was the end of it.

Another way that determination was recognized was in terms of a child's future:

When she decides she wants something, she usually goes after it. So I would imagine that whatever she decides she wants to do, whether it's music or getting into a really good school or becoming a world traveler, I think she will do it. She's extremely determined and she doesn't let anybody tell her her business. Which I've always thought that was really a plus for someone like her who is disadvantaged in a sense, through no fault of her own. She just has really a lot inner resources.

The mothers in these examples see their children as resilient in the face of enormous challenges, both physical and psychological, from their CFAs.

Sociability

Seven of the nine mothers expressed being proud of, and perhaps relieved by, their children's social adeptness. Mothers used words such as "outgoing," "charming," "sociable," "well liked," and "confident" to describe their children. A mother of a 10-year-old with achondroplasia said:

He is funny and smart and charming. . . and wonderful. He is just little. That's all, it's not a big deal. . . He likes people. He's a real people person. In fact, he needs to be around people all the time.

Similarly, a mother of a daughter with hemifacial microsomia and microtia of the left ear said:

She's very kind hearted and very sociable. . . And she leads the way a lot because she's a very strong person. . . She doesn't dwell on things, like all these surgeries she's had.

Clearly, the mothers articulated their beliefs in their children as strong, determined people who have the inner strength—whether it was from being a social person or being persistent—to overcome the obstacles in their way.

Proactive Maternal Behaviors

Mothers reported a range of proactive measures taken to support their children, such as helping a child handle staring or teasing; talking to teachers at school before school starts; facilitating playdates and peer relationships; and supporting the child's emotional health, including deciding when to let go and encourage independence in the child.

School Related

Seven mothers described contacting a teacher or principal in their children's schools about the needs of their children, including how to help other children understand their conditions. This was a common approach to easing the path into school in terms of the child being accepted and not teased and having any special learning needs met:

One of the things I've done, every time we've moved, is an in-service for the teachers. Because my feeling was that if I informed them and educated them, then if somebody had a question in his school, they could give an honest answer about him.

Peer and Social Related

All mothers discussed their involvement in helping their children in the social realm. Maternal roles involve facilitating peer relationships, finding support groups for their children, and helping children in negative peer situations (e.g., teasing). Mothers encouraged friendships by setting up playdates, placing children in after-school activities, encouraging children to seek out friends, and fostering relationships with families of children with CFAs. One mother said:

Any opportunity she would have to cultivate friendships [I encourage]. Like if she wants to have a playdate, immediately I say 'They could come over'. . . I've told her many times to feel free to invite anybody from school you'd like to. I'll even pick them up, whatever is needed.

Several mothers discussed another proactive role, supporting their children when talking about the CFAs to other children:

We were in a baseball field and some people came walking up and said, 'Oh, what happened to you?' I tell them, 'He was born this way.' And then I'd say, 'Wait 'til you see him hit a ball.' I would try to emphasize the similarities of how he was the same as them. It always worked.

Another mother responded to staring:

I tend to be very aggressive about it. . . I'll say, 'Do you have any questions? Can I help you answer it?' Often if it is an adult, I confront them, hostilely, angrily. She doesn't mind that; she does mind when I bring it out in the open, sometimes with kids.

Another way mothers bolster success in the social and emotional realm is helping children feel good about themselves. Many mothers reported enrolling children in support groups, showing them pictures of themselves as babies, or talking to them about their CFAs in positive ways. The mother whose son has achondroplasia described her approach to helping her child fit in:

I get a lot of alterations done on his clothes to make him look as good as you can. You shop all over town to find the cool sneakers the other kids have. You do everything you can so that he can just walk around like everybody else can.

Encouraging Independence

Six mothers reported actions taken to encourage independence in their children. This can be especially hard for mothers of children with CFAs, where the desire to protect the child must be overridden by the mother's knowledge that her child is getting older and needs to be more autonomous. The two main themes that emerged were letting a child make his or her own decisions, especially about elective surgeries, and providing opportunities for the child to handle situations on his or her own (e.g., walk to a friend's house or a corner store, answer questions about the CFA). The mother of a 14-year-old boy with hemifacial microsomia enabled her child to respond to staring in a self-sufficient manner:

With staring, he deals with it more than I do. I see it and I experience it, but we've always taught him to provide one-sentence honest answers to people.

Another mother of a child who has hemifacial microsomia discussed surgery decisions:

. . . they wanted to do another surgery. . . But I would never make decisions for her now. I think, at almost 12 years, she knows enough [to make decisions].

This same mother, discussing her child's future, talked about letting her make her own decisions in general:

I don't have to push her. . . She decides what she wants to do.

Mothers often spoke reluctantly about learning to let go in large and small ways. The conflict involved in letting a child gain independence is poignantly evident here, as a mother discusses the fear of her child getting hurt doing physical activities, yet knowing she needs to give her space:

I tend to feel like I should always be there with her. And yet I do let her go. . . But it just breaks my heart to do it.

Mothers also encourage independence in concrete ways. Four mothers reported giving their children the freedom to walk alone to a friend's house or a local store or to venture out on a bike ride. Moreover, one mother reported that she and her husband encourage more independence in their child with hemifacial microsomia than in their other children:

I think we push him more to be more independent than our other children. My husband and I discussed the fact that we think his self-esteem is probably better intact than our middle son's.

Mothers clearly take an active role in their children's social and emotional lives in a variety of ways, from meeting with school personnel, handling staring and teasing, and promoting friendships to actively supporting their children's emerging needs for independence. In fact, several mothers reported being more active in these areas with their children with CFAs than with other children in their family.

Role of CFAs in Children's and Families' Lives

The final piece of this study aimed to understand how raising a child with a CFA defines people's lives. Some mothers felt simply that "this is life and this is how we're gonna do things," whereas one mother said that medical issues "are the defining thing in our dealings with the outside world" and "[my child's] CFA affects every aspect of her life." Some reported treating such a child more gently than siblings, whereas others reported being more strict. This theme was evident in every interview.

Medical issues can be consuming of family life but may be episodic:

[Early on] your life is centered around [the CFA]. When a child is born with a cleft lip and palate, your life is centered around feeding. . . But now, it's like nothing. It just means a couple of extra doctors' appointments in the city.

[Without these medical problems] then you could just

go places. . . For the first 3 or 4 years we couldn't even make plans. You're invited to a wedding, you couldn't even respond if you were going 'cause you truly didn't know. Your life was totally in that hospital. . . you just didn't live like other families.

The timing of surgeries defined this second family's life for several years. The mother noted the challenge of balancing time among multiple children, a concern expressed by other mothers. Several mothers labeled time constraints due to medical protocols as a major obstacle for the entire family.

Another way that having a child with a CFA affected families was through parenting practices. Some mothers described the need for a more intensive style of parenting:

There are certainly. . . different responsibilities than a parent of a typically developing child has. From deciding, very early on, what medical treatments, how to pursue educational options, social issues, everything is different. And it really is a different country and almost a different world sometimes. . . From the time [my child] was 2 weeks old we started dividing everybody. . . into people who either got it or didn't get it.

You have to be a much more hands-on kind of parent. There's been an awful lot of medical stuff. He was in a body cast from age 13 months to almost 4 years, so he didn't walk until he was almost 4. So we had to carry him a lot. Then he had his legs lengthened when he was 7. And that meant he was wheelchair bound for a couple of years. And then he had the stuff on his jaw. Still we go to the doctor a lot. So it's been a lot of work. . . But it's been enormously rewarding, too.

Although many mothers discussed their children's CFAs as defining the families in a variety of ways, there was an overriding sense that challenges could be managed. As one mother described:

You obviously have medical bills, and you have people who don't live near the city have to travel to the city and it affects your family. But I think it's what you make of it. And I think if you accept it, you make it okay. . . I think that the other thing is important is not to have so many 'Why me? days.' Keep them in perspective, have them, feel it, and go on.

Not only did mothers describe the rewards, but several discussed the CFAs as just one more part of the children—a defining feature that one mother says is similar to saying a "child has blonde hair." Another mother said of her daughter, "If anything, I think it's made her stronger and more resilient than if she didn't have it." And another described using visits to the doctor as a time to "chat" and be with her child. For several mothers, the children's CFAs were framed as not having a major impact on the children at this point in their lives:

I don't think having a cleft lip and palate plays a big role in her life. . . When she was born, all you saw was the cleft. You never saw what's right, you only saw what's wrong. Over time, you see all the kid, who she is. . . So I gave birth to a cleft child, but now, when I look at her, she's just [child's name]. She's not a cleft child anymore.

I never felt he had a handicap. I always felt that he was able to do everything like every other kid was able to do, even though he had some physical restrictions. . . I've never not done something because of his condition.

The role that a child's CFA plays in a family and for the child varies in the eyes of the mothers. Much of this may be because of the complexity of the child's needs. The final quote comes from a mother of a child with Apert syndrome and illustrates the daily challenges of supporting her child:

[You never know] how others will react. Going to a place that kids love—an amusement park—that should just be a happy time. But when you go it could be a happy time or a disaster, you never know. Things that people take for granted could always go in opposite ways.

For this mother, and other mothers who have children with complex medical and physical needs, the CFA plays a prominent role in most activities the mother, child, or family does.

DISCUSSION

Mothers' responses to interview questions about their perceptions of their children and their parenting resulted in some clear patterns that, interestingly, are consistent with findings from some of the empirical work done with this population. Mothers in this study highlighted emotional and social adjustment, both identified by empirical studies as potentially problematic for children and adolescents with CFAs, as primary concerns. Mothers spoke about the challenges of CFAs for children's peer relationships, including prejudice regarding facial differences as well as physical limitations that affect children's ability to participate in age-appropriate activities. Mothers also voiced concern about the possibility of internalizing problems, wondering whether their children may be harboring inner distress and self-doubts. These mothers did not let worry paralyze them; all spoke of strategies they used to address social and emotional problems. In the social realm, mothers were deliberately more active because of the perceived heightened need of their children with CFAs, including encouraging children to interact with peers, inviting other children to play, and advising their children about how to handle social problems such as teasing and exclusion. Mothers were vigilant about the possibility that their children may be emotionally distressed because of various challenges resulting from CFAs; many of their efforts to provide normal childhood experiences appear to be in response to the goal of helping children develop a strong and positive sense of self.

Parental protectiveness, another issue targeted by the empirical literature, was a common theme throughout the interviews. Mothers described their concerns for children's physical safety, which they felt necessitated a certain amount of watchfulness. This was offset by a recognition of the importance of independence for this preadolescent age group; mothers spoke of various strategies they use to promote autonomy in their children. In contrast to previous studies of the CFA population, which have suggested that parents may be overprotective in a way that stifles development, these mothers appear to be consciously aware of the need to strike a healthy balance between the competing needs.

This may be the first study to report mothers' descriptions of strengths in their children with CFAs. Mothers expressed admiration for their children's determination and perseverance in overcoming challenges as well as for their children's sociability. Mothers' descriptions of their children's strengths were imbued with a genuine sense of pride and appreciation that stands in contrast to reports in the literature of poor parental acceptance of children with CFAs.

It comes as no surprise that mothers describe having children with CFAs as a life-altering process. Most acknowledged the challenges while describing a realistic acceptance of their life circumstances. Several mothers found positive aspects, for themselves and their children, of the children's CFAs.

Overall, mothers' interview responses showed them to be actively involved in providing parenting that is responsive to the individual needs of their children. Although all expressed concerns and worries, these appear to be realistic, and mothers use these concerns in thoughtful, creative ways to inform their parenting choices.

It is unclear to what extent the findings from this small group of highly selected mothers can be generalized to the broader group of parents having children with CFAs. All mothers in this study were from a majority ethnicity and middle to upper-middle class, all were volunteers, and all were members of a support organization; hence, these mothers may be particularly high functioning and may have benefited from the resources provided by the organization. Moreover, mothers may have been motivated by social desirability; however, their willingness to voice their anxieties suggests that they did not paint a completely rosy picture. Despite these limitations, this narrative study provides a complement to the existing research literature and may serve to inspire hypotheses for further examination. Future work will need to determine whether there are particular types of parenting strategies that are most adaptive for children with CFAs.

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APPENDIX Maternal Interview Questions

Interview material used in this study resulted from the following questions:

1. Describe what it is like to have a child with (child's diagnosis). (Probe: How do you think things might be different if your child didn't have this condition?)
 2. Do you think you've changed the way you parent because you have a child with (diagnosis)? (Probe: What do you do differently? What do you emphasize or focus on differently than you would have otherwise?) (2a) Do you do anything different as a parent with (child's name) because s/he has (diagnosis) than you do with your other child(ren)?
 3. What advice would you give to another parent who has a child the same age as yours, with the same diagnosis as yours?
 4. Are there things that are more difficult for your child because s/he has (diagnosis)? (4a) What does s/he do to cope with this? (4b) Do you do anything to help him/her with this?
 5. Describe your child. What kind of person is s/he? How is s/he like or not like other children his/her age?
 6. Think about your child in the future, as an adult. What do you think s/he will be like? How do you envision his/her life will be? What do you think s/he will do for a living?
 7. What role do you think you will have in making this happen?
 8. Is there anything you do for your child especially because s/he has (diagnosis) to help him/her feel more comfortable or successful in the world? (Probe: when meeting new kids, entering into a new situation, such as school)
 9. How important is it to you that your child has friends? To your child?
 10. What kinds of things do you do to help your child with friends?
 11. When you have to make decisions about how much independence to give your child, what kinds of things do you think about?
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