

## **Strengths, challenges, and relational processes in families of children with congenital upper limb differences**

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### **Abstract:**

Congenital upper limb differences are physical health conditions in which an individual is born with abnormalities of the upper limbs (i.e., arms, hands, and/or fingers). This article presents a qualitative study about the unique strengths, challenges, and relationship processes in families of children with congenital upper limb differences. Four in-depth focus groups were conducted with parents of children with congenital upper limb differences. Content analysis procedures were used to analyze the data. The results indicated the following: (a) The strengths and resources of these families included a belief in the human universality of differences, connections with similar families, reliance on a strong social support network, and humor; (b) the challenges the families faced included managing grief-related emotions, making medical decisions, and promoting the child's development; and (c) family relationships were affected through the parents' expression of emotion, opportunities for closeness, and relationships with other family members, such as extended family and siblings.

**Keywords:** congenital upper limb differences | families and health | chronic health conditions in children | family systems theory

### **Article:**

This article presents a qualitative study that explores the experiences of families of children with congenital upper limb differences—a chronic health condition involving a visible physical difference. What challenges do these families face in their daily lives and as they make meaning of their experiences? What resources do they draw on and what strengths do they develop as they cope with these challenges? And how are family relationships affected by the children's upper limb differences? To address these questions, we interviewed parents of children with upper limb

differences to examine the processes through which their families adapt to and make meaning of their children's conditions.

The term *congenital upper limb difference* describes a physical health condition in which an individual is born with abnormalities of the upper limbs (i.e., arms, hands, and/or fingers). The broad category of upper limb differences encompasses a wide range of conditions. According to the American Society for Surgery of the Hand (ASSH, 2006),

The differences can range from mild to severe. Examples of congenital abnormalities in the hand include: having more than or fewer than five fingers; fingers that won't bend; fingers that are too short, crooked, or webbed; and constriction bands on the fingers and/or hand. Examples of congenital abnormalities in the arm include: an arm that is bowed, bones and joints that have not formed normally, and a part of or whole arm that has not formed at all. Some of these differences are known to happen along with other problems, while some are isolated differences.  
(para. 1).

For mild differences, surgeries may not be required, and the individual with the upper limb difference can develop adaptive strategies to function effectively with the difference. More severe conditions may result in multiple surgeries to increase the functional capacity of the upper limbs. Upper limb differences that are part of a larger syndrome of chronic health conditions often co-occur with symptoms that affect the individual's other physiological systems (e.g., digestion, circulation, or cognitive development). Individuals who experience these latter conditions may require surgeries that target the upper limb difference in addition to surgeries and medical procedures for the related physical conditions. Upper limb differences may also be acquired after birth as a result of such causes as accidents or amputations (ASSH, 2006). However, all of the upper limb differences of the children whose parents participated in this study were congenital.

Rolland (1999) described a psychosocial typology that categorizes chronic health conditions according to five characteristics: type of onset (acute or gradual), course (progressive, constant, or episodic), outcome (fatal or nonfatal), incapacitation or the degree of impairment (cognitive, sensation, movement, stamina, disfigurement, and social stigma), and uncertainty (the degree of predictability of the course of the condition). Although upper limb differences represent a broad range of conditions, according to Rolland's framework the upper limb differences described in this article typically demonstrate an acute congenital onset, a constant course with possible episodic periods of exacerbation as a result of the child's development as he or she ages, and a nonfatal outcome. Depending on the individual's specific condition, the upper limb difference will demonstrate varying degrees of impairment (particularly in the areas of movement and disfigurement) and of uncertainty. We sought to determine similarities among families who face these challenges.

## **THEORETICAL FRAMEWORK**

This study is grounded in two theories: family systems theory and the family adaptation and adjustment response (FAAR) model (McCubbin, Thompson, & McCubbin, 2001; Patterson, 1988; Patterson & McCubbin, 1983). Family systems theory rests on several basic assumptions about relationship processes within families (Guttman, 1991; Nichols & Schwartz, 2004) and holds that the experiences of one family member affect the experiences of other family members. Therefore, a child's upper limb difference will have significant direct and indirect effects on other family members and their relationships. Family systems theory also suggests that each family will develop a set of rules that apply to how the family organizes around a child's upper limb difference (e.g., which parent is the primary caregiver or how the family responds when the child faces a surgery). In addition, family systems theory highlights the integral influence of the family system on each individual member's development. Together, these principles validate the importance of examining family processes within families of children with congenital upper limb differences to identify strategies that families and health professionals can use to promote positive development for these children and their family systems.

The FAAR model (along with the closely related double ABCX model; McCubbin et al., 2001; Patterson, 1988; Patterson & McCubbin, 1983) represents an application of family systems theory principles to the manner in which families respond to stressors. Patterson and McCubbin (1983) applied this model to explain family adaptation to a child's chronic illness. This model suggests that families grow either stronger or weaker over time in response to the stressors associated with the health condition. Families' perceptions of each stressor combined with the resources that are available to them for managing the stressor result in their vulnerability to that stressor. When families use resources to manage a stressor that they perceive to be manageable, they are likely to become more confident and adaptive. However, when the family is either unable to activate available resources or does not believe it has the ability manage the stressor, there will be an accumulation of the negative effects of stress, which can weaken family relationships.

The model asserts that the primary determinant of a family's response to a stressor is its coping capabilities (Patterson & McCubbin, 1983). *Coping capabilities* refer to the strategies the family uses to manage demands placed on it by stressors (Patterson, 1988). To cope, a family may draw on existing or new resources (Patterson & McCubbin, 1983). When the family is able to cope effectively with the challenges of the chronic health condition, the demands become more manageable. The family is then able to develop a coherent, adaptable meaning system related to the health condition and its related challenges (Patterson, 1988).

The FAAR model emphasizes the important role that resources play in determining the manner in which a family adapts to a child's chronic health condition. On the basis of the guiding principles of family systems theory and the FAAR model, this study aims to advance knowledge about the challenges and stressors faced by families of children with upper limb differences, the resources they use to cope with these challenges, and the manner in which these challenges affect family relationships.

## **REVIEW OF THE LITERATURE**

A search through various academic databases (e.g., PsycINFO, MEDLINE, and the CINAHL nursing database) revealed no existing research examining the family processes of children with upper limb differences. Therefore, this section presents a brief review of existing research that examines challenges associated with visible physical differences and the influence of children's chronic health conditions on their families.

Most of the existing research examining visible physical differences among children as concluded that children with visible difference and their families contend with some degree of internal or external stigma (Tam, Chan, Lam, & Lam, 2003). Joachim and Acorn (2000) explained that others may discredit a person with a visible difference on sight. Similarly, Longoria and Marini (2006) cited the tendency for observers of persons with visible difference to exhibit the *spread phenomenon*, in which children and adults further stigmatize physical impairment by assuming that cognitive disabilities accompany the physical difference. More positively, they hypothesized that the Americans With Disabilities Act has yielded more societal visibility for people with disabilities, and they associated this with data showing that with age children show increasingly positive impressions of disabled children's capabilities.

Specific to visible limb differences, Varni and Setoguchi (1996) examined perceived physical appearance in adolescents with limb differences and its connection with self-esteem. They demonstrated a connection between self-esteem, perceived physical appearance, and lower levels of depression and anxiety. They suggested that practitioners and families can mediate negative self-image in adolescents with limb differences by intervening to increase social support and other boosters of self-esteem. However, their findings are limited to individual reports and do not explore family system dynamics.

Families of children with limb difference and chronic conditions cope with an array of challenges and stressors with varying degrees of ease. The scope and ubiquitous nature of these stressors can become overwhelming. Areas of family life that may be affected include daily routines, developmental transitions, financial decisions, careers, friendships, school performance, parenting strategies, and sibling relationships (Stein, 1983). Some of the specific challenges these families face include tension in family relationships, disrupted family activities, time management struggles, high medical costs, disconnection from social networks, and difficulties interacting with the children's schools (Patterson & McCubbin, 1983). These challenges put family members at increased risk for psychosocial stress (Wallander & Noojin, 1995).

However, these stressors provide opportunities for families to develop problem-solving and coping skills (Patterson & McCubbin, 1993; Sallfors & Hallberg, 2003). Families who face a child's chronic health condition frequently use and develop numerous strengths and resources to manage the child's condition and its related stressors. Previous research has highlighted a number of resources that families may use to cope with a child's chronic health condition, including developing positive meaning systems (Garwick, Kohrman, Titus, Wolman, & Blum, 1999; Patterson & McCubbin, 1983); expressing positive feelings for the child (Heiman, 2002); seeking services and social support (Patterson & McCubbin, 1983); searching for information (Sallfors & Hallberg, 2003; Taanila, Jarvelin, & Kokkonen, 1998; Taanila, Syrjala, Kokkonen, & Jarvelin, 2002); and holding positive expectations for the child's development (Woolfson, 2004).

Once established, these resources may address challenges on multiple levels, which in turn creates opportunity for family members to gain a sense of mastery over these challenges.

Regardless of variations in the characteristic challenges and strengths of different families, every family member is affected when a child has a chronic health condition (Stein, 1983). McDaniel, Hepworth, and Doherty (1992) reported that the unique relationship processes faced by families of children with chronic illnesses include parental guilt, grieving the loss of a normal childhood, heightened difficulties surrounding developmental transitions, and vulnerability to health care professionals and the health care system. A child's health condition affects the family structure and relationships as well as the family's connections with other social systems, such as schools and medical systems (Patterson & McCubbin, 1983). Although the literature commonly emphasizes the negative side of the challenges and stressors that families of children with chronic health conditions confront, other research has indicated that family relationships may strengthen as a result of the child's condition, and these families do not appear to suffer an unusual degree of dysfunction (Cadman, Rosenbaum, Boyle, & Offord, 1991).

The findings presented in this section suggest some general processes that families of children with chronic health conditions may undergo. In addition, the findings establish a point of comparison to determine the unique and similar experiences of families of children with congenital upper limb differences as compared with families of children with other types of chronic health conditions. The current study aims to address the gap in the existing literature that excludes information on relationship processes within families of children with congenital upper limb differences. To this end, we conducted a series of four focus group interviews with parents of these children to learn more about their respective strengths, challenges, and relationship processes.

## **METHOD**

This qualitative study involved focus group research (Piercy & Nickerson, 1996). During a weekend-long intervention for families of children with congenital upper limb differences, we conducted four focus groups with parents. The family-based intervention invites families of children with upper limb differences (including the children with the upper limb differences, parents, siblings, and some grandparents) to engage in a camp setting that is hosted by an interdisciplinary group of professionals. These professionals collaborate to provide family members with support, information, and leisure opportunities. Originally founded by an orthopedic surgeon, the interdisciplinary group of professionals includes occupational therapists, family counselors, recreation therapists, and specialists in adaptive technologies.

### **Participants**

Purposive sampling procedures were used to recruit the maximum variety and number of parents to participate in the focus groups. Every parent who attended the intervention was invited to participate in a focus group. Out of the approximately 45 parents who attended the intervention, 15 volunteered to participate in a focus group session, which represented 12 different families. This sample represented one third of the parents who attended the intervention. Parents who attended the camp intervention had a number of choices about how to spend their time during the

focus group sessions (including participating in camp activities and spending time with their children). Although we did not ask the parents who did not participate in the focus groups their reasons for not doing so, it is likely that these parents were more interested in participating in the other activities offered during the same time frames.

Nine families were represented by one parent each, and three families were represented by two parents each. In the cases in which a family was represented by two parents, individuals from the same couple participated in the same focus group session. Some of the families represented by one parent were single-parent families, and others were dual-parent families in which only one parent opted to participate in a focus group. In 10 of the families, the child with the upper limb difference had at least one sibling. The parents who participated in the focus groups had children with upper limb differences who ranged in age from 1 to 16 years at the time of the study. The children's upper limb differences varied in severity. Some children had experienced multiple surgeries throughout their lifetimes, and other children had not required any previous surgeries. To protect the confidentiality and privacy of the families who participated in the focus groups, additional identifying details are not reported and are disguised throughout this article.

The sample of parents who participated in the focus group sessions was similar in its demographic characteristics to the overall population of parents who attended the camp intervention. As part of a quantitative evaluation study of the intervention that is being reported elsewhere (Murray & Graybeal, 2006), parents representing 16 of the 18 families who attended the camp intervention completed a demographic survey. The findings of this survey indicated that 9 families included married parents, and the remaining 7 families included parents who were single, divorced, or in a committed relationship but not married. Ten of the families included at least one sibling in addition to the child with the upper limb difference. The age of the children with upper limb differences ranged from 1 to 20 years, with a mean of 9 years. The number of surgeries that these children had experienced in their lifetimes ranged from 0 to 14, with a median of 2. A demographic survey was not included as part of the focus group interview, so a direct comparison of the parents who participated in the focus groups with the parents who did not is not possible. Nonetheless, the participants in the focus groups can be considered generally representative of the families who attended the camp intervention.

The focus groups were organized according to unique family background characteristics—parents of an adoptive child with an upper limb difference, parents of a biological child with an upper limb difference, parents of elementary-school-age children, and parents of middle- and high-school-age children. This organization was used for both practical (i.e., scheduling) and methodological (i.e., to help facilitate open dialogue based on common background experiences) purposes. Although it was possible for parents to match more than one of these characteristics, each parent was permitted to participate in only one focus group. Thus, parents were asked to select the focus group representing the characteristic that they defined as most salient to them.

### **Focus Group Procedures**

This study was approved by the Institutional Review Board at the University of North Carolina at Greensboro, where Christine E. Murray works. Each focus group was scheduled to last 1.5 hr. Before the start of each focus group, each participant was asked to read and sign an informed

consent document describing the study. In addition, time was allotted for participants to ask questions about the study before beginning the focus group interview. Christine E. Murray and Erin L. Kelley-Soderholm moderated and audiotaped all focus group sessions. Each focus group consisted of a semi-structured interview protocol that focused on three main questions: (a) What do you think are the biggest challenges you face as a parent of a child with an upper limb difference? (b) what resources are most helpful to you in facing these challenges? and (c) how does your child's upper limb difference affect the relationships in your family? The development of these questions was informed by the FAAR model's emphasis on resources and family adaptation to stressful challenges. During each focus group session, the moderators facilitated the discussion of the three main questions, helped the group remain on task, and asked follow-up questions based on the participants' responses to the initial questions (Piercy & Nickerson, 1996). In addition, the moderators took field notes on the key issues raised by participants during the focus groups.

### **Analysis Procedures**

Following the focus groups, the audiotapes were transcribed by a research assistant. The four combined transcripts yielded 70 total pages of data (single spaced with one line space between each paragraph). Most paragraph breaks were determined by the end of one statement. However, when participants made long statements that included more than one distinct thought, each distinct thought was divided into a unique paragraph before coding. We used content analysis procedures to analyze the transcripts (Piercy & Nickerson, 1996), and our analysis followed the procedures outlined by Stemler (2001). First, we used an emergent coding strategy to identify themes present in the participants' responses during the focus group. Christine E. Murray and Erin L. Kelley-Soderholm worked independently to develop separate lists of codes. We then compiled the separate lists of codes into a consolidated checklist to use for the final coding (Stemler, 2001). The emergent coding scheme was consistent with the three areas of focus for this study: challenges, strengths, and relationship processes. Second, we determined that the coding unit (Stemler, 2001) would be the statements made by each participant regarding a particular topic. Third, we coded the entire transcript independently using the consolidated list of codes. Fourth, we calculated the reliability of the coding using percentage of agreement and Cohen's kappa (Lombard, Snyder-Duch, & Campanella Bracken, 2005; Stemler, 2001). Our independent coding demonstrated an 85.4% agreement and a Cohen's kappa of .708 ( $p < .000$ ). The relatively small number of statements for which the two coders disagreed were not included in the remainder of the analysis, based on the rationale that they were not consistent with the codes as defined in the coding scheme. Fifth, for purposes of establishing validity we used a triangulation procedure that involved a third rater who independently coded a representative subsection of the transcripts (Stemler, 2001). The third rater (Thomas L. Murray, Jr.) was another family counselor who was involved with the family-based intervention. His consistent code choices verified that our coding procedures were accurate and reflected the essence of the participants' statements. Finally, we consolidated our findings into the Results section below.

### **RESULTS**

This section reviews the most significant themes that surfaced from within the strengths, challenges, and relationship processes categories. The themes that emerged across the four focus

group sessions were consistent. Therefore, we report the general themes from all sessions and do not focus this analysis on differences between the groups. Representative quotations from the parents' statements are included in this section to illustrate these themes. Table 1 presents a list and description of each of the codes that made up the final code list used for the analysis. Thomas L. Murray, Jr.'s codes were not included in the final analysis of the transcripts.

## **Strengths and Resources**

Parents mentioned during the focus groups that their belief in the universality of human differences provided an important resource for them. The participants' comments indicated that they took comfort in knowing that their children's differences were part of the normal condition of human uniqueness. Parents described experiences that helped them to recognize the commonality of differences, as reflected in the following anecdote:

I went to have my car washed, and I was sitting with [my child], and she was in a stroller, and a mom was sitting next to me with her baby in a stroller. But, the stroller was turned around, and we're just sitting next to each other for a few minutes and then, she was glancing over. At that point, I was kind of already used to the looks and the stares. I thought, "Well, okay, she's going to look." But, I had totally misjudged her. After a couple of glances, she turned her stroller around and her baby had a cleft in his cheek and an abnormality in his ear. I think that a lot of moms face different challenges; all children are different— everybody's different.

A related resource from which parents drew strength was their connections with other parents of children with congenital upper limb differences. Parents mentioned that Internet Web sites, the family-based intervention in which they were participating, and connections they had made through the assistance of their health care providers were helpful in this regard. One parent stated,

My daughter's specialist put me in touch with another mom, and she had a son that had a limb difference. And, that's been a great resource as far as being able to—all of these horrible thoughts that you may have had in your head when your child was first born. Just a validation that, you know, "I went through that too, it's okay, you're not a bad mom for thinking that."

The parents also expressed appreciation for the support they receive from their social networks, including extended family members, their and their children's friends, health care providers, and church congregations. The focus group participants indicated that they received both practical support—such as assistance with childcare and opportunities for leisure— and emotional support from these sources. One parent said, "You've got to have a network or some type. We got it through friends, family . . . especially our church family helps us when we have issues that we have to deal with." In addition, a number of parents indicated that their children benefited from friendship networks with other children who were understanding, supportive, and willing to help their children manage the teasing that they sometimes encountered from other peers. Specific to support from health care providers, one parent stated, "[We had] a wonderful surgical staff that



was always there at our beck and call. They call us by name, they remember the last surgery. They remember the issues and the funny little things [the kids] do.”

Parents reported that they and their children developed many creative strategies to manage the challenges related to the upper limb differences—notably the use of humor and role-plays. One parent said that humor acts as “a great diffusion of tension—when you can laugh about a situation.” The parents mentioned that their children often used humorous responses to respond to teasing from peers. For example, one parent said, “One time, one child asked her what was wrong with her hand, and she said, ‘I bit ‘em.’” Another parent recalled, “If somebody asks [him] what happened, he’ll come up with different stories . . . [laughter]. You know, mess with their head!” The parents advised that although there is a need for sensitivity when parents and children use humor in reference to the limb differences, humor also provides an outlet for tension and a way for families to take themselves less seriously.

Although only one parent mentioned using role-plays to help prepare her child to manage teasing from peers, this creative strategy deserves mention. Other parents liked this parent’s idea, and health care providers could introduce this to families as a way to cope as well. This parent described her use of role playing with her daughter in the following manner:

I would do [role playing] in the car: if somebody says this—and I would pick something that was not her hand, something that would only seem silly to her like, “Oh gosh, your hair is purple.” And we would practice her responses because it was easier for her to respond because it was not real. And then we would work toward including her hands. She came up with some pretty good things on her own. In other words, “You’re not bothering me.” And, in her own words, “If you have to make me feel bad to make yourself feel good, you’re not my friend.”

In addition to the above resources, the other major theme that developed through the focus groups was the families’ ability to draw on personal resources such as an appreciation for their children’s positive characteristics and their faith to manage the challenges associated with their children’s upper limb differences. Parents frequently described their children as strong, resourceful, and intelligent individuals who coped well with their health conditions. Family members’ religious and spiritual beliefs also played an important role in their ability to develop meaning surrounding the children’s upper limb differences. One parent stated,

Everybody’s belief systems are different, but if I didn’t believe in God and that He had a plan, I think I would flip out. I believe that there is a purpose and good is going to come out of it—if I didn’t, I would be lost in the day-to-day challenges.

Likewise, another parent said, “I think my faith had a lot to do with it, because I truly believe that there’s a reason for everything— that God’s never going to make a mistake with things.” Ultimately, the parents capitalized on an extraordinary range of strengths and resources that helped them to manage the practical and existential challenges they faced as they adapted to their children’s upper limb differences. And still, universality surfaced as a consistent theme. As one

parent summarized, “You get in that survival mode where you just do it. You put one foot in front of the other, and it wasn’t what you planned, but, yet, in the big scheme it is so minor.”

## **Challenges**

The challenges that parents faced included managing their own grief-related emotions and worries about their children, making informed medical decisions, fostering the child’s development, and communicating with their children about their differences. The parents who participated in the focus groups reported a broad range of grief-related emotions related to their children’s upper limb differences, primarily related to an initial sense of a loss of “normalcy” for the children’s lives. These emotions included anger, frustration, guilt, jealousy, and blame. One parent reported, “I guess, sometimes, I have thought to myself, like it’s my fault.” Other statements representative of these emotions include the following:

How do I be sad? Close the door, and I cry. It’s just the line we walk. We’re grieving, but we want them to be able to feel like they can do anything.

I mean, I can’t say, “I wish you had two hands, too” because that is saying, “I wish you were somebody else. . . .” Yeah, I wish she were normal. I wish that she could just go do cartwheel after cartwheel.

Another emotional response was worry, as reflected in the following statement: “I worried that she wouldn’t make it through this or that, but my daughter’s done great, I mean, we’ve had one instance that was terrible for me, personally, but I think I took it worse than she did.”

Medical decisions presented another area in which these parents reported concerns. Parents reported that they struggled to make the “right” choice when faced with decisions about care for their child, particularly when they needed to decide whether to pursue certain surgical options. One parent who was considering such an option said, “We are debating whether or not to do the procedure. An obstacle in my head is, ‘Is he going to blame us if we make what he sees as the wrong decision?’ We want to make the right decision.” Similarly, another parent who had faced similar decisions in the past stated,

There was, “Do we take off a toe and add it to her hand? Does that mean then that not only does she have a hand anomaly, she has a foot anomaly?” But you just make the decision the best that you can given the information that you have, and you run with it.

Thus, medical decisions presented dilemmas as the parents struggled to balance the inconclusive information and advice available to them with the possible implications of their decisions for their children’s futures.

Parents reported challenges related to how best to foster their children’s emotional, social, physical, and adaptive development. Concerns surrounding physical limitations included the following:

I've started thinking, with him going to be 11, when he is old enough to drive—how is he going to do that? You know, with his arms being able to reach the steering wheel, things like that. He *just* figured out how to ride a bike.

Another parent said,

You want him to succeed, and then sometimes it's hard to just let him try and do things. I find out most of the time, he can find out some way of doing it. But, that's sometimes tough because knowing where the line is as to what to let him do, what not to let him do.

Challenges in the area of social development included peer teasing and curiosity. Many parents worried that their children would be negatively affected by teasing about their limb differences, and parents actively worked to prevent and manage the negative effects of this likelihood. One parent used the following strategy to try to prevent her child from being teased:

In kindergarten, our class was divided up into two [parent] groups to meet with the teacher beforehand. I just said, "Excuse me! My daughter doesn't have one of her hands. Your kids are probably going to be talking about it. I wanted to let you know she was born that way, it doesn't hurt, and you can tell your kids that she's fine."

Similarly, other parents indicated that new situations were the most likely contexts for teasing or peer curiosity. For example, one parent said,

Baseball [season] is the worst time of year for us, because every night there are new people there that don't know, and they're all staring. So, I ask her, "Do you want to say something?" So, sometimes we've done it, sometimes we haven't.

A recurrent concern about physical and social development included parents' uncertainty about how they can maximize and promote their child's development of self-esteem in light of the challenges they face. Statements representative of this sentiment include the following:

For me, the biggest challenge is to be able to give them the tools that they need to just be self-confident and independent. Just to help them to get to a point where they are comfortable with themselves.

You want so much for them to grow up realizing how loved and how normal they really are, despite their differences. Just trying to help her, you know make her way through those stages and, in the end, hoping that she is okay in her own skin.

In light of the above challenges, parents in this study reported that they sometimes found communication with their children about their upper limb differences difficult. Some parents felt uncertain when they answered their children's questions, as exemplified by the following statement:

As a parent, or as a loved one, you want to jump in there and give them an answer, but there is no answer, so sometimes you have to say, “Yeah, sometimes it does stink.” Sometimes you have to be the lap that they cry in.

Other parents, like the one who provided the following quotation, struggle to balance giving information with providing encouragement: “I’ve been guilty of this. She’ll say, ‘Mommy, I don’t want three fingers on this hand, I want five. Why can’t I have a hand like everyone else?’ I automatically go into positive mode and explanation mode.”

Overall, the challenges faced by these families cross a number of systemic levels— individual development, physical health, family communication, and peer social relationships. These challenges encompass both practical challenges—such as how to help a child with an upper limb difference tie his or her shoe—and broader challenges to fostering children’s physical, emotional, and social development.

### **Relationship Processes**

Families of children with upper limb differences interact with resources and challenges that influence the families’ relationship processes indirectly and directly. However, because relationships function as both strengths and challenges, we delved further into the dynamics of relationship processes within the families. The themes that emerged from this discussion fall into three categories: the manner in which parents expressed emotions to their children, the way upper limb conditions affect family closeness, and how their family system incorporated relationships with other family members—including extended family and the child’s siblings.

An influential effect on family relationships was the parents’ processing of emotional responses—particularly the relationship between each parent and the child with the upper limb difference. Several parents reported that they experienced stronger emotional responses to the challenges their children faced than their children did. One parent said, “She fell down, and they were laughing at her, but she was like, ‘So what.’ She got up and kept running. It hurt me more than it hurt her.” Many parents also shared concerns about how their personal responses to the limb difference could upset their children. At times, this altered the manner in which they interacted with their children. Two representative comments are as follows:

Having done research online to see what the results of the surgery that my son will have—when I started looking at the pictures, I thought, “My goodness. He’s gonna. . . .” It was the first time I’d seen that. I’m glad my reaction was just in front of a computer and not a live person. It wasn’t out of disgust, it was shock.

I don’t share everything that I’m feeling—that sometimes I grieve the loss, or the inability to be able to do so. I don’t have my complete pity party in front of her.

Most parents reported that their experiences and reactions to their children’s upper limb differences helped bring their families closer together. One parent said, “If we don’t work together as a team, we can’t get anything done.” Another parent declared, “I would say that our

marriage is stronger.” One possible explanation for this increased closeness is that the families often viewed the children’s limb differences as opportunities for increased communication. One parent said,

It could be a positive thing for your relationship because when [my child] will talk about, “Why am I different?” it gives us a good venue of putting it in a positive light. Not minimizing the challenges, but yet, how you can use them for good?

On the other hand, other parents mentioned that they became disconnected from their partners as a result of the numerous challenges they faced together. One mother said, “I think the most difficult thing for us is to find ‘us time.’” Another parent described the following moment of revelation about the change in her relationship with her husband:

I really did not think, as far as my husband, we went to a group [meeting for parents of children with upper limb differences]. I was asking questions, and I was just very matter-of-fact. I look over, and he’s crying. And, it just hit me, that I’ve been so worried about how I’m dealing with the challenges and how [my child] is dealing with the challenges, I have blinders on because my husband. . . . And, I was kind of taken aback.

Finally, the parents also indicated that relationships with other family members— including extended family and siblings— were affected by the challenges they faced as they adjusted to their child’s upper limb differences. The extended family issues cited included how to respond to family members’ questions about the child’s condition and how to cope with family members’ searches for explanations. Siblings also reacted to the children’s upper limb differences. Some of the children’s siblings expressed curiosity about their brothers’ or sisters’ limb differences, as indicated by the following statement:

My middle child came to me when no one was around. I took that as a sign she knew it bothered her sister, and she wanted to ask me away from her. I think it might affect her siblings, make them a little bit more sensitive to [the child with the limb difference].

Other parents expressed concerns about how the time and energy demands of managing a limb difference involve the child’s siblings. One parent said, “My second daughter lives in the car. That’s where she lives, that’s where she eats. So, she has her own little challenge, getting schlepped around everywhere.” Another parent commented:

It was very hard on her sister. When she was born, her sister was 2. She was in intensive care for 10 days, I was away from home for 10 days. By the time I came back I wasn’t. . . you’re not the same person that left the 2-year-old at home.

## **DISCUSSION**

The findings of this study must be considered within the context of its limitations. First, the sample used in this study was small. The purpose of focus group research is to generate

qualitative information and explanations about the topic of the research; it is not to generate statistical inferences about the larger population (Piercy & Nickerson, 1996). Therefore, the findings of this study are exploratory, although they provide theoretical support for the concepts of family systems theory and the FAAR model. This focus group methodology was limited to just parents; therefore, the perspectives of the children and other relevant family members were not included. Another limitation was that the sample included individuals who participated in a single intervention. Because the camp intervention is free of charge for families, the families who attended the intervention represented a wide range of socioeconomic backgrounds (with family incomes ranging from less than \$15,000 to more than \$55,000 per year). However, this intervention provides support and information to families of children with congenital upper limb differences, and the families who participated in this study may demonstrate a greater number of strengths and resources compared with families who have never participated in such an intervention.

Additional limitations of focus group research include the interdependent nature of participant responses, the potential for moderators to bias the data through their behaviors during the session, and the inapplicability of traditional means of establishing validity (Piercy & Nickerson, 1996). For the present study, these potential limitations were addressed by ensuring that each participant had an opportunity to respond to each interview question, by using two moderators for each session—one lead moderator and a secondary moderator who observed the process and took notes, and by triangulating the data with a third rater.

### **Intersections of Family Strengths, Challenges, and Relationship Processes**

Although this article describes the participating families' strengths, challenges, and relationship processes as distinct categories, the findings of this study reveal that numerous intersections exist between these categories. For example, consider the family in which the parents practiced role-play situations with their child to help the child develop confidence in managing peer teasing. This example demonstrates how the families use their strengths—creativity and open communication—to manage the challenges they face—peer teasing and figuring out how best to help the child develop positive self-esteem—thereby affecting the family relationships through increased dialogue and intrafamily social support.

In many ways, the families who participated in this study demonstrated the family systems theory principle that the whole family is affected by the experiences of one family member. The challenges associated with children's upper limb difference may affect family relationships in both positive and negative ways. At times, the families experienced greater opportunities for dialogue and conversations about the upper limb difference. Many families grew closer as they worked together to face the challenges associated with the upper limb difference. However, the demands placed on caregivers' time and energy also created the possibility that other relationships—such as a spousal relationship or relationships with children's siblings—would be negatively affected. Parents also experienced opportunities for growth as they grappled with expressing their emotional reactions to their children's conditions. Thus, families of children with upper limb differences are affected in many powerful ways by their experiences related to these conditions.

Similarly, the findings of this study demonstrate that the same issues can present as strengths, challenges, or relationship processes within families of children with upper limb differences. This dynamic crosses multiple systemic levels. For the child's individual psychology, this dynamic may be seen through the child's positive or negative self-esteem, strong or weak problem-solving skills, and achievement of or failure to reach developmental tasks. At the familial level, issues related to communication, conflict resolution, emotional expression, time management, and extended family involvement can be sources of strength and challenges. Within the larger social context, both stressors and resources may be found in the areas of peer support, extended family relationships, and interactions with the health care system. Across all of these levels, family relationships are affected to the extent to which resources are mobilized and challenges are managed.

### **Implications for Theory, Practice, and Future Research**

The focus group interviews revealed themes surrounding how families cope with the physical, social, and emotional challenges associated with having a family member who has a congenital upper limb difference. In this section, we explore how these families' challenges, strengths, and relationship process might guide and influence family health theory, practice, and research.

#### **Suggestions for Theory**

The findings of this study support the relevance of family systems theory and the FAAR model for studying families of children with upper limb differences. In accordance with family systems theory, the participating families' experiences demonstrate that one person's health condition affects other family members and family relationships. Some parents believed that the child's special time demands weakened other relationships, but others found that the difference only strengthened the family's closeness and offered unique opportunities for communication about difficult issues that all families face, such as peer acceptance and self-esteem.

The central importance of the family context suggests that a need exists for theoretical consideration of how challenges, resources, and strengths might operate within developmental frameworks (i.e., the family life cycle; Carter & McGoldrick, 1999) and how family members' experiences vary across life cycle stages. Because this study focused primarily on parental perceptions, additional studies might probe further into how the presence of a child with a limb difference specifically affects sibling relationships. The families who participated in this study demonstrated a wide range of coping resources and strengths in response to challenges and demands. They showed their capability to both develop new resources (e.g., information seeking and networking with similar families) and use existing ones (e.g., faith, family, and friends). This creative problem solving is in line with the FAAR model's emphasis on the value of coping resources. Future theoretical considerations might incorporate ideas about maximizing the factors that affect the extent to which families recognize these strengths and empower themselves to get the support they need.

Consistent with the literature about the challenges and coping methods of families with children with chronic health conditions, the focus group families felt challenged by time management, developmental transitions, and grief surrounding the loss of a "normal" childhood. They also

used similar resources to manage these challenges. Further theoretical refinement should address how service providers can adjust their approaches relative to the family context and the specific features of the chronic condition. New directions might include theories that address how congenital upper limb differences influence families according to the gender of the affected child or family income or how physical, congenital problems compare with less visible chronic conditions.

### **Suggestions for Practice**

Our findings suggest that families adapt ideas and strategies to suit their distinctive needs and personalities. Practitioners can encourage and support families to develop and use coping strategies that are creative, meaningful, and effective for them, for example, the role-play strategy used by one family. Also, some parents encourage children to make a presentation to educate classmates on the first day of school, and others simply support children as situations arise. Providers might consider how to validate and incorporate families' religious and spiritual beliefs into their services because these often serve as powerful coping resources that contribute to better compliance with health care treatment.

Parents frequently cited health care providers as valuable sources of support and encouragement. Practitioners influence the ease of families' navigation of health care systems, and providers help families when they acknowledge the time, emotional, and financial costs of treatment. Enable families to manage these factors by allowing for payment plan options, minimizing waiting times, and cultivating a nurturing environment.

Finally, practitioners should consider the importance of the language they use and the areas of assessment on which they focus when working with families of children with upper limb differences. The families who attended this intervention prefer the term *upper limb difference* as a more positive descriptor than terms such as *defect*, *deformity*, or *abnormality*. These latter terms are more pejorative in nature and carry the implication that there is something inherently wrong with the child. We recommend that practitioners use the term *difference* instead of any of these latter terms.

The broad range of challenges faced and resources used by the families in this study indicate the importance of assessing the children's and their families' functioning across many dimensions. Practitioners should assess the child's academic, social, and emotional functioning in addition to assessments of physical functioning. The findings of this study suggest that assessment of the families of children with upper limb differences should include their immediate and extended family relationships, the well-being of the children's siblings, the social support the family receives from friends and organizational affiliations, their financial resources, and the extent to which family members are knowledgeable about upper limb differences and their medical treatment. Thorough assessment of these families will help to identify potential needs and areas of support as they face challenges associated with the upper limb difference.

### **Suggestions for Future Research**



Future research can expand on the findings of this exploratory study in a number of ways. Focus groups and surveys gain generalizability when larger, more geographically diverse participant samples are available. Alternatively, more specific comparison of different types of conditions (e.g., minor to severe, number of surgeries required, congenital vs. acquired conditions) will allow practitioners to customize services to the needs of subpopulations. Additional research is needed to examine the similarities and differences between the families of children with upper limb differences and children with lower extremity differences. Researchers might also consider different types of family forms (e.g., adoptive, single parent, gay or lesbian domestic partners, only child or multiple children, or grandparents raising grandchildren) and their relation to family coping strategies.

To enhance quality and continuity of care, researchers might examine the various resources mentioned and how they are helpful to families. For example, what particular qualities of family, faith, and health care professional resources are most meaningful? How do families access and use these resources most effectively? Answers to these questions could be complemented by surveys of health care providers who work with these families. Provider surveys and interviews would illuminate the extent to which providers recognize and address the strengths and challenges faced by the families of children with upper limb differences or other chronic conditions. Finally, researchers should conduct outcome studies to examine the efficacy and effectiveness of various service models when working with this population. With this knowledge, providers will have the tools to formulate and improve services to boost service accessibility and effectiveness.

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