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Social Experiences of Turkish Parents Raising a Child With Apert Syndrome: A Qualitative Study

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Abstract

Objective: Apert syndrome is a rare and understudied craniofacial condition with regard to its psychosocial impact on children and their parents. Due to the lack of studies focusing solely on the social experiences of children and families with Apert syndrome, it is difficult to develop interventions and strategies to support well-being and positive adjustment for this particular population. This study addressed this gap by assessing the unique social experiences of parents who are raising their children with Apert syndrome including difficulties they face and strategies they use to cope with challenges.

Design: Descriptive qualitative study using thematic analysis.

Participants: Participants included 21 parents of 12 children (aged 1-12 years) with Apert syndrome (9 couples, 2 fathers, and 1 mother) who were recruited from a pediatric neurosurgery unit in Turkey.

Results: The qualitative analysis yielded four main themes describing the experiences of parents including (1) social challenges; (2) coping with negative reactions; (3) promoting socialization and independence; and (4) sources of strength.

Conclusions: Parents reported several challenges, including social stigmatization, and utilized a range of strategies to support both their own and their child's positive adaptation and resiliency, including the use of religion and reliance on their spouses for support. Results offer clinically relevant insights about the strengths and challenges of families coping with Apert syndrome.

Keywords

Apert syndrome, stigma, parents, qualitative, resilience, craniofacial conditions

Introduction

Apert syndrome is a congenital anomaly characterized by severe craniosynostosis, midline hypoplasia of the face, bulging eyes, and symmetrical syndactyly in the hands and occasionally in the feet. In some instances, affected individuals may also have cleft palate and an underdeveloped jaw. Apert syndrome has been reported to occur 1 in 65 000 births in North America and Europe (Hilton, 2017). The diagnosis of Apert syndrome can be made at the 16th week of pregnancy by 3D ultrasound (Sarimski, 2008). The occurrence of Apert syndrome has been associated with paternal chromosome 10, which differentiates Apert syndrome from other congenital syndromes such as Crouzon and Pfeiffer (Açikgöz et al., 2006).

In Turkey, Apert syndrome is often diagnosed in utero between the 16th and 32nd weeks of pregnancy by checking for the presence of craniosynostosis and syndactyly. In a private hospital setting, a multidisciplinary team consisting of a pediatric neuroradiologist, a pediatric neurosurgeon, a reconstructive surgeon, a genetics counselor, an orthodontist, a

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pediatric neurologist, and a mental health professional evaluates cases. Patients undergo a 3D computed tomography and cranial magnetic resonance imaging for evaluation to rule out additional brain anomalies and the structure of posterior fossa elements. A front orbital advancement is conducted as the first stage of the treatment between 6 and 12 months of age. Occasionally, Apert syndrome may present with a small posterior fossa and tonsillar herniation. If this is the case, a posterior calvarial expansion and foramen magnum decompression are performed as the first step of treatment followed by frontoorbital advancement. After the cranial expansion, the multidisciplinary team monitors the patient, including sleep studies performed on an annual basis to assess the respiratory function. In case of severe apnea and desaturation problems, a midface advancement should be planned around the age of 7. Hand surgery is also planned for the correction of the fingers (M. M. Ozek, personal communication, June 5, 2020).

Children born with Apert syndrome experience many stressors due to on-going surgeries beginning in the first months of life and are at risk of appearance differences, eye and visual problems, speech and language development difficulties, hearing loss, risks of intellectual disability, and developmental delays, including poor fine motor skills (Hilton, 2017). Further, individuals with Apert syndrome are likely to experience social difficulties, including teasing and social withdrawal, difficulties separating from caregivers, and preferences for playing with younger peers (Sarimski, 2008; Maliepaard et al., 2014). Because of the neurological and psychosocial risks associated with Apert syndrome, regular screenings are indicated (Açikgöz et al., 2006).

In the craniofacial literature, most psychosocial research has focused on more commonly occurring conditions, namely cleft lip and/or palate (Stock & Feragen, 2016; Feragen & Stock, 2017). Among Turkish samples, the literature is quite sparse, with few studies published on the psychological impact of craniofacial conditions (eg, Boztepe et al., 2020). Yet, it is possible that the experiences of parents and children coping with Apert syndrome might differ from those coping with other craniofacial conditions since patients have more significant facial differences, more sensory impairments, difficulties that come from the hand and feet syndactyly, and undergo a greater number of surgeries (Clarke & Braun, 2013). Even with reconstructive surgery, appearance differences and functional deficits may remain.

Recently, there has been a call for more research to understand the experiences and psychosocial outcomes of children with other more complex craniofacial conditions (Stock & Feragen, 2019a, 2019b). However, to date, there are very few studies focusing solely on the psychosocial experiences of children and families coping with Apert syndrome. For example, Renier and colleagues (1996) evaluated 60 children with Apert syndrome with regard to their mental and psychological development before and after surgery. They observed better developmental outcomes among children who had received surgery before the age of 1 and among those raised in a supportive family environment (relative to children in their sample who were raised in an orphanage). A study of 25 children with Apert syndrome (mean age = 8.6 years) documented risks of intellectual and learning disabilities, as well as behavioral problems including separation anxiety, being exposed to bullying, not being accepted by peers, and getting along better with younger rather than same-age peers (Sarimski, 2001). Similarly, a study of parents of preschool to school-age children with Apert syndrome found that mothers reported greater levels of parenting stress relative to norms (Sarimski, 2008). Parents of children with lower cognitive abilities and/or behavioral concerns, such as attention deficit hyperactivity disorder, reported greater levels of stress (Sarimiski, 2008). Based on the findings of these 3 studies, further exploration of the family environment and support parents provide for their children's socialization is needed.

Aside from these few studies, individuals with Apert syndrome constitute a very small portion of craniofacial research participants conducted on individuals with craniofacial anomalies. For example, Klein et al. (2006) conducted in-depth interviews with parents of 9 children with mothers raising their children with craniofacial anomalies. Only one mother had a child with Apert syndrome. Results indicated that mothers were worried about the physical safety and medical health of their children, their negative social experiences (eg, exclusion, ridicule), and their emotional well-being. They also described an overly protective attitude toward their children. The mother of the child born with Apert syndrome stated that her child has difficulty "keeping up" with other children, especially in sports activities so that, "he usually stays with younger kids" (Roberts & Shute, 2011, p 592). The same mother described her child as an "easy target" to both other children and adults (Roberts & Shute, 2011, p 593). Mothers included in the study recognized the strengths of their children, including being determined and persistent to overcome their difficulties, including social challenges. Mothers were proactive in supporting their children by educating teachers and others at school about their children's syndrome to prevent bullying, helping their children to make friends by including them in support groups, and teaching them how to cope with negative reactions. Fathers who have children with craniofacial anomalies also reported supporting their child's social development by facilitating interactions with their peers (eg, inviting another child to their home and to come along on a family outing; Klein et al., 2006).

Pope and Ward (1997) evaluated the social skills of 24 young people aged 11 to 14 years with craniofacial anomalies, 2 of whom had Apert syndrome. They reported a negative correlation between participants' social anxiety and social skills. There was a positive correlation between their social skills and experiences of friendship. Participants who evaluated their appearance, academic, and athletic skills more positively had better social skills. Furthermore, they noted that when parents took an active role in socializing their children, it contributed to better social skills in the children. These findings highlight the importance of parents supporting their children by bringing them into groups where they can make friends, helping them to engage in playing with other children and developing communication skills.

In adulthood, the social difficulties experienced by individuals with Apert syndrome may persist. Roberts and Mathias (2012) observed in their sample of 93 adults with craniofacial conditions (5 of whom had Apert syndrome) that adults with congenital craniofacial conditions experience more appearance-related concerns and more limitations in usual role activities due to emotional problems and in social activities due to physical or emotional problems (Roberts & Mathias, 2012). Moreover, participants reported receiving less social support from friends.

Due to the lack of studies focusing solely on the social experiences of families of children with Apert syndrome, it may be difficult to develop interventions and strategies useful for this particular population. To address this gap, this study assessed the unique social experiences of parents who are raising children with Apert syndrome, including both examination of difficulties they face and the strategies they use to cope with challenges. As Nelson (2009) suggests, personal perspectives and subjective meanings enhance in-depth understanding of parents coping with their children's health issues, which can then be used to influence clinical practice. Interviews offer a way to understand different strategies and strengths that participants use through rich descriptions of experience. Given the lack of research on parents' experiences with raising a child with Apert syndrome, a qualitative approach was utilized to better understand the unique needs of this population.

Method

Design

This is a descriptive qualitative study. The first author conducted semi-structured interviews to explore the social experiences of parents raising their children with Apert syndrome and social strategies they use to navigate negative experiences. The one-time interviews were conducted with parents either in the hospital when they came for their child's medical follow-up appointment or over the phone.

Participants

Participants were 21 parents of 12 children with Apert syndrome including 9 couples, 2 fathers, and 1 mother living in 7 different cities in Turkey. Parents' ages ranged between 29 and 49 years. Eleven parents had high school or lower level of education and 10 parents had college level or higher. Their average monthly family income was 4054 Turkish lira (around 1000 pounds), which would correspond to lower middle class status. Twenty parents were married, and 1 parent was divorced. All participants identified Islam as their religion. The age of the children varied between 1 year and 12 years with an average age of 5.6 years. Of the children in the sample, 2 were diagnosed prenatally, and 10 were diagnosed at birth. Fourteen of the children were male and 7 were female. On average, children had undergone 5.5 surgeries, with a range of 1 to 12 surgical procedures. None of the children had additional diagnoses. Only 1 child was reported to have developmental delays. Four of 12 children had received or were currently receiving psychiatric treatment (eg, medication).

Procedure

Upon receiving institutional review board approval, parents were recruited from the patient pool of a pediatric hospital's neurosurgery unit that offers private (fee-for-service) treatment, in İstanbul, Turkey. All parents of children with Apert syndrome who were operated on by the fifth author at least once and whose native language is Turkish were contacted via telephone. The first author, who did not have any prior relationship with the families, introduced the study and asked for their participation. Twenty-one of 33 parents agreed to participate and were interviewed by the first author. After informed consent was obtained from participants, they were asked to complete a demographic form, and they took part in a semi-structured interview. Parents were interviewed between July 2015 and October 2016 either in person ($n = 12$) or via telephone ($n = 9$). Each parent was interviewed separately even if they were a couple. All interviews were audiotaped. Interview duration lasted from 19 to 64 minutes with an average of 38 minutes. The interview questions focused on social experiences and parenting practices and did not include questions with regard to their satisfaction with medical care (since the fifth author is their neurosurgeon, such questions could prevent the participants from commenting freely on their experiences with treatment). The interview guide included questions such as (1) What kind of reactions do you receive from (a) family members, (b) friends, and (c) outsiders regarding your child' condition? (2) What do you do to cope with other people's reactions? (3) Does your child experience any teasing/bullying in school? How do you react to that? How do you talk about these experiences with your child? What kind of things do you do to help your child with other people's reactions, teasing, bullying etc? (4) Is there anything that you do for your child especially because she/he has Apert syndrome to help her/him feel more comfortable or successful in the world? All interviews were conducted and coded in Turkish. The names of the themes and the participants' quotes were translated to English for this manuscript.

Analysis

Thematic analysis which enables the researcher to identify and organize patterns and to capture the details in a rich data set was used to analyze participant interviews (Clarke & Braun, 2013). Thematic analysis is conducted in an inductive, data-driven approach, aiming to provide descriptive data regarding the experiences of participants and detailed information related to the research questions. The interviews were transcribed and coded using the computer-assisted software program MAXQDA for identifying common themes and subthemes emerging from the interviews. Detailed notes were written throughout the analysis process, and themes were selected

based on their prevalence and/or their importance according to the research questions.

Braun and Clarke (2006) suggest 6 steps for completing thematic analysis including: (1) becoming familiar with the data; (2) identifying interesting features of the data; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) producing the report. In the first phase, 1 researcher transcribed and repeatedly read the interviews to become familiarized with the data. Next, in the second phase, 2 researchers reviewed the data independently. Initial ideas were listed, and codes were generated by adding memos. The codes were generated based on participants' responses and were organized into groups. These groups established the foundations of main themes and subthemes that were used in analyses. With the coding of each consecutive interview, the code list was revised. During this phase, the researcher generated as many codes as possible for potential themes. In the third phase, the generated codes were analyzed to be combined under relevant themes. In the fourth phase, once each researcher finished coding and initial themes emerged, the researchers reviewed and compared their themes. For the fifth phase, final themes were discussed with the research team, including the development of names and definitions. Finalized themes were written as a brief report and sent to the participants for member checking. Eleven parents responded, confirmed the findings, and commented on their need for a program focusing on how to deal with bullying, challenges associated with the transition to adolescence, and financial struggles related to repeated surgeries, a need for more extensive explanation about the risks of the surgeries and the long duration of treatment.

Results

The qualitative analysis yielded 4 main themes: (1) social challenges; (2) coping with negative reactions; (3) promoting socialization and independence; and (4) sources of strength. In the next section, these themes are described by illustrating quotes from parents (using the pseudonyms that parents chose).

Theme 1: Social Challenges

The main challenge for the parents when they are out in public spaces were extended stares and questions, particularly about their children's hands and faces. While parents acknowledged that their children look different and therefore draw attention, strangers examining their children, giving pitying reactions such as "knocking on wood"—a superstitious gesture people do when they hear or witness a negative event to avoid it from happening to them—irritated them. For example, Eren, a father of a 4-year-old boy said;

> There are people who look at my child and say "We should be grateful for what we have, God also creates people like this" out loud or stare at her for 2-3 minutes. It makes me really sad. I actually feel sorry for them, how insensitive they can be. But there are also people who look at him and say "Look at those beautiful eyes!"

Furthermore, parents stated that they are subjected to these stares and questions usually from people living in low-income neighborhoods and people who are not educated. They explained that they draw this conclusion based on their experiences in different parts of the city. Hüseyin said, "When we go to the low income neighborhoods, they look at him as if he is a freak." According to the parents, the level of education was also a determining factor on who will stare and ask disturbing questions. Yeliz, a mother of a 5-year-old girl, compared her experiences of taking her daughter on vacation. She stated that in more liberal and middle-class neighborhoods of the city, where "cultured people live," she was subjected to fewer negative experiences. She said, "Uneducated people ask more disturbing questions. Cultured people ask less. They try not to bother you. But uneducated people – they don't think that you would be bothered." Her husband, Yücel, agrees in a separate interview; "Uneducated people's first question is if it is a kin marriage. 'Is she an inbred? Or if she got burned? Is she spastic?'"

In general, parents agreed that they find these questions coming from strangers intrusive. Most of the questions centered around why the child was born like this, if they used medication during pregnancy or if they knew that the child would be born like this. For example, Hatice, a mother of a 4-year-old boy stated: "Some people don't understand. They ask, 'Why is he like this? Didn't you go to the doctor? Didn't the doctor tell you when you were pregnant?'" She found this question particularly insulting since it insinuates the possibility of abortion, which is against her religious beliefs.

Theme 2: Coping With Negative Reactions

Parents described 2 main ways that they cope with these reactions: (1) They try to educate people about their child's condition or (2) they ignore the reactions. For them, both of these ways of coping were a result of a process in which they had to get used to people's reactions and accept their child's condition themselves. They provide explanations using religion or scientific information. Using a religious basis for the condition, Büşra, a mother of a 7-year-old girl explained, "When people ask, I say 'It's God's will, you could have been in our place, too.'" When children are the ones asking these questions, they try to normalize their child's condition. As an example, Ayşe, a mother of a 4-year-old boy, stated "I explain to the children, 'He was born like this just like you were born like that. His hands are different, your hair is blond, and your eyes are blue. That's just the way he was born.'" She further mentions that she tries to answer people's questions in front of her son so that he learns how to answer them when he is on his own. She says, "Sometimes people ask when he is with us, I try to answer them so that he hears and answers on his own in the future. 'That's how I look. I was born like this.'"

Ignoring is another way of coping reported by parents, which they learned to do over time. They described trying to normalize people's reactions, even finding them funny. They believe that they will be facing these reactions in the future, as

their children grow older, so they have to develop an ability to keep from getting upset or offended by these comments and dwell on it. Mehmet, a father of a 1-year-old girl, said:

> "If I get hung up on it, things would get worse. I will lose my concentration, my family life, my work will suffer. I will not be able to take care of my customers. My social life will suffer, I will be more frustrated."

As they got used to people's reactions and learned to ignore or respond to them, parents also became more open about their children's condition. Zeynep, a mother of a 7-year-old boy, mentioned, "I don't care anymore. I share photos on Whatsapp and on Instagram. You get over it with time."

Theme 3: Promoting Socialization and Independence

In terms of parenting practices that promote their children's socialization and independence, parents describe comforting and educating their children when they face negative reactions, supporting their independence, and prioritizing their socialization. Almost all the parents describe their children as social and popular and take pride in that. For enhancing their children's social life, parents talk about taking their children to all the places that they go and not being ashamed of the way that they look. Akif, a father of an 11-year-old boy, says, "Parents of disabled children usually hide their children. We did not do that. We took him everywhere, to vacations, to weddings, to the mall . . . He was always surrounded by people. We took pride in him." Another strategy that parents used to socialize their children was to engage them in extracurricular activities. As Akif continued to explain, "We took him to art class. He wanted to play the violin and couldn't because of his fingers. So, he plays drums now." Mehmet, a father of a 1-year-old girl, started making these plans early. He says, "First we need to learn her character, what she likes. We need to explain to her how important it is for her to have friends. We need to take her to kindergarten, maybe to swimming lessons, different social environments." Parents also helped their children to make friends and establish play in parks to help them socialize and not to get excluded. Ayşe, a mother of a 4-year-old boy, explained,

> "I want my son to socialize so, when other children come near us, I find them a game to play together. Teach them to ride a bike. Come up with a ball game. So, my son gets included in the play."

Even though their children's social lives were an area of concern for all parents, they viewed their children as social and popular, which was a source of pride for them. Akif was one of the fathers who was full of joy and pride as he described his son. He said, "For example when he gets on the bus, he says hello to everyone. He is very comfortable, at peace with himself. He goes to park and plays with all the children. Plays basketball with the adults." Almost all parents stated that their children have friends from their neighborhoods, schools, or extended family members. It is a reality that they face negative reactions at first, but they manage it by being extraverted. Ahmet, a father of a 5-year-old girl, said,

> "Even when other children stay away from her, she approaches them. For example in the park . . . When another child takes the swing next to her, she talks to the child, 'Hello. Welcome, how are you?' She is very social. She even talks to their moms."

Parents also describe their children getting upset when they face negative reactions themselves from other children. They try to help their children by comforting and educating them on the responses that they may give. They advise their children to ignore the reactions, use healthy boundaries, and see the silver lining. For example, Büşra says, "I tell her, 'sometimes people may not accept you, don't be bothered, just ignore it, you will have other friends. Don't get sad, just stop talking to them. You have other friends, go play with them.'" Nilüfer, whose 12-year-old son, experienced bullying at school uses a similar approach to enforcing healthy boundaries. She states, "I told him, 'if they are bothering you, just tell them, 'Please don't bother me.' Ask them to stay away. If they don't listen to you, go and tell the teacher. You have to protect yourself.'" When Yücel's daughter experienced questions about her hands and went to her father for comfort, he tried to show her the positive sides of the process. He shared his experience:

> I explained to her, "you did not have hands when you were born. You went through 3 surgeries and you have 4 fingers now. What is important is what you do with these fingers; to hold a pencil, to take care of yourself. I have 5 fingers and you do all the things that I do."

Yücel's response complements another strategy that parents use, which is supporting their child's independence. Parents encourage their children to be independent and "stand on their two feet." They believe that this benefits their children's motor skills as well, especially around using their hands and gain self-confidence. For example, Ayşe says, "For example, if he asked for water, I want him to get it himself. If he is able to do it, he must do it. Even if he breaks it, he will be more cautious next time."

Future abilities of the child are a concern for the parents. They want to prepare their children for life so that they can go on after they pass away. For this reason, they encourage and support them to have different experiences and do things by themselves. Akif explained,

> "I want him to do everything that he will need to do in the future. For example, the other day, he wanted to take the bus to school. We allowed it. When he wants to do things himself, we set him free."

Yeliz also dreamed of a world for her daughter where she is able to have a wide range of experiences and enjoy life. That's why she wanted to give her freedom. She said,

> I want her to experience everything. If she wants to go to the bars, she can, if she wants to drink, she can. First with us, of course. I want her to travel, learn a foreign language. I want her to live life to the fullest, be free.

> "Being able to stand on their own two feet" also meant prioritizing education for the parents. Their hopes included their children to get educated and "become someone" as Ali, father of a 7-year-old girl, says, "What is important for us is for her to go to school and become someone. Even more important than her getting married. For example she says she wants to become a doctor . . . "

Theme 4: Sources of Strength

As they try to raise healthy, confident children and cope with negative experiences, parents identified 3 main sources of strength: family and friends, spouses, and religion. They identified their friends and families as a support system both emotionally and financially, especially when putting their children through costly surgeries and a wide range of treatments, sometimes away from where they live. Yeliz explained, "We always knew that our families stood by us, they would support us financially if we need it. They opened their homes to us, they shared their food with us when we come to İstanbul for surgery." Another source of joy frequently reiterated by parents was that their friends and family accepted their children and treated him/her like "a normal child" and loved them. Ali said, "My parents had a normal, positive reaction. Of course they were sad in the beginning. But everyone treats him like a normal child. Thank God." This acceptance created a social circle for both themselves and their children. Ezgi, a mother of a 2-year-old girl, said,

> We never got a negative reaction from our friends. They have children too, we meet weekly. Their children love our daughter. They get along really well, they play together. We never got a weird reaction. On the contrary, everyone is very supportive.

Emotionally, they felt that their spouses were the ones who understood them and comforted them the best because "they were in this together." They cried together during surgeries, calmed each other down when they experienced negative reactions, listened to each other's concerns, and supported each other's decisions around parenting. For example, Aslı, the mother of a 2-year-old boy, says, "When I get frustrated about the stares, my husband tells me, 'you would look too if you were to see a child like this'. He is more mature than me, he is like my psychologist. He is calmer."

Parents also described religion as a major source of strength. Especially when trying to make meaning out of this experience, they described it as "God's will, a gift from God and a gateway to heaven." They repeatedly stated that this religious perspective helped them psychologically and stopped them from becoming bitter. As Büşra explained, "God gives us sickness and health. We become happy when he gives us health, why can't we take it when he gives sickness? If God gave this to us, we have to trust God's plan."

Discussion

The findings of this qualitative study provide rich information about the strengths and challenges of families coping with Apert syndrome in Turkey. As the parents shared their experiences raising their children, they described using strategies that promote adaptation and resilience in the face of a stressor. For example, similar to the previous literature findings, parents report social stigmatization experiences, such as stares, pitying looks, and questions as the most significant challenges (Roberts & Shute, 2011; Bradbury, 2012) Yet, in contrast to previous findings, parents in this study tended to attribute this behavior to lack of education and manners. This appeared to serve as a protective factor for their well-being since this specific type of meaning-making helped them to either ignore or educate these individuals rather than taking it personally. Strauss (2001) identified factors that promote resilience in persons and families of children with craniofacial conditions including acknowledging the loss, openness to sharing experiences, and becoming involved in other relationships and life pursuits. Parents in this study stated that they, themselves, also agree that their children look different, thus acknowledging the loss of having a child that does not have a typical appearance. They stated that their own acceptance helped them to either stay calm and educate the public or ignore these reactions, indicative of using both approach (eg, active problem solving) and avoidant (eg, distraction) coping strategies (Roth & Cohen, 1986). As one of the participants reported, ignoring the reactions of others helped him to stay connected to his family life, social life, and work. For other parents in this study, ignoring the reactions of others also served as a means of self-protection and made them tougher.

Building on the concept of resilience, Egan et al. (2011) noted that family support, faith, inner-strength, valued social circles, social inclusion, and acceptance were important factors that contribute to resiliency in persons with visible appearance differences. Almost all of these factors were reflected by parents in this study. For example, they discussed family support both emotionally and financially, acceptance of their children "like a normal child," using spirituality to make meaning of their child's condition, and the importance of having a valued social circle of friends and neighbors. Our findings are also consistent with Fonseca et al. (2015), who reported that how parents perceive their child's condition can be an important factor to increase parental adaptation and positive parenting practices.

In this sample, parents reported reliance on religion as a source of strength and meaning-making, consistent with other studies in the extant craniofacial literature (eg, Egan et al., 2011; Fonseca et al., 2015; Stock, Feragen, & Rumsey, 2016). Viewing their child's diagnosis with Apert syndrome as a test of their faith, a gateway to heaven or as part of God's plan particularly helped them with their own adaptation and coping with other people's reactions, staying grounded, taking care of their children, and promoting their children's independence and social skills.

Almost all parents in this study repeatedly stated taking their children out in public and taking pride in them as the most important factors that helped their children's social skills, leading them to be social and popular. Edwards et al. (2011) discussed positive social skills such as maintaining eye contact, direct communication about the condition, and good social

initiation skills as key factors in successfully navigating the social challenges associated with craniofacial conditions. Parents in this study discussed actively promoting their children's peer relationships by helping them make friends in parks, taking them to extracurricular activities, sending them to school, and supporting their independence. The craniofacial literature emphasizes the importance of social skills training as a way to reduce stigmatization and bullying, and the parents in our study seemed to incorporate these factors into their parenting (Macgregor, 1990; Rumsey & Harcourt, 2004; Klein et al., 2006; Klein et al., 2010; Edwards et al., 2011)

Implications for Clinical Practice

Findings of this study can be used to support clinical guidelines for building psychological resilience and adaptation in families of children with Apert syndrome. Kish and Lansdown (2000) outline a clinical service for children and families focusing on social skills training for the children, using a cognitive-behavioral approach. Strategies that are used by the parents in this study may be incorporated into clinical practice (eg, routine education offered by craniofacial team psychologists and social workers to families of children with Apert syndrome). More recently, Gaskin and colleagues (2015) advocated for the training of craniofacial health care providers, regardless of discipline, in the use of evidence-based strategies to support patients with appearance differences and their families.

Additionally, our findings underscore the importance of prevention and intervention approaches to address social stigmatization concerns among children with Apert syndrome and their families. Changing Faces (https://changingfaces.org.uk), a UK-based nonprofit group whose mission is to support persons with visible differences regardless of cause, offers web-based information and support, including strategies that can help families of children with Apert syndrome cope with social stigmatization and facilitate positive coping and social integration. Finally, in line with Jewett et al. (2018), societal-level changes and acceptance of appearance differences as a means of reducing social challenges including discrimination and stigmatization should be promoted (eg, positive portrayals of individuals with craniofacial-related speech and appearance differences in the media), particularly since parents in our sample noted that persons who were less educated and/or familiar with craniofacial conditions often had more negative reactions with regard to their child's differences.

Overall, our results reflect commonalities across craniofacial conditions with regard to challenges and needs (Stock & Feragen, 2018). Nonetheless, more research is needed, particularly from the perspectives of children and adolescents themselves, to inform the types and timing of interventions for families of children with Apert syndrome. Promoting the child's independence may be an overlooked factor in clinical interventions developed for families coping with craniofacial conditions. Experiences of the parents in this study may serve as examples for that purpose. Parents also highlighted the importance of spousal support in coping with their child's condition, a factor which has received limited attention to date in the craniofacial literature (Zevtinoğlu et al., 2017). By describing their partners as their "psychologists" or confidants, parents in our sample highlighted the importance of supportive couple relationships in coping with their child's craniofacial condition. This highlights the importance of framing couples as a point of assessment and intervention.

Limitations and Directions for Further Research

There are multiple strengths of this study as this is one of the first studies to specifically focus on experiences of parents coping with Apert syndrome, an understudied craniofacial population. Furthermore, this study included a diverse sample of parents with regard to education and socioeconomic status and was conducted in a non-Western culture, involving an equal number of fathers and mothers. Yet, findings lack generalizability due to the small sample size represented. Furthermore, participants self-selected to be part of the study. It is possible that parents who opted to participate did so because of their positive experiences raising a child with Apert syndrome, while those who were more distressed could have been more reluctant to take part. We also had a heterogeneous sample; children's ages ranged between 1 and 12 years, and 2 of the children were diagnosed prenatally. Some studies indicate that prenatal diagnosis gives the parents more time to prepare and adjust to their child's condition (Zeytinoğlu et al., 2017). Moreover, parenting practices may differ based on the age of the child, and there may be other aspects of parenting that differ for families of children with Apert syndrome, which have yet to be studied. Future studies are needed to better understand how Apert syndrome affects families across the developmental spectrum in order to offer timely support and psychosocial interventions to help families enhance resiliency and navigate challenges.

Conclusion

This study utilized qualitative interviews to characterize the unique social experiences of parents of children with Apert syndrome including both challenges and strategies for coping. Results offer clinically relevant insights about the strengths and challenges of families coping with Apert syndrome and highlight needs for support, particularly around navigating social stigmatization.

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