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In their own words: caregiver and patient perspectives on stressors, resources, and recommendations in craniofacial microsomia care

Alexis L. Johns, PhD ABPP¹, Daniela V. Luquetti, MD PhD², Michelle R. Brajcich, BS³, Carrie L. Heike, MD MS², and Nicola M. Stock, MSc PhD⁴

¹Division of Plastic and Maxillofacial Surgery; Children's Hospital Los Angeles, Los Angeles, CA, USA.

²Seattle Children's Hospital, Craniofacial Center; Seattle Children's Research Institute; University of Washington, Department of Pediatrics, Seattle, WA, USA.

³School of Medicine, University of Washington, Seattle, WA, USA

⁴Centre for Appearance Research, University of the West of England, Bristol, UK.

Abstract

This study describes stressors, resources, and recommendations related to craniofacial microsomia (CFM) care from the perspective of caregivers of children with CFM and adults with CFM in order to inform improved quality of healthcare delivery. A mixed method design was used with fixed-response and open-ended questions from an online survey in English. The survey included demographics, CFM phenotypic information, and items about CFM-related experiences across settings. Themes were identified by qualitative analysis of responses to open-ended questions. Respondents (N = 51) included caregivers (n = 42; 90% mothers) and adults with CFM (n = 9; 78% female), who had a mean age of 45±6 years. Most children were male (71%) with an average age of 7±4 years. Respondents were primarily white (80%), non-Hispanic (89%), from the United States (82%), had a college degree (80%), and had private health insurance (80%). Reflecting the high rate of microtia (84%) in the sample, themes centered on the impact of hearing difficulties across settings with related language concerns. Negative social experiences were frequently described and school needs outlined. Multiple medical stressors were identified and corresponding suggestions included: providers need to be better informed about CFM, treatment coordination among specialists, and preference for a family-centered approach with reassurance, empathy, and clear communication. Advice offered to others with CFM included positive coping strategies. Overall, caregivers' and patients' responses reflected the complexity of CFM treatment. Incorporating these perspectives into routine CFM care has the potential to reduce family distress while improving their healthcare.

Corresponding author: Alexis L. Johns, PhD, ABPP, Division of Plastic and Maxillofacial Surgery, Children's Hospital Los Angeles, 4650 Sunset Blvd, MS#96, Los Angeles, CA 90027, Tel: (323) 361-7060, Fax: (323) 361-4106, ajohns@chla.usc.edu.

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Keywords

craniofacial microsomia; family stressors; family resources; qualitative analysis

Introduction

Craniofacial microsomia (CFM) is a congenital condition associated with underdevelopment of the ear (i.e., microtia) and mandible and has an estimated U.S. birth prevalence of 1 in 3,500–5,600.¹ Other facial features associated with CFM include lateral oral clefts, facial palsy, and eye anomalies. Additionally, CFM may be associated with facial paresis, upper airway obstruction, dysphagia, speech and hearing impairments, extra-cranial anomalies, and learning disabilities.^{2–6} Even though CFM is the second most common congenital facial condition seen within craniofacial teams, consistent diagnostic criteria for CFM have not been established. The lack of criteria is partially due to the wide-ranging phenotypic variability associated with the condition and the unknown etiology for most patients. Children with CFM may be labeled as having hemifacial microsomia (HFM), oculo-auricular-vertebral spectrum (OAVS), or Goldenhar syndrome, among other terms. In addition, individuals with isolated microtia are considered to represent the mild spectrum of CFM.^{4, 7}

Through adulthood, craniofacial surgeries are crucial components of the multidisciplinary care required for CFM.⁸ The burden of treatment for CFM has not been well described; however, children with microtia experience teasing and are at higher risk for psychosocial concerns, while their parents have reported difficulties in communication with providers and in their own coping.^{9–11} Similarly, studies of individuals with chronic medical demands have identified poor outcomes for well-being, burden on significant others, and ineffective resource use.¹²

Children with CFM and their caretakers also face challenges impacting their quality of life beyond their complex medical care.¹³ While little is known about the impact of CFM on families' lives, some evidence suggests parental quality of life may be affected.¹³ In regard to school, parents of children with CFM have reported experiencing higher levels of stress.¹⁴ In addition, teachers have described children with CFM as having lower levels of social competence and peer acceptance compared to peers, which mirrors patterns of lower quality of life in school and social domains for children with hearing loss.^{15,16} In the broader literature, a health condition including a visible difference has been shown to have a psychosocial impact on those affected and their families.¹⁷ Unwanted attention in the form of staring, questions, comments, and teasing may result in individuals feeling “different” or excluded from their peers.¹⁸ Such negative social encounters are associated with social anxiety and social avoidance, as well as low self-esteem, poor body image, and depression.¹⁹

Some findings derived from parent reports have not indicated differences between children with CFM and unaffected peers.¹⁵ Discrepancies have also been identified between child and parent reports of children's psychosocial adjustment.¹³ This highlights the importance of gathering multiple perspectives and the complexity of investigating the impact of a condition such as CFM. Furthermore, the patient experience and burden of treatment is

known to vary by age, type of intervention, and stage in medical and surgical management.¹² Qualitative research provides an effective means of exploring the multifaceted experiences of both caregivers and patients affected by the understudied diagnosis of CFM. There is a paucity of qualitative approaches in health research, particularly for craniofacial conditions.^{20,21} The question of adjustment to CFM is further suited to qualitative methods due to the relatively rare prevalence of the condition.²²

The present study used a mixed methods approach to elicit feedback from caregivers of children with CFM, as well as adult patients with CFM. We describe the experiences of individuals with CFM and their caregivers across their home, school, community, and medical settings. In addition, we report on resources participants found helpful, their advice to others affected by CFM, and their suggestions for improving healthcare. These study questions expand on their reports of overall healthcare and psychosocial experiences.²³ The nuanced perspective of patients and their families reflects the growing recognition of the importance of including patient reported outcome measures and integrating their feedback in ongoing quality improvement in clinical practice.²⁴

Materials and Methods

Institutional Review Board approval was obtained at Seattle Children's Research Institute. Invitations to participate for adults with CFM older than age 18 years and caregivers of children with CFM were posted on American advocacy and family association websites. Invitation letters were sent to families treated for CFM at Seattle Children's Hospital (SCH) and flyers were distributed in clinic at SCH and Children's Hospital Los Angeles. Inclusion criteria were: 1) diagnosis within CFM spectrum, including hemifacial microsomia (HFM), oculo-auriculo-vertebral spectrum (OAVS), microtia, and/or Goldenhar syndrome; 2) CFM-associated features: facial asymmetry, preauricular or facial skin tags, anotia or microtia, aural atresia, lateral oral clefts, and epibulbar dermoid; and 3) fluency in English. Sample images were provided to exemplify craniofacial features. Eligibility was confirmed by two authors reviewing reported phenotypic features, birth history, and healthcare history.

Survey

Data were collected from June 2016 to April 2017 using an online self-report anonymous survey in the REDCap platform.²⁵ Participants reported demographic characteristics and CFM phenotypic information. Items in fixed response and free text formats asked about difficulties in the home, school, medical, and community settings, along with what they have found helpful and their advice.

Data analysis

Descriptive statistics were used for demographics and categorical variables with Stata version 12. Responses to the 15 open-ended questions were grouped by two authors trained in qualitative methodology in an iterative process into themes.²⁶ Authors individually coded based on content to capture both the depth and the breadth of the responses, rather than using a theory-driven analysis.²⁶ Thematic groupings were compared and initial coding had an average agreement of 94% (range 81% - 100%). Authors then reconciled the thematic

groupings together until agreement was reached. Illustrative quotes were selected for each theme and frequency counts calculated.

Results

Participant characteristics

The link was opened by 114 participants and 53 (46%) completed the full survey. Demographic and CFM features provided by 25 of the 61 who did not complete the survey were similar to the study sample, with the exceptions of being only English speakers and reporting fewer major concerns at birth. Two participants who self-identified with Treacher-Collins syndrome were excluded. The sample included 42 caregivers and nine adults with CFM (Table 1), who completed the survey in an average of 38 minutes. Most caregivers were mothers (90%) with male children (71%) who had a mean age of 7 years ($SD = 4$; range 0–17). Most adults with CFM were female (78%) and the mean age was 45 years ($SD = 6$; range 24–76). Respondents were white (80%) and non-Hispanic (89%). Participants were primarily from the United States (82%), as well as Canada (6%), Central/South American (4%), Mexico, (2%), United Kingdom (2%), and other European countries (4%). Most had a college degree (80%), had private health insurance (80%), and spoke English as their primary language (86%). Individuals with CFM generally received the diagnosis at birth (74%) and the most common diagnosis was microtia (84%), with or without HFM, CFM, and/or Goldenhar syndrome. Common facial features of CFM were microtia (86%), aural atresia (78%), and facial asymmetry (75%).

Home and Community Settings

For those who identified difficulties in the home setting, both caregivers (34%) and adults (29%) reported hearing concerns (Table 2). Caregivers identified stressors in speech difficulties, treatment burden, and their own distress (11% each theme). Adults noted difficulties in social comparisons with others, a lack of understanding by others, and not discussing their diagnosis in the home (14% each theme). Correspondingly, social stigma was noted by caregivers (62%) and adults (57%) to be a primary concern in community settings (Table 3). Hearing concerns were also reported as a difficulty in the community by caregivers (21%). Caregivers noted explaining their child's diagnosis to others (17%) as challenging, as well as accommodating for participating in activities and sports (10%). Adults reported hiding their diagnosis in community settings (29%) and one adult described feeling motivated to disprove negative assumptions made by others based on their diagnosis.

When asked about sources of support, caregivers identified online support websites (71%), their spouse/partners (62%), family (57%), and medical providers (48%) as most helpful (Table 4). They also noted friends (41%) and communicating with others who have similar diagnoses (41%) as supportive. Interestingly, a third identified scientific research and articles as important for coping. Adults with CFM offered advice for children with similar diagnoses, including making informed medical decisions (50%), having self-confidence (50%), reframing their experience when they are teased (25%), and openly communicating about their diagnosis (13%). Caregivers had a dozen themes identified in their advice for new parents, with reassurance that their child is a typical child (34%) given most frequently.

They described positive reframing (26%), seeking CFM information and expert care (26%), acceptance (24%), and having patience (13%). Additional advice was to seek online support, normalize the range of parental emotions, and be open about their diagnosis (11% each). They advised teaching their children coping skills and confidence (8%) and keeping calm (8%). When asked specifically about hearing aid use, about a fifth of caregivers reported children were motivated by the benefit of improved hearing. When asked about ways to help promote hearing aid adherence, caregivers suggested introducing aids at a young age (29%), adjusting for comfort (12%), praising use of aids (12%), practicing coping skills for questions about the aid (8%), and using a reward system (2%).

School Setting

Challenges in school reported by caregivers (Table 5) included being shy (19%), difficulties with attention (19%), and being teased (17%). Reading and writing were identified as academic areas in which some children experienced difficulty (12%). Caregivers (94%) and an adult with CFM (11%) described a range of hearing difficulties at school. Active teasing was identified by caregivers (27%) and adults (56%), as well as passive social exclusion (caregivers 12%; adults 33%). Correspondingly, adults with CFM described trying to hide their difference (22%), experiencing social comparison (11%), and having difficulties in romantic relationships (11%). Caregivers noted problems in accessing and navigating school systems (27%) and in poor teacher communication and understanding (24%).

School-aged children received assistance from schools (Table 6) most commonly through consistent preferential seating (caregivers 57%; adults 33%) and in auditory support services (caregivers 45%). Caregivers also noted additional classroom accommodations (14%). Clear and frequent communication from the school to family was reported by caregivers (33%) and adults (22%). Similarly, creating a proactive approach with peers and support for teasing was provided (caregivers 10%; adults 22%). A portion of caregivers (10%) and adults (67%) reported they received no help from their schools. When asked for suggestions for schools, 53% of caregivers noted they were satisfied by their school experience. The most offered suggestion by caregivers (21%) and adults (29%) was addressing hearing needs appropriately. Other suggestions were increasing peer awareness of CFM (caregivers 11%; adults 14%), addressing teasing (caregivers 5%; adults 14%), and improving their own understanding of CFM (caregivers 5%; adults 57%). Improved communication with parents was also suggested by caregivers (11%) and adults (29%) wanted to be treated like their peers.

Medical Setting

Difficulties identified in the medical setting (Table 7) by a quarter of caregivers included a lack of knowledge about CFM among their providers. A lack of empathy or understanding (caregivers 19%; adults 40%) and little guidance about CFM treatment (caregivers 16%; adults 20%) were also concerns. Caregivers described difficulties accessing treatment (13%), receiving conflicting medical recommendations (13%), having difficulty coordinating multiple providers (9%), experiencing treatment burden (9%), and lacking insurance coverage (6%). A group of caregivers (19%) and adults (20%) noted no concerns in the medical setting and another group provided positive feedback about their providers

(caregivers 9%; adults 20%). Among caregivers, helpful components of their healthcare experience (Table 8) included having a specific treatment, such as hearing aids, provided (30%). They also valued clear communication of treatment plans (21%) and using a patient-focused approach (9%). Similarly, caregivers appreciated when medical staff had a positive attitude (9%), provided reassurance (9%), invested time with them (9%), coordinated their care (6%), and allowed for parental control (6%).

When offering suggestions to improve healthcare delivery (Table 9), caregivers (35%) and adults (50%) wanted improved treatment communication and coordination. Both caregivers (6%) and adults (17%) also suggested patient-centered approaches. Caregivers recommended having clear and current data about CFM (16%), making appropriate referrals (13%), being more informed about CFM (13%), supporting parent advocacy (10%), and providing support in gaining insurance coverage (6%). Caregivers also wanted parents to be reassured (6%) and care to be more widely geographically accessible (6%). One adult (17%) suggested providers link individuals with CFM together to experience normalization of their diagnosis and experiences.

Discussion

There is a growing recognition among providers that the related features of CFM are better conceptualized as a unified spectrum to allow for coordinated advances in treatment and research.²⁷ A greater appreciation of the multi-systemic stressors experienced by patients with CFM and their families is a crucial component in improving the provision of healthcare. The present study is one of only a few to comprehensively assess patient and caregiver experiences of CFM and one of the first to utilize a mixed methods approach. The findings provide important insight into the stressors experienced in the home, school, community, and medical settings. It is important to note that within most areas, a substantial subgroup reported that they had not experienced difficulties and may reflect resiliency and effective use of supports and services. Participants also outlined resources that they found helpful and suggestions for the delivery of healthcare.

Participants identified many medical-related stressors, including a perceived lack of knowledge of CFM among health professionals with correspondingly poor treatment coordination and conflicting medical recommendations. Families also reported difficulties accessing appropriate treatment, often related to lack of insurance coverage. Several caregivers and patients described feeling medical providers lacked empathy and understanding. Finally, the burden of ongoing treatment was noted, including frequent appointments, costs, and trying to address poor coordination of care between providers. Responses reflected identified components of treatment burden, including financial burden, time and travel burden, and healthcare access burden.¹²

To help overcome these challenges, participants wanted health professionals to be better informed about CFM, refer to specialists appropriately, and coordinate care. They reported valuing a patient-focused approach with clearly communicated treatment plans and family involvement in medical decision-making. Caregivers noted the importance of providers demonstrating a positive attitude, providing reassurance, and investing time with them.

These suggestions are similar to findings in other populations. For example, patients with a cleft and their caregivers wanted their views to be heard and more treatment coordination and information.²⁸ Similarly, a qualitative study with patients with chronic conditions described the positive impact of well-coordinated care and feeling respected, listened to, and empowered.²⁹

Caregivers' and adults' described multiple ways hearing loss affected them across settings in their daily lives, from tracking each other to safety concerns. As has been well documented, this sample also reported on how children's hearing loss can impact their social and academic functioning and quality of life.^{16,30} Appropriate ENT treatment and follow-up for hearing loss including hearing aids from early childhood can help address these concerns, particularly in language development.³¹ As learning difficulties are also known to be a concern, the importance of supporting families in school advocacy was highlighted, such as ensuring children have preferential seating accommodations, auditory support, and FM system use.^{3,5} Correspondingly, speech and language difficulties were also described as impacting participants in multiple settings. Beyond linking families to language and speech therapy intervention, research drawn from the fields of cleft lip/palate and hearing loss have identified several strategies for overcoming these difficulties in the context of social settings and may also be applicable for those affected by CFM.^{32,33}

Another common theme was the potential impact of negative social encounters, ranging from curious stares or questions to direct teasing and bullying, which contributed to participants trying to hide their CFM features, feeling excluded, and difficulties in romantic relationships. Parents also described their own distress in witnessing their children's response to teasing and called for schools in particular to address teasing and increase CFM awareness. These patterns are reflected in the visible difference literature.¹⁷ Cognitive Behavioral Therapy techniques and social skills training offer potential strategies to help cope with the impacts of a visible difference and are being trialed in an online format.^{19,34–36} Linking families to such interventions may offer valuable support to those affected by CFM. Psychological support, as well as opportunities to meet others affected by CFM, should be offered as standard in a variety of formats and throughout the entire treatment pathway. In addition, public awareness campaigns, such as those promoted by the American Cleft Palate-Craniofacial Association (US), the Cleft Lip and Palate Association (UK), and Changing Faces (UK) may improve social experiences for individuals with CFM and their caregivers.

Psychosocial research in the field of craniofacial conditions has typically focused on the identification of problems and deficits, with less focus on resilience and personal growth. Learning about the supports and coping used by families and incorporating this learning into their routine care has the potential to reduce family distress while improving treatment. For example, in addition to family and friends, many participants identified online support websites, medical providers, others with CFM, and scientific research as sources of support. These responses highlight the vital role healthcare professionals can play in connecting families to support, as well as directly through providing CFM information, clearly communicating about treatment, and maintaining a positive and reassuring attitude. Advice offered to others affected by CFM included many positive coping strategies, including:

reassurance, positive reframing techniques, acceptance, self-confidence, patience, openness about CFM, and seeking medical information and social support.

A study limitation is the small sample that could be due to limited time, interest, internet access, and internet literacy; however, by posting on websites accessed within and outside of the United States, participants came from a more geographically diverse population than previous studies performed in a clinic or hospital setting. Another limitation is the possibility of both negative and positive bias about their experiences based on self-selection of participants. As the majority of respondents were white, non-Hispanic, well-educated individuals who were able to navigate the web-based survey, the sample is not considered representative of the general population. Nonetheless, it would be expected that the issues identified within this higher-functioning sample would be reflected with greater severity among populations that experience more barriers in accessing health information and care. Further qualitative and quantitative research with larger sample sizes, including children and adolescent perspectives, and in other languages and countries will help increase understanding of experiences in multiple cultures.

In conclusion, this study adds to our understanding of the perspective of individuals with CFM and their caregivers' stressors across settings. The range of adaptive coping strategies and supports described and their corresponding suggestions for providers can inform standards for care.

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Table 1.
Characteristics of survey respondents (N = 51)^a

	n	%
Relationship to individual with CFM		
Self	9	18
Mother	38	75
Father	2	4
Other	2	4
Craniofacial Diagnosis		
Microtia	43	84
Hemifacial Microsomia (HFM)	30	59
Goldenhar Syndrome	11	22
Craniofacial Microsomia (CFM)	10	20
Oculo Auriculo Vertebral Syndrome (OAVS)	4	8
Other	3	6
Features		
Microtia	44	86
Aural atresia	40	78
Facial asymmetry	38	75
Skin tags (preauricular or facial)	22	43
Vertebral/rib anomalies	6	12
Congenital heart disease	6	12
Epibulbar dermoid	5	10
Cleft lip and/or cleft palate	5	10
Kidney anomalies	5	10
Lateral oral cleft	4	8
Upper eyelid cleft	2	4
Other	15	29
Surgeries Completed		
Bone anchored hearing aid abutment	14	28
Adenoidectomy and/or tonsillectomy	12	24
Dental restoration/extraction	11	22
Ear reconstruction	11	22
Branchial remnant removal	11	22
Tympanostomy tubes	10	20
Aural atresia repair	6	12
Mandibular surgery	6	12
Cleft lip and/or cleft palate repair	3	6
Alveolar bone graft	3	6
Tracheostomy	2	4
Lateral oral cleft repair	2	4
Other surgery ^b	13	26

	n	%
Race		
White	37	80
Black/African American	1	2
Asian	2	4
Other race	2	4
Multi-racial	4	9
Ethnicity		
Non-Hispanic	41	89
Hispanic/Latino	5	11
Education		
12 years, high school or equivalent secondary education	1	2
Some college/associate degree	8	17
Completed university/college	37	80
Health coverage		
Private health insurance	36	82
Public insurance	5	11
Military health care	3	7
No coverage of any type	2	5

^aSome variables do not total to 100% due to information not reported and the diagnosis total exceeds 100% as some respondents selected more than one diagnosis

^bIncludes strabismus repair, lacrimal duct surgery, facial nerve surgery, upper jaw surgery, jaw implant, bone and fat grafts

Table 2.
Difficulties in the home setting

Theme/Sample response	Caregiver (n = 35)		Adult (n = 8)	
	n	%	n	%
None	12	34	4	57
“none, it’s easy to accommodate at home” (male, age 5)				
Hearing difficulties	12	34	2	29
“just simple hearing that we all take for granted, like locating sound. He could never find me. I have to always remember that I have to tell him where I am.” (male, age 11)				
Speech/language difficulties	4	11	-	-
“frustration with not understanding his speech due to his speech and articulation delays” (male, age 5)				
Treatment burden	4	11	-	-
“mainly just all the ‘upkeep’ it takes for him to be healthy. It’s hard to brush his teeth on the small side of his jaw; we have to put gel in his neurotrophic eye [three times] a day. We have to recover from surgeries sometimes, etc.” (male, age 5)				
Parental distress	4	11	-	-
“it was all very overwhelming and consuming” (female, age 2)				
Unknown etiology	3	9	-	-
“not knowing the cause” (female, age 3)				
Feeding difficulties	2	6	-	-
“feeding has been hard, he can’t suck and had trouble [gaining] weight, at five months [he] hasn’t doubled his birth weight yet” (male, age 5 months)				
Social comparison	-	-	1	14
“comparing yourself to siblings” (female adult)				
Lack of understanding by others	-	-	1	14
“I was told I had ‘selective hearing’ by those who didn’t understand” (female adult)				
Not discussing diagnosis	-	-	1	14
“the lack of discussion” (female adult)				

Table 3.
Difficulties in the community setting

Community Setting	Caregiver (n = 29)		Adult (n = 7)	
	n	%	n	%
Social stigma	18	62	4	57
“At work I see people stop and look at my mouth when they first meet me. I know they wonder what happened, did I have a stroke, am I special needs person?” (female adult)				
Hearing difficulties	6	21	-	-
“his lack of directional hearing concerns me for his safety” (male, age 6)				
None	6	21	1	14
“no problem at all” (male, age 11)				
Explaining diagnosis	5	17	-	-
“always having to address his condition with new playmates who have questions about why he looks that way and what happened to his ear” (male, age 6)				
Activity/sports participation	3	10	-	-
“water activities are difficult” (female, age 8)				
Hiding CFM	-	-	2	29
“hiding my ear, taking a pony tail down and making sure my hair covers my ear” (female adult)				
Motivation to disprove negative assumptions due to CFM	-	-	1	14
“it makes me work harder to prove I’m smart and this does not define me” (female adult)				

Table 4.
Sources of coping and advice for new parents and children

Survey Response	Caregiver (n = 42)	
	n	%
Online support websites/facebook pages	30	71
Spouse/partner	26	62
Family	24	57
Medical providers	20	48
Friends	17	41
Communication with other who have similar conditions	17	41
Scientific research and articles	14	33
School	7	17
Religious community/religious leaders	6	14
Psychologist/mental health counselor	2	5
Theme/Sample response	Caregiver (n = 38)	
Advice from caregivers to new parents		
Reassurance their child is a typical child	13	34
"your child will do and be like all other children" (male, age 6)		
Positive reframing	10	26
"It's not a bad diagnosis. It is very manageable and could have been much worse" (female, age 8)		
Seek information and CFM expert care	10	26
"Try to learn as much as you can. Ask lots of questions. Go to as many doctors as possible to learn as well." (female, age 15)		
Acceptance	9	24
"mourn your mental image of the [child] you thought you'd have but rejoice in the one you have, he/she is just as perfect, just different" (male, age 5)		
Patience	5	13
"patience – you are walking a marathon, not sprinting to first base" (female, age 2)		
Seek online support	4	11
"online support groups are invaluable since this condition is rare and you may not meet anyone close to you familiar with this condition" (male, age 7)		
Normalize range of parental emotions	4	11
"you're going to feel guilt and sadness but you will also feel joy and excitement" (male, age 4)		
Be open about CFM	4	11
"Do not try to hide them. Be open and have an open mind." (male , age 4)		
Keep calm	3	8
"Relax! It's going to be OK." (male, age 13)		
Teach coping skills and confidence	3	8
"give them confidence to go over the topic [of CFM] and learn how to react when people ask/stare at it in public" (male, age 11)		
Religious support	1	3
"God is with us and will always help us no matter how hard the condition is" (male, age 3 months)		
No parental blame	1	3
"there is nothing you've done to cause this" (male, age 5)		

		Caregiver (n = 42)	
Survey Response		n	%
Advice for children from adults with CFM		Adult (n = 8)	
Make informed medical decisions		4	50
“get as much information as you can to make the decision that is best” (female adult)			
Have self-confidence		4	50
“Be yourself and just be positive. Make a difference. You are more than this, don’t let it own you.” (female adult)			
Reframe teasing		2	25
“just don’t let bullies get you down” (female adult)			
Use open communication		1	13
“be honest and talk about it” (female adult)			

Table 5.
Difficulties in the school setting

Survey Response	Caregiver (n = 42)		Adult	
	n	%	n	%
No difficulties	14	33	-	-
Too young for school	10	24	-	-
Being socially shy	8	19	-	-
Difficulties with attention	8	19	-	-
Being teased	7	17	-	-
Difficulties with reading/writing	5	12	-	-
Difficulties with speech	4	10	-	-
Difficulties with math	3	7	-	-
Difficulties in other academic areas	3	7	-	-
Difficulties with hearing	3	7	-	-
Theme/Sample response	(n = 33)		(n = 9)	
Hearing difficulties	31	94	1	11
“hearing loss makes education more difficult...equipment doesn’t always work” (male, age 6)				
Teasing	9	27	5	56
“hearing this precious little girl sob because she was teased and excluded due to her differences” (female, age 17)				
Accessing/navigating school systems	9	27	-	-
“obviously he has an IEP so school is just more complicated for us” (male, age 5)				
Poor teacher understanding/communication	8	24	-	-
“reminding teachers that he is not being defiant, he just did [not hear them]” (male, age 6)				
None	6	18	-	-
“they are wonderful, no frustrations...it was new and they were attentive” (female, age 3)				
Social exclusion	4	12	3	33
“always worrying about acceptance by peers” (male, age 11)				
Being misunderstood	3	9	-	-
“people not understanding him due to his speech issue” (male, age 5)				
Trying to hide difference	-	-	2	22
“I always wore my hair down to hide my left ear so it wasn’t noticed” (female adult)				
Social comparison	-	-	1	11
“comparing yourself to others” (female adult)				
Romantic relationships	-	-	1	11
“I didn’t have a boyfriend until I was 17 because boys were afraid they would be made fun of for talking to me. My first boyfriend was from another school that didn’t know me.” (female adult)				

Table 6.
Assistance received by and suggestions for schools

Assistance Received by Schools Survey response	Caregiver (n = 42)		Adult (n = 9)	
	n	%	n	%
Consistent preferential seating accommodation	24	57	3	33
Auditory support in Individualized Education Program (IEP)	19	45	-	-
Clear and frequent communication with family	14	33	2	22
Other IEP services	10	24	-	-
Too young for school	8	19	-	-
Other classroom accommodations	6	14	-	-
Proactive approach with peers and support for teasing	4	10	2	22
No help from school	4	10	6	67
Psychosocial support	3	7	-	-
Tutoring	2	5	-	-
Suggestions for Schools Theme/Sample response	(n = 19)		(n = 7)	
Satisfied by schools	10	53	-	-
“Nothing, our schools have been amazing in servicing us and his needs” (male, age 5)				
Address hearing needs/equipment	4	21	2	29
“remember to use the FM system” (male, age 13)				
Improve communication with parents	2	11	-	-
“more frequent and more detailed updates” (male, age 5)				
Increase class/peer awareness of CFM	2	11	1	14
“make other students aware of this” (female adult)				
Address teasing	1	5	1	14
“the elementary school essentially ignored brutal teasing and exclusion; anything would honestly be an improvement” (female, age 17)				
Improve understanding of CFM	1	5	4	57
“Demonstrate that they understand the situation - I’m tired of hearing teachers say ‘he can hear just fine’ and doing sneaky little ‘tests’ of his hearing” (male, age 7)				
Treat students with CFM like their peers	-	-	2	29
“not treat them like they are stupid” (female adult)				

Table 7.
Difficulties in the medical setting and with medical providers

Theme/Sample response	Caregiver (n = 32)		Adult (n = 5)	
	n	%	n	%
Lack of knowledge about CFM	8	25	-	-
“the number one issue is competence of medical staff....we can’t just trust that doctors and nurses know what they are doing when it comes to him” (male, age 5)				
None	6	19	1	20
“no problems” (male, age 5)				
Lack of empathy/understanding	6	19	2	40
“understanding my anxiety when asking questions or understanding my concerns with microtia” (male, age 1)				
Lack of guidance about CFM and treatment	5	16	1	20
“it’s hard to know what to do or if you should just do nothing, it seems to depend on the severity of the diagnosis, but I hoped for a more clear answer of what we should expect in terms of time frame” (male, age 3)				
Accessing treatment	4	13	-	-
“early ability to access BAHA was difficult...[he] was not able to capitalize on the ‘speech explosion’ that happens in toddlerhood” (male, age 7)				
Conflicting medical recommendations	4	13	-	-
“doctors provide conflicting recommendations, not just different doctors, but from visit to visit with the same surgeon” (male, age 7)				
Positive feedback	3	9	1	20
“our team is unbelievably wonderful” (male, age 5)				
Difficult coordinating multiple providers	3	9	-	-
“the biggest thing is the coordination among the MANY providers. I’m forced to be this go-between and it is insane! E.g., speech therapist asks me whether the ENT recommends [a] frenulectomy that [the] craniofacial surgeon would actually do.” (female, age 2)				
Treatment burden	3	9	-	-
“to program hearing aids and FM devices requires frequent audiologist visits” (male, age 7)				
Lack of insurance coverage	2	6	-	-
“so many appointments/medical bills that our insurance doesn’t cover (female, age 3)				

Table 8.
Helpful components of healthcare provided

Theme/Sample response	Caregiver (n = 33)	
	n	%
Specific treatment provided	10	30
“hearing aids at five weeks” (female, age 3)		
None	8	24
“not yet” (male, age 4)		
Communicated clear treatment plans	7	21
“The more details doctors give me, the better. I want to know and I make a point of asking educated questions. I’m never going to take any doctor’s advice if it doesn’t make sense to me, even if they are the top specialist in their field.” (male, age 5)		
Used a patient-focused approach	3	9
“doctors who refuse to talk down to the child or to condescend have been much appreciated. Doctors who ask me, as the mother, what I think is wrong are always rock stars” (female, age 17)		
Had a positive attitude	3	9
“they have been positive and optimistic” (female, age 7)		
Provided reassurance	3	9
“our first plastic surgeon repeatedly told me it was not my fault and not to blame myself, but just to love my child and be the best mom I could be to him” (male, age 13)		
Invested time	3	9
“being willing to spend as much time as needed to answer my questions” (female, age 15)		
Coordinated care	2	6
“the second [pediatrician] has guided us...he said we should talk to a geneticist, then he sent us to an audiologist” (male, age 5 months)		
Allowed for parent control	2	6
“I attended conferences in California and DC where there were doctors who have treated many children with this condition and they gave me the best advice, mostly told me not to jump into any unnecessary surgeries too early” (male, age 5)		

Table 9.
Suggestions to improve healthcare delivery

Theme/Sample response	Caregiver (n = 31)		Adult (n = 6)	
	n	%	n	%
Improve treatment communication and coordination	11	35	3	50
“explain with the next step is – we still don’t even know when she’s supposed to go back to see her ENT doctor...they never bothered to let us know what the CT scan result was either” (female, age 3)				
None	6	19	2	33
“can’t think of anything” (male, age 9)				
Provide clear and current CFM data	5	16	-	-
“help with finding/providing research about microtia” (male, age 6)				
Make appropriate referrals	4	13	-	-
“some of the local [doctors] shouldn’t have tried to tell us they were ‘experts’ – they were kind of just interested in the condition and wanted to help, but maybe they weren’t totally qualified” (male, age 13)				
Be better informed about CFM	4	13	-	-
“have the knowledge of the different surgical options” (male, age 1)				
Support parent advocacy	3	10	-	-
“they could do better [by] sometimes telling me I’m doing a good job or complimenting my advocacy skills” (male, age 5)				
Be patient-centered	2	6	1	17
“they could see me as a person and not as something they want to try new procedures on” (female adult)				
Support with insurance coverage	2	6	-	-
“help with the insurance companies to get coverage” (female, age 15)				
Reassure parents	2	6	-	-
“just to tell families when their child is born it will be ok...as long as there aren’t any other health issues of course” (male, age 13)				
Be more geographically accessible	2	6	-	-
“Move to our state!” (male, age 5)				
Link to others with CFM	-	-	1	17
“show me others like me...I felt like I was the only one that had this” (female adult)				