**Psychosocial Experiences of Spanish-Speaking Parents of Children**

**with Craniofacial Microsomia**

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**Abstract**

Craniofacial microsomia (CFM) and microtia psychosocial research in the U.S. is primarily with English-speaking participants. Given that 19% of the U.S. is Latino and there is a higher prevalence of CFM in Latino populations, this study aims to describe psychosocial experiences related to CFM among Spanish-speaking Latino caregivers to better inform healthcare. Narrative interviews (mean 73±17 minutes) were completed in Spanish with parents of children with CFM aged 3-17 (mean age 10.8±4.8 years). Transcripts were analyzed using quantitative linguistic analyses and reflexive thematic analysis. Participants (*N*=12) were mostly mothers (83%) who had immigrated to the U.S. and had low socioeconomic status. Based upon analysis of grouped word counts, participants spent approximately half of their narratives discussing the first two years of their child’s life. Themes selected based on U.S. Latino sociodemographics and cultural values included the *Impact of Language*, *Healthcare Challenges*, *Supportive Healthcare Experiences*, *Caregiver Coping with CFM*, *Family Roles*, and *Addressing Social Implications of CFM*. Results highlighted that the first years of care are of critical importance to parents and suggest this is an optimal time to focus education and support services for families. Additional treatment suggestions include providing interpretation and informational materials in Spanish, addressing care barriers, supporting familial and child coping, accounting for the role of extended family, and helping address social concerns. Ongoing research with Latino families can further assist in guiding culturally sensitive CFM healthcare.

**Keywords:** Craniofacial Microsomia; microtia; Goldenhar Syndrome; Latino; culturally sensitive care

**Introduction**

Craniofacial microsomia (CFM) is a congenital condition that includes a spectrum of clinical features such as hypoplasia of the ear and mandible. Hypoplasia of the external ear (e.g. microtia) is the most common feature associated with CFM and approximately 660 infants are born with microtia in the US each year.[[1]](#endnote-1),[[2]](#endnote-2) International CFM treatment guidelines recommend multidisciplinary care, which includes provision of psychosocial support.[[3]](#endnote-3) A review of 64 studies focused on psychosocial needs of individuals with CFM and microtia from 2000 to 2020 summarized increased risk for social concerns for individuals with CFM and heightened stress for caregivers related to their child’s CFM diagnosis and treatment.[[4]](#endnote-4) However, there was minimal Latino (also referred to as Hispanic and Latinx) representation identified in the review, despite the higher CFM prevalence among individuals of Latino heritage.[[5]](#endnote-5),[[6]](#endnote-6) This gap in the literature needs to be addressed to improve clinical care that is reflective of U.S. demographics. As of 2023, 19% of the U.S. population are Latino.[[7]](#endnote-7) Of the 62 million Latinos in the U.S., about a third are immigrants and a third are not proficient in English.[[8]](#endnote-8),[[9]](#endnote-9) Compared to the general U.S. population, Latino individuals have lower levels of educational attainment and higher rates of poverty.[[10]](#endnote-10) These factors contribute to a wide range of disparities in healthcare, including pediatric care.[[11]](#endnote-11),[[12]](#endnote-12),[[13]](#endnote-13) Within populations with craniofacial conditions, disparities, such as delayed surgeries, that have been identified for minority and non-English speaking patients with craniosynostosis and cleft lip and/or palate may be similar for children with CFM.[[14]](#endnote-14),[[15]](#endnote-15)

 Understanding Spanish-speaking and immigrant Latino caregiver experiences with CFM can help inform culturally sensitive care and provide insight into potential healthcare disparities. While there is considerable intragroup variability, several broadly held cultural values have been described among Latino populations that can help inform CFM care.[[16]](#endnote-16) Given the familial context for pediatric CFM care as well as family networks that support parents, *familismo* is a key value and refers to the strong attachment and comprehensive mutual support expected among family members.[[17]](#endnote-17),[[18]](#endnote-18) *Simpatía* reflects the high value placed on warm, positive social interactions that avoid negativity and conflict.[[19]](#endnote-19),[[20]](#endnote-20) *Simpatía* is particularly relevant to CFM given the social aspects of a visibly different diagnosis as well as expectations families may have of healthcare providers.11,[[21]](#endnote-21),[[22]](#endnote-22) The experience of Latino parents of children with microtia was the focus of one paper based on a sample that was 84% Latino and 66% monolingual Spanish-speaking, which found that parents frequently received incomplete information at diagnosis, leading to negative emotions, misconceptions about causes, and worries about their child's future.[[23]](#endnote-23) Parents in that study described improved coping over time through learning about treatment and receiving social support.17 However, further research is needed to better understand the needs of Spanish-speaking CFM populations.

 This paper describes parental experiences related to their children’s diagnosis and treatment for CFM in a Spanish-speaking Latino sample with a focus on topics relevant to sociodemographic characteristics and cultural values. In the context of a growing Latino U.S. population with higher rates of microtia and CFM and minimal information available for healthcare providers, the aim of this study is to help inform culturally sensitive CFM care.

**Methods**

This study was part of a larger Institutional Review Board approved research program called Craniofacial microsomia: Accelerating Research and Education (CARE).[[24]](#endnote-24) Inclusion criteria for this part of the CARE study was limited to Spanish-speaking caregivers of children with CFM ages 3-17 years who met the FACIAL research inclusion criteria.[[25]](#endnote-25) The FACIAL criteria include a combination of specific features associated with CFM, and eligible participants often have clinical diagnoses that include microtia, hemifacial microsomia, oculo-auriculo-vertebral syndrome, and Goldenhar syndrome. Exclusion criteria were syndromes that can include similar clinical features, such as Treacher-Collins, Townes-Brocks, or Nager, or a major medical condition not associated with CFM, such as cancer. Participants were recruited from Seattle Children’s Hospital and Children’s Hospital Los Angeles. Participants consented prior to providing their children’s health histories and then completed narrative interviews. Interviews were conducted in Spanish by either a Latina or white female interviewer with doctoral level training in psychology. Interviews were completed via a HIPPA-compliant teleconference platform (92%) or by telephone (8%).

 An unstructured narrative interview modified life story format was used to allow participants to direct the content based on what they found relevant to their lived experiences.[[26]](#endnote-26),[[27]](#endnote-27) They were asked to reflect on the story of their child’s journey with CFM and develop ‘chapters’ or stages of their life as well as particularly positive and negative aspects of each chapter. The interviews had a mean length of 73 minutes (standard deviation of 17 minutes). Interviews were transcribed in Spanish and then translated into English.

 Quantitative analyses were completed using Python in order to help describe what caregivers focused on in their narratives.[[28]](#endnote-28) In order to identify the time frame participants spent the most time discussing, a word count analysis was completed based on approximate age ranges identified by a study team member reviewing the transcripts of: 0 – 1 year, 11 months; 2 years – 3 years, 11 months; 4 years – 9 years, 11 months; and 10 years – 16 years, 11 months. An algorithm employing Regular Expression (Regex) based pattern matching and contextual analysis was utilized targeting both categorized and uncategorized segments.[[29]](#endnote-29) Before final analysis, segments not categorizable with confidence were removed. In addition, participants’ chapter titles were grouped by general topic and analyzed to find common patterns. A third analysis created a word count of the most frequently stated words after removing prepositions to further assist in describing the most common experiences discussed by parents.

 A South Asian male with bachelor’s training in data science and a bilingual English-Spanish white female author trained in qualitative methods completed a reflexive thematic analysis.[[30]](#endnote-30),[[31]](#endnote-31),[[32]](#endnote-32),[[33]](#endnote-33) First, the authors became familiar with the interviews through multiple readings before initial coding was completed in NVivo based on the preliminary analysis of English-speaking caregivers in the larger CARE study.[[34]](#endnote-34) Next, additional coding and refining of existing codes was completed in an iterative process focusing on the content that was novel or varied for the Spanish-speaking participants. Codes were grouped into themes with frequent discussion and drew on the perspective of the interdisciplinary group of authors, including a mother of a child with CFM. For the purpose of this paper, results were selected related to areas likely to be particularly relevant to Spanish-speaking Latino immigrant parents with lower socioeconomic backgrounds and drawing on cultural values of *familismo* and *simpatía.* Illustrative quotes were selected and results descriptions follow guidelines for quantifying language where “all” refers to all or all but one, “most” refers to more than half, and “some” refers to less than half, but more than two.[[35]](#endnote-35)

**Results**

**Participants**

Participants (*N*=12) were mostly mothers (83%) with a mean age of 31±19 years who were married/cohabitating (75%) and employed (75%). Most participants (63%) had not graduated from high school and all familial Hollingshead socioeconomic status (SES) scores were in the three lowest categories of V (50%), IV (33%), and III (8%).[[36]](#endnote-36) Parents immigrated to the U.S. from Mexico (67%), Guatemala (17%), Venezuela (8%), and unknown (8%). Children had a mean age of 10.8±4.8 years and 58% were female. All children had microtia and most had mandibular hypoplasia (83%). All children had hearing loss. On average, children had seen 9.7±4.8 healthcare specialists.

**Narratives by Age Ranges and Topics**

As one approach to describe the range of topics covered across narratives and capture the relative time spent on different ages within participants’ narratives, an analysis of the word count per age range was completed. As seen in Figure 1, participants spent nearly half (47.7%) of their narratives discussing the period between birth and the child’s second birthday. On average, they focused 73% of their narratives on the period from birth to their child’s fourth birthday. This pattern was identified even among the participants with older children and illustrates the emphasis participants placed on their children’s early years. Based on their chapter titles, there was an even distribution across four areas. The four areas (along with sample titles) are as follows: Birth and Pregnancy (“The Birth”), Emotional Journey (“Hard Times for Both of Us”), Medical Challenges (“Learning More About Your Syndrome”), and Personal Events (“Her Trip to Mexico”). The chapter titles reflected a range of parental experiences, such as “The Worst Illness”, “Accepting and Loving”, and “The Little Things Matter.” In the word cloud analysis, we found that health, education, and emotional states were the most frequent categories after removing prepositions. The terms “ear” and “surgery” were the most common words in parents’ narratives after removing stop words, e.g. “the” and “said”. Among the sentiments identified from all of the words in the transcripts, 55% were neutral or mixed emotions, 26% were positive emotions, and 19% were negative emotions. Negative emotions were more prevalent initially after birth with more positive emotions reported towards the end of the interview when discussing present-day living.

**Themes**

The themes included in this analysis were the *Impact of Language, Healthcare Challenges, Supportive Healthcare Experiences, Caregiver Coping with Child’s CFM, Family Roles*, and *Addressing* *Social Implications of CFM,* which are described below along with sample quotes.

*Impact of Language*

As participants were monolingual in Spanish, interpreters were described as readily available and helpful, either in person or virtually, with some interpreters also providing emotional support. However, participants felt that not all aspects of provider communications were fully explained by interpreters. Frustration was reported in not being able to communicate directly with providers. Appreciation was expressed for the few Spanish-speaking providers involved in their child’s care. As one participant observed about her communication with her child’s medical team:

 Honestly, it’s very difficult, but most of the time there have been interpreters. The truth is, it’s better when there are doctors who speak Spanish because that way you can talk directly with them. Otherwise, I know that the interpreters help a lot and explain everything well, but honestly it is frustrating for me, because sometimes I want to understand everything myself and I can’t say it. It helps a lot, like the [specialist] who speaks Spanish.

There were a few examples of key medical information being provided in English that were interpreted or translated by an older sibling, for example: “The paper was all in English, we didn’t understand. I showed it to [sibling] and my husband asked ‘What does this paper say?’ and [sibling] said: ‘That my mom is pregnant.’” The importance of verbal communication was highlighted by a mother who did not attend school: “There is no need to be educated to take care of our children. I can’t read, I can’t write, but I know what to do with [my child].” She discussed how conversations with her healthcare team, rather than use of written communication, provided her with the information she needed to address her child’s healthcare needs.

Participants also described challenges of raising their children to be bilingual with Spanish predominantly spoken at home while children learn English once they attend school. Some participants described having difficulty communicating in Spanish when their children became more fluent in English while experiencing ongoing speech and hearing concerns. One mother noted:

 When speaking Spanish, there are times when there are things here at home that we ask several times, because he doesn’t say it well. So, we started guessing, you know? “What do you want?” So, of course, he loses interest and he says: “No, nothing.” And he no longer wants it and he leaves or he repeats it several times and gets upset with himself. I imagine he gets frustrated.

Another participant noted that her son’s general expressive language delays and communication challenges associated with hearing loss were sometimes confused with an assumption of English language learning difficulties.

*Healthcare Challenges*

One of the most discussed healthcare challenges was how children’s frequent medical appointments intersected with limited family financial resources. This included transportation costs and impact on employment, as one participant explained, “I didn't have a car. I worked in the fields…I paid the equivalent of two days of work to go and come back and I had to miss my job a lot when he had the operation.” Other participants noted relying on public transportation had its drawbacks, including lengthier travel times and safety concerns for their children’s health. Effects on employment also included having to take frequent unpaid days off to attend medical visits or quitting altogether to provide care for their child. A participant stated, “We had appointments almost every week for different doctors. That made me look for night work, so I could be free during the day for appointments.”

Participants also reported needing to advocate when experiencing difficulties with accessing specialists, insurance bureaucracy, and healthcare coverage:

I fought a lot for the pediatrician to refer me to [a clinic]. I fought hard, but I didn’t give up. I would call them every day…I explained to him everything and he said that he was going to see if the insurance would authorize it, but they didn’t send it, and they didn’t send it, and they didn’t send it. So, I had to talk directly to the insurance [representative].

Other participants also noted the need for perseverance: “Don’t stop seeking help, especially here in the United States…immigration status doesn’t matter” and “Go knock on doors and if it’s not there or if you don’t agree, go and move…find a place where your child can be helped.” They also described challenges affording what could be perceived to be easily accessible by the medical team: “The doctor told me to buy some creams…I didn't have a lot of money and maybe the cream isn’t expensive, but it was expensive for me.”

Significant financial stressors led participants to rely on extended family for housing and childcare, lacking their own healthcare, and lacking funds for food, despite some public benefit support. One mother said “There are times when I suffer with him too, given that I don’t have money to take food [to the hospital]. I don’t buy anything, I endure hunger so that I can be with him all day.” There were a few participants who described how their child’s healthcare needs led to migration within or to the U.S.:

I made the difficult decision to leave my country and migrate to the United States…I packed up my hope and traveled to the U.S.…The hardest thing was to leave my family so he could get help with his jaw…it was the goal I came for – to be able to give him everything he needs.

In terms of how healthcare was provided, participants described feeling unsure and confused about having variance in treatment plans presented at different healthcare centers. Some learned later about treatment options that were not previously discussed with them, sometimes with a sense of not being given access to appropriate care. One parent said, “When I was in [CITY], the doctor never gave me that surgery option.” There were examples of frustration with significant delays in care, as one mother explained:

They told me the [autologous ear reconstruction] would be at seven or eight and when he was that age, they said no, next year. That’s happened for years. In the end, they scheduled the surgery and then they cancelled it. They called me to tell me that the surgeon had said that he was going to wait another year...As time passed, my husband and I started to think that maybe they weren’t taking good care of us and we wanted to ask for another opinion.

At times, participants perceived that providers were angry with them, for example one mother said:

The translator told me: “The doctor says please have the child leave the hearing aid on.” I told her that the noise bothers him. The doctor was very angry and said: “How is it possible that the noise could hurt him if he can’t hear? He has total hearing loss.” I said to

her, “But he does hear.” She was really angry, she said “He can’t hear.”

There were also difficulties initiating home nursing care, which was sometimes noted to be of poor quality with safety concerns.

Following surgery, participants frequently described a strong sense of responsibility to follow providers’ recommendations closely and to strictly supervise and restrict activities during postoperative healing: “Taking care of him was really hard. It was many days that I slept with him – because I couldn’t let him roll over, even though he had a [protective] cup on his ear, I was afraid that he would hurt himself.” Participants described difficulties in ensuring appropriate local care to follow their child’s CFM specialists’ recommendations, particularly after surgery.

*Supportive Healthcare Experiences*

In addition to the healthcare challenges experienced, most participants also reported receiving support from healthcare providers, with appreciation for having detailed information about their child’s diagnosis, medical and surgical care, and healthcare options explained in accessible terms. As one participant said, “They explained everything to us, all of the risks, the pros and the cons of each surgery.” Parents inquired about the causes of CFM, with some discussions described as helpful, such as being told: “It isn’t anything genetic or anything you gave her, a chemical or something that could have harmed her. No, it’s just a part of nature.”

 The benefits of frequent communication with providers were noted at all stages of care, particularly during inpatient admissions and surgery. For example, while a child was admitted one mother said: “The doctor who was taking care of her called me every day at my job to tell me how she was, that she was fine and stable. Well, I just felt good.” During his child’s surgery, one participant who had immigrated to the U.S. stated:

I had a completely different experience [from home country]. I was able to accompany my son to the entrance of the operating room. While I was waiting, they brought me sheets, coffee, food, and I received constant messages about the surgical process, which brought me a lot of peace.

 A positive and warm communication style with a personal connection was described as helpful, often with a focus on building confidence in children. For example, “The surgeon is someone very special. He gave my daughter a lot of confidence. He told her the whole procedure that was going to happen, and she was always very positive, very, very positive.” The importance of instilling hope for their child’s future and care outcomes was discussed by most participants: “They gave us good recommendations and they gave us hope.” Participants also valued when providers showed confidence in them as parents: “The ear, nose and throat specialist always tells us, ‘Knowing who you are, of course I believe that you can do anything.’”

 Participants appreciated assistance in navigating the healthcare system, referrals, and care coordination with specialists. Most noted the benefits of being linked to community and school resources. As a mother stated “I think God puts everyone on their path and a nurse told me that she also had a child with that same condition and [about a] specialized school for deaf children to teach them to talk.’” Given limited financial resources, families discussed assistance with basic needs: “Since my son has an appointment at the hospital every 15 days or every month, thanks to [social worker], he has transportation and my lunch…[we receive] money for him; with that we buy his diapers, his shoes, his clothes, what he needs.”

*Caregiver Coping with Child’s CFM*

Most participants discussed their CFM coping, their own personal growth, the importance of their faith, and support from parents of children with similar needs. Caregivers described being optimistic and focusing on positive aspects, as one mother said: “Over time, I feel like I have improved, because you have to know how to carry it and to see everything that is positive.” Others contrasted their child to those with more significant health needs: “I consoled myself, I said, ‘Well, there are other babies who have something much more serious.’” Participants found reassurance in trusting the quality of medical care and surgical options available: “I was motivating myself and I said, ‘I think we’re in a good place, so [the medical team] can keep supporting him,’” and “I thanked God that my daughter had something that could be fixed, this motivated me.”

 Some participants remarked on how the demands of their child’s health needs had contributed to their own development: “It’s made me stronger, with more energy…now I feel very capable. I’ve overcome all the problems that she has. I go and arrange everything. I’ve learned a lot of things, things I never imagined.” They also described how they’ve gained strength in seeing how well their children have adapted: “She came out with her hat just after surgery and was smiling. I always tell her, ‘You are my little warrior...you have courage in your heart.’ She taught me.” Another mother stated “I learn a lot from my daughter’s mindset, her attitude to life, her desire to get ahead.”

 Beyond use of faith-based colloquialisms (e.g., “God willing” and “thank God”), the role of faith was frequently noted as playing an important role in coping. As one mother stated, “It's not really that difficult, like they say, everything has a solution, except death…with affection, with love, and with the help of God, we can all pull through.” Another participant explained “I never wanted to think: ‘My poor little girl, she’s not going to achieve anything.’ On the contrary, I always thought that she was sent to me by God for some reason, because she’s here for something big.” Caregivers discussed participating in religious services as well: “I go to church, they always support me with prayers and everything, if I need a prayer, they come to support me. I ask them to pray for me, with my family.”

 Some participants also reported relying on social support from children’s godparents and close family friends. There were a few examples of building social support networks with other parents with children with similar needs:

I met two other colleagues who also had children with hearing loss and we were living in

the same area. So, I told them: “Look, I heard about this school…you drive, but I

don’t, and I can help you with gasoline.” And from the time my girl was two months old I started taking her to that school and for me it was a great blessing.

While participants reported meeting other families through early intervention programs or at hospital clinics, none had used online CFM informational or social media resources.

*Family Roles*

Family themes were present in all interviews, including the important role of immediate and extended family members. Half of the participants described deepened bonds between their children and family members:

 There are eight of us, six children, father, and mother. The truth is we have become very close. Any problem, any concern, we discuss it together, to see what we believe [and what] we want to do…they all give us their opinions. We are very close to him.

Another participant stated that when her daughter was born with CFM, “my children gave me the support, they were happy and that’s when I felt better, that was the best part I think.”

 Participants discussed how they tried to avoid comparing their children and ensuring there weren’t differences between siblings, for example:

 I didn’t wear earrings for years, nor did her sister, because it was a promise I made. I told her, “The day you wear earrings, we’re all going to wear earrings.” All of us now wear earrings and she is the one who enjoys earrings the most.

Parents were cognizant of trying to balance the attention their children with CFM required, as one mother stated, “I can’t leave my little one [with CFM] alone, I have to pay attention to him, but I have to pay attention to the other children as well.” One mother said she felt sad that her son wanted to have CFM like his sister in order to receive similar attention.

Sibling relationships were discussed in most interviews and the majority were described as mutually positive and nurturing: “they really love each other.” There were examples of assistance from older siblings in helping with medical and daily care, as well as socially. One mother stated: “Her big brother said, ‘If someone says something to you, you tell me, I’m going to be there.’ I think that's why she felt okay and protected. He's very noble.” Younger siblings were also described as taking on care responsibilities, which some parents were aware could have drawbacks:

 Even though his brother is younger, he’s been his best support…he’s cared for him, helped him bathe, helped feed him during his recovery process. His brother had to mature much sooner and to worry more than he should at his young age.

Parents described how they encouraged support from siblings: “I told her brother, ‘You’re not here to attack her, but to support her, because people can attack her from anywhere.’”

Half of the participants mentioned positive relationships with cousins, who often lived in the same household or nearby. They established strong bonds: “Her [older and younger] cousins came over to keep her motivated and to give her encouragement. Like little grains of sand supporting, holding her up. So, she recovered.” Participants also noted that cousins attending the same school as their child were helpful in communicating concerns and providing social support at school, particularly in the case of bullying. An exception was one mother who reported a cousin had bullied her son; however, the cousin stopped once he was given an explanation and started therapy for his own mental health concerns.

The role of extended family was described positively: “No one in my family made her feel bad, in spite of her situation – moreover [they] protected her.” Emotional support was common: “My family has always been close…they were available all the time for whatever I needed.” Multiple examples of financial, childcare, housing, and transportation support by extended family were reported, as well as taking their children on family trips when they were unable to travel due to their own immigration status. Conversely, participants whose extended family resided outside of the U.S. discussed feeling isolated and having greater difficulty adjusting to their child’s diagnosis.

*Addressing Social Implications of CFM*

There were a variety of ways in which participants discussed the social implications of their child’s diagnosis of CFM, including how they would be treated by others, their appearance, ways to prepare them for questions, wanting to build their self-confidence, and ensuring they formed friendships. Most participants discussed concerns about how others would perceive their children because of their CFM, as one mother said, “Sometimes kids are kids…they can be cruel, to hurt, to injure, and I wanted her to avoid suffering and questions.”

For some parents, these concerns influenced choices for hair style, as one mother noted, “When she went to school, it was more my worry that they were going to bully her and I was the one who covered her little ear with her hair.” Some parents stated their children elected to have longer hair worn to cover their ears both before and after ear reconstruction and one mother said her son has short hair, but uses clothing with hoods to cover his ears. A mother also commented on glasses helping with differences in the appearance of her child’s eye. In contrast, one mother reported that when her daughter started first grade after ear reconstruction, “She would say, ‘I’m very happy with my new ear because it’s pretty, I like it.’ She wasn’t embarrassed because I would put her hair into pigtails, two braids, or her hair pulled back. She didn’t care.” In addition to hair style changes after surgery, some participants discussed their daughters’ excitement about starting to wear earrings.

Most participants described helping their children respond to questions about their appearance as well as surgeries, for example:

 At about five and a half years old, he told me, “A boy asked me about my ear.” I told him, “Tell him how you were born, so they don’t ask you again. Children just want to know why, you have to tell them, and then they’re not going to ask you anymore.” He told the boy, “I was born that way.” When he had the surgery, they kept asking him and he said, “Oh, they did surgery on me, because I was born with my ear folded and they operated on it.” So then there weren’t any more problems.

Similarly, another participant said around age five:

 I told him there are people who are going to look at you out of curiosity. Or there are people who can give you ugly looks, they can’t really see you. I told him “You have to be happy; that doesn’t have to affect you. When they look at you, say hello, greet them and they’ll feel worse or they’re going to be ashamed, but you just always be happy.”

Most participants described experiences related to questions about their child’s craniofacial condition and staring in public places and often were questioned about their CFM. Some participants noted there were periods of social difficulties that affected their children, often related to the appearance of their ear before and after surgery, postoperative haircuts, and hearing aids. Another mother stated that she, her daughter, and the school nurse presented on CFM to her kindergarten class after she had experienced teasing by a peer:

 Then the other kids stayed with her, supporting her. I said, “[The peer] says things to you

because she doesn’t like herself and so she wants to hurt others. Don’t let her hurt you.” My daughter kept going to school. She didn’t feel bad anymore, she moved forward.

One participant noted that as a younger child, her son gave alternative explanations about the appearance of his ear, for example, that a cat had bitten his ear, before starting to tell people around age nine that was how he was born and explaining his surgeries to peers: “He says ‘They operated on me, they did this here on my rib.’ He lifts his shirt, because he has his scar there. ‘They took out a rib and put it in, they made my ear, and put it in me.’”

Parents frequently discussed building their children’s self-esteem to be comfortable socially. They described coordinating efforts with their spouses: “Chatting with my husband, he told me ‘We have to give her confidence, her self-esteem needs to be high, it must not be low.’” Another mother said:

A friend who also had a girl with hearing loss told me: “Other people are going to see your daughter however you want them to see her. If you see her as sad, they’ll see her as sad. If you want your child to be seen as strong, as a child who wants to get ahead, that’s how they’re going to see her.” Those words stood out so much in my memory. I said: “I want her to get ahead, I don’t want *them* to see her as different, so *I’m* not going to see her as being different.” A lot of people have told me: “If you didn’t tell me she had something like that, we didn’t even realize.” Because she’s all there.

Parents discussed multiple strategies they used to instill confidence in their children, including frequently telling them they are loved, using praise, communicating positive messages about them as individuals and their CFM, reinforcing academic progress, engaging them in extracurricular activities, and building hope for their futures. For example, one mother explained “I’ve always told her, ‘If you program it in your mind, you’re going to achieve everything you want to try for in life.’ She tells me, ‘Yes, mom, I want to study to be a doctor.’” Half of the participants talked about feeling pride in their children and how they have overcome difficulties: “I am proud of what my son has achieved after this process.”

Participants also encouraged their children to form friendships, as one mother said: “I tell her ‘Always play, if you have friends, play with them - play with everyone.’” Most reported that their children had at least a few close friends from a young age, with several who had large groups of friends; however, one participant felt her son didn’t make friends until adolescence. Some parents noted they were concerned about community safety and applied rules about supervision by family members. Finally, participants discussed romantic relationships with their children, such as one mother who told her daughter:

 The right person is going to love you as you are, but in that process there can be a lot of damage. There are very good people, but there are also…those on the [negative] side. I want you to be brave - you tell them [about your CFM]. It’s like wearing glasses for people who don’t see well; you use the device to hear. Like your grandmother says, from bad things come the best things.

**Discussion**

This study describes selected experiences of CFM from the perspective of an underrepresented group of immigrant Spanish-speaking Latino caregivers. Understanding the broader context of CFM care is particularly important given the growing Latino population in the U.S. and the need to better address healthcare disparities.7,13  Using a methodology in which participants led the content of their interviews identified several patterns and themes that can inform CFM care (Figure 2).

 Based on analysis of the word count by age group, it was notable that parents focused about half of their narratives on the first two years of their children’s lives. The disproportionate emphasis on this early period suggests that the initial adjustment to their child’s CFM diagnosis and gaining an understanding of available treatment options is a key point of intervention for providers. Prior research has described stressors during this period related to mixed parental emotional responses, negative or uninformative interactions with healthcare providers, and the demands of diagnostic healthcare.4,[[37]](#endnote-37) Based on a word frequency analysis, parental emotional experiences were most often neutral or mixed, followed by positive emotions. The higher frequency of negative emotions was usually related to healthcare challenges, particularly ear function and appearance and surgeries, and decreased over time. This emotional pattern further highlights the need for early comprehensive care and support.

 In consideration of the one-third of U.S. Latinos who are Spanish-speaking, it was encouraging that participants identified having consistent access to interpreters, which may reflect that much of their children’s healthcare was within the high-resourced clinics they were recruited from and may not be representative of overall U.S. healthcare.9 While participants described primarily positive interactions with interpreters, they also noted feeling that interpretations were incomplete and expressed a strong preference for communicating with providers directly. CFM team members can join in efforts to expand resources to pipelines for Spanish-speaking medical providers.[[38]](#endnote-38) There were a few instances of key written health information being provided only in English. As outlined in national standards for culturally and linguistically appropriate services, CFM teams should ensure Spanish language materials are available and written communications are translated.[[39]](#endnote-39)Additionally, providers may need to assist in appropriate screening and support for the known risk for language learning concerns, which can be conflated with English-language learning difficulties.4

As a third of U.S. Latino individuals have limited financial resources, it is important in culturally sensitive care to recognize the potentially higher burden of frequent medical appointments and care costs.10, [[40]](#endnote-40) Latino immigrant caregivers’ employment options can be limited due to lower education, lack of English proficiency, and immigration status, and thus have a lower likelihood to have workplace leave benefits. The additional burden of frequent appointments was highlighted by participants reporting loss of income due to missing work for their child’s care, challenges maintaining employment, and seeking jobs with night shifts to accommodate weekday medical appointments. Although participants identified multiple instances of concrete supports being facilitated by medical teams (i.e., transportation and meal assistance), addressing employment barriers and the necessary flexibility for children’s medical care remains challenging. This highlights the importance for medical teams to implement efforts to accommodate family work schedules as much as possible, such as offering evening and Saturday clinics, and participating in policy advocacy for workplace protections.[[41]](#endnote-41) Teams should be mindful to not exacerbate healthcare disparities, particularly by inadvertently delaying care for families reliant on public health insurance and lacking resources to advocate for their children.[[42]](#endnote-42)

Participants identified several supportive aspects of their healthcare experiences, including having detailed explanations about CFM and treatment options provided in understandable terms.23,[[43]](#endnote-43),[[44]](#endnote-44) There was a notable emphasis placed on frequent communication by providers, particularly during hospital admissions and surgeries. Parents expressed gratitude for medical staff helped to encourage their children’s self-confidence and fostered hope for their futures. They also valued being recognized for their own range of skills as parents. Additionally, participants spoke positively about effective care coordination and assistance received in accessing medical care, intervention programs, community resources, school supports, and concrete needs.

Coping strategies described by participants were consistent with prior research, including emphasizing positive and optimistic perspectives as well as reframing their child’s needs in comparison to others.23,43,44 CFM providers should model optimism as well as leverage family strengths to promote resiliency.[[45]](#endnote-45) Participants also identified that confidence in their child’s CFM providers and treatment plans as significant contributors to their adaptive coping, which underscores the importance of culturally sensitive care recommendations.39 These findings reinforce that healthcare providers should make intentional efforts to build trust and confidence with Latino caregivers, both in their professional roles and in the interventions recommended for their children.

Participants emphasized the value of connecting with other families facing similar healthcare challenges, which has been established as an important support in prior studies.[[46]](#endnote-46) It is worth noting that participants exclusively engaged with other families through in-person activities without any use of online resources or social media, nor did they seek out CFM information online. This may be reflective of both limited Spanish-language online resources and lower internet literacy in this sample and is a notable difference from research with English-speaking craniofacial populations that report frequent use of online resources.[[47]](#endnote-47),[[48]](#endnote-48),[[49]](#endnote-49),[[50]](#endnote-50) To address these barriers, providers should assess families’ comfort and preferences to ensure the provision of appropriate and accessible resources, including both online and in-person Spanish support groups.[[51]](#endnote-51),[[52]](#endnote-52) Furthermore, encouraging the use of families’ social networks and their identified religious communities can also be beneficial for caregiver coping.

Participants’ narratives highlighted the multiple roles fulfilled by both immediate and extended members, consistent with the cultural value placed on f*amilismo*.17,18 In recognition of this, healthcare providers should incorporate frequent opportunities to include additional family members and friends in their children’s treatment. Considering that siblings may experience stress while acting as a primary source of support for patients and caregivers, providers should also remain cognizant of their needs and have resources available.[[53]](#endnote-53),[[54]](#endnote-54) This may include extracurricular individual and family activities, such as Craniofacial Camps and groups, and community mental health referrals. Extended family members were noted to provide both emotional and instrumental support, including childcare, transportation, housing, and financial assistance. Providers should acknowledge this form of support and be mindful that families isolated from their extended family, such as those whose families continue to reside in their country of origin, may benefit from additional screening and resources.

The social implications of CFM were a central concern for participants, particularly regarding the effect of having a visible difference, which has been recognized as a psychosocial risk factor.19 Some parents expressed anxiety about how their children’s CFM might be perceived by others, leading them to make decisions about their children’s physical presentation, including hairstyles. However, many noted that their children’s positive coping mechanisms reassured them, prompting them to no longer attempt to conceal their CFM features. In keeping with the cultural value of *simpatía*, parents’ guidance to their children in how to handle staring, questions, and teasing was most often to respond in a friendly manner and explain CFM to others.20 Providers can coach families early on in preparing and practicing responses for various social situations.[[55]](#endnote-55) Reinforcing the importance of social connections, parents were focused on facilitating peer friendships for their children. Additionally, participants were intentional in building their children’s self-confidence through frequent expressions of love, praise, positive communication about CFM, and instilling hope for the future. In addition to reinforcing their academic progress, parents actively sought out extracurricular opportunities. Providers can further play a role in this process by connecting families to available activities and providing information for schools.

The larger CARE program includes formulating theoretical frameworks to better understand the psychosocial adjustment of English- and Spanish-speaking caregivers and individuals with CFM as well as collecting surveys with standardized measures of psychosocial functioning.23 The CARE program is also gathering the perspectives of CFM providers across disciplines to assess the state of current practice in relation to the psychosocial needs identified. Future research can expand on these study findings through both qualitative analyses with diverse CFM populations and quantitative study designs with larger Latino samples, such as how to implement meaningful online resources. Another direction for future research is leveraging natural language processing analyses to create predictive models for classifying caregiver strategies that help support in pediatric rehabilitation. Recent studies demonstrate how machine learning algorithms, like Support Vector Machines, can improve interventions in pediatric care for caregivers​​.[[56]](#endnote-56) Echoing prior research, this study supports the need for CFM intervention studies to help address identified psychosocial concerns, particularly during the first years of life.4

*Limitations*

Consistent with qualitative methods and the small sample size, the results are not assumed to be representative of the experiences of all Spanish-speaking immigrant Latino parents. As the content was driven by caregivers recounting their narratives, there may be topics of interest to providers that were not part of what participants chose to discuss. The themes selected for this paper focused on those that were particularly relevant to this population and more general themes from the entire cohort will be presented in future studies along with English-speaking participants from the larger CARE program.

*Conclusion*

This study helps address a gap in the CFM literature and we provide suggestions that providers can take toward facilitating culturally sensitive care for Spanish-speaking Latino immigrant families, who represent a substantial portion of the U.S. population. Based on participants’ narratives, their children’s first years were emphasized as a critical period with opportunities for increased support and education. Drawing from identified themes, treatment suggestions covered Spanish interpretation and translation, ways to address care barriers, advocacy contributions, the benefits of strong interpersonal relationships with families, support for coping, inclusion and reinforcement of larger family systems in care, and actively addressing social concerns related to CFM.

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**Figure 1.** Percentage of Words from Interviews per Age Category (sorted chronologically)

 

**Figure 2.** Craniofacial MicrosomiaCare Recommendations [↑](#endnote-ref-56)