

Barriers to Accessing Medical Care for Hispanic Individuals With Craniofacial Conditions

Rebbeka Carmona, BA
Tanya A. Jones, MA
Janine Rosenberg, PhD

In the United States, having limited access to health care has been an ongoing concern that could cause detrimental effects for minority populations, specifically the Hispanic population. Numerous barriers to accessing health care were identified for both pediatric and adult Hispanic patients who were born with craniofacial conditions. Barriers that were determined to impact Hispanic patients with craniofacial conditions from receiving medical and health services included language and communication, patient–health care provider relationships, socioeconomic status and finances, insurance status, timely access to appointments, citizenship and immigration status, and lack of family and social support. Interventions for these barriers were also proposed to increase support for Hispanic patients. Lamentably, there is scant research that investigates how these barriers affect this special population, despite the limitations that they have in their ability to access health care. In addition, these barriers to treatment have dire consequences for individuals with craniofacial conditions. The findings and proposed interventions discussed in this review article provide measures to minimize these barriers and define ways to benefit Hispanic patients with craniofacial conditions.

Rebbeka Carmona, BA, is with The University of Illinois at Chicago; the University of Illinois Hospital & Health Sciences System Craniofacial Center, Chicago, Illinois.

Tanya A. Jones, MA, is with the University of Illinois Hospital & Health Sciences System Craniofacial Center, Chicago, Illinois.

T. Jones contributed content and was involved in the critical revision of this manuscript.

Janine Rosenberg, PhD, is with the University of Illinois Hospital & Health Sciences System, Craniofacial Center, Chicago, Illinois.

Dr Rosenberg was involved in the supervision, interpretation, and critical revision of this manuscript.

The authors report no conflicts of interest.

Address correspondence to Rebbeka Carmona, BA, University of Illinois Hospital and Health Sciences System, Craniofacial Center, 811 South Paulina Street, MC 588 Chicago, Illinois, 60612).

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Craniofacial conditions refer to a variety of structural malformations of the face, skull, and/or head that are present at birth or occur over time due to injury, trauma, or illness (Cochrane & Slade, 1999; Edwards, Topolski, Kapp-Simon, Aspinall, & Patrick, 2011; Speltz & Richmond, 1997). Approximately one in every 1,600 babies is born with a craniofacial condition that significantly impacts his or her developmental trajectory. The majority of patients at our Craniofacial Center, located in the urban Midwest, are from a diverse population of races, ethnicity, and ages. Most notably, given that more than 50% of our patients are from a Hispanic background, it is imperative to review and discuss factors that influence access to specialty care within this population.

Common congenital craniofacial conditions include cleft lip and/or palate (CL/P), microtia–anotia, craniosynostosis, and those commonly associated with genetic disorders (e.g., Pierre Robin syndrome, Crouzon syndrome, Treacher Collins syndrome). The most prevalent craniofacial condition in the United States is CL/P, affecting one in every 700 live births (American Cleft Palate–Craniofacial Association [ACPA], 2018). Cleft lip and/or palate is the separation of the upper lip, palate, or both due to improper fusion during embryonic development (Abuelfaraj, Daly, McDonald & Scambler, 2018; Mai et al., 2014). In the United States, CL/Ps occur most commonly among Asians, Hispanics, and Native Americans and occur least commonly among African Americans (Mulliken, 2004). Studies of immigrants who have migrated to the United States show that migrant groups have rates of CL/P similar to their country of origin (Mossey, Little, Munger, Dixon, & Shaw, 2009).

Impairments associated with CL/P that require extensive and ongoing surgical procedures and treatments are related to hearing, speech, dental functioning, and facial appearance (e.g., lip, mouth, and nasal defects requiring reconstructive surgery), and psychosocial needs (Lilja, 2003). To best address various aspects of development and functioning from birth to young adulthood, an interdisciplinary team approach should be implemented to treat patients with craniofacial conditions. Interdisciplinary team professionals often include plastic surgeons, nurses, psychologists, speech–language pathologists, audiologists, orthodontists, prosthodontists, dentists, pediatricians,

anaplastologists, and geneticists (ACPA, 2018; McCarthy et al., 2012). Interdisciplinary care allows for a collaborative approach that addresses the whole child, increases the quality of care, and is cost-effective. Our Craniofacial Center is a prime example of a clinic that offers interdisciplinary medical specialty care.

The first step to accessing ongoing and long-term craniofacial services depends on the patient and family's ability to recognize their need for treatment and also relies on their perceptions, attitudes, and beliefs about the available health care services and systems. Previous experience with, as well as access and knowledge of, resources also impacts the utilization of services (Gulliford et al., 2002). However, there are also environmental and external barriers that can further impede access to services, especially among those within an underserved population.

An ethnic group that often struggles with access to health care is the Hispanic population. Mexicans are the largest Hispanic group (33 million) living in the United States (Motel & Patten, 2012). Research shows that 34% of Hispanics do not have health insurance, and 27% do not have a general source for routine health care (Pérez-Escamilla, 2010). Compared with children with chronic illnesses from other races and ethnicities, Hispanic children with chronic conditions have the lowest rates of health care insurance (Flores & Vega, 1998). Despite the recent enactment of the Affordable Care Act in 2010, the discrepancy related to insurance coverage among Hispanics continues to persist (Abraido-Lanza, Mendoza, & Armbrister, 2019). Barriers that impact the Hispanic population from receiving medical and health services include

- language and communication difficulties,
- inadequate patient–health care provider relationship,
- low socioeconomic status (SES) and finances,
- lack of insurance,
- need for timely access to appointments,
- citizenship and immigration status, and
- lack of family and social support.

This article aims to identify these barriers and propose interventions to address the limitations for accessing health care services that adversely impact this growing population (Pérez-Escamilla, 2010).

BARRIER 1: LANGUAGE, COMMUNICATION, AND PATIENT–HEALTH CARE PROVIDER RELATIONSHIP

Language and communication barriers are linked to negative health and medical outcomes for patients with limited English proficiency (Bonilla & Edwards, 2011). Approximately 12% of people in the United States speak fluent Spanish, and nearly half (47%) of these individuals have limited English proficiency (Bonilla & Edwards,

2011). Fostering effective, culturally sensitive communication involves receptive listening as well as mutual understanding (King, Desmarais, Lindsay, Pierart, & Tetreault, 2014). Culturally sensitive communication also involves understanding and respecting cultural beliefs, values, parenting styles, and diagnostic causes (King et al., 2014).

According to a recent research survey, the majority of Hispanic participants reported three principal concerns about language and communication barriers related to medical care. These concerns included

- inability to speak the primary language,
- lack of quality and quantity of Spanish interpreters, and
- frustration over long waiting periods for interpreters (Jacquez, Vaughn, Zhen-Duan, & Graham, 2016).

Spanish-speaking patients rate interpersonal relationships more positively based on the physicians' Spanish proficiency and fluency, regardless of available interpreter services (Fernandez et al., 2004). Patients with limited English proficiency are less involved in medical decision making, less likely to have established rapport with health care providers, and less likely to receive empathetic responses from health care providers (Bonilla & Edwards, 2011; Ferguson & Candib, 2002). Hispanic patients may feel intimidated by the fact that they cannot interact in the health care provider's primary language and may also have varying cultural understandings of the nature of the disability or medical condition (King et al., 2014).

Bonilla and Edwards (2011) found that 59% of the ACPA medical team providers reported that language and communication are ongoing issues with serving this minority population. The same providers also reported that their Hispanic patients may not fully understand and/or might pretend to comprehend the provided medical information (e.g., diagnosis, medications, and discharge instructions). It then becomes difficult for the health care provider to decipher how well the patient and the family understand what is being described to them.

The relationship between health care providers and Hispanic patients with craniofacial conditions and limited English proficiency is also impacted by poor communication and language barriers (Ferguson & Candid, 2002; Saha, Arbelaez, & Cooper, 2003; Schouten & Meeuwesen, 2006). Without cultural sensitivity and humility, unconscious biases, discrimination, and misunderstanding of the patients' beliefs/values can become apparent. In one study, Hispanic participants described interactions with their health care providers as discriminatory. Participants reported that the health care providers asked offensive questions, held assumptions that the participants were less knowledgeable than the providers, and received lower quality health care compared with their White counterparts (Jacquez et al., 2016). This could lead to Hispanic patients feeling unsupported, which, in turn, could lead

to dissatisfaction, distrust, and avoidance of the health care system (Mollborn, Stepanikova, & Cook, 2005).

Having a condition that can impede physical communication also poses problems. Specifically, school-aged children with CL/P are at risk for social-emotional issues because of their limited capacity to produce speech sounds necessary to communicate verbally (Murray et al., 2010). Patients who are not able to verbally communicate also have a more challenging time sharing ideas and asking questions regarding their medical condition.

Interventions for Language, Communication, and Patient-Health Care Provider Relationship

Hiring interpreters is one step toward closing the language and communication gap; however, more progress is needed as interpreters may not always provide consistent and culturally sensitive services. Increasing the number of dedicated, full-time native-Spanish-speaking medical providers may help improve the quality of interpreter services (Muñoz-Blanco, Raisanen, Donohue, & Boss, 2017). Another option to improve interpreter services includes hiring bilingual staff who are also qualified medical interpreters (Centers for Medicare & Medicaid Services, n.d.). A study by Saha, Taggart, Komaromy, and Bindman (2000) found that approximately two-fifths of Hispanic patients select a physician based on his or her ability to communicate in Spanish. This encourages a sense of cultural familiarity for both patients and health care providers. Language concordant care increases the patient's ability to follow guidelines and also increases patient's satisfaction and continuation with care (Jaramillo et al., 2016).

Health care providers should consider patients' cultural backgrounds when educating, communicating with, and treating immigrant families and patients with disabilities and/or craniofacial conditions. Using culturally sensitive communication has been shown to reduce family stress, help patients and family members feel supported in accessing services, and enhance patient outcomes and satisfaction (King et al., 2014). To improve understanding of the patient's needs and desires, health care providers are encouraged to ask sensitive yet open questions about the family and patient's cultural background (King et al., 2014).

Health care providers can help ensure effective communication by presenting information at the family and patient's education and developmental level. Efforts to include the patient and the family in the treatment planning process can be bolstered by offering information multimodally (e.g., using printed handouts, videos, and supplementary aids; Grootens-Wiegers, Hein, van den Broek, & de Vries, 2017). Using interactive handouts (e.g., coloring and activity booklets) can help provide developmentally appropriate and meaningful information that the pediatric patient can understand. Welcoming questions is also essential for the patient and family's understanding,

as they may feel hesitant to ask questions. Instead of asking the child whether he or she has questions, providers can ask the child how he or she would explain the topic to a friend or a teacher (King et al., 2014).

BARRIER 2: SES AND FINANCIAL BURDEN

Lower SES among the Hispanic population is another factor that impacts health care accessibility. About 25% of Hispanics are living at or below the poverty level (Fortuna, n.d.). These patients may also face financial barriers to medical care access because of limited income or financial resources, unemployment, and the high cost of health services (Edward et al., 2018). Some Hispanic families may also have dependents that restrict their financial flexibility.

Financial burdens increase the probability of families not accessing health care. There are limitations on which procedures and treatments are covered on the basis of the type of insurance (i.e., private vs. public). In a study that assessed insurance status and effects on the timeliness of CL/P surgical repair, cleft palate repair was delayed for publicly insured patients by 1.2 weeks and by 1.5–3.5 weeks for non-White and ethnic patients (Abbott, Korowski, & Meara, 2011). In the same study, there was a significant difference in insurance status and ethnicity where 84% of Hispanic and 83% of Black patients were publicly insured whereas only 46% of White patients received public insurance. Hispanic children have longer appointment intervals than White children regardless of the source of the insurance (Pourat & Finocchio, 2010).

Families of children with craniofacial conditions encounter additional medical costs, as their care may require recurring medical appointments and treatments from infancy through young adulthood. Financial constraints persist because of the high costs of specialty care required for optimal habilitation associated with the various craniofacial conditions. Family members caring for the child may quit their jobs to provide the necessary care for their child (Broder, Wilson-Genderson, & Sischo, 2012). Coping with the financial burden associated with the child's craniofacial condition can lead to stress within the family and marriage (Lemacks, Fowles, Mateus, & Thomas, 2013). A child with a craniofacial condition may undergo 3–20 surgical interventions as well as other related treatments before reaching adulthood. The average total cost of treatment per individual is \$100,000 (Boulet, Grosse, Honein, & Correa-Villaseñor, 2009).

Interventions for SES and Financial Burden

To help reduce financial barriers, especially among families with low SES, social and policy-level interventions need to be implemented. Members of the craniofacial community and allies can advocate for public or state

funding for community-based organizations that provide health and related psychological services. At our clinic, we provide service to all patients regardless of financial constraints or types of health insurance, including public aid. We have developed a partnership with Face the Future, a not-for-profit organization, that helps financially support our center's families through its exceptional fundraising program. With such contributions, families that could not afford the recommended treatments may be able to receive services with little to no financial obligation.

Health care providers can become more informed about insurance policies that are available to undocumented families and patients as well as outside resources that can further assist families in need with navigating the health care and legal systems. Health care providers can inform Hispanic immigrants and nonimmigrants that Medicaid is an option and provide information about its processes. States, such as California, allow for lawfully present immigrants and expecting mothers and children to obtain Medicaid or Children's Health Insurance Program coverage.

BARRIER 3: TIMELY ACCESS TO APPOINTMENTS AND TREATMENT

Another barrier that affects minority populations is timely access to critical surgeries in the first year of life. The surgeries that patients with craniofacial conditions must undergo need to be completed in a timely manner to ensure proper development (e.g., craniofacial structure, speech) and achieve the most effective treatment outcome (Abbott et al., 2011).

Hispanic pediatric patients with craniofacial conditions may experience significant treatment delays. Brown et al. (2016) found that Hispanic children with craniosynostosis underwent surgical treatment at the delayed age of 9.1 months compared with White children who underwent surgical treatment at 6.1 months. Similarly, Abbott et al. (2011) found that Hispanic children, on average, had their cleft palate repaired 4 weeks later than White children, and this delay increased for families with limited insurance (Abbott et al., 2011).

Oral health is a crucial component of health and development for individuals with various types of craniofacial conditions (e.g., Treacher Collins syndrome, microsomia). Hispanic children tend to have long intervals between dental visits or may have never attended any dental appointments (Pourat, Charles, & Snyder, 2016). There are several proposed explanations for this. Work obligation is a well-known reason that families miss appointments. In addition, there may be issues with inadequate transportation, which largely affects older individuals, minorities, and individuals with lower SES (MacLeod et al., 2015). Inadequate transportation and location inaccessibility have been linked to lower health and treatment outcomes.

Different cultural perceptions about medical treatment and the influence of health-seeking behaviors can also hinder patients and families from seeking support. Fatalism, the belief that an illness is God's will because of a person's sinful behavior, is common in the Hispanic culture and can influence how a family or a patient may cope with his or her condition (Medina, n.d.). Hispanics often seek treatment from both culturally acceptable experts (e.g., curanderos, herbalists, homeopathic doctors, massage therapists) and medical doctors (Medina, n.d.). When using an interdisciplinary team approach, providers beyond the surgeon, such as psychologists, speech/language pathologists, and social workers, are also experts who play a vital role in the habilitation of individuals with craniofacial conditions.

Interventions for Timely Access to Appointments

To ensure timely access to appointments and reduce transportation costs (e.g., bus, train), clinics and health insurance providers can provide free or reduced rate transportation to and from appointments and offer reduced parking fees. Social workers can assist in providing transportation services designed to accommodate Hispanic patients. In addition, appointments can be scheduled in the early morning, later in the day, or all on the same day to accommodate patient and family schedules to avoid missing school or work.

To address barriers related to cultures, health care providers should be sensitive to patients' varying cultural perspectives and not invalidate their experiences and beliefs. Providers can also educate families about the importance of seeing multiple health care providers regularly as part of a holistic treatment plan to ensure better outcomes that may not be possible with only one provider.

BARRIER 4: UNITED STATES CITIZENSHIP STATUS

An ongoing and predominant issue that concerns the Hispanic population is the barrier to medical health services related to a lack of United States citizenship. Although the Deferred Action for Childhood Arrivals (DACA) and the Development, Relief, and Education for Alien Minors (DREAM) Act provide temporary protection and permanent status, the lack of insurance continues to be a persistent issue (American Immigration Council, 2017). Although undocumented youth may have these temporary opportunities, they are often exempt from receiving insurance under the Affordable Care Act and, consequently, are at risk of lacking access to medical health services (Raymond-Flesch, Siemons, Pourat, Jacobs, & Brindis, 2014). In a study by Raymond-Flesch et al. (2014), the majority of DACA-eligible Hispanic participants (aged 18–31 years) reported that in addition to mistrust of doctors and

physician's lack of understanding about their patients' undocumented status, fear of deportation was a barrier to accessing the health care system. Undocumented youth who are currently receiving public insurance may lose their eligibility for public insurance once they reach adulthood. Given that, in most cases, craniofacial treatment recommendations persist into young adulthood, it is imperative that future research investigate the impact of citizenship status on Hispanic patients' ability to qualify for health care insurance and access medical treatment, especially as they reach adulthood.

There is limited research on the prevalence of craniofacial conditions in the Hispanic community and how the lack of United States citizenship affects ability to access services. When 60 ACPA medical teams who serve Hispanic families were surveyed, 34% reported that citizenship and immigration-related issues were challenges they encountered while providing health care (Bonilla & Edwards, 2011). Furthermore, some providers from these ACPA teams reported that immigration documents, frequent migration, and families' fear of deportation were factors that disrupted their ability to provide health care services. These findings illuminate a cycle that adversely affects patients and health care providers.

Interventions for U.S. Citizenship Status

Providers should remain cognizant of the consequences that disclosure of a lack of United States citizenship can lead to and should, therefore, verify that this information does not have to be shared. Because of a significant increment in immigration-related issues, clinics should offer resources and additional information on advocacy and legal groups that are able to assist immigrant patients (e.g., free consultations, resource outreach). Existing clinics should continue preserving patients' confidentiality and maintaining nondiscriminatory attitudes and policies.

BARRIER 5: FAMILY AND SOCIAL SUPPORT

Family and community support are important resources for parents of children with craniofacial conditions. However, families report having limited satisfactory social support (Sank, Berk, & Cooper, 2003; Tiemens, Nicholas, & Forrest, 2013). For migrant families, not having extended family residing in the same community or country contributes to the paucity of family and community support. In addition, cultural beliefs associated with craniofacial conditions also impact social support systems. This is particularly true for many Hispanic families that believe that their condition was caused by *Mal de Ojo* (evil eye), or through a curse (Alarcón, Oquendo, & Wainberg, 2014). *Mal de Ojo* culturally explains how various medical or mental conditions are given to an individual through another person's stare (Fortuna, n.d.). Such culturally

bound beliefs (i.e., a set of behavioral, affective, or cognitive characteristics seen in a particular culture) may elicit judgmental speculations and can be stigmatizing, making Hispanic families less likely to benefit from community support (Balhara, 2011). Family members may experience feelings of guilt, shame, and self-blame about their child's craniofacial condition (Berger & Dalton, 2011).

If a family member is having a difficult time coping with his or her child's craniofacial condition, the child may also experience difficulties with adjusting and coping (Sischo, Broder, & Phillips, 2015). In addition, it is not uncommon for parents to intentionally withhold the specifics of their child's craniofacial condition from the child believing this will protect the child from any harm, particularly harms related to stigma. During psychological consultations, children have reported that their cleft lip was caused by a fall or an accident when they were infants. This can create a sense of low self-esteem, insecurity, and uncertainty as these children gain an understanding and develop into their identity. Self-perceptions of children with craniofacial conditions affect their overall adjustment to their condition (Johns & Bava, 2018).

Social stigma also impacts peer support for children with craniofacial conditions as they face higher risks of experiencing stigmatization and discrimination (Loewenstein et al., 2008). A meta-analysis on peer victimization among children with or without chronic illnesses found that children with craniofacial conditions and children with hearing and visual impairments were more likely to be victims of bullying than children without these conditions (Pinquart, 2017). Moreover, among all groups, children with craniofacial conditions were most at risk of being bullied (Pinquart, 2017). Children with craniofacial conditions between the ages of 8 and 10 years are at an increased risk for depression and anxiety as well as social difficulties with peers (Volpicelli et al., 2017).

The demands of recurrent appointments, surgical care, and hospitalizations can cause familial disharmony, especially for families presenting with already existing financial restraints (Kapa et al., 2019). One parent may assume the role of the provider while the other assumes complete responsibility for taking care of the child medically and psychologically. The increased medical responsibilities place families at risk of experiencing less familial cohesion due to family stressors related to the burden of care.

Interventions for Family and Social Support

Positive social experiences (e.g., social events, family-offered aid) are strong predictors for optimal social adjustment in Hispanic children. The necessary social skills can be taught to children with craniofacial conditions to increase the opportunity for positive social experiences (Edwards et al., 2011). The interdisciplinary team's psychologist can help facilitate social interactions

by recommending Spanish language resources that are free or low cost (e.g., social events held in park districts, churches, or libraries). In addition, hosting support groups that teach social skills has been found to improve Hispanic children's psychosocial functioning, adaptive skills, and self-esteem (Johns & Bava, 2018).

The psychologist's goal is to create more resilient patients and families, improve family-child relationships, and reduce the child's social risks at school. Psychologists can assist the patient and the family by identifying and addressing negative cognitive and behavioral functioning (e.g., denial, depression, anxiety), as well as by teaching coping skills using cognitive-behavioral therapy (Bradbury, 2012). Parents and caregivers can also be encouraged to share their stories in support groups, role-play with their children, practice a dialogue to communicate information about their condition, and take before and after pictures of their child's medical interventions. Seeing psychological and physical progress from the child can improve the family member's ability to cope.

To improve support within the community, it is vital to ensure that others have a fundamental understanding of these medical conditions. Parents and caregivers should be provided with culturally appropriate resources composed of various mediums (i.e., online, videos, pamphlets). Cleftline.org has information and letters (in Spanish and English) that can be given to school teams (e.g., teachers, principals, school nurses, social workers). Teachers should be informed about a student's craniofacial condition as it may impact their school functioning. Moreover, teachers can serve as role models and promote inclusivity and positive social interactions in the classroom. With the help of teachers, students with craniofacial conditions can practice self-advocacy by giving presentations to their peers about their conditions (Stock & Ridley, 2018). Given that craniofacial conditions increase challenges with learning speech or language, social functioning, and attention, family members are encouraged to advocate for services and supports within the school system (Loewenstein et al., 2008; Prahll & Prahll-Anderson, 2007; Sousa, Devare, & Ghanshani, 2009). Psychologists can assist families in communicating with and advocating for schools to help explain their children's conditions and coordinate effort and care to ensure optimal learning environments.

CONCLUSION

The Hispanic community is a significantly growing population in the United States that continues to face a plethora of barriers limiting its access to health care services. These barriers to treatment have dire consequences for children with craniofacial conditions. This article outlined several barriers, including a lack of U.S. citizenship, language, communication, cultural conditions, lower SES, timely access

to treatment, and insufficient family and social support systems. The findings and interventions discussed in this review can provide useful information about how to better serve this population financially, psychosocially, and culturally. As there is limited research on the effects and proposed interventions for these challenges, future research should investigate these barriers and their impact on the Hispanic craniofacial population.

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