Barriers to Orofacial Cleft Care for Children in South Florida

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Introduction

Orofacial clefts are among the most common congenital birth defects, yet families often face numerous challenges in accessing appropriate care. This study investigates the perceived barriers to craniofacial care among parents of children with orofacial clefts in South Florida—a region home to a diverse population and a growing number of cleft cases. Between 2016 and 2020, South Florida (Miami-Dade, Broward, and Palm Beach counties) reported 107 cases of cleft lip with cleft palate. Previous studies have highlighted the need for outcome-based metrics (Abbott et al., 2010), and geographic disparities have been linked to increased financial hardship and reliance on crowdfunding (Akiki et al., 2021). Additionally, research has shown that Medicaid alleviates some costs but often falls short due to gaps in coverage and prior authorization requirements (Bennett et al., 2019; Nidey et al., 2019).

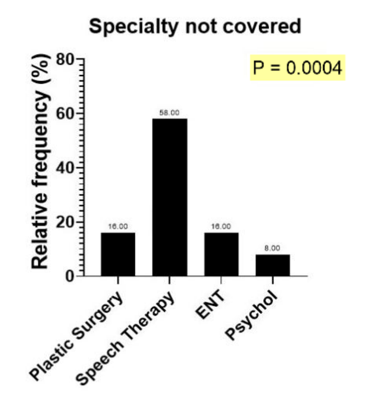
By identifying and analyzing these barriers, this study aims to inform strategies that improve equitable access and delivery of cleft care in South Florida and similar underserved regions.

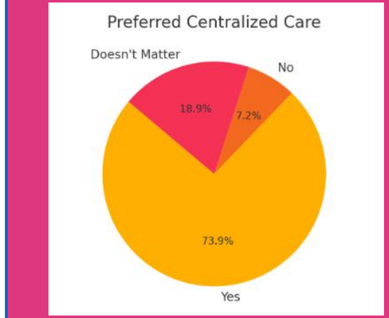
Methods

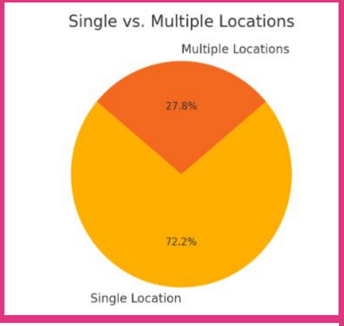
A cross-sectional survey was conducted at Nicklaus Children's Hospital (Miami, FL) from May–December 2024 to assess perceived financial, social, and geographical barriers to cleft care. **Participants:** 114 parents/guardians of children with orofacial clefts were randomly selected during follow-up visits. **Survey:** A 23-question paper-based survey (English/Spanish, 8.5 grade reading level) was administered, covering access to plastic surgery, orthodontics, pediatric dentistry, audiology/ENT, speech therapy, and psychology.

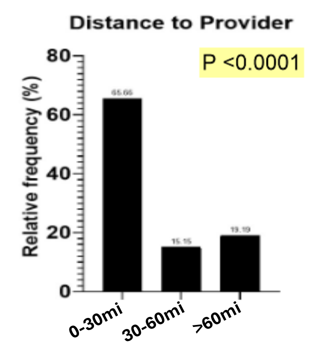
Results

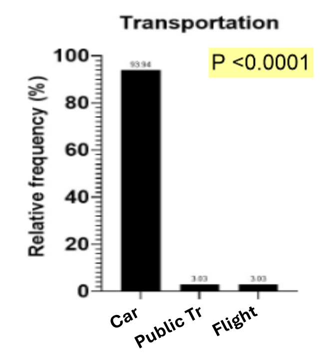
Most participants were mothers (84.9%), married (61.6%), Hispanic (81.8%), that identified as White (77.6%). Spanish was the primary language for 51%, while 88.9% reported that their specialist spoke their preferred language. Insurance coverage was a major barrier. While 56.1% had full coverage, 43.9% reported partial or no coverage for cleft-related services. **Speech therapy** was the most uncovered specialty (58%), regardless of insurance type. Orthodontic treatment was also inconsistently covered, with 38% receiving full coverage and others reporting partial or no benefits. There were no significant differences in booking difficulties across specialties (p=0.76). However, 73.3% of families reported challenges accessing specialists and preferred more clinic locations (66.7%). Despite 65.7% living far from providers, only 17.2% cited travel as difficult, and 93.9% reported no transportation issues. Socially, most participants had strong support systems (92.9%) and had no issues taking time off (84.8%) or balancing responsibilities (86.7%).All reported trends were statistically significant (p<0.0001), reflecting a largely homogeneous sample.











Discussion

The survey of 114 participants provided a comprehensive look at barriers to craniofacial care. Most respondents were mothers (86%), highlighting their central role in healthcare. A majority (58.8%) were married; 40.7% were single, divorced, or separated. Most identified as White (72.8%), with representation from African American (11.4%). Notably, 80.4% identified as Hispanic or Latino, underscoring the importance of culturally and linguistically appropriate care. Employment data showed 51.3% worked full-time, reflecting resilience despite caregiving demands Regarding insurance, 66.4% had public coverage and 37.2% private. Though 58% had full coverage, 21.4% had only partial. Speech therapy was most frequently uncovered (38.6%).Care accessibility was a concern. While 72.2% received care at one location, 27.8% required multiple sites. Centralized care was preferred by 73.9%. Geographic distance affected some; 66.4% lived within 30 miles of treatment, but 18.7% traveled over 60 miles. Still, only 17.3% saw travel as a barrier, likely due to 91.2% having access to personal vehicles. Use of public/shared transport was minimal, showing dependence on private vehicles. About 34.9% had difficulty finding specialists or securing timely appointments, but only 10.8% reported language barriers. Referrals were generally smooth. Support systems helped—91.8% had family or friends for assistance. Despite some traveling long distances, few saw this as a major obstacle, reinforcing the role of transportation access in overcoming geographic challenges.

Conclusions

Despite long travel distances and the demands of full-time employment, the high percentage of participants with access to personal vehicles and strong support systems—within a predominantly Hispanic sample—highlights the family-oriented nature of the Hispanic community. This cultural trait played a key role in helping families navigate challenges and likely contributed to higher satisfaction levels, even under difficult circumstances. While basic healthcare access is relatively strong, findings indicate a need for strategic improvements in insurance policy, service integration, and resource distribution. Enhancing coverage for services like speech therapy, expanding access to multidisciplinary care at single locations, and strengthening cultural competency efforts are essential steps toward improving craniofacial care in South Florida. Given the homogeneity of this sample, it is essential to follow this descriptive analysis with broader, more diverse studies to enable differential analysis and more accurately assess healthcare disparities related to orofacial clefts across the United States..