

The Dynamics of Care Delivery in Cleft and Craniofacial Clinics

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Introduction. Multidisciplinary care is essential for patients with cleft and craniofacial conditions, making it important to understand any challenges in delivering comprehensive treatment. While well-established literature is limited, identifying barriers, fostering discussions, and exploring solutions are key to improving care and advancing cleft and craniofacial treatment. This study aimed to identify current challenges faced by American Cleft Palate-Craniofacial Association (ACPA)-approved teams in providing multidisciplinary cleft and craniofacial care.

Methods. A REDCap[®] survey was distributed to 199 ACPA-approved. It encompassed questions related to team demographics and Likert-scale questions regarding team, insurance, and patient dynamics.

Results. Sixty-eight of the 199 teams (34%) responded, comprising academic (72%) and private (28%) institutions, with 80% affiliated with a children's hospital. While only 14% of teams reported difficulty obtaining insurance reimbursement for cleft team visits, patient affordability remained a concern: surgery (46%), ancillary procedures (51%), and orthodontics (60%). Cost challenges were common in metropolitan areas (population >1 million). Inadequate financial (38%) and administrative (32%) support also posed significant barriers. Loss to follow-up was a common challenge among teams.

Conclusions. This study highlights the need for continued collaboration within the cleft/craniofacial care community to address financial, administrative, and access-related challenges. While access to multidisciplinary care may be available, financial barriers remain a significant concern. Strengthening team collaboration and advocating for systemic change will be essential to effectively meet patient needs. Study limitations include a small sample size and limited depth due to the survey design.