A Pilot Assessment of Cleft Lip and Palate Patients at Children's Hospital in New Orleans

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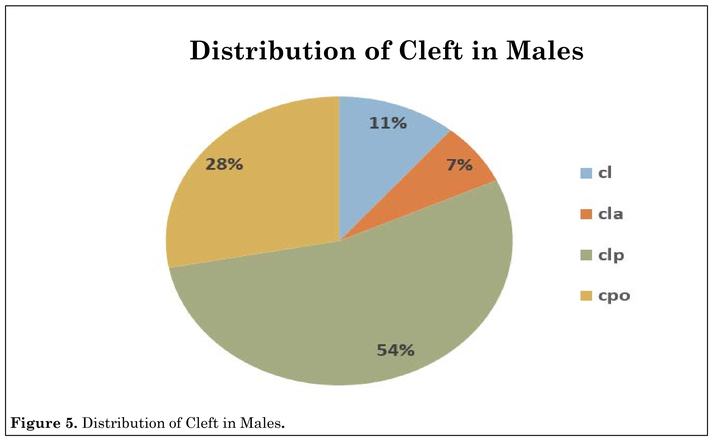

Figure 5. Distribution of Cleft in Males.

Introduction

Clefts of the lip and palate **(CL/P)** are among the most common congenital structural anomalies, and various surgical and rehabilitative interventions are started as a neonate and continued throughout adolescence. A child with CL/P is treated by a multidisciplinary team of specialists over the course of his or her physical, psychosocial, and cognitive development. Thus, outcomes research and assessment in cleft care has traditionally been fraught with complexity due to the longitudinal and multidisciplinary care that is required. Additionally, CL/P can have significant and lasting impacts on the quality of life of both the patient and his or her family, particularly in the financial, social, and familial domains.

This project retrospectively assessed the cleft population at Children's Hospital in New Orleans (CHNOLA) from April 2018 to February 2021 using a standardized set of outcomes developed by the cleft team. This assessment characterizes the specific cleft population in terms of demographic factors and the distribution of cleft anomalies. Surgical data regarding age at primary cleft lip repair (CLR), primary cleft palate repair (CPR), and alveolar bone graft (ABG) was also analyzed.

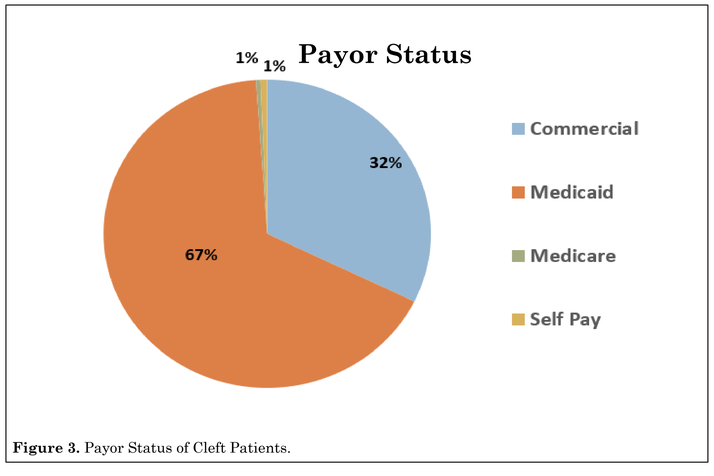

Figure 3. Payor Status of Cleft Patients.

Methods

ICD-10 and CPT codes that correlated with anomalies and surgical procedures of the lip and palate were utilized to generate an EPIC sample of 457 patients evaluated at CHNOLA from April 2018 to February 2021. Information regarding demographics, cleft characterization, and surgical procedures was analyzed using Microsoft Excel.

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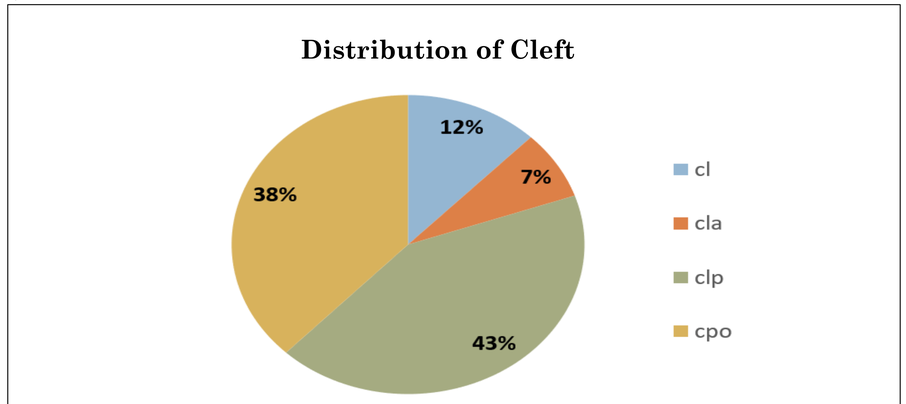

Figure 4. Distribution of Cleft Anomalies.

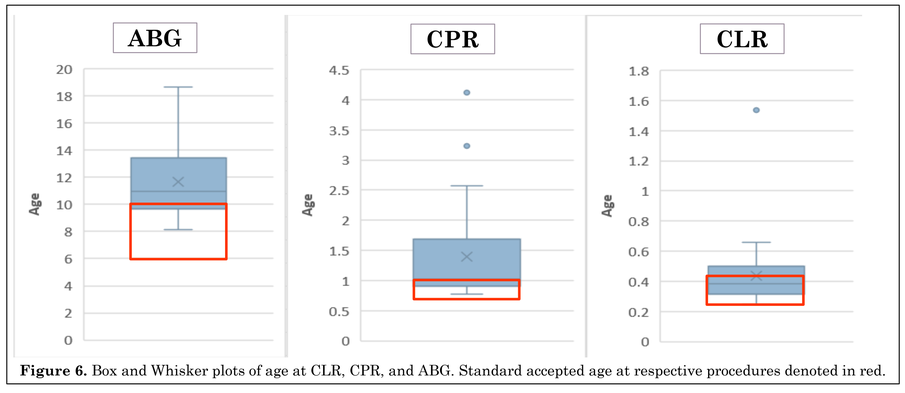

Figure 6. Box and Whisker plots of age at CLR, CPR, and ABG. Standard accepted age at respective procedures denoted in red.

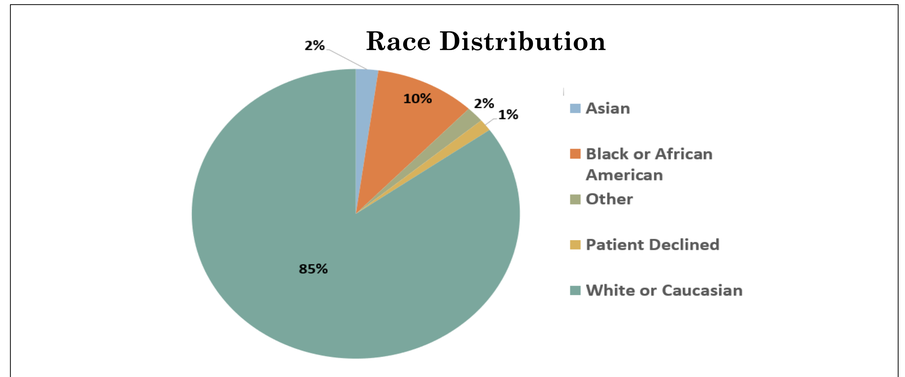

Figure 1. Race Distribution of Cleft Patients.

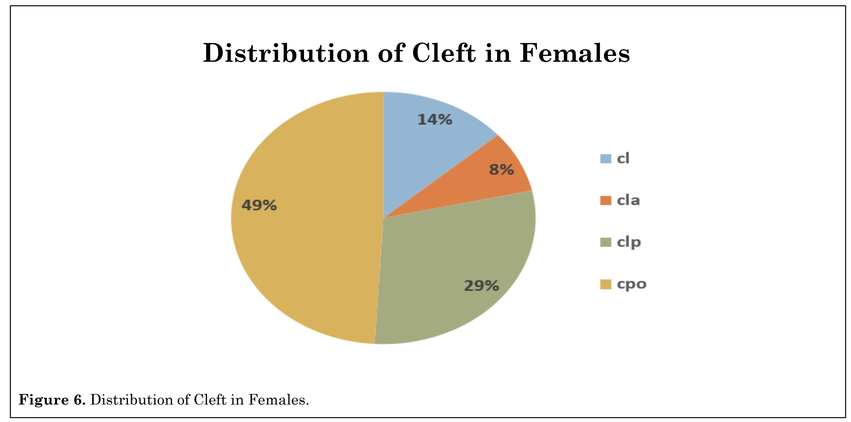

Figure 6. Distribution of Cleft in Females.

Results

The sample identified as 85% Caucasian, 10% African American, 2% Asian, 2% Other, and 1% American Indian (Figure 1). 88% of patients reside in Louisiana, 9% in Mississippi, and 3% Alabama, Texas, and Florida (Figure 2). Payor status indicated 66% Medicaid, 32% Commercial, 1% Self Pay, and 1% Medicare (Figure 3). 43% presented with cleft lip and palate (CL/P), 38% CPO (cleft palate only), 12% CL (cleft lip), and 7% CLA (cleft lip/alveolus) (Figure 4). 53% of patients identify as male and 47% as female. Male patients presented with 54% CL/P, 28% CPO, 11% CL and 7% CLA (Figure 5). Female patients presented with 49% CPO, 29% CL/P, 14% CL, and 8% CLA (Figure 6). The average age at primary CLR was 5.2±2.6 months, primary CPR was 1.4±0.8 years, and ABG was 11.6±3.7 years (Figure 7).

Conclusions

Results were compared to current national statistics regarding the epidemiology of CL±P. The CDC estimates that approximately 2,650 infants are born with a CP and 4,440 are born with CL±P in the US annually.[1] This is represented in our sample; CP alone (38%) presented less frequently than CL±P (62%). There is a 2:1 M:F ratio in individuals with CL±P in the US.[2] This ratio is roughly represented in our sample; of those who presented with CL±P, 61% were male, while 39% were female. There is a 1:2 M:F ratio in individuals with CPO in the US.[2] This is also roughly represented in our sample; of those who presented with CPO, 39% were male, while 61% were female.

Typical care guidelines in the US maintain that primary CLR should be performed at 3-6 months, primary CPR at 8-12 months, and ABG at 6-10 years. As evidenced by the data above, time to surgery aligned with typical cleft guidelines for primary CLR, but not for primary CPR or ABG. Surgical delays are likely attributed to children with complex medical or surgical needs. This pilot study serves to elucidate areas of delayed care to focus future interventions. Specifically, phenotypic characteristics and demographic factors will be compared to age at surgery to illuminate populations that require more surveillance and cleft care coordination.

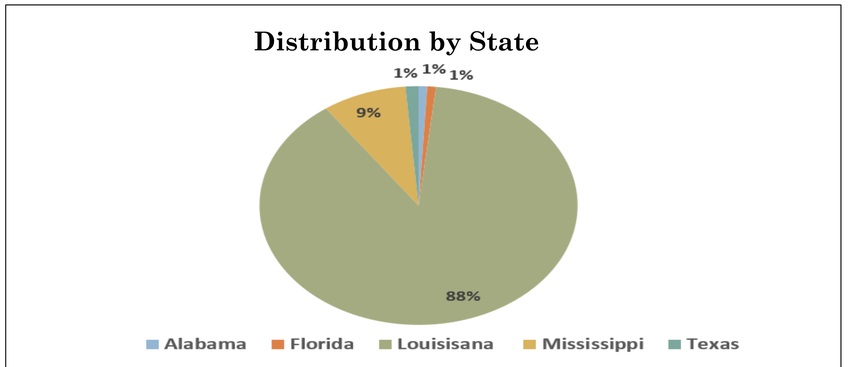

Figure 2. Distribution of Cleft Patients by State.

1. Parker SE, Mai CT, Canfield MA, Rickard R, Wang Y, Meyer RE, Anderson P, Mason CA, Collins JS, Kirby RS, Correa A; National Birth Defects Prevention Network. *Updated National Birth Prevalence estimates for selected birth defects in the United States, 2004-2006.* Birth Defects Res A Clin Mol Teratol. 2010 Dec;88(12):1008-16.
2. Lewis CW, Jacob LS, Lehmann CU; SECTION ON ORAL HEALTH. *The Primary Care Pediatrician and the Care of Children With Cleft Lip and/or Cleft Palate.* Pediatrics. 2017 May;139(5):e20170628. doi: 10.1542/peds.2017-0628. Erratum in: Pediatrics. 2017 Sep;140(3):null