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

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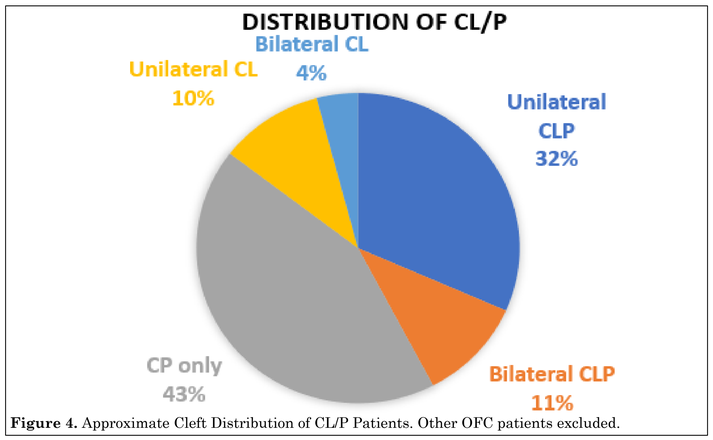

Figure 4. Approximate Cleft Distribution of CL/P Patients. Other OFC patients excluded.

Introduction

Background:

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.

Objectives:

Using a standardized set of outcomes developed by the cleft care team at a large regional Craniofacial center, this project retrospectively assessed the cleft patient population at Children's Hospital in New Orleans, Louisiana (CHNOLA), from March of 2018 through March of 2020. This assessment was intended to characterize the specific cleft patient population at this cleft center. More specifically, the current study aimed to evaluate patient demographic factors, as well as the distribution of cleft anomalies for this patient population.

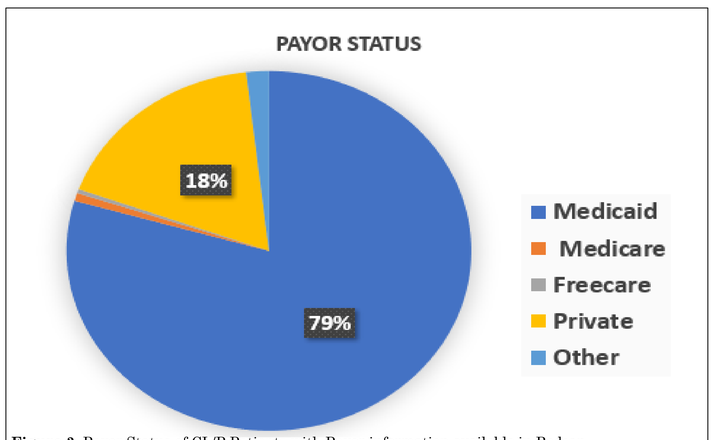

Figure 3. Payor Status of CL/P Patients with Payor information available in Redcap.

Methods

In order to assess the patient population, a retrospective analysis was performed using both Redcap and EPIC medical record interfaces. ICD-10 codes that correlated with anomalies of the lip and palate were utilized to generate a sample from EPIC of 485 patients evaluated at CHNOLA from March of 2018 through March 2020. The list of 485 patients was then cross-referenced with a database of orofacial cleft patients tracked in Redcap from March of 2018 through March 2020. This process yielded a sample of **424 orofacial cleft (OFC) patients** with Redcap information regarding patient demographics, and cleft classification and distribution. Excel worksheets were then used to perform a basic pilot assessment of this patient population.

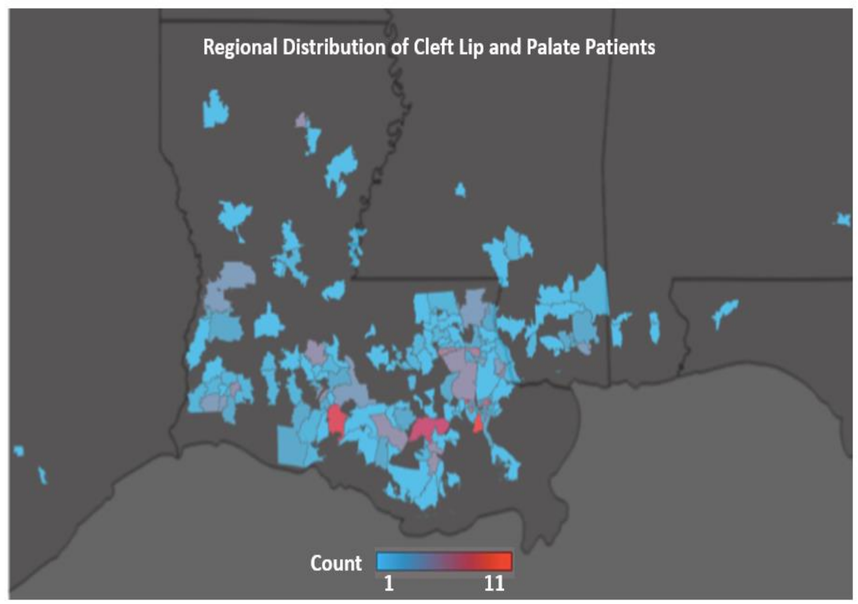

Figure 2. Regional Distribution of Cleft Lip and Palate (CL/P) patients (N=400) at CHNOLA.

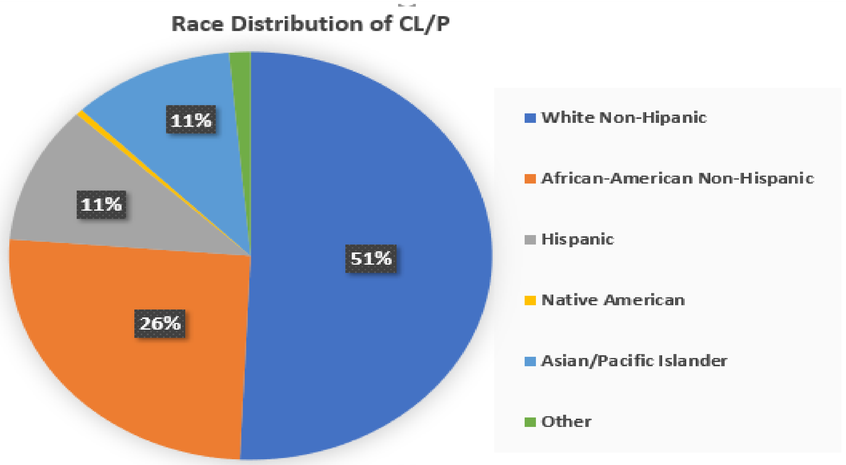

Figure 1. Race Distribution of CL/P Patients with Race information Available in Redcap.

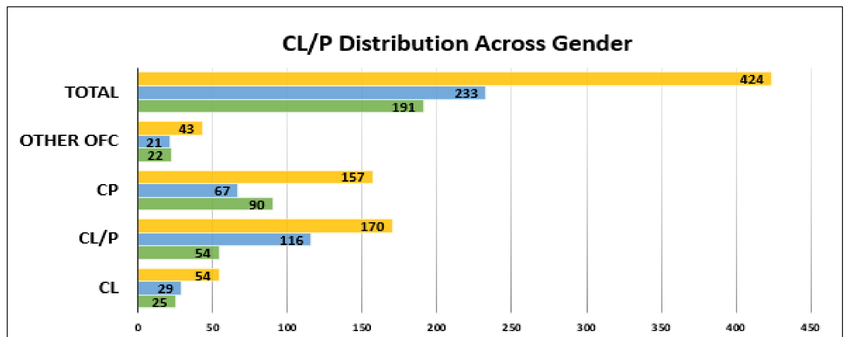

Figure 5. CL/P Distribution Across Gender.

Results

Patient demographic assessment indicated that 50.2% of the 424 patients in Redcap did not have race information available. As seen in **Figure 1**, 211 patients with race identification available identify as the following: 50.7% White Non-Hispanic, 25.6% African American Non-Hispanic, 10.9% Asian/Pacific Islander, 10.9% Hispanic, 1.4% Other, and 0.5% Native American.

89.6% of patients reside in Louisiana, 8.3% in Mississippi, 1.4% in Alabama, 0.4% in Texas, and 0.3% in Florida. **Figure 2** represents the regional distribution of CL/P patients from March 2018 through 2020, as based on zip code.

34.7% of patients did not have insurance information available. Of the 278 patients with payor status available, 79.5% utilized Medicaid, 17.6% used a private form of insurance, 1.8% utilized Medicare, and 1.1% listed Other or Freecare as their form of insurance, as seen in **Figure 3.**

10.1% (43 patients) of patients presented with a facial cleft other than CL/P. As seen in **Figure 4**, of the 381 patients with CL/P, 43.1% presented with CP, 31.6% with unilateral CL/P, 10.7% with bilateral CL/P, 10.4% with unilateral CL, and 4.2% with bilateral CL.

55.0% of patients identify as male and 45.0% of patients identify as female. As seen in **Figure 5**, of the patients who identified as female, 47.1% presented with a CP, 28.3% with a CL/P, 13.1% with a CL and 11.5% with other OFC. Of those patients who identified as male, 49.7% presented with a CL/P, 28.8% presented with a CP, 12.5% presented with a CL, and 9.0% presented with other OFC.

Conclusions

The results of this pilot assessment were compared to current national statistics regarding the **etiology and epidemiology of CL/P,** as well as cleft characterization as published by the American Academy of Pediatrics[1,2]**.** The CDC estimates that approximately 2,650 infants are born with a CP and 4,440 are born with CL±P in the United States annually, with 6.35 and 10.63 estimated prevalence per 10,000 live births. This is represented in our patient sample, as CP alone (43%) presented less frequently than CL±P (57%). Additionally, approximately 75% of CL in the US are unilateral. This is represented in our patient sample, as 14% of the patients presented with CL, with 10% of CL being unilateral.

There is a **2:1 male: female ratio** in individuals with CL±P in the US. While more males presented with CL±P, this ratio is not *completely* represented in our patient sample, as 64.7% of the male patients presented with CL±P , while 35.3% of the female patients presented with CL±P .
There is a **1:2 male: female ratio** in individuals with CP in the US. In our sample, 57.3% of females presented with CP and 42.7% of males presented with CP. While the national CP ratio is not *entirely* represented, our sample does maintain a higher proportion of females with CP.

Within the United States, Native American and Asian racial groups have a higher incidence of CL ± P than do black or white groups. Further analysis will be performed in future studies to determine whether the cleft population at Children's Hospital in New Orleans (CHNOLA) is representative of this varying CL ± P incidence across race.

Additionally, further information regarding **payor status and distance from cleft center** and its effect on **access to cleft care** will be investigated in future studies of the cleft population at CHNOLA.

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