

Sarah N. Rimmer

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LSU Health Sciences Center, New Orleans, LA

Dr. Kyle Fulton

LSUHSC Department of Craniofacial Pediatrics and Plastic Surgery

“Pilot Assessment of Cleft Lip and Palate Patients at CHNOLA”

Background: This project retrospectively assessed the cleft population at a large regional cleft center 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.

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 a regional cleft center from April 2018 to February 2021. Information regarding demographics, cleft characterization, and surgical procedures was analyzed using Microsoft Excel.

Results: The sample identified as 85% Caucasian, 10% African American, 2% Asian, 2% Other, and 1% American Indian. 88% of patients reside in Louisiana, 9% in Mississippi, and 3% Alabama, Texas, and Florida. Payor status indicated 66% Medicaid, 32% Commercial, 1% Self Pay, and 1% Medicare. 43% presented with CL/P (cleft lip/palate), 38% CPO (cleft palate only), 12% CL (cleft lip), and 7% CLA (cleft lip/alveolus). 53% of patients identify as male and 47% as female. Male patients presented with 54% CL/P, 28% CPO, 11% CL and 7% CLA. Female patients presented with 49% CPO, 29% CL/P, 14% CL, and 8% CLA. 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.

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. 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. 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. 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.

