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Timeliness of surgical care in children with special health care needs: delayed palate repair for publicly insured and minority children with cleft palate☆

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Abstract

Background/Purpose: Disparities in access to health care are known to exist for the most vulnerable pediatric population, children with special health care needs. Timely access to surgical care in this population is critical, yet poorly studied.

Methods: A national database of pediatric hospitals in the United States was searched for nonsyndromic, healthy patients younger than 24 months who underwent cleft palate repair from 2003 to 2008. A multivariate, linear regression model was constructed to determine the relationship of public payer status and race with age at palatal repair.

Results: Age at palate repair was significantly delayed for patients who were publicly insured (1.2 weeks, $P = .01$), were of nonwhite race/ethnicity (1.5-3.5 weeks, $P = .009$), and had a diagnosis of cleft lip in addition to cleft palate (3.4 weeks, $P = .006$) compared to their counterparts in a sample of 2995 patients with cleft palate.

Conclusion: There is a small but significant delay in age at repair for patients who are publicly insured or of nonwhite race/ethnicity. These results may herald broader access disparities that could adversely affect clinical outcomes and should be investigated further.

Children with special health care needs (CSHCN) are known to require higher levels of services and more costly care than the general pediatric population [1,2]. Thus, adequate access to care is critical to these patients and their families. Multiple studies have addressed utilization and access to care in these patients as a group [1-4], but few data exist regarding access to care in the population of CSHCN with orofacial clefts (OFCs), which, with an average prevalence of approximately 1 in 600 live births, are the most common birth defects in the United States [5]. Timeliness and access to care were recently listed among

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the top priorities on the research agenda for these children by the Centers for Disease Control and Prevention [6].

One measure of timeliness of care for children with OFCs is the age of palate repair for those with a diagnosis of cleft palate. The presence of a palatal cleft in a large percentage of patients with OFCs has numerous medical, developmental, psychosocial, and financial implications for the patient and his/her family for many years, even after successful repair [7]. The timing of palatal repair must balance the potential for speech delay if the repair is performed too late against the possible interference with normal craniofacial growth if performed too early. The American Cleft Palate-Craniofacial Association advocates repair by 18 months in a normally developing infant [8]. Certain centers support earlier repair to reduce the risk of velopharyngeal insufficiency, which has been shown to increase by 6% for each month the repair is delayed beyond 7 months [9,10].

Despite knowledge that timely care leads to better outcomes in patients with cleft palate and that CSHCN overall have difficulty with access to care, little is known regarding how often these patients receive timely care in the United States. In a recent survey of American Cleft Palate-Craniofacial Association members, 74% of responding members reported performing primary cleft palate repair between the ages of 6 and 12 months, and more than 97% by 15 months. However, the response rate was only 38% and the data were surgeon reported, not patient-level data [11]. A study of publicly insured patients with OFCs in North Carolina revealed that, overall, 78% of patients had surgery within 18 months of age, whereas patients with cleft palate alone met this guideline only 58% of the time. Factors linked to timing of the repair were availability of maternal care coordination, receipt of prenatal care, and residence in certain regions of the state [12].

In this report, we used a national database of free-standing children's hospitals to examine 2 predictors that have been linked to poor access to care in many other patient populations, public payer status and nonwhite race/ethnicity [13-18], for their relationship to timeliness of palatal repair in patients with OFCs. We hypothesized that patients with public insurance and of nonwhite race/ethnicity would undergo later palate repair than their counterparts, which could potentially interfere with normal speech development and educational attainment later in life.

1. Methods

1.1. Data source

We performed a search of the Pediatric Health Information System (PHIS), a national database of administrative and billing data from more than 40 free-standing children's hospitals affiliated with the Child Health Corporation of America (Shawnee Mission, KS). The PHIS database is composed of more than 125 discrete data points drawn from more than 1,000,000 annual pediatric patient encounters, including data from inpatient admissions, ambulatory medical and/or surgical short-stay areas, and emergency department visits. Pediatric Health Information System data are screened for accuracy on a quarterly basis, and data are accepted only when classified errors occur in less than 2% of a hospital's quarterly data.

1.2. Patient selection

We identified all healthy, nonsyndromic patients younger than 24 months undergoing cleft palate repair (*International Classification of Diseases, Ninth Revision, Clinical Modification* [*ICD-9-CM*] procedure code 27.62) between January 2003 and December 2008. Patients were included if they had complete data for the variables of interest. Healthy, nonsyndromic patients were defined as those with no other diagnosis of a congenital anomaly (*ICD-9-CM* 740-759, except cleft diagnoses); a systemic disease, including cardiac, respiratory, or other condition that may cause delay of surgical repair; or a concurrent procedure that might indicate an anomaly or delayed repair. Only patients younger than 24 months were included to minimize the number of revision procedures and submucous cleft palate repairs. Patients were excluded if there was a discrepancy in coding of cleft diagnosis (eg, a patient coded as having undergone palate repair, but with a diagnosis of cleft lip alone), a repeat admission (only the first admission was included), or simultaneous lip repair for those with a combined cleft lip and palate diagnosis. This final exclusion was based on the fact that most centers in the United States do not repair both the lip and the palate at the same time, which was confirmed through personal communication with more than 60% of the participating centers, making miscoding a strong possibility in these repairs.

1.3. Variable selection

We selected predictor variables and covariates based on a priori hypotheses and/or demonstrated associations in the literature: patient race/ethnicity, insurance type, sex, diagnosis of isolated cleft palate vs cleft lip and palate, other minor procedures at the time of palate repair, and average annual cleft palate repair volume per hospital. Self-reported race/ethnicity data were defined as white, Hispanic, black, or other. Insurance status was defined as public or private payer. Other minor procedures that may have altered the timing of repair were examined including ventilation tubes, circumcisions, lingual frenulectomies, and minor laceration repairs or biopsies. Average annual repair volume was calculated by dividing the number of patients with the *ICD-9-CM* code for cleft palate repair (27.62) at each hospital, before exclusions, by number of years the hospital contributed data.