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## Health Disparities Among Children With Cleft

Hillary L. Broder, PhD, MEd, Maureen Wilson-Genderson, PhD, and Lacey Sischo, PhD

### Abstract

Oral health-related quality of life (OHRQoL) is a multidimensional construct that measures well-being associated with the teeth, mouth, and face. This cross-sectional study examined OHRQoL, demographic data, and clinical indicators in 839 treatment-seeking youths with cleft from 6 geographically diverse cleft treatment centers. Individuals without health insurance and representing ethnic minorities had lower OHRQoL scores on the Child Oral Health Impact Profile and a higher rate of surgical recommendations. These findings imply a risk factor for reduced OHRQoL and unmet needs among vulnerable youths with clefts.

In 2000, the US Surgeon General's report, "The Face of the Child: Children and Oral Health," highlighted the importance of children's oral health to their overall health and well-being and the profound impact that oral health can have on the quality of children's lives.<sup>1</sup> Although oral health-related quality of life (OHRQoL) has been investigated in adults, it has not been extensively investigated in children, largely because of the lack of developmentally appropriate, validated instruments.<sup>2,3</sup> The recently validated Child Oral Health Impact Profile (COHIP) is designed specifically to study impact in youths across oral health conditions for epidemiological studies as well as evaluative studies.<sup>4</sup> Children with cleft have lower OHRQoL than do pediatric samples and children seeking dental or orthodontic care.<sup>4</sup>

According to a recent Centers for Disease Control and Prevention report, cleft lip and/or palate (CLP) is the second most common birth defect—occurring 1 in 575 live births.<sup>5</sup> Because it affects speech and language development, dental development, and facial appearance, individuals with cleft have been recognized as a special needs population by the Maternal and Child Health Bureau.<sup>6</sup> Clefting of the secondary palate is associated with hypernasality and speech intelligibility disorders as well as ear infections, liquid leaking from the nose, and hearing loss. Clefting of the primary palate (lip and alveolus) is associated with facial disfigurement (differences), dental anomalies, learning disabilities, and associated psychosocial issues (e.g., self-concept, anxiety, depression).

Cleft and related craniofacial habilitation involves a lengthy process of evaluations and treatment by a multidisciplinary team of specialists. Treatment typically begins during the

Correspondence should be sent to Hillary L. Broder, PhD MEd, NYU College of Dentistry, Cariology and Comprehensive Care, 380 Second Avenue, Suite 301, New York, NY 10010-5615 (hillary.broder@nyu.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

#### About the Authors

Hillary L. Broder and Lacey Sischo are with the Department of Cariology and Comprehensive Care, New York University College of Dentistry, New York, NY. Maureen Wilson-Genderson is with the Department of Social and Behavioral Health, Virginia Commonwealth University School of Medicine, Richmond.

#### Contributors

H. L. Broder designed the study and assisted in article preparation and data analysis. M. Wilson-Genderson conducted the statistical analysis and contributed to article preparation. L. Sischo aided in article preparation.

#### Human Participant Protection

Institutional review board approval was received from each site for this study.

first year of life and terminates by late adolescence or early adulthood. Although the primary surgical interventions are usually completed during the first few years of life, a complex myriad of evaluations and interventions that address tooth development, speech, and facial appearance often ensue during the school-age years until the habilitation process is complete.

Not surprisingly, cleft and craniofacial interventions are costly.<sup>7</sup> The number of interventions for individuals can vary from 3 or 4 to as many as 20 or more surgeries before the affected individual reaches early adulthood. The medical costs of habilitation average more than \$100 000 per individual.<sup>7,8</sup> This figure does not measure other impacts such as psychosocial sequelae (e.g., teasing, missing school, multiple doctor visits by youths and their caregivers, lost wages). Currently, the debate in the United States over health insurance is mounting. It is estimated that in 2010, 44% or 81 million adults between 19 and 64 years of age were either uninsured or underinsured (an increase from 75 million in 2007 and 61 million in 2003).<sup>9</sup> The burden of care for people with cleft conditions without insurance is enormous in both emotional and economic terms.

Drawing on data from the first phase of a multicenter longitudinal study investigating quality of life (QoL) and related outcomes among children undergoing secondary cleft surgery, we examined OHRQoL in a sample of treatment-seeking children with cleft using the COHIP. Specifically, we explored associations between OHRQoL and age, race/ethnicity, gender, and type of payor. COHIP scores were also examined comparing those who received a current surgery recommendation within the year and those without such a recommendation. Current recommendation may be a proxy for extent of defect and unmet needs. Means were compared using a general linear model; analyses were conducted using SAS version 9.2 (SAS Institute, Cary, NC). In short, the purpose of this investigation was to examine surgical needs and OHRQoL in youths with cleft conditions across sociodemographic variables often associated with health disparities.

## METHODS

The sample was composed of 839 school-aged English- or Spanish-speaking children aged 7 to 19 years with cleft who were followed for care at 1 of 6 well-established and geographically diverse cleft or craniofacial centers. These included Children's Healthcare of Atlanta, Atlanta, Georgia; Children's Hospital of Philadelphia, Philadelphia, Pennsylvania; Lancaster Cleft Palate Clinic, Lancaster, Pennsylvania; New York University, New York, New York; University of Illinois at Chicago; and University of North Carolina-Chapel Hill. Data were collected between December 2009 and March 2011. The sites' catchment areas include both rural and urban locations. As per institutional review board-approved protocols, data were collected at the children's regularly scheduled clinic visits with children and caregivers completing the COHIP packets and providing demographic information, respectively. Response rates across centers averaged 90% (range = 78%–95%).

The COHIP is a 34-item, self-report OHR-QoL measure with discrete domains: oral health (varied/specific oral symptoms), functional well-being (ability to carry out specific everyday tasks like eating), emotional well-being (peer interactions and mood states), school (tasks associated with the school environment), and self-esteem (positive feelings about oneself). The COHIP uses a 5-point Likert scale; higher scores indicate better QoL.<sup>4</sup>

## RESULTS

Among the youth participants, the average age was 11.9 years (SD = 3.0), 55% were male, and one third received recommendations for cleft-related surgery within a year. The racial/

ethnic composition included 67% White, 12% Latino or mixed, 10% Black or African American, and 10% Asian participants. Fifty-four percent had private insurance; payor information was missing for 38 participants. COHIP subscales and overall total scores were compared by age, race/ethnicity, gender, type of payor and surgical recommendation status (Table 1). Older participants (aged 14–19 years) had significantly lower emotional well-being scores than did younger participants ( $F [2, 836] = 16.6, P < .001$ ). Black and Latino and ethnically mixed groups had significantly lower scores on emotional well-being ( $F [3, 835] = 7.9, P < .001$ ), school ( $F [3, 835] = 3.65, P < .05$ ), and total COHIP scores ( $F [3, 835] = 3.2, P < .05$ ) than did their White or Asian counterparts. There were no significant gender differences on any subscale or the overall COHIP. Individuals without private insurance had significantly lower scores than did those with insurance on functional well-being ( $F [1, 800] = 17.8, P < .001$ ), emotional well-being ( $F [1, 800] = 7.82, P < .001$ ), school ( $F [1, 800] = 14.8, P < .001$ ), and total COHIP ( $F [1, 800] = 12.8, P < .001$ ) scores. The effect sizes for differences based on surgery status (0.492) and insurance status (0.472) are medium,<sup>10</sup> suggesting they are substantively meaningful.

Participants with a surgical recommendation had significantly lower OHRQoL scores on functional well-being ( $F [1, 836] = 8.45, P < .01$ ), emotional well-being ( $F [1, 837] = 20.4, P < .001$ ), school ( $F [1, 837] = 8.9, P < .01$ ), and total COHIP ( $F [1, 837] = 13.6, P < .001$ ) than did those with no surgical recommendation.

## DISCUSSION

COHIP scores depict differences in OHRQoL among treatment-seeking patients based on specific demographic characteristics. Specifically, we found that Black and mixed ethnicity youths with CLP had lower OHRQoL (e.g., emotional well-being) than did their White and Asian counterparts. Likewise, patients without private health insurance reported lower OHRQoL than did those with private insurance. Finally, youths with surgical recommendations also had lower OHRQoL than did those without such recommendations. Such findings suggest that vulnerable youths with CLP are at risk for reduced OHRQoL and unmet needs.

These results highlight issues regarding health care access and utilization for children with cleft. We found that 1 in 3 school-aged youths received surgical recommendations, and these recommendations were higher among youths without private insurance. Since 2007, the number of families without private health insurance is increasing, which means the actual economic burden is likely also increasing.<sup>9</sup> Historically, health care coverage of the poor is restrictive (e.g., coverage for secondary lip or nasal revisions, implants, orthodontics and related surgery), and provider reimbursement rates for patients who receive public assistance are relatively low compared with private rates.<sup>11–13</sup> Thus, those without private insurance may have less opportunity to utilize health care services because public programs may not cover these “elective” procedures, or the costs of care may be too high for many families who no longer have insurance.

Within the context of evidence-based care, our findings underscore the dearth of health outcomes like health-related QoL and emotional well-being among youths with cleft. To date, it is unresolved whether the surgical needs among youths representing people of color or people lacking private insurance receive the recommended or optimal care. Given the importance of facial attractiveness in our culture,<sup>14</sup> one might hypothesize that denial of recommended services aimed to improve facial appearance may be associated with reduced QoL and emotional well-being. Yet such patient-oriented outcomes are not routinely collected. Additionally, it is unknown whether elective secondary treatment actually improves OHRQoL. In this evidence-based care era, we are advocating that these issues be

addressed systematically using longitudinal research designs. Such research could inform health policy regarding access to care for elective procedures (e.g., secondary lip or nose revisions for children with CLP, orthognathic surgery) and health outcomes. To establish cleft care standards, especially for individuals with reduced access to care, these public policy health issues are crucial. In short, until these issues are fully explored, health policy remains lacking critical evidence regarding access and quality of care.

In summary, this report reveals OHRQoL differences associated with specific demographic characteristics and identifies a possible connection between these differences and disparities in health care utilization and access to care. It also suggests the importance of longitudinal investigation of patient-oriented outcomes to measure treatment effectiveness of secondary cleft treatment among youths.

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**TABLE 1**  
**Scores by Domain: Child Oral Health Impact Profile, Various US States, December 2009-March 2011**

	No. (%)	Oral Health (10 Items), Mean (SE; 95% CI)	Functional Well-Being (6 Items), Mean (SE; 95% CI)	Emotional Well-Being (8 Items), Mean (SE; 95% CI)	School (4 Items), Mean (SE; 95% CI)	Self-Esteem (6 Items), Mean (SE; 95% CI)	Total, Mean (SE; 95% CI)
Total sample		25.2 (0.02; 24.8, 25.7)	18.0 (0.02; 17.6, 18.3)	25.0 (0.02; 24.5, 25.4)	13.4 (0.01; 13.2, 13.5)	16.7 (0.02; 16.4, 17.0)	98.9 (0.06; 97.7, 100.0)
Age, y							
7-9	271 (32)	25.8 (0.4; 25.1, 26.6)	17.8 (0.3; 17.3, 18.3)	26.3 (0.4; 25.5, 27.0)	13.3 (0.2; 12.9, 13.7)	16.9 (0.3; 16.3, 17.4)	100.3 (1.1; 98.2, 102.4)
10-13	269 (32)	24.8 (0.4; 24.0, 25.6)	18.1 (0.3; 17.6, 18.7)	25.5 (0.4; 24.8, 26.3)	13.6 (0.2; 13.3, 13.9)	17.1 (0.3; 16.6, 17.6)	99.8 (1.0; 97.8, 101.8)
14-19	299 (36)	25.2 (0.4; 24.5, 26.0)	17.9 (0.3; 17.4, 18.4)	23.2** (0.4; 22.4, 24.0)	13.2 (0.2; 12.9, 13.5)	16.3 (0.3; 15.8, 16.8)	96.7 (1.1; 94.6, 98.8)
Race/ethnicity							
White	565 (67)	25.0 (0.3; 24.4, 25.5)	18.2 (0.2; 17.8, 18.5)	25.7 (0.3; 25.1, 26.2)	13.5 (0.1; 13.3, 13.8)	16.8 (0.2; 16.4, 17.2)	100.0 (0.7; 98.6, 101.4)
Black	85 (10)	25.2 (0.8; 23.6, 26.7)	17.5 (0.5; 16.5, 18.6)	23.3** (0.8; 21.7, 24.9)	12.8* (0.4; 12.1, 13.5)	17.1 (0.5; 16.1, 18.1)	95.9* (2.1; 91.7, 100.1)
Asian	88 (10)	25.4 (0.6; 24.2, 26.6)	17.8 (0.5; 16.9, 18.7)	24.8 (0.7; 23.4, 26.2)	13.5 (0.3; 13.0, 14.1)	17.0 (0.4; 16.2, 17.8)	98.5 (1.7; 95.1, 101.9)
Latino/mixed	101 (12)	27.0 (0.6; 25.7, 28.2)	17.1 (0.5; 16.2, 18.1)	22.5** (0.8; 21.0, 24.0)	12.7* (0.3; 12.1, 13.3)	15.9 (0.5; 15.0, 16.9)	95.2* (2.0; 91.2, 99.2)
Gender							
Female	375 (45)	25.5 (0.3; 24.8, 26.2)	18.2 (0.2; 17.7, 18.6)	24.4 (0.4; 23.6, 25.1)	13.3 (0.1; 13.0, 13.6)	17.1 (0.2; 16.7, 17.6)	99.2 (1.0; 97.3, 101.1)
Male	464 (55)	25.1 (0.3; 24.5, 25.7)	17.8 (0.2; 17.4, 18.2)	25.4 (0.3; 24.8, 26.0)	13.4 (0.1) 13.1, 13.6)	16.4 (0.2) 16.0, 16.8)	98.6 (0.8; 97.1, 100.1)
Payor <sup>a</sup>							
Private	452 (54)	25.2 (0.4; 24.5, 25.9)	18.6 (0.2; 18.2, 19.0)	24.1 (0.4; 23.4, 24.8)	13.7 (0.1; 13.4, 13.9)	16.9 (0.2; 16.4, 17.3)	100.8 (0.8; 99.2, 102.4)
Public	349 (42)	25.3 (0.3; 24.6, 25.9)	17.2** (0.3; 16.7, 17.7)	25.5** (0.3; 24.8, 26.2)	12.9** (0.2; 12.6, 13.2)	16.6 (0.2; 16.1, 17.0)	96.2** (1.0; 94.3, 98.2)
Surgery recommendation							
Yes	269 (32)	24.8 (0.4; 23.9, 25.6)	17.3** (0.3; 16.7, 17.9)	23.4** (0.4; 22.5, 24.3)	12.9** (0.2; 12.6, 13.3)	16.5 (0.3; 15.9, 17.0)	95.6** (1.1; 93.5, 97.8)
No	570 (68)	25.5 (0.3; 25.0, 26.1)	18.3 (0.2; 17.9, 18.6)	25.7 (0.3; 25.1, 26.2)	13.6 (0.1; 13.3, 13.8)	16.9 (0.2; 16.5, 17.2)	100.4 (0.7; 99.0, 101.8)

Note. CI = confidence interval. The results were taken from the general linear model; means are least squares means. Sample included 839 school-aged English- or Spanish-speaking children aged 7-19 years with cleft who were followed for care at 1 of 6 well-established and geographically diverse cleft or craniofacial centers: Children's Healthcare of Atlanta, Atlanta, GA; Children's Hospital of Philadelphia, Philadelphia, PA; Lancaster Cleft Palate Clinic, Lancaster, PA; New York University, New York, NY; University of Illinois at Chicago; and University of North Carolina-Chapel Hill.

<sup>a</sup> Percentages do not sum to 100 because payor information was missing for 38 participants

\*  $P \leq .05$ ;

\*\*  $P \leq .01$ .