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A Population-Based Exploration of the Social Implications Associated with Cleft Lip and/or Palate

Adam D. Glener, BS*
Alexander C. Allori, MD, MPH†
Ronnie L. Shammas, BS*
Anna R. Carlson, MD*
Irene J. Pien, MD‡
Arthur S. Aylsworth, MD§
Robert Meyer, PhD, MPH¶
Luiz Pimenta, DDS, PhD‖
Ronald Strauss, DMD, PhD‖
Stephanie Watkins, PhD, MSPH**
Jeffrey R. Marcus, MD†

Background: Clefts of the lip and/or palate (CL/P) carry a social stigma that often causes psychosocial stress. The purpose of this study was to consider the association of cleft phenotype and age with self-reported aspects of psychosocial stress.
Methods: Children with nonsyndromic CL/P and unaffected children born between 1997 and 2003 were identified through the North Carolina Birth Defects Monitoring Program and North Carolina birth records, respectively. The psychosocial concerns of children with CL/P were assessed via a 29-question subset of a larger survey. Responses were analyzed according to school age and cleft phenotype (cleft lip with/without cleft alveolus, CL ± A; cleft palate only, CP; or cleft lip with cleft palate, CL + P).
Results: Surveys were returned for 176 children with CL/P and 333 unaffected children. When compared with unaffected children, responses differed for CL ± A in 4/29 questions, for CP in 7/29 questions, and for CL + P in 8/29 questions ($P < 0.05$). When stratified by school age, children with CL/P in elementary, middle, and high school differed from unaffected children by 1/29, 7/29, and 2/29 questions, respectively. Middle school–aged children with CL/P were more affected by aesthetic concerns, bullying, and difficulties with friendship, and social interaction. Children with CL + P reported more severe aesthetic-related concerns than children with CL ± A or CP but experienced similar speech-related distress as children with CP only.
Conclusion: Social implications associated with CL/P are most pronounced during middle school, and less so during elementary and high school. This information identifies areas of social improvement aimed at reducing the stigma of CL/P.
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*From the *Division of Plastic, Maxillofacial and Oral Surgery, Duke University Hospital, Durham, N.C.; †Division of Plastic, Maxillofacial and Oral Surgery, Duke University Hospital and Children's Health Center, Durham, N.C.; ‡Department of Surgery, Division of Plastic and Reconstructive Surgery, University of California, Los Angeles, Calif.; §Departments of Pediatrics and Genetics, University of North Carolina at Chapel Hill, Chapel Hill, N.C.; ¶North Carolina State Center for Health Statistics Birth Defects Monitoring Program, Raleigh, N.C.; ‖Department of Dental Ecology, School of Dentistry, University of North Carolina at Chapel Hill, Chapel Hill, N.C.; and **Center for Health Promotion and Disease Prevention, University of North Carolina at Chapel Hill, Chapel Hill, N.C.*

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INTRODUCTION

Cleft lip and/or palate (CL/P) has many social implications, and children with this condition may be stigmatized for being "different," despite provision of adequate clinical care. Many studies in the literature have characterized the psychosocial implications of CL/P,[1–11] and it is now widely recognized that psychosocial considerations should be included in standardized outcomes assessment for cleft care.[12] Studies have demonstrated that children with CL/P are at an increased risk to encounter psychosocial distresses throughout adolescence.[13] Furthermore, children with CL/P have been found to report more negative interpersonal relationships[14] and to exhibit greater degrees of social inhibition or shyness,[15–17] the etiology of which has been partially attributed to a negative self-perception of appearance. In addition, difficulties with speech throughout adolescence directly impact the child's social environment, and may make it increasingly difficult

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for children with CL/P to form meaningful relationships with their peers.[18–20] In these studies, there is great variability in the method of assessment of psychosocial issues surrounding cleft care.[21] For example, a 2015 study found that more than 60 different measures were being used to evaluate children's ability to socially adjust to CL/P.[22] Recently, great attention has been paid to developing standardized clinician-reported and patient-reported outcome instruments that accurately measure psychosocial distress.[9,23–25]

Despite this attention to the social implications of CL/P, population-based data are still lacking with regard to how common, widespread, and severe cleft-related psychosocial distress can be.[4,22,26–33] Thus, the aim of this exploratory investigation was to consider the association of cleft phenotype and age with self-reported aspects of psychosocial stress.[3,4,26,28–34] This study employed a cross-sectional, population-based approach to provide an age-based and phenotype-based "snapshot" of psychosocial concerns related to CL/P.

METHODS

This study was approved by the institutional review board before survey administration and before review of data from a statewide birth defects registry and medical records.

Participant Population

Children born between 1997 and 2003 with nonsyndromic CL/P were identified via the North Carolina Birth-Defects Monitoring Program, a statewide, population-based, surveillance system operated by the North Carolina Division of Public Health. A comparison group of unaffected children (without known birth defects) born between 1997 and 2003 was established using state birth records. Ages ranged from 9.9 to 17.0 years of age at the time of study participation.

Phenotypic Classification

Children with CL/P were phenotypically classified following review of medical records by a craniofacial surgeon, geneticist, and pediatric dentist. Orofacial clefts can be divided into 4 major classes: cleft lip only (CL), cleft lip with cleft alveolus (CL + A), cleft lip with cleft palate (CL + P), and cleft palate only (CP).[35,36] Considering that the North Carolina Birth-Defects Monitoring Program and medical records did not reliably describe the presence or absence of an alveolar cleft, for the purposes of this study, CL and CL + A were combined into a single category: cleft lip with/without cleft alveolus (CL ± A). In addition, severity of the cleft lip (complete, incomplete, or lesser form), laterality (unilateral or bilateral), and morphology of the cleft palate (e.g., Veau I–IV) were not consistently available from the birth defect registry or medical records and was therefore not considered in this exploratory analysis.

Survey Methods

The psychosocial questionnaire included 29 questions and was included as part of a larger 200-question survey addressing medical, surgical, academic, psychosocial, and economic aspects of cleft care. The 29 psychosocial questions covered the following subdomains: friendships, social interaction, extra-curricular participation, behavioral abnormalities, teasing/bullying, speech-related distress, and appearance-related distress (Fig. 1). It should be noted that the subdomains were not mutually exclusive; for example, a question could relate to both aesthetics and extra-curricular participation. At the time of this study, no uniform validated instrument was available that covered all these subdomains. Thus, we convened an expert working group that included input from multidisciplinary clinicians, social worker, team coordinator, parent representatives, and patient representatives. This working group selected relevant questions from previously validated instruments, combined them into a comprehensive survey, and adapted this survey for direct mail. Response scales were standardized to a Likert-type 5-point scale except for 1 yes/no question.

Surveys were mailed directly to the parents of children with CL/P and unaffected children. Parents were instructed to answer the questions together with their children. Although it was possible for children to complete the psychosocial questions independently (depending on age), for the purpose of this analysis, we considered all questions to be answered by parental proxy.

Statistical Analysis

Survey responses were stratified by age and by cleft phenotype, 2 factors that have been suggested to have a strong association with psychosocial stress related to CL/P.[3,26,28–34] Specifically, age was categorically grouped according to grade level rather than by biological age: elementary school (fourth to fifth grade), middle school (sixth to eighth grade), and high school (ninth to twelfth grade) age. We considered that school age better defined the "social context" for the child, which might better reveal any patterns in psychosocial distress. Cleft phenotype was categorized as CL ± A, CP, and CL + P. Only 1 subgroup analysis (by age or by phenotype) was performed at a time. Sample size limitations precluded our ability to further subdivide groups by a second qualifier (e.g., by phenotype and then by age).

Pearson's chi-square (χ^2) and frequency distributions were used to compare the distribution of responses between children with CL/P and unaffected children. Individual χ^2 tests were performed twice for each of the 29 questions, comparing the responses of unaffected children to responses of children within (1) the school age and (2) the cleft phenotype groupings. *P* values less than 0.05 were considered statistically significant.

RESULTS

Between 1997 and 2003, 559 children were born with CL/P in North Carolina. Of these, 28 children were excluded from further analysis due to the presence of known syndromes, Robin sequence, or other major congenital anomalies, leaving a total of 531 children in the experimental cohort. Per state records, 6,822 children were identified as being born without known birth defects in North

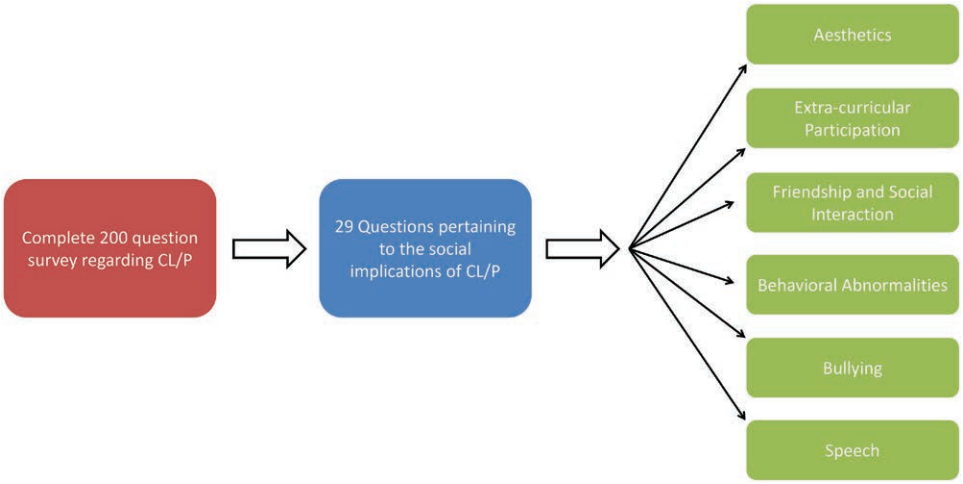

Fig. 1. A graphic depiction of how the questions with social implications were organized. The number of questions in every social subdivision is as follows: aesthetics, 3; extra-curricular participation, 5, friendship and social interaction, 8; behavioral abnormalities, 11; bullying, 6; and speech, 2.

Carolina between 1997 and 2003. From this, 1,201 children were randomly selected to create an unaffected cohort. Completed surveys were returned from 176 children with CL/P (response rate, 33%) and 333 unaffected children (response rate, 27%). Demographic characteristics of the CL/P and unaffected groups are displayed in Table 1.

Social Implications Vary by School Age

The CL/P cohort consisted of 39 elementary (22.1%), 72 middle (41.0%), and 65 high school (36.9%)–aged children. When stratified by school age, responses from children with any form of CL/P significantly differed from the age-matched unaffected cohort in 1/29, 7/29, and 2/29 questions for elementary, middle, and high school–aged children, respectively ($P < 0.05$; Fig. 2). Consideration of the specific questions that differed was quite revealing (Fig. 3): Speech-related dysfunction and distress were reported as more concerning by middle and high school–aged children, whereas less speech-related concern was reported for children in elementary school. Additionally, children with CL/P in middle school reported higher rates of aesthetic concerns and bullying than their younger and older counterparts.

Social Implications Vary by Cleft Phenotype

The CL/P group included 38 children with CL ± A (21.6%), 59 with CP (33.5%), and 79 with CL + P (44.9%). Compared with the unaffected cohort, responses from children with CL ± A, CP, and CL + P significantly differed in 4/29, 7/29, and 8/29 questions, respectively ($P < 0.05$; Fig. 2).

The specific questions that differed for each phenotype shed some light on different considerations for each phenotype (Fig. 3): as expected, children with clefts that included the palate (CP and CL + P) consistently reported more difficulty with speech dysfunction and speech-related distress than children without palatal involvement (CL ± A). Children with CL + P reported more appearance-related concerns than those with CP or CL ± A. Lastly, teasing/bullying was reported to a similar degree in all phenotypes.

DISCUSSION

The Effect of School Age

A child's social environment is in a constant state of flux. Stratification of students by school age allows us to examine how different scholastic atmospheres influence

Table 1. Demographics of participants organized by cleft phenotype

Variable	Cleft Type				Unaffected Group
	Overall CL/P	CL ± A	CP	CL + P	
Number of respondents	176	38 (21.6%)	59 (33.5%)	79 (44.9%)	333
Mean age (y)	13.4±2.0	13.3±2.1	14.0±1.9	13.2±2.1	13.5±1.9
Sex					
Male, n (%)	106 (60.2)	25 (65.8)	30 (50.8)	51 (64.6)	171 (51.4)
School age, n (%)					
Fourth to fifth grade (elementary school)	39 (22.1)	9 (23.7)	12 (20.3)	18 (22.8)	45 (13.5)
Sixth to eighth grade (middle school)	72 (40.9)	15 (39.5)	19 (32.2)	38 (48.1)	163 (49.0)
Ninth to twelfth grade (high school)	65 (36.9)	14 (36.8)	28 (47.5)	23 (29.1)	124 (37.2)
Race/ethnicity, n (%)					
American Indian	3 (1.7)	1 (2.6)	2 (3.4)	0 (0)	6 (1.8)
Asian or Pacific Islander	4 (2.3)	1 (2.6)	2 (3.4)	1 (1.3)	5 (1.5)
Black or African	26 (14.8)	7 (7.8)	8 (13.6)	11 (13.9)	78 (23.4)
Hispanic	8 (4.5)	1 (2.6)	2 (3.4)	5 (6.3)	9 (2.7)
White	135 (76.7)	28 (73.7)	45 (76.3)	62 (78.5)	235 (70.6)

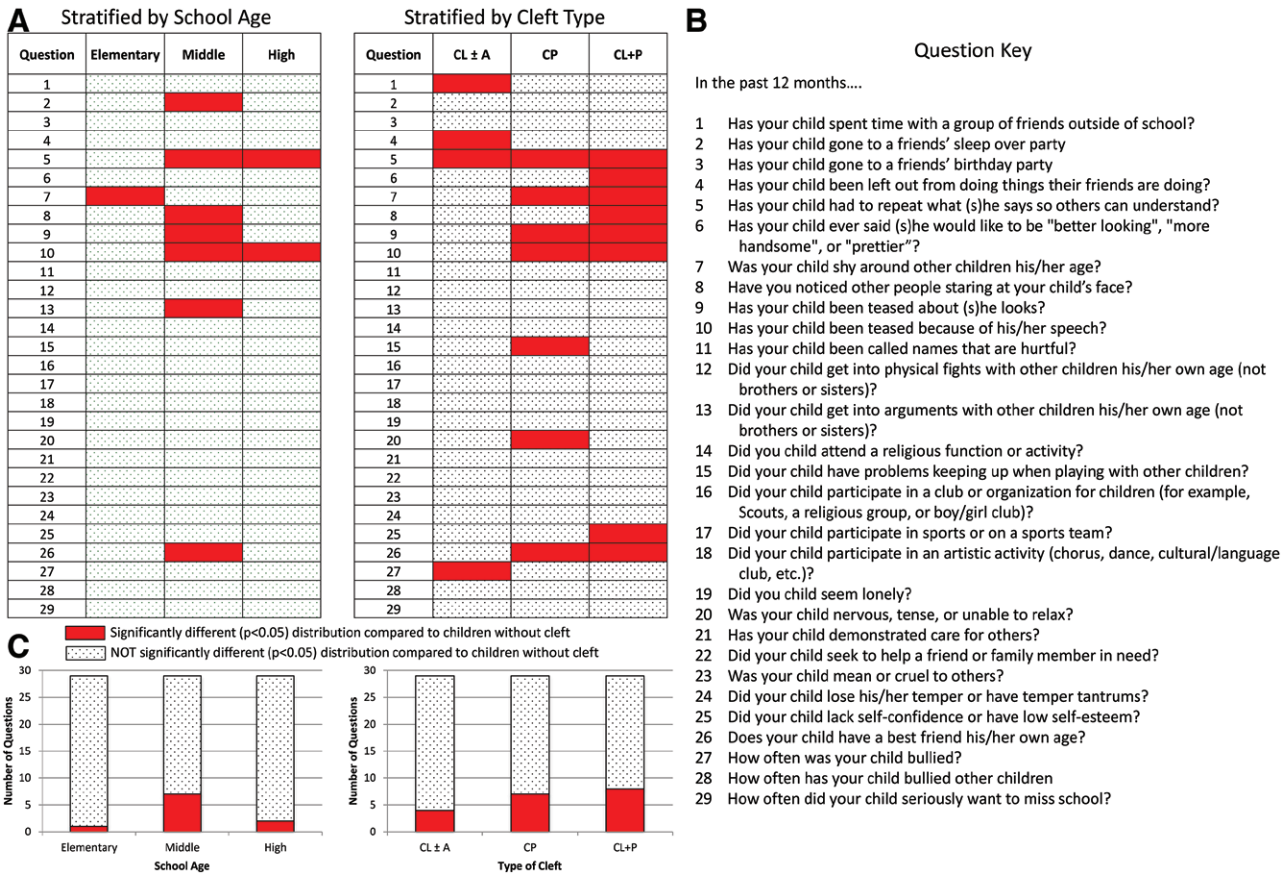

Fig. 2. A question key of the 29 questions with social implications (B) and the results of comparisons between children with CL/P and unaffected children, stratified by school age[35] and cleft type (A). The number of questions for which the responses of the experimental cohort significantly ($P < 0.05$) differed from the unaffected cohort is summated and graphically depicted (C).

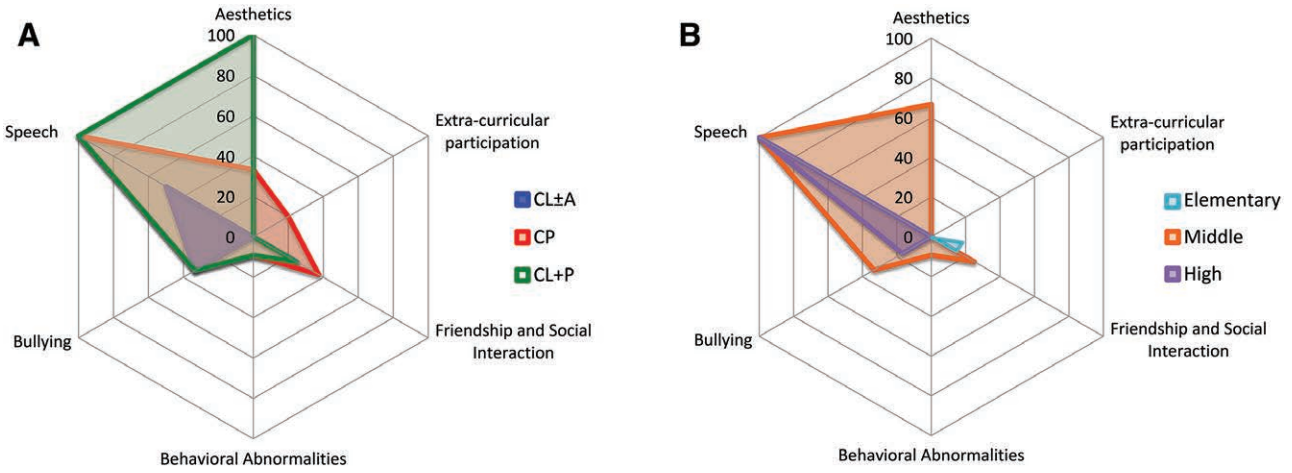

Fig. 3. A radar chart illustrating the trends of CL/P's social implications as determined by cleft type (A)[35] and school age (B). The further the shaded area extends from the center (toward the periphery), the stronger the trend. The numerical values at each level represent the percentage of the questions within the subdivision that were found to significantly differ from the unaffected cohort.

the social implications of CL/P. In this exploratory cross-sectional analysis of population-based survey responses, middle school–aged children reported psychosocial distress to a greater degree than did elementary and high school–aged children (Fig. 2). This is an important confirmation of what has heretofore remained an intuitive assumption for children with CL/P. This finding, regarding psychosocial distress, complements other reports of health-related quality of life scores that demonstrated a difference for middle school-aged children with CL/P when compared with their younger CL/P counterparts.[28] Also, our finding that elementary school–aged children

are largely spared from CL/P's social stigma is consistent with other reports that elementary school–aged children with CL/P do not seem to experience additional psychosocial distress or dysfunction compared with unaffected peers of the same age.[30]

The specific social implications of CL/P also changed with school age (Fig. 3). Middle school–aged children with CL/P were more severely affected in the categories of bullying, friendship and interaction, and appearance compared with their elementary school or high school–aged counterparts. The explanation for middle school–aged children being disproportionately affected by CL/P is likely multifactorial. Certainly, the pronounced social impact that we found during middle school for children with CL/P may be explained by factors that apply to all children, not just those with CL/P. It has been widely documented that during the transition from elementary school to middle school, many children experience their largest decline in personal and interpersonal functioning,[37] and the incidence of teasing/bullying is higher in middle school versus high school.[38] Additionally, the hormonal and physiological changes that middle school–aged children experience as they go through puberty may affect the perceived magnitude of social stigmata. Nevertheless, even though middle school can be a psychosocially stressful time for any child, it stands to reason that the perceived severity of this might be more severe for children with facial differences—as demonstrated in this study by the significant differences in survey responses from children with CL/P versus the unaffected cohort.

The Effect of Cleft Type

This particular study found that cleft phenotype affects both the degree and the pattern of social consequences of CL/P. There are studies that have found cleft type to influence social stigmata,[29,31] as well as studies that state there is no impact.[3,26,32,34,39]

Of the cleft types in this study (CL ± A, CP, and CL + P), children with CL + P and CP were affected to a similar extent, and both more so than CL ± A (Fig. 2). This pattern is consistent with results of studies that found cleft phenotype type to be a valid qualifier. Kramer et al.[29] noted that children with CL + P and CP experience lower quality of life than children with CL. The same study showed that children with CL had superior family functioning compared with children with either CL + P or CP.[29] Broder et al.[31] demonstrated that children with CL + P had lower social and intellectual self-concept compared with children with CL or CP only.

The influence of cleft phenotype on social stigmas may be explained by different functional consequences. Children who suffer from palatal defects (CP and CL + P) often develop speech pathologies such as velopharyngeal insufficiency. This may result in an increased frequency of bullying/teasing. Our study supports this theory: the speech impact for children with palatal defects (CL + P and CP) was higher compared with those without (CL ± A; Fig. 3).

Not all social subdivisions were influenced by cleft type. This study reported a similar bearing on "bullying" for all 3 deformity types, a comparable finding to a study that explained this phenomenon by concluding that bullying/taunting is not solely directed at the physical and visible defect.[39]

One intriguing result of this study was how cleft type affected purely appearance-related social implications. Children with CL + P were the most influenced, followed by children with CP; however, children with CL ± A reported almost no aesthetic social implications. One would reason that children with a lip deformity (CL ± A) would have more aesthetic concerns than children without any visible deformity (CP). However, children without palatal involvement may have less severe aesthetic deformity (e.g., a unilateral CL + A deformity compared with a bilateral CL + P deformity) and, after operative correction, may have superior aesthetic results than do children with palatal involvement. Additionally, this deviation from expectation serves as a reminder that the survey data are heavily influenced by the parents' and child's perception.

Study Limitations and Future Directions

An important limitation relates to the method of completion of the questionnaire. As the questions were completed by the parents with their children, and therefore the responses of the children were known to the parents, this may have influenced either (1) how candid the child was in his/her responses or (2) how accurately the parent recorded the child's responses versus "editorialized" based on his/her own perception. To avoid such sources of reporting bias would require, ideally, private interviews with the child. Alternatively, a separate questionnaire might be sent directly to children and kept confidential from parents, but ensuring or enforcing this process is impossible by a direct-mail survey study. Although the results of this exploratory analysis do support known or suspected relationships between CL/P and psychosocial distress, the frequency of distress revealed by this study is likely slightly underreported. Furthermore, the authors do acknowledge the low response rate to this survey and the limitations that this confers toward the generalizability of the study's results. However, a response rate of 33% is typical for most studies that utilize a survey of this caliber.

We also acknowledge that our analysis is limited to patients within 1 state, which may introduce bias secondary to varying socioeconomic factors and health-care practices that are more predominately present within the Southeastern United States. Another limitation of this study is the inability to consider cleft severity in the analysis, or to match self-reported responses to a "true" clinical outcome (e.g., speech evaluation or rating of appearance). The status of the alveolus could also not be ascertained from the commonly used methods of coding or documentation. This may have an effect on self-perception and social distress, as it may affect the appearance of teeth and the smile. In future work, inclusion of relevant validated questions from such instruments as the Child Oral Health Impact Profile scale or the CLEFT-Q Smile subscale may improve discrimination of the effect of alveolar involvement on appearance-related distress.

Lastly, as this survey is not a patient-reported outcome measure, the data are meant for descriptive purposes and are not an accurate measure of effect size. Nonetheless,

this population-based description is valuable in that it supports the long-held belief by cleft team members that psychosocial stresses exist. Furthermore, these responses give a starting point for further investigations and also support the critical need for inclusion of a validated patient-reported outcome measure—especially as they relate to psychosocial outcomes, speech, and appearance.

CONCLUSIONS

Orofacial clefts result in social stigmas that are challenging to define. The severity and pattern of these social consequences seem to be influenced by both school age and cleft phenotype. Longitudinal studies using validated patient-reported outcome instruments would be beneficial in further exploring these consequences. Based on the observations of this population-based study, researchers may choose to focus on middle school rather than elementary school or high school, with specific attention to psychosocial support mechanisms. These interventions may be best undertaken by social workers and psychological support specialists within the cleft care team. Moreover, researchers may choose to design their studies to better discriminate speech-related distress in children with CP and CL + P and appearance-related distress in CL, CL + A, and CL + P.

Jeffrey R. Marcus, MD
Division of Plastic, Maxillofacial and Oral Surgery
Duke University Hospital and Children's Health Center
200 Trent Drive
Erwin Road
Durham, NC 27710
E-mail: jeffrey.marcus@duke.edu

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