A Population-Based Study of the Social Implications Associated With the Cleft Lip and/or Palate Deformity

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INTRODUCTION: The cleft lip and/or palate (CL/P) deformity carries a social stigma, but the details of this stigma and the associated social implications are not well defined or understood. An improved understanding of this stigma may help to develop interventions to decrease the social difficulties that accompany CL/P. The purpose of this population-based study was to elucidate the social concerns, challenges, and implications that accompany CL/P, and ascertain differences among these concerns based on the age of the affected child and type of deformity.

METHODS: Children with non-syndromic CL/P and unaffected children born during 1997-2003 were identified through the North Carolina Birth Defects Monitoring Program and review of birth certificates, respectively. The social implications of CL/P were measured via a 29-question subset of a larger survey, intended for completion by parental proxy or by the affected child (age permitting). Responses were categorized and analyzed based upon 1) The school age of the child: elementary school aged, middle school aged, and high school aged children and 2) Phenotypic deformity type: cleft lip ± alveolus (CL±A), cleft palate only (CP), and cleft lip and palate (CL+P).

RESULTS: The survey was completed by parental proxy for 176 children with CL/P (response rate = 33%) and 333 controls (response rate = 27%). Compared to 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 ($p<0.05$ for each group). 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. Children with CL+P suffered more severe aesthetic social concerns than did children with CL±A or CP, while experiencing similar difficulties to children with CP in regards to communication. Compared to their older and younger counterparts, middle school-aged children with CL/P were more affected by aesthetic concerns, bullying, and difficulties with friendship and social interaction.

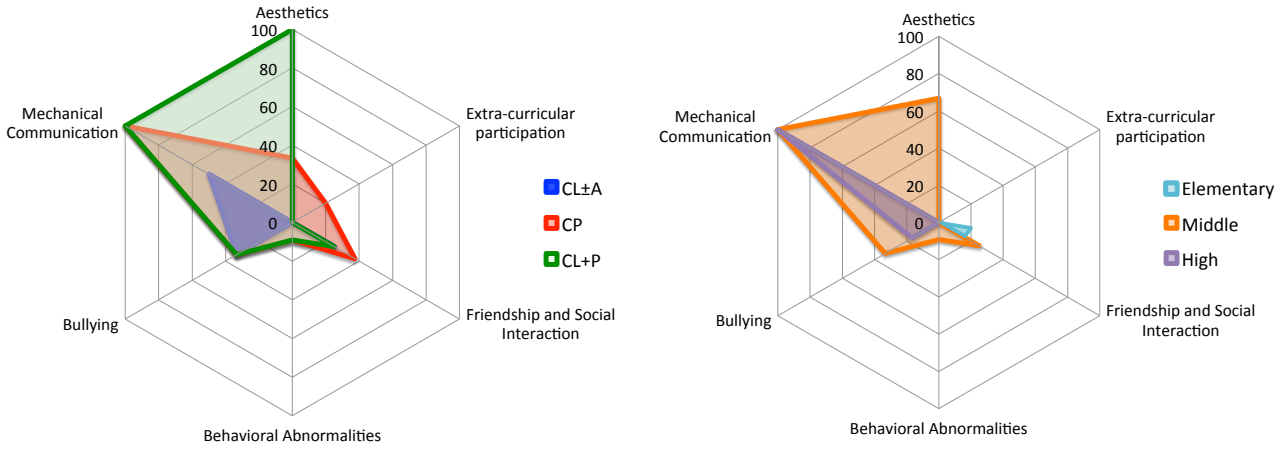

Figure 1: A radar chart illustrating the trends of CL/P's social implications as determined by deformity type (left) and school age (right). The further the shaded area extends from the center (towards the periphery), the stronger the trend. The numerical values at each level represent the percent of the questions within the subdivision that were found to significantly differ from the unaffected cohort.

CONCLUSION: This is the first population-based study describing the social implications of the CL/P deformity and how they are affected by school age and deformity type. These implications change with the children's social environment; they are most pronounced during middle school, and less so during elementary and high school.