

Dental/Prosthodontic Care for Children with Cleft/Craniofacial Conditions

David J. Reisberg

Management of children with cleft lip/palate or other congenital craniofacial conditions requires a team approach. Medical and dental specialists and allied health professionals work together to meet the multiple and complex needs of each child. Treatment begins at birth and continues into adolescence. The maxillofacial prosthodontist is an integral member of this team.

This paper describes the dental/prosthodontic treatment rendered to children born with cleft lip/palate or associated craniofacial conditions. Emphasis is placed on the various intraoral and extraoral prostheses used to establish normal function and appearance and improved quality of life.

Primary Caregiver Perceptions of the Impact of Oral and Craniofacial Conditions on Quality of Life of Children Aged 6 to 14 Years.

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A research project is being undertaken to develop an instrument to assess the impact of oral and craniofacial conditions on quality of life of children and their families. Two analogous measures are being constructed: a Primary Caregiver Perceptions Questionnaires (PCPQ) and a Child Perceptions Questionnaire (CPQ). The conceptual framework for the instrument is based on the WHO definition of health and the American Academy of Pediatrics definition of child health. A preliminary pool of 52 items for the PCPQ was generated through a review of child health status measures. Its content validity was established by a panel of health professionals and primary caregivers (n=45). To select the items for the final PCPQ, the Item Impact Method is being applied. The primary caregivers of the child patients at the Faculty of Dentistry, University of Toronto, and the Craniofacial Unit, The Hospital for Sick Children, Toronto are being asked to identify which items describe problems their children experience as a result of an oral/craniofacial condition and to indicate the importance of these problems on a 5-point Likert scale. Data from the first 50 study participants indicate that the items with the highest impact score (item endorsement proportion x item mean importance) concern chewing dysfunction, pain, dietary restrictions, speech difficulty, various aspects of emotional function (worry, anxiety, frustration), self-esteem (satisfaction with appearance) and self-concept. These results suggest that the impact of oral/craniofacial conditions on daily lives of children as perceived by their primary caregivers is dominated by oral functional limitations and disturbances of emotional well being.

Dental caries in children with cleft lip and palate and craniofacial disorders.

RJ C Shirley DMD, Gordon R Karker DMD, Fred B. Dunkelberger DMD. Center for Craniofacial Disorders, Children's Healthcare of Atlanta, Atlanta GA. Early childhood caries remains a significant health problem. Previous reports have shown that children with cleft lip and palate are at higher risk to develop dental caries.

Purpose: Determine the overall prevalence of dental caries in children with cleft lip and palate and craniofacial disorders in a large craniofacial center. The findings may help us determine if earlier intervention and other methods of education and risk assessment may be needed.

Methods: Records were evaluated of children with visits to the multidisciplinary cleft-craniofacial clinic from July 1998 to June 1999. All patient information including clinical findings and recommendations from pediatric dentistry and orthodontic services were available in a database format. (FileMaker Pro), The patient's age, primary diagnosis, and presence of dental caries with type of treatment recommended were recorded for 306 children that received a dental evaluation.

Results: Fifty-one (16.7%) had dental caries present on visual examination, The mean age of the caries group was 7.12 years with a of range of 13 months to 18 years. Of those patients with caries, 21 (41%) were under 4 years of age and 12 (23.5%) required dental treatment under general anesthesia.

Conclusion: Dental caries remains a concern in this population. The high number of children under age 4 with caries suggests that dental risk assessment and intervention should occur as early as possible. The findings may suggest that other approaches to oral health education and management of dental caries may be beneficial.

Noncleft Hypernasality—An Orphaned Disorder—Implications for Education and Practice

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Objectives: Labeling a speech disorder should accurately reflect its anatomic nature and avoid erroneous or ambiguous connotations. It is common practice to label noncleft hypernasality as a “voice “, which implies that hypernasality results from laryngeal dysfunction. However, hypernasality is disturbance of oral-nasal resonance caused by inappropriate and incomplete closure of the velopharyngeal valving mechanism. This presentation will discuss the critical needs/challenges caused by this mislabeling. Comparisons to the “gold standard” of treating hypernasality in children with cleft palate will be drawn. Critical care issues in identification, referral, management and clinical outcomes will be addressed.

Methods: The source of the mislabeling may lie in the fact that hypernasality is a low incidence speech disturbance. The rate of hypernasality after initial cleft palate repair is only 20 – 30. The incidence of non-cleft hypernasality is not known.

The “voice disorder” label is not used uniformly. Children with cleft palate who are hypernasal are labeled as velopharyngeal incompetent (VPI) and referred to a team of specialists at a craniofacial center. In contrast, hypernasal children without cleft palate are labeled as “voice disordered” and referred to an individual specialist.

Noncleft hypernasality represents 29% of all. The etiology is often an anatomically deep nasopharynx

Results: Mislabeling delays referral. A cleft palate is identified at birth and closed before one year of age. In stark contrast, the average age of referral for noncleft hypernasality resulting from Velo-Cardio-Facial syndrome is 9.2 years.

Delayed management of VPI reduces success of surgical intervention. The rate of success before 6 six years of age is 90.9%. The success rate falls to 73.9% between 6 and 12 years; 70.0% between 12 and 18 year; and 47.0% after 18 years.

Conclusions: Since hypernasality is a low incidence disorder there are few educational or clinical opportunities for developing expertise. Efforts are needed to develop curricula about velopharyngeal function and dysfunction; develop consistent label for noncleft hypernasality that correctly reflects the anatomical origins of the disorder; educate primary care physicians, otolaryngologists and speech-language pathologists about appropriate referral and management practices. Without such efforts we will continue to cause rather than prevent disorders.

Collaboration Between a Private Foundation and a Dental School to Provide Orthodontic Treatment to Children from Working Families

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This unique three-year collaboration between a private family foundation (The Maurice L and Virginia L. Brown Foundation) and the UMKC School of Dentistry provides free orthodontic treatment to 48 children, 9 to 18 years of age, from working families, who could not afford orthodontics. The aim of the project is to increase a child's potential success in life by increasing their function and self-image. Sixteen children with moderate to severe malocclusions are selected each year from either the postgraduate orthodontic program or screenings of children responding to newspaper or radio advertisements. The same orthodontist screens patients to determine the severity of malocclusion and the interest in treatment. The family and the orthodontist reviews each application and intraoral and extraoral pictures for orthodontic and financial need, dental health, academic potential and probability of completing treatment. Parents sign written forms accepting program requirements such as compliance with oral hygiene, keeping appointments, and care of appliances. Parents are financially responsible for other necessary dental procedures. Of the 47 patients currently in the project, 10 have craniofacial anomalies such as cleft lip/palate, Crouzons, or Aperts; 4 patients have families with significant medical problems; one child is in foster care; 13 are from single parent families. Five patients were discontinued for various reasons. The family and the orthodontist periodically review procedures and patient progress, modifying the protocol as necessary. Based on the increasing interest by the public and private agencies, this project is currently being used as a model for expansion to other dental schools.

MONITORING ACCESS BARRIERS TO HEALTHCARE

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Obstacles to receipt of healthcare can account for unsatisfactory healthcare outcomes. Barriers to delivery of cleft lip/palate and other types of craniofacial healthcare are being monitored through the Craniofacial Outcomes Registry. Objectives are to (1) identify occurrences and types of barriers, (2) identify the healthcare procedure that cannot be provided or those delayed in delivery, (3) report these aggregate and individual team data to the interdisciplinary teams participating in the Registry, and (4) report data to agencies that can assist in amelioration of barriers. Methods: Participating teams report occurrences of access barriers, classified according to type (i.e. communication, transportation, culture, availability of the healthcare service, financial, family/patient health status). Barriers also are stratified by type of service the barrier prohibited e.g. diagnosis, pediatric dental care, an operation, orthodontic treatment or follow-up, family/patient instruction, age, and race. Results: Data collection on access barriers by 19 interdisciplinary teams for 1,752 patients who have cleft lip/palate or other craniofacial anomalies, began in October 1999. Results: Within the first month of data collection 50 events documenting barriers to healthcare were reported. With 18 teams reporting, this number will increase for the spring 2000 report. Conclusion: A study of this magnitude has potential for assessing the impact of barriers and focusing efforts toward their reduction or elimination.

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Oral Implants and Age Appropriate Prosthodontic Habilitation of Children and Adolescents with Severe Hypodontia.

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Severe hypodontia may occur isolated or accompanying conditions such as ectodermal dysplasia. Parents or guardians are often anxious to have children receive definitive prosthodontic habilitation as early as possible. Even though there are reports of children < age 6 years receiving dental implants, the benefits of such treatment are unclear. Review of the literature and data from two clinical studies indicates that implants may be successfully used to support oral prostheses in children > age 7 years and that prosthodontic rehabilitation can positively affect oral/facial body image. However, several factors need to be considered. These include: the goals and potential benefits of treatment, the expectations of the parents or guardians and the child, the number and position of permanent teeth present, the amount of bone available for implant placement and the area of the mouth where the implants are to be placed. Based on current information recommendations for the prosthodontic habilitation of children with severe hypodontia which may be appropriate are: (1) utilization of conventional removable prosthodontic prostheses from age 3 to 12 years, (2) possible use of implants for the habilitation of the mandible at age 13 years, with conventional removable prostheses in the maxillae, (3) consideration of implants for rehabilitation of both the maxillary and mandibular arches when growth maturity is reached. Potential areas of future research include the effect of different types of prosthodontic habilitation on growth and development of the oral facial complex, self-esteem, and oral facial body image. Also the cost effectiveness of various types of prosthodontic habilitation requires study.

Developing a Teacher Behavior Rating Scale for Comparing Children with and Without Craniofacial Anomalies.

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Background: Children with oral-facial defects like cleft lip/palate have speech and appearance differences and are at risk for negative psychosocial sequelae. Yet current published psychometric tools are often insensitive to the experience of these children with craniofacial anomalies (CFA).

Objective: This study sought to develop a valid and reliable assessment of behavior among children with and without CFA; and to compare teacher ratings of these two groups of children.

Methods: Teachers were asked prospectively to assess social competence and peer acceptance among 99 consecutively evaluated school-aged patients with CFA and 99 controls (classmates without CFA matched by race, gender, intellectual status, general SES and grade). Sixth grade was the median grade of the subjects.

Outcome Measure: Child Behavior Rating Scale (CBRS)

Results: Using oblique promax rotation, four factors emerged from the CBRS with the CFA patient group and controls. The factors explained 67% of the total variance and 69% of the variance of the two groups, respectively. The four factors included: 1-Self-maintenance, 2-Social Adjustment, 3-Independence, and 4-Teasing. Cronbach's alpha results averaged 0.77 for the CFA group and 0.83 for the controls; test-retest reliability estimates were 0.93. Results demonstrate the consistency of the factors and high level of interrelationship among the items across subject groups. Expected differences ($p < 0.05$) were found between subject groups on the Total score and Factor 4.

Conclusion: The CBRS demonstrated psychometric worthiness. The findings indicated that patients with CFA had lower Total scores on the CBRS, and they were rated as experiencing more teasing about their facial appearance and less than their matched peers.

Implications for health professionals, multidisciplinary teams, school personnel, and health policymakers will be discussed.

A TEAM APPROACH TO IMPLANT SOLUTIONS FOR CHILDREN

M.K. Richter

Children affected by the ectodermal dysplasia (ED) syndromes require extraordinary oral health care. These conditions include missing teeth, malformed teeth and enamel dysplasia. For patients with many missing teeth, osseointegrated dental implants are the optimal treatment because they improve mastication, minimize bone loss, enhance speech and maximize self-esteem. The cost of treatment and lack of insurance coverage are often prohibitive and as a result, patient needs remain unmet. The National Foundation for Ectodermal Dysplasias (NFED) created a Dental Implant Program to enable patients to receive necessary care at no cost or at greatly reduced fees. Partners in this unique program include the Southern Illinois University School of Dental Medicine (SIU/SDM), the University of Washington (UW), Implant Innovations, Inc. (3i) and Nobel BioCare. Because of the generous contributions of the participating partners, costs are significantly reduced. As a result, individuals from across the country have received quality care by experienced clinicians at enormous savings. Most importantly, the care received may not have been possible for the patient had this program not been available. With both programs at capacity, the NFED seeks to expand the program to additional sites to offer services to patients in a broader geographical area. More than 35 patients have successfully completed or are in various stages of treatment at an estimated cost savings of more than \$500,000. In addition, the patient data being collected will provide improved insights of this treatment option not only for children affected by ED but for all children missing teeth.