Policy on Management of Patients With Cleft Lip/Palate and Other Craniofacial Anomalies

Originating Committee
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The American Academy of Pediatric Dentistry (AAPD), in its efforts to promote optimal health for children with cleft lip/palate and other craniofacial anomalies, endorses the current statements of the American Cleft Palate-Craniofacial Association (ACPA).[1,2]

A child born with cleft lip/palate or other craniofacial anomalies has multiple and complex problems, including early feeding and nutritional concerns, middle ear disease, hearing deficiencies, deviations in speech and resonance, dentofacial and orthodontic abnormalities, and psychosocial adjustment problems.

A report on children with special needs[3] issued in 1987 by the US Surgeon General stressed that the care of these children should be comprehensive, coordinated, culturally sensitive, specific to the needs of the individual, and readily accessible. Recognizing that children with clefts and other craniofacial anomalies have special needs, the Maternal and Child Health Bureau in 1991 provided funding to ACPA to develop parameters of care for these patients.

As part of these parameters, several fundamental principles were identified as critical to optimal cleft/craniofacial care. These principles are:

1. Management of patients with craniofacial anomalies is best provided by an interdisciplinary team of specialists.
2. Optimal care for patients with craniofacial anomalies is provided by teams that see sufficient numbers of these patients each year to maintain clinical expertise in diagnosis and treatment.
3. Although referral for team evaluation and management is appropriate for patients of any age, the optimal time for the first evaluation is within the first few weeks of life and, whenever possible, within the first few days.
4. From the time of first contact with the child and family, every effort must be made to assist the family in adjusting to the birth of a child with a craniofacial anomaly and the consequent demands and stress placed upon that family.
5. Parents/caregivers must be given information about recommended treatment procedures, options, risk factors, benefits, and costs to assist them in: (1) making informed decisions on the child's behalf; and (2) preparing the child and themselves for all recommended procedures. The team should actively solicit family participation and collaboration in treatment planning and, when the child is mature enough to do so, he or she should also participate in treatment decisions.
6. Treatment plans should be developed and implemented on the basis of team recommendations.
7. Care should be coordinated by the team, but should be provided at the local level whenever possible; however, complex diagnostic or surgical procedures should be restricted to major centers with appropriate treatment facilities and experienced care providers.
8. It is the responsibility of each team to be sensitive to linguistic, cultural, ethnic, psychosocial, economic, and physical factors that affect the dynamic relationship between the team, patient, and family.
9. It is the responsibility of the team to monitor both short-term and long-term outcomes. Thus, longitudinal follow up of patients, including appropriate documentation and record keeping, is essential.
10. Evaluation of treatment outcomes must take into account the satisfaction and psychosocial well-being of the patient, as well as effects on growth, function, and appearance.

As members of the interdisciplinary team of physicians, dentists, speech pathologists, and other allied health professionals, pediatric dentists should provide dental services in close cooperation with their orthodontic, oral and maxillofacial surgery, and prosthodontic colleagues. All dental specialists should ensure that:

1. Dental radiographs, cephalometric radiographs, and other imaging modalities as indicated should be utilized to evaluate and monitor dental and facial growth and development.
2. Diagnostic records, including properly occluded dental study models, should be collected at appropriate intervals for patients at risk for developing malocclusion or maxillary-mandibular discrepancies.

3. Presurgical maxillary orthopedics to improve the position of the maxillary alveolar segments prior to surgical closure of the lip may be indicated for some infants.
4. As the primary dentition erupts, the team evaluation should include a dental examination and, if such services are not already being provided, referral to appropriate providers for caries control, preventive measures, and space management.
5. Before the primary dentition has completed eruption, the skeletal and dental components should be evaluated to determine if a malocclusion is present or developing.
6. Depending upon the specific goals to be accomplished and also upon the age at which the patient is initially evaluated, orthodontic management of the malocclusion may be performed in the primary, mixed, or permanent dentition. In some cases, orthodontic treatment may be necessary in all 3 stages.
7. While continuous active orthodontic treatment from early mixed dentition to permanent dentition should be avoided, each stage of orthodontic therapy may be followed by retention and regular observation. Orthodontic retention for the permanent dentition may extend into adulthood.
8. For some patients with craniofacial anomalies, functional orthodontic appliances may be indicated.
9. For patients with craniofacial anomalies, orthodontic treatment may be needed in conjunction with surgical correction of the facial deformity.
10. Congenitally missing teeth may be replaced with a removable appliance, fixed restorative bridgework, or osseointegrated implants.
11. Patients should be closely monitored for dental and periodontal disease.
12. Prosthetic obturation of palatal fistulae may be necessary in some patients.
13. A prosthetic speech device may be used to treat velopharyngeal inadequacy in some patients.

References

1. American Cleft Palate-Craniofacial Association. *Parameters for evaluation and treatment of patients with cleft lip/palate or other craniofacial anomalies.* Chapel Hill, NC: The Maternal and Child Health Bureau, Title V, Social Security Act, Health Resources and Services Administration, US Public Health Service, DHHS; 2000. Grant #MCJ-425074.
2. American Cleft Palate-Craniofacial Association, Team Standards Committee. *The cleft and craniofacial team.* Chapel Hill, NC: American Cleft Palate-Craniofacial Association; 1996.
3. US Dept of Health and Human Services. *A report of the Surgeon General: Children with special health care needs.* Rockville, Md: Office of Maternal and Child Health, US Dept of Health and Human Services; 1987.