PARAMETERS

For Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Anomalies

Official Publication of the American Cleft Palate-Craniofacial Association

Revised Edition
November 2009

This Document was developed through a project funded by
The Maternal and Child Health Bureau
Health Resources and Services Administration
U.S. Public Health Service
Department of Health and Human Services
Grant #MCJ-425074
"Development of Standards for Health Care of Infants,
Children and Adolescents with Craniofacial Anomalies"
awarded to the American Cleft Palate-Craniofacial Association

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ACKNOWLEDGMENT

The development of this document was supported in part by Project #MCJ-425074, "Development of Standards for Health Care of Infants, Children and Adolescents with Craniofacial Anomalies" from The Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, U.S. Public Health Service, Department of Health and Human Services. The grant was provided to the American Cleft Palate-Craniofacial Association. The document is the product of the combined efforts of the participants (both members and non- members of the Association) in a consensus conference on recommended practices in the care of patients with craniofacial anomalies, the peer reviewers who suggested revisions to the original draft, and the grant project committee. The staff of the National Office of the American Cleft Palate-Craniofacial Association was invaluable in facilitating both the consensus conference and the completion of the document. The document was ratified by conference participants following revision, and subsequently adopted as a policy statement of the American Cleft Palate-Craniofacial Association by its Executive Council in October 1992. The document will be reviewed periodically by a consensus panel to consider revisions that may be needed to reflect advances in the scientific knowledge base and in instrumentation. (See below)

IMPORTANT NOTICE:
Individual variations in the condition of the patient, status of patient and family, and the response to treatment, as well as other circumstances, mean that the optimal treatment outcome for some patients may be obtained from practices other than those recommended in this document.

Revised Edition, November 2009
A revision to the dental care section and the genetics/dysmorphology services section of the document was approved by ACPA members by ballot, fall 2009.

Revised Edition, December 2007
A revision to the speech-language pathology services section of the document was approved by ACPA members by ballot, fall 2007.

Revised Edition, April 2000
Revisions to the document were approved by ACPA members present and voting at the April 2000 Annual Business Meeting as follows:

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Second Printing, March 1993
This document was originally printed as a supplement to *The Cleft Palate-Craniofacial Journal.*

For reference to this document, the following format is suggested:
Parameters for the Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Anomalies. American Cleft Palate-Craniofacial Association. *Cleft Palate-Craniofacial Journal 1993; 30 (Suppl 1).*

PREFACE

In June of 1987, the Surgeon General of the United States issued a report on children with special health care needs (Koop, 1987). The central theme of the report was that these children require comprehensive, coordinated care provided by health care systems that are readily accessible and responsive to the individual needs of the patients and their families. Among other points, the Surgeon General called for 1) facilitation of parent/professional collaboration in the health care of children, 2) sharing of unbiased and complete information about children with their parents, 3) provision of emotional and financial support for families, 4) sensitivity to cultural differences, 5) encouragement of parent-to-parent support, 6) incorporation of the developmental needs of infants, children, and adolescents into health care plans, 7) assurance of the availability of comprehensive services including social, emotional, and cognitive aspects of health care, and 8) an interdisciplinary approach to care. The following actions were recommended: Commitment to children with special needs; encouragement of community-based services; adequate preparation of providers of services; formation of coalitions to improve delivery of services; development of guidelines to control costs of services; establishment of protocols to assess quality of care; encouragement of adequate health care financing; and conduct of research and dissemination of information about aspects of health care.

Recognizing that children with craniofacial birth defects, including cleft lip and palate, are among those children with special health care needs, the Maternal and Child Health Bureau provided funding (MCJ-425074 - "Development of Standards for Health Care of Infants, Children, and Adolescents with Craniofacial Anomalies") to the American Cleft Palate-Craniofacial Association for the purpose of identifying recommended practices in the care of patients with craniofacial anomalies. This work began in May 1991 with a consensus conference in which 71 individuals participated. The majority of the participants were professionals experienced in the diagnosis and treatment of craniofacial anomalies and related disorders. They were selected from the fields of anatomy, audiology, craniofacial surgery, genetics, nursing, oral and maxillofacial surgery, orthodontics, otolaryngology, pediatric dentistry, pediatrics, plastic surgery, prosthodontics, psychology, social work, speech-language pathology and speech science. The remainder of the participants were selected to represent patients and their families, multilingual-multicultural interests, and government agencies involved in the funding of care for such patients. Following four days of presentations by experts and discussion by participants, the attendees voted by ballot on each of 386 resolutions that the grant project

committee had distilled from the written records of the proceedings. The recommendations on which at least 75% of the conference attendees concurred* were included in a draft of a parameters of practice document. Copies of the document were then distributed for both select and wide-spread peer reviews; subsequent revisions were made by the committee in response to reviewers' comments. The revised document was returned to the participants in the consensus conference for ratification and was subsequently approved as American Cleft Palate-Craniofacial Association policy by the Executive Council.

REFERENCE

Surgeon General's Report: Children with special health care needs. Office of Maternal and Child Health, U.S. Department of Health and Human Services, Public Health Service, June 1987.

** In a few instances in which the recommendation(s) involved specialty-specific issues and individuals outside that specialty were neutral in their responses, the recommendation(s) were based on at least a 75% concurrence of individuals representing that specialty.*

INTRODUCTION

There are numerous types of congenital craniofacial anomalies, the most common of which is cleft lip and/or palate. In the United States, this birth defect affects approximately one in 750 newborns each year. Approximately one-half of these infants have associated malformations, either minor or major, occurring in conjunction with the cleft (Jones, 1988; Rollnick and Pruzansky, 1981; Shprintzen et al., 1985). Although the incidence figures for more complex anomalies or syndromes such as Apert syndrome, Crouzon disease, mandibulofacial dysostosis or hemifacial microsomia are much lower than that for cleft lip and/or palate, the impact of craniofacial birth defects must be viewed in terms of the aggregate effect rather than the impact of any single entity. The impact is twofold: that on the patient and family, and that on society as a whole. The health and well-being of all of these children is dependent upon the clinical expertise of those who serve them. In addition, society as a whole is affected by the quality of their care because the potential of the affected individual for a positive contribution to the community is inevitably influenced by the adequacy of treatment.

Although the treatment of children with cleft lip/palate and other types of craniofacial anomalies in the United States has improved dramatically, many children still receive care that is substantially inferior to what can or should be provided. Inadequate care results from diagnostic errors, failure to recognize and treat the full spectrum of health problems associated with these anomalies, unnecessary and poorly timed treatment, and inappropriate or poorly performed procedures. Each of these persistent problems was addressed in the course of the consensus conference.

Several fundamental principles underlie the recommendations of the conference attendees regarding the optimal care of patients with craniofacial anomalies, regardless of the specific type of disorder:

I. Management of patients with craniofacial anomalies is best provided by an interdisciplinary team of specialists.

II. Optimal care for patients with craniofacial anomalies is provided by teams that see sufficient numbers of patients each year to maintain clinical expertise in diagnosis and treatment.

III. The optimal time for the first evaluation is within the first few weeks of life and, whenever possible, within the first few days. However, referral for team evaluation and management is appropriate for patients at any age.

IV. From the time of the 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 to the consequent

demands and stress placed upon the family.

V. Parents/caregivers must be given information about recommended treatment procedures, options, risk factors, benefits, and costs to assist them in (a) making informed decisions on the child's behalf, and (b) preparing the child and themselves for all recommended procedures. The team should actively solicit family participation and collaboration in treatment planning. When the child is mature enough to do so, he or she should participate in treatment decisions.

VI. Treatment plans should be developed and implemented on the basis of team recommendations.

VII. Care should be coordinated by the team but should be provided at the local level whenever possible; however, complex diagnostic and surgical procedures should be restricted to major centers with the appropriate facilities and experienced care providers.

VIII. 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 and the patient and family.

IX. It is the responsibility of each team to monitor both short-term and long-term outcomes. Thus, longitudinal follow-up of patients, including appropriate documentation and record-keeping, is essential.

X. 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.

The remainder of this document is divided into the following sections: (1) interdisciplinary teams: composition, qualifications of team members, and general responsibilities of teams; (2) contemporary practices of the team during the early months of life of the patient; and (3) longitudinal evaluation and treatment, listing general guidelines and contemporary practices as they pertain to professional specialty areas.

REFERENCES

Jones, MC. Etiology of facial clefts: Prospective evaluation of 428 patients. *Cleft Palate J* 1988; 25: 16-20.

Rollnick, BR, Pruzansky, S. Genetic services at a center for craniofacial anomalies. *Cleft Palate J* 1981; 18: 304-313.

Shprintzen, RJ, Siegel-Sadewitz, VL, Amato, J., Goldberg, RB. Anomalies associated with cleft lip, cleft palate, or both. *Am J Med Genet* 1985; 20: 585-595.

INTERDISCIPLINARY TEAMS

Composition

The staff of the interdisciplinary team may include individuals from the following areas of professional practice: anesthesiology, audiology, diagnostic medical imaging/radiology, genetic counseling, genetics/dysmorphology, neurology, neurosurgery, nursing, ophthalmology, oral and maxillofacial surgery, orthodontics, otolaryngology, pediatrics, pediatric dentistry, physical anthropology, plastic surgery, prosthodontics, psychiatry, psychology, social work, and speech-language pathology. Consultation with other professionals may also be appropriate. The specific staff will be determined by the availability of qualified personnel and by the types of patients served by the team. When the team cannot provide all of the types of examinations or other services required by its patients, team members are responsible for making appropriate referrals, and for communicating with those to whom patients are referred to facilitate the implementation of appropriate and coordinated treatment plans.

Qualifications of Team Members

The paramount interest of both the Bureau of Maternal and Child Health and the American Cleft Palate-Craniofacial Association is the quality of care for patients. It is thus essential that all team members be trained and experienced in the care of patients with craniofacial anomalies. However, this document does not address the scope of practice of individual professional specialties. The educational and experiential requirements for the specialties represented on teams are variously determined by their own specialty boards, professional associations, state licensing boards, etc. These requirements are continually subject to change. Each team must take responsibility for assuring that team members not only possess appropriate and current credentials but also have requisite experience in evaluation and treatment of patients with craniofacial anomalies. Teams should assist members in keeping current with their specialties by supporting and encouraging their participation in continuing education activities and attendance at professional meetings.

Team Responsibilities

The principal role of the interdisciplinary team is to provide integrated case management to assure quality and continuity of patient care and longitudinal follow-up. Each patient seen by the team requires comprehensive, interdisciplinary treatment planning to achieve maximum habilitation with efficient use of parent and patient time and resources. Each interdisciplinary team should do the following:

- Maintain an office with a secretary and/or coordinator and a listed telephone number.
- Maintain centralized and comprehensive records on each patient, including histories, diagnoses, reports of evaluations, treatment plans, reports of treatment, and supporting documentation such as photographs, radiographs, dental models, and audiotaped speech recordings.
- Designate a coordinator who facilitates the function and efficiency of the team, ensures the provision of coordinated care for patients and families, and assists patients and families in understanding, coordinating, and implementing treatment plans.
- Designate a member(s) to make initial contact with the patient and/ or family, and also with direct care providers, as appropriate.
- Evaluate patients at regularly scheduled intervals, the frequency and specific content of those evaluations being determined by the condition and needs of the patient and family.
- Hold regularly scheduled face-to-face meetings for discussion of findings, treatment planning, and recommendations for each patient.
- Develop a longitudinal treatment plan for each patient that is modified as necessitated by craniofacial growth and development, treatment outcomes, and therapeutic advances.
- Weigh all treatment decisions against the expected outcomes and related factors such as facial growth, hearing, speech, dentition, and psychosocial impact on patient and family.
- Communicate the treatment recommendations to each patient and family in written form as well as in face-to-face discussion.
- Provide updated information to families as the treatment plan unfolds, and repeat information frequently enough to assure its assimilation.
- Demonstrate sensitivity and flexibility in provision of care to accommodate linguistic, cultural, and ethnic diversity among patients and their families, ensuring that appropriate interpreters are available to assist in both verbal and written communication.
- Assist families in locating resources for financial assistance necessary to meet the needs of each patient.
- Communicate on a routine and ongoing basis with direct care

providers in the home community, and invite these care providers to participate in team meetings involving their patients.

- Perform regular, formal assessments of the quality of patient care with participation by each member of the team and, when appropriate, utilize external peer review. Teams should also conduct periodic surveys of patient satisfaction.
- Maintain a reliable list of sources for any services that are either not provided by the team itself or are better provided at the community level.
- Assist families in planning for treatment in a new geographic location by referring them to an interdisciplinary team in that area, and facilitate contact with the new team.
- Provide assistance to adolescents and their families in planning for the termination of active treatment, and offer information regarding the services that, if needed, will be available to them as adults.
- Attempt to inform adult patients who may have completed treatment of new developments in diagnosis and treatment as they become available.
- Promote early identification of children with craniofacial anomalies through programs designed to inform delivery room personnel, neonatal care personnel, and primary care providers in the community about these birth defects.
- Provide educational programs for hospital personnel and primary care providers addressing feeding and other critical aspects of early health care for children with craniofacial anomalies.
- Promote understanding of, and sensitivity to, the needs of patients by providing educational information about craniofacial anomalies and related disorders to parents and patients, to other professional people, and to the general public.
- Promote understanding of, and sensitivity to, the concerns of both parents, recognizing that each parent may have separate concerns.
- Aid in the formation and encouragement of parent-run support groups, and encourage cooperation with hospital visitation programs by trained volunteers.

NEONATAL PERIOD AND INFANCY

As stated in Principle III, the optimal time for the first evaluations of a child with congenital anomalies is within the first few days of life. Subsequent evaluations should be scheduled at regular intervals, the frequency and specific content of each of those evaluations being determined by the condition and needs of the individual infant and family.

Team Practices

One or more members of the interdisciplinary team - typically the team nurse - should assume responsibility for providing the following services based on the needs of the infant:

- Contacting the family immediately after referral to provide assistance with feeding and to offer other basic information, as needed, in conjunction with the primary care provider, i.e., the pediatrician or family physician.

- Ensuring weekly assessment of nutritional intake and weight gain during the first month of life.

- Maintaining support for the family through home visits, telephone calls, or a visiting nurse program.

- Instructing caretakers of children with compromised airways in techniques of airway maintenance including positioning, nasogastric tube insertion, care of a tracheostomy, and apnea-bradycardia monitoring.

- Recommending or arranging for hearing assessment of the neonate as soon as possible.

At the time of the infant's first visits, and based on the individual needs of each infant, the team should:

- Obtain a history of pre- and postnatal development.

- Provide a full pediatric evaluation including nutritional and feeding assessments.

- Provide instruction and educational materials on feeding, and

offer other information such as the availability of special feeding devices. (Note: The mother's choice of feeding method should be supported as long as that method sustains a normal suckle-swallow reflex and adequate nutrition is achieved.)

- Perform a genetic/dysmorphology screening with subsequent provision of, or referral for, a complete genetic evaluation as necessary. If a recommendation is to be made for a full genetic evaluation and counseling, consideration should be given to the family's emotional status. If the family declines the recommendation of the team for genetic evaluation and/or counseling, this fact should be documented in the patient's record.

- Arrange for any evaluations pertinent to the genetic/dysmorphologic diagnosis, including imaging studies, chromosome analysis, ophthalmological evaluation, etc.

- Perform or arrange for an otolaryngologic evaluation.

- Perform or arrange for an audiologic evaluation.

- Instruct the caretakers regarding symptoms of otologic disease, hearing loss, and sleep apnea.

- Arrange for cardiopulmonary assessments if the infant is at risk for respiratory obstruction or sleep apnea.

- Offer information to parents, as appropriate, about normal speech and language development, speech and language impairments for which the child may be at risk, and ways in which they may facilitate speech and language development.

- Conduct an assessment of prelinguistic speech-language development.

- Conduct or arrange for a psychosocial interview of the family to obtain information regarding the family history and adjustment of the family to the child; to assess cultural and linguistic influences affecting the family; to identify sources of family support; and to identify financial needs and resources.

- Provide examination by a dental specialist to evaluate factors

that may influence surgical management, to assist in treatment planning, and to obtain baseline diagnostic records.

- Provide counseling on care of the oral cavity and prevention of dental caries, especially nursing bottle caries.

- Provide examination by a surgeon and consultation among team members and family members regarding management procedures and options.

- Provide families with contacts to appropriate parent-run support groups.

The team should monitor the child's development throughout the first year of life, and provide or refer for any required interventions. Areas of specific concern include (a) height, weight gain, nutrition, feeding disorders and growth; (b) continuity of routine pediatric care, including immunizations; (c) motor, cognitive, and social development; (d) speech and language development; (e) otologic health; (f) hearing status; (g) parent-child adaptation, parental skills, behavior management, and nurturance; (h) the condition of the developing dentition and supporting tissues, with counseling regarding early oral hygiene and prevention of nursing caries; (i) the physical status of the child as it pertains to readiness for surgical management; and (j) modifications of the treatment plan as necessitated by any additional information such as more complete genetic/dysmorphologic diagnoses or new developments in family status.

LONGITUDINAL EVALUATION AND TREATMENT

An ongoing relationship between the team and the patient and family allows for longitudinal monitoring of progress and permits the identification of new concerns on a timely basis. Even when the first team visit takes place in later childhood or adulthood, optimization of care requires regular team evaluations for assessment of treatment outcomes and updating of treatment plans. Continuity of care enhances the evaluation and treatment process for patients of any age.

Audiologic Care

Individuals with craniofacial anomalies may have congenital abnormalities of the auditory structures and are also subject to an increased incidence of ear disease. These children are at high risk for hearing disorders that may occur intermittently or become permanent, and that vary from mild to severe. Hearing loss can have a significantly adverse influence on speech and language development, educational and psychological status, and eventually on social and vocational status. For these reasons, children with craniofacial anomalies require ongoing audiologic surveillance.

- Each child should have an appropriate assessment of hearing sensitivity for each ear within the first three months of age.
- The timing of audiological follow-up examinations should be determined on the basis of the child's history of ear disease or hearing loss. Audiological follow-up examinations should continue through adolescence.
- Acoustic-immittance (tympanometric) measures should be obtained as a part of each audiological evaluation to monitor middle ear status.
- All children undergoing myringotomies and placement of ventilating tubes should be seen pre- and postoperatively for audiologic assessment.
- When a persistent hearing loss is identified, amplification (hearing aids, auditory training systems) should be considered.
- When hearing loss occurs in the presence of microtia or atresia, whether unilateral or bilateral, bone conduction amplification should be considered depending upon degree of loss; an implantable bone conduction aid may be a treatment option.
- Once amplification has been provided, a regular follow-up schedule is needed to monitor hearing thresholds and the function of the amplification system.

- For any child with a documented hearing loss, referral should be made to the child's school district for appropriate educational services as soon as the hearing loss is identified.
- In the absence of a positive history of otologic disease or hearing loss, audiologic examination or screening should still be carried out at least yearly through the age of six years to assure adequate monitoring of hearing.

Cleft Lip/Palate Surgery

In addition to primary surgical closure of the lip and palate, many patients will require secondary surgical procedures involving the lip, nose, palate, and jaws that usually are staged from infancy through adulthood. These procedures usually are staged over a period of several years. In all cases, surgical techniques should be individualized according to the needs and condition of the patient. Surgical procedures should be coordinated to minimize the number of anesthetic exposures and hospitalizations. Evaluation of complications (morbidity and mortality) of cleft lip and palate repairs should be completed on an annual basis and subjected to peer review. The major factor in the quality of surgical outcome is the skill, training, and experience of the cleft care team.

Primary Cleft/Lip Palate Surgery:

- An anesthesiologist knowledgeable and experienced in pediatric anesthesia must be present for all surgical procedures involving children.
- Surgical repair of the cleft lip is usually initiated within the first 12 months of life and may be performed as early as is considered safe for the infant.
- Pre-surgical maxillary orthopedics to improve the position of the maxillary alveolar segments prior to surgical closure of the lip may be indicated for some infants.
- The nasal deformity is an integral part of the cleft lip. Depending on the severity, primary nasoplasty may be done at the time of the primary lip repair.
- A preliminary lip adhesion is a procedure that may be used in selected patients preceding definitive lip repair.
- The goal of lip repair is to restore the normal functional and anatomic features.
- In the normally-developing child, the palate should be closed by the age of 18 months and preferably earlier when possible.
- The goal of palate surgery is to achieve normal function. Repair of

the soft palate may include muscle reconstruction.

- Patients with submucous clefts should be monitored closely and their palates repaired only if there is evidence of feeding, otologic, or speech problems.

Secondary Cleft/Lip Palate Surgery:

- Although rhinoplasty and nasal septal surgery are usually advocated only after completion of nasal growth, earlier intervention for reasons of airway problems or nasal tip deformity may be indicated.
- Repair of the cleft lip nasal deformity can be accomplished with limited external incisions on the nose.
- The timing of nasal surgery should be discussed with the patient and parents so that the goals are understood and expectations are realistic.
- The patency of the nasal airway should be considered when planning either nasal reconstructive procedures or secondary velopharyngeal operations such as a pharyngeal flap or other type of pharyngoplasty.
- Secondary palatal and pharyngeal surgery for velopharyngeal inadequacy should be performed only after evaluation of the velopharyngeal mechanism and review by the team.
- Surgical or prosthetic closure of palatal fistulae may be needed if the fistulae are symptomatic.
- The timing of bone grafting of the alveolar cleft should be determined by the stage of dental development. The graft should be placed before the eruption of the permanent maxillary teeth in the region of the cleft, although in late-presenting patients bone grafting may necessarily take place after full eruption of the permanent teeth. The timing of the operative procedure should be determined in collaboration with the orthodontist. Autogenous bone should be used when tooth movement through the graft is anticipated. The occlusion should be stabilized before materials that have potential to impede tooth movement are used.
- In some instances, enlarged tonsils may interfere with velopharyngeal function, and a tonsillectomy may be indicated.
- Tonsillectomy and/or adenoidectomy may be indicated to permit safe performance of a pharyngeal flap or other type of pharyngoplasty.

Craniofacial Surgery and Maxillofacial Surgery

The complex nature of many types of craniofacial anomalies often necessitates multiple operative procedures at different stages of development. Reduction of morbidity and mortality from craniofacial operations requires establishment of a dedicated surgical team, frequent performance of operative procedures, and adequate support facilities. Longitudinal follow-up is necessary for these patients even when the intervention has been successful with respect to the anatomical defect.

- Initial evaluation of cranial vault anomalies should include a pertinent history and physical examination by team members who are specialists in genetics/dysmorphology, neurosurgery, ophthalmology, and craniofacial surgery, among others.

- For patients with orbitocranial anomalies, including abnormalities of orbital position and shape and globe position, the initial evaluation and longitudinal follow-up is the same as that for those with isolated cranial vault defects.

- The specific components of the pre-, peri- and postoperative evaluations of craniofacial surgery should be based upon the type of anomaly and the craniofacial zone(s) affected.

- Conventional skull radiographs may be used for screening, CT scanning and, when indicated, magnetic resonance imaging should be obtained. Such imaging techniques are to be used in preoperative planning and postoperative evaluations.

- Timing of surgery, including distraction osteogenesis, for orbital craniofacial anomalies depends on associated soft tissue defects, functional impairments, and psychosocial concerns.

- An anesthesiologist knowledgeable and experienced in pediatric anesthesia must be present for all surgical procedures involving children.

- Appropriate intensive care facilities must be available for all patients undergoing craniotomy or any procedure that might compromise the airway.

- Patients should be followed at regular intervals at least into adolescence to monitor cranial and facial growth, overall development, neurological status, ocular function, speech and hearing, and psychosocial adjustment.

- For patients with microtia, surgical reconstruction of the external ear, auditory canal and middle ear are treatment options. The

use of ear prostheses which may be attached with adhesive or osseointegrated implants is an alternative. The choice depends on the medical condition and patient preference. Use of osseointegrated implants, however, may compromise future surgical external ear reconstruction.

- Secondary procedures including distraction may be necessary to correct residual deformities of the mandible, maxilla, orbits, zygoma, forehead, and nose.

- Orthognathic surgery (and/or distraction osteogenesis) is indicated when orthodontic treatment cannot achieve functional and/or acceptable esthetic occlusion and facial harmony. Such surgery should be timed to minimize any adverse effect on possible subsequent growth, and the timing should be determined in consultation with the team. Whenever possible, orthognathic surgery should be delayed until physical maturation is essentially completed. Earlier surgery may be indicated when there are serious concerns regarding a compromised air way, jaw function, speech, or psychosocial adjustment. However, the patient and family must understand that additional procedures may be required to optimize the outcome.

- If mandibular ankylosis is present, surgical release should be considered as soon as the condition is diagnosed. Both surgical intervention and subsequent physical therapy may be necessary to facilitate mandibular development, to improve the airway, or to ameliorate feeding difficulties.

- In the case of surgical procedures that may alter dental occlusion, model surgery and prediction tracings should be completed in the treatment planning process.

Dental Care

Dentistry

Patients with craniofacial anomalies require dental services as a direct result of the medical condition and as an integral part of the habilitative process. Due to the often complex nature, patients are generally best treated by referral to a pediatric dentist.

Provision of dental services for these patients includes not only primary care but routine maintenance throughout life. Dental care should occur within six months of the eruption of the first tooth and no later than twelve months of age and continues throughout life. It includes dental examinations, caries control, and preventive, restorative, and prosthetic dental treatment as needed. Patients should be closely monitored for

periodontal disease, anomalies of the dentition and disturbed eruption. Prosthetic appliances in the form of an obturator to close fistulae or a speech appliance for velopharyngeal insufficiency may be indicated in some situations.

Orthodontic Services

Patients with craniofacial anomalies require orthodontic services as a direct result of the medical condition and as an integral part of the habilitative process. Treatment often takes place in phases which may include treatment in infancy, the primary dentition, the transitional dentition, and the permanent dentition. The skeletal and dental components should therefore be regularly evaluated to see if a malocclusion is present or developing. Diagnosis and treatment planning requires a variety of diagnostic records as well as clinical examination. Records are obtained in a serial fashion to monitor dentofacial growth and development as well as the results of ongoing treatment. When indicated, orthodontic treatment prepares a patient for alveolar bone grafting of the cleft maxilla, for correcting malocclusions and for preparation of jaw surgery. In summary, orthodontic care may include primary orthopedic treatment in infancy and can extend through adulthood.

- Dental films, cephalometric radiographs, photographs and computer imaging as indicated should be utilized to evaluate and monitor dental and facial growth and development.

- For patients at risk for developing malocclusion or maxillary-mandibular discrepancy, diagnostic records including properly occluded dental study models should be collected at appropriate intervals.

- As the primary dentition erupts, each team evaluation should include a dental examination and referral to appropriate providers for caries control, preventive measures and restorative dental treatment, and space management if such services are not being provided.

- Before the primary dentition is completed, the skeletal and dental components should be evaluated to determine if a malocclusion is present or developing.

- Depending upon the goals to be accomplished, and also upon the age at which the patient is first seen, orthodontic management of malocclusion may be performed in the primary, mixed or permanent dentition. In some cases, orthodontic treatment may be necessary in all three stages.

- While continuous active orthodontic treatment from early mixed dentition to permanent dentition should be avoided, each stage of therapy may be followed by orthodontic retention and regular observation; the orthodontic retention period for the permanent dentition may extend into adulthood.

- For some patients with craniofacial anomalies, functional orthodontic appliances may be indicated.

- For patients with craniofacial anomalies, orthodontic treatment may be needed in conjunction with surgical correction (and/or distraction osteogenesis) of the facial deformity.

- Congenitally missing teeth may be replaced with a removable appliance, fixed restorative bridgework, or osseointegrated implants.

- Patients should be closely monitored for periodontal disease.

- Prosthetic obturation of palatal fistulae may be necessary in some patients.

- A prosthetic speech appliance may be used to treat velopharyngeal inadequacy in some patients.

Genetic/Dysmorphology Services

A comprehensive clinical genetic evaluation is a key component in the management of patients with congenital craniofacial anomalies and should include (1) diagnosis, (2) recurrence risk counseling, and (3) counseling regarding prognosis. Complex syndromes involving craniofacial anomalies may not fully express clinical manifestations that can be recognized in the first year of life. Thus, genetic screening and follow-up evaluations will be necessary for some patients until puberty. Patients who are first seen by the team at later ages should also be evaluated.

- Prenatal ultrasound will often detect cleft lip with or without cleft palate. Isolated cleft palate is rarely identified by ultrasound. A timely referral to specialists experienced in diagnosis, management and treatment of children with these and related conditions should be made.

- Indications for referral for a complete genetic evaluation include, but are not limited to, (a) positive family history; (b) prenatal growth deficiency; (c) unexplained postnatal growth deficiency; (d) developmental delay or mental retardation; (e) associated major malformations and/or disorders; (f) associated minor

malformations and/or disorders inconsistent with the genetic background; (g) family request; and (h) recognized genetic diagnosis.

- For families who live in areas which are geographically remote, the team should arrange for referral to an accessible source where genetic services can be provided, and should encourage the family to follow through on the referral.

- Personal genetic counseling should be offered to the maturing adolescent.

Nursing Care

Complex interdisciplinary management for individuals with congenital craniofacial anomalies requires a high level of ongoing coordination of services. The patient and family need appropriate information to understand the rationale for, and implications of, such management. Nursing assessment, interventions, and ongoing follow-up evaluations are integral to the long term care needs of the child or individual with congenital craniofacial anomalies and family. Services for the patient and family include:

- Feeding assessments, interventional teaching, and follow-up of nutritional and growth assessments.

- Serving as role models of acceptance and nurturance for the patient and family.

- Preparation of patients and families for what to expect when either in-patient or out-patient surgical procedures are scheduled. Information should be provided on pre- and postoperative feeding, the rationale for the use of restraints, special positioning and equipment, wound care, skin management, activity restriction, anticipated outcome or general status immediately following surgery, and the necessity for, and timing of, postoperative examinations. Instructions must be given in a manner that assures understanding on the part of the family and other caregivers.

In addition to the direct nursing services provided to patients and families, members of the craniofacial team bear the responsibility for education of hospital and community nurses in feeding and other aspects of the special care required by children with craniofacial anomalies.

- Ongoing educational programs for, and consistent liaison with, the nursing staff of hospitals in the community as well as in remote locations improve patient care and facilitate timely referrals for interdisciplinary patient management.

- In addition to emphasizing procedures necessary for providing special care, instructional programs for nurses should stress the role of nurses as models of acceptance and nurturance in their interaction with patients and families.

- Hospital nurses should be instructed in postoperative care, e.g., arm restraints, feeding and hydration, air way maintenance, pain management, surgical site protection, patient and family adjustment, and instructions to be given to the family for home care.

Otolaryngologic Care

Comprehensive care of children with craniofacial anomalies typically requires long-term monitoring of the ears, nose, and throat due to the prevalence of ear disease, ear malformations, and upper airway problems.

- Physical examination of the ears should be provided on a regular basis, beginning within the first six months of life and continue through adolescence.

- Treatment of middle ear disease may include use of antibiotics, myringotomies with insertion of tympanotomy tubes, tympanoplasties, gel foam patches, removal of cholesteatomas, mastoidectomies, and middle ear reconstruction.

- Any child with middle ear disease should be carefully followed during and after treatment to ensure a successful outcome and to be sure that tympanotomy tubes are removed if necessary.

- Although some otolaryngologic operative procedures such as myringotomies may be classified as minor procedures, the potential psychological impact on the child and family attendant upon any surgical procedure must be taken into consideration, particularly when the child is subjected to repeated procedures. All procedures should be preceded by appropriate exchange of information with the patient and family, and every attempt made to allay fears regarding effects of anesthesia, the immediate post-operative course, post-operative precautions, etc.

- Sequential airway assessments may be required to differentiate anatomical causes of airway difficulties from other causes, e.g., allergies. Such assessments may require endoscopy, radiologic studies, airflow studies, CT scans, MRI's, and polysomnography.

- Structural and functional laryngeal problems may exist in these patients, and may require medical as well as surgical treatment.

- An adenoidectomy and/or tonsillectomy as well as other oropharyngeal (tongue reductions, mandibular distraction, etc.) And laryngotracheal procedures may be indicated if the child is experiencing sleep apnea or other signs of airway obstruction. However, the team should provide a speech evaluation and assessment of the velopharyngeal mechanism prior to any decision to perform such a procedure.

Pediatric Care

Pediatric care provided within the context of the team is fundamental in assuring that the health needs of the child with craniofacial anomalies are fully identified and appropriately treated.

- A primary care physician should be identified for each child, and should become an extended member of the team.

- Physical examinations should be provided on a regular basis within the context of the team.

- Parental questions regarding health issues should be addressed.

- Parental understanding of the child's health needs and of the team treatment plan should be monitored.

- When special needs are identified, referral to appropriate specialists should be made in cooperation with the primary physician. Family follow-through on these referrals should be monitored.

- Frequent monitoring is required for children who may be at risk for growth failure, delayed development, abuse and neglect, or any other significant problem.

- The child's health status should be evaluated prior to any surgical procedures that are planned.

Psychological and Social Services

The accomplishment of the goals of treatment of the patient with craniofacial anomalies requires periodic assessment of the psychosocial needs of both the patient and the family. The psychosocial interviewer may come from the ranks of professionals such as those in social work, psychology, pediatrics, nursing, and psychiatry. However, psychological tests must be administered and interpreted under the supervision of a licensed psychologist, preferably a person familiar with craniofacial anomalies and related speech and hearing disorders.

- Psychosocial screening interviews should be conducted

periodically to assess parental competence and nurturance, child management skills, parent-child relationships, and the emotional and behavioral adjustment of the child. The high rate of learning disorders in children with craniofacial conditions requires that each child be screened for potential learning disorders beginning in infancy until cognitive competence has been established. Each family should receive or be referred for psychological evaluation, and, as appropriate, intervention when possible problems are identified through the screening process.

- Parents should receive guidance regarding such problems as behavior management, teasing, rejection by other family members, public attitudes, fear of and expectations from surgical procedures, and emotional adaptation to treatment.

- Screening evaluations should be conducted to identify possible problems in the child's cognitive development, behavior, self concept, educational progress, and psychosocial development. The screening evaluations should be conducted periodically, beginning in infancy and continuing through adolescence. When problems are suspected or identified in these areas, the child should receive or be referred for formal developmental/cognitive evaluations, guidance, counseling, or other assistance as needed.

- When there is concern for possible developmental delay, repeated psychological evaluations are necessary to facilitate appropriate program planning and prevent inappropriate labeling of the child.

- Information about learning performance, through liaison with schools, should be obtained periodically. When problems are suspected or identified, arrangements should be made for cognitive and educational assessments.

- Children who have craniofacial anomalies may benefit from contacts with other children who have similar conditions. The team should facilitate contact with other children and their families through support groups and networking.

- Social skills training programs should be available to help children and adolescents learn how to handle stressful social situations.

- As they mature, children should be given information about their craniofacial anomaly, and should be permitted and encouraged to become active participants in treatment planning. All care providers should be sensitive to how treatment discussions can be perceived by children, and should do everything possible to ensure that the child understands the treatment plan as much as

possible. Towards this end, it is helpful for the team to ensure that each child has someone who will listen to his/her fears, concerns, and opinions regarding treatment.

- Referrals for vocational training and guidance should be provided for adolescents, as appropriate.

Speech-Language Pathology Services

Children who have craniofacial anomalies are at high risk for speech-language disorders. Evaluation of speech and language development provides information that is needed by the team in planning of treatment, particularly surgical and dental management. Further, information about the patient's speech and language is important in the assessment of the outcome of treatment. Speech-language evaluations should occur often enough to assure adequate documentation of each child's progress and to develop appropriate recommendations for intervention.

- Each child and family should be seen for discussion of normal speech and language development and assessment of pre-linguistic speech-language development before or by six months of age.

- When the development of speech and language skills is not at an age-appropriate or developmentally appropriate level or when early speech productions are deviant, arrangements should be made for an early speech-language intervention program to facilitate speech sound development, provide language stimulation, and establish a home program to be carried out by parents and other care providers.

- With the possible exception of children with cleft lip only, speech-language evaluations with appropriate documentation should be conducted for each child at least twice during the first two years of life and at least annually thereafter until the age of six years.

- After the age of six years, even if speech-language development has been appropriate and no problems are noted, screenings should take place annually until after adenoid involution, and at least every two years thereafter until dental and skeletal maturity are reached.

- For children with problems in speech and language development and for those in whom the basis for continuing velopharyngeal inadequacy (VPI) cannot be definitively determined, re-evaluations should take place as often as deemed necessary by members of the interdisciplinary team in consultation with local care providers.

- Speech evaluations, conducted as part of a team visit should always include perceptual assessment of speech articulation, speech resonance, and voice.

- If articulation is deviant and characterized by maladaptive compensatory misarticulation errors associated with cleft palate, speech therapy may result in positive changes in velopharyngeal closure.

- Speech evaluations are necessary pre- and post-treatment to determine candidacy for, and outcomes of, surgical, behavioral and/or prosthetic management of the velopharyngeal system

- For patients with craniofacial anomalies who are candidates for orthognathic surgery, pre- and postoperative perceptual speech evaluations are necessary.

- Instrumental assessment of velopharyngeal function is required for all patients with resonance disorders, audible nasal air emission, or both. Procedures may include multiview videofluoroscopy, nasopharyngoscopy, and, at times, aerodynamic measures and nasometric studies, all of which should be conducted by or with the participation of the team speech-language pathologist.

- When voice is deviant, direct imaging of the larynx is necessary prior to initiating voice therapy.

- Remedial speech-language therapy will be needed for some patients with craniofacial anomalies.

- Biofeedback therapy may be useful in treating some patients with velopharyngeal dysfunction.

- Blowing exercises and oral-motor therapy are not useful in treating velopharyngeal dysfunction.

Quality Management

The quality of care for patients with craniofacial anomalies and related disorders must be carefully monitored by the team providing diagnosis, treatment planning and treatment services. This requires (1) longitudinal assessments of the outcomes of treatment, (2) periodic team review of the clinical outcome data, and (3) team adaptation of treatment procedures when clinical outcome assessments do not reach referenced criteria.

Revisions of Clinical Practices

The clinical practices presented in this document reflect current

knowledge and experience. Changes in these practices will be guided by advances in technology and research, including data on clinical outcome. Thus, timely review and revision of this document will be necessary.

APPENDIX

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