Management of Dental Patients with Special Health Care Needs

Latest Revision

2016

Purpose

The American Academy of Pediatric Dentistry (**AAPD**) recognizes that providing both primary and comprehensive preventive and therapeutic oral health care to individuals with special health care needs (**SHCN**) is an integral part of the specialty of pediatric dentistry.[1] The AAPD values the unique qualities of each person and the need to ensure maximal health attainment for all, regardless of developmental disability or other special health care needs. These recommendations were intended to educate health care providers, parents, and ancillary organizations about the management of oral health care needs particular to individuals with SHCN rather than provide specific treatment recommendations for oral conditions.

Methods

Recommendations on the management of dental patients with SHCN were developed by the Council on Clinical Affairs and adopted in 2004. This document is a revision of the previous version, last revised in 2012. This update is based on a review of the current dental and medical literature related to individuals with SHCN. An search was conducted via PubMed®/MEDLINE using the terms: special needs, disability, disabled patients/persons/children, handicapped patients, dentistry, dental care, and oral health; fields: all; limits: within the last 10 years, human, English, and clinical trials. Papers for review were chosen from the resultant list of articles and from references within selected articles. When data did not appear sufficient or were inconclusive, recommendations were based on expertand/or consensus opinion by experienced researchers and clinicians, including papers and workshop reports from the AAPD-sponsored symposium "Lifetime Oral Health Care for Patients with Special Needs" (Chicago, Ill.; November, 2006).[2]

Background

The AAPD defines special health care needs as "any physical, developmental, mental, sensory, behavioral, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention, and/or use of specialized services or programs. The condition may be congenital, developmental, or acquired through disease, trauma, or environmental cause and may impose limitations in performing daily self-maintenance activities or substantial limitations in a major life activity. Health care for individuals with special needs requires specialized knowledge, as well as increased awareness and attention, adaptation, and accommodative measures beyond what are considered routine."[3]

Individuals with SHCN may be at an increased risk for oral diseases throughout their lifetime.[2,4-6] Oral diseases can have a direct and devastating impact on the health and quality of life of those with certain systemic health problems or conditions. Patients with compromised immunity (e.g., leukemia or other malignancies, human immunodeficiency virus) or cardiac conditions associated with endocarditis may be especially vulnerable to the effects of oral diseases.[7] Patients with mental, developmental, or physical disabilities who do not have the ability to understand, assume responsibility for, or cooperate with preventive oral health practices are susceptible as well.[8] Oral health is an inseparable part of general health and well-being.[4]

SHCN also includes disorders or conditions which manifest only in the orofacial complex (e.g., amelogenesis imperfecta, dentinogenesis imperfecta, cleft lip/palate, oral cancer). While these patients may not exhibit the same physical or communicative limitations of other patients with SHCN, their needs are unique, impact their overall health, and require oral health care of a specialized nature.

According to the U.S. Census Bureau, approximately 37.9 million Americans have a disability, with about two-thirds of these individuals having a severe disability.[9] The proportion of children in the U.S. with SHCN is estimated to be 18 percent, approximately 12.5 million.[10] Because of improvements in medical care, patients with SHCN will continue to grow in number; many of the formerly acute and fatal diagnoses have become chronic and manageable conditions. The Americans with Disabilities Act (**AwDA**) defines the dental office as a place of public accommodation.[11] Thus, dentists are obligated to be familiar with these regulations and ensure compliance. Failure to accommodate patients with SHCN could be considered discrimination and a violation of federal and/or state

ABBREVIATIONS

AAPD: American Academy of Pediatric Dentistry. **AwDA:** Americans with Disabilities Act. **HIPAA:** Health Insurance Portability and Accountability Act. **SHCN:** Special health care needs.

law. Regulations require practitioners to provide physical access to an office (e.g., wheelchair ramps, disabled-parking spaces); however, individuals with SHCN can face many barriers to obtaining oral health care.

Families with SHCN children experience much higher expenditures than required for healthy children. Because of the unmet dental care needs of individuals with SHCN, emphasis on a dental home and comprehensive, coordinated services should be established.[11,12] Optimal health of children is more likely to be achieved with access to comprehensive health care benefits.[13] Financing and reimbursement have been cited as common barriers for medically necessary oral health care.[14,15] Insurance plays an important role for families with children who have SHCN, but it still provides incomplete protection.[16-18] Furthermore, as children with disabilities reach adult-hood, health insurance coverage may be restricted.[17,19,20]

Many individuals with SHCN rely on government funding to pay for medical and dental care and lack adequate access to private insurance for health care services.[19] Lack of preventive and timely therapeutic care may increase the need for costly care and exacerbate systemic health issues.[10]

Nonfinancial barriers such as language and psychosocial, structural, and cultural considerations may interfere with access to oral health care.[18] Effective communication is essential and, for hearing impaired patients/parents, can be accomplished through a variety of methods including interpreters, written materials, and lip-reading. Psychosocial factors associated with access for patients with SHCN include oral health beliefs, norms of caregiver responsibility, and past dental experience of the caregiver. Structural barriers include transportation, school absence policies, discriminatory treatment, and difficulty locating providers who accept Medicaid.[14] Community-based health services, with educational and social programs, may assist dentists and their patients with SHCN.[21]

Priorities and attitudes can serve as impediments to oral care. Parental and physician lack of awareness and knowledge may hinder an individual with SHCN from seeking preventive dental care.[22] Other health conditions may seem more important than dental health, especially when the relationship between oral health and general health is not well understood.[23] Persons with SHCN patients may express a greater level of anxiety about dental care than those without a disability, which may adversely impact the frequency of dental visits and, subsequently, oral health.[24]

Pediatric dentists are concerned about decreased access to oral health care for patients with SHCN as they transition beyond the age of majority.[25] Finding a dental home for non-pediatric SHCN patients could be challenging. Pediatric hospitals, by imposing age restrictions, can create another barrier to care for these patients. This presents difficulties for pediatric dentists providing care to adult SHCN patients who have not yet transitioned to adult primary care. Some pediatric hospitals require dentists to be board certified, thus making it difficult for general dentists to obtain hospital privileges. Outpatient surgery centers and in office general anesthesia may be alternatives, although they may not be appropriate to treat patients with special needs due to medical complexity.[26]

Transitioning to a dentist who is knowledgeable and comfortable with adult oral health care needs often is difficult due to a lack of trained providers willing to accept the responsibility of caring for SHCN patients.[27,28] It should be noted that the Commission on Dental Accreditation of the American Dental Association introduced an accreditation standard requiring dental schools to ensure that curricular efforts are focused on educating their students on how to assess treatment needs of patients with SHCN.[29,30]

Recommendations

Scheduling appointments

The parent's/patient's initial contact with the dental practice allows both parties an opportunity to address the child's primary oral health needs and to confirm the appropriateness of scheduling an appointment with that particular practitioner. Along with the child's name, age, and chief complaint, the receptionist should determine the presence and nature of any SHCN and, when appropriate, the name(s) of the child's medical care provider(s). The office staff, under the guidance of the dentist, should determine the need for an increased length of appointment and/or additional auxiliary staff in order to accommodate the patient in an effective and efficient manner. The need for increased dentist and team time as well as customized services should be documented so the office staff is prepared to accommodate the patient's unique circumstances at each subsequent visit.[31]

When scheduling patients with SHCN, it is imperative that the dentist be familiar and comply with Health Insurance Portability and Accountability Act (**HIPAA**) and AwDA regulations applicable to dental practices.[32] HIPAA insures that the patient's privacy is protected and AwDA prevents discrimination on the basis of a disability.

Dental home

Patients with SHCN who have a dental home[33] are more likely to receive appropriate preventive and routine care. The dental home provides an opportunity to implement individualized preventive oral health practices and reduces the child's risk of preventable dental/oral disease.

When patients with SHCN reach adulthood, their oral health care needs may extend beyond the scope of the pediatric dentist's training. It is important to educate and prepare the patient and parent on the value of transitioning to a dentist who is knowledgeable in adult oral health needs. At a time agreed upon by the patient, parent, and pediatric dentist, the patient should be transitioned to a dentist knowledgeable and comfortable with managing that patient's specific health care needs. In cases where this is not possible or desired, the dental home can remain with the pediatric dentist and appropriate referrals for specialized dental care should be recommended when needed.[34]

Patient assessment

Familiarity with the patient's medical history is essential to decreasing the risk of aggravating a medical condition while rendering dental care. An accurate, comprehensive, and up-to-date medical history is necessary for correct diagnosis and effective treatment planning. Information regarding the chief complaint, history of present illness, medical conditions and/or illnesses, medical care providers, hospitalizations/surgeries, anesthetic experiences, current medications, allergies/sensitivities, immunization status, review of systems, family and social histories, and thorough dental history should be obtained.[35] As many children with SHCN may have sensory issues that can make the dental experience challenging, the dentist should include such considerations during the history intake and be prepared to modify the traditional delivery of dental care to address the child's unique needs. If the patient/parent is unable to provide accurate information, consultation with the caregiver or with the patient's physician may be required.

At each patient visit, the history should be consulted and updated. Recent medical attention for illness or injury, newly diagnosed medical conditions, and changes in medications should be documented. A written update should be obtained at each recall visit. Significant medical conditions should be identified in a conspicuous yet confidential manner in the patient's record.

Comprehensive head, neck, and oral examinations should be completed on all patients. A caries-risk assessment should be performed.[36] Caries-risk assessment provides a means of classifying caries risk at a point in time and, therefore, should be applied periodically to assess changes in an individual's risk status. The examination also should include assessments of trauma and periodontal risk. An individualized preventive program, including a dental recall schedule, should be recommended after evaluation of the patient's caries risk, oral health needs, and abilities.

A summary of the oral findings and specific treatment recommendations should be provided to the patient and parent/caregiver. When appropriate, the patient's other care providers (e.g., physicians, nurses, social workers) should be informed of any significant findings.

Medical consultations

The dentist should coordinate care via consultation with the patient's other care providers. When appropriate, the physician should be consulted regarding medications, sedation, general anesthesia, and special restrictions or preparations that may be required to ensure the safe delivery of oral health care. The dentist and staff always should be prepared to manage a medical emergency.

Patient communication

When treating patients with SHCN, similar to any other child, developmentally-appropriate communication is critical. Often, information provided by a parent or caregiver prior to the patient's visit can assist greatly in preparation for the appointment.[8] An attempt should be made to communicate directly with the patient and, when indicated, to supplement communication with gestures and augmentive methods of communication during the provision of dental care. A patient who does not communicate verbally may communicate in a variety of non-traditional ways. At times, a parent, family member, or caretaker may need to be present to facilitate communication and/or provide information that the patient cannot. According to the requirements of the AwDA, if attempts to communicate with a patient with SHCN/parent are unsuccessful because of a disability such as impaired hearing, the dentist must work with those individuals to establish an effective means of communications.[11]

Planning dental treatment

The process of developing a dental treatment plan typically progresses through several steps. Before a treatment plan can be developed and presented to the patient and/or caregiver, information regarding medical, physical, psychological, social, behavioral, and dental histories must be gathered[37] and clinical examination and any additional diagnostic procedures completed.

Informed consent

All patients must be able to provide signed informed consent for dental treatment or have someone present who legally can provide this service for them. Informed consent/assent must comply with state laws and, when applicable, institutional requirements. Informed consent should be well documented in the dental record through a signed and witnessed form.[38]

Behavior guidance

Behavior guidance of the patient with SHCN can be challenging. Because of dental anxiety or a lack of understanding of dental care, children with disabilities may exhibit resistant behaviors. These behaviors can interfere with the safe delivery of dental treatment. With the parent/caregiver's assistance, most patients with physical and mental disabilities can be managed in the dental office. Protective stabilization can be helpful in patients for whom traditional behavior guidance techniques are not adequate.[39] When protective stabilization is not feasible or effective, sedation or general anesthesia is the behavioral guidance armamentarium of choice. When in-office sedation/general anesthesia is not feasible or effective, an out-patient surgical care facility might be necessary.

Preventive strategies

Individuals with SHCN may be at increased risk for oral diseases; these diseases further jeopardize the patient's health.[3] Education of parents/caregivers is critical for ensuring appropriate and regular supervision of daily oral hygiene. The team of dental professionals should develop an individualized oral hygiene program that takes into account the unique disability of the patient. Brushing with a fluoridated dentifrice twice

daily should be emphasized to help prevent caries and gingivitis. If a patient's sensory issues cause the taste or texture of fluoridated toothpaste to be intolerable, a fluoridated mouth rinse may be applied with the toothbrush. Toothbrushes can be modified to enable individuals with physical disabilities to brush their own teeth. Electric toothbrushes and floss holders may improve patient compliance. Caregivers should provide the appropriate oral care when the patient is unable to do so adequately.

A non-cariogenic diet should be discussed for long term prevention of dental disease.[40] When a diet rich in carbohydrates is medically necessary (e.g., to increase weight gain), the dentist should provide strategies to mitigate the caries risk by altering frequency of and/or increasing preventive measures. As well, other oral side effects (e.g., xerostomia, gingival overgrowth) of medications should be reviewed.

Patients with SHCN may benefit from sealants. Sealants reduce the risk of caries in susceptible pits and fissures of primary and permanent teeth.[41] Topical fluorides may be indicated when caries risk is increased.[42] Interim therapeutic restoration (ITR),[43] using materials such as glass ionomers that release fluoride, may be useful as both preventive and therapeutic approaches in patients with SHCN.[41] In cases of gingivitis and periodontal disease, chlorhexidine mouth rinse may be useful. For patients who might swallow a rinse, a toothbrush can be used to apply the chlorhexidine. Patients having severe dental disease may need to be seen every two to three months or more often if indicated. Those patients with progressive periodontal disease should be referred to a periodontist for evaluation and treatment.

Preventive strategies for patients with SHCN should address traumatic injuries. This would include anticipatory guidance about risk of trauma (e.g., with seizure disorders or motor skills/coordination deficits), mouthguard fabrication, and what to do if dentoalveolar trauma occurs. Additionally, children with SHCN are more likely to be victims of physical abuse, sexual abuse, and neglect when compared to children without disabilities.[44] Craniofacial, head, face, and neck injuries occur in more than half of the cases of child abuse.[45] Because of this incidence, dentists need to be aware of signs of abuse and mandated reporting procedures.[44,45]

Barriers

Dentists should be familiar with community-based resources for patients with SHCN and encourage such assistance when appropriate. While local hospitals, public health facilities, rehabilitation services, or groups that advocate for those with SHCN can be valuable contacts to help the dentist/patient address language and cultural barriers, other community-based resources may offer support with financial or transportation considerations that prevent access to care.[34]

Patients with developmental or acquired orofacial conditions

The oral health care needs of patients with developmental or acquired orofacial conditions necessitate special considerations. While these individuals usually do not require longer appointments or advanced behavior guidance techniques commonly associated with children having SHCN, management of their oral conditions presents other unique challenges.[46] Developmental defects such as hereditary ectodermal dysplasia, where most teeth are missing or malformed, cause lifetime problems that can be devastating to children and adults.[4] From the first contact with the child and family, every effort must be made to assist the family in adjusting to and understanding the complexity of the anomaly and the related oral needs.[47] The dental practitioner must be sensitive to the psychosocial well-being of the patient, as well as the effects of the condition on growth, function, and appearance. Congenital oral conditions may entail therapeutic intervention of a protracted nature, timed to coincide with developmental milestones. Patients with conditions such as ectodermal dysplasia, epidermolysis bullosa, cleft lip/palate, and oral cancer frequently require an interdisciplinary team approach to their care. Coordinating delivery of services by the various health care providers can be crucial to successful treatment outcomes.

Patients with oral involvement of conditions such as osteogenesis imperfecta, ectodermal dysplasia, and epidermolysis bullosa often present with unique financial barriers. Although the oral manifestations are intrinsic to the genetic and congenital disorders, medical health benefits often do not provide for related professional oral health care. The distinction made by third party payors between congenital anomalies involving the orofacial complex and those involving other parts of the body is often arbitrary and without merit.[48] For children with hereditary hypodontia and/or oligodontia, removable or fixed prostheses (including complete dentures or over-dentures) and/or implants may be indicated.[49] Dentists should work with the insurance industry to recognize the medical indication and justification for such treatment in these cases.

Referrals

A patient may suffer progression of his/her oral disease if treatment is not provided because of age, behavior, inability to cooperate, disability, or medical status. Postponement or denial of care can result in unnecessary pain, discomfort, increased treatment needs and costs, unfavorable treatment experiences, and diminished oral health outcomes. Dentists have an obligation to act in an ethical manner in the care of patients.[50] Once the patient's needs are beyond the skills of the practitioner, the dentist should make necessary referrals in order to ensure the overall health of the patient.

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