Guideline on Management of Persons With Special Health Care Needs

Originating Council
Council on Clinical Affairs

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Purpose

The American Academy of Pediatric Dentistry (AAPD) recognizes that persons with special health care needs (SHCN) are an integral part of the specialty of pediatric dentistry. The AAPD values the unique qualities of each person and the need to ensure maximal health attainment for all, regardless of their developmental or other special health care needs. By developing these guidelines, the AAPD accepts its responsibility to assist the dental profession in meeting the unique oral health care concerns of this patient population. This guideline is intended to address management of oral health care particular to persons with SHCN rather than provide specific treatment recommendations for oral conditions.

Methods

This guideline is based on a review of the current dental and medical literature related to SHCN patients. A MEDLINE search was conducted using the terms "special needs", "disabled patients", "handicapped patients", "dentistry", and "oral health".

Background

The AAPD defines persons with special health care needs as individuals who "have a 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 developmental or acquired and may cause limitations in performing daily self-maintenance activities or substantial limitations in a major life activity. Health care for special needs patients is beyond that considered routine and requires specialized knowledge, increased awareness and attention, and accommodation."[1]

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

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

Currently, 56 million Americans have some type of disabling condition and 25 million Americans have a severe disability.[3] Due to improvements in medical care, SHCN patients will continue to grow in number; many of the formerly acute and fatal conditions have become chronic and manageable problems. Historically, many of these patients received care in nursing homes and state-operated institutions. Today, society's trend is to mainstream these individuals to traditional community-based centers, with many seeking care from private dental practitioners. The Americans with Disabilities Act (AwDA) defines the dental office as a place of public accommodation.[4] 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 law.

Although regulations require practitioners to provide physical accessibility to an office (eg, wheelchair ramps, handicapped-parking spaces), patients with SHCN can face many other barriers to obtaining oral health care. A common barrier is a lack of financial resources.[5] Individuals with SHCN rely more on government funding to pay for medical and dental care and generally lack adequate access to private insurance for health care services.[6,7] Lack of preventive and timely therapeutic care may increase the need for costly episodic care.[8] 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.

Nonfinancial barriers such as language and cultural considerations may interfere with access to oral health care.[9] 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. Community-based health services, with

educational and social programs, may assist dentists and their patients with SHCN.[9]

Priorities and attitudes can serve as impediments to oral care. Parental and primary physician lack of awareness and knowledge may limit a SHCN patient from seeking preventive dental care.[10] Other health conditions may seem more important than dental health, especially when the relationship between oral health and general health is not well understood. 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.[11] Limited transportation resources also impact access to care.

Pediatric dentists are concerned about decreased access to oral health care for SHCN patients as they transition beyond the age of majority. Pediatric hospitals, by imposing age restrictions, can create another barrier to care for these patients. 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.

Recommendations

Scheduling appointments

The parent's/patient's initial contact with the dental practice (usually via telephone) 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, also 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 a higher level of 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.

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.[4,12] 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[13] 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 SHCN patients reach adulthood, their oral health care needs may go beyond the scope of the pediatric dentist's training. It is important to educate and prepare the patient and parent/legal guardian 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/legal guardian, 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.[14]

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. 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 (CAT) should be performed.[15] CAT 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. 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 health care providers should be informed.

Medical consultations

The dentist should coordinate care via consultation with the patient's other care providers including physicians, nurses, and social workers. 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, an assessment of the patient's mental status or degree of intellectual functioning is critical in establishing good communication. Often, information provided by a parent or caregiver prior to the patient's visit can assist greatly in preparation for the appointment.[16] An effort should be made to communicate directly with the patient 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 the SHCN patient/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.[4]

Informed consent

All patients must be able to provide appropriate signed informed consent for dental treatment or have someone who legally can provide it 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.[17]

Behavior management

Behavior management of the patient with SHCN can be challenging. Demanding and resistant behaviors may be seen in the person with mental retardation and even in those with purely physical disabilities and normal mental function. 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 management techniques are not adequate.[17] When protective stabilization alone will not allow delivery of comprehensive oral health care, appropriate sedation or general anesthesia is the behavioral management armamentarium of choice. When in-office behavior management including sedation/general anesthesia is not feasible, a hospital or outpatient surgical care facility may be the most appropriate setting to provide treatment.

Preventive strategies

Individuals with SHCN are at increased risk for oral diseases; these diseases further jeopardize the patient's health.[2] Education of parents/caregivers is critical for ensuring appropriate and regular supervision of daily oral hygiene. Dental professionals should demonstrate oral hygiene techniques, including the proper positioning of the person with a disability. They also should stress the need to use a fluoridated dentifrice daily to help prevent caries and to brush and floss daily to prevent gingivitis. Toothbrushes can be modified to enable individuals with physical disabilities to brush their own teeth. Electric toothbrushes may improve patient compliance. Floss holders may be beneficial when it is difficult to place hands into the mouth. Caregivers should provide the appropriate oral care when the patient is unable to do so adequately.

Dietary counseling should be discussed for long term prevention of dental disease. Dentists should encourage a non-cariogenic diet and advise patients/parents about the high cariogenic potential of oral pediatric medications rich in sucrose and dietary supplements rich in carbohydrates. As well, other oral side effects (eg, 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.[18] Topical fluorides (eg, brush-on gels, mouth rinses, fluoride varnish, professional application during prophylaxis) may be indicated when caries risk is increased.[19] Alternative restorative treatment (ART), using materials such as glass ionomers that release fluoride, may be useful as both preventive and therapeutic approaches in patients with SHCN.[18,20] 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 2 to 3 months, or more often if indicated. Those patients with progressive periodontal disease should be referred to a periodontist for evaluation and treatment.

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.

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 management techniques commonly associated with SHCN patients, management of their oral conditions presents other unique challenges. 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.[2] From the first contact with the child and family, every effort must be made to assist the family in adjusting to the anomaly and the related oral needs.[21] 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.

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 unfair.[22] For children with hereditary hypodontia, removable or fixed prostheses (including complete dentures or overdentures) and/or implants may be indicated.[23] 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.[24] When the patient's needs are beyond the skills of the practitioner, the dentist should make appropriate referrals in order to ensure the overall health of the patient.

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