CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

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Oral Health Care for Children and Youth With Developmental Disabilities: Clinical Report

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Oral health is an essential component of overall health for all individuals. The oral health of children and youth with developmental disabilities (CYDD) involves unique characteristics and needs of which pediatricians and pediatric clinicians can be aware. Risk for oral disease in CYDD is multifactorial and includes underlying medical conditions, medications, and ability to participate in preventive oral health care and treatment, and lack of access to providers is common for this population despite being eligible for Medicaid. Pediatric clinicians are uniquely positioned to support the oral health needs of CYDD and their families through the medical home. This clinical report aims to inform pediatric clinicians about the unique oral health needs of CYDD. It provides guidance on assessing caries risk and periodontal status using structured screening instruments; understanding dental trauma, the role of diet and caries risk, trauma prevention, and malocclusion; and providing anticipatory guidance on oral hygiene that includes tooth brushing, use of fluoridated toothpaste, assessing community water fluoridation, advocating for a dental home by 1 year of age, and transition to adult dental care as part of adolescent health care. It also highlights special considerations for dental treatment rendered under sedation or general anesthesia that CYDD may need. Pediatric clinicians can help reduce risk of CYDD developing dental disease by understanding the unique needs of their patients and their barriers to accessing oral health care in their community, communicating with the child's dental home, and advocating for safe and accessible dental procedures.

INTRODUCTION

Children and youth with developmental disabilities (CYDD) often have complex health care needs as well as significant physical and cognitive

abstract

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impairments. Developmental disabilities usually manifest early in childhood and persist throughout the life course of the individual. They include impairments in physical, learning, language, and behavior areas.[1] This heterogeneous population is a subset of children and youth with special health care needs (CYSHCN). It includes, but is not limited to, individuals who may also have the comorbidities of attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), cerebral palsy, developmental delay, epilepsy, hydrocephalus, intellectual developmental disorder, neural tube defects, and syndromes such as Angelman syndrome, Down syndrome or trisomy 21, fragile X syndrome, or Williams syndrome. Oral health is an essential component of overall health for all individuals. CYDD are at increased risk for dental disease because of unique aspects of their medical conditions, the treatments associated with them, or both. As a group, CYDD are more likely to have unmet oral health care needs than typically developing children. The oral health needs of this population are increasing because CYDD are more likely to live longer into adulthood than in previous decades. Regardless of life span, oral health should be prioritized to improve systemic health and overall quality of life.

This clinical report aims to inform the pediatric clinician about the unique oral health needs of CYDD. It provides guidance on assessing their caries risk and periodontal status, understanding dental trauma, and addressing self-injurious behaviors (SIBs). It also highlights the special considerations for dental treatment rendered under sedation or general anesthesia (GA), which many of these individuals may need.

ACCESS TO CARE AND UTILIZATION

Utilization and Barriers

Dental care is one of the greatest unmet needs of CYDD.[2–9] One of the major challenges in understanding and addressing the prevalence and causes of unmet needs is nondescriptive or unspecific data. Research predominantly combines all children with special needs into one category, which makes it difficult to delineate those who have increased dental disease risk, those with barriers to accessing care, and those whose diagnoses significantly impact their oral health.[3]

Most CYDD are eligible for dental coverage under public insurance plans such as Medicaid; however, even children who are enrolled have unmet dental needs.[9] Studies specifically looking at the challenges faced by CYDD are lacking or they are often combined with other CYSHCNs. Studies of children enrolled in Medicaid show that CYSHCN received fewer preventive dental services than those without special health care needs,[10] and as many as 75% of CYSHCN did not access dental services in a year's time.[11] Even when CYSHCN used dental care services in the past year, families still reported unmet needs, indicating that dental utilization data may not adequately capture receiving all needed dental services.[4,12] More information is needed regarding what needs remain unmet.[8] For example, the difficulty may not be in finding a provider but rather in accessing medically necessary hospital-based dental services.[13] States with higher Medicaid payment for preventive dental care services predictably have higher utilization rates.[10] However, CYSHCN with private insurance coverage still struggle with unmet dental needs, especially those with more significant disabilities.[2,3,5,8]

Barriers to dental care for CYDD are numerous. These barriers include challenges finding providers with the skill set to meet the unique needs of children with disabilities, behavioral challenges, working with oral aversions, and the competing needs of medically complex children, such as their many medical and therapeutic appointments. They may also include factors beyond the individual's medical condition, such as inadequate transportation, geographic access, families not recognizing the importance of preventive care, and financial barriers, because of high out-of-pocket health care costs, high deductibles, or lack of insurance coverage (Table 1).[7,10,14] Existing barriers may be exacerbated by other social drivers of health. CYDD who are in foster or ordered kinship care often experience all these barriers, plus added the challenge of obtaining consent from the appropriate and legal decision maker.[15] Dental and medical providers can help caregivers navigate options for consent, which may include state agencies or social workers.

Coordinated Care

Children who used preventive medical care were more likely to use preventive dental care.[14] Having a physician or nurse who knows the child well and is attuned to oral health appears to be a protective factor in mitigating unmet dental needs.[2] Recommendations for pediatricians and other pediatric clinicians during routine office visits include conducting caries risk assessments, applying fluoride varnish as appropriate, and ensuring patients have a dental home or referring those who do not to a dentist.[16] A dental home exists in parallel with a medical home to provide comprehensive care and an ongoing relationship with the dental team; it is ideally established by 12 months of age.[17] Pediatric clinicians can also reinforce recommendations by dentists on the use of fluoridated toothpaste and counsel on strategies to reduce fermentable carbohydrate consumption.[3,18] Preschool and other early intervention programs for CYDD are another avenue through which young children with special needs can be connected with dental resources.[19]

Medically Necessary Care

Some CYDD may exhibit behavior that precludes them from being able to participate or cooperate in receipt of needed treatment. Therefore, sedation or GA may be

TABLE 1 Conceptual Framework for Identifiable Barriers and Potential Mitigation Strategies for Children With Intellectual and Developmental Disabilities (IDD)

	Examples of Barriers	Potential Mitigation of Barriers
Accessibility	Transportation; distance needed to travel to access services; difficulties with physical access to the building or dental chair	Ensure dental services are physically accessible with appropriate parking; educate on availability of transportation services
Availability	Difficulty finding providers willing to care for children with IDD; caregiver awareness of dental issues	Train more providers to see children with IDD; educate caregivers on oral health
Accommodation	Long waiting times for an appointment; wait times at the clinic; appointment length; lack of access to services such as sedation or general anesthesia	Enable providers to tailor services and work in multidisciplinary teams
Affordability	Financial barriers; lack of payment for providers' additional time needed because of behavior or care coordination; lack of dental professionals taking government-funded plans	Pay relative to time and cost; remove barriers to enrolling as a government-funded provider
Acceptability	Dental professionals lack of knowledge about children with IDD; apprehension of staff or providers	Train professionals to be knowledgeable about children with IDD
Appropriateness	Sensory sensitivities; caregiver concern about child's inability to cooperate; ability of provider to deliver a person-centered approach to care	Create person-centered care and appropriate modifications (eg, desensitization therapy) based on unique needs of child with IDD

Adapted from Ummer-Christian et al.[11]

needed to render medically necessary care. Medically necessary care is defined by the American Academy of Pediatric Dentistry (AAPD) as "the reasonable and essential diagnostic, preventive, and treatment services and follow-up care as determined by qualified health care providers in treating any condition, disease injury, or congenital or developmental malformation to promote optimal health, growth, and development."[20,21] The management and treatment of dental caries, periodontal disease, and congenital and acquired orofacial conditions are all medically necessary to the well-being of children. Difficulty finding facilities and anesthesia providers who are comfortable caring for children with behavioral or medical complexities can limit access to care. Furthermore, operating room time is a scarce resource, making it difficult for dentists who are willing and capable of providing care to CYDD.[22] CYDD may need to access medically necessary care more than once to address dental needs at different points in their life course. Payers can facilitate this by not restricting operating room access or limiting the number of times CYDD access the operating room. Pediatric clinicians can provide histories and physical examinations necessary for scheduling GA appointments and advocate for the availability of these services for CYDD.

Transition to Adult Dental Care

The challenges encountered by CYDD are magnified in adulthood. Transitioning to adult dental care can be challenging, with the greatest reported barrier being finding a general or family dentist who is comfortable caring for patients with special health care needs and who accepts Medicaid.[23] Pediatric dentists with specialized training in caring for CYDD may not be comfortable providing more complex procedures (eg, root canal therapy) on permanent teeth. There are fewer dentists trained in caring for adults with developmental disabilities than are needed,[24] although dentists with additional training were more likely to accept patients with developmental disabilities.[25] Furthermore, payment is a tremendous barrier for this patient population as payment under adult Medicaid for dental services is either unavailable, covers limited services, or is inconsistently funded by state legislatures. Even when adult dental Medicaid is available and funded, finding a dental provider who accepts it can be challenging.[24] Pediatric clinicians can assist dental providers during this critical period by providing medical records and including dental care as part of their overall adolescent transition plan to future primary care providers.

CARIES AND CARIES RISK

Epidemiology

About half of all people in the United States have experienced dental caries by the time they reach 18 years of age.[26] A carious lesion, or "tooth decay" is the result of prolonged acid attacks on the tooth's enamel surface, which eventually creates a hole ("a cavity"). Left untreated, this lesion can progress to cause pain and infection. Because the CYDD population is so heterogeneous, studies are inconsistent on their caries experience in relation to their typically developing peers, but it is usually found to be high. Studies of children with developmental disabilities,[27] ASD, cerebral palsy, congenital heart disease, and trisomy 21 all reported higher, but varied, caries prevalence when compared with typical children.[28] Additionally, studies of children with

intellectual disabilities reported higher rates of caries and periodontal disease.[11,29] Studies also suggest that CYDD have more untreated caries, more missing teeth as a result of caries, and fewer restored teeth.[30] Among noninstitutionalized US children and adolescents from 6 to 19 years of age, there was a lower prevalence of protective dental sealants in CYSHCN and documented higher burden of dental disease.[31] A tailored caries risk assessment can aid providers in addressing the individual's unique oral health care needs in relation to their condition.

Caries Risk Assessment

Risk factors for developing caries include a diet high in fermentable carbohydrate, poor plaque control, and inadequate fluoride exposure. CYDD are reported to have more risk factors including more plaque, poorer gingival health, and poorer oral hygiene than typically developing children.[30,32–35] Additionally, other biological and social drivers of oral health (eg, caregivers' caries history, socioeconomic status, family oral health literacy) may exacerbate this risk.[36] CYSHCN are a heterogenous group, so the presence of a developmental disability does not in and of itself explain caries risk; rather, it is multifactorial, involving biological, environmental, socioeconomic, and behavioral factors.[28] Caries risk is individually determined, and a preventive plan can be tailored to their unique needs. In the dental setting, caries risk guides the frequency of radiographic examinations and practitioner treatment decisions, including type of restoration. For pediatric medical providers, the oral health risk assessment tool from the American Academy of Pediatrics (AAP) can guide counseling and prioritize dental referrals.[37,38] Payers may consider providing payment to primary medical home providers for oral health risk assessments for CYDD.

CYDD may be at a higher caries risk secondary to factors inherent to their condition. Behavioral challenges may cause difficulty with home hygiene and dental visits; sensory sensitivities may lead to a preference for soft foods; neuromuscular defects may cause an inability to adequately clear the oral cavity after eating; and enamel defects may increase caries risk.[11,14,38] CYDD may also have additional risk factors related to the management of their condition, including the use of medications dosed in syrups for palatability, diminished salivary flow because of medication leading to xerostomia, and use of fermentable carbohydrate-containing foods for behavioral rewards and/or to promote weight gain.[14,38] Additionally, dietary behaviors such as having more than 4 sugar sweetened beverages per week was significantly associated with dental caries in CYSHCN.[39] Counseling on use of a fluoridated toothpaste and drinking fluoridated community water and in-office fluoride application may lower caries risk (see AAP clinical report "Fluoride Use in Caries Prevention in the Primary Care Setting").[40]

Caries in the primary dentition strongly predicted caries in the permanent dentition in all children, again reinforcing the need for early preventive dental care.[28] Meta-analyses reveal that toothbrushing with fluoridated toothpaste is effective in preventing caries in CYDD.[41]

PERIODONTAL HEALTH

Periodontal health is an important component of overall oral health.[42] The periodontium consists of the gingiva, supporting ligament structures, and alveolar bone surrounding the teeth. Bacteria-mediated inflammation of the gingiva is called gingivitis, which can result in red, swollen, or bleeding gingival tissues. Untreated gingivitis can lead to an immune-mediated inflammatory response called periodontitis, which destroys hard and soft tissue support structures.

Clinical signs of periodontal disease in pediatric and adolescent populations can be measured by assessing visible changes to the color of the gingiva (with more red hues indicating more severe disease), presence of bleeding, and gingival recession and by measuring how attached the soft tissue is to the dental structures using small probes. Clinical signs of gingival disease in populations with special health care needs are common and have been reported to range in prevalence from 60%[43] to 87%.[44]

Prevention

The most effective way to prevent periodontal disease is to disrupt the formation of bacterial films known as plaque on the tooth and gingival surfaces. This preventive measure can be accomplished by regular toothbrushing with a soft-bristled brush and fluoride containing toothpaste and flossing. Caregivers typically oversee young children until they can achieve adequate oral hygiene, but CYDD may have additional barriers that require long-term supervision. These barriers include issues with manual dexterity, possessing the necessary cognitive skills to perform and understand the need for oral hygiene, and associated conditions such as oral sensory sensitivity, behavioral conditions, or a hypersensitive gag reflex.[45,46]

Specially adapted toothbrushes (eg, those with larger handles or multiple heads) may improve both independent and assisted brushing.[41] A Cochrane review of oral hygiene interventions for people with intellectual disabilities found that toothbrushing assisted by caregivers who were trained was more effective than self-hygiene in reducing plaque over 6 to 12 months. No differences were found between using a manual versus an electric toothbrush.[47] In addition to mechanical removal of plaque, rinsing with chlorohexidine may be a useful adjunct in cases of mild gingivitis. Chlorohexidine, an antiseptic, can lower the bacterial load and is effective when used from 4 to 6 weeks or up to 6 months.[48] Long-term use of

chlorohexidine, however, can result in tooth staining, calculus formation, and dysgeusia (unpleasant altered sense of taste).

Dental plaque that is not regularly removed becomes a scaffolding to form dental calculus (tartar). Calcium and phosphate ions expressed from the salivary glands form a precipitate on the dental plaque that adheres to the teeth and can only be removed by a professional dental cleaning called scaling.[49] CYDD may have an increased buildup of calculus because of a combination of inadequate plaque removal, increased salivary volume, or increased concentration of salivary ions.

Calculus is very common in individuals who do not eat by mouth and rely on a gastrostomy tube (g-tube) or other feeding device.[50] Their oral biofilms may remain undisturbed as the act of mastication itself removes some plaque from the dental hard tissues. In some cases, a g-tube may be treating an underlying oral aversion that also makes toothbrushing difficult. Although children who rely on tube feedings have increased calculus, they have fewer caries than other CYDD, because they are not exposed to fermentable carbohydrates.[51] Calculus that can be safely removed by a dental professional may lower an individual's oral bacterial burden. Practitioners can also inquire whether families practice "social tasting" for tube-fed children, because frequent introduction of sugar-sweetened foods may increase their caries risk.

Periodontal Health and Respiratory Diseases

Bacteria implicated in periodontal disease are also factors in some respiratory diseases that CYDD may have as a comorbidity.[52] Professional removal of calculus may be challenging because of medical complexity or behavior, putting individuals at risk for aspiration of small or aerosolized particles of calculus, which can potentially cause aspiration pneumonitis and/or pneumonia. The calculus of children and youth who are tube fed was shown to contain more aspiration pneumonia-associated bacteria than CYSHCN who were not tube fed.[53] Prevention of calculus buildup can reduce this risk.[54] In one study, using a dual-action anticavity and antitartar toothpaste for children and youth who were tube fed versus an anticavity toothpaste alone resulted in a 68% decrease in calculus buildup.[55]

Gingival Overgrowth

Loss of the periodontium is cause for concern, but so is overgrowth of these structures. Multiple medications used by CYDD can cause gingival enlargement, making mastication and cleaning difficult. Drug-induced gingival overgrowth or hyperplasia is multifactorial and has been implicated in some classes of antiseizure medications (eg, phenytoin), immunosuppressants (eg, cyclosporin), and calcium channel blockers (eg, nifedipine).[56] The exact pathophysiology of this unintended side effect is unclear, but it is strongly mediated by plaque levels.[57] Initial treatment is nonsurgical and focuses on appropriate plaque control and/or addition of antibiotics.[58] Surgical treatment may be necessary if the initial treatment is unsuccessful, although recurrence can occur in more than a third of patients.[59]

MALOCCLUSION

CYDD commonly have orofacial structures or habits that contribute to developing malocclusions.[60] Malocclusions are defined as nonideal positioning of the jaws with or without nonideal positioning of the teeth. Some malocclusions are caused by genetic or environmental factors, and some are caused or exacerbated by neurologic status and oral habits, including mouth breathing, prolonged nonnutritive sucking or chewing, tongue posturing, and atypical swallowing.[61] Therapeutic devices such as continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BiPAP) machines have been reported to cause malocclusions secondary to midface hypoplasia if they have prolonged use during critical growth periods.[62]

Risk Factors for Malocclusions

Dysmorphic facial features that are present in some syndromes associated with developmental disabilities may cause malocclusions in both the anterior and posterior dentition. Examples of this include individuals with Au Kline syndrome, Williams syndrome, and orofacial-digital syndrome.[63–65] Anterior open bites are common in individuals with conditions such as cerebral palsy, trisomy 21, spina bifida, brachial arch disorders, and hydrocephalus.[66] Risk factors for an anterior open bite, in which the maxillary front teeth either significantly protrude over the mandibular teeth and/or do not cover them, leaving an open space, include pacifier use, presence of involuntary movements, use of central-acting medications (eg, antiseizure medications such as benzodiazepines), and habitual mouth breathing.[66]

Altered muscle tone can also contribute to malocclusions as the orofacial muscular complex is essential for exuding soft tissue balancing forces on the dentition to promote ideal alignment.[67] This alteration may be common in children with ASD or cerebral palsy.[68,39] Pressure from lips closed at rest is important for preventing malocclusions and for controlling chewing and swallowing. CYDD are more likely to have lips that do not come together, known as incompetent lip posturing.[69] Obligate mouth breathing may contribute to incompetent lip posturing and its sequalae.

Orthodontic Treatment of Malocclusions

Ideally, CYDD who have malocclusions would be treated orthodontically at the appropriate time. The cooperative ability needed for obtaining orthodontic records (eg,

scans, models, and radiographs) and placing appliances (eg, braces) is appreciably variable in this population. In one small study of orthodontic treatment, CYSHCN did not have any differences between number of appointments needed, length of time in braces, or posttreatment outcomes when compared with children who do not have special health care needs; CYSHCN did, however, need considerably more chair time at each appointment.[70] Other studies have also echoed the need for more chair time when working with CYSHCN with variably favorable posttreatment results.[71] For patients with limited ability to cooperate or participate in the dental office, sedation or GA may be contraindicated for routine orthodontic care because of the associated risks outweighing the benefits with repeated procedures. Additionally, most private and public insurance programs do not cover sedation or GA services to place and adjust appliances.

DENTAL TRAUMA

Dental trauma is common worldwide but takes on a special significance in individuals with developmental disabilities because of challenges with treatment.[72] CYDD have a higher incidence and prevalence of primary and permanent tooth injury than children without developmental disabilities.[73] Risk factors for increased dental trauma include a history of seizures, a diagnosis of ADHD, presence of hyperkinetic movements such as in cerebral palsy, use of psychotropic drugs, anterior open bite, lip incompetence, and the existence of SIBs.[73,74] With any trauma, the potential for child abuse ought to be assessed by clinicians (see AAP clinical report "Oral and Dental Aspects of Child Abuse and Neglect"[75]).

Trauma Risk

Anterior teeth are most at risk for traumatic dental injuries. An excessive overjet, in which the maxillary teeth protrude considerably forward from the mandibular teeth, is a risk factor for dental trauma.[76] An excessive overjet may also predispose an individual for lip incompetence, in which the lips do not fully cover and protect the anterior teeth. Children with some types of developmental disabilities are prone to excessive overjet and lip incompetence[77] and are, therefore, at increased risk for dental trauma. Trauma prevention during sports includes mouthguards and helmets, but these devices may not be suitable for sustained, everyday use in CYDD.

Management of Dental Trauma

Oral health professionals classify and manage dental trauma according to the International Association of Dental Traumatology Guidelines (www.iadt.org).[78–81] Additional information for pediatricians in managing dental trauma in the primary care setting is available in the AAP clinical report "Management of Dental Trauma in a Primary Care Setting."[82]

Depending on the type and extent of the injury, treatment can range from active monitoring of the injured teeth to splinting, to restoration with or without management of the pulpal tissues (including root canal therapy), to, in some cases, extraction.[83] Many treatment options require active cooperation from the patient to ensure safety and optimal outcomes, which may be difficult for some CYDD. Dental traumas that are true dental emergencies (eg, permanent tooth avulsion), which must be treated promptly to ensure the best clinical results, are most at risk for poor outcomes if the child or youth is unable to participate in urgent care.[80]

Emergency Management of Dental Trauma

Emergency management of significant dental injuries in CYDD may require sedation with oral medications or treatment under GA. Other behavior modification techniques, such as protective stabilization to provide emergency treatment, are inadequate to provide the prescribed treatment and unfavorable to parents of CYDD.[84] Most private dental offices, even when they provide procedural sedation as part of routine care, are not equipped or prepared to do so on an emergency basis. Procedural sedation for treatment of dental injuries in a hospital emergency department, if and when a dentist is available, is not without complications. A study of healthy children with orofacial dental injuries presenting to an Israeli pediatric emergency department that used oral sedation for treatment found that a third of the patients had sedation adverse events that required intervention.[85] Because of the risks of oral conscious sedation and the need for substantial cooperation for treatment, CYDD presenting with orofacial injuries may need emergency access to GA. Pediatric medical providers can help advocate for this medically necessary service for this population at high risk of oral trauma.

All dental traumas require some amount of follow-up, which is dependent on the type and severity of the dental injury. Some injuries will require subsequent treatments and retreatments after the initial therapy. Medical providers can aid the dental team during the follow-up period by observing changes in signs and symptoms of the original injury.

BRUXISM

Bruxism, or the voluntary or involuntary clenching or grinding of teeth, is common in CYDD. It can happen while awake or asleep and has a reported prevalence between 23% and 69.4% in CYDD.[86,87] Reports of more severe bruxism in CYSHCN is related to a more negatively reported oral health-related quality of life.[88] The exact pathophysiology is unknown, but the current theory poses that there is an imbalance between inhibitory and excitatory neurons,

resulting in dyskinesia.[89] Diagnosis of bruxism comes through self- or caregiver report with or without a clinical examination to assess the presence of wear facets or chipped teeth. Risk factors associated with bruxism in CYDD include being female, a comorbidity of gastroesophageal reflux disease, and presence of central nervous system-mediated involuntary movements.[90]

Initial treatment of bruxism focuses on treating any underlying anxiety and/or depression and improving sleep quality. There are limited studies on pharmacologic management, but use of hydroxyzine, an ^{1}H receptor agonist, was shown to improve sleep bruxism over a placebo.[91] The effect of botulinum toxin on bruxism has been studied, and its use is increasing but with inconclusive evidence of efficacy.[92,93] Use of orthodontic appliances to treat bruxism is questionable because bruxism is not caused by dental malocclusions and is centrally mediated, not peripherally mediated.[94] Additionally, construction of appliances in this population is challenging because of behavioral ability, prevalence of malocclusions, growing dental arches, and difficulties in obtaining an accurate impression in the ideal centric occlusion.[95]

SELF-INJURIOUS BEHAVIOR

CYDD often have difficulty communicating their own pain and discomfort effectively. This can manifest as SIB, which consists of self-directed, repetitive actions that happen without injurious intent but can cause harm.[95] Examples of SIB often include biting, scratching, mouthing of objects or the hand, eye poking, and headbanging. In CYDD, these behaviors are often chronic and can occur in response to a specific triggering event or multiple events.[96–98]

The prevalence of SIB varies and is difficult to quantify. In studies of children with ASD, prevalence of SIB ranges from 26% to 50%.[99,100] The frequency of SIB does not vary between individuals with ASD and those with intellectual developmental disorder from all causes but tends to be higher among individuals with both ASD and intellectual and developmental disability (IDD).[96] Factors such as level of maternal education, public health insurance, and lower median household income are associated with a higher prevalence of SIB but race and ethnicity are not.[101,102]

A thorough medical and behavioral history with the caregiver is important in establishing possible causes. Specific questions to identify whether the behavior is new or an exacerbation of an existing SIB helps to narrow the diagnosis. Changes in behavior, aggravating or relieving factors, and antecedents to the SIB also provide important clues before conducting a physical examination. A multidisciplinary, team-based approach can be helpful to understand subtle clues and provide direction for intervention and ongoing care.

Risk Factors for SIB

Individual risk factors for SIB include severe to profound IDD, physical or sensory-related disability, communication challenges, genetic disorders, and severe ASD.[103–107] Low adaptive skills, poor sleep hygiene, gastrointestinal disorders, behavioral challenges, and avoidance of a patient's previously favorite activities are also commonly associated with SIB.[101] Rarely is there a single cause or a consistent, identifiable antecedent triggering the behavior, and pain elsewhere in the body may trigger SIB to the mouth and face. SIB negatively impacts the quality of life for the individual, family, and caregivers.[108,109]

When SIB occurs suddenly and without an identifiable antecedent or change in environment, it may be related to pain. SIB can be a method to manage the pain being experienced. Pain in the oral facial area can be attributable to lesions on the lips, gums, tongue, or teeth. It can also occur because of biting, scratching at the face, mouthing objects, head banging,[110,111] excessive drooling, self-extraction of teeth, or infection. Response to this pain can lead to further injuries to the lips, gums, buccal mucosa, tongue, periodontal tissues, and teeth. Intraoral lesions include ulcerations of the mucosa and hematomas.[112] Pain and subsequent SIB can also occur alongside gastroesophageal reflux disease, with related tooth erosion with chronic hand mouthing.

Management of SIB

The approach to the management of oral SIB starts with a thorough medical, developmental, and behavioral history. Emphasis can be given to the severity, frequency, aggravating and relieving factors, antecedents, and mode of SIB to better identify factors that can inform treatment. Nonpharmacologic interventions include desensitization interventions as well as intraoral dental appliances that can impede the ability to cause self-injury.[113] Removable splints or appliances are typically made of fixed acrylic or softer material that is kept in place with headgear. The use of such devices is always time limited.[114–116] Tooth extraction is the last resort to prevent chronic injury to the oral mucosa.[117]

Evidence for pharmacologic options to improve SIB is still limited, and use ought to be viewed as time limited. Medications may include atypical antipsychotics or α-adrenergic agonists.[118] Clinicians considering medication management of SIB can carefully examine the potential risks and benefits, dosing, and drug interactions and have a monitoring plan before prescribing. The use of medications may be part of the larger context of shared decision-making with the family and a comprehensive treatment plan that includes nonpharmacologic interventions. Discontinuation of medications needs to be considered when they are not effective or when behaviors have significantly improved.

ADAPTIVE OR CONCURRING BEHAVIORS

Biting on Nonfood Objects

Some CYDD have oral habits that include chewing or biting on nonnutritive objects. These objects, also known as sensory chewies, chew toys, or "chewelry," may be used independently or as part of prescribed occupational therapy. Chewing may provide the individual with a calming and focusing response[119] that can reduce stress and anxiety. Chewing on nonfood objects may also divert a CYDD from chewing on less desirable objects such as clothing, hands, fingers, or found items.

Most chewing objects on the market are made of food grade silicone, but some may have US Food and Drug Administration (FDA)-approved additives to make them more palatable or stronger to withstand forceful biting.[120] Objects manufactured for the purpose of sensory chewing are generally thought to be safe for the developing dentition. Intermittent chewing on objects will generally not lead to the development of malocclusions unless nonnutritive sucking behaviors are also present.

Some CYDD, especially those with developmental delay, may exhibit pica or compulsive ingestion of nonnutritive or nonfood items. The etiology of pica is poorly understood, but it may be a result of nutritional deficiency or psychological response.[121] Clinicians can counsel that some nonfood items may cause dental injury.[122]

Young children are at risk for postoperative lip or cheek biting from the effects of local anesthesia.[123] CYDD may be at higher risk because of their sensory perception or because they may not be able to understand postoperative instructions or be closely monitored by a caregiver. Phentolamine mesylate may be administered to reduce the duration of oral-soft tissue local anesthesia.[124] Treatment of postoperative lip or cheek biting includes palliative care with over-the-counter analgesics and maintaining optimal oral hygiene in the area, which may include swabbing the ulceration with chlorhexidine gluconate (0.12%). Caregivers can follow-up with the child's dentist to monitor the lesion and make plans for future use of local anesthesia during dental visits.

Sialorrhea

Sialorrhea, or excessive drooling, is a common oromotor dysfunction in CYDD, particularly those with cerebral palsy. In one population study from Northern Ireland, 22% of children with cerebral palsy had excessive drooling, which was significantly related to their overall gross motor function abilities.[125] Sialorrhea does not appear to be attributable to an excess production or flow rate, but rather, saliva tends to pool and appear excessive because of poor oromotor control.[126] Sialorrhea is associated with difficulties swallowing, poor self-esteem, dysarthria, and fortunately, lower caries risk.[127–129] Excess saliva can cause perioral skin breakdown and increase the risk for candida infections.[130] Caregivers can report severity and frequency of drooling using validated questionnaires, such as the Drooling Impact Scale or modified Teacher's Drooling Scale.[131,132]

Treatment of sialorrhea can include pharmacologic or surgical interventions. Anticholinergic medications can block receptors that stimulate salivary production. In a study of the effectiveness of 3 common anticholinergic medications (benzhexol hydrochloride, glycopyrrolate, and scopolamine), glycopyrrolate showed the best improvement in drooling with the least amount of side effects.[133] Because other commonly used medications by CYDD may have similar anticholinergic properties, a thorough medication review with discussion of side effects may be helpful in evaluating the risks and benefits of this type of therapy. Injection of botulinum neurotoxin A into salivary glands appears to work for most children (70%) and may provide positive temporary improvement.[134] For moderate or severe drooling that is not responsive to pharmacologic therapy or for individuals that suffer unpleasant side effects, surgery may be indicated. This most commonly involves bilateral relocation of the submandibular ducts to the base of the tongue and removal of the submandibular glands to prevent ranula (major salivary gland cyst) formation.[135] In one study of 72 children who underwent the procedure, the majority had a significant reduction in the amount of drooling and need for caregiver intervention and positive impact on social interactions.[136] For individuals whose saliva pools in the posterior of the mouth, surgical interventions may be contraindicated because of an increased aspiration risk.

ASSESSMENT AND CONTROL OF PAIN

Oral pain can significantly impact health-related quality of life.[137] Identifying the source, measuring the intensity, and finding relief for the pain is important for all individuals but may be difficult for CYDD. A thorough oral examination is the first step to identifying the pain's etiology because oral pain may be physiologic or pathologic.

Diagnosis and Management of Physiologic Oral Pain

Age-appropriate tooth eruption (ie, "teething") can cause pain as the primary teeth erupt between the ages of 6 months and 3 years. Pain may also occur as the adult dentition emerges from ages 6 to 13 years. During this time, molars erupt into the oral cavity and succedaneous teeth replace their exfoliating primary counterparts. Some medical conditions may disrupt the usual eruption sequence timeline, and clinicians can be aware of delayed or advanced dental patterns common in such populations. Rarely, eruption cysts may form over emerging teeth, which can cause pain and may develop into hematomas.[138] Most resolve on their own, but some may need surgical intervention by a dentist.

Management of physiologic oral pain associated with tooth eruption can include chewing on hard or chilled teething rings, massaging the gingiva, or if pain persists, over-the-counter analgesics like acetaminophen.[139] The use of topical anesthetics, such as benzocaine, is contraindicated because of the risk of methemoglobinemia,[140] as is the use of amber teething necklaces because of the risk of strangulation.[141]

Diagnosis of Pathologic Oral Pain

Pathologic causes of oral pain include dental caries, dental infections, and soft tissue lesions. Dental caries initially cause pain when stimuli cause hydraulic pressure changes in exposed dentinal tubules that activate pulpal nerve fibers.[142] As the infection progresses, pulpal nerve inflammation occurs. Unchecked, this infection may spread into the surrounding tissues, causing pain and potentially abscesses and/or cellulitis. Nonodontogenic sources of pain include viral infections (eg, hand, foot, and mouth disease, primary herpetic gingivostomatitis) or trauma (eg, cheek biting, SIB in the oral cavity).

Obtaining a complete history of the pain (eg, when it began, what triggers it, how often it occurs, whether it is acute or chronic) is important to an accurate diagnosis. A validated pain scale appropriate for age and cognitive ability can be used.[143] For young children or CYDD or individuals who are nonverbal, the practitioner can involve the caregivers in assessing pain and identifying behavioral changes indicative of pain in their child.[144] A clinical examination may be performed to assess odontogenic involvement. This may be difficult for patients who are combative because of their acute pain or whose behaviors preclude their ability to cooperate. The costs, benefits, and risks of using protective stabilization in a dental setting to obtain a clinical examination are to be thoroughly discussed with caregivers before initiation. The American Academy of Developmental Medicine and Dentistry (AADMD) has a well-researched and documented policy statement for both physicians and dentists in the case of protective stabilization for medically necessary health care,[145] and Perlman et al give illustrated examples of when its use may be indicated.[146] In general, protective stabilization is only considered and used after other behavior modification approaches have failed and is intended to be used for the shortest amount of time possible.[1487]

Pain Management

Pain management strategies are selected to address the underlying etiology of the pain. For dental caries, pain management may mean initially trying minimally invasive dental techniques (eg, silver diamine fluoride, atraumatic restorations with glass ionomer cements) to treat or arrest the carious lesion and avoid the costs of invasive treatments.[148,149] For larger dental caries or dental infections, pain management may require traditional techniques, such as removing the carious lesion and restoring the tooth, providing indicated pulpal nerve treatment (eg, pulpotomy or root canal therapy), or tooth extraction. For some CYDD, these procedures may require sedation or GA. Until dental treatment can be rendered, oral analgesics with antipyretic effects can alleviate discomfort. Ibuprofen and acetaminophen, used separately or in combination, are commonly used for dental pain[150,151] and have fewer reported acute adverse events than opioid use in pediatric populations.[152]

Use of antibiotics for children and adolescents presenting with acute dental pain may be limited to those with signs that the dental infection has moved outside of the tooth[153] or for CYDD who are immunosuppressed. Signs and symptoms of septicemia and systemic involvement, including facial cellulitis, fever, and general malaise may indicate the need for intravenous antibiotics[154] and instances where emergency dental care may be prioritized. For nonodontogenic pain, such as that caused by a viral infection, antiviral agents may be prescribed, or palliative care can be rendered as the infection resolves.[155] CYDD often take multiple medications, so practitioners can obtain an accurate medication history and check for any potential drug interactions before prescribing analgesics or antibiotics.

SEDATION AND GENERAL ANESTHESIA CONSIDERATIONS

Access to comprehensive oral health care with sedation or GA is medically necessary for many CYDD. There is significant postoperative improvement in oral health-related quality of life for adolescents with developmental disabilities after receiving care using these methods.[156] Additional information on sedation for dental procedures for all children can be found in the AAP and AAPD "Guidelines for Monitoring and Management of Pediatric Patients Before, During, and After Sedation for Diagnostic and Therapeutic Procedures."[157] Consent should be obtained from the appropriate caregiver (or state agency, if the child is in foster or ordered kinship care) and outline the risks, benefits, and alternatives.

Benefits of Dental Care Under Sedation and/or GA

Sedation and/or GA has benefits and risks that are carefully weighed by the care team and family. Some of the benefits to sedation are self-evident. CYDD may not be able to cooperate with dental care. Sedation allows for a comprehensive oral examination, radiographic assessment, and definitive treatment without the need for physical restraint. In addition to the more pleasant patient experience for a dental procedure, there may be longer-term behavioral benefits to sedating children for painful or distressing medical care. Antianxiety measures, such as preoperative midazolam to

reduce periprocedural anxiety, may translate to fewer behavioral problems for children after surgery.[158]

Risks of Sedation and/or GA for Dental Care

The risks of pediatric sedation and anesthesia can be thought of in terms of immediate risks and longer-term risks. Most studies on pediatric sedation and anesthesia have been performed on children without a medical comorbidity, with only some subgroup analysis of CYDD. Several large multicenter databases have been developed to assess immediate risk to children with sedation or GA. The Anesthesia PRactice in Children Observational Trial (APRICOT) study was a prospective study of nearly all pediatric anesthetics in 33 European countries in a 2-week period. Of these 31 000 children, 4.8% had severe events, with the largest number being respiratory in nature (eg, severe laryngospasm [1.2%], bronchospasm [1.2%]). The 30-day mortality rate was 0.1%, with none attributable to anesthesia.[159] The Wake Up Safe multi-institutional US-based registry similarly shows that in the nearly 2 million anesthetic cases collected in a 5-year period, the most common adverse events associated with sedation and anesthesia were respiratory complications (3 per 100 000 patients). Again, the overall mortality rate was very low (0.1 per 100 000), with no deaths for patients with American Society of Anesthesiologists (ASA) physical status of 1 or 2.[160] The Pediatric Sedation Research Consortium (PSRC), a multicenter database of pediatric procedural sedation outside the operating room with over 600 000 procedures, found an overall complication rate of 5.3% with brief oxygen desaturations seen in 157 per 10 000, laryngospasm in 4.2 per 10 000, and no deaths in 30 000 patients.[161] It is important to note that in the PSRC, these data represented sedations performed primarily by established sedation services in the hospital setting with established backup systems.

Several groups have examined the PSRC database to determine patient factors that increased risk for sedation. One factor that may have relevance to some CYDD is the association of preterm birth with sedation complications. Logistic regression analysis of the PSRC database showed that patients born preterm were twice as likely to have sedation adverse events, an effect that persisted up through at least 23 years of age.[162] Other factors that have strong association with increased sedation risk are obesity,[163] age less than 5 years, and ASA physical status greater than 2.[164] Another analysis determined factors associated with failed sedation: obesity, obstructive sleep apnea or snoring, ASA physical status over 2, and age greater than 12 years.[165] Analysis of the APRICOT patient data also showed increased risk for patients with prematurity, snoring, ASA over 2, and those with metabolic or genetic disorder or neurologic impairment.[159]

Information more specific to the risks for CYDD is mostly found in small case series and case reports. One retrospective comparison of 260 patients with developmental disability found that they had a 3 times higher risk of hypoxemia during sedation.[166] One possible explanation for this is the observation that the diameter of the airway is reduced by 40% under sedation in children with developmental delay when compared with controls, predisposing these patients to upper airway obstruction. This higher risk may be attributable to anatomic variations, reduced oropharyngeal muscle tone, a differential response to sedative medications, or some combination of these factors.[167] Patients with trisomy 21 have a particular propensity for airway collapse with sedation. Trisomy 21 is associated with midface hypoplasia, macroglossia, adenoid and tonsillar hypertrophy, laryngotracheal anomalies, obesity, and muscular hypotonia.[168] In addition to these airway concerns, trisomy 21 is associated with a high incidence of congenital cardiac disease and autonomic issues, which are particularly pronounced under anesthesia.[169] Care providers must also exercise caution during intubation and positioning for head and neck surgery for these patients because of the risk of atlantoaxial instability.[170] Patients with cerebral palsy also have several risk factors that can complicate sedation. Anatomic challenges in airway structure as well as scoliosis and fixed contractures can pose difficulties in positioning and airway manipulation. Poor airway tone and ineffective cough or gag reflex can increase risk of airway collapse or aspiration.[171] A literature review of publications mentioning sedation and developmental delay concluded that children with neurologic disorders and developmental delay are at increased risk of adverse events under sedation, most prominently respiratory events.[172] Patients with neuromuscular diseases, such as Duchenne muscular dystrophy, may have impaired cardiac and respiratory functions that can be evaluated before sedation.[173]

Almost half of children with epilepsy present with some iteration of developmental delay.[174] General anesthesia may have a proseizure effect or increase adverse seizure-related effects pre-, peri-, and postoperatively, particularly in children.[175] Additionally, fasting guidelines before sedated procedures may make taking antiseizure medications difficult, particularly if the CYDD needs to take a medication with food. Dental providers can coordinate with the anesthesiologists and the patient's neurology team to create a seizure action plan and discuss timing of antiseizure medication and oral intake before the procedure.

Risks of Sedation and/or GA on the Developing Brain

Studies in rats and nonhuman primates have raised a concern for the deleterious effect of sedative and anesthetic medications on the developing brain. Evidence in these animal models have demonstrated concerning, long-term neurologic sequelae after exposure of immature animals to

anesthetics or sedatives. As a result, the FDA issued a Drug Safety Warning in 2016. Children younger than 3 years and pregnant people can exercise caution when taking prolonged or repeated anesthetics, as multiple exposures may impact future brain development.[176] Several large-scale prospective studies have attempted to find a similar effect in children. The General Anesthesia versus Spinal Anesthesia study has followed children for more than 5 years after random assignment in infancy to general anesthesia or a spinal anesthetic for hernia surgery.[177] The Pediatric Anesthesia Neuro Development Assessment study has long-term follow-up of sibling pairs exposed and nonexposed to a brief anesthetic in infancy.[178] Neither study showed a detrimental effect of a single brief anesthetic on neurodevelopment. The Mayo Anesthesia Safety in Kids study examined the effect of multiple anesthetics and could not find a difference in its primary outcome of "general intelligence."[179] As a result of these human studies, questions have been raised about the applicability of these animal studies to human populations.[180]

In children who have been multiply exposed to anesthesia, some effects have been gleaned on the development of deficits in behavior, executive function, social communication, motor function, and diagnoses of ADHD.[181] Further work will be necessary to determine the magnitude of this effect as well as its causation. As CYDD represent a group of patients who will likely experience multiple anesthetics over the course of their life, the current state of knowledge would dictate prudence in recommending a patient for sedation or anesthesia, while not forsaking medically necessary dental interventions.

Presedation or GA Assessment

The provision of safe sedation or anesthesia to any patient, but particularly patients with comorbid conditions that can increase sedation risk, begins with appropriate patient evaluation. The decision to provide sedation in a dental office versus referral to a hospital-based sedation service or to GA is based on the patient's condition, the experience of the personnel delivering care, and the rescue system that is available to the sedation provider. Patient prescreening to determine optimal care can be aided by a decision tool listing "red flag" conditions, such as those known to be associated with higher sedation or anesthesia risk.[182] Best practices for patient monitoring and management have been established by the AAP and AAPD joint statement on pediatric sedation.[157] Particularly when sedating children with complex medical issues, it is crucial that a trained sedation provider administer sedation and that this be the only role assigned to this person during a procedure.

Timing of GA

Determining the timing of when to provide comprehensive dental care under GA depends on the dental needs, dental development, ability of the child to cooperate, and the risks of, benefits of, and alternatives to GA. Individuals whose dental needs are significant (eg, multiple teeth with carious lesions), acute (eg, pain with or without abscesses or infection, dental trauma), and who cannot be safely managed in the dental office setting have priority for receiving medically necessary care under GA.

Behavioral interventions have been successful in allowing limited dental examinations for some CYDD in the clinic. During these appointments, individuals may accomplish routine cleanings, gain desensitization to the dental environment, and have limited examinations that can inform the timing of GA for more comprehensive treatment.[183,184] Even in the absence of acute dental needs, some CYDD may need comprehensive dental examinations under GA because of their ability to cooperate for these limited examinations in the dental clinic. Dental practitioners consider information from limited clinical examinations, including caries risk, current dental development, capacity to visualize proximal contacts, and need for diagnostic radiographs, before recommending examination under GA. There are no set protocols to direct timing of these examinations under GA, but practitioners can follow clinical guidelines and best practices to minimize repeat operations.[185]

Timing is often dependent on dental development. In the absence of known dental needs, a dentist may elect to first see a child under GA when the first permanent molars are erupting around 6 years of age so they can be sealed, and all primary teeth can be evaluated. Another time that is ideal for a comprehensive examination under GA in the absence of known dental needs is near the completion of eruption of all permanent teeth besides third molars, around 12 or 13 years of age. This timing is recommended so that any over-retained primary teeth can be removed, and sealants can be placed on the premolars and permanent molars. If the individual is going to graduate to an adult dental home at this stage, the dentist can make sure all restorative needs are completed before the transition.

CYDD may need other procedures completed under GA, and these can also represent ideal times for a comprehensive dental examination. These "piggy-back" or combination cases may reduce the number of times an individual needs GA if the dental procedures are not contraindicated (ie, cardiac surgery).[186] Other nonsurgical procedures can be combined with dental care under GA, including giving routine childhood vaccinations, cutting nails or hair, gynecologic examinations, and drawing blood for laboratory tests. Follow-up in the dental clinic after GA depends on the extent of the dental work performed but typically happens between 2 weeks and 6 months postoperatively.[187]

CONCLUSIONS

Oral health is important for the overall health and quality of life of CYDD. This clinical report provides an outline

for pediatric medical providers to promote oral health in this population, understand the barriers to accessing oral health care, communicate effectively with the individual's dental home, and advocate for medically necessary care to safely perform procedures. The unique physical and mental attributes of CYDD may alter how oral health care is delivered and pediatric medical providers are essential in supporting and endorsing dental providers to provide these needed services.

RECOMMENDATIONS

Recommendations for Primary Care and IDD Specialists to Promote Oral Health (Prevention, Early Detection, and Treatment) for CYDD in Primary and Specialty Care Settings Are as Follows:

1. Assess dental and periodontal health for CYDD at least annually.
2. Use structured screening instruments such as the "oral health risk assessment tool" to consistently assess and identify risk factors.[38]
3. Provide anticipatory guidance on oral hygiene, diet, habits, trauma prevention, and malocclusion, including tooth brushing; recommend use of fluoridated toothpaste; assess community water fluoridation; apply fluoride varnish as appropriate; determine sources of fermentable carbohydrates and aim to reduce consumption; and consider transition to adult dental care as part of the adolescent health care transition.[3,34]
4. Advocate for a dental home by 1 year of age, similar to a medical home, for every CYDD, and communicate the individual's intellectual and functional inabilities with their dental providers.
5. Encourage families to access preventive dental care.[7]

Recommendations for Primary Care and IDD Specialists to Reduce Barriers to Receiving Oral Health Services Are as Follows:

1. Routinely assess and support transportation and travel needs for their CYDD.
2. Advocate for new and expansion of existing training programs that educate dental professionals on how to comprehensively care for the oral health needs of CYDD, and advocate for interprofessional training programs in medical and dental schools to prepare clinicians for future collaboration.
3. Identify dental professionals in the community who provide care for CYDD in the office or hospital, optimize referral pathways, and share this information with parents and caregivers.
4. Establish mechanisms to prioritize CYDD in greatest need of care to shorten wait times.
5. Identify insurance options for families of CYDD to reduce costs to families for medically necessary care.
6. Coordinate and facilitate oral health care within the medical home as part of comprehensive care as specialty medical care and surgical services are.[2,10,11]

Recommendations for Dentists and Dental Anesthesiologists Caring for CYDD Are:

1. Develop strategies and environments that accommodate the special needs of CYDD with challenges, such as sensory sensitivities and an individual's inability to follow recommended behaviors.
2. Receive specialized training related to the special needs of CYDD to increase the number of dental professionals able to care for CYDD.
3. Advocate for increased preventive services and accessibility to the full range of oral health services, including minimally invasive dental treatments, for CYDD.[14]
4. Routinely assess receipt of medical preventive services during oral health visits and facilitate referrals when indicated; coordinate medical services with dental services when possible (eg, during general anesthesia).

Recommendations for Hospital Administrators and Leaders:

1. Expand hospital privileges and operating room time for dentists to support oral health needs of CYDD.[8]
2. Encourage medical providers to be educated on and screen for oral health conditions in CYDD.

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ABBREVIATIONS

AAP: American Academy of Pediatrics
AAPD: American Academy of Pediatric Dentistry
ADHD: attention-deficit/hyperactivity disorder
APRICOT: Anaesthesia PRactice in Children Observational Trial
ASA: American Society of Anesthesiologists
ASD: autism spectrum disorder
CYDD: children and youth with developmental disabilities
CYSHCN: children and youth with special health care needs
FDA: US Food and Drug Administration
GA: general anesthesia
IDD: intellectual and developmental disability
PSRC: Pediatric Sedation Research Consortium

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