

## Autistic disorder: a review for the pediatric dentist

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### Abstract

*Dental publications on autism have been sparse since the first comprehensive article geared for the dental profession. New findings on the etiology of autistic disorder (AD) have been discovered, suggesting that it is an organic disorder characterized by abnormalities in the brain, especially the cerebellum and limbic system. This article summarizes the latest medical findings on the etiology, diagnosis, and treatment approaches of AD, and reviews the dental literature since 1969. The main dental topics reviewed are: oral health status and dental needs of patients with AD, characteristics of patients with AD, and self-injurious behavior (SIB) in the context of AD. Clinical behavior-management issues such as pharmacological and communicative techniques and physical restraint and desensitization are described. The affect of the dental office's environment and appointment structure on a patient with AD are presented. (Pediatr Dent 20:5 312-317, 1998)*

Autistic disorder (AD) is the third most common developmental disability in the United States and almost 400 000 people are affected.<sup>1</sup> The disease has been identified internationally with no ethnic propensity.<sup>2</sup> This article provides an update on the current literature and reviews the few dental publications. Attention is given to SIB, desensitization programs, use of restraints, and the possible comforting influence of deep touch pressure on individuals with autistic disorder.

Autism was first described in 1943 by the American child psychiatrist Leo Kanner.<sup>3</sup> He presented 11 children whose behavior was obviously different from others. Kanner suspected that they had an inborn feature which prevented their forming regular social contacts. Autism is now recognized as an organic disorder characterized by abnormalities in the brain, especially the limbic system and cerebellum.<sup>4-7</sup>

### Definition and diagnosis

AD is categorized in the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, 4th ed.)<sup>8</sup> under the section Pervasive Developmental Disorders

(PDD) and is characterized by abnormal emotional and social behavior and linguistic development. The onset of AD usually occurs before three years. The expression of symptoms varies widely. To be diagnosed as autistic, a patient must exhibit a specified number of symptoms,<sup>8</sup> although not all of them must necessarily be present at the same time or to the same degree. The criteria described in the DSM encompass qualitative impairments in social interaction and communication, as well as deviant patterns of behavior, interest, or activities. Parents are important aides in diagnosing AD, as they are usually the first to be concerned about disturbed development of their child: impaired communication, lack of social relationships and imaginative play, and to a lesser extent, hearing impairment and delay in attaining milestones. The mean age noted for these deviations is 17 months and the mean age for final diagnosis is 44 months.<sup>9</sup>

Early detection (18-40 months) is important as early initiation of educational and behavioral treatment is very effective, with long-lasting benefits for these children and their families.<sup>10</sup> Vostanis et al.<sup>11</sup> suggest that primary care providers target children at risk—those with language delay—in order to ensure that more children are diagnosed early.

### Etiology/coexisting medical conditions

Strong evidence suggests that AD is an organically based neurodevelopmental disorder associated with abnormalities in brain structure and function. Characteristic findings are a reduced number of Purkinje cells in the posterior inferior regions of the cerebellar hemispheres, truncation in the dendritic tree development of neurons in the limbic system,<sup>4-6</sup> and hypoplasia of cerebellar lobules VI and VII.<sup>7</sup> Hashimoto et al.<sup>12</sup> verified that the size of brainstem structures and the entire cerebellar vermis and their components were significantly smaller in an autistic group than in a control group using magnetic resonance imaging. With age, the size of all these structures increased in both groups "relatively smoothly". The investigators concluded that these deviations were not the result of a progressive degenerative process but rather an early pre- or peri-

natal insult. Prenatal factors like chromosomal abnormalities, intrauterine viral infections, or metabolic disorders may play an important role in the pathogenesis of AD. Courchesne<sup>13</sup> added that this study furnished the first direct evidence that noticeable brain abnormalities were present at the beginning stages of behavioral abnormalities in infantile autism.

In contrast, no positive association between pre-, peri-, and neonatal factors and AD was found by Piven et al.<sup>14</sup> They collected data on pre-, peri-, and neonatal variables in AD and found that autistic children had significantly lower optimal scores than their matched siblings, but after adjusting data for parity, these differences disappeared.

Multiple indices support a genetic basis for AD. Twin studies<sup>15, 16</sup> find a high concordance rate in monozygotic twins. Although the recurrence risk for AD following birth of an autistic child is only 3%, this risk is 60–100 times greater than the base rate for AD in the general population.<sup>17</sup> The 3–4 times higher prevalence in males suggests an X-linked mode of inheritance, but a study by Hallmeyer et al.<sup>18</sup> could not verify any moderate to strong AD gene effect on the X chromosome.

Coexisting medical conditions in AD are seizure disorder, fragile-X syndrome, tuberous sclerosis, and phenylketonuria. Smalley et al.<sup>19</sup> reported that 0.4–3% of patients with AD had tuberous sclerosis complex (TSC) and 17–58% of TSC subjects had AD. Difficult-to-control seizures are common in these patients, and those having both TSC and AD have significantly more seizures and mental retardation than those not affected with AD.<sup>19</sup> Fragile-X syndrome is found in 2–5% of autistic individuals and represents the largest known subgroup of patients with AD with a known etiology.<sup>17</sup> Damasio and Maurer<sup>20</sup> observed a behavior in autistic subjects that was similar to patients with localized damage of the frontal lobes and closely related structures, whereas others demonstrated symptoms like a postencephalitis Parkinson disease.

### **Incidence**

The incidence of AD varies between 2–15 per 10 000 births, depending on the criteria used for diagnosis.<sup>1, 8, 17, 21</sup> Males are four to five times more affected than females, but females are more likely to exhibit more severe mental retardation.<sup>8</sup>

### **Pharmacological therapy**

The six most often prescribed pharmacotherapeutics for treating autistic symptoms are methylphenidate, thioridazine, diphenhydramine, phenytoin, haloperidol, and carbamazepine. Megadoses of vitamin B<sub>6</sub> are the most widely used alternative medication.<sup>22</sup> Cook et al.<sup>23</sup> treated patients with AD with fluoxetine. About half of the patients showed improvements, but it was

concluded that medications are no substitute for educational, behavioral, and vocational programs. Some patients with AD show abnormalities in the serotonin neurotransmitter system. Treatment of adults with the serotonin uptake inhibitor fluvoxamine showed promising results in reducing aggressive and impulsive behavior.<sup>24</sup>

### **Prognosis**

The best predictor of a favorable outcome is the development of useful speech by 5 years.<sup>25</sup> AD is a life-long disorder, generally with no regression, but symptom patterns do change, or may lessen or disappear. An IQ higher than 50 may be expected in 60% of autistic individuals, 20% may range between 50 and 70, and 20% may be less than 70. Nonverbal intelligence is normal in 20% of autistic children.<sup>17</sup> Low functioning patients with AD need a protected environment their whole lives, whereas individuals with higher IQs will be able to live and work with only minor supervision. High functioning patients with AD can achieve the highest academic degrees and be otherwise successful in life.<sup>26</sup>

### **Oral health status and dental needs**

The oral health and dental needs of autistic children and young adults have been described by Shapira et al.<sup>27</sup> They evaluated periodontal status and DMFT and found that institutionalized autistic individuals had a higher frequency of and more serious periodontal problems than institutionalized schizophrenics, but exhibited a lower caries rate. The periodontal status and caries rate of autistic children in a day care facility were similar to that of their peers. The most common dental services needed were scaling, surgical periodontal procedures, and oral hygiene and nutritional instructions.

Lowe and Lindemann<sup>28</sup> assessed AD patients' dental needs by studying a group of 20 AD subjects and compared them to 20 nonautistic age-matched controls. In the primary dentition, the patients with AD demonstrated a significantly higher caries rate (dmf) than the controls on initial examination, but at recall examinations, dmf values were comparable. In patients with permanent dentition, both at baseline and recall, DMF scores were not different between the groups. No statistically significant differences were found in the oral hygiene indices. They also noted a need for oral hygiene instructions and additional training for patients to increase their motor skills to perform more effective cleaning. A low incidence of dental caries was mentioned by Kamen and Skier.<sup>29</sup> Kopel<sup>30</sup> stated that patients with AD did not exhibit any unique features of hard or soft intra- or perioral tissues and the prevalence of dental disease was similar to other children. Swallow<sup>31</sup> postulated that the actual need of the fam-

ily and patient was not so much dental treatment, but a gradual increase in familiarity with dental and preventive care.

In summary, more authors<sup>27, 28, 30, 31</sup> find caries susceptibility and prevalence of periodontal disease not remarkably different from nonautistic individuals—and maybe even lower.<sup>29</sup> In contrast, some note<sup>32–34</sup> that increased caries susceptibility is due to a preference for soft and sweet food, poorer masticatory abilities, and pouching of food. There is no doubt that prevention of oral disease is of paramount importance and all efforts should be directed to repeated oral hygiene instructions. To achieve this, the parents/caretakers must become involved, which is sometimes difficult. Milius<sup>34</sup> reminds us that this special family situation, adapted to raise a child with extraordinary needs, requires an empathic approach from the dentist, and the family's concerns, worries, or sometimes hostile feelings must be adequately addressed and respected.

#### **Characteristics of patients with AD**

The main challenge to the dental team may be the reduced ability of autistic patients to communicate and relate to others.<sup>29, 33</sup> Further problems include uneven intellectual development, peculiar repetitive body movements, hyperactivity, limited attention span, and a low frustration threshold that may lead to temper tantrums or bizarre vocalization.<sup>29</sup> Although there appears to be no experimental verification, several publications described autistic individuals as having a higher threshold to pain,<sup>8, 29, 30</sup> concluding that short procedures may be carried out without local anesthesia.<sup>29</sup> On the other hand, there is agreement that patients with AD exhibit tactile and auditory hypersensitivity, and may have exaggerated reactions to light and odors.<sup>8</sup> Some authors attribute a strong urge for soft, sticky, and sweet foods to individuals with AD.<sup>32–34</sup> The team should be prepared for unpredictable and unusual responses to sensory stimuli. Patients with AD tend to dislike changes in their environment and need sameness and continuity;<sup>32</sup> they may react with tantrums over small environmental changes.<sup>35</sup> Different physical conditions that can occur include a hyperactive knee jerk, poor muscle tone, and poor muscle coordination.<sup>32</sup> If the oral musculature is involved, drooling and reduced masticatory abilities can result, which can lead to a tendency to pouch food instead of swallowing.<sup>32, 34</sup>

A higher degree of lateral vision in autistic individuals is mentioned by Kopel,<sup>30</sup> who concluded that all lateral movements toward the patient are potential distractions and should therefore be avoided. Some autistic individuals prefer using their peripheral vision because they get more reliable information when they look from the corners of their eyes.<sup>26</sup> In contrast, an experimental study<sup>36</sup> on visual-spatial orienting in AD

showed that probands with AD exhibited the same quality of vision for the detection of lateral stimuli as controls.

#### **SIB**

Self-injurious behavior occurs in 4–5% of individuals with different psychiatric conditions, especially those with AD, schizophrenia, and brain damage.<sup>37</sup> A change in daily routine may initiate or increase it. SIB may range from self-pinching or scratching to severe self-biting or head banging. The etiology is often unclear. An injury might be done to either attract the attention of a family member or clinician or to avoid unwanted events. The interpersonal dynamics (family/patient, clinician/patient) must be understood to determine the therapeutic approach. Case presentations in the literature range from patients engaging in SIB at dental appointments in order to avoid the scheduled procedure<sup>37</sup> or a patient who presented with a deep gingival cleft on a canine caused by repeated scraping of this area with his fingernail.<sup>38</sup> An autistic girl developed excessive lip biting after being admitted to a psychiatric ward.<sup>39</sup> Suggested therapeutic approaches consist of reinforcement of behavior that does not involve self-injury and ignores undesired behavior. This shows the patient that SIB does not help to avoid an undesired situation/procedure. Rewarding good conduct frequently (either immediately or by giving the patients presents after treatment), distracting a patient from an undesired action, and inserting a prefabricated oral screen as a temporary physical distraction also helps.

#### **Clinical management considerations**

AD is a heterogeneous disorder with a wide range of expression. Therefore treatment approaches that yield a positive outcome in one patient may prove ineffective for another. Despite this, dental articles on AD show similarities concerning particular issues dentists have to cope with as well as recommended pharmacological and communicative management techniques. It is important to gather as much information as possible when taking the health history. Carefully listening to the parents/caretakers is a key element in gaining their trust, which in turn will help tremendously in gathering data.

#### **Pharmacological behavior-management techniques**

Several authors<sup>29, 30, 40–42</sup> described the use of pharmacological agents. Frequently used drugs were nitrous oxide, diazepam, hydroxyzine, chloral hydrate, and promethazine, in contrast to chlorpromazine, diphenhydramine, and meperidine. The drugs were administered in different dosages and regimens, such as a sole agent or in various combinations. In some patients, several different regimens and combinations were attempted in order to be successful. Reported

success rates varied from limited<sup>30, 42</sup> to 70% success,<sup>40, 41</sup> but any success was considered unpredictable.<sup>29</sup> In this context, the importance of a thorough health history was stressed, particularly that details on the reaction to previous sedatives should be obtained.<sup>30</sup> Treatment in the operating room using general anesthesia was considered only if all other approaches failed. Some authors<sup>40, 41</sup> noted that a lengthier administration and higher concentrations of nitrous oxide than usual were required to achieve the desired level of sedation in patients with AD.

#### **Communicative behavior-management considerations**

It is imperative to know about the patient's peculiarities concerning behavior and communication and previously applied conditioning methods before initiating any procedure. Techniques commonly advocated and used<sup>28-30</sup> for behavior modification in patients with AD are the same as for nonautistic individuals: tell-show-do and immediate, frequent positive and negative reinforcement paired with firmness where necessary. However, a higher rate of flexibility is required to comply with quickly changing patient needs. Other recommendations, again based on the modeling effects of constant positive reinforcers, are immediate verbal praise after each accomplished step of a procedure and a prize at the end of a dental session.<sup>40, 41</sup> The oral commands should be clear, short, and simple sentences.<sup>32, 35</sup> Inappropriate behavior should be ignored.<sup>34</sup> Hand-over-mouth was not considered an appropriate technique for patients with AD.<sup>30</sup>

#### **Restraints/deep touch pressure**

There is controversy regarding physical restraint for autistic patients. While several authors advocate a restraint board,<sup>32, 41</sup> others disapprove.<sup>29, 40</sup> Beneficial relaxing effects of deep touch pressure for children with AD have been described.<sup>46, 47</sup> Calming effects using a restraint board on patients in a dental setting were also noted by some dentists.<sup>32, 37</sup> Lindemann<sup>37</sup> considered physical restraint in the context of SIB and noted that some AD children appeared to be comforted by physical restraint. McDonald and Avery<sup>32</sup> discussed the use of various physical restraints on either mentally challenged patients or for common oral sedation procedures and warranted them to obtain safer working conditions and a more predictable patient response.

Grandin<sup>46</sup> reviewed the literature on deep touch pressure applied to patients with AD and ADHD, as well as animal literature on this topic, and reported that occupational therapists have observed a relaxing and calming effect of deep pressure, in contrast to Grandin's light touching, which alerts the nervous system. One device to apply self-controlled deep pressure was the author's "squeeze machine". The overall results from case reports and studies suggest that applying a more or less firm wrap, pressure, and/or touch on emotion-

ally disturbed or oversensitive persons can have a positive calming and comforting effect. Elsewhere she described<sup>26</sup> that some people with AD have severe body boundary problems, but being wrapped in blankets or applying tight pressure to the entire body (e.g., a wet suit) lets them feel the limits of their body, and this has a soothing effect. Beneficial relaxing effects of deep touch pressure for a child with AD were also confirmed by an occupational therapist.<sup>47</sup>

#### **Desensitization**

Kopel<sup>30</sup> stated that managing the autistic patient in the dental office often requires a time-consuming conditioning and reinforcement process before the actual treatment can be started. He suggested dividing dental procedures into smaller steps. Rehearsals at home prior to the dental appointment should help to familiarize the child with basic dental instruments and procedures, and may even include the dentist's commands like "Hands down" and "look at me". Swallow<sup>31</sup> advocated a slow and step-wise approach, with time to learn one experience before the next step is introduced. Careful and gentle repetition enabled him to carry out procedures on even the most severely affected individuals.

Luscre and Center<sup>45</sup> described a method to reduce dental fear in children with AD. Their goal was to prepare three severely retarded male AD patients for a dental exam. The patients received treatment consisting of desensitization with guided mastery, symbolic video peer modeling, and reinforcement. After an average of 20 analog and four in-vivo training sessions, one patient was able to undergo a complete dental exam with a new dentist, while the other two tolerated a partial dental exam. The authors rated this outcome as positive and important, because they were able to show that severely retarded autistic individuals can be trained to participate in a formerly upsetting, fear-provoking procedure.

The results sound promising, but in reality limitations of manpower, time, and money restrict the more frequent use of desensitization programs. With a slow and step-wise approach, as described by several authors,<sup>29, 30, 35, 40, 41</sup> in conjunction with pre-medication if necessary, dental treatment may be carried out in patients with AD without such a lengthy modeling process.

#### **The dental environment**

The patient's need for continuity may require several visits to the dental office prior to the treatment appointment to familiarize the autistic patient with the facility and to establish a routine.<sup>32</sup> Gradual and slow exposure to the dental environment with nonthreatening contacts is recommended.<sup>31, 34</sup> Parental presence in the clinic area is usually discouraged. Before hospi-

talization, however, some preadmission visits should be scheduled, with a parent encouraged to stay with the patient.<sup>34</sup>

Many strong stimuli are produced in a dental office; therefore, adverse patient reactions may be elicited. The sensory overload and internal state of hyperarousal that many autistic individuals experience—even under normal conditions—may, in an upsetting situation, lead to impulsiveness, routine behavior, and withdrawal as defense mechanisms.<sup>43</sup> It was shown that an ascetic physical environment effectively decreased those negative behaviors and it was therefore speculated that austerity and order in the surrounding setting would have a soothing effect on the patient.<sup>44</sup>

When translating this into a dental visit it is rather unrealistic to demand a specially designed operatory for patients with AD; however, it may be feasible to treat the patient in a quiet, shielded single operatory versus an open-bay arrangement, with reduced decoration and dimmed lights.

#### **Appointment structure**

Because of the AD patient's limited attention span, short, well-organized appointments should be planned and the waiting time should not exceed 10–15 minutes to avoid upset.<sup>29, 31, 34</sup> To address the autistic individual's preference for sameness and aversion to change, a routine should be established by maintaining days, times, and personnel for each dental visit.<sup>31</sup> Discussions of any aspect of the actual work should be avoided during its course. Light background music might be beneficial. Anyone participating in the procedure should minimize movements because the autistic child is easily distracted.<sup>35</sup>

#### **Conclusions**

1. There is strong evidence that AD is due to a pre- or perinatal insult and is not a progressive degenerative process. Although males are almost four times more affected, no moderate-to-strong gene effect on the X chromosome has been detected.
2. Early (prior to 40 months of age) detection is important, because early therapy results in faster and greater improvement than later intervention. Pediatric dentists are well suited to be primary health care providers for early screening of the risk group because pediatric dental care ideally starts by age 1 and because they are particularly trained in the treatment of individuals with special needs.
3. Autistic individuals generally do not display specific dental findings, but compromised oral hygiene can contribute to an increased risk for caries and especially periodontitis in some patients; patients taking phenytoin or phenobarbital for seizure control are at risk for gingival overgrowth.

4. Tell-show-do, voice control with short, clear commands, and positive reinforcement are successful first-line management techniques for the autistic patient.
5. Various conscious sedation agents/combinations have been suggested, but none of them prove to be consistently more effective than others; an individualized prohibitory approach is necessary. In approximately 30% of patients, no agent was effective and comprehensive treatment had to be performed under general anesthesia.
6. The use of a restraint board to protect patient and care providers to enable treatment and avoid more intrusive measures is warranted after explanation and obtaining written consent. There are indications that it may even have a calming effect in autistic individuals.
7. Autistic individuals don't have a higher degree of peripheral vision; rather a more centrally focused vision and attention pattern is the case.
8. SIB occurs in some patients with AD and requires ingenious intervention.
9. To meet the autistic patient's need for continuity, some organizational changes in the dental office may be necessary: always schedule appointments on the same day and time, use the same quiet operatory and assistant. A high sensitivity to sounds, light, odors, colors, etc., requires special attention to reduce or avoid sensory stimulation.

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