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Message from the Editor: In this issue of the “Reviews and Reports,” authors Hood and Dill introduce us to a hidden area of medical/dental care—the patient who is no longer a minor, is clearly incompetent to make medical decisions, but has not been adjudicated incompetent, has no guardian for medical care, but requires immediate, but not emergent care. This very real case also highlights several other issues important to advancing the care of people with neurodevelopmental/intellectual disabilities. First, a three-part question: Is it ethical, moral, and legal to publish an article like this when the subject of the article can not give informed consent and there is no court-appointed guardian? Important issues to be introduced into this discussion are the potential risk to the subject as well as possible advantages to him of having this information published. Also part of the discussion has to be this: Can removing identifying information from the case make it more palatable for publication? Unfortunately, as in this case, removal of identifying information makes the case much less valuable to teach

other clinicians a higher level of care. Second, if no guardian is present, can a surrogate guardian such as a parent, or in this case, both parents, provide consent for publication? And third, how do the HIPAA regulations affect and guide the publication of a case like this?

It should be noted that the authors developed a therapeutic relationship with the patient and his parents in the course of assessment and obtained consent for publication from the parents, discussed the publication with a bioethicist and obtained legal review of the issues. The parents believe that publication is important to help educate medical/dental providers, thus, they encouraged publication. The clinicians want to provide information to parents of individuals with severe intellectual disability and to allow this patient and his parents to participate in the ongoing dialogue of how to minimize and potentially eliminate the health care disparity so evident in this group of individuals, while maintaining respect in interactions with the patient. —*Steven G. Zelenski, D.O., Ph.D. Co-Editor, R&R*

Twenty-year-old male patient with idiopathic intellectual disability presenting for comprehensive dental evaluation and treatment: The buck stops here!

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ABSTRACT

We present the case of a twenty-year-old male with profound intellectual disability who is referred to the dental clinic by day program staff secondary to the observation of new dysfunctional behaviors. The patient presents a diagnostic challenge in the outpatient setting, but many clues are available to set the stage for both medical and dental diagnostic assessment. Objective information from the

exam is presented along with a treatment plan for subsequent care and evaluation.

Introduction:

Mr. M. is a twenty-year-old male patient with idiopathic intellectual disability, who presents to the Underwood and Lee outpatient dental clinic, accompanied by his father, for comprehensive dental evaluation and treatment. His father is referred to the clinic by the staff at his son’s day program workshop. The day program staff has observed hand mouthing behaviors, and they have voiced concern that the patient may be in pain.

In the waiting room, the patient exhibits behaviors consistent with neurodevelopmental dysfunction. He is non-communicative, and his gaze aversion and tactile defensiveness are suggestive of autism. He is resistant and somewhat combative when directed to the dental chair, and effective behavior management in both the waiting room and operator requires the combined efforts of his father and two staff members. The health history is positive for Attention Deficit Hyperactivity Disorder; there is no history of seizure or neuromotor impairment. The father indicates that, at age ten, the patient was

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Figure 1. Narrow, high-arched palate with multiple malposed and supernumerary maxillary teeth

admitted to an inpatient psychiatric unit for evaluation of his uncontrollable behavior. The following day, the parents were told that managing the patient's behavior was beyond the ability of the psychiatric unit staff, and the parents were asked to take the child home. The father indicates that the psychiatric unit staff described the child's behavior as overwhelming. Although he was designated as having profound intellectual disability as a child, and

although he clearly is not capable of giving informed consent, the patient has never been adjudicated incompetent. The patient was last seen by a dentist twelve years ago; examination and treatment at that time were carried out in the operating room under general anesthesia.

A review of the health history reveals that the patient has no known allergies. His current medications include dextroamphetamine, 20 mg Q day, and amitriptyline, 10 mg Q day. He eats a regular diet with minimal assistance from his parents. He is continent of both bowel and bladder. His health history is, otherwise, unremarkable.

Effective oral examination of this patient requires utilization of papoose restraint and Molt mouth prop. Multiple options for behavior management, including utilization of general anesthesia in the operating room, are discussed with the father, and informed consent to utilize mechanical behavior management techniques for purposes of this examination is obtained and documented prior to taking the patient into the operatory. In the operatory, a dental examination is performed, and a baseline panel of digital radiographs is obtained.

Narrative Summary of Dental Findings:

Gross inspection of the oral cavity reveals poor oral hygiene. A thick plaque accu-

mulate is present throughout, and food debris is noted in multiple quadrants. Calculus accretions are heavy, and gingival tissues are inflamed and friable. Sulcular hemorrhage is elicited with periodontal probing throughout the right upper quadrant (RUQ), and localized areas of frank hemorrhage are evident. Multiple 5 and 6 millimeter periodontal pockets are measured in the RUQ, with a 9 millimeter pocket isolated at the distofacial of the right maxillary third molar (#1). Periodontal probing of the remaining quadrants is deferred until next appointment secondary to resistant behavior.

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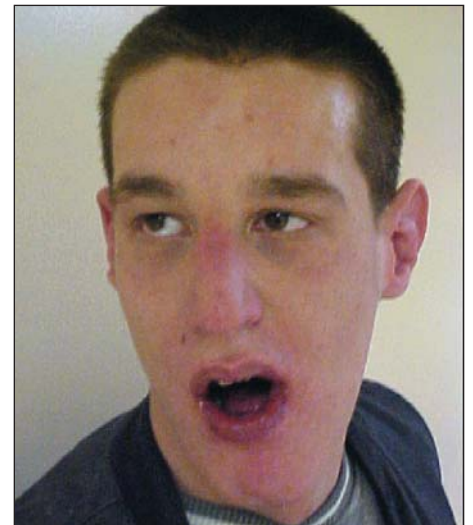


Figure 2. Head and face suggestive of Fragile X Syndrome

INSTRUCTIONS

For CME Credit read the editorial on page 80 and the article that follows and complete the Content Test and CME Evaluation Form at the end. Please read "Information and Instructions" following the article.

Specific learning objectives for this CME activity (please refer to general objectives).

Upon completion of reading of this article the learner will be able to:

1. Appreciate the importance of routine dental care in a person with a profound neurodevelopmental/intellectual disability
2. Describe the challenges that continue to interfere with

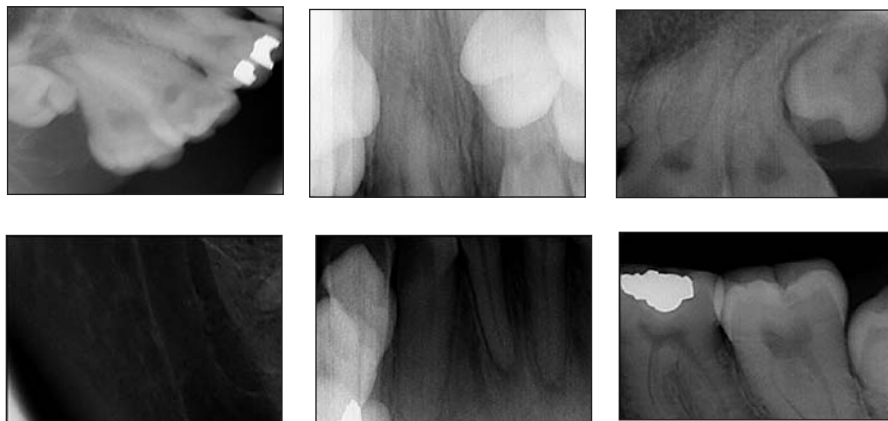
medical and dental care for people with neurodevelopmental/intellectual disability creating a significant health care disparity.

3. Describe phenotypic aspects of Fragile X consistent with the presentation of this patient.

4. Describe key aspects of the initial dental assessment.

Upon receipt and acceptance of the completed evaluation form/post-test, the AADMD CME Program will maintain on file a record for 6 years designating your credits earned. If you should need a written verification, contact Philip May, MD at 908 510-3062.

Figure 3. Six-Image Digital Radiographic Mini-Panel



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Further intraoral inspection reveals an extremely narrowed, high-arched palate, with numerous malposed maxillary teeth. (See: Fig. 1) Two malposed supernumerary maxillary teeth (numbered 7 ? and 10 ?) are noted, as well. Deep in the palatal vault, a scrapable, white lesion is noted. The patient exhibits a 7 millimeter open bite. Examination of the hard tissues reveals occlusal caries in six of the thirty erupted or partially erupted permanent teeth. No mobilities or coronal fractures are evident, nor is there any evidence of occlusal attrition.

Neither auscultation nor palpation of the temporomandibular joints is possible, as the patient is unable to follow verbal commands.

Head and facial features are suggestive of Fragile X syndrome. (See: Fig. 2) The body of the mandible is somewhat elongated; the nose is prominent; the head has somewhat of a triangular shape, and the patient readily averts his gaze. Upon further inquiry, the father indicates that the patient also exhibits macroorchidism although he reports that no physician or dentist has suggested a work up for Fragile X.

Radiographic imaging is complicated by the patient's behavior; however, a six-image digital radiographic mini-

panel is obtained. Radiographs are essentially consistent with clinical findings. There are two apparent radiolucencies at the apices of the two mandibular central incisors. (See: Fig. 3) Numbers 24 and 25, however, exhibit no clinical evidence of decay.

Dental Diagnoses:

- Severe gingivitis
- Clinical gingival attachment loss RUQ
- Occlusal caries #s 2, 5, 16, 18, 31, 32
- Profound class II skeletal malocclusion
- Probable candidiasis palatal vault

CARE PLAN:

Initial Plan of Care (Today):

Note: Father indicates he prefers comprehensive treatment be rendered in the operating room under general anesthesia.

- Obtain palatal epithelial specimen for cytology.
- Rx: Fluconazole 100 mg. Disp: # 10. 2 tabs day 1, then 1 tab daily for 9 days.
- Order Fragile X DNA test and high-resolution chromosomal analysis. (Have results prior to OR date.)
- Order CBC and PT / PTT. (Have results prior to OR date.)
- Assist parents in contacting State Guardianship Office for guidance on limited guardianship options. (Have

limited guardianship in place prior to OR date.)

- Consult with anesthesia for pre-op work-up.
- Consult with oral surgery / coordinate scheduling oral surgeon and developmental dentist in OR.
- Consult with family physician / advise of findings and of initial interventions. Suggest a psychiatric referral upon completion of dental treatment plan.
- Establish consultation appointment with parents prior to OR date.

Pre-Op Consultation Appointment:

Note: Discuss with the parents the risks / benefits of comprehensive dentistry in the OR under general anesthesia vs. sequenced treatment planning and comprehensive care in the clinic under local anesthesia. Emphasize the compression of the consultation and treatment decision-making process (for all parties, including the parents) in the OR setting vs. the clinic setting.

If Fragile X testing is positive, assist parents in obtaining genetic counseling for themselves and for the patient's siblings.

Tentative Plan of Care (OR):

- Obtain necessary additional radiographs.
- Complete additional three quadrants of periodontal charting.
- Oral surgery to extract four impacted third molars. Suture for heme control.
- Restorative dentistry will be performed as indicated.
- Deep scaling and root planning (four quadrants)
- Place subgingival Minacycline in all periodontal pockets 5 millimeters deep, or greater.
- Peridex lavage. •