Inclusive Dentistry: Integral Management of Pediatric Patients with Intellectual Disability and/or Communication Impairments. Case-Series Reports

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Dental treatment for anxious or fearful intellectually disabled children/adolescents (IDCA) may present great challenges, due to deficits in cognitive, intellectual, language, and social abilities, in conjunction with limited adaptive behavior. In many cases, it is necessary for the Dentist to implement advanced behavioral control techniques. Inclusive Dentistry (ID) considers profoundly each patient's individual interests and likes, including the social and family situations, for choosing the respective personalized plan –contemplating potential risks and benefits– for the behavior control, in order to obtain the maximal possible cooperation of the patient in the dental chair. Through ID, the Pediatric Dental Practitioner aims to alleviate the anxiety and fear of IDCA in the clinical setting, in such a way that these patients are positively motivated, on a long-term basis, for current and future oral care, both at the dental office and at home. This management approach may be a time-consuming method or require more effort by the dentist, but it reaps benefits when applied for many mild-to-moderate (and some severe) IDCA. The Practitioner must possess the knowledge, in-depth understanding, and professional training for the adequate use of ID during the behavioral management of anxious or fearful IDCA. The aim of the present report was to describe four representative clinical cases of IDCA at our Clinic, managed under the philosophical principles of ID.

Keywords: *Inclusive Pediatric Dentistry, Behavioral Management, Intellectually Disabled Children/Adolescents, Communication Impairments.*

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INTRODUCTION

Anxiety and fear from children toward the dentist and dental procedures are important issues that contribute to the avoidance of oral preventive care and treatment.[1] Dental anxiety is the child's emotional state that may precede the actual encounter with threatening stimuli related to oral treatment, which often is not even identifiable. Dental fear is a normal reaction –although sometimes exaggerated or irrational– to a perceived or known threat or danger (e.g., physical injury) in the clinical setting.[2,3] Both behavioral responses are frequently linked to increased pain perception, crying, diminished cooperation, even aggression, by the patient, thus demanding more treatment time and resources in the dental office.[4] Fear and anxiety may cause stress in the Pediatric Dental Practitioner, delays in treatment, and unsatisfactory technical results.[2] This concern is particularly evident in children with special health care needs (SHCN). The American Association of Pediatric Dentistry (AAPD) defines SHCN as "any physical, developmental, mental, sensory, behavioral, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention, and/or special services or programs".[5] The etiology of the different disabilities in children involves a large number of risk factors both hereditary and environmental.[6] Oral care for these children involves specialized knowledge, adaptation, and accommodative measures beyond traditional attention.

Intellectually disabled children and adolescents (IDCA; for instance, Down syndrome, certain types of cerebral palsy, autism spectrum disorder, severe psychiatric/behavioral disorders, and encephalopathy) are patients who may exhibit a deficit in intellectual/emotional/learning functioning, poor adaptive behavior (personal independence and social responsibility), limited language, and/or the inability to understand the oral treatment, expected of their age and cultural background.[7-9] As a consequence, IDCA patients are unable to cooperate sufficiently or are resistant to certain procedures in the dental chair.[10] In addition to the related medical problems and poor oral hygiene, simple dental procedures, such as dental prophylaxis, preventive measures, sealant placement, taking radiographs, local anesthesia, conservative tooth restorations, extractions, or pulp treatments may pose a true challenge for the Dentist.[8] Thus, the most important factors by the Clinician for providing high-quality routine oral care to IDCA patients are sufficient self-confidence, in-depth knowledge, clinical experience, and professional training.[7]

Early in the 20th century, IDCA were usually isolated rather than motivated to lead fulfilling and healthy lives.[11] However, during the last three decades, intense changes in sentiments toward these people have taken place, resulting in a turn in public health policies toward an emphasis on normalization and inclusion.[11] Currently, the early identification of children and adolescents with special health care needs, general management for their condition, and the administration of oral care is recognized as a need and a right, including the development of different strategies consisting of exhaustive psychological/behavioral management techniques, in order to avoid other, more invasive behavioral control methods (deep pharmacologic sedation or general anesthesia).[12] In recent years, a new modality of oral care for IDCA (mild, moderate, and some severe cases), denominated *Inclusive Dentistry* (ID), has emerged in several countries, in which each patient is psychologically approached in a very personalized or individually orientated manner. This method consists of deep knowledge by the Pediatric Dentist concerning each child's personal life aspects (personality/temperament features, cognitive level, likes, family environment, home characteristics, schooling, learning skills, etc.), intensive and constant verbal and non-verbal communication (communicative guidance), and the comprehensive employment of traditional methods of behavioral control techniques, such as desensitization, modeling (direct observation) techniques, tell-show-do, voice control, play, distraction, the use of mirrors, and positive reinforcement, always within a clinical context full of respect, tolerance, empathy, love, flexibility, and perseverance. The process also includes a previous thorough individual-risk assessment, correlating the child's general health status, collaboration level, and oral needs. All of these tasks are carried out in close conjunction with the parents/caregivers in order to familiarize the patient with the dental setting in a safe environment and can last for even several sessions until reaching a fair level of cooperation when the child is in the dental chair. For some unusual severe cases (bedridden pediatric patients, children/adolescents with limited mobility, under palliative care, with dementia, etc.), ID also comprises the modality of home oral care provided directly by the dental team, in a multidisciplinary fashion, especially in oral-related emergency circumstances.

The aim of the present report was to provide an overview of the philosophy of ID for children with special care health needs, through the description, treatment, and follow-up of four representative cases of extremely anxious/fearful pediatric patients approached with this recently introduced oral management modality.

Case Reports

It is noteworthy that, for the practice of ID in our Pediatric Dentistry Clinic, there is an extensive interrogation process addressed to the patient´s parents in order to know in depth the individual patient's living environment. Diverse questions are included, such as medical antecedents, current or past psychological, physical, or language therapies, familiar surroundings, and life (relationships with parents, siblings, and other close relatives), likes, fears, daily activities, favorite foods, personal and oral hygiene habits, social life, school relationships, toys, TV programs, among others; however, not all questions are always applied, depending on each patient's health condition. The obtained information is useful for creating an individualized "sociogram", in which the principal contextual features of the child's life are described for designing a personalized behavior-management plan. Furthermore, all dental and behavioral procedures were thoroughly discussed with, and approved by, the parents/caregivers through the signature of an informed consent form. Each patient reported here was orally treated in an especially designed closed operating room.

Case 1: Pediatric patient with Down syndrome and moderate intellectual disability

A male child (aged 7 years, 7 months) came to the appointment with his mother at our Pediatric Dentistry Clinic, seeking dental treatment by "putting the patient to sleep", referred by a local General Dentist. During the initial oral examination, the child was very anxious, fearful, and uncooperative (Frankl scale I). Several small carious lesions were detected. In sessions 2 and 3, fair communication, rapport, and trust were gradually allowed to emerge through the formation of a teacher/student type relationship, by means of the asking simple questions or commands by the Practitioner, with active/reflective listening by the patient; self-disclosing assertiveness techniques, modeling (using the child as the "dentist" and the mother and a student as the "patients"), visual information (pictograms), toys (puppetry), and children's background music were also used during this exhaustive communication process. Commonly used dental instruments were carefully shown and manipulated and oral hygienic measures were comprehensively taught to the child and his mother. At the third appointment, the child exhibited a better cooperation level, which permitted taking two periapical x-rays and a complete dental prophylaxis with the use of disclosing tablets. During sessions 5 and 6, behavioral control techniques (conditioning with the Tell-Show-Do technique, voice control, and distraction) were continuously employed, thus achieving more cooperation by the patient in the dental chair, counting on the constant collaboration of the mother. From appointment 7 on, the child entered the clinic without his mother, sat in the dental chair on his own, and opened his mouth spontaneously (Figure 1). Therefore, it was decided to start the dental restorative treatment with glass ionomer obturations,

Figure 1. A child with Down syndrome and moderate intellectual disability successfully treated after several sessions of intensive behavioral approach (modeling, toys, and verbal reinforcement).

under local anesthesia and rubber dam isolation employing atraumatic clamps. The cooperation level was rated as good-excellent (Frankl scale IV), and it was observed that the child liked to be treated while the dental student sang children's songs (particularly the Chilean/Mexican song "Pin Pon" [https://www.youtube.com/watch?v=vHc8ZYMGn7c]). The patient continues being assessed every 3 or 4 months.

Case 2: Pre-adolescent patient with autistic spectrum disorder

An 11 years, 7 months old male patient presented with his parents at our Clinic, referred by a General Practitioner, due to "impossible management", requesting oral examination and treatment. The autistic disorder was diagnosed when the child was 4 years. Initially, the patient exhibited a Frankl-I behavioral level, with significant anxiety and fear, manifested by constant yelling. The oral examination revealed the presence of abundant dental plaque and calculus, particularly on the lingual surface of the lower anterior teeth; no caries lesions were detected. This examination could not be carried out with the patient in the dental chair. During session 2, the patient and his parents were instructed on tooth brushing, using a fluoride paste with 1,450 ppm, (no more than a pea-sized amount). The child became a little more relaxed. He was conducted on a "guided tour" throughout the entire Clinic, observing particularly well-behaved patients. Additionally, some dental instruments were displayed and their use was explained, including the slow-speed handpiece sounds. Diverse oral hygiene-related pictograms were provided to the parents for use while the patient brushed his teeth at home (Figure 2). The appointment ended with a photograph in which the patient, the student practitioner, and two dental assistants appeared. In session 3, the parents mentioned the patient's improved tooth brushing through use of the pictograms. The child was more cooperative and was able to sit in the dental chair for the first time, during which diverse conditioning techniques were applied. For instance, through the use of the Tell-Show-Do technique, dental instruments were applied to the surface of the patient's fingernail so that the child was able to perceive the sensation; The instruments were again used on the occlusal surfaces of several teeth, with good patient acceptance.

No other dental procedure was carried out. In sessions 4 and 5, exhaustive dental prophylaxis was performed, employing curettes and an ultrasonic scaler. At appointments 6 and 7, pit and fissure sealants were placed on the four first permanent molars. Positive reinforcement and joint attention and vocabulary techniques were constantly utilized during all of the sessions. The parents were always present, following the directions of the student practitioner

Figure 2. This young adolescent with autism spectrum disorder was managed with exhaustive psychological methods including pictograms and verbal/non-verbal communication mainly.

and the dental team. The patient continues to attend the Clinic every 2 months in order to assess his oral hygiene level and sealant status. Now the patient enters the Clinic without his parents and diverse behavioral and distractive techniques are scarcely employed. His current oral health is optimal. The parents often use the provided dental pictograms during the patient's toothbrushing.

Case 3: Patient with total hearing loss

A male patient aged 5 years 3 months attended our Clinic presenting nocturnal and severe acute pain with gingival swelling caused by irreversible pulpitis in the maxillary left primary lateral incisor, which had a preformed metallic crown previously placed elsewhere. Radiographically, it was observed that the tooth had no previous pulp treatment, and there was a radiolucent area in close proximity to the pulp chamber. At that same appointment, the crown was removed to open the pulp chamber, with no local anesthesia. The patient´s behavior in the dental chair was initially very anxious and disruptive (Frankl scale level I); however, the aid of the mother permitted these procedures, especially during the communication of directions, because the child had not yet learned sign language. Additionally, the dental team frequently showed the dental instruments to the patient and let him touch and feel them; some associated pictograms were also exhibited on the laptop screen. The child became more relaxed and cooperative (Figure 3). At session 2, the pulpectomy treatment was carried out, under local anesthesia and rubber dam isolation. The level of cooperation increased notoriously; however, the aid of the mother was again needed, together with the use of thorough non-verbal positive reinforcement. A newly made metallic crown was adapted in session 3, during which no significant behavioral problems occurred. In these appointments, the pictograms were comprehensively employed, which contributed to achieving a quieter and safer clinical environment. The child and his mother received exhaustive instructions on oral hygiene; the patient remains under close follow-up.

Case 4: Adolescent patient with dysmorphic syndrome

A male patient (15 years of age) presented at the Pediatric Dentistry Clinic for dental treatment with a diagnosis of dysmorphic syndrome, neurodevelopmental delay, severe deafness, blindness, and sequelae of cleft and palatal fissure. The parents noted that "We think he has a toothache and it is very difficult to brush his teeth"; they also mentioned that their son was very strong and he used to fight when they attempted to open his mouth. The mother also revealed several past episodes of bites and physical lesions to her hands from the struggles between them. Thus, she had decided not to attempt to clean his teeth anymore. The intraoral examination exhibited generalized severe inflammatory gingivitis and abundant dental plaque and food debris, as well as previous multiple restorative treatments performed under general anesthesia. During this first visit, complete dental prophylaxis was performed with careful use of a mechanical mouth opener. For the next 14 days, chlorhexidine rinses were indicated twice daily, together with tooth brushing, and the application of a chlorhexidine-moisten gauze around the teeth in the morning and before the sleep at night. For facilitating these procedures, a friendly acetate thimble customized for use as a mouth prop was specifically confectioned to the mother's index finger (Figure 4). This device was fabricated directly on the mother's finger, which was protected with a piece of a surgical glove and a separator varnish layer, as follows: the "gloved" finger was covered with cold-cured acrylic resin; while the acrylic was curing, the finger was introduced several times into cold water to avoid undesirable heating. Over the resulting acrylic model a soft ethylene-vinyl acetate sheet (thickness, 4.0 mm) was adapted using a vacuum pressure-forming device; the heated sheet

Figure 3. This child with total hearing loss was approached through comprehensive visual communication. His behavior and cooperation level in the dental chair was later considered as "definitely cooperative" (Frankl scale IV).

Figure 4. An adolescent with dysmorphic syndrome. A soft acetate thimble was especially fabricated and adapted to the mother's index finger. This device notoriously improved the practice of the patient's oral hygiene at home.

was pressed against the model, followed by vacuum forming for 15 s and compression molding for 1 min; finally, after cooling, the device was trimmed. Once the finger thimble was properly adapted, the mother received instructions for practicing its use directly in the child's mouth, with the child in the dental chair. Fifteen days later, and thanks to the mother's noteworthy performance, gingivitis had significantly diminished. Since then, the patient has been orally examined in regular fashion. His current oral condition is good. Chlorhexidine is still regularly applied and the child has become used to the finger thimble.

DISCUSSION

Pediatric patients with an intellectual disability need special attention during dental care, particularly if this care causes significant stress in the child.[13] The most important features of anxious and fearful IDCA interfering with oral care include hyperactivity, impulsiveness, distractibility, agitation, persistent fighting, poor language comprehension, irritability, sudden mood changes, and a decreased ability to follow directions.[6,14] According to the AAPD, the behavioral control of pediatric patients with disabilities is a process by which the dentist can identify the level of cooperation and related problems in the dental chair, design strategies for solving cases of fear and anxiety, and develop communication, empathy, and self-esteem in the patient.[9] This process is accomplished through an adequate interaction involving the Practitioner, auxiliaries, and the patient and their parents, with the purpose of providing quality oral care and promoting a child's positive attitude toward dentistry; on the other hand, behavior guidance techniques should not include punishment, power assertion, or attitudes that hurt, shame or humiliate the patient.[4] These principles must be thoroughly applied when anxious IDCA are orally treated. However, many Clinicians find several difficulties while providing oral care to patients with disabilities, including deficiency of professional training, insecurity, ergonomic limitations, changes in routine tasks in the consulting room (physical adaptations and special equipment), and lack of scientific knowledge.[12]

At present, it is very important to address the issue of the inclusion in Pediatric Dentistry as carried out by sufficiently trained Practitioners able to provide preventive and comprehensive oral treatments to IDCA, a vulnerable and increasing population worldwide. Parents of children with special health care needs demand more and more dental attention with the same quality and costs with regard to the general population. ID considers it an ethical duty to offer quality dentistry to any person, independently of her/his socioeconomic level, ethnicity, health or mental condition, without excluding or discriminating against anyone. This management modality takes into account the reality and needs of every patient with extensive sensitivity. The most important purpose of ID is to provide an integral and social approach to oral care following a personalized well-designed treatment plan.[15] Unfortunately, many countries lack public health services that provide specialized care for this vulnerable population –particularly those living in situations of poverty–, hindering access to prevention and treatment for oral disease.[9] On the other hand, IDCA are nearly twice as likely to have unmet oral health attention needs with respect to their peers without some type of disabling condition.[14]

Methods for managing any type of misbehavior aim to avoid unpleasant and unproductive confrontations, in a trusting environment that facilitates the ability of the child with disabilities to accept care, as well as to enhance the quality of work and efficiency of the dental team's performance.[1] For these cases, the Pediatric Dentist should take into account the cognitive development of the patient, as well as the existence of possible communication deficits (e.g., hearing impairments, autism spectrum disorder, or short attention span) when employing the different behavior- modification techniques; for example, when the dentist decides to use audiovisual electronic devices.[5] Another common practice in Latin-American countries is the employment of affectionate physical contact for reducing fear and anxiety, in the form of kissing on the cheek, patting, praising, and hugging.[1] However, in some cultures, the touch given without accompanying proper verbal comments by a stranger can be perceived by some children as threatening or unfriendly, which may give rise to stress and insecurity. Some additional useful measures are allowing the patient to hold and manipulate toys, mirrors, or dental instruments, or the raising of a patient's hand to stop treatment. It is also essential to encourage the professional to continue to coax or persuade them when they exhibit signs of poor cooperation.

Other important considerations to take on account when practicing ID in intellectually disabled patients are the following:

- Very early oral clinical examination of IDCA is essential. According to Soares-Salles and colleagues,[9] if General Dentists or Pediatricians were to refer their patients to a Pediatric Dentist when the first tooth appears or before the first year of life, an enormous impact on the long-term oral health on intellectually disabled children would probably be observed.
- Prevention of oral disease mainly focused on feeding practices and dental hygiene must be closely controlled and followed up, especially at home. Maintaining good oral health in IDCA is crucial for adequate mastication, digestion, esthetic appearance, speech, and general status.[16]
- The employment of mouth props or finger thimble props is extremely important. Physical restraining devices to control the movements of the extremities, such as papoose boards, pedi-wraps, tape straps, and bed sheets, should be rationally considered by the Dentist and carefully discussed with the patient's parents/caregivers.[6,9]
- The use of positive pre- and trans- dental appointment imagery, in which positive images (short videos, photos, pictograms, or drawings) of dentistry and well-performed dental treatment are shown, is also quite helpful.[4] As mentioned previously, the parents are previously interviewed on their child's likes (colors, food, TV programs, toys, hobbies, and behavioral attitudes at home) in order to create the child's individualized "sociogram", which serves to design personalized pictograms, according to the information obtained.

Additionally, in difficult cases of disrupted or wandering attention (e.g., autism spectrum disorder, attention deficit hyperactivity disorder), the joint attention (JA) method is a useful strategy for avoiding unnecessary distractions in the dental chair.[8] This process promotes adequate communication and language learning through the coordination of looks between the child and an object.[17] JA

consists of drawing the patient's attention to a stimulus or event in the dental environment using a cue, such as gazes or gestures. Thus, the patient shares the focus on an item or area with the Dentist. For example, the Dentist points to an object-of-interest that attracts the child's attention to that object; JA is reciprocated when the patient focuses on the object being referenced by the person providing the cue.[8,17]

CONCLUSIONS

Through the judicious employment of ID principles, Pediatric Dental Practitioners can create a safe and friendly clinical environment with regard to the dental chair when treating IDCA. It is fundamental for the Dentist to be knowledgeable concerning each patient's behavioral features and the level of involvement needed to achieve successful integration into oral procedures and a reduction of in-office time. This management modality is very useful for providing oral care to mild/moderate (and sometimes severe) intellectual disabled children and may help the patient to better cope with dentistry. Thus, the Dentist and the auxiliary team can significantly exert an impact, not only on oral health but also on the quality of life of these patients with special health care needs. Finally, we recommend the Pediatric Dental Practitioner to receive supplementary and exhaustive training in order to carry out the best ID-based oral practice; additionally, this alternative management philosophy could be incorporated, in the near future, in the Pediatric Dentistry specialization or in updating academic programs worldwide.

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