

## Education and dentistry: advanced synergy in the dental treatment of children with autism; a pilot clinical trial

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### Abstract

**Background.** From the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), autism is considered a pervasive developmental disorder. It manifests as a behavioral syndrome characterised by impairment in social interaction and communication, restricted interests and activities, as well as repetitive and stereotyped patterns. Such profile renders prevention measures and dental care seriously compromised so that usually autistic children are treated and cared following general anesthesia.

**Aims.** We aimed at developing a target-specific educational approach allowing to avoid general anesthesia in autistic patients subjected to dental care treatments (e.g. sealing, plaque ablation, minimal carious lesions etc.); such protocol should also facilitate the implementation of prevention measures.

**Design.** It is proposed a target-specific educational research protocol adopting individual strategies and methodologies, including Augmentative and Alternative Communication (AAC) for patients with speech and language impairments. The dentists are trained by the educator, who acts as a filter between the patient and the medical team. The team is required until a relationship of trust with the patient is built and the dentist is able to continue independently

**Results.** We present a pilot clinical trial in which out of 34 patients between 6 and 12 years old showed a positive response to the application of the protocol, allowing the execution of dental therapies together with a long-term prevention programme and in 32 of them the general anesthesia was avoided. Negative results regarded two patients who had not undergone any behavioral, psychomotor or speech rehabilitation therapy

**Conclusions.** Though the results should be considered as preliminary, the application of the method with the synergistic action of the people in the team allowed the execution of dental therapies. Given the positive outcomes, the Pediatric Dentistry Unit of the Umberto I Hospital (Rome) decided to continue the trials following such methodological approach, in order to improve patient compliance in autistic children and to avoid the operating room.

**Keywords:** autism, prevention, oral health.

### Introduction

Autism spectrum disorders (ASD), also known as pervasive neurodevelopmental disorders, have an estimated incidence of one every 150 (Rice et al., 2007) and are characterized by social impairments,

communication difficulties, repetitive and stereotyped behavioral patterns and limited activities and interests. For patients with such kind of disorders dental care requires special procedures and adaptations. Actually, many patients with moderate or slight intellectual disorders can be successfully treated with some general

attention in the procedures. Such patients learn and adapt slowly and with difficulty. Normal daily activities such as tooth brushing and getting dressed as well as understanding the behavior of other individuals constitute a challenge and a major difficulty for the parents.

While most patients with psychiatric disorders do not pose particular problems to the dentist, in autistic children a major obstacle arising during dental care treatments is anxiety. A dentist room, with its peculiar environment and equipments, may represent a very fearful stimulus. Some patients react with overt uncooperative behavior such as crying or physical and verbal aggression in order to avoid the treatments. In autistic children it is often more difficult to interpret in advance the signs of fear and anxiety and thereby to prevent the loss of cooperation, but it could be possible to carry out dental care when such anxiety signs are recognized. People affected by intellectual disorders have significantly more untreated caries and a higher prevalence of periodontitis and gingivitis compared to the general population (1,3,5,8,11,12,15).

The first case that came to our observation was a 12 years old autistic patient with a destructive carious lesion on 3.6. For this patient the general anesthesia was unavoidable, since the canal root therapy requires a period of time sitting on the chair, which is too long for. Notably, the educational approach on this patient allowed to carry out a first medication and after the intervention he maintained a good level of collaboration during the next visits. This first positive case motivated the team to implement a standard protocol intended as guidelines to approach such kind of patients, more than a rigid schema. In fact we could note that a diagnosis of "autism", common to all our patients there are multiple, individual facets of the disease (autistic spectrum). The dentist must realize that autism is not a "label" characterizing a category of patients, but must adopt individual, case-based strategies of approach.

In order to improve by an educational approach the response to endodontic dental treatments in patients showing "uncooperative" behavior (e.g. autism), in 2008 at the Unit of Pediatric Dentistry of the Policlinico Umberto I Hospital (Rome), a team consisting of a teacher-educator, two dental hygienists and three dentists, was constituted. Patients selected for the trials were in pediatric age and showed serious developmental disorders cognitive-behavioral rules, relational problems and speech difficulties.

Upon a two year intensive team work, an "educational sensory-based" method was established. It focuses on peculiar attitudes of each patient and how they may be selectively modulated in order to facilitate dental care operations, management and maintenance either in hospital and at home also thanks to the valuable collaboration of the families (5,8,12,16).

In this pilot study we had two main goals: i) to demonstrate that through an educational approach it is possible to carry out a series of minimal dental intervention (such as small carious lesions, plaque ablation, control visits) without recurring to general anesthesia; ii) evaluate the effectiveness of a collaboration between pedagogists and dentists for patients with special needs.

## Materials and method

**Training:** the dental team is trained on autism issues and the related educational procedures.

**First meeting with parents:** in the first meeting, parents are thoroughly informed about the educational approach adopted across each step of dental treatment. Then they are instructed about its value as a support to the dentist work. Finally, they are asked about all the interventions, psychological, behavioral, motor, or other speech therapy performed in the past on their child. All the available information about the patient is recorded on a chart together with the medical diagnosis of autism and a signed written informed consent form was obtained from the parents for treatment. This procedure allows an understanding on how the child was approached and treated, hence his potential ability to adapt to the proposed educational intervention. It also helps to identify more easily acquired and emerging skills that are essential to achieve collaboration of the patient upon dental treatments (e.g. imitative/associative ability, or to point finger at something). Following the meeting parents are also asked to list the behavioral and language signs of "liking" and "disliking" of their autistic child, including for instance stereotypy or echolalia. Parents are invited to bring the filled list in the subsequent appointment in order to be able to recall in detail as much information as possible. The acquired material is essential for the operators to identify the patient signals during the treatments and to achieve the best management in terms of time, environment and relationship with the patient. During the first meeting with the parents, the autistic child is present so that the educator can observe his behavior and have opportunities for spontaneous interactions. There are no time limits for the conversation and the atmosphere should be relaxed for the parents, in order to obtain the maximum amount of information and a good cooperation for the maintenance of proper oral health state.

**The first visit:** the educator, who has first established a relationship with the patient and his parents, picks up the child in the waiting room and accompanies him into the therapy room, without the parental presence. All dental therapy is performed in a room separated from the remaining open space of the dental ambulatory. This

room will remain the same until the end of each dental care session. At the end, the dentist will bring the child by hand to his parents in order to further strengthen the bond. All cues concerning environment, timing and mode of the first approach should be derived from the information list received by parents. However, it is important that everything remains in a perspective of flexibility, reversibility and adaptability to meet children needs and to be prepared to unexpected events during dental therapy.

*The environment:* the environment should be conceived in order to prevent distractions during the therapy. It should be safe for the child (e.g. avoid the presence of dangerous liquid that may be ingested) and for the operating team (e.g. avoid the presence of objects that may be pulled by the patient). The room should be equipped with a screen to allow the patient to watch his favorite cartoons, while a headphone set may be also available in case the child prefers to remain more isolated. These equipments will also allow to listen to music and to use videogames. These various entertainments are represent for the autistic child tools to release emotional tensions and to give motivation to work or just to relax. Timing for habituation is adjusted on the patient needs in relation to the manifested behaviour. at first, it consists of 15 minutes for the sensory approach to the tools, sitting still, and subsequently 5 minutes for the dental intervention.

*The approach:* in the first observation the patient will be checked for his ability to understand and to promptly react using a sequential depiction of the therapy, in accordance with the Augmentative and Alternative Communication method (AAC). Sequence of images will be shown on a rigid panel representing all the steps of the dental intervention. If necessary, this could be done for the whole duration of the dental treatment. For instance, it may be shown a picture of a diseased tooth that needs to be cared by the dentist. Pictures of the relevant instruments employed are also used as well as images of cured teeth, SMILE-comics, tempting ice creams and any other reward that could motivate the child to stay on the chair. Image choice will be driven by its success in communication with the child and could be represented by a drawing or a photo. During the first visit it is important to create opportunities for familiarization with the environment and with the dentistry tools. The educator is responsible to achieve this task proposing several activities to do with the patient. In this phase of the sensory education the child should become familiar with his mouth and show confidence to dentistry.

*Operative sequence (flexible according to patient needs):*

1) The child will play with a big plastic mouth and a toothbrush, he will be invited to count its teeth and

touch them especially focusing on those that are diseased. By the use of the plastic mouth the dentist will show how to properly brush the teeth.

2) The child will watch his mouth in the mirror and will see where the diseased tooth is located (it is important to indicate it and that the child can even touch it with his finger). If the mirror creates a state of tension, avoid it and use only the patient finger to touch the target tooth.

3) Following the information of the educator the dentist will begin to touch with his fingers the patient teeth, slowly massaging them. Further, he will wrap his finger with a gauze and massage the gingiva. At this stage the educator interacts with the patient through a gesture or communication with the panel-images, encouraging the empathy with the dentist.

4) The sensory perception of the tools is an important phase of the educational intervention. The autistic child should be able to touch all the used instruments, including water and air that will be put in contact with his mouth, even by himself. During the sensory approach the educator constantly observes the child in order to identify his needs or specific reactions that may require the adoption of a different strategy. The sensory approach can take several sessions and its duration will depend on the confidence level of the patient with the dentist and the dental care instruments.

Once the child has acquired a certain degree of security, the dental treatment can take place. The entire procedure requires a time ranging from 5 to a maximum of 20 minutes. The educator is intended as a support in observation and to suggest educational strategies, until the team will not become independent in managing the relationship with the patient. At the end of each session, the educator will explain his observations concerning not only the child behavior, but also the dentist one. In this way a continuous training on communication and body language will be given to the medical team together with a formation on teaching and learning. It will also provide important information to improve or change the used educational strategies when not successful.

The pilot study have received formal review and approval by Board of Department of Oral and Maxillo-Facial Science, Unit of Pediatric Dentistry, of the Policlinico Umberto I Hospital (Rome).

## Results

The trial was carried out between 2010 and 2013, involving 34 autistic children of both sexes, aged between 6 and 12 years, at the Department of Pediatric Dentistry of the Policlinico Umberto I Hospital (Rome). Thanks to the educational intervention approach it was possible to treat 30 patients with lesions of their deciduous teeth without recurring to general anesthesia (Fig. 1). Dentistry

mirror and stylets, excavator, turbine and other tools were used to seal the molars. In addition, after 4 sessions on average, the collaboration time recorded from the patients increased from 5 minutes up to 20-25 minutes. Good results were obtained with the oldest patient (12 years), who had a destructive carious lesion on 3.6, requiring a root canal therapy. Through the educational intervention it was possible to make all the first medications without local anesthesia, but for the root canal therapy the general anesthesia was unavoidable. Nevertheless, it was important to see how the educational intervention during the early treatment steps was sufficient to create a cooperation, which was also maintained through all the control visits subsequent to the operating room. After one year this child returned to the department for a fractured tooth. He was confident and easily allowed the dentist to take his dental fingerprints. The last case showed only in part positive results, e.g. ability of the patient to sit and remain on the dental chair and mouth introduction of mirrors or dentist fingers for teeth counting. Possible explanations may be the fact that this patient had not been followed by any psychological/behavioural rehabilitation center for two years and that after four meetings in our structure the parents gave up because of the amount of travel hours to reach the department. At that point it was decided to test the validity of the protocol in another context, the CERRIS (Rehabilitation Research and Education Center for Social Intervention) of the ULSS 20 (Verona). There, four autistic patients, 2 males and 2 females between 6 and 12 years old were subjected to our educational intervention approach. As a confirmation of our protocol, we obtained for three cases the same positive results in terms of prevention and care treatments without general anaesthesia. We were able also to perform an extraction of a deciduous tooth and an ozone therapy. For the fourth patient, who was not receiving any rehabilitation therapy since a year, we encountered similar difficulties and negative patterns as well as limited outcomes as recorded for the aforementioned patient visited in the Department of Pediatric Dentistry in Rome. For this child it was only possible to make a fluoride treatment. It is likely that the effectiveness of the approach may depend also on the rehabilitation process followed by the patient.

## Discussion

In Italy, many families are forced to give up dental care for their autistic children in part because of elevated costs but mostly for the lack of properly trained medical personnel, particularly in the psychological/behavioral management of the patient. As a consequence, the treatment of such cases is usually resolved recurring to general anesthesia.

We developed a specific protocol by which the “teacher-educator” can work with the dentist taking a well-defined role both as a trainer of the doctor and as a guide for the patient. His role also extends to the family context to enable a process of prevention supervised by dentists and dental hygienists. The educator, well trained in turn by the dentist team, devises and coordinates an educational sensory method through which the patient improves its level of cooperation by extending its time of resistance in the dentist armchair.

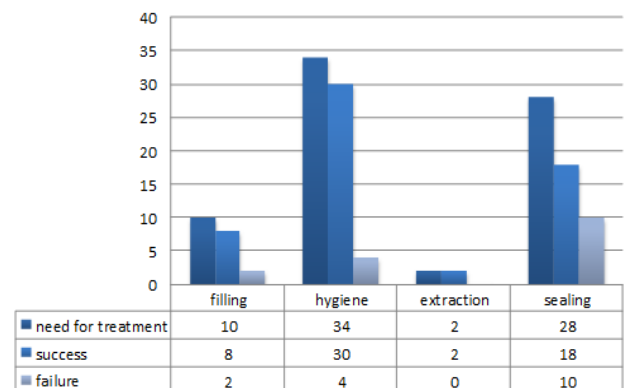


Fig 1: treatment

Pedagogy, defined as the science of education, operates in various contexts to understand and act on all processes and educational problems of infancy, childhood, adolescence and adulthood. Special educational skills and attitudes for disabilities have been developed in Italy and The Netherlands first by Maria Montessori (1870-1952). We are proposing here a figure of teacher-educator who has expertise in communication, education of disabled people in general and in the specific case of this research, of autism and behavioral disorders (2,6,10,18). This figure must provide the clinician the basic strategies and the communicative skills to understand and cope with the “difficult” patients. It must then stimulate dentistry problem solving abilities and devise educational strategies to deal with behavioral problems and sudden reactions/situations otherwise unmanageable. With such a figure behind, the dentist has to develop a new way of approaching the patient, with special attention on feelings, perception and observation.

Our experience has put as a first priority the need to plan for the medical team a period of training on mental disability and autism, both in theory and practice with briefing to identify targets and implement procedures and debriefing to discuss strategies and activities carried out together with the problems encountered. With regard to the activities of the educator in direct contact with the autistic patients, these are aimed at redirecting and modifying the behavior of the patient to facilitate dental treatments. The research team has worked in a continuous synergistic way to identify and satisfy the

needs of both the dentist and the patient, with special focus on environmental variables both social and physical.

In the department of Pediatric Dentistry it was made available a box adjacent, but separated from the open space and with an own private entrance in order to offer the autistic children a 'appropriate care. The teacher has given precise indications for the organization of the physical and social environment receiving the disabled patient, which should consist of repetitive and routinized patterns because of the lack of adaptability to changes typical of autism. The dentist is the crucial figure when working with autistic individuals being the only point of reference of the patient for the whole duration of the treatment, in order to avoid excessive emotional impacts. Among the environmental variables, it is also important the management of the relationship with the parents, whose participation was decided only after careful consideration of the whole team during the briefing.

In the patient all sensory channels are stimulated, but especially touch, through which he familiarizes with the equipment (gloves, cotton, water, air, mirror, explorer, excavator, turbine) and with parts of his mouth as well. In this way the autistic child learns about the state of his teeth, gingiva and treatment methods and tools. Furthermore, the patient should be aware in advance of the intentions of the doctors, building balanced relationships of trust sustained over time. An added value of this protocol is obtained in case of sensory/cognitive biases in the patient. In this case the experience can become an opportunity to improve and/or compensate such biases. The young patients come into contact not only with the dentistry instruments, but also with doctors, building relationships of trust, enabling the implementation and extension of health care and visits for preventive purposes that could also be valid in contexts other than dental care.

The autistic patient, through such educational intervention, also becomes aware of his own pain, improving to communicate it more properly, hence improving his cognitive social competencies in interactions not only with his body, but also with other individuals. The method could be a valuable educational and sensory support also in patients affected by other kinds of behavioral and cognitive disorders, since it does not use a verbal language, but sensory analogues of gestures, movements, body postures, proxemics, gaze and tones of voice, integrating all sensory channels. To communicate with patients, we used Augmentative and Alternative Communication. Through a logical and chronological sequence of images the patient can place himself in the new environment, from the instruments to the people, strongly minimizing the "novelty" stress. The effectiveness of this communication strategy could be seen directly on the patient, who remained more self-controlled, strongly reducing high distress states. The potential of such educational intervention to improve patient compliance with autism would not only facilitate the work of the dentist, but will also ensure a path of prevention which results in the maintenance of both deciduous and permanent teeth in physiological time, avoiding the onset of carious disease with a gain over the entire palate, chewing and speech development. It therefore becomes important to begin such educational programs as early as possible, even if there is not an actual urgent need, in order to familiarize with the environment, noise, smells and dental personnel through the use of hands and instruments within his mouth. We should consider the results of this experience as preliminary, with the goal to design and conduct more systematic clinical trials that could fully adhere to the CONSORT statement (19).

**What this paper adds**

The behavioral profile of autistic children, which are very prone to anxiety in new situations, renders prevention measures and dental care seriously compromised so that usually they are treated and cared following general anesthesia. This paper reports and presents practical suggestions based on a three year planned experience with autistic children.

**Why this paper is important to pediatric dentists**

It highlights the importance to use an educational approach to improve the relationship and dental care success with the autistic patient.



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