

UPDATE

Ethical Considerations In Dental Care For People With Developmental Disabilities

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Developmental disabilities exist in children and adolescents, enabling them to live an independent and self-governing life, requiring special health related services. We are intended to inform dental professionals in planning and implementing a dental treatment for people with developmental disabilities. Cerebral palsy is defined as being a group of motor abnormalities and functional impairments that affect muscle coordination, and characterized by uncontrolled body movements, intellectual disabilities, balance-related abnormalities or seizure disorders. These patients can be successfully treated in normal dental practices, but because they have problems with movements, care must be tailored accordingly. Down syndrome, a very common genetic disorder, is usually associated with different physical and medical problems, intellectual disabilities, and a developmental delay. These patients can be treated with success in dental offices, this way making a difference in the medical care for people with special needs. Autism is a neurodevelopmental disorder characterized by impaired social interaction, verbal and non-verbal communication and by restricted and repetitive behavior. Self-injurious behavior, obsessive routines and unpredictable body movements can influence dental care. Because of the coexisting conditions (epilepsy or intellectual disability), one can find this people among the most challenging to treat. There is a need of greater awareness, focus and education in the field of the unique and complex oral health care that people with disabilities need. Making a difference their oral health positively influences an already challenged existence. According to the ethical principles, patients with developmental disabilities should be treated equitably depending on their necessities.

Keywords: developmental disabilities, dental care, ethical principles

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Introduction

Developmental disabilities, causing functional limitation in more than three aspects of daily life, such as the capacity for independent living, self-care, ability to move, to adapt to the environment, being at increased risk for a persistent emotional, behavioral, physical and developmental condition, therefore constantly requiring health related services beyond that required by apparently healthy youngsters and children in general, exist in children and adolescents all over the world, enabling them to live an independent and self-governing life [1].

Clinical ethics consists in the identification, definition, analysis and settlement of moral issues arising from caring. The main ethical principles used as guidelines for caring and treating patients with disabilities are the following: beneficence, non-maleficence, justice and equity. The principle of beneficence refers to the duty of the doctor of doing what is the best for each patient, while the principle of non-maleficence refers to the duty to do no harm. The principle of justice and equity refers to the duty of treating each patient equitably, depending on the needs. There is also the ethical principle of autonomy which underlies the initiation of the informed consent [2]. The patients with developmental disabilities shall be considered with no decisional capacity, so this will be exercised by the family or by the legal representative.

Cerebral palsy (CP) is defined as being a group of motor abnormalities and functional impairments that affect muscle coordination. Uncontrolled body movements, intellectual disabilities, balance-related abnormalities or seizure disorders can occur along with CP. A part of these patients require a wheelchair and constant day-to-day supervision a lifetime, while others experience a mild form and need less help. According to the associated motor impairments, there are several types of cerebral palsy: spastic (the most common type; exaggerated reflexes, rigid muscles on one side and stiffness in all limbs, sometimes even in the tongue or mouth; seizures; intellectual disabilities; dysarthria); dyskinetic, divided into two categories: athetoid (changes in muscle tone in all areas of the body, slow movements, dysarthria) and dystonic (trunk movements are more affected than limb muscles, resulting in a twisted posture); ataxic (tremors, voluntary movements are not well coordinated, depth perception disorders) and mixed (combination on the anterior symptoms). Although, this kind of disorder doesn't cause oral abnormalities, some pathological conditions are more severe and common in this group than in the healthy population (for example because of the gastro-esophageal reflux, many individuals present dental abrasion). Like children with Down syndrome, those with cerebral palsy can be successfully treated in normal dental practices, but because this patients have problems with movements, care must be tailored accordingly [3].

Down syndrome, a very common genetic disorder, is usually associated with different physical and medical

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problems (e.g. Cardiac disorders, hearing loss, hypotonia, infectious diseases), a mild or moderate, even severe (in a small percentage) intellectual disability, and a developmental delay (for example in speech or language). Taking care of the oral routine and dental treatment of people with Down syndrome requires an adaptation of skills. It is very important to review the patient's medical history because they may also present challenges that have implication for their oral care. Actually, children with moderate or mild Down syndrome disorder can be treated with success in dental offices, this way making a difference in the medical care for people with special needs. Another risk for these patients is mouth breathing which influences the production of saliva, diminishing the secretion (xerostomia), therefore increasing the risk of caries, burning mouth syndrome, gum changes and difficulty in swallowing [4].

Autism is a neurodevelopmental disorder characterized by impaired social interaction, verbal and non-verbal communication and by restricted and repetitive behavior. People with autism appear distant and detached of their surroundings and not reacting properly to common verbal stimuli. Self-injurious behavior, obsessive routines and unpredictable body movements can be symptoms that influence dental care. Having a various range of symptoms and coexisting conditions (epilepsy or intellectual disability), one can find this people among the most challenging to treat [5].

Individuals with developmental disabilities require an interdisciplinary treatment. Maintaining a recommended oral hygiene may prove itself as being very challenging for many children and adolescents with Down syndrome, autism spectrum disorders, cerebral palsy and other intellectual disabilities, therefore putting them at risk for many dental diseases. The access to routine, preventative and curative dental services can pose a quotidian challenge because of environmental factors (e.g. heavy access to dental offices for patients with physical limitations, difficulty in managing the child with intellectual disability by the dental practitioner, the costs of the oral services, difficulty in finding dentists specialized in the care of patients with special needs) and non-environmental barriers (e.g. the reluctance and fear of parents or caregivers). This problem is ranking third with regard to unmet needs of this group of people, following residential and accommodation needs and employment opportunities. In addition, medication containing sugar, in syrup forms, the need to eat often and special diets can increase the risk of caries.

Because of the population growth and the increased longevity, along with the developed, accurate and more improved methods of diagnosis and treatment of the health problems, the number of people with developmental disabilities is higher, concretizing itself in a higher demand for different services, including health and dental care ones. Therefore efforts must be made to ensure that youngsters and children with special health care needs receive the proper adapted oral health care, like everyone else, so that

the oral health status won't have an impact on their health and quality of life.

Children with cerebral palsy, autism and Down syndrome face the most barriers to oral care. Because of their chronic illnesses, this particular group of children has a limited movement or motor function, a poor intellectual apprehension, communication problems and attention disorders consequently facing daily challenges in maintaining a flawless oral health and assimilating oral hygiene habits. Untreated caries, missing teeth, periodontal disease, malocclusions and damaging oral habits are common problems [6-8].

There is a shortage of dentists specialized in providing oral care for children and adolescents with developmental disabilities, and also a lack of skills and knowledge. Therefore, it is imperative for the dental practitioners and health professionals (physicians, dietitians and nurses) to work interdisciplinary in order to give these individuals the care that they need.

Mental and physical challenges affecting the oral care compel dental practitioners to obtain an accurate medical history of the patient, before the appointment, consulting the parents or caregivers and physicians. It is imperative to determine who is legally signing the informed consent for the treatment [9].

The following procedures are intended to inform dental professionals in planning, implementing and successfully managing a dental treatment of a child or adolescent with developmental disabilities, assuring the triumph over the intellectual disabilities, mental, behavior and physical challenges as well as over the oral health problems of the patient [10].

Intellectual disability and mental challenges

Mental capabilities vary. Some of the people with cerebral palsy have some kind of intellectual disability (mild, moderate and severe form in only 25%) and some have normal intelligence.

Limiting their ability to communicate and adapt to their environment and impairing their learning ability, the mental intelligence of people with Down syndrome varies, but it has been demonstrated that they may understand more than can verbalize.

The most important concerns when treating autistic people are communication and understanding problems. Learning slowly and with difficulty and perceiving simple daily tasks as brushing the teeth, washing and getting dressed are major challenges for people with intellectual disabilities like autism. Understanding the behavior of others, relating with them, as well as their own behavior can prove itself to be difficult. Consequently, the dentist is advised to follow and explain simple steps to assure the success of the visit.

The stage has to be set by involving everybody from the dental practice, from the receptionist's caring greeting to the gentle and friendly attitude of the doctor and the assis-

tant. Everybody in the dental office, the entire dental team, should be aware and should pay a special attention to the patient's mental challenges.

The intellectual and functional abilities of the patient are very important, therefore it's important to find out everything concerning the mental status from the parents or the caregivers. Each procedure must be explained to the parents and the caregivers, and most importantly to the patient, at a level they are able to understand. The demonstration of the procedure and the explaining of the instruments being used and of the instructions subsequently to the treatment, impose the necessity to take extra time.

Simple instructions are advisable as well as repetition to compensate potential short-term memory problems. One direction at a time is sufficient, because the patient may have difficulties following more than one. Slow speaking is a must.

Establishing a direct rapport with the patient is very important, even if the parent or the caregiver is present in the room, so address all of the questions and all of the comments directly to your patient.

Since usually long-term memory is unaffected, it is important for the doctor to be consistent in everything he says or does, in every aspect of the oral care. It is also recommended to have the same staff (assistant, receptionist etc.) every time the patient comes to sustain familiarity, and increase the chances of cooperation of the patient.

Verbalizing their needs is often difficult for this particular group of patients, so it is compulsory for the doctor to listen actively, showing the patient whether he understands. To improve the communication, the doctors have to demonstrate a special attention to the whole range of methods they may use to communicate (verbal and non-verbal requests, and all kinds of gestures)

Explaining each procedure before begging it may help the communication with the patient. „Tell-show-do” approach is useful in managing patients with special needs. Take the time to demonstrate each procedure. It can encourage patient's cooperation [11,12].

Behavior challenges

Special needs children that are unfamiliar with a dental practice, with oral care procedures, dental instruments and equipment may exhibit fear. Uncooperative behavior (wiggling, aggressive language, crying, kicking) can be a reaction at the fear factor, trying to avoid the treatment. In order to turn dental care experience into a pleasant one, acknowledging their anxiety and comforting the patient is important. The key of a successful treatment is gaining the trust of the patient.

There are several possible causes and solutions for behavioral problems found in cerebral palsy patients. Frustration is one of the most common problems; when a child has difficulty completing a task, they become discouraged and angry so they may need some help. The inability to com-

municate and walk around freely without the caretaker's presence in its surroundings is also a problem.

Managing the behavior of a child or adolescent with Down syndrome may not pose many problems, because they have the tendency to be warm and very well behaved. Although they can be stubborn, most of them need just a little more time and attention to feel comfortable.

In patients with autism the oral care attempt is more problematic. Invasive dental procedures may trigger violent behavior, presenting even the risk of hurting themselves, like head banging and temper tantrums.

A desensitization appointment is advisable. It can help the patient to get familiarized with the practice, the dental team, instruments and equipment, in a step-by-step process. It may take several visits before the actual treatment. First letting the patient have a sit on the dental unit to get used to it, while the doctor examines him using only the fingers; after that using a normal tooth brush the dentist can start brushing patient's teeth gaining more access to his mouth, so that in the end the patient can be properly examined.

Finding out the effective techniques in managing the patient from the parent or the caregiver is advisable. Early in the day may be a better time to schedule the dental appointment, reducing the waiting time as much as possible. The appointment should be positive and short. The dentist should invite the caregivers to come into the treatment office to ensure a familiarity helping him to communicate with the patient. The dentist can also install a calm atmosphere by holding hands with the patient. Difficult procedures must be postponed until after the patient becomes familiar with the doctor, the assistant and the dental treatment setting and instruments. Encouraging the patient and their parents to bring to the appointment their comfort items (blankets or toys) is also a good idea.

Immobilization should be used only for the team's protection during dental treatment – not as a convenience. Immobilization has no universal guidelines and the consent of the patient's legal guardian is a must. It is advisable to choose the least restrictive technique; discomfort and physical injuries caused by the immobilization should be avoided of all costs.

If all other strategies do not work, pharmacological options can be used in managing some of the patients. In special condition general anesthesia can be advisable, but with caution because of the unpredictable reactions that people with developmental disabilities can have to medication [12,13].

Physical challenges

Although many people with special needs have distinguishing features (unsteady gait, orofacial abnormalities, hypotonia, scoliosis) due to coexisting conditions, specific physical trait isn't always present. Regarding physical challenges is important to pay attention to details. Maintaining a simple and clear path throughout the dental

treatment setting is important. If the patient needs to be moved from the wheelchair into the dental chair it is advisable to ask the parent or the caregiver for instructions to make the transfer smoother. Some of the patients cannot be moved from the wheelchair, but instructions can be asked about the positioning of the chair in order to facilitate the dental treatment by locking the wheels and using a sliding board (transfer board) behind the patient's back. This board will provide support during the dental care for the patient's neck and head. If the patient can be moved, he or she must be placed in the center of the unit to avoid potential injuries. Some pillows can also be placed on both sides of the patient to provide stability.

Seizures are a very common problem for patients with cerebral palsy. During a seizure the mouth is at risk, the patients can bite his cheeks or tongue or may chip a teeth. It is important to consult with the physician who takes care of the patient about the trigger factors, the frequency and the medication used to control the seizures. It is essential as a doctor to know how to control a seizure if it happens during oral care. Removing all instruments from the mouth is advisable along with clearing the area around the dental unit, avoiding with all costs the insertion of any object between the teeth. If the patient has an episode of seizure he or she has to be turned on one side and to have the airways cleared.

In some of the patients with Down syndrome, hypotonia can affect the muscle in some particular areas of the body. When hypotonia involves the mouth, it leads to an open bite, because of the imbalanced forces. Speaking, swallowing, chewing and drooling may be impaired if mastication and facial expression muscles are affected.

Children with autism tend to have extreme reactions to sensory stimulation; they are hypersensitive (over-sensitive) or hyposensitive (under-sensitive). Also they frequently show delays in developing fine motor skills. These are things the doctor has to be aware of in order to give the patient the level of care that he or she needs.

Hearing loss, deafness and visual impairments can further complicate the oral care treatment and the communication with the patient. If any of this senses are affected, using the other ones to connect with the patient and therefore to establish trust and making the treatment a pleasant experience, is advisable. If they have hearing problems, eye contact, removing face masks or maybe asking an interpreter to come to the treatment session comes in handy. If the patient suffers of visual impairments, the doctor should speak clearly facing the patient, telling then each upcoming step, using a descriptive language explaining how each procedure might feel or sound. Even written instructions are useful [14-17].

Conclusions

It is important for the doctors to write in the patient's chart every strategy that proves to be useful when managing their oral care with success. Any unique detail (music, flavors, comfort words, gestures or items) can assure a favorable

result of the treatment making it a pleasant experience for any of the parties involved, it all depends on the patient.

There is a need of greater awareness, focused specialization and continuing education in this less explored field of the unique and complex oral health care that people with disabilities need. Making a difference in a special needs person's life by influencing their oral health may go slowly at first, but with determination, specialization and adopting all necessary strategies the doctor can have a significant impact, positively influencing an already challenged existence, with invaluable rewards.

According to the ethical principles, the patients with developmental disabilities should not be treated differently than other patients. Therefore, observing the fact that any patient, including them, must be treated equitably depending on the necessities; disabilities should not be a criterion in choosing an option of diagnosis, treatment and care.

Conflict of interest

None to declare.

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