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Issues in the Dental Care of Children with Intellectual Disability

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Abstract

Children with intellectual disability are increasingly seen in pediatric and general dental practice. They have a variable combination of intellectual and adaptive dysfunction which poses a challenge to the dental team. The provision of timely and appropriate preventive and therapeutic oral health care is beset with problems which may be influenced by factors related to the patient, caregiver, dentist or health care system. These obstacles can be overcome by sensitizing students and oral health professionals; encouraging home-based preventive services and facilitating access of patients and caregivers to the clinic. Seamless integration of care at all levels may be achieved by building a workforce of dental and allied professionals committed to delivery of cost-effective care aligned to the needs of the patient.

Introduction

Children with special needs constitute a significant segment of the population. In the USA, about 13 % of children from birth to 18 years of age fall in this category. Among them are those with intellectual disability (ID) which is included in a complex group of intellectual and developmental neurobiological disorders [1,2] characterized by cognitive and adaptive deficits of varying degrees. Traditionally, the intellectual disability may range from a mild to profound. The majorities have a mild deficit (IQ of 55-70) and often merge into the general population over time. Those with moderate disability (IQ of 40-55) need life-long supportive services but may live well within their local communities. Those having severe (IQ of 25-40) and profound (IQ of 25 and below) deficits need specialized care with close and sometimes total supervision [3]. The prevalence of ID, derived from studies published in between 1980-2009, has been estimated to be 10.37 per 1000 population with higher rates in low-middle income countries and in children-adolescents as compared to adults [4]. In South Africa the prevalence among children aged 2-9 years was 0.64 per 1000 to 29.1 per 1000 for severe and mild ID, respectively [5]. In the past, a majority of these individuals were on the fringes of society, facing isolation and stigma but in recent years they are a part of its mainstream reflecting a need for a change in mindset of the dental practitioners who will care for them in the community [6]. As a large proportion of the world population live in India and other emerging economies it is not difficult to visualize the enormity of the problem in terms of delivery of appropriate care for these children. The author identified the need for this review while participating in the clinical care of the children with special needs at the local government institute linked to the medical college. In this process, the author had interacted with these children as well as their parents, care-givers and teachers. While there is abundant literature on dental management of patients with special care needs [7], the author considered it pertinent to review the subject with the focus on issues in the dental care of children with ID.

The structure of the review article was: The profile and dental care needs of the ID patient; problems in access to oral health care services (patient and care-giver, dental care team); sensitization of students, dentists and caregivers; delivery of oral health care (dental clinic, restraint, sedation and anesthesia, preventive dental care) and interdisciplinary cooperation. The aim was to provide an overview of the topic for the general dental professionals with the objective of enabling them in overcoming impediments in the delivery of oral health care to these children in the community and to promote interdisciplinary interest in this field. A PubMed search was performed using the search words “Intellectual disability”, “Children”, “Oral health” and 212 journal articles were accessed. Of these 58 were identified as related to ID after excluding case reports, uncommon syndromes and those without abstracts. Thirty two articles addressed prevalence and determinants of oral health status as well as perceptions and treatment needs; nine were review articles; eight were on oral health practice management; four each were on program evaluation and access to care; and one study on instrument validation. Some of the articles are cited in the present review. Further search identified additional articles related to the review subject.

The Profile of the id Patient and Dental Care Needs

The patient of ID is an amalgamation of varying levels of cognitive impairment and adaptive functioning. Within different levels of IQ, the deficits in some adaptive behaviors are evident including those involving communication, interpersonal, social and functional academic skills as well as in abilities like living at home, self-care, work, leisure, health and safety [3,8]. In addition there may be emotional problems, musculoskeletal, visual and hearing impairments, limited mobility or abnormal movements. The use of multiple medications may produce a variety of side-effects and drug-interactions [2].

A systematic review of original articles on oral health of adults concluded that patients with ID had poor oral hygiene as well as higher prevalence and greater severity of periodontal disease than the general population. The caries rates were similar or lower in these patients but they had a higher rate of untreated caries [9]. A study on Indian children with special health care needs estimated a high prevalence of caries (89.1%) as well as poor periodontal health and malocclusion [10]. Australian children with disabilities in the age group 9-13 years had a mean DMFT of 2.2 which was higher than the national average of 1.0 for 12 year old children. This was attributed to medications, diet (snacking and beverages) and poor hygiene. Seventy percent of these

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patients needed assistance in oral hygiene and 90% had periodontal treatment needs [11]. On the basis of the Medical Expenditure Panel Survey 2005, the average dental care expenditure was not statistically different between children with and without special health care needs. The variability in the ability of children with special health care needs to obtain dental care services was explained by the diversity of this population [12].

Problems in Access to Oral Health Care Services

Patient and caregiver

Access to oral health care including preventive and restorative services in the ID patient is limited by physical, psychological, behavioral and economic impediments [11,13]. These include distance from the treatment facility, transportation problems, inconvenience of access and an underestimation of the dental health problems which are overshadowed by the existing medical diseases [14,15]. Varying grades of anxiety and fear of visiting a dental clinic has been observed 27 9% of these children [16] which is not very different from the anxiety exhibited in 26% of a sample of healthy school going Italian children [17]. The perceptions of mother's of patients with Down's syndrome regarding barriers in their care included time, financial constraints and lack of access to the dental facilities [18]. Failure to obtain needed dental care among children with special health care needs has been related to a lower income [19]. While patients with ID are prone to traumatic facial injuries there is often a delay in reaching a dental treatment facility [20]. Medicaid enrolled children aged 3-8 years having intellectual or developmental disability (IDD) were 31% more likely to have a delayed first dental visit in comparison to those without IDD but there was no significant delay in the first recall visit [21,22]. Access to dental care was higher in the persons with disabilities (73.2%) as compared to the general population (70%) in Ontario [14].

Dental care team

Parents and caregivers, over a period, learn to cope with the unpredictable behaviors and responses of the children with ID. On the other hand, the greatest impediment for the dental professionals in the management of these patients is their inability to handle the complex situations posed by them. This comes from a lack of education, knowledge, training and experience in this subject [2,13]. In developed countries, there is no tangible financial gain for the dentist as management of the ID patients is time-consuming and poorly reimbursed with the procedure based payments not accounting for the extra time spent on their care. ID patients undergo similar procedures as those without disability, but much more time has to be spent on preparing and treating them. The results of treatment in these patients are often unpredictable as it is difficult to ensure compliance with instructions [13]. An obstacle in the continued care of these children when they attain adulthood may be the dearth of available and willing general dentists who can transfer these new patients to their practice from the pediatric dentist [23]. In Greece, 79.3% of the oral health care of persons with physical and intellectual impairment was by general practitioners of whom 70% had no special training in their care [24]. In the USA, the mean number of children with special health care needs per available provider was 1792 suggesting that the dental care system had a limited capacity to care for them [25]. The goal of special needs dentistry is to provide the patients who have medical, physical, cognitive and psychological limitations with dental care that is aligned to their individual needs through appropriate novel approaches which extend beyond routine care [26,27].

Sensitization of students, dentists and caregivers

A wide range of approaches have been used by dental schools in USA and Canada to train students on the issues of special needs in children. While 91% of the programs covered the topic, 64% offered it as a separate course. One of the challenges to the success of these programs was curriculum overload [28]. An interactive virtual patient module developed at the University of Kentucky enabled dental students to make decisions in providing sensitive and competent care for these children [29]. In France, an oral health intervention for carers of persons with special needs was moderately successful and emphasized the importance of ongoing training for carers and dental professionals [30]. A randomized controlled trial on the effect of a multi-tiered oral health education program resulted in an improvement in the knowledge, attitude, self-efficacy and reported behaviors of staff caring for persons with ID [31]. Development of innovative learning tools like e-modules for continuing professional development will meet the need of improving the skills of dentists and allied professionals in the holistic care of this population [32].

Delivery of oral health care

The dental clinic

The dental clinic management of the ID patient can be made comfortable for the child, parents and dental staff by some simple guidelines. Except for an emergency, time spent in planning the visit is vital for success. Some of the guidelines are similar for both children with and without disabilities. As a first step, information should be collected on the patient's medical condition, medications, habits including dental hygiene, previous dental visits and their outcome, allergies and medical prognosis. It is relevant to focus on abilities rather than disabilities of these children which should be used to gain leverage in the management of the children. Communication with the primary physician and parent or caregiver helps to identify the problems, expectations and enables the setting of common goals [2,33].

The schedule of appointments should be comfortable for the child and minimal time should be spent in the waiting areas. The easiest access route to the clinic in a busy hospital should be used. The dentist should have free time around the scheduled appointment as the procedure or visit may take longer than planned. Identification of the time of day that suits the patient is important. Some schedule it as the first appointment of the day [2].

The first visit of the ID patient should be a familiarization visit for the child and caregiver to meet the dentist and staff in the clinic. The dentist should address the need for local positional changes for access to the dental chair, ability of the child to open the mouth, respond to commands and tolerance of the proposed procedure. The visual, auditory and olfactory stimuli like operatory light, sounds of hand pieces and water jets as well as smell of medicines should be minimized and arrangement should be made for coping objects (toys) or rewards to be within reach. The child should gradually be familiarized with the instruments [2].

Identification of the need for dental treatment, the influence of the disability on dental treatment, the necessity for caregiver support, precautions, sedation or anesthesia should be made. In case of oral hygiene procedures, it needs to be seen whether they can be performed outside the clinic setting and in case of appliances whether they can be retained. In general, the dentist should aim for maximum treatment in as few visits as possible [2,33].

All dental problems do not need to be treated. While malocclusion

is common in this population, removable appliances require a high level of compliance and fixed appliances may need general anesthesia. Treatment in this situation is often avoided unless the patient is very cooperative [11]. Similarly, the dentist must be aware of the side effects of anti-epileptic drugs (e.g. Dilantin) in the development of gingival hyperplasia for which preventive measures like maintenance of good oral hygiene must be reinforced. The prognosis of the underlying disorder influences the treatment plan and aggressive forms of treatment are avoided in patients with a poor long-term prognosis. As most of these children and adults are not capable of giving informed consent, it has to be obtained from the parent or legal guardian [2,33].

The design of the dental office may not be suitable for ID patients who may have physical disabilities, need wheelchairs, may not be able to climb stairs or may have a fear of closed, crowded spaces and unfamiliar surroundings. A disability friendly hospital and clinic design should address some of these concerns. The structural design should include non-skid tiles, auto-assisted or automatic doors, handrails, prominent signs for locating the service areas and clinics; architectural plan should include convenient parking, special elevators, and the operatory should be obstacle-free [2,34]. Some dental institutions have special clinics for children with special needs while others prefer to treat these patients in the regular clinic with minor modifications.

Restraint, sedation and anesthesia

Most children with mild forms of ID can be managed with usual care. However, patients who have moderate or profound form of the disorder may need adjunctive sedation or general anesthesia. The use of general anesthesia increases with acute, painful conditions and a lack of cooperation on the part of these patients [35]. A study on the use of fixed 50% nitrous oxide/oxygen mixture was successful in 91.4%, with the occurrence of minor side effects in this population [36]. The need for physical restraints was observed to be seven times higher in patients with ID [37]. While this was earlier a popular method to control children during dental procedures, current recommendations are to use it in a limited manner only after desensitization, distraction and acclimatization techniques and not for the convenience of the dental care team [38].

Preventive dental care

Preventive oral hygiene needs to be designed for patient and caregiver convenience and capability. Home-based care requires the setting of realistic goals in community based oral health programs developed by dental health professionals specially trained in the care of children with special needs and delivered or supervised by knowledgeable caregivers. Successful delivery of home based dental care identifies those patients with ID who may tolerate more complex clinic procedures. Difficulty in management comes from lack of cooperation, behavioral problems or poor tolerance on the part of the patient, lack of effective caregiver support or inexperience of the dentist. In these situations, dental professionals may use a variety of behavior modification techniques and sometimes acceptable physical restraint or pharmacological control measures. For consistent maintenance of oral cleanliness the patient and caregiver must be made to appreciate the presence of plaque through disclosing aids and trained in the proper use of the toothbrush. The accretions which cannot be removed by toothbrush may be dealt with by dental prophylaxis [39]. The electric tooth brush has been observed to be superior to the manual toothbrush in removal of plaque [40]. Home oral health care for these children is cost-effective and improves general as well as dental health.

Interdisciplinary cooperation

To overcome factors like lack of trained manpower and finances for providing health services, initiatives like those initiated by the American Academy of Developmental Medicine and Dentistry (AADMD) which involve academic centers of excellence in medical and dental schools to collaborate and provide services, teaching and research as well as community based programs for primary care, intermediate care and private service delivery systems need to be encouraged [41]. Interdisciplinary cooperation between dental hygiene students and school nurses in two academic settings mutually benefited both professional groups. The school nurses learned of the importance of oral health while they mentored the dental hygiene students in behavior management of these children [42,43].

The care of patients with ID is multidisciplinary, involving pediatricians, physicians, pediatric and general dentists, anesthetists, neurologists, psychiatrists, physiotherapists, paramedical personnel, caregivers and parents or guardians. Appropriate and successful treatment can be accomplished by their collaborative efforts in improving integrated or seamless treatment, facilitating training programs, enhancing research and providing support services.

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