‘Emily goes to the dentist’ - oral care for individuals with Down syndrome in the Netherlands

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Summary

This article is primarily based on an Editorial in the Journal of Oral Health and Disability that describes the visits of a patient with Down syndrome named Emily. Oral health care for individuals with Down syndrome and other people with an impairment or disability in the Netherlands is discussed. Due to the syndrome-related oral aspects and specificity, the authors argue strongly in favour of multidisciplinary working within oral health care centres. The dependency of persons with Down syndrome necessitates an appeal to parents, (primary) carers and oral care professionals to work cooperatively to maintain oral health. Client-centred care is mandatory for optimal oral health in this vulnerable group.

Key words: Down syndrome, oral care

Introduction

Good oral care for individuals with Down syndrome and others with a cognitive impairment requires concerted action. Professional care alone is no guarantee of good oral health; support from parents and (primary) carers is of crucial importance.

An example of such a combined approach was described in the Journal of Disability and Oral Health in an Editorial in April 2005. This described a mother’s story about oral health care for her daughter with Down syndrome, including the genesis of the booklet Emily goes to the dentist. The British Society of Disability and Oral Health presented its members with a copy of this booklet. What follows is a review of some of the issues pertinent to people with Down syndrome and the perspective on oral care for people with Down syndrome in the Netherlands following on from this publication.

Down syndrome

About 1,000 children are born with a chromosomal anoma- lity in the Netherlands each year, an estimated 800 of whom have Down syndrome, which is the result of an extra chromosome 21 (trisomy 21). Thus, trisomy 21 is the most frequent chromosomal cause of cognitive impairment. Duplication of the genetic material on the long arm of chromosome 21 gives the specific clinical picture of Down syndrome (Antonarakis, 1993). The clinical diagnosis is usually made soon after birth, based on the baby’s characteristic appearance (Figure 1). Down syndrome often co-occurs with generalised hypotonia, congenital heart defects, joint laxity, higher susceptibility to infections (Reuland-Bosma, 1986), and autoimmune diseases. These comorbidities determine the course of life in children with Down syndrome. In addition, they show growth retardation: individuals with Down syndrome are small people who age quickly. At least one third of the population with Down syndrome greater than 40 years of age show signs of dementia and will develop Alzheimer’s disease (St-Clair and Blackwood, 1985). The severity of the cognitive impairment may vary among individuals; their IQ is around 50 on average, ranging from 20 to 80. On the other hand, their social-emotional development is often faster than that of similar age peers with a cognitive impairment. This observation has contributed to the notion that autistic-like disorders are less frequent in individuals with Down syndrome. Among the population with a cognitive impairment, however, behaviour consistent with the autistic spectrum has been found to occur more often with decreasing level of cognitive functioning (Kraijer, 1994).

Research from the Netherlands shows that this holds true for Down syndrome as well.

In the Netherlands, the primary dental care practitioner is pivotal in the oral care for individuals with Down syndrome and other cognitively impaired individuals. Adequate regulations are in place, ensuring dentists can invest sufficient time and attention for these individuals. Since the implementation in 1990 of the Regulation for Special Care Den- tistry, integrated oral care, under a time based fee system, can be offered to disabled individuals living at home as well as those who owing to relocation lose their right of oral care in long stay residential care units.

Special Care Dentistry (SCD) may be provided in the general practice setting and in centres for SCD. Ideally, the primary dental care practitioner should provide care – close to home. Nevertheless, should the general practitioner feel
lacking in the knowledge, experience and empathy required in the care for this group of patients, (s)he has two options: first, referral to a colleague general dentist with affinity for this group of patients; or referral to a centre for SCD or a paediatric dentist. There are now over 20 centres for SCD in the Netherlands, unequally distributed over the regions and strongly varying in size and treatment possibilities. These centres are in great demand, but capacity is found to be far from sufficient. From the outcomes of a survey in seven daycare facilities for severely cognitively impaired children, it appeared that 32% of them were found to receive no dental care at all, while among children from ethnic minority groups this number exceeded 50% (Houtem et al., 2007). The Dutch Association for Special Care Dentistry (COBIJT) reports long waiting times for treatment under general anaesthesia due to an increasing demand and a failing financing structure within hospitals (Nederlands Tandartsenblad, 2007).

Yet, this is not a plea only for greater capacity of the centres for SCD as the most important mission will be stimulating training of future providers of specialised oral care. Special attention should be focused on preventive dental health measures tailored to the specific patient-groups (Gabre, 1997; Desai, 2001; Van Houtem, 2007). Protocol driven care, on the basis of research and clinical practice ought to lead to high-quality care with predictable results. This in its turn will allow for more efficient use of efforts and resources.

**Conclusion**

A thorough diagnostic process is of crucial importance to individuals with Down syndrome or others with a cognitive impairment. All aspects that play a role in oral care and that will determine oral health in the long term must be accurately planned. Developing tools aimed at a patient’s individual needs, such as the photo book Emily’s mother made for her, is a challenge, not only for oral health care professionals and parents, but also for primary carers. Parents are well aware of the barriers in the oral care for their children with a cognitive impairment. The Dutch Federation of Parents’ Associations carried out a review of parental experiences with oral care for their children with a cognitive impairment (Van Leeuwen, 2004). A plea was made for the recognitions of SCD, as well as for collaboration between general dentists and providers of oral care in the centres for SCD, with primary importance attached to timely referral of children whose treatment poses problems.

Irrespective of the disabled person’s living arrangements, adequate oral care is possible within the framework of the relevant oral health care regulations in the Netherlands. Nevertheless, many people still fail to access care. The long waiting times for dentistry under general anaesthesia, in particular, form a bottleneck. In addition, it is conceivable that, seeing the decreasing number of available caregivers
as well as the lag in scientific research to underpin protocols and guidelines, oral care for disabled people will not be able to fulfil contemporary quality requirements of our time. The introduction in 2004 of a three-year postgraduate programme, leading to specialisation in SCD for people with an impairment or disability (Tandarts Gehandicaptenzorg TG) under the direction of the Dutch Association for Oral Health and Disability (Vereniging tot Bevordering der Tandheelkundige Gezondheidszorg voor Gehandicapten VBTGG) is of great importance in this respect (Broers et al., 2006).

A specific guideline for treatment of children with Down syndrome has been developed in the Netherlands (Reuland-Bosma and Ongkosuwito, 2011) with special attention on retarded growth in facial bony structures (Figure 2) (Cronk et al., 1988), the hypotonia of facial muscles and the frequent occurrence of agenesis (Figure 3) (Reuland-Bosma, 2010; Shapira et al., 2000). This could lead to an unpleasant facial impression which could be disadvantageous for the man or woman with Down syndrome in building social contacts (Langloi and Stephan, 1981). Provided there is a good patient selection, guiding teeth to the right positions, with or without orthodontic management, is very feasible (Chadwick and Asher-McDade, 1997; Reuland-Bosma, 2005).

Individuals with Down syndrome and others with a cognitive impairment will always remain dependent on others for management of oral care. Cooperation between providers of oral care mutually and between each of them with the parents and the (primary) carers is crucial for this vulnerable group of patients, as a means to obtain the oral health that is of essential importance for (social) functioning.

References