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Oral health in children with Down syndrome: Parents' views on dental care in Flanders (Belgium)

ABSTRACT

Aim Evaluate the views and knowledge, regarding dental care, of parents who have a child with Down syndrome (DS).

Methods Parents of children with DS were invited to fill in a questionnaire. They were recruited by the Flemish Organization for DS, from schools for children with special needs and by four multidisciplinary medical DS teams at four University Hospitals.

Statistics Chi-square tests were used to test the correlation between different variables. Results were assessed in the 95% confidence interval with $p < 0.05$.

Results Mean age of the children was 10.1 years old (SD: 5.3). Oral health was indicated as rather good by 53% of the parents. Of the children, 66% went to a dentist within the last six months. Most of the children (64%) received a dental examination. In 53% of the cases, parents visited the same dentist for their child with DS as their other child(ren) without DS. Eighty-three percent of the parents are pleased with their dentist. They expect the dentist to be kind and reassuring. Children aged 10 years or younger get significantly more help with tooth brushing (79%) than children older than 10 years (36%). However 20% of the parents never received any oral hygiene instructions for their child with DS.

Conclusion Prevention is the most frequent service provided by the dentist. Parents seem to be pleased with the dentist who treats their child with DS.

Keywords Oral Health, children, Down Syndrome, Belgium.

Introduction

Every year 45 babies in Flanders (Belgium) are born with Down syndrome. That means that Down syndrome is diagnosed in almost 1 of 2,000 births. (Downsyndroom Vlaanderen, Kind en Gezin).

Prenatal screening has improved and has a specificity and sensitivity of 80-85%, but the incidence of births of children with Down syndrome (DS) is remaining stable [Roizen and Patterson, 2003]. Increasing maternal age in Western society is a major risk factor, as it has been proved that women older than 35 are at higher risk giving birth to a child with DS [Sherman et al., 2005].

It is known that children with DS are at higher risk to suffer from numerous medical problems. Screening for congenital heart diseases, visual impairment and hearing problems is encouraged shortly after birth [Roizen and Patterson, 2003]. It is recommended to visit a physician on a regular basis to monitor and prevent those medical problems [Jobling and Cuskelly, 2006]. Anatomical and developmental differences in the middle third of the face can cause functional problems affecting chewing, swallowing and speech. Children with DS also have dental problems. Tooth agenesis, hypoplasia and hypocalcification are regularly seen [Van Amerongen et al., 2004]. In the study of Loureiro et al. [2007] gingivitis was observed in 91% of the children with DS aged between 6 and 20 years old. Attachment loss due to periodontitis was found in 36% of the children younger than 6 and 94% of the children between 16 and 20 years old were diagnosed to have an aggressive form of periodontitis. Due to the underdevelopment of the facial middle third, children with DS have a hypoplastic maxilla in relation to their mandible. A higher prevalence of anterior open bite and posterior crossbite is found [Bauer et al., 2012]. Reduced muscle tone causes the underdevelopment of the facial middle third. The tongue seems to be larger and therefore can give the appearance of macroglossia. Children with DS tend to protrude their tongue, due to the hypotonic orofacial muscles and, in the attempt to obtain a more stable occlusion, they also protrude their mandible. The combination of tongue thrusting and a prognathic mandible can lead to open mouth breathing which can be a trigger for OSAS and airway infections [Hennequin et al., 1999].

It is still not clear whether children with DS are at higher risk for caries or not. It is stated that children with DS have lower caries experience rates than adults with DS because their intake of food is controlled by proxies [Hennequin et al., 1999]. Delayed tooth eruption, tooth agenesis, microdontia and spacing are other possible reasons for a lower caries risk in children with DS [Van Amerongen et al., 2004]. A lower pH value due to the presence of interdental food residues can cause demineralisation and a higher prevalence of caries [Hennequin et al., 1999]. Allison et al. [2000] showed that 51.4% of the children with DS younger than 8

years are not supported to brush their teeth daily. This confirmed the results found by Randall et al. [1992]: manual dexterity skills are limited and this has an impact on oral hygiene. Therefore children always need help from their parents when they brush their teeth [Martens et al., 2000]. Parents tend to pay more attention to the medical problems and postpone the dental care and dental visits [Randall et al., 1992]. On the other hand, parents often have problems finding a dentist who is willing to treat their child with DS [Allison et al., 2000].

Children with DS need a lot of medical care and not much information is available regarding the knowledge and experience of parents with dental care of their DS child. We were interested in the responses to three major questions: 1) What do parents know about dental care for their child with DS?; 2) Have they ever been to a dentist?; 3) How would they describe their experience of this dental visit?

Materials and methods

Participation

The questionnaire developed for the present study utilised questions from other internationally available questionnaires on the topic [Allison and Hennequin, 2000; Hennequin et al., 2000; Kaye et al., 2005; Collado et al., 2008; Prahbu et al., 2010].

A first draft was proofread by several dentists and non-dentists, to ensure that questions and terms were clear. During a second step, the questionnaire was completed by a couple of parents who were interviewed afterwards about the content and lay-out of the questionnaire. Based on their suggestions the questionnaire was finalised and made available as a web survey and as paper copies. We set up a pilot study where parents of children with DS were invited to fill in the questionnaire. Afterwards they were interviewed and asked to give their opinion about the questionnaire. Those parents were excluded from the final study group of parents. Invitations to complete the questionnaire and paper copies were spread by the Flemish Organization for DS, by schools for children with special needs and by four multidisciplinary medical DS teams at four University hospitals. Participation was voluntary and anonymous and by filling in the questions, permission was given to use the data. Study approval was obtained from the Ethics committee of the Ghent University Hospital (B670201214007, EC UZG 2012/236).

Data

The questionnaire comprised five sections. In the first part, sociodemographic and medical information about the children was collected. In the second part data were collected about dental visit(s). Parents were asked if they ever went to a dentist with their child with DS. The questions were related to dental examination and dental treatment [Collado et al., 2008], the use of local

anaesthesia [Prahbu et al., 2010], interaction between the child and the dentist and between the dentist and the parents [Kaye et al., 2005]. For some questions a four point Likert scale was used (Yes; More or less, No; I don't know). In the third part, questions were asked about tooth brushing. We wanted to know if the children receive help from their parents and if parents have been informed about tooth brushing [Allison and Hennequin, 2000; Hennequin et al., 2000; Kaye et al., 2005]. In part four we used nine short questions about oral problems from the OADS (Oral Assessment in Down syndrome questionnaire), a validated instrument used to evaluate oral health problems in individuals with DS by Allison and Hennequin [2000]. In addition, parents were asked to rate the oral health of their child, again on a five point Likert scale (Excellent; Rather good; Average; Rather poor; Very poor) [Allison and Hennequin, 2000; Hennequin et al., 2000]. In the fifth and last part sociodemographic questions were asked about the parent who filled in the questionnaire.

Data analysis

Questionnaires had to be filled in completely, when a question was not filled in the questionnaire was not considered as valid. Therefore, I don't know was always mentioned as a possible answer.

Data were collected in a database using an Excel 2010 file. Findings have been analysed with SPSS statistics 20 (SPSS Inc., Chicago, IL, USA). Descriptive statistics was used to report the results and chi-square tests were used to test the correlation of different variables. Statistically significant results were defined as $p < 0.05$.

Results

Descriptive results

After exclusion of 6 questionnaires that missed too much information, questionnaires related to 100 children (55 boys and 45 girls) aged between 2 and 21 years old (mean age: 10.1/ SD: 5.3) were considered as valid. In 86% of the questionnaires it was a mother and in 14% it was a father who answered the questions. The age range of the parents was 22 to 55 years old, the mean age of the parents was 41.9 (SD: 7.0).

Visual problems (62%), diseases of ear, nose and throat (ENT) (39%) and cardiovascular disorders (31%) are the most common medical problems, reported by the parents. Other comorbidities are reported in Figure 1. Almost half the parents (47%) rated the general health of their child as 'Rather good' and 31% as Very good. The majority (87%) of the children had not been referred to a hospital during the previous 12 months.

Only four children, aged between 2 and 4, had never attended a dentist as their parents considered their child too young. Most children had seen the dentist either during the previous 6 months (66%) or during

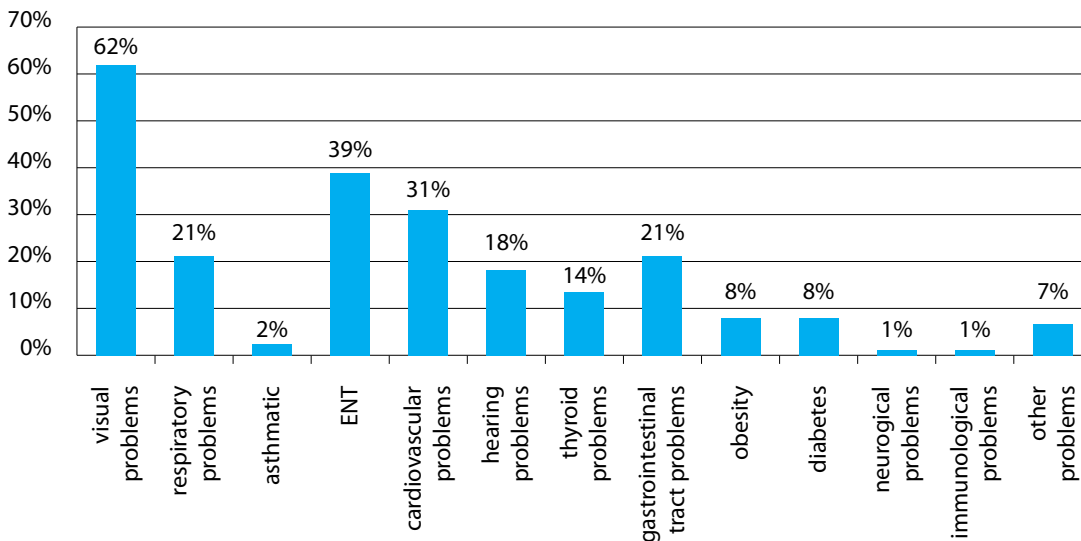


FIG. 1 Medical problems in children with DS.

Oral examination	61 (64%)
Visit together with siblings	30 (31%)
Advice from a specialised centre for children with DS at the University Hospital	21 (22%)
Pain in the oral cavity due to an accident	3 (3%)
Advice from a paediatrician at school	2 (2%)
Information read in a leaflet from the Flemish Organization for Down syndrome	2 (2%)
Toothache	1 (1%)
Discoloured tooth	1 (1%)
Tooth decay	1 (1%)
Advice from a physician	1 (1%)
Other	1 (1%)
N=96, Respondents could check more than one reason	

TABLE 1 Reported reason for dental visit of children with DS.

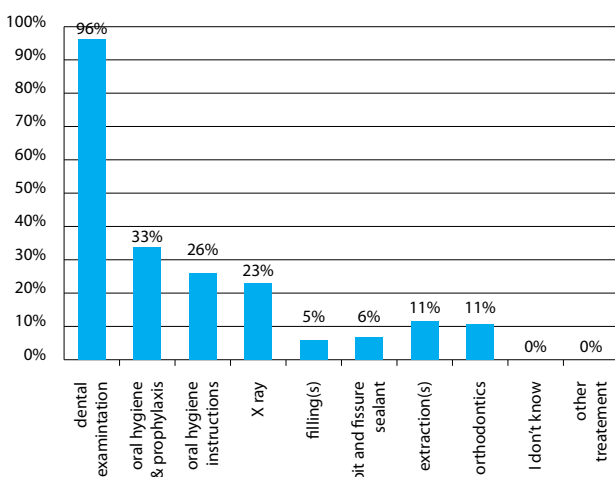


FIG. 2 Reported dental treatment experience of children with DS.

the previous year (23%). The main reasons that children with DS had a dental appointment are: a (bi) annual oral examination (64%), because they join their siblings

(31%) or because their parents received advice from a specialised centre for children with DS at the University Hospital (22%) (Table 1). Half the parents took their child to see a dentist in a private dental office, while 32% went to the hospital. In 53% of the cases, the child with DS saw the same dentist as their siblings. Difficulties concerning dental examination were reported for 35% of the children and difficulties during dental treatment in 33%. Anaesthesia for dental treatment was given to 42% of the children. The dentist administered local anaesthesia (15%), general anaesthesia (18%) or a combination of both (9%). The treatments most commonly reported were: oral examination (96%), and removal of calculus (33%), and oral hygiene instructions (26%) (Fig. 2). According to the parent, the dentist gave information on oral hygiene (68%), agenesis (26%) and tooth eruption (26%) and advice concerning use of fluoride (20%) during the last year (Fig. 3). In the opinion of 83% of the parents, a good dentist for their child needs to be sympathetic (71%), reassuring (53%) and needs to involve the child while explaining (48%). Only 7% of the parents prefer a dentist specialised in treating children with special needs (Table 2).

Half of the parents reported that their child(ren) (50%) brush their teeth once a day. Another 43% of the children brush their teeth twice a day while 6% of the children brush once a week. Of the parents, 58% help their child to brush on a daily basis. Twelve per cent of the parents never help with tooth brushing because they believe that their child is able to do this independently. Problems concerning rinsing the mouth after brushing are reported in 59% of the children. Help in rinsing is not received by 53% of the DS children. An electric toothbrush is used by 22% of the children and a manual toothbrush by 61% of the children; some parents (17%) use both techniques. Parents received information on oral hygiene for their child from their dentist (70%) or from the school teacher or a tutor (10%), while 20% of the parents never received any kind of oral hygiene

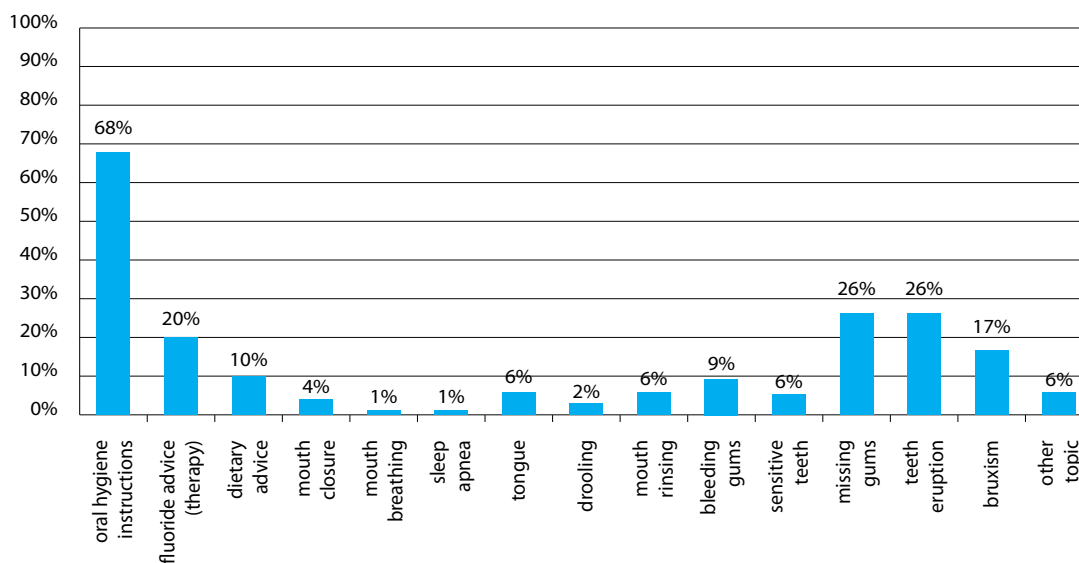


FIG. 3
Reported topics discussed by the dentist for children with DS.

Sympathetic	67 (71%)
Reassuring	50 (53%)
Involving the child	46 (48%)
Patient	43 (45%)
Able to explain	36 (38%)
Taking extra time	31 (33%)
Enthusiastic	17 (18%)
Specialised in treating children with DS	7 (7%)
Willing to help in case of emergency	6 (6%)
I don't know	1 (1%)
Other	1 (1%)
N= 95, Respondents could check more than one quality (max: 3)	

TABLE 2 Desirable qualities of dentists.

advice specifically for their child with DS (Fig. 4).

Thirty-two percent of the parents think that their children avoid specific hard food (carrot/apple). Difficulties during sucking when being breast or bottle fed was reported for 46% of the children. About 10% of the children encounter difficulties during drinking from a mug. Choking while drinking or eating is seen in 36% of the children. Parents rated the oral health of their child as 'Rather good' (53%) and 'Very good' (27%). Half of the parents (54%) brush their child teeth once a day and 43% brush their child teeth twice a day. Two parents did not brush their teeth daily and one parent did not brush them at all. For 81% of the parents, the last dental examination was less than one year prior.

When we consider the highest level of education, 67% of the parents graduated from higher education (bachelor/master). Dutch was the only language spoken at home for 93% families. In 6 families, Dutch was spoken in combination with another language and in one family only French was spoken.

Comparative statistics

When we compare the parents' perception of their child's general and dental health we find that most of them think that dental health is better than general health status. Also, 86% of the parents who rate the general health as good, thought dental health was good as well; 59% of parents who reported the general health as average still think that dental health is good. No significant association was found between both variables (Table 3). A statistically significant association ($p < 0.001$) was found between the age of the children and the help they obtained from their parents while tooth brushing: the younger age group (i.e. younger than 10 years old.) were more likely to be offered help. About 36% of the children older than 10 years received help every day in comparison with the youngest age group where the proportion of those who received help was 79%. A quarter (25%) of the children never received any assistance with tooth brushing. Ten years of age was chosen a cutoff because in Belgium it is recommended that parents should help their child (even without disabilities) with tooth brushing until the age of ten years [van Amerongen et al., 2004] (Table 4, 5).

Discussion and conclusion

Until now similar research and data about oral care in children with DS are scarce. In many studies, it is difficult to isolate specific data about children with DS because they are included in mixed study groups containing people with other disabilities. Hennequin and Allison [2000] asked parents attending a congress of the FAIT21 (Fédération des associations pour l'insertion sociales des personnes porteuses d'une trisomie 21) in France, to fill in two questionnaires dealing with oral healthcare, one for their child with DS and one for a sibling. The same study was performed in 2005 by Allison and Lawrence [2005]. In the present study, visual problems (62%), ENT diseases (39%) and cardiovascular disorders (31%)

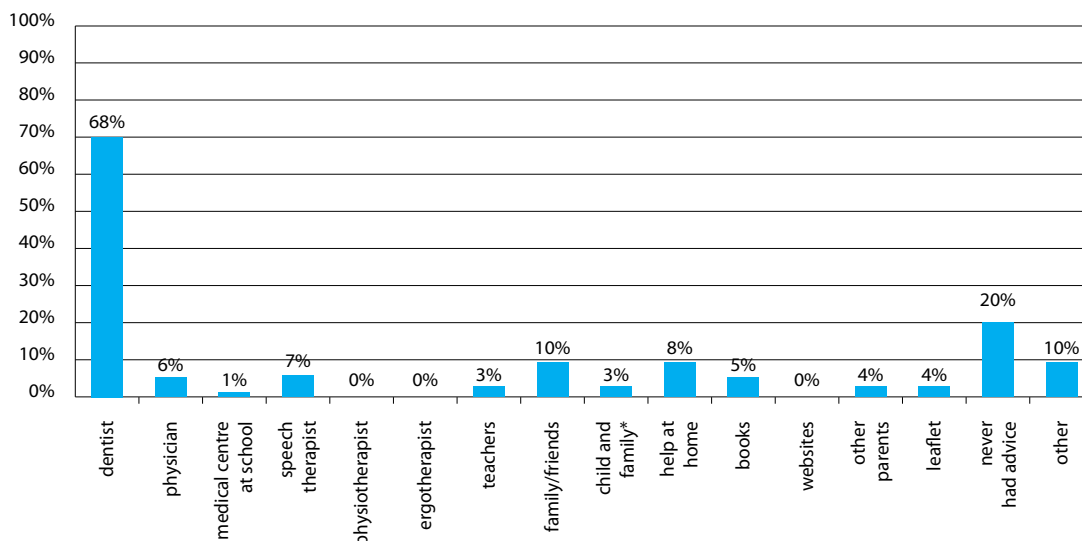


FIG. 4 Reported sources of information concerning oral hygiene for children with DS.

Dental health					Total
		(rather) not good	good	average	
General health	(rather) not good	0	1	2	3
	good	1	69	10	80
	average	0	10	7	17
Total		1	80	19	100

TABLE 3 Relationship between the general and dental health, as rated by parents (N:100).

Help with tooth brushing				Total
	daily	1 time a week average	Never (I believe my child is able to do this alone)	
Age	42	10	1	53
	16	17	11	44
Total	58	27	12	97

TABLE 4 Reported reason for dental visit of children with DS.

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	21.150a	2	0.000
Likelihood Ratio	22.832	2	0.000
N of Valid Cases	97		

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 5.44.

TABLE 5 Chi-Square Tests.

are the most common medical problems, reported by the parents. This corroborates the earlier findings of Hennequin et al. [2000].

Oliveira et al. [2010] stated that mothers of children with DS make an association between the number of hospital admissions and the general health of their child by rating health as very good when no hospitalisation was needed. Although no statistically significant association was found, almost 87% of the children whose parents rated the general health as (very) good did not need a hospitalisation during the last 12 months. Results from the rating of general health in the present study support the findings of Hennequin et al. [2000].

There are benefits of an online questionnaire: it is less expensive, it requires less time to be completed, the researcher obtains the results instantly, no mistakes are made by copying the results and parents only see the questions reflecting their personal situation. In addition, sending a questionnaire by mail gives you a better idea of the non-response rate. According to our findings, 4 children younger than 5 (22%) had never been previously seen by a dentist. Randell et al. [1992] asked parents of children with DS aged from 1 to 14 years old to fill in a questionnaire. They reported that 88% of the children younger than 5 years never went to a dentist. The study was executed 20 years ago and ideas concerning oral health have changed since then.

This may (in part) explain the difference between the findings of Randell et al. and those of the present study.

It is remarkable that 47% of the parents take their child to a dentist specialised in treating children with disabilities. More difficulties were seen during dental treatment than during dental examination. This is comparable to percentages (43%) found in the research of Collado et al. [2008] in France. In this study, only 18% of the study group had DS [Collado et al., 2008].

More than half of the children (56%) never received any anaesthesia as part of their dental treatment. Dentists appear to use local anaesthesia only in children where behavioural problems during dental examination and/or treatment are present. No children received any nitrous oxide sedation. A lack of places where this form of sedation can be given and the fact that in Belgium dentists must be certified to administer nitrous oxide sedation, can be possible explanations for this.

Kaye et al. [2005] asked 127 members of the DSA (Down syndrome Association, UK) chosen at random, to fill in a questionnaire about oral healthcare. The average dental treatments reported by the parents (dental

examination, removing calculus and giving oral hygiene instructions) are the same actions that were reported by the parents in the present study. The authors also found that parents want the dentist to be sympathetic and involve the subject with DS in treatment decisions. In this same study, parents obtained information from charity organisations and other parents of children with DS, and 21% indicated that a healthcare professional advised them to visit a dentist [Kaye et al., 2005]. In the present study, information about tooth brushing was usually given by a dentist and a comparable 25% were advised to visit a dentist by a healthcare professional.

Daily tooth brushing was reported in 93% of the children, 43% of them brush their teeth twice a day. This is comparable to the 91%/55% found in an earlier study of Matthias et al. [2011]. Hennequin et al. [2000] found that almost 60% of the parents in their study assisted the child with tooth brushing. That means that more than 40% of the children did not receive help on a daily basis. In comparison, in the present study for the group of children older than 10, nearly 64% are not supported every day. Parents who brush their own teeth once or twice a day are more likely to brush the teeth of their children daily, however no significant association was found. In both groups, parents and children, only 43% brush their teeth twice a day. This is remarkable knowing that tooth brushing is recommended at least twice a day.

One fifth of the parents did not receive any instruction on oral hygiene. That means that some dentists did not take the time to give information about tooth brushing.

The OADS questionnaire (Oral Assessment Down syndrome) is a validated instrument used to evaluate oral health problems in individuals with DS [Allison and Hennequin, 2000]. We used some questions, translated into Dutch. When comparing the results of Hennequin et al. [2000] and those of the present study we see similar percentages for children with a reported difficulty with chewing (44.5 vs. 38%) and choking (16.6 vs. 16%). Parents seem to be more positive while rating the oral health of their child in the present study. These results contrast with the findings of Hennequin et al., possibly because the parents in the present study only had to fill in one questionnaire and did not have to compare their child with DS with a sibling [Hennequin et al., 2000].

The study group was not small; data from 100 children were included, but it must be recognised that there are limitations to the data gathered in the present study. Parents who filled in the questionnaire are probably more aware of the importance of dental health and may therefore be more motivated to participate with this study. These parents are not representative for all parents of a child with DS so generalisation should be avoided.

Questionnaires were anonymous and responses have not been checked with medical and dental records, so the outcomes of this study depend on the knowledge of the parents. Despite these limitations, the findings are useful. Information gathered from this study is interesting and

may be used to evaluate the ideas and concerns of parents about dental healthcare for their child with DS. Although the studies of Hennequin et al. were carried out 10 years ago, it is remarkable to see very similar results. We can conclude that not much has changed in the meantime. It is positive that 96% of the children were reported to have visited a dentist and parents did not mention problems concerning access to oral health care. In the case of dental treatment provided, we observed that many children received preventive treatment. Prevention is an absolute must in dentistry but when a dental problem occurs, it is unacceptable to postpone treatment. We recommend that dental problems are treated as they arise or, if the dentist does not have the proper knowledge or skills, the patient should be referred for care to providers of dental health services able to manage the problem.

Acknowledgements

Thanks to Dr. R. Leroy for her extended contribution in the project.

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