

## Parental Awareness of Oral Function and Development of Children with Down Syndrome– An Online Questionnaire Study

Dima A Akkielah<sup>1\*</sup> and Reem R AL Natsha<sup>2</sup>

<sup>1</sup>Dental Resident, SFH Hospital, Riyadh, KSA

<sup>2</sup>Pediatric Dentist Consultant, SFH hospital, Riyadh, KSA

\*Corresponding Author: Dima A Akkielah, Dental Resident, SFH Hospital, Riyadh, KSA.

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### Abstract

**Background and Aim:** The prevalence of Down syndrome (DS) in Saudi Arabia is considerably higher than the rest of the world. The purpose of this study was to assess oral function in Saudi children with DS when compared to their unaffected siblings.

**Methodology:** 168 questionnaires of the Arabic version of the OADS distributed online parents of children with DS in Riyadh city. The answers for the children and their siblings were then statistically analyzed using the SPSS ver. 25 data processing software.

**Results:** The children with DS (110 males, 58 females) ranged from ages 3.3 years to 18.2 years (mean age 9.04 years SD + 3.93 years) while their siblings (129 males, 39 females) ranged from ages 4.1 to 18.8 years (mean age 10.59 years SD+ 3.09 years). Significant differences existed between children with DS and their siblings in the function, development and signs domains.

**Conclusion:** Saudi parents are aware of the difficulties in oral function and development faced by their children with DS.

**Keywords:** Down Syndrome; Oral Function; Oral Development

### Introduction

Down syndrome (DS) is the most common genetic cause of intellectual disability, occurring in approximately 1 in 700 live births [1]. The prevalence of DS in Saudi Arabia is considerably higher, and has been estimated at 1 in 554 live births [2]. The characteristic oral features of DS [3,4], dental problems of these individuals [5,6], and the importance of oral care for individuals with DS [7,8] are topics that have been studied and reviewed in detail. It has been noted that though several studies have focused extensively on the prevalence and management of oral diseases in several countries the concept of oral function has received far less attention [9]. Despite the high prevalence of DS in Saudi Arabia, the studies on the oral health of children with DS have been limited and have focused on access to dental care and oral hygiene practices rather than oral function and development [10,11].

The Oral Assessment - Down Syndrome questionnaire (OADS), is a validated French language measure of oral health status in individuals with DS [12,13]. The questionnaire, which is filled by the parents, evaluates several aspects of the oral health of children with Down syndrome including oral function [14]. Though the validity of this questionnaire has been demonstrated, questionnaires, like all subjective tools, are subject to cultural and linguistic differences [15].

While most case-control studies on children with DS tend to use convenience based sampling, the matching of children with DS to unaffected siblings allows researchers to view with greater depth the problems of these individuals from a parental perspective [14]. There is currently no study in literature that has attempted to describe the oral function and development of children in Saudi Arabia in this manner.

### Aim of the Study

The purpose of this study was to validate an Arabic translation of the OADS questionnaire and use a part of this questionnaire to assess oral function in Saudi children with Down syndrome when compared to their unaffected siblings.

### Methodology

Ethical approval for the study was obtained from the educational and research department in SFH hospital.

The Oral Assessment Down Syndrome (OADS) questionnaire 12 was translated from English to Arabic using the translate re-translate technique [16]. The questionnaire was first translated from English to Arabic by a native Arabic speaker who was fluent in English; this version was then retranslated to English by a native English speaker fluent in Arabic. In order to avoid bias the translators chosen were

professional teachers of English and Arabic respectively who were blinded as to the objective of the study. An initial pilot study was conducted on 10 parents of children with DS. It was found that parents found difficulty in clearly understanding the terms “a little” or “sometimes”, and it was therefore decided to keep the entire questionnaire (except the global domain in a yes/no format).

Parents who had a child with DS and an unaffected sibling were identified from a register of patients with local DS registry. An online survey was created using a website (www.surveymonkey.com) and distributed. The questionnaires were only distributed to parents who also had a child who was not affected by DS. The children with DS and their siblings were then grouped into three groups based on the type of dentition (primary, mixed and permanent). Completed questionnaires were then analyzed and subjected to statistical analyses using the SPSS ver. 19 data processing software.

The questionnaire was re-administered to 20 parents in person after an interval of one month. The responses to individual questions were then checked for reproducibility using the Cronbach’s alpha test.

Oral function was assessed by comparing the response of parents to the oral function, disability and signs domain of the OADS questionnaire. Differences in parental responses between the children with DS and their siblings were compared using the Pearson’s Chi-square test.

**Results**

Of the 200 questionnaires distributed we received 168 completed questionnaires for both children with DS and their siblings. The children with DS (110 males, 58 females) ranged from ages 3.3 years to 18.2 years (mean age 9.04 years SD + 3.93 years) while their siblings (129 males, 39 females) ranged from ages 4.1 to 18.8 years (mean age 10.59 years SD + 3.09 years).

The translated version of the questionnaire showed good reproducibility among the 20 questionnaires re-administered to the parents with and overall Cronbach’s alpha score of 0.83. The individual question scores varied from 0.66 (Problems with Suckling) to 0.99 (How do you rate your child’s health).

The questions of the OADS related to general health and health service utilization are not within the scope of this paper and are therefore not presented here. Analyzing the Function Domain it was reported that while children with DS had significantly more difficulty in chewing meat and a whole apple, there was no significant difference in the ability to chew a cut apple (Table 1). However when compared among the individual dentitions it was observed that although the ability of the child to chew an apple varied across the groups the difficulty in chewing meat was statistically greater in the children with DS only in the mixed dentition group (Table 3).

| Domain                                 |     | Down Syndrome |       | Sibling |       | Chi Square | Sig   |
|--|-----|---------------|-------|---------|-------|------------|-------|
|  |     | Count         | N %   | Count   | N %   |            |       |
| Function                               |     |               |       |         |       |            |       |
| Difficulty in chewing a whole apple    | Yes | 84            | 50.0% | 20      | 11.9% | 57.040     | .000* |
|  | No  | 84            | 50.0% | 148     | 88.1% |            |       |
| Difficulty chewing a slice of an apple | Yes | 30            | 17.9% | 21      | 12.5% | 1.872      | .171  |
|  | No  | 138           | 82.1% | 147     | 87.5% |            |       |
| Difficulty chewing Meat                | Yes | 70            | 41.7% | 41      | 24.4% | 11.314     | .001* |
|  | No  | 98            | 58.3% | 127     | 75.6% |            |       |

**Table 1:** Comparison of Function, Development and Disability domains of the OADS.

\*Results are significant at  $p < 0.05$

The Disability domain showed that children with DS were also significantly less able to brush their teeth or chew their food when compared to their siblings (Table 1). However once again when the results were compared according to the type of dentition it was observed that these findings remained highly significant only in the mixed dentition group (Table 2).

| Function Domain                          |            | Type of dentition |        |           |
|--|------------|-------------------|--------|-----------|
|  |            | Primary           | Mixed  | Permanent |
| Difficulty in chewing a whole apple      | Chi-square | 6.655             | 18.935 | 8.711     |
|  | Sig.       | .010*             | .000*  | .003*     |
| Difficulty chewing a slice of an apple   | Chi-square | 1.022             | .483   | .119      |
|  | Sig.       | .312              | .487   | .730      |
| Difficulty chewing meat                  | Chi-square | 4.235             | 2.150  | .863      |
|  | Sig.       | .040*             | .143   | .353      |
| <b>Disability Domain</b>                 |            |                   |        |           |
| Ability to brush teeth                   | Chi-square | 2.856             | 33.851 | 2.707     |
|  | Sig.       | .091              | .000*  | .100      |
| Ability to chew all kinds of Food        | Chi-square | 1.988             | 19.240 | 2.763     |
|  | Sig.       | .159              | .000*  | .096      |
| <b>Development Domain</b>                |            |                   |        |           |
| Problems in Suckling                     | Chi-square | 1.412             | .020   | 1.359     |
|  | Sig.       | .235              | .887   | .244      |
| Problems Changing form soft to hard food | Chi-square | 1.309             | 9.278  | 11.237    |
|  | Sig.       | .253              | .002*  | .001*     |
| Delayed exfoliation of primary teeth     | Chi-square | NA                | 10.544 | 4.898     |
|  | Sig.       |                   | .001*  | .027*     |

**Table 2:** Differences in the Function, Development and Disability domains when compared according to the type of dentition.

\*Results are significant at  $p < 0.05$

Analyses of the development domain revealed that parents were aware that children with DS had significantly later eruption of teeth and also were more likely to have problems changing from soft to hard food (Table 1).

However a majority of the parents surveyed found no significant difference in problems with suckling with either children with DS or their siblings.

When the signs domain was analyzed it was found that overall, children with DS showed significantly worse scores than their siblings for all signs except gingival bleeding (Table 3). However a more detailed analysis, comparing the groups according to the type of dentition showed that while some signs like inadequate chewing of food, constipation, bad breath and excessive gag reflex go unnoticed in the primary dentition and are only observed in the mixed or permanent dentition; others like belching, or tongue sticking out disappear in the permanent dentition (Table 4).

| Signs Domain                    |     | Down Syndrome |            | Sibling |            | Chi Square | Sig   |
|---------------------------------|-----|---------------|------------|---------|------------|------------|-------|
|                                 |     | Count         | Column N % | Count   | Column N % |            |       |
| Chews food for a short duration | Yes | 120           | 71.4%      | 137     | 81.5%      | 4.783      | .029* |
|                                 | No  | 48            | 28.6%      | 31      | 18.5%      |            |       |
| Belches                         | Yes | 66            | 39.3%      | 97      | 57.7%      | 11.451     | .001* |
|                                 | No  | 102           | 60.7%      | 71      | 42.3%      |            |       |
| Constipation                    | Yes | 70            | 41.7%      | 9       | 5.4%       | 61.580     | .000* |
|                                 | No  | 98            | 58.3%      | 159     | 94.6%      |            |       |
| Tongue sticking out             | Yes | 36            | 21.4%      | 13      | 7.7%       | 12.639     | .000* |
|                                 | No  | 132           | 78.6%      | 155     | 92.3%      |            |       |
| Gingival Bleeding               | Yes | 24            | 14.3%      | 19      | 11.3%      | .667       | .414  |
|                                 | No  | 144           | 85.7%      | 149     | 88.7%      |            |       |
| Bad Breath                      | Yes | 68            | 40.5%      | 12      | 7.1%       | 51.450     | .000* |
|                                 | No  | 100           | 59.5%      | 156     | 92.9%      |            |       |
| Teeth Grinding                  | Yes | 68            | 40.5%      | 9       | 5.4%       | 58.648     | .000* |
|                                 | No  | 100           | 59.5%      | 159     | 94.6%      |            |       |
| Food Spilling from the mouth    | Yes | 32            | 19.0%      | 11      | 6.5%       | 11.761     | .001* |
|                                 | No  | 136           | 81.0%      | 157     | 93.5%      |            |       |
| Excessive Gag Reflex            | Yes | 38            | 22.6%      | 0       | .0%        | 42.846     | .000* |
|                                 | No  | 130           | 77.4%      | 168     | 100.0%     |            |       |
| Sleeps with Mouth Open          | Yes | 116           | 69.0%      | 16      | 9.5%       | 124.777    | .000* |
|                                 | No  | 52            | 31.0%      | 152     | 90.5%      |            |       |

**Table 3:** Comparison of the Signs domains of the OADS.

\* Results are significant at  $p < 0.05$

| Pearson Chi-Square Tests        |            |                   |                   |                    |
|---------------------------------|------------|-------------------|-------------------|--------------------|
| Signs Domain                    |            | Type of dentition |                   |                    |
|                                 |            | Primary Group     | Mixed Group       | Permanent Group    |
| Chews food for a short duration | Chi-square | 1.210             | 1.796             | 9.521              |
|                                 | df         | 1                 | 1                 | 1                  |
|                                 | Sig.       | .271              | .180              | .002*              |
| Belches                         | Chi-square | 5.005             | 11.214            | 1.209              |
|                                 | df         | 1                 | 1                 | 1                  |
|                                 | Sig.       | .025*             | .001*             | .272               |
| Constipation                    | Chi-square | 2.695             | 37.569            | 10.411             |
|                                 | df         | 1                 | 1                 | 1                  |
|                                 | Sig.       | .101 <sup>a</sup> | .000*             | .001 <sup>a*</sup> |
| Tongue sticking out             | Chi-square | 1.309             | 7.635             | .986               |
|                                 | df         | 1                 | 1                 | 1                  |
|                                 | Sig.       | .253              | .006*             | .321               |
| Gingival Bleeding               | Chi-square | .529              | 3.275             | .005               |
|                                 | df         | 1                 | 1                 | 1                  |
|                                 | Sig.       | .467 <sup>a</sup> | .070              | .941               |
| Bad Breath                      | Chi-square | 2.695             | 37.381            | 5.106              |
|                                 | df         | 1                 | 1                 | 1                  |
|                                 | Sig.       | .101              | .000*             | .024*              |
| Teeth Grinding                  | Chi-square | 3.025             | 30.400            | 10.411             |
|                                 | df         | 1                 | 1                 | 1                  |
|                                 | Sig.       | .082              | .000*             | .001*              |
| Food Spilling from the mouth    | Chi-square | 1.864             | .153              | 2.123              |
|                                 | df         | 1                 | 1                 | 1                  |
|                                 | Sig.       | .172 <sup>a</sup> | .696 <sup>a</sup> | .145 <sup>a</sup>  |
| Excessive Gag Reflex            | Chi-square | 1.629             | 14.952            | 20.328             |
|                                 | df         | 1                 | 1                 | 1                  |
|                                 | Sig.       | .202              | .000*             | .000*              |
| Sleeps with Mouth Open          | Chi-square | 9.626             | 66.311            | 22.273             |
|                                 | df         | 1                 | 1                 | 1                  |
|                                 | Sig.       | .002*             | .000*             | .000*              |

**Table 4:** Differences in the signs domain when compared according to the type of dentition.

\* difference is significant at  $p < 0.05$

The global domain showed that despite their many problems, parents were more likely to rate the DS affected child’s health as good or poor when compared to their unaffected sibling, while they were significantly more likely to rate their child’s overall health as fair if the child was unaffected with DS. When it came to oral health a significantly higher number of parents rated the oral health of children with DS as poor when compared to their unaffected siblings (Figure 1).

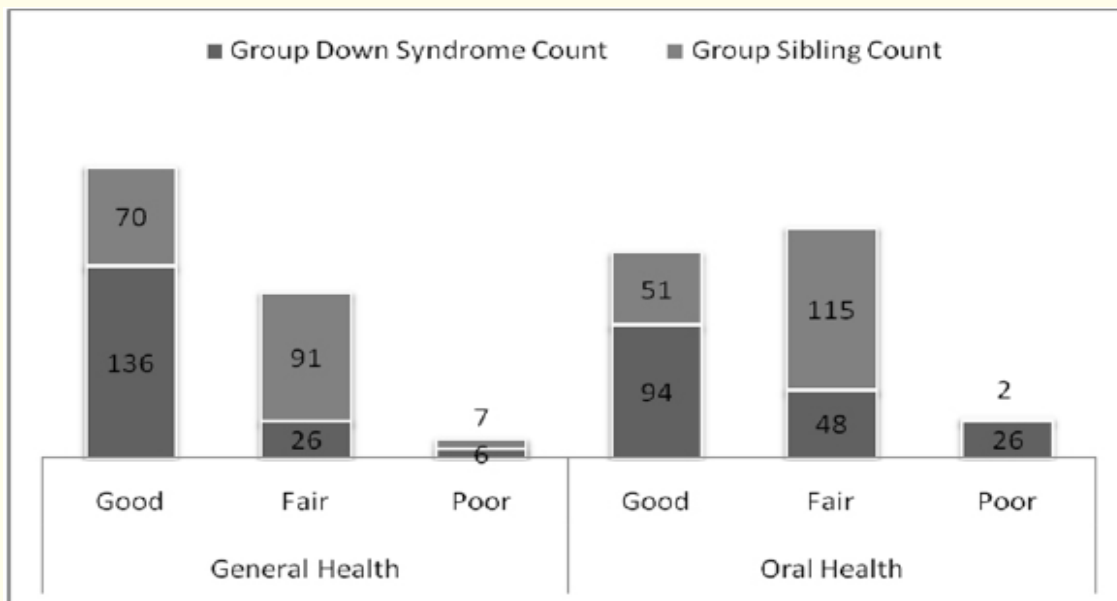


Figure 1: Parental perceptions of overall General and Oral Health.

### Discussion

Since its development in 2000 the OADS, or parts of the questionnaire, have been used to assess oral function and access to dental care in children with DS around the world [14,17,18]. These studies utilized the French language version of the questionnaire. The validity and cross-cultural adaptability of questionnaires is a point that has been repeatedly discussed in literature [16,19,20]. Our decision to use the ‘translate-retranslate’ [16] technique was based on the literature reviewed. The relatively high Cronbach’s alpha scores obtained suggests that the proper application of translation techniques can greatly help to ease linguistic barriers in the adaptability of translated questionnaires.

When the oral function domain was assessed we found significant differences in the ability of the child to chew on a whole apple, which is in keeping with those of Hennequin, *et al* [14]. However we found that parents found no difference in their child’s ability to chew a slice of apple and the difficulty in chewing meat was only significantly different in the primary dentition. One possible explanation for this could be the high amounts of meat and relatively low amounts of fresh fruits consumed in Saudi families in general [21]; and children in particular [22,23].

Individuals with DS have been reported to have poorer oral hygiene practices than their unaffected counterparts [24]. However recent literature has suggested that there is a growing awareness among parents, especially mothers, of individuals with DS regarding the difficulties in maintaining oral health and a willingness to act on those concerns [25,26]. Our findings that show that parents have a good understanding of these difficulties in their children especially in the mixed dentition however the lack of a significant difference in parental perception of difficulty in brushing teeth can suggest two explanations. It has been suggested that older individuals with DS can with family support cope with the many tasks of daily life [27], an ability to maintain oral hygiene or effectively chew food could be a manifestation of that ability. However the other, less pleasant, explanation; of decreased parental involvement with increased age of the child [28], cannot be completely ruled out.

Our analyses of the developmental domain showed that while parents in Saudi Arabia, were aware of significant differences in the transition of their affected child to solid food and delays in the eruption of teeth when compared to the unaffected sibling they found no difference in difficulties faced by the child during suckling. While the first two findings are in accordance with other studies on children with DS, the observation on suckling is in sharp contrast to them [4,5,14]. A possible reason for this could be that multiple studies have

shown that adherence to exclusive breast feeding of infants in Saudi Arabia is low, with most parents opting to bottle feed or “mixed-feed” the child [28,29]. Furthermore it has been shown that infant feeding practices of mothers of Saudi children with DS tend to be the same as those followed in unaffected children with the only difference being a delayed introduction of solid foods [30].

The OADS has been shown to be an accurate predictor of oral health signs in children with DS [14,17,18]. It was therefore strange to observe that parents found no significant difference in the levels of gingival bleeding between the individuals with DS and their siblings. A possible explanation for this finding could be overall poor oral health of Saudi children, with studies reporting up to a third of children surveyed never brushing their teeth [31-33]. Halitosis in individuals with DS has been attributed by some to poor oral hygiene [5,6] while others have attributed it to specific oral flora [34]. The significant perception of bad breath in children with DS even when they perceived no difference in gingival bleeding could support the argument that the cause of halitosis in individuals in DS is not wholly due to poor oral hygiene.

Comparisons of chewing cycles have shown that children with DS show prolonged chewing cycles [35] while reduced chewing frequency has been reported in adults with DS [36]. These findings could explain why only parents of individuals with permanent dentition reported their children with DS chewing their food for significantly shorter time. The increased of bruxism in individuals with DS has been documented in literature [37,38]. It was therefore not surprising to see that parents found a significantly higher prevalence of grinding of teeth in individuals with DS in the mixed and permanent dentition.

The studies using the OADS in France and Canada showed that parents felt the overall health of their child with DS to be significantly worse than that of the unaffected sibling. Perceptions of overall wellbeing of individuals with special needs in the middle-east tend to vary from those observed in the west, with parents being involved in the care of their child despite taking a fatalistic approach towards the cause of disability [39,40]. This could explain why many parents rated the overall health of their child with DS as ‘good’ in the absence of life threatening disability. When the findings of overall oral health were considered our findings matched those of other studies. This fact supports recent reports in literature that have shown a good parental awareness and eagerness among parents to seek dental care for individuals with DS in Saudi Arabia [11,41].

## Conclusion

Our study shows that the OADS is a valid instrument that overcomes most of the cross-cultural barriers posed by translation into Arabic. The questionnaire shows that even though cultural differences may result in parents seeming to have perceptions that differ from those seen in Western studies, Saudi parents are aware of the difficulties in oral function and development faced by their children with DS. There is a need for future studies in the Kingdom to adequately address these concerns.

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