

REVIEW ARTICLE

## Profiles of orofacial dysfunction in different diagnostic groups using the Nordic Orofacial Test (NOT-S)—A review

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### Abstract

**Objective.** The Nordic Orofacial Test-Screening (NOT-S) was developed as a comprehensive method to assess orofacial function. Results from the screening protocol have been presented in 11 international publications to date. This study reviewed these publications in order to compile NOT-S screening data and create profiles of orofacial dysfunction that characterize various age groups and disorders. **Materials and methods.** NOT-S results of nine reports meeting the inclusion criteria were reviewed. Seven of these studies not only provided data on the mean and range of total NOT-S scores, but also on the most common domains of orofacial dysfunction (highest rate of individuals with dysfunction scores), allowing the construction of orofacial dysfunction profiles based on the prevalence of dysfunction in each domain of NOT-S. **Results.** The compiled data comprised 669 individuals, which included healthy control subjects ( $n = 333$ ) and various patient groups ( $n = 336$ ). All studies reported differences between individuals with diagnosed disorders and healthy control subjects. The NOT-S data could measure treatment effects and provided dysfunction profiles characterizing the patterns of orofacial dysfunction in various diagnoses. **Conclusions.** This review corroborates previous results that the NOT-S differentiates well between patients and healthy controls and can also show changes in individuals after treatment. NOT-S could be used as a standard instrument to assess orofacial dysfunction, evaluate the outcomes of oral habilitation and rehabilitation and improve comparability in clinical practice and research.

**Key Words:** *chewing, oral disability, rare disorders, screening, speech*

### Introduction

The Nordic Orofacial Test-Screening (NOT-S), which assesses orofacial function, was developed by a Scandinavian network of speech-language pathologists and specialists in dentistry. The NOT-S registers difficulty speaking, chewing and swallowing in subjects as young as 3 years and performs a basic examination of their trigeminal, facial, glossopharyngeal and hypoglossal nerves [1]. Developed for use together with a picture manual, NOT-S consists of a

structured interview and a clinical examination, each evaluating six domains of orofacial function (Table I). Young children and some adolescents or adults with cognitive or physical impairment may need assistance from a parent, friend or caregiver when answering the interview questions. The examination form can be downloaded in the Nordic languages and in Brazilian Portuguese, Chinese, English, Estonian, French, German, Japanese, Portuguese and Spanish (<http://mun-h-center.se/en/Mun-H-Center/Mun-H-Center-E/NOT-S/>).

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Table I. Domains assessed in the Nordic Orofacial Test–Screening (NOT-S) [1].

Structured interview (Domain I–VI)					
I	II	III	IV	V	VI
Sensory function	Breathing	Habits	Chewing and swallowing	Drooling	Dryness of the mouth
Clinical examination (Domain 1–6)					
1	2	3	4	5	6
Face at rest	Nose breathing	Facial expression	Masticatory muscles and jaw function	Oral motor function	Speech

I: A, Does brushing your teeth elicit a gag reflex (every time)? B, Do you put so much food into your mouth that it becomes difficult to chew (every day)?

II: A, Do you use any breathing support? B, Do you snore much when you sleep (every night)?

III: A, Do you bite your nails or suck your fingers or other subjects every day? B, Do you suck or bite your lips, your tongue or your cheeks every day? C, Do you bite your teeth together hard or grind your teeth during the day?

IV: A, Does not eat with the mouth; B, Do you find it difficult to eat foods with certain consistencies? C, Does it take you 30 min or more to eat a main meal? D, Do you swallow large bites without chewing? E, Do you often cough during meals?

V: A, Do you get saliva in the corner of the mouth or on the chin almost every day?

VI: A, Do you have to drink to be able to eat a cracker? B, Do you suffer from pain in the mucous membrane in your mouth or on your tongue (not blisters)?

1: A, Asymmetry; B, Deviant lip position; C, Deviant tongue position; D, Involuntary movements.

2: A, Close your mouth and take five deep breaths through your nose (smell).

3: A, Close your eyes tightly (symmetrically); B, Show your teeth (symmetrically, teeth visible); C, Try to whistle (cannot pout and round the lips).

4: A, Bite hard on your back teeth, B, Open your mouth as wide as you can.

5: A, Stick out your tongue as far as you can (outside the Vermillion border of the lips); B, Lick your lips (cannot reach the corners of the mouth); C, ‘Blow up’ your cheeks and hold for at least 3 s; D, Open your mouth wide and say ah-ah-ah (elevation of the uvula).

6: A, Does not speak; B, Count out loud to 10 (unclear); C, Say pataka, pataka, pataka.

The NOT-S protocol allows trained professionals to perform a screening of orofacial functions without special equipment [1]. It has been shown to be both a reliable and valid screening method for dysfunction, with a method error for the NOT-S score of 5.3% and fair agreement between calibrated examiners ( $\kappa = 0.42\text{--}0.44$ ) [1]. Significant correlations of NOT-S scores with oral health-related quality-of-life, as assessed by the Oral Health Impact Profile 49 (OHIP-49) [2], and with the diagnostic criteria for Parkinson’s disease—the Hoehn & Yahr and Unified Parkinson’s Disease Rating Scale (UPDRS—motor impairment)—have also been found [3].

The method study of NOT-S included 120 individuals with a variety of disabilities and chronic diseases and 60 control subjects [1]. Since then, the screening protocol has been used by professionals in several countries, establishing norm data with reference values for healthy subjects in different age groups [1–4] (Tables II and III). These investigations have also studied orofacial dysfunction in patients with ectodermal dysplasia [5], adenotonsillar hypertrophy [6], Parkinson’s disease [3], Prader-Willi syndrome [7], oromandibular dystonia [8] and Treacher Collins syndrome [9]. Specific domains of dysfunction characteristic for each of these disorders were identified.

Table II. Total values in control subjects reported in international publications using the Nordic Orofacial Test–Screening (NOT-S).

Age, years (M)	n	Sex		Disorders (ICD-10 classification)	Total NOT-S score (0–12) M ± SD (range)	Most frequent domain	Reference
		F	M				
Norm data							
3	53	26	27	Control subjects	1.6 ± 1.1 (0–4)	5	McAllister and Lundeborg [4]
4	49	24	25	Control subjects	1.6 ± 1.4 (0–6)	5	McAllister and Lundeborg [4]
5	41	22	19	Control subjects	1.6 ± 1.0 (0–4)	6	McAllister and Lundeborg [4]
6	38	28	10	Control subjects	1.6 ± 1.1 (0–4)	6	McAllister and Lundeborg [4]
7	50	32	18	Control subjects	1.4 ± 1.2 (0–4)	6	McAllister and Lundeborg [4]
3–78 (30)	60	35	25	Control subjects	0.4 ± 0.6 (0–2)	II + III	Bakke et al. [1]
18–25 (23)	30	15	15	Control subjects	1.8 ± 1.4 (0–5)	—	Strini et al. [2]
61–82 (68)	15	9	6	Control subjects	0.7 ± 0.0 (0–3)	IV	Bakke et al. [3]

Table III. Total values in subjects with various disorders reported in international publications using the Nordic Orofacial Test–Screening (NOT-S).

Age, years (M)	n	Sex		Disorders (ICD-10 classification)	Total NOT-S score (0–12) M ± SD (range)	Most frequent domain	Reference
		F	M				
Patient data							
3–86 (26)	120	61	59	Various disabilities and chronic diseases	4.1 ± 2.6 (0–10)	IV	Bakke et al. [1]
3–55 (15)	46	16	30	Ectodermal dysplasia (Q82)	3.5 ± 1.9 (0–8)	IV	Bergendal et al. [5]*
4–5 (5)	67	28	39	Adenotonsillar hypertrophy (J35)	4.7 ± 1.7 (1–9)	II	Lundeberg et al. [6]*
61–82 (68)	15	9	6	Parkinson's disease (G20)	5.5 ± 2.9 (2–11)	3	Bakke et al. [3]*
6–41 (20)	45	22	23	Prader-Willi syndrome (Q87)	3.9 ± 2.1 (0–10)	5	Saeves et al. [7]
27–78 (57)	21	13	8	Oromandibular dystonia (G24)	4.2 ± 1.8 (0–7)	1	Bakke et al. [8]
5–74 (32)	19	13	6	Treacher Collins syndrome (Q75)	4.6 ± 1.5 (2–7)	1	Asten et al. [9]*

\*Supplementary information based on original data not published earlier.

In addition, the NOT-S protocol has also been used to assess treatment outcomes of surgery in children with adenotonsillar hypertrophy [6]. To date, results concerning ratings of quality-of-life [10,11], personality traits [12] and NOT-S data [4,13] have been illustrated using diagrams or profiles with connected plots. Such presentations may be useful to facilitate the understanding of results and for the comparison of data between studies.

Our aim was to review the data from studies that used the NOT-S in order to: (i) compare scores of healthy subjects with scores of patients with specific diagnoses and (ii) create dysfunction profiles that characterize the patterns of orofacial dysfunction associated with each of these diagnoses.

## Materials and methods

We included only international journal publications with obtainable NOT-S score data that had used NOT-S to assess orofacial function. These included data were found by searching (i) 'Nordic Orofacial Test' in the PubMed/Medline database (US National Library of Medicine, National Institutes of Health) and (ii) previously unreported details from our own, published NOT-S studies. All studies had been published or accepted for publication by 4 March 2013. Exclusion criteria were studies that did not report complete data and studies that did not report both NOT-S components (interview, examination).

To describe NOT-S results across age groups and patient groups, we compiled the mean and range of total NOT-S scores and the most common domains of orofacial dysfunction (highest prevalence of individuals with dysfunction). Further we created orofacial dysfunction profiles for each reported diagnosis based on the distribution of dysfunction across the 12 orofacial domains assessed by the NOT-S.

Microsoft Office Excel 2007 was used for calculations and basis of illustrations.

## Results

Our search revealed 11 reports. In the review two were excluded: one study because the age-range of examined children was not available and another because it used only the clinical examination part of the NOT-S. The remaining nine studies included data from 669 individuals, about half ( $n = 333$ ; Table II) with norm data in two studies on healthy subjects [2,4], supplemented by data from control subjects in two patient studies [1,3] and half ( $n = 336$ ; Table III) with data on patients in relation to different diagnoses [1,3,5–9]. The studies of patient groups (Table III) included one study of patients with various disabilities and chronic diseases; three studies of patients with rare disorders, including rare congenital malformations, deformations and chromosomal abnormalities (ICD-10: Q75, 82 and 87); two studies on diseases of the nervous system (ICD-10: G20 and 24); and one study on diseases of the respiratory system, before and after treatment (ICD-10: J35) [14].

Seven of these studies not only provided data on the mean and range of total NOT-S scores, but also on the most common domains of orofacial dysfunction (highest rate of individuals with dysfunction scores), allowing the construction of orofacial dysfunction profiles based on the prevalence of dysfunction in each domain of NOT-S.

Total NOT-S scores ranged from 0–6 domains of oral dysfunction in the control groups, out of a possible 12 domains, and from 0–11 in the patient groups (Tables II and III). However, the original study by Bakke et al. [1] returned negative screenings

(0 domains of dysfunction) for 63% of control subjects, but only for 4% of diagnosed patients. The means of total NOT-S scores were also generally higher in patient groups than in the control groups. Mean NOT-S scores varied from 3.5–5.5 in the patient groups and from 0.4–1.8 in the control groups (Tables II and III). Furthermore, NOT-S scores were significantly higher for patients in two studies comparing them with matched control subjects [3,6], as well as three studies with statistical comparisons between data from patients and healthy controls [1,5,7].

Results compiled from control subjects showed that, in children, the most common dysfunction found in the clinical examination was in Speech, while, in the structured interview, dysfunction was most commonly found in Breathing and Habits for subjects of any age (Table III). Compiled results from the patient groups showed that patients' most frequent orofacial dysfunction was in the Chewing and Swallowing domain for the structured interview and in the Face at rest domain for the clinical examination (Table III).

Figure 1A shows the orofacial dysfunction profiles for norm data in children and adults [1,3,4]. More than 25% of healthy children aged 3–4 years showed dysfunction in Chewing and swallowing, Facial expression and Oral motor function. In children of 5–7 years, the most frequent dysfunctions occurred in Habits, Chewing and swallowing and Speech. Their most frequent dysfunction was in Speech (31.8%), which has more stringent testing criteria beginning at age 5 years. Among healthy adults, the most frequent domains for dysfunction were Breathing and Habits, but only 11.5% showed dysfunction in these domains. Scores in Breathing were mostly related to snoring.

Figure 1B shows an orofacial dysfunction profile based on data from the initial NOT-S study [1] reporting on 120 individuals with a variety of disabilities and chronic diseases and 60 healthy controls. In three domains, Chewing and swallowing in the interview part, Face at rest and Speech in the examination part, more than 45% of the patients had dysfunction scores. The most frequent dysfunction was in Chewing and swallowing (63%).

Figure 1C shows orofacial dysfunction profiles for a neurodegenerative disease, together with a matched control group [3]. More than 50% of patients with Parkinson's disease had problems in Habits, Chewing and swallowing, Facial expression, Oral motor function and Speech. Also, 40% or more of patients had dysfunction in Breathing, Drooling and Masticatory muscle and jaw function. The most frequent dysfunction occurred in Facial expression (87%).

Figure 1D shows the orofacial dysfunction profiles in individuals with three different rare congenital disorders: ectodermal dysplasia, Prader-Willi syndrome and Treacher Collins syndrome [5,7,9]. Each diagnosis shows a different profile of orofacial

dysfunction. Over 50% of individuals with ectodermal dysplasia had problems in Chewing and swallowing and over 50% of patients with Prader-Willi syndrome had dysfunction in Habits, Face at rest and Oral motor function. In Treacher Collins syndrome, 89% had a score in Face at rest.

Figure 1E illustrates the orofacial dysfunction profiles of children with adenotonsillar hypertrophy, before and after treatment [6]. Before treatment, over 60% of the patients had one or more dysfunction score in Breathing, Chewing and swallowing, Face at rest and Speech. The most frequent dysfunction was in Breathing (97%). After treatment, there was a marked reduction to less than 30% in orofacial dysfunction in all of these domains but Speech, in which almost 50% of the patients still had problems.

## Discussion

The present review indicates that orofacial problems are common in many patient groups including children. Several body functions are concentrated in the orofacial area: some vital, like breathing and nutrition, and some necessary for social interaction and communication [15–17]. Deviant or delayed development may be associated with orofacial dysfunction. As an example, searching the Winter-Baraitser Dysmorphology database, the search term *face* matched 1491 of the nearly 4000 syndromes, while the term *mouth* matched 1074 [18]. Our review shows that the mean NOT-S scores differed between patients and control subjects in all studies, while the dysfunction profiles clearly illustrate the typical characteristics of orofacial dysfunction associated with different diagnoses.

Most studies report that the NOT-S is easy to use, identifying areas of orofacial dysfunction for further assessment or treatment. The NOT-S is a screening instrument and should be used to indicate areas of dysfunction requiring further interview or more detailed examinations and referral. In 37% of cases, the control subjects registered a NOT-S dysfunction score. In adults, these dysfunctions were usually quite mild, with most occurring in Breathing and Habits. Suggestions for further assessments of domains with positive scores can be found on the website <http://mun-h-center.se/en/Mun-H-Center/Mun-H-Center-E/NOT-S/>.

In typically-developing children, dysfunction scores mostly occurred in Oral motor function in the youngest children and Speech, beginning at age 5 years. Children below 5 years of age showed less dysfunction in Speech compared to older children. This is probably due to the addition of a parameter in Speech starting at age 5 years, as well as generally increased demands on speech clarity from that age.

The orofacial dysfunction profiles were based on the frequencies of individuals with compromised orofacial

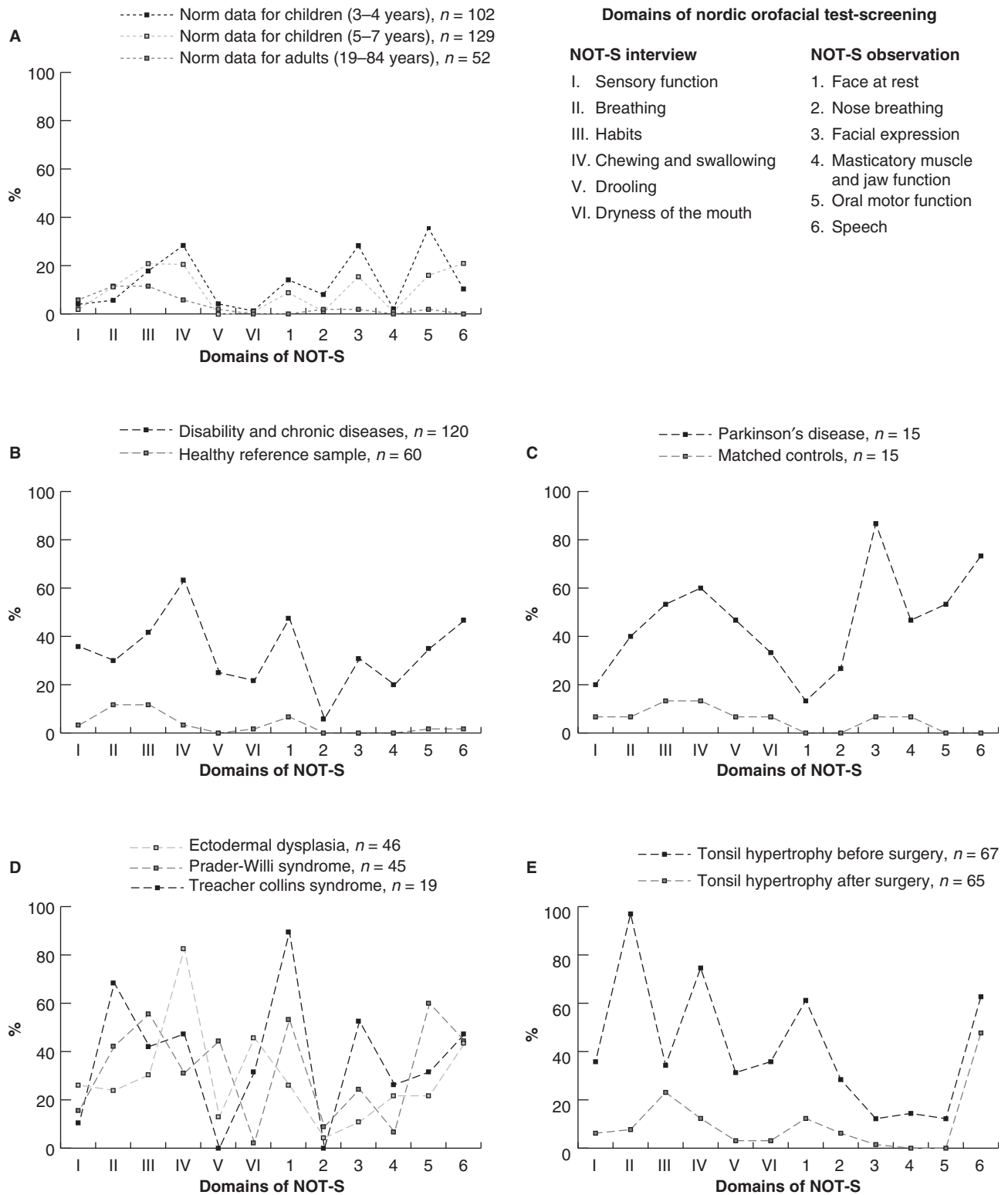


Figure 1. Orofacial dysfunction profiles based on frequencies of NOT-S domain scores (%) in different groups of individuals reported in publications using the Nordic Orofacial Test-Screening, NOT-S. (A) Norm data for children (3–7 years) and adults (19–86 years) [1,3,4]. The 12 domains of NOT-S are listed to the right. (B) Patients with disabilities and chronic diseases (3–86 years) and a healthy reference sample (3–78 years) [1]. (C) Patients with Parkinson's disease (61–82 years) and age- and gender-matched controls [3]. (D) Individuals with three rare disorders: ectodermal dysplasia (3–55 years), Prader-Willi syndrome (5–50 years) and Treacher Collins syndrome (5–74 years) [5,7,9]. (E) Children with adenotonsillar hypertrophy, before and after surgery (4–5 years) [6].

function in the various domains examined by NOT-S. Because they illustrate characteristic symptom features, the profiles may help to identify patients who need to be examined for specific diagnoses. When looking at domains in which over 40% of the subjects had dysfunction scores, patterns of orofacial dysfunction correlate well with the typical phenotypes, clinical signs and symptoms of the diagnoses.

In the study on ectodermal dysplasia (ED), an umbrella term for more than 200 different diagnoses, 70% of subjects had hypohidrotic ED. The others had different forms of ED, often with more severe symptoms. Common clinical signs of ED include missing teeth and reduced salivary secretion, which are known to affect chewing, swallowing and speech, while cognitive function is usually normal. These symptoms accord with ED's dysfunction profile, in which the most common domains for dysfunction scores were, in order of frequency, Chewing and swallowing, Speech and Dryness of the mouth (82.6–43.5%) [5].

In Prader-Willi syndrome (PWS), common symptoms include muscular hypotonia, developmental delay and mental retardation. Orofacial complications present with a small mouth, imprecise articulation and clarity of speech, dental abnormalities and thick, viscous saliva with decreased salivary flow [7]. The most common domains for dysfunction scores, found in 60.0–42.2% of PWS patients, were, in order of frequency, Oral motor function, Habits, Face at rest, Drooling, Speech and Breathing. The dysfunction profile for PWS highlights that this diagnosis has a strong impact on orofacial function and quality-of-life.

Treacher Collins syndrome (TCS) is a rare disorder of craniofacial development. Its orofacial features include altered profile, increased mandibular angle, narrow hypopharynx and facial asymmetry [8]. The dysfunction profile shows that over 40% of TCS subjects had scores in six of the 12 domains (from 89.5–42.1%). In order from most to least frequent, these were Face at rest, Breathing, Facial expression, Chewing and swallowing, Speech and Habits [8]. These results show that many individuals experience major orofacial dysfunction associated with TCS. The results for three different rare disorders, with different facial and oral features, show that NOT-S differentiates well between groups with different kinds of orofacial disability.

Parkinson's disease is an irreversible, slowly progressive, neurodegenerative movement disorder, with tremors, rigidity and bradykinesia as its primary symptoms [3]. Over 40% of patients with Parkinson's disease registered orofacial dysfunction in eight of the 12 domains, ranging from 86.7–40.0%. The domains were, from most to least frequent, Facial expression, Speech, Chewing and swallowing, Habits, Oral motor function, Masticatory muscle and jaw function, Drooling and Breathing. The strong clinical expression of impaired orofacial function was related to the

rather late stage of degenerative symptoms in this cohort. Our review of results for different diagnoses confirms the potential for NOT-S to indicate the typical signs and symptoms of orofacial dysfunction.

NOT-S was also used to assess orofacial function, before and after surgery, in children with adenotonsillar hypertrophy [6]. Before treatment, dysfunction prevalence exceeded 40% in four domains, ranging from 97.0–61.2%: Breathing, Chewing and swallowing, Speech and Face at rest. As expected, the results 6 months after surgery showed a general improvement in orofacial function, as a consequence of the treatment. The only remaining domain with prevalent dysfunction was Speech (47.7%), demonstrating a remaining need for speech therapy. NOT-S may also be used to evaluate the effect of other forms of habilitation and rehabilitation, surgical or non-surgical, in the orofacial region.

## Conclusion

Our review corroborates earlier findings that NOT-S differentiates well between individuals with orofacial disorders and healthy controls and also identifies differences in patients before and after treatment. In addition the NOT-S dysfunction profiles seemed useful to illustrate differences and characteristic orofacial dysfunctions associated with specific disorders.

Together, the literature suggests that NOT-S could be used as a standard instrument for trained examiners in the assessment of orofacial dysfunction, identifying patients and domains needing specialist evaluation. Furthermore, NOT-S could be useful to evaluate oral habilitation and rehabilitation outcomes and could also help improve comparability between clinics and clinical investigations.

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