

## **Abstract**

*Objectives:* Determine and compare the prevalence of orofacial pain in older nursing home residents with and without dementia and explore the association between orofacial pain and health factors.

*Methods:* Cross-sectional study conducted in four UK nursing homes. We used the Orofacial-Pain Scale for Non-Verbal Individuals (OPS-NVI) to identify orofacial pain in residents with dementia. Residents who were able to communicate self-reported orofacial pain. A brief oral examination was conducted. Information on demographics, Clinical Dementia Rating, Charlson Comorbidity Index, Cohen Mansfield Agitation Inventory, Barthel Index, 5-level EQ-5D, Oral Health Impact Profile 14, Mini Nutritional Assessment Short Form, and medication was collected. Chi-squared tests, independent sample t-tests, and Mann-Whitney U-tests were used to compare outcomes between groups. Multivariable logistic regression was used to evaluate predictors of orofacial pain.

*Results:* Orofacial pain, assessed with the OPS-NVI, was present in 48.8% (95% C.I. 36.1, 50.7) of residents with dementia. Self-reported orofacial pain, was present in 37.8% (95% C.I. 20.4, 53.7) of residents with dementia, and in 14.8% (95% C.I. 0.5, 30.4) residents without dementia. Orofacial pain was significantly more prevalent in residents with dementia than those without (OPS-NVI;  $p=0.002$ , self-report;  $p=0.04$ ). Having a soft diet, xerostomia, being dentate, and poor oral hygiene in dentate residents were significant predictors of orofacial pain in residents with dementia.

*Conclusion:* Orofacial pain was more prevalent in residents with dementia. Oral health care should be part of routine care for residents, especially for those with dementia, to improve oral health and decrease the risk of developing orofacial pain.

**Keywords:** Dementia; Orofacial pain; Nursing Home; Oral health; OPS-NVI

### **Key Points:**

1. The prevalence of orofacial pain in older nursing home residents with dementia is 48.8% compared to 14.8% of those without dementia.
2. The oral health of nursing home residents with dementia is poorer than of those without.

3. Oral health care should be a routine aspect of care for nursing home residents.

## **Introduction**

Pain in older people with dementia, including orofacial pain, is often underdiagnosed and undertreated[1]. Undertreated pain may increase the risk of delirium, decrease quality of life, and can cause distress leading to depression or agitation[2]. This may lead to clinicians prescribing inappropriate anti-psychotic drugs, which increase mortality risk and other adverse events[3, 4].

Orofacial pain, which can be caused by dental problems or non-odontogenic problems (e.g., inflammation of the gums or pain in masticatory muscles), is common in older people[4]. Oral health problems are common in older people due to multiple factors such as high sugar intake, unavailability of fluoride throughout life, hyposalivation, etc., and are more common in people with dementia, due to reduced self-care and challenging behaviour[5, 6]. Epidemiological studies show that nursing home residents have poorer oral health than the general population of older people, and that they have inequitable access to dental care[6, 7].

The prevalence of orofacial pain in older people without dementia is 6.7-18.5%, and the few studies on orofacial pain in people with dementia show a prevalence of 7.4-21.7%[8]. A study conducted in UK acute hospitals reported a prevalence of 11.9-21.9% in older people with dementia[9]. Remarkably, there is little research on orofacial pain in older people with dementia in nursing homes, who may have problems with verbal communication and poor oral health.

For pain assessment, self-report is the 'gold-standard'. However, self-report is challenging for people with severe dementia and direct observation is needed[1]. An observational diagnostic tool, the Orofacial-Pain Scale for Non-Verbal Individuals (OPS-NVI), has been developed to diagnose orofacial pain in people who are unable to communicate verbally[10]. Previous studies on reliability and validity of the OPS-NVI showed promising results[11-13].

The aims of this study were to 1) determine the prevalence of orofacial pain in older nursing home residents with dementia, 2) determine whether orofacial pain is more prevalent in older nursing home residents with dementia, than in those without, 3) explore the association between the presence of orofacial pain and health factors, 4) to assess the validity of the OPS-NVI.

## **Methods**

### *Study design and participants*

Cross-sectional observational data was collected from four nursing homes in London, UK. These are residential settings that are staffed by qualified nurses and can provide nursing care [14]. In group 1, residents were eligible for inclusion if they had a diagnosis of dementia in their notes, aged 65 years or above, and a suitable level of English. In group 2, the comparison group, residents were included if they were aged 65 years or above, no diagnosis of dementia, a suitable level of English, and had capacity. We excluded patients who indicated that they did not wish to participate, those with delirium, or those with clinical concerns.

### *Consent and ethical approval*

Capacity legislation was followed (Mental Capacity Act 2005, Sections 30-34). Informed consent was obtained from participants with capacity to consent. If they did not have capacity, a personal or professional consultee gave agreement for the person's participation, and signed for this. The study was approved by the London Queen Square Research Ethical Committee (19/LO/0100).

### *Measurement instruments*

Participants with dementia were observed, using the OPS-NVI[15]. The researcher began with a 3-minute observation period during rest, drinking, eating, and oral care. The researcher completed the OPS-NVI during or as soon as possible after the observations. During oral care, only dentate participants were observed.

For participants who were able to communicate verbally and understood the task, a brief self-report pain scale, the Numeric Rating Scale (NRS), was used to identify orofacial pain during the four activities.

Information on demographics (date of birth, gender, ethnicity, marital status, years of schooling, highest completed level of education) was collected via interview. Dementia severity was determined using the Clinical Dementia Rating (CDR) score, and co-morbidity with the Charlson Comorbidity Index (CCI)[16, 17]. The Cohen Mansfield Agitation Inventory (CMAI) was used to assess for behavioural changes[18]. Functional ability was determined, using the Barthel Index[19]. Quality of life was measured with the 5-level EQ-5D (EQ-5D-5L) and the Oral

Health Impact Profile 14 (OHIP-14)[20, 21]. Nutritional status was determined with the Mini Nutritional Assessment Short Form (MNA-SF)[22]. Medication taken on the day of assessment was documented, with a special focus on analgesics, antidepressants, and antiepileptics.

A brief oral examination was conducted, considering the dental situation and oral health habits: Summated Xerostomia Inventory (SXI), dental status, Denture Hygiene Index (DHI), Decayed Missing Filled Teeth (DMFT), retained roots, occlusal units (number of contacts between upper- and lower (pre)molars), and Debris Index (DI) of the Simplified Oral Hygiene Index (OHI-S)[23-25].

The same information was collected for participants with and without dementia, except for the observations with the OPS-NVI, dementia severity (CDR), and the CMAI.

#### *Sample size*

Previously reported prevalence of orofacial pain in people without dementia of 6.7%, and 20.7% with dementia was utilised[26]. Using the sample size formula for the Chi-squared test, with a level of confidence of 95%, and a power of 80%, 94 participants were needed per group.

#### *Data analysis*

Descriptive statistics were used to report cohort demographic features. We used Chi-squared tests, independent sample t-tests, and Mann-Whitney U-tests (depending on data distribution) to compare demographics, oral health, orofacial pain, and quality of life between the groups.

Orofacial pain, according to the OPS-NVI, was deemed present when the estimated pain intensity was rated 1 or higher by the researcher, and as absent when the estimated pain intensity was rated 0 by the researcher. Orofacial pain, according to self-report, was marked as present when the estimated pain intensity was rated 1 or higher by the participant, and as absent when the estimated pain intensity was rated 0 by the participant.

Multivariable logistic regression was used to explore the relationship between the presence of orofacial pain, according to the OPS-NVI, and multiple oral health factors, adjusting for confounders (age, comorbidity). Regression analysis for self-reported orofacial pain, were not conducted due to low number of events.

To assess the validity of the OPS-NVI, the sensitivity, specificity and Area Under the Receiver Operating Curve (AUROC) for each activity was calculated. The outcome of the self-report pain scale, the NRS, was used as gold-standard.

## **Results**

In total, 107 residents with dementia meeting the inclusion criteria were approached and 84 were recruited (response rate 79%). The response rate of residents without dementia was 61%. Of the 44 residents approached without dementia that met the inclusion criteria, 27 residents were recruited (see flowchart, **Appendix 1** in the supplementary data on the journal website (<http://www.ageing.oxfordjournals.org/>)).

The average age of the sample was 83.9 (SD 7.95) years old, and 62.2% were female. There was no significant difference in demographics between residents with dementia and those without (see **Table 1**).

In those with dementia, 63.1% were categorised as “severe” on the CDR. Using the CMAI, 13.1% showed aggressive behaviour, 10.7% showed physically nonaggressive behaviour, and 29.8% showed verbally agitated behaviour. There was no significant difference between residents with dementia and those without, regarding comorbidity (CCI), quality of life (EQ-5D), and oral-health related quality of life (OHIP-14). Function (Barthel Index) and nutrition status (MNA-SF) were significantly poorer in residents with dementia than in those without.

### *Oral health*

Significantly more residents with dementia were on a soft diet, compared to those without. Dentate residents with dementia had significantly fewer natural teeth, more retained roots, more DMFT, more missing teeth, and fewer OU present than dentate residents without dementia. Denture hygiene in residents with dementia was significantly poorer than in those without (see **Table 1**).

### *Orofacial pain*

The prevalence of orofacial pain, during rest, drinking, chewing, and oral care are given in **Table 2**. The overall score includes orofacial pain observed or self-reported during at least one of the activities. The overall prevalence of orofacial pain, according to the OPS-NVI, in residents with

dementia was 48.8% (95% C.I. 36.1, 60.7), and was significantly higher than the 14.8% (95% C.I. 0.5, 30.4) prevalence in those without dementia. The prevalence of orofacial pain, according to self-report, in the 37 residents with dementia who were able to self-report, was 37.8% (95% C.I. 20.4, 53.7), and this was also significantly higher than the 14.8% (95% C.I. 0.5, 30.4) prevalence in residents without dementia. The sensitivity of the OPS-NVI was 66.5-100%, the specificity was 76.9-100%, the AUROC was 0.794-1.0, and the accuracy was acceptable to outstanding[27]. The sensitivity, specificity, and AUROC of each activity separately are shown in **Appendix 2**.

#### *Associations between orofacial pain and oral health*

Correlations between orofacial pain and general health and oral health factors are given in **Appendix 3**. The presence of orofacial pain was significantly associated with poorer quality of life in both residents with dementia and those without. Physically nonaggressive behaviour, as measured by the CMAI was associated with orofacial pain in those with dementia. Associations between the presence of orofacial pain and oral health factors are shown in **Table 3**. Having a soft diet (OR 3.06; 95% C.I. 1.21, 7.77), being dentate (OR 7.04; 95% C.I. 2.20, 22.50), and poor oral hygiene in dentate participants (OR 3.80; 95% C.I. 1.13, 12.73), after adjusting for age and comorbidity, were significant predictors for the presence of orofacial pain, according to the OPS-NVI, in residents with dementia.

## **Discussion**

Orofacial pain, assessed with the OPS-NVI, was present in nearly half of residents with dementia. Orofacial pain, according to self-report, was present in nearly 40% of residents with dementia, and in 15% of residents without dementia. Orofacial pain was significantly more common in residents with dementia than in those without. Having a soft diet, xerostomia, being dentate, and poor oral hygiene in dentate residents were significant predictors for the presence of orofacial pain in residents with dementia. The accuracy of the OPS-NVI was acceptable to outstanding.

A previous study (conducted in the Netherlands) found a prevalence of orofacial pain of 4-22%, according to the OPS-NVI in older people with Mild Cognitive Impairment (MCI) or dementia, living in nursing homes or in the community[28]. Of the participants with MCI or dementia who

were still able to self-report, 25.7% reported orofacial pain[28]. These findings differ to our study possibly because of the poorer oral health of our sample. For example, Delwel et al. found that only 18.1% of the participants had one or more retained roots, while in our study 41.7% of participants with dementia had one or more retained roots[28]. Similar to our findings, de Souza et al. found that orofacial pain was more prevalent in older people with mild dementia (20.7%), than in those without (6.7%), although their study was conducted in community-dwelling older people[26]. Having a soft diet, xerostomia, being dentate, and poor oral hygiene in dentate residents were significant predictors for orofacial pain, according to the OPS-NVI. Another study reported more xerostomia, including burning sensations, in people with orofacial pain[29]. Being dentate, and having poor oral hygiene give an increased risk of oral health problems causing dental pain, the most common cause of orofacial pain[30].

### *Strengths and limitations*

This is the first study assessing the prevalence of orofacial pain and oral health in older nursing home residents with and without dementia, including people with dementia lacking capacity. The OPS-NVI is the first observational tool identifying orofacial pain in people with dementia who cannot verbally express this. It is important to acknowledge the risk of misinterpreting behaviour, when using observational tools. Observed behavioural change could be a response to the oral care itself, rather than pain causing these behaviours.

Nevertheless, there is a great need for a validated observational tool to identify orofacial pain in this population. Unfortunately, the target sample size of 94 participants per group was not met due to recruitment challenges and the ratio of residents with and without dementia being unequal (over two-thirds have dementia). Therefore, it is important to acknowledge that the control group of people without dementia may not be “typical” UK care home residents. Due to the low number of events, regression analysis for self-reported orofacial pain, was not conducted, and adjusted analysis for the following confounding factors could not be performed; analgesics, dementia severity, and functional ability. Furthermore, only a brief oral examination was performed. To establish a full dental diagnosis, more extended examination is necessary. As a result, the estimation of oral health problems is probably an under-estimation. To assess the influence of care home admission on oral health status, a prospective cohort study which collects longitudinal data on oral health status following admission is recommended.

### *Clinical Implications*

Orofacial pain was more prevalent in older nursing home residents with dementia than in those without. Oral hygiene may be poor, because residents with dementia are unable to clean their own teeth or may not allow others to do this for them. Greater oral health problems, increase the risk of orofacial pain. This frail population is often irregularly seen by dental professionals[6]. We recommend that oral health care should be included in the routine health care of nursing home residents, especially those with dementia. Personalised needs regarding oral hygiene and dental treatment could be established during the earlier stages of dementia. If oral health care is implemented in routine care, the risk of orofacial pain will be reduced. Our findings support the recent call of the Care Quality Commission (CQC) to improve oral health in care homes across England[31]. One of the main findings of this review was that over half of inspected care homes had no policy to improve or protect residents' oral health[31].

### **Conclusion**

Orofacial pain significantly impacts the quality of life of older care home residents but has been a neglected area of research. Oral health care should be part of routine care for nursing home residents, especially for those with dementia, to improve oral health and decrease the risk of developing orofacial pain. Care home staff may need support and training to deliver this.

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**Table 1:** Descriptive characteristics of all participants and residents with and without dementia separately

	<b>Total (n=111)</b>	<b>Dementia (n=84)</b>	<b>No Dementia (n=27)</b>	<b>Test value</b>	<b>P-value</b>
<b>Gender [n (%)]</b>				$\chi^2(1) = 0.010$	0.921
<b>Female</b>	69 (62.2%)	52 (61.9%)	17 (63.0%)		
<b>Male</b>	42 (37.8%)	32 (38.1%)	10 (37.0%)		
<b>Age <i>M, SD</i> (range)</b>	83.9, 7.95 (65-101)	84.5, 7.62 (65-101)	82.3, 8.86 (66-99)	$t(109) = 1.229$	0.222
<b>Ethnicity [n (%)]</b>				$\chi^2(3) = 4.195$	0.241
<b>White</b>	70 (63.1%)	54 (64.3%)	16 (59.3%)		
<b>Asian/Asian British</b>	9 (8.1%)	8 (9.5%)	1 (3.7%)		
<b>Black/African/Caribbean/Black British</b>	28 (25.2%)	18 (21.4%)	10 (37.0%)		
<b>Other ethnic group</b>	4 (3.6%)	4 (4.8%)	0 (0.0%)		
<b>Marital status [n (%)]</b>				$\chi^2(3) = 2.827$	0.419
<b>Married</b>	28 (25.7%)	21 (25.3%)	7 (26.9%)		
<b>Divorced</b>	9 (8.3%)	5 (6.0%)	4 (15.4%)		
<b>Widowed</b>	48 (44.0%)	37 (44.6%)	11 (42.3%)		
<b>Single</b>	24 (22.0%)	20 (24.1%)	4 (15.4%)		
<b>Years in general education <i>M, SD</i> (range)</b>	9.69, 3.78 (0-18)	9.12, 3.61 (0-16)	10.6, 3.94 (0-18)	$t(52) = -1.388$	0.171
<b>Highest completed level of education [n (%)]</b>				$\chi^2(4) = 4.133$	0.388
<b>Degree</b>	1 (0.9%)	1 (1.2%)	0 (0.0%)		
<b>GCSE (or equivalent)</b>	9 (8.2%)	5 (6.0%)	4 (14.8%)		
<b>No qualification</b>	50 (45.5%)	36 (43.4%)	14 (51.9%)		
<b>Other</b>	3 (2.7%)	2 (2.4%)	1 (3.7%)		
<b>Unknown</b>	47 (42.7%)	39 (47.0%)	8 (29.6%)		
<b>CDR [n (%)]</b>			-	N/A	N/A
<b>None</b>	0 (0%)	0 (0%)			
<b>Questionable</b>	1 (1.2%)	1 (1.2%)			
<b>Mild</b>	8 (9.5%)	8 (9.5%)			
<b>Moderate</b>	22 (26.2%)	22 (26.2%)			
<b>Severe</b>	53 (63.1%)	53 (63.1%)			
<b>CCI median (<i>IQR</i>)</b>	4 (3-5)	4 (3-5)	4 (2-5)	$Z = -0.807$	0.420
<b>CMAI [n (%)]</b>			-	N/A	N/A
<b>Aggressive behaviour</b>	11 (13.1%)	11 (13.1%)			
<b>Physically nonaggressive behaviour</b>	9 (10.7%)	9 (10.7%)			
<b>Verbally agitated behaviour</b>	25 (29.8%)	25 (29.8%)			
<b>Barthel Index median (<i>IQR</i>)</b>	15 (10-35)	10 (10-30)	30 (15-40)	$Z = -2.936$	0.003*
<b>EQ-5D Index <i>M, SD</i> (range)</b>	0.105, 0.299 (-0.352-0.906)	0.075, 0.279 (-0.352-0.806)	0.199, 0.344 (-0.256-0.906)	$t(109) = -1.899$	0.060
<b>OHIP-14 median (<i>IQR</i>)</b>	1 (0-5)	1 (0-4)	2 (0-5.5)	$Z = -0.969$	0.333
<b>MNA-SF [n (%)]</b>				$\chi^2(1) = 8.382$	0.015*
<b>Normal nutrition status</b>	21 (18.9%)	12 (14.3%)	9 (33.3%)		
<b>At risk of malnutrition</b>	51 (45.9%)	37 (44.0%)	14 (51.9%)		
<b>Malnourished</b>	39 (35.1%)	35 (41.7%)	4 (14.8%)		
<b>Medication [n (%)]</b>					
<b>Analgesics</b>	92 (82.9%)	69 (82.1%)	23 (85.2%)	$\chi^2(1) = 1.33$	0.715
<b>Regular</b>	54 (58.1%)	36 (51.4%)	18 (78.3%)	$\chi^2(2) = 5.625$	0.060

<b>PRN</b>	34 (36.6%)	29 (41.4%)	5 (21.7%)		
<b>Regular + PRN</b>	5 (5.4%)	5 (7.1%)	0 (0.0%)		
<b>Antidepressants</b>	29 (26.1%)	20 (23.8%)	9 (33.3%)	$X^2(1) = 0.960$	0.327
<b>Anti-epileptics</b>	19 (17.1%)	11 (13.1%)	8 (29.6%)	$X^2(1) = 3.937$	0.047*
<b>Anti-psychotics</b>	18 (16.2%)	14 (16.7%)	4 (14.8%)	$X^2(1) = 0.052$	0.820
<b>Dental status, dentate [n (%)]</b>	77 (69.4%)	59 (70.2%)	18 (66.7%)	$X^2(1) = 0.123$	0.726
<b>Dental situation upper jaw [n (%)]</b>				$X^2(3) = 3.257$	0.354
<b>Own dentition</b>	50 (45.0%)	38 (45.2%)	12 (44.4%)		
<b>Partial dentition</b>	16 (14.4%)	10 (11.9%)	6 (22.2%)		
<b>Full denture (wearing)</b>	27 (24.3%)	20 (23.8%)	7 (25.9%)		
<b>Full denture (not wearing/lost)</b>	18 (16.2%)	16 (19.0%)	2 (7.4%)		
<b>Dental situation lower jaw [n (%)]</b>				$X^2(3) = 1.412$	0.703
<b>Own dentition</b>	57 (51.4%)	43 (51.2%)	14 (51.9%)		
<b>Partial dentition</b>	18 (16.2%)	14 (16.7%)	4 (14.8%)		
<b>Full denture (wearing)</b>	18 (16.2%)	12 (14.3%)	6 (22.2%)		
<b>Full denture (not wearing/lost)</b>	18 (16.2%)	15 (17.9%)	3 (11.1%)		
<b>Last visit dentist median (IQR)</b>	2 (0.75-5)	3 (1-5)	2 (0.5-4.5)	$Z = -1.018$	0.309
<b>Brush frequency [n (%)]</b>				$Z = -1.204$	0.228
<b>&gt;2x daily</b>	1 (0.9%)	1 (1.2%)	0 (0.0%)		
<b>2x daily</b>	19 (17.6%)	12 (14.8%)	7 (25.9%)		
<b>1x daily</b>	60 (55.6%)	45 (55.6%)	15 (55.6%)		
<b>Few times a week</b>	10 (9.3%)	9 (11.1%)	1 (3.7%)		
<b>Never</b>	18 (16.7%)	14 (17.3%)	4 (14.8%)		
<b>Subjective swallowing quality [n (%)]</b>				$X^2(2) = 3.084$	0.214
<b>Good</b>	81 (73.0%)	59 (70.2%)	22 (81.5%)		
<b>Moderate</b>	25 (22.5%)	22 (26.2%)	3 (11.1%)		
<b>Bad</b>	5 (4.5%)	3 (3.6%)	2 (7.4%)		
<b>Subjective chewing quality [n (%)]</b>				$X^2(2) = 4.180$	0.124
<b>Good</b>	58 (52.3%)	40 (47.6%)	18 (66.7%)		
<b>Moderate</b>	38 (34.2%)	30 (35.7%)	8 (29.6%)		
<b>Bad</b>	15 (13.5%)	14 (16.7%)	1 (3.7%)		
<b>Soft diet [n (%)]</b>	39 (35.8%)	35 (42.7%)	4 (14.8%)	$X^2(1) = 6.865$	0.009*
<b>SXI median (IQR)</b>	6 (5-11.75)	7 (5.5-13)	6 (5-10)	$Z = -1.220$	0.222
<b>Present teeth median (IQR)</b>	16 (7-22)	14 (6-21)	22 (12.75-24.25)	$Z = -2.302$	0.021*
<b>Retained roots median (IQR)</b>	1 (0-2)	1 (0-2)	0 (0-0.25)	$Z = -2.444$	0.015*
<b>DMFT median (IQR)</b>	24 (19-29)	25 (20-29)	18 (12.5-24.25)	$Z = -3.460$	0.001*
<b>Decayed Teeth</b>	2 (0-3.5)	2 (0-3)	1.5 (0-4)	$Z = -0.491$	0.623
<b>Missing Teeth</b>	16 (10-25)	18 (11-26)	10 (7.5-19)	$Z = -2.405$	0.016*
<b>Filled Teeth</b>	2 (0-5.5)	1 (0-5)	3 (0.75-6)	$Z = -0.382$	0.382
<b>OU median (IQR)</b>	0 (0-4)	0 (0-3)	4 (0-7)	$Z = -2.625$	0.009*
<b>DI of the OHI-S median (IQR)</b>	2.67 (2.0-3.0)	2.67 (2.0-3.0)	2.30 (1.33-2.83)	$Z = -1.857$	0.063
<b>DHI [n (%)]</b>				$X^2(2) = 7.173$	0.028*
<b>Excellent</b>	7 (21.2%)	2 (8.7%)	5 (50.0%)		
<b>Fair</b>	9 (27.3%)	7 (30.4%)	2 (20.0%)		
<b>Poor</b>	17 (51.5%)	14 (60.9%)	3 (30.0%)		

Note. M=mean, SD=standard deviation, IQR=interquartile range, CDR=Clinical Dementia Rating, CCI=Charlson Comorbidity Index, CMAI=Cohen-Mansfield Agitation Inventory, EQ-5D=Euroqol 5 Dimension, OHIP=Oral Health Impact Profile, MNA-SF=Mini Nutritional Assessment Short Form, PRN=Pro Re Nata, SXI=Summated Xerostomia Inventory, DMFT=Decayed Missing and Filled Teeth, OU=Occlusal Units, DI=Debris Index, OHI-

*S=Simplified Oral Hygiene Index, X<sup>2</sup>=Chi-squared test, T=independent sample t-test, Z=Mann-Whitney U-test, N/A=Not Applicable, \*=p<0.05.*

**Table 2:** Prevalence of orofacial pain, according to the Orofacial-Pain Scale for Non-Verbal Individuals (OPS-NVI) and according to self-report, during resting, drinking, chewing, and oral care in nursing home residents with and without dementia

	<i>Dementia</i>						<i>No Dementia</i>								
	<i>N</i>	<i>OPS-NVI in dementia</i>	<i>95% CI of %</i>	<i>N</i>	<i>OPS-NVI in verbal PD</i>	<i>95% CI of %</i>	<i>N</i>	<i>OPS-NVI in non-verbal PD</i>	<i>95% CI of %</i>	<i>N</i>	<i>Self-report in verbal PD</i>	<i>95% CI of %</i>	<i>N</i>	<i>Self-report</i>	<i>95% CI of %</i>
<b>Resting</b>	84	9 (10.7%)	2.6-19.9	37	2 (5.4%)	0.0-13.2	47	7 (14.9%)	4.1-27.0	37	2 (5.4%)	0.0-15.7	27	1 (3.7%)	0.0-13.6
<b>Drinking</b>	84	14 (16.7%) <sup>a</sup>	8.7-23.6	37	3 (8.1%)	0.3-18.4	47	11 (23.4%)	11.6-37.2	37	3 (8.1%)	0.0-21.2	27	0 (0.0%) <sup>a</sup>	100-100
<b>Chewing</b>	83	24 (28.9%)	16.9-38.6	37	8 (21.6%)	9.0-40.5	46	16 (34.8%)	23.5-49.0	37	9 (24.3%)	12.9-39.3	27	3 (11.1%)	0.0-24.1
<b>Oral care</b>	43	26 (60.5%) <sup>a</sup>	48.8-74.4	25	12 (48.0%) <sup>b</sup>	26.9-68.1	18	14 (77.8%) <sup>b</sup>	60.4-99.3	24	11 (45.8%) <sup>c</sup>	24.1-63.9	19	2 (10.5%) <sup>a,c</sup>	0.0-100
<b>Overall</b>	84	41 (48.8%) <sup>a</sup>	36.1-60.7	37	15 (40.5%)	25.8-55.4	47	26 (55.3%)	37.7-73.6	37	14 (37.8%) <sup>c</sup>	20.4-53.7	27	4 (14.8%) <sup>a,c</sup>	0.5-30.4

Note. OPS-NVI=Orofacial-Pain Scale for Non-Verbal Individuals, PD=participants with dementia, CI=Confidence interval.

<sup>a</sup> = significant difference between OPS-NVI in the dementia group and self-report in the no dementia group ( $p < 0.05$ )

<sup>b</sup> = significant difference between OPS-NVI in verbal PD and OPS-NVI in non-verbal PD ( $p < 0.05$ )

<sup>c</sup> = significant difference between self-report in the dementia group and self-report in the no dementia group ( $p < 0.05$ )

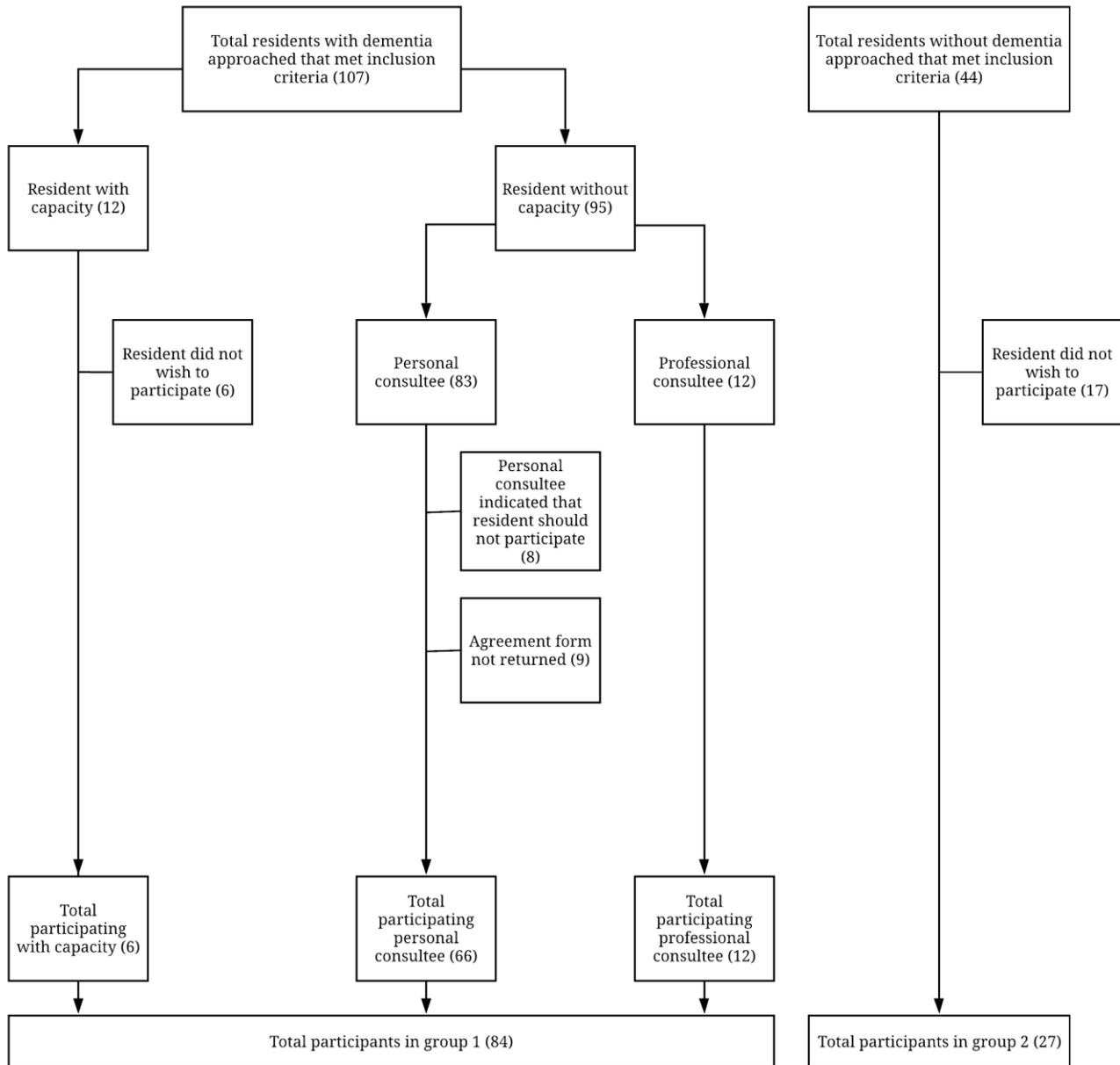
The overall score includes pain observed or self-reported during at least one of the activities. Orofacial pain during oral care was only identified in dentate participants.

**Table 3:** Association of oral health factors with the presence of orofacial pain, according to the Orofacial-Pain Scale for Non-Verbal Individuals (OPS-NVI) in nursing home residents with dementia. Odds ratios were calculated by performing univariate and multivariable logistic regression, adjusted for age and comorbidity (Charlson Comorbidity Index)

	<b>Dementia</b>	
	<b>OPS-NVI (n=84)</b>	
	<b>OR (95% CI)</b>	<b>AOR (95% CI)</b>
<b>Soft diet</b>	2.99 (1.21-7.40)*	3.06 (1.21-7.77)*
<b>SXI</b>	1.04 (0.91-1.18)	1.04 (0.91-1.20)
<b>D vs ED</b>	4.62 (1.61-13.26)*	7.04 (2.20-22.50)*
<b>Number of teeth</b>	0.95 (0.89-1.02)	0.96 (0.90-1.04)
<b>Retained roots</b>	1.29 (0.96-1.74)	1.28 (0.93-1.75)
<b>DMFT</b>	1.12 (1.02-1.24)*	1.11 (1.00-1.23)
<b>OU</b>	0.91 (0.77-1.07)	0.95 (0.80-1.14)
<b>DI of the OHI-S</b>	4.69 (1.46-15.09)*	3.80 (1.13-12.73)*

*Note.* SXI=Summated Xerostomia Inventory, D vs ED=Dentate vs Edentate, DMFT=Decayed Missing and Filled Teeth, OU=Occlusal Units, DI=Debris Index, OHI-S=Simplified Oral Hygiene Index, OR=Odds Ratio, AOR=Adjusted Odds Ratio, CI=Confidence Interval, \*= $p < 0.05$ .

## Supplementary Materials



*Appendix 1: Recruitment flowchart residents with and without dementia*

**Appendix 2:** Sensitivity, specificity, and Area Under the Receiver Operating Curve (AUROC) of the Orofacial-Pain Scale for Non-Verbal Individuals (OPS-NVI), during resting, drinking, chewing, and oral care in verbal nursing home residents with dementia

	<i>Sensitivity</i>	<i>Specificity</i>	<i>AUROC</i>	<i>Accuracy</i>
<i>Resting</i>	100%	100%	1.0	Outstanding
<i>Drinking</i>	66.6%	97.1%	0.819	Excellent
<i>Chewing</i>	77.8%	96.4%	0.871	Excellent
<i>Oral Care</i>	81.8%	76.9%	0.794	Acceptable

*Note. AUROC = Area Under the Receiver Operating Curve.*

*Sensitivity, specificity and AUROC are calculated based on the comparison between the OPS-NVI and self-report in verbal nursing home residents with dementia.*

*An AUROC of 0.9 to 1.0 indicates the accuracy of a diagnostic test as outstanding [27], 0.8 to 0.9 excellent, 0.7 to 0.8 acceptable, and 0.5 suggests no discrimination.*

**Appendix 3:** Correlation between the presence of orofacial pain, according to the Orofacial-Pain Scale for Non-Verbal Individuals (OPS-NVI) and according to self-report, and general health and oral health factors in nursing home residents with and without dementia

	<b>Dementia</b>		<b>Self-report (n=37)</b>		<b>No Dementia</b>	
	<b>OPS-NVI (n=84)</b>		<b>Self-report (n=37)</b>		<b>Self-report (n=27)</b>	
	<b>Test-value</b>	<b>p-value</b>	<b>Test-value</b>	<b>p-value</b>	<b>Test-value</b>	<b>p-value</b>
<b>Age</b>	t (82) = 1.515	0.134	t (35) = -0.211	0.834	t (25) = -0.289	0.775
<b>CDR</b>	Z = -0.686	0.493	Z = -1.008	0.314	N/A	N/A
<b>CCI</b>	Z = -0.484	0.628	Z = -0.517	0.605	Z = -0.345	0.730
<b>CMAI</b>						
<b>Aggressive behaviour</b>	X <sup>2</sup> (1) = 0.785	0.376	X <sup>2</sup> (1) = 1.987	0.159	N/A	N/A
<b>Physically nonaggressive behaviour</b>	X <sup>2</sup> (1) = 6.480	0.011*	N/A	N/A	N/A	N/A
<b>Verbally agitated behaviour</b>	X <sup>2</sup> (1) = 0.009	0.923	X <sup>2</sup> (1) = 0.014	0.904	N/A	N/A
<b>Barthel Index</b>	Z = -1.509	0.131	Z = -1.702	0.089	Z = -0.447	0.655
<b>EQ-5D Index</b>	t (82) = -2.006	0.048*	t (35) = 2.661	0.012*	t (25) = 1.860	0.075
<b>OHIP-14</b>	Z = -1.549	0.121	Z = -2.248	0.025*	Z = -2.289	0.022*
<b>MNA-SF</b>	X <sup>2</sup> (2) = 4.598	0.100	X <sup>2</sup> (2) = 0.770	0.681	X <sup>2</sup> (2) = 4.675	0.079
<b>Analgesics</b>	X <sup>2</sup> (1) = 0.034	0.855	X <sup>2</sup> (1) = 0.011	0.915	X <sup>2</sup> (1) = 0.386	0.534
<b>Soft diet</b>	X <sup>2</sup> (1) = 5.729	0.017*	X <sup>2</sup> (1) = 1.967	0.161	X <sup>2</sup> (1) = 4.606	0.032*
<b>SXI</b>	Z = -0.563	0.573	Z = -2.006	0.045*	Z = -3.261	0.001*
<b>Dentate vs edentate</b>	X <sup>2</sup> (1) = 8.768	0.003*	X <sup>2</sup> (1) = 1.854	0.173	X <sup>2</sup> (1) = 0.587	0.444
<b>Number of teeth</b>	Z = -1.491	0.136	Z = -0.464	0.643	Z = -0.634	0.526
<b>Retained roots</b>	Z = -1.950	0.051	Z = -0.721	0.471	Z = -2.905	0.004*
<b>DMFT</b>	Z = -3.016	0.003*	Z = -0.734	0.463	Z = -1.690	0.091
<b>OU</b>	Z = -1.146	0.252	Z = -0.518	0.605	Z = -1.868	0.062
<b>DI of the OHI-S</b>	Z = -2.739	0.006*	Z = -1.752	0.080	Z = -0.212	0.832
<b>DHI</b>	X <sup>2</sup> (2) = 1.071	0.585	X <sup>2</sup> (2) = 0.300	0.861	X <sup>2</sup> (2) = 1.111	0.574

Note. CDR=Clinical Dementia Rating, CCI=Charlson Comorbidity Index, CMAI=Cohen-Mansfield Agitation Inventory, EQ-5D=Euroqol 5 Dimension, OHIP=Oral Health Impact Profile, MNA-SF=Mini Nutritional Assessment Short Form, SXI=Summated Xerostomia Inventory, DMFT=Decayed Missing and Filled Teeth, OU=Occlusal Units, DI=Debris Index, OHI-S=Simplified Oral Hygiene Index, X<sup>2</sup>=Chi-squared test, T=independent sample t-test, Z=Mann-Whitney U-test, N/A=Not Applicable, \*=p<0.05.