Orofacial pain and its potential oral causes in older people with mild cognitive impairment or dementia

Suzanne Delwel1,2 | Erik J. A. Scherder2 | Cees de Baat3 | Tarik T. Binnekade2 | Johannes C. van der Wouden4 | Cees M. P. M. Hertogh4 | Andrea B. Maier5,6 | Roberto S. G. M. Perez7 | Frank Lobbezoo1

1Department of Oral Kinesiology, Academic Centre for Dentistry Amsterdam (ACTA), University of Amsterdam and Vrije Universiteit Amsterdam, Amsterdam, The Netherlands
2Department of Clinical Neuropsychology, Faculty of Behavioural and Movement Sciences, Vrije Universiteit Amsterdam, Amsterdam, The Netherlands
3Department of Oral Function and Prosthetic Dentistry, Radboud University Medical Center, Nijmegen, The Netherlands
4Department of General Practice & Elderly Care Medicine, Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, The Netherlands
5Department of Medicine and Aged Care, @AgeMelbourne, The Royal Melbourne Hospital, University of Melbourne, Melbourne, Victoria, Australia
6Department of Human Movement Sciences, @AgeAmsterdam, Faculty of Behavioural and Movement Sciences, Amsterdam Movement Sciences, Vrije Universiteit, Amsterdam, The Netherlands
7Department of Anesthesiology, Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, The Netherlands

Correspondence
Suzanne Delwel, ACTA Amsterdam, Faculty of Dentistry, Department of Oral Kinesiology, Amsterdam, The Netherlands. Email: s.delwel@vu.nl

Funding information
This study was supported by grants from Alzheimer Nederland [WE.09-2012-02], Amstelring [RVB U-9107-2013/HM/wb], Arnold Oosterbaan Hersenstichting, Fonds NutsOhra [1130-046], Roomsch Catholijk Oude Armen Kantoor [U-9128-2012 HM/lw], Stichting Beroepsopleiding Huisartsen (SBOH) and Stichting Henriëtte Hofje. The authors have no conflict of interests to declare.

Roberto S. G. M. Perez: Deceased

Summary

Background: The number of people with dementia and natural dentition is growing. As dementia progresses, the degree of self-care decreases and the risk of oral health problems and orofacial pain increases.

Objectives: To examine and compare the presence of orofacial pain and its potential causes in older people with Mild Cognitive Impairment (MCI) or dementia.

Methods: In this cross-sectional observational study, the presence of orofacial pain and its potential causes was studied in 348 participants with MCI or dementia with all levels of cognitive impairment in two outpatient memory clinics and ten nursing homes.

Results: Orofacial pain was reported by 25.7% of the 179 participants who were considered to present a reliable pain self-report (Mini-Mental State Examination score ≥14 points), while it could not be determined in people with more severe cognitive impairment. The oral health examination of the 348 participants indicated that potential painful conditions, such as coronal caries, root caries, tooth root remnants or ulcers were present in 50.3%. There was a significant correlation between the level of cognitive impairment and the number of teeth, \( r = 0.185 \), \( P = 0.003 \), teeth with coronal caries, \( r = -0.238 \), \( P < 0.001 \), and the number of tooth root remnants, \( r = -0.229 \), \( P = 0.004 \), after adjusting for age.

Conclusions: This study indicated that orofacial pain and its potential causes were frequently present in participants with MCI or dementia. Therefore, a regular oral...
The prevalence of dementia in people aged 60 years or older is 5%-7% in most world regions, and the number of people with dementia is expected to grow from 35.6 million in 2010 to 65.7 million in 2030 worldwide. Dementia is characterised by a decline in cognitive and motor functions. As dementia progresses, the degree of oral hygiene self-care and oral healthcare utilisation decreases, leading to more oral health problems. Simultaneously, oral health problems may cause or aggravate general health problems, such as aspiration pneumonia, diabetes mellitus and cardiovascular disease. Although the occurrence and mechanism of the association between oral health and cognitive status remain inconclusive, some studies indicate that tooth loss and oral inflammation, specifically periodontal disease, could be related to cognitive decline.

Although the number of people with dementia with natural dentition is increasing and oral health problems can also play a role in the aetiology of orofacial pain, orofacial pain in dementia has been scarcely studied. De Souza Rolim and colleagues studied oral infections and orofacial pain in 29 people with mild Alzheimer’s dementia and in 30 controls. The conclusion of that study was that orofacial pain and periodontal disease were present more often in people with Alzheimer’s dementia (20.7% myofascial pain and 20.7% severe periodontal disease) than in controls (6.7% myofascial pain and 6.7% severe periodontal disease).

To date, no large studies have been carried out on orofacial pain in older people with mild cognitive impairment (MCI) or dementia. The aim of the present study was to examine and compare the presence of orofacial pain and its potential causes in older people with MCI or dementia. The research questions were (a) How frequent is orofacial pain present in older people with MCI or dementia? (b) How frequent are potential painful conditions, such as coronal caries, root caries, tooth root remnants or ulcers present in older people with MCI or dementia? (c) Is there a correlation between the level of cognitive impairment and the number of teeth with coronal caries, root caries and tooth root remnants?

The study population consisted of participants with MCI or dementia aged 60 years or older, recruited at the outpatient memory clinics of the VU Medical Center and the Amstellaand hospital and at ten nursing homes. This study was part of the PainDemIA study, of which the study protocol has been previously published. The study protocol was approved by the Medical Ethics Review Committee of the VU University Medical Center Amsterdam (approval number NL 43861.029.13). The study data were collected between April 2014 and December 2015. The study meets the STROBE Guidelines.

The method for diagnosing (the subtype of) dementia was extensively described in the study protocol. The global cognitive functioning of the participants was assessed with the Mini-Mental State Examination (MMSE) by a nurse at the VU Medical Center and by a neuropsychologist at the Amstellaand Hospital and the nursing homes. The MMSE measures verbal and nonverbal episodic memory, visuospatial capacities, and orientation in time and place, resulting in a maximum score of 30.

In the outpatient memory clinics, 264 people were approached for participation, 203 signed the informed consent letter and 153 participated. The main reason for refusal was the (expected) burden of participation. Exclusion took place, if participants had no MCI or dementia diagnosis.

The legal representatives of 679 nursing home residents were sent an information and consent form, 252 of them did not respond and 208 refused participation. The main reason for refusal was the expected burden for the participants, especially for those with more advanced dementia. Of the 219 people with signed informed consent letters, 197 were examined and 22 people appeared to have no dementia diagnosis, did not cooperate, had moved or had passed away (Figure S1).

In the outpatient memory clinic, the examination took place alongside the regular screening day of the clinic, whereas nursing home residents were examined at their nursing home. First, all participants were observed for the presence of pain during rest, drinking, chewing and oral hygiene care. Second, the verbal participants were asked if pain was present during these activities. Subsequently, the oral health examination took place in all participants. The variables will be described in further detail hereafter.

**2 | MATERIALS AND METHODS**

**2.1 | Study design, setting and participants**

This cross-sectional observational study describes the presence of orofacial pain and its potential causes in older people with MCI or dementia.

**2.2 | Demographics and characteristics**

The demographic characteristics age, gender and educational level were derived from the medical records. The oral characteristics were collected by one dentist (SD) with a short, standardised interview with the participants in the memory clinics and with the care
providers in the nursing homes. The interview included questions about the period since the last dentist visit (>6 months, 6-12 months or more than 12 months), tooth brushing frequency (less than once a day, one time a day, two times a day, more than two times a day), degree of oral hygiene care assistance (independent, assisted, by nurse) and experienced barriers of oral hygiene care, such as not opening the mouth or guarding (no, somewhat, yes). The oral hygiene care assistance and the barriers experienced during oral hygiene care were only determined in the nursing home participants.

2.3 | Orofacial pain

The presence of orofacial pain during rest, drinking, chewing and oral hygiene care was observed in all participants using the Orofacial Pain Scale for Nonverbal Individuals (OPS-NVI), by a dentist (SD) and trained research assistants.17,19,20 With the OPS-NVI, facial activities, body movements, vocalisations and specific oral behaviours were observed and the presence of pain was estimated and scored on a Numeric Rating Scale from 0 to 10, at which 0 is no pain and 10 the worst pain imaginable.20 A value of 1 or higher was considered as observed pain presence.

Verbal participants were asked about the presence of pain during rest, drinking, eating and oral hygiene care. Furthermore, sensory testing took place, including tests with a cotton roll, brush and probe at the three innervation areas of the trigeminal nerve.21 For the sensory testing, first, a cotton roll was used to make three strokes of one to two centimetres on the left and right skin above the eyebrow (N. ophthalmicus), below the eye (N. maxillaris) and below the lower lip (N. mandibularis). Thereafter, the test was repeated with a brush and a light pin prick with a dental probe.21 Directly after each test, the participant was asked if pain was present. In addition, pain during active and guided mouth opening was examined. For the active mouth opening, the participants were asked to open their mouths as far as possible. During the guided mouth opening, the participants were asked to relax their jaw as much as possible, while the dentist guided the mouth opening.22 If pain was reported, the guided mouth opening was stopped and the participants were asked whether the pain was familiar to them.23 People with an MMSE score of 14 or higher were considered to present a reliable pain self-report.24

2.4 | Oral health

A standardised oral health examination took place by a dentist experienced in geriatric dentistry (SD), with a standard mouth mirror, sickle probe, and periodontal probe (Carl Martin 973/14W, Germany) and a head light (Black Diamond, UT, USA). The examination consisted of an extra-oral and intra-oral examination. The presence of abnormalities, such as swellings, ulcers and fistulas, was recorded. During the intra-oral examination, the dental status was assessed, including missing and restored teeth, coronal caries, root caries and tooth root remnants (retained roots). A participant was considered dentate if one or more natural teeth were present.

In teeth with caries profunda, additional examination, such as palpation, percussion and a sensitivity test with a cold cotton pellet, was performed. Furthermore, periodontal health was assessed using the Dutch Periodontal Screening Index (DPSI), with a DPSI score 0 indicating healthy periodontium, DPSI 1 bleeding pocket ≤3 mm, DPSI 2 supra- or subgingival calculus, DPSI 3– pockets 4–5 mm without recession, DPSI 3+ pockets 4-5 mm with recession and DPSI 4 pockets ≥6 mm.25 In addition, teeth with mobility grade 2 or 3 were registered, with grade 2 indicating mobility of 1-2 mm in horizontal direction and grade 3 indicating horizontal mobility of ≥2 mm or vertical mobility.26 In dentate participants, the oral hygiene level was assessed using the Plaque Index of Silness & Löe, with score 0 indicating no visible plaque, score 1 plaque adhering to the free gingival margin, which can only be seen using a dental probe, score 2 moderate accumulation of plaque which can be seen with the naked eye and score 3 abundance of plaque.27 In participants with removable dental prostheses, the denture hygiene was inspected visually and qualitatively assessed as good, moderate or poor.

2.5 | Statistical analyses

Data were analysed with IBM Statistics SPSS 23 (SPSS Inc., Chicago, IL, USA). Continuous variables were expressed as means and standard deviations (SD) for normally distributed data, and medians and inter quartile rates (IQR) for non-normally distributed data. Categorical variables were expressed as numbers and percentages. Association between two continuous variables, meeting the assumptions for parametric tests, was analysed with Pearson correlation or linear regression, while nonparametric data were analysed with Spearman’s rank or rho partial correlation. The association between continuous dependent and categorical independent variables was analysed with the independent T test for parametric data and the Mann-Whitney U test for nonparametric data. For ordinal categorical data, the Mann-Whitney U test was used. Association between two categorical variables was analysed with the Pearson chi-square test if all expected frequencies were greater than five or the Fisher’s exact test if the expected frequencies were below 5. For all tests, a P-value < 0.05 was considered statistically significant. Outliers with a z-score 3.29 or higher were considered significant outliers and were replaced by a score three times the standard deviation to the mean for a sensitivity analysis.

3 | RESULTS

3.1 | Descriptive data

Table 1 shows the characteristics of the 348 participants. Their age ranged from 66 to 102 years, with a median of 83.0 (IQR = 79.0-87.0) years. The sample consisted of 65.7% women, 303 participants with dementia and 45 participants with MCI. The group with dementia had a significantly lower MMSE score (median = 17.0, IQR = 6.0-22.0) and was significantly older (median = 84.0, IQR = 80.0-88.0) than the group with MCI (median age = 80.0,
IQR = 76.0-84.5 and median MMSE = 27.0, IQR = 25.8-28.0), P < 0.001. The dementia group consisted of 52.6% participants with Alzheimer’s dementia, 18.4% with mixed dementia, 10.3% with vascular dementia, 1.3% with frontotemporal dementia and 2.9% with Lewy bodies dementia. The participants with dementia used analgesics significantly more often, $\chi^2 (1) = 3.98, P = 0.055$ and antipsychotics significantly more often $\chi^2 (1) = 7.45, P = 0.010$ than the participants with MCI. The participants within the MCI group were significantly more often dentate (77.8%) than those within the dementia group (52.0%); $\chi^2 (1) = 10.54, P = 0.001$. Furthermore, the period since the last dentist visit was significantly longer in participants with dementia than in those with MCI, $U = 4917.00, P = 0.021$. It was reported that the tooth brushing frequency was twice each day in 54.8% of the participants, with no significant differences between the MCI and the dementia group. Oral hygiene care was provided by a nurse for 60.4% of the nursing home participants with dementia, and no barriers were experienced during oral hygiene care in 69.6%.

### 3.2 Orofacial pain

The observed orofacial pain with the OPS-NVI was 4% in rest, 10% during drinking, 19% during chewing and 22% during oral hygiene care among the 348 participants with MCI or dementia. However, the psychometric evaluation of the OPS-NVI indicated that the negative agreement and specificity of the OPS-NVI were high, while the positive agreement and sensitivity were low, as a result of a low self-report of orofacial pain. Therefore, the results of the pain observations with the OPS-NVI were not used any further in the current study.

The self-reported pain of the 179 participants with MMSE score 14 or higher was considered reliable and was included in this study. Table 2 shows the presence of reported orofacial pain during daily oral activities: 0.6% reported pain during rest, 9.6% during chewing and 2.5% during oral hygiene care. No pain was reported during drinking. Pain during sensory testing using a brush was reported by 0.6% and using a probe by 10.1%.

### Table 1 Descriptive variables by cognitive status

|                          | Total, 348 (100.0%) | MCI, 45 (12.9%) | Dementia, 303 (87.1%) | Test value | P-value |
|--------------------------|---------------------|-----------------|-----------------------|------------|---------|
| Age in years, median (IQR) | 83.0 (79.0-87.0)    | 80.0 (76.0-84.5) | 84.0 (80.0-88.0)      | M-W U = 9072.50 | <0.001  |
| Gender, N (%) women       | 230 (65.7%)         | 25 (55.6%)      | 205 (67.2%)           | $\chi^2 (1) = 2.37$ | 0.133   |
| Educational level, median (IQR) | 10.0 (8.0-12.0)     | 11.0 (9.0-13.3) | 10.0 (8.0-12.0)       | M-W U = 1675.50 | 0.157   |
| MMSE, median (IQR)        | 18.0 (10.0-24.0)    | 27.0 (25.8-28.0)| 17.0 (6.0-22.0)       | M-W U = 572.50  | <0.001  |
| Medication use            |                     |                 |                       |             |         |
| Analgesics                | 119 (36.0%)         | 9 (22.0%)       | 110 (37.9%)           | $\chi^2 (1) = 3.98$ | 0.055   |
| Antipsychotics            | 129 (39.0%)         | 8 (19.5%)       | 121 (41.7%)           | $\chi^2 (1) = 7.45$ | 0.010   |
| Dentate, N (%)            | 192 (55.3%)         | 35 (77.8%)      | 157 (52.0%)           | $\chi^2 (1) = 10.54$ | 0.001   |
| Last dentist visit, N (%) | 318 (100.0%)        | 45 (100.0%)     | 273 (100.0%)          |             |         |
| <6 mo                     | 155 (48.7%)         | 28 (62.2%)      | 127 (46.5%)           | M-W U = 4917.00 | 0.021   |
| 6-12 mo                   | 51 (16.0%)          | 7 (15.6%)       | 44 (16.1%)            |             |         |
| >12 mo                    | 76 (23.9%)          | 9 (20.0%)       | 67 (24.5%)            |             |         |
| unknown                   | 36 (11.3%)          | 1 (2.2%)        | 35 (12.8%)            |             |         |
| Tooth brushing frequency, N (%) | 334 (100.0%)     | 45 (100.0%)     | 289 (100.0%)          |             |         |
| <1x/d                     | 14 (4.2%)           | 0 (0.0%)        | 14 (4.8%)             | M-W U = 5784.00 | 0.182   |
| 1x/d                      | 113 (33.8%)         | 15 (33.3%)      | 98 (33.9%)            |             |         |
| 2x/d                      | 183 (54.8%)         | 24 (53.3%)      | 159 (55.0%)           |             |         |
| >2x/d                     | 24 (7.2%)           | 6 (13.3%)       | 18 (6.2%)             |             |         |
| Oral hygiene care, N (%)  | n/a                 | n/a             | 187 (100.0%)          |             |         |
| Independent               | -                    | -               | 40 (21.4%)            |             |         |
| Assisted                  | -                    | -               | 34 (18.2%)            |             |         |
| By nurse                  | -                    | -               | 113 (60.4%)           |             |         |
| Barriers of oral hygiene care, N (%) | n/a         | n/a             | 184 (100.0%)          |             |         |
| No                        | -                    | -               | 128 (69.6%)           |             |         |
| Somewhat                  | -                    | -               | 29 (15.8%)            |             |         |
| Yes                       | -                    | -               | 27 (14.7%)            |             |         |

MCI, mild cognitive impairment; M-W U, Mann-Whitney U test; $\chi^2$ (n), chi-square test (df); n/a, not available/not applicable.
pain was experienced by using a cotton roll. Pain during active mouth opening was reported by 3.1% and pain during guided mouth opening by 13.8%. Of dentate, verbal participants who had teeth with caries profunda, 1.7% experienced pain during palpation, 4.2% during percussion and 1.7% after application of a cold cotton pellet. There were no significant differences between the MCI or dementia group with regard to reported pain during daily oral activities, sensory testing, active and guided mouth opening, and additional examination of teeth with caries profunda. When these aspects of pain, with the exception of guided mouth opening, were combined, 46 (=25.7%) of the 179 participants with MMSE score of 14 or higher experienced at least 1 aspect of orofacial pain during the examination. Within the group of participants with MMSE score of 14 or higher, there was no significant association between the presence of orofacial pain and the MCI or dementia diagnosis, \( \chi^2 (1) = 0.84, P = 0.430 \). If the dementia group was split in dementia subtypes, orofacial pain was present in 17/74 (=23.0%) of the participants with AD, 10/31 (=32.3%) of those with vascular dementia, 1/3 (=33.3%) of those with frontotemporal dementia, 0/3 (=0.0%) of those with Lewy bodies dementia. There was no significant association between the presence of orofacial pain and the subtype of dementia, Fisher’s exact = 2.37, P = 0.672.

### 3.3 Oral health

Table 3 shows the oral health characteristics. The number of present teeth (Figure S2) was significantly \( (P < 0.001) \) lower in participants with dementia (median = 2.0, IQR = 0.0-18.0) than in participants with MCI (median = 18.0, IQR = 5.5-24.0). However, when solely dentate participants were considered, there were no significant differences \( (U = 2170.50, P = 0.058) \) between the groups concerning number of teeth (median = 18.0, IQR = 9.0-24.0).

Moreover, dentate participants with dementia had significantly less restored teeth (median = 8.5, IQR 4.0-13.0), \( U = 2000.00, P = 0.013 \), more teeth with coronal caries (median = 1.0, IQR 0.0-2.0), \( U = 3604.00, P = 0.001 \), more teeth with root caries (median 0.0, IQR 0.0-1.0), \( U = 3342.50, P = 0.001 \), and more tooth root remnants (median 0.0, IQR 0.0-1.0), \( U = 3619.50, P < 0.001 \) than dentate participants with MCI (Figures S3 and S4).

Table 4 shows the correlation between the oral health variables (with significant P-values in Table 3) and the MMSE score, adjusted for age. There was a significant correlation between the level of cognitive impairment and the number of present/missing teeth, \( r = 0.185, P = 0.003 \), restored teeth \( r = 0.164, P = 0.038 \), oral implants, \( r = 0.143, P = 0.022 \) and teeth with coronal caries, \( r = -0.283, P < 0.001 \), when adjusted for age. The number of teeth with root

### Table 2 Pain reported by participants with an MMSE score of 14 or higher, by cognitive status

| Pain reported during | Total N (%) | MCI N (%) | Dementia N (%) | Test value | P value |
|----------------------|-------------|-----------|---------------|------------|--------|
| Daily oral activities, N (%) | 179 (100.0%) | 44 (100.0%) | 135 (100.0%) | \( \chi^2 (1) = 25.90 \) | <0.001 |
| Rest | 1 (0.6%) | 0 (0.0%) | 1 (0.7%) | - | 1.000 |
| Drinking | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) | n/a | n/a |
| Chewing | 17 (9.6%) | 4 (9.1%) | 13 (9.8%) | - | 1.000 |
| Oral hygiene care | 3 (2.5%) | 0 (0.0%) | 3 (3.5%) | - | 0.554 |
| Neurosensory testing, N (%) | 179 (100.0%) | 44 (100.0%) | 135 (100.0%) | - | - |
| Cotton | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) | n/a | n/a |
| Brush | 1 (0.6%) | 0 (0.0%) | 1 (0.7%) | - | 1.000 |
| Probe | 18 (10.1%) | 3 (6.8%) | 15 (11.1%) | - | 0.568 |
| Mouth opening, N (%) | 162 (100.0%) | 43 (100.0%) | 119 (100.0%) | - | - |
| Active mouth opening | 5 (3.1%) | 1 (2.3%) | 4 (3.4%) | - | - |
| Recognisable | 1 (0.6%) | 1 (2.3%) | 0 (0.0%) | - | - |
| Guided mouth opening | 22 (13.8%) | 6 (14.3%) | 16 (13.7%) | \( \chi^2 (1) = 0.01 \) | 1.000 |
| Recognisable | 2 (1.3%) | 2 (4.8%) | 0 (0.0%) | - | 0.065 |
| Additional testing caries profunda, N (%) | 120 (100.0%) | 33 (100.0%) | 85 (100.0%) | - | - |
| Palpation | 2 (1.7%) | 1 (2.9%) | 1 (1.2%) | - | 0.488 |
| Percussion | 5 (4.2%) | 1 (2.9%) | 4 (4.7%) | - | 1.000 |
| Sensitivity | 2 (1.7%) | 0 (0.0%) | 2 (2.3%) | - | 1.000 |
| Overall, N (%) | 46 (25.7%) | 9 (20.5%) | 37 (27.4%) | \( \chi^2 (1) = 0.84 \) | 0.430 |

In case of a low number of observations within a category, no test value was given. The “Overall” score includes pain reported during oral daily activities, neurosensory testing, active mouth opening and additional testing of teeth with caries profunda.

MCI, mild cognitive impairment; \( \chi^2 (n) \), chi-square test (df); n/a, not available/not applicable.
| Number, median (IQR) | Total (n = 348) | MCI (n = 45) | Dementia (n = 303) | Test value M-W U | P-value |
|----------------------|-----------------|-------------|--------------------|------------------|---------|
| | Present teeth | 5.0 (0.0-19.0) | 18.0 (9.0-24.0) | 22.0 (10.0-26.0) | 450.00 | 2170.50 | <0.001 | 0.058 |
| | Missing | 27.0 (13.0-32.0) | 14.0 (8.0-23.0) | 14.0 (8.0-26.5) | 9128.00 | 3289.50 | <0.001 | 0.058 |
| | Restored | 1.5 (0.0-10.0) | 9.0 (4.0-14.0) | 13.0 (6.0-17.0) | 4425.50 | 2000.00 | <0.001 | 0.013 |
| | Oral implants | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 6057.50 | 2591.50 | 0.012 | 0.300 |
| | Coronal caries | 0.0 (0.0-1.0) | 0.0 (0.0-1.0) | 0.0 (0.0-1.0) | 7399.00 | 3604.00 | 0.237 | 0.001 |
| | Root caries | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 7308.00 | 3342.50 | 0.254 | 0.014 |
| | Tooth root remnants | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 7900.00 | 3619.50 | 0.010 | <0.001 |

All participants with mild cognitive impairment (MCI) were compared with all participants with dementia. Dentate participants with MCI were compared with dentate participants with dementia. *M-W U*, Mann-Whitney U test.

### 4.1 Strengths and limitations

One of the strengths of this study is the large study population. Furthermore, oro-facial pain was examined extensively, including intra-oral and extra-oral conditions.

The aim of this study was to examine and compare the presence of oro-facial pain and its potential causes in older people with MCI or dementia. Furthermore, it showed that there was a statistically significant and clinically relevant correlation between the level of oro-facial pain and its potential causes in older people with MCI or dementia. This study indicated that oro-facial pain and its potential causes were frequently present in participants with MCI or dementia. Moreover, in 73.8% of the participants, oro-facial pain was assessed as good in 19%, moderate in 55.3%, and bad in 25.3% of the participants. The denture hygiene index was significantly worse in the MCI group than in the dementia group.

### 4 DISCUSSION

**4.1 Strengths and limitations**

One of the strengths of this study is the large study population. Furthermore, oro-facial pain was examined extensively, including intra-oral and extra-oral conditions.

The aim of this study was to examine and compare the presence of oro-facial pain and its potential causes in older people with MCI or dementia. Furthermore, it showed that there was a statistically significant and clinically relevant correlation between the level of oro-facial pain and its potential causes in older people with MCI or dementia. This study indicated that oro-facial pain and its potential causes were frequently present in participants with MCI or dementia. Moreover, in 73.8% of the participants, oro-facial pain was assessed as good in 19%, moderate in 55.3%, and bad in 25.3% of the participants. The denture hygiene index was significantly worse in the MCI group than in the dementia group.
care, as well as sensory testing and active mouth opening. This is the first study that included sensory testing of the trigeminal nerve area in people with dementia. In addition, the MMSE score was used to determine the validity of the pain self-report. Moreover, potential causes of pain were examined with a structured dental examination in all participants by the same dentist experienced in geriatric dentistry.

A major limitation of this study was that the psychometric evaluation of the OPS-NVI took place in parallel with the current study. The initial plan was to use the observations with the OPS-NVI to include participants with all MMSE scores. However, the psychometric evaluation indicated that the negative agreement and specificity of the OPS-NVI were high, while the positive agreement

| Variable               | Group | Correlation with MMSE | P-value | Correlation with MMSE | P-value |
|------------------------|-------|-----------------------|---------|-----------------------|---------|
| Present/Missing        | All   | 0.228                 | <0.001  | 0.185                 | 0.003   |
| Restored               | All   | 0.223                 | <0.001  | 0.179                 | 0.004   |
|                        | Dentate | 0.180               | 0.022   | 0.164                 | 0.038   |
| Implants               | All   | 0.150                 | 0.015   | 0.143                 | 0.022   |
| Coronal caries         | Dentate | −0.296             | <0.001  | −0.283                | <0.001  |
| Root caries            | Dentate | −0.190             | 0.016   | −0.152                | 0.054   |
| Root remnants          | All   | −0.115                | 0.064   | −0.105                | 0.091   |
|                        | Dentate | −0.256             | 0.001   | −0.229                | 0.004   |

| Condition present      | Total n = 348 | MCI n = 45 | Dementia n = 303 | Test value | P-value |
|------------------------|---------------|------------|------------------|------------|---------|
| Coronal caries, N (%)  | 94 (27.0%)    | 10 (22.2%) | 84 (27.7%)       | 0.60       | 0.478   |
| Root caries, N (%)     | 66 (19.0%)    | 6 (13.3%)  | 60 (19.8%)       | 1.07       | 0.322   |
| Root remnant, N (%)    | 63 (18.1%)    | 2 (4.4%)   | 61 (20.1%)       | 6.50       | 0.011   |
| Ulcer, N (%)           | 47 (14.1%)    | 4 (8.9%)   | 43 (14.9%)       | 1.16       | 0.361   |
| Overall, N (%)         | 175 (50.3%)   | 17 (37.8%) | 158 (52.1%)      | 3.24       | 0.080   |

| Condition present      | Total n = 160 | MCI n = 33 | Dementia n = 127 | Test value | P-value |
|------------------------|---------------|------------|------------------|------------|---------|
| Tooth mobility         |               |            |                  |            |         |
| Grade II               | 36 (18.8%)    | 7 (20.0%)  | 29 (18.6%)       | χ² (1) = 0.04 | 1.000   |
| Grade III              | 11 (5.8%)     | 1 (2.9%)   | 10 (6.4%)        | -          | 0.692   |

MCI, mild cognitive impairment; M-W U, Mann-Whitney U test; χ² (n), chi-square test (df).
and sensitivity were low, as a result of a low self-report of orofacial pain.\textsuperscript{20} Therefore, the results of the pain observations with the OPS-NVI were not further used in the current study. Furthermore, this study had a cross-sectional observational design, which did not include older people without cognitive impairment. In addition, it was not possible to polish the teeth before examination and make X-rays at the research settings. Although the teeth were brushed, an under-estimation of potential painful oral conditions is probable.

4.2 | Interpretation

In the current study, orofacial pain was reported by a quarter of the participants with MCI or dementia who were considered to be able to present a reliable self-report, while it could not be determined for people with more severe cognitive impairment. The percentage of participants with orofacial pain in this study is somewhat higher than the reported 7.4\%-21.7\% in previous studies.\textsuperscript{15} The higher orofacial pain percentage in the current study can be explained by the extensive pain assessment, which included evaluation after drinking, eating, oral care, mouth opening, sensory testing, as well as additional testing of teeth with caries profunda. Furthermore, the participants were asked if pain was present directly after each activity, to minimise the role of memory loss in the pain self-report.

The oral health examination in the current study indicated that participants with more severe cognitive impairment had significantly less present teeth, more teeth with coronal caries and more tooth root remnants. The number of teeth with coronal caries and tooth root remnants in this study fit in the (wide) margins of previous studies in participants with dementia, with a mean of 0.1-2.9 for teeth with coronal caries and a mean of 0.2-10 for tooth root remnants.\textsuperscript{15} Some of the previous studies examined the association of age and gender with the development of caries in people with dementia.\textsuperscript{29-31} One cohort study found that males with dementia had higher odds of coronal caries increments than women with dementia, but age group (viz. younger or older than 80 years) was not a significant predictor.\textsuperscript{29} Another cohort study found an increased risk of Alzheimer’s dementia in participants with 4 or more active root caries lesions, after adjusting for age, gender and marital status.\textsuperscript{31} These two cohort studies indicated that dementia status was associated with coronal caries and root caries, after controlling for age and gender. Although the current cross-sectional study found an association between cognitive status and number of teeth with coronal caries, it did not find an association with the number of teeth with root caries, after adjusting for age. In other words, the higher number of teeth with root caries could be explained by higher age.

Other findings from the current study were the high number of intra-oral abnormalities, gingival inflammation, plaque and periodontal pockets. Previous studies also showed that the absence of gingival bleeding was rare\textsuperscript{32,33} and oral hygiene was insufficient in people with dementia.\textsuperscript{34} At the same time, the presence of severe periodontitis, with periodontal pockets of 6 mm or more, seems higher in the current population than in previous studies.\textsuperscript{16,35,36} This can be explained by the higher age and lower MMSE score of the current sample. The lower MMSE score might also explain the current finding that participants with dementia had significantly worse oral and denture hygiene compared to those with MCI.

4.3 | Implications

Although the self-reported pain presence during daily oral activities was low, the examined presence of oral diseases was high. This indicates that regular oral examination by (oral) healthcare providers remains imperative, even if no pain is reported, because oral diseases may be a source of (future) discomfort or pain and inflammation, as well as general health and cognitive problems.\textsuperscript{13,28} This is even more important in people with dementia, who are not able to report pain verbally.

As a result of the low reported presence of pain during sensory testing with a cotton pellet and a brush, it is not recommended to add sensory testing to the regular oral health screening procedure of people with MCI or dementia.

4.4 | Future research

The OPS-NVI has been used to observe orofacial pain in all participants of this study, but the observed pain presence could not be used because the OPS-NVI in its current form lacked validity for diagnostic use. However, a diagnostic tool for orofacial pain in people with communication impairments could be a helpful tool to identify hidden discomfort or pain.

5 | CONCLUSION

The reported presence of orofacial pain was 25.7\% in participants with MCI or dementia who were able to deliver a reliable pain self-report. The oral health examination indicated that participants with more severe cognitive impairment had significantly less present teeth, more teeth with coronal caries and more tooth root remnants. When the number of teeth with coronal caries or root caries, the number of tooth root remnants and the number of ulcers were combined, potential painful oral conditions were present in 50.3\% of the participants.

This study indicated that orofacial pain and its potential causes were frequently present in participants with MCI or dementia. Therefore, a regular oral examination by (oral) healthcare providers in people with MCI or dementia remains imperative, even if no pain is reported.

ACKNOWLEDGMENTS

The authors thank the participants and their care providers for their cooperation with the study. Furthermore, they thank the staff of the outpatient clinics at the VU Medical Center and the Amstelland hospital, and the staff at the ten participating nursing homes of Amsteling, Cordaan and Zonnehuisgroep Amstelland for their
cooperation. Moreover, they thank the students of the Department of Clinical Neuropsychology, Vrije Universiteit Amsterdam and the Department of Oral Kinesiology, Academic Center for Dentistry Amsterdam (ACTA) for their assistance. In addition, they thank Drs. Janine van Kooten of the Department of General Practice and Elderly Care Medicine, VU University Medical Center for her help with the acquisition of participants and the collection of the demographic data at the nursing homes.

**ORCID**

Suzanne Delwel [http://orcid.org/0000-0002-6836-5394](http://orcid.org/0000-0002-6836-5394)

Frank Lobbezoo [http://orcid.org/0000-0001-9877-7640](http://orcid.org/0000-0001-9877-7640)

**REFERENCES**

1. Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W, Ferri CP. The global prevalence of dementia: a systematic review and meta-analysis. Alzheimers Dement. 2013;9(1):63-75. e2.

2. Ghezzi EM, Ship JA. Dementia and oral health. Oral Surg Oral Med Oral Pathol Oral Radiol Endod. 2000;89(1):2-5.

3. Chalmers J, Pearson A. Oral hygiene care for residents with dementia: a literature review. J Adv Nurs. 2005;52(4):410-419.

4. Lee KH, Wu B, Plassman BL. Dental care utilization among older adults with cognitive impairment in the USA. Geriatr Gerontol Int. 2015;15(3):255-260.

5. Otomo-Corgel J, Pucher JJ, Rethman MP, Reynolds MA. State of the science: chronic periodontitis and systemic health. J Evid Based Dent Pract. 2012;12(3 Suppl):20-28.

6. van der Maarel-Wierink CD, Vanobbergen JNO, Bronkhorst EM, Schols JMG, de Baat C. Oral health care and aspiration pneumonia in frail older people: a systematic literature review. Gerodontology. 2013;30(1):3-9.

7. van der Putten G-J, de Baat C, De Visschere L, Schols J. Poor oral health, a potential new geriatric syndrome. Gerodontology. 2014;31(Suppl 1):17-24.

8. Batchelor P. The changing epidemiology of oral diseases in the elderly, their growing importance for care and how they can be managed. Age Ageing. 2015;44(6):1064-1070.

9. Wu B, Fillenbaum GG, Plassman BL, Guo L. Association between oral health and cognitive status: a systematic review. J Am Geriatr Soc. 2016;64(4):739-751.

10. Tonsekar PP, Jiang SS, Yue G. Periodontal disease, tooth loss and dementia: Is there a link? A systematic review Gerodontology. 2017;34(2):151-163.

11. Stein PS, Desrosiers M, Donegan SJ, Yepes JF, Kryscio RJ. Tooth loss, dementia and neuropathology in the Nun study. J Am Dent Assoc 2007;138(10):1314-1322.

12. Kaye EK, Valencia A, Baba N, Spiro A, Dietrich T, Garcia RI. Tooth loss and periodontal disease predict poor cognitive function in older men. J Am Geriatr Soc. 2010;58(4):713-718.

13. De Rossi SS. Orofacial pain: a primer. Dent Clin North Am. 2013;57(3):383-392.

14. Kossioni AE, Hajto-Bryk J, Maggi S, et al. An expert opinion from the european college of gerodontology and the european geriatric medicine society: european policy recommendations on oral health in older adults. J Am Geriatr Soc. 2018;66(3):609-613.

15. Delwel S, Binnekade TT, Perez RSGM, Hertogh CMPM, Scherder EJA, Lobbezoo F. Oral health and orofacial pain in older people with dementia: a systematic review with focus on dental hard tissues. Clin Oral Investig. 2017;21(1):17-32.

16. de Souza Rolim T, Fabri GMC, Nitrini R, et al. Oral infections and orofacial pain in Alzheimer’s disease: a case-control study. J Alzheimers Dis. 2014;38(4):823-829.

17. van Kooten J, Delwel S, Binnekade TT, et al. Pain in dementia: prevalence and associated factors: protocol of a multidisciplinary study. BMC Geriatr. 2015;15(1):29.

18. Folstein MF, Folstein SE, McHugh PR. “Mini-mental state”. A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res 1975;12(3):189-198.

19. de Vries MW, Visscher C, Delwel S, et al. Orofacial pain during mastication in people with dementia: reliability testing of the orofacial pain scale for non-verbal individuals. Behav Neurol. 2016;2016(4):1-7.

20. Delwel S, Perez RSGM, Maier A, et al. Psychometric evaluation of the Orofacial Pain Scale of Non-Verbal Individuals (OPS-NVI) as a screening tool for orofacial pain in people with Mild Cognitive Impairment or dementia. Gerodontology. 2018:35:200-213.

21. Svensson P. Drangsholt M, Pfau DB, List T. Neurosensorv testing of orofacial pain in the dental clinic. J Am Dent Assoc. 2012;143(8):e37-e39.

22. Naije M, van Loon LAJ. Cranionamboolilu Runc Funct En Dysfunc. First. Hutten, the Netherlands: Bohn Stafleu van Loghum; 1998.

23. Kouris M, Visscher CM, Lobbezoo F, Naeije M. Comorbidity negatively influences the outcomes of diagnostic tests for musculoskeletal pain in the orofacial region. Pain. 2013;154(6):927-932.

24. Hadjistavropoulos T, Fitzgerald TD, Marchildon GP. Practice guidelines for assessing pain in older persons with dementia residing in long-term care facilities. Physiother Can. 2010;62(2):104-113.

25. Van der Velden U. The Dutch periodontal screening index validation and its application in The Netherlands. J Clin Periodontol. 2009;36(12):1018-1024.

26. Dijk LJ, Spijkervet FKL, Tromp JAH. Atlas van de Parodontale Diagnostiek. Hutten, the Netherlands: Bohn Stafleu van Loghum; 2011.

27. Silness J, Loe H. Periodontal disease in pregnancy. II. Correlation between oral hygiene and periodontal condition. Acta Odontol Scand. 1964:22:121-135.

28. Weijenberg RAF, Delwel S, Ho BV, Wierink CD, Lobbezoo F. Mind your teeth - the relationship between mastication and cognition. Ned Tijdschr Tandheelkd. 2017;124(9):435-440.

29. Chalmers JM, Carter KD, Spencer AJ. Caries incidence and increments in community-living older adults with and without dementia. Gerodontology. 2002;19(2):80-94.

30. Ellefsen B, Holm-Pedersen P, Morse DE, Schroll M, Andersen BB, Waldemar G. Caries prevalence in older persons with and without dementia. J Am Geriatr Soc. 2008;56(1):59-67.

31. Ellefsen B, Holm-Pedersen P, Morse DE, Schroll M, Andersen BB, Waldemar G. Assessing caries increments in elderly patients with and without dementia: a one-year follow-up study. J Am Dent Assoc. 2009;140(11):1392-1400.

32. Chen X, Clark JJ, Naorungroj S. Oral health in older adults with dementia living in different environments: a propensity analysis. Spec Care Dent. 2013;33(5):239-247.

33. Srisilapanan P, Jai-Ua C. Oral health status of dementia patients in Chiang Mai Neurological Hospital. J Med Assoc Thai. 2013;96(3):351-357.

34. Delwel S, Binnekade TT, Perez RSGM, Hertogh CMPM, Scherder EJA, Lobbezoo F. Oral hygiene and oral health in older people with dementia: a comprehensive review with focus on oral soft tissues. Clin Oral Investig. 2018;22(1):93-108.

35. Hopcroft MS, Morgan MV, Satur JG, Wright FAC, Darby IB. Oral hygiene and periodontal disease in Victorian nursing homes. Gerodontology. 2012;29(2):e220-e228.
36. Ide M, Harris M, Stevens A, et al. Periodontitis and cognitive decline in Alzheimer’s disease. PLoS ONE. 2016;11(3):e0151081.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

How to cite this article: Delwel S, Scherder EJA, de Baat C, et al. Orofacial pain and its potential oral causes in older people with mild cognitive impairment or dementia. J Oral Rehabil. 2019;46:23–32. https://doi.org/10.1111/joor.12724
Author/s: Delwel, S; Scherder, EJA; de Baat, C; Binnekade, TT; van der Wouden, JC; Hertogh, CMPM; Maier, AB; Perez, RSGM; Lobbezoo, F

Title: Orofacial pain and its potential oral causes in older people with mild cognitive impairment or dementia

Date: 2019-01-01

Citation: Delwel, S., Scherder, E. J. A., de Baat, C., Binnekade, T. T., van der Wouden, J. C., Hertogh, C. M. P. M., Maier, A. B., Perez, R. S. G. M. & Lobbezoo, F. (2019). Orofacial pain and its potential oral causes in older people with mild cognitive impairment or dementia. JOURNAL OF ORAL REHABILITATION, 46 (1), pp.23-32. https://doi.org/10.1111/joor.12724.

Persistent Link: http://hdl.handle.net/11343/271289

File Description: Published version

License: CC BY-NC-ND