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Orofacial pain in older people with dementia

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SUMMARY IN ENGLISH

The first aim of this thesis was to develop and evaluate an orofacial pain scale for people with cognitive impairment, especially dementia: the Orofacial Pain Scale for Non-Verbal Individuals (OPS-NVI). The second aim was to study the presence of orofacial pain and its potential causes in older people with Mild Cognitive Impairment (MCI) or dementia. The third aim of this thesis was to study oral (dys)function in older people with MCI or dementia.

Below the main results of each chapter of this thesis will be summarized.

PART I: REVIEWS

CHAPTER 2 – SYSTEMATIC REVIEW OF ORAL HARD TISSUES AND OROFACIAL PAIN IN PEOPLE WITH DEMENTIA

This chapter provides a systematic review of literature concerning the health of oral hard tissues and orofacial pain in older people with dementia, compared to older people without dementia [1]. The 37 included studies indicated that the number of teeth present, the Decayed Missing Filled Teeth (DMFT) index, percentage of edentulous people, and prosthesis use was comparable in people with and without dementia. However, the presence of caries and tooth root remnants was higher in older people with dementia than in those without. Moreover, it was indicated that orofacial pain was scarcely studied.

CHAPTER 3 – COMPREHENSIVE REVIEW OF ORAL SOFT TISSUES AND ORAL HYGIENE IN PEOPLE WITH DEMENTIA

In addition to the previous chapter, a comprehensive review with focus on the health of oral soft tissues and oral hygiene in older people with dementia is provided [2]. The 36 included studies showed that older people with dementia had high scores for gingival bleeding, periodontitis, plaque, and assistance for oral hygiene care. In addition, candidiasis, stomatitis, and reduced salivary flow were frequently present in older people with dementia.

PART II: METHODOLOGY

CHAPTER 4 – STUDY PROTOCOL OF THE PAIN IN DEMENTIA AMSTERDAM (PAINDEMIA) STUDY

This chapter describes the protocol of the PainDemiA study [3], of which the current thesis is a part. The participants of the PainDemiA study were recruited in outpatient clinics and nursing homes to include different levels of cognitive impairment and various subtypes of dementia, e.g. Alzheimer's disease, mixed dementia, vascular dementia, Frontotemporal dementia, and Dementia with Lewy Bodies. The inclusion criteria were MCI or dementia diagnosis and aged 60 years or older. All participants were examined by an elderly care medicine trainee, a dentist with experience in geriatric dentistry, and a neuropsychologist. The primary outcome variable was pain and the secondary outcome variables were oral health, autonomic responses to pain, vital and gnostic sensibility, musculoskeletal functioning, cognitive functioning, neuropsychiatric symptoms, and quality of life. This thesis describes the dentistry related outcomes: orofacial pain and oral health and function.

CHAPTER 5 – RELIABILITY TESTING OF THE 'CHEWING' SUBSCALE OF THE OPS-NVI

The reliability of the subscale 'chewing' of the OPS-NVI is discussed in this chapter [4]. For this study, 237 video clips of the 'STA-OP!' study were observed by two observers to examine the inter- and intra-observer reliability of the subscale 'chewing' of the OPS-NVI. After item-reduction, 6 items remained, with an Intraclass Correlation Coefficient (ICC) 0.40-0.47 for interobserver reliability and an ICC 0.40-0.92 for intraobserver reliability. In conclusion, the subscale 'chewing' shows fair-to-good to excellent interobserver and intraobserver reliability.

CHAPTER 6 – DEVELOPMENT AND PSYCHOMETRIC EVALUATION OF THE OPS-NVI

In this chapter the development and psychometric evaluation of the OPS-NVI as a screening tool for orofacial pain older people with MCI or dementia is presented [5]. The OPS-NVI is based on general items of the Pain Assessment in Impaired Cognition (PAIC) meta-tool [6,7] and specific items for orofacial pain, as suggested by Lobbezoo

et al. after reviewing existing observational tools for orofacial pain [8]. For the cross-sectional observational study that is described in this chapter, firstly, the presence of orofacial pain during rest, drinking, chewing, and oral hygiene care was observed in 348 PainDemiA participants with MCI or dementia using the OPS-NVI. Secondly, the participants who were considered to present a reliable pain self-report were asked about the presence of orofacial pain right after the aforementioned activities. Thirdly, in all participants the oral health was examined by a dentist for the presence of potentially painful conditions. In addition, the level of cognitive functioning was evaluated with the Mini Mental State Examination (MMSE). For the psychometric evaluation, item-reduction, inter-reliability and criterion validity were determined. **Summarizing table 1** shows the psychometric evaluation of the OPS-NVI for overall orofacial pain presence during rest, drinking, chewing, and oral hygiene care. The presence of orofacial pain in this population was low (0-10%), resulting in a positive agreement of 43-64%, a negative agreement of 88-96%, a sensitivity of 0-53%, and a specificity of 88-99% for the overall presence of orofacial pain observed with the OPS-NVI.

Summarizing table 1: Psychometric evaluation of the OPS-NVI for orofacial pain presence

Orofacial pain presence	Rest	Drinking	Chewing	Oral care
Positive agreement	62%	64%	61%	43%
Negative agreement	96%	92%	91%	88%
Observed TP+FP	1%	2%	16%	15%
Reported TP+FN	1%	0%	10%	3%
Sensitivity TP/(TP+TN)	0%	n/a	53%	12%
Specificity TN/(TN+FP)	99%	98%	88%	99%

TP: True Positive, **FP:** False Positive, **FN:** False Negative, **FP:** False Positive, **N/A** not applicable

Summarizing table 2 shows the psychometric evaluation of the individual items of the OPS-NVI. The individual items of the OPS-NVI show a positive agreement of 0-100%, a negative agreement of 77-100%, a sensitivity of 0-100%, and a specificity of 66-100%.

Summarizing table 2: Psychometric evaluation of the individual items of the OPS-NVI

Individual items	Rest	Drinking	Chewing	Oral care
Positive agreement	0-90%	0-100%	31-77%	0-100%
Negative agreement	86-100%	77-100%	80-99%	84-100%
Observed TP+FP	0-34%	0-19%	0-34%	0-34%
Reported TP+FN	1%	0%	10%	3%
Sensitivity TP/(TP+TN)	0-100%	n/a	0-41%	0-67%
Specificity TN/(TN+FP)	66-100%	73-100%	67-100%	66-100%

TP: True Positive, **FP:** False Positive, **FN:** False Negative, **FP:** False Positive, **N/A** not applicable

Furthermore, oral health problems, such as ulcers, tooth root remnants, and caries, were present in 64.5% of all participants. The cross-tables in the article show that oral health problems were frequently present, while no pain was reported.

In conclusion, the presence of orofacial pain in this population with MCI or dementia is low, resulting in low scores for average positive agreement and sensitivity and high scores for average negative agreement and specificity. Therefore, the OPS-NVI in its current form cannot be recommended as a screening tool for orofacial pain in people with MCI or dementia. However, the psychometric evaluation provides further insight for the adjustment of the OPS-NVI for diagnostic use. Notably, oral health problems are frequently present, although no pain is observed or reported. This finding indicates that the presence of oral health problems cannot be used as a new reference standard for the presence of orofacial pain in the development of a diagnostic tool. Furthermore, this observation suggests that a regular oral examination of people with cognitive impairment by care providers and oral care professionals remains indispensable to maintain oral health.

PART III: CLINICAL STUDIES

CHAPTER 7 – OROFACIAL PAIN AND ITS POTENTIAL CAUSES IN OLDER PEOPLE WITH MCI OR DEMENTIA

This chapter describes the presence of orofacial pain and its potential oral causes in older people with MCI or dementia [9]. In this cross-sectional observational study, the presence of orofacial pain and its potential causes was studied in 348 PainDemiA

participants with MCI or dementia in two outpatient memory clinics and ten nursing homes. Orofacial pain was reported by 25.7% of the 179 participants who were considered to present a reliable pain self-report (MMSE score ≥ 14 points), while it could not be determined for people with more severe cognitive impairment. The oral health examination of the 348 participants indicated that potentially painful conditions such as coronal caries, root caries, tooth root remnants, or ulcers were present in 50.3%. There was a significant, but weak correlation between the level of cognitive impairment and the number of teeth, $r = .185$, $p = .003$, teeth with coronal caries, $r = -.238$, $p < .001$, and the number of tooth root remnants, $r = -.229$, $p = .004$, after adjusting for age. In conclusion, this study indicates that orofacial pain and its potential causes are frequently present in people 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.

CHAPTER 8 – ORAL (DYS)FUNCTION OF OLDER PEOPLE WITH MCI OR DEMENTIA

Clinical aspects of the oral function in older people with MCI or dementia are described in this chapter [10]. This cross-sectional observational study included 348 PainDemiA participants with MCI or dementia aged 60 years or older. Global cognitive functioning was evaluated with the MMSE and the oral function was evaluated with subjective and objective assessments, including the perceived quality of chewing and swallowing, the function of the prostheses, the number of Occluding Pairs, the degree of tooth wear, and the active and passive maximum mouth opening. The quality of chewing and swallowing was perceived as good in respectively 86.0% and 90.9% of the participants. Full or partial prostheses were worn by 63.8% of the participants and the retention was good in 58.4% of the upper and 50.0% of the lower prostheses. Participants with MCI had a median of 3.0 (IQR 0.0-7.5) occluding pairs, while participants with dementia had a median of 0.0 (IQR 0.0-1.0) occluding pairs, $U = 3838.50$, $p < 0.001$. There was a weak positive correlation between the number of occluding pairs and the MMSE score, $r = 0.267$, also when adjusted for age, $r = 0.230$. The median tooth wear score was 2.0 (IQR 2.0-2.0) in participants with MCI or dementia. The active maximum mouth opening was 45.8 (SD 9.3) mm in participants with dementia, while it was 49.8 (SD 8.1) mm in those with MCI, $t(253) = 2.67$, $p = 0.008$. In conclusion, for most participants with MCI or dementia the swallowing and chewing ability was perceived as good. In addition, more than half of the prostheses

had good retention and occlusion. Participants with more severe cognitive impairment had fewer occluding pairs and a smaller active mouth opening. The degree of tooth wear was less than one third of the clinical crown in most participants with MCI or dementia.

SYNOPSIS

This thesis adds to the development of an observational tool for non-verbal people with cognitive impairment and the psychometric evaluation of the Orofacial Pain Scale for Non-Verbal (OPS-NVI) in people with cognitive impairment, especially dementia. In addition, this thesis indicates that almost half of the examined people with MCI or dementia have potentially painful conditions, such as caries, tooth root remnants, and pressure ulcers. Furthermore, it discusses aspects of oral function that are scarcely studied in people with MCI or dementia, such as the number of occluding pairs, mouth opening, and degree of tooth wear.

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