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### Every smile matters

*Oral health and orofacial pain in older people with dementia in UK care settings*

van de Rijt, L.J.M.

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## General Discussion

The general aims of this thesis were to assess the prevalence of oral health problems and orofacial pain and its associated factors in older people with dementia in different care settings in the UK, and to contribute to the development of a validated tool to identify orofacial pain in this population. The results of the included studies show that orofacial pain was identified in 11.9% to 48.8% of older people with dementia. Poor oral health was also common in older people with dementia, and was often associated with orofacial pain. The concurrent and predictive validity testing of the Orofacial Pain Scale for Non-Verbal Individuals (OPS-NVI) showed promising results. In this general discussion, we will elaborate on three main subjects. Firstly, we will discuss the poor oral health status in our sample of older people with dementia in the UK. Secondly, we will evaluate the validation process of the OPS-NVI. Thirdly, we will discuss recommendations and future directions.

## Oral health status of older people with dementia in the UK

The results of this thesis show that the oral health in our sample of older people with dementia in the UK, both in nursing homes and in acute hospitals, is poor. For example, in acute hospitals, 55.8% of the dentate participants had  $\geq 1$  retained roots, while 55.2% of the dentures had a poor hygiene (*Chapter 3*) [1]. In nursing homes, 57.1% of older people with dementia had 0 to 2 occlusal units without dentures, and 60.9% of the dentures had a poor hygiene (*Chapters 5 and 6*).

In 2016, the National Institute for Health and Care Excellence (NICE) published a guideline (NG48), to help improve oral health among care home residents in the UK [2]. Although this guideline is very thorough and clear, it is often not implemented in this setting. In June 2019, the Care Quality Commission (CQC) evaluated the current status of oral health care in 100 UK care homes [3]. They reported that only 28% of the care home managers have read the NICE guideline, of which only 38% implemented all recommendations [3]. On admission, only 44% of care homes use a recognised tool to assess oral health, and 47% of the care homes indicated that staff did not receive specific training to perform oral care [3]. Besides the lack of guideline usage and lack of training, work overload and high turnover of staff are barriers to performing oral care routinely. In older people with dementia, especially in the more advanced stages, challenging behaviour can further complicate delivery of oral care by care home staff. As a result of the barriers mentioned above, oral care is often skipped or performed inadequately. This leads to further

deterioration in the oral health status of persons with dementia, with all its possible negative consequences for both oral and general health.

A controlled clinical trial, performed in Germany, showed improved oral health indicators after both six months and one year, as a result of the implementation of an education programme, including lectures and supervised practical training, within care homes [4, 5]. An RCT, conducted in the USA, showed that specific training to perform oral care in people with dementia with challenging behaviour improves the odds of people with dementia allowing oral care to be performed [6]. To improve oral health care provision for older people with dementia in UK care homes, guidelines for this specific population need to be developed, and implemented, ensuring adequate support for care home staff. Furthermore, care home staff may benefit from further training to perform oral care in older people with dementia, which will increase their knowledge, practical skills and confidence. To improve and maintain the oral health of community dwelling older people with dementia, the project 'Don't forget the mouth!' was developed [7]. This project consists of an education program and interdisciplinary collaborations between health care professionals and informal caregivers and is still ongoing [7].

Besides the implementation of routinely providing oral care, the accessibility to professional oral health care needs to be improved as well. Experienced barriers to professional oral health care are fear, financial issues, mobility problems, and difficulty in finding an available dentist, experienced with the complex needs of this specific population [3]. In the UK, dentists who work for the National Health Service (NHS) often have long waiting lists and do not accept new NHS patients [3]. Around one-third of the care home managers indicated that they often have no or only partial access to emergency dental care, which often results in calling a General Practitioner or even taking a person to the emergency room in the hospital [3].

To overcome the challenges described above, the implementation of professional oral health care within care homes should be encouraged. A study conducted in Belgium showed improved knowledge and attitude towards oral health care amongst care home staff after implementation of an education programme, including the implementation of a mobile dental team visiting the care home [8]. Apart from the ability to offer dental treatment within the care home, regular visits from a mobile dental team also improves the awareness and provision of daily oral care, and establishes continuous oral health care as part of the general care in care homes. Ultimately, a more preventive approach should be ensured, instead of only curative and emergency treatment. Ideally, personalised oral care and treatment planning

can be established in the earlier stages of dementia, to prevent extensive necessary treatment in the more advanced stages.

## Validation of the OPS-NVI

In people with dementia, who are no longer able to verbally communicate, observational methods are necessary to identify orofacial pain. In this thesis, the validity of the OPS-NVI was evaluated. We will discuss the subscales 'resting', 'drinking', 'chewing', and 'oral care' separately. The subscale 'resting' showed excellent to outstanding accuracy (*Chapter 4 and 5*) [9]. Although the presence of orofacial pain according to self-report was low, these results are promising. To establish a baseline measurement of the behaviour of the person involved, we recommend that the subscale 'resting' should remain part of the observational tool. During drinking, only 8.1% of the participants self-reported pain, but still an excellent accuracy was reported. The validity of the subscale 'drinking' was not assessed before, due to a previously found prevalence of 0% [10]. Since cold drinks could provoke pain as a result of pulpitis, we think it is important to retain the subscale 'drinking', although the prevalence might be low. For the subscale 'chewing', the results of this thesis showed a sensitivity of 77.8-83.3%, and a specificity of 96.4-100%, indicating an excellent to outstanding accuracy (*Chapter 4 and 5*) [9]. The previous study of Delwel et al. reported a more limited sensitivity, namely 53% [10]. In that study, only 9.7% self-reported pain during chewing, while in our studies 10.7-24.3% self-reported pain during chewing [10]. Orofacial pain during chewing could be caused by painful apical periodontitis or painful temporomandibular disorder, and is therefore an important subscale of the observational tool. The subscale 'oral care' showed an acceptable accuracy (*Chapter 5*). The study of Delwel et al. reported a sensitivity of only 12%. It is important to acknowledge that the observed behaviour during oral care could also be a response to the oral care, instead of behaviour caused by pain. As a result, the observed behaviour, especially in those with more severe dementia, can easily be misinterpreted. Therefore, we recommend the removal of the 'oral care' subscale from the observational tool.

Since the studies included in this thesis were performed by one researcher only, reliability testing was not possible. A previous study reporting on the reliability of the OPS-NVI showed fair-to-good to excellent inter-observer and intra-observer reliability of the subscale 'chewing' [11]. Delwel et al. reported the inter-rater reliability in average Negative Agreement of 88-96%, and in average Positive Agreement of 53-64%, indicating only an insufficient Positive Agreement for the subscale 'oral care' [10].

In conclusion, it is recommended that the subscales ‘resting’, ‘drinking’, and ‘chewing’ are retained in the observational tool, while subscale ‘oral care’ is removed. Although the validity assessment of the OPS-NVI showed promising results, further validity and reliability testing is still needed.

## Recommendations and future directions

To facilitate proper sensitivity testing, a study population with higher prevalence of orofacial pain is necessary. This could be established by including participants with oral health problems that could potentially cause pain. Although the OPS-NVI is developed for non-verbal individuals, hence people with more advanced dementia, construct validity testing can only be performed in a population that is still able to self-report pain. Therefore, people with mild dementia should be included in future validity testing studies as well.

In all previous studies, the observations were performed by researchers with a dental background (i.e., dentists and dental students). In future research, it is recommended to assess the validity and reliability of the OPS-NVI, when observations are performed by people who are more involved in the daily care of the person involved, such as care home staff or ward staff in the acute hospital. As a result, the OPS-NVI could then be used in clinical practice as a screening tool to indicate the presence of orofacial pain and indicate when referral to a dental professional is necessary.

Although being free of pain is of high importance to preserve quality of life in older people with dementia, it is important to acknowledge the high prevalence of oral health problems in this population, which do not always cause pain (*Chapter 3 and 5*) [1, 12]. The possible impact of a poor oral health on general health and quality of life in this frail population should be emphasized [13, 14]. For example, an association between a pathogen involved in gingival inflammation and Alzheimer’s disease has recently been reported [15].

It is highly recommended that oral health care is implemented as part of the routine care of older people with dementia. This could be established by including oral health care programs within multidisciplinary programs, both in long-term care facilities and in acute hospitals. Besides the development of such programs (including education and training), implementation and sustainability of these programs within the care facilities is essential. To achieve this, such programs

should continuously undergo a Plan-Do-Study-Act (PDSA) cycle, which is a simple and effective approach to guarantee continual improvement [16].

## Conclusion

This thesis contributed to improved insight on oral health, orofacial pain, and its associated factors in older people with dementia. Furthermore, this thesis contributed to the further development of the first observational tool to identify orofacial pain in non-verbal individuals. To be able to use the OPS-NVI in clinical practice, further validation is highly recommended. The ultimate goal is to fully implement oral health care in the routine health care of older people with dementia and to carry out a preventive and personalized treatment approach.