Every smile matters

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

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Summary

The number of older people with dementia has increased enormously over the past few decades. Due to increased comorbid diseases, reduced self-care, and increased tooth retention, more oral health problems are expected in this population. These oral health problems can lead to orofacial pain, which is often under-detected and under-treated in older people with dementia. Remarkably, there is little research available on orofacial pain in older people with dementia.

In the more advanced stages of dementia, when self-reporting of pain becomes challenging or even impossible, observational methods are needed. To identify orofacial pain in non-verbal persons, the Orofacial-Pain Scale for Non-Verbal Individuals (OPS-NVI) has recently been developed.

The main aim of this thesis was to assess the prevalence of oral health problems and orofacial pain and its associated factors in older people with dementia in different care settings, and to contribute to the further development of a validated tool to identify orofacial pain in this population.

In *Chapter 2*, a systematic review of the literature is provided on the association between oral health factors and Oral Health-related Quality of Life (OHQoL) in people aged 65 years or older. A comprehensive search was performed in five databases, using the following terms as index terms or free-text words: 'Oral Health', 'Quality of Life', and 'Older People'. The 68 eligible studies indicated that OHQoL in people aged 65 years or older is positively associated with a higher number of teeth, a higher number of occluding pairs, implant-retained overdentures, and the Shortened Dental Arch concept; and negatively associated with xerostomia, orofacial pain, and poor chewing ability. In the current literature, there is no consensus on the association between edentulism, caries, and periodontal conditions on the one hand and OHQoL. In conclusion, having a functional dentition (either natural or prosthetic) is important for good OHQoL, whereas painful or functional complaints are associated with impaired OHQoL.

In *Chapter 3*, the prevalence of orofacial pain and its associated oral health factors in older people with dementia in acute hospitals in the UK are described. This cross-sectional observational study was carried out on acute medical wards in two UK hospitals. Using the OPS-NVI to identify orofacial pain, 101 older people with dementia were observed for at least 3 min during rest and 3 min during chewing. Finally, a brief oral assessment was performed. Orofacial pain was present in 11.9% (95% C.I. 5.9, 18.8) of participants at rest and in 21.9% (95% C.I. 14.6, 31.3) whilst chewing. Participants who were no longer able to self-report pain were significantly

more likely to experience orofacial pain. Oral health in both dentate and edentate participants was poor. Low brush frequency, poor subjective chewing quality, being on a soft diet, presence of extra-oral abnormalities, mouth care performed by a nurse, and poor oral hygiene in dentate participants were significant predictors for the presence of orofacial pain. Improving oral care in acute hospital patients with dementia, particularly those who cannot self-report pain, may significantly reduce pain and suffering in this population.

In *Chapter 4*, the validity of the resting and chewing components of the OPS-NVI was assessed. A total of 56 participants with dementia, admitted to the acute hospital, who were still able to self-report pain, were observed for 3 minutes during rest and during chewing, and the OPS-NVI was used to identify orofacial pain. Afterwards, the participants were asked about the presence of orofacial pain using self-report pain scales. The specificity of the OPS-NVI was 98.1% to 100%, the sensitivity was 66.7% to 83.3%, and the AUROC was 0.824 to 0.917. The predictive validity showed a strong correlation (0.633 to 0.930, P<.001) between the number of positive behaviour items and the self-reported presence of orofacial pain. The resting and chewing components of the OPS-NVI showed promising concurrent and predictive validity. Nevertheless, further validation is required and highly recommended.

In *Chapter 5,* the prevalence of orofacial pain in older nursing home residents with and without dementia was assessed and the prevalence in those with dementia was compared with the prevalence of those without, and the association between orofacial pain and health factors was explored. This cross-sectional study included 111 nursing home residents aged 65 years or older from four UK nursing homes, of which 84 had dementia and 27 had no dementia. Of 84 participants with dementia, 37 were still able to self-report pain. The OPS-NVI was used to identify orofacial pain in residents with dementia. Residents, who were able to communicate, self-reported orofacial pain. A brief oral examination was conducted in all participants. Orofacial pain, assessed with the OPS-NVI, was present in 48.8% (95% C.I. 36.1, 50.7) of 84 residents with dementia. Self-reported orofacial pain was present in 37.8% (95% C.I. 20.4, 53.7) of 37 residents with dementia, and in 14.8% (95% C.I. 0.5, 30.4) of 27 residents without dementia. Orofacial pain was significantly more prevalent in residents with dementia than in 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 for orofacial pain in residents with dementia.

In *Chapter 6*, the oral function, nutritional status, and quality of life were compared between residents with and without dementia, and the associations between oral function, nutritional status, and quality of life were examined. The nursing home residents described in Chapter 5 were also involved in this part of the study. Residents, their carers, and/or nursing staff were interviewed and a brief oral examination was performed. Residents with dementia had significantly fewer teeth (p=0.021), fewer occlusal units (p=0.001) and poorer functional categories (i.e., number of occlusal units combined with denture usage) (p=0.001), and nutritional status was significantly poorer than those without dementia (p=0.002). In the regression model, quality of chewing (p=0.010) was significantly correlated with nutritional status. Almost half of residents had insufficient oral function, which was negatively associated with quality of life and nutritional status.

In *Chapter 7*, a general discussion on three main subjects is provided. To improve the oral health of older people with dementia in the UK, it is recommended to develop and implement oral health care guidelines for this specific population and to establish continuous oral health care as part of the general care in care homes and hospitals. Ultimately, a more preventive approach and personalised oral care and treatment should be assured. Regarding the OPS-NVI, it is recommended to retain the subscales 'resting', 'drinking', and 'chewing' in the observational tool, and to remove the subscale 'oral care'. Although the validity assessment of the OPS-NVI showed promising results, further validity and reliability testing is still needed. Finally, recommendations and future directions are discussed.

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 oral care and treatment approach.