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Every smile matters

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

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General Introduction

Due to global ageing, the number of older people has increased substantially over recent years [1]. A report from the United Nations showed that the population of older people is expected to double in size in 2050, compared to 2015 [1]. As a result, the prevalence of people with dementia will double every 20 years. In 2050, the expected number of people with dementia will be 115 million [2]. Dementia is an umbrella term used to describe a range of diseases and symptoms caused by neurodegenerative conditions [3]. Dementia is characterised by memory loss, decline in cognitive function, impaired communication (e.g., apraxia and/or aphasia), behaviour changes, and decline of functional ability [3, 4]. Often, co-morbidities and behavioural and psychological symptoms of dementia (BPSD), like aggression and agitation, co-exist with dementia [4]. Further progression of these characteristics can ultimately lead to complete loss of capacity and eventually to death. The most common type of dementia is Alzheimer's disease, which is diagnosed in approximately 80% of all cases [5]. After that, the second commonest type of dementia is vascular dementia [6]. Some less common subtypes of dementia are Lewy body dementia and frontotemporal dementia [7]. There are over 100 different diseases and conditions that can ultimately cause dementia [8]. Since there is considerable overlap between the underlying pathologies, there is often difficulty in distinguishing different subtypes of dementia [9]. Sometimes the clinical presentations can be misleading and often the diagnosis is only confirmed post-mortem [10].

Pain in dementia

Daily, around half of people with dementia experience pain [11]. People with dementia may have altered sensory perception due to the disorder. It is unclear whether people with dementia have an increased or decreased pain perception as a result of the same stimulus than those without [10]. A systematic review showed that the patterns of changes in pain experienced in people with dementia can be different between subtypes of dementia, due to differences in neuropathology [10]. In the literature, it is suggested that people with frontotemporal dementia and Alzheimer's disease experience less pain, while people with vascular dementia experience more pain than people without dementia as a result of similar stimuli [12, 13]. It is important to acknowledge that the methodology of the conducted studies was characterized by some limitations and that clinical diagnoses of subtypes during lifespan might differ post-mortem [10].

Most common causes of pain in people with dementia are cardiac pain, gastrointestinal pain, and musculoskeletal conditions, pressure ulcers, genitourinary infec-

tions, orofacial pain, and neuropathic pain [11]. Despite these numerous causes of pain, epidemiological studies show that pain in people with dementia is often undetected and undertreated, compared to healthy counterparts [14, 15]. Identifying pain and managing pain in this frail population is often difficult and clinical approaches vary. Pain, a subjective experience, can be challenging to detect in people who are no longer able to communicate stress or discomfort verbally or non-verbally [16]. As a result, untreated pain may lead to increased BPSD (e.g., aggression, sleep disturbance, agitation), further functional decline, poor appetite, impaired quality of life, and impaired movement [17-20].

Although the possible correlation between pain and dementia remains unclear, we can conclude that pain and dementia are often co-existing comorbidities, which is a growing problem due to the aging population and communication barriers. Therefore, assessment of prevalence rates of pain and validated tools to identify pain in this frail population are necessary to gain a clear overview of the problem for caregivers and to be able to establish suitable management strategies for pain.

Orofacial Pain

Orofacial pain is common in older people [21]. It can be caused by problems in the face or oral cavity (e.g., problems with the teeth or the masticatory system) [22]. In general, oral health problems increase with age, due to increased comorbid diseases and decreased self-care [23]. Nowadays, more oral health problems are expected in the older population, since older people tend to retain more natural teeth, due to improved dental care during lifespan [24]. Older people with dementia might develop apraxia and might not be able to properly perform oral care, which further increases the risk of oral health problems [25]. In advanced stages of dementia, oral care may become even more difficult, due to dependency on other people and BPSD [26].

Quality of life

Improving the oral health of older people, including those with comorbid diseases, can lead to better quality of life [27]. The definition of quality of life of the World Health Organization is ‘an individual’s perception of their position in life in context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’ [28]. A person’s physical health, social rela-

tions, personal beliefs, and psychological health can be compromised when quality of life is impaired [28]. Quality of life is a subjective construct, which is ideally reported by the person concerned. However, in people with advanced dementia, self-report is no longer possible, and information on quality of life needs to be obtained via a proxy (e.g., family carer or formal caregiver). However, the possibility of misinterpreting another person’s beliefs and feelings needs to be taken into account. In general, self-reported quality of life is higher than quality of life reported by a proxy [29]. For care home residents with dementia, there is no significant difference in reported quality of life outcome between care home staff and family carers [30].

The concept of oral health-related quality of life (OHQoL) is based on the perspective that someone’s self-image and self-esteem can be undermined by oral health problems [31]. Furthermore, oral health problems can lead to pain, stress, or even depression [31]. Poor oral health can influence vital functions, such as breathing and swallowing [32]. It is important to acknowledge that a person’s perceptions and values may change during ageing. Because of global ageing, the number of older people needing dental care and treatment will increase. To provide adequate treatment for this population, it is important for dental care professionals to know which factors contribute to better quality of life. However, there is a lack of reviews describing the associations between oral health and quality of life in this specific population.

Pain assessment

To provide effective treatment for orofacial pain, adequate diagnosis is essential. In the general population, self-report is the gold-standard for pain assessment [33, 34]. For a successful assessment, it is important that the person is able to communicate verbally and understands what the task involves [16]. In the more advanced stages of dementia, when verbal communication becomes challenging or even impossible, even simple yes-or-no questions may not be suitable anymore [16]. In those cases, observational methods are the only way to indicate the possible presence of pain [11, 16]. To establish one internationally agreed-upon tool for the assessment of pain in general, representatives from 16 European countries collaborated and developed the Pain Assessment in individuals with Impaired Cognition (PAIC15) [35]. However, there is lack of research and instruments to assess dental and orofacial pain via observational methods [21]. Therefore, the Orofacial-Pain Scale for Non-Verbal Individuals (OPS-NVI) has been developed to identify orofacial pain in people who are no longer able to communicate verbally [11]. The OPS-NVI consists of four activities (viz., resting, drinking, chewing, and oral care) in which the person is observed for behaviour

that may indicate pain. Previous studies on reliability and validity of the OPS-NVI showed promising results [36, 37]. However, to establish a valid tool for clinical use, more validity testing is necessary.

Oral function and nutrition

Oral health problems, such as periodontitis and caries, can lead to loss of teeth [38]. As a result, the oral function of a person can be diminished [38]. Besides the number of teeth, the distribution of those teeth is very important to maintain chewing ability [38]. To maintain adequate oral function, previous studies reported that 3-5 occlusal units (i.e., the number of contacts between upper- and lower (pre)molars) are sufficient [39]. Besides the number and distribution of natural teeth, xerostomia, pain, and swallowing difficulties can also diminish oral function [40, 41]. When chewing becomes challenging, this may lead to avoiding certain foods and diminished food intake [42]. Older people with dementia are at higher risk of oral health problems, and therefore at higher risk of impaired chewing ability and decreased nutritional status [43]. Impaired chewing ability, decreased food intake, and poor nutrition can eventually lead to increased morbidity and mortality risk and decreased quality of life [44, 45]. Strikingly, the association between oral function, nutrition, and quality of life in older people with dementia has hardly been studied.

The context of acute hospitals in the United Kingdom

Annually, a quarter of people with dementia in the United Kingdom (UK) have at least one admission to an acute hospital [46]. More than 25% of hospital beds in the UK are occupied by people aged 65 years or older with dementia [47]. The person with dementia might experience the acute hospital ward as a distressing environment, due to unfamiliar busy surroundings, increased noise, unfamiliar staff, and strange people walking by. Conversely, hospital staff are often less familiar with the person with dementia or their habits, preferences (i.e., how they like to be communicated with, factors they find worrying or upsetting, or personal care preferences), and behaviour patterns, compared to care home staff.

During their admission, 75% of people with dementia have BPSD, such as aggression and agitation [18, 48]. BPSD is associated with decreased quality of life, increased costs of care, and may lead to depression and burden among caregivers [49-51]. Some of the symptoms of BPSD could be worsened by the combination of

the unfamiliar environment of the acute hospital and poor pain control [18, 52]. The misinterpreted pain could then lead to inappropriate prescription of antipsychotics [53]. As a result, adverse events during admission are more likely to appear and hospital stay is often extended compared to those without dementia [54].

In general, during admission, there is no routine assessment of pain. To determine the requirement of analgesics, often simple questioning is used, regardless of barriers of communication [55]. Another method described, in which familiarity with the person is vital, is the use of an intuitive approach for the management of pain [56]. As a result, older people with dementia with impaired verbal communication are less likely to receive analgesics than those without dementia [15]. More than half of hospital staff are not satisfied with their ability to identify pain [47]. They indicate they would like more training in the detection of pain [47]. In addition to the issue of commonly undetected pain, the oral health of older people, especially those with dementia admitted to acute hospital wards, is often poor [57]. Furthermore, their oral health may even worsen by the presence of BPSD, due to for example decreased self-care [58]. Therefore, they are at higher risk of developing orofacial pain [59]. There is very little data available on the prevalence of orofacial pain in older people with dementia, especially in those who are unable to communicate verbally, in acute hospitals.

The context of care homes with nursing in the United Kingdom

As a result of declined functional ability, increased frailty, and co-morbid conditions, independent living in the community can become too challenging or even impossible for older people, and moving to a care home is then necessary. Currently in the UK, almost half a million older people aged 65 or older live in residential care [60]. As a result of global ageing, an increase in number of care home beds is expected. However, over recent years, the number of beds have remained stable [61]. The average number of residents per nurse is 18 during the day and 26 at night [62]. In the UK there are two types of care homes: 1) residential homes which provide support, accommodation and day to day care; and 2) care homes with nursing, which have qualified nursing staff available 24/7. In this thesis care homes with nursing will subsequently be referred to as 'nursing homes'. The health care profile of nursing home residents has changed, leading to increased numbers of comorbid diseases, increased frailty, and more need for physical care [63, 64]. Unfortunately, there is an enormous turnover and shortfall of nursing staff in the UK [65]. Cuts in

funding led to a decrease of 44% in the number of fulltime district nurses between 2010 and 2017 [66]. The turnover for care workers and registered nurses was around 30% in 2017 [65].

Epidemiological studies reported that the oral health of nursing home residents is poorer, compared to older people living in the community [23]. More than two-thirds of nursing home residents have dementia, which further increases their risk of developing oral health problems [25, 67]. Unfortunately, access to dental care for nursing home residents is often limited [68]. Nursing home managers indicate that waiting time for services, problems with mobility and transport, and fear of dentists are the most common barriers to dental care [69]. Providing oral care to nursing home residents, especially to those with dementia, can be challenging due to perceived care-resistant behaviour [26]. Nursing home staff indicate they have insufficient knowledge and training in how to prevent and manage this behaviour, which often leads to completely skipping oral care provision [70]. Ultimately, insufficient oral care provision in the nursing homes and lack of access to professional dental care lead to more oral health problems and thus to a higher risk to develop orofacial pain.

General aim

The main aim of this thesis is 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 development of a validated tool to identify orofacial pain in this population. Eventually, this will contribute to improvement of oral health care provision, establishing strategies for the suitable management of oral health problems and orofacial pain for caregivers of older people with dementia, and improving oral health-related quality of life.

Objectives

Firstly, oral health factors that are associated with OHQoL in people aged 65 years or older will be identified in a systematic review of the literature. Secondly, the prevalence of orofacial pain and oral health problems in older people with dementia will be examined in the acute hospital and nursing home setting in the UK. Thirdly, the validity of the OPS-NVI will be assessed in both settings. Finally, the oral function of nursing home residents with and without dementia, and its association with nutritional status and quality of life will be examined.

Outline of this thesis

Chapter 1 is the general introduction to this thesis.

Chapter 2 provides a systematic review of the literature 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 is performed in five databases. All results are reported descriptively and categorized according to the following oral health domains: (1) natural dentition; (2) caries; (3) periodontal conditions; (4) prosthetic status; and (5) other oral health-related factors.

Chapter 3 describes the presence of orofacial pain in older people with dementia admitted to acute hospital wards. Furthermore, it explores associations between orofacial pain and oral health factors.

In *Chapter 4*, the results of the concurrent and predictive validity testing of the resting and chewing components of the Orofacial-Pain Scale for Non-Verbal Individuals (OPS-NVI) in the acute hospital setting are presented.

In *Chapter 5*, the prevalence of orofacial pain in nursing home residents with and without dementia is reported. The associations between the presence of orofacial pain and health factors are described. In addition, the results of the concurrent validity testing of the four components of the OPS-NVI in the nursing home setting are given.

Chapter 6 describes the oral function, nutritional status, and quality of life of older nursing home residents with and without dementia. Associations between oral function, nutritional status, and quality of life are reported.

In *Chapter 7*, a general discussion is provided.

Chapter 8 presents the English summary of this thesis.

Chapter 9 presents the Dutch summary of this thesis.

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