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Dental care for people living with dementia: current challenges and planning for the future. The UK perspective

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Dementia is a major public health challenge, and its impact on oral health and oral healthcare delivery can be drastic. More people are living with dementia, and the proportion of people living longer is growing. This review summarises dementia and its impact on oral health, dental care access and dental services. People living with dementia (PLwD) face a substantial risk of developing oral diseases and experiencing orofacial pain. PLwD face many barriers to dental care. When care is accessed, there can be practical and ethical challenges in receiving person-centred treatment. PLwD with the most complex needs are increasing in number and more are likely to require specialist care. Recommendations are made regarding preventative care, dental care access, domiciliary care, workforce planning and treatment decision-making. Those commissioning and facilitating dental care for PLwD should ensure that suitably trained staff are available in accessible services to plan the necessary care and provide active treatment where appropriate. It is almost inevitable that more care will need to be commissioned to support this growing patient group. This need should be anticipated and planned for at a population and policy level to reduce the detrimental impacts of oral diseases and orofacial pain for PLwD.

Keywords*: Geriatric dentistry, Patient Participation, Health services research Treatment planning, Patient Care Planning, Clinical outcomes*

Introduction

It is well documented that people generally retain more teeth into later life and that the prevalence of edentulism is decreasing (Clayton, 2022). Edentulousness in the UK fell in prevalence from 28% in 1978 to 6% in 2009 (Steele *et al*., 2012), and this trend continues, meaning those living longer are retaining more teeth, many of which may be heavily restored (Clayton, 2022). Whilst this is a welcome population level-change, it has implications for oral health and dental care in the older population. Specifically, older people are now more likely than previous generations to experience dental problems alongside comorbidities, frailty, or cognitive impairment (Watt *et al*., 2013; Marchini *et al*., 2019).

To appreciate the full impact of older people's changing oral status, it is necessary to examine the proportion of older people within the population. Within the UK, the population of people aged over 65 is increasing and is projected to account for over a quarter of the total population by 2041 (Office for National Statistics, 2018). Within this group, the proportion aged over 85 is growing the fastest, and will reach 2.8 million people by 2036 (Age UK, 2017). When these demographic trends are considered alongside the changes in dental status of older people, it becomes clear that there may be many partial and heavily restored dentitions that may require management in situations where patients may be less able to receive care.

Dementia is a key age-associated condition that impacts oral health and dental care. Dementia is an umbrella descriptor incorporating a range of conditions, including Alzheimer's disease, dementia with Lewy bodies, vascular dementia, and frontotemporal dementia. Each form of dementia is characterised by irreversible neuro-degeneration that occurs to an extent beyond that expected with normal ageing and which negatively impacts daily living (Weintraub, 2014; Camicioli, 2014). Symptoms vary considerably both within and between conditions, with comprehensive summaries provided in the relevant literature (Lobo *et al*., 2000; Camicioli, 2014). The prevalence of dementias will increase with the changes in population demographics. At least 7.1% of UK people aged 65 or above currently have a diagnosis of dementia (Prince *et al*., 2014). This equates to over 850,00 people, yet a 40% increase is anticipated before 2030 (Wittenberg *et al*., 2019). Even more concerning is that a 55% increase in those living with later-stage dementia is expected simultaneously. Clearly, the oral and dental care requirements of people living with dementia (PLwD) will become ever more impactful to dental services.

Dental care is associated with numerous challenges for PLwD, including with treatment decision-making, treatment tolerance and treatment outcomes (Faculty of General Dental Practitioners, 2017; Geddis-Regan *et al*., 2020; Curl *et al*., 2022). This review summarises the literature on oral care delivery, oral health status for PLwD and the impact of oral diseases on this patient group. It also considers how health services in the UK may support dental care for PLwD who retain their teeth throughout their dementia.

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Oral care for people living with dementia

Numerous age-related factors can impact the effectiveness of oral self-care, such as xerostomia and reduced oral clearance (Gil-Montoya *et al*., 2016). Additional factors complicate oral care in dementia, whether by PLwD themselves or their carers (Marchini *et al*., 2019). Specific symptoms such as memory loss and disorientation may mean oral care is forgotten about, or may be less effective (Chen *et al*., 2013; Grönbeck Lindén *et al*., 2017). As dementia progresses, people become dependent on others for personal care, including oral care. This may be provided by care home staff or by family members, yet both groups encounter difficulties in supporting it, especially dementia symptoms mean people are resistant.

Systematic reviews exploring barriers and facilitators to effective carer-delivered oral hygiene in older people (Hoben *et al*., 2017; Göstemeyer *et al*., 2019) have found that carers lacked knowledge on how to deliver oral care and had concerns about the appropriateness and safety of providing oral care when people appeared to resist it. More recent qualitative studies have provided further insight into how these barriers manifest (Weening-Verbree *et al*., 2021; Gomez-Rossi *et al*., 2022). Without these barriers being addressed, oral care standards appear to remain low (Care Quality Commission, 2019). Göstemeyer et al. (2019) identified that specific training for care home staff and relatives, as well as the support of dental professionals, could facilitate better oral care for dependent adults. Specific interventions, including those in conjunction with care teams, may support better oral hygiene delivery (Langley *et al*., 2022).

Access to care and dental attendance

Limited home care may mean PLwD need careful assessment and treatment by dental teams. Dental attendance for PLwD living in the community and care homes is consistently found to decline following diagnosis. Studies from several countries higlight factors associated with reduced attendance that are likely to apply to the UK. In particular, Parkinson's-related and mixed dementia, isolated living and rapid progression of dementia restrict dental attendance (Lee *et al*., 2015; Lexomboon *et al*., 2021; Fereshtehnejad *et al*., 2018; Jockusch *et al*., 2021).

The mechanisms behind this decline in attendance are unclear. However, there is merit in considering what factors may prevent people from being motivated or able to receive dental treatment. Two systematic reviews have explored barriers to dental attendance for older people (Göstemeyer *et al*., 2019; Legge *et al*., 2021). Though these are not specific to PLwD, the same barriers may apply or may be compounded by cognitive impairment. Both reviews identified limited service availability and physical access were key barriers. Kc et al. (2021) detailed how barriers to dental care are heavily related to the nature of underlying healthcare systems.

Studies by Legge et al. (2021), Kc et al. (2021) and Curtis et al. (2021) all explore people's views of oral health care over time, informed by their past experiences. Those who have routinely sought dental care throughout their lives may face new barriers related to dementia or age-related comorbidities, whilst irregular attenders may find it even more difficult to access care in later life. Torppa-Saarinen et al. (2019) summarised how such non-regular service use could lead to poor oral health-related quality of life. The impact of barriers to dental attendance, therefore, compounds the existing substantial oral health challenges faced by PLwD.

Prevalence of oral diseases and orofacial pain in dementia

Numerous studies and reviews have explored the oral health of PLwD: these typically compare the dental status of PLwD with age-matched controls. Different studies focus on specific diseases or disease processes. Two systematic reviews (Delwel *et al*., 2017; Foley *et al*., 2017) summarise how oral health is poor for PLwD, with multiple oral diseases being highly prevalent. Delwel et al. (2017) found that PLwD have more teeth with coronal caries (0.1-2.9 vs 0.0-1.0), more teeth with root caries (0.6-4.9 vs 0.3-1.7) and more retained roots (0.2-10 vs, 0.0-1.2). Foley et al. (2017) also identified more carious teeth in general. The studies differ in their conclusions about the number of teeth retained by PLwD: Delwel et al. (2017) did not identify a difference, yet Foley et al. (2017) concluded that PLwD have, on average, 1.52 fewer teeth than people who do not have dementia.

Following the earlier review, Delwel et al. (2018) published a separate narrative review focusing on oral soft tissues. It was unclear whether gingival inflammation, bleeding, or periodontal pocketing were more prevalent for PLwD than age-matched people without dementia. However, the burden of these conditions affecting PLwD is substantial and largely preventable. The studies consistently present a stark picture of poor oral health for PLwD, noting a dose-response with more severe cognitive impairment associated with more and more severe oral disease.

Studies have also explored the prevalence of orofacial pain in PLwD. Delwel et al. (2017) concluded that between 7.4 and 21.7% of PLwD experienced orofacial pain but this did not differ between PLwD and controls. In another study, Delwel et al. (2018) discoved that orofacial pain affected 25.7% of PLwD attending memory clinics but 50.3% had oral diseases that could cause orofacial pain. Orofacial pain affected 21.9% of hospital inpatients with PLwD during function and 11.9% at rest (van de Rijt *et al*., 2018). Pain may have been more common in those less able to self-report due to more severe dementia. Much higher prevalence of orofacial pain was found among care home residents (van de Rijt *et al*., 2019) with 37.8% of those able to self-report and 48.8% of those unable to report had pain.

In summary, PLwD are likely to have fewer teeth, and any teeth retained are more likely to be affected by coronal or root surface caries. There is a substantial burden of oral diseases and orofacial pain for PLwD and this burden is greatest in those with the most advanced dementia and possibly greatest in those unable to self-report. Oral diseases are affecting a growing number of PLwD and there are stark health inequalities affecting them.

The impact of poor oral health in dementia

Many studies of oral health in older people have used disease prevalence as a marker of oral health rather than subjective reports of patients' experiences and perceptions. Studies of the impact of oral diseases often consider how oral diseases or orofacial pain impact oral health-related quality of life (OHR-QoL). Many studies explore OHR-QoL for older people, yet only few include PLwD. Van de Rijt et al. (2019) undertook a systematic review which included 53 studies exploring how oral diseases impact OHR-QoL in people aged 65 or above. This study details varied findings about whether dental caries or periodontal disease limit OHR-QoL. However, OHR-QoL was negatively affected in those experiencing orofacial pain. This suggests that asymptomatic dental diseases alone are not a specific issue, but that OHR-QoL is reduced once symptoms arise.

Separate studies have investigated whether dementia directly impacts OHR-QoL. A surprising finding is that Zuluaga et al. (2012) found mild cognitive impairment (MCI) was associated with better OHR-QoL than those with normal cognition. In contrast, Lee et al. (2013) explored a similar association for individuals. They found that compared to controls, OHR-QoL is worse in community-dwelling people with MCI and worsens in mild dementia. Zenthöfer et al. (2014) and Klotz et al. (2017) also found poor OHR-QoL in care home residents, but noted it was not necessarily worse for those with dementia than those without.

The reasons for the varied findings may reflect different classifications of cognitive impairment and dementia and different health and social care systems. It should be noted that none of these studies specifically investigated OHR-QoL among people with moderate or advanced dementia. Only one study has reported the effects of oral conditions among people with advanced dementia, including those lacking capacity to consent to research (Van de Rijt *et al*., 2021). Oral function and nutritional status were worse in those with dementia than in those without. Unfortunately, self-reports of OHR-QoL were precluded for those with advanced dementia, so that despite their inclusion in the study, the subjective impacts on people with advanced dementia remains unknown and remains a complex area needing further research.

Implications.

The nature and impact of poor oral health for PLwD has been summarised comprehensively in numerous studies, as has the nature of dental attendance for this patient group. The combination of poor oral health and restricted dental attendance paints a concerning picture for the oral health and well-being of PLwD. As the number of people living with dementia and later-stage dementia increases, those seeking care are likely to have more advanced dementia symptoms and more substantial oral health problems. The complexities of treatment for PLwD increase as dementia progresses (Geddis-Regan *et al*., 2020; Curl *et al*., 2022), meaning treatment risk and the volume of required resources may increase. Some PLwD may need sedation or anaesthesia to deliver treatment, with the attendant risks and potential long-term impacts on the health of PLwD, meaning they should be considered cautiously. (White *et al*., 2019; Geddis-Regan *et al*., 2022).

Through considering the broad literature in this area, several recommendations can be made:

Access to comprehensive preventative dental care should be prioritised for PLwD in the community and those living in care homes.

Delivery of the National Guideline NG48 (National Institute for Health and Care Excellence, 2016) is essential. Targeting resources toward preventative oral care, particularly for care home residents, should prevent oral disease (Davies and Doshi, 2022) and subsequently reduce the adverse treatment requirements and impact of oral diseases and orofacial pain on quality of life of PLwD (Torppa-Saarinen *et al*., 2019). DCPs can play a vital role in preventative care and should be able to work within their scope of practice with PLwD, including direct access provision of preventative care.

Dental attendance should be encouraged and supported for people diagnosed with dementia.

Doing so can allow early identification of dental diseases or presentations with the potential to cause pain before they adversely impact OHR-QoL. Attendance could maximise the opportunity for preventative care, so reducing the need for specialist care or sedation/anaesthesia to facilitate treatment.

Dental services must be commissioned and available for older adults, including PLwD.

To address oral health problems and their impact on PLwD, there must be accessible and affordable services. The disease burden affecting PLwD cannot be ignored in a health system that continues to offer publicly-funded healthcare.

Barriers to care should be reduced, including through innovations in domiciliary provision.

Limited transport and physical access to dental services are key barriers to dental care and could be addressed if basic assessments and non-invasive care were provided in residential settings. Eighty per cent of care home residents have dementia (Prince *et al*., 2014), and utilisation of domiciliary care is not associated with either age or deprivation, even though these factors are associated with oral healthcare needs (Geddis-Regan and O'Connor, 2018). Commissioning and facilitating domiciliary care may allow more basic dental care for more patients, enabling more of those requiring complex treatment to be seen in specialist settings.

An appropriately trained dental workforce must be planned to address the current and anticipated needs of PLwD.

Changing demographics mean dentists and DCPs in all settings will need education on oral health care for patients with complex needs (Inglehart *et al*., 2022). The care required by many PLwD will fall within the remit of general dental practitioners and the NHS GDS contract (NHS England, 2015). To support the care of those with more advanced diseases or dementia symptoms, the dental

workforce will need dentists additional relevant skills (Inglehart *et al*., 2022; Clayton, 2022). Specialist-level care is not required for every person with complex needs (NHS England, 2015). However, it is paramount there are adequate clinicians with additional skills, particularly in Special Care Dentistry, which will in turn require greater training capacity (Woolley and Lau, 2021). Restorative dentists will also need to care for those with complex treatment needs who can attend for and accept it (Clayton, 2022).

Shared Decision-Making

PLwD will have their own perspectives about the treatment they receive. They should therefore be actively involved in treatment discussions where possible (National Institute for Health and Care Excellence, 2021) to ensure that their best interests are considered comprehensively if or when they lack the capacity to consent (National Institute for Health and Care Excellence, 2018). People transition from independent decision-making to situations where decisions are made on their behalf (Lahey and Elwyn, 2020), yet insight on a person's views and their preferences for treatment may be sought from their family members to guide decisions. Where shared or best interests decision-making processes apply to specific situations, they should consider the individual and the approach they would wish for treatment. Doing so can ensure that limited resources are used only for those who desire and can benefit from treatment. Dentists should be comfortable not delivering care to those who decline it, or for whom treatment could harm their overall wellbeing.

Summary

Older people, particularly those living with dementia, are at substantial risk of oral diseases, orofacial pain, and their adverse impacts. Barriers to effective oral hygiene and services are substantial and mean that PLwD are less likely to receive necessary care. Stark health inequalities could be exacerbated if population trends in age and dementia prevalence continue to increase in a health system that is seen as inaccessible. Whilst prevention of diseases is desirable, accessible services, including domiciliary dental services, must be commissioned to meet the needs of this population now and in the future. Domiciliary and clinic-based care, from both general and specialist services, will have a role in supporting different patients. The overall UK workforce will require a range of skills, including preventative care for PLwD, the use of pharmacological aids where needed, and training in supporting patients with decision-making. Dental care remains rooted in a biomedical model (McGrath *et al*., 2022) despite the numerous psychosocial impacts of dental diseases and how each person views oral health differently. Re-designing health services and targeting resources at this high-need group should mitigate some of the major challenges PLwD may encounter. This should allow oral diseases and orofacial pain to be managed appropriately by suitably trained staff with necessary time and resources.

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