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Oral health experiences of people living with Parkinson's disease: a scoping review

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Key points

Highlights the increasing prevalence of Parkinson's disease in the population and the potential public health challenge it represents.	Describes current published literature on oral health in Parkinson's.	Suggests further work is needed to explore and co-design research projects, to understand the experiences of people living with Parkinson's and interventions to support oral health.

Abstract

Background and aim Parkinson's disease is the fastest growing and second most common progressive neurodegenerative condition in the UK; poised to represent a major societal and health care challenge. The scoping review aims to provide an overview of the literature on the oral health (OH) experiences of people living with Parkinson's, identifying current research gaps and future priorities.

Method Search strategies included three electronic databases, two grey literature databases, relevant organisations, specialist journals and hand searching of the reference lists. A data extraction tool was developed and piloted.

Results A total of 121 items were included in the review. Four themes were identified: OH impact, education and training, service delivery and wider impacts of OH for people with Parkinson's (PwP). The majority of studies included were cross-sectional in design, describing the OH status of PwP.

Conclusion The majority of research to date has focused on OH impact. Areas for future research include use of qualitative studies exploring the experiences, attitudes and priorities of PwP and their care partners. Inclusion of medical, dental and allied health care professionals, together with people with lived experience, is required to develop, implement and evaluate interventions to support OH.

Introduction

The Global Burden of Disease study identified Parkinson's disease (PD) as the fastest growing neurological disorder worldwide.[1] PD is the second most common progressive neurodegenerative condition in the UK,[2] and although age is a primary risk factor,[1] many people under the age of 50 develop PD.[3]

Non-motor symptoms (NMS) include cognitive impairment, sensory changes and depression.[4] Xerostomia, orofacial pain, altered taste and burning mouth are commonly identified.[5] NMS remains relatively underappreciated, which is concerning when data suggest total NMS burden is a major quality of life determinant.[5]

Oral health (OH) is not always prioritised within PD management, as focus is generally given to more immediate high-priority areas, including dementia and motor dysfunction.[6] However, progressive loss of fine motor control, reduced manual dexterity and tremor impair the ability to carry out day-to-day oral care and access dental appointments. Dysphagia and involuntary movements of the orofacial region impair the ability to receive dental treatment.

PD is poised to represent a major societal and health care challenge. However, currently, little is known about person-reported experiences of OH[7] or factors associated with oral health-related quality of life (OHRQoL) in PD.[8] This scoping review aimed to examine the evidence on OH experiences of people with Parkinson's (PwP), identify research gaps and make recommendations for future research.

Methods

Information sources and search

The six-stage scoping review framework by Arksey and O'Malley[9] was used (Supplementary File 1). The search included the electronic databases Medline via Ovid, Web of Science and Scopus, and grey literature databases Overton and Ethos. The search was limited to articles in the English language. The time frame included publications up to 31 December 2022, with no start date specified. The search terms 'parkinson*' AND ('oral health' OR 'oral hygiene' OR 'dent*') were used (Supplementary File 2).

Reference lists and table of contents of specific journals including the *Journal of Disability and Oral Health* were reviewed. Websites consulted included Parkinson's UK,[10] Parkinson's Care and Support UK,[11] Parkinson's Europe[12] and National Institute for Health and Care Excellence.[13]

Papers were processed in Zotero and duplicates removed (JT). A data extraction tool was designed to extract initial themes and piloted (JT, SRB) on ten articles to aid

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Fig. 1 A flowchart of the literature search

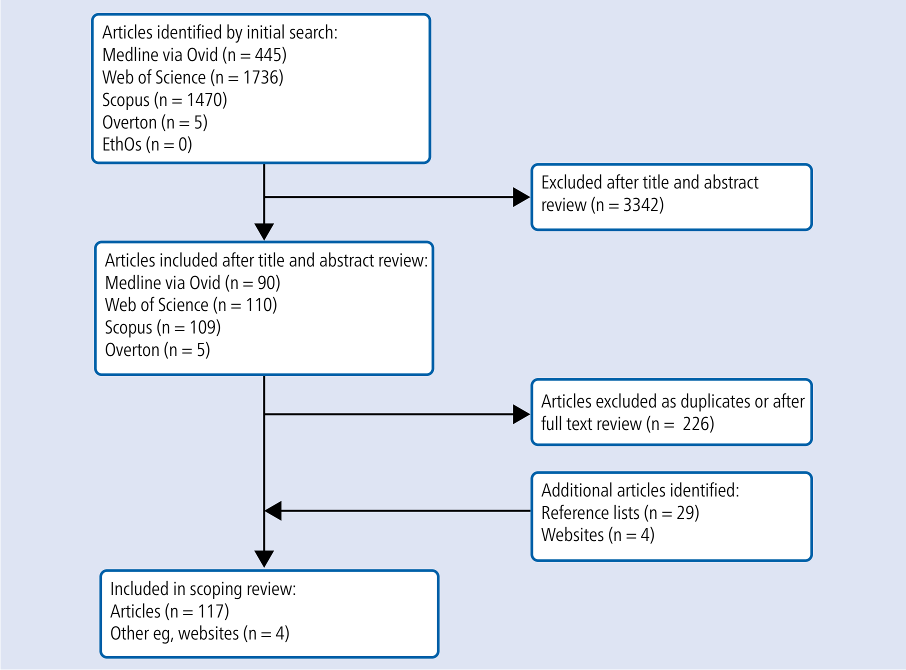

Table 1 Four themes identified within the existing literature on oral health experiences of people with Parkinson's

Oral health impacts	Education and training	Service delivery	Wider impacts of oral health for Parkinson's
• Orofacial function • OHRQoL • Dental status • Xerostomia • Sialorrhoea • Dysphagia • Temporomandibular dysfunction • Bruxism • Burning mouth syndrome • Halitosis • Smell/taste alteration • Orofacial pain • Ability to carry out oral hygiene practice • Soft tissue conditions • Awareness of changes	• Interprofessional education • Educational resources	• Access • Barriers/facilitators • Cost • Anxiety attending for/receiving treatment • Utilising the wider dental team • Co-ordination of care • Prevention • Multidisciplinary working • Ability to accept dental treatment • Rehabilitative dentistry, for example, implants	• Reduced awareness of changes • Impaired nutrition, ability to eat and weight loss • Aspiration risks and risks of chest infection • Exacerbation of chronic disease • Reliance on care partner(s) • Challenges performing oral hygiene behaviours

consistency and agreement. Initial themes were discussed and refined by the authors (for example, quality of life, dental status, education) and additional themes identified were added (for example, participant involvement) before extracting data (Supplementary Files 1 and 3). These were refined into four key themes after further discussion once extraction was complete. Quality assessment does not form part of the scoping review remit[9] and was not used.

The final stage of the scoping review included a consultation phase to aid in triangulation of themes, provide further insights and prioritise future research. Stakeholders included two general dental practitioners, one dental hygienist, nine PwP and three informal carers of PwP, with discussions held virtually and through email follow-up (Supplementary File 1).

Results

The electronic search of the databases identified 3,656 articles, of which 3,342 were excluded after title and abstract review. A further 226 papers were excluded as duplicates or after full-text review. An additional 33 papers were identified through searching of reference lists and relevant organisation websites. After full-text screening, 121 sources were included (Fig. 1).

Study characteristics

Of the 117 articles, 53 were cross-sectional studies and 33 were review articles or opinion pieces. Articles were from a range of countries, including the USA (n = 21), Brazil (n = 12), UK (n = 12) and The Netherlands (n = 11) (Supplementary File 4). In addition, four patient information items were identified from Parkinson's organisation websites.

Study themes

Four key themes were identified within the literature: OH impacts of PD; education and training; service delivery; and wider impacts of OH for PD (Table 1).

Oral health impacts

The sources describe the adverse impacts of PD on OH and ability to perform OH behaviours. The majority of studies were cross-sectional, with three systematic reviews examining OH, drooling and quality of YouTube videos on maintaining OH.

Dental status and soft tissue conditions

In total, 14 studies described dental status, which generally appeared to be poorer in PwP.[14,15] Studies indicate that PwP have greater prevalence of periodontal disease, with deeper pocketing,[14,16,17] tooth mobility[15,17,18] and tooth loss.[19] However, others found that although more PwP reported presence of tooth mobility, there was no significant difference between PwP (n = 74) and sex-matched controls (n = 74).[18] The relationship between untreated caries and PD was found to be inconclusive, with some studies finding higher rates,[20,21] while others found similar or lower rates compared to matched and unmatched controls.[22,23,24]

Presence of poorly fitting dentures were identified on clinical examination,[20,25,26] along with denture-related stomatitis, ulcers[20] and other mucosal lesions.[26] However, one study in Brazil identified more denture defects in unmatched controls (n = 20), despite more negative perceptions from PwP towards their prostheses (n = 17).[22]

Orofacial function

In total, 16 studies looked at different aspects of orofacial function. PwP appeared to have reduced biting force,[27] more problems chewing[18,28] and reduced range of orofacial movement, including jaw opening.[23,29] Significant associations were found between masticatory efficiency and duration of removable prosthesis use in PwP,[30] although no association was found between masticatory efficiency and PD severity.

The ability to manipulate and recognise objects in the mouth (stereognostic ability) was assessed in two studies. The improvement of this through the presence of a prosthesis was inconclusive, with studies showing contradictory results.[25,31] There was a strong association of dysarthria, dysphagia and sialorrhoea occurring together, with increasing prevalence in the more advanced stages.[32]

Two randomised controlled trials (RCTs) reported on interventions to improve orofacial function, focusing on chewing ability[33] and improving facial expression, respectively.[34] Chewing time was significantly improved at up to four months using a standardised exercise programme, improving unassisted maximum jaw opening.[33] DVD-based rehabilitation intervention for facial expression showed no significant improvement.[34]

Oral hygiene-related practices

No studies specifically examined the ability to carry out oral hygiene behaviours, although PwP reported challenges with performing OH behaviours.[20] Significant differences in daily brushing were found between PwP (n = 31) and unmatched controls (n = 104).[24] Significant differences in plaque accumulation were identified between PwP and matched controls, despite no self-reported difference in daily oral hygiene behaviours.[35]

A significant decline in oral hygiene practices has been found with increasing disease severity and motor impairment,[36] although there is conflicting evidence on the self-reported difficulties with toothbrushing by PwP.[37] Self-reported difficulties with toothbrushing appeared to depend on the extent of dyskinesia.[23] More PwP (n = 74) report daily support with oral hygiene by voluntary or professional care providers (15%).[18] There is conflicting evidence on electric toothbrush use[14,38] and indications that few PwP use additional or adapted devices.[37] PwP may be uncomfortable with mouth rinses for fear of choking.[17] Self-reported interdental cleaning was found to be lower in PwP.[16,35]

Non-motor symptoms

Non-motor symptoms commonly identified in PD include sialorrhoea (drooling), xerostomia and sensory changes. Drooling is reported in up to 74% of PwP, although its impact on daily and social functioning may only be mildly or moderately concerning.[39] Significant increases in severity and prevalence were associated with advancing disease stage and duration.[40] Although drooling may develop later than other OH symptoms, individuals with more orofacial changes at baseline examination, may progress faster to the more advanced stages of PD.[41] Self-reported drooling was significantly reduced in a RCT aiming to improve orofacial function.[8]

Seven studies assessed the presence of xerostomia,[20,42] which may be related to use of medications including L-Dopa and disease progression.[43] An awareness of the links between drooling or xerostomia and PD was mixed in PwP,[42,44] with few reporting it to their physicians.[44] PwP report minimal support being offered by dental teams on this topic.[42]

Two studies of smell and taste impairment showed contradicting results.[45,46] In one, PwP did not report any perceived changes in taste;[45] in the other, sweet perception was the most conserved taste quality.[46] No significant preference for sweeter foods has been identified in PwP compared to unmatched controls,[24] despite reported increased consumption of sweeter foods by PwP.[35]

Subjective halitosis was reported more frequently by PwP (n = 26), although this was not found to be significant versus matched controls (n = 26), with 40% PwP reporting they had been told they had bad breath.[47]

Dysphagia

Three studies focused on dysphagia. Swallowing difficulties were found to be significantly different between PwP and age-matched controls.[30] In addition, swallowing-related quality of life was found to be significantly associated with dysphagia symptoms and depression scores.[48] No significant relationship was found with duration of PD.[48]

Facial pain, temporomandibular joint dysfunction and bruxism

PwP may demonstrate increased risk of developing temporomandibular disorder (TMD),[49] with a prevalence of up to 20.3% (n = 12) in PD.[50] Fewer asymptomatic individuals were found with PD (45%) and increased symptom severity was identified,[38] with presence of pain, clicks and crepitus being significantly increased in PwP.[51] One analysis found no significant relationship between TMD symptoms and PD severity.[51] However, a significant relationship was found between TMD present and OH impact in PwP.[50]

Bruxism is inconsistently reported in PwP. Presence of awake and sleep bruxism was found in less than 50% of PwP, with no association with medication.[52] The same authors found significantly more bruxism self-reported by PwP and significantly more pain.[53]

One UK-based cross-sectional survey (n = 1,916) explored the prevalence of self-reported orofacial pain in PD (7.3%), finding it to be comparable to the general population.[54]

Two studies reported the prevalence of burning mouth syndrome in PD. One identified a lower prevalence (4%)[55] and one identified a higher prevalence (24%), exceeding that of the general population.[56] In this study, none of the PwP reported presence of burning mouth syndrome before their PD diagnosis.[56]

Oral health-related quality of life

A total of 31 studies assessed OHRQoL, using validated measures such as the Oral Health Impact Profile-14 (OHIP-14), OHIP-49,[27] Dental Impact on Daily Living Assessment (DIDL)[57] and General Oral Health Assessment Index (GOHAI).[22] The impact of PD on and the relationship between clinical severity and OHRQoL appeared mixed in comparison to the general population or control groups where used.

Differences in the perceptions of PwP on their OH compared to the clinical picture on examination were identified. Often, PwP were found to have a reduced awareness of the decline of their OH. Despite no self-reported differences in daily toothbrushing, significant differences in plaque accumulation were identified in PwP compared to matched controls.[35] A single RCT of 29 participants aiming to improve OH and orofacial function found no significant improvement in OHIP-14 scores at two months.[8,33]

One study looked at the OHRQoL of caregivers (n = 80) of PwP, with the majority identifying as formal caregivers.[58] The average OHIP-14 score indicated a low impact of PD on OHRQoL for both formal and informal caregivers.[58] Caregivers who were related to patients (for example, spouse) were more negatively impacted on both OHRQoL and general health.[58]

Education and training

Four studies examined education and training interventions to improve aspects of the OH impacts associated with PD; two points were highlighted, which were interprofessional collaboration and supporting OH.

Interprofessional collaboration

A piloted interprofessional learning programme helped to improve participant knowledge of the importance of OH.[59] Educational interventions increased interest in interprofessional collaboration, helping to see where dentistry fits into the management of PwP.[60]

The Parkinson's UK website details the professionals to be expected in the PD multi-disciplinary team (MDT) and does not include dentists, although there was reference to referral to special care dentists.[10] Parkinson's Europe referenced both dentists and dental hygienists as professionals able to support OH.[12] Parkinson's Europe referenced speech and language therapists as being able to assist with improved denture control.[12]

Interventions to support oral health

The importance of supporting OH and maintaining self-care has been recognised.[61] Improved denture hygiene was achieved in PwP through verbal instruction and positive reinforcement.[62] An RCT including individualised oral hygiene programmes containing advice, counselling and instruction showed significant reductions in oral debris at two months and maintained at four months.[33] One non-randomised educational intervention for PwP included a session from a dental hygienist discussing OH, xerostomia and drooling which found no significant improvement in OHRQoL.[63]

There has been development of OH guidelines for PwP and their caregivers.[64] Those diagnosed with PD for longer found the guidelines were more helpful and applicable, whereas those more recently diagnosed thought OH was more important than those diagnosed for longer. Caregivers had a more positive overall view of the guidelines than PwP.[64]

Parkinson's UK and Parkinson's Europe provide information on maintaining OH.[10,12] Parkinson's Care Support UK provides information on exercises to improve facial expression[65] and speech therapy.[66] A systematic review analysing quality of OH education videos on YouTube found that university-produced materials were of higher quality.[67]

Service delivery

Service delivery was commonly discussed in review articles (Table 1), with authors commenting on the need for dentistry to be included within the MDT, allowing a more seamless approach to patient management.[68,69] The common message was the need for interprofessional working[6,70] and providing reasonable adjustments to support PwP in accessing and receiving dental care.[47,49,50]

The articles suggest that clinical guidelines include information on timing and length of dental appointments, collaboration between medical and dental professionals, referrals to speech and language therapists and minimising risk of aspiration during treatment.[64] It was recognised that the dental team, including dental nurses, hygienists and therapists, have roles to play in supporting the OH of PwP.[63,68,71] One survey sought information from dental professionals on their experiences of managing PwP, showing dentists felt there were no significant barriers in managing PwP and that barriers were likely experienced more by patients.[72]

With regard to specific dental treatments, the provision of implants was discussed in four articles and one cross-sectional study. In an observational study of nine PwP, implants appeared to improve chewing function and quality of life after three months, which was maintained up to 12 months.[57] One review discussed several cases which demonstrated successful implant placement for up to eight years.[73] Early failure of implants was noted in this review, with fractures of prostheses and oral hygiene concerns cited.[73] However, a review of the effectiveness of implants concluded survival appeared to be worse in people with neurodegenerative conditions.[74]

Wider impacts of oral health for PD

Identified throughout a number of papers were the wider impacts of OH for PwP. One non-randomised study found tooth absence was a contributing factor in failure of exercise-based interventions to improve swallowing.[75] Dental health was examined as an influencing factor in a cohort study of weight losing adults with PD.[76] Increased numbers of missing teeth have been associated with increasing difficulty eating and speaking in one cross-sectional study (n = 28).[16]

A cohort study found dental clinical visits, dental care and toothbrushing frequency were associated with reduced risk of developing PD.[77] Regular dental scaling appeared to reduce the risk of PD development based on data from a case control study.[78] A secondary analysis revealed a positive relationship between missing teeth and blood pressure in PwP, although age was identified as a confounding factor.[19]

Box 1 Gaps identified within existing literature relating to the oral health experiences of people living with Parkinson's

- Qualitative research about the experiences, attitudes and priorities of PwP and their care partners about mouth care
- Qualitative research with dental and other professionals regarding OH improvement for PwP.
- Co-designed interventions to support mouth care with PwP and their care partners.

Some studies included additional quality of life measures, including 36-item Short Form Survey (SF-36),[38,58] Parkinson's Disease Questionnaire (PDQ-8)[16] and PDQ-39.[32] Significantly higher scores on the Hamilton Depression Rating Scale[79] were found in those experiencing drooling. Dysarthria was associated with significantly higher PDQ-39 scores and Hospital Anxiety and Depression Scale, with drooling and dysphagia significantly increasing scores on PDQ-39, representing worse health-related quality of life.[32]

Participant involvement within research

As part of the scoping review, the involvement of PwP within research studies was assessed to identify whether they were seen as either subjects of research or as active participants within the process (for the full details see Supplementary File 5). Of the 117 studies, none included the active involvement of participants, with PwP perspectives included from the outset, or involvement in project design, conduct or the inclusion of qualitative methods. A total of 27 studies appeared to view participants as objects of study to be examined and measured without consultation. Participants were viewed as subjects of research in 53 studies through the completion of self-reporting structured questionnaires and rating scales.

Gaps within the research

From the findings of the scoping review, gaps in the research were identified by the research team, which were then discussed with stakeholder groups. A summary can be seen in Box 1.

Stakeholder consultation

The findings of the scoping review and gaps identified in the literature were discussed with stakeholders. PwP thought that for them, something to raise awareness of the importance of OH to 'get ahead of the game' would be useful. They often cited a lack of appropriate information available on OH, limited contextualisation or tailoring to their circumstances, poor timing and accessibility. Few were aware of the OH information identified on key websites, such as Parkinson's UK. Their perspective was that currently available information was too generic. They stated they would be happy to receive OH information from any member of the health care or dental team.

The patient stakeholders supported the idea that future research should be more inclusive of PwP and develop collaborations between health care professionals. It was important for them to be treated as equals within this process and to be supported by someone with an interest in them and their situation. A good outcome voiced by many would be to retain their teeth and reduce their treatment need.

The stakeholders identified additional gaps, including:

- Inclusion of those in nursing home and hospital settings
- Inclusion of PD nurse specialist perspectives and other partners in care
- Identifying OH impacts on PD progression and other general health outcomes.

In summary, the stakeholder consultation – the final stage of the scoping review – supported the findings and in addition, provided valuable insights from PwP to inform the future research agenda.

Discussion

This scoping review summarised the current literature on the OH experiences of people with PD and identified potential areas for future research. Studies to date indicate that poorer OH exists for PwP compared to the general population. Most studies were cross-sectional or opinion or review articles. Studies primarily focused on the presence of dental disease and included only small sample sizes and were published outside the UK. There was an absence of longitudinal observational studies and limited intervention studies on OH. Where control groups were used, these were often recruited from dental outpatient clinics with age and sex matching or utilised caregivers and family members. There were no studies focused on exploring the priorities, attitudes, or experiences around OH of either PwP, carers or medical and allied health care professionals.

The main strengths of this review include the use of a broad search strategy and inclusion of a consultation stage, which added valuable insights unavailable from the published evidence alone. The review was limited by the exclusion of non-English language articles. The use of a modified scoping review method and only one researcher conducting the data extraction were other limitations.

The key findings from the scoping review suggest a need to better understand how to maintain OH and the broader benefits of this, as well as a need to engage with wider health and social care teams. Further research is important given that PD is a growing population group and will be seen with increasing frequency in dental practice. It is important to remember that declines in OH are not inevitable and therefore it is essential to understand the key challenges of this group and strategies to prevent or mitigate these.

The findings from the consultation phase suggested a number of priorities which fit within the current NHS strategy to provide personalised care, supporting people to age well.[80] Undertaking qualitative research with these groups will help us to understand their perspectives and experiences. There is a need for earlier stage involvement and use of co-production with stakeholders in future research processes.[81] This will allow improved sharing of knowledge and ideas and the building of beneficial relationships to develop research with those participants who may be most affected and leading to improved outcomes.[82,83]

At present, there have been no UK studies exploring the perspectives of dentists and dental care professionals or members of the PD MDT about the role of OH within PD care pathways. Collaborative research could help to identify the possibilities of multidisciplinary interventions, supporting maintenance of OH and delivery of more holistic care.[84,85]

Finally, there is a need for more research on OH (including OHRQoL impacts) and links with systemic health, rather than just on the impacts on dental status.[86] In addition, more co-designed, prospective studies are needed to identify which interventions would best support improvements and maintenance of OH in this group.[81,87]

Conclusion

To date, the majority of evidence about OH and PD focuses on describing dental status and implications for dental management. There has been little research on OH interventions and little involvement of PwP in studies or research with dental and health and social care professionals. The scoping review has added to the existing knowledge by summarising the literature to date, and alongside key stakeholders, identified future research priorities.

Ethics declaration

The authors declare no conflicts of interest. Ethical approval was not required as this was a review of electronic databases. Key stakeholders consulted during the course of this review whose input is presented within the review are not considered to be participants or subjects of research, rather the informants of future research questions. All stakeholders gave consent to participate in the consultation stages.

Data availability

The authors confirm that the data supporting the findings of this study are available within the article and its supplementary materials. The corresponding author may be contacted for further details if required.

Author contributions

The idea for the review was conceived by J.E.T, Z.M and S.R.B and they designed the review together. J.E.T completed the data collection, analysis and prepared the final manuscript for submission. Z.M contributed to the analysis and synthesis and revised the manuscript before submission. S.R.B ensured consistency of data collection and contributed to the analysis and synthesis of the data and revised the manuscript before submission.

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