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"If you don't sort out these problems, you end up building problems": a qualitative study exploring mouthcare at home with people with Parkinson's and their partners in care

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ABSTRACT

Purpose: To explore the experiences of people with Parkinson's (PwP) and their partners in care, of performing mouthcare activities at home.

Methods: This qualitative study used semi-structured interviews, conducted with 20 individuals: 13 people with Parkinson's and 7 partners in care. The interviews were adapted to ensure inclusivity of participants experiencing the different symptoms of Parkinson's. Data was analysed inductively using a reflexive thematic analysis approach.

Results: Three themes were identified: maintaining normality, familiar and unexpected problems, and negotiating help. Motor and non-motor barriers to performing mouthcare at home included reduced dexterity, fatigue, apathy, and the practical challenges of accessing the bathroom and finding the time and focus to perform the activity. Participants had developed small adaptations and strategies to help manage these challenges. Oral health was considered a personal, not often talked about activity, creating a dilemma for partners in care who could see that support was needed but were uncertain how and when to offer it.

Conclusion: Findings of this study highlight a variety of challenges experienced by PwP in performing mouthcare at home. A proactive, multidisciplinary approach providing earlier information and tailored practical support will be beneficial in supporting PwP to maintain their oral health at home.

IMPLICATIONS FOR REHABILITATION

- Rehabilitation professionals working with people with Parkinson's should routinely consider oral health as part of broader self-care assessment, recognising that motor and non-motor symptoms can significantly impact the ability to perform mouthcare at home.
- Rehabilitation professionals and members of the Parkinson's multidisciplinary team are well placed to suggest practical adaptations to support people with Parkinson's to maintain their oral health independently for longer.
- Consider the role of partners in care, supporting them to navigate conversations about oral health in a way that respects the dignity and independence of the person they are supporting.
- Consider other options for supporting mouthcare without defaulting to direct provision of toothbrushing.

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Parkinson's; oral health; mouthcare; toothbrushing; qualitative research; oral hygiene

Background

Parkinson's has been identified as the fastest growing neurological disorder globally [1], with around 153,000 people currently diagnosed. However, this figure is likely to be an underestimate, given the long timescales involved in diagnosis [2], as well as concerns of underdiagnosis across groups including younger people [3], women [4], older people [5] and ethnic minority communities [6].

Parkinson's is a complex, multisystem condition characterised by both motor and non-motor symptoms (NMS) [7]. Motor symptoms include slowed movement, tremor, muscle stiffness and rigidity [8]. Of

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relevance to oral health, motor impairment reduces upper limb function and fine motor skills, affecting manual dexterity and the ability to perform daily oral health behaviours (mouthcare). Almost a third of people with Parkinson's (PwP) have reported difficulties performing mouthcare [9], with some reporting requiring assistance with brushing teeth and dentures [10].

NMS with direct implications for oral health include xerostomia, orofacial pain, altered taste and burning mouth [11]. The pharmacological management of Parkinson's further compounds these challenges: multiple medications are commonly required and are associated with a range of oral side effects, including xerostomia [12]. Reduction in saliva production increases the risk of dental plaque accumulation, dental decay, advanced gum disease, opportunistic infections, and difficulties tolerating dentures.

Existing evidence suggests that PwP are more likely to experience dental problems including dental decay and gum disease, leading to tooth loss, infection and pain [13]. Research points to increasing prevalence and severity of dental disease with advancing Parkinson's symptoms [14], with associations between increased tremor and rigidity, and increased plaque accumulation and gum disease [15]. The advanced stages of Parkinson's can create significant challenges for dental care provision, requiring substantial adjustments to treatment approaches and in some cases, requires specialist input [16,17].

Oral health is increasingly recognised as a key component of systemic health [18]. Poor oral health has been linked to increased risks of aspiration pneumonia, particularly in combination with dysphagia, which is itself frequently present in Parkinson's [19]. Developing aspiration pneumonia is estimated to be up to three times more common in PwP, with a 10% hospital mortality rate [19]. Improvements in oral health have been shown to reduce the risk of aspiration pneumonia [20].

Beyond clinical outcomes, declining oral health can significantly influence individual's quality of life, leading to experiences of pain, difficulty eating and speaking, and social isolation [21]. Oral health-related quality of life (OHRQoL) encompasses these factors, such as comfort when eating, sleeping, social interactions, self-esteem, satisfaction with overall oral health [22], and influencing individual's broader perceptions of their wellbeing [23]. Studies have demonstrated negative impacts on OHRQoL for PwP [13,24]. Parkinson's is already recognised as being associated with substantial impacts on quality of life and wellbeing [25], with PwP reporting experiences of stigma and prejudice [26]. Poor oral health by further affecting appearance, speech, social confidence and interpersonal interaction, may potentially exacerbate this.

There is limited discussion within the literature of the preventative support that PwP may be receiving, or of how contextual factors including the home environment, availability of support, and daily routines shaped by motor and NMS, influence the maintenance of oral health. There remains a gap in the research exploring how PwP can be supported at home to maintain oral health. This is particularly significant given that oral health is largely determined by consistent daily self-care behaviours that may be disrupted by Parkinson's symptoms.

To date, qualitative evidence exploring PwP's lived experiences of maintaining oral health at home remains limited [27]. Therefore, the aim of this study was to explore the experiences of PwP and their partners in care of performing mouthcare at home. The findings will inform the development of an intervention targeting modifiable barriers to performing oral health behaviours, supporting PwP to maintain oral health at home.

Methods

This study adopted a semi-structured qualitative approach, which allowed for flexibility in both questions and answers. Qualitative methods are appropriate for research in fields where little is known about the topic concerned [28], and for research focussing on understanding the experiences of potentially vulnerable groups [29].

Recruitment

Participants were recruited through a range of different methods including Patient and Public Involvement (PPI) networks and in-person events, Parkinson's UK, regional support groups, and social media. Inclusion criteria were broad to include adults aged over 18 years, diagnosed with idiopathic Parkinson's, or who

identified as a partner in care (e.g. family, spouse) for someone with Parkinson's. Those diagnosed with drug-induced Parkinsonism, Progressive Supranuclear Palsy, Lewy Body disease and other atypical forms of Parkinson's were excluded as these conditions typically progress faster than idiopathic Parkinson's and are less responsive to Levodopa medication. Individuals with an unconfirmed diagnosis or who lacked capacity and were unable to consent to participation, were also excluded.

Potential participants were provided with digital copies of the participant information leaflet, consent form, and the opportunity for an introductory discussion. The purpose of this was to discuss the project, consent procedures, answer questions and arrange the interview. For those unable to access documents online, a telephone number was provided and the option of posting paper copies of these documents.

Sampling

Potential participants were asked screening questions to gain a better understanding of their Parkinson's history and how it had affected them. To meet the study objectives, purposive sampling ensured that participants were included who represented the different stages of Parkinson's. This included those who were more recently diagnosed, through to those who had been living with the condition for some time. To ensure data adequacy, this study considered the broader aim of exploring 'oral health behaviours', and identifying barriers and enablers in performing these, the sample specificity i.e., PwP, quality of the dialogue, and experience of the researcher (JT) with the subject matter. Ongoing reflection and review of the data collected, and the information power provided continued to influence impressions of the required sample size throughout the study. A sampling matrix including gender, age, and time since diagnosis was developed to monitor and guide recruitment, and was applied to help address potential gaps in the study sample (Supplemental file 1). Baseline characteristics of participants can be seen in Table 1.

Setting

Parkinson's symptoms may make participating in conventional interviews challenging. Using different methods to involve people or a combination of such, can support inclusion in research [29]. Participants were offered options including conducting interviews by telephone call, face to face, online video calls, inviting a nominated individual to be present to support their participation, or asynchronously by email. For those where interviews were carried out virtually, resources were developed to support participants unfamiliar with virtual interviewing, guiding them in using the interview platform.

Flexible interview timings were offered including early evenings, to maximise opportunities for participation. In total, twenty individuals took part in 17 interviews, including PwP ($n = 13$) and partners in care

Table 1. Participants involved in the interviews.

Participant number	Person with Parkinson's (PwP/ Partner in care	Gender	Years since formal diagnosis
Participant 1	PwP	F	3
Participant 2	PwP	M	12
Participant 3	PwP (dyad)	M	23
Participant 4	PwP (dyad)	M	11
Participant 5	PwP (dyad)	M	2
Participant 6	PwP	M	>30
Participant 7	PwP	F	5
Participant 8	PwP	F	11
Participant 9	PwP	M	9
Participant 10	PwP	M	19
Participant 11	PwP	F	6
Participant 14	PwP	F	5
Participant 15	PwP	M	1
Participant 18	Partner in care (dyad)	F	na
Participant 19	Partner in care (dyad)	F	na
Participant 20	Partner in care (dyad)	F	na
Participant 21	Partner in care	F	na
Participant 23	Partner in care	F	na
Participant 24	Partner in care	F	na
Participant 27	Partner in care	F	na

($n = 7$). Interviews were conducted in a private, quiet space, *via* video platform ($n = 19$), and face-to-face in a university meeting room ($n = 1$) with further follow-up *via* email ($n = 4$). Three PwP chose to be interviewed as a dyad with their partner in care to support their participation. In dyadic interviews, it was emphasised at the outset that the focus remain on the PwP and their experiences of performing mouthcare, and then the nominated individual's experience in relation to this.

Data collection

Semi-structured interviews were conducted by JT between March 2024 and June 2025. The interviews aimed to explore the lived experiences of PwP and their partners in care in performing mouthcare at home, with the intention that this information would support identification of modifiable barriers to oral health behaviours and inform the development of a future behavioural intervention. Topic guides were developed for PwP and partners in care, drawing on the Theoretical Domains Framework (TDF) [30], which provided a structure for exploring the different factors influencing mouthcare, and exemplar topic guides from comparable studies [31,32]. The guides were refined iteratively through feedback from PPI contributors and ongoing reflection across the interview process (Supplemental file 2).

The interviews lasted on average around 60 min, with some lasting up to 90 min, depending on the participant and the need for breaks. The interviews were recorded using an encrypted digital voice recorder and transcribed by JT or a professional transcription company. Participants were offered a £15 voucher for their time. Care was taken to create a positive experience, maintaining an empathic and sensitive approach throughout. Participants were advised that they could stop the interviews at any time especially in the event of experiencing emotional upset. One participant did experience this and was offered a break and the opportunity to stop the interview, but they did not wish to do so and resumed after a brief pause. No repeat interviews were conducted.

Data analysis

Transcripts were shared for participant review, enabling clarifications and additions, supporting trustworthiness through respondent validation [33]. This stage was important as some participants expressed frustration that they could not be as articulate during the interview as they would like. Word-finding difficulties are commonly identified in neurological conditions such as Parkinson's [34] and having the opportunity to review the transcript and make amendments is valuable in supporting participants to get their views across. One participant made small changes and additional comments to their interview transcript, to better reflect the meaning in what they had said. One participant supplied additional written responses to the interview questions. No participants withdrew from the study.

Data were anonymised and analysed using a reflexive thematic approach structured by the Braun and Clarke six-phase process [35]. The first phase involved JT familiarising herself with the data, reading and re-reading three interview transcripts and recording initial ideas about the codes and themes. JT generated the initial codes which were discussed with ZM after independent review of the same transcripts. After discussion, this process was repeated for a further two interview transcripts until agreement on the initial codes was reached. JT collated the codes into themes which shared the same concept, or which related to the domains of the TDF. Three preliminary themes were constructed from these phases, with regular meetings between JT and ZM (Table 2).

Ongoing review and checking to see if themes worked in relation to the coded extracts and overall data sets was conducted, together with refining of themes, generating definitions and names for each. A final thematic structure was developed through regular discussion and consensus between JT and ZM. In the final phase, the themes and points within these are reported and described in this study, together with extracts to illustrate each. Codes, identified themes and associated extracts from the transcripts were collated and organised using Microsoft Excel. The writing of this report was informed by the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines to enhance transparency [36].

Table 2. Summary of the themes, subthemes, and example coding of the experiences and perceptions of PwP and partners in care, in performing mouthcare at home.

Theme	Subtheme	Codes
Maintaining normality	–	Routine
		Adverse dental experiences
		Masking decline
		Fear of stigma / judgement
Familiar and unexpected problems	Physical influences	Manual dexterity
		Balance
		Slowed movement
		Stooped posture
	Other influences	Fatigue
		Loss of focus / easily distracted
		Apathy
Negotiating help	Strategies	Adapting technique
		Assistive equipment
		Support at home
	The dilemma	Who can help?
		When to help?
		How to help?

Ethical considerations

Ethical approval was granted by the University of Sheffield Research Ethics Committee (Reference: 057175). Given the potentially sensitive nature of exploring oral health within the context of a progressive condition, participants were informed during consent that the topic might evoke emotional responses. Participants showing signs of distress were offered the option to pause, stop the recording, or withdraw, and a debrief was offered following each interview, which was not recorded. Contact details for the Parkinson's UK Helpline were provided to participants who wished to seek further support.

Informed consent was obtained prior to interviews and re-confirmed verbally at the start of each recorded session. JT's clinical background ensured familiarity with assessment of capacity, and in confirming continuing consent throughout the process. Where participants experienced communication difficulties, knowledge of this was established in advance of the interview so that appropriate adjustments could be made, including participants inviting an individual to be present during the interview to support them in getting their views across.

Patient and public involvement (PPI)

Patients, partners in care and public advisors were involved throughout this project, from initial discussions to identification of research priorities, and the development of a larger NIHR-funded research project, to which these findings have contributed. This involved a core advisory group of 8 individuals, who were identified through local and personal networks, and Parkinson's UK. In addition, PPI activities relating to this project were conducted with local Parkinson's support groups and the East London Parkinson's Project.

Specifically, advisors were involved in:

- Development and review of interview guides
- Review of recruitment materials
- Advertising the study
- Identifying potential participants
- Participating in the study (n = 2)
- Review of study themes and subthemes to support analysis (n = 5)

Due to constraints of the current ethics approval and time limitations, advisors were unable to act as co-authors for this report.

Reflexivity

The research team brought together clinical experience of the dental management of PwP (JT) and expertise in qualitative research and dental public health (ZM) (Supplemental file 3). JT's preconceptions

on entering the study included an assumption that oral health might not be a priority for PwP relative to the broader demands of managing their condition, and an anticipation that participants would focus predominantly on lack of access to National Health Service (NHS) dentists during conversations about professional support. These preconceptions were consciously reflected on throughout the research process.

Oral health was not always something participants had actively considered prior to interview. Some expressed uncertainty at the outset about how much they would have to say, or noted afterwards that they had been surprised by how much the topic prompted. They appeared to reflect on and reconsider its importance during the interview. Some participants explained that their motivation to take part in the study came from seeing the topic as unusual or not often considered; itself a meaningful observation on the limited attention given to oral health in Parkinson's care. A further reflection was the extent to which participants did identify oral health as relevant to their self-esteem, confidence and sense of identity.

JT maintained a reflexive journal throughout data collection and analysis to examine how these preconceptions, and the dual identity of being both an interviewer and a dental professional, may have influenced interview conduct and the interpretation of findings. Participants were not made aware of JT's professional background in advance, though some established this through direct questioning; reflections on how this may have shaped responses were recorded.

Results

Three themes were identified in the data: *maintaining normality*, *familiar and unexpected problems*, and *negotiating help*, with associated subthemes (Table 2). Themes and anonymised illustrative quotes were shared with PPI contributors, who felt they strongly reflected their own lived experiences. Contributors emphasised the importance of oral health in relation to appearance, confidence, and self-esteem, and its role in maintaining a sense of control, independence, and identity. They highlighted that small acts of self-care could carry real psychological benefits, that maintaining teeth helped people stay socially active and avoided additional reasons to withdraw.

Maintaining normality

Participants discussed the reasons they wished to maintain their oral health, and why they might want to prioritise carrying out mouthcare at home. For some, looking after their teeth was a routine or habit instilled in childhood, while for others, it was because of painful dental experiences like toothache or an adult tooth extraction.

Maintaining oral health was seen by participants to be a part of maintaining their sense of self. Participants often placed emphasis on the idea of "*looking decent*" (Participant 3), identifying a role for oral health in managing their social identity, facilitating interactions, and avoiding isolation. For many, the mouth acted as a visible sign of their overall health. Having 'good teeth' served as proof to others that they were coping, despite the challenges of Parkinson's. Healthy teeth projected an overall impression of being healthy, masking their declining health:

> Trying to look healthy even if you're not feeling healthy gives an impression to the outside world that you're coping. If people see that your teeth are declining because you got Parkinson's, that's yet another thing that is a minus on your CV. (Participant 6, Male, PwP)

In the context of Parkinson's, where physical symptoms can cause visible changes to movements, behaviours, and communication, maintaining healthy natural teeth became a way to mask or control people's perceptions of the individual. Participants could project an image of "*coping*" (Participant 6) to the world and protect themselves from possible stigma and judgement.

PwP expressed a desire to "*fit in*" (Participant 6), in part driven by their awareness of their own standards that they used to judge other people, and how these might in turn be used by others to judge them. They had noticed that other PwP had "*bad teeth*" (Participant 8) and how interacting with

someone with "*unattractive*" teeth could be unpleasant (Participant 2). They recognised that while Parkinson's might produce different visible changes, having a healthy mouth could support positive interactions:

> Because smiling's hard enough, so you want, you know, on the occasions that you actually manage it, you want to flash a nice pair of gnashers, don't you? (Participant 7, Female, PwP)

Fear of stigma and social isolation was further complicated by sensory changes such as the loss of sense of smell. This created a specific anxiety around the presence of bad breath. Because participants could no longer smell their own breath, this enforced the importance of performing mouthcare and reassure themselves it was less likely to happen:

> Just because we've lost our sense of smell, doesn't mean others have. And we can't smell dog breath - they can. (Participant 1, Female, PwP)

Participants recalled their own responses to individuals in their lives with bad breath and feared experiencing this for themselves, recognising potential social consequences:

> So, if we don't attend to her mouth when she talks, you can't help it. You just tend to hold your breath and it's quite embarrassing. (Participant 21, Female, partner in care)

For these people, looking after the mouth becomes a way to protect their dignity. It ensured that, despite the progression of Parkinson's, they could still present themselves to the world as the person they wished to be.

Familiar and unexpected problems

Participants described the various physical challenges they experienced when performing mouthcare at home. These might directly relate to the act of toothbrushing itself, for example, issues with hand, wrist and arm movements due to stiffness, and difficulty holding and manipulating the toothbrush. Using electric toothbrushes helped to mitigate some dexterity issues, reducing the need for generating repetitive movements and the need to perform as much manual manipulation of the toothbrush:

> As the Parkinson's has progressed, it's become apparent that I can really even only get by doing a proper job with that, the electric toothbrush. (Participant 9, Male, PwP)

The electric toothbrush still came with challenges including the financial implications of buying one, limited battery life, increased weight and difficulty switching it on and off. Sometimes a momentary loss of co-ordination or an involuntary movement would mean the brush missed their teeth, catching or traumatising the gums:

> My hand moves involuntarily. It just goes down the back of my throat, you know, missing my teeth sometimes. (Participant 8, Female, PwP)

> I've been trying to brush, and I've been a bit dyskinetic. And I've actually sort of put my toothbrush across the top of my gums and that's made my gums bleed (Participant 6, Male, PwP)

Physical challenges were not limited to the act of toothbrushing. Altered grip and dexterity could affect the ability to use toothpaste, with participants finding it difficult to get it from the tube and onto their toothbrush:

> He found it difficult squeezing it out of, which actually, it's a little thing you put your toothpaste container in it, and you turn like a key, and that squeezes it up which he's found a lot easier to use as well. (Participant 4, Male, PwP, and Participant 19, Female, partner in care)

These physical challenges associated with mouthcare might not come as a surprise when considering the motor symptoms of a movement disorder such as Parkinson's; the direct impact on the ability to perform mouthcare is a familiar problem for dental teams. However, participants also described how other symptoms – motor and non-motor - could influence their ability to maintain their mouth and teeth at home (the unexpected problems) by impacting the wider context within which these

activities were occurring, making their performance more challenging and therefore, less likely to happen.

Mouthcare was chiefly conducted in the bathroom. Participants described challenges negotiating staircases and getting into the bathroom itself, which could result in mouthcare not being completed. Development of a stooped posture caused discomfort standing at the basin and could mean the individual could not see what they were doing in the bathroom mirror. Issues with strength, fatigue, and balance reduced participant's ability to stand for the required two minutes to brush their teeth, especially with the fear of falling over and risk of injury:

> When his balance is poor, it's very easy to think oh well i'm not going in the bathroom because i'm going to fall over, let's just head straight for the bedroom. And then his teeth don't get brushed at all. (Participant 3, Male, PwP, and Participant 18, Female, partner in care)

Slowed movements meant that things during the day took longer than before, and certain activities could get squeezed out because people simply ran out of time:

> Because I'm slow at most things that I'm doing. I'm just short of time so often and brushing my teeth is one of the regular parts of the day that is put under pressure by a shortage of time. (Participant 10, Male, PwP)

For some, distractions and loss of focus meant it could be forgotten altogether. Mouthcare was increasingly likely to be skipped, and whilst the odd missed toothbrushing episode might not cause immediate problems, over time this can result in developing decay, infection, pain, and a need for invasive dental treatment. For some participants, avoiding this outcome was precisely what motivated them to maintain their oral health, recognising that their Parkinson's symptoms could make receiving dental treatment more complex:

> I'm so fidgety now, being still while somebody jabs around in your mouth with a pointy hook can be quite difficult, so the less I have to have of that done the better. (Participant 9, Male, PwP)

Emotional changes such as apathy could limit the performance of mouthcare. Those experiencing apathy found it harder to motivate themselves to carry out their usual activities of daily living, including mouthcare, which could be even more challenging for those where this had not previously been a priority or where there was no clear mouthcare routine already in place:

> I really have to persuade myself that I do want to clean my teeth or have a shave or whatever. It's a matter of apathy almost I guess. (Participant 2, Male, PwP)

Participants described a gradual accumulation of small challenges, each one perhaps manageable on its own, but building to a point where mouthcare had become genuinely difficult to perform, and on harder days, something that simply did not happen.

Negotiating help

Within this theme, two subthemes were identified: the *strategies* adopted by PwP to manage their mouthcare; the *dilemma* experienced by partners in care on recognising support was needed, and uncertainty about how or when to provide it.

Strategies

One commonly occurring strategy centred around timing the performance of mouthcare with taking medications. Participants often talked about waiting until they were 'ON' and their movement improved, before completing these tasks:

> He chooses a good time, so when he's feeling slightly normal, so he can get up the stairs and he can get into the bathroom. (Participant 27, Female, partner in care)

Some described swapping hands, using their non-dominant and usually lesser affected hand to complete toothbrushing. Swapping to an electric toothbrush appeared to provide significant support or purchasing other aids such as Participant 19 buying a key to support Participant 4 in using their toothpaste.

Others had tried toothpaste pump dispensers, although they had found it difficult to keep the pump standing upright while getting the toothpaste out.

Partners in care found small strategies to support their family members in terms of ensuring they brushed for the required amount of time, and did not become distracted:

> I initiate a conversation to make her brush longer. We talk about family, extended family. We talk about movies […] While talking, I just tend to point out those areas I need her to concentrate on. (Participant 21, Female, partner in care)

Other support at home did not just include physical performance of toothbrushing; denture cleaning, pre-loading toothbrushes with toothpaste, purchasing items, and sharing information or products all helped:

> So, if I sort of see the toothbrush and I'm passing and I think, oh I'll just help, so I put the toothpaste on the toothbrush to make it as simple as possible for him. (Participant 27, Female, partner in care)

Some used specialist equipment, or adaptive aids:

> We've got a thing called a perching stool which the [occupational therapist] has provided us with … I think you could use that to sit on when you are doing your teeth couldn't you? (Participant 3, Male, PwP, and Participant 18, Female, partner in care)

Strategies and adaptations described by participants might be small but could determine whether mouthcare happened or not. As with the accumulation of daily challenges being experienced, small things mattered and could make a significant difference to the ability to complete mouthcare. There was recognition that mouthcare could not always be carried out as they would like:

> I suppose that if I find two minutes was too long, i'd break it down to minutes. Gaps. Do it through the day … it wouldn't really be thorough enough would it, but it would be better than nothing. (Participant 1, Female, PwP)

Participant 1 chose to focus on what was within their control, thinking ahead, making small adaptations and continuing to do their best - an idea that was often mentioned by participants. For others, thinking too far ahead about what might change was not considered helpful as "*things might not get worse, so let's not anticipate what might happen*" (Participant 20). Sometimes, focusing on what is possible today was enough.

The dilemma

Oral health appeared to be something participants did not often talk about, except potentially with close or trusted individuals, and generally when triggered by an event, like an upcoming dental appointment or toothache. Toothbrushing seemed to be considered a private, personal activity. Opinions were divided as to who could, or should, support this:

> There's some things he can do and there's some things he can't do […] I can't see him doing my teeth for me. I think that would be impossible to do someone else's teeth. And I just wouldn't like that. (Participant 7, Female, PwP)

For others, the prospect of a loved one supporting toothbrushing was not ruled out entirely, but still considered to be a last resort:

> I would accept that if he needed to do it. I wouldn't like him to, but I think I'd have to wouldn't I, if they need to be done. (Participant 8, Female, PwP)

There was discomfort from PwP at the prospect of potentially requiring support to perform this normal, everyday activity, and what that might mean. For many, the ability to manage their own personal care including toothbrushing, was closely tied to their sense of independence. Partners in care understood this, even when it complicated their ability to help:

> If he was happy with it, and he said, would I help him, you know, he'd really like that, then that's alright. But if I'm trying to get him to agree to it when he actually doesn't want it, that's a problem. I mean the teeth might be better, but it's a problem for his sort of self-respect if you like. (Participant 3, Male, PwP and Participant 18, Female, partner in care)

For partners in care, there were challenges in knowing how to raise the subject of oral health and mouthcare, despite noticing the declining ability of the individual to maintain it. These conversations had to be done at the right time; pressing too hard, or at the wrong moment, risked doing more harm than good:

> I'll be trying my best to maybe talk to him once in a while, but I wouldn't really force things. (Participant 24, Female, partner in care)

> If you don't sort out these problems, you end up building problems. (Participant 27, Female, partner in care)

For those already providing significant support at home, taking on something even as seemingly small as toothbrushing did not necessarily feel sustainable. This was not through lack of care or concern, but because there was a limit to what could reasonably be expected of them each day, despite a desire to do more, and feelings of guilt at not doing so. There was uncertainty about how they might best support that person; it felt uncomfortable asking to check an individual's toothbrushing. Often, partners in care chose to respect the individual's independence until such a time as they could no longer manage alone, risking potentially preventable declines in oral health.

Discussion

To the authors' knowledge, this is the first study to explore, in depth, the experiences of PwP and their partners in care of performing mouthcare at home. Current evidence demonstrates a mixed picture for performance of mouthcare in PwP, with 29% – 47% of PwP reporting challenges in performing toothbrushing [9,37]. Studies have chiefly based performance of mouthcare activities on self-reported frequency (quantity) versus the quality of the behaviour, and the lived experience surrounding it. Qualitative explorations have touched on aspects of the challenges experienced [38], and the present study builds on this, offering a more detailed and nuanced exploration of these.

Participants described their engagement in a wide range of mouthcare activities at home. While studies have highlighted the direct impact of deteriorating motor skills on toothbrushing [9], this study highlights a variety of broader challenges which can relate either directly to this, or which influence the wider context in which these activities are being completed. This makes performance of mouthcare, especially in the evenings, more vulnerable to being missed. Over time, this has adverse consequences for oral health, as well as general health and quality of life outcomes.

What needs to happen next?

This study recognised that oral health and the ability to maintain it through daily performance of mouthcare was not often considered or discussed with PwP. This led to participants often having to respond to changing situations in reactive rather than proactive ways, and without clear information or guidance. There is a need for improved and earlier provision of information and support to PwP and partners in care about oral health, and more practical and individualised guidance and support on how best to maintain it at home.

Who should be involved?

Many of the challenges described by participants in this study were not purely dental in nature. Dentistry is often siloed, with healthcare professionals potentially feeling unable to support mouthcare or that this may fall outside their remit. Within the UK, programmes such as Mouth Care Matters are challenging this, helping healthcare professionals to recognise that oral health is everybody's business and improve confidence in supporting it [39].

Management of the broader impacts of Parkinson's on mouthcare which relate to manual dexterity, movement and mobility, balance, fatigue and apathy does fall within the remit of the multidisciplinary team such as neurology, specialist nurses, physiotherapy and occupational therapy. Individuals with a focus on supporting the performance of activities of daily living are well placed to support different

elements of mouthcare, providing a more holistic approach to supporting oral health. Consideration of oral health, as part of broader self-care assessments and recognising mouthcare as a key activity of daily living can support this. As participants in this study recognised, if someone was struggling to brush their teeth, they were likely to be struggling with other things too.

Dental teams also have a role to play, which extends beyond the clinical environment, in both supporting and learning from the Parkinson's multidisciplinary team. This includes raising awareness of the links between oral health and general health, provision of oral health education, and learning about PwP to better support conversations with this group.

Future work

There has been limited development of interventions to support conduct of mouthcare and maintenance of oral health in PwP [27]. This study demonstrates an opportunity for the development of educational and practical resources, created with PwP and the healthcare professionals involved in their care, to support the maintenance of oral health at home. Resources would need to establish a baseline understanding of good oral health practice and its broader implications for general health, and offer practical ideas and inspiration around adaptations and strategies that could make a meaningful difference to the ability to manage mouthcare at home. The findings of this study suggest that people do not always need big solutions, they just need to know what is possible.

To do this, it will be key to work closely with end-users, as well as wider stakeholders such as healthcare professionals involved in the Parkinson's multidisciplinary team. Adopting participatory methodologies such as co-design, together with human-centred and inclusive approaches can support the meaningful engagement of individuals within these processes. In co-design, designers, end-users and other stakeholders engage in iterative processes from exploring initial situations and developing an understanding of the challenges to be addressed, to defining and developing ideas, developing and delivering different outcomes or solutions to the initial situation [40]. These approaches seek to facilitate dialogue among individuals from diverse backgrounds leading to heightened ownership, strengthened advocacy, and broader adoption of interventions, grounded in real life context [41].

Mouthcare and maintenance of oral health is a collection of complex and multifactorial activities, influenced by a range of interdependent factors. These factors include functional and cognitive ability, environmental, and socioeconomic determinants. However, it has also been recognised that much of what determines oral health is also behavioural in nature [42]. Changing behavioural patterns, habits or routines can be highly challenging, and the application of behaviour change theory to intervention development has been shown to be effective [43]. Evidence from the Parkinson's self-management literature highlights the integral components of effective self-management interventions, including self-monitoring techniques, promoting independence, encouraging social engagement, and providing relevant knowledge and information [44,45].

The maintenance and support of independence is particularly pertinent, given the discomfort demonstrated by participants in this study at the potential prospect of needing support with mouthcare. The loss of an individual's ability to perform their own mouthcare, coupled with potential visible impacts on appearance, represents a profound threat to self-identity and personal dignity. For PwP, maintaining independent mouthcare is not just a daily physical task, but a means of preserving a sense of self in the face of a progressive condition.

Strengths and limitations

The strengths of this study were the inclusion of participants from across the different stages of Parkinson's - those living with milder to more advanced symptoms, those more recently diagnosed to those who had been diagnosed for over thirty years. Recognition of the different potential challenges which might prevent participants from engaging fully were identified and strategies used to mitigate the risk of exclusion. This included addressing potential communication challenges by giving participants the option to bring someone to support them in the interview, providing transcripts for participant comment, and following up with written questions or clarifications where indicated.

The inclusion of partners in care, either to support the participant in the interview or as participants themselves was a further strength of this study. Partners in care are an under-represented group within research [46] and provide vital additional perspectives, as key stakeholders in supporting oral health at home. For some participants, their participation would not have been possible without the support of their partner in care.

The limitations of this study relate to methods of recruitment, utilising charities and support groups which may exclude those who do not engage with these groups, either through choice or because they are unable to. These individuals may have offered alternative perspectives. Certain groups including those over 80 years old or recently diagnosed (under a year since formal diagnosis) were more challenging to recruit. This reflects challenges in engaging these groups, including identification and access, the physical and cognitive demands of participation, and navigating the emotional challenges associated with a diagnosis. Reflecting on the aim of the study, the specificity of the sample, the quality of the data generated, and the depth of analysis achieved, the authors are satisfied that the sample provided sufficient information power to address the study's aims.

Conclusion

This study provides insight into the mouthcare experiences of PwP at home, highlighting the range of challenges they face in maintaining their oral health. The findings suggest that oral health is not well integrated into the broader management of Parkinson's, resulting in adverse oral health consequences. This study identifies that challenges in maintaining oral health in this group are not solely a dental problem and addressing it will require a joined-up response from across the multidisciplinary team, providing tailored, individualised support and practical help for this group.

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Author contributions

CRediT: **Jessie Tebbutt**: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Writing – original draft, Writing – review & editing; **Zoe Marshman**: Conceptualization, Formal analysis, Methodology, Writing – review & editing.

Author contributions (CRediT roles)

Conceptualisation: JT, ZM, Funding acquisition: JT, Methodology: JT, ZM, Data curation: JT, Formal analysis: JT, ZM, Investigation: JT, Writing – original draft: JT, Writing – review & editing: JT, ZM

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