Remote Consultations for People with Parkinson's and Cognitive Impairment – An Interview Study with Patients, Caregivers and Healthcare Professionals

Abstract

Background

The Covid-19 pandemic led to many consultations being conducted remotely. Cognitive impairment is recognised as a potential barrier to remote healthcare interactions and is common and heterogeneous in Parkinson's. Research studies have shown remote consultations in Parkinson's to be feasible, but little is known about real life experience, especially for those with cognitive impairment. We explored the experiences and perceptions of remote consultations for people with Parkinson's and cognitive impairment.

Objective

To explore the experiences of remote consultations for People with Parkinson's and Cognitive Impairments, from the perspective of service users and professionals, and investigate considerations for future service delivery.

Method

Semi-structured interviews were conducted remotely with 11 people with Parkinson's and cognitive impairment, 10 family caregivers and 24 Healthcare Professionals in 2020-2021. Purposive sampling was used. Interviews were audio-recorded, transcribed and analysed using thematic analysis.

Results

Four themes were identified: The Nature of Remote Interactions; Challenges Exacerbated by Being Remote; Expectation versus Reality; and Optimising for the Future. Remote consultations were considered to be 'transactional' and less personal, with difficulties building rapport, and different in role to in-person consultations. The loss of non-verbal communication and ability of Healthcare Professionals to 'sense' led to remote consultations being perceived as riskier by all groups. Issues arising from communication and cognitive impairment, balancing of the person with Parkinson's and

caregiver voice, and discussions of the future, affect this population specifically. Remote consultations were reported to have been more successful than anticipated in all three groups. Obstacles were not always as expected, for example age was less of a barrier than predicted. Video consultations were perceived as being preferable to telephone consultations by most participants, but not accessible to all people with Parkinson's. With widespread expectation of ongoing remote consultations, potential improvements for these three groups and healthcare services were identified, including practice, preparation, increased awareness of issues, expectation management by Healthcare Professionals, and more time and flexibility for consultations.

Conclusion

Advantages and challenges of remote consultations for this population are identified. Consultations could be improved with increased support, practice, preparation, awareness of issues, and more time and flexibility within services.

Introduction

On declaring Covid-19 a pandemic in March 2020, the World Health Organisation advocated strict social distancing and quarantine measures to avoid virus spread[1]. Health services rapidly employed 'telemedicine' to deliver care for many conditions, including Parkinson's[2–6]. 'Telemedicine' is the delivery of healthcare services, where distance is a critical factor, using information and communication technologies[7].

Parkinson's is a heterogeneous neurodegenerative condition, affecting over 6.1 million people globally, with rates rising[8]. People with Parkinson's (PWP) frequently experience cognitive symptoms[9] with impairment increasing with age and duration of disease: 80% of people with Parkinson's have dementia by 20 years disease duration[10].

Remote consultations (telephone or video call) are not completely new. Studies have shown feasibility of specialist consultations and delivery of therapy for PWP[11–15], and high rates of interest in telemedicine among PWP have been reported[16,17]. Patient perspectives have tended to be explored within research contexts, a qualitative survey within a US-based trial of Parkinson's specialist "virtual visits" collated feedback from specialist and patient participants[18]. They identified positive and negative perceptions driven by three themes: personal benefits (e.g. lack of travel; frustration), perceived quality of care (e.g. more frequent visits; technical troubles), and quality of interpersonal engagement (e.g. liked the doctor; difficult communication). Studies of remote consultations in Parkinson's have predominantly been undertaken with educated, digitally literate samples with digital resources provided and technical support available, therefore little is known about real-life use. A recent study of neurologists' experiences of remote consultations (not Parkinson's specific) found perceived improved access and efficiency, and an expectation that telemedicine will continue to be

utilised beyond the pandemic. However, in-person consultations were not felt to be fully replaceable due to greater uncertainty when working remotely, technical and administrative problems and 'difficult consultations'. Consultations reported as being experienced as 'difficult' included those with new patients and those with cognitive impairment; and consultations requiring difficult decisions or significant discussions (e.g. breaking bad news)[4]. A recent qualitative study exploring the impact of the Covid-19 pandemic on Parkinson's management, from the perspective of PWP and HCPs reported mixed reactions to remote consultations[19]. Most study participants were able to use virtual technologies, acknowledged to potentially not be representative of the wider older population living with Parkinson's, and cognitive impairment was not explored.

A qualitative study exploring the experiences of remote consultations for people living with non-Parkinson's Dementia and their carers identified various difficulties: the lack of prompts to remember problems, dealing with new emerging difficulties, rescheduling/missed calls, and inclusion of the person with dementia's voice[20]. However, to our knowledge, no studies have investigated remote consultations for PWP who have cognitive impairments. The combination of physical and cognitive impairments and the pattern of cognitive deficits in Parkinson's differs from other types of dementia[21–24] which may convey different experiences and needs. The aim of this study is to explore the experiences of remote consultations for PWP and Cognitive Impairments, and considerations for future service delivery.

Methods

Design

An exploratory qualitative design using semi-structured interviews, analysed using thematic analysis, with reporting guided by the Standards for Reporting Qualitative Research framework[25].

Sample and Recruitment

This study was approved by the (anon). Three groups of participants were recruited between October 2020 and July 2021: PWP and Cognitive Impairment, Family Caregivers and Healthcare Professionals (HCPs) working with this group. PWP and Caregiver participants were purposively sampled to ensure representation of different clinical and social backgrounds in terms of age, ethnicity, education, living arrangements, duration of disease, and severity impairments (functional and cognitive), managed through different healthcare services. Potential participants were identified through clinicians in primary and secondary care or self-presented to the research team following charity sector advertisement. Additional recruitment sites were approached in more ethnically diverse areas to try to improve recruitment from ethnic minorities.

For HCPs, a range of different professional backgrounds was sought, working within different geographical areas and services, with a variety of experience of remote consultations. HCP participants were also identified through snowballing, making use of professional networks. HCP participants needed adequate experience of working with PWP to recall clinical encounters for discussion, but a range of expertise was sought. In order to represent the broad range of disciplines involved in the care of PWP[26], greater numbers of HCPs compared to PWP and Caregivers were required. All potential participants were screened for eligibility using inclusion and exclusion criteria detailed in table 1; and sent detailed information via post or email. All participants provided formal consent, either as written, digital or audio-recorded verbal consent.

Table 1: Inclusion & Exclusion Criteria

Sample	Criteria

People with Parkinson's and Cognitive Impairment	1. Diagnosis of idiopathic Parkinson's disease made by a clinical specialist. 2. Cognitive symptoms – by subjective report[a]: described in lay terms as "changes in memory, thinking, concentration" **Exclusions:** Care home residents, atypical Parkinsonian disorders, participants anticipated to be approaching end of life.
Caregivers	A person who closely supported the person with Parkinson's. (Person being supported must meet inclusion criteria above.)
Healthcare Professionals	A person working within, or in collaboration with, healthcare, who encounters people with Parkinson's and cognitive impairment in a professional capacity.

[a]Participants reporting subjective cognitive symptoms, having been identified by a clinician as having cognitive impairment, were included even in absence of formal diagnosis since cognitive symptoms are common but often missed in clinical practice[27]. Participants were not included if they denied cognitive symptoms despite a clinician identifying them, since it would not be appropriate to attempt detailed interview discussion of these symptoms with them.

Data Collection

Topic guides were designed following a review of the literature and refined with multidisciplinary and Patient and Public Involvement (PPI) input, to explore experiences and perceptions of remote interactions for health and social support. Interviews were conducted by (anon) (a geriatrician trained in qualitative research methods), by either telephone or video call. Interviews were audio-recorded and transcribed. Data collection continued until the team were confident that breadth of representation and the depth of information obtained was sufficient to address the study aim.

Analysis

Interviews were transcribed 'verbatim' and analysed using reflexive thematic analysis within a predominantly experiential qualitative framework [28,29]. The coding framework was generated

following discussions among the team who had all read a sample of transcripts, and revised iteratively as it was applied to remaining transcripts (anon) and presented for wider team review. Line-by-line coding was conducted in NVivo 12 [30]. All extracts assigned to each code were reviewed and grouped to organize themes, further refined through discussion and interpretation with the research team and PPI. The multidisciplinary team included those with background in geriatric medicine (anon), nursing (anon) psychology (anon), neurology (anon) and general practice (anon).

Results

Eleven PWP, 10 Caregivers, and 24 HCPs were interviewed. Five were conducted as PWP-Caregiver dyad interviews, with one Caregiver subsequently also interviewed alone. Five individual Caregiver interviews were conducted where the PWP felt unable to take part. Eight PWP/Caregiver interviews were conducted by video and nine by telephone, duration ranging from 41-121 minutes. Twenty-one HCP interviews were via video, two by telephone and one in person, duration range 41-98 minutes. All PWP/Caregiver participants were from the Southeast of England; HCPs were from the Southeast of England, the Midlands and Scotland.

Table 2: Demographic Details for People with Parkinson's and Caregivers

People with Parkinson's Represented	
Age	Mean 75.7yrs (SD 8.2)
Sex	9 Male 6 Female
Ethnicity	12 White British 1 White Other 1 Asian (Indian) 1 Black (other)

Duration of Parkinson's	Mean 13.6yrs (SD 6.7)
	Range 2-25yrs
Cognitive Impairment	8 subjective symptoms, without formal diagnosis (varying severity)
	1 existing diagnosis of Mild Cognitive Impairment
	6 existing diagnosis of Dementia (2 interviewed directly, 4 Caregiver only)
Educational Background	Age leaving full time education ranged from 14 to 25yrs.
	Qualifications range from none, through to degrees.
Schwab & England Scale[31][b]	Mean 47.5% (SD 30)
	Range 10-100%
Living Arrangements	6 live with spouse/partner
	4 with family
	5 alone
Location	13 urban/suburban
	1 semi-rural
	1 rural
Caregivers	
Relationship	5 Spouse
	5 Daughter
Age	Mean 62.8yrs (SD 11.1)
	Range 46 – 78yrs
Sex	3 Male
	7 Female
Ethnicity	8 White British
	1 Asian (Indian)
	1 Black Caribbean

[b]Indicates degree of impairment, with 100% being independent and 0% being fully dependent.

Table 3: Roles of Healthcare Professional Participants

Professional Role	n
Parkinson's Nurse Specialist (PDNS)	4
Neurologist	3
Geriatrician	3
General Practitioner (GP)	3
Clinical Neuropsychologist	2
Speech & Language Therapist (SLT), Neurology Services	2
Occupational Therapist (OT), 1 Memory Service, 1 Movement Disorders Service	2
Physiotherapist, Movement Disorders Service	1
Older Adult Psychiatrist	1
Mental Health Nurse, Memory Service	1
Palliative Care Physician	1
Charity Sector: Parkinson's UK (PUK) Local Advisor[c]	1

[c]Charity sector role to help PWP, including providing advice and information and supporting access to services.

Participants described their uses of remote communication technology in different aspects of their lives. All PWP and Caregiver participants used telephones for personal communications; several had used video calls socially in the past and all had during the pandemic. All PWP/caregivers had experienced telephone consultations, but few PWP/caregivers had experienced video consultations so spoke about their experience of video technology in general. HCPs experience of video consultations was varied, with most consultations remaining by telephone (experienced by all). Whilst not the focus of discussion, some described use of asynchronous email or text message communication. All remote consultations had been a result of the pandemic, with a few now expressing it as a preference. Several Caregivers for PWP with severe impairments explained that the PWP could not utilise the telephone or video themselves. All PWP/Caregiver participants had established Parkinson's; HCPs recalled experience of both new and established patient encounters. The interview discussions led to four themes: 'The Nature of Remote Interactions', encompassing

subthemes of 'A Transactional Exchange', 'Is it "Real?"' and 'A Risky Process'; 'Challenges Exacerbated by Being Remote' encompassing subthemes of 'Communication & Understanding', 'Interpersonal Dynamics' and 'Significant Discussions'; 'Expectation vs Reality' encompassing subthemes 'Anticipated Barriers' and 'Expected Advantages'; and 'Optimising for the Future' encompassing 'Support for People with Parkinson's and Cognitive Impairment & Caregivers', 'Professional Development' and 'Service Improvement'.

Table 4: Themes and Subthemes

Theme	Subtheme
The Nature of Remote Interactions	A Transactional Exchange
	Is it "Real"?
	A Risky Process
Challenges Exacerbated by Being Remote	Communication & Understanding
	Interpersonal Dynamics
	Significant Discussions
Expectation vs Reality	Anticipated Barriers
	Expected Advantages
Optimising for the Future	Support for People with Parkinson's and Cognitive Impairment & Caregivers
	Professional Development
	Service Improvement

THE NATURE OF REMOTE INTERACTIONS

Differences in the interaction via remote technologies were described, typically in relation to the lack of physical contact (including examinations) and/or visual information and cues. The consequences are encompassed by three subthemes: *A Transactional Exchange; Is it "Real"?;* and *A Risky Process.*

A Transactional Exchange

Participants described the 'transactional' nature of remote consultations. Most participants, across the groups, felt that building rapport was more difficult remotely, exacerbated by technical issues. Some felt this improved over time with multiple consultations and with video over telephone. Many HCPs found it more difficult to manage PWP/caregiver emotions and offer reassurance remotely, for both video and telephone. Many participants, particularly PWP, perceived the consultation as more automatic and functional, with less personalisation:

> *"I don't always feel that there is a proper dialogue. It's a question-and-answer sort of thing that goes on. But it sounds a bit mechanical. Sort a list of things to tick off" PWP1*

HCPs often attributed the dynamic to the lack of physical contact or visual interaction or environmental factors, affecting both telephone and video consultations, but more so with telephone:

> *"I think when they're with you in a room and they feel safe in that environment then they will talk to you more" HCP25 (OT)*

On the other hand, PWP/Caregivers were more likely to attribute this to the clinician approach and style of questioning (such as checklists). They felt more rushed, sensing they were a burden:

> *"I think it removes some of the pastoral nature of the role, because it feels like you're just taking up their time" Caregiver2*

HCPs did indeed report making use of techniques like checklists and closed questioning, trying to overcome the difficulties of assessing remotely:

> *"I have found a checklist works really well, because when you're trying to juggle the phone and the video or whatever, knowing I'm going through a checklist and I know where I am." HCP19 (Neurologist)*

Several participants reflected on a nebulous concept of human interaction, "*hard to put into words*" that is lost remotely, whether telephone or video, leading to less *"enjoyable"* or *"fulfilling"*

interactions. It is something more than just visual, related to *"more dimensions of engagement"* (HCP24, Palliative Care Physician) with physical presence. This impacted satisfaction across participant groups.

Is it "Real"?

Some participants perceived a remote consultation to take a different role than an in-person consultation, with some HCPs observing that PWP did not 'count' remote consultations, *"they don't see it as a consultation" (HCP21, PDNS),* but rather perceived as an informal "chat" or "check-in", in some cases a 'steppingstone' to an in-person consultation. This impression was substantiated across all groups by participants' language, contrasting remote consultations to "*real life*" (HCP10, Geriatrician) or referring to in-person as being *"properly seen"* (Caregiver14). This was reported for both telephone and video, but more emphasised for telephone consultations. Consequences of this were the impact on the professional-patient relationship. HCPs implied that they detected less respect for remote consultations:

> *"But patients will say, "Yes, yes, that's fine. I can do that," and then they don't turn up [for the video call]. And I find they haven't even bothered to try. They've gone in the garden because, actually, it just seemed like too much bother." HCP27 (Physiotherapist)*

Conversely, a sense of distrust emerged from some PWP and Caregivers:

> *"They didn't say they got it [prescription] wrong. But I still don't know whether they, they had got it wrong. So there's that element in view of the virus, doing it all from arm's length… if I'm being honest, I wasn't totally sure that they were being that straight with me." PWP1*

A Risky Process

Participants from all three groups spoke of deficiencies in remote consultations, both telephone and video, that generated anxiety. Several HCPs were concerned about the medico-legal standing and "*unintentionally being negligent*" due to lack of "*standardised procedure*" *(HCP24 Palliative care Physician)*. Increased risk was described in relation to perceiving a higher chance of error. HCPs universally reported difficulty in making assessments without the usual information, frequently citing the importance of physical examination or observing task performance for Parkinson's and cognitive assessments, particularly in diagnostic contexts. Several were concerned about not getting the 'full picture' remotely, where in-person they would rely on different information streams (e.g. verbal and non-verbal cues, observation and examination) especially for complex cases. This could be somewhat alleviated by good quality video consultations, but observation by video was frequently inadequate and it still lacked hands-on examination. Some elaborated further, describing reliance on a 'sense' for clinical judgments when in-person:

> *"As psychologists there is a lot of, you know, you can feel from people, you know, there is, kind of, actually, 'I feel that you seemed quite upset when I said that', and that's sometimes difficult to do over Near Me* [video conferencing] *apparatus, as well. So, it's the kind of, non-spoken subtleties I think that you miss sometimes over the technology." HCP18 (Neuropsychologist)*

All participant groups were concerned that impairments could be concealed in remote consultations, which may have been picked up in-person. From the PWP/Caregiver perspective, there was a sense of unease about HCP judgments relying on their symptom descriptions during telephone calls:

> *"…sometimes you get a doctor who I've never met, and you're talking to you over the phone. They've never met my father, and it's, it just feels a bit tenuous. Can you – can you really? It feels, it's too much responsibility to me. Have I described everything?" Caregiver2*

Further risk related to who is present for remote consultations: both expressing concern if consultations were unsupervised and from the presence of unknown others (not visible for telephone;

out of view on video). HCPs reported that PWP were potentially exposed to physical risk in performing assessment tasks or emotional vulnerability when discussing sensitive topics if alone:

> *"There have been occasions where patients with low mood do, kind of, talk about suicidal thoughts and things like that, in the hospital environment it feels safe enough to discuss those sorts of things, whereas, when you're not with the patient I wouldn't feel comfortable about those kinds of things with them."* *HCP25 (OT)*

Conversely, some participants from each group questioned digital security; non-private healthcare work environments; and confidentiality with others on the call:

> *"I just think that everyone seems to be talking at once at all times and you don't know who you're talking to as a GP, and it makes me feel a bit uncomfortable like who actually is in the room."* *HCP13 (GP)*

CHALLENGES EXABERBATED BY BEING REMOTE

Participants described challenges in healthcare interactions driven by the condition, many of which were exacerbated by being remote, falling into three subthemes: *Communication & Understanding*; *Interpersonal Dynamics*; and *Significant Discussions*.

Communication & Understanding

The dual impact of physical (e.g. quiet speech) and cognitive (e.g. difficulty multitasking, memory problems) symptoms of Parkinson's, impeded communication, sometimes compounded by for example hearing impairment. They led to problems for PWP understanding and retaining information or instructions. HCPs described frustration at not being able to physically *show* PWP what to do or give hard-copies of information leaflets as they would in-person. These communication difficulties were

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felt to be extra challenging remotely, due to unfamiliarity with technology for video and reliance on verbal communication for telephone:

"I hate using the phone. I get on the phone and then I don't understand people" PWP6

Some participants from each group described PWP finding it more difficult to keep up with conversation over remote communication methods (both video and telephone) due to slowed speech, slowed processing and forgetting:

"He can't really remember what's been said, so he finds it difficult to process the information. So, having a telephone conversation with him is even more difficult than a face-to-face conversation" Caregiver12

Difficulties in sustaining engagement, perhaps related to concentration or apathy, were worse remotely due to additional distractions and lack of eye contact. The pace of conversation needed to be slower. Breakdown of video feeds due to unstable connections could interfere with communication and by telephone pauses could be misinterpreted due to lack of visual cues:

"On the phone the other day there were these silences and I was thinking, have they not heard, are they shaking their heads or are they tutting, what's going on at the other end, you know, I had no idea, it was a bit unsettling." HCP17 (Geriatrician)

For all types of remote consultation, the lack of usual contextual cues could lead to increased disorientation for the PWP - several HCPs described PWP forgetting the purpose of a call or who they were. The cognitive burden, and in some cases associated anxiety, of remote consultations, particularly video, was typically perceived as greater:

"If there is cognitive impairment that's massive, actually, yes, that's quite a big deal because, again, the multiple stimuli that you have can confuse the conversation." HCP24 (Palliative Care Physician)

This was not however universal: a few participants described finding the familiarity of their own environment more relaxed and conducive to remembering and understanding:

"You're in your own comfort zone and you absorb it better than what you do when you have to travel"

Caregiver3

Interpersonal Dynamics

Whilst similar to in-person appointments, the additional communication and technical challenges of remote consultations led to increased need for PWP who had cognitive impairments to have Caregiver support. In many cases, there was increased reliance on family or friends beyond a spousal care partnership to use remote technologies as Caregivers also had difficulties. Many participants found that these increased support needs led to a greater tendency to exclude the PWP, either through the consultation being solely with the Caregiver, or the PWP being 'spoken for' within a joint consultation:

"I think the patient is a bit more cut out, and I'm aware of that, that when they're in the clinic and I talk to both, it's a bit more the carer but the patient is still there." HCP19 (Neurologist)

Many participants appeared dissatisfied with this shift in dynamic. Sometimes it was implied or requested by the PWP, but for the most part it appeared to be automatic, from perceived necessity:

"…it's quite hard, because sometimes I feel like I could take over from it. I try not to; I try to get her to explain herself, but she does – I feel like she's not explaining herself properly. So I end up, OK, then I'll explain what I've seen to the doctor." Caregiver15

Significant Discussions

For HCPs delivering them and for PWP/Caregivers receiving them, diagnoses and prognoses were considered potentially difficult conversations. There was universal agreement that these should be conducted in-person rather than remotely. Discussions about progression, the future and advanced care planning were perceived by HCPs as difficult but important topics, particularly in this population. Most found them even more challenging through remote interactions:

> *"it [talking about the future remotely] probably takes longer, in that people- it's probably slightly more intense, you can't soften it as much. Being in person you can probably soften those conversations a bit more and make them slightly less stark."* HCP8 (GP)

The difficulties might even prevent them from being held: *I've been terrible at doing it [advanced care planning]"* HCP14 (Neurologist).

Participants from all groups indicated that PWP and Caregivers may feel less confident or secure to ask about the future in a remote consultation, with a few feeling that video was marginally less of a barrier than telephone:

> *"Yeah… not on the phone I think… I think it's having the confidence to speak to them and if I've got any questions and the thought of really having something bad going on in your head, that's, that's the frightening bit."* PWP3

EXPECTATION VS REALITY

With the rapid implementation of remote consultations due to the Covid-19 pandemic, many participants reflected on what they had expected the experience to be like compared to the reality. This is encompassed by two subthemes: *Anticipated Barriers* and *Expected Advantages*.

Anticipated Barriers

Whilst participants reported their experiences critically, reporting challenges, most participants actually indicated being "*surprised*" at how well remote consultations had gone. They reported it being easier and more like in-person than expected, for video and even telephone- *"in some respects that's exactly what we would be doing when we saw them face-to-face."* (HCP5 OT).

Across all groups, many anticipated older age to be a barrier to video consultations, but this was often not the case. Some HCPs did indicate that older PWP had more reservations or difficulties with the technology, but most thought the barrier was lack of experience or personality rather than age. The

reported use of technology by the PWP/Caregivers participants also suggested familiarity was more relevant than age.

> *"If it's not someone who's familiar with a computer, an iPad, for example, then it's all new learning and it's quite a lot of ask. But, if somebody is familiar with it and has been using it during their life, which lots of people have and do, irrelevant of age, actually, then there's a bit of that information already there"* HCP9 (Neuropsychologist)

There were however some descriptions of remote technology being embraced more by younger generations, since *"it suits working people that they can just duck out, make a phone call and then they can go back to work" (HCP15, GP).* Additionally, even if PWP owned and were familiar with digital devices, they may be anxious, *"the fact is that they haven't got the confidence to press that button" (HCP12 PUK Advisor).*

Cognitive impairment was not a universal barrier, but rather depended on the degree of impairment and support provided. Difficulties with technology were reported across the participant groups, likely related to cognition. All but the most impaired PWP appeared to be able to undertake telephone consultations (some requiring support), but HCP participants had found that video consultations were less accessible for this population, and PWP/Caregiver participants reported barriers to use of video calls in their personal lives. For some PWP, cognitive impairments prevented new learning and even some with past experience had lost their technological capability:

> *"I just find anything I do, on a laptop or a computer, never seems to work out the way it's supposed to."* PWP4

Several issues described, such as lack of visual/touch information, whilst perceived as challenging, were not *as* restrictive as had been anticipated; more could be achieved remotely than expected. Universally, discussing potentially sensitive symptoms (e.g. bowels or sexual function) remotely was *not* considered problematic; *"I mean sensitive is sensitive"* (PWP1). Ease of discussion was more

dependent on the individuals involved, their relationship and the manner in which it was approached, rather than method of consultation, though some topics, particularly mental health, were more difficult, typically due to lack of rapport. However, across the groups, a few participants expressed opposing views, finding the remoteness helpful for sensitive topics:

> *"I feel I can have quite probing conversations and not feel awkward. So maybe for me that layer of the subconscious awkwardness has been stripped off and therefore they can respond to that over the phone"* HCP10 (Geriatrician)

Expected practical barriers were sometimes a reality for all three groups (with regional variation in healthcare infrastructure), for example poor quality connections or lack of digital device, though rarely prevented consultations. Over time familiarity increased confidence, overcame *some* reservations, and some reported improved quality of interactions:

> *"It* [telephone consultation] *is quite different, but I think I've got used to it."* PWP13

Expected Advantages

Some advantages of remote consultations over in-person consultations, particularly for PWP and Caregivers, were reported across the participant groups as having been a reality, including comfort "*sitting here, he was relaxed*" (Caregiver4) and saving travel "*It did save us a long train journey*" (Caregiver11).

Expectations of improved efficiency and cost-effectiveness existed from participants, "*I thought I would be quicker*" (HCP19, Neurologist), organisations *"our practice thought that telephone consultations would be quicker"* (HCP13, GP) and those in authority, "*the government and stuff think*

this is going to save time" (HCP11, Neurologist). However, HCPs were disappointed to find this was not the case, as more time was needed to circumvent limitations:

> *"At times they're even taking a little bit longer because you haven't got your eyes on the patient and you can't reassure yourself that they look OK" HCP13 (GP)*

Conversely, many PWP and Caregivers still held this perception that HCPs were 'freed up' by remote consultations:

> *"And the doctor is quite busy anyway and I know with a phone call, it frees him time up a bit more." Caregiver3*

Advantages of video over telephone were frequently described, with the addition of visual information. Several PWP and Caregivers who commented on telephone consultations felt that communication and rapport would improve with video. Some HCP participants with greater expertise with video calls reported that with well positioned cameras, body language could be discerned, and observational components of clinical examination could be conducted. It appeared that more specialist HCPs (Neurologists, PDNS' and Neuro-therapists) placed greater value in these advantages than generalists (GPs, Geriatricians), who were less convinced that the benefits outweighed the obstacles:

> *"I'm not getting that much extra information from a phone call to a video, generally." HCP8 (GP)*

Whilst better than telephone, many participants still felt communication, rapport, observation and examination over video was inferior to in-person: Subtleties may be lost, eye contact not possible, the field of view incomplete and breakdown in digital connection disruptive.

OPTIMISING FOR THE FUTURE

Participants from all three groups anticipated that remote technology will continue to be utilised in healthcare beyond the pandemic and reflected on how that could best be navigated. Their suggestions cover three domains: *Support for People with Parkinson's & Caregivers; Professional Development; and Service Improvement.*

Support for People with Parkinson's & Caregivers

Given the range of potential barriers to remote consultations, participants felt that support needs to be tailored to the individual user, *"identifying why that person's a bit afraid of doing that, or put off by it, and then working with that" (HCP7 Mental Health Nurse).*

Participants described ways that practical help could be or had been beneficial, with greater need for help with video than telephone. For some, support was desired to initiate the call (video or telephone), then it could be undertaken independently; for others, technological checks or a trial run was helpful; for many troubleshooting technological issues was the priority. Some participants felt that technical training would be helpful, though capacity to learn may vary, and many felt this required a person to teach step-by-step:

> *"It would be very nice if you could afford to have somebody in to teach you how to use things, to make it easier for yourself." PWP9*

Actions that PWP and Caregivers could undertake to optimise the consultation were proposed, including practising the technology, and reflecting on their condition in advance:

> *"Because you've got to be prepared. I did my research, I interviewed my mother beforehand, found out how she was feeling therefore what I wanted to know. So, I was ready for the call." Caregiver10*

Ways for HCPs to support PWP/Caregivers were raised. It was universally emphasised that they required time - to tackle communication barriers, give explanations and reassurance, and allow for

technological obstacles. Several HCPs described introducing the consultation with an explanation of the process and back-up plan to reassure PWP:

> *"I explain that all* [back-up plans etc] *but it's to reduce that anxiety, and I don't need to do that when I'm face-to-face, so that's taking up another ten minutes of my time."* HCP18 (Neuropsychologist)

Participants from across the groups felt that guidance was needed to set-up optimally for video consultations, including camera position and choice of device (HCPs generally recommended laptops over telephones). HCPs described ways to maintain PWP-Caregiver balance, such as agreeing a time for the Caregiver to leave and ensuring both can be seen on video:

> *"If you set up on a sofa with the iPhone pressed up against your face, which is what people often do, then that isn't very helpful really. Whereas if you were to have it on a table with a couple of chairs behind it so that you're getting a good view of the person, a good view of the relative, you can interact with both of them, and you can have some room behind them to get them to walk"* HCP11 (Neurologist)

Many participants described existing instructions provided for utilising technology, but also felt it needed simplifying, and in some cases written information was not sufficient:

> *"Some of the information that is provided to help you solve problems that come along is not as clear as it might be […] Partly language and partly generations I think. People who live in certain environments, in IT environments, learn to have their own language and think everyone else understands it."* PWP1

Professional Development

HCPs held varied views about training for remote consultations. Some felt attitudes toward video consultation needed to change first, through better understanding of the benefits. Many identified an initial hurdle that required optimism and confidence to jump. HCPs recalled experiencing or witnessing improvement and increased confidence over time: one participant recalled having previously found

video consultations "*much harder*" and "*come out feeling quite tired*" *(HCP11, Neurologist),* but this had improved:

> *"I think a lot of it is just being familiar with what you're doing, being happy with using the technology and using your devices and so forth." HCP11 (Neurologist)*

Varying degrees of confidence using technology were expressed. Some had received training on the digital platforms; many had picked it up through use; others felt they needed training to get started. Like PWP, many desired ongoing support and troubleshooting rather than training. Whilst generally feeling confident using video technology themselves, several HCPs felt that they could not help patients if something went wrong their end.

Beyond technology, some HCPs felt that remote consultations required the same skills as in-person consultations, whereas others felt they demanded new trainable skills. Similar techniques were described to in-person, though adapted:

> *"The same as phone consults; trying to build that rapport, the active listening skills, and you just need to be a little bit more pronounced in your active listening" HCP13 (GP)*

Some HCPs described modifications to their consultations, for example questions to remotely assess cognition, or subjective reports of function where objective physical measures would have been used in-person, but several desired a standardised approach:

> *"What I would like: a validated video exam that we all get used to doing. It'd be nice to get a validated telephone exam" HCP14 (Neurologist)*

There was a sense among many HCPs that what an 'optimal' remote consultation entailed remained unknown; several asked what other participants had said or described learning from colleagues. All participants, especially HCPs, shared recommendations for HCPs undertaking remote consultations, as summarised in table 5.

Table 5. Consultation Recommendations from participants from all groups

Tips and techniques for HCPs undertaking remote consultations with People with Parkinson's and Cognitive Impairment	
Before the Consultation	
Environment	• Consider the PWP environment – comfort, reducing stress, privacy • Consider the healthcare environment – privacy, quiet, equipment
Patient-focussed Preparation	• As for an in-person consultation, read the relevant clinical information before the consultation • Where possible, determine the preferred method of consultation for that individual; find out how they best communicate, and any support needed • Consider the best time of day for that person, considering their response to medication
Prepare for the technology	• Familiarise and practice with the technology. For video, ensure adequate screen size or two screens • For video, consider accessing the platform via patient access to be able to guide them through difficulties
Preparatory Instructions & Guidance for the PWP and Caregiver	• Simplicity is key • Encourage reflection of their condition, noting any issues or questions they want addressed in the consultation • Consider practical advice for example camera positioning for video calls. Tailor to the needs of your consultation, for example, device preference: laptop may be preferred over telephone for multiple participants, to ensure all are visible, and for examination e.g. to include space for gait observation, whereas a mobile device may be preferred if review of the wider home environment is desired

Practical Support for the PWP and Caregiver	Depending on availability within the service and tailoring to the individual needs, consider identifying if there is someone who could help by: • Checking their technological set-up in advance • Providing a practice run • Provide technology-training • Initiating the call, then handing over to the PWP • Guiding them through the whole consultation • Being available to troubleshoot in advance and/or during the consultation
During the Consultation	
General consultation management	• Explain the process of the consultation at the start, acknowledging the difficulties and offering reassurance and a 'back-up plan' in case technology fails • Ask who is present • Minimise distractions • Consider taking notes
Making the best of technology	• Speak loudly & clearly, looking at the camera • Consider using audio from telephone alongside video for image • Consider using a second screen for clinical records
Communication skills	• Be confident to reduce their anxiety • Take it slowly, using simple and concise sentences, avoiding frequent or abrupt subject changes, and allowing opportunity for questions. • Be friendly to build rapport • Frequently recap and check understanding to support cognitive impairments • Help when people forget, or offer to come back to it

Awareness of the PWP-Caregiver dynamic	• Make a conscious effort to include PWP, speaking to them directly • Consider agreeing at the start how the time will be split between PWP and Caregiver
After the Consultation	
Corroborate	• Speak to others involved in the PWP's care if applicable and consented • Consult other team members to evaluate if information matches • Consider if further appointment (potentially in-person) is needed
Review suitability of method for future consultations	• Reflect on how the consultation method was experienced • Revisit the PWP's preferences • Consider categorising the PWP as to suitability for different methods of consultation

Service Improvement

The majority of participants across the groups favoured a blended model for the future: in-person or remote consultations depending on context, necessitating changes to services to enable personalisation. Participants described who remote consultations should be used for, how services need to adapt, what is needed to deliver a better service and why improvement is needed.

Who?

Remote consultations were felt most suited for routine appointments for stable conditions, and when a PWP-HCP relationship already existed, whereas complex cases or those experiencing complications and consultations involving significant discussions (e.g. advanced care planning) were thought better to be in-person:

> *"The only time you need to see a doctor, I think, if things are not going too well" Caregiver3*

However, caution may be needed: some PWP hypothesised that if their appointment were changed to in-person they would anticipate bad news:

> "Trouble is if the doctor says to you now, 'come in and let's talk about it' then you start to worry even more." PWP5

Overall participants felt that method of consultation should be tailored to the individual, assessing the pros and cons on a case-by-case basis, taking into consideration the resource, access and capability of the individual to utilise remote communication technology, in particular factoring in their communication and cognitive symptoms, to ensure value is added to their care, and factoring in PWP/Caregiver preferences:

> "…for lots of things, it has been useful. And then for certain people, it's just not useful at all. So, it is again about thinking about the individual and what is potentially best for them." HCP5 (OT)

How?

Participants discussed how this can be operationalised, potentially using telephone triage and categorizing to consultation type. Several participants impressed the importance of contingency planning, being able to undertake in-person assessment if the remote consultation is unsuccessful.

For service delivery, all participants felt that having flexibility and adequate time was essential, with many HCPs impressing that remote consultations did not save time. Sometimes separate consultations for PWP and Caregiver may be required and some participants felt that more frequent appointments were preferable over very long ones to reduce the risk of tiring. Some HCPs had experienced problems of fixed scheduling, whereas others positively recounted flexible systems:

> "the nice thing about telephone consultation clinics is actually there's a bit more flexibility so we're not giving patients specific times of when they'll be called, we're giving them windows. So we can be slightly flexible if people then say, 'No, can you call me at this time?'" HCP8 (GP)

What?

There was evidence of variation in equipment availability, administrative support and suitable environments across services, which correlated to the apparent success of remote consultations. Use of asynchronous remote communication, such as text messaging and emails were valuable for some participants from all groups when simple and responsive. Overall, the need for improvement to infrastructure was stressed:

> *"…just making sure every computer you use has got the access to it all, I think that's really important."*
> *HCP25 (OT, Parkinson's service)*

Several participants across the groups reported issues related to PWP lacking simple and suitable devices for video calls. Many HCPs felt that the platforms currently utilised in healthcare settings needed to be improved. Many reflected that platforms popular for personal use, such as Zoom, Skype and WhatsApp, were more easily managed and that familiarity could help in overcoming barriers:

> *"people that had previously been a little bit, 'oh, I'm not sure about the technology', realised they were quite capable of using Zoom, it was an easy platform."* HCP20 (SLT)

Why?

The importance of improving services was impressed by several participants, typically citing concerns about exclusion through "*provision disparity." (HCP8, GP)*, or competence and confidence in using them*; "The people that do take the service up are probably the people that least need it."* (HCP12, PUK Advisor).

Discussion

Summary

HCPs, PWP and Caregivers, perceived remote interactions as more transactional, lacking personalisation and challenging rapport-building. They questioned whether they could substitute for "real" in-person consultations. Limitations of remote consultations were perceived, in particular in conferring greater risk. These issues were more prominently perceived for telephone than video consultations, but existed for both modes of remote consultation.

Issues for this population were intensified through remote technology, including communication and cognitive challenges, balancing the PWP and Caregiver within consultations, and significant discussions, e.g. about the future. Perspectives had evolved, with some anticipated barriers not materialising (such as age being a restriction to access) and some expected advantages not coming to fruition (such as time saving). Whilst participants were generally surprised by the relative success of remote consultations and confidence in remote technologies was increasing, most still preferred in-person consultations. PWP/Caregivers and HCPs had divergent perceptions about efficiency of remote consultations with the former reporting them to improve efficiency and free up time, but HCPs typically rejected the notion of time being saved. Participants proposed ideas to improve services, anticipating a combination of remote and in-person healthcare consultations moving forwards.

Context of Existing Literature

To our knowledge, this is the first study to explore remote consultations for PWP in a real-life setting, to explore these three group perspectives, and to focus on PWP with cognitive impairment.

Both human and technical aspects of telemedicine have been identified as contributing to quality[32]; which were also apparent in our study. Within Parkinson's, telemedicine has been shown to be both feasible[11–14] and associated with high rates of satisfaction both in research studies [13,14,18,33,34] and in the limited reports of real-life application[35,36]. Studies have been small, heterogeneous (for

example for frequency of consultation and whether telemedicine replaced or supplemented routine care), and produced mixed results regarding quality of life and clinical outcomes[37]. As such, effectiveness of remote models compared to in-person remains inconclusive. The advantage of reduced travel burden for patients, and barriers from technological problems and limited physical examination have been consistently reported. Studies have recruited predominantly digitally-literate, well-educated, white samples, so may not be representative of the wider Parkinson's population[37] and few report cognitive status. Studies typically provided equipment, software and technical support, with consultations delivered by clinicians trained and experienced in telemedicine, so may not be applicable to standard clinical care models. The current study gives insight into the real-life experiences of clinical remote consultations in a typically understudied population, within the UK National Health Service (NHS). An evolving body of literature, typically based on HCP reports of personal experience, offers tips to clinicians undertaking remote consultations [38–41]. The current study bolsters this with the patient and caregiver perspective and nuance for this population as detailed in table 6.

Accounts of remote consultations as 'transactional' are in keeping with study of other conditions and contexts. An analysis of primary care telephone encounters found more biomedical information exchange than psychosocial and a less patient-centred approach, attributed to telephone consultations being shorter[42], though in our study remote consultations were not thought to be shorter in this population. The relationship between duration and quality of consultation is debated[43,44]. Participants in our study strongly believed more consultation time was beneficial, perhaps reflecting the condition complexity. The inconsistency however suggests that loss of personability remotely is not purely time driven. A qualitative study of neurology consultations identified a 'business-like' style and ability to 'take control' in remote consultations, perceived as advantageous. The perception of the dynamic as 'transactional' was however portrayed as a

disadvantage by PWP, Caregivers and some HCPs in our study. The reduced HCP enjoyment of interactions when remote resonates with reduced consultation satisfaction previously reported[4].

Whilst not widely reported previously, the perception of remote consultations as not being 'real' resonates with a primary care study reporting some people expected telephone encounters to determine if/when they would be seen in-person[42]. This may be more pronounced in the current study due the rapid shift to remote consultations in the pandemic and highlights the need to promote understanding of their purpose. The perception of increased risk with remote consultations is mirrored in studies of clinicians perspectives within primary and secondary care[4,45]. The importance of observation and physical examination is particularly widely reported in neurology[4] and Parkinson's[6,16,18], though there has been less attention to clinicians 'sensing' clinical judgments which was quite marked in our study. Clinician '6th sense' has been discussed in psychology and acute care patient safety literature[46], but perhaps is more widely applicable.

Communication problems in Parkinson's are well known[47,48] and health communication research has long established the importance of non-verbal communication[49], which is unavailable in telephone consultations. Difficulties relating to memory, and discussion being directed to caregivers with risk of exclusion of the patient themselves have been reported in remote consultations for dementia[20]. Cognitive impairments are widely perceived to be potential barriers to remote consultations[4,39,40,50]; consideration of mental capacity for suitability of remote consultation is highlighted in the UK General Medical Council guidance[51]. The effect of non-memory cognitive impairments, such as executive dysfunction[52], alongside speech and behavioural symptoms, may create even more difficulty in sustaining complex discussions for PWP. This is particularly relevant for significant discussions (such as diagnoses and prognoses), which are difficult remotely anyway, across disciplines[4,53].

In a recent study of remote primary care consultations for people with dementia[20], older age conferred more barriers, but this was not replicated in the current study, where mixed experiences were reported but not predictable from age. Instead, familiarity with technology was a facilitator, though those with more significant cognitive impairments may have lost digital skills and confidence or be unable to transfer it to a new context. Increased confidence with remote consultations over time has been recognised during the pandemic[45,54], supporting the concept of practice. Advantages regarding convenience and comfort for remote consultations appear widespread[4,6,53], but perhaps more so in Parkinson's due to exacerbation of symptoms with stress[55,56]. A qualitative study of the effects of the Covid-19 pandemic which touched on remote consultations[57], and another of PWP and HCPs experiences of Parkinson's management during the Covid-19 pandemic[19] both similarly found mixed opinions of remote consultations. In the latter, several HCPs reported improved service efficiency, which was not experienced by the HCP participants of our study. This may be a particular issue for those with cognitive impairment, which was not explored as a factor in either of these studies.

The need for evolution of platforms, infrastructure and resource within clinical healthcare systems such as the NHS, whilst preventing health inequalities, corresponds with other UK-based studies of remote consultations[4,53,54], but with specific needs of this population: time, simplicity and flexibility. Flexibility is recognised to be necessary in delivering personalised care[58]. The expectations of remote consultations are varied, and importantly perceptions of efficiency and timesaving differed between PWP/Caregivers and HCPs. This discrepancy may lead to dissatisfaction on both sides. Our findings highlight that 'cognitive impairment' covers a range of abilities and support for individuals varies, so blanket procedures will not be appropriate. The barriers to remote consultations were for the most part portrayed as *challenges* rather than absolute *disadvantages*,

perhaps due to the expectation that remote models of care will continue but offering hope that these issues can be surmounted.

Strengths & Limitations

This is the first study including an under-represented population (people with Parkinson's and cognitive impairment) and triangulating the perspectives of patients, caregivers and HCPs. Conducting the study remotely enabled inclusion of health services from multiple geographical areas and snowballing enabled a wider reach but may have predominantly reached individuals with specific interest in the topic. Inclusion of participants with subjective cognitive symptoms rather than a formal diagnostic process prevented being restricted by underdiagnosis, which is a recognised problem[27]. Conversely, we cannot formally consider interpretation by objective severity of impairment. As has been a longstanding issue in Parkinson's research[59], challenges were faced in recruitment of ethnic minority participants, despite targeted efforts, which may limit the applicability of the findings to these groups. Clinical audit data shows 92% of PWP in Neurology and Elderly Care services in the UK to be White[60] but even use of primary care recruitment in ethnically diverse areas did not increase diversity of our participants. Validity of interpretation was ensured through PPI consultation and a multidisciplinary clinical and academic team.

An unavoidable challenge for research with this population is that the condition conveys communication difficulties. Some participants had difficulty expressing their views and caregivers proxy views could be biased. Individuals not comfortable or able to communicate with telephone or video, or with limited English language skills may be underrepresented. Whilst the range of professional backgrounds represented brings richness to this data, it is important to recognise regional variation in health services[61], many PWP will not routinely encounter this range of specialist

professionals[62]. The study was conducted within the UK and may not be representative of other health services in other countries.

Implications for Clinical Practice and Research

This study adds to the literature on remote consultations, with consideration to this subset of patients and caregivers. Whilst it was clear that care and consultation method needs to be personalised to the individual, awareness of these issues and the suggested improvements can help manage expectations and optimise remote interactions, as summarised in Table 6. Future research should continue to evaluate remote service delivery in real-life as it evolves and as the pandemic situation changes. Further research on advantages of video over telephone consultations and on asynchronous remote e-consultations with people with Parkinson's would also be of value.

Table 6. Key Messages for Clinical Practice

Key Messages for Clinical Practice	
Lessons for HCPs	• HCPs should be aware of the perceived transactional nature of checklists and closed questions • HCPs should be aware of potential exclusion of PWP's voice • Pauses by telephone can be difficult to interpret but caution not to let that lead to cutting people off as they may need more time for communication • Manage expectations, clarifying the role of the consultation, and offer reassurance and a back-up plan

Tips for PWP & Caregivers	• Practice using the technology and platform in advance
	
	• Preparation can improve the consultation
	
	    o Reflect and record points for discussion in advance
	
	    o Optimise the environment/device used for the consultation

	• Inform the healthcare providers of the better times for your condition, e.g. when medication is working best
Considerations for Service Design	• Written guidance for remote consultations may not be sufficient to enable use. Guided use of technology may be necessary for PWP with cognitive impairment and caregivers. • Services should be flexible, enabling individually optimised timing and communication methods for interactions, avoiding exclusion of those with impairments that affect use of remote interactions • Platforms for remote consultations should be simplified, utilising familiar concepts from those widely used for personal communications • Should not assume telemedicine is quicker or more efficient - more time is needed for consultations with this population, though this may be best achieved through increased frequency appointments to minimise risk of tiring in very long appointments

Conclusion

Many advantages and challenges of remote consultations are universal, but there are some specific issues to consider for those with cognitive impairments in Parkinson's, owing to the combination of physical and cognitive symptoms, as well as psychological factors, such as exacerbation of impairments from anxiety. HCPs, PWP and Caregivers, perceived remote interactions as more transactional; lacking personalisation and challenging rapport-building; not "real" consultations; and riskier due to their limitations. This applied particularly to telephone consultations but also to video calls, to a lesser extent. Access and technical barriers limited the use of video consultations. Contrary to PWP/Caregivers perception and reports in previous studies in PWP, HCPs denied time being saved with the change to remote consultations.

Whilst challenges and descriptions of negative experiences were universal, remote consultations had in practice worked better than expected by many participants and some anticipated barriers were not actually experienced, for example many older people were unexpectedly accessing consultations remotely. These experiences should be considered when planning future remote healthcare for PWP.

Acknowledgements

Conflicts of Interest

The authors declare that they have no conflicts interests.

Abbreviations

PWP = People/Person with Parkinson's

HCP = Healthcare Professional

PPI = Patient and Public Involvement

PDNS = Parkinson's Nurse Specialist

GP = General Practitioner

SLT = Speech & Language Therapist

OT = Occupational Therapist

PUK = Parkinson's UK

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