










ORIGINAL ARTICLE

Managing Parkinson's during the COVID-19 pandemic: Perspectives from people living with Parkinson's and health professionals

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Abstract

Objectives: The aim of this study was to understand how people living with Parkinson's and healthcare professionals perceived their care management and interactions with health services were affected during the COVID-19 pandemic.

Background: During the COVID-19 pandemic, many governments introduced restrictions and services that support Parkinson's care management had to cease or be delivered remotely. These changes may have had an impact on the well-being of people living with Parkinson's.

Methods: A qualitative exploratory UK study was carried out. Semi-structured individual interviews with people living with Parkinson's and health professionals were recorded, transcribed verbatim and analysed using Braun's and Clarke's thematic analysis. Eleven patients and 10 health professionals were recruited between April and September 2020. The study was reported using the COREQ.

Results: Two main themes were identified. In the first theme, many patients and professionals reported that the COVID-19 pandemic made some people living with Parkinson's feel isolated and vulnerable due to disruptions to their social networks and usual activities related to Parkinson's disease care. However, other patients remained connected with their networks. In the second theme, patients and most professionals mentioned that some clinical practices were cancelled, delayed or transformed to remote consultation.

Conclusion: The COVID-19 restrictions had an impact on how people living with Parkinson's managed their care and in their interactions with healthcare services. Health professionals should assess the risk of vulnerability, social isolation, physical inactivity and confidence with remote consultations in people living with Parkinson's.

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This might inform a rethinking of existing clinical interactions with people living with Parkinson's towards a flexible, sustainable, person-centred care model.

Relevance to clinical practice: This study has shown that Parkinson's care management and interactions with healthcare services should provide personalised and flexible support. To meet this challenge, the design of the organisation of health services should include greater involvement of patients and person-centred care models.

KEYWORDS

care management, COVID-19 pandemic, nursing, older people, Parkinson, qualitative

1 | INTRODUCTION

Parkinson's is a progressive neurological condition affecting about 145,000 people in the UK (Parkinson's UK, 2018) and around 10 million globally (EPDA, 2021). Living with a long-term condition like Parkinson's can affect many aspects of the person's life and can also impact the wider family (Prakash et al., 2016). As there is currently no cure for Parkinson's, people living with Parkinson's (PwPD) depend on the management of the condition, consisting of medication, treatments and therapies to maintain their quality of life. The UK national guidelines state PwPD should have an expert review of their Parkinson's at least annually. During the COVID-19 pandemic, much of this usual care and support was disrupted in many countries (Cheong et al., 2020; Fasano et al., 2020; Helmich & Bloem, 2020). To our knowledge, there is limited evidence on how the COVID-19 pandemic has affected PwPD, their care management and interactions with health services, in the UK.

1.1 | Background

PwPD can not only experience motor-related symptoms such as tremor, muscle rigidity and slowness of movement, but also experience non-motor symptoms, such as pain, anxiety and depression (EPDA, 2021). Parkinson's is usually managed in the community, and self-management, combined with medication and other therapies, is considered a key component of managing Parkinson's (Kessler & Liddy, 2017). Furthermore, physical activity and social interactions are fundamental in maintaining their well-being and quality of life of PwPD (Oliveira de Carvalho et al., 2018; Subramanian et al., 2020). Studies have indicated that lack of physical activity and social isolation can be a risk factor for worsened health outcomes and increased mortality for PwPD (Oliveira de Carvalho et al., 2018; Subramanian et al., 2020), and thus, it is important for this population to keep physically and socially active as much as possible.

During the global COVID-19 pandemic, many governments gradually introduced national and local restrictions that impacted people's activities, health and well-being. As a susceptible clinical group (Antonini et al., 2020; Elbeddini et al., 2020), PwPD had to modify their care routines and the healthcare systems underwent changes in the ways clinicians and PwPD interacted in response to restrictions

What does this paper contribute to the wider global clinical community?

- People living with Parkinson's were affected to different degrees during the COVID-19 pandemic with some feeling isolated and vulnerable while others maintained social connections so these findings highlight the need to provide personalised and flexible support.
- In some cases appointments and services were cancelled or delayed because they could not be undertaken online or by phone so these results could inform guidelines on how to prioritise interactions with health services in Parkinson's disease management which could be transferable to other long-term conditions and other countries.
- The rapid transition into remote consultation and support provided exemplars for how flexible approaches may work for Parkinson's management in the community for some care services and some people living with Parkinson's

of the COVID-19 pandemic (Thomas et al., 2020). This meant that services that support Parkinson's care management had to cease or be delivered remotely. The diagnosis and follow-up of long-term conditions (such as PD) were affected by this service interruption in many countries (WHO, 2020). During that period, maintaining social interactions and physical exercise was difficult for many PwPD and this had an impact on their daily lives and well-being (Brooks et al., 2021; Elbeddini et al., 2020).

In the UK, a national report indicated that the lockdowns, the social distancing, the loss of routines and limited access to support and services to manage health conditions impacted the physical condition and well-being of millions of older people (Age UK, 2021). Specifically, the report highlighted that people's mobility, confidence, mood and independence were negatively affected. There have been other studies that reported experiences of PwPD during the COVID-19 pandemic in Europe, namely Spain (Santos-Garcia et al., 2020), Germany (Zipprich et al., 2020), Italy (Schirinzi et al., 2020), the Netherlands (van der Heide et al., 2020) and the rest of

the world, such as India (Kumar et al., 2020; Prasad et al., 2020), Egypt (Shalash et al., 2020), Canada (Angelescu et al., 2022) and USA (Feeney et al., 2021). For example, in Spain, the Netherlands and Germany, PwPD reported that, although they tried to remain active and social during confinement, most of them perceived that the COVID-19 pandemic had a negative impact on them and had worsened symptoms such as rigidity, fatigue, tremor, pain and concentration (van der Heide et al., 2020; Santos-Garcia et al., 2020; Zipprich et al., 2020). Anxiety, depression and fear about the current situation were reported in these and other studies (Angelescu et al., 2022; Shalash et al., 2020). However, due to differing healthcare provision for PwPD due to the National Health Service free at point of clinical need or the national coverage with Parkinson's disease Nurse Specialist, findings may not be applicable to the lived experience of PwPD in the UK.

To our knowledge, there is limited research that reports the experiences of PwPD and their family carers in the UK (Simpson et al., 2020) and no studies on the experiences of healthcare staff. This study will address this gap. It is important not only to understand both PwPDs' and clinicians' perspectives, but also how life and clinical practices changed with the aim of critically rethinking the support needs of PwPDs and approaches for future care provision for this population and services involved.

The aim of this study was to explore the perspectives and experiences of PwPD and healthcare professionals regarding the impact of the COVID-19 pandemic on the management of PD care and interactions with health services.

2 | METHODS

2.1 | Design

This paper reports on the first qualitative phase of a wider mixed-method study with a sequential exploratory design (OPTIM-PARK project). Findings from this qualitative exploratory study will inform the second phase of this mixed-method study to design and evaluate community-based interventions to support PwPD in four European countries (Denmark, Norway, Spain, UK). The present paper reports on the experiences of PwPD and healthcare professionals in the UK.

2.2 | Sample/Participants

A purposive sampling approach was used (Miles et al., 2014) to gather different perspectives and diversity in terms of types of gender, age, ethnicity, years of diagnosis/work experience and location. Participants were recruited between April and September 2020 in community settings, largely in the South and South West of England with one participant from Wales and two from London, representing rural and urban areas. Different strategies were used to recruit PwPD: advertisements with details of the study were shared through social media, local newsletters, Parkinson's UK local groups,

community organisations and the specialised neurological services. Adverts aimed at professionals were shared through social media and local newsletters. Snowball sampling was also used to ensure participants could suggest colleagues from different professional profiles. The study included all participants who had contacted the researcher to express an interest in participating. Following informed written consent, each interview began by gathering basic demographic data, was digitally recorded and later transcribed verbatim. The recorded interviews lasted 43–94 minutes (average 55 mins).

2.3 | Data collection

Eligible participants received a study leaflet from the researcher (CR) after responding to an advert about the study, which was placed within the relevant organisation or via social media explaining the study and inviting them to take part. Interested participants contacted the researcher (CR) indicating their availability and had the opportunity to ask questions. A mutually convenient time was arranged for a telephone interview.

Following written consent, individual semi-structured telephone qualitative interviews were used with both PwPD and healthcare staff to explore their views and experiences and also whether there had been any change due to COVID-19 restrictions. An interview guide was used based on patient and public involvement (PPI) consultations and study objectives to capture participants' experiences and interactions on how life and health practices had changed during the COVID-19 pandemic restrictions (see Table 1). Field notes were made during the interviews.

A shopping voucher (£10) was given to all participants as a 'thank you' gesture at the end of the study. Two researchers with extensive experience (CR and MCP) undertook all interviews over the telephone, apart from one which was carried out via online video conference. No relationship was present between researchers and participants prior to study commencement. Following the analysis, a session with members of the PPI group was held to verify the validity and relevance of the results.

2.4 | Ethics considerations

This study was approved by the University of Southampton Ethics Committee (48708) and the Health Research Authority (HRA), IRAS Number: 265184. Participants were informed of the purpose of the research, the possible interview duration, the recording methods, confidentiality, anonymity issues and data management. They were allocated a study number; all names were removed from written reports, and pseudonyms were used. All participants signed an informed written consent. Due to social restrictions during the COVID-19 pandemic, consent was digitally recorded and followed by the posting of the written consent, which participants signed and posted back to the research team before the interview. Participants were informed that their participation was voluntary and that they

TABLE 1 Interview guide

Questions for people with Parkinson's	Questions for healthcare professionals
Can you tell me about your experience of living with Parkinson's?	Can you tell me about your experience of providing care for people diagnosed with Parkinson's?
Has anything changed in relation to your experience of living with Parkinson's due to the COVID-19 virus?	Has anything changed in relation to your experience of providing care for people diagnosed with Parkinson's due to the COVID-19 virus?
Has anything changed in your way of caring for and managing your illness due to the COVID-19 virus?	Has anything changed in the way people with Parkinson's care for and manage their illness due to the COVID-19 virus?
Has COVID-19 had any impact on your ability to access any services, support or information?	Has COVID-19 had any impact on the ability of people with Parkinson's to access any services, support or information?
Has COVID-19 changed your interactions with healthcare professionals?	Has COVID-19 changed your clinical interactions with people with Parkinson's?

could withdraw at any time for any reason without affecting their rights. Participants were also informed that if they withdrew from the study, the information collected about them up to that point may still be used for the purposes of achieving the objectives of the study only. No study participant decided to withdraw from the study.

2.5 | Data analysis

The verbatim transcribed data were analysed inductively using thematic analysis in six steps (Braun & Clarke, 2006), with the aid of Excel[®] spreadsheet. All transcripts were repeatedly read, and preliminary interesting points were noted. Each line of each transcript was then coded to capture all interesting features related to the research questions. Following that, the initial codes were grouped together to reveal a similar topic/point. These grouped codes (initial themes) were carefully checked back against each transcript to review the meaning and redefine and ensure they related back to the original text. The themes were developed by the first author (DS) and were later presented and discussed with the second coder (MCP), who helped to refine them. The final themes were then formed keeping the participants' story as vivid as possible and illustrated with quotes from participants.

Previous conceptual work on the topic of living with Parkinson's was used as a framework (Ambrosio et al., 2015), which provided the general orientation and informed the data analysis more specifically by raising awareness, refining of constructs and providing key concepts related to the process of living with Parkinson's Disease.

2.6 | Rigour

To reduce biases, we aimed to interview PwPD and healthcare professionals from a broad range of ages and disciplines (see Table 2). In order to improve credibility, two researchers (DS and MCP) initially coded and categorised different interviews independently (Lincoln & Guba, 1985). The analysis began after the first interviews to identify data saturation (Lincoln & Guba, 1985). After the initial analysis, they met to discuss and refine the final themes and subthemes. Furthermore, the study was reported using the Consolidated criteria for reporting qualitative research (COREQ) (see Supplementary File S1) (Tong et al., 2007).

3 | RESULTS

All 21 participants (13 female and 8 male) were White British, 11 were PwPD (mean age 65.1 years, SD 12.7), and 10 were healthcare professionals (mean age 48 years, SD 9.4) (Table 2). Most of the PwPD lived in rural areas ($n = 5$), followed by urban ($n = 3$) and semi-rural ($n = 2$). The majority came from lower income ($n = 6$) (self-reported by participants according to the average income in the UK of £29,588 per year and three answer options, lower/ average/ higher) and had other illnesses ($n = 7$). Most healthcare professionals were female ($n = 8$) and had long work experience (ranging from 10 to 41 years) in their profession.

Two main themes were identified, each one with two subthemes:

- Theme 1. Impact on social support
- Subtheme Feeling isolated and vulnerable
- Subtheme Maintaining connections
- Theme 1. Impact on social support
- Subtheme Adjustments in usual healthcare and increased demand
- Subtheme Mixed reactions on remote consultations

3.1 | THEME1: Impact on social support

Both PwPD and health professionals noted that the COVID-19 pandemic had an impact on their social interactions, access to and support from family and their social support networks. Every person living with Parkinson's was affected differently, ranging from not being able to see family and health professionals, to not being able to attend their groups and other social activities. Although many felt isolated and vulnerable (subtheme 3.1.1.), others found ways to remain connected and active (subtheme 3.1.2.).

3.1.1 | Feeling isolated and vulnerable

PwPD reported that they missed their social networks and stated that they were afraid to meet even friends and family, due to

TABLE 2 Participants' demographic characteristics (N = 21)

No	Name (pseudonym)	Gender	Age	Status	Area
1	Sandra	Female	38	Clinical Psychologist	London
2	Katy	Female	38	Physiotherapist	Cornwall
3	Olivia	Female	59	Physiotherapist	Hampshire
4	Peter	Male	51	Parkinson's specialist nurse	Wessex
5	Mary	Female	63	Speech and language therapist	Southampton
6	Anna	Female	46	Geriatrician	Southampton
7	William	Male	51	Nurse Consultant	Wessex
8	Lisa	Female	35	Geriatrician	Southampton
9	Louise	Female	55	Speech language therapist	Southampton
10	Caroline	Female	44	Geriatrician	Southampton
11	Sarah	Female	76	PwPD ^a —Widowed, retired	Wales
12	Wendy	Female	71	PwPD—Married or in partnership, retired	Hampshire
13	Valerie	Female	49	PwPD—Married or in partnership, retired	Buckinghamshire
14	Jarvis	Male	52	PwPD—Married or in partnership, retired	Suffolk
15	Ted	Male	63	PwPD—PwPD- Widowed, working	Cornwall
16	Andy	Male	49	PwPD—Married or in partnership, working	Berkshire
17	Natasha	Female	61	PwPD—Married or in partnership, retired	Devon
18	Nick	Male	78	PwPD—Married or in partnership, retired	Hampshire
19	Monica	Female	56	PwPD—Married or in partnership, working	London
20	Ryan	Male	78	PwPD—Married or in a partnership, retired	Dorset
21	Colin	Male	83	PwPD—Widowed, retired	Dorset

^aPwPD: person with Parkinson's disease

concerns about virus transmission. As a result, they felt isolated, stressed and vulnerable.

'... I can't see my son, so I feel isolated because he used to come down quite regularly. I think people are a bit frightened of this virus, and they're feeling a bit isolated because contact with their relatives has been stopped'. [Natasha—PwPD]

Family routines of PwPD were disturbed during (and after) the first lockdown, it became difficult to travel to family or even plan for future family gatherings, so physical contacts were minimised, and tensions felt around the possibility of future interactions:

'Because of the lockdown, we can't visit [their children], or they can't visit. So that's been deep sadness. Really... So that's another hammer blow for us. All these things, I think they build up a certain amount of pressure, stress. You try not to think so, but they do... we do attend

church, but that's all been closed down... we've got quite a few friends, but we don't know when we're going to be able to see them all again....' [Ryan—PwPD]

Due to social distancing restrictions, many private and organised social activities were stopped. PwPD reported feelings of frustration and isolation because they could not continue their social activities. Some found this very frustrating and isolating as they could not do their usual activities related to their PD care (swimming, physical exercise classes and physiotherapy) and, most importantly, could not remain active.

'And we've had to give up the dance class on a Monday, exercise class on a Wednesday. And then there is table tennis, I used to do once a week... Well, we have a Zoom meeting on a Monday, Wednesday, and Friday just for half an hour... obviously all you can do is listen to the talk and that's it... I really miss that, not being able to do that [exercise classes].. - [Nick—PwPD]

'I like the swimming and the swimming helped me a lot with the physio but now it's closed. I feel it's a bit more tough now.' [Monica—PwPD]

Like the PwPDs, all health professionals also mentioned some of the interventions and programmes (e.g. dance, singing, tai chi and gym) that were considered helpful for PwPD, which had to cease due to COVID-19 restrictions.

'...and it is because people are getting worried because things were... they feel more vulnerable because the world was loosening up again... You're unable to access your normal coping strategies. So I've got one... a younger patient, who was absolutely climbing the walls purely because he was a gym bunny, he lifts weights.' (Peter—Parkinson's specialist nurse)

Healthcare professionals also explained that these disruptions in the daily activities of PwPD for coping with the PD might have an impact on PwPDs' emotional and physical well-being and on their PD's symptoms.

"...a lot of my patients are low in mood... because they aren't doing their clubs and their dance groups of whatever physically they're less mobile. I think, yeah they are definitely missing all those group activities.' (Lisa—Geriatrician)

Healthcare professionals highlighted that some services were cancelled and could not provide adapted support within the new circumstances. This was a particular issue for PwPD in the later stages, whose lives were affected negatively as they were left unsupported due to the impact of COVID-19 pandemic on the activities of the Day centres.

'I think [name of organisation] is really good for patients who are in clinic, like there's lots of things going on, things like tai chi going on across the city, singing groups, all sorts of stuff, that patients really like. But the ones that are out of bounds, there are lots of them, but they can't get out to them. What a lot of dementia patients do is they go to day centres and stuff and actually with COVID that has all gone wrong...' (Caroline—Dr/Geriatrician)

3.1.2 | Maintaining connections

Other PwPD reported that there had not been much change since the COVID-19 pandemic; reporting that they continued to get support from their family, friends and extensive social circles.

'Luckily, it is a very narrow friendly street so although we are all isolated and locked down, you have only got to put your head out of the window, and somebody is quite near you... I mean, we are not isolated here really. There is lots of people, I mean people come out and talk... There is plenty of help out there... If my neighbour has a [delivery] slot, she will say, "I have got a slot, do you need anything?" So, between us we have enough slots to go around Oh yes, that has been good' [Sarah—PwPD]

Some positive aspects of the lockdowns, workarounds and new means of interacting with others, such as increased contact and support from and closeness with neighbours, more time available, reduced need for travel and long commuting and ability to continue with certain social activities (e.g. meeting with friends and neighbours in their garden) were discussed. Those who lived in populated areas or had family living nearby appeared to be able to stay more connected.

'I guess it's been beneficial to me the Covid period because my days are easier, they're less physically demanding, you know, I haven't got to concentrate on driving the car, I haven't got to concentrate on having a conversation with my lift share mate... There's less pressure... I walk the dog early, have breakfast, have a shave and now I've got twice the time to do that it's great.' [Ted—PwPD]

PwPD welcomed the fact that voluntary organisations (e.g., Parkinson's UK and Salvation Army) remained operational, and some were able to adapt and move some of their support activities online. This enabled PwPD to still get access to information and support and even link up with PwPD from other parts of the country who they would not usually meet during face-to-face activities.

'The online [part of support] has stayed the same and perhaps got a bit stronger.' [Andy—PwPD]

'I think we had about five people joined in this last meeting from other parts of the country who had just discovered it on our website. So, potentially you could get hundreds of people watching [online]'. [Nick—PwPD]

PwPD indicated that they received significant emotional support from their extensive social networks, including voluntary organisations and online support groups.

'...I have got a volunteer picking up my pills, which could have been a real problem really, but there are lots of people helping... well this is the Salvation Army, but they sort of all got together.' [Sarah—PwPD]

These social networks proved helpful during the COVID-19 pandemic, when family, friends, neighbours and volunteers were helping with various practical tasks (e.g., shopping and picking up medication) offered social stimulation and emotional support.

'Emotional support from the online forums... Well, my group, the group that I set up, I've got a lot of friends in there... I'm in there every day... I support some people, and when I need it, people will support me. It's a very close group really'. [Andy—PwPD]

3.2 | Theme 2: Changes in health services and demand

Consultations and clinical reviews of PwPD had to be adapted due to social restriction measures implemented during the COVID-19 lockdown, especially for those populations that needed to shield due to their clinical vulnerability. Some of the clinical practices had to cease or be modified, and there was an increase in vulnerability and mental health needs (subtheme 3.2.1). Also, sessions that were normally delivered in a face-to-face format had to be adapted to a remote version (subtheme 3.2.2.), which was received with mixed reactions.

3.2.1 | Adjustments in usual healthcare and increased demand

PwPD reported that the COVID-19 pandemic had a negative effect on their management of their condition and the interaction and support from health professionals and treatments received. For some participants, this meant that they were unable to book their regular appointments, and in some cases, appointments and clinics were cancelled, delayed or undertaken online/over the phone.

'It was normal to go every single week to hospital for physiotherapy... [now] at home but it's not the same thing, like when you do in the hospital with somebody to watch you how to do [the exercises]' [Monica—PwPD]

For other participants, it meant that they could not have important face-to-face interactions, for example continue with treatments such as deep brain stimulation (DBS), physiotherapy, or clinical trial participation.

'This is where COVID has affected me because I really could do with going in for a reprogramming of my DBS and, of course, I can't go in... the nurses did try and do it over the phone and I did have an old programme on my system that they swapped me to which I could do on my handheld device. But if you want a proper reprogramming you have to be connected in the hospital to their laptop'. [Valerie—PwPD]

Participants who had other co-morbidities (e.g. cancer) or other health appointments (e.g., dental) reported that these services were also affected (postponed or cancelled) or carried out on online or over the telephone:

'I'm involved in a couple of trials at the moment, but that's all stopped because of the virus... The cancer services, that's stopped at the moment, and I've gone past my date that I should have a scan. I'm scanned on a yearly basis, but I'm waiting for that to come back now because obviously that stopped because of the virus'. [Andy—PwPD]

'The Parkinson's Clinic... has been suspended since the lockdown of course. So, the Parkinson's Outpatient Clinic doesn't exist at the moment'. [Nick—PwPD]

Similarly, the health professionals commented on how the prioritisation system for referrals had been clearly impacted by COVID-19, moving many consultations to telephone consultations because of the perceived risk of becoming infected if undertaking face to face in consultation. This was decided by the organising NHS trust to reduce appointments to allow for social distancing and cleaning, and was also based on clinical prioritisation for those PwPDs who needed face-to-face consultation or could manage with telephone consult.

'Basically, with COVID we are now focusing obviously on our high risk dysphagic patients so... We've had to prioritise our patients who are at risk of swallowing or choking and readmission to hospital...' [Louise—Speech and Language therapist]

Health professionals stressed the need to refer to NICE guidelines to develop their role and manage scheduling periodic consultations, or network with other services to support PwPD. Guidelines around consultation adjustments during and after COVID-19 restrictions were essential to understand how reviews for PwPD should now take place, and how often. The system was not considered sustainable or really supporting PwPD and carers to live independently in the community, with a perceived increased number of admissions. For example, Parkinson's clinics, perceived as an essential hub providing proactive services to prevent crises for PwPDs, were impacted by COVID-19 and were only seeing new PwPD for whom complications were not that prevalent:

'...part of the clinic is the education and part of the clinic is recognising that they're starting to develop and it's perhaps before they recognise it themselves, and certainly before it's reached a crisis point, and then you can get the services involved in a timely manner... I suppose the clinics were actually quite proactive... now [after Covid] I think they've gone from bringing patients in... every six months... to... I think they're just seeing the

new patients face to face... so the service has kind of been cut right back'. [William—Nurse Consultant]

Moreover, services were moving to online consultations, which were sometimes limiting their work and accuracy of assessments. In this regard, there were different perceptions across health professionals as some stated that they were reaching more PwPD, and therefore, online consultations due to COVID-19 were seen as a positive change. However, others reported that they were not able to see or prioritise the needs of PwPD at all as the focus of services shifted to COVID-19 related emergencies.

'... our referral numbers went down massively anyway, because I think it seemed to us that patients were doing their own risk assessments and they were like "oh we are high risk if we get Covid," so I am just going to manage, or whatever it was they would normally phone us for and try to get on with it myself...' [Sandra—Clinical Psychologist]

A further negative consequence of the affected health services mentioned by two professionals was the increase in the PwPDs' and families' vulnerability and mental health needs and consequent higher need for resources:

'With the Covid scenario... I have heard, anecdotally, I think some of the other nurses in the region have noticed this, a higher incidence of people experiencing psychosis, possibly because of the stress burden that they've had... in the last four weeks, the numbers of calls and emails have increased for me, so maybe just by half...' [Peter—Parkinson's specialist nurse]

'From the patients' point of view the thing that we've really noticed is, you know, during lockdown... is the impact mentally and physically that lockdown has taken. You know, a lot of my patients are low in mood, probably getting some mild depression'. [Lisa—Geriatrician]

Health professionals' support to manage emotional distress during the COVID-19 lockdown was extremely limited. They faced complex situations for which they often did not feel prepared and had to opt for a wider family approach especially for highly vulnerable cases living alone.

'Her husband died. So she was grieving. And then the Covid stuff hit. Now, she has got a really big family. And with the Covid stuff, she was missing, the company and the hugs... I ended up speaking to her family member, and it was quite obvious that there wasn't actually anything physical, it was purely an emotional response... I spoke to her granddaughter, and got an idea of what this woman's family life was like...' [Peter—Parkinson's specialist nurse].

3.2.2 | Mixed reactions on remote consultations

Most PwPD did not mind the change in format to remote consultations, but for some, it was not ideal. Only one participant mentioned a positive side, and he thought that *'they might be able to give more time if you haven't got to go travelling all over the place'* [Colin, PwPD].

The health professionals in the study had a more positive experience using remote consultations with the PwPDs, including those who were newly diagnosed, where they use other resources, reaching out to populations they could not work with easily before or improving the waiting lists for nurses' consultations:

'One of the physios and one of the OTs, they run a group at the local hospital (rural area) for newly diagnosed Parkinson's patients, and education group. But, all of those things they have stopped but I think now if things are going to continue like this, they will move to doing that online'. [Sandra—Clinical Psychologist]

'They [nurses] did have a massive waiting list, which really skewed the whole system, because the patient would get diagnosed, and then they were waiting, like, six months/a year to see the nurse.... But since Covid, like I said, they've completely eliminated their waiting list, because they've done it all virtually, and the system works a lot better' [Katy—Physiotherapist]

Some health professionals also mentioned the positive aspects of delivering online consultations such as being able to see more PwPD and thus run the consultations more cost-effectively.

'Certainly, the whole Parkinson's nurse service, the nurses are offering virtual consultations as their first choice and they're going to carry on doing that even if they can see people now, because it is so much more efficient for the nurses to have a virtual consultation that it is... and it's quicker for the patient, so they can potentially see the patient more times... they're not going to go back to clinics unless they absolutely have to.' [Katy—Physiotherapist]

Other professionals pointed out that virtual consultations could discriminate against older people and PwPD in terms of accessibility to health services.

'...managers are all... rubbing their hand and enjoying the fact that it is costing them much less providing these services because you've got clinicians just sat in front of a computer, not needing a clinic room or not needing to visit... [but] if we're not going to be allowed to go back to what we were doing before, it's going to discriminate older people and people with Parkinson's...' [William—Nurse Consultant]

Interestingly, some health professionals noted that another advantage of the remote consultations was the involvement of their PwPD's family members during and after COVID-19 lockdown. The health professionals also commented on the shifting towards more of a family approach during online/telephone consultations, that is to obtain valuable information from the family for the assessment of the PwPDs, which was considered a positive outcome of adaptations made to health service management and organisation during the COVID-19 pandemic.

'This is a challenge for some people in themselves, because a lot of people with Parkinson's don't like using telephones. But one of the things that I have noticed then is that a lot of people, because of that, their partners are more involved in their lives, because they're in that wee bubble...' [Peter—Parkinson's specialist nurse]

'Covid has given us some solutions. The IT [information technology] is not perfect, videoconferencing would be great, but phoning, you just realise actually a phone call is good enough, if you have seen the patient three or four months ago. Even if partners are on speakerphone, so speakerphone is the best thing to have a three-way conversation-partner, patient and me.' [Anna—Geriatrician]

There were also barriers identified to using these resources and access to other organisations' activities that could prevent some PwPD from accessing the information and training, such as communication difficulties and unfamiliarity with online technology. Healthcare professionals mentioned that some PwPD could be disadvantaged because they did not use the Internet or tablets and therefore, opted for telephone consultations.

'so, they kind of had buddies and peer support and things, and that worked quite well in the face-to-face sessions, even if it was informally, people were, like, swapping numbers and chatting about their experiences, which is really powerful in group settings, and you obviously lose all of that virtually, because you do not have that level of communication... the reasons that most of them didn't attend [online session], a couple of didn't attend because they just weren't confident with the technology, even though they probably could have done... but what I'm also hoping is that as people get more familiar with the idea of getting healthcare virtually... they might be a bit more accommodating...' [Katy—Physiotherapist]

Other participants preferred telephone rather than Internet to overcome communication difficulties they could encounter at early diagnosis stages.

'It's all about information as well, because people, the internet is a disaster area waiting to happen for some, and you've got people at the other end of the spectrum who are... they are not internet savvy at all, and they don't know who to talk to, and it's just... how do people manage a new diagnosis, the stress, it's always nice to have somebody on the other end of a telephone, and you can have a chat and just double check things' [Peter—Parkinson's specialist nurse]

4 | DISCUSSION

The findings indicate that during the COVID-19 pandemic, the social networks and support of PwPD living mainly in southern England were greatly affected. Some PwPD managed to maintain their connections and social support networks, whereas others were left isolated and unsupported. This was perceived to be problematic as it was affecting not only their physical but also their mental health. It is unclear why some PwPD managed to remain active and whether there were some personal and social factors that enabled or impeded this. Some participants suggested they had strong neighbourly connections and family members, or other social network members close by who could provide some support and assistance. Available support at home and adoption of new exercises were found to be associated with better outcomes (Kumar et al., 2020). Evidence suggests that some PwPD engaged with online exercise classes, but questions remain as to whether benefits of online provision are similar to face-to-face interactions (Langer et al., 2021).

This study adds to the existing evidence that older people with chronic conditions were negatively affected from the COVID-19 pandemic (Age UK, 2021). PwPD in this study felt isolated which is consistent with previous studies worldwide that reported increased perceptions of loneliness, psychological stress and isolation as a result of the COVID-19 pandemic (Angheliescu et al., 2022; Kumar et al., 2020; Santos-Garcia et al., 2020; Subramanian et al., 2020). Similarly, in studies from India (Kumar et al., 2020; Prasad et al., 2020), Germany (Zipprich et al., 2020), Italy (Schirinzi et al., 2020) and Spain (Santos-Garcia et al., 2020), PwPD reported increased symptoms (motion and sleep problems) and reduced rehabilitation. What is important to note is that loneliness and social isolation have been associated with poor outcomes and worsened quality of life for PwPD and should not be overlooked (Subramanian et al., 2020). Although some participants experienced stress and isolation, there was not adequate social and mental support offered to them or accessible to them. Some of the existing mental health initiatives were paused due to COVID, and this resulted in a worsening of some PwPDs' emotional well-being. Although there is some evidence from our findings and previous research (Antonini et al., 2020) that PwPD are indeed a vulnerable group, yet they were not perceived as a UK healthcare priority during the COVID-19 pandemic.

Another interesting finding was that during the COVID-19 pandemic, healthcare professionals reported less contact from PwPD, and PwPD, reported less contact with the health services, although for different reasons. From the perspective of health professionals, that could be perceived as an advantage, encouraging PwPD to take more control and self-manage their condition. But, it can be also seen as a sign of further vulnerability for the PwPD and their families indicating that they were left unsupported, and the families were left with the difficult role of caring for a complex and long-term condition. Evidence to date suggests potential negative consequences of worsening physical and mental health symptoms, social isolation and reduced physical activity levels (Age UK, 2021; Langer et al., 2021), but the full impact can only be assessed once we have emerged from the COVID-19 pandemic. Research confirms that the stress of the COVID-19 pandemic has exacerbated some long-term conditions (such as PD) with many people experiencing more severe symptoms, or progression of their condition irreversibly (Age UK, 2021). It is also reported that family carers had been affected negatively as well, as indicated by a UK survey (Simpson et al., 2020) and other studies (Age UK, 2021; Dang et al., 2020).

As we learn to live with COVID-19, and the potential of other pandemics in the future, we need to ensure continuity of care for people living with chronic conditions. It is important that personalised and tailored strategies of care and support reach this vulnerable group, and that health care is flexible enough to withstand and adapt to change, in order to ensure continuity of care. Appropriate social prescribing programmes and virtual social engagement provided by various voluntary organisations should be offered to PwPD, especially in relation to the online activities and virtual consultations which involve small risks for virus contagion and studies have reported that PwPD are interested in these (Ketigian et al., 2022; Shalash et al., 2020). Online consultation can offer many benefits to the PwPD and their families (Schirinzi et al., 2020), although it has been reported that its use has been linked to PwPD with higher income and higher education (Feeney et al., 2021). Most of the participants in this study were able to use some virtual technologies and did not perceive them as a barrier, although they may not be representative of the wider older population living with Parkinson's. However, other studies reported that digital poverty, technological difficulties (e.g., connection issues and lack of IT literacy), communicational difficulties (e.g., simultaneous speaking) and lack of socialisation and intimacy could be barriers to PwPD joining online activities (Angheliescu et al., 2022; Elbeddini et al., 2020; Mañago et al., 2021; Norman et al., 2021). Thus, remote provision of care and support could potentially be offered as an alternative option post-COVID to some care practices or patients with no serious health risks and for those who are able to use such approaches (while also ensuring those that are not left behind). This could potentially ease some pressure on neurological services (Thomas et al., 2020). Future studies could explore whether and how widespread the implementation of remote services is, the perception of service users and healthcare

professionals in other countries and regions and the perceived benefits of online exercise provision in comparison with face-to-face provision, particularly in relation to intensity, safety and amount of physical activity achieved. It would also be interesting to explore how decisions are made on which services to keep online to maintain the benefits of online provision (less travel, less cost, more people can be seen, access to clinicians from across the UK would be possible) and which services necessitate face-to-face continuation. Finally, future studies could investigate the impact of COVID-19 on the family carers and their views on telehealth.

4.1 | Limitations

Although we aimed for a variety of characteristics in terms of age and profile, we recruited a relatively small sample and all participants were of White British ethnicity, so our findings may not be transferable to other PwPD and healthcare staff. In addition, the fact that most PwPD in the sample were able and happy to use some virtual technologies may limit the transferability of our findings. However, our sample also included people living with multimorbidities and from a wide geographical area (Southern England, Eastern England, London and Wales), including rural and urban areas. Second, to ensure rigour in the analysis two researchers were involved in the analysis of the data but their professional background and personal experiences may have influenced the analysis. Nonetheless, while recognising these limitations, the team met and discussed any disagreements and refined the final themes and selected quotations.

5 | CONCLUSIONS

By expanding our knowledge of the ways that COVID-19 has and is still affecting the lives of PwPD and the health professionals involved in their care, we can reflect on current practices and explore the development of more tailored health service provision, and potential interventions to support PwPD to live with Parkinson's better, even during times where face-to-face support from clinicians may be limited. Assessing the risk of vulnerability, social isolation, physical inactivity and confidence with remote consultations might inform a rethinking of existing clinical interactions with PwPD towards a flexible, hybrid (online/face-to-face), sustainable and person-centred care model. Offering social prescribing programmes, online consultations, and other remote support, for some PwPD and family carers, could provide another avenue for supporting PwPD to live better with Parkinson's.

6 | RELEVANCE TO CLINICAL PRACTICE

As we continue to live with coronavirus and vaccination advances, it is important to continue facilitating ongoing care for PwPD by

widening participation and access to health care through incorporating online provision with face-to-face provision based on the experiences and lessons learned during the COVID-19 pandemic. We should also consider and explore self-management strategies to help PwPD to deal with challenges and consequences of this COVID-19 pandemic (Helmich & Bloem, 2020). It is also important to consider and expand implementation of virtual consultations and therapies (e.g., online exercise classes) to include additional therapies and reach diverse populations (Feeney et al., 2021). The design of all new services should include greater involvement of patients and person-centred care models to provide personalised and flexible support.

AUTHOR CONTRIBUTIONS

All authors meet the criteria for authorship, and all those entitled to authorship are listed as authors. MCP, HR, SE, DK and MVNS involved in conceptualisation. CR and MCP collected the data. MCP, DK, CR, HR, DK and SE contributed to formal analysis. MCP, DS and MVNS involved in manuscript draft preparation. All authors involved in manuscript reviewing and editing and approval of the final article.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interests.

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