The impact of Covid-19 restrictions in Ireland on symptom severity in mild to moderate Parkinson's disease

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Abstract

Introduction: The COVID pandemic and public health restrictions significantly impacted those living with neurological conditions such as Parkinson's Disease due to the curtailment of therapies. Patients attending a single centre movement disorders clinic reported reduced physical activity and quality of life during the pandemic. This study aimed to assess the impact of pandemic restrictions on Parkinson's Disease symptom severity in people with mild to moderate Parkinson's Disease.
Method: A cross-sectional study design with a convenience sample of 20 people living with mild to moderate Parkinson's Disease was adopted. A telephone survey questionnaire was completed to measure changes in symptom severity on the 14 most common Parkinson's Disease symptoms. Data were analysed using descriptive statistics.
Results: Nineteen participants completed the survey. Participants frequently reported a decline in nine symptoms of Parkinson's Disease; bradykinesia, rigidity, walking, sleep, mood, memory, quality of life and fatigue. Nil changes in freezing were reported. No change was reported in the nonmotor symptoms of constipation, speech and pain in 75, 65 and 95% of participants, respectively.
Conclusion: Findings of this study acknowledge the negative impact of restrictions on the motor and nonmotor symptoms of Parkinson's Disease. Flexibility to access and delivery of service should be considered to mitigate any future potential restrictions.

Introduction

Parkinson's disease (PD) is a complex neurodegenerative disorder characterised by motor and nonmotor symptoms due to the neurodegeneration of the nigrostriatal pathway (Galvan and Wichmann, 2008). It is the second most common neurodegenerative disease worldwide with approximately 10 million people living with the condition (Marras et al., 2018). In Ireland, there are approximately 12,000 people living with PD (Parkinson's Association of Ireland, 2022). The management of PD focuses on symptom management through pharmacological therapy and early assessment and intervention by allied health professionals such as physiotherapists and occupational therapists (Goodwin et al., 2008; Parkinson's Association of Ireland, 2022). It is well recognised that maintaining functional and physical activities are key factors in staying well and minimising deterioration in people living with PD (NICE, 2017). The rate of progression of the disease can vary extensively from person to person. For instance, a variety of studies have reported an of average annual progression of between 2 and 7% as assessed using a variety of outcome measures such as

the unified Parkinson's disease rating scale, the Hohen and Yahr scale and the Schwab and England scale (Miller et al., 2019). This variability in progression rate is likely due to the heterogeneity of study methodologies and the use of cross-sectional study designs which are likely to inflate progression rates (Marinus et al., 2014).

Coronavirus (COVID) is an infectious disease caused by the SARS-CoV-2 virus. The majority of people infected with the virus experience mild to moderate levels of illness. Older people and those with underlying medical conditions are at risk of developing serious illness compared to younger healthy individuals (World Health Organization, 2022). Although people living with PD are not more susceptible to infection than the general population, people living with PD who contract COVID are likely to experience a marked

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deterioration in their motor and nonmotor symptoms (Cilia et al., 2020). Moreover, an international study reported that COVID infection in people living with PD resulted in worsening motor function, increased levodopa dose requirements, fatigue, cognitive disturbances and sleep disruption (Leta et al., 2021).

The COVID pandemic has severely disrupted the lives of people at all levels of society but especially those living with chronic conditions such as PD (Schirinzi et al., 2020). The general population has been required to adopt social distancing measures, adhere to restrictions and in some cases 'cocoon' or 'shield'. These measures have had severe effects on physical and emotional well-being throughout the wider populations (Adams et al., 2020; Duan and Zhu, 2020; Van der Heide et al., 2020). COVID restrictions and shortages of medical staff due to redeployments and COVID infection have resulted in a curtailment of healthcare services, socialisation and community support groups for people living with PD which has had a deleterious effect on motor and nonmotor symptoms (Elbeddini et al., 2020; Shalesh et al., 2020). A recent study from a Dutch PD cohort reported that 47% of people living with PD were less physically active due to pandemic restrictions which coincided with a subjective worsening of all PD symptoms especially rigidity, fatigue, tremor, pain and concentration (Van der Heide et al., 2020). Moreover, the social isolation resulting from these restrictions has had a significant negative impact on the quality of life (QoL) of people living with PD (Van der Heide et al., 2020).

The movement disorders clinic at St James's Hospital, Dublin, provides care for people living with PD with access to physiotherapy (PT) and occupational therapy (OT) on an outpatient basis. The therapy services are predominantly accessed by individuals with mild to moderate PD (Hohen and Yahr 1–3) whereas those at a more advanced or complex stage of the condition can avail of a day hospital service. A total of 115 referrals to OT and PT were received from January 2020 to June 2021. Best practice guidelines state that those living with PD should have access to medical and therapy services throughout the disease trajectory (NICE, 2017). However, access and delivery of care changed due to COVID restrictions. For instance, clinics were adapted to a telehealth platform from March 2020 until July 2020 when face-to-face reviews were permitted and a blended model of care was adopted. In addition, community services and supports were suspended resulting in reduced access to exercise classes, day centres and PD support groups. When face-to-face services resumed, an initial hesitancy by service users to attend was reported by therapists. However, service users remained motivated to engage with therapy services. Anecdotally, service users reported deconditioning and reduced physical activity during the pandemic with some associated worsening of symptoms. Therefore, the aim of this study was to investigate the impact of the pandemic on

Table 1. Symptoms of PD assessed.

Symptom
Rigidity
Fatigue
Tremor
Pain
Attention
Memory
Mood
Walking
Constipation
Freezing
Bradykinesia
Sleep
Speech
Dyskinesia
Quality of life

symptom severity reported by people with mild to moderate PD attending for PT and OT.

## Methods

Study design and setting

A cross-sectional study design was used. A questionnaire was completed over the phone with community-dwelling individuals living with PD who attended the movement disorders clinic of St. James's Hospital Dublin, and who accessed PT and OT services within the hospital. A convenience sample of 20 individuals who had been referred for and attended both PT and OT between January 2020 and June 2021 ($n = 115$) was selected. In order to participate in the study, individuals were required to provide informed consent to complete the questionnaire. The questionnaire was completed over the phone by a healthcare professional (PT or OT) involved in the patient's care. All questionnaires were completed between June and July 2021. Approval to complete the project was granted by the research and innovation office of St. James's Hospital, Dublin (Research and Innovation project number 7072).
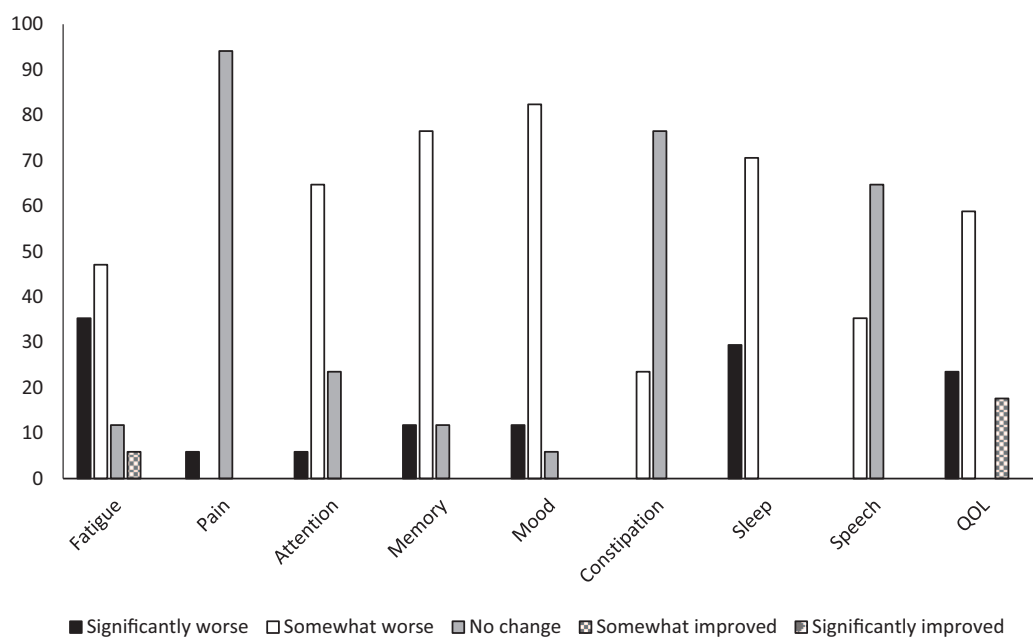
Questionnaire

The questionnaire was adapted from that used by Van Der Heide et al. (2020) and focused on 14 symptoms of PD (See Table 1). Participants were required to rate the perceived change in each symptom over the previous 12 months over a Likert scale. Each symptom was rated as being 'significantly worse', 'somewhat worse', 'no change', 'somewhat better' or 'significantly better'.

Data analysis

Descriptive statistics were used to analyse the questionnaire responses using Microsoft Excel. Data are mean ± standard deviation unless otherwise stated.
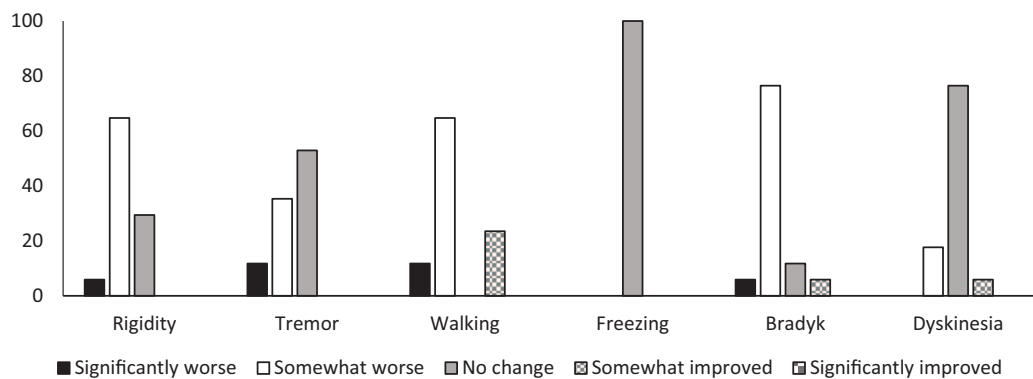
Figure 1. Motor symptoms.

Figure 2. Nonmotor symptoms.

Results

Study participants

Nineteen of the participants from the convenience sample completed the questionnaire giving a response rate of 95% (male/female: 11/8; mean age 63.3 ± 11.3 years, range 44–81 years). Two participants had recovered from COVID.

Motor symptoms

Self-reported changes in the severity of motor symptoms are shown in Figure 1. Bradykinesia, rigidity and walking were the most commonly reported motor symptoms to have declined with over 70% of respondents reporting a worsening of these symptoms. No respondents reported a change in freezing.

Nonmotor symptoms

Self-reported changes in the severity of nonmotor symptoms are shown in Figure 2. A marked decline in all nonmotor symptoms was reported by the participants with the exception of constipation, speech and pain. Every participant reported a decline of their sleep quality while 94% reported a decline in their mood. Over 80% of participants reported a decline in their memory and fatigue level, and 82% of participants reported an overall decline in their QoL.

Discussion

This study used a convenience sample of 20 community-dwelling individuals with mild to moderate PD and examined the impact of COVID restrictions on the severity of motor and nonmotor symptoms of PD. The main findings are that (1) An overall decline in nine PD symptoms was reported by participants, (2) that the most commonly reported motor symptoms to decline were rigidity, walking and bradykinesia and (3) the most commonly reported nonmotor symptoms to decline were sleep, mood, fatigue memory and overall QoL.

Our findings are in agreement with recent studies in Dutch and Egyptian PD cohorts that reported a marked reduction in physical activity and a significant decline in fatigue, walking ability, rigidity and tremor during periods of COVID restrictions (Shalash et al., 2020; Van der Heide et al., 2020). The deterioration in walking reported by our study participants is likely due to the curtailment of exercise classes, community services and social outlets due to COVID restrictions. In addition, cocooning or shielding may have contributed to a reduction in physical activity levels thus, causing a reduction in walking ability and confidence. A recent study in older Irish adults found that after a 3-month period of cocooning or shielding, 40% of participants (n = 150) reported a marked decrease in physical activity levels, physical fitness and physical health (Bailey et al., 2021). In PD, best practice guidelines state that to minimise symptom severity and deterioration the maintenance of functional and physical activity through regular therapy and exercise are essential, while recent evidence suggests that structured regular physical exercise can attenuate symptom progression in PD. (NICE, 2017; Schenkman et al., 2018; Van der Kolk et al., 2019). Therefore, it is likely that the loss of regular therapy services and exercise opportunities due to COVID restrictions resulted in the observed decline in self-reported walking ability in the present study. Although significant numbers of therapists adopted telehealth in an effort to continue therapeutic input, the well-known limitations of this media may have limited its ability to outweigh the impact of public health restrictions. Telehealth has been shown to increase access to services; however, limitations such as lack of digital skills, poor internet connectivity and lack of access to technology can limit its impact (Haberlin et al., 2020). It would be of benefit for further studies to investigate how therapy delivery can be adapted to patient needs during future pandemics.

It is of note that several studies have shown a significant correlation between stress and deterioration in the motor symptoms of PD. For instance, worsening of tremor, rigidity and pain have all been shown to be linked to levels of stress and anxiety in the PD population (Boman, 1971; Van der Heide et al., 2020, Zach et al., 2015). It is possible that stress and anxiety experienced by participants due to the pandemic may have physically manifested as a decline in physical function.

Many studies have demonstrated that public health restrictions during the pandemic correlated with a deterioration in QoL in people with and without PD (Antonini et al., 2020; Luis-Martínez et al., 2021). These restrictions have had a particularly deleterious effect on those living with chronic neurological conditions such as PD who experience both motor and nonmotor symptoms. The findings of the present study echo this sentiment with the observed deterioration in the majority of the nonmotor symptoms of PD. The most commonly reported nonmotor symptoms to deteriorate

in the present study were sleep, mood, fatigue, memory and overall QoL. This is in agreement with Van der Heide et al. (2020) who found that the nonmotor symptoms most impacted by public health restrictions were fatigue, pain and concentration. In addition, a study in an Italian cohort living with PD found that the most effected nonmotor symptoms included anxiety, fatigue, cognitive impairment and psychosis (Antonini et al., 2020). Moreover, an Italian study based in an inpatient unit, found that ten weeks of lockdown led to a decline in cognitive and behavioural symptoms in addition to a reduction in motor function in those with PD and mild cognitive impairment (Baschi et al., 2020). There are several factors that could have contributed to the decline in nonmotor symptoms observed in this study. Firstly, fatigue and reduced sleep quality are well-known consequences of psychological stress and anxiety (Van Dongen et al., 2003); therefore, it is possible that the stress induced by the pandemic may have resulted in a reduction in sleep quality and increased fatigue in these participants. In addition, Helmich et al. (2020) reported that people living with PD are more susceptible to stress due to reduced dopamine levels which could further exacerbate changes in sleep patterns and fatigue levels. Secondly, the lack of social interaction and isolation due to pandemic restrictions may have resulted in the reduced QoL and low mood reported by the study participants. This idea is supported by a recent review that reported that social distancing and loss of social interaction negatively impacted the mental health of those with PD (Elbeddini et al., 2020).

In contrast to other studies, we observed no change in self-reported pain levels in this study cohort during the pandemic. Pain is common symptom in PD with over 80% of individuals with early stages of PD reporting pain (Beiske et al., 2009). Furthermore, stress and anxiety have been linked to exacerbated pain responses in the general population (Reinhardt et al., 2013). One possible explanation for this observation may be that our cohort did not experience any pain pre pandemic that could have changed during the study period. This explanation most likely also explains the observations that 75% of participants identified no changes in constipation, which can also be effected by stress and anxiety (Yu et al., 2018). However, due to a study limitation of no baseline measures of constipation, we are unable to ascertain how many of our participants experienced this symptom pre pandemic.

In a somewhat unexpected finding, approximately 20% of participants reported an improvement in QoL. Possible reasons for this may be due to the newly available option of working from home resulting in a more controllable pace of life and increased time with family. This idea is supported by Kowalski et al. (2021) who identified benefits for the general population from public health restrictions adopted during the pandemic such as a slower pace of life and more time for family and friends. Furthermore, an Australian

study recognised the health associated benefits from working from home such as greater flexibility to allow for exercise, healthy eating and engage in nonwork activities (Pirzadeh and Lingard, 2021). Since our sample included younger individuals with milder forms of PD, it is likely that they experienced these benefits resulting in an overall improvement in QoL.

Limitations

There are several limitations to this study which the authors wish to acknowledge. The small sample size limits the generalisation of the study results to the PD population. However, our convenience sample represented approximately 20% of our clinical population and the response rate to the questionnaire was high (95%). Despite the small sample size, useful insights are provided for descriptive purposes. The study results were in line with those of larger PD cohort studies (Van Der Heide et al., 2020).

The limitations of self-reported questionnaires are well documented. Recall bias could have affected the study results. The timing of the study is another potential limitation to the study. This study was completed in June 2021. Pandemic restrictions have been ongoing since March 2020; thus, the study responses may not capture the initial impact of COVID restrictions but may more so represent the chronic impact of fluctuating levels of restrictions. The questionnaire accommodated this limitation by asking participants to reflect on changes since the commencement of public health restrictions to give a true reflection of their impact on PD symptom severity.

The use of physical objective measures would have strengthened the study. This would have allowed an objective comparison of symptom severity pre pandemic and during the pandemic. These additional measures could have helped to differentiate if changes in symptoms were due to deconditioning or a general deterioration in symptoms. Furthermore, current evidence would suggest that PD symptoms progress at between 2 and 7% per year (Miller et al., 2019); thus, pre-pandemic measurements would have allowed for a clear demarcation between normal symptom progression rates and rates accelerated by the pandemic restrictions.

Conclusion

The main finding of the present study is that pandemic restrictions had a negative effect on the severity of motor and nonmotor symptoms in people living with PD. It is likely that the curtailment of therapy services, cessation of community services and reduced opportunities for social interactions were the cause of the decline in symptom severity. The results of the present study add to the existing evidence highlighting the impact of pandemic restrictions on people living with PD.

This study highlights the importance of continued therapy and community supports for those living with PD in order to prevent deterioration in symptoms and functional ability. The flexibility to access and deliver therapies should be considered to mitigate the impact of any future public health restrictions. A further survey study reflecting on the past year since the lifting of pandemic restrictions would be of interest to assess if function has been restored since the reopening of face-to-face therapies and community supports.

Key findings

- Pandemic restrictions have had a deleterious effect on the motor and nonmotor symptoms of PD.
- People living with PD experienced a decline in nine symptoms during the pandemic.

What the study has added

This study highlights the impact of pandemic restrictions on people living with mild to moderate PD. The importance of continued therapy and community support amidst public health restrictions are recognised.

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