

An in-depth, longitudinal analysis of people with Parkinson's experiences during the COVID pandemic

Jane Simpson

Professor of the Psychology of Neurodegenerative Conditions

Faculty of Health and Medicine

A complementary study....

- Qualitative, in-depth individual interviews with 10 people
- Recruited from Parkinson's UK
- 6 men and 4 women, from the North West
- Online interviews in May 2020, August 2020, May 2021 with same people
- Mean age 63.8 years and living with the disease for 8 years
- Most were managing at home without additional help, although one participant had 24-hour live-in care since the start of the pandemic
- Generally, participants were relatively independent and with no severe psychological distress at the time of interview.

Data analysis

- We used thematic analysis to analyse the data and used a specific theoretical perspective called illness uncertainty
- Illness uncertainty is defined as “the inability to determine the meaning of illness-related events [that] occur in situations where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking” (Mishel, 1990, p. 256).
- While uncertainty can be associated with positive outcomes (freedom to choose etc), more commonly experienced negatively.
- E.g., associated with increased anxiety, depression and anger, and less hope, higher illness intrusiveness (Mullins et al., 2001) and fewer practical coping responses (e.g., Webster, Christman, & Mishel, 1988).
- High levels of Illness uncertainty in people with Parkinson’s



When this came into being, it sort of, like, made it more of a challenge'

How COVID 19 highlighted/amplified existing fears and difficulties relating to the uncertainty of Parkinson's

Fears include:

- Hospitalisation
- Independence
- Identity and choice
- Loss of function



I do think it's gonna be the next few years before we are in control'

Practical and psychological efforts to manage an uncertain situation

- All participants attempted to gain control of the uncertainty of the situation
- Some attempts more successful than others: acceptance, community feeling, online engagement, hope, following rules, belief in experts, vaccine uptake
- Participants also accepted that the uncertainty they were experiencing was additional to the uncertainty normally experienced as part of having Parkinson's and that each of the two sources of uncertainty (Parkinson's - and COVID- related) amplified the other.



‘I feel as though, well, everybody is in it together’

Benefit finding as a way of acknowledging the positives from the lockdown restrictions

“In some ways it has been a relief to let go of some responsibilities. I am lucky to live in a retirement village with lovely grounds, so I can walk.”

“People offering help more, thinking of one another more [...] plus more time to pursue hobbies and try new ones. At least — for us oldies!! The weather has certainly helped as well. I’m not that proficient with all this techno stuff but am getting better almost without realising it! Another bonus.”



I like to think, if I did get it... I can throw it off'

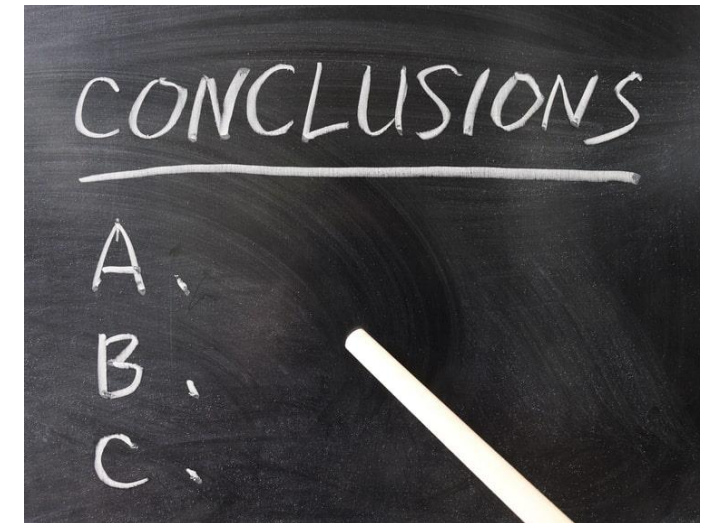
Future managing in the context of uncertainty

- Participants had fears relating to:
- contracting COVID-19
- Possible permanent effects on their health and well-being – lack of exercise a major concern
- Cancelled health appointments - very much a deeper concern in later interviews as some Ps not had face to face contact and paid for private neurology
- Being stereotyped in an unhelpful way when they considered others might be assessing their risk.
- Lockdown/distancing effects- queueing difficult



Conclusions

- COVID and Parkinson's = 'double whammy'
- Even in early interviews the coping strategies for managing illness uncertainty had been honed and were primed to cope with the additional COVID-19 challenge.
- A reflection of the practical skills and responses needed to manage a complex chronic condition which all the participants reported having had to develop?
- Uncertainty had become embedded in participants' lives and therefore had given them the skills to cope (reasonably successfully) with additional uncertainty.



Why is this study useful?

- By understanding individuals' reactions over time – and, importantly – what has helped, we can:
 - Liaise with patient groups to best inform support
 - Liaise with health care professionals about psychologically informed work to cope with the illness uncertainty, with an emphasis on opportunity and hope. Stress negative effect of wholly online health care and lack of face to face consultations for movement assessment
 - Individual interventions, e.g., mindfulness, have demonstrated effects in relation to illness uncertainty

