**‘It’s a double whammy’: a qualitative study of illness uncertainty in individuals with Parkinson’s in the context of COVID-19**

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Abstract

Objectives: The purpose of this study was to explore the experiences of individuals with Parkinson’s during the initial stage of the COVID-19 pandemic (during the first UK lockdown period) through the theoretical lens of illness uncertainty.

Design: Thematic analysis was carried out on individual semi-structured interviews with a focus on illness uncertainty and taking a realist, phenomenological perspective.

Methods: Interviews were carried out via telephone with ten individuals (six men and four women) with Parkinson’s recruited from Parkinson’s UK, a UK-based charity for people affected by Parkinson’s.

Results: Four themes were constructed from the interview data: 1) ‘*When this came into being, it sort of like made it more of a challenge’*: how COVID 19 highlights/amplifies existing fears and difficulties relating to the uncertainty of Parkinson’s 2) ‘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; 3) *‘I feel as though, well, everybody is in it together’*: Benefit finding as a way of acknowledging the positives from the lockdown restrictions; 4) *‘I like to think, if I did get it… I can throw it off’:* future managing in the context of uncertainty.

Conclusions: Participants reported a range of implicit and explicit strategies to cope with the ‘double whammy’ of uncertainty. While these were generally successful in maintaining well-being, it is important that such successful accounts are used to help inform interventions and strategies for those in different situations and who might need additional support.

Introduction

Chronic illnesses often cause uncertainty for the individual (Mast, 1995; Mishel, 1999). While not without criticism (Hurt, Cleanthous, & Newman, 2017), Mishel’s theory of illness uncertainty (1999) remains the most influential work on illness uncertainty and has been reformulated specifically for chronic illness (Mishel, 1990, 2014). This theory highlights four factors that tend to form part of the illness uncertainty experience: ambiguity about the state of the illness, complexity regarding treatment and healthcare systems, lack of information about diagnosis and seriousness, and unpredictability about course and prognosis (Mishel, 1988). Mishel defines illness uncertainty 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 and can confer some psychological benefits (Mishel, 1988), it is more commonly experienced negatively. Indeed, illness uncertainty, when not managed well, is not only psychologically uncomfortable, but has also been associated with lower psychological well-being, including increased anxiety, depression and anger, and other maladaptive emotional and cognitive responses, such as less hope, higher illness intrusiveness (Mullins et al., 2001) and fewer problem-focused coping responses (e.g., Webster, Christman, & Mishel, 1988). Given the difficulties/impossibility of eliminating uncertainty in unpredictable chronic conditions, the optimal management of uncertainty has become an important clinical topic (Etkind, Bristowe, Bailey, Selman, & Murtagh, 2017).

Illness uncertainty has also been theorised in relation to coping response and is an important influence at both stages of Lazarus and Folkman’s theory of stress and coping (Lazarus & Folkman, 1984). As part of this theory’s primary appraisal stage, where manageability is assessed, an illness appraisal of uncertainty may increase the perception of the illness as one with which it is difficult to cope. In this formulation, uncertainty has been conceptualised as a cognitive stressor (Johnson, Zautra, & Davis, 2006). This primary appraisal then influences secondary appraisal, which is the individual’s assessment of the available resources – personal, systemic, societal - to manage the threats and challenges of the illness and its symptoms. Therefore, a secondary appraisal of general uncertainty incorporates the broader societal context in which an illness is being managed. Where that wider context is also characterised by uncertainty, this may increase stress and result in increased/different attempts to manage that additional uncertainty.

One condition where illness uncertainty features prominently is Parkinson’s disease, hereafter called Parkinson’s, the preferred term of the largest UK charity for the condition, Parkinson’s UK. This is a neurodegenerative condition which is mostly idiopathic, i.e. of no known cause (Kalia & Lang, 2015). While considered mainly a movement disorder, it can also be associated with a number of other physical, cognitive and psychological difficulties. The illness trajectory is unpredictable and response to medications – which are symptomatic due to the unavailability of a cure – can also become increasingly variable as the disease progresses (Nijhof, 1996; Pinder, 1990). The path to diagnosis can be fraught, and effective health care communication is often reported as lacking (Anestis, Eccles, Fletcher, French, & Simpson, 2020; Warren, Eccles, Travers, & Simpson, 2016).

Considering the overlap between the experiences of people with Parkinson’s and the four characteristics of Mishel’s theory of illness uncertainty (complexity, unpredictability, lack of information and ambiguity), it is not surprising that high levels of uncertainty have been well established in this population (Choi et al., 2018), including among those with younger onset (i.e., before age 50; Ravenek, Rudman, Jenkins, & Spaulding, 2017). Moreover, individuals with Parkinson’s are also generally reported to experience uncertainty negatively (Ahn, Lee, Chu, & Sohn, 2017; Pinder, 1990), especially due to lack of clarity about the symptoms (e.g., confusion about what is related to Parkinson’s and what might be a product of normal ageing), concerns about the unpredictability of the future, and consequent avoidance of long-term planning (Haahr, Kirkevold, Hall, & Østergaard, 2011). In turn, a number of maladaptive strategies have been argued to result, at least in part, from this uncertainty, including impulse control disorders (e.g., excessive behavioural responses; Simpson, McMillan, & Reeve, 2013). Higher levels of uncertainty in individuals with Parkinson’s have also been shown to be associated with increased disease severity, lower perceived social support, and lower levels of resilience (Choi et al., 2018). However, a number of informal strategies have been reported to reduce uncertainty, such as focused information-gathering and strategies aimed at increasing perceived control (Eccles, Murray, & Simpson, 2011).

Since January 2020, the threat of the COVID-19 pandemic has led to unprecedented responses globally (Ahir, Bloom, & Furceri, 2020). Even in countries with a certain confidence in health care systems, wider support social structures (both formal and informal) and economic stability, this has been progressively replaced with a degree of uncertainty much higher than in other recent pandemics (Roy et al., 2020). However, although some provisional research has indicated that people with chronic illness are more at risk of psychological difficulties in the current global situation (Horesh, Kapel Lev-Ari, & Hasson-Ohayon, 2020), very little is known about the experiences of people with neurodegenerative diseases such as PD during the pandemic, especially in terms of mental health. Moreover, little qualitative research exists regarding uncertainty in individuals with Parkinson’s, although quantitative research has identified this as important, and the COVID-19 pandemic presents a particular set of circumstances likely to exacerbate uncertainty in PD. Consequently, the current study offers an opportunity to provide a more in-depth understanding of both uncertainty (and how this might be exacerbated and change in response to societal and health care changes) and required personal behavioural changes in response to the COVID pandemic.

Method

Design

 The current study examines a subset of the data being collected as part of a longer-term, qualitative examination of the COVID-19 outbreak for people with Parkinson’s. The main arm of the qualitative component of this project focuses on exploring each participant’s daily life, health status and activity levels prior to the COVID-19 outbreak, understanding their experiences of social distancing/self-isolation and any impact on their lives and wellbeing. The approach to data collection and analysis is one of pluralism (e.g., Clarke et al., 2015); that is, data have been collected in a manner that allows different analyses to be conducted in order to produce “multiple, complex and varied understandings of phenomena” (Clarke et al., 2015; p.182). Having conducted the first set of interviews with participants, the present study analyses the resultant data in order to understand illness uncertainty in individuals with Parkinson’s in the context of COVID-19. Thematic analysis (Braun & Clarke, 2006) is used here as it is a flexible approach which can accommodate both inductive and deductive approaches to analysing data. Our own approach sits in between these two poles: while the data have not been collected with theory in mind, the analysis does draw upon theory and empirical findings regarding illness uncertainty to identify data which illuminate these particular aspects of participants’ experiences. Moreover, the data set offers particular advantages in this regard. As the data were collected without this aim in mind, neither the original protocol nor questions asked of participants directed them to discuss experiences of uncertainty. This means that to the extent participants raised these issues, they were done so spontaneously and therefore reflected their own concerns and priorities.

Participants

Ten individuals (six men and four women) with Parkinson’s were interviewed in May 2020 in the UK. Their mean age was 63.8 years and, on average, they had been living with the disease for eight years (Table 1). All participants were recruited online via Parkinson’s UK, the UK’s largest charity dedicated to the condition. Most of the participants were managing at home without additional help, although one participant had 24-hour live-in care since the start of the pandemic, likely due to their advanced stage of illness (i.e., Stage 4; Hoehn & Yahr, 1967). Participants were generally younger (*M* = 63.8) than is reported more generally (Kalia & Lang, 2015) and with a mean of 8 years since diagnosis. Generally, therefore, the sample was relatively independent, functioning well and with no reported signs of severe psychological distress at the time of interview.

Procedure

An invitation to take part in the study was sent to individuals via Parkinson’s UK’s mailing lists. Those who expressed interest were then sent the participant information sheet and contacted to answer any further questions. Of twelve individuals who expressed their interest, two could not participate due to not being contactable or having a diagnosis different from Parkinson’s. Ethical permission was granted from the first author’s academic institution (REF: FHMREC19077).

All interviews were conducted by two authors (JS, AE) via telephone and on an individual basis. A semi-structured interview approach was adopted, consisting of open questions exploring individuals’ experiences during lockdown. Interviews were digitally recorded and transcribed verbatim. They were conducted between early to late May 2020 when UK Government guidance included restrictions on personal freedom (limited time for exercise, no social contact outside the immediate household) and changes in health care availability, with routine appointments being cancelled and only some re-scheduled; Simpson, Eccles, & Doyle, 2020). In addition, at the time of the interviews, many individuals with Parkinson’s were taking additional measures such as shielding, which meant only contact within a household and no going out beyond house/garden.

Analysis

Data were collected via semi-structured interviews and subject to thematic analysis. Braun and Clarke (2006) argue that thematic analysis can be used with different theoretical frameworks. In this study, themes were derived from a focus on illness uncertainty, taking a realist, phenomenological perspective. That is, a close relationship is assumed between how people think, behave and what they say about these and that the language they use to describe such thoughts and behaviour is reflective of their understandings and meanings. To begin with, each transcript was read to identify themes from a psychological perspective and with a focus on the phenomena being researched (expressions of illness uncertainty). On each interview transcript space was left on the left side of the text to record summaries and to make initial interpretations. Anything considered of significance to the research topic was noted as an initial code in the right-hand margin of the text. This helped summarise initial interpretations and formed the basis when searching for patterns across the data set. Codes generated from all interview transcripts were grouped iteratively. Throughout the process, themes were constantly reviewed to ensure they had sufficient supporting data. In this way, coding and generating themes from the data was an on-going process.

Principles outlined by Yardley (2008) were used to ensure quality. The analysis was conducted by the first author but then discussed with the other authors, alongside the transcripts to ensure rigour, transparency and coherence, and that the work was grounded in the data (Braun & Clarke, 2006). All researchers considered the findings alongside their knowledge of Parkinson’s and/or older adults, to assess the sensitivity to the context of existing research (Yardley, 2008) and credibility to the reader. Verbatim quotations are also provided to enhance transparency of the analysis (Elliott, Fischer, & Rennie, 1999) while having described the recruitment method and participant demographics situates the sample (Yardley, 2008).

Results

Four themes were created from the data:

1. ‘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

This theme illustrates how existing fears and concerns associated with managing the uncertainty of living with Parkinson’s were amplified during the lockdown period. These fears include those relating to hospitalisation, independence, identity and choice, and fears of loss of function.

The fear of hospitalisation was either based on actual previous experience or negative expectations. Specific anxieties relating to hospitalisation were around the necessary medication potentially not being available at the right time given the other priorities that medical staff would be facing:

*P5 - So, the big thing with Parkinson’s is you should get it [medication] on time. And the number of pills I'm taking are many and varying. I would worry that, if they'd known, if that was put aside and cause they're concentrating on oxygen and breathing and what have you. How would I react, how would it be? I've never gone without medication more than half an hour or so I've been late,*

Other fears included the isolation and fear of medical procedures such as being on a ventilator. These fears were also anxiety-provoking:

*P2 - If it got to that on the ventilator and then it would set off a lot of other things with your Parkinson's, your Parkinson's wouldn't just go away. Me thinking about it, I'm now shaking.*

Hospitalisation also had a negative symbolic value, representing a belief that life was potentially at its end.

As well as specific fears about hospitalisation, other more general fears relating to the psychological effects and implications of living with the uncertainties of the condition during the epidemic emerged. For example, for one participant with a carer who had previously only visited for a few hours a day, COVID had resulted in him deciding that he needed 24-hour support, and the carer therefore moved into his house. While this conferred some benefits in terms of safety and support, it also resulted in a loss of independence. Similarly, this participant felt ‘lunged at’ by the full-time carer, guessing the participant was going to fall, and wanting to help:

*P1 - because outside, I have no balance problems. Inside they {carers} see me wobble, they don't know that I know I am wobbly and I'm about to correct it.*

The restrictions intensified the limits already placed on individuals with the condition. As participant 2 commented:

*P2 - The inability to go somewhere you wanna go, even if you didn't wanna go, the choice is gone from you. The choices have been lessened.*

Participants felt *“as though you are prisoned”* (P2), with negative effects on identity and beliefs around their role in their domestic partnership:

*P4 - I can't go shopping on my own, which I didn't do before, I went with my husband but I felt I was contributing at least.*

Participants reported fears around the loss of independence, which were amplified due to the decision to put people with Parkinson’s on the ‘vulnerable’ list. This curtailed social events and the option of using other contacts to take part in social events:

*P8 - And because I'm labelled as someone with a problem, who is vulnerable. Then people are making decisions for me, and I'm losing independence even more. That would be a good way of putting it, yes losing your independence. So, my wife has to take me, whereas I would usually have several other options, she's the only person that could take me.*

The loss of individuality also seemed to have occurred for some, with the Parkinson’s label now determining more than previously how individuals were both regarded and treated. For example, participant 3 had been working in school and wanted to continue providing support to the children of key workers. However, he was encouraged to be ‘furloughed’:

*P3 - I was made to realise that, I was sort of, not trouble, but indicated quite strongly that perhaps I shouldn't... I shouldn't really be volunteering, it wouldn't be a good idea to do that particular one anyway, which was a bit disappointing, but... I don't know, I'm in this medium, high risk register, but I don't feel medium, high risk ‘cause I am fairly young and I have Parkinson's. I think Parkinson's is in the high-risk register because it's an older persons' disease and, obviously, the older you get, the greater the risk.*

Finally, the effects of the COVID restrictions on deteriorating physical function were also a cause of concern:

*P7 - I didn't feel too bad, apart from the fact that I've been diagnosed with Parkinson's, I drag my left leg a little bit when I'm walking on the flat, I 've lost strength in the left hand, not too much wrong with me really. Whereas now I feel there's something wrong.*

Such actions lead to concerns that Parkinson’s symptoms would gain more prominence in any assessment of general overall physical ability and their individual ability would be overshadowed by narratives which over-emphasised the importance of their Parkinson’s.

2. ‘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

This theme details how all participants attempted to gain control of the uncertainty of the situation, with some attempts more successful than others. 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.

The association of Parkinson’s with uncertainty, outside of the COVID-19 situation, was noted by all participants:

*P2 - You know, it keeps you on your toes and you don't know what's gonna happen. That's the uncertainty of Parkinson's, you don't know how you 're gonna be like in the next half hour.*

For many participants, their approach to the additional uncertainty created by the UK Government response to COVID, was pragmatic and focused on acceptance:

*P9 - I think even, they're talking about opening some shops next week but then they say you can't touch anything and you can't this or that. Life is going to be quite different, but it's going to be different for everybody, we've all got to cope with it and get on with it. Erm, again it's something I can't change and we've all got to do, so, just get on with it.*

Others managed by not only accepting the situation but also the restrictions. The restrictions seemed to provide some certainty and helped create a feeling of control:

*P2 - So, I'm all for rules and regulations, ‘cause I like to obey by the rules and regulations. If you tell me to do something, I will do it.*

Other efforts to become in control resulted in being practical and positive, learning (or ‘embracing’) new technology such as Zoom (often to facilitate social contact) and opening up their learning more generally (reading new books or exploring new areas of knowledge). Being flexible in relation to timeframes for a resumption of ‘normality’ was also important.

*P2: Yeah, I think there's light at the end of the tunnel. Ι've moved my goal post now, this is to get out of the lockdown.*

The importance of psychological strategies to maintain a sense of control was also emphasised. Positive comparisons of self to others were used to mitigate the effects of the restrictions and to maintain self-esteem; These comparisons were used for specific aspects of the restrictions (*P5 - We've got a large garden at the back of the house, so it doesn't feel penned in like, those, you know, fifth floor in a high rise flat with 3 children type of things, don't know how you'd cope)* but also for overall comparisons:

*P6 - I mean, my auntie who lives in (town), she is in her 80s, she has long-term health problems and she's on her own. So, she's in worse situation than us.*

In terms of practical strategies, it was also important to make plans after lockdown and to have faith and hope that events would be re-scheduled. Such plans were often detailed and carefully considered:

*P5 - We have plans ready for our ability to call the Wednesday meeting [of support group] and have it safely. I got a broom, I measured a brush handle, a sweeping brush handle. And if I have it out with my arm, and the handle stretched horizontally, it's 2 metres*

Hope was clearly articulated for a return to ‘normal’, with events considered ‘not cancelled but postponed’ (participant 10). Positive expectations related to the resumption of specific activities (‘I'd love to be able to think that in the non-distant future, perhaps with a face mask on, perhaps we'll be able to go in the same car for a day out somewhere, for a drive, you know’: participant 7) but also for a general end to the pandemic through the discovery of a vaccine:

*P7 - And I do think it's gonna be the next few years before we are in control probably, but again, I think they are making promises that they can't stick to, I don't think the vaccine is going to be here in September like they're saying, I think it's twelve months away.*

Participants also discussed their faith in experts and how knowledge improved their sense of control over the situation:

*P7 - but I got a good friend, she's a research microbiologist and she directs me, she’s involved in all this, so I get quite a bit of inside information, so... I probably reacted to things before the general public did.*

The psychological toll of dealing with COVID-19 against a backdrop of also managing a serious health condition was acknowledged by all participants. Some participants were also able to accept the negative feelings they occasionally felt:

*P2 - Well I say to people 'Everyone feels it's difficult with this lockdown, but my life was difficult before this anyway, so it's even more difficult now’. I think there's a little bit of self-pity but I'm entitled to that I think, sometimes.*

The theme therefore showed acknowledgement of the additional difficulties caused by the virus but often these challenges had been met or psychologically managed by reframing the issue. As participant 5 noted: ‘I was due an appointment to be sent out at by the end of April. And I'm loathed to ring I think erm, possibly they've got enough on at the moment, er, to me it's a query as opposed to a problem, I haven't got a problem’. Attempts to increase control and reduce uncertainty were clear and references to ‘increasing control’ were common across transcripts.

3. ‘I feel as though, well, everybody is in it together’: Benefit finding as a way of acknowledging the positives from the lockdown restrictions

This theme describes the finding that, despite the challenges, participants were able to see positives in the situation both on an individual and societal level. These benefits were important in balancing the potential psychological damage from having to manage an additional set of stressors.

Many participants reported an increase in personal resilience; as Participant 2 indicated, ‘it's [COVID-19 situation] made me even stronger’. It was felt that societal changes necessitated by COVID-19 had caused a welcome re-assessment of previous priorities:

*P2 - It's given everyone a bit of a kick up the backside. I think society in general will benefit… family and friends and loved ones are more important than anything else and I think it might make the world a better place,*

Indeed, many accounts detailed how community cohesion and the strengthening of bonds with neighbours had increased. Activities had changed, with the overarching result being a more satisfying distribution of their time:

*P3 - We're closer to the neighbours than we even were and me and my wife are in a committee for the local community. My next-door neighbour, who is 86, I think, we do shopping for him when he needs, I give him a phone call every day, check he's alright, that sort of thing. So, it's changed, some of the things we are not doing, but some things we are doing.*

It was also apparent that the societal experience had also led to a sense of ‘togetherness’ which helped mitigate the ‘difference’ often felt by individuals with Parkinson’s:

*P2 - To some degree I feel as though, well, everybody is in it together, the COVID, we are. So, I do feel a sense of belonging to others.*

Where negatives were experienced these were also mitigated by the sense of this being a shared community response:

*P7 - I can't say I don't get down with it occasionally, but I think everyone is getting down.*

Another positive experienced was the release from some of the everyday pressures of managing the condition. While previously medication regimes had been strictly adhered to, the changes in social routine dictated by the need to restrict social contact had also, perhaps paradoxically, brought some relief. The deliberate decision to release control of their medication regime was experienced as psychologically liberating:

*P4 - So, in some ways, it's been easier. I don't have to worry about making sure I 've taken me tablets so that I can go to the pub on Monday night for the quiz and walking, walk in or out alright, which is my priority.*

Others had also appreciated the lessening of some social obligations as a *“sabbatical from my normal life”* (P10). This then had a positive effect on levels of stress and well-being:

*P10 - Yes, I think so, yes. That's right, less things, less commitments, commitments, that's the word I'm looking for. I don't have the commitments I used to have, which used to make me stressed. I was worried that I might go off when I'm out or have a fall or whatever. I'm a lot more relaxed when I'm at the house and garden with my husband, yeah.*

While such benefit finding (Helgeson, Reynolds, & Tomich, 2006) can be common in individuals with illnesses, the benefits here had the effect of mitigating the psychological challenges and threats to positive self-identity which the participants had worked hard to develop since the diagnosis of Parkinson’s.

4. ‘I like to think, if I did get it… I can throw it off’: future managing in the context of uncertainty

This theme describes how participants viewed the uncertain future, both generally and with specific reference to their condition and symptoms. While fears were discussed relating to contracting COVID-19, a similar level of anxiety was expressed about the lockdown situation causing more permanent effects on their health and well-being. Cancelled health appointments were acknowledged to be source of concern. It was commonly felt that Parkinson’s would compound difficulties in controlling the assessment of all types of risk – either by creating difficulties in the assessment of the specific risk or by being stereotyped in an unhelpful way when they considered others might be assessing their risk.

All participants expressed some anxiety for the future:

*P6 - Well, I am really worried, because I don't think this is over with. I am not being pessimistic, I 'm being realistic really, because I know it can spike again and I 'm really worried about that.*

For some, however, adopting a more *laissez-faire* attitude was made in the context of their condition and the belief that their life-expectancy was limited:

*P8 - I think I've got to the point now where …because I've got such a serious problem I'm getting to the point where, you know, I wouldn't say I'm 'cavalier' about it, but at the most, I have no fear. Because my life long prospects are not that great, so I'm almost thinking 'bugger it'.*

Anxiety was also expressed that the physical changes they had experienced during the lockdown restrictions might become permanent. Their condition was viewed as a potential impediment to re-attaining previous levels of activity:

*P7 - I've become more dormant, more lethargic and I'm hoping that when everything's lifted and we go back to the walking, my health will come back to me, but with the Parkinson's, I'm not sure about that really.*

Moreover, the anxiety associated with the risk of going out after lockdown was considered to have the potential to exacerbate Parkinson’s symptoms.

*P2 - But if I was to go out, I'd become, my tremors cause me problems, if I went out, I'd be more anxious cause of people. So, I'm not saying I wouldn't go out, but I'd be anxious going out now because of the COVID, so I'd stop bringing attention to myself and I'd probably be shaking.*

A further challenge in assessing risk was difficulty in differentiating between problems exacerbated by the COVID restrictions and the deterioration in Parkinson’s symptoms:

*P5 - But since the lockdown it's been worse in terms of, half an hour beforehand I'm due, I get the warning signals that I'm due [ to take medication] and I look at my watch and 'what's going on? I feel bad' but they seem to wear off more quickly, which can't, I mean it can't be the virus cause I haven't got it. But my body is reacting differently... and my 'not good' feelings are coming more often.*

*P9 - It's easy just to sit about, watch TV and read the paper. So, I don't know how much of that is actually the COVID {situation], but I do think that the Parkinson's is worsening as well. So, unfortunately, I think I've got the double whammy:*

Assessing the uncertain future was therefore of concern to all participants, although strategies to deal with this differed. The assessment of the future was complicated by their condition and, for many participants, what was felt to be an overreliance on generalisations around the condition.

Discussion

As a general overview of the data, many of the same negative and positive predictors of mental health response reported in the non-Parkinson’s population during the COVID pandemic were evident here such as enhanced social interactions benefitting well-being (Lades, Laffan, Daly, & Delaney, 2020). The findings also confirmed that anxiety relating to COVID-19 was a specific and additional source of stress, with both psychological and somatic consequences (Shevlin et al., 2020). Clearly there were also individual differences in how participants were able to tolerate this additional level of uncertainty created by the COVID-19 pandemic (Taha, Matheson, Cronin, & Anisman, 2014). These differences also resulted in different coping mechanisms, with some participants taking major steps to manage the situation (e.g., the decision to have 24-hour support) with others still wanting to work and be regarded as having the same level of risk as they would without Parkinson’s. It was also interesting to note that the community experience and feeling of ‘all being in the same boat’ mitigated the stigma that can accompany some enforced health quarantines (Brooks et al., 2020). It should be noted that ‘taking control’ has voiced as an important goal for people with Parkinson’s (Simpson et al., 2020) and given that illness uncertainty has also been theoretically formulated as loss of control (Wiener & Dodd, 1993), attempts to gain control were for many part of the coping process.

It was clear from Theme 1 that the ‘double whammy’ of living with Parkinson’s and dealing with a global pandemic both accentuated existing challenges and created new ones. These challenges were both physical and psychological, and served to amplify the fears and concerns generated from living with an unpredictable chronic condition. However, in response, many of the empirical and theoretical responses to managing uncertainty both from an illness perspective and more widely were present in the participants’ narratives. As outlined in theme 2, these included a broad range of attempts to regain control including following rules/guidance, referring to experts, making detailed plans and, where control was not possible, adopting a non-critical approach to their own emotional reaction. These attempts resulted in participants generally considering they were managing well, or as well as they could expect to. As can be seen in theme 3, participants were also able to see the positives of the consequences of the pandemic, another indication of the wide range of strategies used to manage the uncertainties caused by the illness and amplified by the pandemic. This finding is consistent with several theoretical approaches, perhaps most notably the theory of cognitive adaptation (Taylor, 1983; Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000).This theory proposes that perceiving benefits in response to a chronic stressor can be viewed as a cognitive strategy employed to mitigate the negative impact of a disease. Moreover, one of the hypothesised functions of benefit-finding is to gain mastery, seen here as an overarching attempt to maintain control in the face of an extremely challenging situation (Taylor et al., 2000). On this basis, the theory argues that benefit finding can reduce adverse health outcomes by reducing distress, which can result in a number of other ways in which health and well-being can be maintained (Taylor et al., 2000). Benefit finding as a way to manage illness uncertainty is a common response to chronic illness and it is possible here that the strategy has also been extended to provide similar support for managing the effects of the pandemic. Theme 4 indicates how participants had decided to evaluate risk, a key factor in dealing with uncertainty, in the context of the personal and global uncertainties.

For managing uncertainty in chronic illness (as opposed to other illnesses), Mishel (1990, 2014) suggests that growth and adapting to a new value system are important goals. In order to achieve this position, consideration of the four stages of managing uncertainty is useful: 1) understanding the causes of uncertainty; 2) perceiving uncertainty as a threat or opportunity; 3) attempts to manage or maintain the uncertainty according to whether it is a threat or opportunity; 4) the state of adaptation that results from implementing coping efforts. This study has provided evidence consistent with this formulation in that the themes confirmed that participants understood the causes of the uncertainty in their lives from both the illness and the pandemic, were able to judge these uncertainties as conferring both threats (e.g., from hospitalisation) and opportunities (e.g., to connect more with their neighbourhood), and manage accordingly. For most participants they demonstrated an adaptive position where they had recorded personal growth and adapted to a new way of being, albeit with hope for some return to previous activities in an unspecified future. The timescale for this development was relatively short – only four months from the announcement of the pandemic to the interviews – which suggests that the coping strategies for managing illness uncertainty had been honed and were primed to cope with the additional COVID-19 challenge. Perhaps this proactive problem-focused approach reflects 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 their lives and therefore had given them the skills to cope with additional uncertainty. A number of strategies were used to manage the uncertainty, decided upon after careful consideration and in response to, for example, the level of impairment felt, social support available and consideration of wider resources. In this way, it can be seen that Lazarus and Folkman’s conceptualisation, with illness uncertainty and the pandemic-related uncertainty affecting firstly primary and then secondary appraisals, was also supported.

Limitations

This study has a number of limitations. It is clearly not being suggested that all individuals with Parkinson’s will have the same generally adaptive response to the double threat posed by the uncertainties of their condition and the pandemic. The sample was self-selecting, with access to the internet and with IT skills, and, as noted in the Participant section, was generally younger, supported by spouses/other family and relatively well physically. Moreover a directed focus on illness uncertainty in the interviews could have produced further insights than available from the current study. That is, although we identify it as a benefit that we were able to explore participants’ spontaneously produced discussions of illness uncertainty, an interview that focussed specifically on these matters would allow further opportunities to deepen an understanding of this.

Clinical implications

Despite calls for more research on how to manage uncertainty (Shaha, Cox, Talman, & Kelly, 2008; Wright et al., 2009), interventions designed specifically for this are still scarce. Those interventions which have been developed (e.g., Germino et al., 2013; Hoff et al., 2005) have often included a range of tools including relaxation training and reframing threat related illness uncertainty cognitions to ones emphasising opportunity.

Intervention studies have indicated that illness uncertainty can be reduced by many of the techniques implicitly used by participants in this study - for example, emotion regulation and psychoeducation. Other factors are also suitable targets for intervention – for example social support, illness support, establishing confidence in health care. Discuss of coping mechanisms is an important part of managing illness uncertainty. Our ﬁndings are consistent with those of Mishel (1990),

who argued that if the coping strategies are effective,

adaptation will occu

Health care communication outside specific interventions is also important (Madar & Bar-Tal, 2009; McCormick, 2002), especially if framed in a way which supports hope, and the tendency for consultations with neurologists, specialist nurses and other health professionals to be cancelled during this pandemic is therefore worrying (Simpson, Eccles, & Doyle, 2020). A recent review on how nursing support can reduce illness uncertainty indicated that organising effective patient trajectories through the health care system is important, and this is emphasised in times of health care crisis (Hansen et al., 2012). Other interventions which can augment patients’ tolerance for uncertainty may also be helpful. Mindfulness-based interventions can allow participants to tolerate uncertainty generally (Nekić & Mamić, 2019) and provisional evidence has shown they can be effective in people with Parkinson’s in improving general well-being and psychological distress (see Zarotti et al., in press, for a recent review)). Furthermore, although reduction in tolerance of uncertainty has not been formally measured as an outcome in mindfulness studies with people with Parkinson’s, it has been reported as an outcome in qualitative evaluations (Fitzpatrick, Simpson, & Smith, 2010).

In conclusion, this study has shed light on the experiences of individuals with Parkinson’s at a time of an unprecedented international health crisis. While not without significant challenges, participants reported a range of implicit and explicit strategies to cope with the ‘double whammy’ of uncertainty. While these were generally successful in maintaining well-being, it is important that such successful accounts are used to help inform interventions and strategies for those in different situations and who might need additional support.

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Table 1. Participant demographic and clinical characteristics

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| P | Age at interview 1 | Gender | T since diagnosis | T since onset | Living status | Main PD symptoms |
| 1 | 67 | Male | 13 years | 13.5 years | Lives alone (carer 24/7 during lockdown) | Poor balance, Shuffling, Hallucinations |
| 2 | 60 | Male | 5 years | 6 years | Lives alone | Resting and action tremor, impaired fine motor skills |
| 3 | 59 | Male | 3 years | 5 years  | Lives with wife (and daughter during lockdown) | Resting tremor |
| 4 | 63 | Female | 5 years | 6 years | Lives with husband | Rigidity, shuffling, freezing |
| 5 | 66 | Male | 10 years | 11 years | Lives with wife | Shuffling, fatigue, (difficulty walking, falls), loss of smell, memory problems |
| 6 | 65 | Female | 8 years | 12 years | Lives with husband | Tremor, falls, freezing, dyskinesia |
| 7 | 62 | Male | 4 years | 3 years | Lives alone | Loss of strength in left leg and hand, loss of synchronisation in the left leg and hand, rigidity, fatigue |
| 8 | 63 | Male | 9 years | Not able to pinpoint | Lives with wife (and daughter during lockdown) | Posture problems, pain, shuffling |
| 9 | 71 | Female | 5 years | 7 years | Lives alone | Tremor, freezing, pain, poor movement coordination, poor blood circulation |
| 10 | 62 | Female | 18 years | 6-9 months | Lives with husband | Falls, freezing, poor movement coordination |

Extra quotes – expect will be taken out

1

*P1 I couldn't put up with the, the repair work they have to do and the time it takes for a night on the ventilators needing 8 people to turn me in bed and I 've got a chance that I am not going to get any better, so I don't want to be any worse and with there's a lot recovery, required, afterwards, my body is just not fit enough for that*

*P10 - I am missing going to the supermarkets and to get to choose what I want (as opposed to online shopping) it stopped me impulse buying, but I enjoy impulse buying,*

2

Faith in experts

*P5 - it's such an unknown disease. Parkinson’s or no Parkinson’s we don't want to find out too much about it so to speak. I hope the experts will inform us when hopefully it's over at some stage, more about it.*

4

*P6 - So, I don't know how I'll feel when we are actually set free.*

Effect on relationships

One man’s relationship had stopped due to covid. Others had stressors… caring relationships so important so any fracture would be serious:

*P3 - Because, she's been doing all the shopping and I haven't and that's a little bit unfair on her, erm, cause it's a (???) on the most stressful times for her during the week is when she gets in the car and goes to meet other people and I get out of that, so, that causes a few bad vibes, but nothing terminal or anything like that.*

*P4 - I think the only thing I want to say is if I've lived on my own, it would be a different story. Obviously, because I've got my husband here and he's very supportive, so he's, you know, done the shopping when needed to, on his own, and anything that needs doing he will do and... if you're on your own you'd be a lot more worried I think about being able to get essential supplies and so on, unless you got family close by.*

And for other the situation seemed a little unreal:

*P10 - there's nobody around us and we are just staying in our house and garden and we haven't, we heard friends of friends who had it, but in a sense, it feels like it's not real, we are in our own little world and I just can't believe the numbers that come on television that say almost forty thousand people have died in the UK. It just bamboozles me,*

*P9 - I certainly think I've not, I can't do as much walking at the minute as I was doing beforehand. So, I mean I started the walking, the five miles a day to keep my muscles strong and I was told that was the best thing to do. So, I can't work out in my head, whether it's the less walking, cause I only do a mile or two a day now or whether it's just the disease progressing or whether it's just older age.*

*P4 - and I try to keep myself fairly fit, so I wasn't too worried that I was put in a vulnerable group, cause I didn't think that applied to me really. You know... I know obviously certainly with advanced Parkinson's, it's different, if you got respiratory problems and that sort of thing, swallowing and so on... But I've not had that kind of thing yet. So, no I don't feel any more vulnerable than anybody else really.*

*P3 - hate being in hospital. I absolutely hated it. I didn't think it would be that bad, but I couldn't wait, I was only in for one night. I had the operation and stayed overnight and left the evening on the second day. I couldn't wait to get home, didn't like being in the hospital at all, so... yeah. That wasn't good.*

*P4 - That did worry me when I had the symptoms, I thought 'Oh my goodness', you know, 'I have to go into hospital’. That would be horrible.*

As participant 8 commented, when asked whether he would worry about going into hospital:

*P8 - Yeah, I would yeah, I mean, you don't know if you're gonna come out.*

Potential addition here or theme 4, cancellation and uncertainty around cancellation of medical appointments

P1 - Well, the vast majority has shut down, I don't think I 've been to a medical appointment now since February

P9 - Now, I should have an appointment, next week and it's not been cancelled touch wood. So, hopefully I'm going to discuss medication, cause I think I'm at the stage where I need it.

And will this be a face to face appointment?

Should be! They haven't cancelled it yet, I mean everything else I had, I mean my brain scans and other things were cancelled, so, erm, I don't know what to do about it, if they do suddenly cancel it. But I don't see why it shouldn't go ahead.

P10 - I had an appointment with my oncologist which has been cancelled and I'll have a telephone consultation this week.

And I didn't have any others. I have my next appointment with a neurologist and it's likely to be cancelled cause that's in July and he, he normally sees me in a private hospital in X, but actually I will be surprised if he doesn't cancel it and give me a telephone appointment instead. The dentist's cancelled my appointment as well cause me and my husband are vulnerable people, so... we got a new appointment for the dentist, yeah.

P5- I was due an appointment to be sent out at by the end of April. And I'm loathed to ring I think erm, possibly they've got enough on at the moment, er, to me it's a query as opposed to a problem, I haven't got a problem.