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Thinking about motor fluctuations: An examination of metacognitions in Parkinson's disease

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ABSTRACT

Objective: Motor fluctuations (characterised by a sudden increase in symptom intensity, referred to as an 'off-period') are common side effects after treatment of Parkinson's disease (PD) with dopaminergic medication. A proportion of these people find motor fluctuations highly distressing. This study aimed to identify metacognitions associated with cognitive and attentional responses to these experiences.
Methods: Ten individuals with PD who experience motor fluctuations were interviewed for this study using an adapted metacognitive profiling schedule. Participants were asked about their metacognitions, and the cognitive processes and attentional strategies activated in response to a distressing off-period.
Results: Metacognitions identified were more often related to conceptual thinking about symptoms rather than symptom focus and data suggested trends for increased depressive symptoms among individuals with stronger metacognitive beliefs.
Conclusion: Metacognitions may play a role in determining or maintaining off-period distress in PD.

Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disorder after Alzheimer's disease. A recent systematic review and meta-analysis revealed a population prevalence of approximately 250 per 100,000, but this increases to more than one in a hundred in those over the age of 70 [1]. PD is defined by a constellation of motor symptoms including slowness in the initiation and execution of movement, reduced movement amplitude, tremor and stiffness, leading to progressive disability affecting mobility and fine motor control, balance, swallowing and speech. PD is also associated with a wide range of non-motor symptoms, although their pattern and severity can vary more widely. These can include cognitive impairment, anxiety, depression, psychosis, pain, autonomic dysfunction, sleep problems, and fatigue [2]. Such symptoms have been shown to have a greater impact on health related quality of life than the motor symptoms [3,4].

In the first few years of the disease, effective management of the motor symptoms is offered by the use of dopaminergic medication such as levodopa or dopamine agonists. With progression of the disease, however, such drugs become less effective, and complications can emerge with long-term use. The most commonly used drug, levodopa, is associated with the emergence of fluctuations in symptoms over the course of the day. These periods of symptom worsening (off-periods) can happen at the end of a dose before the next tablet ('wearing off'), or less predictably with the dose stopping working unexpectedly or possibly not working at all [5]. Apart from a worsening of the motor symptoms, many patients report the emergence or exacerbation of non-motor symptoms during these off-periods [5] including depression and anxiety, as well as pain, fatigue, and other symptoms.

Off-periods can be a significant source of distress for patients. Some of this may reflect from a physiological response to variations in brain dopamine during the off-period, or a reaction to unpleasant symptoms such as pain, fatigue, or immobility. Another potential psychological factor is the role of metacognitions. This psychological construct refers to higher order 'thinking about thinking'. Specifically, in the context of mental health, it refers to explicit beliefs held by an individual about the value of the specific cognitive (thinking) processes (such as worry and rumination) and attentional strategies. Metacognitions can be positive (e.g. 'worry helps me prepare') or negative (e.g. 'my worry is uncontrollable'). Evidence suggests that both types of beliefs can result in the activation and persistence of worry and ruminative thinking [6,7] because, while the goal of these cognitive processes is often a reduction in or elimination

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of distress, this 'stop signal' is seldom achieved. Metacognitions have been shown to be associated with levels of worry and the severity of anxiety in GAD [8], as well as a tendency to ruminate and depressive symptoms in Major Depressive Disorder [6]. More relevant to this study, metacognitions about conceptual thinking about symptoms (CTS: i.e. worry and rumination about symptoms) and symptom focus (SF) have been shown to predict the severity of fatigue symptoms in Chronic Fatigue Syndrome (CFS; 9). In PD, metacognitive style has previously been shown to be associated with psychological distress [10], while a recent study demonstrated that general metacognitions concerning a patients' beliefs about uncontrollability and danger were found to be significantly related to distress reported during off-periods, while the predictability of motor fluctuations was not [11].

We report here a small proof-of-concept, mixed-methods study aimed to: [1] determine whether patients express metacognitions specifically related to their individual off-period experiences, [2] characterise those metacognitions, and [3] examine whether they might be meaningfully related to psychological distress in relation to current models. The existence of potentially maladaptive metacognitions associated with off-periods and off-period symptoms, even in some patients, would support the exploration of novel tailored treatment approaches to help manage off-period distress.

Method

Participants

Ten participants with PD (six males; mean age 59.2 years, SD 7.0 years, range 48 to 71 years) reporting motor fluctuations were recruited from movement disorders services at King's College Hospital NHS Foundation Trust and Lewisham University Hospital, London. The mean number of years since PD diagnosis was 9.6 (SD 5.2; range 3 to 20). All but one participant self-identified as White-British.

Eligibility criteria were: [1] a clinical confirmed diagnosis of idiopathic PD; [2] current use of dopaminergic medication; [3] the presence of off-periods for at least 25% of the day on average; [4] recent evidence of significant psychological distress (not specifically related to off-periods); [5] self-reported distressing off-periods; [6] understanding written and spoken English; and [7] able to provide informed consent. 13 patients who met inclusion criteria following case note review and screening interview were invited to participate, of these 10 (79.4%) consented to participate. Those who agreed were seen in their own home or at the research site (to their preference) for assessment after providing signed consent.

Materials

Case note screening measures and screening interviews

Potential participants were first identified from a case note review by a member of the clinical team and cognitive status was assessed during screening interviews by author LK (neurologist) as part of a separate study to rule out significant cognitive impairment likely to impact on the ability to provide informed consent. The presence of recent motor fluctuations was indicated by the Movement Disorders Society Unified Parkinson's Disease Rating Scale Part IV (MDS–UPDRS; [12]). The existence of off-period distress was established during the screening interviews conducted by author LK. Recent psychological distress was indicated by the Hospital Anxiety and Depression Scale (HADS; [13]) with a score of seven or more on the depression or anxiety subscale.

Depression and anxiety

For the included participants, the 9-item Patient Health Questionnaire (PHQ 9; [14]) provided a measure of depression severity over the preceding two weeks. The scale taps into the Diagnostic and Statistical Manual IV-R (DSM-IV-R; [15]) criteria for Major Depressive Disorder. The Parkinson's Anxiety Scale (PAS) is a 12-item scale measuring avoidance behaviour, and persistent and episodic anxiety over the past four weeks, and shows good psychometric properties [16]. PAS factors can be totalled to provide a global anxiety score. Higher scores on either scale indicate higher levels of negative affect.

Worry, rumination, and metacognitions

A 5-item version of the Penn State Worry Question (bPSWQ; 17) was used to assess participants' level of worry, and a 5-item version of the Ruminative Response Scale (bRRS; 17) was used to measure participants' tendency to respond to negative events with rumination. Despite being brief, both scales have good psychometric properties [17] although they have not been used previously in PD. With both measures, higher scores indicate an increased tendency to worry or ruminate. Finally, the 17-item Metacognitions about Symptom Control Scale (MaSCS) was used to assess general levels of positive and negative metacognitions pertaining to both CTS and SF [9]. Higher scores on the MaSCS indicate the presence of stronger beliefs in positive and negative metacognitions.

Eliciting metacognitive about off-periods

The Metacognitive Profiling interview template [18] is a non-quantitative tool devised as an aid to clinical assessment to elicit positive and negative metacognitions and related components that an individual may hold. In this study, the interview was adapted to focus on cognitive processes and attentional strategies activated during an off-period. Participants were asked to recall a particular recent off-period that they found difficult or distressing. They were asked to describe both their chain of thoughts and focus of attention (i.e. was it on their thoughts, feelings, or symptoms, on the situation or something else?) during this off-period. They were then asked about the advantages and disadvantages of these cognitive processes and attentional strategies, as well as the goal they were attempting to achieve by utilising them and how they would know that this had been achieved (i.e. the stop signal).

Data analysis

All interviews were conducted by the author BAF and transcribed before further analysis. Author BAF (a clinician and researcher in the field of metacognitions and PD) reviewed the transcribed material and identified a pool of probable metacognitions. These were subsequently reviewed by authors RGB (an expert in PD) and MMS (an expert in metacognitions) to identify the final set reported here (Table 2). We did not undertake a formal qualitative analysis of this small dataset, but took the opportunity to identify and describe individual variability and possible common themes.

Finally, scatterplots were used to explore and illustrate any potential relationship between positive and negative metacognitions as measured by the MaSCS and depression (PHQ-9) and anxiety (PAS).

Results

Relationship between metacognitions and distress

Table 1 shows that the mean PHQ-9 score for the sample was above the clinical cut-off of 10 [19] and that the mean self-rated PAS was above both the screening and diagnostic (13 and 14 respectively) cut-offs for any anxiety disorder [16], suggesting that that the sample represented high-distress PD patients.

The planned sample size was not intended to enable a quantitative test of the relationship between metacognitions and distress. Nevertheless, it is possible to discern interpretable relationships between the quantitative scores on the MaSCS (which measured trait metacognitions pertaining to CTS and SF) and measures of depression (PHQ-9) and anxiety (PAS). Fig. 1 shows scatterplots of emotional distress and level of trait metacognitions for the participants. These data indicate a possible positive relationship with higher levels of depression tending to be associated with higher levels of both positive and negative metacognitions (Spearman's Rho: $r = .63$ and $r = .41$, respectively), and between positive metacognitions and anxiety ($r = .66$) but not negative metacognitions ($r = .02$).

Nature of metacognitions

All participants were able to recollect a recent difficult or distressing off-period experience. Table 2 shows all elicited metacognitions classified as positive or negative and

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