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Title: An exploration of worry content and catastrophic thinking in middle and older aged adults with and without Parkinson's disease

Running head: Worry content in Parkinson's disease

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Key Words: worry, Parkinson's disease, content, older adult, catastrophising

Word Count: 3381

Key Points:

- Worry is a common and distressing problem in Parkinson's disease. Understanding worry content can help in the identification and treatment of problematic worry
- The Catastrophising Interview successfully identified the root cause of worry which frequently differed to initially reported worries
- Interventions designed to alleviate problematic worry in PD need to take account of the realities of living with PD and the potentially realistic nature of worries that may appear catastrophic in a healthy population.

ABSTRACT

Objective: Worry is a common and distressing problem in Parkinson's disease(PD). However, little is known about the nature and content of worry in PD and how it might differ to non-PD populations. The study aimed to explore the content and nature of worry in middle and older aged adults with and without PD.

Method:4 groups of participants: 20 PD patients(10 high worry, 10 low worry) 19 middle and older aged adults(10 high worry, 9 low worry) completed the Catastrophising Interview(CI) for three worry topics. Worriers were classified(high/low) based on Penn State Worry Questionnaire scores. Data were analysed using Framework Analysis.

Results:High worriers showed a greater diversity of worry topics than low worriers. Health worries differentiated high and low worriers in the non-PD sample but were common across all PD participants. The CI revealed that the root concern of worry was often different to that initially described. In particular, PD high worriers were more likely to express underlying concerns about negative self-perception and death/severe incapacity.

Conclusion:The CI was able to identify the root cause of worry, demonstrating the value of this technique in the exploration and treatment of worry and psychological distress. Exploring worry content may help to distinguish patients with problematic worry, with worries about self-perception and death/severe incapacity characteristic of high worriers. Therapeutic interventions designed to alleviate problematic worry and distress in PD need to take account of the realities of living with PD and the potentially realistic nature of worries which may appear catastrophic in a healthy population.

INTRODUCTION

Worry is a cognitive process, typically verbal, that focuses on real or potential future negative events, often where the outcome is uncertain (Barlow, 2002). Worry cognitions may build in chains with one worry leading to another, often without resolution or solution. Worry is typically associated with anxiety or a sense of apprehension. Worry is a common phenomenon which often reflects realistic concerns and can act as a protective mechanism; for example, increasing engagement in health promoting activities (Zhang et al., 2012). However, persistent, frequent and uncontrollable worry can be problematic and is associated with a range of psychiatric disorders including anxiety disorders and depression, but is most characteristic of Generalized Anxiety Disorder (GAD) (Newman et al., 2013).

While much worry research examines the frequency and severity of worrying thoughts or the associated cognitive processes, a small body of literature has explored the nature and content of worry. Individuals tend to worry about issues that are particularly salient in their lives where there is a real or perceived threat; for example, worries about work and finances are more common in younger than older adults (Lindesay et al., 2006). Worry content varies as a function of age, gender, ethnicity, income, health, marital status, educational attainment and number of traumatic life events (Cohen et al., 2006; Diefenbach et al., 2001; Gonçalves and Byrne, 2013; Hunt et al., 2003; Lindesay et al., 2006; Stanley et al., 2009). The content of worry has been suggested to play an important role in the identification of problematic worry (Diefenbach et al., 2001). Comparing worry content between high and low worriers may aid recognition of pathological worry.

Exploring the content of worry may further aid the development of interventions to alleviate pathological worry (Diefenbach et al., 2001). Cognitive behaviour therapy (CBT) is recommended for the treatment of worry in GAD (NICE, 2011) and has shown efficacy in middle and older aged adults

(Covin et al., 2008; Hendriks et al., 2008; Stanley et al., 2009). A pilot study in Parkinson's disease worriers suggests that CBT based guided self-help may be of value (Lawson et al., 2013). Such approaches typically focus on strategies to reduce or cope better with worry (e.g. relaxation techniques and self-control methods), or reframe worrying thoughts (e.g. cognitive restructuring). Alternative approaches include increasing acceptance of worrying thoughts (e.g. mindfulness and acceptance exercises) (Behar et al., 2009), or challenging unhelpful beliefs about the need to control worry and the benefits of worry as a mechanism for coping with negative thoughts (Metacognitive therapy)(Wells et al., 2010). However when using CBT strategies, particularly challenging and positive re-framing, to reduce worry it is essential that the real limitations experienced by groups such as older adults are taken into consideration (Diefenbach et al., 2001).

Little research has explored worry content in specific clinical conditions. Parkinson's disease (PD) is the second most common neurodegenerative disorder in the UK affecting 120,000 people (Parkinson's UK, 2007). It has an average age of onset of 60 years and is characterised by muscle rigidity, tremor, postural abnormalities and a shuffling gait (Quinn, 2003). In a sample of over 500 patients with PD, over two thirds reported worry (Brown et al., 2011). It was persistent and troubling in approximately 25% and less marked but still significant in another 43% of patients (Brown et al., 2011). Worry in PD tends to be chronic, and worriers are more likely to be younger, female, with greater motor symptom severity, more motor symptom fluctuations, and poorer quality of life (Whitehead, 2009).

PD significantly impacts on an individual's daily activities (Behari et al., 2005; Goetz et al., 2008) and is likely to be highly salient in patients' lives. Consequently we might expect that a high proportion of worry in PD would concern health-related issues, and more so than might be expected in healthy older adults. However, health-related worry has been shown to distinguish problematic worriers

more generally (e.g. (Wells and Morrison, 1994) and so may be unlikely to distinguish those problematic worriers with physical health problems. Exploring the nature and content of worry in PD may help to identify problematic worry more accurately and inform the development of therapeutic interventions to alleviate problematic worry and associated distress.

Past research exploring worry content has been criticised for being overly general and likely to miss important, functionally relevant information about basic threats underlying reported worries (Roemer et al., 1997). The Catastrophising Interview (CI) aims, under controlled conditions, to provoke a period of worry (worry chain) that mimics what the individual normally experiences, and can be used to identify the real or perceived threat (Roemer et al., 1997). The CI, through repeated questioning about the significance of a particular worry can identify a core or root concern. These represent the worst imaginable outcome and are known as a 'catastrophic thought' (Vasey and Borkovec, 1992).

The present research used the CI to address a number of aims: (i) to compare the nature and content of worry between middle and older aged adults with and without PD; (ii) to examine worry content and nature in 'high' and 'low' worriers, and (iii) to compare the content of catastrophic thoughts between PD and non-PD and high and low worry groups.

METHOD

Participants

39 individuals participated in the study and were classified into four groups: 10 PD high worriers, 10 PD low worriers, 10 non-PD high worriers, and 9 non-PD low worriers. PD participants were recruited *via* an existing cohort (PROMS-PD study, Brown et al., 2011) and *via* Neurology Outpatient clinics at local hospitals. Non-PD participants were recruited via the Institute of Psychiatry, King's College

London (KCL) MindSearch database of volunteers, friends/relatives of existing participants, KCL circular email to students and staff and local community groups.

The qualitative data reported in this study were collected as part of a wider study on worry that involved speeded neuropsychological measures, in addition to the catastrophizing interview. Patients were purposively sampled from the existing cohort and outpatient sources that met the following criteria: age between 40 and 90 years; capacity to provide informed consent, and (for the patient group only) a diagnosis of idiopathic PD. Patients were not approached to participate if they had a Mini-Mental State Examination (MMSE) (Folstein et al., 1975) score of less than 26, or clinical evidence of dementia, or if their motor impairment or communication problems were judged likely to interfere with completion of the neuropsychological tasks or interview.

The sample consisted of 24 males (61.5%) and 15 (38.5%) females, with a mean age of 65.3 (range = 47.1-82.7, SD = 9.0). Average duration of PD was 7.3 years (range = 1.0-23.9, SD = 5.9). 92.3% of participants were white British. The average MMSE score was 29.3 (range = 27-30, SD = 0.8). The four participant groups did not differ significantly in sex and age, but the non-PD sample had attained a higher level of education ($p = 0.015$).

Measures

The Penn State Worry Questionnaire (Meyer et al., 1990)

The Penn State Worry Questionnaire (PWSQ) is a 16 item self-report measure of trait worry. The scale has been found to have high internal consistency, good test-retest reliability and good validity (Meyer et al., 1990). The PSWQ was used to classify 'high' and 'low' worriers. Cut-off scores were derived from the top and bottom third of PSWQ scores in a previously assessed sample of 100 PD patients. Scores of 45 and above indicated high worry, and 30 and below indicated low worry in this

study. A cut-off of 45 has previously been reported as optimal for the screening of GAD in the general population (Behar et al., 2003)

The Worry Domains Questionnaire – Short Form (Tallis et al., 1992)

The Worry Domains Questionnaire – Short Form (WDQ-SF) is a 10 item self-report measure designed to assess the content of pathological and non-pathological worry in the general adult population. The WDQ-SF assesses worry across five domains – relationships, lack of confidence, aimless future, work incompetence and finances. It has been found to have high internal consistency (Tallis et al., 1992). In the current study an additional open-ended question was added to allow respondents to specify additional worry topics and to rate the extent of their worry about these.

The Catastrophising Interview (Vasey and Borkovec, 1992)

Worry was explored using the catastrophising interview (Vasey and Borkovec (1992)), based on the version described by Davey and Levy (1998), and adapted to verbal responses rather than written. Participants' three most frequent worries were identified using the WDQ-SF for reference. For each worry in turn, the interviewer began by asking "What is it that worries you about X?" where X was the worry generated by the participant. The interviewer then repeated this question substituting the participant's response for X. The interview was terminated when the participant was unable to generate a novel response. This final worry was classified as the Catastrophic Thought. An example of a catastrophizing interview is provided in Box 1.

[Box 1 near here]

Procedure

Potential participants completed postal screening questionnaires (PSWQ and WDQ). Individuals scoring as 'high' or 'low' worriers were invited to participate in the study. Interviews were conducted at the participant's home or a private room at the university. All participants provided written consent to participate in the study (ethics ref 10/H0716/32).

Qualitative and Statistical Analysis

Deductive Framework Analysis (Ritchie and Spencer, 2002) was used to examine the content and nature of the worries that emerged through the interviews, from the initial worry through to the final catastrophic thought. Framework Analysis was selected due to its structured method and suitability for research involving group comparison. An initial framework of worry topics was developed from previous research, and the interviews were indexed using this. Instances of themes were recorded using NVivo (Version 9 QSR International, PTY. Ltd.). In line with the process of framework analysis worries were compared against each of the topics in the framework. Topics were refined as data analysis progressed to develop the final index. 20% of transcripts were indexed by an independent researcher who showed high consistency with the original indexing (75%). Disagreements were discussed and a consensus reached before the main researcher coded the remaining transcripts. Instances were then charted or organised by theme. The final stage of the analysis, mapping and interpretation, involved the identification of patterns, key differences and explanations within the data. A pragmatic rating of content severity (mild, moderate or severe) of the final worry was made by two Psychologists (DW, CH) and the researcher (AW).

Mann-Whitney U tests and Kruskal-Wallis tests were used to statistically compare the number of worry topics between groups.

RESULTS

The nature and content of worry in PD and Non-PD participants

Content of initial worries

The worries initially reported by the sample were classified into 10 major topics outlined in Table 1. The frequency of each worry topic reported by both PD and non-PD participants is presented in Table 2. Very similar patterns of worry content were noted between groups; however, minor worries and worries about friends and family members were more common in non-PD than PD participants. As expected health worries were reported more often in PD than non-PD participants.

[Tables 1 & 2 near here]

Number of worry topics

Each step of the CI can potentially reveal a new worry topic as illustrated in the earlier example (Box 1). The median number of discrete worry topics (rather than elaborations on the same topic) for participants in each group is shown in Table 3. The number of worry topics mentioned in each interview gives an indication of the diversity of worry content. No significant differences were found in the number of worry topics reported by PD and non-PD participants (U = 158.00, z = 0.91, p = 0.372).

[Table 3 near here]

The nature and content of worry in high and low worriers

Content

High worriers reported a higher frequency of idiosyncratic worries than low worriers. A similar frequency of health worries was seen for high and low PD worriers, unlike the non-PD sample, where the frequency of health worries appeared much greater in the high worry group. This suggests that

worries about health may be indicative of problematic worry amongst a healthy older adult group but cannot be used to define pathological worry in PD. PD high worriers had a greater number of self-perception worries than PD low worriers.

Number of worry topics

Overall, high worriers reported significantly more discrete worry topics during the interview than low worriers (U = 73.00, z = -3.33, p = 0.001), indicating longer worry chains before reaching the final worry. Post-hoc tests showed that this was true in both the PD and non-PD groups. (PD: U = 21.50, z = -2.18, p = 0.028, Non-PD: U = 16.50, z = 2.36, p = 0.015).

Catastrophic thought content

Several new themes emerged with the final catastrophic worry. These were identified as (i) 'all-encompassing negative statements' where the individuals envisaged a wholly negative scenario for themselves and other people, such as *"Hell and damnation for me and unpleasantness for my family"*, (ii) 'engagement in activities' where the worry focused on not being able to do certain activities that they would like to do, such as *"Missing out on doing the things I want to do during my retirement"*, and (iii) 'death/severe incapacity' where the worry concerned a situation in which they would die or have an extremely low quality of life due to a severe mental or physical incapacity, such as *"Experiencing a gradual decline in health and a very lonely death"*. When the catastrophic final thought contained two or more conceptually different worries, these were coded separately. The number of final worries falling into each category is shown in Table 4 including the initial coding set and the three new themes.

[Table 4 near here]

In 65% of the cases the theme of the initially reported worry differed from the final catastrophic thought, with this trend being more pronounced in high (74%) than low worriers (56%). Comparing Tables 2 and 5 there was a change in pattern in both PD and non-PD groups. In all groups, worry related to health, finances, work and minor concerns became less evident in the final catastrophic worry, while worry about interpersonal relationships and self-perceptions were more frequent, along with the newly elicited worries, particularly concern about death and severe incapacity. A limited set of three concerns about interpersonal relationships, negative self-perception and death/incapacity characterised a larger proportion of the catastrophic worries in the high worry PD group than the low worry group, in contrast fewer differences were seen between the high and low worry non-PD groups. In PD, many of the interpersonal relationships worries focused upon being a burden on others or inconveniencing them while the self-perception worries focused on participants perceiving themselves as worthless or a failure based on their incapacity or burden they felt they were placing on others. The majority of catastrophic thoughts were classified as 'moderate' or 'severe' with a similar proportion of moderate-severe worry in all groups (PD high worry 80%, PD low worry 74%, non-PD high worry 67%, non-PD low worry 67%)

DISCUSSION

The present study aimed to characterise the content and nature of worry in high and low worriers with and without Parkinson's disease. Consistent with previous research, PD patients reported worrying about a range of areas including health, family and friends, interpersonal relationships, finances and miscellaneous concerns (Whitehead, 2009). Based on the initially reported sources of worry, PD and non-PD participants reported similar concerns although, as would be expected, health worries were more common in the PD group. High worriers in both groups generated a greater range of worry topics than low worriers suggesting that problematic worry is likely to be wide-ranging and encompass many areas of their life, as seen in GAD (Diefenbach et al., 2001; Hoyer et

al., 2001; Montorio et al., 2003). Also in line with previous research (Wells and Morrison, 1994) health worries were found to differentiate high and low worriers in the non-PD group suggesting that they could be an indicator of pathological worry in this population. In contrast, health concerns did not differentiate high and low PD worriers. This suggests that screening tools such as the WDQ and the Anxious Thoughts Inventory (Wells, 2006) which measure health worries may not be ideal in identifying pathological worry in PD.

More revealing and informative for any therapeutic intervention, were the concerns expressed in the final catastrophic thoughts, which revealed a different and more limited profile compared to the initially reported worries. In PD and non-PD participants, catastrophic thoughts were most frequently concerned with interpersonal relationships, self-perception and death/severe incapacity. High worriers reported a higher frequency of these worries than low worriers, consistent with previous research which found worriers to report more concerns around personal failure and ineffectiveness (Craske et al., 1989; Hazlett-Stevens and Craske, 2003; Vasey and Borkovec, 1992). Interestingly a new worry topic around engagement in activities appeared in the final catastrophic thoughts but only within the non-PD group. This may be a consequence of most PD participants already having experienced limitations on their activities caused by their PD and therefore associated with less future uncertainty.

These findings suggest that measuring initial worries only is unlikely to identify the underlying cause of worry and distress, particularly in PD where a degree of health concern is probably ubiquitous. The CI is a useful technique for doing this and should be used in both research and clinical contexts.
The differences between PD and non-PD groups suggest that certain theoretical models of worry may be more helpful in PD, where worry may be more realistic in its nature and the severity of content. For example, Dugas and colleagues' have proposed an intolerance of uncertainty model for

worry in GAD. This suggests a treatment that focuses on problem solving around subjects of concern that are tractable, while aiding acceptance of areas that cannot be changed (Dugas et al., 1998). CBT could also be used to target self-perception worries where cognitions are maladaptive, such as feeling worthless or a failure (Cully et al., 2009), while Acceptance and Commitment Therapy (ACT) and Mindfulness-based Stress-reduction (MBSR) may help with distressing concerns around death and severe incapacity (Behar et al., 2009). Such therapies aim to develop awareness and acceptance and so may foster healthy coping styles among PD patients where concerns may not be solvable.

There may also be value in exploring approaches which tackle beliefs about worry itself, rather than specific worry content. Metacognitions include the appraisals and attitudes that individuals have about their thoughts, including repetitive processes such as worry and rumination. There is some evidence that such metacognitions are significant predictors of distress in PD, particularly negative beliefs about worry such as its uncontrollability and danger (Allott et al. 2005). Metacognitive therapy could be effective in reducing unhelpful beliefs about worry and aid patients to develop adaptive ways of coping with distressing repetitive thoughts (Well, 2010).

The current study has a number of limitations which must be acknowledged. The sample size limited statistical testing of differences in worry content between groups. The exclusion of patients with significant cognitive impairment or marked motor impairment may mean that the results obtained do not generalise to patients with advanced disease. Worry content may be different in such groups, particularly if their concerns may be closer to the objective reality than reflection of catastrophic beliefs about the future driven by uncertainty. The non-PD sample comprised a convenience sample of adults aged 40 years and above, however there is a high prevalence of chronic illness in community samples, suggesting that many of the non-PD participants may have health problems

which also influenced their worry (Craig and Mindell, 2007). Given the important distinctions in PD and non-PD worry a larger study of worry content is warranted.

CONCLUSION

The present study gives some preliminary insights into the nature and content of worry in PD and contrasts it with a non-PD sample. The findings suggest that worry in PD is distinct in a number of respects, including the high number of worries that relate to PD itself and its consequences including high number of worries about family burden, loss, death and severe incapacity and negative perceptions of the self. Any therapeutic interventions may need to acknowledge the potentially realistic nature of worry in PD and attempt to reduce worry through acceptance and tackling maladaptive self-beliefs.

There are no potential conflicts of interest.

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Table 1 Description of worry domains identified in the sample

Worry Topic	Description of worry and example
Family and friends	Worries about family members and friends. This includes worrying about the health of these individuals. Example: *'I worry about how many daughter is going to cope with her three sons'*
Interpersonal relationships	Worries about relationships with other people. This includes worrying about being a burden. Example: *'I worry that my friends don't enjoy spending time with me anymore, than I'm just a burden when we go out.'*
Self-perceptions	Worries about other peoples' perception of the individual; commenting on interpersonal emotions such as embarrassment, shame and guilt; worries affecting self-concept (this includes being an effective member of society; being worthless; being a failure; and loss of independence impacting upon self-concept). Example: '*I worry that people who come to visit think badly of me because I can't keep the house as clean as I used to*'
Finances	Worries about financial issues. This includes the impact of lack of finances on quality of life (QoL). Example: '*I worry about not being able to pay the bills and having to sell this house*'
Work	Worries about work issues (whether paid or voluntary). This includes problems with colleagues. Example: '*I worry that I'm going to make a serious mistake at work*'

Health	Worries about illness, health, and injury. This includes worries about ageing linked to health decline. This also includes worries about the impact of poor health on QoL. Example: '*I worry about my Parkinson's getting worse and stopping me getting out the house*.'
Minor concerns/routine concerns/daily hassles	Worries about everyday problems that many individuals encounter. These worries were not associated with distress for the individual. Example: '*Not being able to work my mobile phone properly*'
Social-political-environmental	Worries about social problems, the political situation, environmental concerns, or other global issues Example: '*I worry about researchers not finding a cure or better drugs for neurodegenerative diseases in an increasingly ageing population*'
Worry about worry	Worrying about worry itself. Example: '*Not being able to let things go and stop going over and over them*'
Idiosyncratic	Items that do not fit into other categories, or idiosyncratic worries. Example: '*I worry about my travel arrangements going wrong*

Table 2. Main Worry Content by participant group

	PD			Non-PD		
	High	Low	Total	High	Low	Total
Worry category	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Family and friends	5 (17)	4 (14)	9 (16)	4 (13)	10 (37)	14 (25)
Finances	3 (10)	4 (14)	7 (12)	5 (17)	4 (15)	9 (16)
Health	8 (27)	8 (29)	16 (28)	7 (23)	4 (15)	11 (19)
Interpersonal relationships	3 (10)	4 (14)	7 (12)	1 (3)	2 (7)	3 (5)
Minor/routine/daily hassles	0 (0)	2 (7)	2 (3)	4 (13)	3 (11)	7 (12)
Miscellaneous	5 (17)	2 (7)	7 (12)	4 (13)	1 (4)	5 (9)
Self-perceptions	3 (10)	0 (0)	3 (5)	1 (3)	0 (0)	1 (2)
Social-political-environmental	0 (0)	2 (7)	2 (3)	1 (3)	1 (4)	2 (4)
Work	2 (7)	2 (7)	4 (7)	3 (10)	2 (7)	5 (9)
Worry about worry	1 (3)	0 (0)	1 (2)	0 (0)	0 (0)	0 (0)
Total	30	28	58	30	27	57

Table 3. Median number of worry topics per interview by participant group

	Median N of worry topics	Interquartile range
PD High (*N* = 10)	5.00	4.25
PD Low (*N* = 10)	2.00	3.00
Non-PD High (*N* = 10)	5.00	1.75
Non-PD Low (*N* = 9)	2.00	2.50

Table 4. Content of the final catastrophic thought by participant group

	PD			Non-PD		
	High	Low	Total	High	Low	Total
Worry Category	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Family and friends	2 (6)	5 (16)	7 (10)	2 (5)	9 (30)	11 (16)
Finance	2 (6)	2 (6)	4 (6)	1 (3)	3 (10)	4 (6)
Health	3 (9)	2 (6)	5 (7)	3 (8)	1 (3)	4 (6)
Interpersonal relationships	9 (26)	8 (25)	17 (25)	6 (16)	9 (30)	15 (22)
Minor/routine/daily hassles	1 (3)	2 (6)	3 (4)	1 (3)	3 (10)	4 (6)
Miscellaneous	1 (3)	0 (0)	1 (1)	1 (3)	0 (0)	1 (1)
Self-perceptions	8 (23)	5 (16)	13 (19)	7 (18)	2 (7)	9 (13)
Social-political-environment	0 (0)	2 (6)	2 (3)	1 (3)	2 (7)	3 (4)
Work	0 (0)	0 (0)	0 (0)	2 (5)	0 (0)	2 (3)
Worry about worry	0 (0)	1 (3)	1 (1)	1 (3)	0 (0)	1 (1)
All-encompassing negative statements	1 (3)	0 (0)	1 (1)	2 (5)	0 (0)	2 (3)
Engagement in activities	0 (0)	0 (0)	0 (0)	4 (11)	0 (0)	4 (6)
Death/Severe incapacity	8 (23)	5 (16)	13 (19)	7 (18)	1 (3)	8 (12)
Total	35	32	67	38	30	68