



Citation for published version:

Nash, K, Dysch, L, Todd Jones, J, McQueen, R & Marks, E 2021, 'The contribution of cognitive-behavioural factors to social anxiety in Parkinson's disease', *Behavioural and Cognitive Psychotherapy*.
<https://doi.org/10.1017/S1352465821000291>

DOI:

[10.1017/S1352465821000291](https://doi.org/10.1017/S1352465821000291)

Publication date:

2021

Document Version

Peer reviewed version

[Link to publication](#)

This article has been published in Behavioural and Cognitive Psychotherapy.
<https://doi.org/10.1017/S1352465821000291>. This version is free to view and download for private research and study only. Not for re-distribution, re-sale or use in derivative works. © The Authors, 2021.

University of Bath

Alternative formats

If you require this document in an alternative format, please contact:
openaccess@bath.ac.uk

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Abstract

Background: Social anxiety is prevalent in idiopathic Parkinson's disease however why this is, is not yet well understood. Social cognitions, safety-seeking behaviours and internally-focused attention are all known to predict social anxiety in the general population. These associated factors have not yet been explored in idiopathic Parkinson's disease, where disease severity and motor symptoms might also influence the experience of social anxiety.

Aims: This study aimed to explore the relationship between cognitive-behavioural factors and social anxiety in Parkinson's disease.

Method: Using a cross-sectional design, 124 people with Parkinson's disease completed self-report questionnaires including measures of Parkinson's disease severity, social anxiety, negative social cognitions, safety seeking behaviours, internally focused attention, anxiety and depression.

Results: The final regression model accounted for 71.6% of variance in social anxiety. Cognitive-behavioural variables accounted for the largest magnitude of unique variance (43.5%). Sex, anxiety and depression accounted for 23.4%, and Parkinson non-motor symptom severity for 4.7%. Negative social cognitions and safety-seeking behaviours were statistically significant predictors while an internal focus of attention was not.

Conclusions: Social anxiety in Parkinson's disease is associated with negative social cognitions and safety-seeking behaviours. Findings indicate the need for further research into cognitive-behavioural approaches to social anxiety in Parkinson's disease.

Keywords: "Cognitive-behavioural", "Parkinson's Disease", "Anxiety", "Social Anxiety", "Psychological Therapy"

Introduction

Social anxiety is one of the most commonly reported experiences of anxiety among people with Idiopathic Parkinson's Disease (PwIDP). Currently there is no specific guidance around the best clinical interventions to support PwIDP who experience social anxiety. This paper begins to explore the associated factors of social anxiety for PwIDP. It will contribute to the assessment of whether existing evidence based cognitive-behavioural approaches for social anxiety are applicable in this population. This paper will first introduce Idiopathic Parkinson's Disease (IPD) and the prevalence of anxiety disorders. Existing

cognitive-behavioural models of social anxiety are outlined before the specific area of social anxiety in IPD is discussed.

Idiopathic Parkinson's Disease (IPD) is a complex neurodegenerative condition that is not yet fully understood. Pathophysiological changes such as a loss of dopaminergic neurons in the basal ganglia, an area of the brain associated with voluntary motor movement, worsen over time (Stoker & Greenland, 2018). To establish a clinical diagnosis of IPD there must be evidence of Parkinsonism. Parkinsonism is defined by the presence of bradykinesia in combination with either muscular rigidity and/or resting tremor. These symptoms are assessed against a set of exclusion criteria and supportive positive criteria before a diagnosis can be made (Postuma et al., 2015).

In addition to the physical presentation, there is increased recognition of non-motor symptoms (NMS). Although it is proposed that these commonly present before the onset of motor symptoms (Chaudhuri, Healy, & Schapira, 2006), they are often overlooked at this early stage and not recognised as part of a complex neurodegenerative condition (Klingelhoefer & Reichmann, 2017). NMS include autonomic, sensory and sleep changes (Ishihara & Brayne, 2006). Anxiety and depression are also often conceptualised as NMS of IPD. While there are undoubtedly neurobiological changes associated with anxiety and depression, conceptualising both this way risks viewing such experiences as inevitable pathological consequences of IPD. In doing so, potentially treatable components of these understandable mental health responses to a challenging physical condition could be overlooked (Stephens, Dysch, & Gregory, 2018). Despite their substantial influence on disability and quality of life (Weintraub, Moberg, Duda, Katz, & Stern, 2004), NMS and mental health symptoms have received less attention than motor symptoms in IPD (Pachana et al., 2013). There is increasing demand for a better understanding of these important aspects through research (Deane et al., 2014).

Prevalence of Mental Health Difficulties in PwIPD

Existing research has highlighted that a range of mental health problems are frequently reported by PwIPD including generalised anxiety, low mood and

social anxiety (Broen, Narayen, Kuijf, Dissanayaka, & Leentjens, 2016; Gultekin, Ozdilek, & Bestepe, 2014; Nègre-Pagès et al., 2010; Reijnders, Ehrh, Weber, Aarsland & Leentjens, 2008). Social Anxiety Disorder (SAD) is among the most prevalent anxiety disorders in PwIPD (Broen et al, 2016). Social anxiety is highly prevalent in people with visible differences, for example people who have a scar, mark or condition that makes their face or body look different (Rumsey, Clarke, & White, 2003). IPD could arguably be perceived as a condition that causes visible differences for some people. For example it can cause changes to posture, movement and facial expressions, all visible to others. Symptoms can also cause changes to competency with motor tasks such as walking, pouring a drink or speaking. Performance might be visibly different compared to other people and/or a persons own previous ability in these areas. Although one could hypothesise that these visible objective differences might be related to the experience of social anxiety in some people with IPD (for example their beliefs about their symptoms and how they are perceived by others are distorted and exaggerated) this hasn't been yet been explored in research.

It has been highlighted in previous research that some items on general anxiety self-report measures overlap with symptoms of IPD. For example the Becks Anxiety Inventory (BAI), (Beck & Steer, 1993) contains *hands trembling* (Salazar, Le, Nearing, & Cronin-Golomb, 2017). Such an item might reflect motor symptoms in IPD rather than or perhaps in addition to genuine symptoms of anxiety and therefore inflate scores. Therefore using these measures in the context of IPD might effect their validity, regardless if symptoms are objective or subjective in the context of self-report measures. This could also be true of social anxiety measures where some symptoms could be attributed to either social anxiety, IPD or some combination of the two. Clinical observations indicate that people with IPD are often aware that anxiety exacerbates their IPD symptoms but find it difficult to know how much of their experience is attributable to IPD and/or anxiety. Examples of items presenting ambiguity include references to *sweating* and *trembling/shaking* in the Social Phobia Inventory (Connor et al, 2000) and *shaking/trembling* and *losing control* in the Social Phobia Scale (Mattick & Clake, 1998). Performance related items such

as *I would get tense if I had to carry a tray across a crowded cafeteria* and *I would find it difficult if I had to drink something in a group of people* in the Social Phobia Scale (Mattick & Clake, 1998) could also arguably be contaminated by the physical symptoms of IPD. Some measures such as *The Liebowitz Social Anxiety Scale* (LSAS) (Liebowitz, 1987) do not include such items and are situational based as opposed to perceived symptom or performance based.

The numerous different anxiety measures used in the literature might contribute to the large variability in prevalence estimates across studies from 6%-55% (Broen et al., 2016). In relation to social anxiety in particular, Gultekin et al (2014) found that 42.5% of PwIPD met diagnostic criteria for SAD. This is higher than the 12% prevalence rate estimated in the general population (NICE, 2013) and closer to the 30.6% reported in multiple sclerosis (MS), another neurodegenerative condition (Poder et al., 2009). Even after accounting for possible score inflation due to symptom overlap, Salazar et al (2017) demonstrated that anxiety scores remained high in PwIPD compared to the general population, indicating a need for closer clinical attention. *Finding approaches to reduce stress and anxiety in IPD* was identified as a top research priority by PwIPD (Deane et al., 2014). Most attention to date has been paid to depression in IPD. Although depression and anxiety are referred to in NICE clinical guidance for IPD, there is not yet acknowledgement that social anxiety is also a common problem in this population.

Social Anxiety

Social anxiety disorder (SAD) is characterised by a marked fear of one or more social situations that involves exposure to possible scrutiny from others (APA, 2013). SAD is associated with poor quality of life (QoL) (Barrera & Norton, 2009; Safren, Heimberg, Brown, & Holle, 1996). Cognitive Behavioural Therapy (CBT) is recommended as first line treatment (NICE, 2013) and is based upon two empirically supported cognitive-behavioural models (see Figure 1.1).

[Figure 1.1: Models of SAD](#)

Common to both models in the maintenance of SAD are:

- 1. *Negative cognitions* about oneself in social situations and the perception of the social situation as threatening.**
- 2. *Safety-seeking behaviours* (Salkovskis, 1991) such as total avoidance or more subtle avoidance to cope with the perceived threat. Safety seeking behaviours are often employed to conceal symptoms that are perceived to be observable and negatively judged by others. If objective symptoms are present as well as perceived symptoms, the severity of these and the perception of negative judgement by others is often largely overestimated.**
- 3. Attention to threat stimuli which feeds negative assumptions about how one appears to others. For example noticing a racing heart and feeling highly anxious may lead to the conclusion that one must also appear anxious.**

Although both models are conceptually similar, Clark & Wells place an emphasis on an internal, self-focus of attention that is interpreted as threatening whereas Heimberg, Brozovich & Rapee (2010) include attention to environmental cues that are interpreted as negative in addition. This study will focus on the Clark and Wells' (1995) model primarily due to the operationalised measures available for the processes outlined above. Support for these models have been demonstrated in the general population (McManus, Sacadura, & Clark, 2008; Spurr & Stopa, 2002; Woody, Chambless, & Glass, 1997); young people (Ranta, Tuomisto, Kaltiala-Heino, Rantanen, & Marttunen, 2014; Schreiber, Höfling, Stangier, Bohn, & Steil, 2012) and support for CBT interventions based on these models have been demonstrated in the context of autism (Cardaciotto & Herbert, 2004); visible differences (Kleve, Rumsey, Wyn-Williams, & White, 2002) and a single case study of social anxiety in IPD (Heinrichs, Hoffman, & Hoffman, 2001). These findings indicate that cognitive-behavioural approaches to SAD may be widely generalisable to populations including PwIPD.

Social anxiety in PwIPD

SAD in the context of a medical condition was excluded from the Diagnostic and Statistical Manual (DSM) until its most recent revision (DSM-IV; APA, 2013). Social anxiety in a medical context was regarded as having a different symptom profile, pathophysiology, demographic, course and treatment outcome compared with the general population (Heimberg et al., 2014). Therefore, existing cognitive-behavioural interventions for SAD were deemed potentially inappropriate, leading to a lack of understanding and support for social anxiety in these groups.

Some have suggested that an association between anxiety and IPD severity indicates that anxiety in PwIPD is fundamentally different to that in the general population (e.g. Sagna, Gallo, & Pontone, 2014). Theories have explained the association as a result of pathological dopamine dysfunction (Moriyama et al., 2011; Weintraub et al., 2005), i.e. that anxiety results from organic pathology. However not all studies have replicated this finding and some have found anxiety in PwIPD to be independent of disease severity (Brown & Fernie, 2015). As seen in MS (Wood et al., 2013) Brown & Fernie (2015) attributed anxiety in PwIPD largely to psychological variables. Some qualitative research findings are consistent with psychological explanations of anxiety in PwIPD. One finding showed that some PwIPD described feeling trapped in an unpredictable, unreliable body (Goddard, 2014). Another study showed that some PwIPD reported anxiety around others and a sense of being visibly different (Chen & Marsh, 2014) while other PwIPD reported fear and embarrassment regarding visible symptoms. For example some participants described worries that their tremor will cause them to spill food when eating (Goddard, 2014; Heinrichs et al., 2001). The way PwIPD thought about their symptoms (their metacognitions) was found to be a better predictor of anxiety than IPD symptom severity (Brown & Fernie, 2015; Fernie, Spada, Ray Chaudhuri, Klingelhofer, & Brown, 2015). This finding indicates that a purely biomedical view of anxiety in PwIPD is inadequate. It suggests that psychosocial factors, particularly how symptoms are interpreted by an individual, are influential in an individual's level of distress. A recent generic cognitive-behavioural model has attempted to describe how disease-related and psychosocial-related vulnerabilities interact in the development and maintenance of psychological distress including social anxiety

in PwIPD (Stephens et al., 2018). It posits that the way PwIPD think, interpret and react to IPD influences anxiety. Though conceptually appealing, this model remains to be empirically tested, possibly due to a lack of available operationalised constructs.

The current study aims to test the applicability of a specific cognitive-behavioural conceptualisation of social anxiety in PwIPD. Negative social cognitions, safety seeking behaviours and focus of attention were chosen as key variables because they are common to both NICE recommended cognitive-behavioural models and they have been operationalised. In line with the Clark & Wells (1995) model, the presence of internally focused attention in PwIPD during social interactions was included. Based on current literature, it was hypothesized that:

(1a) Negative social cognitions, safety seeking behaviours and internally focused attention (cognitive behavioural variables) would all be positively associated with social anxiety in PwIPD.

(1b) These cognitive-behavioural variables will account for a unique portion of variance in social anxiety in PwIPD even after accounting for demographic and IPD related variables.

(2a) Social anxiety will be negatively associated with QoL in PwIPD.

(2b) Social anxiety will account for a unique portion of variance in QoL in PwIPD.

Method

Participants and procedure

Recruitment was supported by an NHS Movement Disorders Clinic in the South West and the charity Parkinson's Disease UK. Both organisations shared study adverts with potential participants. Interested participants contacted the researcher who conducted a telephone screen to establish eligibility. Table 1.1 below outlines exclusion criteria. Eligible participants completed informed consent and received their preference of either a paper questionnaire pack or link to an electronic version. If they were recruited via the clinic, they also had the option of face to face support. Participants were given researcher contact

details for any clarification or technical support during participation. Some participants received practical support from a relative or carer to complete the study, however they were instructed to provide their own answers to the questions. Participants were given the option to have £2 donated to a relevant charity for their participation. The triple data collection strategy (online, post or in person) maximised recruitment in a potentially hard-to-reach population. The opportunity to take part remotely facilitated accessibility for participants across the UK who might otherwise be unable to attend face-to-face (e.g. due to high levels of social anxiety, physical impairment or resource limitations).

Table 1.1: Exclusion criteria

Design

This study used a cross-sectional design. Participants were asked to complete a battery of self-report measures at one time point.

Sample size

G*Power statistical software (version 3.41) was used to estimate sample size. The following assumptions were made: Linear multiple regression; Fixed Model R²; deviation from 0 Alpha of 0.05; power of 0.80; 9 predictors and a medium effect size (0.15) (based on Hodson et al (1995)). The estimated required sample was 114 participants for the primary analysis.

Demographics

124 PwIPD took part. 52% were male. Participants were predominantly White British (95.9%). Most participants were aged between 51-79 (90.3%). 44.3% had been living with IPD for <5 years, 40.3% for 5-10 years, 12% for 11-15 years and 0.8% >15 years. Over half (52.4%) reported mild-to-moderate IPD, 37.9% reported moderate IPD and 9.7% moderate-to-severe IPD. 54.8% reported fluctuating IPD symptoms. 60% of the sample scored above the recommended clinical cut-off for social anxiety.

Primary outcome variable

The Liebowitz Social Anxiety Scale (LSAS) (Liebowitz, 1987) is a NICE recommended screening tool for social anxiety. Cronbach's alpha is reported as 0.95 indicating good internal consistency with test-retest reliability 0.83 at 12 weeks (NICE, 2020). The self-report version (used in this study) correlates well with the original clinician reported version (Fresco et al., 2001). A cut-off of 41/42 is reportedly the best balance between sensitivity (77.8%) and specificity (64.3%) for PwIPD (Kummer, Cardoso, & Teixeira, 2008) and was used to determine the prevalence of clinically relevant social anxiety in this sample.

Secondary outcome variable

The Quality of Life Index generic version (QLI) (Ferrans & Powers, 1985) measures quality of life and is reported to have good psychometric properties with Cronbach's α ranging from 0.89-0.96 (Ferrans & Powers, 1992).

Key predictor variables

All key predictor variables have been used to test the applicability of a cognitive-behavioural understanding of social anxiety in other populations (Hodson, McMannus, Clark, & Doll, 2008; Schreiber et al., 2012).

The Social Cognitions Questionnaire (SCQ) (Wells, Stopa, & Clark, 1993) measures the frequency and belief in negative social cognitions (only frequency was used in this study). This decision was based on limiting the number of variables in this study to essential core variables to reduce loss of power. If frequency of SCQ is found to be a relevant variable then further studies may wish to include percentage belief ratings. This would advance the research question from, *are negative social cognitions present*, to *what influences the impact of negative social cognitions*. Stopa (1995) is reported to have factor analysed data from 335 participants and established good internal consistency of this measure across three factors: negative self-beliefs $\alpha=.72$, fear of performance failure $\alpha=.84$ and fear of negative evaluation $\alpha=.81$ (Stopa, 1995 unpublished data referred to in Tanner, Stopa & De Hower, 2006; Calvet, Orue, Hankin, 2013). For the purposes of this study, mean scores were used as recommended (Clark, 2005).

The Social Behaviour Questionnaire (SBQ) (Clark, Wells, Salkovskis, & Hackmann, 1995) measures safety seeking behaviours in social situations. It has good internal consistency $\alpha = 0.8$ and good discrimination between anxiety disorders (Clark, 2005). Mean scores were used as recommended (Clark, 2005).

The internal subscale of *The Focus of Attention Questionnaire* (FAQ) (Woody, 1996) measures internally focused attention. It has acceptable internal consistency (Cronbach's $\alpha = .76$, (Woody et al., 1997)). The FAQ was modified by asking participants where they 'usually' focused their attention during a social interaction to fit the study design.

Control variables

The Movement Disorder Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS) was used as a measure of IPD severity and is considered to have good reliability and validity (Goetz. et al., 2008). It has a reliable factor structure supporting the use of each part separately with the lowest Cronbach's α reported to be .79 (Goetz. Et al., 2008). Only self-report items in parts I and II were used in this study to fit the study design. Self-report items of NMS severity (Part I) and motor symptom severity (Part II) significantly model clinician rated reports, suggesting patient perceptions of disability represent valid estimates of symptom severity (Goetz, Luo, & Stebbins., 2019). Recommended motor symptom severity cut-off scores are: mild/moderate, 12/13 and moderate/severe, 28/29 (Martínez-Martín et al., 2015). These cut-offs were used to establish IPD severity in the sample. Part II has appropriate performance in assessing IPD disability compared to other measures (Rodríguez-Blázquez et al., 2017).

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used to assess anxiety and depression. It is shown to have satisfactory psychometric properties in PwIPD (Anxiety subscale Cronbach's $\alpha = 0.86$; depression subscale $\alpha = 0.78$) (Marinus, Leentjens, Visser, Stiggelbout, & van Hilten, 2002).

Statistical Analysis

IBM SPSS statistics version 25 was the statistical software package used to perform a 3-step hierarchical linear regression with social anxiety as the dependent variable (Table 1.3). In step 1 the effects of age, sex, depression and anxiety were controlled for due to associations with anxiety in previous literature (Bolluk, Ozel-Kizil, Akbostanci, & Atbasoglu, 2010). Age was not entered into the model after observing insufficient evidence for a linear relationship with social anxiety (see Table 1.2). In step 2, NMS and motor symptom severity were controlled for due to their possible associations with anxiety (Sagna et al., 2014). In step 3 cognitive-behavioural variables were entered. A second hierarchical regression was conducted with QoL as the dependent variable: Anxiety and depression were entered in step 1, IPD variables were entered in step 2 and social anxiety was entered in the final step. The final model is reported (Table 1.4).

Missing Data

Guidance on handling missing items was followed for each measure where available. SCQ, SBQ and QLI mean scores were calculated which automatically deals with missing items. As recommended, no more than one item from part I or two items from part II of the MDS-UPDRS was pro-rated (Goetz et al., 2015). Mean imputation was applied when no more than 20% of items were missing (Enders, 2003). Where more than 20% of items were missing, data were removed. See table 1.5 below for a breakdown of missing data across each measure. To maximise use of data, cases were excluded pairwise during statistical analysis (Pallant, 2010).

Table 1.5: Missing data

Ethical Statement

Authors have abided by the Ethical Principles of Psychologists and Code of Conduct as set out by the BABCP and BPS. Ethical approval was granted by the East of Scotland Research Ethics Service (ESRES), Health and Care Research Wales (HCRW) committee and Health Research Authority (HRA), Ref: 18/ES/0140, the University of Bath Psychology Department ethics

committee, PREC 18/19 030 and Research Governance at VirginCare, BRD Ref 2019_006.

Results

Parametric Assumptions

Spearman rho correlations (Table 1.2) were used to assess all bivariate relationships. Tolerance (0.409-0.936) and Variance Inflation Factor (VIF) values (1.069-2.445) for all predictors fell within acceptable thresholds suggesting no evidence of multicollinearity (Pallant, 2010). Visual inspection of a histogram, normal P-P plot and scatter plot of standardised residuals indicated no evidence that parametric assumptions were violated (Field, 2013).

Table 1.2: Spearman's Rho Correlation Matrix

Hypothesis 1a

Spearman's Rho correlations indicated moderate-to-strong positive linear relationships between each cognitive-behavioural variable and social anxiety. Results indicated support for hypotheses 1. The association between social anxiety and negative social cognitions was strong ($R_s = .772$, $N=122$, $P<0.001$), moderate with safety-seeking behaviours ($R_s = .694$, $N=123$, $P<0.001$) and moderate with an internal focus of attention ($R_s = .511$, $N=119$, $P<0.001$).

Hypothesis 1b

The hypothesis that each cognitive-behavioural factor would explain a unique portion of variance in social anxiety was partly supported. Hierarchical linear regression (Table 1.3) indicated that cognitive-behavioural factors accounted for 43.5% of variance in social anxiety in PwIPD. The final model accounted for 71.6% of variance overall and was statistically significant ($F=32.10$, $df=8$, 102 , $p<0.001$). Negative social cognitions ($t(102) = 7.30$, $p<.001$) and safety-seeking behaviours ($t(102) = 4.19$, $p<.001$) were statistically significant predictors however an internal focus of attention ($t(102) = -.70$, $p=.677$) was not.

IPD NMS severity ($t(102) = -2.47$, $p=.015$) and depression, ($t(102) = 2.25$, $p=.026$) were significant predictors of social anxiety however motor symptoms ($t(102) = 1.97$, $p=.051$), sex ($t(102) = 1.26$, $p=.21$) and anxiety ($t(102) = -.53$, $p=.60$) were not.

Table 1.3: Hierarchical Regression Model with Social Anxiety (LSAS) as the outcome variable

Hypothesis 2a

Spearman's Rho correlations indicated a weak negative linear association between social anxiety and QoL providing some support for this hypothesis ($R_s = -.39$, $N=116$, $p < .01$).

Hypothesis 2b

The hypothesis that social anxiety would explain a unique portion of variance in QoL was not supported. Hierarchical regression indicated that social anxiety was not predictive of QoL in PwIPD ($t(106) = -1.65$, $p = .10$). The final model (Table 1.4) which accounted for 38.8% of the variance in QoL indicated that only depression and NMS made significant contributions to the model. Anxiety, motor symptoms and social anxiety did not. This model was statistically significant ($F=13.45$, $df=5$, 106 , $p < .01$).

Table 1.4 Final model with QoL as the outcome

Discussion

This is the first study to demonstrate that negative social cognitions and safety-seeking behaviours are strongly associated with social anxiety in PwIPD. Social anxiety was more strongly correlated with negative social cognitions and safety-seeking behaviours than symptoms of IPD severity. When the influence of other relevant factors were statistically controlled for, both negative social cognitions and safety seeking behaviours predicted unique variance in social anxiety in PwIPD. Internally focused attention did not. Social anxiety was not predicted by motor symptoms and NMS were a very weak predictor.

These findings are consistent with the theoretical position that psychological factors are influential to the experience of social anxiety in PwIPD. Results indicate that a cognitive-behavioural understanding of social anxiety may be a useful conceptual framework in PwIPD. This contrasts with a purely biomedical disease model and is consistent with existing evidence that psychological factors play a role in influencing distress in PwIPD (Brown & Fernie, 2015; Fernie et al., 2015).

Negative social cognitions were the strongest predictor of social anxiety while motor symptom severity did not predict any variance in the final model. This study did not specifically look at individual interpretations of IPD symptoms. However given the initial finding that negative social cognitions are associated with social anxiety in PwIPD, it might be a reasonable next step to tentatively hypothesise that the way someone interprets their IPD symptoms, has an impact on their behaviour and experience of social anxiety. It would be useful to gain a fuller understanding on what the content of their negative social cognitions are and what are the specific safety seeking behaviours PwIPD are using to cope. For future research to test this hypothesis adequately, the subjective interpretations of IPD symptoms from self-report measures would have to be compared against an objective measure of IPD symptom severity. Completing the full MDS-UPDRS alongside a gold standard measure of social anxiety based on the DSM-IV or ICD criteria as well as a semi-structured interview schedule to capture a detailed account of how each participant interprets their symptoms of IPD would be one way to achieve this. It would enable a fuller understanding of common cognitive biases that may be present in this population that would be useful for clinicians working with PwIPD to be mindful of.

This is the first study to demonstrate that the degree to which a PwIPD engages in safety-seeking behaviours (e.g. putting one's hand in a pocket to hide a tremor) is moderately predictive of social anxiety. This is consistent with a cognitive-behavioural understanding of SAD, where thoughts about oneself can drive behavioural responses intended to reduce social anxiety but actually exacerbate it. Future research would also benefit from measuring a more detailed account of the safety seeking behaviours PwIPD use and whether these are carried out in response to particular IPD symptoms. This would allow a richer understanding of how PwIPD use safety seeking behaviours and help inform clinicians working with PwIPD of what to be mindful of in this context.

The finding that depression and NMS were predictive of social anxiety in IPD was consistent with previous literature (Bolluk et al., 2010). The finding that motor symptom severity was not predictive of social anxiety was also consistent with previous literature in PwIPD (Brown & Fernie, 2015).

The association between NMS and social anxiety in this study was not predicted. One possible explanation is symptoms overlap. For example, question 1.9 in the MDS-UPDRS part I asks about *pain and other sensations such as uncomfortable feelings in the body like tingling*. Another explanation is that NMS such as urinary problems or fainting are interpreted as more socially threatening than motor symptoms. Future qualitative studies could explore PwIPD interpretations of NMS and motor symptoms to gain insight into this finding and develop a more IPD specific understanding of social anxiety.

The finding that social anxiety shared a negative linear relationship with QoL was consistent with previous literature (Barrera & Norton, 2009; Safren et al., 1996). Although this was predicted, the association was weak and social anxiety did not predict QoL. Findings therefore suggest that depression and NMS might be more important factors when considering QoL in PwIPD. It is also possible that variance shared by depression and social anxiety might have masked a more complex relationship reflecting a limitation of the sensitivity and specificity of the measures used in this study.

As expected, the prevalence of social anxiety in this sample was high with 60% scoring above the clinical cut-off. This is higher than the prevalence in the general population, other samples of PwIPD and people with other movement disorders such as MS (Gultekin et al., 2014; Poder et al., 2009). Sampling bias to a study designed to explore SAD in PwIPD and a screening tool to assess social anxiety could have contributed to this high prevalence. Even so, such high prevalence in this sample supports the argument that SAD is a clinically relevant problem for PwIPD warranting further attention.

Contrary to Schreiber et al (2012) and Hodson et al (2008), an internal focus of attention did not predict social anxiety in this study. While this might represent a genuine finding it might also be due to methodology. This study adapted the FAQ from situation specific to generic questions to fit the non-experimental design. This may have impacted recall accuracy. The importance of an internal focus of attention to social anxiety in PwIPD could be clarified by using the original FAQ questions and

directing participants to focus on a specific recent social interaction via semi-structured interview in future research. Another possible explanation could be the regression analysis which involved entering all cognitive-behavioural variables during the same step. This could have led to an overlap of variance accounted for between the 3 predictors masking the unique contributions of self-focused attention. One way to test this in future studies would be to enter cognitive-behavioural variables in a hypothesis led step wise way in line with cognitive models.

Limitations

The cross-sectional design means that causality cannot be inferred limiting the conclusions that can be drawn about associations in this study. All data in this study was self-reported, a necessary strategy to maximise recruitment in a hard-to-reach population. Truly objective estimates of IPD symptom severity were thus not achieved, limiting conclusions about the relationship between social anxiety, NMS and motor symptoms of IPD. Self-report alone prevents elimination of the possible contamination of cognitive biases that could have otherwise been ruled out by contrast with clinician ratings. Although Goetz, Luo & Stebbins (2019) indicate that self-report items on the MDS-UPDRS correlate well with clinician reported items, future research would benefit from controlling more robustly for the potential cognitive bias of symptoms of IPD by using the full MDS-UPDRS.

This sample consisted largely of PwIPD who had an interest in research. Evidence suggests volunteer bias can influence outcomes that aren't representative more generally (Jordan et al., 2013). Therefore caution should be drawn about generalising the findings of this study. While the sample was geographically diverse, non-white British and severe levels of IPD were under-represented. This could be related to the online recruitment strategy and inclusion criteria which attracted younger, therefore on average people in earlier stages of disease. PwIPD in earlier stages are more likely to be adjusting to their diagnosis and the challenges IPD brings to their identity in different social circumstances. For example, they may still be working and have an active role in larger social networks that might challenge their functional abilities. Arguably they might therefore experience a heightened level of self-consciousness compared to people in latter stages, who may be more adjusted making social anxiety less relevant. Assessment of social anxiety

experiences among people with severe IPD would deepen our understanding of social anxiety across the course of IPD.

Clinical implications

These findings are consistent with the revision in the DSM-5 which now accepts that people within a medical context may also meet criteria for SAD (Heimberg et al., 2014). As we know from other medical conditions, how an individual interprets their disability is a critical part of their distress and experience, regardless of how their disability may 'objectively' appear when measured clinically or using standardised tools.

This study thus partially supports the applicability of a cognitive-behavioural understanding of social anxiety in PwIPD. In practice, assessment of a PwIPD's interpretation of their IPD should be regarded as equally important to the assessment of disability or disease 'severity'. Anxiety cannot be assumed to be linearly associated with disease progression or 'organic pathology'. Clinicians should pay attention to any such incongruence and consider referral for psychological intervention when social anxiety levels are high.

Such interventions may include Cognitive Behavioural Therapy (CBT) particularly if there are clear cognitive biases and safety-seeking behaviours likely to maintain anxiety. However, further research must clarify which processes from the available models would be most applicable for PwIPD. For example combining the key processes from disorder specific models such as Clark & Wells (1995) and Heimberg (1997) with a more generic context that acknowledges the vulnerabilities that arise due to IPD such as those proposed by Stephens et al (2018) might offer more tailored interventions for PwIPD and social anxiety. Such an approach offers great hope as such psychological interventions have been shown effective in other populations.

Conclusion

This novel study provides evidence that negative social cognitions and safety-seeking behaviours are cognitive-behavioural variables that are associated with and predictive of social anxiety in PwIPD. Results are similar to what we might expect to

see in the general population. Interpretations and reactions to IPD symptoms and the relationship of these factors with social anxiety are important areas for further research.

1.1 References

- APA. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed ed.). Washington, DC.
- Barrera, T. L., & Norton, P. J. (2009). Quality of life impairment in generalized anxiety disorder, social phobia, and panic disorder. *J Anxiety Disord*, 23(8), 1086-1090. doi:10.1016/j.janxdis.2009.07.011
- Beck, A.T., & Steer, R.A. (1993). Beck Anxiety Inventory Manual. San Antonio, TX: Psychological Corporation.
- Bolluk, B., Ozel-Kizil, E. T., Akbostanci, M. C., & Atbasoglu, E. C. (2010). Social anxiety in patients with Parkinson's disease. *J Neuropsychiatry Clin Neurosci*, 22(4), 390-394. doi:10.1176/jnp.2010.22.4.390
- Broen, M. P., Narayan, N. E., Kuijff, M. L., Dissanayaka, N. N., & Leentjens, A. F. (2016). Prevalence of anxiety in Parkinson's disease: A systematic review and meta-analysis. *Mov Disord*, 31(8), 1125-1133. doi:10.1002/mds.26643
- Brown, R. G., & Fernie, B. A. (2015). Metacognitions, anxiety, and distress related to motor fluctuations in Parkinson's disease. *Journal of Psychosomatic Research*, 78(2), 143-148. doi:<https://doi.org/10.1016/j.jpsychores.2014.09.021>
- Cardaciotto, L., & Herbert, J. D. (2004). Cognitive behavior therapy for social anxiety disorder in the context of Asperger's Syndrome: A single-subject report. *Cognitive and Behavioral Practice*, 11(1), 75-81. doi:[https://doi.org/10.1016/S1077-7229\(04\)80009-9](https://doi.org/10.1016/S1077-7229(04)80009-9)
- Connor K. M., Davidson J.R., Churchill L.E., Sherwood A., Foa E., & Weisler R.H. Psychometric properties of the Social Phobia Inventory (SPIN). New self-rating scale. *British Journal of Psychiatry*. 2000 Apr;176:379-86
- Chaudhuri, K. R., Healy, D. G., & Schapira, A. H. V. (2006). Non-motor symptoms of Parkinson's disease: diagnosis and management. *The Lancet Neurology*, 5(3), 235-245. doi:[https://doi.org/10.1016/S1474-4422\(06\)70373-8](https://doi.org/10.1016/S1474-4422(06)70373-8)
- Chen, J. J., & Marsh, L. (2014). Anxiety in Parkinson's disease: identification and management. *Ther Adv Neurol Disord*, 7(1), 52-59. doi:10.1177/1756285613495723
- Clark, D. (2005). *Three Questionnaires for measuring Central Constructs in the cognitive model of social anxiety: Preliminary Analysis*. unpublished.
- Clark, D., Wells, A., Salkovskis, P., & Hackmann, A. (1995). *The Social Behaviours Questionnaire*. Unpublished manuscript. Department of Psychiatry, Oxford University, Oxford, UK.
- Deane, K. H. O., Flaherty, H., Daley, D. J., Pascoe, R., Penhale, B., Clarke, C. E., Sackley, C., & Storey, S. (2014). Priority setting partnership to identify the top 10 research priorities for the management of Parkinson's disease. *BMJ Open*, 4(12), e006434. doi:10.1136/bmjopen-2014-006434

- Enders, C. K. (2003). Using the expectation maximization algorithm to estimate coefficient alpha for scales with item-level missing data. *Psychol Methods*, 8(3), 322-337. doi:10.1037/1082-989X.8.3.322
- Fernie, B. A., Spada, M. M., Ray Chaudhuri, K., Klingelhofer, L., & Brown, R. G. (2015). Thinking about motor fluctuations: An examination of metacognitions in Parkinson's disease. *J Psychosom Res*, 79(6), 669-673. doi:10.1016/j.jpsychores.2015.05.001
- Ferrans, & Powers. (1985). Quality of life index: development and psychometric properties. *Advances in Nursing Science*, 8(1), 15-24.
- Ferrans, & Powers. (1992). Psychometric assessment of the Quality of Life Index. *Research in nursing & health*, 15(1), 29-38.
- Fresco, D. M., Coles, M. E., Heimberg, R. G., Liebowitz, M. R., Hami, S., Stein, M. B., & Goetz, D. (2001). The Liebowitz Social Anxiety Scale: a comparison of the psychometric properties of self-report and clinician-administered formats. *Psychol Med*, 31(6), 1025-1035.
- Goddard, J. (2014). *An exploration into the experiences of Parkinson's disease and its relationship with emotional well-being*. (Doctorate in Clinical Psychology). University of Leicester,
- Goetz, Luo, & Stebbins. (2019). Modeling the Effect of Patient's Perception of Non-Motor and Motor Function on Parkinson's Disease Severity [abstract]. *Mov Disord*, 34.
- Goetz, Luo, S., Wang, L., Tilley, B. C., LaPelle, N. R., & Stebbins, G. T. (2015). Handling missing values in the MDS-UPDRS. *Mov Disord*, 30(12), 1632-1638. doi:10.1002/mds.26153
- Goetz., Tilley, B. C., Shaftman, S. R., Stebbins, G. T., Fahn, S., Martinez-Martin, P., . . . Force, M. D. S. U. R. T. (2008). Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS): scale presentation and clinimetric testing results. *Mov Disord*, 23(15), 2129-2170. doi:10.1002/mds.22340
- Gultekin, B. K., Ozdilek, B., & Bestepe, E. E. (2014). Social phobia in Parkinson's disease: Prevalence and risk factors. *Neuropsychiatric disease and treatment*, 10, 829-834. doi:10.2147/NDT.S62942
- Heimberg, R. G., Hofmann, S. G., Liebowitz, M. R., Schneier, F. R., Smits, J. A., Stein, M. B., . . . Craske, M. G. (2014). Social anxiety disorder in DSM-5. *Depress Anxiety*, 31(6), 472-479. doi:10.1002/da.22231
- Heinrichs, N., Hoffman, E., & Hoffman, S. (2001). Cognitive-behavioral treatment for social phobia in Parkinson's disease: A single-case study. *Cognitive Behavioural Practice*, 8(4), 328-335.
- Hodson, K., McMannus, F., Clark, D., & Doll, H. (2008). Can Clark and Wells' (1995) Cognitive Model of Social Phobia be Applied to Young People? *Behavioural and Cognitive Psychotherapy*, 36, 449-461.
- Ishihara, L., & Brayne, C. (2006). A systematic review of depression and mental illness preceding Parkinson's disease. *Acta Neurologica Scandinavica*, 113(4), 211-220. doi:10.1111/j.1600-0404.2006.00579.x
- Jordan, S., Watkins, A., Storey, M., Allen, S. J., Brooks, C. J., Garaiova, I., . . . Morgan, G. (2013). Volunteer bias in recruitment, retention, and blood sample donation in a randomised controlled trial involving mothers and their children at six months and two years: a longitudinal analysis. *PLoS One*, 8(7), e67912. doi:10.1371/journal.pone.0067912

- Kleve, L., Rumsey, N., Wyn-Williams, M., & White, P. (2002). The effectiveness of cognitive-behavioural interventions provided at Outlook: a disfigurement support unit. *Journal of Evaluation in Clinical Practice*, 8(4), 387-395. doi:10.1046/j.1365-2753.2002.00348.x
- Klingelhofer, L., & Reichmann, H. (2017). Parkinson's disease as a multisystem disorder. *Journal of Neural Transmission*, 124(6), 709-713. doi:10.1007/s00702-017-1692-0
- Kummer, A., Cardoso, F., & Teixeira, A. L. (2008). Frequency of social phobia and psychometric properties of the Liebowitz social anxiety scale in Parkinson's disease. *Mov Disord*, 23(12), 1739-1743. doi:10.1002/mds.22221
- Liebowitz, M. R. (1987). Social phobia. *Mod Probl Pharmacopsychiatry*, 22, 141-173. doi:10.1159/000414022
- Marinus, J., Leentjens, A. F., Visser, M., Stiggelbout, A. M., & van Hilten, J. J. (2002). Evaluation of the hospital anxiety and depression scale in patients with Parkinson's disease. *Clin Neuropharmacol*, 25(6), 318-324.
- Martínez-Martín, P., Rodríguez-Blázquez, C., Mario, A., Arakaki, T., Arillo, V. C., Chaná, P., . . . Merello, M. (2015). Parkinson's disease severity levels and MDS-Unified Parkinson's Disease Rating Scale. *Parkinsonism & Related Disorders*, 21(1), 50-54. doi:<https://doi.org/10.1016/j.parkreldis.2014.10.026>
- Mattick, R.P., & Clarke, J.C. (1998). Development and validation of measures of social phobia scrutiny fear and social interaction anxiety. *Behaviour Research and Therapy*, 36(4), 455-470. doi: 10.1016/S0005-7967(97)10031-6
- McManus, F., Sacadura, C., & Clark, D. M. (2008). Why social anxiety persists: An experimental investigation of the role of safety behaviours as a maintaining factor. *Journal of Behavior Therapy and Experimental Psychiatry*, 39(2), 147-161. doi:<https://doi.org/10.1016/j.jbtep.2006.12.002>
- Moriyama, T. S., Felicio, A. C., Chagas, M. H., Tardelli, V. S., Ferraz, H. B., Tumas, V., . . . Bressan, R. A. (2011). Increased dopamine transporter density in Parkinson's disease patients with Social Anxiety Disorder. *J Neurol Sci*, 310(1-2), 53-57. doi:10.1016/j.jns.2011.06.056
- NICE. (2013). *Social anxiety disorder: recognition, assessment and treatment*. <https://www.nice.org.uk/guidance/cg159>
- Nègre-Pagès, L., Grandjean, H., Lapeyre-Mestre, M., Montastruc, J. L., Fourrier, A., Lépine, J. P., . . . Group, o. b. o. t. D. S. (2010). Anxious and depressive symptoms in Parkinson's disease: The French cross-sectionnal DoPaMiP study. *Movement Disorders*, 25(2), 157-166. doi:10.1002/mds.22760
- Pachana, N. A., Egan, S. J., Laidlaw, K., Dissanayaka, N., Byrne, G. J., Brockman, S., . . . Starkstein, S. (2013). Clinical issues in the treatment of anxiety and depression in older adults with Parkinson's disease. *Movement Disorders*, 28(14), 1930-1934. doi:10.1002/mds.25689
- Pallant, J. (2010). *SPSS survival manual : a step by step guide to data analysis using SPSS*: Fourth edition. Maidenhead : Open University Press/McGraw-Hill, 2010.
- Poder, K., Ghatavi, K., Fisk, J. D., Campbell, T. L., Kisely, S., Sarty, I., . . . Bhan, V. (2009). Social anxiety in a multiple sclerosis clinic population. *Mult Scler*, 15(3), 393-398. doi:10.1177/1352458508099143
- Ranta, K., Tuomisto, M. T., Kaltiala-Heino, R., Rantanen, P., & Marttunen, M. (2014). Cognition, Imagery and Coping among Adolescents with Social Anxiety and

- Phobia: Testing the Clark and Wells Model in the Population. *Clinical Psychology & Psychotherapy*, 21(3), 252-263. doi:10.1002/cpp.1833
- Reijnders, J.S., Ehrst, U., Weber, W.E., Aarsland, D. and Leentjens, A.F. (2008), A systematic review of prevalence studies of depression in Parkinson's disease. *Mov. Disord.*, 23: 183-189. <https://doi.org/10.1002/mds.21803>
- Rodríguez-Blázquez, C., Alvarez, M., Arakaki, T., Campos Arillo, V., Chaná, P., Fernández, W., . . . Martínez-Martín, P. (2017). Self-Assessment of Disability in Parkinson's Disease: The MDS-UPDRS Part II Versus Clinician-Based Ratings. *Mov Disord Clin Pract*, 4(4), 529-535. doi:10.1002/mdc3.12462
- Rumsey, N., Clarke, A., & White, P. (2003). Exploring the psychosocial concerns of outpatients with disfiguring conditions. *J Wound Care*, 12(7), 247-252. doi:10.12968/jowc.2003.12.7.26515
- Safren, S. A., Heimberg, R. G., Brown, E. J., & Holle, C. (1996). Quality of life in social phobia. *Depression and Anxiety*, 4(3), 126-133. doi:10.1002/(SICI)1520-6394(1996)4:3<126::AID-DA5>3.0.CO;2-E
- Sagna, A., Gallo, J. J., & Pontone, G. M. (2014). Systematic review of factors associated with depression and anxiety disorders among older adults with Parkinson's disease. *Parkinsonism & Related Disorders*, 20(7), 708-715. doi:10.1016/j.parkreldis.2014.03.020
- Salazar, R. D., Le, A. M., Nearing, S., & Cronin-Golomb, A. (2017). The impact of motor symptoms on self-reported anxiety in Parkinson's disease. *Parkinsonism & Related Disorders*, 38, 26-30. doi:10.1016/j.parkreldis.2017.01.011
- Schreiber, F., Höfling, V., Stangier, U., Bohn, C., & Steil, R. (2012). A Cognitive Model of Social Phobia: Applicability in a Large Adolescent Sample. *International Journal of Cognitive Therapy*, 5(3), 341-358. doi:10.1521/ijct.2012.5.3.341
- Spurr, J. M., & Stopa, L. (2002). Self-focused attention in social phobia and social anxiety. *Clinical Psychology Review*, 22(7), 947-975. doi:[https://doi.org/10.1016/S0272-7358\(02\)00107-1](https://doi.org/10.1016/S0272-7358(02)00107-1)
- Stephens, E. J., Dysch, L., & Gregory, J. (2018). Diagnostic Overshadowing of Anxiety in Parkinson Disease: Psychosocial Factors and a Cognitive-Behavioral Model. *Cogn Behav Neurol*, 31(3), 123-132. doi:10.1097/WNN.0000000000000161
- Stoker, T. B., & Greenland, J. C. (2018). Parkinson's Disease: Pathogenesis and Clinical Aspects. In.
- Weintraub, D., Moberg, P. J., Duda, J. E., Katz, I. R., & Stern, M. B. (2004). Effect of psychiatric and other nonmotor symptoms on disability in Parkinson's disease. *J Am Geriatr Soc*, 52(5), 784-788. doi:10.1111/j.1532-5415.2004.52219.x
- Weintraub, D., Newberg, A. B., Cary, M. S., Siderowf, A. D., Moberg, P. J., Kleiner-Fisman, G., . . . Katz, I. R. (2005). Striatal Dopamine Transporter Imaging Correlates with Anxiety and Depression Symptoms in Parkinson's Disease. *Journal of Nuclear Medicine*, 46(2), 227-232.
- Wells, A., Stopa, L., & Clark, D. (1993). *The Social Cognitions Questionnaire*. unpublished.
- Wood, B., van der Mei, I. A., Ponsonby, A. L., Pittas, F., Quinn, S., Dwyer, T., . . . Taylor, B. V. (2013). Prevalence and concurrence of anxiety, depression and

- fatigue over time in multiple sclerosis. *Mult Scler*, 19(2), 217-224.
doi:10.1177/1352458512450351
- Woody. (1996). Effects of focus of attention on anxiety levels and social performance of individuals with social phobia. *J Abnorm Psychol*, 105(1), 61-69.
doi:10.1037//0021-843x.105.1.61
- Woody, Chambless, & Glass. (1997). Self-focused attention in the treatment of social phobia. *Behaviour Research and Therapy*, 35(2), 117-129.
doi:[https://doi.org/10.1016/S0005-7967\(96\)00084-8](https://doi.org/10.1016/S0005-7967(96)00084-8)
- Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67(6), 361-370. doi:10.1111/j.1600-0447.1983.tb09716.x