Behavioural and Cognitive Psychotherapy, 2022, **50**, 57–73
doi:10.1017/S1352465821000291

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The contribution of cognitive behavioural factors to social anxiety in Parkinson's disease

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(Received 14 July 2020; revised 6 June 2021; accepted 8 June 2021; first published online 07 September 2021)

Abstract

Background: Social anxiety is prevalent in idiopathic Parkinson's disease but 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: anxiety; cognitive behavioural; Parkinson's disease; psychological therapy; social anxiety

Introduction

Social anxiety is one of the most commonly reported experiences of anxiety among people with idiopathic Parkinson's disease (PwIPD). Currently there is no specific guidance around the best clinical interventions to support PwIPD who experience social anxiety. This paper begins to explore the associated factors of social anxiety for PwIPD. 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.

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 and 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 *et al.*, 2006), they are often overlooked at this early stage and not recognised as part of a complex neurodegenerative condition (Klingelhoefer and Reichmann, 2017). NMS include autonomic, sensory and sleep changes (Ishihara and 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 *et al.*, 2018). Despite their substantial influence on disability and quality of life (Weintraub *et al.*, 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 people with IPD

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 *et al.*, 2016; Gultekin *et al.*, 2014; Nègre-Pagès *et al.*, 2010; Reijnders *et al.*, 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 *et al.*, 2003). IPD could arguably be percieved 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 with other people and/or a person's 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 has not 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 Beck Anxiety Inventory (BAI) (Beck and Steer, 1993) contains *hands trembling* (Salazar *et al.*, 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 affect 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 excaerbates 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 and Clarke, 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 and Clarke, 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

https://doi.org/10.1017/S1352465821000291 Published online by Cambridge University Press

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 to 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 (National Institute for Health and Care Excellence [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 with 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

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 and Norton, 2009; Safren *et al.*, 1996). Cognitive behavioural therapy (CBT) is recommended as first-line treatment (NICE, 2013) and is based upon two empirically supported cognitive behavioural models (see Fig. 1).

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 over-estimated.
(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 and Wells (1995) place an emphasis on an internal, self-focus of attention that is interpreted as threatening whereas Heimberg *et al.* (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 *et al.*, 2008; Spurr and Stopa, 2002; Woody *et al.*, 1997); young people (Ranta *et al.*, 2014; Schreiber *et al.*, 2012) and support for CBT interventions based on these models have been demonstrated in the context of autism (Cardaciotto and Herbert, 2004); visible differences (Kleve *et al.*, 2002) and a single case study of social anxiety in IPD (Heinrichs *et al.*, 2001). These findings indicate that cognitive behavioural approaches to SAD may be widely generalisable to populations including PwIPD.

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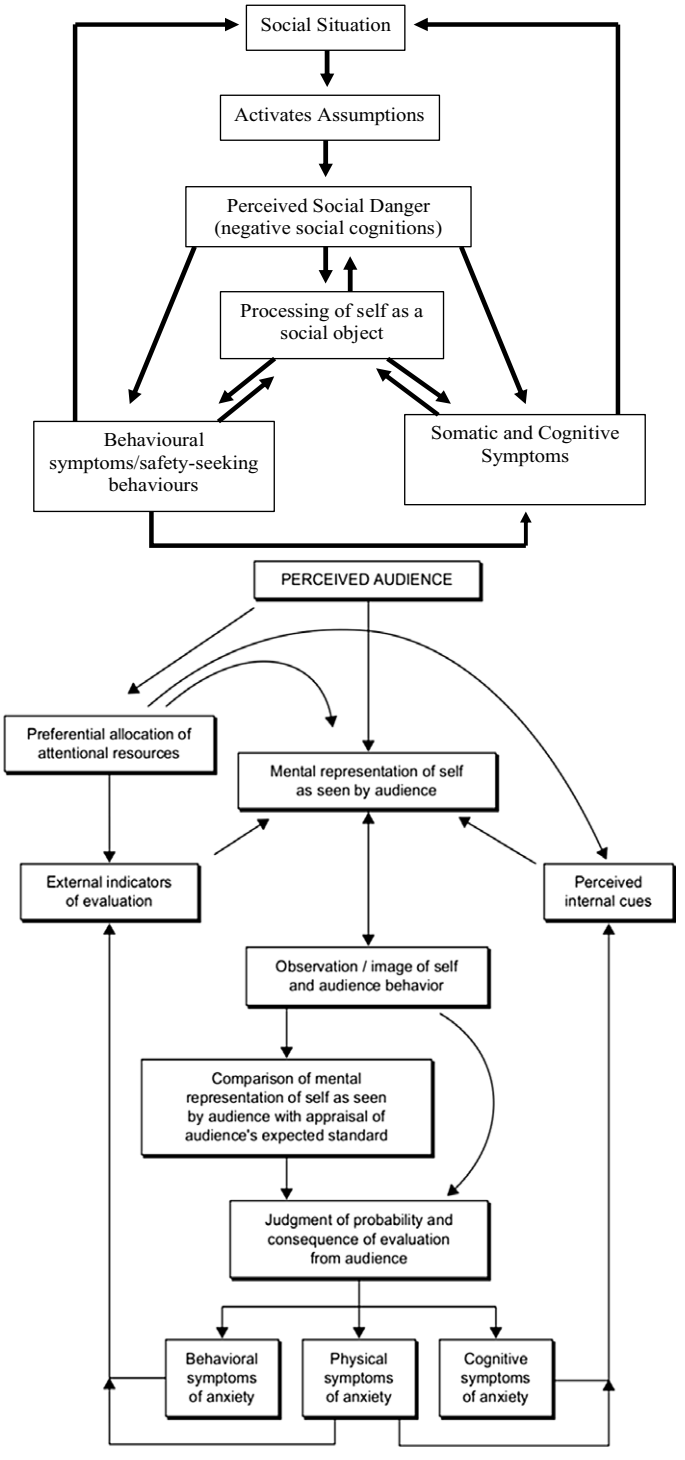

Figure 1. Models of SAD. Top: a cognitive model of social phobia, Clark and Wells, from Heimberg *et al.* (1995); reprinted with permission of Guilford Press. Bottom: an updated cognitive behavioural model of social anxiety; Heimberg *et al.* (2010).

https://doi.org/10.1017/S1352465821000291 Published online by Cambridge University Press

Social anxiety in people with IPD

SAD in the context of a medical condition was excluded from the *Diagnostical 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 from that in the general population (e.g. Sagna *et al.*, 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 and Fernie, 2015). As seen in MS (Wood *et al.*, 2013), Brown and 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 and 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 and Fernie, 2015; Fernie *et al.*, 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. Although 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 and 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.
(2c) Social anxiety will be negatively associated with QoL in PwIPD.
(2d) Social anxiety will account for a unique portion of variance in QoL in PwIPD.

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Table 1. Exclusion criteria

Exclusion criteria
Participant unable to confirm diagnosis of IPD
Less than 18 years old
Does not satisfy the capacity assessment (e.g. unable to understand, retain, weigh up or communicate information about the study and taking part)
Insufficient English language skills to complete questionnaires
Insufficient motor skills to complete questionnaires (paper or online)
Diagnosis of another significant disorder that affects the neurological system, e.g. MS, dementia
A history that includes a severe head injury that resulted in hospitalization, loss of consciousness and/or a significant rehabilitation period

Method

Participants and procedure

Recruitment was supported by an NHS Movement Disorders Clinic in the South West and the charity Parkinson's Disease UK (PDUK). Both organisations shared study advertisements with potential participants. Interested participants contacted the researcher who conducted a telephone screen to establish eligibility. Table 1 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).

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 R^2; deviation from 0 alpha of 0.05; power of 0.80; nine predictors and a medium effect size (0.15) (based on Hodson *et al.*, 2008). The estimated required sample was 114 participants for the primary analysis.

Demographics

One hundred and twenty-four PwIPD took part; 52% were male. Participants were predominantly White British (95.9%). Most participants were aged between 51 and 79 years (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. Sixty per cent of the sample scored above the recommended clinical cut-off for social anxiety.

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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–re-test reliability 0.83 at 12 weeks (National Institute for Health and Care Excellence [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 *et al.*, 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 and Powers, 1985) measures quality of life and is reported to have good psychometric properties with Cronbach's α ranging from 0.89 to 0.96 (Ferrans and 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 *et al.*, 2008; Schreiber *et al.*, 2012).

The Social Cognitions Questionnaire (SCQ) (Wells *et al.*, 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 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 *et al.*, 2006); (Calvete *et al.*, 2013). For the purposes of this study, mean scores were used as recommended (Clark, 2005).

The Social Behaviour Questionnaire (SBQ) (Clark *et al.*, 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 that patient perceptions of disability represent valid estimates of symptom severity (Goetz *et al.*, 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 with other measures (Rodríguez-Blázquez *et al.*, 2017).

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The Hospital Anxiety and Depression Scale (HADS) (Zigmond and 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 *et al.*, 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 3). In step 1 the effects of age, sex, depression and anxiety were controlled for due to associations with anxiety in previous literature (Bolluk et al., 2010). Age was not entered into the model after observing insufficient evidence for a linear relationship with social anxiety (see Table 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 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 5 for a breakdown of missing data across each measure. To maximise use of data, cases were excluded pairwise during statistical analysis (Pallant, 2010).

Results

Parametric assumptions

Spearman's rho correlations (Table 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).

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 hypothesis 1a. 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 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 ($F = 32.10$, d.f. $= 8$, 102, $p<0.001$). Negative social cognitions ($t_{102} = 7.30$, $p<.001$) and safety-seeking

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Table 2. Spearman's Rho Correlation Matrix

			LSAS total social anxiety	Gender	Age	HADS_Anx	HADS_Dep	MDSUPDRS_ NonMotorTotal	MDSUPDRS_ MotorTotal	SCQ Total (Mean Freq per week)	SBQ Total (Mean)	FAQ_Internal Total
Spearrnan's rho	LSAS Total Social Anxiety	Correlation Coefficient	1.000	0.129	-0.020	.405**	.446**	.183*	.298**	.772**	.694**	.511**
		N	124	124	123	116	116	117	115	122	123	119
	Gender	Correlation Coefficient	0.129	1.000	0.023	.226*	0.057	0.082	-0.128	0.076	0.149	-0.043
		N	124	124	123	116	116	117	115	122	123	119
	Age	Correlation Coefficient	-0.020	0.023	1.000	0.055	0.087	0.152	0.153	-0.061	0.116	0.072
		N	123	123	123	116	116	117	115	121	122	118
	HADS_Anx	Correlation Coefficient	.405**	.226*	0.055	1.000	.621**	.510**	.310**	.519**	.399**	.370**
		N	116	116	116	116	116	116	114	115	116	115
	HADS_Dep	Correlation Coefficient	.446**	0.057	0.087	.621**	1.000	.474**	.458**	.388**	.362**	.344**
		N	116	116	116	116	116	116	114	115	116	115
	MDSUPDRS_Non-MotorTotal	Correlation Coefficient	.183*	0.082	0.152	.510**	.474**	1.000	.560**	.250**	.321**	.190**
		N	117	117	117	116	116	117	115	116	117	116
	MDSUPDRS_ MotorTotal	Correlation Coefficient	.298**	-0.128	0.153	310**	458**	.580**	1.000	269**	.244**	0.162
		N	115	115	115	114	114	115	115	114	115	114
	SCQ Total (Mean Freq per week)	Correlation Coefficient	.772**	0.076	-0.061	.519**	.388**	250**	269**	1.000	.637**	.582**
		N	122	122	121	115	115	116	114	122	122	118
	SBQ Total (Mean)	Correlation Coefficient	.694**	0.149	0.116	.399**	.362**	.321**	.244**	.637**	1.000	.652**
		N	123	123	122	116	116	117	115	122	123	119
	FAQ_Internal Total	Correlation Coefficient	.511**	-0.043	0.072	.370**	.344**	.190*	0.162	.582**	.652**	1.000
		N	119	119	118	115	115	116	114	118	119	119

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

Table 3. Hierarchical regression model with social anxiety (LSAS) as the outcome variable*

Model	Predictor	*B*	95% CI for *B*	*SE*	Standardised β	R^2 change	Total R^2
1	(Constant)	19.66	.61, 38.70	9.61	*		
	Sex	2.09	−9.47, 13.66	5.83	.031		
	Anxiety	2.07	.29, 3.85	.90	.261*		
	Depression	2.58	.47, 4.69	1.07	.267*	.234	.234
2	(Constant)	17.46	−3.98, 38.90	10.82			
	Sex	3.74	−7.68, 15.15	5.76	.056		
	Anxiety	2.54	.71, 4.33	.92	.320**		
	Depression	2.15	−.03, 4.33	1.10	.222		
	IPD motor symptom severity	1.24	.20, 2.27	.52	.251*		
	IPD NMS severity	−1.69	−3.29, −.10	.81	−.232*	.047	.281
3	(Constant)	−52.83	−72.17, −33.48	9.75	**		
	Sex	4.76	−2.72, 12.25	3.77	.071		
	Anxiety	−.35	−1.65, .95	.66	−.044		
	Depression	1.60	.19, 3.01	.71	.166*		
	IPD motor symptom severity	.66	−.00, 1.33	.34	.134		
	IPD NMS severity	−1.28	−2.31, −.25	.52	−.176*		
	Negative social cognitions	25.06	18.25, 31.87	3.43	.561**		
	Safety seeking behaviours	25.19	13.28, 37.10	6.01	.335**		
	Internal focus of attention	−.42	−1.59, .76	.59	−.051	.435	.716

* $p < 0.05$, ** $p < 0.001$

Table 4. Final model with QoL as the outcome

Model	Predictor	*B*	95% CI for *B*	*SE*	Standardised β	R^2 change	Total R^2
3	(Constant)	24.34	20.10, 23.84	.72	**		
	Anxiety	.00	−.22, .22	.11	.00		
	Depression	-.46	−.72, −.20	.13	−.37**		
	NMS	−.27	−.46, −.07	.10	−.28**		
	Motor symptoms	.01	−.11, .13	.06	−.28		
	Social anxiety	-.02	−.04, .00	.01	−.15	.02	38.8

** $p < 0.1$

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.

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 4), which accounted for 38.8% of the variance in QoL, indicated that only depression and NMS made significant contributions to

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Table 5. Missing data

Measure	No. of complete cases	No. of cases where mean imputation was used	No. of cases excluded due to >20% missing data
LSAS	85	15 (1 item missing) 18 (2 items missing) 3 (3 items missing) 2 (4 items missing) 1(6 items missing)	0
SCQ	115	6 (1 item imputed) 1 (2 items imputed)	2
SBQ	112	7 (1 item imputed) 3 (2 items imputed) 1 (3 items imputed)	1
FAQ internal subscale	116	3	5
HADS anxiety subscale	116	0	8
HADS depression subscale	116	1 (1 item imputed)	7
Ferrens and Powers QLI Generic version	14	51 (1 item missing) 26 (2 items missing) 11 (3 items missing) 6 (4 items missing) 5 (5 items missing) 1 (6 items missing) 3 (7 items missing)	7
MDS-UPDRS part Ib non-motor experiences of daily living subscale (7 self-report items)	115	2 (1 item imputed)	7
MDS-UPDRS part II motor experiences of daily living subscale	114	1 (1 item imputed)	9

the model. Anxiety, motor symptoms and social anxiety did not. This model was statistically significant ($F = 13.45$, d.f. $= 5, 106$, $p < .01$).

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 and 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 specific safety-seeking behaviours PwIPD are using to cope. For future research to test this hypothesis

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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 better 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 and Fernie, 2015).

The association between NMS and social anxiety in this study was not predicted. One possible explanation is symptom 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 and 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 FAQs 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 three predictors masking the unique contributions of self-focused attention. One way to test this in future studies would be

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to enter cognitive behavioural variables in a hypothesis led in a 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 were 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 in contrast with clinician ratings. Although Goetz *et al.* (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 that volunteer bias can influence outcomes that are not representative more generally (Jordan *et al.*, 2013). Therefore caution should be used 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 that attracted younger participants, who were therefore on average 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 with 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 and Wells (1995) and Rapee and Heimberg (1997) with a more generic context that acknowledges the vulnerabilities arising 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.

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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.

Acknowledgements. The authors would like to thank all participants with Parkinson's disease who showed interest in this study and those who took the time to talk with the researcher and complete the measures. We extend our thanks to PDUK for supporting the researchers with all aspects of this study including enabling contact with people with experience to pilot measures and circulating the study details to many people affected by Parkinson's disease. Without the help of PDUK this study might not have met its recruitment target. Thanks to all those the staff at the Clara Cross Centre, St Martins Hospital in Bath for their consultation and support regarding recruitment.

Financial support. This research was completed at the University of Bath Department of Psychology and did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Conflicts of interest. The authors have no conflicts of interest to report.

Ethics 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.

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Cite this article: Nash K, Dysch L, Todd Jones J, MacQueen R, and Marks E (2022). The contribution of cognitive behavioural factors to social anxiety in Parkinson's disease. *Behavioural and Cognitive Psychotherapy* **50**, 57–73. https://doi.org/10.1017/S1352465821000291