Parkinson's and Anxiety: Examining the Efficacy of Psychological Interventions and the Co-Development of a Standardised Measure

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Thesis Portfolio Abstract

Background: Parkinson's[1] is a progressive neurodegenerative condition, which is often accompanied by anxiety. The anxiety experienced by people with Parkinson's is poorly characterised, and often undiagnosed and undertreated. Establishing accurate and reliable means of characterising and treating anxiety in this population may aid diagnosis and improve treatment. At present, only a few studies have investigated the effectiveness of psychological interventions specifically for people with Parkinson's and anxiety.

Methods: This thesis portfolio consists of a systematic review with meta-analysis, and an empirical study. The systematic review examined the efficacy of psychological interventions for people with Parkinson's and anxiety. The empirical study conducted secondary analyses of a database of 254 people with Parkinson's and anxiety to develop a new scale, in long and short forms. The scales were developed using exploratory factor analysis, validity and reliability analyses, and confirmatory factor analysis.

Results: The systematic review identified 12 studies (n = 170) using a range of study designs, including case studies, uncontrolled, and controlled trials. Meta-analyses of randomised controlled trials (k = 4) and pre-post intervention data (k = 6) found preliminary evidence that psychological interventions can be efficacious for people with Parkinson's and anxiety. The empirical study developed and provided initial validation for the 'Comprehensive Anxiety and Parkinson's Scale' (CAPS), in its long (54 items), and short (24 items) versions.

Conclusions: Psychological interventions may be beneficial in reducing anxiety for people with Parkinson's. However, more, high quality randomised controlled trials are needed. The standardised CAPS scales offer comprehensive means of assessing the experience of anxiety in Parkinson's.

[1] 'Parkinson's' is the preferred term by people with Parkinson's (Parkinson's UK, 2021) and will be used throughout this thesis portfolio, with the exception of the main papers (Chapter 2 and Chapter 4) written for submission to the Movement Disorders journal which uses the term Parkinson's disease.

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Chapter One: Introduction to Thesis Portfolio

Parkinson's is described as a disorder of movement (Poewe et al., 2017), and is the second most common progressive neurodegenerative condition after Alzheimer's disease (Lee & Gilbert, 2016; Poewe et al., 2017; Wirdefeldt et al., 2011). The estimated worldwide prevalence is 0.3 percent (Poewe et al., 2017), which rises to one percent in people over the age of 60, and more than three percent in people over the age of 80 (Lee & Gilbert, 2016). Parkinson's is characterised by motor and non-motor symptoms (Fernie et al., 2015; Poewe et al., 2017). Motor symptoms of Parkinson's include bradykinesia (slowness of movement), tremor (shaking), postural instability (difficulties with balance), rigidity (stiffness of muscles), and repetitious movements (Jankovic, 2008; Schapira et al., 2017). Non-motor symptoms of Parkinson's include hallucinations, depression, pain, sleep disturbance, and anxiety (Poewe et al., 2017; Schapira et al., 2017).

Anxiety is a commonly experienced non-motor symptom (Brown et al., 2011; Dissanayaka et al., 2010; Pontone et al., 2009; Rocha & Teixeira, 2018; Shapira et al., 2017; Yamanishi et al., 2013; Zhu, et al., 2017), which can occur from the prodromal pre-motor stage to the latter stages of Parkinson's (Shapira et al., 2017). The reported prevalence of anxiety in people with Parkinson's varies greatly in the literature (Broen et al., 2016), with research reporting up to 60 percent (Dissanayaka et al., 2010; Pontone et al., 2009; Shapira et al., 2017; Yamanishi et al., 2013). However, a recent systematic review and meta-analysis examining prevalence reported an average finding of 31 percent (Broen et al., 2016). This is significant considering worldwide anxiety prevalence of the general population is estimated at seven percent (Baxter et al., 2013).

For a number of reasons, it can be challenging to characterise the anxiety experienced by people with Parkinson's (Pontone et al., 2019). Firstly, it can be associated with variations and fluctuations in Parkinsonian motor symptoms and medications (Siemers et al., 1993; Witjas et al., 2002). Secondly, it can be difficult to distinguish the

manifestation of anxiety and Parkinson's symptoms as there is significant overlap (Higginson et al., 2001). Lastly, these symptoms can also interact, with one triggering the other (Pontone, 2013). The challenges of characterising anxiety in Parkinson's are reflected by current difficulties with accurate and timely diagnosis. Disorder-specific anxiety diagnoses among people with Parkinson's include; generalised anxiety disorder, social anxiety disorder, specific phobia, panic disorder, agoraphobia, and anxiety not otherwise specified (ANOS; Dissanayaka et al., 2010; Dissanayaka et al., 2014; Hermida, 2019). Of these, ANOS is most commonly experienced (Pontone et al., 2009), and is defined as clinically significant anxiety which does not meet criteria for any specific anxiety disorders in the *Diagnostic and Statistical Manual for Mental Disorders* (DSM; American Psychological Association, 2013). People with Parkinson's have also reported symptoms of anxiety that do not meet disorder-specific thresholds for frequency or severity, yet are understandably distressing experiences (Richard, 2005).

Challenges with understanding and diagnosing anxiety in Parkinson's are problematic given the associated negative effects. For instance, anxiety in the context of Parkinson's has been found to negatively impact cognitive ability (Rocha & Teixeira, 2018), activities of daily living (Dissanayaka et al., 2010), and quality of life (Curran et al., 2021a; Zhu et al., 2017). In fact, anxiety has been found to have a significantly greater impact on quality of life among people with Parkinson's, than depression, motor symptoms or cognitive functioning (Hanna & Cronin-Golomb, 2012). Despite this, the area only started to receive interest as a primary research focus in recent years, and as a result, is not as well understood as other non-motor symptoms of Parkinson's (Chen & Marsh, 2014; Dissanayaka et al., 2014). Depression has been the focus of a greater proportion of the mental health research in Parkinson's (Dissanayaka, et al., 2015), despite having lower prevalence than anxiety (Reijnders, et al., 2008). Whilst depression in Parkinson's is an

area of significant importance, it would seem beneficial for research to also focus on the lesser-researched domain of anxiety in Parkinson's.

Establishing accurate and reliable means of assessing and measuring symptoms of anxiety in this population is a necessity (Martinez-Martin et al., 2016; Pontone et al., 2019). This will aid diagnosis, which in turn could lead to appropriate and relevant treatment options (Leentjens et al., 2014). Only recently have anxiety measures for people with Parkinson's started to receive attention. Leentjens and colleagues (2014) noted a gap in the literature for a measure of anxiety in Parkinson's and so developed the Parkinson Anxiety Scale (PAS). At the time, the PAS offered a reliable and valid measure of anxiety for people with Parkinson's, which could be administered quickly and easily (Leentjens et al., 2014). However, the PAS has since been critiqued for a number of reasons. In a recent systematic review, the PAS was found to have lower sensitivity than the Geriatric Anxiety Inventory (GAI) among adults with Parkinson's (Mele et al., 2018). What is more, Pontone and colleagues (2019) suggest that the PAS is restricted to assessing common anxiety presentations and does not measure the unique experience of anxiety for people with Parkinson's. They add that future research should focus on defining and validating measures of anxiety in this population (Pontone et al., 2019). Not only could new measures result in better detection of anxiety in Parkinson's, but also provide clinicians and researchers with a tool to examine effectiveness of interventions for this population.

Unsurprisingly, research into the management of anxiety has been requested by people with Parkinson's (Deane et al., 2014). In a study by Deane and colleagues (2014), people with Parkinson's, their carers, and clinicians, were asked to rank their priorities for unanswered research questions. The study produced a ranked list of top 10 research priorities, with the second relating to the investigation of 'approaches that effectively manage stress and anxiety'. Thereby, this is an area deemed an important issue to those that matter most; people with personal experience of Parkinson's.

Despite people with Parkinson's requesting that this area receive more attention, there remains a limited evidence-base for the management of anxiety. At present, pharmaceutical intervention is the first-line treatment (Egan et al., 2015). Anxiolytic medications for people with Parkinson's include selective serotonin reuptake inhibitors (SSRIs), buspirone, and benzodiazepines (Chen & Marsh, 2014; Hermida, 2019; Pontone et al., 2013). It is noteworthy, that much of the research into the effects of these medications has focussed on anxiety only as an outcome secondary to depression (Chen & Marsh, 2014). Furthermore, there are a number of studies which have failed to find evidence to support the efficacy of pharmacology for anxiety in Parkinson's. For example, a randomised controlled trial (RCT) found no significant differences between venlafaxine, paroxetine, and a placebo for the outcome of anxiety (Richard et al., 2012). In addition, a meta-analysis found non-significant results for the effect of medication on anxiety among people with Parkinson's (Troeung et al., 2013). The adverse effects of these medications for people with Parkinson's is also of importance (Pontone et al., 2013). In particular, increased blood pressure and falls have been highlighted, alongside worsened tremor, cognitive function, and gait stability (Hermida, 2019).

Researchers have started to show an interest in psychological treatments for non-motor symptoms of Parkinson's such as depression and anxiety (Armento et al., 2012; Egan et al., 2015). To date, most have studied the efficacy of non-pharmacological interventions for depression, or depression and anxiety combined (for a review, see Zarotti et al., 2020). This is interesting given that anxiety in Parkinson's is under-treated (Dissanayaka et al., 2014; Dissanayaka et al., 2015; Pachana et al., 2013), and can be experienced in the absence of depression among people with Parkinson's (Liu et al., 1997; Richard, 2005; Yamanishi et al., 2013). Fewer studies have investigated the effectiveness of psychological interventions specifically focussed on Parkinson's and anxiety (Moonen et al., 2021; Mulders et al., 2018).

This thesis portfolio aimed to develop a standardised measure of anxiety in Parkinson's and to explore the efficacy of psychological interventions in this population. Chapter Two presents a systematic review and meta-analysis written for publication in the 'Movement Disorders' journal. The review examined the efficacy of psychological interventions for people with Parkinson's and anxiety. Chapter Three offers a bridge between the systematic review and the empirical study. Chapter Four presents the empirical study, also written for publication in 'Movement Disorders'. The empirical study developed a new scale of anxiety and Parkinson's, in long and short forms, and provided initial validation. The final chapter of the portfolio, Chapter Five, provides an overview of findings from both papers, alongside critical appraisal, and reflection on clinical and research implications. Strengths and limitations of the thesis portfolio are discussed with directions for areas of future development. References and appendices from each of the chapters are presented at the end of the portfolio.

Chapter Two: Systematic Review and Meta-Analysis

Psychological Interventions for People with Parkinson's Disease and Anxiety: A Systematic Review and Meta-Analysis.

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Written for submission to *Movement Disorders*

(Author guidelines for manuscript preparation in Appendix A)

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Abstract

Background: Anxiety is a common non-motor symptom of Parkinson's disease. There is a small, but growing, evidence-base for psychological interventions for people with Parkinson's disease and anxiety. The evidence to date is equivocal and, as yet, there have been no known attempts to synthesise studies capturing a range of study designs and different psychological interventions within samples of clinical anxiety and Parkinson's disease.

Objectives: This systematic review and meta-analysis aimed to investigate the efficacy of psychological interventions for people with Parkinson's disease and a diagnosed anxiety disorder.

Methods: Twelve studies (n = 170) reporting a range of study designs including case studies, uncontrolled, and controlled trials were synthesised and quality assessed. Meta-analyses of randomised controlled trials (k = 4) and pre-post intervention data (k = 6) were conducted using random-effects models.

Results: Randomised controlled trials showed a significant moderate sized effect (g = -0.51, 95% CI -0.86 to -0.15, $p < 0.01$) for psychological interventions for people with Parkinson's disease and anxiety, whilst pre-post intervention data showed a significant large sized effect (g = 0.90, 95% CI 0.53 to 1.27, $p < 0.0001$).

Conclusions: This review provides preliminary evidence for the efficacy of psychological interventions for people with Parkinson's disease and anxiety. These results must be interpreted with caution, given the small sample sizes, quality of studies, and lack of control group in eight studies. Clinical and research implications are discussed.

Introduction

Anxiety is a commonly experienced non-motor symptom of Parkinson's disease (PD) with an average reported prevalence of 31 percent [for a review, see 1]. At present, however, anxiety in people with PD remains undertreated [2-4]. It follows, that people with PD, their caregivers and health professionals, ranked 'approaches that effectively manage stress and anxiety' as second in a list of top 10 research priorities [5].

There is a small, but growing, evidence-base for psychological interventions for people with PD and anxiety. Much of this research has focussed on depression, with anxiety reported as a secondary outcome [e.g., 6]. A recent review of self-management of anxiety in PD found that eight out of 13 studies reported anxiety as a secondary outcome [7]. Equally, many studies appear to assess anxiety and depressive symptoms together, resulting in systematic reviews considering these symptoms combined [e.g., 8, 9]. However, studies with a primary focus on anxiety are emerging.

A 2020 scoping review of psychological interventions for people with PD was conducted [10], providing a comprehensive and useful overview of the effectiveness of interventions for a range of disorders, including anxiety. It was stated that evidence for the effectiveness of psychological interventions for people with PD and anxiety is inconsistent and insufficient [10]. The authors recommended that the use of such interventions be approached with caution. However, in an effort to capture all research related to anxiety, the review did not require an anxiety diagnosis within study inclusion criteria, making it uncertain whether or not all study participants experienced clinically-significant anxiety. As a scoping review, quality and risk of bias were not evaluated and there was no quantitative synthesis of findings (i.e., a meta-analysis).

The aim of this systematic review was to investigate the efficacy of psychological interventions for people with PD and a diagnosed anxiety disorder, to complement and extend the earlier scoping review [10]. We placed no restraints on study design, and

extended Zarotti and colleagues' work, by evaluating study quality and risk of bias. Additionally, meta-analyses of data from randomised controlled trials and pre-post interventions were conducted.

Methods

This systematic review was registered on the PROSPERO International Prospective Register of Systematic Reviews (PROSPERO-ID CRD42021192309) and conducted in accordance with the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analyses [PRISMA; 11].

Inclusion Criteria

Articles were assessed for their eligibility for full-text review according to the following inclusion criteria: participants 1) had a diagnosis of idiopathic PD; 2) had a diagnosis of an anxiety disorder; and 3) were aged 18 or above; and the study 4) described the delivery of any psychological intervention; 5) measured anxiety as an outcome; 6) had a quantitative research design and reported quantitative data, and 7) was available in English.

Database Search Strategies

A comprehensive literature search was performed from inception to February 2021 using three major databases (Medline, PsycINFO, and CINAHL). Three sets of free text search terms were adopted covering Parkinson's, anxiety, and psychological interventions. These are listed as follows:

1. (Parkinson Disease OR Parkinson*) AND
2. (Anxiety Disorders OR Anxi* OR Trauma and Stressor Related Disorders) AND
3. (Psychotherapy OR Compassion Focus* Therapy OR CFT OR Psychoeducation OR Cognitive Analytical Therapy OR CAT OR Cognitive Therap* OR CT OR Behavio* Therap* OR BT OR Cognitive Behavio* Therap* OR CBT OR Mindful* OR MBCT OR MBSR OR Acceptance and Commitment Therap* OR ACT OR Cognitive Processing

Therap* OR CPT OR Dialectical Behavio* Therap* OR DBT OR Psycho* Therap* OR Psychotherap* OR Emoti* Therap* OR Counsel* OR Couple* Therap* OR Eye Movement Desensiti* and Reprocessing Therap* OR EMDR OR Famil* Therap* OR Interpersonal Therap* OR IPT OR Motivation* Interview* OR MI OR Person Cent* Therap* OR Psycho* Intervention OR Rational Emoti* Behavio* Therap* OR REBT OR Schema* Therap* OR System* Therap* OR Solution Focus* Therap* OR Integrative Therap*)

The search strategy for each database is provided in Appendix B. Reviews and reference lists of included articles were also hand-searched for additional relevant studies.

Study Selection and Data Extraction

All identified articles were transferred to Endnote, and duplicate articles were removed. The authors of two articles not available in English were contacted, however the authors did not respond, so the articles could not be obtained. Study selection was conducted by two reviewers independently (C.I.-C. and D.C.). The main author (C.I.-C.) reviewed all titles/abstracts and full-text articles, while D.C. reviewed 30 percent. Discrepancies were discussed until a consensus was achieved. Data extraction of the included studies was then completed by the main author (C.I.-C.).

Quality Assessment

To assess study quality and risk of bias, 13 relevant items were selected (Appendix C) from the 22-item Psychotherapy Outcome Study Methodology Rating Form [12; Appendix D]. Each item is rated on a 3-point scale (0 = poor, 1 = fair, 2 = good), and accompanied by a verbal description. Overall quality scores were not calculated, as not every scale item is equally weighted in its impact [13]. Items that were not applicable for a given study were marked as NR. The main author (C.I-C.) and co-reviewer (D.C.) independently evaluated all 12 studies (Appendix E). Rating discrepancies were resolved through discussion until a consensus was reached (Table 3).

Data Analysis

Meta-analyses were performed using the MAVIS Shiny package [Version 1.1.3; 14] in R [15]. Effect sizes (Hedge's *g*), with 95% confidence intervals (CI), and associated *p* values were calculated using means and standard deviations when available. To calculate the mean effect size (Hedge's *g*) for the group of studies, individual effect sizes were pooled using a random effects model. A random effects model was adopted because each study used a different primary outcome measure of anxiety and employed different psychological interventions. Random effects models permit more generalisable conclusions to be drawn [16]. Effect sizes of 0.2 were interpreted as small, 0.5 as moderate and 0.8 as large [17]. The chi-square statistic [Cochran's *Q*; 18] and *I* squared statistic [I2; 19] were computed to assess heterogeneity among the studies. I^2 provides a percentage of total observed variability across studies attributed to heterogeneity rather than chance and is not affected by low statistical power. An I^2 of 25% is deemed low, 50% is moderate and 75% is high [19]. The I^2 statistics were supplemented with confidence intervals given the small number of studies included in the meta-analyses [20]. Moderation and subgroup analyses were not conducted due to the small number of studies in the meta-analyses.

Results

Four hundred and six articles were identified using the search terms. Following exclusion of 122 duplicates, the titles and/or abstracts of the remaining 284 identified articles were screened in accordance with the inclusion criteria. This resulted in the exclusion of 208 articles, leaving 76 articles for full-text review. Sixty-four full-text articles were excluded as they did not meet the inclusion criteria (Appendix F). A PRISMA flow diagram outlines the process of study selection (Figure 1).

Narrative Synthesis

In total, 12 studies were included in the narrative synthesis [21-32]. Four of the studies provided intervention and control data and were therefore included in a meta-

analysis [25, 27, 28, 31]. Six of the 12 studies provided pre- and post-intervention data and were included in a second meta-analysis [21, 22, 25, 28, 29, 31].

The demographic and clinical characteristics of participants included in each study are reported in Table 1. Study characteristics are reported in Table 2. The studies were published between 2001 and 2021, and conducted in Italy [21], Australia [22, 23], the USA [24, 26, 28-30, 32], Netherlands [25], the UK [27] and multi-site Netherlands and France [31].

Sample sizes of all 12 studies were small, with a total of just 170 participants (Mean = 14; Range = 1-44). The participants were relatively young for inclusion in Parkinson's research (Mean = 63.2 years; Range = 53.1-74.0 years). The characteristics of participants were erratically described, with just three studies specifying ethnicities (Mean = 100% Caucasian) [24, 29, 30], nine specifying disease duration (Mean = 6.3 years) [23-28, 30-32], and nine specifying gender [21-23, 25, 27-29, 31, 32]. Nine studies reported disease severity measured using the Hoehn and Yahr [33] Staging Scale in a variety of ways; five studies reported mean scores [21, 22, 24, 27, 30]; three studies reported a range [25, 28, 32]; and one reported a median [31].

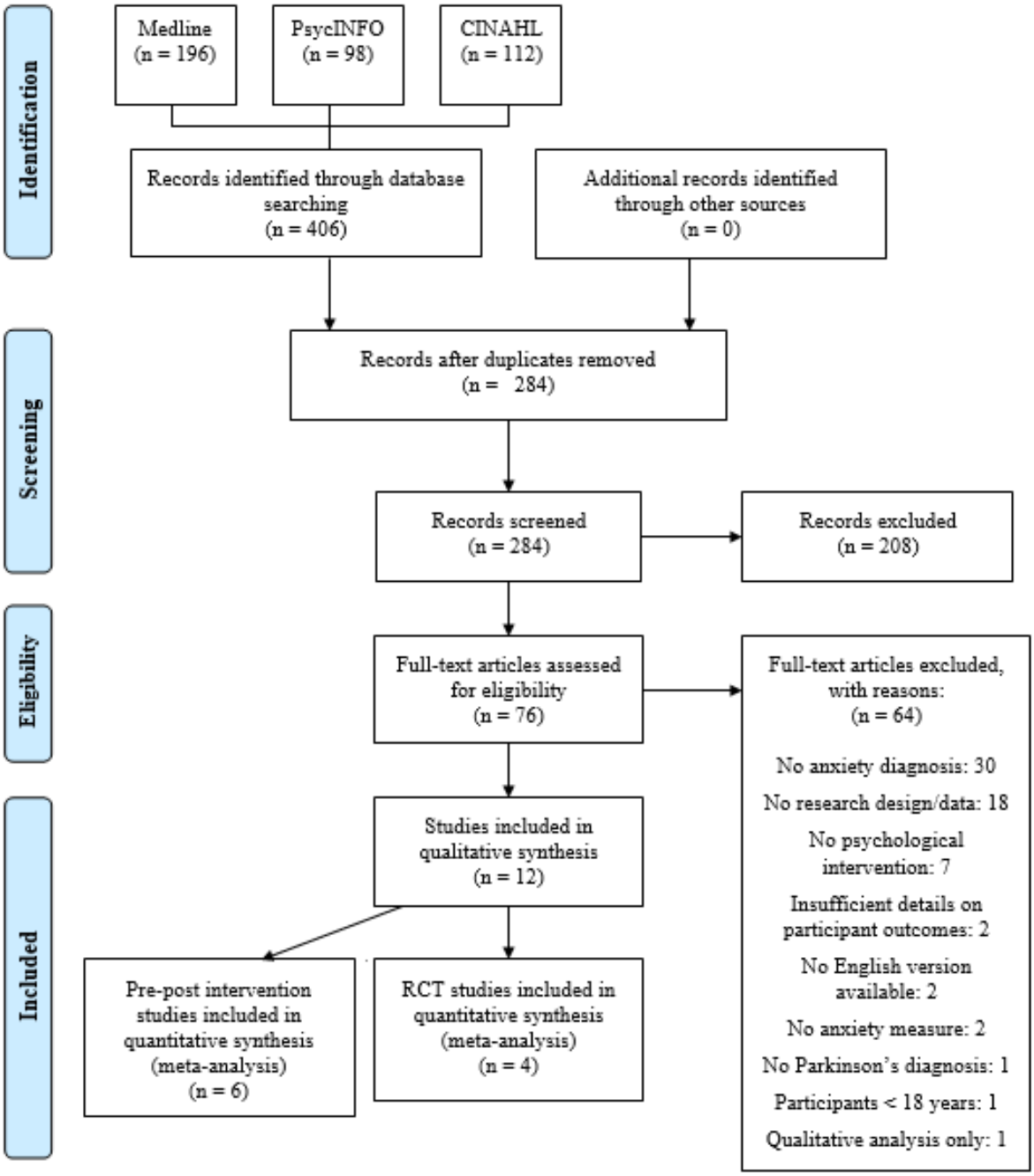
Diagnosis of PD was made according to the UK Disease Society Brain Bank criteria [21, 22, 25, 32], the Queens Square Brain Bank criteria [31], or not reported [23, 24, 26-30]. Anxiety diagnostic tools varied across the 12 studies; three studies used structured interview schedules [22, 26, 32] such as the Anxiety Disorders Interview Schedule for DSM-5 (ADIS-5), four studies used psychometric measures [25, 27, 28, 31] such as the Beck Anxiety Inventory (BAI), and five studies used a combination of both [21, 23, 24, 29, 30], such as the Mini International Neuropsychiatric Interview (MINI) and the State Anxiety Subscale of the State-Trait Anxiety Inventory (STAI-S).

Primary outcome measures of anxiety included the Hamilton Anxiety Rating Scale [HAM-A; 21, 22, 24, 29-31], the Beck Anxiety Inventory [BAI; 25, 32], the State-Trait

Anxiety Inventory – State Anxiety Subscale [STAI-S; 23], the State-Trait Anxiety Inventory – Trait Anxiety Subscale [STAI-T; 26], the Penn State Worry Questionnaire [PSQW; 27], and the Parkinson's Anxiety Scale [PAS; 28].

Figure 1

PRISMA Flow Diagram of Study Selection Process



Note. Adapted from Moher and colleagues [11].

Of the 12 studies, only four used randomised controlled trial designs [27, 28, 31, 34], three of which were feasibility or pilot studies [27, 28, 34]. Of the remaining studies, four used uncontrolled, pre-test post-test, trial designs [21-23, 29], one used a multiple-baseline single-case experimental design [SCED; 32], and three used a single case study design [24, 26, 30].

Psychological intervention types included cognitive behavioural therapy [CBT; 21, 22, 23, 27, 31, 32], combined Attention Processing Therapy (APT) and CBT [24, 29, 30], mindfulness training [28], and an acceptance and commitment therapy (ACT) based intervention [25]. Of the six CBT studies, five used a transdiagnostic approach. Eight of 12 studies adopted an individual mode of intervention delivery, two of which gave the option of attending with a caregiver [22, 29], whilst the remaining four studies adopted a group delivery mode [21, 23, 25, 26].

The psychological interventions tested in six studies specifically targeted anxiety in PD, two targeted anxiety alone, two targeted anxiety and depression in PD, and one targeted emotional disorders in general. The psychological interventions tested by the 12 studies varied by total session number and session duration. The total number of sessions ranged from four sessions [27] to 84 sessions [28], but mainly 8-12 sessions were adopted. Session length was at least 10 minutes [28], maximum 120 minutes [23, 24, 26, 30], but mainly 50-90 minutes.

Information relating to intervention facilitators, training and supervision was reported for nine studies. Intervention facilitators included doctorate psychology students [22, 24, 32], study personnel [27, 29], registered psychologists [31], therapists [26], a CBT-trained psychiatrist [21], and psychology, physical therapy and psychiatry professionals [25]. Training ranged from extensive APT and CBT training [24], "ample" CBT experience [31], mandatory workshops/training [22], and weekly training [21]. Supervision varied in professional role and frequency, with supervisory roles including

licensed/registered psychologists [22, 29, 32], and a registered CBT therapist [31]. Frequency of supervision ranged from all sessions [32], weekly [21, 22, 29], 'regular' [31], or was not reported.

Psychological intervention adaptations for PD were reported in seven studies [21-23, 25, 29, 31, 32]. The studies that used adapted interventions varied in the methods of evaluating such interventions, and only two used a control group [25, 31]. Adaptations included the intervention being specifically tailored to the experience of anxiety and PD, in-session attendance of a caregiver/family member [22, 29], reduction of in-session writing [23], and a psychoeducation session for a caregiver/family member [32].

For the 12 studies, attrition ranged from 0 to 30 percent. As expected, attrition was zero for the three single case studies [24, 26, 30], whilst attrition for the SCED was 10% [32]. Attrition for the uncontrolled studies ranged from 0 to 28.6% [21-23, 29]. For the RCTs, attrition ranged from 0 to 28.6% for the intervention groups and 0 to 19.2% for the control groups [25, 27, 28, 31].

Table 1

Demographic and Clinical Characteristics of Participants

Study	Sample				Parkinson's Disease	
	Size	Mean Age (Years)	Gender (% Female)	Ethnicity (% Caucasian)	Mean Duration (Years)	Mean Hoehn & Yahr Score
Berardelli et al[21]	7	53.1	42.9	NR	NR	1.3
Dissanayaka et al[22]	12	66.4	42.0	NR	NR	2.2
Feeney et al[23]	4	65.7	33.3	NR	2.3	NR
Georgescu[24]	1	58.0	0	100	9.0	3.0
Ghielen et al[25]	38 (I: 19; C: 19)	I: 59.6 C: 66.6	I: 35.0 C: 45.0	NR	I: 10.5 C: 12.3	I: Range: 2-3 C: Range: 2-3
Heinrichs et al[26]	1	60.0	0	NR	5.0	NR
Lawson et al[27]	32 (I: 17; C: 15)	65.9*	56.3*	NR	5.2*	2.4*
Lingaiah et al[28]	11 (I: 5; C: 6)	I: 68.0 C: 60.3	I: 80.0 C: 66.7	NR	I: 4.3 C: 7.5	I: Range: 1-3 C: Range: 1-3
Mohlman et al[29]	10	63.0	40.0	100	NR	NR
Mohlman et al[30]	1	74.0	0	100	6.0	2.0

Study	Sample				Parkinson's Disease	
	Size	Mean Age (Years)	Gender (% Female)	Ethnicity (% Caucasian)	Mean Duration (Years)	Mean Hoehn & Yahr Score
Moonen et al[31]	44 (I: 22; C: 22)	I: 63.3 C: 63.3	I: 54.0 C: 50.0	NR	I: 7.4 C: 4.7	I: Median: 2.0 C: Median: 2.0
Reynolds et al[32]	9	61.2	55.6	NR	6.6	Range: 1-2

Note. C = Control group; I = Intervention group; NR = Not reported. *Study did not report separate values for control and intervention groups on these demographics.

Table 2

Study Characteristics

Study / Country	Parkinson's Diagnostic Tool	Anxiety Diagnostic Tool/s	Intervention				
			Type	Mode	*N* Sessions / Session Length	Facilitator and Training	Adaptations
Single Case Studies							
Georgescu[24] / USA	NR	SIGH-A ASI BAI HAM-A STAI-T	APT and CBT 'Brain and Mind Fitness Program'	Individual F2F	10 / 90-120 mins	Doctorate psychology student with extensive APT and CBT training	NR
Heinrichs et al[26] / USA	NR	ADIS-IV-L	CBT based on Self-focused Exposure Therapy	Group F2F	12 / 120 mins	Two therapists from Center for Anxiety and Related Disorders (Boston University)	NR
Mohlman et al[30] / USA	NR	SCID BAI HAM-A PSWQ STAI	Combined CBT and APT	Individual	10 / 90-120 mins	NR	NR
Multiple Baseline Single Case Experimental Study							

Study / Country	Parkinson's Diagnostic Tool	Anxiety Diagnostic Tool/s	Intervention				
			Type	Mode	*N* Sessions / Session Length	Facilitator and Training	Adaptations
Reynolds et al[32] / USA	UK Disease Society Brain Bank	ADIS-5 ≥ 4	I: Manualised CBT C: Participants served as own control i.e., baseline data was compared with intervention and follow-up data	Individual F2F / Online	12 / 50-60 mins	Doctorate student; ADIS trained. All sessions supervised by a licensed clinical psychologist	Psychoeducation session for partner/family member
Uncontrolled Studies							
Berardelli et al[21] / Italy	UK Brain Bank	SCID HAM-A	CBT	Group	12 / 90 mins	CBT trained psychiatrist and a Neurologist; received weekly supervision and training	Tailored to Parkinson's-specific anxiety
Dissanayaka et al[22] / Australia	UK Brain Bank	MINI	Manualised CBT	Individual (or with caregiver) F2F	8 / 60-90 mins	Doctorate/Masters Clinical Psychology and Neuropsychology students; received weekly supervision by registered psychologists; attended mandatory workshops/training	Tailored to Parkinson's-specific anxiety; option for caregiver to join

Study / Country	Parkinson's Diagnostic Tool	Anxiety Diagnostic Tool/s	Intervention				
			Type	Mode	*N* Sessions / Session Length	Facilitator and Training	Adaptations
Feeney et al[23] / Australia	NR	MINI STAI-S	CBT 'Mood Management'	Group	9 / 120 mins	NR	Amount of in-session writing was reduced
Mohlman et al[29] / USA	NR	MINI 5.0.0 HAM-A ≥ 15	Combined CBT and APT	Individual	10 / 90 mins	Study personnel received weekly supervision from a licenced CBT and APT trained psychologist	Tailored to Parkinson's-specific anxiety; option for caregivers to attend 50% of sessions
Randomised Controlled Trial Studies							
Ghielen et al[25] / Netherlands	UK Brain Bank	BAI > 26	I: ACT-based intervention 'BEWARE' C: Group physical therapy based on Royal Dutch Society guidelines for Parkinson's	Group F2F	12 / 60 mins	Psychology, physical therapy and psychiatry professionals	A section focussed on Parkinson's 'wearing-off' symptoms

Study / Country	Parkinson's Diagnostic Tool	Anxiety Diagnostic Tool/s	Intervention				
			Type	Mode	*N* Sessions / Session Length	Facilitator and Training	Adaptations
Lawson et al[27] / UK	NR	HADS-A ≥ 8	I: CBT Self-help book: 'What? Me Worry!?!' C: One chapter of 'What? Me Worry!?!' (i.e., information about worry but no advice); one phone contact but no advice	Individual Phone and Biblio-therapy	8 chapters 4 phone contacts	Study researchers	NR
Lingaiah et al[28] / USA	NR	PAS ≥ 14	I: Mindfulness training via tracker and biofeedback device 'Spire' C: Received Spire device but mindfulness exercises were deactivated	Individual Online / via App	84 (twice-daily) / 10 mins	NR	NR
Moonen et al[31] / Netherlands and France	Queens Square Brain Bank	PAS (persistent subscale > 9 and/or avoidance subscale > 3)	I: CBT plus clinical monitoring C: Clinical monitoring only (i.e., given general education leaflets on coping with anxiety)	Individual F2F	11 / 60-75 mins	Registered psychologists with ample CBT experience; received regular supervision from a registered CBT therapist	Tailored to Parkinson's-specific anxiety (based on focus groups with patients and caregivers)

Note. ADIS-IV-L = Anxiety Disorders Interview Schedule for DSM-IV-Lifetime; ADIS-5 = Anxiety Disorders Interview Schedule for DSM-5; APT = Attention Process Training; ASI = Anxiety Sensitivity Index; BAI= Beck Anxiety Inventory; C = Control; CBT = Cognitive Behavioural Therapy; F2F = Face to face; GAI = Geriatric Anxiety Inventory; HADS-A = Hospital Anxiety and Depression Scale - Anxiety Subscale; HAM-A = Hamilton Anxiety Rating Scale; I = Intervention; MINI = Mini International Neuropsychiatric Interview; NA = Not applicable; NR = Not reported; OASIS = Overall Anxiety Severity and Impairment Scale; PAS = Parkinson's Anxiety Scale; PSWQ = Penn State Worry Questionnaire; SCID = Structured clinical interview for DSM-IV; SIGH-A = Structured Interview Guide for the Hamilton Anxiety Rating Scale; SPAI = Social Phobia and Anxiety Inventory; STAI = State-Trait Anxiety Inventory; STAI-S = State-Trait Anxiety Inventory – State Anxiety Subscale; STAI-T = State-Trait Anxiety Inventory – Trait Anxiety Subscale.

Quality Assessment

The results of the quality assessment highlighted substantial variation in the quality of the studies (Table 3), with few studies assessed to be of high quality overall. The highest quality study was by Moonen and colleagues [31], scoring 'good' on 10 items and 'fair' on the remaining 3 items. The rest of the studies scored 'good' on just 4 items or fewer. Studies by Feeney et al. [23] and Lawson et al. [27] scored 'poor' on 6 items, the most of all the studies, despite an RCT design being used in the case of the latter.

The representativeness of the samples was mostly 'fair', with only two studies found to be 'poor' [26, 32]. Outcome measures were mostly scored as 'fair', as although they are common standardised anxiety measures, they have limited reliability and/or validity in people with Parkinson's [3]. Only one study used a Parkinson's-specific measure found reliable and valid in this population [3], and therefore scored a 'good' [28]. Assignment to treatment was not applicable to eight of the 12 studies, as they did not have control groups. However, two of the four RCTs scored 'fair' for this item [27, 28], whilst the other two scored 'good' [25, 31]. The latter two studies were the only two to conduct and report power analysis, with the remaining ten studies failing to do so.

None of the studies achieved a score of 'good' for the item relating to 'assessment points', as follow-up data did not exceed a one-year period. All but one study [28], employed and reported manualised, replicable treatment programmes, seven of which scored 'good' [22, 24-27, 29, 31]. Seven studies scored at least 'fair' for therapist training and experience [21, 22, 24-26, 31, 32]. Half the studies demonstrated a check of treatment adherence [21, 22, 28, 29, 31, 32]. Handling of attrition was not applicable for the three case studies and not reported for one other study [21]. The remaining studies scored at least 'fair' for this item. Finally, all but one study [28], scored at least 'fair' for statistical analyses and presentation of results.

Table 3

Quality and Risk of Bias Assessment for Included Studies

Study	Quality and Risk of Bias Criteria												
	1	2	3	4	5	6	7	8	9	10	11	12	13
Berardelli et al[21]													
Dissanayaka et al[22]													
Feeney et al[23]													
Georgescu[24]													
Ghielen et al[25]													
Heinrichs et al[26]													
Lawson et al[27]													
Lingaiah et al[28]													
Mohlman et al[29]													
Mohlman et al[30]													
Moonen et al[31]													
Reynolds et al[32]													

Note. Quality and Risk of Bias Criteria: 1 = Representativeness of sample; 2 = Reliability and validity of outcome measures; 3 = Use of blind evaluators; 4 = Assignment to treatment; 5 = Power analysis; 6 = Assessment points; 7 = Manualised, replicable specific treatment programmes; 8 = Number of therapists; 9 = Therapist training/experience; 10 = Checks for treatment adherence; 11 = Control of concomitant treatments; 12 = Handling of attrition; 13 = Statistical analyses and presentation of results. Red = Poor; Orange = Fair; Green = Good; Blue = Not applicable.

Meta-Analyses

The first meta-analysis examined the efficacy of psychological interventions for people with PD and anxiety, using control and intervention data from the four RCT studies

[25, 27, 28, 31]. Total sample size for the four studies was 120 participants (M = 30; Range = 11-44). To be maximally inclusive, the meta-analysis was conducted using the earliest post-intervention data point for the four studies. Three studies provided post intervention data [25, 28, 31], whilst the fourth study [27] provided 3-month post-intervention data as the earliest data point. In each study, anxiety was measured using a different primary outcome measure, i.e., BAI, PSWQ, PAS and HAM-A, and different psychological interventions were employed, i.e. mindfulness, ACT, and CBT. Effect sizes ranged from small (g = -0.32) to large (g = -1.31). Overall, psychological interventions had a significant medium sized effect on anxiety for people with PD (g = -0.51, 95% CI -0.86 to -0.15, p < 0.01). The value of the Q statistic was non-significant [$Q(3) = 1.9744$, $p > 0.5$], and I^2 was 0%, 95% CI 0% to 28%, indicating low heterogeneity across the studies. A forest plot is illustrated in Figure 2.

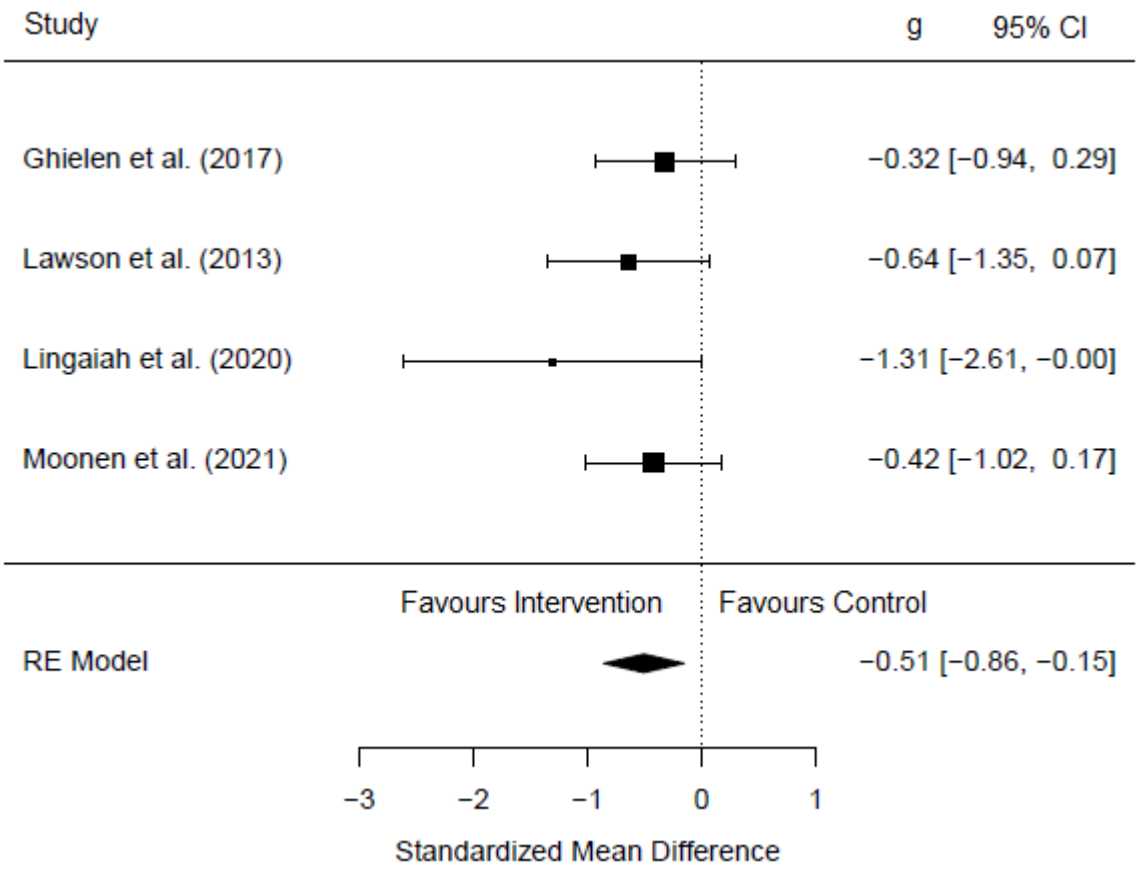
The randomised controlled trial by Moonen and colleagues [31] reported that the post-treatment effect size (Cohen's d) for the secondary outcome measure (PAS) was not only significant but also larger (d = 0.74, p = 0.03) than the primary outcome measure (HAM-A), which was moderate in size but not significant (d = 0.57, p = 0.14).

The second meta-analysis examined the efficacy of psychological interventions for people with PD and anxiety, using pre- and post-intervention data. Six studies [21, 22, 25, 28, 29, 31] were meta-analysed in this way as they provided the appropriate data. The pre-intervention sample size totalled 77 participants (Range = 5–24), whilst the post-intervention sample size totalled 75 participants (Range = 5–22). Effect sizes ranged from small (g = 0.36) to large (g = 1.23). Overall, psychological interventions had a significant large sized effect on anxiety for people with PD pre- to post-intervention (g = 0.90, 95% CI 0.53 to 1.27, p < 0.0001). The value of the Q statistic was non-significant [$Q(5) = 5.3052$,

p > 0.5.], and I^2 was 15.03%, 95% CI 0% to 66%, indicating low heterogeneity across the studies. A forest plot is illustrated in Figure 3.

Figure 2

Forest Plot for RCTs of Psychological Interventions for People with Parkinson's Disease and Anxiety at the Earliest Post-Intervention Data Point



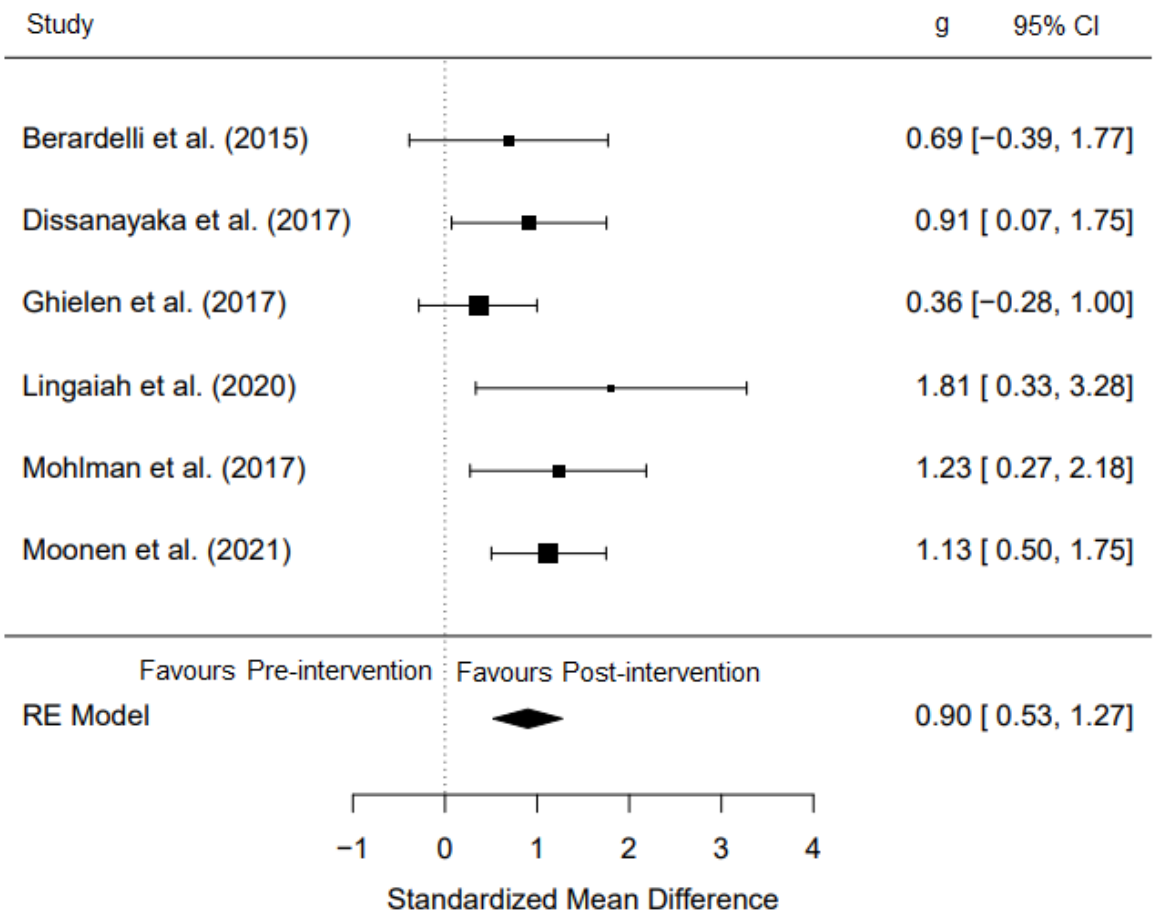
Note. g = Hedge's g (effect size); CI = confidence interval.

Publication Bias

Due to the limited sample size across the studies, firm conclusions about publication bias cannot be made.

Figure 3

Forest Plot for Psychological Interventions for People with Parkinson's Disease and Anxiety at Pre-Post Intervention Data Points



Note. g = Hedge's g (effect size); CI = confidence interval.

Discussion

This was the first systematic review and meta-analysis to examine the efficacy of psychological interventions for people with PD and a diagnosed anxiety disorder. Twelve studies of varying research designs, spanning a 20-year period, were included. Only four small RCTs, of which three were feasibility or pilot studies, were identified. Sample sizes were small, and so the review provided data on just 170 people with PD and anxiety. Psychological interventions were largely CBT-based or adopted third-wave CBT approaches, such as mindfulness or ACT. Only seven studies made adaptations for people

with PD, to varying degrees, and only two of these used a control group. At best, the interventions were adapted to Parkinson's-specific anxiety based on findings from focus groups with patients and carers [e.g., 35], but some only included minor adaptations such as reducing the amount of in-session writing [e.g., 23]. Quality assessment of the studies found significant methodological and reporting limitations, such as poor assessment of treatment adherence, and lack of information regarding power analysis.

A preliminary finding from the meta-analysis of the four RCTs suggests that psychological interventions, compared to control conditions, can reduce anxiety for people with PD. The meta-analysis was statistically significant and involved very low heterogeneity. However, given that studies were limited in methodological quality and sample size, results should be approached with caution. A second meta-analysis pooling pre-post intervention data provides initial evidence that psychological interventions are associated with reductions in anxiety for people with PD. Again, this meta-analysis was statistically significant and involved low heterogeneity. Heterogeneity, as reported by the I^2 statistic, was low in each of the meta-analyses. However, the I^2 statistic should be interpreted with caution as it has been found to have substantial bias when a small number of studies (i.e., ≤ 7) are meta-analysed [20]. In line with recent guidance [20], confidence intervals were therefore reported to supplement the I^2 statistic. Additional caution must be applied to these findings given that pre-post intervention data is uncontrolled and therefore the effects cannot be confidently attributed to the intervention rather than other factors, such as passage of time.

A final finding relates to the measurement of anxiety in this population, with only one study adopting a Parkinson's-specific measure of anxiety as a primary outcome. The extent to which anxiety has been accurately measured in the remaining studies might therefore need consideration. This is exemplified by the Moonen et al. [31] study which

did not find a significant effect using the HAM-A, but did using a Parkinson's-specific anxiety measure (PAS).

Strengths and Limitations

This review has several important strengths. Firstly, as a systematic review and meta-analysis, it was not limited to RCTs or by publication date, but instead included a range of study designs from inception to date. By excluding studies which did not require participants to have a diagnosis of anxiety, the current review was the first to examine the efficacy of psychological interventions for clinically-significant anxiety in this population.

The use of meta-analysis allowed for results of a number of studies to be statistically combined, thus increasing power and improving estimates of effect size [36]. This is of particular benefit given the small number of studies and limited sample sizes. Extending the scoping review by Zarotti and colleagues [10], this review conducted quality assessment of all studies by two independent reviewers. For the first time, this allowed for critical appraisal of the included studies. Each of these strengths contribute to providing a more comprehensive picture of this research area.

The primary limitation of this review relates to the small number of studies available for inclusion for analysis and the limited number of participants within each study. Secondly, restricting study inclusion to those written in English may have excluded research published in languages other than English. The decision to include a range of study designs is considered a strength, in that all quantitative data has been synthesised in this review. However, the inclusion of non-RCT studies increases the risk of bias inherent in such research. Similarly, whilst the decision was taken to only include studies that required a diagnosis of anxiety, it is important to acknowledge the difficulties associated with accurately diagnosing anxiety in this population. Each of these weaknesses have implications for the interpretations of findings.

Clinical and Research Implications

It is essential that the development of approaches that effectively manage anxiety experienced by people with PD is prioritised [5]. Until now, no systematic review or meta-analysis determining the efficacy of psychological interventions for people with PD and diagnosed anxiety existed. Overall, this review reports early indications that psychological interventions, namely CBT and third-wave CBT, may be efficacious in reducing anxiety among with people with PD. However, it also found that the majority of studies are underpowered and lack methodological quality. Therefore, until high-quality, appropriately powered, research studies are trialled, firm conclusions cannot be drawn. It is recommended that future trials are specifically adapted for people with PD, using robust methodologies such as RCTs and accurate and reliable measures of anxiety for this population. The findings of such research will be integral to establishing more confident conclusions in relation to efficacy and the subsequent development of clinical treatment protocols.

Conclusions

The findings of this review extend the scoping review by Zarotti and colleagues [10], by incorporating quantitative analysis and quality assessment. This provides a more comprehensive picture of the efficacy of psychological interventions for people with PD and anxiety. Notably, psychological interventions may be efficacious in reducing anxiety among with people with PD. However, since there are only four existing RCTs, three of which are pilot or feasibility studies, the research area remains in its infancy. Until further RCTs are conducted, conclusions must be approached tentatively.

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Chapter Three: Bridging Chapter

Chapter Three provides a bridge between the systematic review reported in the previous chapter and the empirical study reported in the next chapter.

The systematic review not only highlighted the paucity of research focussed on psychological interventions for people with Parkinson's and anxiety, but also the lack of high-quality studies. One element affecting the quality of the studies reviewed in Chapter Two related to the measures adopted for evaluation purposes. Many of the studies adopted generic anxiety measures such as the Hamilton Anxiety Rating Scale (HAM-A; Hamilton, 1959) or the Beck Anxiety Inventory (BAI; Beck & Steer, 1990). These measures, although valid and reliable per se, are not Parkinson's-specific and have limited validity and reliability in research with people with Parkinson's (Dissanayaka et al., 2015). Moonen and colleagues (2021) demonstrated that although a generic measure of anxiety (HAM-A) did not detect significant changes in anxiety for people with Parkinson's, change was detected using a Parkinson's-specific measure; the Parkinson's Anxiety Scale (PAS; Leentjens et al., 2014). This suggests that reliable and valid measures of anxiety specific to people with Parkinson's appear to be more sensitive to anxiety in the context of this condition. Such measures would also be considered integral for the evaluation of psychological interventions in research and clinical practice alike (Dissanayaka et al., 2015).

Another element affecting the quality of the studies reviewed in Chapter Two, related to adaptation of interventions for people with Parkinson's. Tailoring interventions to the specific nature of anxiety in Parkinson's is important (Egan et al., 2015). Despite this, the systematic review highlighted that in most studies there was limited, or no attempt to adapt interventions for the specific needs of people with Parkinson's. This may reflect the difficulties of tailoring interventions given limited assessment of Parkinson's-specific

factors. Adopting brief measures of anxiety such as the BAI or the PAS, is less likely to provide a rich understanding of the anxiety experienced by people with Parkinson's. This may have implications for psychological formulations and interventions.

The development of a comprehensive, reliable and valid anxiety scale for people with Parkinson's is fundamental. This could offer clinicians a means of assessing the experience of anxiety for people with Parkinson's. For example, determining whether people are more concerned about disease progression or current difficulties, or whether specific motor symptoms are a source of anxiety. This in turn could help guide psychological formulation and tailor treatment interventions (Meyer et al., 2001). Moreover, it could offer researchers and clinicians an additional means of more accurately evaluating the effectiveness of psychological interventions for anxiety among people with Parkinson's.

The empirical study, presented in Chapter Four, aimed to develop a comprehensive scale to characterise the specific nature of anxiety in the context of Parkinson's. This involved secondary analyses of data collected as part of a study by Curran and colleagues (2021b). Secondary analysis of existing data refers to the process of novel analyses being applied to previous research data, and has become increasingly valued (Doolan et al., 2017). The empirical study benefits from the advantages of secondary analysis of existing data, such as enhanced efficiency of research, cost-effectiveness (Cheng & Phillips, 2014; Doolan et al., 2017), the generation of new knowledge (Magee et al., 2006), and reduction in participant burden (Doolan et al., 2017).

Chapter Four: Empirical Study

The Comprehensive Anxiety and Parkinson's Scale (CAPS): Co-development and initial validation of the long (CAPS-54) and short (CAPS-24) versions.

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Abstract

Background: Anxiety is a prevalent non-motor symptom of Parkinson's disease, but is often underrecognised and challenging to characterise. The development of an accurate and reliable measure of anxiety for people with Parkinson's disease is essential for timely identification and intervention.

Objectives: The present study aimed to develop a comprehensive new scale for people with Parkinson's disease and anxiety. A shortened version of the scale was also developed. The psychometric properties of both versions of the scale were assessed for reliability and validity.

Methods: Secondary analyses were conducted on data from 254 people with Parkinson's disease and anxiety collected during a recent study by Curran et al. [1]. Secondary analyses included exploratory factor analysis, reliability and validity analyses, and confirmatory factor analysis.

Results: A standardised scale of anxiety and Parkinson's disease, in its long (CAPS-54) and short versions (CAPS-24), was developed. Reliability and validity analyses of the scales demonstrated excellent factorial and internal consistency, as well as good convergent validity.

Conclusions: The standardised scales offer comprehensive means of understanding the experience of Parkinson's disease and anxiety. Initial validation of the scales is promising and future validation with an independent sample is recommended. Implications of the findings, alongside strengths and limitations are discussed.

Introduction

Anxiety is a commonly experienced non-motor symptom of Parkinson's disease [PD; 2], with an estimated prevalence of 31 percent [for a review, see 3]. The experience of anxiety among people with PD is thought to be underrecognised and undertreated [4]. It is argued that a better understanding of anxiety experienced by people with PD will lead to more timely identification and patients receiving more appropriate and effective intervention [2, 5, 6]. A recent set of surveys identified that whilst Parkinsonian anxiety shares many characteristics of anxiety in the general population, three quarters of anxiety factors were impacted by the experience of Parkinson's [1].

A review of anxiety measures for people with PD highlighted that existing anxiety scales omitted fundamental clinimetric information and showed inadequate evidence of validity in this population [7]. This drove the development of the Parkinson's Anxiety Scale [PAS; 5]. It was claimed that this was an accurate and reliable measure of anxiety for use with people with PD which could be administered quickly and easily [8, 9]. Whilst this brief measure of only 12 items is quick to administer, it has since received significant criticism. A recent systematic review found that the PAS was less sensitive to anxiety in adults with PD, than the Geriatric Anxiety Inventory [GAI; 10]. Notably, the internal consistency of the 'Avoidance Behaviour' subscale is relatively low (r = .67), and below the recommended Cronbach's alpha value of .70 [11]. Moreover, Pontone and colleagues [4] have suggested that the PAS focuses on common anxiety presentations and not the unique experience of anxiety for people with PD. This supports the argument for the development of an accurate and reliable measure of anxiety for people with PD [8, 12].

To characterise the experience of anxiety for people with PD, Curran and colleagues [1] conducted a mixed-methods study, co-developed with two lay advisers with lived experience of PD and anxiety. Survey questions relating to the characterisation of

anxiety experiences in people with PD, were generated in a two-stage process using a modified nominal group technique. Firstly, the qualitative accounts of anxiety from 205 people with PD were collected and analysed (16,503 words). Next, the qualitative accounts were coded into 137 unique statements. Finally, in a ranking survey, 341 people with PD and anxiety, rated these statements on a five-point Likert scale according to representiveness of their experience.

The present study used the ranking survey data [1], to develop and validate a comprehensive standardised psychometric scale of anxiety for people with PD. We aimed to develop a scale to characterise the specific and nuanced experience of anxiety in people with PD, as well as overcome the limitations of existing measures. A shortened version of the comprehensive scale was also developed. As part of this process, the psychometric properties of both versions of the scale were assessed in terms of reliability (e.g., internal consistency) and validity (e.g., factorial and convergent).

Methods

Design

Scale development and validation analyses were conducted on ranking survey data of anxiety experiences by people with PD [1].

Participants

Curran and colleagues [1], collected data from 341 participants recruited from the Research Support Network of Parkinson's UK and Parkinson's UK support groups. Participants were 18 years old and above, able to read and write in English, had a diagnosis of PD, and had experienced anxiety that impacted quality of life since PD diagnosis.

For the current study, 87 participants were excluded due to insufficient data for the purposes of scale development analysis. Data were deemed to be missing at random and were deleted listwise. Using this method, an entire case was excluded if any response value

on any item was missing. Therefore, this study used data from 254 participants. Participant characteristics are described in Table 1.

Table 1

Demographic and Parkinson's-related Data of the Sample (N = 254)

Variable	Frequency (%)	*M*	*SD*	Range
Age (Years)		65.7	8.5	38-83
Sex				
Female	107 (42.1)			
Male	147 (57.9)			
Ethnic Origin				
Black or Black British	1 (0.4)			
Mixed/Multiple Ethnic Groups	1 (0.4)			
Other	1 (0.4)			
White	251 (98.8)			
Sexual Orientation				
Bisexual	6 (2.4)			
Heterosexual/Straight	243 (95.7)			
Homosexual/Gay	1 (0.4)			
Other	1 (0.4)			
Prefer Not to Say	3 (1.2)			
Years Since Parkinson's Diagnosis		5.4	4.4	0-31
PAS (Total Score, Max = 48)		29.8	8.8	12-44
Avoidance Behaviour (Max = 12)		6.8	2.7	3-11

Variable	Frequency (%)	*M*	*SD*	Range
Episodic Anxiety (Max = 16)		8.1	3.3	4-16
Persistent Anxiety (Max = 20)		14.9	4.3	5-20

Ranking Survey Data

This scale development study used the final dataset generated by Curran and colleagues [1]. The data represented participant Likert ratings for each of the 137 unique statements (Appendix G) relating to their experiences of anxiety. A 5-point Likert response scale was used. Further details of the methodology and analysis are reported elsewhere [1].

Parkinson's Anxiety Scale (PAS)

Curran and colleagues [1] administered the PAS [5] as a standardised measure of anxiety in PD. This is a 12-item self-report measure with items reflecting three subscales; persistent anxiety (5 items), episodic anxiety (4 items) and avoidance behaviour (3 items). For each item participants respond using a 5-point Likert scale, ranging from 0 (not at all or never) to 4 (severe or almost always), with a total score of 48. A cut-off score of 14 or above is used to identify people meeting criteria for anxiety. The internal consistency for the PAS within a Parkinson's population is reasonable (Cronbach's α = .87) for the measure as a whole [8, 5], and as follows for the sub-scales: Persistent Anxiety (α = .88), Episodic Anxiety (α = .78) and Avoidance Behaviour (α = .67) [5]. In the current study, the PAS was used for assessing the convergent validity of both versions of the new scale, which is an important part of the scale development and validation process [13].

Ethical Approval

The study by Curran and colleagues [1] and subsequent secondary analyses received ethical approval from the University of East Anglia (UEA) Faculty of Medicine and Health Sciences Research Ethics Committee (FMH REC; Appendix H). Additional

ethical approval for the specific secondary analyses of the current study was subsequently confirmed by the FMH REC (Appendix I).

Patient and Public Involvement

Two lay advisors with lived experience of anxiety and PD, JM and RC, were recruited from Parkinson's UK Research Support Network. They were involved in the Curran et al. [1] study and in the development of the two versions of the scale described in this paper. JM and RC reviewed, completed and provided feedback on the content, design, presentation, and experience of completion.

Data Analysis

Data analysis was completed in three main phases:

1. Development of the scale and its underlying factor structure via exploratory factor analysis (EFA) and initial validation
2. Development of the shortened version of the scale via a scale reduction optimisation strategy and initial validation
3. Confirmation of the factor structure of the shortened version of the scale via confirmatory factor analysis (CFA) and initial validation

Scale Development and Initial Validation

Scale development and initial validation was conducted using IBM SPSS Statistics [Version 25.0; 14]. An EFA was carried out on the 137 items to identify underlying dimensions of anxiety experienced by people with PD. Principal axis factor analyses were conducted with a direct oblimin rotation. An oblique rotation was adopted because it was predicted that the underlying dimensions of anxiety experienced by people with PD would be interrelated. Factor extraction was based on an eigenvalue of greater than 2.0 and a confirmatory inspection of the scree plot. For the interpretation of the extracted factors, item loadings with a value of < .30 were considered for deletion [15, 16]. All items with

high cross-loadings, meaning those with secondary loadings with a value of .30 or more, were deleted. Items with primary factor loadings with a value of .30 or less were also deleted. The strength of the factor loadings was evaluated using recommendations by Kline [17], with loadings considered moderately high if above .3 and considered high if above .6.

The internal consistency of each factor was assessed using Cronbach's alpha [11], based on the criterion that alpha values of at least .70 represent good reliability. In line with Cronbach's [11] recommendation, reliability analyses were applied separately to each subscale, to ensure that the subscales are reliable measures of the components of anxiety they are tapping. This is particularly important if the subscales are used independently in future clinical practice or research. Applying reliability analyses to each subscale separately also accounts for a potentially inflated Cronbach's alpha value in relation to scales with a high number of items. To assess convergent validity, correlation analyses (Pearson's *r*) were performed on the overall and subscale scores of the CAPS-54 and the overall and subscale scores of the PAS. Correlations were evaluated as very weak (*r* = .00 –.19), weak (*r* = .20 –.39), moderate (*r* = .40 –.59), strong, (*r* = .60 –.79), or very strong (*r* = .80 –1.0) [18].

Scale Reduction and Initial Validation

Scale reduction was conducted using the Oasis application [19] in R [20]. Oasis offers an optimisation strategy for shortening scales which is more psychometrically defensible than previous methods of scale reduction, as it considers multiple important criteria simultaneously [19]. Previous methods have, either assumed that all reliability and validity of a full-length scale is applicable to the shortened version [21], or only required a single criterion of a Cronbach's alpha value equal to, or larger, than .7 [19]. In contrast, the multiple criteria considered in Oasis include, Cronbach's alpha, Guttman's λ_2, part-whole correlation and convergent validity. All subscale items from the CAPS-54, and the PAS for

convergent validity, were inputted into Oasis. Oasis identified each possible way that the CAPS-54 items could be combined to make a shortened scale. The item combinations were then analysed and interpreted, to balance scale quality and internal consistency of the subscale scores, in order to establish the most robust combination, i.e. the shortened scale. Scale quality and internal consistency were evaluated in accordance with a Cronbach's alpha value greater than .70 [11], a Guttman's (λ_2) value greater than .75, and a part-whole correlation (r_{pt}) value greater than .90 [19]. Assessment of convergent validity was performed using correlation analyses (Pearson's *r*) on the total PAS and CAPS-24 scores, as well as the total PAS and the CAPS-24 subscale scores. Correlations were evaluated as very weak (*r* = .00 –.19), weak (*r* = .20 –.39), moderate (*r* = .40 –.59), strong, (*r* = .60 –.79), or very strong (*r* = .80 –1.0) [18].

Confirmation of Factor Structure of the Shortened-Version (CAPS-24)

The factor structure of the shortened scale was analysed via CFA using EQS 6.1 [22]. The robust maximum likelihood (ML) estimation procedure was used to account for multivariate non-normality of the data. Detection of multivariate non-normality in large samples (200-500 participants) [23] was corrected for, using a robust $\chi 2$ statistic, the Satorra-Bentler scaled statistic (S-B $\chi 2$) [24] and robust indices.

Goodness-of-fit was assessed using the $\chi 2$ goodness-of-fit index, Robust Comparative Fit Index (RCFI), the Robust Bentler-Bonett Non-Normed Fit Index (RNNFI), Robust Root Mean Square Error of Approximation (RRMSEA), and Standardized Root Mean Square (SRMR). Excellent model-to-data fit is typically evaluated in accordance with a RCFI value of .90 or greater, a RNNFI value of .95 or greater, a RRMSEA value of .08 or less, and a SRMR value of .06 or less [25, 26, 27, 28].

Results

Comprehensive Anxiety and Parkinson's Scale (CAPS-54)

Following examination of the pattern matrix, whilst employing the aforementioned criteria, a series of factor analyses removed 72 items from the original 137. Therefore, the final EFA included 65 items which loaded on to six factors and accounted for 48.46% of the total item variance. Eleven of these items were identified as having a poor conceptual fit and therefore low face validity and were removed from the EFA solution. This resulted in a simpler 6 factor solution which accounted for a greater amount of variance. The final clean solution included 54 items which loaded on to six factors and accounted for 49.35% of the total item variance. Item means ranged from 1.8 (*SD* = 0.9) to 3.6 (*SD* = 1.2) on the 5-point Likert scale, and strength of factor loadings ranged from moderately high .30 to high .86 (Table 2).

Inspection of item content confirmed that the extracted items could be represented by six dimensions (subscales). Subscale 1 was named 'Impact of Parkinson's' and consists of 13 items that reflect concerns about the impact of Parkinson's in the present and future. For example; 'my anxiety is triggered or made worse when I see others at the later stage of Parkinson's' and, 'when I am anxious, I worry about the rate at which my Parkinson's symptoms progress and how I will cope at their worst'. Subscale 2, named 'Environment', consists of 11 items that reflect feared, problematic, and avoided environmental settings. For example, 'my anxiety is triggered or made worse when I am in crowded and/or noisy places' and, 'my anxiety is triggered or made worse if people are too close and I feel my movement is restricted'. Subscale 3, named 'Cognitions', consists of 9 items that reflect the content and process of generalised worry and rumination. For example, 'there is no fixed focus to my worry; I worry about anything, including irrational things, things I have no control over' and, 'I blow things out of proportion and make mountains out of molehills'. Subscale 4, named 'Physical Sensations', consists of 7 items that reflect physiological symptoms of anxiety. For example, 'when I am anxious, I experience

changes to body temperature' and, 'when I am anxious, I experience increased sweating'. Subscale 5, named 'Physical Consequences', consists of 7 items that reflect the consequences, and feared consequences, of Parkinson's and/or anxiety on bodily functions. For example, 'my anxiety is triggered or made worse when I am unsure if I can reach the toilet in time' and, 'when I am anxious, I worry about dribbling and that others will judge me negatively'. Subscale 6, named 'Anxiety Triggers', consists of 7 items that reflect situations triggering the experience of anxiety. For example, 'my anxiety is triggered or made worse when I am alone' and, 'my anxiety is triggered or made worse when I am not occupied/busy'.

Table 2

Item Means, Standard Deviations, and Factor Loadings

CAPS-54 Subscale and Item	*M*	*SD*	Factor					
			1	2	3	4	5	6
1. Impact of Parkinson's								
My anxiety is triggered or made worse when I do not meet demands or expectations*	3.1	1.2	*.37*	.22	.19	.01	.05	-.03
My anxiety is triggered or made worse when I see others at the later stage of Parkinson's	3.6	1.2	*.72*	.03	.04	.05	-.02	.12
My anxiety is triggered or made worse when reading about Parkinson's	3.0	1.2	*.64*	.05	.02	.02	-.03	-.01
When I am anxious, I compare my health status to those who are in better health*	2.8	1.2	*.59*	.08	.03	-.08	.04	-.10
When I am anxious, I worry about the rate at which my Parkinson's symptoms progress and how I will cope at their worst	3.6	1.0	*.71*	.04	-.03	.00	.08	-.04
When I am anxious, I worry I will get dementia	3.3	1.3	*.71*	-.09	.03	.00	-.01	.01
When I am anxious, I worry about my death	2.6	1.3	*.54*	-.09	-.04	.02	.07	-.21
When I am anxious, I worry I will lose control and won't be able to do my everyday tasks*	3.3	1.1	*.61*	.00	.02	.05	.12	-.13
When I am anxious, I worry I will lose my identity	2.7	1.3	*.57*	-.03	.05	.21	.04	.01
When I am anxious, I worry about upsetting those close to me or making things difficult for them*	3.4	1.0	*.49*	.11	-.01	.08	.03	-.15
When I am anxious, I worry that I stand out as different*	2.5	1.2	*.36*	.26	.07	.02	.20	-.06
When I am anxious, I compare my current abilities to my past abilities	3.4	1.1	*.57*	.08	.10	.00	.05	-.01

CAPS-54 Subscale and Item	*M*	*SD*	Factor					
			1	2	3	4	5	6
When I am anxious, I worry about feeling anxious; how long it will last for, whether it will impact on my health, or how I will cope with it*	3.0	1.2	*.44*	-.05	.24	.11	.03	-.23
2. Environment								
My anxiety is triggered or made worse when in confined or enclosed spaces*	2.7	1.3	-.06	*.59*	-.03	.17	.05	-.17
My anxiety is triggered or made worse when in public settings*	3.0	1.1	.04	*.68*	.05	-.01	.07	-.13
My anxiety is triggered or made worse when I am in crowded and/or noisy places	3.2	1.1	.00	*.77*	.09	.04	.03	.01
My anxiety is triggered or made worse if people are too close and I feel my movement is restricted	3.1	1.3	.01	*.71*	.03	.11	-.03	-.06
My anxiety is triggered or made worse when I am travelling*	3.0	1.1	.16	*.56*	.03	.07	-.14	-.06
When I am anxious, or to avoid becoming anxious, I prefer to be accompanied by someone familiar when going into new places/situations	3.4	1.2	.18	*.52*	.02	-.02	.06	.05
When I am anxious, or to avoid becoming anxious, in public I select food or drink that is easier to manage or I avoid eating or drinking altogether	2.8	1.3	.02	*.53*	.00	-.03	.18	.04
When I am anxious, or to avoid becoming anxious, I avoid busy or crowded places*	2.9	1.1	.05	*.70*	.13	.09	-.05	.03
When I am anxious, or to avoid becoming anxious, I avoid confined spaces or places that are not easy to escape from*	2.8	1.3	.03	*.52*	.10	.26	.10	.04
When I am anxious, or to avoid becoming anxious, I avoid driving	2.5	1.4	.03	*.46*	.03	-.01	.05	-.07
When I am anxious, or to avoid becoming anxious, I avoid some methods of travel (e.g. public transport, car travel, plane travel, etc.)	2.5	1.3	-.13	*.62*	.02	.04	.01	-.04

CAPS-54 Subscale and Item	*M*	*SD*	Factor					
			1	2	3	4	5	6
3. Cognitions								
When I am anxious, I think about past events over and over again*	2.7	1.2	.26	-.02	*.36*	.10	.04	-.20
I view my anxiety as largely irrational and out of proportion	2.9	1.1	.00	-.01	*.46*	.04	.00	-.01
There is no fixed focus to my worry; I worry about anything, including irrational things, things I have no control over	3.3	1.2	-.05	-.05	*.75*	-.05	.10	.04
I feel out of control with my worry and find it hard to stop*	2.8	1.2	.07	-.16	*.64*	.03	.09	-.19
I worry about small things that never used to bother me as much	3.5	1.1	-.02	.09	*.72*	.02	-.06	.05
I blow things out of proportion and make mountains out of molehills	3.2	1.2	-.01	.09	*.84*	-.04	-.08	-.05
When I am anxious, or to avoid becoming anxious, I avoid decision making and/or positions of responsibility	2.7	1.1	.03	.20	*.37*	-.04	.11	-.05
When I am anxious, or to avoid becoming anxious, I over-analyse or check things more than I need to*	3.1	1.2	.14	.14	*.50*	.05	.02	.01
When I am anxious, it is hard to think clearly*	2.9	1.1	.23	.15	*.37*	-.01	.06	-.12
4. Physical Sensations								
When I am anxious, I experience changes to body temperature*	2.6	1.3	.01	.10	-.06	*.77*	-.06	.10
When I am anxious, I experience increased sweating*	2.8	1.3	-.01	.11	-.06	*.75*	.07	.14
When I am anxious, I experience increased heart rate*	2.5	1.1	.08	-.11	.06	*.72*	.02	-.04
When I am anxious, I experience headache	2.1	1.1	.08	.10	.07	*.45*	.01	-.10
When I am anxious, I experience muscle tension	3.0	1.2	.15	.02	-.03	*.60*	.02	-.06
When I am anxious, I experience chest discomfort	1.9	1.0	-.08	-.08	.05	*.53*	.18	-.14
When I am anxious, I experience feeling very alert and focused	2.0	1.0	-.05	.10	.04	*.41*	-.05	-.10
5. Physical Consequences								

CAPS-54 Subscale and Item	*M*	*SD*	Factor					
			1	2	3	4	5	6
My anxiety is triggered or made worse when I am unsure if I can reach the toilet in time*	3.0	1.4	-.14	.14	.05	.01	*.80*	-.05
When I am anxious, I worry about falling and/or the consequences of falling	3.0	1.2	.29	.16	-.08	-.01	*.30*	-.11
When I am anxious, I worry about my speech (e.g. not speaking clearly or being understood)	3.1	1.1	.29	.09	-.01	-.03	*.31*	-.08
When I am anxious, I worry about dribbling and that others will judge me negatively	2.4	1.2	.22	.18	-.06	.00	*.40*	-.01
When I am anxious, I am embarrassed by the urgency with which I need to urinate	2.7	1.4	.05	-.05	.03	.04	*.86*	.05
When I am anxious, I worry about the embarrassment of having a toileting accident (being incontinent)*	2.8	1.3	.08	-.12	.10	.06	*.84*	.05
When I am anxious, I need to use the toilet*	2.9	1.2	.05	.09	.04	.14	*.53*	-.08
6. Anxiety Triggers								
My anxiety is triggered or made worse when I am alone*	2.5	1.2	-.02	.00	.02	-.01	.00	*-.78*
My anxiety is triggered or made worse when I am not occupied/busy*	2.6	1.1	.04	.06	-.05	-.02	-.01	*-.75*
My anxiety is triggered or made worse when I wake up*	2.2	1.1	.09	-.03	.09	.05	-.05	*-.58*
My anxiety is triggered or made worse at night	2.6	1.1	.03	.02	.03	.11	.03	*-.62*
My anxiety is triggered or made worse when I am tired	2.9	1.1	.18	.11	-.01	.11	.01	*-.45*
My anxiety is triggered or made worse when I am at home	2.3	1.0	-.04	-.05	.11	-.00	.02	*-.67*
My anxiety is triggered or made worse when exercising	1.8	0.9	.03	.24	-.04	-.03	.08	*-.46*

Note. Factors: 1 = Impact of Parkinson's, 2 = Environment, 3 = Cognitions, 4 = Physical Sensations, 5 = Physical Consequences, 6 = Anxiety Triggers. Italicised numbers indicate primary loadings. Factor loadings are considered moderately high if above .3 and considered high if above .6 [17]. Items marked with an asterisk (*) form the CAPS-24. All items were scored on a 5-point Likert scale.

Table 3

CAPS-54 Subscale Factor Correlations and Internal Consistency

Subscale	Number of Items	α	Factor					
			1	2	3	4	5	6
Impact of Parkinson's	13	.92	1.00					
Environment	11	.91	.56	1.00				
Cognitions	9	.87	.54	.49	1.00			
Physical Sensations	7	.84	.45	.51	.33	1.00		
Physical Consequences	7	.87	.65*	.58	.44	.38	1.00	
Anxiety Triggers	7	.86	.58	.48	.52	.42	.48	1.00

Note. α = Cronbach's Alpha. Good internal consistency was evaluated in accordance with a Cronbach's alpha value greater than .70 [11]. Factors: 1 = Impact of Parkinson's, 2 = Environment, 3 = Cognitions, 4 = Physical Sensations, 5 = Physical Consequences, 6 = Anxiety Triggers. *Factor correlations are considered strong if above .6.

The six subscales had excellent internal consistency, with alphas ranging from α = .84 to α = .92 (Table 3). Factor correlations ranged from weak (r = .33) to strong (r = .65; Table 3). A strong factor correlation was found between subscale 1 (Impact of Parkinson's) and subscale 5 (Physical Consequences). Correlations between subscale 3 (Cognitions) and subscale 4 (Physical Sensations), and between subscale 4 (Physical Sensations) and subscale 5 (Physical Consequences) were weak. All other subscale factor correlations were moderate.

Analysis of convergent validity found a very strong, positive correlation between the total overall scores on the CAPS-54 and the PAS (r = .824, p < .001; Table 4). Analysis of convergent validity between the total subscale scores of the CAPS-54 and the PAS ranged from moderate (r = .43) to strong (r = .69). The strongest correlations were found between the CAPS-54 subscales of 'Cognitions' (r = .69), 'Anxiety Triggers' (r = .69), and 'Impact of Parkinson's' (r = .61), with the PAS subscale of 'Persistent Anxiety'. Another a strong correlation was found between the CAPS-54 subscale 'Environment' and the PAS subscale 'Avoidance Behaviour' (r = .67). All correlations were significant at p < .001. (Table 5).

The final 54 items were shared and discussed with the lay advisors (JM and RC) to establish the order of items, scale and subscale names and overall presentation. In addition, they completed the final scale and provided feedback on the experience and completion time (Mean = 5.5 minutes). The final measure was named the Comprehensive Anxiety and Parkinson's Scale (CAPS-54; Appendix J).

Comprehensive Anxiety and Parkinson's Scale - Short Version (CAPS-24)

The aforementioned criteria were used to evaluate the different combinations of the subscale items generated in Oasis. For each subscale, the item combination which scored optimally across the four indices (Cronbach's α, Guttman's λ_2, part-whole correlation, and Pearson's r) was retained. Subscale 1 (Impact of Parkinson's) was reduced from 13 to 6 items. Subscale 2 (Environment) was reduced from 11 to 5 items. Subscale 3 (Cognitions) was reduced from 9 to 4 items. Subscale 4

(Physical Sensations) was reduced from 7 to 3 items. Subscale 5 (Physical Consequences) was reduced from 7 to 3 items. Subscale 6 (Anxiety Triggers) was reduced from 7 to 3 items. This resulted in a more parsimonious scale of 24-items which still had face and content validity, and reflected the constructs encompassed by each subscale. To ensure content validity, larger subscales retained more items.

Table 4

Correlations between CAPS-54, CAPS-24, and PAS Total Scores

	CAPS-54 Total Score	CAPS-24 Total Score
PAS Total Score	.824*	.820*

Note. *Correlations are significant at $p < .001$. Correlations were evaluated as very weak ($r = .00 – .19$), weak ($r = .20 – .39$), moderate ($r = .40 – .59$), strong, ($r = .60 – .79$), and very strong ($r = .80 – 1.0$) [18]. A significant, very strong correlation was found between the CAPS-54 and CAPS-24 ($r = .980$, $p < .001$).

The six subscales demonstrated excellent internal consistency with Cronbach's alpha (α) ranging from .77 to .86, Guttman's (λ_2) ranging from .75 to .84, and a part-whole correlation (r_{pt}) ranging from .90 to .94. Analysis of convergent validity between the total overall scores on the CAPS-24 and the PAS found a strong, positive correlation ($r = .820$, $p < .001$; Table 4). The six subscales also demonstrated good convergent validity (Pearson's r), with positive, and statistically significant ($p < .001$) correlations with the PAS subscales (Table 5). The strongest correlations were found between the CAPS-24 subscales of 'Cognitions' ($r = .71$), 'Impact of Parkinson's' ($r = .61$), and 'Anxiety Triggers' ($r = .61$), with the PAS subscale of 'Persistent Anxiety'. Another strong correlation was found between the CAPS-24 subscale 'Environment' ($r = .67$) and the PAS subscale 'Avoidance Behaviour'.

Confirmation of Factor Structure of the Shortened-Version (CAPS-24)

Confirmatory factor analysis confirmed that the 24-item solution held the same six-factor structure as the 54-item solution. Examination of Mardia's normalized coefficient (14.33) indicated that the data departed from multivariate normality. Subsequently, the robust maximum likelihood (ML) estimation procedure was used. The model displayed a good fit to the data, S-B $\chi 2(237) = 475.35$, $p < .001$, RCFI = .92, RNNFI = .91, SRMR = .06, and RRMSEA = .06 (90% CI = .05 – .07).

As with the CAPS-54, the final 24 items were shared and discussed with the lay advisors (JM and RC) to establish the order of items and overall presentation. In addition, they completed the final scale and provided feedback on the experience and completion time (Mean = 3 minutes). The final measure was named the Comprehensive Anxiety and Parkinson's Scale – Short Version (CAPS-24; Appendix K).

Table 5

Correlations between CAPS-54, CAPS-24, and PAS Subscales Scores

Scale and Subscale	CAPS-54						CAPS-24					
	1	2	3	4	5	6	1	2	3	4	5	6
PAS												
1	.61	.47	.69	.44	.47	.69	.61	.49	.71	.39	.38	.61
2	.51	.48	.45	.43	.50	.57	.54	.49	.49	.44	.40	.51
3	.51	.67	.46	.48	.45	.43	.53	.67	.48	.41	.41	.39

Note. PAS: 1 = Persistent Anxiety; 2 = Episodic Anxiety; 3 = Avoidance behaviour. CAPS-54 and CAPS-24: 1 = Impact of Parkinson's, 2 = Environment, 3 = Cognitions, 4 = Physical Sensations, 5 = Physical Consequences, 6 = Anxiety Triggers. All correlations are significant at $p < .001$. Correlations were evaluated as very weak ($r = .00 – .19$), weak ($r = .20 – .39$), moderate ($r = .40 – .59$), strong, ($r = .60 – .79$), and very strong ($r = .80 – 1.0$) [18].

Table 6

CAPS-24 Subscale Internal Consistency

Subscale	Number of Items	α	λ_2	r_{pt}
Impact of Parkinson's	6	.85	.84	.94
Environment	5	.86	.84	.94
Cognitions	4	.77	.75	.92
Physical Sensations	3	.83	.78	.90
Physical Consequences	3	.84	.80	.91
Anxiety Triggers	3	.80	.76	.91

Note. α = Cronbach's Alpha. λ_2 = Guttman's. r_{pt} = part-whole correlation. Pearson's *r* = convergent validity. Good internal consistency was evaluated in accordance with a Cronbach's alpha value greater than .70 [11], a Guttman's (λ_2) value greater than .75, and a part-whole correlation (r_{pt}) value greater than .90 [19].

Discussion

The aim of this study was to develop a new standardised psychometric scale that captured the unique and nuanced experience of anxiety in people with PD, overcoming limitations of existing measures. Accordingly, the 'Comprehensive Anxiety and Parkinson's Scale' was developed in its full (CAPS-54) and shortened (CAPS-24) versions. This offers a significant contribution to meeting the identified need for an accurate and reliable measure of anxiety for people with PD [8, 12].

For both the CAPS-54 and the CAPS-24, factor analyses confirmed that the extracted items could be represented by six subscales: Anxiety Triggers, Physical Sensations, Physical Consequences, Cognitions, Environment, and Impact of Parkinson's. The psychometric properties of the two versions of the scale were assessed for reliability

and validity. The overall scales, and each of the subscales, demonstrated excellent levels of reliability. The lowest subscale alpha value of the CAPS-54 was for 'Physical Sensations' (α = .84), and for the CAPS-24 was for 'Cognitions' (α = .77). In contrast, the internal consistency of the 'Avoidance Behaviour' subscale of the PAS is relatively low (α = .67) [5], and below the recommended Cronbach's alpha value (α = .70) [11]. This supports that both the CAPS-54 and CAPS-24, and all subscales, demonstrated adequate reliability in the current sample.

The overall scales, and each of the subscales, demonstrated good levels of validity. Good factorial validity was demonstrated by inter-factor correlations of the EFA. Good convergent validity was demonstrated by a statistically significant, strong and positive correlation between the total scores on the CAPS-54 and the PAS. Good convergent validity suggests that the CAPS-54 and the PAS measure dimensions related to the same construct. Correlations between the CAPS-54 and PAS subscales were also all significant and positive, and ranged from moderate to strong. The stronger correlation coefficients were found between the CAPS-54 individual subscales of 'Anxiety Triggers', 'Cognitions' and 'Impact of Parkinson's' and the PAS subscale of 'Persistent Anxiety'. Another strong correlation was found between the CAPS-54 subscale 'Environment' and the PAS subscale 'Avoidance Behaviours'. Again, good convergent validity suggests that these CAPS-54 and PAS subscales measure related constructs. Further, weaker correlations suggest that the CAPS-54 may tap additional constructs of anxiety in PD not captured by the PAS. This highlights that the CAPS-54 may offer a more comprehensive and nuanced understanding of the anxiety experienced by people with PD.

A similar pattern of findings was found when assessing convergent validity between the CAPS-24 and the PAS. Correlation coefficients indicated a significant, strong and positive relationship between the total scores on the CAPS-24 and the PAS, indicating

good convergent validity. Correlations between the CAPS-24 subscales and the PAS subscales were all significant and positive, and ranged from weak (borderline moderate) to strong. Stronger correlations were found between the CAPS-24 subscales of 'Anxiety Triggers', 'Cognitions', and 'Impact of Parkinson's' and the PAS subscale of 'Persistent Anxiety'. Another strong correlation was found between the CAPS-24 subscale 'Environment' and the PAS subscale 'Avoidance Behaviours'. These findings are consistent with findings for the CAPS-54 and suggest that the CAPS-24 also measures dimensions related to the same construct as the PAS.

Correlations between the CAPS-24 subscales 'Physical Sensations', and 'Physical Consequences' with the PAS subscale 'Persistent Anxiety' were weakest. This was also true for the correlation between the CAPS-24 subscale 'Anxiety Triggers' and the PAS subscale 'Avoidance Behaviours'. These three CAPS-24 subscales appear to measure aspects of anxiety in Parkinson's not assessed by the PAS, suggesting that the CAPS is a more comprehensive measure.

The two versions of the scale begin to overcome limitations of existing measures. Firstly, the psychometric properties indicate improved levels of reliability and good levels of validity. Secondly, the new scales focus on the unique and nuanced experience of anxiety in PD, as opposed to the PAS which focuses on common anxiety presentations [4]. Despite the comprehensive nature of the new scales, they remain quick and easy to administer, in line with a principal strength of the PAS [8, 9].

Strengths and Limitations

Two comprehensive and nuanced versions of a new measure of anxiety in the context of PD have been developed, which demonstrate satisfactory clinimetric properties. A primary strength of these scales is that the overall content, design, and presentation were co-constructed by the target population, that is, people with lived experience of PD and

anxiety. Specifically, the content of the scale items was derived from a rich, dataset collected as part of the largest survey characterising anxiety in people with PD to date [1], as well as benefiting from co-development through lay advisor input throughout. Lay advisors also provided significant contribution to the scale development process. This has resulted in the development of two versions of the scale which capture specific experiences of the population in a way not previously achieved. This paper supports that the involvement of lay advisors is instrumental in improving the relevance, quality, and impact of research [29].

A significant strength of the empirical study relates to the opportunity of conducting secondary analysis on data collected by Curran and colleagues [1], enabling the development of a standardised scale. Strengths of secondary analysis on existing data include enhanced efficiency of research, cost-effectiveness [30, 31], the generation of new knowledge [32], and reduction in participant burden, all of which have become increasingly valued [31].

Another strength relates to the rigour employed in the development of the two scales. Recommended scale development procedures were adopted, including psychometric evaluation [13]. The rigour employed during scale reduction was achieved through the Oasis application, which offers psychometrically defensible methods compared to previous approaches [19]. Specifically, a range of reliability indices were considered simultaneously, as opposed to sole dependence on Cronbach's alpha.

Whilst the comprehensive nature of the CAPS-54 is clearly a strength, there are noticeably more items than the existing measure of Parkinson's and anxiety (i.e., the PAS). An increased number of items will undoubtedly increase completion time slightly, a factor which may be viewed as a limitation. However, Wechsler [33] advises it is fundamental that, regardless of time constraints, clinicians find the time for comprehensive assessment.

Whilst we agree, it is also important that measures are as accessible as possible to patients and clinicians, and therefore a shortened version (CAPS-24) is offered in addition. This provides researchers and clinicians the option to select the version most appropriate to their needs, knowing that each offers adequate reliability and validity. For example, a clinician may prefer to select the longer version (CAPS-54) to help inform comprehensive assessment and psychological formulation, whereas the short version may be preferred for briefer assessment or screening purposes.

Finally, it is important to consider the generalisability of the CAPS to a wider population of people with PD. For this, the demographics of the sample which informed the development of the CAPS can be compared with the demographics of the wider PD population. Parkinson's UK recently published a reference report on the UK prevalence of PD [34]. This report was informed by data from the Clinical Practice Research Datalink [35], which involved more than five million primary care patients considered representative of the UK population in relation to sex, ethnicity, and age. The reference report stated that 57.7 percent of people with PD were male [34], which is very similar to the CAPS sample (57.9 percent). For ethnicity, Parkinson's UK estimate that 7.1 percent of people with PD are from minority ethnic backgrounds. In comparison, just 1.2 percent of CAPS participants were from these backgrounds. These findings indicate that the current sample may be considered representative in terms of sex, but not truly representative of ethnicity.

Implications for Practice and Recommendations for Future Research

Given that the experience of anxiety among people with PD is underrecognised and undertreated [4], it is hoped that this new scale will improve the assessment of anxiety in this population. As a result, this could lead to more timely identification and patients receiving more appropriate and effective intervention [2, 5, 6]. What is more, the

comprehensive and rich nature of the information gathered as a result of completing either version of the scale could help guide psychological formulation and treatment. This may be of particular use to psychological or therapeutic practitioners who have limited knowledge of the anxiety experienced by many people with PD.

It is recommended that future research further validates the CAPS-54 and CAPS-24 with independent samples. This is required to confirm the factor structure, as well as reliability and validity of both versions of the scale and their subscales. It is also recommended that future research compares the CAPS with alternative measures of anxiety suitable for people with PD. This may overcome known limitations of the PAS and provide additional validation for the CAPS. Also in an independent sample, appropriateness of the CAPS could be explored for PD subgroups (e.g., people with different PD phenotypes, or at different intervals following PD diagnosis). Findings from such research could support clinical practice to better support people with PD and anxiety. Whilst feedback from lay advisors has been encouraging, it is important to extend our understanding of the acceptability of these scales in the wider PD population. This could be achieved through focus groups that include people with lived experience, their families, carers and clinicians. Acceptability and utility of the new scales could also be explored in clinical settings.

Conclusion

This empirical paper generates and provides initial validation for two versions of a new psychometric scale of anxiety for people with PD, overcoming limitations of existing measures. In doing so, it offers an exciting contribution to the field that may aid clinicians and researchers to capture the specific and nuanced experience of anxiety for people with PD.

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Chapter Five: Discussion and Critical Evaluation

Introduction

The overarching aim of the thesis portfolio was to explore the experience of anxiety for people with Parkinson's, firstly, by examining the efficacy of psychological interventions, and secondly, by developing two standardised measures. The aim of this final chapter is to provide a summary and critical evaluation of the main findings. Overall implications and recommendations for future areas of development are discussed, alongside reflections on the process of completing the portfolio.

Main Findings

Systematic Review and Meta-Analysis

The review examined the efficacy of psychological interventions for people with Parkinson's and anxiety by systematically identifying, selecting, synthesising, and assessing studies which had investigated this. Twelve studies were included in the review, of which, four were case studies, four were uncontrolled trials and four were randomised controlled trials. The psychological interventions tested in the studies included CBT (n = 7), combined CBT and APT (n = 3), and third-wave CBT (n = 2). All studies were examined for quality and risk of bias, finding that many studies were of low quality. As part of the review, the randomised controlled trials (k = 4) and pre-post intervention data (k = 6) were meta-analysed using a random effects model. Findings from the randomised controlled trials demonstrated a significant moderate sized effect (g = -0.51, 95% CI -0.86 to -0.15, $p < 0.01$) for psychological interventions for people with Parkinson's and anxiety, whilst pre-post intervention data demonstrated a significant large sized effect (g = 0.90, 95% CI 0.53 to 1.27, $p < 0.0001$). Low heterogeneity was found for both meta-analyses, indicating low levels of variance between effect sizes of the individual studies. The review provided preliminary evidence for the efficacy of psychological interventions, namely

CBT and third-wave CBT, for people with Parkinson's and anxiety. These results, although contributing to the growing evidence-base, were interpreted with caution, due to small sample sizes, low quality of the studies, and lack of a control group in eight out of 12 studies.

Empirical Study

For the empirical paper, a standardised scale of Parkinson's and anxiety was developed, in its long (CAPS-54) and short forms (CAPS-24). As part of the process, both versions were assessed for reliability and validity. The scales were the product of secondary analyses conducted on data from 254 people with Parkinson's and anxiety collected during a recent study (i.e., Curran et al., 2021b). These analyses included exploratory factor analysis, reliability and validity analyses, and confirmatory factor analysis. Both scales demonstrated excellent reliability and good convergent validity. The new scale offers comprehensive means of understanding the experience of Parkinson's and anxiety, and initial validation of both versions is promising.

Critical Evaluation

Systematic Review and Meta-Analysis

A critical evaluation of the systematic review was covered in Chapter 2, however the strengths and limitations will be discussed further here. This is due to the limited word count stipulated by the criteria of the journal selected for publication.

To my knowledge, this portfolio presents the first systematic review and meta-analysis of psychological interventions for people with Parkinson's and diagnosed anxiety, using a range of research designs. The review examined the efficacy of psychological interventions for people with Parkinson's and anxiety for a variety of intervention types (e.g., CBT, Combined APT and CBT, mindfulness, and ACT) and included different modes of delivery (e.g., individual, with carer, group, face-to-face, telephone, and virtual).

The review was not limited to RCTs or by publication date, and therefore included a range of study designs from inception to date. These inclusion criteria maximised the scope of the review to provide a clear picture of research to date. This was achieved and a comprehensive overview and synthesis of existing research was provided.

A limitation of the review is that study inclusion criteria were restricted to those written in English. This may have excluded research published in languages other than English, which could increase the risk of bias. Studies also required a diagnosis of anxiety. There are difficulties with accurately diagnosing anxiety in this population, however, so this criterion may have excluded people who experience clinically significant anxiety not detected by existing measures. It is understood that variations and fluctuations in Parkinsonian motor symptoms and medications can make diagnosis of anxiety more challenging (Siemers et al., 1993; Witjas et al., 2002). Therefore, diagnostic accuracy in these studies cannot be completely assumed. However, inclusion of participants without such a diagnosis further increases the likelihood that participants are not clinically anxious. By excluding studies without a diagnosis of anxiety, the current review was the first to examine the efficacy of psychological interventions for clinically-significant anxiety in this population.

This review extended the scoping review by Zarotti and colleagues (2020), by conducting quantitative synthesis and quality assessment. Quantitative synthesis was conducted in the form of meta-analyses of data from randomised controlled trials and pre-post studies. The meta-analyses synthesized the results of multiple studies, increasing power and improving estimates of effect size (Stone & Rosopa, 2017). This is of particular benefit for the current review, given the small number of studies and limited sample sizes. Assessment of quality and bias was deemed another important strength of the systematic review. Despite psychological reviews in the field not attending to quality (e.g., Schrag et

al., 2015; Zarotti et al., 2020), it is an essential part of the review process and has an impact on the interpretations of findings and subsequent conclusions (Cuijpers, 2016). Study quality, using an established quality assessment tool (Ost, 2008), was assessed by two independent reviewers. This allowed for critical appraisal of the included studies for the first time. Overall, the quality of the included studies was poor so the results are at risk of bias and need to be interpreted with caution.

The primary limitation of the review related to the paucity and quality of existing research, in particular randomised controlled trials. This, paired with the small sample sizes within each study, mean that the findings must be interpreted tentatively and therefore only provide preliminary evidence at this stage for psychological interventions for people with Parkinson's and anxiety. This also meant that neither moderator nor subgroup analyses could be conducted. This would have allowed for the exploration of variation in efficacy of psychological intervention type and mode of delivery. Analyses of this nature are helpful in guiding recommendations for clinical practice. An additional limitation resulted from the psychological interventions lacking adaptations for people with Parkinson's. Only seven studies used a psychological intervention specifically adapted to people with Parkinson's, which ranged from focussing on Parkinson's-specific anxiety to minimal changes such as reducing the amount of in-session writing. Of the seven studies, only two used a control group. This means it is difficult to evaluate potential benefits of adapting interventions for the specific needs of people with Parkinson's.

The systematic review and meta-analysis highlighted the lack of studies and therefore provided further evidence that the area remains in its infancy. It would be helpful for this review to be repeated following the publication of more, high-quality, fully powered, randomised controlled trials.

Empirical Study

The empirical study produced a new, comprehensive scale of Parkinson's and anxiety (with long and short versions), which demonstrated good psychometric properties. A critical evaluation of the empirical paper was covered in Chapter 4. However, as with the systematic review, the strengths and limitations will be discussed further in this chapter, due to the limited word count stipulated by the journal selected for publication.

A primary strength of the empirical study related to the co-development of the scales with people with lived experience of Parkinson's and anxiety. Specifically, the content of the scale items was derived from a rich dataset collected as part of the largest survey characterising anxiety in people with Parkinson's (Curran et al., 2021b), as well as benefiting from co-development through lay advisor input. Lay advisors provided significant contribution to the scale development process by informing the overall content, design, and presentation of the scales. The co-development process has resulted in two scales which capture the specific experience of anxiety in Parkinson's, in a way that has not been previously accomplished.

It is important to highlight the opportunity of conducting secondary analysis on existing data collected as part of the study by Curran and colleagues (2021b). This analysis enabled the development of two standardised scales from a range of 137 descriptive statements. Secondary analysis of existing data has become increasingly valued (Doolan et al., 2017), with benefits including enhanced efficiency of research, cost-effectiveness (Cheng & Phillips, 2014; Doolan et al., 2017), the generation of new knowledge (Magee et al., 2006), and reduction in participant burden (Doolan et al., 2017). Given that the Curran et al. (2021) study was the largest survey characterising anxiety in Parkinson's and was informed by lay advisors, it seems that secondary analysis of such valuable data is a significant strength of this empirical study. Limitations of secondary analysis concern the lack of control of the research design, including the selection of measures. For example,

there are limitations of using the PAS for convergent validity, given that its sensitivity as a measure of anxiety for people with Parkinson's has been questioned (Mele et al., 2018). For the current empirical study, it would have been helpful if at least one other measure of anxiety had been administered. One such measure is the GAI which, although not Parkinson's specific, has been found to be more sensitive in a Parkinson's population.

An additional strength relates to the rigour employed in the development of the two scales. Recommended scale development procedures were adopted, including psychometric evaluation (Clark & Watson, 2019), informed by COSMIN guidelines (Mokkink et al., 2019). Scale reduction is a common modification of scales, mainly used to overcome time constraints often associated with full length scales (Heggestad et al., 2019). Cortina et al. (2020) highlighted the importance of researchers modifying scales adequately by appropriately evidencing, validating, and accurately reporting the process for publication. Despite this, scale modifications often do not meet these standards (Heggestad et al., 2019). For the empirical study, established methods of scale reduction were adopted with rigour to overcome the common shortfalls of scale reduction. Firstly, the Oasis application (Cortina et al., 2020) was used, which is more psychometrically defensible than previous methods of scale reduction. Specifically, it considers multiple important criteria simultaneously (Cortina et al., 2020). Previous methods have, either assumed that all reliability and validity of a full-length scale is applicable to the shortened version (Smith et al., 2000), or only required a single criterion of a Cronbach's alpha value equal to, or larger, than .7 (Cortina et al., 2020). Secondly, the methods were appropriately and accurately evidenced in the empirical paper (Chapter 4).

It is important to note that, although the comprehensive nature of the CAPS-54 is a strength, there are considerably more items than the only other existing measure of Parkinson's and anxiety (i.e., the PAS). Despite the comprehensive information and insight

the CAPS-54 will provide, it may be critiqued for an increase in completion time. Nevertheless, it is helpful to hold in mind that the CAPS-54 was completed by the lay advisors in a mean time of 5.5 minutes. Moreover, it is advised that clinicians find the time for comprehensive assessment (Wechsler, 1967). That being said, it is important that measures are as accessible as possible, and so it is hoped that the shortened version (CAPS-24) will achieve this. Researchers and clinicians can benefit from the long and short versions of the scale, by selecting the one most appropriate to their needs and knowing that each offers adequate reliability and validity. For example, the longer version (CAPS-54) may help inform comprehensive assessment and psychological formulation with a psychological intervention in mind, whereas the short version (CAPS-24) may be preferred for briefer assessment, triage, or screening purposes.

Implications for Research and Clinical Practice

The introduction of a reliable and valid, comprehensive measure of anxiety for people with Parkinson's may facilitate the development of interventions tailored to the specific needs of this population. This could offer clinicians a means of assessing the experience of anxiety for people with Parkinson's. For example, determining whether people are more concerned about disease progression or current difficulties, or whether specific motor symptoms are a source of anxiety. This in turn could help guide formulation and tailor treatment interventions (Meyer et al., 2001). Moreover, it could offer researchers and clinicians an additional means of more accurately evaluating the effectiveness of psychological interventions for anxiety among people with Parkinson's.

The systematic review identified some tentative evidence that psychological interventions may be of benefit to people with Parkinson's and anxiety. However, the quality of the evidence was poor, and the size of the samples underpowered, meaning good quality, fully powered RCTs are needed. The CAPS-54 measure may be of use in these

studies as it would provide comprehensive evaluation of the impact of the psychological intervention on the character of the anxiety experienced by participants.

Areas for Future Development

For the systematic review, only 12 studies were identified. The studies spanned a 20-year period and only included four randomised controlled trials, three of which were feasibility or pilot studies. This provides further evidence that the area remains in its infancy. Given the prevalence of anxiety for people with Parkinson's, and the negative impact on cognitive ability (Rocha & Teixeira, 2018), activities of daily living (Dissanayaka et al., 2010), and quality of life (Curran et al., 2021a), this does not seem adequate. Further, this limited evidence-base does not meet the request for research into the management of stress and anxiety by people with Parkinson's, their carers, and clinicians (Deane et al., 2014). The current systematic review highlights that in the year 2021, there remains a paucity of research in the field. In order to provide effective, evidence-based psychological interventions for people with Parkinson's and anxiety, this must be overcome. It is hoped that the SR provides further support to this rationale.

The systematic review found that many interventions were not tailored to the specific needs of people with Parkinson's. As Curran's (2021b) work highlights that over 70 percent of anxiety experiences are impacted by Parkinson's, this appears to be a significant gap. It is therefore recommended that future research trials psychological interventions which are adapted specifically for people with Parkinson's and anxiety. Examining the effectiveness of adapted interventions could provide insight into the suitability and acceptability of such adaptations by people with Parkinson's, their carers, and clinicians, and clinical practice could be adapted accordingly.

For the empirical study, both the CAPS-54 and CAPS-24, require further validation to confirm factor structure, reliability, and validity, using an independent sample. To

overcome limitations of using the PAS for convergent validity, future research could compare the CAPS to alternative measures such as the GAI. This would also provide additional validation for the CAPS. As part of this process, gaining qualitative feedback from people with Parkinson's and anxiety, clinicians and researchers, would extend the feedback received from the lay advisors. Finally, research exploring the acceptability and utility of the new scale in clinical settings would be invaluable.

Future research could extend secondary analysis conducted in the current empirical study to co-develop a novel conceptual model of Parkinson's and anxiety. At present, there is only one existing model related to anxiety in Parkinson's and it considers depression in the same model (e.g., Egan et al., 2015). Whilst, the model of depression and anxiety in Parkinson's was founded in theoretical principles of cognitive behavioural therapy (CBT; Egan et al., 2015), it was not data-driven nor empirically tested. Further, while the model suggests that dimensions such as 'Parkinson's related cognitions' are important to consider, it does not specify the nature of such cognitions. Lastly, the model was developed by clinicians, with no consultation with people with Parkinson's. A new model could overcome limitations of the existing model and inform clinical practice by guiding the development of a Parkinson's-specific treatment of anxiety.

Reflections on Completing the Thesis Portfolio

My initial reflections relate to the use of secondary analysis of existing data for the empirical study. Making sense of, becoming familiar with, and then performing secondary analysis on data collected by researchers other than myself was a novel experience. This was somewhat challenging, for example, the fact that the data had not been collected for the purposes of scale development proved tricky at times and required problem solving and flexibility. However, the rewards of conducting secondary analysis were twofold. Firstly, the complexity of analysis required for scale development, scale reduction and validation

has resulted in the acquisition of a new set of research skills. In the future, I hope to take advantage of these skills, not only for the development of new scales, but also in the evaluation of existing scales. This will undoubtedly enhance my ability to select and administer appropriate measures in clinical practice, as well as improve my critical evaluation of research e.g., outcome measure selection. Secondly, using existing data has numerous benefits and it is pleasing to learn that the strengths of secondary analysis are increasingly acknowledged (Doolan et al., 2017).

Other reflections relate to the involvement of two lay advisors, JM and RC, in the empirical study. Knowing of their previous involvement in the study with Curran and colleagues (2021b), I was aware of the significant value they had added. Learning first-hand about the experiences of living with Parkinson's and anxiety, and the impact of this not being recognised nor offered treatment as a result, served as a constant motivator and reminder of the importance of this research. This is in line with previous findings that involvement of lay advisors helps researchers to better understand patient experience and also increases researcher motivation (Hanson & Hanson, 2017; Wilson et al., 2015). In the current study, the lay advisors offered important and much needed contributions to the development of both versions of the new scale. In particular their expert-by-experience stance provided invaluable feedback on the content, design, presentation, and experience of completing the measures. It is hoped that this will have a positive impact for people with Parkinson's when completing the scales. Lay advisor involvement in research is fundamental for the improvement of relevance, quality, and impact (Ocloo & Matthews, 2016), and I would agree that lay advisor contributions are invaluable. I am proud that my empirical study was informed by lay advisors, particularly as this is encouraged in health research (Wilson et al., 2015), and more recently in doctoral thesis research (Tomlinson et al., 2019).

Final reflections relate to being part of the scale development process from the beginning. Having produced a new standardised scale of anxiety and Parkinson's as part of my doctoral thesis feels like a significant achievement. It has been exciting to be a part of this process and I hope to continue to contribute to the next steps, including further validation. Learning the rigour of processes involved in scale development has given me insight, and a newfound level of respect, for the scales I use in my clinical practice.

Overall Conclusions

Anxiety is prevalent among people with Parkinson's yet remains underrecognised and undertreated. It is hoped that as our understanding of this experience improves over time, so will psychological assessment, formulation, and treatment. This thesis portfolio contributed to the small, but growing, evidence-base, by pooling data from uncontrolled and controlled trials to determine the efficacy of psychological interventions for people with Parkinson's and anxiety. The portfolio also generated a new psychometric scale of anxiety for people with Parkinson's, providing both a long and a short version. This portfolio offers an exciting contribution to the field. It is hoped that it aids clinicians and researchers to capture the specific and nuanced experience of anxiety for people with Parkinson's and to select and tailor an intervention driven by evidence.

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Thesis Portfolio Appendices

Appendix A: Author Guidelines for Manuscript Submission to Movement Disorders

Author Guidelines

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2. authors' names, degrees, and affiliations (indicate the specific affiliation of each author by superscript, Arabic numerals);
3. name, address, telephone and email address of the corresponding author;
4. word count;
5. a running title not exceeding 45 letters and spaces;
6. Key words – up to 5;
7. Financial Disclosure/Conflict of Interest concerning the research related to the manuscript: All information on support and financial issues from all authors relative to the research covered in the submitted manuscript must be disclosed regardless of date. Other financial information unrelated to the current research covering the past year will be documented at the end of the manuscript (see below).
8. Funding sources for study.

(2) Abstract

Structured Abstract: We require that authors submit structured abstracts. The page following the title page of Full-Length Articles should include an abstract of up to 250 words. The abstract should be structured. The page following the title page of a Brief Report should include a structured abstract of up to 150 words. Reviews should include an unstructured abstract. Viewpoints do not need any abstract.

(3) Introduction

Give a brief description of the background and relevance of the scientific contribution.

(4) Methods

Describe the methodology of the study. For experimental investigation of human or animal subjects, please state in this section that an appropriate institutional review board approved the

project. For those investigators who do not have formal ethics review committees, the principles outlined in the "Declaration of Helsinki" should be followed. For investigations in human subjects, state in this section the manner in which informed consent was obtained from the subjects. A letter of consent must accompany all photographs, patient descriptions, and pedigrees in which a possibility of identification exists. The authors are responsible for ensuring anonymity.

(5) Results

No specific regulations.

(6) Discussion

No specific regulations.

(7) Acknowledgment

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(8) Authors' Roles

List all authors along with their specific roles in the project and preparation of the manuscript.

These may include but are not restricted to:

1) Research project: A. Conception, B. Organization, C. Execution;

2) Statistical Analysis: A. Design, B. Execution, C. Review and Critique;

3) Manuscript: A. Writing of the first draft, B. Review and Critique.

(9) Financial Disclosures of all authors (for the preceding 12 months)

Full Financial Disclosures of all Authors for the Past Year: Information concerning all sources of financial support and funding for the preceding twelve months, regardless of relationship to current manuscript, must be submitted with the following categories suggested.

List sources or "none".

Stock Ownership in medically-related fields

Intellectual Property Rights

Consultancies

Expert Testimony

Advisory Boards

Employment

Partnerships

Contracts

Honoraria

Royalties

Grants

Other

(10) References

See "Details of Style" below for the proper formatting of citations and References.

(12) Figures

Figures and Illustrations: Adapt any figures to an appropriate size of art and letters to make them readable in the printed version. Illustrations in full color are accepted at additional charge from the publisher. In the case of review articles or in special circumstances, color articles may be included at no charge with the permission of the Chief Editor. Any illustration or figure from another publication must be acknowledged in the figure legend, and the copyright holder's written permission to reprint in print and online edition of *Movement Disorders* must be submitted to the editors.

In addition, figures to illustrate concepts are welcome particularly in review articles, and may be enhanced by a professional artist at no cost to author at the discretion of the Editors.

(13) Tables

Tables should be typed neatly, each on a separate page, with a title above and any notes below. Explain all abbreviations. Do not repeat the same information in tables and figures that is present in text. Tables and figures should be uploaded as individual files and not part of the manuscript text. (You do not need to mail hard copies of your manuscript).

***Tables and Figure Legends**

Double-space legends of fewer than 40 words for tables and figures. For photomicrographs, include the type of specimen, original magnification, and stain type. Include internal scale-markers on photomicrographs when appropriate. Where applicable, indicate the method used to digitally enhance images.

Copyright and Disclosure Forms

The corresponding author should upload one PDF file that includes copyright and disclosure forms for all authors to the *Movement Disorders* submission site with the revised version of the paper. These forms also can be emailed to mdjedoffice@movementdisorders.org.

Details of Style

No patient identifiers (e.g., patient initials) are to be included in the manuscript or video (e.g., case reports, tables, figures, etc.).

Units of measure: Conventional units of measure according to the Systeme International (SI) are preferred. The metric system is preferred for length, area, mass, and volume. Express temperature in degrees Celsius.

Drug Names: Use generic names only in referring to drugs, followed in parentheses after first mention by any commonly used generic variant.

Abbreviations: Follow the list of abbreviations given in "Uniform Requirements for Manuscripts Submitted to Biomedical Journals" (see section on References). For additional abbreviations, consult the CBE Style Manual (available from the Council of Biology Editors, 9650 Rockville Pike, Bethesda, Maryland 20814, USA) or other standard sources. We encourage authors to minimize the use of abbreviations except where they are routinely employed and the full term would be cumbersome (e.g. MPTP).

Spelling: American spelling is used throughout the Journal.

References *Movement Disorders* complies with the reference style given in "Uniform Requirements for Manuscripts Submitted to Biomedical Journals". (See Annals of Internal Medicine 1982;96:766-771, or British Medical Journal 1982:284:1766-1770.) References are to be cited in the text by number, and in the list of References they are to be numbered in the order in which they are cited.

The reference section should be double-spaced at the end of the text, following the sample formats given below.

Provide all authors' names when fewer than seven; when seven or more, list the first three and add et al.

Provide article titles and inclusive pages.

Accuracy of reference data is the responsibility of the author.

For abbreviations of journal names, refer to List of Journals Indexed in Index Medicus (available from the Superintendent of Documents, U.S. Government Printing Office, Washington DC 20402, USA, DHEW Publication No. (NIH) 83-267; ISSN 0093-3821).

Sample References

- Journal article: 1. Krack P, Benzzzouz A, Pollak P, et al. Treatment of tremor in Parkinson's disease by Subthalamic nucleus stiumulation. Mov Disord 1998; 13: 907-914.
- Book: 2.Fahn S, Jankovic J, editors. Principles and Practice of Movement Disorders, Philadelphia, Churchill Livingstone, 2010, pp 96.
- Chapter in a book: 3. Olanow CW. Hpyerkinetic Movement Disorders. In: Fauci A, Braunwald E, Kasper D, Hauser S, Longo D, Jameson JL, Loscalzo J. Eds. Harrison's Textbook of Medicine 17th edition. 2008; p2560-2565.

Appendix B: Complete search strategies for each database (Medline, PsycINFO, CINAHL)

Database: Medline

#	Query	Limiters/Expanders	Last Run Via	Results
S35	S3 AND S6 AND S34	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	196
S34	S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	1,129,050
S33	AB "Integrative Therap*" OR TI "Integrative Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	383
S32	AB "Solution Focus* Therap*" OR TI "Solution Focus* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	92
S31	AB "System* Therap*" OR TI "System* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced	17,035

			Search Database - MEDLINE Complete	
S30	AB "Schema* Therap*" OR TI "Schema* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	194
S29	AB "Rational Emoti* Behavio* Therap*" OR TI "Rational Emoti* Behavio* Therap*" OR AB "REBT" OR TI "REBT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	96
S28	AB "Psycho* Intervention" OR TI "Psycho* Intervention"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	5,702
S27	AB "Person Cent* Therap*" OR TI "Person Cent* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	31
S26	AB "Motivation* Interview*" OR TI "Motivation* Interview*" OR AB "MI" OR TI "MI"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database -	50,456

			MEDLINE Complete	
S25	AB "Interpersonal Therap*" OR TI "Interpersonal Therap*" OR AB "IPT" OR TI "IPT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	2,653
S24	AB "Famil* Therap*" OR TI "Famil* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	3,841
S23	AB "Eye movement desensiti* and reprocessing therap*" OR TI "Eye movement desensiti* and reprocessing therap*" OR AB "EMDR" OR TI "EMDR"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	570
S22	AB "Couple* Therap*" OR TI "Couple* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	737
S21	AB "Counsel*" OR TI "Counsel*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	109,332

S20	AB "Emoti* Therap*" OR TI "Emoti* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	95
S19	AB "Psycho* Therap*" OR TI "Psycho* Therap*" OR AB Psychotherap∗ OR TI Psychotherap∗	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	4,593
S18	AB "Dialectical Behavio* Therap*" OR TI "Dialectical Behavio* Therap*" OR AB "DBT" OR TI "DBT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	2,995
S17	AB "Cognitive Processing Therap*" OR TI "Cognitive Processing Therap*" OR AB "CPT" OR TI "CPT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	9,651
S16	AB "Cognitive Processing Therap*" OR TI "Cognitive Processing Therap*" OR AB "CPT" OR TI "CPT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	9,651
S15	AB "Acceptance and Commitment Therap*" OR TI "Acceptance and	Expanders - Apply related words; Apply	Interface - EBSCOhost	277,138

	Commitment Therap*" OR AB "ACT" OR TI "ACT"	equivalent subjects Search modes - Find all my search terms	Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	
S14	AB Mindful* OR TI Mindful* OR AB "MBCT" OR TI "MBCT" OR AB "MBSR" OR TI "MBSR"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	10,811
S13	AB "Cognitive Behavio* Therap*" OR TI "Cognitive Behavio* Therap*" OR AB "CBT" OR TI "CBT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	20,449
S12	AB "Behavio* Therap*" OR TI "Behavio* Therap*" OR AB "BT" OR TI "BT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	35,574
S11	AB "Cognitive Therap*" OR TI "Cognitive Therap*" OR AB "CT" or TI "CT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	343,898
S10	AB "Cognitive Analytical Therapy" OR TI "Cognitive Analytical Therapy" OR AB "CAT" OR TI "CAT"	Expanders - Apply related words; Apply equivalent subjects	Interface - EBSCOhost Research Databases	102,482

		Search modes - Find all my search terms	Search Screen - Advanced Search Database - MEDLINE Complete	
S9	AB Psychoeducation OR TI Psychoeducation	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	3,080
S8	AB "Compassion Focus* Therap*" OR TI "Compassion Focus* Therap*" OR AB "CFT" OR TI "CFT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	2,488
S7	(MH "Psychotherapy+")	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	199,001
S6	S4 OR S5	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	295,827
S5	AB Anxi* OR TI Anxi*	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced	217,464

			Search Database - MEDLINE Complete	
S4	MH "Anxiety Disorders+" OR MH "Trauma and Stressor Related Disorders+"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	118,887
S3	S1 OR S2	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	128,516
S2	AB Parkinson* OR TI Parkinson*	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	120,774
S1	MH "Parkinson Disease"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	68,265

Database: PsycInfo

#	Query	Limiters/Expanders	Last Run Via	Results
S35	S3 AND S6 AND S34	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	98
S34	S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	297,008
S33	AB "Integrative Therap*" OR TI "Integrative Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	443
S32	AB "Solution Focus* Therap*" OR TI "Solution Focus* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	498
S31	AB "System* Therap*" OR TI "System* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	1,547
S30	AB "Schema* Therap*" OR TI "Schema* Therap*"	Expanders - Apply related words; Apply equivalent subjects	Interface - EBSCOhost Research	467

		Search modes - Find all my search terms	Databases Search Screen - Advanced Search Database - APA PsycInfo	
S29	AB "Rational Emoti* Behavio* Therap*" OR TI "Rational Emoti* Behavio* Therap*" OR AB "REBT" OR TI "REBT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	957
S28	AB "Psycho* Intervention" OR TI "Psycho* Intervention"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	6,642
S27	AB "Person Cent* Therap*" OR TI "Person Cent* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	369
S26	AB "Motivation* Interview*" OR TI "Motivation* Interview*" OR AB "MI" OR TI "MI"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	7,886
S25	AB "Interpersonal Therap*" OR TI "Interpersonal Therap*" OR AB "IPT" OR TI "IPT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	1,720

S24	AB "Famil* Therap*" OR TI "Famil* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	17,420
S23	AB "Eye movement desensiti* and reprocessing therap*" OR TI "Eye movement desensiti* and reprocessing therap*" OR AB "EMDR" OR TI "EMDR"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	1,787
S22	AB "Couple* Therap*" OR TI "Couple* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	3,628
S21	AB "Counsel*" OR TI "Counsel*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	106,913
S20	AB "Emoti* Therap*" OR TI "Emoti* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	1,060
S19	AB "Psycho* Therap*" OR TI "Psycho* Therap*" OR AB Psychotherap* OR TI Psychotherap*	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	8,052

			Database - APA PsycInfo	
S18	AB "Dialectical Behavio* Therap*" OR TI "Dialectical Behavio* Therap*" OR AB "DBT" OR TI "DBT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	2,261
S17	AB "Cognitive Processing Therap*" OR TI "Cognitive Processing Therap*" OR AB "CPT" OR TI "CPT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	2,633
S16	AB "Cognitive Processing Therap*" OR TI "Cognitive Processing Therap*" OR AB "CPT" OR TI "CPT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	2,633
S15	AB "Acceptance and Commitment Therap*" OR TI "Acceptance and Commitment Therap*" OR AB "ACT" OR TI "ACT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	75,501
S14	AB Mindful* OR TI Mindful* OR AB "MBCT" OR TI "MBCT" OR AB "MBSR" OR TI "MBSR"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	16,617
S13	AB "Cognitive Behavio* Therap*" OR TI "Cognitive Behavio* Therap*" OR AB "CBT" OR TI "CBT"	Expanders - Apply related words; Apply equivalent subjects	Interface - EBSCOhost Research Databases	25,483

		Search modes - Find all my search terms	Search Screen - Advanced Search Database - APA PsycInfo	
S12	AB "Behavio* Therap*" OR TI "Behavio* Therap*" OR AB "BT" OR TI "BT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	33,644
S11	AB "Cognitive Therap*" OR TI "Cognitive Therap*" OR AB "CT" or TI "CT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	15,808
S10	AB "Cognitive Analytical Therapy" OR TI "Cognitive Analytical Therapy" OR AB "CAT" OR TI "CAT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	10,251
S9	AB Psychoeducation OR TI Psychoeducation	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	4,255
S8	AB "Compassion Focus* Therap*" OR TI "Compassion Focus* Therap*" OR AB "CFT" OR TI "CFT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	541

S7	DE "Psychotherapy+"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	0
S6	S4 OR S5	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	213,617
S5	AB Anxi* OR TI Anxi*	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	213,617
S4	DE "Anxiety Disorders+"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	130,257
S3	S1 OR S2	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	34,819
S2	AB Parkinson* OR TI Parkinson*	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	34,238

			Database - APA PsycInfo	
S1	DE "Parkinson's Disease"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - APA PsycInfo	23,340

Database: CINAHL

#	Query	Limiters/Expanders	Last Run Via	Results
S35	S3 AND S6 AND S34	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	112
S34	S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	410,395
S33	AB "Integrative Therap*" OR TI "Integrative Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	299
S32	AB "Solution Focus* Therap*" OR TI "Solution Focus* Therap*"	Expanders - Apply related words; Apply equivalent subjects	Interface - EBSCOhost Research Databases	122

		Search modes - Find all my search terms	Search Screen - Advanced Search Database - CINAHL Complete	
S31	AB "System* Therap*" OR TI "System* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	4,644
S30	AB "Schema* Therap*" OR TI "Schema* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	131
S29	AB "Rational Emoti* Behavio* Therap*" OR TI "Rational Emoti* Behavio* Therap*" OR AB "REBT" OR TI "REBT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	95
S28	AB "Psycho* Intervention" OR TI "Psycho* Intervention"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	3,131
S27	AB "Person Cent* Therap*" OR TI "Person Cent* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced	68

			Search Database - CINAHL Complete	
S26	AB "Motivation* Interview*" OR TI "Motivation* Interview*" OR AB "MI" OR TI "MI"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	14,684
S25	AB "Interpersonal Therap*" OR TI "Interpersonal Therap*" OR AB "IPT" OR TI "IPT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	763
S24	AB "Famil* Therap*" OR TI "Famil* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	2,749
S23	AB "Eye movement desensiti* and reprocessing therap*" OR TI "Eye movement desensiti* and reprocessing therap*" OR AB "EMDR" OR TI "EMDR"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	284
S22	AB "Couple* Therap*" OR TI "Couple* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database -	773

			CINAHL Complete	
S21	AB "Counsel*" OR TI "Counsel*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	58,749
S20	AB "Emoti* Therap*" OR TI "Emoti* Therap*"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	60
S19	AB "Psycho* Therap*" OR TI "Psycho* Therap*" OR AB Psychotherap∗ OR TI Psychotherap∗	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	2,566
S18	AB "Dialectical Behavio* Therap*" OR TI "Dialectical Behavio* Therap*" OR AB "DBT" OR TI "DBT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	972
S17	AB "Cognitive Processing Therap*" OR TI "Cognitive Processing Therap*" OR AB "CPT" OR TI "CPT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	2,597

S16	AB "Cognitive Processing Therap*" OR TI "Cognitive Processing Therap*" OR AB "CPT" OR TI "CPT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	2,597
S15	AB "Acceptance and Commitment Therap*" OR TI "Acceptance and Commitment Therap*" OR AB "ACT" OR TI "ACT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	53,078
S14	AB Mindful* OR TI Mindful* OR AB "MBCT" OR TI "MBCT" OR AB "MBSR" OR TI "MBSR"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	8,735
S13	AB "Cognitive Behavio* Therap*" OR TI "Cognitive Behavio* Therap*" OR AB "CBT" OR TI "CBT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	11,408
S12	AB "Behavio* Therap*" OR TI "Behavio* Therap*" OR AB "BT" OR TI "BT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	13,621

S11	AB "Cognitive Therap*" OR TI "Cognitive Therap*" OR AB "CT" or TI "CT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	71,950
S10	AB "Cognitive Analytical Therapy" OR TI "Cognitive Analytical Therapy" OR AB "CAT" OR TI "CAT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	4,996
S9	AB Psychoeducation OR TI Psychoeducation	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	1,641
S8	AB "Compassion Focus* Therap*" OR TI "Compassion Focus* Therap*" OR AB "CFT" OR TI "CFT"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	390
S7	(MH "Psychotherapy+")	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	200,729
S6	S4 OR S5	Expanders - Apply related words; Apply	Interface - EBSCOhost	118,963

		equivalent subjects Search modes - Find all my search terms	Research Databases Search Screen - Advanced Search Database - CINAHL Complete	
S5	AB Anxi* OR TI Anxi*	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	87,432
S4	MH "Anxiety Disorders+"	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	45,581
S3	S1 OR S2	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	31,430
S2	AB Parkinson* OR TI Parkinson*	Expanders - Apply related words; Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	27,729
S1	MH "Parkinson Disease"	Expanders - Apply related words; Apply equivalent subjects	Interface - EBSCOhost Research Databases	22,644

		Search modes - Find all my search terms	Search Screen - Advanced Search Database - CINAHL Complete	

Appendix C: Risk of Bias and Quality Assessment Tool

Modified Psychotherapy outcome study methodology rating form (Ost, 2008)

1. Representativeness of the sample

0 Poor. Sample is very different from patients seeking treatment for the disorder (e.g. there are excessively strict exclusion criteria).

1 Fair. Sample is somewhat representative of patients seeking treatment for the disorder (e.g. patients were only excluded if they met criteria for other major disorders).

2 Good. Sample is very representative of patients seeking treatment for the disorder (e.g. authors made efforts to ensure representativeness of sample).

2. Reliability and validity of outcome measures

0 Poor. Measures have unknown psychometric properties, or properties that fail to meet current standards of acceptability.

1 Fair. Some, but not all measures have known or adequate psychometric properties.

2 Good. All measures have good psychometric properties. The outcome measures are the best available for the authors' purpose.

3. Use of blind evaluators

0 Poor. Blind assessor was not used (e.g. assessor was the therapist, assessor was not blind to treatment condition, or the authors do not specify).

1 Fair. Blind assessor was used, but no checks were used to assess the blind.

2 Good. Blind assessor was used in correct fashion. Checks were used to assess whether the assessor was aware of treatment condition.

4. Assignment to treatment

0 Poor. Biased assignment, e.g. patients selected their own therapy or were assigned in another non-random fashion, or there is only one group.

1 Fair. Random or stratified assignment. There may be some systematic bias but not enough to pose a serious threat to internal validity. There may be therapist by treatment confounds. N may be too small to protect against bias.

2 Good. Random or stratified assignment, and patients are randomly assigned to therapists within condition. When theoretically different treatments are used, each treatment is provided by a large enough number of different therapists. N is large enough to protect against bias.

5. Power analysis

0 Poor. No power analysis was reported or made prior to the initiation of the study.

1 Fair. A power analysis based on an estimated effect size was reported or used.

2 Good. A data-informed power analysis was made and the sample size was decided accordingly, and this process was reported.

6. Assessment points

0 Poor. Only pre- and post-treatment, or pre- and follow-up.

1 Fair. Pre-, post-, and follow-up <1 year.

2 Good. Pre-, post-, and follow-up ≥1 year.

7. Manualized, replicable, specific treatment programs

0 Poor. Description of treatment procedure is unclear, or treatment is not based on a publicly available, detailed treatment manual. Patients may be receiving multiple forms of treatment at once in an uncontrolled manner.

1 Fair. Treatment is not designed for the disorder, or description of the treatment is generally clear and based on a publicly available, detailed treatment manual, but there are some ambiguities about the procedure. Patients may have received additional forms of treatment, but this is balanced between groups or otherwise controlled.

2 Good. Treatment is designed for the disorder. A detailed treatment manual is available, and/or treatment is explained in sufficient detail for replication. No ambiguities about the treatment procedure. Patients receive only the treatment in question.

8. Number of therapists

0 Poor. Only one therapist, i.e. complete confounding between therapy and therapist.

1 Fair. At least two therapists, but the effect of therapist on outcome is not analysed.

2 Good. Three, or more therapists, and the effect of therapist on outcome is analysed.

9. Therapist training/experience

0 Poor. Very limited clinical experience of the treatment and/or disorder (e.g. students).

1 Fair. Some clinical experience of the treatment and/or disorder.

2 Good. Long clinical experience of the treatment and the disorder (e.g. practicing therapists).

10. Checks for treatment adherence

0 Poor. No checks were made to assure that the intervention was consistent with protocol.

1 Fair. Some checks were made (e.g. assessed a proportion of therapy tapes, supervision or training).

2 Good. Frequent checks were made (e.g. weekly supervision of each session using a detailed rating form).

11. Control of concomitant treatments (e.g. medications)

0 Poor. No attempt to control for concomitant treatments, or no information about concomitant treatments provided. Patients may have been receiving other forms of treatment in addition to the study treatment.

1 Fair. Asked patients to keep medications stable and/or to discontinue other psychological therapies during the treatment.

2 Good. Ensured that patients did not receive any other treatments (medical or psychological) during the study.

12. Handling of attrition

0 Poor. Proportions of attrition are not described, or described but no dropout analysis is performed.

1 Fair. Proportions of attrition are described, and/or dropout analysis or intent-to-treat analysis is performed.

2 Good. No attrition, or proportions of attrition are described, dropout analysis is performed, and results are presented as intent-to-treat analysis.

13. Statistical analyses and presentation of results

0 Poor. Inadequate statistical methods are used and/or data are not fully presented.

1 Fair. Adequate statistical methods are used but data are not fully presented.

2 Good. Adequate statistical methods are used and data are presented with M and SD.

NB. If not enough information is given regarding a specific item a rating of 0 is given.

Appendix D: Psychotherapy Outcome Study Methodology Rating Form (Ost, 2008)

1. Clarity of sample description
0 Poor. Vague description of sample (e.g. only mentioned whether patients were diagnosed with the disorder).
1 Fair. Fair description of sample (e.g. mentioned inclusion/exclusion criteria, demographics, etc.).
2 Good. Good description of sample (e.g. mentioned inclusion/exclusion criteria, demographics, and the prevalence of comorbid disorders).

2. Severity/chronicity of the disorder
0 Poor. Severity/chronicity was not reported and/or subsyndromal patients were included in the sample.
1 Fair. All patients met the criteria for the disorder. Sample includes acute (<1 yr) and/or low severity.
2 Good. Sample consisted entirely of chronic (>1 yr) patients of at least moderate severity.

3. Representativeness of the sample
0 Poor. Sample is very different from patients seeking treatment for the disorder (e.g. there are excessively strict exclusion criteria).
1 Fair. Sample is somewhat representative of patients seeking treatment for the disorder (e.g. patients were only excluded if they met criteria for other major disorders).
2 Good. Sample is very representative of patients seeking treatment for the disorder (e.g. authors made efforts to ensure representativeness of sample).

4. Reliability of the diagnosis in question
0 Poor. The diagnostic process was not reported, or not assessed with structured interviews by a trained interviewer.
1 Fair. The diagnosis was assessed with structured interview by a trained interviewer.
2 Good. The diagnosis was assessed with structured interview by a trained interviewer and adequate inter-rater reliability was demonstrated (e.g. kappa coefficient).

5. Specificity of outcome measures
0 Poor. Very broad outcome measures, not specific to the disorder (e.g. SCL-90R total score).
1 Fair. Moderately specific outcome measures.
2 Good. Specific outcome measures, such as a measure for each symptom cluster.

6. Reliability and validity of outcome measures
0 Poor. Measures have unknown psychometric properties, or properties that fail to meet current standards of acceptability.
1 Fair. Some, but not all measures have known or adequate psychometric properties.
2 Good. All measures have good psychometric properties. The outcome measures are the best available for the authors' purpose.

7. Use of blind evaluators
0 Poor. Blind assessor was not used (e.g. assessor was the therapist, assessor was not blind to treatment condition, or the authors do not specify).
1 Fair. Blind assessor was used, but no checks were used to assess the blind.

2 Good. Blind assessor was used in correct fashion. Checks were used to assess whether the assessor was aware of treatment condition.

8. Assessor training
0 Poor. Assessor training and accuracy are not specified, or are unacceptable.
1 Fair. Minimum criterion for assessor training is specified (e.g. assessor has had specific training in the use of the outcome measure), but accuracy is not monitored or reported.
2 Good. Minimum criterion of assessor training is specified. Inter-rater reliability was checked, and/or assessment procedures were calibrated during the study to prevent evaluator drift.

9. Assignment to treatment
0 Poor. Biased assignment, e.g. patients selected their own therapy or were assigned in another non-random fashion, or there is only one group.
1 Fair. Random or stratified assignment. There may be some systematic bias but not enough to pose a serious threat to internal validity. There may be therapist by treatment confounds. N may be too small to protect against bias.
2 Good. Random or stratified assignment, and patients are randomly assigned to therapists within condition. When theoretically different treatments are used, each treatment is provided by a large enough number of different therapists. N is large enough to protect against bias.

10. Design
0 Poor. Active treatment vs. WLC, or briefly described TAU.
1 Fair. Active treatment vs. TAU with good description, or placebo condition.
2 Good. Active treatment vs. another previously empirically documented active treatment.

11. Power analysis
0 Poor. No power analysis was made prior to the initiation of the study.
1 Fair. A power analysis based on an estimated effect size was used.
2 Good. A data-informed power analysis was made and the sample size was decided accordingly.

12. Assessment points
0 Poor. Only pre- and post-treatment, or pre- and follow-up.
1 Fair. Pre-, post-, and follow-up <1 year.
2 Good. Pre-, post-, and follow-up ≥1 year.

13. Manualized, replicable, specific treatment programs
0 Poor. Description of treatment procedure is unclear, and treatment is not based on a publicly available, detailed treatment manual. Patients may be receiving multiple forms of treatment at once in an uncontrolled manner.
1 Fair. Treatment is not designed for the disorder, or description of the treatment is generally clear and based on a publicly available, detailed treatment manual, but there are some ambiguities about the procedure. Patients may have received additional forms of treatment, but this is balanced between groups or otherwise controlled.
2 Good. Treatment is designed for the disorder. A detailed treatment manual is available, and/or treatment is explained in sufficient detail for replication. No ambiguities about the treatment procedure. Patients receive only the treatment in question.

14. Number of therapists
0 Poor. Only one therapist, i.e. complete confounding between therapy and therapist.
1 Fair. At least two therapists, but the effect of therapist on outcome is not analyzed.
2 Good. Three, or more therapists, and the effect of therapist on outcome is analyzed.

15. Therapist training/experience
0 Poor. Very limited clinical experience of the treatment and/or disorder (e.g. students).
1 Fair. Some clinical experience of the treatment and/or disorder.
2 Good. Long clinical experience of the treatment and the disorder (e.g. practicing therapists).

16. Checks for treatment adherence
0 Poor. No checks were made to assure that the intervention was consistent with protocol.
1 Fair. Some checks were made (e.g. assessed a proportion of therapy tapes).
2 Good. Frequent checks were made (e.g. weekly supervision of each session using a detailed rating form).

17. Checks for therapist competence
0 Poor. No checks were made to assure that the intervention was delivered competently.
1 Fair. Some checks were made (e.g. assessed a proportion of therapy tapes).
2 Good. Frequent checks were made (e.g. weekly supervision of each session using a detailed rating form).

18. Control of concomitant treatments (e.g. medications)
0 Poor. No attempt to control for concomitant treatments, or no information about concomitant treatments provided. Patients may have been receiving other forms of treatment in addition to the study treatment.
1 Fair. Asked patients to keep medications stable and/or to discontinue other psychological therapies during the treatment.
2 Good. Ensured that patients did not receive any other treatments (medical or psychological) during the study.

19. Handling of attrition
0 Poor. Proportions of attrition are not described, or described but no dropout analysis is performed.
1 Fair. Proportions of attrition are described, and dropout analysis or intent-to-treat analysis is performed.
2 Good. No attrition, or proportions of attrition are described, dropout analysis is performed, and results are presented as intent-to-treat analysis.

20. Statistical analyses and presentation of results
0 Poor. Inadequate statistical methods are used and/or data are not fully presented.
1 Fair. Adequate statistical methods are used but data are not fully presented.
2 Good. Adequate statistical methods are used and data are presented with M and SD.

21. Clinical significance
0 Poor. No presentation of clinical significance was done.
1 Fair. An arbitrary criterion for clinical significance was used and the conditions were compared regarding percent clinically improved.
2 Good. Jacobson's criteria for clinical significance were used and presented for a selection

(or all) of the outcome measures, and conditions were compared regarding percent clinically improved.

22. Equality of therapy hours (for non-WLC designs only)
0 Poor. Conditions differ markedly (≥20% difference in therapy hours).
1 Fair. Conditions differ somewhat (10–19% difference in therapy hours).
2 Good. Conditions do not differ (<10% difference in therapy hours).

Note: If not enough information is given regarding a specific item a rating of 0 is given.

Appendix E: Quality and Risk of Bias Assessment by Individual Raters (C.I.-C./D.C.)

Quality and Risk of Bias Assessment for Included Studies by Main Author (C.I.-C.)

Study Reference	1	2	3	4	5	6	7	8	9	10	11	12	13
Berardelli et al. (2015)													
Dissanayaka et al. (2017)													
Feeney et al. (2005)													
Georgescu (2013)													
Ghielen et al. (2017)													
Heinrichs et al. (2001)													
Lawson et al. (2013)													
Lingaiah et al. (2020)													
Mohlman et al. (2010)													
Mohlman et al. (2017)													
Moonen et al. (2021)													
Reynolds et al. (2020)													

Note. 1 = Representativeness of sample; 2 = Reliability and validity of outcome measures; 3 = Use of blind evaluators; 4 = Assignment to treatment; 5 = Power analysis; 6 = Assessment points; 7 = Manualised, replicable specific treatment programmes; 8 = Number of therapists; 9 = Therapist training/experience; 10 = Checks for treatment adherence; 11 = Control of concomitant treatments; 12 = Handling of attrition; 13 = Statistical analyses and presentation of results; Red = Poor; Orange = Fair; Green = Good; Blue = Not applicable.

Quality and Risk of Bias Assessment for Included Studies by Co-Rater (D.C.)

Study Reference	1	2	3	4	5	6	7	8	9	10	11	12	13
Berardelli et al. (2015)													
Dissanayaka et al. (2017)													
Feeney et al. (2005)													
Georgescu (2013)													
Ghielen et al. (2017)													
Heinrichs et al. (2001)													
Lawson et al. (2013)													
Lingaiah et al. (2020)													
Mohlman et al. (2010)													
Mohlman et al. (2017)													
Moonen et al. (2021)													
Reynolds et al. (2020)													

Note. 1 = Representativeness of sample; 2 = Reliability and validity of outcome measures; 3 = Use of blind evaluators; 4 = Assignment to treatment; 5 = Power analysis; 6 = Assessment points; 7 = Manualised, replicable specific treatment programmes; 8 = Number of therapists; 9 = Therapist training/experience; 10 = Checks for treatment adherence; 11 = Control of concomitant treatments; 12 = Handling of attrition; 13 = Statistical analyses and presentation of results; Red = Poor; Orange = Fair; Green = Good; Blue = Not applicable.

Appendix F: Articles Reviewed for Full-Text Screening and Reasons for Exclusion

Author(s)	Year	Article Title	Reason(s) for Exclusion	Exclusion Code
Advocat, Jenny, Enticott, Joanne, Vandenberg, Brooke, Hassed, Craig, Hester, Jennifer and Russell, Grant	2016	The effects of a mindfulness-based lifestyle program for adults with Parkinson's disease: a mixed-methods, wait list controlled randomised control study	Anxiety diagnosis not inclusion criteria.	1
Ahc, Media	2019	Mindfulness Yoga for Managing Psychological Symptoms of Parkinson's Disease	Not an empirical study; a review.	2
Ballanger, Benedicte, Bath, Kevin G. and Mandairon, Nathalie	2019	Odorants: a tool to provide nonpharmacological intervention to reduce anxiety during normal and pathological aging	Not an empirical study.	2
Beck, Eric N., Wang, Mary T. Y., Intzandt, Brittany N., Almeida, Quincy J. and Ehgoetz Martens, Kaylena A.	2020	Sensory focused exercise improves anxiety in Parkinson's disease: A randomized controlled trial	No psychological intervention (exercise only).	3
Bega, Danny, Palmentera, Pamela, Wagner, Abby, Hovde, Matt, Barish, Becca, Kwasny, Mary J. and Simuni, Tanya	2017	Laughter is the best medicine: The Second City ® improvisation as an intervention for Parkinson's disease	No psychological intervention (theatre-based improvisation course).	3
Berardelli, Isabella, Bloise, Maria Carmela, Bologna, Matteo, Conte, Antonella, Pompili, Maurizio, Lamis, Dorian A., Pasquini, Massimo and Fabbrini, Giovanni	2018	Cognitive behavioral group therapy versus psychoeducational intervention in Parkinson's disease	All pts diagnosed with a psychiatric disorder (does not specify anxiety and does not provide separate data for pts with anxiety).	1

Birtwell, Kelly, Dubrow-Marshall, Linda, Dubrow-Marshall, Rod, Duerden, Tim and Dunn, Annette	2017	A mixed methods evaluation of a Mindfulness-Based Stress Reduction course for people with Parkinson's disease	No clinical diagnosis of anxiety criteria.	1
Blandy, Laura M., Beevers, Winifred A., Fitzmaurice, Kerry and Morris, Meg E.	2015	Therapeutic Argentine Tango Dancing for People with Mild Parkinson's Disease: A Feasibility Study	No psychological intervention (dance classes only).	3
Bogosian, Angeliki	2021	Acceptability and Feasibility of a Mindfulness Intervention Delivered via Videoconferencing for People with Parkinson's	No criteria for clinical diagnosis of anxiety.	1
Bogosian, A., Hurt, C. S., Vasconcelos E Sa, D., Hindle, J. V., McCracken, L. and Cubi-Molla, P.	2017	Distant delivery of a mindfulness-based intervention for people with Parkinson's disease: the study protocol of a randomised pilot trial	Study protocol for RCT, not actual RCT	2
Boso, Marianna, Politi, Pierluigi, Barale, Francesco and Enzo, Emanuele	2006	Neurophysiology and neurobiology of the musical experience	Not an empirical study.	2
Burt, Jacqueline, Ravid, Einat, Bradford, Sandra, Fisher, Nancy J., Zeng, Yiye, Chomiak, Taylor, Brown, Lesley, McKeown, Martin J., Hu, Bin and Camicioli, Richard	2020	The Effects of Music-Contingent Gait Training on Cognition and Mood in Parkinson Disease: A Feasibility Study	No psychological intervention (music and gait training only).	3
Calleo, Jessica S., Amspoker, Amber B., Sarwar, Aliya I., Kunik, Mark E., Jankovic, Joseph, Marsh, Laura, York, Michele and Stanley, Melinda A.	2015	A Pilot Study of a Cognitive-Behavioral Treatment for Anxiety and Depression in Patients with Parkinson Disease	Patients with depression and/or anxiety included (does not specify anxiety and does not provide separate data for pts with anxiety).	1

Cash, Therese Verkerke, Ekouevi, Vanessa Sepopo, Kilbourn, Christopher and Lageman, Sarah K.	2016	Pilot study of a mindfulness-based group intervention for individuals with Parkinson's disease and their caregivers	Excluded participants with a diagnosis of anxiety or depression.	1
Chow, Rebecca	2021	Investigating Therapies for Freezing of Gait Targeting the Cognitive, Limbic, and Sensorimotor Domains	No criteria for clinical diagnosis of anxiety.	1
Craig, Lauren H., Svircev, Anna, Haber, Michael and Juncos, Jorge L.	2006	Controlled pilot study of the effects of neuromuscular therapy in patients with Parkinson's disease	No psychological intervention (neuromuscular therapy and music relaxation only).	3
Dattilio, Frank M.	2005	Anxiety-induced tremors in a 131/2-year-old female with idiopathic Parkinson's disease	Patient under 18 years of age.	8
Dissanayaka, Nadeeka N. W., Idu Jion, Farah, Pachana, Nancy A., O'Sullivan, John D., Marsh, Rodney, Byrne, Gerard J. and Harnett, Paul	2016	Mindfulness for Motor and Nonmotor Dysfunctions in Parkinson's Disease	No criteria for clinical diagnosis of anxiety.	1
Dreisig, Hanne, Beckmann, Jørn, Wermuth, Lene, Skovlund, Søren and Bech, Per	1999	Psychologic effects of structured cognitive psychotherapy in young patients with Parkinson disease: A pilot study	No anxiety diagnosis.	1
Elkis-Abuhoff, Deborah L. and Gaydos, Morgan	2018	Medical Art Therapy Research Moves Forward: A Review of Clay Manipulation with Parkinson's Disease	Anxiety diagnosis not inclusion criteria.	1
Elkis-Abuhoff, Deborah L., Goldblatt, Robert B., Gaydos, Morgan and Convery, Caitlin	2013	A pilot study to determine the psychological effects of manipulation of therapeutic art forms among patients with Parkinson's disease	Anxiety diagnosis not inclusion criteria.	1

Feldman, M. C. and DiScipio, W. J.	1972	Integrating physical therapy with behavior therapy. A case study	No diagnosis of Parkinson's.	7
Fitzpatrick, Lee, Simpson, Jane and Smith, Alistair	2010	A qualitative analysis of mindfulness-based cognitive therapy (MBCT) in Parkinson's disease	Qualitative data and analysis only.	9
Fleisher, Jori E., Sennott, Brianna J., Myrick, Erica, Niemet, Claire J., Lee, Monica, Whitelock, Courtney M., Sanghvi, Maya, Liu, Yuanqing, Ouyang, Bichun, Hall, Deborah A., Comella, Cynthia L. and Chodosh, Joshua	2020	KICK OUT PD: Feasibility and quality of life in the pilot karate intervention to change kinematic outcomes in Parkinson's Disease	No psychological intervention (karate class). No anxiety diagnosis.	1
Gandy, Milena, Karin, Eyal, McDonald, Sarah, Meares, Susanne, Scott, Amelia J., Titov, Nickolai and Dear, Blake F.	2020	A feasibility trial of an internet-delivered psychological intervention to manage mental health and functional outcomes in neurological disorders	No anxiety diagnosis.	1
Goldblatt, R., Elkis-Abuhoff, D., Gaydos, M. and Napoli, A.	2010	Understanding clinical benefits of modeling clay exploration with patients diagnosed with Parkinson's disease	No anxiety diagnosis; no psychological intervention	1
Goodrich, Elena, Wahbeh, Helané, Mooney, Aimee, Miller, Meghan and Oken, Barry S.	2015	Teaching mindfulness meditation to adults with severe speech and physical impairments: An exploratory study	No anxiety diagnosis; only 1 participant with PD.	1
Hampson, Natalie, King, Lorraine, Eriksson, Linda-Mary and Smee, Hannah	2020	The effects of relaxation training on depression and anxiety in people living with long-term neurological conditions	No clinical diagnosis of anxiety.	1
Hanagasi, Hasmet A. and Emre, Murat	2005	Treatment of behavioural symptoms and dementia in Parkinson's disease	Not an empirical study.	2

Heisters, Daiga	2011	Focus on Parkinson's: causes, treatment and support	Not an empirical study.	2
Jonderko, Gerard and Marcisz, Czesław	2005	Music application in the therapy of psychic and somatic diseases	Polish edition only (attempted contact with Authors - no response).	5
Kalyani, H. H. N., Sullivan, K. A., Moyle, G., Brauer, S., Jeffrey, E. R. and Kerr, G. K.	2019	Impacts of dance on cognition, psychological symptoms and quality of life in Parkinson's disease	No anxiety diagnosis; no psychological intervention (dancing exercise class only).	1
Kraepelien, Martin, Schibbye, Robert, Månsson, Kristoffer, Sundström, Christopher, Riggare, Sara, Andersson, Gerhard, Lindefors, Nils, Svenningsson, Per and Kaldo, Viktor	2020	Individually Tailored Internet-Based Cognitive-Behavioral Therapy for Daily Functioning in Patients with Parkinson's Disease: A Randomized Controlled Trial	No anxiety diagnosis.	1
Kwok, Jojo Y. Y., Kwan, Jackie C. Y., Auyeung, M., Mok, Vincent C. T., Lau, Claire K. Y., Choi, K. C. and Chan, Helen Y. L.	2019	Effects of Mindfulness Yoga vs Stretching and Resistance Training Exercises on Anxiety and Depression for People with Parkinson Disease: A Randomized Clinical Trial	No anxiety diagnosis as part of inclusion criteria.	1
Lauretani, Fulvio, Saginario, Antonio, Ceda, Gian Paolo, Galuppo, Laura, Ruffini, Livia, Nardelli, Anna and Maggio, Marcello	2014	Treatment of the motor and non-motor symptoms in Parkinson's disease according to cluster symptoms presentation	No psychological intervention (pharmacological treatment only).	3
Lieberman, Morton A.	2007	Psychological characteristics of people with Parkinson's disease who prematurely drop out of professionally led Internet chat support groups	No clinical diagnosis of anxiety as part of inclusion criteria.	1

Lundervold, Duane A., Ament, Patrick A., Holt, Peter S. and Hunt, Lauren S.	2013	Comparison of Younger and Older Adults' Acceptability of Treatment for Generalized Anxiety Disorder Co-Occurring with Parkinson's Disease	No psychological intervention; no anxiety diagnosis; no PD diagnosis	1
Lundervold, D. A., Pahwa, R. and Lyons, K. E.	2009	Effect of behavioral intervention on comorbid general anxiety disorder and Parkinson's disease	Does not appropriately report outcome measures.	4
Lundervold, Duane A., Pahwa, Rajesh and Lyons, Kelly E.	2013	Behavioral Relaxation Training for Parkinson's Disease Related Dyskinesia and Comorbid Social Anxiety	Does not appropriately report outcome measures.	4
Macht, M., Gerlich, C., Ellgring, H., Schradi, M., Rusiñol, A. B., Crespo, M., Prats, A., Viemerö, V., Lankinen, A., Bitti, P. E. R., Candini, L., Spliethoff-Kamminga, N., de Vreugd, J., Simons, G., Pasqualini, M. S., Thompson, S. B. N., Taba, P., Krikmann, Ü and Kanarik, E.	2007	Patient education in Parkinson's disease: formative evaluation of a standardized programme in seven European countries	No anxiety diagnosis; no measurement of anxiety pre-post.	1
Macht, Michael, Pasqualini, Marcia Smith and Taba, Pille	2007	Cognitive-behavioral strategies for Parkinson's disease: A report of three cases	Only measures "psychological stress" not anxiety.	6
Menza, M. and Dobkin, R. D.	2005	Anxiety and Parkinson's disease	Not an empirical study.	2
Mulders, A. E. P., Moonen, A. J. H., Dujardin, K., Kuijf, M. L., Duits, A., Flinois, B., Handels, R. L. H., Lopes, R. and Leentjens, A. F. G.	2018	Cognitive behavioural therapy for anxiety disorders in Parkinson's disease: Design of a randomised controlled trial to assess clinical effectiveness and changes in cerebral connectivity	Study protocol for RCT, not actual RCT.	2

Nagatsu, Toshiharu	2020	Hypothesis: neural mechanism of psychotherapy for the treatment of Parkinson's disease: cognitive behavioral therapy (CBT), acceptance and commitment therapy (ACT), and Morita therapy?	Not an empirical study.	2
Naismith, Sharon L., Mowszowski, Loren, Diamond, Keri and Lewis, Simon J. G.	2013	Improving memory in Parkinson's disease: a healthy brain ageing cognitive training program	No anxiety diagnosis; no anxiety measure pre-post intervention	1
Petkus, Andrew J., Filoteo, J. Vincent, Schiehser, Dawn M., Gomez, Megan E. and Petzinger, Giselle	2019	Worse cognitive performance predicts increased anxiety and depressive symptoms in patients with Parkinson's disease: A bidirectional analysis	No psychological intervention.	3
Port Rosenstein, Carol	2017	Researchers Find Music is Powerful Medicine	Not an empirical study.	2
Rabinstein, A. A. and Shulman, L. M.	2000	Management of behavioral and psychiatric problems in Parkinson's disease	Not an empirical study.	2
Ray, Sudeshna and Agarwal, Pinky	2020	Depression and Anxiety in Parkinson Disease	Not an empirical study.	2
Rodgers, Sephora H., Schütze, Robert, Gasson, Natalie, Anderson, Rebecca A., Kane, Robert T., Starkstein, Sergio, Morgan-Lowes, Katherine and Egan, Sarah J.	2019	Modified Mindfulness-Based Cognitive Therapy for Depressive Symptoms in Parkinson's Disease: A Pilot Trial	Inclusion criteria did not specify a clinical diagnosis of anxiety.	1
Routh, L. C., Black, J. L. and Ahlskog, J. E.	1987	Parkinson's disease complicated by anxiety	No measures of anxiety or change.	6
Schrag, Anette, Sauerbier, Anna and	2015	New clinical trials for nonmotor manifestations of Parkinson's disease	Not an empirical study; review article.	2

Chaudhuri, Kallol Ray				
Slomski, Anita	2019	Yoga for Anxiety and Depression Associated with Parkinson Disease	Not an empirical study; an update excerpt only.	2
Son, Hye Gyeong and Choi, Eun-Ok	2018	The Effects of Mindfulness Meditation-Based Complex Exercise Program on Motor and Nonmotor Symptoms and Quality of Life in Patients with Parkinson's Disease	Inclusion criteria did not specify a clinical diagnosis of anxiety.	1
Sproesser, Erika, Viana, Maura A., Quagliato, Elizabeth M. A. B. and de Souza, Elisabete Abib Pedroso	2010	The effect of psychotherapy in patients with PD: a controlled study	No clinical diagnosis of anxiety.	1
Szeto, Jennifer Y. Y. and Lewis, Simon J. G.	2016	Current Treatment Options for Alzheimer's Disease and Parkinson's Disease Dementia	Not an empirical study.	2
Tarsy, Daniel	2006	Initial treatment of Parkinson's disease	Not an empirical study.	2
Thangavelu, Karthick, Hayward, Joshua A., Pachana, Nancy A., Byrne, Gerard J., Mitchell, Leander K., Wallis, Guy M., Au, Tiffany R. and Dissanayaka, Nadeeka N.	2020	Designing Virtual Reality Assisted Psychotherapy for Anxiety in Older Adults Living with Parkinson's Disease: Integrating Literature for Scoping	Not an empirical study; a review.	2
Troeung, Lakkhina, Egan, Sarah J. and Gasson, Natalie	2014	A waitlist-controlled trial of group cognitive behavioural therapy for depression and anxiety in Parkinson's disease	Patients were included if they had depression and/or anxiety (does not specify anxiety and does not provide separate data for pts with anxiety).	1

van der Heide, Anouk, Meinders, Marjan J., Speckens, Anne E. M., Peerbolte, Tessa F., Bloem, Bastiaan R. and Helmich, Rick C.	2021	Stress and Mindfulness in Parkinson's Disease: Clinical Effects and Potential Underlying Mechanisms	Not an empirical study; a review.	2
Veazey, Connie, Cook, Karon F., Stanley, Melinda, Lai, Eugene C. and Kunik, Mark E.	2009	Telephone-administered cognitive behavioral therapy: a case study of anxiety and depression in Parkinson's disease	Patients with depression and/or anxiety included (does not specify anxiety and does not provide separate data for pts with anxiety).	1
Wuthrich, Viviana M. and Rapee, Ronald M.	2019	Telephone-Delivered Cognitive Behavioural Therapy for Treating Symptoms of Anxiety and Depression in Parkinson's Disease: A Pilot Trial	Patients with depression and/or anxiety included (does not specify anxiety and does not provide separate data for pts with anxiety).	1
Zhu, Mingjin, Zhang, Yonghua, Pan, Jiafei, Fu, Changyong and Wang, Yaqun	2020	Effect of simplified Tai Chi exercise on relieving symptoms of patients with mild to moderate Parkinson's disease	No psychological intervention; no anxiety diagnosis.	1
배은숙 and 염동문	2015	Effect of a Telephone-administered Cognitive Behavioral Therapy for the Management of Depression, Anxiety, and Chronic Illness Anticipated Stigma in Parkinson's Disease	Korean edition only (contacted Authors - no English version).	5

Note. 1 = Anxiety diagnosis not part of inclusion criteria; 2 = No research design/data; 3 = No psychological intervention; 4 = Insufficient details on participant outcomes; 5 = No English version available; 6 = No anxiety measure; 7 = No Parkinson's diagnosis; 8 = Participants under 18 years; 9 = Qualitative analysis only.

Appendix G: The 137 Unique Statements from the Curran et al. Study (2021b)

1. My anxiety is triggered or made worse when I am alone

2. My anxiety is triggered or made worse When I am not occupied/busy

3. My anxiety is triggered or made worse When I wake up

4. My anxiety is triggered or made worse at night

5. My anxiety is triggered or made worse when I am tired

6. My anxiety is triggered or made worse by specific seasons or extremes of weather

7. My anxiety is triggered or made worse when I drink caffeine

8. My anxiety is triggered or made worse when I smell strong smells or odours

9. My anxiety is triggered or made worse when I have tremor

10. My anxiety is triggered or made worse when I have difficulty with movement or coordination

11. My anxiety is triggered or made worse when I am at home

12. My anxiety is triggered or made worse by being outside my home

13. My anxiety is triggered or made worse when exercising

14. My anxiety is triggered or made worse when walking

15. My anxiety is triggered or made worse when the ground looks slippery

16. My anxiety is triggered or made worse when in confined or enclosed spaces

17. My anxiety is triggered or made worse when in public settings

18. My anxiety is triggered or made worse when I am in crowded and/or noisy places

19. My anxiety is triggered or made worse if people are too close and I feel my movement is restricted

20. My anxiety is triggered or made worse when I am travelling

21. My anxiety is triggered or made worse when I am in social situations (where one may be observed or evaluated by others, such as speaking in public or meeting new people)

22. My anxiety is triggered or made worse when I am ignored in social situations

23. My anxiety is triggered or made worse when I eat in public

24. My anxiety is triggered or made worse when I am unsure if I can reach a toilet in time

25. My anxiety is triggered or made worse when I feel time pressured (for example making it to an appointment in time or at a supermarket till where I have to coordinate tasks quickly)

26. My anxiety is triggered or made worse when others do not understand what I am experiencing

27. My anxiety is triggered or made worse when loved ones get upset

28. My anxiety is triggered or made worse when I have disagreements with others or am criticised by others

29. My anxiety is triggered or made worse when I am stressed by life or work (e.g. when a number of tasks fall together)

30. My anxiety is triggered or made worse when I do not meet demands or expectations

31. When I am not able to perform a task or role that I previously would have been able to

32. My anxiety is triggered or made worse when trying to organise myself and make decisions

33. My anxiety is triggered or made worse when I am having a medical consultation/appointment

34. My anxiety is triggered or made worse when I am unhappy about the healthcare I am receiving

35. My anxiety is triggered or made worse when I see others at the later stage of Parkinson's

36. My anxiety is triggered or made worse when reading about Parkinson's

37. My anxiety is triggered or made worse I am not aware what the trigger is or why the anxiety occurs

38. My anxiety is triggered or made worse my anxiety was triggered or made worse in the period just after my diagnosis of Parkinson's

39. My anxiety is triggered or made worse when I have hallucinations

40. My anxiety is triggered or made worse when I have difficulties with sexual performance

41. My anxiety is triggered or made worse when I am in pain

42. My anxiety is triggered or made worse around menstruation

43. When I am anxious, I compare my health status to those who are in better health

44. When I am anxious, I worry about the rate at which my Parkinson's symptoms progress and how I will cope at their worst

45. When I am anxious, I worry about falling and/or the consequences of falling

46. When I am anxious, I worry about my speech (e.g. not speaking clearly or being understood)

47. When I am anxious, I worry I will freeze (stop moving) in hazardous situations

48. When I am anxious, I worry I will get dementia

49. When I am anxious, I worry about my employability

50. When I am anxious, I worry about money and my ability to maintain financial security

51. When I am anxious, I worry that I am not able to contribute and will let others down or become a burden

52. When I am anxious, I fear being left alone because others are not able to cope with my symptoms

53. When I am anxious, I worry about the impact of my Parkinson's on my family and how they will cope

54. When I am anxious, I am worried that others are embarrassed to be with me

55. When I am anxious, I worry about my death

56. When I am anxious, I focus too much on my medication (e.g. when its due, side effects, whether it's working)

57. When I am anxious, when I am anxious, I worry I will lose control and won't be able to do my everyday tasks

58. When I am anxious, I worry I will lose my identity

59. When I am anxious, I worry about my future ability to be an effective parent or carer for those who need my support

60. When I am anxious, I worry about having to go into a care home and the quality of the care I would receive there

61. When I am anxious, I worry about upsetting those close to me or making things difficult for them

62. When I am anxious, I worry how others will perceive my Parkinson's symptoms and that they will judge me negatively

63. When I am anxious, I worry that someone will knock me over in busy places

64. When I am anxious, I worry about eating in public and that others will judge me negatively

65. When I am anxious, I worry about dribbling and that others will judge me negatively

66. When I am anxious, I am embarrassed by the frequency and urgency with which I need to urinate

67. When I am anxious, I worry about the embarrassment of having a toileting accident (being incontinent)

68. When I am anxious, I worry that I will be not be able to function properly in public situations (e.g. on escalators, in supermarkets, in pubs)

69. When I am anxious, I worry that I stand out as different

70. When I am anxious, I compare my current abilities to my past abilities

71. When I am anxious, I worry about feeling anxious; how long it will last for, whether it will impact on my health, or how I will cope with it

72. When I am anxious, when experiencing physical symptoms of anxiety, I worry that they mean something more catastrophic (for example that I will stop breathing, pass out, have a stroke or a heart attack)

73. When I am anxious, I worry about what is causing my anxiety

74. When I am anxious, I worry that others will notice I'm anxious

75. When I am anxious, I think about past events over and over again

76. When I am anxious, I worry about the possibility of failing or making a mistake

77. When I am anxious, I worry about the possibility of being late to appointments

78. When I am anxious, I worry about the welfare of others

79. I view my anxiety as a proportionate and rational response to the difficulties I experience with Parkinson's

80. I view my anxiety as largely irrational and out of proportion

81. There is no fixed focus to my worry; I worry about anything, including irrational things, things I have no control over

82. I feel out of control with my worry and find it hard to stop

83. I worry about small things that never used to bother me as much

84. I blow things out of proportion and make mountains out of molehills

85. When I am anxious, I experience changes to body temperature

86. When I am anxious, I experience increased sweating

87. When I am anxious, I experience increased heart rate

88. When I am anxious, I experience a headache

89. When I am anxious, I experience muscle tension

90. When I am anxious, I experience chest discomfort

91. When I am anxious, I experience fatigue or tiredness

92. When I am anxious, I experience stomach discomfort (churning/butterflies)

93. When I am anxious, I experience I need to use the toilet

94. When I am anxious, I experience nausea

95. When I am anxious, I experience feeling disorientated or dizzy

96. When I am anxious, I experience restlessness

97. When I am anxious, I experience difficulty breathing

98. When I am anxious, I experience feeling very alert and focused

99. When I am anxious, I experience feeling overwhelmed

100. When I am anxious, I experience feeling of dread

101. When I am anxious, I experience feeling nervous

102. When I am anxious, I experience feeling panicked

103. When I am anxious, I experience feeling frightened/scared/terrified

104. When I am anxious, I experience feeling upset

105. When I am anxious, I experience feeling irritated

106. When I am anxious, I experience feeling angry

107. When I am anxious, or to avoid becoming anxious, I am more argumentative or short tempered

108. When I am anxious, or to avoid becoming anxious, I try to disguise my anxiety

109. When I am anxious, or to avoid becoming anxious, I try to distract myself from the anxiety

110. When I am anxious, or to avoid becoming anxious, I drink alcohol to try to reduce my anxiety and/or Parkinson's symptoms

111. When I am anxious, or to avoid becoming anxious, I physically harm myself when anxious

112. When I am anxious, or to avoid becoming anxious, I plan things in great detail, including how to get out of a situation/location quickly (e.g. sit near the exit or toilet)

113. When I am anxious, or to avoid becoming anxious, when I enter an anxiety provoking situation I try to get in and out of the situation as quickly as possible

114. When I am anxious, or to avoid becoming anxious, I prefer to be accompanied by someone familiar when going into new places/situations

115. When I am anxious, or to avoid becoming anxious, I withdraw and isolate myself

116. When I am anxious, or to avoid becoming anxious, I avoid giving an opinion or disagreeing with others

117. When I am anxious, or to avoid becoming anxious, I avoid decision making and/or positions of responsibility

118. When I am anxious, or to avoid becoming anxious, I avoid social interactions

119. When I am anxious, or to avoid becoming anxious, I avoid leaving home

120. When I am anxious, or to avoid becoming anxious, I over-analyse or check over things more than I need to

121. When I am anxious, or to avoid becoming anxious, I avoid public situations

122. When I am anxious, or to avoid becoming anxious, in public, I select food or drink that is easier to manage or I avoid eating or drinking altogether

123. When I am anxious, or to avoid becoming anxious, I avoid busy or crowded places

124. When I am anxious, or to avoid becoming anxious, I avoid confined spaces or places that are not easy to escape from

125. When I am anxious, or to avoid becoming anxious, I avoid driving

126. When I am anxious, or to avoid becoming anxious, I avoid some methods of travel (e.g. public transport, car travel, plane travel, etc.)

127. Anxiety has impacted my confidence

128. Anxiety has restricted me and impacted my freedom and independence

129. Anxiety has made my Parkinson's symptoms worse

130. Anxiety has impacted my sleep

131. Anxiety has impacted my relationships

132. Anxiety has made me more isolated

133. Anxiety has made it harder to complete daily tasks

134. Anxiety has made it hard to think clearly

135. Anxiety has made it hard to express myself

136. Anxiety has impacted my ability to work

137. Anxiety has impacted my ability to be an effective parent or carer for those who need my support

Appendix H: Confirmation of Approval from the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee for the Study by Curran and Colleagues (2021b)

Faculty of Medicine and Health Sciences Research Ethics Committee

Daniel Curren
MED

Research & Innovation Services
Floor 1, The Registry
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

10 January 2019

Dear Daniel

Title: **Anxiety in Parkinson's: A mixed methods investigation**

Reference: 201819 - 046

Your submission (above) was considered by the Faculty Research Ethics Committee at their meeting on 13 December 2018, and following subsequent review of some minor amendments, I confirm that your proposal has been approved.

Please could you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance and also that any adverse events which occur during your project are reported to the Committee. Please could you also arrange to send us a report once your project is completed.

Approval by the FMH Research Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

Yours sincerely

Professor M J Wilkinson
Chair
FMH Research Ethics Committee

Appendix I: Confirmation of Approval from the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee for the Current Study

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

Charlotte Irving-Curran
School of Health Sciences
Queen's Building QBO.1
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University of East Anglia
Norwich Research Park
Norwich
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NORWICH MEDICAL SCHOOL
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27th February 2020

Dear Charlotte

Project title: The Co-Development of a Parkinson's-Specific Standardised Psychometric Measure of Anxiety and a Parkinson's-Specific Model of Anxiety

Reference: 2019/20-068

Your submission was considered by the Faculty Research Ethics Committee at their meeting on 27th February 2020 and I can confirm that your proposal has been approved.

Please can you ensure that any amendments to either the protocol or documents submitted are notified to us in advance, and that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

Please could you also arrange to send us a report once your project is completed.

Yours sincerely

Prof Alastair Forbes
Chair
FMH Research Ethics Committee

Appendix J: The Comprehensive Anxiety and Parkinson's Scale (CAPS-54)

Comprehensive Anxiety and Parkinson's Scale (CAPS-54)

Below are 54 statements about the experience of anxiety and Parkinson's. Please read each statement and mark the box that best describes your experience. Please only tick one box for each statement and try not to miss any.

My anxiety is triggered or made worse…

		Never / almost never	Rarely	Sometimes	Often	Always / almost always
1	when I am alone	☐	☐	☐	☐	☐
2	when I see others at the later stage of Parkinson's	☐	☐	☐	☐	☐
3	when in confined or enclosed spaces	☐	☐	☐	☐	☐
4	when I am unsure if I can reach a toilet in time	☐	☐	☐	☐	☐
5	when I am not occupied/busy	☐	☐	☐	☐	☐
6	when I do not meet demands or expectations	☐	☐	☐	☐	☐
7	when I am travelling	☐	☐	☐	☐	☐

My anxiety is triggered or made worse…

		Never / almost never	Rarely	Sometimes	Often	Always / almost always
8	when I wake up	☐	☐	☐	☐	☐
9	when reading about Parkinson's	☐	☐	☐	☐	☐
10	when I am in crowded and/or noisy places	☐	☐	☐	☐	☐
11	at night	☐	☐	☐	☐	☐
12	if people are too close and I feel my movement is restricted	☐	☐	☐	☐	☐
13	when I am at home	☐	☐	☐	☐	☐
14	when in public settings	☐	☐	☐	☐	☐
15	when I am tired	☐	☐	☐	☐	☐
16	when exercising	☐	☐	☐	☐	☐

When I am anxious…

		Never / almost never	Rarely	Sometimes	Often	Always / almost always
17	I need to use the toilet	☐	☐	☐	☐	☐
18	I think about past events over and over again	☐	☐	☐	☐	☐
19	I compare my health status to those who are in better health	☐	☐	☐	☐	☐
20	I worry about falling and/or the consequences of falling	☐	☐	☐	☐	☐
21	I worry I will get dementia	☐	☐	☐	☐	☐
22	I worry about my speech (e.g. not speaking clearly or being understood)	☐	☐	☐	☐	☐
23	It is hard to think clearly	☐	☐	☐	☐	☐
24	I worry I will lose control and won't be able to do my everyday tasks	☐	☐	☐	☐	☐
25	I worry about dribbling and that others will judge me negatively	☐	☐	☐	☐	☐
26	I worry I will lose my identity	☐	☐	☐	☐	☐

When I am anxious…

		Never / almost never	Rarely	Sometimes	Often	Always / almost always
27	I am embarrassed by the frequency and urgency with which I need to urinate	☐	☐	☐	☐	☐
28	I worry about the rate at which my Parkinson's symptoms progress and how I will cope at their worst	☐	☐	☐	☐	☐
29	I worry about my death	☐	☐	☐	☐	☐
30	I worry about upsetting those close to me or making things difficult for them	☐	☐	☐	☐	☐
31	I worry that I stand out as different	☐	☐	☐	☐	☐
32	I compare my current abilities to my past abilities	☐	☐	☐	☐	☐
33	I worry about the embarrassment of having a toileting accident (being incontinent)	☐	☐	☐	☐	☐
34	I worry about feeling anxious; how long it will last for, whether it will impact on my health, or how I will cope with it	☐	☐	☐	☐	☐

When I am anxious, I experience…

		Never / almost never	Rarely	Sometimes	Often	Always / almost always
35	changes to body temperature	☐	☐	☐	☐	☐
36	increased sweating	☐	☐	☐	☐	☐
37	increased heart rate	☐	☐	☐	☐	☐
38	headache	☐	☐	☐	☐	☐
39	muscle tension	☐	☐	☐	☐	☐
40	chest discomfort	☐	☐	☐	☐	☐
41	feeling very alert and focused	☐	☐	☐	☐	☐

When I am anxious, or to avoid becoming anxious…

		Never / almost never	Rarely	Sometimes	Often	Always / almost always
42	I prefer to be accompanied by someone familiar when going into new places / situations	☐	☐	☐	☐	☐

When I am anxious, or to avoid becoming anxious…

		Never / almost never	Rarely	Sometimes	Often	Always / almost always
43	I over-analyse or check over things more than I need to	☐	☐	☐	☐	☐
44	I avoid driving	☐	☐	☐	☐	☐
45	I avoid decision making and/or positions of responsibility	☐	☐	☐	☐	☐
46	in public, I select food or drink that is easier to manage or I avoid eating or drinking altogether	☐	☐	☐	☐	☐
47	I avoid busy or crowded places	☐	☐	☐	☐	☐
48	I avoid some methods of travel (e.g. public transport, car travel, plane travel, etc.)	☐	☐	☐	☐	☐
49	I avoid confined spaces or places that are not easy to escape from	☐	☐	☐	☐	☐

How much do you agree with the following statements about your anxiety?

		Strongly Agree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
50	I view my anxiety as largely irrational and out of proportion	☐	☐	☐	☐	☐

How much do you agree with the following statements about your anxiety?

		Strongly Agree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
51	There is no fixed focus to my worry; I worry about anything, including irrational things, things I have no control over	☐	☐	☐	☐	☐
52	I feel out of control with my worry and find it hard to stop	☐	☐	☐	☐	☐
53	I worry about small things that never used to bother me as much	☐	☐	☐	☐	☐
54	I blow things out of proportion and make mountains out of molehills	☐	☐	☐	☐	☐

Thank you for completing the questionnaire!

Subscale Scoring

Anxiety Triggers: 1, 5, 8, 11, 13, 15, 16

Physical Consequences: 4, 17, 20, 22, 25, 27, 33

Physical Sensations: 35, 36, 37, 38, 39, 40, 41

Cognitions: 18, 23, 43, 45, 50, 51, 52, 53, 54

Environment: 3, 7, 10, 12, 14, 42, 44, 46, 47, 48, 49

Impact of Parkinson's: 2, 6, 9, 19, 21, 24, 26, 28, 29, 30, 31, 32, 34

Appendix K: The Comprehensive Anxiety and Parkinson's Scale – Short Version (CAPS-24)

Comprehensive Anxiety and Parkinson's Scale - Short Version (CAPS-24)

Below are 24 statements about the experience of anxiety and Parkinson's. Please read each statement and mark the box that best describes your experience. Please only tick one box for each statement and try not to miss any.

My anxiety is triggered or made worse…

		Never / almost never	Rarely	Sometimes	Often	Always / almost always
1	when I am alone	☐	☐	☐	☐	☐
2	when in confined or enclosed spaces	☐	☐	☐	☐	☐
3	when I am unsure if I can reach a toilet in time	☐	☐	☐	☐	☐
4	when I am not occupied/busy	☐	☐	☐	☐	☐
5	when I do not meet demands or expectations	☐	☐	☐	☐	☐
6	when I am travelling	☐	☐	☐	☐	☐
7	when I wake up	☐	☐	☐	☐	☐
8	when in public settings	☐	☐	☐	☐	☐

When I am anxious…

		Never / almost never	Rarely	Sometimes	Often	Always / almost always
9	I need to use the toilet	☐	☐	☐	☐	☐
10	I think about past events over and over again	☐	☐	☐	☐	☐
11	I compare my health status to those who are in better health	☐	☐	☐	☐	☐
12	It is hard to think clearly	☐	☐	☐	☐	☐
13	I worry I will lose control and won't be able to do my everyday tasks	☐	☐	☐	☐	☐
14	I worry about upsetting those close to me or making things difficult for them	☐	☐	☐	☐	☐
15	I worry that I stand out as different	☐	☐	☐	☐	☐
16	I worry about the embarrassment of having a toileting accident (being incontinent)	☐	☐	☐	☐	☐
17	I worry about feeling anxious; how long it will last for, whether it will impact on my health, or how I will cope with it	☐	☐	☐	☐	☐

When I am anxious, I experience…

		Never / almost never	Rarely	Sometimes	Often	Always / almost always
18	changes to body temperature	☐	☐	☐	☐	☐
19	increased sweating	☐	☐	☐	☐	☐
20	increased heart rate	☐	☐	☐	☐	☐

When I am anxious, or to avoid becoming anxious…

		Never / almost never	Rarely	Sometimes	Often	Always / almost always
21	I over-analyse or check over things more than I need to	☐	☐	☐	☐	☐
22	I avoid busy or crowded places	☐	☐	☐	☐	☐
23	I avoid confined spaces or places that are not easy to escape from	☐	☐	☐	☐	☐

How much do you agree with the following statements about your anxiety?

		Strongly Agree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
24	I feel out of control with my worry and find it hard to stop	☐	☐	☐	☐	☐

Thank you for completing the questionnaire!

Subscale Scoring

Anxiety Triggers: 1, 4, 7

Physical Consequences: 3, 9, 16

Physical Sensations: 18, 19, 20

Cognitions: 10, 12, 21, 24

Environment: 2, 6, 8, 22, 23

Impact of Parkinson's: 5, 11, 13, 14, 15, 17