

Doctorate in
Clinical Psychology

Lancaster
University



Cognition, Compassion and Wellbeing among People with Parkinson's

**Thesis submitted in partial fulfilment of the Lancaster University Doctorate in Clinical
Psychology**

June 2019

Natalie Sowter

Division of Health Research

Faculty of Health and Medicine

Lancaster University

Statement of Word Count

Thesis Section	Main Text (including abstracts)	Appendices (including tables, figures & references)	Total
Thesis Abstract	290	-	290
Section One: Literature Review	7979	12,332	20,311
Section Two: Empirical Paper	7447	7501	14,948
Section Three: Critical Appraisal	3980	793	4773
Section Four: Ethics and Appendices	3958	5161	9119
Total	23,654	25,787	49,441

Thesis Abstract

This thesis considers some of the cognitive, social and psychological factors which impact upon the wellbeing of people with Parkinson's. Section One reports a systematic literature review of the relationship between anxiety and cognition for people with Parkinson's. The electronic databases CINAHL, Medline, PsycINFO and Web of Science were searched and 39 eligible studies were identified. The findings suggested that higher anxiety is associated with worse global cognition and worse performance in specific cognitive domains (attention, working memory, executive functioning, memory, language, semantic verbal fluency and visuospatial skills) among people with Parkinson's. However, several studies did not identify significant relationships. Studies varied in design and quality, several having small samples. Relationships between anxiety and cognition among people with Parkinson's appear to be complex and may be influenced by other factors. Implications for clinical practice are discussed. Section Two describes a quantitative, cross-sectional, observational study into the relationships between self-compassion, stigma and psychological distress among people with Parkinson's. Participants were 138 people with Parkinson's, who completed questionnaires measuring self-compassion, enacted and felt stigma, and depression, anxiety and stress. All variables were found to correlate significantly in the expected directions. The stigma variables were significant mediators in the relationships between self-compassion and the three outcome variables - depression, anxiety and stress. Part of the relationship between self-compassion and psychological distress appears to occur via the internalisation of stigma. These findings may be relevant to individualised and societal interventions with the aim of improving the psychological wellbeing of people with Parkinson's. Section Three provides a critical appraisal of the thesis. This includes a summary of the main findings, consideration of language and concepts, a discussion of some of the issues relating to each paper and suggestions for further research.

Declaration

This thesis was completed in part fulfilment of the Doctorate in Clinical Psychology at Lancaster University, between September 2017 and June 2019. The work has not been submitted for any other academic award. The work submitted is my own and does not contain the work of any other authors, except where due reference is made.

Natalie Sowter

16.06.2019

Acknowledgements

I would like to thank my supervisors, Fiona and Terry, for their guidance and support. A huge thank you to Fiona for her endless enthusiasm, patience and warmth, and for being excited about statistics with me! Special thanks also to Terry, for his gentle encouragement, thoughtful contributions and ongoing support, despite moving countries when the thesis was in its early stages. Thank you to Jane for taking the time to read and comment on the final drafts of the literature review and empirical papers.

I would also like to thank Natasha and the Patient and Public Involvement volunteers at Parkinson's UK for their invaluable contributions to developing the research, and Amelia at Parkinson's UK for her help with advertising the study. I am also extremely grateful to everyone who took the time to participate in the study.

Thank you to Cliff and Alistair, not only for their contributions to developing the search terms for the literature review, but for always being so generous with their time and knowledge. I feel incredibly fortunate to have worked with such inspirational people, from whom I have learned so much.

Thank you to my wonderful family and friends for all their love and support. Finally, very special thanks to Dan, for always being there for me, for believing in me and for somehow knowing exactly what I need, even when I don't know it myself.

Contents

Section 1: Literature Review	1-1
Abstract	1-2
Introduction	1-3
Methodology	1-6
Method	1-7
Results	1-12
Discussion	1-24
Conclusions	1-28
References	1-29
Figure 1.1: Study selection	1-47
Table 1.1: Search terms used	1-48
Table 1.2: Quality assessment tool	1-51
Table 1.3: Summary of study characteristics and relevant findings	1-52
Table 1.4: Quality assessment summary	1-74
Table 1.5: Summary of relationships found between cognition and anxiety	1-77
Appendix 1A: Author guidelines for the British Journal of Health Psychology	1-80
Appendix 1B: Search strategy used in the electronic database CINAHL	1-90
Appendix 1C: Quality assessment tool for observational studies	1-92
Appendix 1D: Adaptations to quality assessment tool	1-97
Appendix 1E: Quality appraisals by second reviewer	1-100
Section 2: Empirical Paper	2-1
Abstract	2-2
Introduction	2-3
Method	2-8
Results	2-14
Discussion	2-19
Conclusion	2-27
References	2-28
Figure 2.1: The simple mediation model	2-36
Figure 2.2: Mediation models tested	2-37
Figure 2.3: Mediation models (felt stigma)	2-38

Figure 2.4: Mediation models (enacted stigma)	2-39
Table 2.1: Demographic and clinical characteristics of sample (continuous)	2-40
Table 2.2: Demographic and clinical characteristics of sample (categorical)	2-41
Table 2.3: Descriptive statistics and internal consistency of measures	2-42
Table 2.4: Spearman's rho correlations between variables	2-43
Appendix 2A: Author Guidelines for the British Journal of Health Psychology	2-44
Appendix 2B: SPSS outputs for mediation analyses	2-55
Section 3: Critical Appraisal	3-1
Introduction	3-2
Summary of findings	3-2
Use of language and constructs	3-4
Issues specific to the literature review	3-6
Issues specific to the empirical study	3-9
Directions for future research	3-13
Conclusions	3-14
References	3-15
Section 4: Ethics and Appendices	4-1
Application for ethical approval	4-2
Study protocol	4-11
Appendix 4A: Note to ethics committee regarding online survey	4-26
Appendix 4B: Paper version of participant materials	4-27
Appendix 4C: Ethics amendment request form	4-51
Appendix 4D: Letter of ethical approval	4-53

Section One: Literature Review

Anxiety and Cognitive Functioning among People with Parkinson's: A Systematic
Review

Natalie Sowter

Doctorate in Clinical Psychology

Lancaster University

Formatted for submission to the British Journal of Health Psychology (Author Guidelines
attached in Appendix 1A)

Word count (including abstract but excluding references, appendices, figures and tables):

7980

Correspondence should be addressed to:

Natalie Sowter

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

Lancaster, L1 4YG

Email: n.sowter@lancaster.ac.uk

Abstract

Purpose. Cognitive decline is common among people with Parkinson's and is negatively associated with quality of life. Previous systematic reviews have found greater cognitive difficulties among people with Parkinson's to be associated with increased symptoms of depression and apathy, but have identified relatively few studies examining relationships between cognitive factors and anxiety. The current review aimed to address this gap by expanding upon the search strategies used in the previous reviews.

Methods. A quantitative systematic literature review was conducted. The electronic databases CINAHL, Medline, PsycINFO and Web of Science were searched for studies which analysed relationships between cognitive factors and anxiety among people with Parkinson's. A total of 3883 studies were identified, of which 39 were eligible for inclusion in the review.

Results. There was evidence to suggest that higher anxiety is associated with worse global cognition and worse performance in specific cognitive domains (attention, working memory, executive functioning, memory, language, semantic verbal fluency and visuospatial skills). There was also evidence to suggest predictive relationships between the variables, in both directions. However, there were inconsistencies between the papers, with several studies also finding null results. Studies varied in terms of design and quality, a common weakness being small sample sizes.

Conclusions. Relationships between anxiety and cognition among people with Parkinson's appear to be complex and may be influenced by other factors. Clinicians working with people with Parkinson's should ensure that assessments, formulations and interventions consider the impact of, and relationships between, cognitive difficulties and experiences of anxiety.

Anxiety and Cognitive Functioning among People with Parkinson's: A Systematic Review

Parkinson's disease (referred to throughout this review as "Parkinson's": the preferred terminology by the charity Parkinson's UK) is a common neuro-degenerative condition with a worldwide prevalence rate of around 0.3% (Pringsheim, Jette, Frolkis & Steeves, 2014). Parkinson's is classified as a movement disorder (Fahn, 2011), characterised by difficulties with initiating movement (akinesia), slowed movement (bradykinesia), tremor, rigidity, gait disturbance and speech difficulties (Moustafa et al., 2016). Other difficulties experienced by people with Parkinson's can include symptoms of anxiety and depression, cognitive impairments, sensory disturbances, sexual dysfunction and continence problems (Rana, Ahmed, Chaudry & Vasan, 2015; Stacy, 2011).

The cognitive sequelae of Parkinson's are heterogeneous (Kehagia, Barker & Robbins, 2010), but often include impairment or decline in the domains of memory, attention, executive function and visuospatial abilities (Aarsland et al., 2010; Elgh et al., 2009). Changes in cognitive functioning can occur early in the progression of Parkinson's, with around 30% of people newly diagnosed with Parkinson's exhibiting impairments in at least one of the domains of semantic verbal fluency, episodic memory and executive function, while phonemic verbal fluency, naming, working memory and visuospatial skills remain relatively unaffected (Elgh et al., 2009). Cognition gradually declines over time as Parkinson's progresses, with a broader range of domains affected, including a deterioration in visuospatial skills (Muslimović, Schmand, Speelman & De Haan, 2007; Roheger, Kalbe & Liepelt-Scarfone, 2018). Approximately half of all people with Parkinson's develop Parkinson's Disease Dementia (PDD) within ten years of diagnosis (Williams-Gray et al., 2013), and approximately 80% develop PDD within 20 years (Hely, Reid, Adena, Halliday & Morris, 2008). Parkinson's Disease-Mild Cognitive Impairment (PD-MCI) is defined as the stage of

cognitive decline which is greater than expected given an individual's age and level of education, but which, unlike PDD, does not negatively impact upon functional independence (Litvan et al., 2012; Weil, Costantini & Schrag, 2018). People with PD-MCI are at an increased risk of developing PDD (Janvin, Larsen, Aarsland & Hugdahl, 2006; Litvan et al., 2012).

Cognitive difficulties have been found to be associated with poorer quality of life (Lawson et al., 2014; Schrag, Jahanshani & Quinn, 2000), lower life-satisfaction (Rosqvist et al., 2017), higher levels of depression (Fernandez et al., 2009; Santangelo et al., 2009) and increased apathy (Butterfield, Cimino, Oelke, Hauser & Sanchez-Ramos, 2010) for people with Parkinson's. Two previous reviews have sought to synthesise the literature concerning the relationships between cognitive and affective factors among people with Parkinson's (Alzahrani & Venneri, 2015; Poletti, De Rosa & Bonuccelli, 2012). Both identified symptoms of depression and apathy to be associated with impairments in cognition, particularly in the executive functioning domain. However, both reviews highlighted a dearth of research into the relationship between anxiety and cognition: Alzahrani and Venneri (2015) finding only two studies addressing this relationship (Bogdanova & Cronin-Golomb, 2012; Foster et al., 2010), and Poletti et al. (2012) finding just one (Foster et al., 2010). A scoping review by Lutz, Holmes, Ready, Jenkins and Johnson (2016) focused on correlates of anxiety for people with Parkinson's, and found only three papers relating to cognition (Lee, Tsai, Gauthier, Wang & Fuh, 2012; Ryder et al., 2002; Zahodne, Marsiske & Bowers, 2013). All three reviews found evidence suggesting that greater cognitive impairment is associated with higher levels of anxiety, but recommended that further research should be carried out to clarify and expand upon existing findings.

This apparent lack of research is surprising, particularly given that clinically significant levels of anxiety affect around one third of people with Parkinson's (Broen,

Narayan, Kuijf, Dissanayaka & Leentjens, 2016), and relationships between anxiety and cognition in other populations are well-evidenced. For example, in older adults, anxiety has been found to be associated with impairments in memory, learning and executive functioning (Mantella et al., 2007; Yochim, Mueller & Segal, 2013). Similar relationships between anxiety and cognitive factors have been identified in people with other neurological conditions including multiple sclerosis (Julian & Arnett, 2009; Simioni, Ruffieux, Bruggimann, Annoni, & Schluep, 2007), traumatic brain injury (Gould, Ponsford & Spitz, 2014) and stroke (Barker-Collo, 2007). These relationships may be bi-directional: anxiety may limit the resources available to engage in cognitive tasks (Vytal, Cornwell, Arkin & Grillon, 2012), while cognitive problems (particularly with executive functioning) might make it more difficult to implement cognitive strategies to reduce anxiety (Yochim et al., 2013).

It appears important for clinical psychologists, clinical neuropsychologists and other professionals to understand the relationship between anxiety and cognition when seeking to assess and formulate problems reported in either domain by people with Parkinson's, in order to guide effective interventions. This is in line with the British Psychological Society's (BPS) briefing document regarding psychological services for people with Parkinson's (Macniven & Gaskill, 2009), which recommends a holistic approach to understanding the cognitive, psychological and social factors affecting each individual. Although previous reviews have considered the relationship between anxiety and cognition (Alzahrani & Venneri, 2015; Lutz et al., 2016; Poletti et al., 2012), they did so within broad research questions, therefore the search strategies may have lacked the specificity and sensitivity to identify all relevant papers. Additionally, an initial scoping search of the literature identified several relevant papers published since the previous reviews, suggesting that they may have drawn attention to the need for further research.

Therefore, this review sought to search, comprehensively and systematically, the literature regarding the relationship between anxiety and cognition among people with Parkinson's, to enhance understanding of the current state of knowledge in the area. It was hypothesised that, as with other populations and the findings of the previous reviews, higher anxiety would be associated with greater cognitive impairments.

Methodology

Given the nature of the review question, it was anticipated that the relevant studies for inclusion in the review would be largely observational in design. Mueller et al. (2018) highlight that much of the guidance for conducting systematic literature reviews is aimed at reviews of randomised controlled trials (RCTs), despite a large proportion of systematic reviews including observational data (Page et al., 2016). Mueller et al. (2018) have synthesised the existing guidance for systematically reviewing observational studies; this was referred to throughout the process of this review. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) statement was also followed as closely as possible in the reporting of this review; this being a recommendation for systematic review submissions to the target journal. Any deviations from the PRISMA statement are due to it being aimed at reviews of RCTs (Moher et al., 2009). No such reporting guidelines appear to exist for reviews of observational studies (Mueller et al., 2018).

The purpose of a quantitative systematic literature review is to search the existing literature thoroughly and methodically, using explicit criteria to identify the relevant research papers, which are then critically reviewed. The intended outcome is a critical synthesis of the extant literature pertaining to a particular research question (Petticrew & Roberts, 2006). Given a systematic and explicit approach to searching, selecting and critiquing the literature, systematic reviews should be reproducible and relatively unbiased (Biondi-Zoccai, Lotrionte,

Landoni, & Modena, 2011; Gopalakrishnan & Ganeshkumar, 2013). Nonetheless, there remains a degree of subjectivity in the defining of the research question and selection criteria (Biondi-Zoccai et al., 2013). Therefore, throughout the current review, I have attempted to give an explicit account of, and rationale for, the procedures followed.

Method

Defining the Research Question

A well-defined research question which is both meaningful and useful is vital for conducting a systematic review (Moher et al., 2009; Petticrew & Roberts, 2006). However, there are conflicting guidelines regarding how broad or specific the research question should be, and at what stage the research question should be defined, for systematic reviews of observational studies (Mueller et al., 2018). While some researchers argue that a precise research question is more scientific and economical (Rosenthal & DiMatteo, 2001; Thomas, Ciliska, Dobbins & Micucci, 2004), others suggest that the breadth of a review question should be determined by what the most meaningful outcomes may be (Price, Jefferson & Demicheli, 2004). Due to how little is known about the topic of this review, as confirmed by three previous reviews (Alzahrani & Venneri, 2015; Lutz et al., 2016; Poletti et al., 2012), a fairly broad question was decided to be appropriate. It was decided to be more useful to look at the relationship between anxiety and all aspects of cognitive functioning among people with Parkinson's rather than focusing on a specific domain of cognitive functioning, given that there is not yet an empirical basis to support such a focus. Nonetheless, the current review question is more specific than the three prior reviews. The increased specificity was economical, allowing more resources to be used on defining the search terms relating to cognition, with the aim of identifying papers which may not have been retrieved by the search strategies used in the previous reviews.

A tool frequently used to formulate systematic review questions is PICO: an acronym for population, intervention, comparison and outcome (Richardson, Wilson, Nishikawa & Hayward, 1995). Given the breadth of the research topic and the aforementioned aim of looking at relationships between two types of outcome (anxiety and cognitive functioning) for people with Parkinson's, it was decided that only the "population" and "outcome" variables were relevant to this review. Both anxiety and cognitive functioning were considered outcomes, rather than "exposure" and "outcome" (Moola et al., 2015), given that there was insufficient evidence to hypothesise about causality between these two variables. Thus, the question was defined with the "population" being people with Parkinson's, and the "outcomes" being anxiety and cognitive functioning.

Search Strategy

A systematic search of the literature was completed in March 2019, using the electronic databases CINAHL, Medline, PsycINFO and Web of Science. The search strategy was reviewed and approved by an Academic Librarian.

Cognitive function is an extremely broad outcome variable. As such, myriad search terms might have been used to identify papers measuring aspects of cognition. To address this, multiple sources were consulted from which the relevant terms were identified and extracted. The sources included: three recent systematic reviews concerning cognition and people with Parkinson's (D'itorio, Maggi, Vitale, Trojano & Santangelo, 2018; Fengler et al., 2017; Pushpanathan, Loftus, Thomas, Gasson & Bucks, 2016), two Cochrane systematic reviews concerning cognition and other neurological conditions (Hoffmann, Bennett, Koh & McKenna, 2010; Rosti-Otajärvi & Hämäläinen, 2014) and consultation with two clinical neuropsychologists working in services for people with Parkinson's. Once several terms had been identified, they were used to search subject heading libraries within the databases to generate further terms. The final list of terms searched in each database is summarised in

Table 1.1. The results of single-term subject heading searches and multiple-term free-text searches (in the Title and Abstract fields for CINAHL, Medline and PsycINFO, and in the Topic field for Web of Science) were combined using Boolean logic. The full electronic search strategy used in CINAHL is presented in Appendix 1B.

<INSERT TABLE 1.1>

The search results were collated in the reference management software Endnote. Duplicates were removed. Using the selection criteria, the records were screened by title and abstract, and the remaining papers were read in full to determine eligibility. The reference lists of the selected papers, and the three previous reviews in the area of the topic (Alzahrani & Venneri, 2015; Lutz et al., 2006; Poletti et al., 2012) were hand-searched for any additional relevant papers.

Selection Criteria

The included papers were required to report on empirical studies which were quantitative in design, available in English, and published in a peer-reviewed journal. Grey literature was excluded since this is likely to be of lower quality so can introduce bias (Egger, Juni, Bartlett, Hoenstein & Sterne, 2003). Although previous reviews have addressed similar research questions to the current review in recent years (Alzahrani & Venneri, 2015; Lutz et al., 2006; Poletti et al., 2012), for comprehensiveness no date limits were set on the search. Therefore, all studies published up until the date of the search (March 2019) were considered.

Studies were required to have human participants, with a diagnosis of Parkinson's, whose data were separable from any data from participants without Parkinson's. Participants were required to be aged 18 and over. Studies had to include either a validated self-report measure of anxiety, or examination by a suitably qualified professional against widely-

accepted criteria for the diagnosis of “anxiety disorders”. Data regarding anxiety had to be separable from other psychological or psychiatric data. Cognitive function had to be assessed using validated tools. Diagnoses of PDD or PD-MCI, in the absence of cognitive assessment data, were not sufficient measures of cognitive function, nor were self-report measures of cognitive function. Studies were required to have statistically analysed the relationships between anxiety and cognition.

Search Results

The search returned a total of 3883 records: 113 from CINAHL; 1266 from Medline; 740 from PsycINFO and 1764 from Web of Science. After removing duplicates, 1604 records remained. Screening by titles and abstracts left 158 papers, which were read in full and assessed against the inclusion and exclusion criteria. This left 39 papers which were eligible for inclusion in the review. Manual searches did not identify any further papers for inclusion. Figure 1.1 shows the study selection process.

< INSERT FIGURE 1.1 >

Assessment of Risk of Bias

The PRISMA statement (Moher et al., 2009) and its associated *Explanation and Elaboration* paper (Liberati et al., 2009) state that the methodological quality of the studies included in a systematic review should be assessed to gain an understanding of the risk of bias in each study, which may influence the findings of the review. Numerous tools exist for assessing risk of bias, with Sanderson, Tatt and Higgins (2007) identifying 86 different tools for assessing the methodological quality of observational studies. In this review, an adapted version of a tool developed for assessing the risk of bias in observational studies by the Agency for Healthcare Research and Quality (Williams, Plassman, Burke, Holsinger &

Benjamin, 2010) was utilised. This tool was originally designed for research into cognitive decline among people with Alzheimer’s disease. The tool was selected due to its applicability to observational studies and the overlap in the research questions concerning neurodegenerative conditions and cognitive decline. Furthermore, the tool uses a qualitative rating system based upon the presence or absence of bias-related issues, rather than numerical summary scores. This allows the quality issues consistently affecting the research in the topic area to be identified, which is more meaningful to the findings of the review (Jüni, Witschi, Bloch, and Egger, 1999; Liberati et al., 2009).

Some small adaptations to Williams et al.’s (2010) tool were required to ensure its relevance to the current research question. For example, items relating to “intervention” or “exposure” were removed since these were not applicable to the research question, as described above. The original 11-item tool, with descriptions of what should be considered when rating each item, is attached in Appendix 1C. A table explaining the adaptations made to the tool for this review is attached in Appendix 1D, and the final adapted eight-item tool is displayed in Table 1.2.

<INSERT TABLE 1.2>

Each study was given a rating of “yes” (y), “no” (n), “partially” (p), “can’t tell” (c) or “not applicable” (n/a) for each item. The risk of bias assessment was completed by the author, and a subset of the papers were also assessed by a trainee clinical psychologist colleague, who acted as a second reviewer to check the author’s fidelity to the tool. The second reviewer’s appraisals are attached in Appendix 1E. No differences in ratings were noted between reviewers. No studies were excluded from the review based on their risk of bias, since awareness of the methodological quality of the papers was valuable for developing

an understanding of the overall picture of research pertaining to the research question (Jüni et al., 1999). However, quality was considered when synthesising the results.

Data Extraction

Data were extracted from the papers by the author. The information collected for each paper included: study design and methods of data analysis; a description of the sample including country of recruitment, sample size, sex distribution, age of participants and time since diagnosis; tools used to measure anxiety and cognition; and a summary of the relevant results (findings from all reported analyses of relationships between anxiety and cognition variables).

Results

Characteristics of Studies

The characteristics of the studies included in this review are reported in Table 1.3. The characteristics reported are those relevant to the analyses pertaining to the research question of this review where these are different to the study as a whole (for example, sometimes the relevant analyses only used a subset of the participants).

The studies were published between 1993 and 2019. Ten of the 39 studies were conducted in the USA, six in the UK, three in Italy and three in China. Other studies were conducted in Australia, Brazil, Canada, Croatia, Egypt, France, Israel, Malaysia, the Netherlands, Portugal and Taiwan. Two studies recruited internationally (Petkus, Filoteo, Schiehser, Gomez & Petzinger, 2019; Starkstein et al., 2014). Most of the studies were cross-sectional, either in their overall design or in the design of the analyses pertaining to the question of this review. Only two of the papers (Petkus et al., 2019; Rutten et al., 2017) reported relevant longitudinal analyses. Many of the studies measured the relationships between the variables of interest using correlation or regression analyses, while others compared the means of groups of participants split by cognitive abilities or anxiety levels.

Sample sizes ranged from 22 to 468 participants. Apart from two studies, females made up 24-53% of the samples, suggesting that the sex distribution of the population of people with Parkinson's (Wooten, Currie, Bovbjerg, Lee & Patrie, 2004; Moisan et al., 2016) was generally reflected in the samples. In one study (Starkstein, Robinson, Leiguarda & Preziosi, 1993), it was not possible to ascertain the sex distribution of participants due to inconsistencies in the participant information table. Ryder et al. (2002) recruited male participants only. The average age of participants ranged from 59 to 77 years. Where reported, the average number of years since diagnosis ranged from zero to 13 across the studies, with four of the 39 studies specifically investigating newly-diagnosed or early-stage Parkinson's (Dissanayaka et al., 2017; Hu et al., 20014; LaBelle, Walsh & Banks, 2017; Rutten et al., 2017). Ten of the papers did not report participants' time since diagnosis.

Self-report tools used for measuring anxiety included the Beck Anxiety Inventory (BAI; Beck, Epstein, Brown & Steer, 1988), Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), Hamilton Anxiety Rating Scale (HAM-A; Hamilton, 1959), Leeds Anxiety and Depression Scale (LADS; Snaith, Bridge & Hamilton, 1976), Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS; Goetz et al., 2007), Neuropsychiatric Inventory (NPI; Cummings et al., 1994), State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, Lushene, Vagg & Jacobs, 1983), Symptom Checklist-90-Revised (SCL-90-R; Derogatis, 1994), and the anxiety subscale of the Geriatric Depression Scale (GDS; Adams, Matto & Sanders, S, 2004; Yesavage et al., 1982). Structured clinical interviews used to identify the presence or absence of clinical levels of anxiety included variations of the Mini-International Neuropsychiatric Interview (MINI, MINI-plus; Sheehan et al., 1998) and the Chinese-Bilingual Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders—4th Edition (CB-SCID-DSM-IV; So et al., 2003).

A multitude of tools were used to measure cognition. Thirteen of the studies used only a summary score from a measure of global cognition – the Mini-Mental State Exam (MMSE; Folstein, Folstein & McHugh, 1975) or the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005) - in the relevant analyses (although other studies included global measures as part of their battery of tests). Five studies used batteries of tests to assess participants for PD-MCI, then analysed relationships between PD-MCI status and anxiety. The remaining studies analysed relationships between anxiety and single subtest and/or cognitive domain scores.

The relationship between anxiety and cognition was a main research question in 21 of the studies. In the remaining 18 studies, the relationship was analysed as a supplement to the main research question, for example to check whether anxiety was a confounding variable in some other relationship.

< INSERT TABLE 1.3 >

Quality Assessment

Table 1.4 shows the quality assessment ratings given for each of the reviewed studies, using the adapted version of the quality appraisal tool by Williams et al. (2010).

< INSERT TABLE 1.4 >

To be rated “yes” for sample representativeness and validity, studies were required to specify appropriate inclusion and exclusion criteria, recruit from more than one source, explain how participants were confirmed to have a diagnosis of Parkinson’s, and describe the characteristics of the sample including age, gender and time since diagnosis. Thirteen studies

met these criteria. The study by Ryder et al. (2002) had a small, all-male sample, recruited from one source, therefore was not considered to be representative of the population of people with Parkinson's, and the study by Foster et al. (2010) did not report how participants were recruited, nor how their Parkinson's diagnosis was confirmed. The remaining studies were missing only one of the criteria for this item, therefore were rated "partial".

Almost all studies adequately described their samples in terms of age and gender, however ten of the studies lacked information about time since diagnosis. This was considered an important oversight, since both cognition and anxiety have been found to be related to disease duration (Stefanova, Ziropadja, Petrovic, Stojkovic & Kostic, 2013; Verbaan et al., 2007). The study by Starkstein et al. (1993) was unclear in the reporting of demographic information, with some inconsistencies in the participant information table. The study by Manor, Balas, Giladi, Mootanah and Cohen (2009) adequately described the sample for their main research question, but not the subset of the sample upon which the analyses relevant to this review were based.

Eighteen of the samples were limited in their representativeness through recruiting from only one clinic or site. Pauletti et al. (2017) did not describe from where they recruited their sample. The remaining studies recruited from multiple sites or large databases.

The "comparable groups" item was only relevant to the sixteen studies which split participants into groups. A "partial" rating was given to the eight studies which demonstrated a degree of demographic similarity between groups, and a "yes" rating was given to the five studies where groups were demonstrated to be comparable in all measured variables apart from the experimental variables, or where differences in groups were controlled for within the analyses. In three studies, there was insufficient evidence to assess the comparability of groups.

Only one study (Klepac, Hajnšek & Trkulja, 2010) reported a power analysis – though not for the part of the analysis relevant to this review. However, for studies which used simple analyses and clearly reported the parameters of the data, it could be established whether sample sizes were large enough to detect medium effects at 80% power for $p < .05$. For other studies this could not be achieved with the information available. Eight studies were found to be adequately powered, ten studies were found not to be adequately powered, and 21 were rated “can’t tell”. Six of the ten underpowered studies (according to my power calculations), found significant effects, therefore power was not an issue in these cases.

To be rated “yes” on the “measures” item of the quality assessment, it was required that authors reported the conditions in which cognitive assessments took place, that these were consistent across participants, and that the individual(s) administering and scoring the assessments were adequately qualified to do so. Eleven studies met these criteria. The remaining studies were rated “can’t tell” due to a lack of clarity in reporting.

Given that all studies were observational, uncontrolled trials, it was expected to be difficult to identify and control for all possible confounding variables. However, all studies reported some consideration of potential confounding variables, thus were rated “partial”. The method of data analysis was judged to be appropriate in all the included studies.

Synthesis of Findings

Anxiety and global cognition. Of 33 analyses which compared scores on a measure of global cognition to scores on a measure of anxiety (from 26 studies, as some studies used multiple measures), 22 did not identify significant relationships between anxiety and cognition. However, only six of the 22 analyses with non-significant results could be confirmed to be adequately powered, suggesting that several studies may have failed to find an effect due to their samples being too small. However, some analyses had sufficient participants to detect an effect, but did not, indicating that some other factors were involved

in whether a relationship was detected (or existed for that particular group). Upon comparison of the studies which did and did not find effects, it was not obvious what these factors might be.

The 11 analyses (from ten studies) which found significant relationships, all found higher levels of anxiety to be associated with higher levels of global impairment. Most of these were correlation analyses. A regression analysis controlling for age, sex, and education found higher LADS anxiety scores to significantly predict lower scores (indicating greater impairment) on the MoCA (Hu et al., 2014). Trait anxiety was also found to account for a significant proportion of variance in total scores on the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS; Randolph, Tierney, Mohr & Chase, 1998) when controlling for depression (Ryder et al., 2002). When participants were split by MoCA scores, participants with low MoCA scores (indicating more cognitive impairment) had significantly higher HAM anxiety ratings (indicating a higher level of anxiety) than participants with high MoCA scores (Zhang et al., 2016). When participants were split by levels of trait anxiety on the STAI, the high trait anxiety group showed significantly more impairment on the MMSE than the low trait anxiety group (Manor et al., 2009). Additionally, lower MoCA scores at baseline were associated with an increase in state anxiety, as measured by the STAI, over a two-year period (Rutten et al., 2017). In summary, although there were inconsistencies as to whether relationships were found (sometimes within studies, depending on the measures used), the relationships identified were consistent in nature and appeared to be bi-directional.

Anxiety and PD-MCI. Three of the five studies which assessed participants for PD-MCI found no significant relationships between PD-MCI status and anxiety (Leroi, Pantula, McDonald & Harbishettar, 2012; Mamikonyan et al., 2009; Monastero, Di Fiore, Ventimiglia, Camarda & Camarda, 2013). Participants were grouped differently in each of

these studies. Leroi et al. (2012) studied differences between no cognitive impairment, PD-MCI and PDD groups, Mamikonyan et al. (2009) looked for predictors of PD-MCI (compared to no PD-MCI) and Monastero et al. (2013) compared non-cognitively-impaired, amnesic PD-MCI and non-amnesic PD-MCI groups.

Baschi et al. (2018) found a significant effect of group membership on anxiety, in a study examining the correlates of subjective memory complaints (SMC) for participants with and without PD-MCI. Participants were divided into four groups: PD-MCI with SMC; PD-MCI without SMC; no PD-MCI but SMC; and neither PD-MCI nor SMC. Participants in the PD-MCI with SMC group were significantly more likely to report clinical levels of anxiety than participants with neither PD-MCI nor SMC. However, there was no significant difference in anxiety prevalence between participants with PD-MCI without SMC and participants with neither PD-MCI nor SMC. These findings suggest that the relationship between anxiety and PD-MCI may be influenced by an awareness or perception of cognitive decline. A further study by Dissanayaka et al. (2017) grouped participants by the presence or absence of anxiety using the MDS-UPDRS, and tested a range of cut-offs for classifying PD-MCI. The Movement Disorder Society Task Force criteria (Litvan et al., 2012) specify that impairment should be between one and two standard deviations (SD) below normative values for individuals to be classed as having PD-MCI. Dissanayaka et al. (2017) found that participants with anxiety were three times more likely than those without anxiety to show PD-MCI using the 1SD cut-off, controlling for age, education and motor severity. However, anxiety did not significantly predict PD-MCI when cut-offs of 1.5SD and 2SD were used (the authors suggested this to be attributable to the small sample size).

Anxiety and cognitive domains. The findings concerning relationships between anxiety and cognitive domains are collated in Table 1.5. Because the studies were not directly comparable in terms of measures used, sample demographics or overall quality, the columns

stating the numbers of studies with and without significant results are intended to summarise the findings, rather than to indicate the strength of the evidence.

< INSERT TABLE 1.5 >

Attention. Of the 11 studies that reported using measures of attention, only three found significant relationships with anxiety. Hepp et al. (2013) found anxiety to be significantly but weakly correlated with part A of the Trail Making Test (TMT-A; Reitan & Wolfson, 1985), which was used to assess visual attention. Higher anxiety was associated with a longer time taken to complete the task, suggesting greater attentional impairment, though this may also have been related to other factors such as reduced psychomotor speed (Muslimović, Post, Speelman & Schmand, 2005). Similarly, Klepac et al. (2010) found higher anxiety to be an independent predictor of worse performance on TMT-A. However, other studies that used TMT-A found no association with anxiety (Ehgoetz Martens et al., 2016; Reynolds, Hanna, Nearing & Cronin-Golomb, 2017), though it should be noted that these studies had particularly small sample sizes, reducing the power of their analyses to detect effects. Ehgoetz Martens, Silveira, Intzandt and Almeida (2018) found a significant relationship between state anxiety and an attention/working memory domain, however the tests used did not primarily measure attention, therefore these results are reported in the next section.

Working memory. Five studies used measures of working memory, of which three found significant relationships with anxiety. Ehgoetz Martens et al. (2018) calculated attention/working memory domain scores using the Corsi Block Test, which is primarily a visuospatial short-term memory task (Corsi, 1973), and the Digit Span backwards test from the Wechsler Adult Intelligence Scale-4th Edition, designed to test working memory (WAIS-

IV, Wechsler, 2008). Higher state anxiety significantly predicted worse performance in this domain. Also using the Digit Span task, Ehgoetz Martens (2016) found significantly worse working memory in participants “with anxiety” (indicated by HADS anxiety scores above 8) scores compared to those “without anxiety”. Foster et al. (2010) found a significant interaction of side of onset (right or left) and anxiety (high or low) on Digit Span score, with participants with left-hemibody onset and high anxiety scoring significantly lower on Digit Span than those with left-hemibody onset with low anxiety (with disease duration entered as a covariate). Meanwhile, participants with left-hemibody onset and high anxiety scored significantly lower than participants with right-hemibody onset and high anxiety, suggesting that side of onset is a factor in the relationship between anxiety and working memory for people with Parkinson’s.

Klepac et al. (2010) and Reynolds et al. (2017) also used the Digit Span task to measure working memory, but did not find significant relationships with anxiety. Reynolds et al.’s (2017) study was underpowered for its correlation analysis, therefore the lack of effect may have been due to the small sample size. It could not be established whether Klepac et al.’s (2010) study was adequately powered for its multiple regression analysis.

Executive functioning. Of the ten studies that used measures of executive functioning, five found significant relationships with anxiety. There was inconsistency among the findings, with two of three studies using versions of the Stroop task (e.g. Golden, 1978) and three of four studies using Part B of the Trail Making Task (TMT-B; Reitan & Wolfson, 1985) finding significant effects. These tasks measure elements of cognitive flexibility: response inhibition on the Stroop, and set-shifting on the TMT-B. Reynolds et al. (2017) found that higher anxiety correlated significantly with poorer set-shifting (TMT-B), even after removing the psychomotor component. Klepac et al. (2010) and Ehgoetz Martens et al. (2018) both found higher anxiety to significantly predict worse performance on

executive tasks, with Ehgoetz Martens et al. (2018) controlling for age, depression and symptom severity within their analysis. Comparing groups with and without anxiety, as described above, Ehgoetz Martens et al. (2016) found the group without anxiety to perform significantly better on TMT-B. There were also significant but weak correlations found between anxiety and performance on the executive functioning domain of the Brazilian version on the Scales for Outcomes in Parkinson's Disease – Cognition (SCOPA-COG; Carod-Artal, Martínez-Martin, Kummer & da Silveira Ribeiro, 2008), with lower levels of anxiety correlating with better performance.

Five studies (Athey et al., 2005; Bugalho, da Silva, Cargaleiro, Serra & Neto, 2012; Dissanayaka et al., 2017; Fonoff et al., 2015; Schiehser et al., 2009) did not find significant relationships between anxiety and tests of executive function. Only one of these (Athey et al., 2005) could be confirmed to be adequately powered.

Memory. Eleven studies investigated the relationship between anxiety and memory, of which five found significant effects. Carod-Artal et al. (2008) found a weak but significant correlation between higher anxiety and lower scores on the SCOPA-COG memory domain (indicating worse memory). Three further significant findings (Ehgoetz Martens et al., 2018; Klepac et al., 2010; Ryder et al., 2002) came from regression analyses, with higher anxiety predicting worse memory performance in each case across tests of both verbal and visual memory, when controlling for appropriate variables. In the study by Dissanayaka et al. (2017), where memory impairment was a dichotomous dependent variable in a logistic regression analysis, the relationship between anxiety and memory was significant when the cut-off for impairment was set at one SD below the normative mean, but not when the cut-off was set at 1.5 or 2SD. The authors suggested that this may have been due to the small sample.

Ehgoetz Martens et al. (2016) found that the relationship between anxiety and performance on an immediate story recall task was approaching significance at the 5% level,

but that the relationship between anxiety and delayed story recall was not significant. Five further studies found no significant relationships between anxiety and memory (Athey et al., 2005; Brown & Fernie, 2015; Gao et al., 2015; Hurt et al., 2012; Sarno et al., 2019). Sample size did not appear to be a problem in these studies, and there were no obvious differences in the design or quality between these studies and those which did find significant effects. Therefore, the relationship between anxiety and memory for people with Parkinson's may be complex and influenced by other variables.

Language. Seven studies used tasks aimed at assessing language skills, including naming, fluency and verbal comprehension. Two of these found significant effects. Ehgoetz Martens et al. (2018) found that state anxiety, but not trait anxiety, predicted performance on language tasks after controlling for age, depression, and motor symptom severity. Conversely, Ryder et al. (2002) found that trait anxiety accounted for a significant proportion of the variance in language scores after controlling for depression (they did not measure state anxiety). Five studies (Athey et al., 2005; Brown & Fernie, 2015; Dissanayaka et al., 2017; Hurt et al., 2012; Sarno et al., 2019) did not find significant relationships between anxiety and performance on language tasks, and this did not seem to be attributable to any particular design or quality issues.

Bogdanova and Cronin-Golomb (2012) examined the interaction between side of Parkinson's onset and performance on verbally-mediated and non-verbally-mediated tasks. It was found that anxiety strongly correlated with performance on verbally mediated tasks in right-side onset Parkinson's, with better cognitive performance associated with lower levels of anxiety.

Verbal fluency. In some studies, semantic and phonemic verbal fluency tasks were used alongside other tasks to obtain domain scores for executive functioning and language abilities, and so are reported in the sections above. In seven studies the analyses relating

specifically to the relationship between verbal fluency and anxiety were extractable, but only one of these found a significant effect: Klepac et al. (2010) found higher anxiety to significantly predict worse semantic (but not phonemic) fluency. There were no obvious factors differentiating this study different from those which found no significant effects (Brown & Fernie, 2015; Ehgoetz Martens et al., 2016; Hepp et al., 2013; Hurt et al., 2012; Reynolds et al., 2017; Sarno et al., 2019).

Visuospatial abilities. Visuospatial abilities, assessed by tasks where participants were asked to copy simple line drawings and judge the orientation of lines, were found to be significantly related to anxiety in two of the nine relevant studies. Higher anxiety was weakly associated with better performance in this domain (Carod-Artal et al., 2008) and accounted for a significant proportion of variance after controlling for depression (Ryder et al., 2002). Again, there were no obvious factors making these studies different to those which found no significant effects (Athey et al., 2005; Brown & Fernie, 2015; Dissanayaka et al., 2017; Ehgoetz Martens et al., 2018; Hurt et al., 2012; Klepac et al., 2010; Sarno et al., 2019).

Bi-directional findings. The only study examining bi-directional relationships was by Petkus et al. (2019). This was a particularly robust study in terms of quality, with a large, international sample; it was also one of only two longitudinal studies. Using bivariate latent change modelling, Petkus et al. (2019) found worse cognitive performance (in the domains of attention, working memory, episodic memory and semantic fluency) to be significantly associated with subsequently higher state and trait anxiety. The strongest association was in the domain of working memory. Conversely, they found that higher state and trait anxiety scores were not significantly associated with subsequent declines in cognitive performance over time. These findings suggest a causal influence of cognitive factors upon anxiety over time.

Discussion

This review considers the evidence regarding relationships between anxiety and cognition for people with Parkinson's. Previous reviews (Alzahrani & Venneri, 2015; Lutz et al., 2016; Poletti, De Rosa & Bonuccelli, 2012) have addressed this question but have found minimal research in this area (between one and three studies), whereas the current review found 39. This review has unearthed many relevant papers not included in the previous reviews by increasing the specificity of the question, using broad inclusion criteria and an expansive list of search terms to identify cognitive data. This review also identified several relevant studies published since the publication of the previous reviews.

The nature of relationships between anxiety and cognition was similar in all studies with significant results: higher levels of anxiety (or the presence of anxiety) was consistently associated with more cognitive impairment (or the presence of cognitive impairment), while lower levels of anxiety (or the absence of anxiety) was consistently associated with better cognitive performance (or the absence of cognitive impairment). However, there were inconsistencies as to whether significant results were identified, even in studies using apparently similar methodologies. It is likely that these inconsistencies were influenced by the wide range of tools used to measure both anxiety and cognition, differences in the demographics of the samples, and differences in the quality of the studies (of particular note, many of the studies had small samples, reducing their power to detect effects).

Significant correlations were identified between anxiety and cognition (global cognition, PD-MCI status and the cognitive domains of attention, working memory, executive functioning, memory, language, semantic verbal fluency and visuospatial abilities). This suggests that, at least in some circumstances, there is some relationship between these variables for people with Parkinson's. Moreover, significant predictive relationships and group differences in means between anxiety and cognition were found (given that all studies

were observational, no causal relationships could be inferred). Most studies of these designs took cognitive findings as their dependent variables, though some took anxiety. There were significant findings in both directions. This is in keeping with findings in other (and potentially overlapping) populations such as older adults (Mantella et al., 2007; Yochim et al., 2013), and people with other neurological conditions (Barker-Collo, 2007; Gould et al., 2014; Julian & Arnett, 2009; Simioni et al., 2007).

There are various potential explanations for the relationships identified between anxiety and cognition. Several authors have suggested that neuroanatomical factors play a role, highlighting that the striatum and prefrontal circuits projecting to ventral areas of the brain, which are affected by Parkinson's, are important for both cognition and anxiety regulation (Lago, Davis, Grillon, & Ernst, 2017; Sylvester et al., 2012). A cognitive perspective may suggest that anxiety limits the resources available for cognitive activity (Vytal et al., 2012), and that cognitive impairments (particularly with executive functioning) lead to difficulties with identifying and managing stressors (Petkus et al., 2019) and implementing strategies to reduce anxiety (Yochim et al., 2013). From a psychological perspective, the findings of Baschi et al. (2018) and Petkus et al. (2019) suggest that an awareness or perception of cognitive decline can be a source of anxiety for people with Parkinson's.

Limitations of the Included Studies

In addition to the limitations described above, there were some limitations concerning the validity of the variables. Although all studies used validated measures, not all could be confirmed to have been sufficiently validated for use with people with Parkinson's. Skorvanek et al. (2017) reviewed global cognitive measures commonly used with people with Parkinson's. Of significance to this review, the RBANS, CAMCOG and MMSE were not recommended due to problems with, or lack of evidence for, validity, reliability and

sensitivity to change. Cognitive assessments have also been shown to lack ecological validity, scores not always predicting how people perform in complex real-life situations (Burgess, Alderman, Evans, Emslie & Wilson, 1998). Therefore, studies may not have provided an accurate representation of participants' cognitive abilities.

Additionally, despite evidence that symptoms of anxiety and depression commonly co-occur among people with Parkinson's (Sagna, Gallo & Pontone, 2014), and the well-evidenced relationship between depression and cognition (Alzahrani & Venneri, 2015; Poletti et al., 2012), relatively few of the identified studies attempted to control for symptoms of depression in their analyses. Indeed, although some studies did control for potentially confounding variables, it cannot be concluded that any of the studies were able to isolate anxiety as a variable, as discussed in the *Quality Assessment* section.

Limitations of this Review

A common criticism of systematic literature reviews is the likelihood of heterogeneity, making it difficult to synthesise the data in a truly meaningful way and reach a clear conclusion (Biondi-Zoccai, Lotrionte, Landoni, & Modena, 2011; Gopalakrishnan & Ganeshkumar, 2013). There was certainly evidence of heterogeneity in the samples, methodologies and findings in the current review. This is reflected in the variation among studies as to whether significant results were found. Further clarification might have been gained by considering effect sizes and conducting meta-analyses on some of the findings.

It should also be highlighted that there was a great deal of variation in the cognitive assessment measures used across the studies, from very crude global measures such as the MoCA and MMSE, to highly sensitive measures of specific cognitive functions. There was also some variation between studies in the cut-off scores or normative data adopted for each measure. These differences in the measurement of cognition are likely to have contributed to

some of the variation in the findings of the studies, and therefore to the validity of the overall findings of this review.

The method of synthesising findings by cognitive domain in this review is also likely to have had an impact on the findings. The domains were selected based on which function the authors of the papers intended to measure with each cognitive test. However, cognitive assessments tend to load onto more than one cognitive domain. For example, verbal fluency was considered by some studies a cognitive domain in its own right; in others, a component of executive functioning or language abilities. The findings of this review are therefore likely to have been affected by how the cognitive domains were conceptualised. A more rigorous conceptualisation may have been achieved by grouping the tests in a consistent way. For example, by using the compendium of cognitive tests by domain according to Lezak, Howieson, Bigler and Tranel (2012).

Clinical Implications

The findings of this review have implications for clinical psychologists and neuropsychologists working with people with Parkinson's, in keeping with BPS recommendations for a holistic approach to considering the cognitive, psychological and social factors affecting people with Parkinson's (Macniven & Gaskill, 2009). Given the seemingly bidirectional relationship between anxiety and cognition, psychological assessment of either factor should include due consideration of the other. Exploration of relationships between anxiety and cognitive factors at the individual level might point towards the utility of certain psychological interventions. For example, if an awareness of cognitive decline is a source of anxiety, psychoeducation and psychological models focussing on acceptance, such as acceptance and commitment therapy (ACT) and mindfulness, may have a role. A systematic review found ACT to be a promising intervention for long term and chronic conditions (Graham, Gouick, Krahe & Gillanders, 2016), whilst qualitative research

has suggested that a mindfulness-based cognitive therapy group was an acceptable intervention for people with people with Parkinson's (Fitzpatrick, Simpson & Smith, 2010). Furthermore, interventions focussing on anxiety should be adapted according to each individual's cognitive abilities (Knight, Dissanayaka & Pachana, 2016).

Research Implications

Given that the findings of the studies included in this review were somewhat inconsistent as to whether relationships between anxiety and cognition were found, it is likely that other variables affect or are involved in their interaction. As such, more complex models may be useful in future research for developing understanding of how anxiety and cognition interact among people with Parkinson's. Variables for inclusion in these models might include depression, side of onset, time since diagnosis and subjective cognitive performance. Qualitative research into the psychological impact of cognitive decline for people with Parkinson's might identify further areas for exploration.

Conclusions

A systematic review of the literature found inconsistent evidence for a relationship between anxiety and cognition among people with Parkinson's. The quality of studies was variable, with many studies having small samples, possibly contributing to the lack of consistency as to whether significant relationships were found. The significant relationships identified were consistent in nature, and suggested a bidirectional relationship between anxiety and cognition, with higher anxiety associated with more cognitive impairment. Clinicians working with people with Parkinson's should consider the potential interaction between these factors in assessments and interventions. Future research should focus on better understanding the relationship between anxiety and cognition among people with Parkinson's through more complex quantitative models and qualitative research.

References

- Aarsland, D., Bronnick, K., Williams-Gray, C., Weintraub, D., Marder, K., Kulisevsky, J., ... & Emre, M. (2010). Mild cognitive impairment in Parkinson's disease: A multicenter pooled analysis. *Neurology*, 75(12), 1062–1069. Doi: 10.1212/WNL.0b013e3181f39d0e
- Adams, K. B., Matto, H. C., & Sanders, S. (2004). Confirmatory factor analysis of the geriatric depression scale. *The Gerontologist*, 44(6), 818-826. Doi: 10.1093/geront/44.6.818
- Alzahrani, H. & Venneri, A. (2015). Cognitive and neuroanatomical correlates of neuropsychiatric symptoms in Parkinson's disease: A systematic review. *Journal of the Neurological Sciences*, 356(1-2), 32-44. Doi: 10.1016/j.jns.2015.06.037
- Athey, R. J., Porter, R. W., & Walker, R. W. (2005). Cognitive assessment of a representative community population with Parkinson's disease (PD) using the Cambridge Cognitive Assessment–Revised (CAMCOG-R). *Age and Ageing*, 34(3), 268–273. Doi: 10.1093/ageing/afi098
- Barker-Collo, S. L. (2007). Depression and anxiety 3 months post stroke: Prevalence and correlates. *Archives of Clinical Neuropsychology*, 22(4), 519–531. Doi: 10.1016/j.acn.2007.03.002
- Baschi, R., Nicoletti, A., Restivo, V., Recca, D., Zappia, M., & Monastero, R. (2018). Frequency and correlates of subjective memory complaints in Parkinson's disease with and without mild cognitive impairment: Data from the Parkinson's disease cognitive impairment study. *Journal of Alzheimer's Disease*, 63(3), 1015-1024. Doi: 10.3233/JAD-171172

- Beck, A.T., Epstein, N., Brown, G., & Steer, R.A. (1988). An inventory for measuring clinical anxiety: Psychometric properties. *Journal of Consulting and Clinical Psychology*, 56(6), 893-897. Doi: 10.1037/0022-006X.56.6.893
- Biondi-Zoccai, G., Lotrionte, M., Landoni, G., & Modena, M. G. (2011). The rough guide to systematic reviews and meta-analyses. *HSR Proceedings in Intensive Care & Cardiovascular Anesthesia*, 3(3), 161–173. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/23439862>
- Bogdanova, Y., & Cronin-Golomb, A. (2012). Neurocognitive correlates of apathy and anxiety in Parkinson's disease. *Parkinson's Disease*, 2012. Doi: 10.1155/2012/793076
- Broen, M. P., Narayan, N. E., Kuijf, M. L., Dissanayaka, N. N. and Leentjens, A. F. (2016). Prevalence of anxiety in Parkinson's disease: A systematic review and meta-analysis. *Movement Disorders*, 31(8), 1125-1133. Doi: 10.1002/mds.26643
- Brown, R. G., & Fernie, B. A. (2015). Metacognitions, anxiety, and distress related to motor fluctuations in Parkinson's disease. *Journal of Psychosomatic Research*, 78(2), 143-148. Doi: 10.1016/j.jpsychores.2014.09.021.
- Bugalho, P., da Silva, J. A., Cargaleiro, I., Serra, M., & Neto, B. (2012). Psychiatric symptoms screening in the early stages of Parkinson's disease. *Journal of Neurology*, 259(1), 124-131. Doi: 10.1007/s00415-011-6140-8
- Burgess, P. W., Alderman, N., Evans, J., Emslie, H., & Wilson, B. A. (1998). The ecological validity of tests of executive function. *Journal of the International Neuropsychological Society*, 4(6), 547-558. Doi: 10.1017/S1355617798466037
- Butterfield, L. C., Cimino, C. R., Oelke, L. E., Hauser, R. A., & Sanchez-Ramos, J. (2010). The independent influence of apathy and depression on cognitive functioning in Parkinson's disease. *Neuropsychology*, 24(6), 721–730. Doi: 10.1037/a0019650

- Carod-Artal, F. J., Martínez-Martin, P., Kummer, W., & da Silveira Ribeiro, L. (2008). Psychometric attributes of the SCOPA-COG Brazilian version. *Movement Disorders*, 23(1), 81-87. Doi: 10.1002/mds.21769
- Caviness, J. N., Driver-Dunckley, E., Connor, D. J., Sabbagh, M. N., Hentz, J. G., Noble, B., ... & Adler, C. H. (2007). Defining mild cognitive impairment in Parkinson's disease. *Movement Disorders*, 22(9), 1272-1277. Doi: 10.1002/mds.21453
- Chen, Y. K., Lu, J. Y., Chan, D. M. L., Mok, V. C. T., Wong, K. S., Ungvari, G. S., ... & Yeung, M. A. (2010). Anxiety disorders in Chinese patients with Parkinson's disease. *The International Journal of Psychiatry in Medicine*, 40(1), 97-107. Doi: 10.2190/PM.40.1.h
- Corsi, P. M. (1973). Human memory and the medial temporal region of the brain. *Dissertation Abstracts International*, 34(2-B), 819. Retrieved from: <https://psycnet.apa.org/record/1976-04900-001>
- Derogatis, L. R. (1994). *SCL-90-R: Administration, scoring and procedures manual* (3rd ed.). Minneapolis: NCS Pearson.
- D'iorio, A., Maggi, G., Vitale, C., Trojano, L., & Santangelo, G. (2018). "Pure apathy" and cognitive dysfunctions in Parkinson's disease: A meta-analytic study. *Neuroscience and Biobehavioral Reviews*, 94, 1-10. Doi: 10.1016/j.neubiorev.2018.08.004
- Dissanayaka, N. N. W., Lawson, R. A., Yarnall, A. J., Duncan, G. W., Breen, D. P., Khoo, T. K., ... & Burn, D. J. (2017). Anxiety is associated with cognitive impairment in newly-diagnosed Parkinson's disease. *Parkinsonism & Related Disorders*, 36, 63-68, Doi: 10.1016/j.parkreldis.2017.01.001
- Dissanayaka, N. N. W., White, E., O'Sullivan, J. D., Marsh, R., Silburn, P. A., Copland, D. A., ... & Byrne, G. J. (2015). Characteristics and treatment of anxiety disorders in

- Parkinson's disease. *Movement Disorders Clinical Practice*, 2(2), 155–162. Doi: 10.1002/mdc3.12157
- Egger, M., Juni, P., Bartlett, C., Holenstein, F., & Sterne, J. (2003). How important are comprehensive literature searches and the assessment of trial quality in systematic reviews? Empirical study. *Health Technology Assessment*, 7(1), 1-76. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/12583822>
- Elhgoetz Martens, K. A., Silveira, C. R. A., Intzandt, B. N., & Almeida, Q. J. (2018). State anxiety predicts cognitive performance in patients with Parkinson's disease. *Neuropsychology*, 32(8), 950–957. Doi: 10.1037/neu0000478
- Elhgoetz Martens, K. A., Szeto, J. Y. Y., Muller, A. J., Hall, J. M., Gilat, M., Walton, C. C., & Lewis, S. J. G. (2016). Cognitive function in Parkinson's disease patients with and without anxiety. *Neurology Research International* (2016), Doi: 10.1155/2016/6254092
- Elgh, E., Domellof, M., Linder, J., Edstrom, M., Stenlund, H., & Forsgren, L. (2009). Cognitive function in early Parkinson's disease: A population-based study. *European Journal of Neurology*, 16, 1278–1284. Doi: 10.1111/j.1468-1331.2009.02707.x
- Fahn, S. (2011). Classification of movement disorders. *Movement Disorders*, 26(6), 947-957. Doi: 10.1002/mds.23759
- Fan, J-Y., Chang, B-L., & Wu, Y-R. (2016). Relationships among depression, anxiety, sleep, and quality of life in patients with Parkinson's disease in Taiwan. *Parkinson's Disease*, 2016, Doi: 10.1155/2016/4040185
- Fengler, S., Liepelt-Scarfone, I., Brockmann, K., Schäffer, E., Berg, D., & Kalbe, E. (2017). Cognitive changes in prodromal Parkinson's disease: A review. *Movement Disorders*, 32(12), 1655-1666. Doi: 10.1002/mds.27135

- Fernandez, H. H., See, R. H., Gary, M. F., Bowers, D., Rodriguez, R. L., Jacobson IV, C., & Okun, M. S. (2009). Depressive symptoms in Parkinson disease correlate with impaired global and specific cognitive performance. *Journal of Geriatric Psychiatry and Neurology*, 22(4), 223-227. Doi: 10.1177/0891988709335792
- Fitzpatrick, L., Simpson, J., & Smith, A. (2010). A qualitative analysis of mindfulness-based cognitive therapy (MBCT) in Parkinson's disease. *Psychology and Psychotherapy: Theory, Research and Practice*, 83(2), 179-192. Doi: 10.1348/147608309X471514
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12(3), 189-198. Doi: 10.1016/0022-3956(75)90026-6
- Fonoff, F. C., Fonoff, E. T., Barbosa, E. R., Quaranta, T., Machado, R. B., de Andrade, D. C., ... & Fuentes, D. (2015). Correlation between impulsivity and executive function in patients with Parkinson disease experiencing depression and anxiety symptoms. *Journal of Geriatric Psychiatry and Neurology*, 28(1), 49–56. Doi: 10.1177/0891988714541870
- Foster, P. S., Drago, V., Yung, R. C., Skidmore, F. M., Skoblar, B., Shenal, B. V., ... & Heilman, K. M. (2010). Anxiety affects working memory only in left hemibody onset Parkinson disease patients. *Cognitive and Behavioral Neurology*, 23(1), 14-18. Doi: 10.1097/WNN.0b013e3181cc8be9
- Gao, L., Nie, K., Tang, H., Wang, L., Zhao, J., Gan, R., ... & Wang, L. (2015). Sex differences in cognition among Chinese people with Parkinson's disease. *Journal of Clinical Neuroscience*, 22(3), 488-492. Doi: 10.1016/j.jocn.2014.08.032
- Goetz, C. G., Fahn, S., Martinez-Martin, P., Poewe, W., Sampaio, C., Stebbins, G. T., ... & LaPelle, N. (2007). Movement Disorder Society-sponsored revision of the Unified

- Parkinson's Disease Rating Scale (MDS-UPDRS): Process, format, and clinimetric testing plan. *Movement Disorders*, 22(1), 41-47. Doi: 10.1002/mds.21198
- Golden, C. J. (1978). *Stroop Color and Word Test*. Chicago: Stoelting.
- Gopalakrishnan, S., & Ganeshkumar, P. (2013). Systematic reviews and meta-analysis: Understanding the best evidence in primary healthcare. *Journal of Family Medicine and Primary Care*, 2(1), 9–14. Doi:10.4103/2249-4863.109934
- Gould, K. R., Ponsford, J. L., & Spitz, G. (2014). Association between cognitive impairments and anxiety disorders following traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology*, 36(1), 1-14. Doi: 10.1080/13803395.2013.863832
- Graham, C. D., Gouick, J., Krahe, C., & Gillanders, D. (2016). A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions. *Clinical Psychology Review*, 46, 46-58. Doi: 10.1016/j.cpr.2016.04.009
- Hamilton, M. (1959). The assessment of anxiety states by rating. *British Journal of Medical Psychology*, 32, 50–55. Retrieved from:
<https://dcf.psychiatry.ufl.edu/files/2011/05/HAMILTON-ANXIETY.pdf>
- Hely, M. A., Reid, W. G., Adena, M. A., Halliday, G. M., & Morris, J. G. (2008). The Sydney multicenter study of Parkinson's disease: The inevitability of dementia at 20 years. *Movement Disorders*, 23(6), 837-844. Doi:10.1002/mds.21956
- Hepp, D. H., da Hora, C. C., Koene, T., Uitdehaag, B. M., van den Heuvel, O. A., Klein, M., ... & Foncke, E. M. (2013). Cognitive correlates of visual hallucinations in non-demented Parkinson's disease patients. *Parkinsonism & Related Disorders*, 19(9), 795-799. Doi: 10.1016/j.parkreldis.2013.04.026
- Hoffmann, T., Bennett, S., Koh, C. L., & McKenna, K.T. (2010). Occupational therapy for cognitive impairment in stroke patients. *Cochrane Database of Systematic Reviews*, 2010(9), 1-15. Doi: 10.1002/14651858.CD006430.pub2

- Hu, M. T., Szewczyk-Królikowski, K., Tomlinson, P., Nithi, K., Rolinski, M., Murray, C., ... & Ben-Shlomo, Y. (2014). Predictors of cognitive impairment in an early stage Parkinson's disease cohort. *Movement Disorders*, 29(3), 351–359. Doi: 10.1002/mds.25748
- Hurt, C., Landau, S., Burn, D., Hindle, J., Samuel, M., Wilson, K., & Brown, R. (2012). Cognition, coping, and outcome in Parkinson's disease. *International Psychogeriatrics*, 24(10), 1656-1663. Doi: 10.1017/S1041610212000749
- Julian, L. J., & Arnett, P. A. (2009). Relationships among anxiety, depression, and executive functioning in multiple sclerosis. *The Clinical Neuropsychologist*, 23(5), 794-804. Doi: 10.1080/13854040802665808
- Jüni, P., Witschi, A., Bloch, R., & Egger, M. (1999). The hazards of scoring the quality of clinical trials for meta-analysis. *Journal of the American Medical Association*, 282(11), 1054-1060. Doi: 10.1001/jama.282.11.1054
- Kehagia, A. A., Barker, R. A., & Robbins, T. W. (2010). Neuropsychological and clinical heterogeneity of cognitive impairment and dementia in patients with Parkinson's disease. *The Lancet Neurology*, 9(12), 1200-1213. Doi: 10.1016/S1474-4422(10)70212-X
- Khedr, E. M., El Fetoh, N. A., Khalifa, H., Ahmed, M. A., & El Beh, K. M. (2012). Prevalence of depression, anxiety, dementia and other non motor features of a large cohort of Egyptian Parkinson's disease patients. *Life Science Journal*, 9(2), 509-518. Retrieved from: http://www.lifesciencesite.com/ljsj/life0902/076_8764life0902_509_518.pdf
- Klepac, N., Hajnšek, S., & Trkulja, V. (2010). Cognitive performance in nondemented nonpsychotic Parkinson disease patients with or without a history of depression prior

- to the onset of motor symptoms. *Journal of Geriatric Psychiatry and Neurology*, 23(1), 15–26. Doi: 10.1177/0891988709351831
- Knight, B., Dissanayaka, N., & Pachana, N. (2016). Adapting psychotherapy for older patients with Parkinson's disease. *International Psychogeriatrics*, 28(10), 1631-1636. Doi: 10.1017/S1041610216000569
- LaBelle, D. R., Walsh, R. R., & Banks, S. J. (2017). Latent cognitive phenotypes in de novo Parkinson's disease: A person-centered approach. *Journal of the International Neuropsychological Society*, 23(7), 551–563. Doi: 10.1017/S1355617717000406
- Lago, T., Davis, A., Grillon, C., & Ernst, M. (2017). Striatum on the anxiety map: Small detours into adolescence. *Brain Research*, 1654, 177–184. Doi: 10.1016/j.brainres.2016.06.006
- Lawson, R. A., Yarnall, A. J., Duncan, G. W., Khoo, T. K., Breen, D. P., Barker, R. A., ... & Burn, D. J. (2014). Severity of mild cognitive impairment in early Parkinson's disease contributes to poorer quality of life. *Parkinsonism & Related Disorders*, 20(10), 1071-1075. Doi: 10.1016/j.parkreldis.2014.07.004
- Lee, W., Tsai, C., Gauthier, S., Wang, S., & Fuh, J. (2012). The association between cognitive impairment and neuropsychiatric symptoms in patients with Parkinson's disease dementia. *International Psychogeriatrics*, 24(12), 1980-1987. Doi: 10.1017/S1041610212001317
- Leroi, I., Pantula, H., McDonald, K., & Harbishettar, V. (2012). Neuropsychiatric symptoms in Parkinson's disease with mild cognitive impairment and dementia. *Parkinson's Disease*, 2012. Doi: 10.1155/2012/308097
- Lezak, M. D., Howieson, D. B., Bigler, E. D., & Tranel, D. (2012). *Neuropsychological assessment* (5th ed.). New York: Oxford University Press.

- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J.P., ... & Moher, D. (2009). The PRISMA Statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: Explanation and elaboration. *Journal of Clinical Epidemiology*, 62(10), e1-34. Doi: 10.1016/j.jclinepi.2009.06.006
- Litvan, I., Goldman, J. G., Tröster, A. I., Schmand, B. A., Weintraub, D., Petersen, R. C., ... & Emre, M. (2012). Diagnostic criteria for Mild Cognitive Impairment in Parkinson's disease: Movement Disorder Society Task Force guidelines. *Movement Disorders*, 27(3), 349-356. Doi:10.1002/mds.24893
- Lutz, S. G., Holmes, J. D., Ready, E. A., Jenkins, M. E., & Johnson, A. M. (2016). Clinical presentation of anxiety in Parkinson's disease: A scoping review. *Occupation, Participation and Health*, 36(3), 134–147. Doi: 10.1177/1539449216661714
- Macniven, J., & Gaskill, A. (2009). *Psychological services for people with Parkinson's disease*. Leicester: British Psychological Society
- Mamikonyan, E., Moberg, P. J., Siderowf, A., Duda, J. E., Have, T. T., Hurtig, H. I., ... & Weintraub, D. (2009). Mild cognitive impairment is common in Parkinson's disease patients with normal Mini-Mental State Examination (MMSE) scores. *Parkinsonism & Related Disorders*, 15(3), 226–231. Doi: 10.1016/j.parkreldis.2008.05.006
- Manor, Y., Balas, M., Giladi, N., Mootanah, R., & Cohen, J. T. (2009). Anxiety, depression and swallowing disorders in patients with Parkinson's disease. *Parkinsonism & Related Disorders*, 15(6), 453 – 456. Doi: 10.1016/j.parkreldis.2008.11.005
- Mantella, R. C., Butters, M. A., Dew, M. A., Mulsant, B. H., Begley, A. E., Tracey, B., ... & Lenze, E. J. (2007). Cognitive impairment in late-life generalized anxiety disorder. *The American Journal of Geriatric Psychiatry*, 15(8), 673-679. Doi: 10.1097/JGP.0b013e31803111f2.

- Mioshi, E., Dawson, K., Mitchell, J., Arnold, R., & Hodges, J. R. (2006). The Addenbrooke's Cognitive Examination Revised (ACE-R): A brief cognitive test battery for dementia screening. *International Journal of Geriatric Psychiatry*, 21(11), 1078-1085. Doi: 10.1002/gps.1610
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA Statement. *Journal of Clinical Epidemiology*, 62(10), 1006-1012. Doi: 10.1016/j.jclinepi.2009.06.005
- Moisan, F., Kab, S., Mohamed, F., Canonico, M., Le Guern, M., Quintin, C., ... & Elbaz, A. (2016). Parkinson disease male-to-female ratios increase with age: French nationwide study and meta-analysis. *Journal of Neurology, Neurosurgery & Psychiatry*, 87(9), 952-957. Doi: 10.1136/jnnp-2015-312283
- Monastero, R., Di Fiore, P., Ventimiglia, G. D., Camarda, R., & Camarda, C. (2013). The neuropsychiatric profile of Parkinson's disease subjects with and without mild cognitive impairment. *Journal of Neural Transmission*, 120(4), 607-611. Doi: 10.1007/s00702-013-0988-y
- Moola, S., Munn, Z., Sears, K., Sfetcu, R., Currie, M., Lisy, K., ... & Mu, P. (2015). Conducting systematic reviews of association (etiology): the Joanna Briggs Institute's approach. *International Journal of Evidence-Based Healthcare*, 13(3), 163-169. Doi: 10.1097/XEB.0000000000000064
- Moustafa, A. A., Chakravarthy, S., Phillips, J. R., Gupta, A., Keri, S., Polner, B., . . . Jahanshahi, M. (2016). Motor symptoms in Parkinson's disease: A unified framework. *Neuroscience and Biobehavioral Reviews*, 68, 727-740. Doi: 10.1016/j.neubiorev.2016.07.010

- Mueller, M., D'Addario, M., Egger, M., Cevallos, M., Dekkers, O., Mugglin, C., & Scott, P. (2018). Methods to systematically review and meta-analyse observational studies: A systematic scoping review of recommendations. *BMC Medical Research Methodology*, 18(1), 44. Doi: 10.1186/s12874-018-0495-9
- Munn, Z., Stern, C., Aromataris, E., Lockwood, C., & Jordan, Z. (2018). What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences. *BMC Medical Research Methodology*, 18(1), 5-13. Doi: 10.1186/s12874-017-0468-4
- Muslimović, D., Post, B., Speelman, J. D., & Schmand, B. (2005). Cognitive profile of patients with newly diagnosed Parkinson disease. *Neurology*, 65(8), 1239-1245. Doi: 10.1212/01.wnl.0000180516.69442.95
- Muslimović, D., Schmand, B., Speelman, J. D., & De Haan, R. J. (2007). Course of cognitive decline in Parkinson's disease: A meta-analysis. *Journal of the International Neuropsychological Society*, 13(6), 920–932. Doi: 10.1017/S1355617707071160
- Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., ... & Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, 53(4), 695-699. Doi: 10.1111/j.1532-5415.2005.53221.x
- Nègre-Pagès, L., Grandjean, H., Lapeyre-Mestre, M., Montastruc, J. L., Fourrier, A., Lépine, J. P., & Rascol, O. (2010). Anxious and depressive symptoms in Parkinson's disease: The French cross-sectionnal DoPaMiP study. *Movement Disorders*, 25(2), 157-166. Doi: 10.1002/mds.22760
- Page, M. J., Shamseer, L., Altman, D. G., Tetzlaff, J., Sampson, M., Tricco, A. C., ... & Moher, D. (2016). Epidemiology and reporting characteristics of systematic reviews

- of biomedical research: A cross-sectional study. *PLoS Medicine*, 13(5), e1002028.
- Retrieved from: <https://doi.org/10.1371/journal.pmed.1002028>
- Pauletti, C., Mannarelli, D., Locuratolo, N., Pollini, L., Currà, A., Marinelli, L., . . . & Fattapposta, F. (2017). Attention in Parkinson's disease with fatigue: Evidence from the attention network test. *Journal of Neural Transmission*, 124(3), 335-345. Doi: 10.1007/s00702-016-1637-z
- Petkus, A. J., Filoteo, J. V., Schiehser, D. M., Gomez, M. E., & Petzinger, G. (2019). Worse cognitive performance predicts increased anxiety and depressive symptoms in patients with Parkinson's disease: A bidirectional analysis. *Neuropsychology*, 33(1), 35–46. Doi: 10.1037/neu0000498
- Petticrew, M., & Roberts, H. (2006). *Systematic reviews in the social sciences [electronic resource]: A practical guide*. Hoboken: Wiley.
- Poletti, M., De Rosa, A., & Bonuccelli, U. (2012). Affective symptoms and cognitive functions in Parkinson's disease. *Journal of the Neurological Sciences*, 317(1-2), 97-102. Doi: 10.1016/j.jns.2012.02.022
- Price, D., Jefferson, T., & Demicheli, V. (2004). Methodological issues arising from systematic reviews of the evidence of safety of vaccines. *Vaccine*, 22(15-16), 2080-2084. Doi: 10.1016/j.vaccine.2004.01.009
- Pringsheim, T., Jette, N., Frolkis, A., & Steeves, T. D. (2014). The prevalence of Parkinson's disease: A systematic review and meta-analysis. *Movement Disorders*, 29(13), 1583-1590. Doi: 10.1002/mds.25945
- Pushpanathan, M. E., Loftus, A. M., Thomas, M. G., Gasson, N., & Bucks, R. S. (2016). The relationship between sleep and cognition in Parkinson's disease: A meta-analysis. *Sleep Medicine Reviews*, 26, 21-32. Doi: 10.1016/j.smrv.2015.04.003

- Rana, A. Q., Ahmed, U. S., Chaudry, Z. M., & Vasan, S. (2015). Parkinson's disease: a review of non-motor symptoms. *Expert Review of Neurotherapeutics*, 15(5), 549-562. Doi: 10.1586/14737175.2015.1038244
- Randolph, C., Tierney, M. C., Mohr, E., & Chase, T. N. (1998). The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS): Preliminary clinical validity. *Journal of Clinical and Experimental Neuropsychology*, 20(3), 310-319. Doi: 10.1076/jcen.20.3.310.823
- Reitan, R. M., & Wolfson, D. (1985). *The Halstead-Reitan Neuropsychological Test Battery: Theory and clinical interpretation*. Tucson: Neuropsychology Press.
- Reynolds, G. O., Hanna, K. K., Nearing, S., & Cronin-Golomb, A. (2017). The relation of anxiety and cognition in Parkinson's disease. *Neuropsychology*, 31(6), 596–604. doi:10.1037/neu0000353
- Richardson, W. S., Wilson, M. C., Nishikawa, J., & Hayward, R.S. (1995). The well-built clinical question: a key to evidence-based decisions. *ACP Journal Club*, 123(3), A12–A13. Doi: 10.7326/ACPJC-1995-123-3-A12
- Roheger, M., Kalbe, E., & Liepelt-Scarfone, I. (2018). Progression of cognitive decline in Parkinson's disease. *Journal of Parkinson's Disease*, 8(2), 183–193. Doi: 10.3233/JPD-181306
- Rosenthal, R., & DiMatteo, M. R. (2001). Meta-analysis: Recent developments in quantitative methods for literature reviews. *Annual Review of Psychology*, 2001(52), 59-82. Retrieved from: <https://doi-org/10.1146/annurev.psych.52.1.59>
- Rosqvist, K., Hagell, P., Odin, P., Ekström, H., Iwarsson, S., & Nilsson, M. H. (2017). Factors associated with life satisfaction in Parkinson's disease. *Acta Neurologica Scandinavica*, 136(1), 64–71. Doi: 10.1111/ane.12695

- Rosti-Otajärvi, E.M., & Hämäläinen, P.I. (2014). Neuropsychological rehabilitation for multiple sclerosis. *Cochrane Database of Systematic Reviews*, 2014(2), 1-82. Doi: 10.1002/14651858.CD009131.pub3
- Roth, M., Huppert, F. A., Mountjoy, C. Q., & Tym, E. (1998). *CAMDEX-R boxed set: the revised Cambridge examination for mental disorders of the elderly*. Cambridge: Cambridge University Press
- Rutten, S., van der Ven, P. M., Weintraub, D., Pontone, G. M., Leentjens, A., Berendse, H. W., ... & van den Heuvel, O. A. (2017). Predictors of anxiety in early-stage Parkinson's disease - Results from the first two years of a prospective cohort study. *Parkinsonism & Related Disorders*, 43, 49–55. Doi: 10.1016/j.parkreldis.2017.06.024
- Ryder, K. A., Gontkovsky, S. T., McSwan, K. L., Scott, J. G., Bharucha, K. J., & Beatty, W. W. (2002). Cognitive function in Parkinson's disease: Association with anxiety but not depression. *Aging, Neuropsychology, and Cognition*, 9(2), 77-84. Doi: 10.1076/anec.9.2.77.9543
- Sagna, A., Gallo, J. J., & Pontone, G. M. (2014). Systematic review of factors associated with depression and anxiety disorders among older adults with Parkinson's disease. *Parkinsonism & Related Disorders*, 20(7), 708-715. Doi: 10.1016/j.parkreldis.2014.03.020.
- Sanderson, S., Tatt, I. D., & Higgins, J. P. T. (2007). Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: a systematic review and annotated bibliography. *International Journal of Epidemiology*, 36(3), 666-676. Doi: 10.1093/ije/dym018
- Santangelo, G., Vitale, C., Trojano, L., Longo, K., Cozzolino, A., Grossi, D., & Barone, P. (2009). Relationship between depression and cognitive dysfunctions in Parkinson's

- disease without dementia. *Journal of Neurology*, 256(4), 632-638. Doi: 10.1007/s00415-009-0146-5
- Sarno, M., Gaztanaga, W., Banerjee, N., Bure-Reyes, A., Rooks, J., Margolesky, J., ... & Levin, B. (2019). Revisiting eligibility for deep brain stimulation: Do preoperative mood symptoms predict outcomes in Parkinson's disease patients? *Parkinsonism & Related Disorders*, 2019. Doi: 10.1016/j.parkreldis.2019.02.019
- Schiehser, D. M., Han, S. D., Lessig, S., Song, D. D., Zizak, V., & Filoteo, J. V. (2009). Predictors of health status in nondepressed and nondemented individuals with Parkinson's disease. *Archives of Clinical Neuropsychology*, 24(7), 699–709. Doi: 10.1093/arclin/acp064
- Schrag, A., Jahanshahi, M., & Quinn, N. (2000). What contributes to quality of life in patients with Parkinson's disease? *Journal of Neurology, Neurosurgery & Psychiatry*, 69(3), 308-312. Doi: 10.1136/jnnp.69.3.308
- Skorvanek, M., Goldman, J. G., Jahanshahi, M., Marras, C., Rektorova, I., Schmand, B. ... & members of the MDS Rating Scales Review Committee. (2018). Global scales for cognitive screening in Parkinson's disease: Critique and recommendations. *Movement Disorders*, 33(2), 208-218. Doi: 10.1002/mds.27233
- Sheehan, D. V., Lecrubier, Y., Sheehan, K. H., Amorim, P., Janavs, J., Weiller, E., ... & Dunbar, G. C. (1998). The Mini-International Neuropsychiatric Interview (MINI): The development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. *Journal of Clinical Psychiatry*, 59(Suppl 20), 22-33. Retrieved from: <https://europepmc.org/abstract/med/9881538>
- Simioni, S., Ruffieux, C., Bruggimann, L., Annoni, J. M., & Schluep, M. (2007). Cognition, mood and fatigue in patients in the early stage of multiple sclerosis. *Swiss Medical Weekly*, 137(35-36), 496-501. Doi: 2007/35/smw-11874

- Snaith, R. P., Bridge, G. W. K., & Hamilton, M. (1976). The Leeds scales for the self-assessment of anxiety and depression. *The British Journal of Psychiatry*, 128(2), 156-165. Doi: 10.1192/bjp.128.2.156
- So, E., Kam, I., Liu, Z., Fong, S., Chung, D., & Leung C. M. (2003). The Chinese bilingual SCID-I/P project: Stage I—Reliability for mood disorders and schizophrenia. *Hong Kong Journal of Psychiatry*, 13(1), 7-18. Retrieved from:
<https://psycnet.apa.org/record/2004-10013-002>
- Spielberger, C. D. Gorsuch, R. L., Lushene, R., Vagg, P. R., & Jacobs, G. A. (1983). *Manual for the State-Trait Anxiety Inventory*. Consulting Psychologists Press: CA, USA.
- Starkstein, S. E., Dragovic, M., Dujardin, K., Marsh, L., Martinez-Martin, P., Pontone, G. M., ... & Leentjens, A. F. G. (2014). Anxiety has specific syndromal profiles in Parkinson disease: A data-driven approach. *The American Journal of Geriatric Psychiatry*, 22(12), 1410-1417. Doi: 10.1016/j.jagp.2013.09.006
- Starkstein, S. E., Robinson, R. G., Leiguarda, R., & Preziosi, T. J. (1993). Anxiety and depression in Parkinson's disease. *Behavioural Neurology*, 6(3), 151-154. Doi: 10.3233/BEN-1993-6306
- Stefanova, E., Ziropadja, L., Petrovic, M., Stojkovic, T., & Kostic, V. (2013). Screening for anxiety symptoms in Parkinson disease: A cross-sectional study. *Journal of Geriatric Psychiatry and Neurology*, 26(1), 34-40. Doi: 10.1177/0891988713476368
- Sylvester, C. M., Corbetta, M., Raichle, M. E., Rodebaugh, T. L., Schlaggar, B. L., Sheline, Y. I., ... & Lenze, E. J. (2012). Functional network dysfunction in anxiety and anxiety disorders. *Trends in Neurosciences*, 35(9), 527–535. Doi: 10.1016/j.tins.2012.04.012
- Thomas, B. H., Ciliska, D., Dobbins, M., & Micucci, S. (2004). A process for systematically reviewing the literature: Providing the research evidence for public health nursing

- interventions. *Worldviews on Evidence-Based Nursing*, 1(3), 176-184. Doi: 10.1111/j.1524-475X.2004.04006.x
- Verbaan, D., Marinus, J., Visser, M., van Rooden, S. M., Stiggelbout, A. M., Middelkoop, H. A., & van Hilten, J. J. (2007). Cognitive impairment in Parkinson's disease. *Journal of Neurology, Neurosurgery & Psychiatry*, 78(11), 1182-1187. Doi: 10.1136/jnnp.2006.112367
- Vytal, K., Cornwell, B., Arkin, N., & Grillon, C. (2012). Describing the interplay between anxiety and cognition: From impaired performance under low cognitive load to reduced anxiety under high load. *Psychophysiology*, 49(6), 842-852. Doi: 10.1111/j.1469-8986.2012.01358.x
- Wan Mohamed, W. N. A., Che Din, N., & Ibrahim, N. (2015). Cognitive profiles in Parkinson's disease and their correlation with dementia, anxiety and depression: A preliminary study. *The Malaysian Journal of Medical Sciences*, 22(Spec Issue), 29-35. Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4795519/>
- Wechsler, D. (2008). *Wechsler Adult Intelligence Scale–Fourth Edition (WAIS–IV)*. San Antonio: NCS Pearson
- Weil, R. S., Costantini, A. A., & Schrag, A. E. (2018). Mild Cognitive Impairment in Parkinson's disease-What is it? *Current Neurology and Neuroscience Reports*, 18(4), 17. Doi:10.1007/s11910-018-0823-9
- Williams, J.W., Plassman, B.L., Burke, J., Holsinger, T., & Benjamin, S. (2010). *Preventing Alzheimer's Disease and Cognitive Decline* [Evidence Reports/Technology Assessments]. Retrieved from: <https://www.ncbi.nlm.nih.gov/books/NBK47456/>
- Wooten, G. F., Currie, L. J., Bovbjerg, V. E., Lee, J. K., & Patrie, J. (2004). Are men at greater risk for Parkinson's disease than women? *Journal of Neurology, Neurosurgery & Psychiatry*, 75(4), 637-639. Doi: 10.1136/jnnp.2003.020982

- Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M., & Leirer, V. O. (1982). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, 17(1), 37-49. Doi: 10.1016/0022-3956(82)90033-4
- Yochim, B. P., Mueller, A. E., & Segal, D. L. (2013). Late life anxiety is associated with decreased memory and executive functioning in community dwelling older adults. *Journal of Anxiety Disorders*, 27(6), 567-575. Doi: 10.1016/j.janxdis.2012.10.010
- Zahodne, L. B., Marsiske, M., & Bowers, D. (2013). A latent class analysis of psychological disturbance in Parkinson's disease. *International Journal of Geriatric Psychiatry*, 28(10), 1054-1060. Doi:10.1002/gps.3927
- Zhang, S., Ou, R., Chen, X., Yang, J., Zhao, B., Yuan, X., ... & Shang, H-F. (2016). Correlative factors of cognitive dysfunction in PD patients: a cross-sectional study from Southwest China. *Neurological Research*, 38(5), 434-440. Doi: 10.1080/01616412.2016.1139320
- Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67(6), 361-370. Doi: 10.1111/j.1600-0447.1983.tb09716.x

Figure 1.1

Study Selection (adapted from Moher et al. (2009))

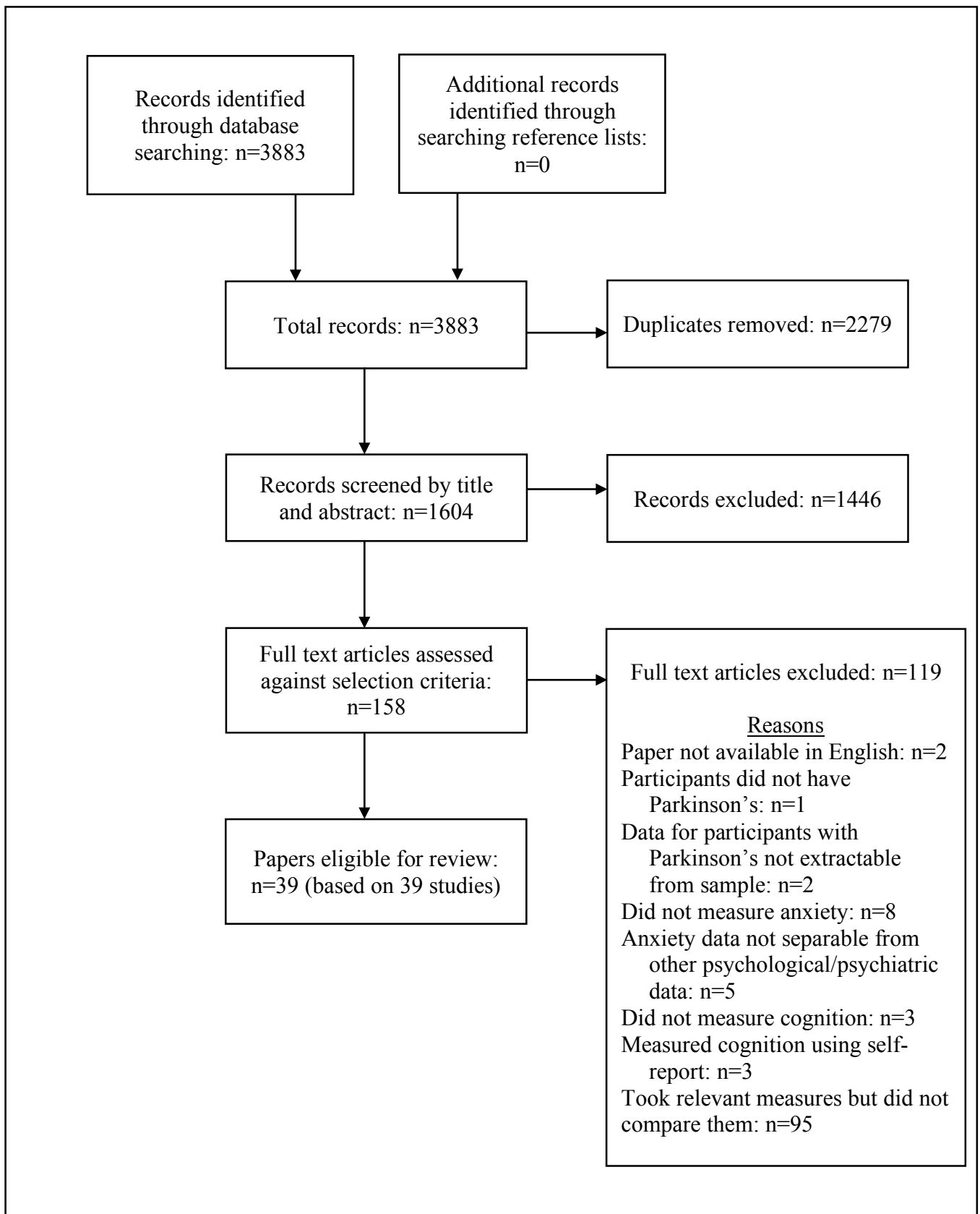


Table 1.1

Search Terms Used

Database	Subject Heading Terms	Free-Text Terms
CINAHL	Parkinson Disease;	parkinson*;
	Anxiety; Anxiety Disorders;	anxiet*;
	Cognition Disorders;	“cognit*”; “neuropsych*”;
	Neuropsychology;	“executive”; “metacognit*”; “frontal”;
	Neuropsychological Tests; Mental	“process*”; “problem solv*”;
	Processes; Impulsive Behavior;	“reason*”; “concept formation”;
	Attention; Memory; Perception;	“sequenc*”; “*shift*”; “impulsiv*”;
	Dementia.	“distract*”; “initiat*”;
		“perseverat*”; “attention”;
		“concentration”; “memory”;
		“perception*”; “orient*”; “spatial”;
		“visuospatial”; “visuoconstruct*”;
		“language”; “verbal”; “comprehen*”;
		“learn*”; “dement*”; “MCI”.
Medline	Parkinson Disease;	parkinson*;
	Anxiety; Anxiety Disorders;	anxiet*

Cognition; Cognitive Dysfunction;	“cognit*”; “neuropsych*”;
Cognitive Neuroscience; Mental	“executive”; “metacognit*”; “frontal”;
Processes; Neuropsychology;	“process*”; “problem solv*”;
Neuropsychological Tests;	“reason*”; “concept formation”;
Executive Function; Metacognition;	“sequenc*”; “*shift*”; “impulsiv*”;
Problem Solving; Concept	“distract*”; “initiat*”;
Formation; Set (Psychology);	“perseverat*”; “attention”;
Impulsive Behavior; Attention;	“concentration”; “memory”;
Memory; Memory Disorders;	“perception*”; “orient*”; “spatial”;
Perception; Orientation;	“visuospatial”; “visuoconstruct*”;
Communication Disorders;	“language”; “verbal”; “comprehen*”;
Learning; Dementia.	“learn*”; “dement*”; “MCI”.

PsycINFO

Parkinson’s Disease;	parkinson*;
----------------------	-------------

Anxiety; Anxiety Disorders;	anxiet*
-----------------------------	---------

Cognition; Cognitive Ability;	“cognit*”; “neuropsych*”;
Cognitive Processes; Cognitive	“executive”; “metacognit*”; “frontal”;
Assessment; Neurocognition;	“process*”; “problem solv*”;
Neuropsychology; Executive	“reason*”; “concept formation”;
Function; Dysexecutive Syndrome;	“sequenc*”; “*shift*”; “impulsiv*”;
Metacognition; Cognitive	“distract*”; “initiat*”;
Processing Speed; Problem	“perseverat*”; “attention”;
Solving; Reasoning; Concept	“concentration”; “memory”;

Formation; Set Shifting;	“perception*”; “orient*”; “spatial”;
Impulsiveness; Distractibility;	“visuospatial”; “visuoconstruct*”;
Perseveration; Attention;	“language”; “verbal”; “comprehen*”;
Concentration; Memory; Memory	“learn*”; “dement*”; “MCI”.
Disorders; Perception;	
Communication Disorders;	
Learning; Dementia.	

**Web of
Science**

-

parkinson*;

anxiet*;

“cognit*”; “neuropsych*”;

“executive”; “metacognit*”; “frontal”;

“process*”; “problem solv*”;

“reason*”; “concept formation”;

“sequenc*”; “*shift*”; “impulsiv*”;

“distract*”; “initiat*”;

“perseverat*”; “attention”;

“concentration”; “memory”;

“perception*”; “orient*”; “spatial”;

“visuospatial”; “visuoconstruct*”;

“language”; “verbal”; “comprehen*”;

“learn*”; “dement*”; “MCI”.

Table 1.2

Quality Assessment Tool (Adapted from Williams et al., 2009)

Short Title	Criterion
Sample	Sample is valid and representative
Comparable groups	Selection minimizes baseline differences in prognostic factors (only relevant to studies using between-groups comparisons)
Power	Sample size is large enough to detect a significant effect/relationship in at least one primary outcome measure at the 5% level
Measures	Measures implemented consistently across participants and cognitive assessments are carried out by a suitably qualified individual
Follow-up consistency	The length of follow-up is the same across all groups (only relevant to longitudinal, between-groups studies)
Follow-up completeness	Completeness of follow-up (only relevant to longitudinal studies)
Confounding variables	Analysis controls for confounding variables
Analysis	Analytic methods are appropriate

Table 1.3

Summary of Study Characteristics and Relevant Findings

Paper	Country of origin	Design; methods of analysing the relevant data	Total N (% female)	Mean age in years (SD); range	Mean time since diagnosis in years (SD); range	Anxiety measure	Cognition measure(s)	Relevant findings
Athey, Porter & Walker (2005)	UK	Cross- sectional; correlation	94 (52%)	74.6 (not stated); 51- 85	6.1 (not stated); 1- 28	HADS-A	CAMCOG-R	No significant correlations found between anxiety scores and any of the CAMCOG-R domain scores (orientation, comprehension, expression, memory, attention and calculation, praxis, abstract thinking, perception) or total CAMCOG-R score

Baschi et al. (2018)	Italy	Cross-sectional; ANOVA	147 (37%)	67.9 (9.4); not stated	Median = 1 (not stated); 0-3	HADS-A	MMSE; MoCA; Story Recall Test; RAVLT; TMT; RCPM; FAB; Token Test; Naming subtest from the AAB; Constructional Apraxia; Clock Drawing	Participants with PD-MCI and subjective memory complaints reported significantly more anxiety than participants with neither PD-MCI nor subjective memory complaints; there was no significant difference in anxiety ratings between participants with PD-MCI (and no subjective memory complaints) and participants with neither PD-MCI nor subjective memory complaints
Bogdanova & Cronin- Golomb (2012)	USA	Cross-sectional; correlation and multiple regression	22 (50%)	Right-side onset: 63.2 (6.0); not stated. Left-side onset: 61.3	Right-side onset: 8.4 (3.7); not stated. Left-side onset: 9.0	BAI	COWAT; Digit Span subtest from WMS-III; Clock Reading Test; BNT; CVLT-II;	In left-side onset Parkinson's, anxiety was not associated with performance on non-verbally mediated tasks (TMT B, Spatial Span, Visual Symbol Search); in right-side onset Parkinson's, anxiety significantly and

				(6.2); not stated	(4.0); not stated		RCPM; TMT; Spatial Span subtest from WMS-III; Visual Symbol Search Test; ROCF	strongly correlated with performance on verbally mediated tasks (BNT, CVLT, Clock Reading, and Controlled Oral Word Association), with better cognitive performance associated with lower levels of anxiety
Brown & Ferne (2015)	UK	Cross- sectional; correlation	106 (31%)	65.6 (9.3); 43-85	Not stated	HADS-A	ACE-R	No significant correlations were found between anxiety and any of the ACE-R domains (attention and orientation, memory, fluency, language, visuospatial) or ACE-R total score
Bugalho, da Silva, Cargaleiro,	Portugal	Cross- sectional; correlation	36 (53%)	72.8 (7.0); not stated	3.1 (1.3); not stated	SCL-90-R Anxiety subscale	MMSE; FAB	No significant correlations were found between anxiety and the MMSE or FAB total scores

Serra & Neto

(2012)

Carod-Artal, Martínez- Martin, Kummer & da Silveira Ribeiro (2008)	Brazil	Cross- sectional; correlation	152 (40%)	63.2 (11.3); not stated	7.8 (5.1); not stated	HADS-A	SCOPA-COG	Significant but weak correlations were found between anxiety and total SCOPA-COG scores, and anxiety and SCOPA-COG domains memory, executive functions and visuospatial functions; better SCOPA-COG performance was associated with lower levels of anxiety; there was also a weak negative correlation between anxiety and SCOPA-COG attention, but this was not significant.
--	--------	-------------------------------------	--------------	-------------------------------	--------------------------	--------	-----------	--

Chen et al. (2010)	China	Cross- sectional; Mann-	133 (44%)	66.3 (11.2); not stated	7.4 (6.5); not stated	Diagnostic criteria: CB-	CC-MMSE	No significant difference in CC- MMSE total scores was found
-----------------------	-------	-------------------------------	--------------	-------------------------------	--------------------------	-----------------------------	---------	---

		Whitney U					SCID-DSM	between participants with and	
		test					IV	without an anxiety disorder diagnosis	
Dissanayaka et al. (2017)	UK	Cross- sectional; Mann- Whitney U test and hierarchical logistic regression	185 (36%)	65.9 (9.5); not stated	5.6 months (5.2 months); not stated	MDS- UPDRS Anxiety item	MMSE; MoCA; Power of Attention and Digit Vigilance Accuracy subtests from the CDR; Pattern Recognition Memory, Spatial Recognition Memory, Paired Associates Learning and	No significant difference in total MMSE or MoCA scores was found between the anxious and non-anxious groups; participants with anxiety were significantly more likely than participants without anxiety to have PD-MCI (with cut-off set at 1 SD below the mean) and to show impairment (1 SD below the mean) on memory tasks; there were no significant relationships found between anxiety and the other cognitive domains (attention, executive function, visuospatial function and language); when the	

							One Touch Stockings subtests from the CANTAB; Phonemic Fluency; Semantic Fluency	‘impairment’ cut-off was set at 1.5 and 2 SDs below the mean, no significant relationships were found between anxiety and any of the cognitive domains
Dissanayaka et al. (2015)	Australia	Cross- sectional; binomial logistic regression	90 (38%)	67.0 (9.1); not stated	Not stated	MINI-plus; HAM-A	MMSE; PDCRS	No significant associations were found between anxiety and total MMSE or PDCRS scores
Ehgoetz Martens, Silveira,	Canada	Cross- sectional; hierarchical	48 (27%)	69.0 (8.4); not stated	5.6 (4.6); not stated	STAI	MoCA; Digit Span; Corsi Block Test;	Neither trait or state anxiety predicted overall cognitive function (MoCA) scores; after controlling for age,

Intzandt & Almeida (2018)	multiple regression						Stroop; TMT; CVLT; ROCF; Semantic Fluency; BNT; Intersected Pentagons; JoLO	depression, and motor symptom severity, state anxiety predicted performance in the attention/working memory, executive function, memory and language domains but not visuospatial function; after controlling for age, depression and symptom severity, trait anxiety predicted performance in the executive function domain but not the other domains
---------------------------------	------------------------	--	--	--	--	--	---	--

Ehgoetz Martens et al. (2016)	Australia	Cross- sectional; independent t –tests/ Mann– Whitney <i>U</i> -tests	50 (44%)	With anxiety: 64.9 (8.1); not stated. Without anxiety:	With anxiety: 6.6 (5.6); not stated. Without anxiety: 6.6 (4.2)	HADS-A (score>8 = PDA+ group, score<6 = PDA- group)	TMT; Digit Span and logical memory subtests from the WMS-III; COWAT; MMSE	There were no differences between the scores of the PDA+ and PDA- groups on the MMSE, TMT-A, Logical Memory II test performance or % retention, or COWAT semantic fluency or phonemic fluency; the PDA+ group demonstrated
-------------------------------------	-----------	--	-------------	---	---	---	---	--

				68.3 (8.9); not stated				significantly worse performance than the PDA- group on the TMT-B and Digit Span forward and backward; on the Logical Memory I immediate recall test there was a trend approaching significance that the PDA+ group had worse new verbal learning and immediate recall abilities than the PDA– group
Fan, Chang & Wu (2016)	Taiwan	Cross-sectional; correlation and one-way ANOVA	134 (37%)	65.0 (9.2); 41-87	7.9 (5.6); 0-23	BAI	MMSE	There was no significant correlation found between BAI and MMSE scores; there was no significant difference in MMSE scores between groups split by BAI classification (normal, mild, moderate and severe)

Fonoff et al. (2015)	Brazil	Cross-sectional; correlation	28 (43%)	59.3 (10.3); not stated	13.3 (6.5); not stated	HAM-A	CPT-II; WCST	There was a significant moderate correlation between anxiety and CPT-II reaction time, with higher anxiety associated with a slower reaction time; no significant correlations were found between anxiety and any other subscales
Foster et al. (2010)	USA	Cross-sectional; ANOVA/ ANCOVA	59 (39%)	65.0 (10.8); 29- 83	5.9 (5.0); not stated	STAI	MMSE; DRS-II, Digit Span from WMS-III	An ANOVA found no significant direct effect of anxiety group (high or low) on MMSE or DRS-II scores; an ANCOVA with disease duration as a covariate found a significant interaction effect of side of onset (right or left) and anxiety (high or low) on Digit Span score; participants with left hemibody onset and high anxiety scored significantly lower on

								Digit Span than those with left hemibody onset with low anxiety.
Gao et al. (2015)	China	Cross-sectional; correlation	311 (45%)	60.9 (11.4); not stated	3.8 (5.1); not stated	HAM-A	MMSE; MoCA; WAIS-RC; WMS-RC	There was a weak but significant correlation between anxiety and WAIS-RC total scores, with higher anxiety associated with lower WAIS-RC scores; there were no significant correlations found between anxiety and the other cognitive test scores
Hepp et al. (2013)	Netherlands	Cross-sectional; correlation	62 (39%)	65.5 (11.0); not stated	7.5 (5.5); not stated	BAI	RAVLT; TMT-A	No significant correlations were found between RAVLT and BAI scores; scores on TMT-A correlated significantly with BAI – higher anxiety was associated with a longer time taken to complete the task

Hu et al. (2014)	UK	Cross-sectional; multiple regression	468 (39%)	67.8 (9.4); not stated	1.5 (1.0); not stated	LADS Anxiety subscale	MoCA	Higher anxiety significantly predicted lower scores on the MoCA (indicating more impairment)
Hurt et al. (2012)	UK	Cross-sectional, correlation	347 (35%)	65.8 (10.1); 32-93	6.6 (5.9); 0-39	HADS-A	ACE-R	No significant correlations were found between anxiety and any of the ACE-R domains (attention and orientation, memory, fluency, language, visuospatial) or ACE-R total score
Khedr, El Fetoh, Khalifa, Ahmed & El Beh (2012)	Egypt	Cross-sectional; correlation	112 (31%)	61.0 (12.1); 28-88	6.2 (5.9); .5-25	HAM-A	MMSE	There was a weak but significant correlation between anxiety and total MMSE scores, with higher anxiety associated with lower MMSE scores

Klepac, Hajnšek & Trkulja (2010)	Croatia	Cross- sectional; multiple regression	137 (44%)	History of depression : 60.8 (11.0); not stated. No history of depression : 60.6 (10.0); not stated	Not stated	HAM-A	Stroop; Digit Span; COWAT; SDMT; RAVLT; ROCF; TMT	Higher anxiety independently predicted worse performance in Stroop 1, Stroop 3, COWAT Plant, SDMT, RAVLT, ROCF recall, and TMT-A tests; anxiety did not predict performance in Stroop 2, Digits forward or backward, COWAT FAS, and ROCF copy; none of the cognitive test scores predicted anxiety scores
LaBelle, Walsh & Banks (2017)	USA	Cross- sectional; latent class analysis/ ANOVA	424 (34%)	61.7 (9.7); not stated	6.5 months (6.5 months); not stated	STAI	HVLT-R; word- list learning task; JoLO; letter-number sequencing from the WAIS- IV; SDMT;	Six classes were identified with different cognitive profiles; there were no significant differences in state anxiety or total anxiety between the classes; the “weak-overall” class (scoring below the 25 th percentile in all cognitive tests) had significantly

							Semantic Fluency	higher trait anxiety than the “typical-overall” class (scoring between the 25 th and 75 th percentiles for most cognitive tests)
Lee, Tsai, Gauthier, Wang & Fuh (2012)	Taiwan	Cross-sectional; correlation	127 (40%)	77.0 (6.3); not stated	Median =6, lower quartile =3, upper quartile =10	NPI Anxiety subscale	MMSE	There was a very weak but significant correlation between anxiety and MMSE scores, with higher anxiety associated with lower MMSE scores
Leroi, Pantula, McDonald & Harbishettar (2012)	UK	Cross-sectional; ANOVA/Kruskall-Wallis	127 (33%)	65.4 (11.2); not stated	93.8 months (64.1 months); not stated	NPI Anxiety subscale; HADS-A	TMT; Serial 7’s; Digit n-back; Phonemic Fluency task;	There were no significant differences found in NPI Anxiety scores between groups with no cognitive impairment, PD-MCI and PDD; there was no significant difference found in HADS-A scores between groups with

							WCST; 5-minute recall of 3 words; Intersecting Pentagons	no cognitive impairment and PD-MCI (the PDD group did not complete the HADS-A)
Mamikonyan et al. (2009)	USA	Cross-sectional; univariate logistic regression	106 (30%)	64.6 (10.3); not stated	6.5 (5.8); not stated	STAI – State Anxiety subscale	HVLT-R; Stroop; Semantic Fluency; TOL-DX; Digit Span from Halstead-Reitan battery	State anxiety was not a significant predictor of PD-MCI
Manor, Balas, Giladi, Mootanah &	Israel	Cross-sectional; correlation	Unclear for relevant part of	Unclear for relevant	Unclear for relevant	STAI Trait Anxiety subscale	MMSE	Significantly lower MMSE scores were found in the high anxiety group (the 25% of participants with the highest anxiety scores) compared to

Cohen			the	part of the	part of the			the low anxiety group (the 25% of
(2009)			analysis	analysis	analysis			participants with the lowest anxiety
								scores)

Monastero,	Italy	Cross-	410	Normal	Not stated	NPI Anxiety	MMSE; Story	There were no significant differences
Di Fiore,		sectional;	(40%)	cognition:		subscale	Recall Test;	in NPI Anxiety scores between the
Ventimiglia,		ANOVA		64.9 (9.8);			RAVLT; Token	three groups: normal cognition,
Camarda &				not stated.			Test; Naming	amnesic PD-MCI and non-amnesic
Camarda				Amnesic			subtest from the	PD-MCI
(2013)				PD-MCI:			AAB; Visual	
				69.9 (8.7);			Search; TMT;	
				not stated.			Phonemic	
				Non-			Fluency;	
				amnesic			RCPM; FAB;	
				PD-MCI:			Copy Drawing	
				71.0 (8.5);			Test; Position	
				not stated			Discrimination	

subtest from the VOSP								
Nègre-Pagès et al. (2010)	France	Cross- sectional; bivariate analysis (unclear which)	422 (43%)	68.6 (9.8); not stated	Not stated	HADS-A	MMSE	There was no significant difference in mean MMSE scores between participants with HADS-A ≤ 7 and participants with HADS-A > 7
Pauletti et al. (2017)	Italy	Cross- sectional; correlation	32 (31%)	With fatigue: 69.1 (6.6); 56–82. Without fatigue: 70.0 (9.4); 55–84	With fatigue: 7.8 (9.7); 2–38. Without fatigue: 5.3 (4.2); 2–14	STAI	ANT	No significant correlations were found between anxiety (state or trait) and ANT scores

Petkus, Filoteo, Schiehser, Gomez & Petzinger (2019)	USA (but additional study sites in Europe)	Longitudinal (over 4 years); bivariate latent change modelling	362 (31%)	65.6 (6.2); not stated	Not stated	STAI	SDMT; letter- number sequencing from the WAIS- IV; HVL-T-R; Semantic Fluency	Across all cognitive domains, worse performance was significantly associated with higher state and trait anxiety over time; working memory had the largest effect size in terms of subsequent increases in anxiety; however higher state and trait anxiety scores were not significantly associated with declines in cognitive performance over time
Reynolds, Hanna, Neargarder & Cronin- Golomb (2017)	USA	Cross- sectional; correlation	77 (49%) – but not all included	62.9 (7.4); not stated	6.5 (5.4); not stated	BAI	Digit Span from WMS-III; TMT; Word Association Test	Higher anxiety correlated with poorer set-shifting (TMT-B), even after removing the psychomotor component (TMT B-A). Anxiety did not correlate with performance on tests of attention, working memory,

			in every analysis					phonemic fluency, or categorical fluency.
Rutten et al. (2017)	Netherlands	Longitudinal (over 2 years); linear mixed model analysis	306 (32%)	61.5 (10.1); 34- 84	Not stated	STAI	MoCA	Lower MoCA scores at baseline were associated with an increase in STAI State Anxiety scores over time
Ryder et al. (2002)	USA	Cross- sectional; multiple regression	27 (0%)	69.0 (7.7); 54-87	8.0 (4.5); 2-19	STAI	MMSE; RBANS	Stepwise multiple regression analyses, including all significant correlates except MMSE, showed that Trait Anxiety accounted for a significant proportion of the variance in the RBANS indexes Immediate Memory, Delayed Memory, Visuospatial/Construction and

								Language, and RBANS total score, but not the Attention index
Sarno et al. (2019)	USA	Cross- sectional; ANOVA	49 (24%)	63.7 (8.3); not stated	9.5 (4.8); not stated	BAI	MMSE; SDMT; BNT; COWAT; JoLO – 15-item version; CVLT- II	No significant differences were identified between participants with (BAI \geq 10) and without (BAI < 10) anxiety on any of the cognitive measures
Schiehser et al. (2009)	USA	Cross- sectional; correlation	32 (44%)	66.6 (9.9); 46-89	6.9 (5.0); 1-23	GDS Anxiety subscale	MDRS; CVLT- II; WCST; DKEFS verbal fluency; JoLO	No significant correlations were found between anxiety and any of the cognitive measures
Starkstein et al. (2014)	USA, Australia, France,	Cross- sectional; latent class	338 (39%)	65.4 (9.1); not stated	Not stated	MINI; HAM-A; BAI	MMSE	There were no significant differences in MMSE scores found between the classes with anxiety and the class without anxiety

	Netherlands and Spain	analysis/ ANOVA						
Starkstein, Robinson, Leiguarda & Preziosi (1993)	USA	Cross- sectional; ANOVA	40 (unclear)	Not reported for whole sample	Not reported for whole sample	HAM-A	MMSE	No significant correlation was found between MMSE and HAM-A scores
Wan Mohamed, Che Din & Ibrahim (2015)	Malaysia	Cross- sectional; correlation	30 (50%)	Not stated (not stated); 50- 90	Not stated. <10 years n=21; >10 years n=9	HADS-A	PDCRS	The PDCRS subtest scores for confrontation naming, sustained attention, working memory, unprompted clock drawing and copy clock drawing were significantly correlated with anxiety, with lower scores associated with higher anxiety; there were no significant associations found between anxiety and verbal

								memory, delayed free recall, alternating verbal fluency or action verbal fluency
Zahodne, Marsiske & Bowers (2013)	USA	Cross- sectional; correlation	95 (32%)	66.2 (9.9); not stated	8.7 (5.7); not stated	STAI	MMSE	There were weak but significant correlations found between MMSE scores and both state and trait anxiety scores, with higher anxiety associated with lower MMSE scores
Zhang et al. (2016)	China	Cross- sectional; binomial logistic regression	454 (43%)	61.5 (11.0); not stated	4.8 (4.2); not stated	HAM-A	MoCA	HAM-A scores were significantly higher in participants with cognitive dysfunction (MoCA \leq 24) than participants without cognitive dysfunction (MoCA $>$ 24)

Note. AAB = Aachener Aphasie Battery; ACE-R = Addenbrookes Cognitive Examination - Revised; ANT = Attention Network Test; BAI = Beck Anxiety Inventory; BNT = Boston Naming Test; CAMCOG-R = Cambridge Cognitive Assessment –Revised; CANTAB = Cambridge Neuropsychological Test Automated Battery; CB-SCID-DSM IV = Chinese-Bilingual Structured Clinical Interview for DSM-IV; CC-MMSE = Chinese-Cantonese Mini-Mental State Examination; CDR = Cognitive Drug Research Battery; COWAT = Controlled Oral Word Association Test; CPT-II = Continuous Performance Test – Second Edition; CVLT-II = California Verbal Learning Test – Second Edition; DKEFS = Delis-Kaplan Executive Function System; DRS-II = Dementia Rating Scale-2; FAB = Frontal Assessment Battery; GDS

= Geriatric Depression Scale; HADS-A = Hospital Anxiety and Depression Scale – Anxiety subscale; HAM-A = Hamilton Anxiety Scale; HVLT-R = Hopkins Verbal Learning Test - Revised; JoLO = Benton's Judgement of Line Orientation; LADS = Leeds Anxiety and Depression Scale; MDRS = Mattis Dementia Rating Scale; MDS-UPDRS = Movement Disorder Society Unified Parkinson's Disease Rating Scale; MMSE = Mini-Mental State Examination; MoCA = Montreal Cognitive Assessment; NPI = Neuropsychiatric Inventory; PDCRS = Parkinson's Disease Cognitive Rating Scale; PDD = Parkinson's Disease Dementia; PD-MCI = Parkinson's Disease Mild Cognitive Impairment; PoA = Power of Attention; RAVLT = Rey Auditory Verbal Learning Test; RBANS = Repeatable Battery for the Assessment of Neuropsychological Status; RCPM = Raven's Coloured Progressive Matrices; ROCF = Rey-Osterrieth Complex Figure; SCL-90-R = Symptom Checklist – Revised; SCOPA-COG = Scales for Outcomes in Parkinson's Disease – Cognition; SDMT = Symbol Digit Modality Test; STAI = State Trait Anxiety Inventory; TMT = Trail Making Test; TMT-A = Trail Making Test – Part A; TOL-DX = Tower of London Test; VOSP = Visual Object and Space Perception Battery; WAIS-IV = Wechsler Adult Intelligence Scale – Fourth Edition; WAIS-RC = Wechsler Adult Intelligence Scale – Revised by China; WCST = Wisconsin Card Sorting Test; WMS-III = Wechsler Memory Scales – Third Edition; WMS-RC = Wechsler Memory Scales – Revised by China.

Table 1.4

Quality Assessment Summary

Study	Sample	Comparable groups	Power	Measures	Follow-up consistency	Follow-up completeness	Confounding variables	Analysis
Athey et al. (2005)	p	n/a	y	c	n/a	n/a	p	y
Baschi et al. (2018)	y	p	c	c	n/a	n/a	p	y
Bogdanova & Cronin-Golomb (2012)	y	n/a	n	c	n/a	n/a	p	y
Brown & Fernie (2015)	p	n/a	y	c	n/a	n/a	p	y
Bugalho et al. (2012)	p	n/a	n	c	n/a	n/a	p	y
Carod-Artal et al. (2008)	p	n/a	y	y	n/a	n/a	p	y
Chen et al. (2010)	y	y	c	y	n/a	n/a	p	y
Dissanayaka et al. (2017)	y	y	c	c	n/a	n/a	p	y
Dissanayaka et al. (2015)	p	p	c	y	n/a	n/a	p	y
Ehgoetz Martens et al. (2018)	p	n/a	c	c	n/a	n/a	p	y

Ehgoetz Martens et al. (2016)	y	y	c	c	n/a	n/a	p	y
Fan et al. (2016)	p	p	c	c	n/a	n/a	p	y
Fonoff et al. (2015)	y	n/a	n	c	n/a	n/a	p	y
Foster et al (2010)	n	y	c	c	n/a	n/a	p	y
Gao et al. (2015)	p	n/a	y	c	n/a	n/a	p	y
Hepp et al. (2013)	p	n/a	n	c	n/a	n/a	p	y
Hu et al. (2014)	y	n/a	c	y	n/a	n/a	p	y
Hurt et al. (2012)	y	n/a	y	c	n/a	n/a	p	y
Khedr et al. (2012)	p	n/a	y	c	n/a	n/a	p	y
Klepac et al. (2010)	p	y	c	y	n/a	n/a	p	y
LaBelle et al. (2017)	y	p	c	c	n/a	n/a	p	y
Lee et al. (2012)	p	n/a	y	c	n/a	n/a	p	y
Leroi et al. (2012)	y	y	c	c	n/a	n/a	p	y
Mamikonyan et al. (2009)	y	p	c	y	n/a	n/a	p	y
Manor et al. (2009)	p	c	c	c	n/a	n/a	p	y
Monastero et al. (2013)	p	p	c	c	n/a	n/a	p	y
Nègre-Pagès et al. (2010)	p	c	c	c	n/a	n/a	p	y
Pauletti et al. (2017)	p	n/a	n	y	n/a	n/a	p	y

Petkus et al. (2019)	p	n/a	c	c	y	c	p	y
Reynolds et al. (2017)	y	n/a	n	c	n/a	n/a	p	y
Rutten et al. (2017)	p	n/a	c	c	y	y	p	y
Ryder et al. (2002)	n	n/a	n	y	n/a	n/a	p	y
Sarno et al. (2019)	p	c	c	y	n/a	n/a	p	y
Schiehser et al. (2009)	p	n/a	n	c	n/a	n/a	p	y
Starkstein et al. (2014)	y	p	c	c	n/a	n/a	p	y
Starkstein et al. (1993)	p	p	n	y	n/a	n/a	p	y
Wan Mohamed et al. (2015)	p	n/a	n	c	n/a	n/a	p	y
Zahodne et al. (2013)	p	n/a	y	c	n/a	n/a	p	y
Zhang et al. (2016)	p	p	c	y	n/a	n/a	p	y

Note. y= yes; p= partial; n= no; c= can't tell; n/a= not applicable.

Table 1.5

Summary of Relationships Found between Cognition and Anxiety, by Cognitive Domain

Domain	Number of studies which failed to find a significant relationship	Number of studies which found a significant relationship	Nature of relationships found	Cognitive assessment tools used
Orientation	3	0	-	ACE-R; CAMCOG
Attention	7	3	Higher anxiety was associated with and predictive of worse performance on attention tasks	ACE-R; ANT; CAMCOG; Corsi Block Test*; Digit Span backwards from WAIS-IV*; Digit Vigilance Accuracy from CDR; PoA; RBANS; TMT-A°
Working memory	2	3	Higher anxiety was associated with and predictive of worse performance on working memory tasks.	Corsi Block Test*; Digit Span from WAIS-IV°; Digit Span from WMS-III
Executive function	3	5	Higher anxiety was associated with and predictive of worse	CAMCOG; FAB; SCOPA-COG*; Stroop°; TMT°; WCST;

performance on executive tasks				
Memory	5	6	Higher anxiety was associated with and predictive of worse performance on memory tasks	ACE-R; CAMCOG; CANTAB*; CVLT-II°; RAVLT*; RBANS*; ROCF*; SCOPA-COG*; WMS-III
Language	5	2	Higher anxiety was associated with and predictive of worse performance on language tasks	ACE-R; BNT*; CAMCOG; MoCA; RBANS*
Verbal fluency	6	1	Higher anxiety was predictive of worse performance on a semantic fluency task	ACE-R; COWAT°; RAVLT; Word Association Test
Visuospatial abilities	7	2	Higher anxiety was associated with and predictive of worse performance on visuospatial tasks	ACE-R; CAMCOG; Intersected Pentagons; JoLO; MMSE; RBANS*; ROCF; SCOPA-COG*

Note. * = effect found in all analyses using this test; ° = effect found in some analyses using this test but not in others; ACE-R = Addenbrookes Cognitive Examination - Revised; ANT = Attention Network Test; BNT = Boston Naming Test; CAMCOG = Cambridge Cognitive Assessment; CANTAB = Cambridge

Neuropsychological Test Automated Battery; CDR = Cognitive Drug Research Battery; COWAT = Controlled Oral Word Association Test; CVLT-II = California Verbal Learning Test – Second Edition; FAB = Frontal Assessment Battery; JoLO = Benton’s Judgement of Line Orientation; MMSE = Mini-Mental State Examination; MoCA = Montreal Cognitive Assessment; PoA = Power of Attention; RAVLT = Rey Auditory Verbal Learning Test; RBANS = Repeatable Battery for the Assessment of Neuropsychological Status; ROCF = Rey-Osterrieth Complex Figure; SCOPA-COG = Scales for Outcomes in Parkinson’s Disease – Cognition; SDMT = Symbol Digit Modality Test; TMT = Trail Making Test; TMT-A = Trail Making Test – Part A; WAIS-IV = Wechsler Adult Intelligence Scale – Fourth Edition; WCST = Wisconsin Card Sorting Test; WMS-III = Wechsler Memory Scales – Third Edition.

Appendix 1A

Author Guidelines for the British Journal of Health Psychology

The aim of the British Journal of Health Psychology is to provide a forum for high quality research, including Registered Reports, relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the Journal Overview.

The types of paper invited are:

- papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;
- theoretical papers which report analyses on established theories in health psychology;
- we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses); and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

Authors who are interested in submitting papers that do not fit into these categories are advised to contact the editors who would be very happy to discuss the potential submission.

All papers published in The British Journal of Health Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers describing quantitative research (including reviews with quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words, or 6,000 words for qualitative papers)

4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission and the declaration of competing interests. You may also like to use the Submission Checklist to help you prepare your paper.

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at <https://authorservices.wiley.com/statements/data-protection-policy.html>.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use this template. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the Project CRediT website for a list of roles.

- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found [here](#).
- Statement of Contribution: All authors are required to provide a clear summary of ‘what is already known on this subject?’ and ‘what does this study add?’. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.
- Conflict of interest statement: We are now including a brief conflict of interest statement at the end of each accepted manuscript. You will be asked to provide information to generate this statement during the submission process.
- The main document must be anonymous. Please do not mention the authors’ names or affiliations (including in the Method section) and always refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be

listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:

Author, A., Author, B., & Author, C. (1995). Title of book. City, Country: Publisher.

Author, A. (2013). Title of journal article. Name of journal, 1, 1-16. doi: 10.1111/bjep.12031

- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.
- Manuscripts describing clinical trials are encouraged to submit in accordance with the CONSORT statement on reporting randomised controlled trials.
- Manuscripts reporting systematic reviews and meta-analyses are encouraged to submit in accordance with the PRISMA statement.
- Manuscripts reporting interventions are encouraged to describe them in accordance with the TIDieR checklist.

If you need more information about submitting your manuscript for publication, please email Hannah Wakley, Managing Editor (bjhp@wiley.com) or phone +44 (0) 116 252 9504.

6. Supporting information

We strongly encourage submission of protocol papers or trial registration documents, where these are in the public domain, to allow reviewers to assess deviations from these protocols. This will result in reviewers being unblinded to author identity.

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files. Supporting Information should be cited within the article text, and a descriptive legend should be included. Please indicate clearly on submission which material is for online only publication. It is published as supplied by the author, and a proof is not made available prior to publication; for these reasons, authors should provide any Supporting Information in the desired final format.

For further information on recommended file types and requirements for submission, please visit the Supporting Information page on Author Services.

7. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive. A full list of terms and conditions is available on Wiley Online Library.

Any authors wishing to send their paper OnlineOpen will be required to complete the payment form.

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

8. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. You can then access Kudos through Author Services, which will help you to increase the impact of your research. Visit Author Services for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

9. Copyright and licences

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services, where via the Wiley Author Licensing Service (WALS) they will be able to complete the licence agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs .

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons Licence Open Access Agreements (OAA):

- Creative Commons Attribution Non-Commercial Licence (CC-BY-NC)
- Creative Commons Attribution Non-Commercial -NoDerivs Licence (CC-BY-NC-ND)

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs and you may also like to visit the Wiley Open Access Copyright and Licence page.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) or the Austrian Science Fund (FWF) you will be given the opportunity to publish your article under a CC-BY licence supporting you in complying with your Funder requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit our Funder Policy page.

10. Colour illustrations

Colour figures may be published online free of charge; however, the journal charges for publishing figures in colour in print. If the author supplies colour figures at Early View publication, they will be invited to complete a colour charge agreement in RightsLink for Author Services. The author will have the option of paying immediately with a credit or debit

card, or they can request an invoice. If the author chooses not to purchase colour printing, the figures will be converted to black and white for the print issue of the journal.

11. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found in Author Services. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

12. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from Adobe's web site. This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

13. Early View

British Journal of Health Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors'

final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. Eg Jones, A.B. (2010). Human rights Issues. Journal of Human Rights. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Further information about the process of peer review and production can be found in this document. What happens to my paper? Appeals are handled according to the procedure recommended by COPE.

Appendix 1B

Search Strategy used in the Electronic Database CINAHL

1. MH "Parkinson Disease"
2. Ti: Parkinson*
3. Ab: Parkinson*
4. 1 OR 2 OR 3
5. MH "Anxiety"
6. MH "Anxiety Disorders"
7. Ti: anxiet*
8. Ab: anxiet*
9. 5 OR 6 OR 7 OR 8
10. MH "Cognition Disorders"
11. MH "Neuropsychology"
12. MH "Neuropsychological Tests"
13. MH "Mental Processes"
14. MH "Impulsive Behavior"
15. MH "Attention"
16. MH "Memory"
17. MH "Perception"
18. MH "Dementia"
19. Ti: cognit* OR neuropsych* OR executive OR metacognit* OR frontal OR process*
OR problem solv* OR reason* OR concept formation OR sequenc* OR *shift* OR
impulsiv* OR distract* OR initiat* OR perseverat* OR attention OR concentration
OR memory OR perception* OR orient* OR spatial OR visuospatial OR

visuoconstruct* OR language OR verbal OR comprehen* OR learn* OR dement* OR
MCI

20. Ab: cognit* OR neuropsych* OR executive OR metacognit* OR frontal OR
process* OR problem solv* OR reason* OR concept formation OR sequenc* OR
shift OR impulsiv* OR distract* OR initiat* OR perseverat* OR attention OR
concentration OR memory OR perception* OR orient* OR spatial OR visuospatial
OR visuoconstruct* OR language OR verbal OR comprehen* OR learn* OR dement*
OR MCI

21. 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20

22. 4 AND 9 AND 21

Appendix 1C

Quality Assessment Tool for Observational Studies (Williams et al., 2010; unmodified)

1) Unbiased selection of the cohort?

Factors that help reduce selection bias:

- Prospective study design and recruitment of subjects
- Inclusion/exclusion criteria
 - o Clearly described (especially re: age and cognitive status)
 - o Assessed using valid and reliable measures
- Recruitment strategy
 - o Clearly described
 - o Relatively free from bias (selection bias might be introduced, e.g., by recruitment via advertisement)

2) Selection minimizes baseline differences in prognostic factors?

Factors to consider:

- Was selection of the comparison group appropriate? Note: This may not be an issue in the cohort studies we review. In general, the exposed and unexposed groups should be from the same source. However, it is possible that for some medical condition exposures the exposed group will be patients from a specialty medical clinic and the unexposed comparison group will be from another source. Consider whether these two sources are likely to differ on factors related to the outcome (besides the exposure factor).
- In addition to selecting the cohort in an unbiased way, did study investigators do other things to ensure that exposed/unexposed groups were comparable, e.g., by using stratification, matching, or propensity scores?

3) Sample size calculated/5% difference?

Factors to consider:

- Did the authors report conducting a power analysis or describe some other basis for determining the adequacy of study group sizes for the primary outcome(s) of interest to us?
- Was the sample size sufficiently large to detect a clinically significant difference of 5% in event rates or an OR/RR increase of ≥ 1.5 or decrease of ≥ 0.67 between groups in at least one primary outcome measure of interest to us?

4) Adequate description of the cohort?

Consider whether the cohort is well-characterized in terms of baseline:

- Age
- Sex
- Race
- Educational level
- Cognitive status
- For genetic association studies, were the diseased and non-diseased populations drawn from groups with the same ethnic/racial mix?

5) Validated method for ascertaining exposure?

Factors to consider:

- Was the method used to ascertain exposure clearly described? (Details should be sufficient to permit replication in new studies.)
- Was a valid and reliable measure used to ascertain exposure? (Subjective measures based on self-report tend to have lower reliability and validity than objective measures such as clinical reports and lab findings.)

- For gene association studies, is the “call rate” of genotyping (the proportion of samples in which the genotyping provides an unambiguous reading) reported? Were quality checks implemented or rules established to determine when genotyping results would be considered valid? To clarify your score, please make a note of the method/measure used to ascertain exposure.

6) Validated method for ascertaining clinical outcomes?

Factors to consider:

- Were primary outcomes (AD and/or cognitive decline) assessed using valid and reliable measures? (See details below.)
- Were these measures implemented consistently across all study participants?

7) Outcome assessment blind to exposure?

- Were the study investigators who assessed outcomes blind to the intervention or exposure status of participants?

8) Adequate follow-up period?

Factors to consider:

- Minimum adequate follow-up period is 2 years for AD and 1 year for cognitive decline
- Follow-up period should be the same for all groups
 - o In cohort studies, length of follow-up should be the same across all groups.
 - o In nested case-control studies, period between the intervention/exposure and outcome should be the same for cases and controls.
 - o OK if differences in follow-up time were adjusted for using statistical techniques, e.g., survival analysis.

9) Completeness of follow-up?

Factors to consider:

- Did attrition from any group exceed 30%? (Attrition is measured in relation to the time between baseline/allocation and outcome measurement. Where different numbers of patients are followed up for different outcomes, use the number followed up for the primary outcome for this calculation.)
- Did attrition differ between groups by more than 10% percent?

10) Analysis controls for confounding?

Factors to consider:

- Did the analysis control for any baseline differences between groups?
- Does the study identify and control for important confounding variables and effect modifiers? (Confounding variables are risk factors that are correlated with the intervention/exposure and outcome and may therefore bias the estimation of the effect of intervention/exposure on outcome if unmeasured. Effect modifiers are not correlated with the intervention/exposure, but change the effect of the intervention/exposure on the outcome. Age, race/ethnicity, education, and measures of SES are examples of effect modifiers and confounding variables for the exposures and outcomes of interest in this study.)

11) Analytic methods appropriate?

Factors to consider:

- Was the kind of analysis done appropriate for the kind of outcome data?
 - o Dichotomous – logistic regression, survival
 - o Categorical – mixed model for categorical outcomes
 - o Continuous – ANCOVA, mixed model
- Was the analysis done on an intention-to-treat basis? (That is, was the impact of loss to follow-up [or differential loss to followup] assessed, e.g., through sensitivity analysis or another intent-to-treat adjustment method?)

- Was the number of variables used in the analysis appropriate for the sample size?

(The statistical techniques used must be appropriate to the data and take into account issues such as controlling for small sample size, clustering, rare outcomes, multiple comparison, and number of covariates for a given sample size. The multiple comparisons issue may be a problem particularly when performance results on numerous cognitive measures are being compared. When assessing change on cognitive measure over time, consider whether change score should be adjusted for baseline score, and consider distribution of baseline scores and change scores.)

- For gene association studies:
 - o Did the investigators conduct statistical tests to check whether the observed genotype frequencies are consistent with the Hardy-Weinberg Equilibrium?
 - o Did the investigators adjust for multiple comparisons?

Appendix 1D

Adaptations to Williams et al.'s (2009) Quality Assessment Tool

Item	Original criterion	Adaptations made	Reasons for adaptations
1	Unbiased selection of the cohort	Combined with Item 4 to become "sample is valid and representative"	It was difficult to establish bias in sampling methods or the representativeness of the sample without the sample being adequately described
2	Selection minimizes baseline differences in prognostic factors (only relevant to studies using between-groups comparisons)	None	-
3	Sample size calculated / 5% difference	Sample size required to be large enough to detect a significant effect/relationship in at least one primary outcome measure at the 5% level	To increase relevance to the research question

4	Adequate description of the cohort	Combined with Item 1 to become “sample is valid and representative”	It was difficult to establish bias in sampling methods or the representativeness of the sample without the sample being adequately described
5	Validated method for ascertaining exposure	Item removed	Not relevant to research question
6	Validated method for ascertaining clinical outcomes	Changed to: measures implemented consistently across participants and cognitive assessments are carried out by a suitably qualified individual	Part of this criterion was covered by study selection criteria (since it was required that validated measures were used), therefore only part of the original item was relevant
7	Outcome assessment blind to exposure	Item removed	Not relevant to research question
8	Adequate follow-up	Changed to: in longitudinal, between-groups studies, the	Selected the part of the criterion which was relevant to the research question

length of follow-up is the
same across all groups

9	Completeness of follow-up (only relevant to longitudinal studies)	None	-
10	Analysis controls for confounding variables	None	-
11	Analytic methods appropriate	None	-
-	All	Addition of “not applicable” (n/a) rating	Some items were not applicable to all included studies

Appendix 1E

Quality Appraisals by Second Reviewer

Paper	Sample	Comparable Groups	Power	Measures	Follow-up consistency	Follow-up completeness	Confounding Variables	Analysis
Athey et al, 2005	p	na	y	ct	na	na	p	y
Dissanayaka et al, 2017	y	y	ct	ct	na	na	p	y
Hepp et al, 2013	p	na	n	ct	na	na	p	y
Mamikonyon et al, 2009	y	p	ct	y	na	na	p	y
Ryder et al, 2002	n	na	n	y	na	na	p	y

Note. y= yes; p= partial; n= no; na= not applicable; ct= can't tell

Section Two: Empirical Paper

Stigma, Self-Compassion and Psychological Distress among People with Parkinson's

Natalie Sowter

Doctorate in Clinical Psychology

Lancaster University

Formatted for submission to the British Journal of Health Psychology (Author Guidelines
attached in Appendix 2A)

Word count (including abstract but excluding references, appendices, figures and tables):

7447

Correspondence should be addressed to:

Natalie Sowter

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

Lancaster, L1 4YG

Email: n.sowter@lancaster.ac.uk

Abstract

Objectives: People with Parkinson's can experience stigma, both through the attitudes and actions of others (enacted stigma) and through anticipation of enacted stigma and internalisation of negative stereotypes (felt stigma). Previous research has suggested that self-compassion protects against the impact of enacted stigma upon felt stigma and negative outcomes. This study aimed to investigate the relationships between self-compassion, stigma and psychological distress among people with Parkinson's.

Design: In a quantitative, questionnaire-based design, correlation and mediation models were used to investigate the relationships between the variables.

Methods: 138 people with Parkinson's completed questionnaires measuring self-compassion, enacted and felt stigma, and depression, anxiety and stress.

Results: All variables correlated significantly in the expected directions. The stigma variables were found to be significant mediators in the relationships between self-compassion and the three outcome variables - depression, anxiety and stress. Higher self-compassion was associated with less reported stigma, which was in turn associated with lower levels of psychological distress.

Conclusions: Part of the relationship between self-compassion and psychological distress appears to occur via the internalisation of stigma. Self-compassion may also predict how likely a person is to notice or report enacted stigma. Therefore, people with Parkinson's who are higher in self-compassion may experience less enacted stigma (even when they are exposed to it), and therefore experience lower levels of distress. These findings may be relevant to the development of individualised and societal interventions with the aim of improving the psychological wellbeing of people with Parkinson's.

Stigma, Self-Compassion and Psychological Distress among People with Parkinson's

Parkinson's disease (referred to throughout this paper as "Parkinson's": the preferred terminology by the charity Parkinson's UK) is a neuro-degenerative condition affecting around 0.3% of people worldwide (Pringsheim, Jette, Frolkis & Steeves, 2014), with increasing prevalence after the age of 60 (Tysnes & Storstein, 2017). Parkinson's is classified as a movement disorder (Fahn, 2011). Accordingly, people with Parkinson's can experience problems with initiating movement (akinesia), slowed movement (bradykinesia), tremor, rigidity, gait disturbance and speech difficulties (Moustafa et al., 2016). Other difficulties experienced by people with Parkinson's can include anxiety, depression, cognitive impairments, sensory disturbances, sexual dysfunction and continence problems (Rana, Ahmed, Chaudry & Vasan, 2015; Stacy, 2011).

Experiences of psychological distress are common among people with Parkinson's. A systematic review of the literature found that 35% of people with Parkinson's experience clinically significant symptoms of depression (Reijnders, Ehrt, Weber, Aarsland & Leentjens, 2008), while the prevalence of anxiety is estimated at 25% (Dissanayaka et al., 2010). Conceptualisations of these experiences have traditionally assumed a neuro-biological stance, suggesting that psychological distress occurs as a direct consequence of pathological processes, such as changes in dopaminergic, serotonergic, and noradrenergic systems and fronto-striatal circuitry (Aarsland, Marsh & Schrag, 2009; Kano et al., 2011; Remy, Doder, Lees, Turjanski & Brooks, 2005). However, in addition to the recognised role of neuro-biological changes, growing evidence suggests that social and psychological factors are important in the development of psychological distress (Garlovsky, Overton & Simpson, 2016). It is important to develop a better understanding of these factors so that holistic assessment and support can be provided, as recommended in the British Psychological

Society's (BPS) briefing document regarding psychological services for people with Parkinson's (Macniven & Gaskill, 2009). The current paper therefore focusses on two psycho-social factors in relation to psychological distress among people with Parkinson's: stigma and self-compassion.

Goffman's (1963) early conceptualisation of stigma described it as an individual attribute which is discredited by society, leading to loss of social status. Later, stigma was more comprehensively defined as a phenomenon whereby individuals are labelled, stereotyped, discredited and discriminated against, based on certain attributes which are devalued by society, in a context where they have reduced power (Link & Phelan, 2001; 2006). "Enacted stigma" is a term used to describe the negative reaction that the stigmatised individual receives from others, through their attitudes and actions (Scambler, 1989). When an individual expects or fears enacted stigma, this is known as "felt stigma", or "internalised stigma" (Corrigan, Watson & Barr, 2006). Felt stigma may also involve identification with negative stereotypes, and the application of discrediting attitudes to the self (Watson, Corrigan, Larson & Sells, 2007). Experiences of felt stigma have been found to be associated with feelings of shame and low self-esteem (Link & Phelan, 2001; Rao et al., 2009).

In the context of illness and impairment, where difference may be highly visible, individuals may be at a higher risk of stigmatisation (Campbell & Deacon, 2006; Joachim & Acorn, 2000). People with Parkinson's may present with visible differences, through the more overt motor and facial symptoms and communication difficulties, increased dependence on others, and lifestyle changes necessitated by symptoms (Hermanns, 2013). Research has demonstrated stigmatising views towards people with Parkinson's held by both professionals (Tickle-Degnen, Zebrowitz & Ma, 2011) and members of the public (Hemmesch, 2014; Moore & Knowles, 2006). Several qualitative studies have described the enacted and felt stigma that people with Parkinson's can experience in relation to the more visible symptoms

of the condition (Bramley & Eatough, 2005; Caap-Ahlgren & Lannerheim, 2002; Hermanns, 2013; Nijhof, 1995). Experiences of stigma have been found to be associated with heightened levels of anxiety, depression and stress among people with Parkinson's (Ma et al., 2016; Simpson, Lekwuwa, & Crawford, 2014; Schrag, Jahanshahi & Quinn, 2001). Felt stigma has been found to be prevalent among people with Parkinson's even in the absence of direct experience of enacted stigma, demonstrating the importance of implicit public attitudes (Ma et al., 2016). Simpson, McMillan and Reeve (2013) describe the structural disablism faced by people with Parkinson's (active barriers to inclusion at the public level, such as workplace discrimination, costs of care and inaccessibility of information), and how this may lead to psycho-emotional disablism (the internalisation of oppressive attitudes and subsequent restrictions placed upon the self). Therefore, enacted stigma can contribute to the internalisation of stigma and experiences of psychological distress (Simpson et al., 2013). Ma et al. (2016) found a stronger relationship between felt stigma and depression than enacted stigma and depression, suggesting that the internalisation of stigma is an important factor relating to the development of psychological distress.

Self-compassion is defined as a non-judgemental acknowledgement of one's own suffering, and a self-directed response based upon "kindness, concern and support" (Neff & Dahm, 2015, pp.121). Self-compassion is considered an important element of emotional regulation, access to which is affected by early relational experiences (Gilbert, 2009; 2010). Gilbert (2009; 2010; 2014) describes how, if a child receives attuned care when they are distressed, where they are soothed and helped to feel safe, then they will internalise the ability to recognise their distress and self-soothe (i.e. to show compassion towards themselves). Conversely, difficult early relational experiences (such as miss-attuned caregiving, abuse and neglect) present few opportunities to learn self-compassion or access affiliative emotion regulation systems; instead a child may learn to be hypervigilant to

potential threats and experience heightened shame and self-criticism (Gilbert, 2009; 2010). Thus, the development of self-compassion affects how we cope with difficult life events and experiences – how we appraise threats, experience affiliative emotions, view and relate to ourselves and self-soothe. Across a range of populations, self-compassion has been shown to be positively associated with psychological wellbeing (Zessin, Dickhäuser & Garbade, 2015) and negatively associated with symptoms of depression and anxiety (MacBeth & Gumley, 2012). Further, it has been demonstrated that interventions aimed at increasing self-compassion can alleviate psychological distress in people with neurological problems – for example, traumatic brain injury (Ashworth, Gracey & Gilbert, 2011), dementia (Collins, Gilligan & Poz, 2018) and multiple sclerosis (Nery-Hurwit, Yun & Ebbeck, 2018). However, self-compassion does not appear to have yet been studied among people with Parkinson's.

Individuals whose early experiences have supported the development of self-compassion may have different interpretations of, and responses to, experiences of stigma than those who have had limited opportunities to develop self-compassion. Wong, Knee, Neighbors and Zvolensky (2019) offer a theoretical framework for how self-compassion may protect against the effects of enacted stigma upon felt stigma and negative outcomes (such as psychological distress). Drawing upon the literature, Wong et al. (2019) suggest that there are cognitive, emotional, and social mechanisms through which self-compassion affects the processing of stigma, which are summarised here. Cognitively, an individual with higher self-compassion may be more able to accurately appraise the threats of stigmatisation and positively reframe experiences of enacted stigma, allowing them to feel safer and more content, and thus internalise stigma less. In line with the aforementioned conceptualisation by Gilbert (2009; 2010), Wong et al. (2019) also describe how self-compassion can facilitate the processing and regulation of emotions, allowing an individual to better cope with both enacted and felt stigma and therefore experience less distress. Finally, it is suggested that

more self-compassionate individuals are both more able to seek social support, and are more forgiving of stigma enactments, due to a sense of shared humanity and connection (given their increased capacity for affiliative emotions); this may in turn reduce anxieties about social rejection due to the stigmatised attribute (Wong et al., 2019). It is currently unclear whether this framework is applicable to people with Parkinson's, since this has not previously been investigated.

Consequently, the overall aim of this study was to investigate the relationships between the constructs of stigma, self-compassion, and psychological distress (as measured by depression, anxiety and stress scores) among people with Parkinson's. A survey was used to measure these constructs quantitatively. Correlation analyses were employed to assess the strength and direction of the relationships between these constructs, and mediation models were utilised to establish whether any relationships between self-compassion and psychological distress occurred via (i.e. were mediated by) experiences of stigma.

It was hoped that the findings of this study would be useful to professionals working with people with Parkinson's in clinical or community psychology contexts, by further developing theoretical understandings in this area. It was anticipated that the findings may have implications for clinical and therapeutic interventions, as well as providing evidence to support activism addressing stigmatised attitudes towards people with Parkinson's.

It was expected that individuals who experienced more stigma would have higher levels of depression, anxiety and stress, and that more self-compassionate individuals would experience lower levels of depression, anxiety and stress. Given Wong et al.'s framework, it was hypothesised that more self-compassionate individuals would be less threatened or concerned by enacted stigma (therefore might report less of it), and would not experience as much felt stigma as those who were lower in self-compassion. Finally, it was anticipated that both felt and enacted stigma would mediate the relationships between self-compassion and

depression, anxiety and stress.

Method

Design

This was a cross-sectional, observational study. Quantitative data were collected by means of a series of self-report questionnaires. The main statistical model used to analyse the data was simple mediation, using Hayes' Process Tool (Hayes, 2018). The simple mediation model is used to investigate whether a relationship between a predictor variable and an outcome variable operates via a third (mediator) variable (Field, 2018; Hayes, 2018), as depicted in Figure 2.1. Mediation analysis tests four relationships, using linear regression: (i) does the predictor variable significantly predict the outcome variable (the direct effect, denoted by c' in the Figure)? (ii) does the predictor variable significantly predict the mediator variable (denoted by a)? (iii) when the predictor and mediator variables are both entered into the regression model, does the mediator variable significantly predict the outcome variable (denoted by b)? (iv) is there an indirect effect (denoted by ab) of the predictor upon the outcome variable via the mediator variable? Mediation is said to have occurred when the confidence interval of the indirect effect does not contain zero (Field, 2018; Hayes, 2018).

< INSERT FIGURE 2.1 >

The predictor variable in each case was self-compassion. The mediator variables were felt and enacted stigma, and the outcome variables were scores on measures of depression, anxiety and stress. The six models tested are displayed in Figure 2.2.

< INSERT FIGURE 2.2 >

Participants

A total of 153 individuals completed the survey, however 15 were removed due to large amounts of missing data. The participants were therefore 138 individuals with a self-reported diagnosis of Parkinson's.

A priori power calculations were conducted to determine the sample size required. Fritz and MacKinnon (2007) provide empirical estimates of the sample sizes required in mediation analyses to achieve statistical power at 80%. They suggest that a bias-corrected bootstrapped mediation analysis with medium effect sizes between the independent and mediator variables (α) and the mediator and dependent variables (β) ($\alpha, \beta = 0.39$) requires 71 participants to be adequately powered. It was also calculated that, to detect a moderate correlation ($\rho = 0.3$) and for $p=0.05$ at 80% power, a two-tailed Spearman's rho correlation requires 85 participants. Therefore, the sample of 138 participants was adequate.

Participants were recruited via advertisements on the Parkinson's UK website, in the Parkinson's UK online newsletter, and on the social media platform Twitter. Participants were asked to confirm that they met the inclusion criteria for the study, namely that they: had a diagnosis of Parkinson's; had had their diagnosis for a minimum of 6 months; and were aged 18 years or older. Four individuals contacted the researcher for paper copies of the questionnaires, which were posted along with stamped addressed envelopes for their return, however only one was returned. The remainder of the sample completed the questionnaires in online format.

Procedure

Early in the development of the study, consultation was sought with Patient and Public Involvement Volunteers from Parkinson's UK. Four volunteers provided feedback, via email, on the layout, content, accessibility and wording of the proposed materials (apart from

standardised measures). Adaptations were made accordingly, including changing the wording of the survey title and providing a greater level of detail about the background to the study. Once the materials had been developed and ethical approval had been granted (as below), the study was advertised on the Parkinson's UK website, in the Parkinson's UK online newsletter, and on the social media platform Twitter. The study was active between November 2018 and March 2019. Potential participants were presented with a link to an "Information for Participants" page (attached in *Section 4: Ethics and Appendices*) and invited to either complete an online survey (via the web-based survey tool Qualtrics), or to contact the lead researcher via phone, text or email to request a hard copy be posted to them, along with a stamped addressed envelope in which to return it.

Materials

The materials for this study consisted of an online or paper-based survey comprising: an "Information for Participants" sheet; four questions to confirm eligibility to participate and informed consent; a demographic and clinical information questionnaire; a series of validated questionnaire measures; and a "Debrief" sheet (attached in *Section 4: Ethics and Appendices*). The demographic and clinical information questionnaire asked about age, gender, ethnic group or background, current place of living (country), current living arrangements, partnership status, employment status, time since diagnosis, and current treatment for Parkinson's. In addition to these questions, the Functional Status Questionnaire (FSQ; Jette et al., 1986) was used to situate the sample in terms of severity of physical symptoms.

Validated measures.

Functional Status Questionnaire – physical function subscales. The FSQ - physical function subscales were included in the survey following the demographic and clinical information questions. The first subscale contains three items designed to assess functioning

in basic activities of daily living (ADLs), such as washing and dressing and moving around the home. The second subscale has six items and measures functioning in intermediate ADLs, such as completing housework and physical activities outside of the home. Items are scored from four (usually did with no difficulty) to one (usually did not do because of health), with the additional option, “usually did not do for other reasons”, which scores zero. Scaled scores (between zero and 100) are derived from the total scores for each subscale, with higher scaled scores representing higher levels of functional ability. Each subscale has a “warning zone” cut-off score, above which their functional ability is deemed “good”. In a systematic review of disability rating scales for people with Parkinson’s (Shulman et al., 2016), this measure was recommended for both clinical and research use. Jette et al. (1986) report that it has good internal consistency (Cronbach's alpha = 0.92).

Self-Compassion Scale. The Self-Compassion Scale (SCS; Neff, 2003) is a 26-item validated measure of self-compassion, consisting of six subscales: self-kindness, self-judgment, common humanity, isolation, mindfulness and over-identification. Each item describes a self-compassion-related experience and is rated from one (almost never) to five (almost always). The self-judgement, isolation and over-identification subscales are reverse-coded. The total self-compassion score is the mean of the six subscale means, therefore is also a number between one and five. Neff (2003) reports that the scale’s internal consistency is high (Cronbach’s alpha = 0.92), as is the its test-retest reliability ($r=93$). Though initially validated using a student sample (Neff, 2003), this scale has been widely used in research with people with chronic illness (Pinto-Gouveia, Duarte, Matos & Fráguas, 2014; Sirois, Molnar & Hirsch, 2015), people with neurological conditions (Baker, Caswell & Eccles, 2019; Nery-Hurwit et al., 2018) and older adults (Allen, Goldwasser & Leary, 2012).

Stigma Scale for Chronic Illness. The Stigma Scale for Chronic Illness (SSCI; Rao et al., 2009) is a 24-item multiple-choice questionnaire, designed and validated for use with

people with Parkinson's (as well as other chronic illnesses). The first 13 items measure felt stigma, and the remaining 11 items measure enacted stigma. The total score measures overall stigma. Each item asks about a stigma-related experience, which is rated on a scale of one (never) to five (always). A higher total score indicates more stigma. Both the bifactor (felt and enacted stigma) and unifactor (overall stigma) models have been found to be valid (Rao et al., 2009). Cronbach's alpha was reported by the authors of the scale at 0.97, although this analysis was conducted on a draft version of the questionnaire with 26 items, rather than the final 24-item version. Cronbach's alphas were not available for the subscales.

Depression, Anxiety and Stress Scale. The Depression, Anxiety and Stress Scale – 21-item version (DASS-21; Lovibond & Lovibond, 1995) is a validated questionnaire designed for use with both clinical and non-clinical populations as a dimensional, rather than diagnostic, tool. The scale is comprised of 21 items, falling into three subscales: depression, anxiety and stress. Each item is rated for how much it applied over the last week, from zero (did not apply to me at all) to three (applied to me very much, or most of the time). A total score is generated for each subscale, with a higher score indicating a higher level of depression, anxiety or stress. Cronbach's alphas have been found to be 0.94 for depression, 0.87 for anxiety, and 0.91 for stress (Antony, Bieling, Cox, Enns, & Swinson, 1998). The DASS-21 is frequently used in studies with people with Parkinson's (e.g. Birtwell, Dubrow-Marshall, Dubrow-Marshall, Duerden, & Dunn, 2017; Troeung, Egan & Gasson, 2014).

Ethical Considerations

Ethical approval was granted by the Lancaster University Faculty of Health and Medicine Research Ethics Committee (reference: FHMREC18052). An amendment was sought (and granted) in January 2019, such that the recruitment strategy could be expanded to include advertisement on Twitter. A letter confirming ethical approval is attached in *Section 4: Ethics and Appendices*. The research team at Parkinson's UK agreed that this was

sufficient for them to promote the research.

Efforts were made to ensure, as far as possible, that informed consent was given by every participant. Participants were asked to confirm that they had read and understood the “Information for Participants” and gave their consent for their data to be used in the research. This was deemed sufficient by the Research Ethics Committee. The potential for participants to experience distress as a result of completing the questionnaires was also considered. The details of organisations participants could contact for support in the event of distress were provided as part of the Information for Participants and Debrief sections of the survey. To protect participants’ right to privacy, data were submitted anonymously and stored securely on password protected software.

Data Analysis

The data were tabulated in the software IBM SPSS Statistics (Version 25.0). Participants with large amounts of missing data were removed from the dataset (four had missed at least one full measure, nine had missed more than one full measure and two had completed only the eligibility and consent questions). There were no participants with missing items within measures. Total and mean scores were calculated for the questionnaire measures as necessary. The data were visually and statistically inspected for outliers using a series of box plots and z-score calculations, with data points more than 3.29 standard deviations from the mean considered outliers (Field, 2018). One extreme data point in the “enacted stigma” variable was winsorized (replaced with the next highest score), to reduce the likelihood of biasing the results (Field, 2018).

Next, the data distributions were visually inspected for normality using histograms. The “enacted stigma”, “depression” and “stress” data were all skewed towards lower scores. The assumptions of linearity and homoscedasticity of residuals were tested by visual inspection of a series of linear and multiple regression scatterplots, with standardised

residuals plotted against standardised predicted values, as outlined by Field (2018) and Kane and Ashbaugh (2017). The assumption of normality of error distributions was assessed using Q-Q plots (Field, 2018). All relationships appeared to respect the assumptions of linearity, homoscedasticity of residuals and normality of error distributions.

Cronbach's alphas for each of the questionnaire measures were calculated to assess their internal validity for the sample. Then, to assess the strength and direction of relationships between demographic, predictor, mediator and outcome variables, Spearman's rho correlation coefficients were calculated. This test was selected due to the non-normal distributions of questionnaire scores, meaning that the data did not fit the assumptions for a parametric test.

Finally, a series of mediation analyses were run using Hayes' Process Tool (Hayes, 2018), which employs a bias-corrected bootstrap model, enabling it to cope with non-normal data distributions. In each analysis, 5000 bootstrap samples were used to estimate the confidence intervals. In the first model, self-compassion was entered as the predictor variable, felt stigma as the mediator variable and depression as the outcome variable. This was repeated with anxiety and stress as outcomes. The same models were then repeated with enacted stigma entered as the mediator variable.

Results

Demographic and Clinical Characteristics

Of the 138 participants whose data were included in the study, 79 (57%) identified as female. The remaining 59 participants (43%) identified as male. The ages of participants ranged from 36 to 89 years, with a mean of 64 years. Most participants (92%) identified their ethnic group or background as "white British" and 83% reported living in England. The majority of participants (68%) reported being retired from work.

Participants had held their diagnosis of Parkinson's for between six months and 30

years, with a mean of five years (the distribution was skewed, with most participants having been diagnosed relatively recently). The majority of participants (93%) were taking prescribed oral medication to treat their Parkinson's symptoms.

There was a wide range of functional ability among the sample, as measured by FSQ scores. On the "basic activities of daily living" scale, 62% of participants scored above the "warning zone" cut-off score of 88, indicating a "good" level of basic functional ability. On the "intermediate activities of daily living" scale, 46% of participants scored above the "warning zone" cut-off score of 78.

The demographic and clinical characteristics of the sample which were measured on a continuous scale are summarised Table 2.1, and the categorical variables are presented in Table 2.2.

< INSERT TABLES 2.1 AND 2.2 >

Descriptive Statistics and Internal Consistency for Standardised Measures

Table 2.3 shows the means, standard deviations, ranges and Cronbach's alphas for the sample on each of the standardised measures. Of note, the mean total stigma score on the SCS among the sample was 49: somewhat higher than the normative sample mean (23% of whom had Parkinson's) of 42.7 (Rao et al., 2009). Mean scores on the DASS-21 variables fell in the "mild" range for depression and stress, and the "moderate" range for anxiety.

< INSERT TABLE 2.3 >

The FSQ Basic ADLs subscale demonstrated adequate internal consistency (Cronbach's alpha = .74) and the Intermediate ADLs subscale showed good internal

consistency (Cronbach's alpha = .86). The SCS demonstrated excellent internal consistency (Cronbach's alpha = .92). The SSCI also demonstrated excellent internal consistency for each of the felt stigma, enacted stigma and total stigma scales (Cronbach's alpha = .93, .94 and .95 respectively). The depression and stress scales of the DASS-21 both showed excellent internal consistency, with Cronbach's alphas .96 and .92 respectively. However, the anxiety scale had a much lower Cronbach's alpha of .73. Further inspection revealed that the item "I experienced trembling (e.g., in the hands)" was reducing the internal consistency of the scale. When this item was removed, Cronbach's alpha increased to .80, indicating good internal consistency. Therefore, this item was removed for the subsequent analyses, meaning that the new possible range of scores was from zero to 19.

Correlational Analyses

A correlation matrix (using Spearman's rho correlation coefficients) is displayed in Table 2.4. All tests were two-tailed.

< INSERT TABLE 2.4 >

Demographic and clinical variables and self-compassion. There was a weak relationship between age and self-compassion ($\rho = .212, p < .05$) such that self-compassion increased with age.

Demographic and clinical variables and stigma. Age correlated weakly and negatively with felt, enacted and total stigma ($\rho = -.305, -.383, -.354$ respectively, all $p < .01$) such that higher age was associated with lower levels of reported stigma. Time since diagnosis was weakly and positively associated with experiences of enacted stigma ($\rho = .174, p < .05$) but was not significantly associated with felt stigma.

Demographic variables and psychological distress. There were weak, negative

relationships between age and anxiety ($\rho = -.172, p < 0.05$) and age and stress ($\rho = .232, p < .01$).

FSQ scores. The FSQ Basic ADLs scaled scores showed moderate, negative correlations with felt and total stigma scores ($\rho = -.409, -.455$ respectively, all $p < .01$), with lower functional abilities associated with more reported stigma. The FSQ Intermediate ADLs scaled scores showed a moderate, negative correlation with total stigma scores ($\rho = -.403, p < .01$). The FSQ scores correlated significantly but weakly with all other questionnaire scores, in the expected directions.

Self-compassion, stigma and psychological distress.

Moderate to strong relationships were observed between self-compassion and depression, anxiety and stress ($\rho = -.722, -.477, -.634$ respectively, all $p < .01$). As expected, higher self-compassion was associated with lower levels of depression, anxiety and stress. A weak correlation was observed between self-compassion and enacted stigma ($\rho = -.392, p < .01$), while a moderate correlation was observed between self-compassion and felt stigma ($\rho = -.555, p < .01$). Again, these relationships were in the expected directions, with higher self-compassion associated with lower levels of stigma. As anticipated, there were moderate to strong correlations between felt stigma and depression, anxiety and stress ($\rho = .648, .591, .610$ respectively, all $p < .01$), with higher levels of felt stigma associated with higher levels of depression, anxiety and stress. Moderate relationships in the same direction were also observed between enacted stigma and the DASS-21 variables ($\rho = .414, .489, .486$ respectively, all $p < .01$).

Mediation Analyses

Since the demographic and clinical variables (excluding the FSQ) correlated only weakly with the questionnaire measures ($\rho < .40$), they were not included as covariates in the models. Given the moderate associations between FSQ scores and the stigma scales, both

FSQ variables were initially entered as covariates. Upon further inspection, these variables did not make significant contributions in several of the regression models, nor did they have any great impact upon the findings. Therefore, they were not included in the final models tested. In each analysis, the predictor variable was self-compassion, the mediator variable was felt or enacted stigma and the outcome variable was depression, anxiety or stress (as shown in Figure 2.2). Five-thousand bias-corrected bootstrap samples were used to estimate the confidence intervals. The main findings of the mediation analyses are displayed in Figures 2.3 and 2.4 and the SPSS outputs are attached in Appendix 2B.

The mediating effects of felt stigma. Higher self-compassion was predictive of lower felt stigma ($a = -8.414, p < .01$), and lower felt stigma was subsequently predictive of lower depression scores ($b = .181, p < .01$). A 95% bias-corrected confidence interval based on 5000 bootstrap samples found the indirect effect ($ab = -1.524$) to be entirely below zero, $CI = [-2.323, -.847]$, indicating a significant effect of self-compassion on depression through felt stigma. The size of the indirect effect was reported at $-.201$. There was also a direct effect of self-compassion on depression, with higher self-compassion predicting lower depression scores ($c' = -4.024, p < .01$).

In the next analysis, higher self-compassion was predictive of lower felt stigma ($a = -8.414, p < .01$), and lower felt stigma was subsequently predictive of lower anxiety scores ($b = .165, p < .01$). A 95% bias-corrected confidence interval based on 5000 bootstrap samples found the indirect effect ($ab = -1.388$) to be entirely below zero, $CI = [-2.030, -.834]$, indicating a significant effect of self-compassion on anxiety through felt stigma, with an effect size of $-.278$. A direct effect of self-compassion on anxiety was also identified, with higher self-compassion predicting lower anxiety scores ($c' = -1.002, p < .05$).

Also, higher self-compassion predicted lower felt stigma ($a = -8.414, p < .01$), and lower felt stigma subsequently predicted lower stress scores ($b = .158, p < .01$). A 95% bias-

corrected confidence interval based on 5000 bootstrap samples found the indirect effect ($ab = -1.325$) to be entirely below zero, $CI = [-2.177, -.607]$, indicating a significant effect of self-compassion on stress through felt stigma. The size of this effect was reported at $-.180$. A direct effect of self-compassion on stress was found, with higher self-compassion predicting lower stress scores ($c' = -3.377, p < .01$).

The mediating effects of enacted stigma. Higher self-compassion was predictive of less reported enacted stigma ($a = -3.333, p < .01$), and less reported enacted stigma was subsequently predictive of lower depression scores ($b = .101, p < .05$). A 95% bias-corrected confidence interval based on 5000 bootstrap samples found the indirect effect ($ab = -.335$) to be entirely below zero, $CI = [-.767, -.003]$, indicating a significant effect of self-compassion on depression through enacted stigma, with an effect size of $-.044$. There was also a direct effect of self-compassion on depression, with higher self-compassion predicting lower depression scores ($c' = -5.213, p < .01$).

Higher self-compassion was predictive of lower reported enacted stigma ($a = -3.333, p < .01$), and lower reported enacted stigma was subsequently predictive of lower anxiety scores ($b = .190, p < .01$). A 95% bias-corrected confidence interval based on 5000 bootstrap samples found the indirect effect ($ab = -.633$) to be entirely below zero, $CI = [-1.0854, -.2609]$, indicating a significant effect of self-compassion on anxiety through enacted stigma. The size of this effect was reported at $-.167$. There was also found to be a direct effect of self-compassion on anxiety, with higher self-compassion predicting lower anxiety scores ($c' = -1.756, p < .01$).

In the final analysis, higher self-compassion was predictive of less reported enacted stigma ($a = -3.333, p < .01$), and less reported enacted stigma was subsequently predictive of lower stress scores ($b = .182, p < .01$). A 95% bias-corrected confidence interval based on 5000 bootstrap samples found the indirect effect ($ab = -.608$) to be entirely below zero, $CI = [-$

1.121, -.183], indicating a significant effect of self-compassion on stress through enacted stigma, with an effect size of -.083. A direct effect of self-compassion on stress was also found, with higher self-compassion predicting lower stress scores ($c' = -4.094, p < .01$).

< INSERT FIGURES 2.3 AND 2.4 >

Discussion

This study investigated the relationships between the variables of self-compassion, stigma (both felt and enacted) and psychological distress (depression, anxiety and stress) among people with Parkinson's. This was considered important in order to develop understandings of psychological and social conceptualisations of distress for people with Parkinson's, where neuro-biological understandings currently dominate.

Significant relationships were observed between self-compassion and the DASS-21 variables, with higher self-compassion associated with lower levels of depression, anxiety and stress. This fits with previous findings about such relationships in the wider population (MacBeth & Gumley, 2012). Also as expected in keeping with previous research (Ma et al., 2016; Simpson et al., 2014; Schrag et al., 2001), significant correlations were found between felt stigma and depression, anxiety and stress, with higher levels of felt stigma associated with higher levels of distress. Similarly, moderate relationships in the same direction were found between enacted stigma and depression, anxiety and stress. Providing support for Wong et al.'s (2019) framework, self-compassion was observed to significantly correlate with both stigma variables, with higher self-compassion associated with less reported stigma.

Moreover, the two stigma variables were found to mediate the relationships between self-compassion and the three outcome variables - depression, anxiety and stress. All six of the mediation analyses indicated significant indirect effects via the mediators of felt and

enacted stigma. The extent to which participants were self-compassionate was predictive of the degree of stigma they reported, which in turn was predictive of their levels of psychological distress. This provides support for Wong et al.'s (2019) framework for the effects of self-compassion on how stigma is experienced and internalised, and demonstrates the applicability of this framework to people with Parkinson's.

Part of the relationship between self-compassion and psychological distress among people with Parkinson's appears to occur via the internalisation of stigma; people who are higher in self-compassion experience less felt stigma, and therefore experience lower levels of distress. If individuals who are higher in self-compassion are less prone to feelings of shame (Gilbert, 2009) then it follows that they may be less likely to attribute negative Parkinson's-related stereotypes to themselves, or internalise potentially shaming identities. Lesser experiences of felt stigma are then associated with lower levels of psychological distress, as supported by previous research with people with Parkinson's (Ma et al., 2016).

The mediating effect of enacted stigma appears less straightforward, since self-compassion is unlikely to predict actual enacted stigma. Rather, it may predict how a person is able to process experiences of enacted stigma (Wong et al., 2019). As such, people with Parkinson's who are higher in self-compassion may experience less enacted stigma (even when they are exposed to it) because they cognitively appraise experiences of enacted stigma less negatively (Wong et al., 2019). Meanwhile, those who are less self-compassionate may be more hypervigilant to potential threats (Gilbert, 2010; Wong, 2019), with enacted stigma being a social threat associated with having Parkinson's. These individuals may therefore be more likely to attend to and ruminate on enacted stigma. Further, less self-compassionate individuals may be less able to self-soothe (Gilbert, 2009; 2010; 2014) when confronted with enacted stigma, which may have contributed to the higher levels of distress for the less self-compassionate participants in this study.

Notably, effect sizes were higher for felt stigma as a mediator than for enacted stigma, indicating that, for people with Parkinson's, the internalisation of stigma is more important in the relationship between self-compassion and distress than the experience of enacted stigma. This expands upon the findings of previous research that felt stigma is more strongly associated with psychological distress than experiences of enacted stigma (Ma et al., 2016).

Limitations and Considerations

A key limitation of this study was the heterogeneity of the sample. A large majority of participants described their ethnic background as white British, with only one participant reporting that they did not identify as white. Although Parkinson's may be slightly more prevalent among people who are white than people from black or Asian backgrounds (Van Den Eeden et al., 2003), the sample in this study was disproportionately white, therefore may not represent the totality of experiences of people with Parkinson's. Additionally, although Parkinson's is more common among men, at an incidence ratio of three men to every two women (Wooten, Currie, Bovbjerg, Lee & Patrie, 2004), in this study the majority of participants (57%) identified as female. However, the sample was also relatively young, with a mean age of 64 years, at which sex ratios for incidence are more equal (Moisan et al., 2016). The relatively young average age of the sample may also account for the level of functional ability among the sample and the fact that no participants reported living in sheltered housing, residential homes or care homes, despite this being fairly common for people with Parkinson's in the UK (Porter, Henry, Gray & Walker, 2010). The younger age of the sample may be attributable to the online advertising of the survey. Although the option was given to receive a paper copy of the survey in the post, younger people are more likely than older people to participate in research advertised on the internet and social media (Topolovec-Vranic & Natarajan, 2016), therefore the recruitment strategy was likely to be biased. Additionally, it is assumed that participants had some level of engagement with

Parkinson's-related websites or newsletters. It might be argued that individuals with higher levels of internalised stigma and/or psychological distress would be less likely to access such forums or participate in Parkinson's-related research, due to shame, avoidance or low motivation. Therefore, this research may demonstrate a bias towards the experiences of people with Parkinson's who have relatively high levels of psychological wellbeing and relatively low levels of internalised stigma, and who identify with and participate in Parkinson's related forums, which may have affected the findings of the study. Overall, the sample in this study was not diverse, and therefore the findings may not be generalisable to all people with Parkinson's.

A further possible limitation of this study was the use of the DASS-21 as an outcome measure for anxiety. Johnson et al. (2016) examined the factor structure of the DASS-21 for people with Parkinson's and found that, while the depression and stress subscales fit the factor structures well, the anxiety subscale loaded poorly onto the factor structure and had problems with internal consistency. Similarly, in the current study, it was required that an item was removed in order to bring internal consistency to an acceptable level, and even with the new six-item subscale Cronbach's alpha was notably lower than the other two subscales. Johnson et al. (2016) suggest that this problem may be related to the emphasis within the subscale upon physiological symptoms of anxiety, which may have a great deal of overlap with other difficulties experienced by people with Parkinson's. In the current study, the removed item asked about shaking of the hands, which people with Parkinson's might be more likely than other populations to report, and which may not be associated with anxiety at all. Consequently, the findings of this study relating to anxiety should be interpreted cautiously.

Hayes (2018) highlights that the use of mediation analysis with correlational or observational data has limitations in how the findings can be interpreted, since cause and

effect cannot be inferred. Therefore, despite the significant findings of this study, it cannot be assumed that having more self-compassion *causes* people with Parkinson's to experience less stigma, which causes them to experience less distress. Rather, it appears that there are interactions between each of the variables such that the relationships between self-compassion and depression, anxiety and stress operate via their relationships with experiences of felt and enacted stigma. It may be that some of the relationships identified in this study are bi-directional (for example, that people who are exposed to more enacted stigma become less self-compassionate), or that there are additional factors which mediate or moderate the relationships found. There may also be underlying factors contributing to the relationships which were not controlled for. For example, people with lower levels of education have been found to demonstrate less self-compassion (López, Sanderman, Ranchor & Schroevers, 2018).

Clinical Implications

The findings of this study may have implications for direct psychological interventions with people with Parkinson's who are experiencing distress. The finding that self-compassion predicted the amount of felt and enacted stigma participants experienced, and that this in turn predicted the degree of psychological distress, suggests that interventions aimed at increasing self-compassion may be helpful for people with Parkinson's. That there were significant (direct and indirect) effects of self-compassion on all three outcome variables – depression, anxiety and stress – suggests that the impact of such interventions could be beneficial across a range of presenting psychological difficulties. There is a growing evidence base for the use of Compassion-Focussed Therapy, which has a strong focus on reducing experiences of shame and developing feelings of compassion towards the self and others (Gilbert, 2010), for reducing distress among people with neurological illness and injury (Ashworth, Gracey & Gilbert, 2011; Collins, Gilligan & Poz, 2018; Nery-Hurwit, Yun

& Ebbeck, 2018). It may be hypothesised, based on the findings of this study, that this approach might also be helpful for people with Parkinson's - allowing them to process enacted stigma differently and internalise it less, or respond to felt stigma in a more resilient way through more effective self-soothing, leading to increased wellbeing.

Although approaches aimed at increasing self-compassion at the individual level may be helpful for reducing distress, it is important to also consider how the wider social and relational context contributes to distress for people with Parkinson's (Simpson et al., 2013). Enacted stigma is clearly a societal problem, being defined as the attitudes and behaviour of others in society on the basis of some socially discredited attribute (Scambler, 1989). The findings of this study suggest that experiences of enacted stigma and experiences of psychological distress are interrelated for people with Parkinson's. Thus, there is clear scope for interventions at the societal level aimed at reducing stigma against people with Parkinson's, which may in turn have a positive effect on psychological wellbeing. Heijnders and Van Der Meij (2006) reviewed a number of interventions for reducing health-related stigma. They suggest that interventions should take place at multiple levels – interpersonally (in the person with the stigmatised attribute's immediate relational environment), organisationally, in the community, and at government and structural levels. Based on Heijnders and Van Der Meij's (2006) findings, types of stigma-reduction interventions for people with Parkinson's might include providing education and training, increasing the visibility of people with Parkinson's in communities, advocacy programmes, and lobbying for the rights of people with Parkinson's.

Therefore, the findings of this study may be relevant to the development of individualised and wider societal interventions with the aim of improving the psychological wellbeing of people with Parkinson's. Clinical psychologists are well-placed to design and deliver both types of intervention, in line with BPS guidance (Macniven & Gaskill, 2009).

Research Implications

It may be useful to replicate this study with more diverse samples to increase the generalisability of the findings. Broadening the recruitment approach to community locations in addition to the online survey may ensure that more older people are able to take part (Topolovec-Vranic & Natarajan, 2016), while the cultural/ethnic sensitivity of the recruitment strategy might be improved with the assistance of cultural consultants (Gallagher-Thompson et al., 2004). Further research might build upon the current study by considering the interaction of the mediating variables of felt and enacted stigma, since this would provide further information about how enacted stigma becomes internalised.

There does not appear to be any published research which considers the role of self-compassion for people with Parkinson's. Given the expanding evidence-base for compassion-focussed psychological interventions and importance of self-compassion for wellbeing more generally, this may be an important area for further exploration in future research. For example, studies might explore the effectiveness of compassion-focused interventions for people diagnosed with Parkinson's. Questions might include how group-based interventions (where there may be chance to develop a sense of shared humanity with others: a key component of compassion) might compare to individualised interventions; and how compassion-focussed approaches might be adapted to the cognitive needs of people with Parkinson's.

As noted previously, there are likely to be other factors apart from stigma which mediate or moderate the relationship between self-compassion and psychological distress for people with Parkinson's. A better understanding of this relationship might be useful for guiding interventions to support people with Parkinson's who are experiencing psychological distress.

Conclusions

Mediation analyses indicated that part of the relationship between self-compassion and psychological distress occurs via the internalisation of stigma: people with Parkinson's who are higher in self-compassion experience less felt stigma, and therefore experience lower levels of distress. Self-compassion is unlikely to predict actual enacted stigma, but may predict how likely a person is to notice or report it. Therefore, people with Parkinson's who are higher in self-compassion may experience less enacted stigma (even when they are exposed to it), and therefore experience lower levels of distress. These findings may be relevant to the development of individualised and societal interventions with the aim of improving the psychological wellbeing of people with Parkinson's.

References

- Aarsland, D., Marsh, L. & Schrag, A. (2009). Neuropsychiatric symptoms in Parkinson's disease. *Movement Disorders*, 24(15), 2175-2186. Doi:10.1002/mds.22589
- Allen, A. B., Goldwasser, E. R., & Leary, M. R. (2012). Self-compassion and well-being among older adults. *Self and Identity*, 11(4), 428-453. Doi: 10.1080/15298868.2011.595082
- Antony, M. M., Bieling, P. J., Cox, B. J., Enns, M. W., & Swinson, R. P. (1998). Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological Assessment*, 10(2), 176-181. Doi: 10.1037/1040-3590.10.2.176
- Ashworth, F., Gracey, F., & Gilbert, P. (2011). Compassion focused therapy after traumatic brain injury: Theoretical foundations and a case illustration. *Brain Impairment*, 12(2), 128-139. Doi: 10.1375/brim.12.2.128
- Baker, D. A., Caswell, H. L., & Eccles, F. J. R. (2019). Self-compassion and depression, anxiety, and resilience in adults with epilepsy. *Epilepsy and Behavior*, 90, 154-161. Doi: 10.1016/j.yebeh.2018.11.025
- Bramley, N., & Eatough, V. (2005). The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study. *Psychology & Health*, 20(2), 223-235. Doi: 10.1080/08870440412331296053
- Campbell, C., & Deacon, H. (2006). Unravelling the contexts of stigma: From internalisation to resistance to change. *Journal of Community & Applied Social Psychology*, 16(6), 411-417. Doi: 10.1002/casp.901
- Caap-Ahlgren, M., & Lannerheim, L. (2002). Older Swedish women's experiences of living with symptoms related to Parkinson's disease. *Journal of Advanced Nursing*, 39(1), 87-95. Doi: 10.1046/j.13652648.2002.02245.x

- Collins, R. N., Gilligan, L. J., & Poz, R. (2018). The evaluation of a compassion-focused therapy group for couples experiencing a dementia diagnosis. *Clinical Gerontologist*, 41(5), 474-486. Doi: 10.1080/07317115.2017.1397830
- Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology*, 25(8), 875-884. Doi: 10.1521/jscp.2006.25.8.875
- Dissanayaka, N. N., Sellbach, A., Matheson, S., O'Sullivan, J. D., Silburn, P. A., Byrne, G. J., ... & Mellick, G. D. (2010). Anxiety disorders in Parkinson's disease: Prevalence and risk factors. *Movement Disorders*, 25(7), 838-845. Doi:10.1002/mds.22833
- Fahn, S. (2011). Classification of movement disorders. *Movement Disorders*, 26(6), 947-957. Doi: 10.1002/mds.23759
- Field, A. (2018). *Discovering statistics using IBM SPSS Statistics* (Fifth ed.). London: Sage.
- Gallagher-Thompson, D., Singer, L. S., Depp, C., Mausbach, B. T., Cardenas, V., & Coon, D. W. (2004). Effective recruitment strategies for Latino and Caucasian dementia family caregivers in intervention research. *American Journal of Geriatric Psychiatry*, 12(5), 484-90. Doi: 10.1176/appi.ajgp.12.5.484
- Garlovsky, J. K., Overton, P. G. & Simpson, J. (2016). Psychological predictors of anxiety and depression in Parkinson's disease: A systematic review. *Journal of Clinical Psychology*, 72(10), 979-998. Doi: 10.1002/jclp.22308
- Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in Psychiatric Treatment*, 15(3), 199-208. Doi: 10.1192/apt.bp.107.005264
- Gilbert, P. (2010). *Compassion Focussed Therapy: Distinctive features*. London: Routledge.
- Gilbert, P. (2014). The origins and nature of compassion focussed therapy. *British Journal of Clinical Psychology*, 53(1), 6-41. Doi: 10.1111/bjc.12043
- Goffman, E. (1963). *Stigma: Notes on a spoiled identity*. New York: Simon & Schuster.

- Hayes, A. (2018). *Introduction to mediation, moderation and conditional process analysis: A regression-based approach* (Second ed.). London: Guilford Press.
- Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, Health & Medicine, 11*(3), 353-363. Doi: 10.1080/13548500600595327
- Hemmesch, A. R. (2014). The detrimental effects of atypical nonverbal behavior on older adults' first impressions of individuals with Parkinson's disease. *Psychology and Aging, 29*(3), 521–527. Doi: 10.1037/a0036637
- Hermanns, M. (2013). The invisible and visible stigmatization of Parkinson's disease. *Journal of the American Association of Nurse Practitioners, 25*(10), 563–566. Doi: 10.1111/1745-7599.12008
- Jette, A. M., Davies, A. R., Cleary, P. D., Calkins, D. R., Rubenstein, L. V., Fink, A., ... & Delbanco, T. L. (1986). The functional status questionnaire. *Journal of General Internal Medicine, 1*(3), 143-149. Doi: 10.1007/BF02602324
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing, 32*(1), 243-248. Doi: 10.1046/j.1365-2648.2000.01466.x
- Johnson, A. R., Lawrence, B. J., Corti, E. J., Booth, L., Gasson, N., Thomas, M. G., ... & Bucks, R. S. (2016). Suitability of the Depression, Anxiety, and Stress Scale in Parkinson's disease. *Journal of Parkinson's Disease, 6*(3), 609-616. Doi: 10.3233/JPD-160842
- Kane, L., & Ashbaugh, A. R. (2017). Simple and parallel mediation: A tutorial exploring anxiety sensitivity, sensation seeking, and gender. *The Quantitative Methods for Psychology, 13*(3), 148-165. Doi: 10.20982/tqmp.13.3.p148
- Kano, O., Ikeda, K., Cridebring, D., Takazawa, T., Yoshii, Y., & Iwasaki, Y. (2011). Neurobiology of depression and anxiety in Parkinson's disease. *Parkinson's Disease,*

2011. Doi:10.4061/2011/143547

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27(1), 363-385. Doi: 10.1146/annurev.soc.27.1.363

Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *The Lancet*, 367(9509), 528-529. Doi: 10.1016/S0140-6736(06)68184-1

López, A., Sanderman, R., Ranchor, A. V., & Schroevers, M. J. (2018). Compassion for others and self-compassion: Levels, correlates, and relationship with psychological well-being. *Mindfulness*, 9(1), 325–331. Doi: 10.1007/s12671-017-0777-z

Lovibond, S. H. & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales* (2nd. Ed.). Sydney: Psychology Foundation

Ma, H. I., Saint-Hilaire, M., Thomas, C. A., & Tickle-Degnen, L. (2016). Stigma as a key determinant of health-related quality of life in Parkinson's disease. *Quality of Life Research*, 25(12), 3037-3045. Doi: 10.1007/s11136-016-1329-z

MacBeth, A., & Gumley, A. (2012). Exploring compassion: A meta-analysis of the association between self-compassion and psychopathology. *Clinical Psychology Review*, 32(6), 545–552. Doi: 10.1016/j.cpr.2012.06.003

Macniven, J., & Gaskill, A. (2009). *Psychological services for people with Parkinson's disease*. Leicester: British Psychological Society

Moisan, F., Kab, S., Mohamed, F., Canonico, M., Le Guern, M., Quintin, C., ... & Elbaz, A. (2016). Parkinson disease male-to-female ratios increase with age: French nationwide study and meta-analysis. *Journal of Neurology, Neurosurgery & Psychiatry*, 87(9), 952-957. Doi: 10.1136/jnnp-2015-312283

Moore, S., & Knowles, S. (2006). Beliefs and knowledge about Parkinson's disease. *E-Journal of Applied Psychology: Clinical and Social Issues*, 2(1), 15-21. Doi: 10.1.1.581.9012

- Moustafa, A. A., Chakravarthy, S., Phillips, J. R., Gupta, A., Keri, S., Polner, B., . . . Jahanshahi, M. (2016). Motor symptoms in Parkinson's disease: A unified framework. *Neuroscience and Biobehavioral Reviews*, 68, 727-740. Doi: 10.1016/j.neubiorev.2016.07.010
- Neff, K. D. (2003). The development and validation of a scale to measure self-compassion. *Self and Identity*, 2(3), 223–250. Doi:10.1080/15298860309027
- Neff, K. D. & Dahm, K. A. (2015). Self-compassion: What it is, what it does, and how it relates to mindfulness. In: B.D. Ostafin, M. D. Robinson, & B. P. Meier (Eds.), *Handbook of mindfulness and self-regulation* (pp. 121-137). Springer, New York.
- Nery-Hurwit, M., Yun, J., & Ebbeck. V. (2018). Examining the roles of self-compassion and resilience on health-related quality of life for individuals with Multiple Sclerosis. *Disability and Health Journal*, 11(2), 256-261. Doi: 10.1016/j.dhjo.2017.10.010
- Nijhof, G. (1995). Parkinson's Disease as a problem of shame in public appearance. *Sociology of Health & Illness*, 17(2), 193-205. doi:10.1111/1467-9566.ep10933386
- Pinto-Gouveia, J., Duarte, C., Matos, M., & Fráguas, S. (2014). The protective role of self-compassion in relation to psychopathology symptoms and quality of life in chronic and in cancer patients. *Clinical Psychology and Psychotherapy*, 21(4), 311-323. Doi: 10.1002/cpp.1838
- Porter, B., Henry, S. R., Gray, W. K., & Walker, R. W. (2010). Care requirements of a prevalent population of people with idiopathic Parkinson's disease. *Age and Ageing*, 39(1), 57–61. Doi: 10.1093/ageing/afp199
- Pringsheim, T., Jette, N., Frolkis, A., & Steeves, T. D. (2014). The prevalence of Parkinson's disease: A systematic review and meta-analysis. *Movement Disorders*, 29(13), 1583-1590. Doi: 10.1002/mds.25945
- Rana, A. Q., Ahmed, U. S., Chaudry, Z. M., & Vasan, S. (2015). Parkinson's disease: a

- review of non-motor symptoms. *Expert Review of Neurotherapeutics*, 15(5), 549-562.
Doi: 10.1586/14737175.2015.1038244
- Rao, D., Choi, S. W., Victorson, D., Bode, R., Peterman, A., Heinemann, A., & Cella, D. (2009). Measuring stigma across neurological conditions: The development of the stigma scale for chronic illness (SSCI). *Quality of Life Research*, 18(5), 585–595.
Doi: 10.1007/s11136-009-9475-1
- Reijnders, J. S., Ehrt, U., Weber, W. E., Aarsland, D. & Leentjens, A. F. (2008). A systematic review of prevalence studies of depression in Parkinson's disease. *Movement Disorders*, 23(2), 183-189. Doi:10.1002/mds.21803
- Remy, P., Doder, M., Lees, A., Turjanski, N., & Brooks, D. (2005). Depression in Parkinson's disease: Loss of dopamine and noradrenaline innervation in the limbic system. *Brain*, 128(6), 1314–1322. Doi: 10.1093/brain/awh445
- Rose, A., & Rimes, K. (2018). Self-criticism self-report measures: Systematic review. *Psychology and Psychotherapy*, 91(4), 450-489. Doi:10.1111/papt.12171
- Scambler, G. (1989). *Epilepsy: the experience of illness series*. Routledge; London.
- Schrag, A., Jahanshahi, M., & Quinn, N. P. (2001). What contributes to depression in Parkinson's disease? *Psychological Medicine*, 31(01), 65–73. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/11200961>
- Shulman, L., Armstrong, M., Ellis, T., Gruber-Baldini, A., Horak, F., Nieuwboer, A., ... & Martinez-Martin, P. (2016). Disability rating scales in Parkinson's disease: Critique and recommendations. *Movement Disorders*, 31(10), 1455-1465. Doi: 10.1002/mds.26649
- Simpson, J., Lekwuwa, G., & Crawford, T. (2014). Predictors of quality of life in people with Parkinson's disease: evidence for both domain specific and general relationships. *Disability and Rehabilitation*, 36(23), 1964-1970. Doi:

10.3109/09638288.2014.883442

Simpson, J., McMillan, H., & Reeve, D. (2013). Reformulating psychological difficulties in people with Parkinson's disease: The potential of a social relational approach to disablism. *Parkinson's Disease*, 2013. Doi:10.1155/2013/608562.

Sirois, F. M., Molnar, D.S., & Hirsch, J. K. (2015). Self-compassion, stress, and coping in the context of chronic illness. *Self and Identity*, 14(3), 334-347, Doi:

10.1080/15298868.2014.996249

Stacy, M. (2011). Nonmotor symptoms of Parkinson's disease. *International Journal of Neuroscience*, 121(suppl2), 9-17. Doi: 10.3109/00207454.2011.620196

Tickle-Degnen, L., Zebrowitz, L. A., & Ma, H. I. (2011). Culture, gender and health care stigma: Practitioners' response to facial masking experienced by people with Parkinson's disease. *Social Science and Medicine*, 73(1), 95–102. Doi:

10.1016/j.socscimed.2011.05.008

Topolovec-Vranic, J., & Natarajan, K. (2016). The use of social media in recruitment for medical research studies: A scoping review. *Journal of Medical Internet Research*, 18(11), e286. Doi: 10.2196/jmir.5698

Troeung, L., Egan, S. J., & Gasson, N. (2014). A waitlist-controlled trial of group cognitive behavioural therapy for depression and anxiety in Parkinson's disease. *BMC Psychiatry*, 14(1), 19-29. Doi: 10.1186/1471-244X-14-19

Tysnes, O., & Storstein, A. (2017). Epidemiology of Parkinson's disease. *Journal of Neural Transmission*, 124(8), 901-905. Doi: 10.1007/s00702-017-1686-y

Van Den Eeden, S. K., Tanner, C. M., Bernstein, A. L., Fross, R. D., Leimpeter, A., Bloch, D. A., & Nelson, L. M. (2003). Incidence of Parkinson's disease: Variation by age, gender, and race/ethnicity. *American Journal of Epidemiology*, 157(11), 1015–1022. Doi: 10.1093/aje/kwg068

- Watson, A. C., Corrigan, P., Larson, J. E., & Sells, M. (2007). Self-stigma in people with mental illness. *Schizophrenia Bulletin*, 33(6), 1312–1318. Doi:10.1093/schbul/sbl076
- Whatley, A. D., Dilorio, C. K., & Yeager, K. (2010). Examining the relationships of depressive symptoms, stigma, social support and regimen-specific support on quality of life in adult patients with epilepsy. *Health Education Research*, 25(4), 575–584. Doi: 10.1093/her/cyq001
- Wong, C., Knee, C., Neighbors, C., & Zvolensky, M. (2019). Hacking stigma by loving yourself: A mediated-moderation model of self-compassion and stigma. *Mindfulness*, 10(3), 415-433. Doi: 10.1007/s12671-018-0984-2
- Wong, C., Mak, C., & Liao, Y. (2016). Self-compassion: A potential buffer against affiliate stigma experienced by parents of children with autism spectrum disorders. *Mindfulness*, 7(6), 1385-1395. Doi: 10.1007/s12671-016-0580-2
- Wooten, G. F., Currie, L. J., Bovbjerg, V. E., Lee, J. K., & Patrie, J. (2004). Are men at greater risk for Parkinson's disease than women? *Journal of Neurology, Neurosurgery & Psychiatry*, 75(4), 637-639. Doi: 10.1136/jnnp.2003.020982
- Zessin, U., Dickhäuser, O., & Garbade, S. (2015). The relationship between self-compassion and well-being: A meta-analysis. *Applied Psychology Health and Well-Being*, 7(3), 340–364. Doi: 10.1111/aphw.12051

Figure 2.1

The Simple Mediation Model

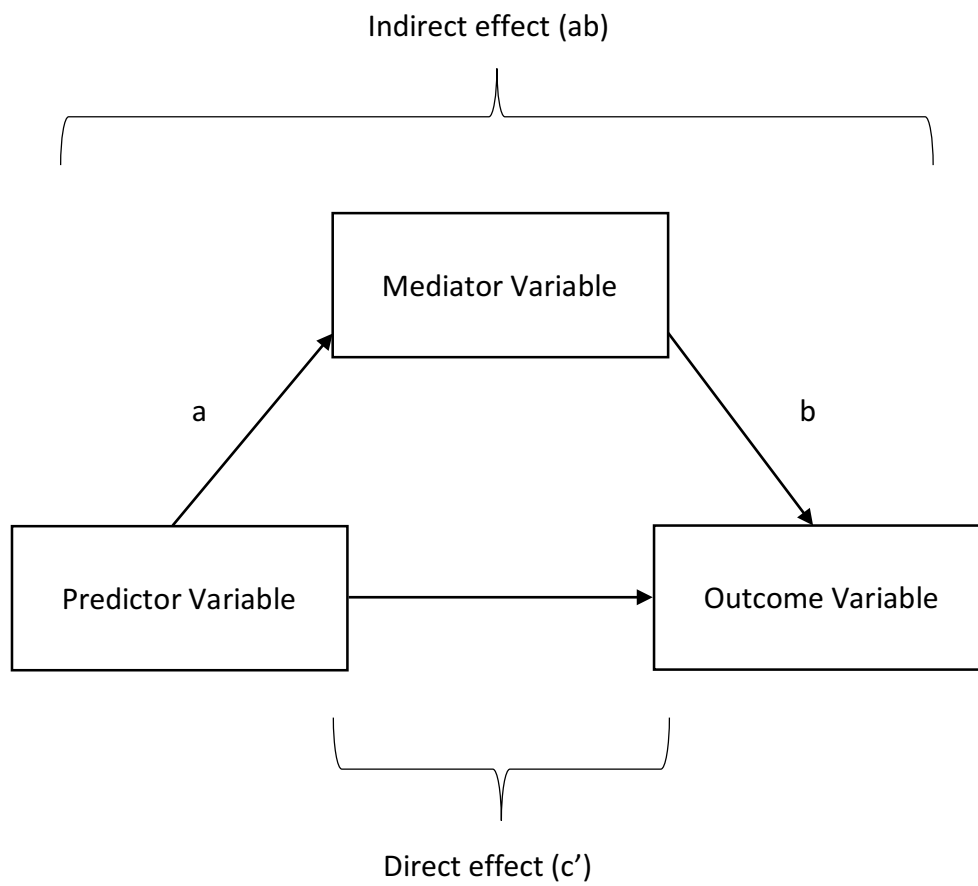


Figure 2.2

Mediation Models Tested

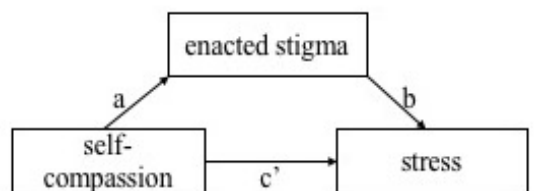
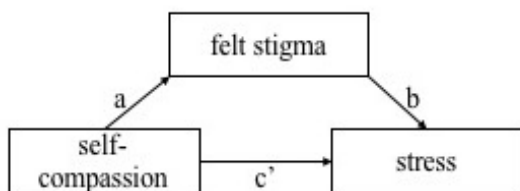
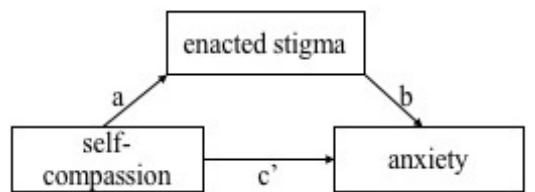
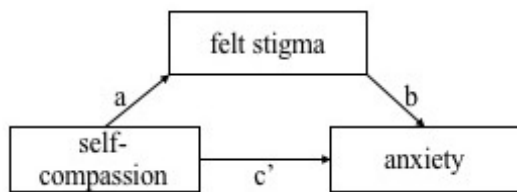
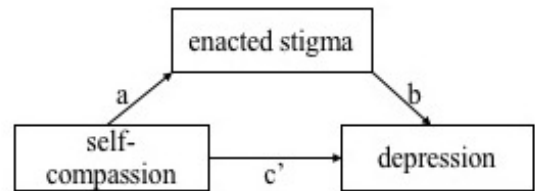
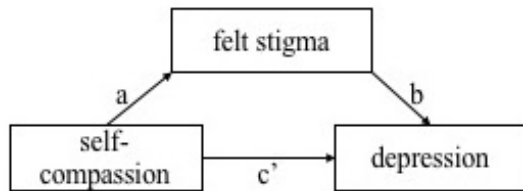


Figure 2.3

Mediation Models (Felt Stigma)

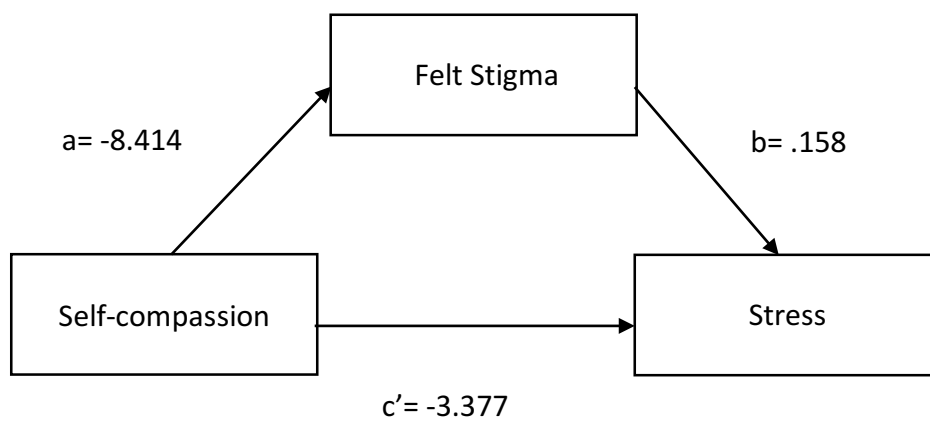
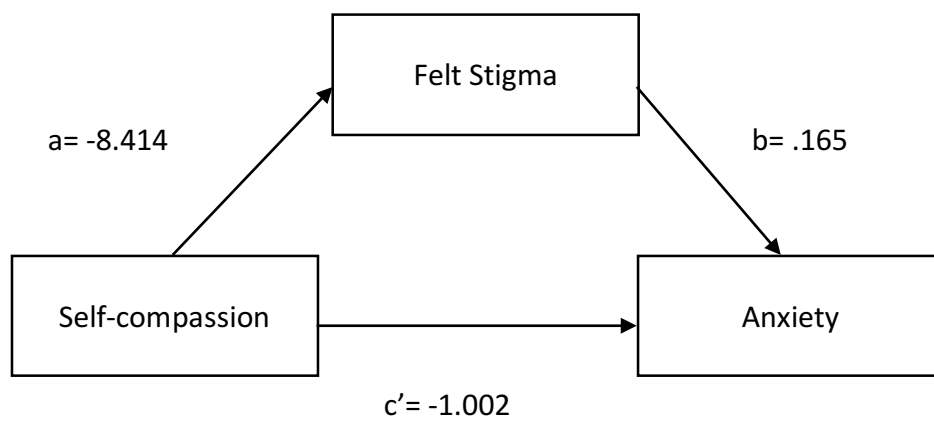
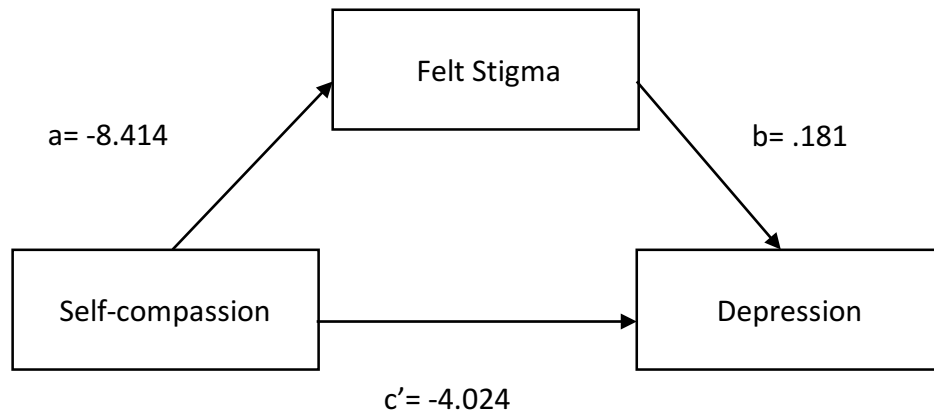


Figure 2.4

Mediation Models (Enacted Stigma)

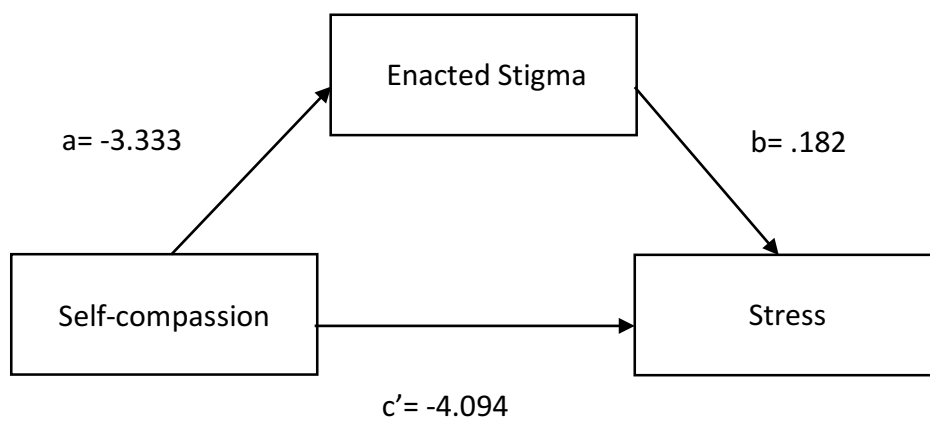
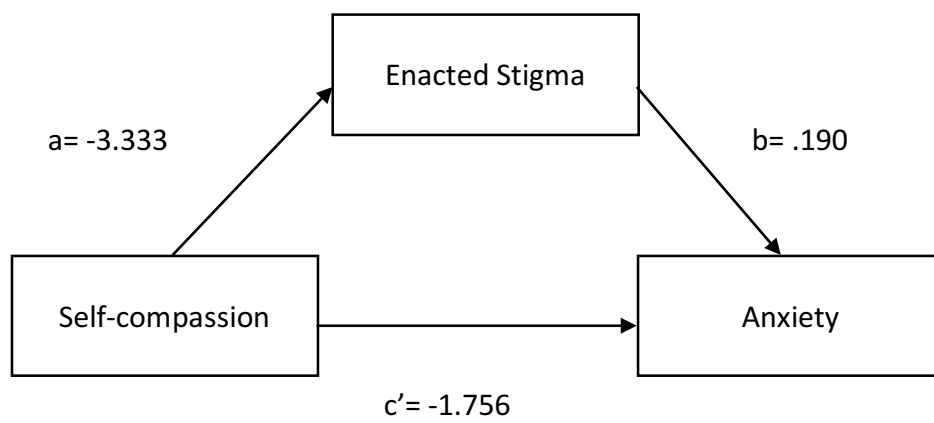
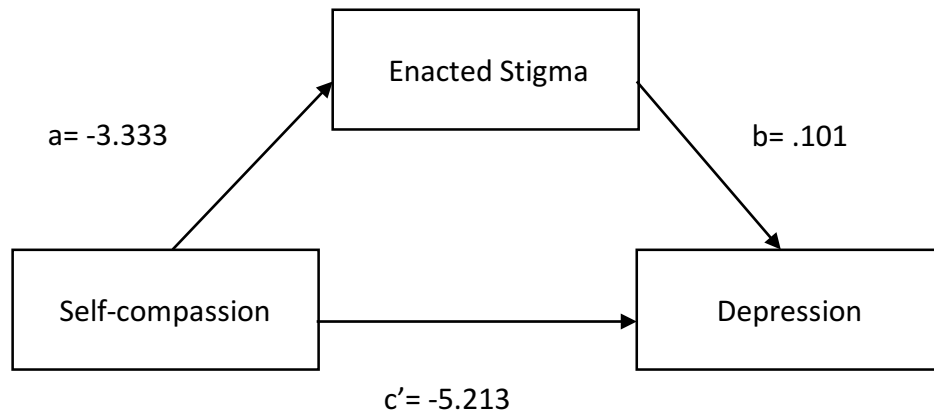


Table 2.1

Demographic and Clinical Characteristics of Sample: Continuous Variables

Variable	Mean (SD)	Range
Age (in years)	64.35 (9.43)	36-89
Time since diagnosis (in years)	5.11 (4.76)	0-30
FSQ subscale scores:		
Basic activities of daily living	84.14 (16.71)	33.33-100
Intermediate activities of daily living	72.83 (24.53)	0-100

Note. All values rounded to two decimal places; SD = Standard deviation; FSQ = Functional Status Questionnaire.

Table 2.2

Demographic and Clinical Characteristics of Sample: Categorical Variables

Variable	Frequency	Percentage
Gender:		
Female	79	57.25
Male	59	42.75
Ethnic group or background:		
White British	127	92.03
White Irish	3	2.17
White European	2	1.45
White American	2	1.45
White Traveller	1	.72
Sri-Lankan	1	.72
Did not disclose	2	1.45
Location:		
England	115	83.33
Scotland	8	5.80
Wales	4	2.90
USA	4	2.90
Northern Ireland	3	2.17
Spain	1	.72
European country outside of UK (not specified)	1	.72
Sri-Lanka	1	.72
Did not disclose	1	.72
Living arrangements:		
With spouse/partner/family/others	109	78.99
Alone	27	19.57
With a live-in carer	1	.72
Did not disclose	1	.72
Partnership status:		
Spouse or partner, co-habiting	102	73.91
Single	26	18.84
Spouse or partner, living separately	9	6.52

Widowed	1	.72
Employment status:		
Retired	94	68.12
Currently unable to work or on sick leave	13	9.42
Employed (full-time)	13	9.42
Self-employed	8	5.80
Employed (part-time)	7	5.07
In full-time education	2	1.45
Unemployed	1	.72
Current treatment for Parkinson's symptoms*:		
Prescribed oral medication	128	92.75
No treatment	7	5.07
DBS	4	2.90
Apomorphine/Duodopa Pump	4	2.90
Prescribed exercise programmes	2	1.45
CBD Oil	1	.72

*Note. Percentages rounded to two decimal places; *Some participants were using more than one type of treatment therefore percentages do not sum to 100; DBS = Deep Brain Stimulation.*

Table 2.3

Descriptive Statistics and Internal Consistency for Standardised Measures

Measure	Mean (SD)	Range	Cronbach's alpha
FSQ scaled scores:			
Basic ADLs	84.14 (16.71)	33.33-100	.74
Intermediate ADLs	72.83 (24.53)	0-100	.86
SSCI total scores:			
Felt stigma	31.33 (11.37)	13-63	.93
Enacted stigma	17.67 (7.57)	10-41	.94
Total stigma	49.00 (17.48)	24-96	.95
SCS scaled score	3.07 (.76)	1.25-4.78	.92
DASS-21 total scores:			
Depression	6.47 (5.78)	0-21	.96
Anxiety	5.85 (4.05)	0-18	.73
Anxiety (item 7 removed)	4.38 (3.79)	0-17	.80
Stress	7.53 (5.60)	0-20	.92

Note. All values rounded to two decimal places; SD = Standard deviation; FSQ = Functional Status Questionnaire; ADLs = activities of daily living; SSCI = Stigma Scale for Chronic Illness; SCS = Self-Compassion Scale; DASS-21 = Depression, Anxiety and Stress Scale.

Table 2.4

Spearman's Rho Correlations Between Variables

	1 Age	2 Years since diagnosis	3 FSQ Basic ADLs scaled	4 FSQ Intermediate ADLs scaled	5 SSCI Felt Stigma total	6 SSCI Enacted Stigma total	7 SSCI Total Stigma	8 SCS scaled	9 DASS-21 Depression total	10 DASS-21 Anxiety total	11 DASS-21 Stress total
1	-	.869*	-.088	-.134	-.305**	-.383**	-.354**	.212*	-.137	-.172*	-.232**
2	-	-	-.330**	-.280**	.079	.174*	.133	-.002	.049	.131	.065
3	-	-	-	.701**	-.409**	-.388**	-.455**	.179*	-.218*	-.363**	-.263**
4	-	-	-	-	-.379**	-.346**	-.403**	.105	-.207*	-.386**	-.257**
5	-	-	-	-	-	.716**	.960**	-.555**	.648**	.591**	.610**
6	-	-	-	-	-	-	.865**	-.392**	.414**	.489**	.486**
7	-	-	-	-	-	-	-	-.520**	.593**	.597**	.600**
8	-	-	-	-	-	-	-	-	-.722**	-.477**	-.634**
9	-	-	-	-	-	-	-	-	-	.666**	.711**
10	-	-	-	-	-	-	-	-	-	-	.680**

Note. All correlation coefficients rounded to three decimal places; SD = Standard deviation; FSQ = Functional Status Questionnaire; ADLs = activities of daily living; SSCI = Stigma Scale for Chronic Illness; SCS = Self-Compassion Scale; DASS-21 = Depression, Anxiety and Stress Scale; DASS-21 Anxiety total used 6-item subscale to increase internal consistency; * $p < 0.05$; ** $p < 0.01$.

Appendix 2A

Author Guidelines for the British Journal of Health Psychology

The aim of the British Journal of Health Psychology is to provide a forum for high quality research, including Registered Reports, relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the Journal Overview.

The types of paper invited are:

- papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;
- theoretical papers which report analyses on established theories in health psychology;
- we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses); and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

Authors who are interested in submitting papers that do not fit into these categories are advised to contact the editors who would be very happy to discuss the potential submission.

All papers published in The British Journal of Health Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers describing quantitative research (including reviews with quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words, or 6,000 words for qualitative papers)

4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission and the declaration of competing interests. You may also like to use the Submission Checklist to help you prepare your paper.

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at <https://authorservices.wiley.com/statements/data-protection-policy.html>.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use this template. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the Project CRediT website for a list of roles.

- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found [here](#).
- Statement of Contribution: All authors are required to provide a clear summary of ‘what is already known on this subject?’ and ‘what does this study add?’. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.
- Conflict of interest statement: We are now including a brief conflict of interest statement at the end of each accepted manuscript. You will be asked to provide information to generate this statement during the submission process.
- The main document must be anonymous. Please do not mention the authors’ names or affiliations (including in the Method section) and always refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be

listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:

Author, A., Author, B., & Author, C. (1995). Title of book. City, Country: Publisher.

Author, A. (2013). Title of journal article. Name of journal, 1, 1-16. doi: 10.1111/bjep.12031

- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.
- Manuscripts describing clinical trials are encouraged to submit in accordance with the CONSORT statement on reporting randomised controlled trials.
- Manuscripts reporting systematic reviews and meta-analyses are encouraged to submit in accordance with the PRISMA statement.
- Manuscripts reporting interventions are encouraged to describe them in accordance with the TIDieR checklist.

If you need more information about submitting your manuscript for publication, please email Hannah Wakley, Managing Editor (bjhp@wiley.com) or phone +44 (0) 116 252 9504.

6. Supporting information

We strongly encourage submission of protocol papers or trial registration documents, where these are in the public domain, to allow reviewers to assess deviations from these protocols. This will result in reviewers being unblinded to author identity.

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files. Supporting Information should be cited within the article text, and a descriptive legend should be included. Please indicate clearly on submission which material is for online only publication. It is published as supplied by the author, and a proof is not made available prior to publication; for these reasons, authors should provide any Supporting Information in the desired final format.

For further information on recommended file types and requirements for submission, please visit the Supporting Information page on Author Services.

7. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive. A full list of terms and conditions is available on Wiley Online Library.

Any authors wishing to send their paper OnlineOpen will be required to complete the payment form.

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

8. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. You can then access Kudos through Author Services, which will help you to increase the impact of your research. Visit Author Services for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

9. Copyright and licences

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services, where via the Wiley Author Licensing Service (WALS) they will be able to complete the licence agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs .

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons Licence Open Access Agreements (OAA):

- Creative Commons Attribution Non-Commercial Licence (CC-BY-NC)
- Creative Commons Attribution Non-Commercial -NoDerivs Licence (CC-BY-NC-ND)

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs and you may also like to visit the Wiley Open Access Copyright and Licence page.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) or the Austrian Science Fund (FWF) you will be given the opportunity to publish your article under a CC-BY licence supporting you in complying with your Funder requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit our Funder Policy page.

10. Colour illustrations

Colour figures may be published online free of charge; however, the journal charges for publishing figures in colour in print. If the author supplies colour figures at Early View publication, they will be invited to complete a colour charge agreement in RightsLink for Author Services. The author will have the option of paying immediately with a credit or debit

card, or they can request an invoice. If the author chooses not to purchase colour printing, the figures will be converted to black and white for the print issue of the journal.

11. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found in Author Services. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

12. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from Adobe's web site. This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

13. Early View

British Journal of Health Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors'

final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. Eg Jones, A.B. (2010). Human rights Issues. *Journal of Human Rights*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Further information about the process of peer review and production can be found in this document. What happens to my paper? Appeals are handled according to the procedure recommended by COPE.

Appendix 2B

SPSS Outputs for Mediation Analyses

Key:

X = predictor variable

Y = outcome variable

M = mediator variable

SELFCOMP = self-compassion

INTSTIGM = felt stigma

ENACSTIG = enacted stigma

D_TOTAL = DASS-21 depression score

A_NO_7 = DASS-21 anxiety score (without item 7)

S_TOTAL = DASS-21 stress score

Analysis 1: self-compassion, felt stigma and depression

***** PROCESS Procedure for SPSS Version 3.3 *****

Written by Andrew F. Hayes, Ph.D. www.afhayes.com
Documentation available in Hayes (2018). www.guilford.com/p/hayes3

Model : 4
Y : D_TOTAL
X : SELFCOMP
M : INTSTIGM

Sample
Size: 138

OUTCOME VARIABLE:
INTSTIGM

Model Summary

R	R-sq	MSE	F	df1	df2	p
.5627	.3167	88.9451	63.0254	1.0000	136.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	57.1211	3.3469	17.0667	.0000	50.5024	63.7399
SELFCOMP	-8.4141	1.0599	-7.9389	.0000	-10.5100	-6.3181

Standardized coefficients

	coeff
SELFCOMP	-.5627

OUTCOME VARIABLE:
D_TOTAL

Model Summary

R	R-sq	MSE	F	df1	df2	p
.7870	.6194	12.9023	109.8471	2.0000	135.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	13.1340	2.2595	5.8129	.0000	8.6655	17.6025
SELFCOMP	-4.0243	.4883	-8.2411	.0000	-4.9901	-3.0586
INTSTIGM	.1811	.0327	5.5464	.0000	.1166	.2457

Standardized coefficients

	coeff
SELFCOMP	-.5294
INTSTIGM	.3563

***** TOTAL EFFECT MODEL *****

OUTCOME VARIABLE:

D_TOTAL

Model Summary

R	R-sq	MSE	F	df1	df2	p
.7298	.5327	15.7260	155.0083	1.0000	136.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	23.4810	1.4073	16.6848	.0000	20.6979	26.2641
SELFCOMP	-5.5485	.4457	-12.4502	.0000	-6.4298	-4.6672

Standardized coefficients

	coeff
SELFCOMP	-.7298

***** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y *****

Total effect of X on Y

Effect	se	t	p	LLCI	ULCI	c_ps	c_cs
-5.5485	.4457	-12.4502	.0000	-6.4298	-4.6672	-.9600	-.7298

Direct effect of X on Y

Effect	se	t	p	LLCI	ULCI	c'_ps	c'_cs
-4.0243	.4883	-8.2411	.0000	-4.9901	-3.0586	-.6963	-.5294

Indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
INTSTIGM	-1.5241	.3726	-2.3225	-.8470

Partially standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
INTSTIGM	-.2637	.0635	-.3989	-.1511

Completely standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
INTSTIGM	-.2005	.0476	-.3006	-.1140

***** BOOTSTRAP RESULTS FOR REGRESSION MODEL PARAMETERS *****

OUTCOME VARIABLE:

INTSTIGM

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	57.1211	57.1333	3.6753	49.8322	64.3046

SELFCOMP -8.4141 -8.4277 1.1854 -10.7844 -6.1300

OUTCOME VARIABLE:

D_TOTAL

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	13.1340	13.0842	2.6989	7.9323	18.3038
SELFCOMP	-4.0243	-4.0142	.5899	-5.1615	-2.8772
INTSTIGM	.1811	.1813	.0338	.1155	.2469

***** ANALYSIS NOTES AND ERRORS *****

Level of confidence for all confidence intervals in output:

95.0000

Number of bootstrap samples for percentile bootstrap confidence intervals:

5000

NOTE: Variables names longer than eight characters can produce incorrect output.

Shorter variable names are recommended.

----- END MATRIX -----

Analysis 2: self-compassion, felt stigma and anxiety

Run MATRIX procedure:

***** PROCESS Procedure for SPSS Version 3.3 *****

Written by Andrew F. Hayes, Ph.D. www.afhayes.com
Documentation available in Hayes (2018). www.guilford.com/p/hayes3

Model : 4
Y : A_NO_7
X : SELFCOMP
M : INTSTIGM

Sample
Size: 138

OUTCOME VARIABLE:
INTSTIGM

Model Summary

R	R-sq	MSE	F	df1	df2	p
.5627	.3167	88.9451	63.0254	1.0000	136.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	57.1211	3.3469	17.0667	.0000	50.5024	63.7399
SELFCOMP	-8.4141	1.0599	-7.9389	.0000	-10.5100	-6.3181

Standardized coefficients

	coeff
SELFCOMP	-.5627

OUTCOME VARIABLE:
A_NO_7

Model Summary

R	R-sq	MSE	F	df1	df2	p
.6295	.3963	8.8120	44.3163	2.0000	135.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	2.2898	1.8673	1.2263	.2222	-1.4031	5.9826
SELFCOMP	-1.0019	.4036	-2.4827	.0143	-1.8000	-.2038
INTSTIGM	.1649	.0270	6.1098	.0000	.1115	.2183

Standardized coefficients

	coeff
SELFCOMP	-.2008
INTSTIGM	.4942

***** TOTAL EFFECT MODEL *****

OUTCOME VARIABLE:

A_NO_7

Model Summary

R	R-sq	MSE	F	df1	df2	p
.4790	.2294	11.1659	40.4872	1.0000	136.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	11.7093	1.1859	9.8741	.0000	9.3642	14.0544
SELFCOMP	-2.3894	.3755	-6.3630	.0000	-3.1320	-1.6468

Standardized coefficients

	coeff
SELFCOMP	-.4790

***** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y *****

Total effect of X on Y

Effect	se	t	p	LLCI	ULCI	c_ps	c_cs
-2.3894	.3755	-6.3630	.0000	-3.1320	-1.6468	-.6300	-.4790

Direct effect of X on Y

Effect	se	t	p	LLCI	ULCI	c'_ps	c'_cs
-1.0019	.4036	-2.4827	.0143	-1.8000	-.2038	-.2642	-.2008

Indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
INTSTIGM	-1.3875	.3030	-2.0301	-.8341

Partially standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
INTSTIGM	-.3658	.0675	-.5076	-.2419

Completely standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
INTSTIGM	-.2781	.0498	-.3762	-.1843

***** BOOTSTRAP RESULTS FOR REGRESSION MODEL PARAMETERS *****

OUTCOME VARIABLE:

INTSTIGM

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	57.1211	57.1417	3.7162	49.6263	64.3700
SELFCOMP	-8.4141	-8.4305	1.1968	-10.7747	-6.0317

OUTCOME VARIABLE:

A_NO_7

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	2.2898	2.2983	1.7573	-1.2399	5.7060
SELFCOMP	-1.0019	-1.0007	.4270	-1.8305	-.1557
INTSTIGM	.1649	.1643	.0277	.1099	.2198

***** ANALYSIS NOTES AND ERRORS *****

Level of confidence for all confidence intervals in output:

95.0000

Number of bootstrap samples for percentile bootstrap confidence intervals:

5000

NOTE: Variables names longer than eight characters can produce incorrect output.

Shorter variable names are recommended.

----- END MATRIX -----

Analysis 3: self-compassion, felt stigma and stress

Run MATRIX procedure:

***** PROCESS Procedure for SPSS Version 3.3 *****

Written by Andrew F. Hayes, Ph.D. www.afhayes.com
Documentation available in Hayes (2018). www.guilford.com/p/hayes3

Model : 4
Y : S_TOTAL
X : SELFCOMP
M : INTSTIGM

Sample
Size: 138

OUTCOME VARIABLE:
INTSTIGM

Model Summary

R	R-sq	MSE	F	df1	df2	p
.5627	.3167	88.9451	63.0254	1.0000	136.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	57.1211	3.3469	17.0667	.0000	50.5024	63.7399
SELFCOMP	-8.4141	1.0599	-7.9389	.0000	-10.5100	-6.3181

Standardized coefficients

	coeff
SELFCOMP	-.5627

OUTCOME VARIABLE:
S_TOTAL

Model Summary

R	R-sq	MSE	F	df1	df2	p
.6912	.4778	16.6040	61.7577	2.0000	135.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	12.9465	2.5632	5.0510	.0000	7.8774	18.0156
SELFCOMP	-3.3767	.5540	-6.0956	.0000	-4.4723	-2.2812
INTSTIGM	.1575	.0370	4.2517	.0000	.0842	.2308

Standardized coefficients

	coeff
SELFCOMP	-.4586
INTSTIGM	.3199

***** TOTAL EFFECT MODEL *****

OUTCOME VARIABLE:

S_TOTAL

Model Summary

R	R-sq	MSE	F	df1	df2	p
.6386	.4079	18.6889	93.6761	1.0000	136.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	21.9443	1.5342	14.3036	.0000	18.9103	24.9782
SELFCOMP	-4.7021	.4858	-9.6786	.0000	-5.6629	-3.7414

Standardized coefficients

	coeff
SELFCOMP	-.6386

***** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y *****

Total effect of X on Y

Effect	se	t	p	LLCI	ULCI	c_ps	c_cs
-4.7021	.4858	-9.6786	.0000	-5.6629	-3.7414	-.8400	-.6386

Direct effect of X on Y

Effect	se	t	p	LLCI	ULCI	c'_ps	c'_cs
-3.3767	.5540	-6.0956	.0000	-4.4723	-2.2812	-.6033	-.4586

Indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
INTSTIGM	-1.3254	.4037	-2.1774	-.6074

Partially standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
INTSTIGM	-.2368	.0714	-.3876	-.1091

Completely standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
INTSTIGM	-.1800	.0536	-.2918	-.0835

***** BOOTSTRAP RESULTS FOR REGRESSION MODEL PARAMETERS *****

OUTCOME VARIABLE:

INTSTIGM

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	57.1211	57.0640	3.6644	49.8280	64.1158
SELFCOMP	-8.4141	-8.4060	1.1784	-10.7080	-6.0885

OUTCOME VARIABLE:
S_TOTAL

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	12.9465	12.9511	3.1138	6.5930	18.7329
SELFCOMP	-3.3767	-3.3780	.6412	-4.5788	-2.0597
INTSTIGM	.1575	.1571	.0415	.0781	.2401

***** ANALYSIS NOTES AND ERRORS *****

Level of confidence for all confidence intervals in output:
95.0000

Number of bootstrap samples for percentile bootstrap confidence intervals:
5000

NOTE: Variables names longer than eight characters can produce incorrect output.
Shorter variable names are recommended.

----- END MATRIX -----

Analysis 4: self-compassion, enacted stigma and depression

Run MATRIX procedure:

***** PROCESS Procedure for SPSS Version 3.3 *****

Written by Andrew F. Hayes, Ph.D. www.afhayes.com
Documentation available in Hayes (2018). www.guilford.com/p/hayes3

Model : 4
Y : D_TOTAL
X : SELFCOMP
M : ENACSTIG

Sample
Size: 138

OUTCOME VARIABLE:
ENACSTIG

Model Summary

R	R-sq	MSE	F	df1	df2	p
.3346	.1119	51.3276	17.1403	1.0000	136.0000	.0001

Model

	coeff	se	t	p	LLCI	ULCI
constant	27.8928	2.5425	10.9706	.0000	22.8648	32.9207
SELFCOMP	-3.3333	.8051	-4.1401	.0001	-4.9255	-1.7411

Standardized coefficients

	coeff
SELFCOMP	-.3346

OUTCOME VARIABLE:
D_TOTAL

Model Summary

R	R-sq	MSE	F	df1	df2	p
.7403	.5481	15.3199	81.8611	2.0000	135.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	20.6769	1.9071	10.8423	.0000	16.9053	24.4485
SELFCOMP	-5.2134	.4668	-11.1694	.0000	-6.1365	-4.2903
ENACSTIG	.1005	.0468	2.1459	.0337	.0079	.1932

Standardized coefficients

	coeff
SELFCOMP	-.6858
ENACSTIG	.1318

***** TOTAL EFFECT MODEL *****

OUTCOME VARIABLE:

D_TOTAL

Model Summary

R	R-sq	MSE	F	df1	df2	p
.7298	.5327	15.7260	155.0083	1.0000	136.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	23.4810	1.4073	16.6848	.0000	20.6979	26.2641
SELFCOMP	-5.5485	.4457	-12.4502	.0000	-6.4298	-4.6672

Standardized coefficients

	coeff
SELFCOMP	-.7298

***** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y *****

Total effect of X on Y

Effect	se	t	p	LLCI	ULCI	c_ps	c_cs
-5.5485	.4457	-12.4502	.0000	-6.4298	-4.6672	-.9600	-.7298

Direct effect of X on Y

Effect	se	t	p	LLCI	ULCI	c'_ps	c'_cs
-5.2134	.4668	-11.1694	.0000	-6.1365	-4.2903	-.9020	-.6858

Indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
ENACSTIG	-.3351	.1936	-.7672	-.0033

Partially standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
ENACSTIG	-.0580	.0337	-.1326	-.0006

Completely standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
ENACSTIG	-.0441	.0259	-.1025	-.0004

***** BOOTSTRAP RESULTS FOR REGRESSION MODEL PARAMETERS *****

OUTCOME VARIABLE:

ENACSTIG

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	27.8928	27.8555	2.9250	22.2582	33.7413
SELFCOMP	-3.3333	-3.3265	.9079	-5.1168	-1.5785

OUTCOME VARIABLE:
D_TOTAL

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	20.6769	20.7104	2.5212	15.7651	25.5813
SELFCOMP	-5.2134	-5.2292	.5729	-6.3297	-4.1234
ENACSTIG	.1005	.1008	.0543	.0009	.2117

***** ANALYSIS NOTES AND ERRORS *****

Level of confidence for all confidence intervals in output:
95.0000

Number of bootstrap samples for percentile bootstrap confidence intervals:
5000

NOTE: Variables names longer than eight characters can produce incorrect output.
Shorter variable names are recommended.

----- END MATRIX -----

Analysis 5: self-compassion, enacted stigma and anxiety

Run MATRIX procedure:

***** PROCESS Procedure for SPSS Version 3.3 *****

Written by Andrew F. Hayes, Ph.D. www.afhayes.com
Documentation available in Hayes (2018). www.guilford.com/p/hayes3

Model : 4
Y : A_NO_7
X : SELFCOMP
M : ENACSTIG

Sample
Size: 138

OUTCOME VARIABLE:
ENACSTIG

Model Summary

R	R-sq	MSE	F	df1	df2	p
.3346	.1119	51.3276	17.1403	1.0000	136.0000	.0001

Model

	coeff	se	t	p	LLCI	ULCI
constant	27.8928	2.5425	10.9706	.0000	22.8648	32.9207
SELFCOMP	-3.3333	.8051	-4.1401	.0001	-4.9255	-1.7411

Standardized coefficients

	coeff
SELFCOMP	-.3346

OUTCOME VARIABLE:
A_NO_7

Model Summary

R	R-sq	MSE	F	df1	df2	p
.5976	.3572	9.3839	37.5014	2.0000	135.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	6.4124	1.4925	4.2963	.0000	3.4606	9.3642
SELFCOMP	-1.7564	.3653	-4.8081	.0000	-2.4789	-1.0340
ENACSTIG	.1899	.0367	5.1795	.0000	.1174	.2624

Standardized coefficients

	coeff
SELFCOMP	-.3521
ENACSTIG	.3793

***** TOTAL EFFECT MODEL *****

OUTCOME VARIABLE:

A_NO_7

Model Summary

R	R-sq	MSE	F	df1	df2	p
.4790	.2294	11.1659	40.4872	1.0000	136.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	11.7093	1.1859	9.8741	.0000	9.3642	14.0544
SELFCOMP	-2.3894	.3755	-6.3630	.0000	-3.1320	-1.6468

Standardized coefficients

	coeff
SELFCOMP	-.4790

***** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y *****

Total effect of X on Y

Effect	se	t	p	LLCI	ULCI	c_ps	c_cs
-2.3894	.3755	-6.3630	.0000	-3.1320	-1.6468	-.6300	-.4790

Direct effect of X on Y

Effect	se	t	p	LLCI	ULCI	c'_ps	c'_cs
-1.7564	.3653	-4.8081	.0000	-2.4789	-1.0340	-.4631	-.3521

Indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
ENACSTIG	-.6330	.2125	-1.0854	-.2609

Partially standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
ENACSTIG	-.1669	.0510	-.2718	-.0761

Completely standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
ENACSTIG	-.1269	.0393	-.2055	-.0562

***** BOOTSTRAP RESULTS FOR REGRESSION MODEL PARAMETERS *****

OUTCOME VARIABLE:

ENACSTIG

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	27.8928	27.8177	2.9575	21.8183	33.3914
SELFCOMP	-3.3333	-3.3180	.9180	-5.0738	-1.4623

OUTCOME VARIABLE:
A_NO_7

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	6.4124	6.4275	1.6194	3.3670	9.6092
SELFCOMP	-1.7564	-1.7650	.4199	-2.5837	-.9677
ENACSTIG	.1899	.1903	.0414	.1110	.2726

***** ANALYSIS NOTES AND ERRORS *****

Level of confidence for all confidence intervals in output:
95.0000

Number of bootstrap samples for percentile bootstrap confidence intervals:
5000

NOTE: Variables names longer than eight characters can produce incorrect output.
Shorter variable names are recommended.

----- END MATRIX -----

Analysis 6: self-compassion, enacted stigma and stress

Run MATRIX procedure:

***** PROCESS Procedure for SPSS Version 3.3 *****

Written by Andrew F. Hayes, Ph.D. www.afhayes.com
Documentation available in Hayes (2018). www.guilford.com/p/hayes3

Model : 4
Y : S_TOTAL
X : SELFCOMP
M : ENACSTIG

Sample
Size: 138

OUTCOME VARIABLE:
ENACSTIG

Model Summary

R	R-sq	MSE	F	df1	df2	p
.3346	.1119	51.3276	17.1403	1.0000	136.0000	.0001

Model

	coeff	se	t	p	LLCI	ULCI
constant	27.8928	2.5425	10.9706	.0000	22.8648	32.9207
SELFCOMP	-3.3333	.8051	-4.1401	.0001	-4.9255	-1.7411

Standardized coefficients

	coeff
SELFCOMP	-.3346

OUTCOME VARIABLE:
S_TOTAL

Model Summary

R	R-sq	MSE	F	df1	df2	p
.6797	.4619	17.1084	57.9470	2.0000	135.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	16.8586	2.0153	8.3653	.0000	12.8730	20.8443
SELFCOMP	-4.0944	.4933	-8.3008	.0000	-5.0699	-3.1189
ENACSTIG	.1823	.0495	3.6829	.0003	.0844	.2802

Standardized coefficients

	coeff
SELFCOMP	-.5561
ENACSTIG	.2467

***** TOTAL EFFECT MODEL *****

OUTCOME VARIABLE:

S_TOTAL

Model Summary

R	R-sq	MSE	F	df1	df2	p
.6386	.4079	18.6889	93.6761	1.0000	136.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	21.9443	1.5342	14.3036	.0000	18.9103	24.9782
SELFCOMP	-4.7021	.4858	-9.6786	.0000	-5.6629	-3.7414

Standardized coefficients

	coeff
SELFCOMP	-.6386

***** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y *****

Total effect of X on Y

Effect	se	t	p	LLCI	ULCI	c_ps	c_cs
-4.7021	.4858	-9.6786	.0000	-5.6629	-3.7414	-.8400	-.6386

Direct effect of X on Y

Effect	se	t	p	LLCI	ULCI	c'_ps	c'_cs
-4.0944	.4933	-8.3008	.0000	-5.0699	-3.1189	-.7315	-.5561

Indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
ENACSTIG	-.6078	.2418	-1.1211	-.1833

Partially standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
ENACSTIG	-.1086	.0430	-.2002	-.0336

Completely standardized indirect effect(s) of X on Y:

	Effect	BootSE	BootLLCI	BootULCI
ENACSTIG	-.0825	.0327	-.1534	-.0249

***** BOOTSTRAP RESULTS FOR REGRESSION MODEL PARAMETERS *****

OUTCOME VARIABLE:

ENACSTIG

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	27.8928	27.8260	2.9942	21.9143	33.6817
SELFCOMP	-3.3333	-3.3190	.9281	-5.1375	-1.4946

OUTCOME VARIABLE:

S_TOTAL

	Coeff	BootMean	BootSE	BootLLCI	BootULCI
constant	16.8586	16.8840	2.4997	11.8583	21.6779
SELFCOMP	-4.0944	-4.1003	.5540	-5.1868	-3.0058
ENACSTIG	.1823	.1817	.0558	.0720	.2943

***** ANALYSIS NOTES AND ERRORS *****

Level of confidence for all confidence intervals in output:

95.0000

Number of bootstrap samples for percentile bootstrap confidence intervals:

5000

NOTE: Variables names longer than eight characters can produce incorrect output.

Shorter variable names are recommended.

----- END MATRIX -----

Section Three: Critical Appraisal

Natalie Sowter

Doctorate in Clinical Psychology

Lancaster University

Formatted to the specifications of the British Journal of Health Psychology

Word count (excluding references): 3959

Correspondence should be addressed to:

Natalie Sowter

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

Lancaster, L1 4YG

Email: n.sowter@lancaster.ac.uk

Critical Appraisal

This paper will firstly summarise the main findings of the literature review and empirical papers, followed by a discussion of some of the decision points, challenges, strengths and limitations of this thesis. I will consider issues relating to the use of language and constructs, and issues specific to the design of each paper.

Summary of Findings

A systematic search of the literature was conducted, which identified 39 papers that had analysed relationships between cognitive factors and anxiety among people with Parkinson's. These papers were reviewed and their findings synthesised. Overall, there was evidence to suggest that higher anxiety is associated with worse global cognitive abilities and worse performance in specific cognitive domains (attention, working memory, executive functioning, memory, language, semantic verbal fluency and visuospatial skills). There was also evidence to suggest that anxiety predicts cognitive abilities, and vice versa, thus that there may be some bi-directionality to the relationship between anxiety and cognition (this was in keeping with reported findings in other populations). However, there were inconsistencies between the papers, with several studies also finding null results. This could not be ascribed to any particular differences in design or quality. It was noted that many of the studies had small sample sizes, decreasing their power to detect significant effects, but this was not the case for all studies finding null results. Studies also varied as to which potentially confounding variables were controlled for. Therefore, firm conclusions could not be drawn and it was hypothesised that relationships between anxiety and cognition among people with Parkinson's are complex and likely to be influenced by other factors (for example, awareness or perception of cognitive decline, side of onset, or time since diagnosis). Consequently, directions for further research were suggested. The paper also highlighted the need for clinical psychologists and clinical neuropsychologists who work with people with

Parkinson's to be aware of potentially complex relationships between anxiety and cognitive factors, and to ensure that assessments, formulations or interventions relating to either construct should include due consideration of the other. I believe that the publication of this paper would be a useful contribution to the literature since it provides a comprehensive overview of the existing research, which prior reviews on this topic have not achieved (perhaps due to limited search terms and selection criteria).

The empirical paper reports the findings of a quantitative, cross-sectional study which examined the relationships between self-compassion, stigma and psychological distress among people with Parkinson's. Both enacted stigma (disparaging attitudes and actions of others) and felt stigma (the anticipation of enacted stigma and application of stigmatising views towards the self) were measured. Psychological distress was assessed by measures of depression, anxiety and stress. Significant correlational relationships were identified: higher levels of self-compassion were associated with lesser experiences of enacted stigma, less felt stigma and lower levels of depression, anxiety and stress; meanwhile higher levels of reported stigma (both felt and enacted) were associated with higher levels of depression, anxiety and stress. A series of mediation analyses found the stigma variables to mediate the relationships between self-compassion and depression, anxiety and stress. Therefore, it was concluded that for people with Parkinson's, part of the relationship between self-compassion and psychological distress occurs via the ways in which stigma is experienced and internalised. This may have important implications for clinical psychologists and clinical neuropsychologists working with people with Parkinson's who are experiencing distress. It may be useful for psychological assessments with people with Parkinson's to take levels of self-compassion and experiences of stigma into account, while direct psychological interventions might benefit from a focus on developing self-compassion where this is found to be low. Meanwhile, societal-level interventions might address stigma through education

and training, facilitating inclusion of people with Parkinson's in communities and advocacy. This study is the only research I am aware of into the construct of self-compassion among people with Parkinson's, meaning that its publication may be a valuable contribution to the field.

Use of Language and Constructs

A consideration early in the development of this thesis was the language I wanted to use when referring to Parkinson's. It was apparent from an initial scoping search of the literature that most peer-reviewed articles used the terminology "Parkinson's disease". However, the charity Parkinson's UK, who supported the development and advertising of my empirical study, opt to leave out "disease" from the label and simply refer to "Parkinson's". This is also reflected in the language used by organisations run by and for people with Parkinson's, such as Parkinson's Movement and Parkinson's Foundation, and campaigns such as Unite for Parkinson's. People with Parkinson's are said to have reported finding the "disease" terminology stigmatising (Ramaswamy, Jones & Carroll, 2018; Worth, 2019) – though original research or reports stating this could not be located. Given my understanding of the impact of stigma (whether enacted or felt) upon people with Parkinson's through my work on the empirical paper, I believed that it was important from an ethical perspective to avoid the use of potentially stigmatising language in my thesis. However, I acknowledge Worth's (2019) assertions that the use of "Parkinson's" is grammatically unusual ("Parkinson's what?"; pp. 3) and risks confusion with other similarly labelled conditions. When preparing my papers for publishing, I may need to liaise with the target journal regarding my language choices. If I am required to weigh up my ethical stance regarding use of language with the likelihood of the research being published (which raises its own ethical issues around sharing knowledge and not wasting participants' and other contributors' time), I will liaise with the research team at Parkinson's UK for advice.

Further terminologies which I grappled with throughout the development of this thesis were the diagnostic labels of anxiety and depression. I am aware that some people with Parkinson's may not identify with these labels, despite how they might be categorised based on questionnaire scores or whether they meet diagnostic criteria. While these labels may be less contentious and less stigmatising than other psychiatric labels such as personality disorder and schizophrenia (Markham & Trower, 2003; Wood, Birtel, Alsawy, Pyle & Morrison, 2014), they remain somewhat reductionist and still carry a degree of stigma (Corrigan, 2007; Wood et al., 2014). Nonetheless, these concepts are commonly used in quantitative health psychology and neuropsychology research in order to pragmatically measure distress: this approach was also taken in this thesis. Indeed, in the literature review paper, the construct of anxiety was a core component of the research question. Most of the papers considered anxiety as a continuous variable, which is more in keeping with my preferred conceptualisation, but some categorised participants according to the presence or absence of "anxiety disorders" or clinically significant levels of anxiety. I was also required to include diagnostic and potentially stigmatising labels such as "anxiety disorders" in the search terms; this was necessary to ensure the identification of relevant studies. In the empirical study, the constructs of depression and anxiety were used as outcome variables. A key reason for selecting the Depression, Anxiety and Stress Scale – 21-item version (DASS-21; Lovibond & Lovibond, 1995) to measure these variables was that it is expressly not a diagnostic tool. Rather, it was developed as a dimensional measure of distress on the basis that differences between "normal" and "clinical" experiences of depression, anxiety and stress are differences in the degree (as measured on a continuum), rather than the nature, of distress (Lovibond & Lovibond, 1995).

For the empirical paper, I also considered the conceptualisation of cognition. Differentiation of cognitive domains is challenging due to a large degree of overlap between

functions, multiplicity of terms, and contradictory findings of factor analyses - especially with regards to executive functioning (Baggetta & Alexander, 2016; Packwood, Hodgetts & Tremblay, 2011). Further, very few cognitive tests measure any cognitive domain in its pure form as there is often some overlap in the skills required. Taking a critical realist perspective, I consider that cognitive domains exist in the “actual” level of reality, but that they cannot be directly observed, since they occur beyond our sensory experience (Danermark, Ekström, Jakobsen & Karlsson, 2002). Performance on cognitive tests, therefore, may be considered an outcome of the “causal” level of reality (Danermark et al., 2002): cognitive tests are a mechanism through which we can empirically observe the actual reality of the cognitive domains, but this is determined by our own conceptualisations and the tools we select. As such, assessment of cognition cannot be entirely objective. The same might be inferred about the measurement of the constructs of self-compassion and stigma in the empirical paper.

Issues Specific to the Literature Review

Developing the review question.

Due to how the thesis process is set up on the Lancaster University Doctorate in Clinical Psychology course, I had already designed the protocol for my empirical study before I arrived at the task of selecting a focus for the literature review. I was interested in reviewing a topic close to that of the empirical paper, however my initial searches did not reveal any studies into self-compassion among people with Parkinson’s, and very few studies into self-compassion in any neurological or long-term health conditions. The correlates of stigma among people with Parkinson’s had already been reviewed in a previous trainee clinical psychologist’s thesis (Verity, 2018). At the time, there was an additional variable in my empirical study: self-critical rumination (the reasons for later excluding this variable are discussed in the next section of this paper). Therefore, I began to explore topics in this area

and decided upon a cognitive focus: a systematic review of the relationships between attentional inflexibility and psychological distress among people with Parkinson's.

Attentional inflexibility was taken to include the constructs of perseveration, set-shifting and attentional control (Stahl & Pry, 2005). Based on metacognitive models of depression and anxiety (Wells, 2009) which emphasise the role of rumination in the development and maintenance of psychological distress, along with evidence that attentional flexibility can be affected by Parkinson's (Dirnberger & Jahanshahi, 2013), and the overlap in the constructs of attentional inflexibility and rumination (Ehring et al., 2011), I anticipated that significant relationships would be found between attentional inflexibility and distress.

Unfortunately, following a lengthy systematic search of the literature (the search strategy necessarily lacked specificity since the target cognitive domains were rarely mentioned in titles or abstracts), I decided not to pursue this review. Almost all the identified research assumed both the affective and cognitive sequelae of Parkinson's to be a result of altered dopamine levels in the brain causing disruption to fronto-striatal circuitry involved in cognition, and did not consider the potential roles of psychological, social or cognitive factors. Therefore, a review from a psychological perspective at this level of specificity seemed premature. Consequently, I decided to expand the review to consider relationships between cognitive and affective factors among people with Parkinson's. Previous reviews appeared to have adequately considered relationships of the constructs of depression and apathy with cognition (Alzahrani & Venneri, 2015; Poletti, De Rosa & Bonuccelli, 2012), and there was a clear gap in the research with regards to anxiety. Thus, the final review question was decided upon. Given the later removal of the cognitive variable from the empirical paper, there is less continuity between the two papers than I had hoped for.

Measuring cognition.

Some of the issues around conceptualising and measuring aspects of cognition are discussed in the *Use of Language and Constructs* section of this paper. Additionally, the measures used in some of the studies included in the review (Repeatable Battery for the Assessment of Neuropsychological Status, Cambridge Cognitive Test, Mini-Mental State Examination) are not recommended for use with people with Parkinson's due to issues with validity, reliability and sensitivity to change (Skorvanek et al., 2017). Therefore, it is possible that these studies did not accurately reflect relationships between anxiety and cognition due to problems in measurement.

Depression as a potentially confounding variable.

One of the weaknesses identified in the body of research into relationships between anxiety and cognition was that many of the studies did not consider the potential for shared variance between the concepts of anxiety and depression (Beuke, Fischer & McDowall, 2003). This was surprising given the evidence that symptoms of anxiety and depression frequently co-occur among people with Parkinson's (Sagna, Gallo & Pontone, 2014), and that the relationship between depression and cognition is well evidenced (Alzahrani & Venneri, 2015; Poletti et al., 2012). Thus, it could not always be concluded that the studies truly measured relationships between 'pure' anxiety and cognition. The use of the State-Trait Anxiety Inventory (Spielberger, Gorsuch, Lushene, Vagg & Jacobs, 1983) as a measure of anxiety in several of the studies was potentially problematic, since research has found that neither subscale (state nor trait) adequately differentiates between symptoms of anxiety and depression (Bieling, Antony & Swinson, 1998; Kennedy, Schwab, Morris & Beldia, 2001).

Synthesising the results.

Since previous reviews had identified so few relevant studies, I had not expected to find such a large number of results to synthesise. Given the time constraints of the thesis process, this was a challenging endeavour. In addition to the quantity of results, the

inconsistencies between findings of different studies (with some finding significant relationships and others not) made it difficult to draw conclusions.

A weakness of the literature review is that I did not extract (or calculate, where necessary) effect sizes for each of the analyses (due to time constraints, given the number of papers and the number of analyses within each). This might have added some clarity to the findings if, for example, effect sizes tended to be small even when they were significant, which might have indicated that some studies had failed to find effects because they were fairly weak (especially where sample sizes were small). It was identified that most of the significant correlations found between anxiety and cognitive factors were weak (correlation coefficient $<.3$; Cohen, 1988), indicating small effects in these studies, however it could not be confirmed whether this was the case for all significant findings. I will consider meta-analysing subsets of the data prior to submitting the literature review paper for publication in order to strengthen the results, increase objectivity, and overcome the problems presented by small sample sizes (Walker, Hernandez & Kattan, 2008). This may not be advisable for the separate cognitive domains, given the wide variety of measures and methods used across studies, but might be useful for the global cognition data, where the studies were less heterogeneous in design. A forest plot to assess for relative homogeneity of results (using confidence intervals of the estimated effects) may be used to determine whether a meta-analysis is appropriate and justified (Walker et al., 2008).

Issues Specific to the Empirical Study

Self-critical rumination.

I had initially planned to include self-critical rumination as a variable in the empirical study. This is defined as a ruminative focus specifically upon on self-critical thoughts (Smart, Peters and Baer, 2016). Self-critical rumination has been found to be positively associated with symptoms of depression, anxiety, and stress, and negatively associated with self-

compassion in a non-neurological population (Smart et al., 2016). As such, one of the original aims of the study was to investigate whether these relationships also existed for people with Parkinson's. Given that one of the cognitive problems that people with Parkinson's can experience is a tendency to perseverate (as discussed above), I hypothesised that becoming stuck upon negative thoughts about the self may be a pertinent issue, and one which could affect psychological wellbeing. I also considered that self-criticism, as the antithesis of self-compassion (Gilbert, 2010), might be positively associated with felt stigma, through the internalisation of negative stereotypes which are inherently critical. The Self-Critical Rumination Scale (SCRS; Smart, et al., 2016) was therefore included in the survey. The SCRS has been used in a limited number of research studies, and does not appear to have yet been used with people with neurological conditions.

As I researched the topic area further, it became clear that there were theoretical distinctions in the potential relationships between self-compassion, stigma and distress versus self-critical rumination, stigma and distress. The theoretical framework proposed by Wong, Knee, Neighbors and Zvolensky (2019), whereby self-compassion allows people to internalise stigma less and leads to more positive outcomes, supported a mediation model with self-compassion as the predictor, stigma as the potential mediator and the psychological distress variables at the outcomes. This framework was published after the research protocol had been developed, at which time I had proposed that self-compassion would be the mediator. However, this model would not make sense with self-critical rumination in the place of self-compassion, since the idea that self-critical rumination would predict stigma is not theoretically supported. Self-critical rumination would have been required to be the mediator variable, with stigma as the predictor. This would therefore comprise an entirely different research question, introducing an additional layer of complexity to the paper that I would struggle to adequately describe in the prescribed word count. I therefore agreed with

my supervisors that it might be preferable to write two theoretically distinct papers: one about the relationships between self-compassion, stigma and psychological distress (as submitted as part of this thesis) and another about the relationships between stigma, self-critical rumination and psychological distress. Therefore, the SCRS data may be analysed and written up in a separate paper at a later date.

Recruitment strategy.

Participants were recruited via online advertisement on the Parkinson's UK website, in the Parkinson's UK online newsletter and on the social media platform Twitter. The survey was in a computerised format but participants were given the option to request a paper copy by post. This recruitment strategy was selected due to Parkinson's UK having an extremely active Research Support Network, and the success of a previous trainee clinical psychologist in using a similar recruitment strategy for a similar research project (Verity, 2018). It was also cost-effective and allowed for recruitment across geographical barriers. However, there were limitations to this strategy in that it favoured individuals who were computer-literate and had access to a computer, and may have excluded people who did not meet these criteria. I did receive emails from family members of people with Parkinson's who had seen the research advertised online and requested a paper-copy for their (non-computer-literate) relative, but only one of these was returned. To aid with computerised completion, the survey was designed such that individuals could save and return to their responses at any time. The Patient and Public Involvement volunteers from Parkinson's UK, who participated in the design of the materials, were positive about the online format and did not foresee any problems with the recruitment strategy, given the option to request a paper copy if preferred.

A recent report by the charity Age UK states that 36% of people over the age of 65 do not currently use the internet, and that the likelihood of internet use is reduced among people with mobility problems (Age UK, 2018). Additionally, younger people are more likely than

older people to participate in research advertised on the internet and social media (Topolovec-Vranic & Natarajan, 2016). As such, my chosen recruitment strategy may have been a factor in the sample being relatively young and functionally able. Future studies may benefit from broader recruitment strategies (such as visiting clinics and care homes), to be more inclusive of older and less functionally able people with Parkinson's and to increase generalisability.

People experiencing higher levels of psychological distress and/or stigma might have been less likely to participate in the study due to, for example, shame, avoidance or low motivation. Although it is important to understand the experiences of this group in order to improve care, recruitment strategies aimed at including these individuals require the consideration of ethical issues, since participation could be distressing. Future research might address this issue by providing additional support, both at the time of participation and afterwards, perhaps by building links with services for people with Parkinson's who could facilitate recruitment and provide this support.

Limitations of the study design.

As discussed in the empirical paper, since the study was observational and cross-sectional, cause and effect cannot be established. Hayes (2018) recommends that mediation analyses with correlational and cross-sectional data need not be avoided, despite causality being assumed in the mediation model, so long as the results are interpreted cautiously. As such, it cannot be assumed that having more self-compassion causes people with Parkinson's to experience less stigma, which causes them to experience less distress. Rather, it appears that there are interactions between each of the variables such that the relationships between self-compassion and depression, anxiety and stress operate via their relationships with experiences of felt and enacted stigma. Therefore, there may be additional underlying variables contributing to the relationships, such as social, demographic or economic factors.

Mediation is only one of many possible ways of investigating the relationships between the variables in this study. A moderation model, where self-compassion might be predicted to moderate the relationships between experiences of stigma and distress, would be an alternative analysis. This would test a different aspect of Wong et al.'s (2019) model to that which was tested by the mediation analysis. If significant (and in the expected direction), this would suggest that as self-compassion increases, the relationship between stigma and psychological distress becomes less strong. This moderation analysis was considered for analysing the data in the empirical study but the sample size was considered inadequate (consideration of this model was prompted by the Wong et al. (2019) paper, which was not identified until after data collection was complete). This may be an area for future research. Additionally, it was considered that self-compassion may mediate the relationship between stigma and distress. However, this was less theoretically supported, self-compassion being conceptualised as something which develops in response to early caregiving relationships (Gilbert, 2010) and therefore unlikely to be predicted by Parkinson's-related stigma.

In addition to the above, the survey-based nature of the study meant a reliance on self-report measures. This was particularly problematic for the enacted stigma variable, in which participants were required to make judgements as to whether others' attitudes and actions towards them were as a result of their Parkinson's. Self-reports of enacted stigma may therefore reflect an individual's subjective experiences of stigma (potentially influenced by their beliefs and interpretations) rather than actual enactments of stigma. Arguably, the subjective experience of stigma is more important from a psychological perspective, however I was required to exercise caution in my interpretations of the meaning of the enacted stigma variable.

Directions for Future Research

Some areas for future research might include further exploration of the correlates of self-compassion among people with Parkinson's, and the efficacy of compassion-focussed approaches to working with this population (potential outcomes for efficacy might be psychological distress and internalisation of stigma, based on the findings of the empirical paper). The mediation model identified in the empirical paper might be built upon by considering the interaction of the mediating variables of felt and enacted stigma, or by considering other potential mediators in the relationship between self-compassion and distress. Studies investigating the impact of interventions for reducing the stigma around Parkinson's would also be valuable.

Future research might also investigate the complexities of the relationships between anxiety and cognitive factors from a psycho-social perspective, for example by considering experiences of stigma, subjective cognitive performance or depression. Qualitative research into the social and psychological impact of cognitive decline for people with Parkinson's might highlight further areas for exploration.

Conclusions

Two pieces of research were conducted, a systematic review and an empirical study, in which relationships between cognitive, psychological and social factors for people with Parkinson's were explored. There were strengths in the originality of the research, and both papers will hopefully provide a useful contribution to knowledge for clinical psychologists and clinical neuropsychologists working with people with Parkinson's. However, there were also limitations to both studies. Some of these might be addressed in preparing the papers for publication or in future research projects.

References

- Age UK. (2018). *Digital Inclusion Evidence Review 2018*. Retrieved from:
https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/age_uk_digital_inclusion_evidence_review_2018.pdf
- Alzahrani, H. & Venneri, A. (2015). Cognitive and neuroanatomical correlates of neuropsychiatric symptoms in Parkinson's disease: A systematic review. *Journal of the Neurological Sciences*, 356(1-2), 32-44. Doi: 10.1016/j.jns.2015.06.037
- Baggetta, P., & Alexander, P. A. (2016). Conceptualization and operationalization of executive function. *Mind, Brain, and Education*, 10(1), 10-33. Doi: 10.1111/mbe.12100
- Beuke, C. J., Fischer, R. & McDowall, J. (2003). Anxiety and depression: Why and how to measure their separate effects. *Clinical Psychology Review*, 23(6), 831-848. Doi: 10.1016/S0272-7358(03)00074-6
- Bieling, P. J., Antony, M. M., & Swinson, R. P. (1998). The State-Trait Anxiety Inventory, Trait version: Structure and content re-examined. *Behaviour Research and Therapy*, 36(7-8), 777-788. Doi: 10.1016/S0005-7967(98)00023-0
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. New York: Routledge Academic
- Corrigan, P. W. (2007). How clinical diagnosis might exacerbate the stigma of mental illness. *Social Work*, 52(1), 31–39. Doi: 10.1093/sw/52.1.31
- Danermark, B., Ekström, M., Jakobsen, L., & Karlsson, J. C. (2002). *Explaining society: Critical realism in the social sciences*. London: Routledge
- Dirnberger, G., & Jahanshahi, M. (2013). Executive dysfunction in Parkinson's disease: A review. *Journal of Neuropsychology*, 7(2), 193-224. Doi :10.1111/jnp.12028

- Ehring, T., Zetsche, U., Weidacker, K., Wahl, K., Schönfeld, S., & Ehlers, A. (2011). The Perseverative Thinking Questionnaire (PTQ): Validation of a content-independent measure of repetitive negative thinking. *Journal of Behavior Therapy and Experimental Psychiatry*, 42(2), 225-232. Doi: 10.1016/j.jbtep.2010.12.003
- Gilbert, P. (2010). *Compassion focused therapy: The CBT distinctive features series*. Hove: Routledge
- Hayes, A. (2018). *Introduction to mediation, moderation and conditional process analysis: A regression-based approach* (Second ed.). London: Guilford Press
- Kennedy, B. L., Schwab, J. J., Morris, R. L., & Beldia, G. (2001). Assessment of state and trait anxiety in subjects with anxiety and depressive disorders. *Psychiatric Quarterly*, 72(3), 263-276. Doi: 10.1023/A:1010305200087
- Lovibond, S. H. & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales* (2nd. Ed.). Sydney: Psychology Foundation
- Markham, D. & Trower, P. (2003). The effects of the psychiatric label 'borderline personality disorder' on nursing staff's perceptions and causal attributions for challenging behaviours. *British Journal of Clinical Psychology*, 42(3), 243-256. Doi: 10.1348/01446650360703366
- Packwood, S., Hodgetts, H. M., & Tremblay, S. (2011). A multiperspective approach to the conceptualization of executive functions. *Journal of Clinical and Experimental Neuropsychology*, 33(4), 456-470. Doi: 10.1080/13803395.2010.533157
- Poletti, M., De Rosa, A., & Bonuccelli, U. (2012). Affective symptoms and cognitive functions in Parkinson's disease. *Journal of the Neurological Sciences*, 317(1-2), 97-102. Doi: 10.1016/j.jns.2012.02.022

- Ramaswamy, B., Jones, J., & Carroll, C. (2018). Exercise for people with Parkinson's: A practical approach. *Practical Neurology*, 18(5), 399-406. Doi: 10.1136/practneurol-2018-001930
- Sagna, A., Gallo, J. J., & Pontone, G. M. (2014). Systematic review of factors associated with depression and anxiety disorders among older adults with Parkinson's disease. *Parkinsonism & Related Disorders*, 20(7), 708-715. Doi: 10.1016/j.parkreldis.2014.03.020
- Skorvanek, M., Goldman, J. G., Jahanshahi, M., Marras, C., Rektorova, I., Schmand, B. ... & members of the MDS Rating Scales Review Committee. (2018). Global scales for cognitive screening in Parkinson's disease: Critique and recommendations. *Movement Disorders*, 33(2), 208-218. Doi: 10.1002/mds.27233
- Smart, L., Peters, J., & Baer, R. (2016). Development and validation of a measure of self-critical rumination. *Assessment*, 23(3), 321-332. Doi: 10.1177/1073191115573300
- Spielberger, C. D., Gorsuch, R. L., Lushene, R., Vagg, P. R., & Jacobs, G. A. (1983). *Manual for the State-Trait Anxiety Inventory*. Consulting Psychologists Press: CA, USA
- Stahl, L., & Pry, R. (2005). Attentional flexibility and perseveration: Developmental aspects in young children. *Child Neuropsychology*, 11(2), 175-189. Doi: 10.1080/092970490911315
- Topolovec-Vranic, J., & Natarajan, K. (2016). The use of social media in recruitment for medical research studies: A scoping review. *Journal of Medical Internet Research*, 18(11), e286. Doi: 10.2196/jmir.5698
- Verity, D. (2018). *Stigma, perceived control and health-related quality of life for individuals experiencing Parkinson's disease* (Unpublished doctoral thesis). Lancaster University, Lancaster, UK. Retrieved from: <https://eprints.lancs.ac.uk/id/eprint/128027>

- Walker, E., Hernandez, A. V., & Kattan, M. W. (2008). Meta-analysis: Its strengths and limitations. *Cleveland Clinic Journal of Medicine*, 75(6), 431-439. Retrieved from: <https://www.mdedge.com/ccjm/article/94919/practice-management/meta-analysis-its-strengths-and-limitations>
- Wells. A. (2009). *Metacognitive Therapy for Anxiety and Depression*. New York: Guildford Press
- Wong, C., Knee, C., Neighbors, C., & Zvolensky, M. (2019). Hacking stigma by loving yourself: A mediated-moderation model of self-compassion and stigma. *Mindfulness*, 10(3), 415-433. Doi: 10.1007/s12671-018-0984-2
- Wood, L., Birtel, M., Alsawy, S., Pyle, M., & Morrison, A. (2014). Public perceptions of stigma towards people with schizophrenia, depression, and anxiety. *Psychiatry Research*, 220(1-2), 604-608. Doi: 10.1016/j.psychres.2014.07.012
- Worth, P. F. (2019). Taking the 'Disease' out of 'Parkinson's': Has the disease had its day? *Practical Neurology*, 19(1), 2-4. Doi: 10.1136/practneurol-2018-002066

Section Four: Ethics and Appendices

Natalie Sowter

Doctorate in Clinical Psychology

Lancaster University

Word count (including ethics application form content and protocol, but excluding ethics application form wording, references and appendices): 3958

Correspondence should be addressed to:

Natalie Sowter

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

Lancaster, L1 4YG

Email: n.sowter@lancaster.ac.uk

**Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University**

Application for Ethical Approval for Research

for additional advice on completing this form, hover cursor over 'guidance'.

Guidance on completing this form is also available as a word document

Title of Project: Stigma, self-compassion, self-critical rumination and psychological distress amongst people with Parkinson's

Name of applicant/researcher: Natalie Sowter

ACP ID number (if applicable)*: N/A

Funding source (if applicable) N/A

Grant code (if applicable): N/A

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [\[link\]](#).**

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist, Division of Health Research

2. Contact information for applicant:

E-mail: n.sowter@lancaster.ac.uk

Telephone: 07817757231 (please give a number on which you can be contacted at short notice)

Address: Furness College, Lancaster University, Lancaster, LA1 4YT

3. Names and appointments of all members of the research team (including degree where applicable)

Dr Fiona Eccles, Lecturer in Health Research, Lancaster University

Dr Jane Simpson, Lecturer in Health Research, Lancaster University

Dr Terry Spokes, Clinical Psychologist, Tameside and Glossop Integrated Care NHS Foundation Trust

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the [FHMREC website](#))

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant: Dr Fiona Eccles; Dr Terry Spokes

5. Appointment held by supervisor(s) and institution(s) where based (if applicable): Dr Fiona Eccles, Lecturer in Health Research, Lancaster University; Dr Terry Spokes, Clinical Psychologist, Tameside and Glossop Integrated Care NHS Foundation Trust

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)

Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' ☐ n o

4c. If yes, where relevant has permission / agreement been secured from the website moderator? ☐ n o

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? ☐ n o

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain? ☐ n o

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? ☐ yes

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

Research suggests that people affected by Parkinson's experience stigma (signs of disapproval) from others, which can lead to an increase in psychological distress. The aim of this study will be to investigate this relationship between stigma and psychological distress, by looking at other factors which might influence it.

The other factors which will be considered are self-compassion (the ability to recognise one's own suffering and take steps to relieve it, using a kind and caring approach) and self-critical rumination (persistent critical thoughts about the self).

Potential participants (adults with a diagnosis of Parkinson's) will be approached through online advertising (via the Parkinson's UK website, the websites of other organisations who support people with Parkinson's, and Twitter). Participants will be asked to complete questionnaires (with online and paper options) relating to stigma, self-compassion, self-critical rumination and psychological distress. Participants' scores will then be analysed. A minimum of 84 participants will be needed to minimise the chance of errors in the analysis of the findings.

2. Anticipated project dates (month and year only)

Start date: October 2018

End date: May 2019

Data Collection and Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

Participants will be adults (i.e. aged 18 years and older) with Parkinson's who have had their diagnosis for a minimum of 6 months (as determined by self-report). No upper age limit will be set. Participants can be any gender.

A-priori power calculations indicate that a sample of at least 84 participants will be required in order to achieve sufficient statistical power for the intended statistical analyses (mediation analysis and correlation). The maximum number of participants will be approximately 300.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

Participants will be accessed via the charitable organisation Parkinson's UK through online advertising (the charity have a dedicated page for this on their website - <https://www.parkinsons.org.uk/research/take-part-research>). This has been agreed with the Parkinson's UK research team. Participants will see the title of the research and a brief description, and when clicking on this will be taken to the landing page of the Qualtrics survey (the first page being the Information for Participants sheet).

The study will also be advertised on the social media platform Twitter, via Natalie Sowter's Twitter account. This account is used for professional purposes and is not a personal account. Twitter posts will provide a brief description of the study, and a link to the landing page of the Qualtrics survey (the first page being the Information for Participants sheet). Organisations who support people with Parkinson's may be "tagged" in the posts and asked to "retweet".

Additionally, we may approach other organisations who support people with Parkinson's (including, but not limited to, Parkinson's Association of Ireland, Parkinson's Australia, and Parkinson's New Zealand), to ask them to advertise the study through their websites.

Regardless of recruitment route, participants will be able to choose to complete the online survey through Qualtrics, or to contact the lead researcher via phone, text or email to request a hard copy be posted to them, along with a stamped addressed envelope in which to return it. Information about these options is provided on the Information for Participants sheet.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Data will be collated on the lead researcher's password-protected Qualtrics account. Responses submitted in hard copy format will be entered into Qualtrics by the lead researcher and then destroyed. Once data collection is complete, the relevant data for each analysis will be transferred from Qualtrics to SPSS data files.

A correlation analysis will firstly be performed between self-compassion and self-critical rumination scores, then between all other variables (Pearson or Spearman depending on the distribution of scores). A series of hierarchical regression analyses will then be conducted with the DASS variable scores as the dependent variable for each analysis (i.e. depression, anxiety, and stress), stigma and self-compassion and/or self-critical rumination scores as independent variables, and controlling for demographic and clinical variables if appropriate.

If the assumptions are met to carry out a mediation analysis with stigma as the independent variable, DASS scores as the dependent variable, and self-compassion and/or self-critical rumination as potential mediator(s), then this will also be completed (with bias-correction and bootstrapping).

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Data will be submitted anonymously and stored securely on password protected software (Qualtrics and SPSS) on the secure server provided by Lancaster University. Responses submitted in hard copy format will be entered into Qualtrics by the lead researcher and then destroyed. In the meantime they will be stored in a locked cabinet. Data will be accessible only to Natalie Sowter and the project supervisors named above (and the research coordinator in the DClinPsy team and the Programme and/or Research Directors once the assignment is submitted). Once the project is complete, data will be sent to the research coordinator of the DClinPsy team for storage for 10 years on the Lancaster University secure Network or Box. Fiona Eccles will be the data custodian and will be responsible for overseeing the data being destroyed after 10 years.

7. Will audio or video recording take place? ☒ no ☐ audio ☐ video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data. N/A

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?
N/A

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

The data will be stored securely and confidentially by the DClinPsy course at Lancaster University on the secure server or on Box, in electronic form, for 10 years but it will not be put onto PURE and will not be shared more widely in its raw form. This is due the sensitive nature of the data. Questions about sensitive topics such as symptom severity, depression and stigma may not be answered honestly if participants know that their raw data will be made publicly available, potentially affecting the integrity of the data and the reliability of the findings. It may also reduce willingness to participate. There are also concerns that the data from any participants with more diverse demographics may be identifiable.

8b. Are there any restrictions on sharing your data ?
Yes, the raw data will not be made publicly available.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Potential participants will be presented with the “Information for Participants” to read. This will be followed by forced choice questions asking participants to confirm that they have read and agreed to the information, and that they give their consent to participate.

On the online survey, the next page cannot be reached unless the participant answers these questions to state that they have read the information and give their consent.

If a potential participant returns the paper forms without selecting the answers to these questions to indicate their informed consent, their data will be destroyed and will not be used.

The consent process will not require participants to give their name, or any other identifying information, as this would compromise their anonymity.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

There is a slight possibility that participants may feel distressed as a result of completing the questionnaires. The details of organisations participants can contact for support in the event of distress will be provided as part of the debrief information.

Once participants have begun the online survey, or returned a survey by post, they will no longer be able to withdraw their data. This is because their data will not be identifiable. This will be made clear in the Information for Participants.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

None identified.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There is not expected to be any direct benefit to participating in this study. However, people may find participation an interesting or positive experience, because the study may add new knowledge to the field of Parkinson’s research.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

None

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? ☒ yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Surveys completed online will be anonymous. Participants (and potential participants) who would like the hard-copy survey posted to them will be required to provide their name and address to the lead researcher. Their telephone number may also be available to the lead researcher if they choose to call the research phone without withholding their number. Any such information will be destroyed as soon as the survey has been posted.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

Patient and Public Involvement Volunteers, recruited by Parkinson's UK, have provided feedback on all materials to be used in the study (information sheet, consent form, demographics questionnaire, standardised questionnaire, debrief) regarding content, layout, and accessibility for people with Parkinson's.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The findings of this study will be submitted as part of Natalie Sowter's thesis for her Doctorate in Clinical Psychology (DClinPsy). It is also anticipated that the findings will be submitted for publication in a peer-reviewed journal. The findings will be presented to trainee clinical psychologists, service users and course staff at the DClinPsy thesis presentation day at Lancaster University, and may also be presented at a meeting of the North West Neuropsychology Special Interest Group, or at other conferences or seminars. Finally, the findings will be summarised in written form for presentation on the Parkinson's UK website.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

It is hoped that the option to complete the questionnaires either online or in hard-copy (paper) format will enable people to participate who may wish to contribute but be otherwise unable. Participants will also be allowed to have help to fill in the questionnaires by a relative, friend or caregiver.

SECTION FOUR: signature

Applicant electronic signature: Natalie Sowter
20/08/18

Date

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review ☒

Project Supervisor name (if applicable): Dr Fiona Eccles
08/08/18

Date application discussed

Submission Guidance

1. Submit your FHMREC application by email to Diane Hopkins (d.hopkins@lancaster.ac.uk) as two separate documents:

- i. **FHMREC application form.**
Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line*.
- ii. **Supporting materials.**
Collate the **following materials for your study, if relevant, into a single word document:**
 - a. **Your full research proposal (background, literature review, methodology/methods, ethical considerations).**
 - b. Advertising materials (posters, e-mails)
 - c. Letters/emails of invitation to participate
 - d. Participant information sheets
 - e. Consent forms
 - f. Questionnaires, surveys, demographic sheets
 - g. Interview schedules, interview question guides, focus group scripts
 - h. Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:

- i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to **Diane Hopkins by the committee deadline date**. Committee meeting dates and application submission dates are listed on the [FHMREC website](#). Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
- ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required]**. Those involving:
 - a. existing documents/data only;
 - b. the evaluation of an existing project with no direct contact with human participants;
 - c. service evaluations.

3. **You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application**

**Stigma, self-compassion, self-critical rumination and psychological distress amongst
people with Parkinson's**

Protocol Version 2

Applicants

Principal Investigator

Natalie Sowter

Trainee clinical psychologist, Lancaster University, Lancaster, LA1 4YT

Tel: 01524 592754, email: n.sowter@lancaster.ac.uk

Supervisors

Dr Fiona Eccles

Lecturer in health research, Lancaster University, Lancaster, LA1 4YT, UK

Tel: 01524 592807, email: f.eccles@lancaster.ac.uk

Dr Terry Spokes

Clinical Psychologist, Tameside and Glossop Community Neurological Rehabilitation Team,
Selbourne House, Hyde, SK14 1NG

Tel: 0161 366 2323, email: terry.spokes@nhs.net

Advisor

Dr Jane Simpson

Lecturer in health research, Lancaster University, Lancaster, LA1 4YT, UK

Tel: 01524 592858, email: j.simpson2@lancaster.ac.uk

(Jane has agreed to provide advice on specific aspects of the project (analysis and interpretation of results) but will not be involved in the day to day running of the project.)

Introduction

Parkinson's¹ is the second most common neuro-degenerative condition (after Alzheimer's disease) and affects 0.1-0.2% of the population, with increasing prevalence after the age of 60 (Tysnes & Storstein, 2017). The symptoms of Parkinson's are often categorised within the literature into motor and non-motor characteristics. Typical motor symptoms, as reviewed by Moustafa et al. (2016), include difficulty initiating movement (akinesia), slowed movement (bradykinesia), tremor, rigidity, gait disturbance and speech difficulties. Non-motor symptoms can include cognitive impairments, difficulties with impulse control, and visual disturbances, as delineated by Stacy (2011).

Several qualitative studies have described the stigma that people with Parkinson's can experience in relation to the more visible symptoms of the condition (Caap-Ahlgren & Lannerheim, 2002; Bramley & Eatough, 2005; Hermanns, 2013). Further research has demonstrated stigmatizing views held by both professionals and members of the public towards people with Parkinson's (Tickle-Degnen, Zebrowitz & Ma, 2011; Hemmesch, 2014). It has also been suggested that experiences of stigma can lead to an increase in psychological distress (as measured by symptoms of depression scales), both amongst people with Parkinson's (Schrag, Jahanshahi & Quinn, 2001) and other neurological conditions such as epilepsy (Whatley, Dilorio & Yeager, 2010). For clinical psychologists working with people

¹ "Parkinson's" as opposed to "Parkinson's Disease" is the label used by the charitable organisation Parkinson's UK. Therefore this language has been adopted throughout this document, and on all participant materials.

with Parkinson's with experiences of stigma and psychological distress, it appears important to gain a greater understanding of the relationship between these constructs.

A factor which may be considered as a potential component in the relationship between stigma and psychological distress is self-compassion. Self-compassion is defined by Neff and Dahm (2015) as an acknowledgement of one's own suffering (in line with principles of mindfulness), and a self-directed response based upon "kindness, concern and support". No research could be found looking at self-compassion amongst people with Parkinson's, however it has been demonstrated that interventions aimed at increasing self-compassion can alleviate psychological distress in people with other neurological problems – for example, traumatic brain injuries (Ashworth, Gracey & Gilbert, 2011) and dementia (Collins, Gilligan & Poz, 2017).

It may therefore be reasonable to hypothesise that self-compassion could have a role in the relationship between stigma and psychological distress amongst people with Parkinson's – where stigma and psychological distress might be conceptualized as suffering. Indeed, self-compassion has been shown to protect against the effects of stigma on psychological distress in parents of children with autism (Wong, Mak & Liao, 2016). However, no literature could be found exploring similar relationships in people with neurological conditions.

An additional construct which will be considered is self-critical rumination. This is defined as a ruminative focus specifically upon on self-critical thoughts (Smart, Peters and Baer, 2016). Self-critical rumination has been found to be positively associated with symptoms of depression, anxiety, and stress, and negatively associated with self-compassion in a non-neurological population (Smart, Peters and Baer, 2016). As such, it may be useful to investigate whether these relationships also exist for people with Parkinson's and whether

self-critical rumination might play a role in the relationship between stigma and psychological distress.

The overall aim of this study is to explore the relationships between the constructs of self-compassion, self-critical rumination, stigma and psychological distress amongst people with Parkinson's. It is hoped that the findings of this research will be useful to clinical psychologists working with individuals with Parkinson's: it may deepen understanding of the relationships between internal and external experiences for people with Parkinson's; it could highlight a possible future role for compassion-focussed, cognitive and metacognitive therapeutic approaches; and more broadly, it may highlight a role for clinical psychologists in addressing the stigma faced by people with Parkinson's.

Method

Participants

Participants will be accessed via the charitable organisation Parkinson's UK, through online advertising (the charity have a dedicated page for this on their website -

<https://www.parkinsons.org.uk/research/take-part-research>). The study will also be advertised on the social media platform Twitter, via Natalie Sowter's Twitter account. We may also approach other organisations who support people with Parkinson's (including, but not limited to, Parkinson's Association of Ireland, Parkinson's Australia, and Parkinson's New Zealand), to ask them to advertise the study through their websites.

Participants will be adults (i.e. 18 years and older) with Parkinson's who have had their diagnosis for a minimum of 6 months. No upper age limit will be set.

A-priori power calculations indicate that a sample of at least 84 participants will be required in order to achieve sufficient statistical power for the intended statistical analyses (mediation analysis and correlation). Fritz and MacKinnon (2007) provide empirical

estimates of the sample sizes required in mediation analyses to achieve statistical power at 80%. They suggest that a bias-corrected bootstrapped mediation analysis with medium effect sizes between the independent and mediator variables (α) and the mediator and dependent variables (β) ($\alpha, \beta = 0.39$) requires 71 participants, in order to be adequately powered. For a moderate correlation ($r = 0.3$) and for $p=0.05$ at 80% power, a two-tailed Pearson's correlation requires 84 participants. Therefore, a minimum of 84 participants will be recruited. A maximum of 300 participants will be recruited.

Design

This study will employ a cross-sectional, correlational design: it will aim to measure the strength and direction of relationships between several variables, using only one group of participants, at one time-point. The null hypotheses are as follows:

There is no relationship between participants' self-critical rumination scores and self-compassion scores.

There is no relationship between participants' stigma scores and psychological distress (as measured by anxiety, depression and stress scores)

Stigma, self-compassion and self-critical rumination scores do not predict psychological distress (as measured by anxiety, depression and stress scores).

Neither self-compassion nor self-critical rumination mediate any relationship found between stigma and psychological distress .

Materials

The participant materials for this study will be available both online (via Qualtrics) and in hard copy. The participant materials have been kindly reviewed by Patient and Public Involvement Volunteers from Parkinson's UK, and amended in line with the feedback provided. The participant materials will consist of:

1. Information for Participants – briefly outlining the purpose of the research, how the data will be stored and used, how to contact the research team with any questions or complaints, etc. If this is accessed via Qualtrics, the option will be provided to download a printable copy of this document.

2. Eligibility and consent questions – 4 questions to check that participants are eligible to participate, have read the Information for Participants and give consent for their data to be included in the study.
3. Demographics questionnaire – 10 questions to gather demographic and clinical information about participants.
4. Functional Status Questionnaire (FSQ; Jette et al., 1986) physical function subscale – 9 items designed to assess functioning in basic and intermediate activities of daily living. This has been included for the purpose of situating the sample in terms of severity of physical symptoms. In a systematic review of disability rating scales for people with Parkinson's by Shulman et al. (2016), this measure was recommended for both clinical and research use. Jette et al. (1986) report that it has good internal consistency (Cronbach's alpha = 0.92).
5. Stigma Scale for Chronic Illness (SSCI; Rao et al., 2009) – a 24 item multiple-choice questionnaire, validated for use with people with Parkinson's. Measures both felt (internalised) stigma and enacted (experienced behaviourally from others) stigma. This distinction may be helpful in reducing bias due to the possibility that people who are more self-compassionate may experience less felt stigma. Cronbach's alpha was reported by the authors of the scale at 0.97, although this analysis was conducted on a draft version of the questionnaire with 26 items.
6. Self-Compassion Scale (SCS; Neff, 2003) – a 26 item validated measure of self-compassion. Neff (2003) reports that the scale's internal consistency is high (Cronbach's alpha = 0.92).
7. Self-Critical Rumination Scale Scale (SCRS; Smart, Peters & Baer, 2016) – a 10 item questionnaire; the only self-report measure of self-criticism found to have

good content and structural validity in a systematic review of available measures (Rose & Rimes, 2018). Smart et al. (2016) report a Cronbach's alpha of 0.92, suggesting good internal consistency. Test-retest reliability is also reported for this measure at 0.86 (Smart et al., 2016).

8. Depression, Anxiety and Stress Scale - 21 (DASS-21; Lovibond & Lovibond, 1995) – a 21 item questionnaire which is validated for clinical and non-clinical populations. Cronbach's alphas have been found to be 0.94 for depression, 0.87 for anxiety, and 0.91 for stress (Antony, Bieling, Cox, Enns, & Swinson, 1998).
9. Debrief – additional information about the purpose of the research, contact details for queries or concerns, and resources in the case that the research leads to any distress.

Additional materials which will be required are:

1. Research phone (to enable participant contact)
2. Prepaid envelopes and stamps (for postage of hard copies)
3. Qualtrics software
4. SPSS software including Hayes PROCESS tool

Procedure

Participants will be recruited via Parkinson's UK (<https://www.parkinsons.org.uk/research/take-part-research>). This has been agreed with the Parkinson's UK research team. Participants will see the title of the research and a brief description, and when clicking on this will be taken to the landing page of the Qualtrics survey (the first page being the Information for Participants sheet). The study will also be advertised on the social media platform Twitter, via Natalie Sowter's Twitter account. Twitter posts will provide a brief description of the study, and a link to the landing page of

the Qualtrics survey (the first page being the Information for Participants sheet).

Organisations who support people with Parkinson's may be "tagged" in the posts and asked to "retweet". Additionally, we may approach other organisations who support people with Parkinson's (including, but not limited to, Parkinson's Association of Ireland, Parkinson's Australia, and Parkinson's New Zealand), to ask them to advertise the study through their websites.

Participants will be able to choose to complete the online survey via Qualtrics, or to contact the lead researcher via phone, text or email to request a hard copy be posted to them, along with a stamped addressed envelope in which to return it.

Data will be collated on the principal investigator's password-protected Qualtrics account, and will at this stage be accessible only to the principal investigator and supervisors. Responses submitted in hard copy format will be entered into Qualtrics by the principal investigator and then destroyed.

Data Analysis

The relevant data for each analysis will be transferred from Qualtrics to SPSS data files. A correlation analysis will firstly be performed between self-compassion and self-critical rumination scores, then between all other variables (Pearson or Spearman depending on the distribution of scores). A series of hierarchical regression analyses will then be conducted with the DASS variable scores as the dependent variable for each analysis (i.e. depression, anxiety, and stress), stigma and self-compassion and/or self-critical rumination scores as independent variables, and controlling for demographic and clinical variables if appropriate.

If the assumptions are met to carry out mediation analyses (e.g. Hayes & Rockwood, 2017), then this will also be completed (with bias-correction and bootstrapping as required).

The first proposed mediation analysis will take stigma as the independent variable, DASS scores as the dependent variable, and self-compassion as the potential mediator. The second proposed mediation analysis will take stigma as the independent variable, DASS scores as the dependent variable, and self-critical rumination as the potential mediator.

Dissemination

It is anticipated that the findings of this study will be disseminated as follows:

1. Submitted as part of the principal investigator's thesis for her Doctorate in Clinical Psychology (DClinPsy).
2. Submitted for publication in a peer-reviewed journal
3. Presented to trainee clinical psychologists, service users and course staff at the DClinPsy thesis presentation day at Lancaster University.
4. Summarised for presentation on the Parkinson's UK website.
5. Presented at a meeting of the North West Neuropsychology Special Interest Group, and/or at other conferences and seminars.

Practical issues

It is hoped that the option to complete the questionnaires either online or in hard-copy (paper) format will enable people to participate who may wish to contribute but be otherwise unable. Participants will also be allowed to have help to fill in the questionnaires by a relative, friend or caregiver.

Data will be submitted anonymously and stored securely on password protected software (Qualtrics). Data will be accessible only to Natalie Sowter and the supervisors named above (and the research coordinator and Research and/or Programme Director in the

DClinPsy team once the assignment is submitted). Once the project is complete, data will be sent to the research coordinator of the DClinPsy team for storage for 10 years on the Lancaster University secure Network or Box. Fiona Eccles will be the data custodian and will be responsible for overseeing the data being destroyed after 10 years.

The licences for the necessary statistical analysis software are available through Lancaster University.

Ethical concerns

Since participant recruitment will be carried out through Parkinson's UK, NHS ethical approval is not required and ethical approval is being sought via the FHMREC only. The research team at Parkinson's UK have confirmed that this is sufficient.

There is a slight possibility that participants may feel distressed as a result of completing the questionnaires. The details of organisations participants can contact for support in the event of distress will be provided as part of the debrief information. No risks to researchers have been identified.

As above, data will be submitted anonymously and stored securely on password protected software (Qualtrics). Data will be accessible only to Natalie Sowter and the supervisors named above (and the research coordinator and Research and/or Programme Director in the DClinPsy team once the assignment is submitted). Once the project is complete, data will be sent to the research coordinator of the DClinPsy team for storage for 10 years on the Lancaster University secure Network or Box. Fiona Eccles will be the data custodian and will be responsible for overseeing the data being destroyed after 10 years.

Timescale

September 2018: Submission of ethics application.

October-December 2018: Data collection.

January 2019: Data analysis.

December 2018-April 2019: Write-up.

May 2019: Submission of report as part of thesis.

Autumn/Winter 2019: Submission for publication; dissemination of findings by presentation (written and verbal).

References

- Antony, M. M., Bieling, P. J., Cox, B. J., Enns, M. W., & Swinson, R. P. (1998). Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological Assessment, 10*(2), 176. Doi: 10.1037/1040-3590.10.2.176
- Ashworth, F., Gracey, F., & Gilbert, P. (2011). Compassion focused therapy after traumatic brain injury: Theoretical foundations and a case illustration. *Brain Impairment, 12*(2), 128-139. Doi: 10.1375/brim.12.2.128
- Bramley, N., & Eatough, V. (2005). The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study. *Psychology & Health, 20*(2), 223-235. Doi: 10.1080/08870440412331296053
- Caap-Ahlgren, M., & Lannerheim, L. (2002). Older Swedish women's experiences of living with symptoms related to Parkinson's disease. *Journal of Advanced Nursing, 39*(1), 87-95. Doi: 10.1046/j.13652648.2002.02245.x
- Collins, R., Gilligan, L., & Poz, R. (2017). The Evaluation of a Compassion-Focused Therapy Group for Couples Experiencing a Dementia Diagnosis. *Clinical Gerontologist, 1*-13. Doi: 10.1080/07317115.2017.1397830
- Fritz, M., & MacKinnon, D. (2007). Required Sample Size to Detect the Mediated Effect. *Psychological Science, 18*(3), 233-239. Doi: 10.1111/j.1467-9280.2007.01882.x
- Hayes, A. F., & Rockwood, N. J. (2017). Regression-based statistical mediation and moderation analysis in clinical research: Observations, recommendations, and implementation. *Behaviour Research and Therapy, 98*, 39-57. Doi: 10.1016/j.brat.2016.11.001

- Hemmesch, A. R. (2014). The detrimental effects of atypical nonverbal behavior on older adults' first impressions of individuals with Parkinson's disease. *Psychology and Aging, 29*(3), 521–527. Doi: 10.1037/a0036637
- Hermanns, M. (2013). The invisible and visible stigmatization of Parkinson's disease. *Journal of the American Association of Nurse Practitioners, 25*(10), 563–566. Doi: 10.1111/1745-7599.12008
- Jette, A. M., Davies, A. R., Cleary, P. D., Calkins, D. R., Rubenstein, L. V., Fink, A., ... & Delbanco, T. L. (1986). The functional status questionnaire. *Journal of General Internal Medicine, 1*(3), 143-149. Doi: 10.1007/BF02602324
- Lovibond, S.H. & Lovibond, P.F. (1995). *Manual for the Depression Anxiety Stress Scales*. (2nd. Ed.) Sydney: Psychology Foundation.
- Moustafa, A. A., Chakravarthy, S., Phillips, J. R., Gupta, A., Keri, S., Polner, B., . . . Jahanshahi, M. (2016). Motor symptoms in Parkinson's disease: A unified framework. *Neuroscience and Biobehavioral Reviews, 68*, 727-740. Doi: 10.1016/j.neubiorev.2016.07.010
- Neff, K. D. (2003). The development and validation of a scale to measure self-compassion. *Self and Identity, 2*(3), 223–250. Doi:10.1080/15298860309027
- Neff K.D. & Dahm K.A. (2015). Self-Compassion: What It Is, What It Does, and How It Relates to Mindfulness. In: Ostafin B., Robinson M., Meier B. (eds) *Handbook of Mindfulness and Self-Regulation*. Springer, New York.
- Rao, D., Choi, S. W., Victorson, D., Bode, R., Peterman, A., Heinemann, A., & Cella, D. (2009). Measuring stigma across neurological conditions: The development of the stigma scale for chronic illness (SSCI). *Quality of Life Research, 18*(5), 585–595. Doi: 10.1007/s11136-009-9475-1

- Rose, A., & Rimes, K. (2018). Self-criticism self-report measures: Systematic review. *Psychology and Psychotherapy*, 18 January 2018 (E-pub ahead of print).
Doi:10.1111/papt.12171
- Schrag, A., Jahanshahi, M., & Quinn, N. P. (2001). What contributes to depression in Parkinson's disease? *Psychological Medicine*, 31(01), 65–73. Retrieved from:
<https://www.ncbi.nlm.nih.gov/pubmed/11200961>
- Shulman, L., Armstrong, M., Ellis, T., Gruber-Baldini, A., Horak, F., Nieuwboer, A., . . . Martinez-Martin, P. (2016). Disability rating scales in Parkinson's disease: Critique and recommendations. *Movement Disorders*, 31(10), 1455-1465. Doi: 10.1002/mds.26649
- Smart, L., Peters, J., & Baer, R. (2016). Development and Validation of a Measure of Self-Critical Rumination. *Assessment*, 23(3), 321-332. Doi: 10.1177/1073191115573300
- Stacy, M. (2011). Nonmotor symptoms of Parkinson's disease. *International Journal of Neuroscience*, 121(suppl2), 9-17. Doi: 10.3109/00207454.2011.620196
- Tickle-Degnen, L., Zebrowitz, L. A., & Ma, H. I. (2011). Culture, gender and health care stigma: Practitioners' response to facial masking experienced by people with Parkinson's disease. *Social Science and Medicine*, 73(1), 95–102. Doi: 10.1016/j.socscimed.2011.05.008
- Tysnes, O., & Storstein, A. (2017). Epidemiology of Parkinson's disease. *Journal of Neural Transmission*, 124(8), 901-905. Doi: 10.1007/s00702-017-1686-y
- Whatley, A. D., Dilorio, C. K., & Yeager, K. (2010). Examining the relationships of depressive symptoms, stigma, social support and regimen-specific support on quality of life in adult patients with epilepsy. *Health Education Research*, 25(4), 575–584.
Doi: 10.1093/her/cyq001

Wong, C., Mak, C., & Liao, Y. (2016). Self-Compassion: A Potential Buffer Against
Affiliate Stigma Experienced by Parents of Children with Autism Spectrum
Disorders. *Mindfulness*, 7(6), 1385-1395. Doi: 10.1007/s12671-016-0580-2

Appendix 4A

Note to Ethics Committee Regarding Online Survey

The online version contains the same materials and questionnaires as the paper version enclosed below. Any changes in wording are purely to facilitate online use.

Link to qualtrics survey:

https://lancasteruni.eu.qualtrics.com/jfe/form/SV_eKUy6NVbspAjRMV

Note: the eligibility and consent questions in the online version must be answered in order to proceed to the following pages. Any responses will not be stored.

Appendix 4B

Paper Version of Participant Materials

Begin overleaf

How are people with Parkinson's treated by others, how do they view themselves, and how is their psychological wellbeing affected?

Information for Participants

My name is Natalie Sowter and I am conducting this research as a student on the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

This study aims to find out about the relationships between four types of experiences for people with Parkinson's. The types of experiences we want to find out about are:

- signs of psychological distress (e.g. symptoms of anxiety, depression and stress),
- signs of disapproval from oneself and others (stigma),
- persistent critical thoughts about the self (self-critical rumination) and
- the ability to recognise one's own suffering and take steps to relieve it, using a kind and caring approach (self-compassion).

Previous research has suggested that people affected by Parkinson's may experience stigma, which can lead to an increase in psychological distress. The aim of this study is to investigate the relationship between stigma and psychological distress, by looking at other factors which might influence it. The other factors which we are considering are 'self-compassion' and 'self-critical rumination'. We hope to find out about the relationship between these two concepts for people with Parkinson's. We also hope to find out whether either (or both) of these concepts are important in explaining the relationship between stigma and psychological distress for people with Parkinson's. We hope that an understanding of how these experiences are connected may help professionals to support people with Parkinson's who are experiencing distress.

Who can take part in this study?

To participate in this study, you need to be aged 18 years or over. You also need to have a diagnosis of Parkinson's, and to have received this diagnosis at least 6 months ago.

Do I have to take part?

No. It's completely up to you to decide whether or not to take part.

What will I be asked to do if I take part?

If you decide that you would like to take part, you will be asked to complete a survey. The survey should take around 30 minutes to complete and need not be completed in one sitting. You can ask somebody to help you to complete the survey if you would like.

How do I take part?

You can take part by filling in the questionnaires in this pack and returning them in the stamped addressed envelope provided. Alternatively, you can complete the survey online by going to <https://www.parkinsons.org.uk/research/take-part-research>.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided below.

Will my data be identifiable?

The information you provide in the survey will remain anonymous, i.e. we will not be able to tell which information belongs to you. If you provide your name and address to receive a paper copy of the survey, this information will be destroyed once the survey has been posted to you. Your responses to the survey will be combined with other participants' data and stored in an electronic file space on the secure server provided by Lancaster University. Paper copies of the survey will be stored in a locked cabinet until they have been added to the electronic file space, after which time they will be destroyed. The electronic file space will be password protected such that it will only be accessible to the researchers for this study. Since this research will be submitted for assessment as part of the Doctorate in Clinical Psychology, the anonymised data may also need to be accessed by the course's admin staff and the Programme and/or Research Directors. The data will be held securely in its anonymised electronic form by Lancaster University for 10 years, after which time it will be destroyed. For further information about how Lancaster University processes personal data for research purposes, and your data rights, please visit our webpage: www.lancaster.ac.uk/research/data-protection.

What will happen to the results?

The results will be summarised and reported in a thesis and may also be submitted for publication in an academic journal and presented at seminars and conferences. The summarised results will also be made available on the Parkinson's UK website.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher Natalie Sowter (Trainee Clinical Psychologist) by email at n.sowter@lancaster.ac.uk or by telephone on (07508 375 665). You can also contact my research supervisor, Fiona Eccles (Lecturer in Health Research) by email at f.eccles@lancaster.ac.uk or by telephone on 01524 592 807.

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Bill Sellwood, Research Director for Doctorate in Clinical Psychology Programme

Tel: 01524 593998

Email: b.sellwood@lancaster.ac.uk

Division of Health Research, Faculty of Health and Medicine Lancaster University,
Lancaster, LA1 4YG

If you wish to speak to someone outside of the Doctorate in Clinical Psychology Programme, you may also contact:

Professor Roger Pickup, Associate Dean for Research

Tel: 01524 593746

Email: r.pickup@lancaster.ac.uk

Division of Biomedical and Life Sciences, Faculty of Health and Medicine Lancaster University, Lancaster, LA1 4YG

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Parkinson's UK

Website: www.parkinsons.org.uk

Helpline: 0808 800 0303

Samaritans

Website: <https://www.samaritans.org/>

Helpline: 116 123

If you would like to take part in this study, please continue by answering the questions below.

Please note that if you answer "Yes" to the questions below, and you return these questionnaires, then you will not be able to withdraw your data. This is because your responses will be stored anonymously and therefore we will not know which data belong to you.

Are you aged 18 years or over?

☐ Yes

☐ No

Have you been given a diagnosis of Parkinson's?

☐ Yes, over 6 months ago

☐ Yes, less than 6 months ago

☐ No

Have you read and understood the Information for Participants?

☐ Yes

☐ No

Do you give consent for your responses to this survey to be used for the trainee clinical psychologist's research study, as described in the Information for Participants?

☐ Yes

☐ No

The following questions are to help us to understand more about the people who take this survey, and to see whether the data we get is representative of people with Parkinson's across the UK. We will not be able to identify you from this information.

How many years ago were you diagnosed with Parkinson's?
(If unsure, please make your best guess)

- ☐ I was diagnosed _____ years ago
- ☐ I'd prefer not to say

How are your Parkinson's symptoms currently being treated?
Please select all that apply:

- ☐ Medication prescribed by GP / neurologist / other healthcare professional
- ☐ Deep Brain Stimulation surgery
- ☐ Apomorphine pump
- ☐ Other (please describe) _____
- ☐ No current treatment
- ☐ I'd prefer not to say

What is your age?

- ☐ I'd prefer not to say
- ☐ I am _____ years old

Where do you currently live?

- ☐ England
- ☐ Northern Ireland
- ☐ Scotland
- ☐ Wales

☐ European country outside of the UK (please specify)

☐ Country outside of Europe (please specify)

☐ I'd prefer not to say

Please select the option which best describes your ethnic group or background.

☐ Arab

Asian / Asian British:

☐ Bangladeshi

☐ Chinese

☐ Indian

☐ Pakistani

☐ Any other Asian background, please describe _____

Black / Black British

☐ African

(continues overleaf)

☐ Caribbean

☐ Any other Black background, please describe _____

Mixed / Multiple ethnic background

☐ White and Asian

☐ White and Black African

☐ White and Black Caribbean

☐ Any other Mixed / Multiple ethnic background, please describe

White

☐ British (English / Northern Irish / Scottish / Welsh)

☐ Irish

☐ Traveller

☐ Any other White background, please describe _____

Other

☐ Any other ethnic background, please describe _____

☐ I'd prefer not to say

Which option best describes your current living situation?

- ☐ In my own home, by myself
- ☐ In my own home, with my spouse/ partner/ family/ friends/ others
- ☐ In my own home, with a live-in carer
- ☐ In supported accomodation
- ☐ In a nursing home
- ☐ Long-term hospital stay
- ☐ Other (please describe) _____
- ☐ I'd prefer not to say

What is your gender identity? Please select all that apply:

- ☐ Female
- ☐ Male
- ☐ Non-binary
- ☐ Gender non-conforming
- ☐ I'd prefer to self describe _____
- ☐ I'd prefer not to say

Which option best describes your current partnership status?

- ☐ I have a spouse or partner, whom I live with
- ☐ I have a spouse or partner, whom I do not live with
- ☐ I do not have a spouse or partner
- ☐ I am widowed
- ☐ Other (please describe) _____
- ☐ I'd prefer not to say

Which option best describes your current employment status?

- ☐ In full-time education
- ☐ In part-time education
- ☐ Employed (full-time)
- ☐ Employed (part-time)
- ☐ Self-employed
- ☐ Unemployed
- ☐ Retired
- ☐ Unable to work
- ☐ Other (please describe) _____
- ☐ I'd prefer not to say

The following questions ask about how Parkinson's affects you physically. This will help us to understand more about the people who take this survey.

During the past month have you had difficulty:

	Usually did with no difficulty	Some difficulty	Much difficulty	Usually did not do because of health	Usually did not do for other reasons
Taking care of yourself, that is, eating, dressing or bathing?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moving in and out of a bed or chair?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking indoors, such as around your home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking several blocks?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking one block or climbing one flight of stairs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing work around the house such as cleaning, light yard work, home maintenance?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing errands, such as grocery shopping?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Driving a car or using public transportation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing vigorous activities such as running, lifting heavy objects or participating in strenuous sports?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

A number of experiences are described on the following pages. Please indicate how frequently you have had each experience lately, in relation to your Parkinson's.

	Never	Rarely	Sometimes	Often	Always
Because of my illness, I felt emotionally distant from other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I felt left out of things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I felt embarrassed in social situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I worried about other people's attitudes towards me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was unhappy about how my illness affected my appearance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, it was hard for me to stay neat and clean	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I worried that I was a burden to others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt embarrassed about my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt embarrassed because of my physical limitations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt embarrassed about my speech	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I felt different from others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tended to blame myself for my problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Rarely	Sometimes	Often	Always
I avoided making new friends to avoid telling others about my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, some people seemed uncomfortable with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, some people avoided me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, people were unkind to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, people made fun of me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, people avoided looking at me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, strangers tended to stare at me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I was treated unfairly by others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, people tended to ignore my good points	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some people acted as though it was my fault I have this illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with my illness lost their jobs when their employers found out about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Rarely	Sometimes	Often	Always
I lost friends by telling them that I have this illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement on the following pages carefully before answering. For each item, indicate how often you behave in the stated manner, using the following scale:

- 1 = Almost never
- 2
- 3
- 4
- 5 = Almost always

	1 (almost never)	2	3	4	5 (almost always)
1. I'm disapproving and judgmental about my own flaws and inadequacies.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. When I'm feeling down I tend to obsess and fixate on everything that's wrong.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. When things are going badly for me, I see the difficulties as part of life that everyone goes through	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I try to be loving towards myself when I'm feeling emotional pain.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. When I fail at something important to me I become consumed by feelings of inadequacy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. When times are really difficult, I tend to be tough on myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. When something upsets me I try to keep my emotions in balance.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I'm intolerant and impatient towards those aspects of my personality I don't like.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. When I'm going through a very hard time, I give myself the caring and tenderness I need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	1 (almost never)	2	3	4	5 (almost always)
13. When I'm feeling down, I tend to feel like most other people are probably happier than I am.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. When something painful happens I try to take a balanced view of the situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. I try to see my failings as part of the human condition.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. When I see aspects of myself that I don't like, I get down on myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. When I fail at something important to me I try to keep things in perspective.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. When I'm really struggling, I tend to feel like other people must be having an easier time of it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. I'm kind to myself when I'm experiencing suffering.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. When something upsets me I get carried away with my feelings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. When I'm feeling down I try to approach my feelings with curiosity and openness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. I'm tolerant of my own flaws and inadequacies.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. When something painful happens I tend to blow the incident out of proportion.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. When I fail at something that's important to me, I tend to feel alone in my failure.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. I try to be understanding and patient towards those aspects of my personality I don't like.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rate how well each item describes you.

	Not at all	A little	Moderately	Very well
1. My attention is often focused on aspects of myself that I'm ashamed of.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I always seem to be rehashing in my mind stupid things that I've said or done.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Sometimes it is hard for me to shut off critical thoughts about myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I can't stop thinking about how I should have acted differently in certain situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I spend a lot of time thinking about how ashamed I am of some of my personal habits.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I criticise myself a lot for how I act around other people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I wish I spent less time criticising myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I often worry about all of the mistakes I have made.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I spend a lot of time wishing I were different.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I often berate myself for not being as productive as I should be.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please read each statement on the following pages and select a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0 Did not apply to me at all**
- 1 Applied to me to some degree, or some of the time**
- 2 Applied to me to a considerable degree, or a good part of time**
- 3 Applied to me very much, or most of the time**

	0 (did not apply to me at all)	1 (applied to me to some degree, or some of the time)	2 (applied to me a considerable degree, or a good part of the time)	3 (applied to me very much, or most of the time)
I found it hard to wind down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of dryness of my mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I couldn't seem to experience any positive feeling at all	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to work up the initiative to do things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tended to over-react to situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced trembling (e.g. in the hands)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was using a lot of nervous energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried about situations in which I might panic and make a fool of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I had nothing to look forward to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found myself getting agitated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to relax	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt down-hearted and blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was intolerant of anything that kept me from getting on with what I was doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0 (did not apply to me at all)	1 (applied to me to some degree, or some of the time)	2 (applied to me a considerable degree, or a good part of the time)	3 (applied to me very much, or most of the time)
I felt I was close to panic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was unable to become enthusiastic about anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I wasn't worth much as a person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was rather touchy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt scared without any good reason	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that life was meaningless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Debrief

Thank you for taking the time to complete this survey.

This paragraph provides some background information to explain why we are doing this study. Previous research suggests that people affected by Parkinson's experience stigma (signs of disapproval) from others, which can lead to an increase in psychological distress (symptoms of anxiety, depression and stress). The aim of this study is to investigate this relationship between stigma and psychological distress, by looking at other factors which might influence it. The other factors which we are considering are self-compassion (the ability to recognise one's own suffering and take steps to relieve it, using a kind and caring approach) and self-critical rumination (persistent critical thoughts about the self). These two concepts have been found to be related to one another: people who demonstrate more self-compassion tend to engage less in self-critical rumination. We hope to find out whether this same relationship exists for people with Parkinson's. We also hope to find out whether either (or both) of these concepts are important in explaining the relationship between stigma and psychological distress (as found in previous studies), for people with Parkinson's. We hope that an understanding of how these experiences are connected may help professionals to support people with Parkinson's who are experiencing distress. Once this research study is complete, the findings will be made available via the Parkinson's UK website. The results will also be summarised and reported in a thesis and may be submitted for publication in an academic journal and presented at seminars and conferences.

Your responses to this survey will be combined with other participants' data and stored in an electronic file space on the secure server provided by Lancaster University. The file space will be password protected such that it will only be accessible to the researchers for this study. Since this research will be submitted for assessment as part of the Doctorate in Clinical Psychology, the anonymised data may also need to be accessed by the course's admin staff and the Programme and/or Research Directors. The data will be held securely in its anonymised electronic form by Lancaster University for 10 years, after which time it will be destroyed. For further information about how Lancaster University processes personal data for research purposes, and your data rights, please visit our webpage: www.lancaster.ac.uk/research/data-protection.

Should you feel distressed either as a result of taking part in this study, or in the future, you may find the following resources helpful:

- Parkinson's UK
Website: www.parkinsons.org.uk
Helpline: 0808 800 0303
- Samaritans
Website: <https://www.samaritans.org/>
Helpline: 116 123

If you have any questions about your participation in this study, please contact me (Natalie Sowter) by email at n.sowter@lancaster.ac.uk or by telephone on 07508 375 665. You can

also contact my research supervisor, Fiona Eccles (Lecturer in Health Research) by email at f.eccles@lancaster.ac.uk or by telephone on 01524 592807.

Thank you for your time.

Appendix 4C

Ethics Amendment Request Form



Faculty of Health and Medicine Research Ethics Committee (FHMREC) Lancaster University Application for Amendment to Previously Approved Research

1. Name of applicant:

Natalie Sowter

2. E-mail address and phone number of applicant:

n.sowter@lancaster.ac.uk, 07817757231

3. Title of project:

Stigma, self-compassion, self-critical rumination and psychological distress amongst people with Parkinson's

4. FHMREC project reference number:

FHMREC18002

5. Date of original project approval as indicated on the official approval letter

15/10/2018

(month/year):

6. Please outline the requested amendment(s)

Note that where the amendment relates to a change of researcher, and the new researcher is a student, a full application must be made to

We would like to expand the recruitment strategy by putting a link to the survey on social media (Twitter), through the lead researcher's professional account. We would also like to approach other charities for people with Parkinson's (including, but not limited to, Parkinson's Association of Ireland, Parkinson's Australia, and Parkinson's New Zealand), to ask them to advertise the study through their websites.

FHMREC

7. Please explain your reason(s) for requesting the above amendment(s):

The current recruitment strategy has been slower than expected. More participants are required in order to ensure adequate statistical power for the study.

Guidance:

- a) Resubmit your research ethics documents (**the entire version which received final approval, including all participant materials, your application form and research protocol**), with all additions highlighted in yellow, and any deletions simply 'struck through', so that it is possible to see what was there previously.
- b) This should be submitted as **a single PDF** to [Becky Case](#) There is no need to resubmit the Governance Checklist

Applicant electronic signature:

Date

Natalie Sowter

24/01/2019

Student applicants: please tick to confirm that you have discussed this amendment application with your supervisor, and that they are happy for the application to proceed to ethical review ☒

Project Supervisor name (if applicable):

Date application discussed

Dr Fiona Eccles

24/01/2019

You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application

July 2016

Appendix 4D

Letter of Ethical Approval



Applicant: Natalie Sowter
Supervisor: Fiona Eccles
Department: Health Research
FHMREC Reference: FHMREC18052

28 January 2019

Dear Natalie

Re: Stigma, self-compassion, self-critical rumination and psychological distress amongst people with Parkinson's

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

R.E. Case

Becky Case
Research Ethics Officer, Secretary to FHMREC.