An exploration of psychological wellbeing support for individuals with Parkinson's disease

Jessica Whyte (BSc Hons)

Submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology

Institute of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

September 2021

Table of Contents

List of Tables

List of Figures

Acknowledgements

I would like to begin by thanking the participants who gave their time to the project. It was a privilege to hear your insights and reflections.

I would also like to thank my academic supervisor, Dr Breda Cullen, for her unwavering support and guidance throughout the project. Breda, I can't thank you enough.

Thank you to my field supervisor, Dr Susan O'Connell, for your help, positivity and encouragement. I would also like to express my gratitude to Dr Luke Williams for being our point of contact in the service, and Paula Hewat for taking the time to single-handedly carry out the project recruitment.

Thank you to my research advisor, Dr Naomi White, for sharing her insights into qualitative methodology, and Paul Cannon for his patience and generosity in looking over multiple iterations of my systematic review searches.

I am grateful to my fellow trainee Thomas Campbell for his assistance with the systematic review and his mutual support in our Zoom research meetings. I would also like to thank Rachel for kindly offering to proof-read, and Lauren and Fiona for all the study days, takeaway coffees, walks and chats that kept me going through thesis writing in a pandemic.

I would also like to express my gratitude to study authors Dr Anousha Hadinia, Dr Eun-Ok Choi, Dr Sarah Egan, Dr Jenny Advocat, Dr Kenneth Murdoch, Professor Derick Wade, Dr Cindy Canivet and Dr Roseanne Dobkin for kindly providing additional information for the systematic review via email.

Thank you to my placement team in Ayrshire & Arran Medical Paediatric Psychology and to my clinical supervisor, Dr Kim Campbell, for your encouragement and understanding.

I am forever grateful to my friends for being an endless source of reassurance and motivation. And to my family I would like to say thank you for always supporting me on this career path, and to my mum for proof-reading every single thing I've ever written.

Foreword

The major research project (Chapter 2) has been subject to several changes due to the COVID-19 pandemic. The original proposal stated that data collection would be carried out through in-person focus groups. Due to the pandemic this was not feasible and so the method of data collection was changed to one-to-one interviews using phone or video call, as detailed in the revised proposal (Appendix 2.1, p.101). Due to this change in the study design, the process of applying for ethical approval was started later than originally planned. Consequently, ethical approval was only granted on 18th January 2021. R&D approval was then sought. However, extra measures were in place due to the pandemic and R&D approval was received on 25th January. As a result of these delays, recruitment for the project did not begin until February 2021. Due to the pandemic, one of the Clinical Nurse Specialists who was due to assist with recruitment was not able to help with this, leaving just one Clinical Nurse Specialist to carry out recruitment. Following delays with these approvals and recruitment, data collection did not begin until March 2021. Consequently, it was not possible to carry out some aspects of the project that had been specified in the revised proposal; member reflections were carried out with two participants rather than all participants who had consented to this, and one indexed interview transcript was checked by one supervisor rather than both supervisors.

Chapter 1

Psychosocial group interventions for wellbeing in Parkinson's disease: A systematic review

Jessica Whyte*, BSc (Hons)

University of Glasgow, NHS Ayrshire & Arran

*Correspondence address:

Mental Health and Wellbeing

University of Glasgow

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow

G12 0XH

Prepared in accordance with the author requirements for the Journal of Geriatric Psychiatry and Neurology; Appendix 1.1, p.92.

Abstract

Group psychosocial interventions may provide benefits compared to individual therapy such as increased social support for patients and reduced treatment costs for healthcare services. However, no systematic review has been published to date focusing solely on psychosocial group interventions for wellbeing in Parkinson's disease (PD). This review therefore aimed to synthesise and evaluate this literature. Medline, Embase, PsycINFO and CENTRAL databases were searched up to May 2021 for randomised controlled trials of group psychosocial interventions for people with PD with outcome measures related to wellbeing. Twelve studies were included in the narrative synthesis. All studies were found to be at high risk of bias using the RoB2 tool. Group mindfulness-based interventions and group cognitive behavioural therapy (CBT) were found to improve multiple wellbeing measures for people with PD, with effect sizes ranging from small to large for mindfulness and medium to large for CBT. Improvements in quality of life were reported for group psychoeducation and a group acceptance and commitment therapy-based intervention. Group counselling and a group behavioural intervention were not found to be effective. Findings differed across studies, indicating that replication is required before conclusions can be drawn regarding effectiveness and safety of group interventions for PD.

Keywords: Group Psychosocial Interventions, Wellbeing, Parkinson's Disease.

Introduction

Parkinson's disease (PD) is a progressive neurodegenerative condition with both motor and non-motor symptoms. Motor symptoms include rigidity, resting tremor and bradykinesia, while non-motor symptoms include anxiety, depression, sleep problems and cognitive impairments (Prediger et al., 2012).

Estimates of non-motor symptoms in PD are high. One study from Yamanishi et al. (2013) identified point prevalence rates of 55% for anxiety and 56% for depression, with 41% of patients with PD in their study presenting with both anxiety and depression. PD has also been associated with a lowering of health-related quality of life (Karlsen et al., 2000), and depression and sleep-related problems have been shown to increase levels of distress in this population (Karlsen et al., 1999). Non-motor symptoms of PD do not always respond to dopaminergic medication (Chaudhuri et al., 2006), and so other forms of treatment are required.

Some previous reviews have found psychosocial interventions, such as Cognitive Behavioural Therapy (CBT), to be effective in treating anxiety and depression in patients with PD (Yang et al., 2012; Zhang et al., 2020). Psychosocial interventions such as CBT and mindfulness are also recommended in evidence-based guidelines for the treatment of anxiety, depression and stress in people with PD (The British Psychological Society, 2021). Other reviews have concluded that while therapies such as CBT are likely to be efficacious in treating depression in people with PD, there are limitations in the existing evidence base such as poor methodological rigour and lack of replication of results (Pontone & Mills, 2021; Seppi et al., 2019; Xie et al., 2015). Additionally, a scoping review from Zarotti et al. (2020) concluded that existing evidence supports the use of CBT to treat depression and sleep problems for people with PD but there is still a lack of research and mixed evidence

regarding CBT and mindfulness-based interventions for improving anxiety and quality of life in this population. A similar conclusion regarding psychosocial interventions for anxiety was reached in a comprehensive review from Chandler et al. (2019).

In non-neurological populations, group interventions have been found to be effective in treating conditions such as depression (Moore et al., 2017). Additionally, it has been argued that group interventions are more cost effective than individual treatments (Brown et al., 2011). Group formats may also provide other benefits to participants (van der Heijden et al., 2017), such as a feeling of social cohesion that has been reported in some group interventions for PD (Fitzpatrick et al., 2010).

While some existing meta-analyses such as Zhang et al. (2020) and scoping reviews such as Zarotti et al. (2020) included a small number of group intervention studies, no systematic review has been published to date focusing solely on psychosocial group interventions for a PD population. This review therefore aimed to synthesise and evaluate the existing literature on psychosocial group interventions aimed at improving wellbeing for people with PD. Van der Heijden et al. (2017) report high psychological wellbeing as a state of "feeling happy, capable, well-supported, and satisfied with life".

Cognitive rehabilitation studies were not included in this review as these studies target cognitive processes, and resulting improvements in cognition may then have an indirect impact on wellbeing. The mechanisms of change in cognitive rehabilitation studies may therefore differ to studies which aim to improve wellbeing directly through psychosocial intervention.

Objective

This review aimed to answer the following research question: what is the effectiveness of group interventions for people with PD aimed at improving psychosocial outcomes related to wellbeing?

Methods

Protocol and Registration

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Page et al., 2021) guidelines were followed when writing this report. The protocol for this review was registered on Open Science Framework (OSF), DOI: https://osf.io/3dukz

Types of Studies

Randomised controlled trials (RCTs) were included in the review with any type of control condition such as no intervention, waitlist and active controls. All other study designs were excluded. Reports were required to be available in English language.

Population

People aged 18 or over with a diagnosis of PD. Samples with comorbid dementia were not included. Studies with mixed samples which included some participants with PD were eligible for inclusion only where results were reported separately for PD participants.

Interventions

Any psychosocial group intervention using any therapeutic or psychoeducational model. Group interventions were defined as interventions conducted in groups of three or more attendees who are not related. If mixed interventions were used (e.g. combined psychoeducation and exercise interventions), at least 50% of the intervention must be psychosocial in nature and delivered in a group format. Pharmacological and brain stimulation intervention studies were not eligible, nor were studies with mixed pharmacological/brain stimulation and psychosocial interventions. Participants in treatment or control conditions of eligible studies could have been on pharmacological treatment as part of usual care, however (e.g. antidepressant medication prescribed outside the study).

As outlined in the introduction, it was decided in advance that treatments dominated by a cognitive rehabilitation or cognitive training model were not within the scope of this review.

Outcomes

Studies must have had a psychosocial outcome related to wellbeing as either the primary or secondary outcome. Appropriate psychosocial outcomes included quality of life, mood, distress, depression, anxiety, stress, wellbeing, life satisfaction, apathy, coping, adjustment and happiness. Studies in which only motor symptoms or a cognitive outcome were measured were not eligible for inclusion. To be eligible for inclusion outcome measures must use a published instrument pre and post intervention. The principal summary effect measure was the between-group difference in mean change scores pre to post intervention.

Searches

Searches were conducted from database inception up to 25.05.21 using the search strategies detailed in Appendix 1.2, p.95. RCT filters were used to refine searches in Ovid Medline and Embase (Wolters Kluwer Health Learning Research & Practice, 2021) and the search terms used to identify relevant psychosocial interventions were developed based on those used in van der Heijden et al. (2017). The final search strategy was reviewed by author BC and a librarian from the University of Glasgow. The following electronic databases were searched: Medline (via Ovid), Embase (via Ovid), PsycINFO (via EBSCOhost) and the CENTRAL database (via the Cochrane Library). Sensitivity checks were completed using previously identified relevant studies. Hand searches were then conducted of reference lists of eligible papers.

Screening

Duplicates were removed using EndNote software. The titles and abstracts of remaining search results were screened by author JW using an eligibility checklist developed for this review (see OSF registration for details). If papers appeared to meet eligibility criteria or where this was unclear, the full text was screened to determine eligibility for inclusion. Author TC independently screened 100 search results at the title and abstract stage and 20 papers at the full text stage. Any discrepancies between author decisions were resolved through discussion, involving author BC where necessary.

Data Extraction and Synthesis

Data were extracted from included studies by author JW using a modified version of the Cochrane data extraction template. Authors were contacted by email where there was insufficient information to make a decision regarding eligibility. Data extracted included: participant characteristics, inclusion and exclusion criteria, recruitment, randomisation procedure, drop-out, intervention type and format, control group, outcome measures, statistical methods and results for relevant outcomes. Five data extraction forms were checked for accuracy by author TC. Data were synthesised by intervention type using a narrative synthesis method with results summarised in text and tables.

Quality Ratings

The Cochrane risk of bias tool for randomized trials (RoB2; Sterne et al., 2019) was used to rate the methodological quality of included studies. Where relevant, published protocols and trial registry records were sought to supplement information in the published articles when conducting the ratings. Risk of bias ratings were completed for the primary psychosocial outcome of each paper. Where the primary outcome was not specified or where there were multiple primary psychosocial outcomes, measures of depression were used for the ratings (as depression and quality of life were the most common outcomes across included studies). All included studies were rated by author JW and five papers were also rated independently by author TC. Any discrepancies between author ratings were resolved through discussion, involving author BC where necessary.

Results

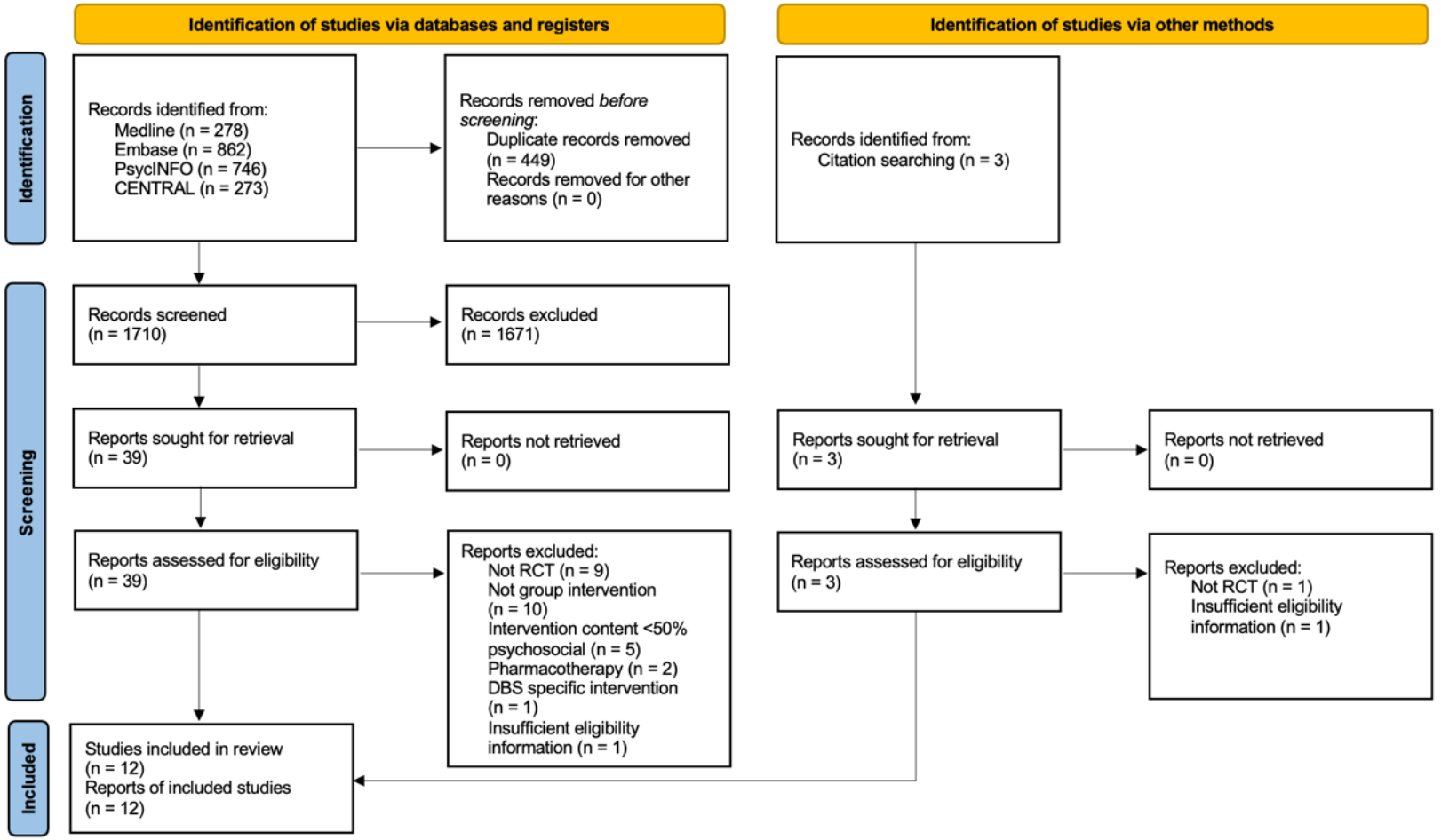
Results of the Search

A total of 2,159 studies were identified through database searches. Following removal of duplicates, 1,710 studies remained. Three further studies were identified through hand searches of reference lists. Title and abstract screening resulted in 1,671 studies being excluded. Following full text screening of the remaining 42 papers, 12 were included in the review. A PRISMA flow diagram detailing the screening process can be seen in Figure 1. The authors agreed on 98% of decisions at the title and abstract stage (Cohen's k=0.79) and 95% at the full text stage (Cohen's k=0.83).

Two studies which were considered for inclusion (Pickut et al., 2015; Sproesser et al., 2010) were excluded as authors were contacted regarding group size and no response was received. One study by Flores Alves Dos Santos et al. (2017) was considered for inclusion however it was decided that this paper was too conceptually different from other studies included in the review as it involved a psychoeducation intervention specifically designed for patients undergoing deep brain stimulation.

Figure 1

PRISMA flow diagram (Page et al., 2021)



Study Characteristics

Characteristics of included studies are detailed in Table 1. None of the included studies appeared to have overlapping samples. Only four studies used active control conditions, while eight studies included wait-list or usual care control conditions. Active control conditions comprised education sessions (Ayromlou et al., 2020; Hadinia et al., 2017), group physical therapy (Ghielen et al., 2017) and a "nonspecific" psychological intervention which involved education, group discussion, breathing exercises, brief relaxation imagery practices and physical exercises (Mohr et al., 1996). One paper (Troeung et al., 2014) included both a randomised and non-randomised sample. For the purposes of this review, only results for the randomised sample are included.

Six studies did not include a follow-up period. One included a 6-week follow-up (Murdoch et al., 2020), three included a 3-month follow-up (Bogosian et al., 2021; Chlond et al., 2016; Ghielen et al., 2017), and two a 6-month follow-up (Advocat et al., 2016; Troeung et al., 2014). Separate follow-up data for control conditions was only available in Chlond et al. (2016) and Ghielen et al. (2017) as wait-list groups had received interventions prior to follow-up measurements in all other studies.

The most common wellbeing outcomes were quality of life, depression, anxiety and stress. Each of these outcomes is summarised below. A small number of other relevant outcomes were identified but are not reported here due to space constraints.

Table 1

Characteristics of Included Studies

Study	Intervention & control	Number & duration of sessions	N	Group size	Relevant outcome measures	Gender	Age (Mean (SD) unless otherwise noted)	Inclusion criteria	Exclusion criteria
A'Campo et al. (2010)	I: group Patient Education Program Parkinson (PEPP) C: usual care	I: 8 weekly 90-min sessions over 8 weeks C: N/A	I: 35 C: 29	I: 5-7 C: N/A	Hr-QoL: PDQ-39 Depression: SDS	I: 20 male, 15 female C: 15 male, 14 female	I: 65.54 (8.94) C: 64.24 (9.13)	Idiopathic PD diagnosis.	Severe psychiatric problems (psychotic symptoms or personality disorders).
Advocat et al. (2016)	I: group mindfulness-based lifestyle program C: wait-list	I: 6 weekly 2-hr sessions over 6 weeks C: N/A	I: 35 C: 37	20-30	Hr-QoL: PDQ-39 Depression: DASS-D Anxiety: DASS-A Stress: DASS-S	I: 16 female C: 17 female	I: 62.8 (7.6) C: 63.7 (8.6)	Aged 18-75, fluent in English, able to attend ≥4 sessions, living in the community, disability congruent H&Y stage 2 PD.	-
Ayromlou et al. (2020)	I: group mindfulness-based stress reduction (MBSR) C: education sessions	I: 8 weekly 2-hr sessions over 8 weeks, plus one 7-hr retreat day C: 8 1-hr sessions over 8 weeks	I: 20 C: 20	I: 4-5 C: not reported	QoL: PDQ-39	I: 14 male, 6 female C: 13 male, 7 female	I: 67.3 (6.39) C: 68.60 (7.32)	PD diagnosis, H&Y stage 1-3, stabilised on PD medication for 6 months, MMSE score 17-30, commitment to participate in sessions and home practices.	Focal neurologic deficit, brain imaging suggestive of lesions, medical conditions that would impact quality of life, antiepileptic drugs, psychosis symptoms.
Bogosian et al. (2021)	I: online group mindfulness-based intervention C: wait-list	I: 8 1-hr weekly sessions over 8 weeks C: N/A	I: 30 C: 30	I: 5 C: N/A	Depression: HADS Anxiety: HADS	I: 13 female C: 17 female	I: 59.50 (11.12) C: 62.23 (8.96)	PD diagnosis, home computer & internet access, fluent in English, stabilised on PD medication, antidepressants or anxiolytics (if taken) for minimum 1 month.	Self-reported severe cognitive impairment, TICS-M score <20, severe psychiatric condition, severe hearing impairment, participation in other psychological therapies, prior formal training in mindfulness or current meditation practice.

Study	Intervention & control	Number & duration of sessions	N	Group size	Relevant outcome measures	Gender	Age (Mean (SD) unless otherwise noted)	Inclusion criteria	Exclusion criteria
Chlond et al. (2016)	I: group Patient Education Programme Parkinson (PEPP) C: usual care	I: 8 90-min weekly sessions for 8 weeks C: N/A	I: 38 C: 29	I: 4-8 C: N/A	Hr-QoL: PDQ-39 & EQ-5D Coping behaviour: FKV-LIS-SE Depression: HADS Anxiety: HADS	I: 22 male, 16 female C: 19 male, 10 female	I: 63.2 (10.6) C: 66.2 (10.3)	Idiopathic PD diagnosis.	MMSE score ≤24, clinically relevant psychosis or depression.
Ghielen et al. (2017)	I: group body awareness training (BEWARE) based on Acceptance and Commitment Therapy C: group physical therapy	I: 12 1-hr twice weekly sessions for 6 weeks C: 12 1-hr twice weekly sessions for 6 weeks	I: 19 C: 19	I: 4-6 C: 4-6	Anxiety: BAI Depression: BDI QoL: PDQ-39	I: 35% female C: 45% female	I: 59.6 (9.7) C: 66.6 (8.4)	Idiopathic PD diagnosis, one or more wearing-off symptoms, BAI score ≥26.	MMSE score <24, insufficient motivation for participation, neurological, orthopaedic or cardiopulmonary problems that could interfere with participation.
Hadinia et al. (2017)	I: group Cognitive Behaviour Therapy (CBT) C: group Health Enhancement Program (HEP)	I: 9 2-hr weekly sessions for 9 weeks C: 9 2-hr weekly sessions for 9 weeks	I: 16 C: 14	Not reported[a]	QoL: PDQ-39 Stress: BELA & FKK	I: 4 female C: 3 female	I: 65 (8.7) C: 67 (11)	PD diagnosis.	Severe dementia, physical impairment, severe neurologic or psychiatric deficit.
Mohr et al. (1996)	I: group behavioural treatment C: “nonspecific” psychological treatment	I: 20 sessions for 10 weeks C: 10 weeks	I: 20 C: 21	I: 3-4 C: 5-7	Depression: BDI Contentment: Contentment of life questionnaire Mood: UPDRS Mentation, Behavior, and Mood subtest	I: 5 female C: 9 female	I: 63.6 (7.27) C: 60.4 (6.65)	Idiopathic PD diagnosis, willingness to participate in sessions.	DSM-III-R diagnosis of major depression, dementia or other psychiatric disorder, history of alcohol abuse or other significant physical illness.
Murdoch et al. (2020)	I: group Strength, Hope and Resourcefulness	I: 6 weekly 2-hr sessions for 6 weeks	I: 15 C: 16	Not reported[a]	Hr-QoL: PDQ8 Depression: PHQ9	I: 7 male, 8 female	I: 65.53 (9.11) C: 67.37 (9.8)	PD diagnosed within last 5 years, capacity to provide consent.	Psychotic symptoms, unable to speak English,

Study	Intervention & control	Number & duration of sessions	N	Group size	Relevant outcome measures	Gender	Age (Mean (SD) unless otherwise noted)	Inclusion criteria	Exclusion criteria
	Program for people with PD (SHARP-PWP) C: wait-list	C: N/A			Anxiety: BAI Wellbeing: MHC-SF	C: 6 male, 10 female			dementia or cognitive impairment.
Rodgers et al. (2019)	I: group mindfulness-based cognitive therapy (MBCT) C: wait-list	I: 6 2-hr sessions over 8 weeks C: N/A	I: 17 C: 14	Not reported[a]	Depression: GDS-15 & DASS-D Anxiety: GAI & DASS-A Stress: DASS-S Hr-QoL: PDQ-39	I: 67% male C: 58% female	Whole sample: 63.70 (8.76)	Idiopathic PD diagnosis, age 18-90, provided written consent, able to access transport to attend treatment.	Receiving psychotherapy, MMSE score <24, active suicidality.
Son & Choi (2018)	I: group Mindfulness Meditation-based Complex Exercise Program (MMBCEP) C: wait-list	I: 8 weekly 2-hr sessions over 8 weeks C: N/A	I: 33 C: 30	Not reported[a]	Depression: GDS Anxiety: STAI QoL: PDQL	I: 14 male, 19 female C: 9 male, 21 female	I: <60 = 6, 60-69 = 17, ≥70 = 14 C: <60 = 3, 60-69 = 21, ≥70 = 6	H&Y stage 1-3, regular outpatient hospital visits, doctor recommended able to communicate and walk independently, clinically stable.	Received alternative therapies e.g., aromatherapy, acupuncture, laughter therapy, or foot reflexology.
Troeung et al. (2014)	I: group CBT C: wait-list	I: 8 2-hr sessions over 8 weeks C: N/A	Randomised sample[b]: I: 7 C: 7	I: 6-8 C: N/A	Depression: DASS-D Anxiety: DASS-A Stress: DASS-S QoL: PDQ-39	Not reported for subsample extracted for this review	Not reported for subsample extracted for this review	≥6 months since PD diagnosis, DSM-IV-TR diagnosis of at least one depressive and/or anxiety disorder, medications stabilised for 3 months.	TICS score <18, concurrent psychological treatment, current psychotic disorder assessed by MINI, MINI suicidality score >17.

Note. Abbreviations: I: Intervention; C: Control; HrQoL: Health-related Quality of Life; QoL: Quality of Life; SD: Standard Deviation. Measures: BAI: Beck Anxiety Inventory; BDI: Beck Depression Inventory; BELA: Belastungsfragebogen für Parkinsonpatienten (Burden Questionnaire for Patients with Parkinson's disease); DASS-A: Depression Anxiety and Stress Scale-Anxiety; DASS-D: Depression Anxiety and Stress Scale-Depression; DASS-S: Depression Anxiety and Stress Scale-Stress; EQ-5D: Euroqol-5D; FKK: Fragebogen zur krankheitsbezogenen Kommunikation (Questionnaire for Disease-Related Communication); FKV-LIS-SE: Freiburg Coping with Disease Questionnaire; GAI: Geriatric Anxiety Inventory; GDS: Geriatric Depression Scale; GDS-15: Geriatric Depression Scale-Short Form; HADS: Hospital Anxiety and Depression Scale; H&Y: Hoehn & Yahr stage; MHC-SF: Mental Health Continuum–Short Form; MINI: Mini International Neuropsychiatric Interview; MMSE: Mini-Mental State Examination; PDQ8: Parkinson's Disease Questionnaire Short Form; PDQ-39: Parkinson's Disease Questionnaire; PDQL: Parkinson's Disease Quality of Life Questionnaire; PHQ9: Patient Health Questionnaire; SDS: Self-rating Depression Scale; STAI: State Trait Anxiety Inventory; TICS-M: Modified Telephone Interview for Cognitive Status; UPDRS: Unified Parkinson's Disease Rating Scale.

[a] Number of participants per group not reported but authors confirmed group size ≥3.

[b] Troeung et al. (2014) include both a randomised and non-randomised sample. Only results for the randomised sample are included in this review.

Risk of Bias

All included studies were found to be at high risk of bias in at least one of the five RoB2 domains, resulting in all twelve papers receiving high overall risk of bias ratings (Table 2).

Potential bias arising from the randomisation process was most frequently due to unclear reporting on allocation sequence concealment prior to group assignment. Bias due to deviations from intended interventions tended to be low. However, intention to treat analysis was not used in Hadinia et al. (2017), which may increase the risk of bias in this domain. Several of the included studies reported problems with drop-out rates, potentially leading to bias due to missing outcome data.

Eleven of the twelve included studies were rated as high risk of bias in measurement of the outcome. Appropriate outcome measures were used in all studies; however, outcome measures were often self-report. As wait-list or usual care control groups were utilised in eight studies, blinding of participants to group assignment was not possible and so knowledge of group assignment may have impacted self-reported outcomes. Three of the four studies with active control conditions did not specify whether participants were blinded to group assignment and so may also have been at risk of potential bias in outcome measurement.

Pre-specified analysis plans were not available for most of the included studies, making it difficult to determine bias in selection of the reported result. Consistent with RoB2 guidance, these studies were given ratings of "some concerns". One study (Ghielen et al., 2017) employed an analysis method which adjusted for baseline characteristics however this was not specified in their protocol analysis plans. The protocol also stated that missing values would be imputed however the final paper did not report this.

Table 2

Risk of Bias Within Studies

Study	Bias arising from the randomisation process	Bias due to deviations from intended interventions (*effect of assignment to intervention*)	Bias due to missing outcome data	Bias in measurement of the outcome	Bias in selection of the reported result	Overall risk of bias
A'Campo et al. (2010)	Low	Low	Some concerns	High	Some concerns	High
Advocat et al. (2016)	Low	Low	Some concerns	High	Low	High
Ayromlou et al. (2020)	Some concerns	Low	Low	High	Some concerns	High
Bogosian et al. (2021)	Low	Low	Some concerns	High	Low	High
Chlond et al. (2016)	Some concerns	Low	Some concerns	High	Some concerns	High
Ghielen et al. (2017)	Low	Low	Some concerns	High	High	High
Hadinia et al. (2017)	Some concerns	High	Some concerns	Low	Some concerns	High
Mohr et al. (1996)	Some concerns	Low	Low	High	Some concerns	High
Murdoch et al. (2020)	Some concerns	Low	Some concerns	High	Some concerns	High
Rodgers et al. (2019)	Some concerns	Low	Some concerns	High	Low	High
Son & Choi (2018)	Some concerns	Low	Low	High	Some concerns	High
Troeung et al. (2014)	Low	Low	Some concerns	High	Some concerns	High

Quality of Life

Ten papers included quality of life outcomes. Relevant results are displayed in Table 3 and grouped by intervention type. Eight studies used the Parkinson's Disease Questionnaire summary index (PDQ-39-SI), one used the Parkinson's Disease Questionnaire Short Form (PDQ-8) and one the Parkinson's Disease Quality of Life Questionnaire (PDQL).

Mindfulness

Ayromlou et al. (2020) found a small to medium improvement in the PDQ-39-SI following intervention but not in the active control group. Similarly, Son and Choi (2018) found significantly higher PDQL post-intervention scores in their intervention condition compared to the control group (effect size not reported). In contrast, Advocat et al. (2016) found no significant differences in the PDQ-39-SI between their intervention and control conditions, and Rodgers et al. (2019) found improvements in the PDQ-39-SI over time in both intervention and control conditions, with a medium effect size.

CBT

Hadinia et al. (2017) found a significant improvement in the PDQ-39-SI in their group CBT condition compared to an active control, with a medium to large effect size. This study had only one RoB2 domain at low risk of bias. Troeung et al. (2014) did not report PDQ-39 scores separately for their randomised sample.

Psychoeducation

Chlond et al. (2016) found improved PDQ-39-SI following the Patient Education Program Parkinson (PEPP) and at a 3-month follow-up compared to the control condition (effect size not reported). These authors also found that Euroqol-5D (EQ-5D) visual analogue scales improved in the intervention group and decreased in the control group post-intervention (p=0.003). However, these changes were not maintained at follow-up and no between-group differences were found on the EQ-5D index. This paper had only one RoB2 domain at low risk of bias. A'Campo et al. (2010) did not find a significant difference in the PDQ-39-SI between the PEPP and control groups.

ACT-Based Intervention

Ghielen et al. (2017) was at highest risk of bias of the included studies, with two RoB2 domains rated as high. They did not report the PDQ-39-SI and so results from the emotional wellbeing subscale are considered here. Large improvements in the emotional wellbeing subscale were found post-intervention and at 3-month follow-up for the intervention group compared to the control.

Counselling

Only one RoB2 domain was rated as low risk of bias in Murdoch et al. (2020). Large improvements in the PDQ-8 over time were found for both the counselling group and control condition.

Table 3

Quality of Life Scores in Intervention and Control Groups

Intervention type	Study	Measure	Intervention pre M (SD) (unless otherwise reported) N	Intervention post M (SD) (unless otherwise reported) N	Control pre M (SD) (unless otherwise reported) N	Control post M (SD) (unless otherwise reported) N	Results for group differences
Mindfulness	Advocat et al. (2016)	PDQ-39-SI	22.2 (12.4) *n* not reported for baseline means	Change from baseline: -0.54 (95% CI: -3.41 to 2.32) *n*=24	26.8 (17.5) *n* not reported for baseline means	Change from baseline: -1.53 (95% CI: -3.64 to 0.57) *n*=33	Paired t-tests showed that within-group change from baseline was non-significant and there was no difference between the intervention and control groups (t=-0.59, *p* value not reported).
Mindfulness	Ayromlou et al. (2020)	PDQ-39-SI	33.93 (6.2) *n*=20	31.88 (6.5) *n*=20	35.50 (7.1) *n*=20	35.23 (7.5) *n*=20	Within groups t-tests revealed a significant difference between baseline and post-intervention scores in the intervention group ($p<0.001$, delta=-2.05) but not in the control group ($p=0.29$, delta=-0.27).
Mindfulness	Rodgers et al. (2019)	PDQ-39-SI	17.28 (1.94) *n*=14	15.51 (3.21) *n*=14	23.64 (2.75) *n*=11	20.69 (1.63) *n*=11	Generalised linear models revealed a main effect of time ($F[1,48]=7.78$, $p=0.008$, Cohen's $d=0.53$). The main effect of group ($F[1,48]=2.92$, $p=0.094$, Cohen's $d=0.32$) and group x time interaction ($F[1,48]=0.50$, $p=0.482$, $\eta_p^2=0.01$) were non-significant.
Mindfulness	Son & Choi (2018)	PDQL	136.27 (30.45) *n*=33	153.63 (21.66) *n*=33	147.83 (24.77) *n*=30	139.27 (17.84) *n*=30	Between-groups comparisons revealed a significant difference in post-test scores between intervention and control groups (t=2.86, $p=0.006$, effect size not reported).
CBT	Hadinia et al. (2017)	PDQ-39-SI	Not reported	Change from baseline (scales inverted): 5.31 (13.94) *n*=16	Not reported	Change from baseline (scales inverted): 3.25 (6.30) *n*=14	A MANOVA using change scores showed a significant difference between intervention and control groups ($p=0.03$, $\eta^2=0.13$).
CBT	Troeung et al. (2014)	PDQ-39	PDQ-39 scores not reported for the randomised sample	-	-	-	-

Intervention type	Study	Measure	Intervention pre M (SD) (unless otherwise reported) N	Intervention post M (SD) (unless otherwise reported) N	Control pre M (SD) (unless otherwise reported) N	Control post M (SD) (unless otherwise reported) N	Results for group differences
Psychoeducation	A'Campo et al. (2010)	PDQ-39-SI	33.04 (13.49) *n*=35	Change from baseline: 3.07 (7.81) *n*=29	26.58 (12.09) *n*=29	Change from baseline: -1.79 (6.73) *n*=28	Between-groups t-tests on the change scores were non-significant following Bonferroni corrections (*p*=0.015, mean between-group difference in change scores=4.86, 95% CI: 0.98 to 8.73).
Psychoeducation	Chlond et al. (2016)	PDQ-39-SI	34.21 (17.97) *n*=38	29.95 (13.90) *n*=30	35.72 (20.02) *n*=29	39.41 (22.31) *n*=21	Comparisons using the general linear model showed a significant decrease in scores in the intervention group compared to the control group post-intervention and at 3-month follow-up (*p*=0.001, effect size not reported).
ACT-based intervention	Ghielen et al. (2017)	PDQ-39 emotional wellbeing subscale (summary index not reported)	32.02 (19.89) *n*=19	26.94 (9.15) *n*=19	40.28 (21.10) *n*=19	40.10 (17.93) *n*=19	Linear mixed model analyses corrected for baseline differences revealed a significant improvement in scores on the emotional wellbeing subscale for the intervention group compared with the control group at both post-intervention and 3-month follow-up (Overall treatment effect: β=-10.89, *p*=0.009, 95% CI: -18.78 to -3.00).
Counselling	Murdoch et al. (2020)	PDQ-8	Scale mean: 1.93 (0.67) *n*=15	Scale mean: 1.73 (0.64) *n*=15	Scale mean: 1.63 (0.55) *n*=16	Scale mean: 1.52 (0.47) *n*=16	A 2x2 ANOVA compared scale means in the groups across time. A significant main effect of time was found ($F[1,29]=5.98$, $\eta_p^2=0.17$, $p<0.05$). The main effect of group ($F[1,29]=1.63$, $\eta_p^2=0.05$) and group x time interaction ($F[1,29]=0.69$, $\eta_p^2=0.02$) were non-significant.

Note. PDQ8: Parkinson's Disease Questionnaire Short Form; PDQ-39-SI: Parkinson's Disease Questionnaire Summary Index; PDQL: Parkinson's disease quality of life questionnaire.

Depression

Ten studies included depression outcomes and results are displayed in Table 4. Scales used to measure depression varied substantially among the included studies.

Mindfulness

Son and Choi (2018) reported lower post-test scores on the Geriatric Depression Scale (GDS) in the intervention group compared to the control group (effect sizes not reported). Rodgers et al. (2019) found no impact of their intervention on their primary outcome measure, the Geriatric Depression Scale-Short Form (GDS-15), compared to the control. However, they did find a large significant improvement in scores on a secondary outcome measure, the Depression Anxiety and Stress Scale-Depression (DASS-D), for the intervention group (interaction effect: $p<0.001$). Bogosian et al. (2021) found changes on the Hospital Anxiety and Depression Scale (HADS) over time in both their intervention and control groups, with a medium effect size. One study (Advocat et al., 2016) actually found a small increase in DASS-D scores over time in the intervention group. Both Bogosian et al. (2021) and Advocat et al. (2016) had the lowest risk of bias across RoB2 domains out of the included studies.

CBT

Troeung et al. (2014) report decreased DASS-D scores in the intervention group compared to the control. This difference was not significant but the effect size was large.

Psychoeducation

No significant differences in scores were found between intervention and control groups on the Self-rating Depression Scale (SDS; A'Campo et al., 2010) or the HADS (Chlond et al., 2016).

ACT-Based Intervention

No significant differences in Beck Depression Inventory (BDI) scores were found between intervention and control groups (Ghielen et al., 2017).

Counselling

No significant differences were found in Patient Health Questionnaire (PHQ-9) scores between intervention and control groups (Murdoch et al., 2020).

Behavioural Intervention

BDI scores were reduced post-intervention for both intervention and control groups (Mohr et al., 1996).

Table 4

Depression Symptoms/Scores in Intervention and Control Groups

Intervention type	Study	Measure	Intervention pre M (SD) (unless otherwise reported) N	Intervention post M (SD) (unless otherwise reported) N	Control pre M (SD) (unless otherwise reported) N	Control post M (SD) (unless otherwise reported) N	Results for group differences
Mindfulness	Advocat et al. (2016)	DASS-D	4.50 (5.22) *n* not reported for baseline means	Change from baseline: 1.92 (95% CI: 0.20 to 3.63) *n*=24	7.19 (7.83) *n* not reported for baseline means	Change from baseline: 1.06 (95% CI: -0.84 to 2.97) *n*=33	t-tests showed a significant increase in symptoms over time in the intervention group (exact *p* value not reported). No between-group differences were found in change scores (t=−0.66, *p*=0.51).
Mindfulness	Bogosian et al. (2021)	HADS	7.23 (3.46) *n*=30	5.53 (3.74) *n*=30	5.73 (3.00) *n*=30	5.33 (3.20) *n*=30	A 2(group: intervention, control) x4(time: baseline, mid-intervention, post-intervention, follow-up) mixed ANOVA revealed a significant main effect of time (F[2.61,151.43]=5.49, *p*=0.002, η_p^2=0.086). Main effect of group (F[1,58]=1.16 *p*=0.287, η_p^2=0.020) and interaction effect (F[2.61,151.43]=2.08, *p*=0.114, η_p^2=0.035) were non-significant.
Mindfulness	Rodgers et al. (2019)	GDS-15[a]	2.78 (0.35) *n*=15	1.87 (0.11) *n*=15	3.59 (1.29) *n*=12	3.88 (0.73) *n*=12	Generalised linear models were conducted. The group x time interaction (F[1,50]=2.65, *p*=0.110, η_p^2=0.05), main effects of time (F[1,50]=0.71, *p*=0.405, Cohen's *d*=0.16) and group (F[1,50]=1.93, *p*=0.171, Cohen's *d*=0.26) were all non-significant.
Mindfulness	Son & Choi (2018)	GDS	14.25 (7.53) *n*=33	10.85 (6.41) *n*=33	17.25 (7.07) *n*=30	16.24 (6.07) *n*=30	Between-groups comparisons found a significant difference in post-test scores between intervention and control groups (t=-3.78, *p*<0.001, effect size not reported).
CBT	Troeung et al. (2014)	DASS-D	11.00 (3.69) *n*=7	6.28 (2.56) *n*=7	11.00 (5.17) *n*=7	10.71 (6.13) *n*=7	The change in scores across time for intervention and control groups were compared. The time x group interaction was non-significant (F[1,12]=3.62, *p*=0.080, Cohen's *d*=0.94). Main effects not reported.

Intervention type	Study	Measure	Intervention pre M (SD) (unless otherwise reported) N	Intervention post M (SD) (unless otherwise reported) N	Control pre M (SD) (unless otherwise reported) N	Control post M (SD) (unless otherwise reported) N	Results for group differences
Psychoeducation	A'Campo et al. (2010)	SDS	54.41 (9.37) *n*=35	Change from baseline: 1.96 (6.51) *n*=29	51.63 (8.70) *n*=29	Change from baseline: -1.55 (6.73) *n*=28	Bonferroni adjusted t-tests on change scores in the two groups were non-significant (p=0.050, mean between-group difference in change scores=3.51, 95% CI: -0.00 to 7.02).
Psychoeducation	Chlond et al. (2016)	HADS	7.5 (3.8) *n*=38	Data not reported	7.1 (3.1) *n*=29	Data not reported	Comparisons of intervention and control groups across time were non-significant (test statistics not reported).
ACT-based intervention	Ghielen et al. (2017)	BDI	9.80 (7.63) *n*=19	9.07 (6.01) *n*=19	12.30 (8.39) *n*=19	12.44 (5.41) *n*=19	Linear mixed model analyses corrected for baseline differences showed posttreatment effects and overall treatment effects (including follow-up) were non-significant (Overall treatment effect: β=1.49, p=0.19, 95% CI: -0.78 to 3.77).
Counselling	Murdoch et al. (2020)	PHQ-9	Scale means: 0.66 (0.58) *n*=15	Scale means: 0.58 (0.49) *n*=15	Scale means: 0.61 (0.70) *n*=16	Scale means: 0.50 (0.49) *n*=16	A 2x2 ANOVA compared scale means in the groups across time. Main effects of time ($F[1,29]=1.81$, $\eta_p^2=0.06$) and group ($F[1,29]=0.13$, $\eta_p^2=0.00$) were non-significant, as was the group x time interaction ($F[1,29]=0.02$, $\eta_p^2=0.00$).
Behavioural intervention	Mohr et al. (1996)	BDI	9.65 (6.06) *n*=20	7.90 (4.60) *n*=20	10.52 (4.91) *n*=21	8.14 (4.40) *n*=21	A two-way ANOVA revealed a main effect of time ($F[1,39]=10.6$, $p<0.002$, effect size not reported). No between-group differences were found (test statistics not reported).

Note. BDI: Beck Depression Inventory; DASS-D: Depression Anxiety and Stress Scale-Depression; GDS: Geriatric Depression Scale; GDS-15: Geriatric Depression Scale-Short Form; HADS: Hospital Anxiety and Depression Scale; PHQ-9: Patient Health Questionnaire, SDS: Self-rating Depression Scale.

[a] Rodgers et al. (2019) measured depression using both the GDS-15 and DASS-D. The GDS-15 is reported here as this was the primary outcome.

Anxiety

Eight studies included anxiety outcomes and results are summarised in Table 5. Again, a large number of different scales to measure anxiety were used across included studies.

Mindfulness

Only one study found improvements in anxiety symptoms (measured by the State Trait Anxiety Inventory [STAI]) post-intervention in the intervention group compared to the control (Son & Choi, 2018). One study found improvements in HADS scores over time in both intervention and control groups, with a large effect (Bogosian et al., 2021). Two studies found no effect of mindfulness-based interventions compared to controls on anxiety symptoms measured by the DASS-Anxiety (DASS-A; Advocat et al., 2016; Rodgers et al., 2019) and Geriatric Anxiety Inventory (GAI; Rodgers et al., 2019).

CBT

Troeung et al. (2014) found a large reduction in DASS-A scores in the intervention group compared to the control.

Psychoeducation

Chlond et al. (2016) found no difference over time in HADS anxiety scores between intervention and control groups.

ACT-Based Intervention

Ghielen et al. (2017) found no significant differences in Beck Anxiety Inventory (BAI) scores between intervention and control groups.

Counselling

No significant differences were found over time in BAI scores between intervention and control groups (Murdoch et al., 2020).

Table 5

Anxiety Symptoms/Scores in Intervention and Control Groups

Intervention type	Study	Measure	Intervention pre M (SD) (unless otherwise reported) N	Intervention post M (SD) (unless otherwise reported) N	Control pre M (SD) (unless otherwise reported) N	Control post M (SD) (unless otherwise reported) N	Results for group differences
Mindfulness	Advocat et al. (2016)	DASS-A	7.58 (4.79) *n* not reported for baseline means	Change from baseline: 0.33 (95% CI: -1.67 to 2.34) *n*=24	9.81 (7.56) *n* not reported for baseline means	Change from baseline: -0.63 (95% CI: -2.92 to 1.67) *n*=33	t-tests showed no difference in change scores between the two groups (t=-0.62, *p*=0.54).
Mindfulness	Bogosian et al. (2021)	HADS	8.70 (4.24) *n*=30	7.53 (4.22) *n*=30	7.73 (3.59) *n*=30	6.20 (3.75) *n*=30	A 2(group: intervention, control) x4(time: baseline, mid-intervention, post-intervention, follow-up) mixed ANOVA revealed a significant main effect of time (F[3,174]=12.61, *p*<0.001, η_p^2=0.179). Main effect of group (F[1,58]=0.98, *p*=0.325, η_p^2=0.017) and interaction effect (F[3,174]=0.32, *p*=0.809, η_p^2=0.006) were non-significant.
Mindfulness	Rodgers et al. (2019)	GAI[a]	4.27 (0.15) *n*=15	2.70 (0.10) *n*=15	2.92 (0.05) *n*=12	4.13 (1.41) *n*=12	Generalised linear models were conducted. There was no significant group x time interaction (F[1,50]=3.53, *p*=0.066, η_p^2=0.07), and no main effect of time (F[1,50]=0.06, *p*=0.816, Cohen's *d*=0.04) or group (F[1,50]=0.003, *p*=0.954, Cohen's *d*=0.01).
Mindfulness	Son & Choi (2018)	STAI total	82.92 (9.33) *n*=33	76.38 (18.80) *n*=33	82.46 (15.42) *n*=30	91.89 (16.13) *n*=30	Between-groups comparisons found a significant difference between the post-test scores of the intervention and control groups (t=-3.50, *p*=0.001, effect size not reported).
CBT	Troeung et al. (2014)	DASS-A	9.00 (2.31) *n*=7	5.38 (2.56) *n*=7	8.14 (4.84) *n*=7	7.86 (4.63) *n*=7	The change in scores across time for the intervention and control group were compared. The time x group interaction was significant (F[1,12]=9.50, *p*=0.007, Cohen's *d*=0.89). Main effects not reported.

Intervention type	Study	Measure	Intervention pre M (SD) (unless otherwise reported) N	Intervention post M (SD) (unless otherwise reported) N	Control pre M (SD) (unless otherwise reported) N	Control post M (SD) (unless otherwise reported) N	Results for group differences
Psychoeducation	Chlond et al. (2016)	HADS	6.9 (3.5) *n*=38	Data not reported	7.3 (3.8) *n*=29	Data not reported	No significant between-group differences were found across time (test statistics not reported).
ACT-based intervention	Ghielen et al. (2017)	BAI	40.47 (13.71) *n*=19	35.69 (12.14) *n*=19	39.05 (9.23) *n*=19	39.25 (9.43) *n*=19	Linear mixed model analyses corrected for baseline differences revealed non-significant posttreatment effects and overall treatment effects (Overall treatment effect: β=-3.29, *p*=0.17, 95% CI: -8.03 to 1.45).
Counselling	Murdoch et al. (2020)	BAI	Scale means: 1.68 (0.57) *n*=15	Scale means: 1.60 (0.38) *n*=15	Scale means: 1.53 (0.46) *n*=16	Scale means: 1.51 (0.46) *n*=16	The main effects of time (F[1,29]=0.58, η_p^2=0.02) and group (F[1,29]=0.61, η_p^2=0.02) were non-significant, as was the group x time interaction (F[1,29]=0.23, η_p^2=0.00).

Note. BAI: Beck Anxiety Inventory; DASS-A: Depression Anxiety and Stress Scale-Anxiety; GAI: Geriatric Anxiety Inventory; HADS: Hospital Anxiety and Depression Scale; STAI: State Trait Anxiety Inventory.

[a] Rodgers et al. (2019) measured anxiety using both the GAI and DASS-A. The GAI is reported here as this was the primary outcome.

Stress

Only four studies included stress-related outcomes and results are summarised in Table 6.

Mindfulness

Rodgers et al. (2019) did not report results for the DASS stress subscale (DASS-S). Another study, with one of the lowest risk of bias ratings across domains, found a small but significant increase in DASS-S scores at post-intervention for the intervention group compared to the control group (Advocat et al., 2016).

CBT

Troeung et al. (2014) did not find a significant impact of group CBT on DASS-S scores. However, Hadinia et al. (2017) found a significant improvement in stress measured by both the BELA (Belastungsfragebogen für Parkinsonpatienten [Burden Questionnaire for Patients with Parkinson's disease]) and FKK (Fragebogen zur krankheitsbezogenen Kommunikation [Questionnaire for Disease-Related Communication], p=0.04) in the intervention group compared to the control. Effect sizes were large and medium respectively, however, only one RoB2 domain was at low risk of bias in this study.

Table 6

Stress Symptoms/Scores in Intervention and Control Groups

Intervention type	Study	Measure	Intervention pre M (SD) (unless otherwise reported) N	Intervention post M (SD) (unless otherwise reported) N	Control pre M (SD) (unless otherwise reported) N	Control post M (SD) (unless otherwise reported) N	Results for group differences
Mindfulness	Advocat et al. (2016)	DASS-S	8.78 (6.35) *n* not reported for baseline means	Change from baseline: 2.17 (95% CI: 0.12 to 4.23) *n*=24	12.44 (9.65) *n* not reported for baseline means	Change from baseline: -1.63 (95% CI: -3.68 to 0.43) *n*=33	t-tests showed a significant increase in stress over time in the intervention group compared to the control (t=−2.61, *p*=0.01, Cohen's *d*=0.32).
Mindfulness	Rodgers et al. (2019)	DASS-S	DASS-S results not reported	-	-	-	-
CBT	Hadinia et al. (2017)	BELA[a]	Not reported	Change from baseline: 5.56 (11.48) *n*=16	Not reported	Change from baseline: -2.75 (9.36) *n*=14	A MANOVA found a significant difference in change scores between the two groups (*p*=0.026, η^2=0.14).
CBT	Troeung et al. (2014)	DASS-S	10.57 (3.95) *n*=7	8.43 (4.50) *n*=7	8.71 (2.29) *n*=7	8.14 (4.14) *n*=7	Comparisons of the change in scores over time for the intervention and control group were non-significant (*p*=0.169, Cohen's *d*=0.47).

Note. BELA: Belastungsfragebogen für Parkinsonpatienten (Burden Questionnaire for Patients with Parkinson's disease); DASS-S: Depression Anxiety and Stress Scale-Stress.

[a] Hadinia et al. (2017) measured stress using both the BELA and FKK. Results from the BELA are reported here.

Discussion

Summary of Findings

The findings indicate the potential effectiveness of group mindfulness-based interventions and group CBT on multiple measures of wellbeing. However, these impacts were not consistent across studies, and one mindfulness-based intervention appeared to have a negative impact on some wellbeing measures. The mixed nature of mindfulness results may be attributable to differences in the content of interventions, which varied substantially across studies. Additionally, a range of measures were used to assess outcomes, which may further contribute to the heterogeneity of results. Moreover, all studies included in the review were identified as high risk of bias, indicating that findings should be interpreted with caution.

The impact of the PEPP psychoeducation intervention and ACT-based BEWARE programme on wellbeing outcomes were limited to measures of quality of life. The SHARP-PWP group counselling intervention and the group behavioural intervention were not found to be more effective than control conditions, suggesting that these interventions may be less effective for people with PD.

The current review's positive findings regarding group CBT mirror those of previous reviews of mixed individual and group CBT approaches (Yang et al., 2012; Zhang et al., 2020). A scoping review from Zarotti et al. (2020) into psychological interventions for PD concluded that there is contrasting evidence regarding the impact of CBT on anxiety and quality of life. In comparison, the current review found positive impacts of group CBT on these outcomes. However, only two group CBT studies were included in the current synthesis, highlighting the need for further research into group CBT. The mixed findings regarding group mindfulness interventions identified in the current review are similar to those reported by Zarotti et al. (2020). These authors also reviewed psychoeducation interventions,

although they did not include the psychoeducation studies included in the current review. The reason for this is unclear, as they did include an uncontrolled study of the PEPP. In contrast to their predominantly negative findings regarding psychoeducation, the current review reported improvements in quality of life measures following group psychoeducation in one study utilising the PEPP. The current review builds on this previous research and provides a unique focus on group psychosocial interventions for people with PD.

Study Limitations and Risk of Bias

Eleven of the twelve studies included in the review were rated as at high risk of bias in measurement of the outcome. This resulted from a combination of the use of self-report measures and either lack of or unclear blinding of participants to their group assignment. Consequently, awareness of group assignment may have impacted on self-reported outcomes following intervention. Another limitation was the small number of studies utilising active control conditions. Only four of the included studies employed active control conditions and only one of these specified that participants were not informed of their group allocation. Where wait-list or usual care controls were used, blinding was not possible. The use of these types of control conditions also makes it challenging to identify intervention specific effects as opposed to placebo effects or the impacts of informal social support in a group setting which have been reported by participants in studies such as Fitzpatrick et al. (2010).

Sample sizes were small in many of the included studies. Some papers such as Rodgers et al. (2019) were pilot studies in which small sample sizes were expected, while others such as Troeung et al. (2014) reported recruitment difficulties leading to smaller samples than anticipated. Consequently, several papers report being underpowered in their

analyses, which may have impacted results and limits the conclusions that can be drawn regarding intervention effectiveness.

Several of the included studies also reported high drop-out rates, at times resulting in further reductions in the available sample for analysis. Where reasons for dropout and outcome data are not available for participants who discontinued interventions, it is difficult to determine if dropout was associated with negative impacts of the intervention itself or a worsening of symptoms. Consequently, reasons for dropout should be sought and reported where possible and efforts should be made to obtain outcome data from all participants when appropriate. Given that one study found an increase in depression and stress following intervention, recording and reporting of adverse events may be a useful addition to future research. This lack of adverse event monitoring has previously been highlighted as a limitation of CBT trials with PD populations (Seppi et al., 2019).

Additionally, there were some issues related to reporting of information. As noted above, some authors did not report effect sizes of their findings, or sufficient data to allow a reviewer to calculate these. Additionally, separate follow-up data for intervention and control groups was only gathered in two studies. Wait-list control conditions where participants subsequently receive the intervention can make it difficult to provide longer term follow-up data. Finally, most papers included in the review did not include demographic information on important characteristics such as ethnicity.

Review Strengths and Limitations

This review used the Cochrane Handbook for Systematic Reviews of Interventions (Higgins et al., 2021) as a guide where feasible. The authors sought to minimise subjective

biases and errors in this review by including a second rater at all stages of the review process, although it was not feasible to do this for 100% of records at each stage. Extra information on included studies was sought from study protocols and registers, and authors were contacted where required to clarify information regarding eligibility for review. Another strength of the review is the consideration of a wide range of interventions and outcomes, resulting in a comprehensive synthesis.

Statistical synthesis was not used in this review. There was substantial variation in outcome measures used in included studies, which made comparisons challenging. This issue has also been reported in other reviews on nonpharmacological interventions for people with PD (Chandler et al., 2019).

When rating the risk of bias, ratings of "some concerns" were given to papers where information was not reported, such as pre-specified statistical analysis plans. It should be noted that analysis plans may exist for these studies but as these were not reported a rating of "some concerns" was given, consistent with RoB2 guidance.

This review only included published RCTs. While this resulted in the inclusion of methodologically more robust trials, it may also have led to the exclusion of potentially relevant evidence from unpublished studies or studies using other designs. Additionally, only studies available in English were included, which may have omitted relevant trials published in other languages. It was not feasible to conduct forward citation searching in this review, which may have caused relevant papers to be missed. However, the comprehensive search strategy returned a large number of results and sensitivity checks of search strategies found that no relevant studies known to the authors were omitted. Additionally, backward citation searching was completed to minimise omission of appropriate studies.

Future Recommendations and Conclusions

The findings of this review suggest that group psychosocial interventions such as mindfulness-based interventions and CBT may be efficacious for use in clinical settings for people with PD. However, given the small number of RCTs in this area, the small sample sizes of included studies and resulting impact on statistical power, the high risk of bias of included studies, and the mixed results found for some interventions, further research into group interventions for people with PD is required to establish their clinical safety and effectiveness. Additionally, the high numbers of dropouts reported in several studies suggest that group psychosocial interventions may not be acceptable to some people with PD. Therefore, people with PD should be offered choice in psychosocial interventions when possible. Future research should aim to address quality issues in the existing literature. Suggestions to improve methodological rigour and reduce risk of bias include: conducting analyses as intention to treat, monitoring adverse events, utilising active control conditions, and blinding participants to group assignment where self-report outcome measures are used.

The current review demonstrates the promising nature of group psychosocial interventions while highlighting the need for further high-quality research. This review builds on previous work and provides a unique synthesis of the evidence-base for group psychosocial interventions for people with PD.

References

A'Campo, L., Wekking, E., Spliethoff-Kamminga, N., Le Cessie, S., & Roos, R. (2010). The benefits of a standardized patient education program for patients with Parkinson's disease and their caregivers. *Parkinsonism & Related Disorders, 16*(2), 89-95.

Advocat, J., Enticott, J., Vandenberg, B., Hassed, C., Hester, J., & Russell, G. (2016). The effects of a mindfulness-based lifestyle program for adults with Parkinson's disease: a mixed methods, wait list controlled randomised control study. *BMC Neurology, 16*(1), 1-11.

Ayromlou, H., Najmi, S., Ranjbar, F., Ghaemian, N., & Rikhtegar, R. (2020). The Impact of Mindfulness on Quality of Life in Parkinson's Disease:(A Randomized Clinical Trial). *British Journal of Medical Practitioners, 13*(1).

Bogosian, A., Hurt, C. S., Hindle, J. V., McCracken, L. M., Vasconcelos e Sa, D. A., Axell, S., Tapper, K., Stevens, J., Hirani, P. S., & Salhab, M. (2021). Acceptability and Feasibility of a Mindfulness Intervention Delivered via Videoconferencing for People With Parkinson's. *Journal of Geriatric Psychiatry and Neurology*, 0891988720988901.

Brown, J. S., Sellwood, K., Beecham, J. K., Slade, M., Andiappan, M., Landau, S., Johnson, T., & Smith, R. (2011). Outcome, costs and patient engagement for group and individual CBT for depression: a naturalistic clinical study. *Behavioural and Cognitive Psychotherapy, 39*(3), 355-358.

Chandler, S. K., Robins, J. L., & Kinser, P. A. (2019). Nonpharmacologic interventions for the self-management of anxiety in Parkinson's disease: A comprehensive review. *Behavioural Neurology, 2019,* 8459579-9.

Chaudhuri, K. R., Healy, D. G., & Schapira, A. H. (2006). Non-motor symptoms of Parkinson's disease: diagnosis and management. *The Lancet Neurology, 5*(3), 235-245.

Chlond, M., Bergmann, F., Güthlin, C., Schnoor, H., Larisch, A., & Eggert, K. (2016). Patient education for patients with Parkinson's disease: a randomised controlled trial. *Basal Ganglia, 6*(1), 25-30.

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.

Flores Alves Dos Santos, J., Tezenas du Montcel, S., Gargiulo, M., Behar, C., Montel, S., Hergueta, T., Navarro, S., Belaid, H., Cloitre, P., & Karachi, C. (2017). Tackling psychosocial maladjustment in Parkinson's disease patients following subthalamic deep-brain stimulation: A randomised clinical trial. *PLoS One, 12*(4), e0174512.

Ghielen, I., van Wegen, E. E., Rutten, S., de Goede, C. J., Houniet-de Gier, M., Collette, E. H., Burgers-Bots, I. A., Twisk, J. W., Kwakkel, G., & Vermunt, K. (2017). Body awareness training in the treatment of wearing-off related anxiety in patients with Parkinson's disease: Results from a pilot randomized controlled trial. *Journal of Psychosomatic Research, 103*, 1-8.

Hadinia, A., Meyer, A., Bruegger, V., Hatz, F., Nowak, K., Taub, E., Nyberg, E., Stieglitz, R.-D., Fuhr, P., & Gschwandtner, U. (2017). Cognitive behavioral group therapy reduces stress and improves the quality of life in patients with Parkinson's disease. *Frontiers in Psychology, 7*, 1975.

Higgins, J., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M., & Welch, V. (2021). *Cochrane Handbook for Systematic Reviews of Interventions*. Cochrane. www.training.cochrane.org/handbook

Karlsen, K. H., Larsen, J. P., Tandberg, E., & Mæland, J. G. (1999). Influence of clinical and demographic variables on quality of life in patients with Parkinson's disease. *Journal of Neurology, Neurosurgery & Psychiatry, 66*(4), 431-435.

Karlsen, K. H., Tandberg, E., Årsland, D., & Larsen, J. P. (2000). Health related quality of life in Parkinson's disease: a prospective longitudinal study. *Journal of Neurology, Neurosurgery & Psychiatry, 69*(5), 584-589.

Mohr, B., Müller, V., Mattes, R., Rosin, R., Federmann, B., Strehl, U., Pulvermüller, F., Müller, F., Lutzenberger, W., & Birbaumer, N. (1996). Behavioral treatment of Parkinson's disease leads to improvement of motor skills and to tremor reduction. *Behavior Therapy, 27*(2), 235-255.

Moore, L. M., Carr, A., & Hartnett, D. (2017). Does group CBT for depression do what it says on the tin? A systemic review and meta-analysis of group CBT for depressed adults (2000–2016). *Journal of Contemporary Psychotherapy, 47*(3), 141-152.

Murdoch, K. C., Larsen, D., Edey, W., Arsenault, C., Howell, A., Joyce, A., Sandham, T., & Miyasaki, J. M. (2020). The efficacy of the Strength, Hope and Resourcefulness Program for people with Parkinson's disease (SHARP-PWP): A mixed methods study. *Parkinsonism & Related Disorders, 70*, 7-12.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., & Brennan, S. E. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ, 372*.

Pickut, B., Vanneste, S., Hirsch, M. A., Van Hecke, W., Kerckhofs, E., Mariën, P., Parizel, P. M., Crosiers, D., & Cras, P. (2015). Mindfulness training among individuals with Parkinson's disease: neurobehavioral effects. *Parkinson's Disease, 2015*, 816404-6.

Pontone, G. M., & Mills, K. A. (2021). Optimal treatment of depression and anxiety in Parkinson's disease. *The American Journal of Geriatric Psychiatry, 29*(6), 530-540.

Prediger, R. D., Matheus, F. C., Schwarzbold, M. L., Lima, M. M., & Vital, M. A. (2012). Anxiety in Parkinson's disease: a critical review of experimental and clinical studies. *Neuropharmacology, 62*(1), 115-124.

Rodgers, S. H., Schütze, R., Gasson, N., Anderson, R. A., Kane, R. T., Starkstein, S., Morgan-Lowes, K., & Egan, S. J. (2019). Modified mindfulness-based cognitive therapy for depressive symptoms in Parkinson's disease: a pilot trial. *Behavioural and Cognitive Psychotherapy, 47*(4), 446-461.

Seppi, K., Ray Chaudhuri, K., Coelho, M., Fox, S. H., Katzenschlager, R., Perez Lloret, S., Weintraub, D., Sampaio, C., Collaborators of the Parkinson's Disease Update on Non-Motor Symptoms Study Group on behalf of the Movement Disorders Society Evidence-Based Medicine Committee, & Chahine, L. (2019). Update on treatments for nonmotor symptoms of Parkinson's disease—an evidence-based medicine review. *Movement Disorders, 34*(2), 180-198.

Son, H. G., & Choi, E.-O. (2018). The effects of mindfulness meditation-based complex exercise program on motor and nonmotor symptoms and quality of life in patients with Parkinson's disease. *Asian Nursing Research, 12*(2), 145-153.

Sproesser, E., Viana, M. A., Quagliato, E. M., & de Souza, E. A. P. (2010). The effect of psychotherapy in patients with PD: a controlled study. *Parkinsonism & Related Disorders, 16*(4), 298-300.

Sterne, J. A., Savović, J., Page, M. J., Elbers, R. G., Blencowe, N. S., Boutron, I., Cates, C. J., Cheng, H.-Y., Corbett, M. S., & Eldridge, S. M. (2019). RoB 2: a revised tool for assessing risk of bias in randomised trials. *BMJ, 366*, 14898.

The British Psychological Society. (2021). Psychological interventions for people with Huntington's disease, Parkinson's disease, motor neurone disease, and multiple sclerosis: Evidence-based guidance. https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Psychological%20interventions%20-%20Huntingtons%2C%20Parkinsons%2C%20motor%20neurone%20disease%2C%20multiple%20sclerosis.pdf

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), 1-11.

van der Heijden, I., Abrahams, N., & Sinclair, D. (2017). Psychosocial group interventions to improve psychological well-being in adults living with HIV. *Cochrane Database of Systematic Reviews* (3).

Wolters Kluwer Health Learning Research & Practice. (2021). *Ovid Tools & Resources Portal*. https://tools.ovid.com/ovidtools/expertsearches.html

Xie, C.-L., Wang, X.-D., Chen, J., Lin, H.-Z., Chen, Y.-H., Pan, J.-L., & Wang, W.-W. (2015). A systematic review and meta-analysis of cognitive behavioral and

psychodynamic therapy for depression in Parkinson's disease patients. *Neurological Sciences, 36*(6), 833-843.

Yamanishi, T., Tachibana, H., Oguru, M., Matsui, K., Toda, K., Okuda, B., & Oka, N. (2013). Anxiety and depression in patients with Parkinson's disease. *Internal Medicine, 52*(5), 539-545.

Yang, S., Sajatovic, M., & Walter, B. L. (2012). Psychosocial interventions for depression and anxiety in Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology, 25*(2), 113-121.

Zarotti, N., Eccles, F. J., Foley, J. A., Paget, A., Gunn, S., Leroi, I., & Simpson, J. (2020). Psychological interventions for people with Parkinson's disease in the early 2020s: Where do we stand? *Psychology and Psychotherapy: Theory, Research and Practice*.

Zhang, Q., Yang, X., Song, H., & Jin, Y. (2020). Cognitive behavioral therapy for depression and anxiety of Parkinson's disease: A systematic review and meta-analysis. *Complementary Therapies in Clinical Practice, 39*, 101-111.

Chapter 2

Developing psychological wellbeing support for patients with Parkinson's disease: A qualitative study of patients' preferences and barriers to participation

Jessica Whyte*, BSc (Hons)

University of Glasgow, NHS Ayrshire & Arran

*Correspondence address:

Mental Health and Wellbeing

University of Glasgow

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow

G12 0XH

Prepared in accordance with the author requirements for the Journal of Geriatric Psychiatry and Neurology; Appendix 1.1, p.92.

Plain Language Summary

Title: Developing psychological wellbeing support for patients with Parkinson's disease: A qualitative study of patients' preferences and barriers to participation

Background: Parkinson's disease (PD) is associated with high rates of depression and anxiety, for which group talking therapies such as Cognitive Behavioural Therapy (CBT) may be an effective treatment. Previous research has found that incorporating the preferences of patients into psychological treatment can increase the effectiveness of treatment and decrease dropout prior to treatment completion. There is currently limited research into the preferences of patients with PD for psychological support and potential barriers to taking part in this form of support.

Aims: The aim of this project was to gain a better understanding of the preferences of patients with PD for psychological support, and how barriers to participation can be overcome.

Methods: Patients with PD in one UK health board were invited to take part in the study. To take part participants were required to have a diagnosis of PD without dementia, be aged 18 or over, be fluent in English, have experienced difficulties with mental health, be able to consent to taking part, and be able to take part in an interview independently over phone or video call. Twelve adults with PD were recruited and one-to-one semi-structured interviews were conducted. Interviews covered topics such as content and format of psychological support, and barriers to participation. Framework analysis was conducted to identify themes in the interview data, and two participants were invited to provide further reflections on results to increase credibility.

Main findings: Three factors were identified which influence people with PD when considering accessing support from psychological services: the perceived need for support, choosing whether to engage in support given a need has been identified, and the barriers to accessing support. Subthemes highlight the importance of providing support that is flexible, realistic and individually tailored to each person's needs and preferences. Suggestions are also provided for overcoming barriers to accessing psychological support for this population such as providing information on available services and offering choice.

Conclusions: Identified barriers to accessing psychological support were found to mirror those reported in previous research. The current study expands on previous findings through the identification of barriers regarding group psychological support and the impact of the Covid-19 pandemic, as well as investigating preferences for the content and format of support, and exploring strategies to overcome barriers. The findings demonstrate the importance of increasing awareness of psychological services, improving service accessibility, and identifying the individual needs of patients with PD when delivering psychological support for wellbeing.

Abstract

Previous research has identified that incorporating the preferences of patients into psychological treatment can increase the effectiveness of interventions and decrease dropout rates prior to treatment completion. There is currently limited research into the preferences of patients with Parkinson's disease (PD) for psychological support and potential barriers to participation. This study therefore aimed to gain a better understanding of the preferences of patients with PD for psychological support, and how barriers to participation can be overcome. Semi-structured interviews were conducted with 12 people with PD, covering topics such as content of psychological support and barriers to participation. Themes from the interviews were identified through framework analysis. The resulting framework represents the factors influencing people with PD when considering accessing support from psychological services. Three interlinked factors were identified: the perceived need for support, choosing whether to engage in support given a need has been identified, and the barriers to accessing support. These themes are explored and suggestions provided for overcoming barriers to accessing psychological support for this population.

Keywords: Wellbeing, Psychological Support, Barriers, Parkinson's Disease.

Introduction

Parkinson's disease (PD) is a neurodegenerative disorder characterised by both motor symptoms, such as a resting tremor and rigidity, and non-motor symptoms, such as cognitive and olfactory problems (Prediger et al., 2012). PD is also associated with high rates of depression and anxiety, with one study finding point prevalence rates as high as 55% for anxiety and 56% for depression (Yamanishi et al., 2013).

There are limited available treatments for mood disorders in PD (Chen & Marsh, 2014). However, Cognitive Behavioural Therapy (CBT) may be effective in reducing depression and anxiety symptoms in individuals with PD (Zarotti et al., 2020; Zhang et al., 2020), and this approach has been recommended in recent evidence-based guidelines for psychological interventions for people with PD (The British Psychological Society, 2021). There is also some evidence to suggest that group CBT and group mindfulness-based interventions may be effective in improving wellbeing in people with PD, as shown in the systematic review (Chapter 1). However, results of studies included in the systematic review were mixed and some group interventions were not found to be effective.

Previous research has found that incorporating patient preferences into treatment can increase the effectiveness of psychological interventions and decrease dropout prior to treatment completion (Swift et al., 2018). These authors found that when patient preference is taken into consideration, patients are significantly less likely to end treatment early than patients whose preferences are not adhered to, and intervention outcomes are significantly more positive. These findings demonstrate the importance of understanding patient preferences for treatment. However, at present there is limited research into the preferences of people with PD for psychological support.

When considering increasing patient engagement and reducing dropout prior to treatment completion, it is also important to consider barriers to participation in support. A small number of previous studies have investigated barriers to engaging in support for people with PD. Dobkin et al. (2013) surveyed individuals with PD and found that issues with transport, availability of services and physical impairments were perceived as barriers to using mental health services. Practical issues were also reported as a barrier to participation in a group exercise intervention study for people with PD (Sajatovic et al., 2017). Study participants reported enjoying social aspects of groups but found it difficult to attend sessions at fixed times, and problems with transportation and meeting locations made participation difficult.

Another survey study from Troeung et al. (2015) found that younger age and a belief that mental health interventions will be effective were significant predictors of uptake of mental health care, while stigma was reported as a concern for a small proportion of people with PD. A qualitative study from Oehlberg et al. (2008) also found that some participants with PD had concerns about engaging in psychotherapy due to stigma, as well as discomfort in talking about personal problems to people they did not know, and issues with transportation.

The previous research described above has mainly been quantitative, with a lack of scope for further exploration of participant views. Additionally, the one qualitative study from Oehlberg et al. (2008) touched on barriers to engaging in psychotherapy but did not explore patients' treatment preferences for psychological support. Thus, further research into patient preferences for psychological support, and the barriers to engaging in this support, is required.

Consequently, this study will aim to form a better understanding of the preferences of patients with PD for psychological support, and how barriers to participation can be overcome. The results will be used to guide recommendations for psychological services for patients with PD. By developing psychological support for patients with PD driven by the preferences and experience of patients themselves, it is hoped that patient engagement in psychology services will be increased and the effectiveness of support enhanced.

Aims

The aims of this study were to gain a better understanding of the preferences of patients with PD for psychological support, and how barriers to accessing this form of support can be overcome.

Research Questions

1. What are the preferences of patients with PD for the content and format of support for psychological wellbeing?

2. What views and experiences do patients have on the barriers to participation in psychological support and how these can be overcome?

3. What are the opinions of patients on what would be helpful to include in an initial invitation letter to be sent to patients to provide more information about the services offered?

Methods

This study is reported in accordance with the COnsolidated criteria for REporting Qualitative research (COREQ) checklist (Appendix 2.2, p.121; Tong et al., 2007).

Design

The study employed a qualitative interview design.

Participants and Setting

Participants were adults with a diagnosis of PD who were registered with the movement disorders service in the NHS Ayrshire & Arran health board in Scotland. The Neuropsychology service in this region had previously offered a group psychological intervention to people with PD but had experienced poor uptake of this, and so this was a relevant setting in which to conduct the research. Inclusion criteria required participants to: have a clinical diagnosis of idiopathic PD with no concurrent dementia diagnosis; have experienced problems with their mental health (as judged by the Clinical Nurse Specialist [CNS] who screened case records); be aged ≥18; be fluent in English; have the capacity to provide informed consent to take part in the study; be able to contribute independently to the interview; and have access to either a phone or device for video call.

Ethical Approval

Ethical approval (20/WS/0172) was granted by the West of Scotland NHS Research Ethics Committee on 18th January 2021 (See Appendix 2.3, p.123 for a copy of approval

letter). All participants provided verbal informed consent, which was audio-recorded at the start of the interview, and were provided with a copy of the consent form (Appendix 2.4, p.129) and information sheet (Appendix 2.5, p.130).

Recruitment

Participants were recruited through the NHS Ayrshire & Arran health board. To identify eligible participants a PD CNS reviewed the files of patients with PD living in the health board. Patients who met inclusion criteria were then purposively selected by the CNS to receive an invitation letter. The CNS selected a range of eligible patients such that some had previously received support from psychological services while others had not, as the research team felt it was important to hear the views of both groups. Eligible patients were sent an invitation pack by the CNS, containing an information sheet, invitation letter and reply slip (Appendix 2.6, p.136), and a pre-addressed and pre-paid envelope. Patients were asked to return the reply slip if they were interested in participating and consented to be contacted by the lead researcher (JW). Those patients were then contacted by the researcher to provide the opportunity to ask questions about the study and to arrange the interview. All participants were offered a £5 supermarket voucher as a thank you for their time.

Materials

The interview schedule (Appendix 2.7, p.138) was developed based on the research questions and previous literature.

The first part of the schedule consisted of demographic and clinical self-report questions, adapted from Dobkin et al. (2013). Patients were also asked for their postcode to

calculate the Scottish Index of Multiple Deprivation (SIMD). The SIMD is a measure of relative deprivation by area and can be expressed as quintiles, where quintile 1 represents the most deprived areas.

The second part of the schedule covered topics such as: content, format and practicalities of psychological support, what participants would hope to gain from psychological support, barriers to participation and how these could be addressed (Krueger et al., 2001; Letourneau et al., 2012; Todd et al., 2013). Participants were also asked their opinions on content to include in an invitation letter to be sent to patients in the health board providing information about psychological services. A draft of the schedule was reviewed by members of the charity Parkinson's UK and a charity representative. Feedback indicated that it would be helpful to provide details of what psychology services do. A paragraph describing psychology services was added to the schedule and participants were given the opportunity to ask questions about this.

Procedure

Following the initial call, participants were contacted at the agreed time for the interview. Participants took part in interviews from home either by telephone or secure video call using Attend Anywhere software provided by NHS Scotland. No others were present during the interviews. The interviews were audio-recorded using handheld digital devices and field notes were taken by the researcher. Interview schedule questions were supplemented with clarifying questions and probes to encourage expansion on provided answers. Participants were also asked if they would be willing to participate in member reflections and if they consented to being re-contacted for this purpose. Following the interviews,

participants were sent an information sheet containing contact details of local NHS clinicians and relevant support organisations. No repeat interviews were carried out.

Following initial analysis of interview data two participants who had consented to take part in member reflections were contacted to arrange for a summary of themes, conclusions and interpretations (Embi et al., 2004) of their individual interview data to be sent by post. Full copies of the interview transcripts were not returned to participants. Following receipt of the summaries the researcher then re-contacted these participants by phone and asked for their reflections on the findings.

Following the interviews, the CNS gathered basic data from medical records on participant age, gender, diagnosis, years since diagnosis, history of mental health problems, whether the patient had previously received mental health support, and whether the patient was invited to take part in a psychological wellbeing group previously offered by the local NHS service.

Data Analysis

Audio recordings were transcribed verbatim by the lead researcher as part of the familiarisation process. The resulting data was then analysed using framework analysis (Ritchie & Spencer, 2002) to identify key themes in the data. Framework analysis is a type of thematic analysis that is a grounded and systematic approach to synthesising and interpreting qualitative data (Ritchie & Spencer, 2002). It was chosen as the analysis method for the current study as it is a thematic approach in which themes can be identified both from the data itself and from the original research questions (Rabiee, 2004), and it is regularly used for analysing data from semi-structured interviews (Gale et al., 2013).

Data were organised and interpreted using the five-step approach proposed by Ritchie and Spencer (2002). The first stage involved the researcher familiarising themselves with the data by listening to and reading interview transcripts, and noting any initial themes. A combined inductive and deductive approach was then taken to construct a thematic framework. This was done by identifying themes driven by the interview schedule itself, issues expressed by participants, and concepts that were evident from patterns or repetitions in discussions with participants. The third stage involved the researcher indexing the individual interview transcripts according to the framework, and the fourth involved rearranging summaries of the data in Microsoft Excel charts according to theme. The final stage involved the researcher analytically studying the charted data to discover patterns and explanations, and using these findings to inform recommendations. Coding was carried out by the lead researcher. Another member of the research team (BC) reviewed one indexed interview transcript and provided reflections on the indexing process and initial themes. The aim of incorporating the views of a second researcher was to develop a fuller and deeper understanding, in keeping with the goals of 'crystallisation' (Madill et al., 2000; Tracy, 2010).

Following initial analysis and charting, member reflections were carried out with two participants to increase the credibility of the findings and methodological rigour of the study. The two participants were sent a summary of themes at the charting stage, with content from their individual interviews summarised according to theme. The participants were invited to give reflections on the framework themes and content of their initial interview. These member reflection interviews were audio recorded, transcribed, indexed and charted, and any clarifications or additional perspectives were incorporated into the final analysis.

Sample Size

The sample sizes detailed in previous qualitative interview studies utilizing the framework approach have varied substantially, from samples of 6 participants (Hackett & Strickland, 2018) through to samples as large as 77 participants (Parkinson et al., 2016). However, there often does not appear to be any clear theoretical justification for the choice of sample size, and this is a problem that has been reported in the wider field of qualitative health research (Vasileiou et al., 2018). The concept of theoretical saturation is used by some papers to justify sample size, and saturation has been reported by some researchers early in the process of thematic analysis of individual interviews. For example, Guest et al. (2006) reported that broad themes became apparent after analysis of just 6 interviews, and Hennink et al. (2017) reported discovering 84% of codes by the 6th interview they carried out. Additionally, literature on data sufficiency has found that codes can be identified with just 6-9 participants and 7-10 participants are needed for substantial theme identification, with further participants providing increased nuance (Young & Casey, 2019). Given these findings, the current study aimed for a sample size of 12 participants to ensure that codes and themes could be sufficiently identified.

Reflexivity

The researcher's theoretical stance is one of contextual constructionism. This epistemology posits that the analysis process and subsequent findings are subjective and dependent on the context of the participants and researcher, although still grounded in participant accounts. The goal of analysis is therefore to develop a richer understanding rather than to discover objective 'truths' (Madill et al., 2000).

Data collection and analysis were conducted by the lead researcher JW. JW is a female, university graduate, Trainee Clinical Psychologist with 2.5 years experience working within NHS Ayrshire and Arran. JW did not have contact with participants prior to recruitment. Participants were made aware of the researcher's job title and reasons for conducting the research in the participant information sheet.

Interviews took place in March and April 2021 during the COVID-19 pandemic and were consequently conducted by video or phone call.

A reflective log was kept by JW during the interview, transcription and coding phases to provide a reminder of issues not captured in the transcripts (such as contextual information) and to support the researcher's reflexivity. Samples of reflections are detailed in Appendix 2.8, p.142.

Results

Participant Characteristics

A total of 40 patients were invited to take part, 14 of whom responded. The first 12 individuals to reply were invited to participate in the interview, all of whom agreed. The length of interviews ranged from 28 to 95 minutes, with a mean duration of 55 minutes. Six participants were female and the age range of the sample was 56-74, with a mean age of 67. Eight participants were retired, two employed full-time, one employed part-time, and one unemployed. The time since PD diagnosis ranged from 1-12 years, with a mean of 5.58 years. One participant self-reported a mild impact of PD on their daily life, one mild to moderate, seven moderate, one moderate to severe, and two severe. Eleven participants were living in owned accommodation and one in rented accommodation. Six participants lived within

SIMD quintile 1 areas, one in quintile 2, two in quintile 3, and three in quintile 5. All participants were identified by the CNS as having had mental health difficulties and six were formally reported as having a history of mental health problems in their medical record. Interestingly only nine participants self-reported mental health difficulties during the interviews, although the remaining three mentioned some impact of PD or stress on their mental health. Eight participants reported having received support for their mental health.

Development of the Framework

An initial framework consisting of six main themes was used to index interview transcripts (Appendix 2.9, p.143), with new subthemes added as they were identified in the data. A sample of indexing is provided in Appendix 2.10, p.145. Review of one full indexed transcript by a second researcher informed the identification of a new theme which was incorporated into the framework. The framework was then condensed to five main themes which were used to structure the data during charting. Clarifications and feedback from the two member reflections were then incorporated into the charts. The two participants who took part in member reflections reported that the summaries sent to them were a good reflection of their individual interviews and they advised that the themes made sense and flowed well. The member reflections also led to elaboration of topics from the initial interviews, which allowed the researcher to develop a deeper understanding of these participants' experiences and opinions.

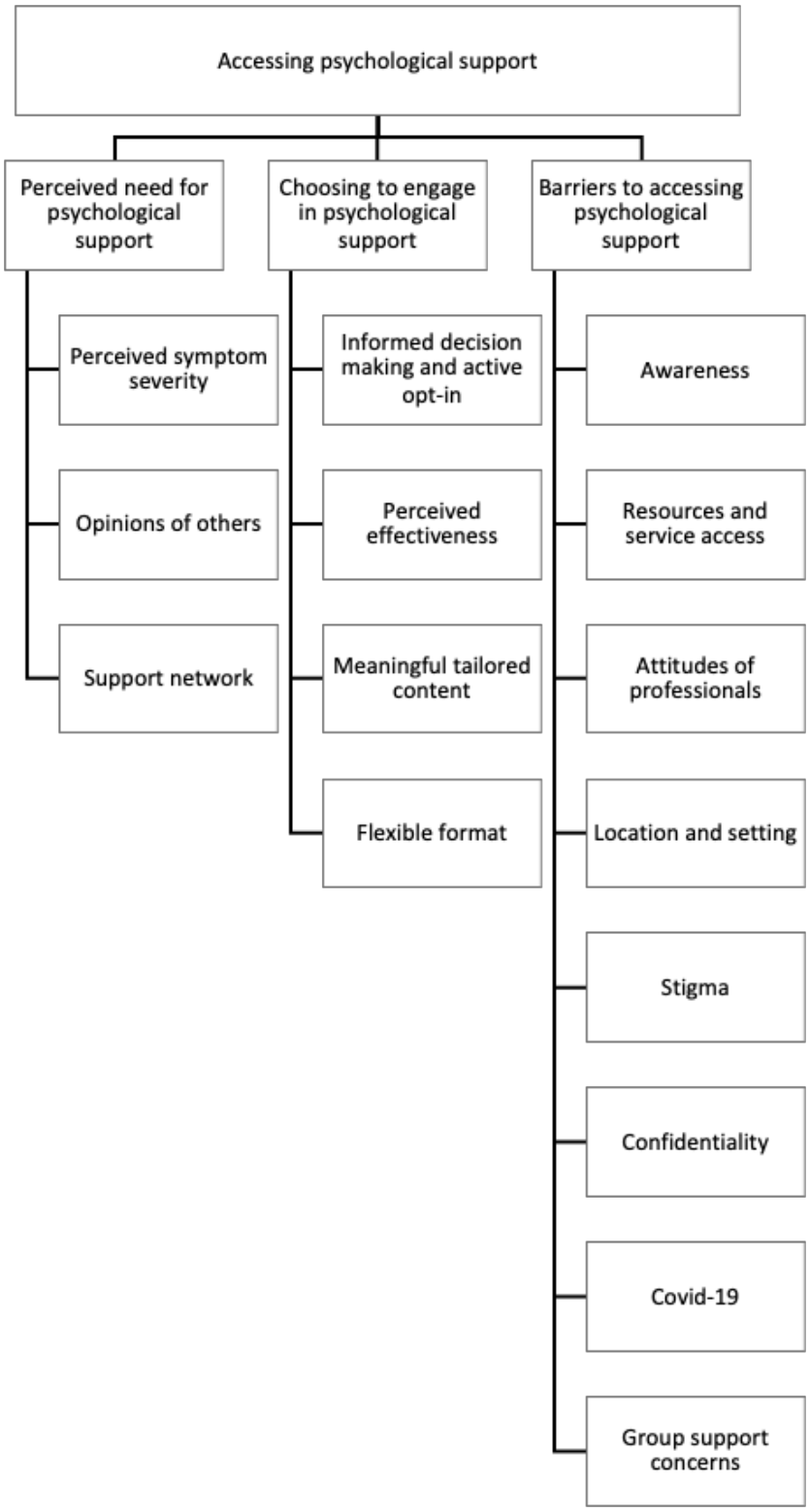
The framework was refined during mapping and interpretation stages to the final three core themes and fifteen subthemes displayed in Figure 2. All themes and subthemes were identified by the eighth interview, consistent with findings from data sufficiency literature (Young & Casey, 2019). The final framework represents the factors influencing people with

PD when considering accessing support from psychological services. This appears to be guided by three interlinked factors: the perceived need for support, choosing whether to engage in support given a need has been identified, and the barriers to accessing support. Each subtheme is described below, with relevant quotes from participants in italics.

The interviews produced further data relating to other issues (e.g. the impact of PD, personal experiences of support) which were indexed and charted but are not presented in the thesis as this was beyond the scope of the research questions.

Figure 2

Diagrammatic Representation of the Final Co-Constructed Themes and Subthemes



Perceived Need for Support

Perceived Symptom Severity

Throughout the interviews it became apparent that a shared criterion for accessing support from psychology services related to feeling that symptoms were "severe enough" that help is required: *"I just realised I'd got to rock bottom and I really needed the help. I think you really need to admit to yourself that you need it before you can accept it"* (P107).

The concept of resilience was also raised by a small number of participants who reported that they possessed a characteristic of "strength" and therefore did not need to access help: *"Personally I'm quite strong and so I don't feel the need"* (P102). Curiously, one participant who reported this also mentioned having previously sought counselling when experiencing difficult personal circumstances. Some participants also voiced an air of reluctance in seeking help: *"Well you don't want to admit when you need some help, you know, with your thoughts"* (P103).

Opinions of Others

Several participants noted that healthcare professionals identified the need for psychological support, at times before the participant themselves:

> *When I was diagnosed at first I thought I was OK but people around me and my consultant, my doctor said I wasnae handling it so I had to go and see a Psychologist. Well I didn't have to go. I went to her, she helped* (P108).

The importance of others identifying the need for support was also highlighted by a participant who had not previously accessed support: *"if I've heard that I definitely need some help I would definitely do it yeah"* (P111).

Support Network

Another factor impacting on the perceived need for psychological support was the quality and utilisation of participants' support networks. Two main sources of social support were identified. The first was support from family and friends. This was highlighted by some participants as a reason that psychological support was not needed: *"Personally for me it's not really something I would want to do. It would be OK if you didn't have any family or anybody to speak to, it would be an ideal situation"* (P106). However, it was recognised by participants that social support does not completely offset the need for psychological support, particularly when symptoms are more severe. Others noted concerns about sharing worries with family: *"it was really again just about offloading and feeling that I could speak about my fears and my concerns for the future without my family having to be burdened with it"* (P102).

The second source of support identified were peer support networks. Local community groups were described as a positive source of peer support by several participants: *"sometimes we just bounced off each other, you know, about things, which was quite good"* (P103). The groups also appeared to provide a sense of meaning and purpose for some participants, providing opportunity to meet others with PD and to give something back through shared activities such as fundraising.

Choosing to Engage in Support

Informed Decision Making and Active Opt-In

An issue that arose in many interviews related to providing patients with adequate appropriate information about the available services and allowing patients to make the decision on whether to attend: *"I think if you tell people the right information they can make an informed choice. Just getting it right first time, getting it out there and then people can make up their own mind"* (P102). Participants also noted the importance of not being put under pressure to attend: *"I think it's just you know making things a voluntary type of thing, you know people aren't being coerced into doing it"* (P104) or to share unwillingly: *"As long as you don't push people to talk about things they don't want to talk about"* (P107).

However, other participants advised that they would need to be "convinced" to try psychological support: *"I guess somehow it would just be a case of trying to be… convinced that you can't knock it 'til you've tried it, you know?"* (P111). This may also reflect the subtheme 'Opinions of others' whereby some would prefer for others to advise them that it would be helpful to try psychological support. Crucially, though, others can advise but the final decision must always be left to the patient themselves to actively opt-in or out.

Perceived Effectiveness

Some participants raised that their decision to engage in psychological support would be influenced by expectations of its effectiveness. When asked what would encourage them to participate in psychological support, one participant said: *"Well improving my mind, my mood. If that… if you improve that"* (P105). Considering this alongside the above subthemes regarding the opinions of others and informed decision making, it may be important to make

the potential benefits of psychological support apparent when it is offered: *"If it's explained to the person properly that it's going to help them, what would they be feart of? Why would they no want to go through with it?"* (P108).

Meaningful Tailored Content

Another factor that may impact on engagement is the content of what is being offered. When asked about preferences for the content of support, there was no unanimous preference across all participants. Some noted a desire for having a safe place to talk and be listened to, while others were looking for more practical coping strategies. One participant found CBT and Acceptance and Commitment Therapy (ACT) approaches helpful, while another was looking to discuss their worries, and another expressed a strong dislike for mindfulness, wellness and imagery approaches: *"if I found out when I was due to go to a group thing that it was this wellness thing all the time, these fangled words don't mean anything different. For me, it would still be a no"* (P109). Similarly, participants had different aims for attending support, from reducing muscle tension and anxiety to improving mood, to gaining confidence in managing PD. Participants also had different preferences for the temporal focus of support. Some were looking for a here-and-now focus and were strongly against discussion of the possible progression of PD:

> *I don't want to know these things. I know about these things and I'll face that when I come to it so I would hate for somebody to tell me what's ahead. I know what's ahead, I don't need to be told and I'll deal with that when it comes. So that would be a definite no-no to me* (P102).

Conversely, others expressed that they wanted to discuss the future and how life would be different with PD.

This highlights the differences between individuals and the need for treatment content and aims to be individualised and meaningful to each person. Indeed, this was raised by several participants and it was noted that it would be helpful to advise people of treatment options:

> *You could tell them what sort of things you can offer by the visit. Somebody who's further along would have different needs than somebody who's just been diagnosed. So maybe it would need to be suitable for the individual rather than just a group thing or just a set of questions or rules that you would have. You'd try and tailor it to the individual* (P112).

Similarly, participants advised that suggestions given in treatment would need to be manageable and realistic given the person's age and the stage of PD:

> *Some of the exercises they talk about like you know playing squash or racquet sports, well there's no way on earth can I run around a squash court or a tennis court. I'm 70 years of age with Parkinson's and all these other things wrong with me. So there's no point in someone trying to encourage me to play tennis* (P104).

On a similar note, some participants mentioned helpful adaptations to therapy such as avoiding jargon, breaking down the conversation into manageable sections, and providing short handouts: *"To break it down into fragments because... Well me, I tend not to- I take so much of the conversation and I don't remember the rest. You know what I mean? It's just sometimes there's too much"* (P103).

Flexible Format

The majority of participants indicated a preference for one-to-one psychological support over group support, with other participants being open to both formats. Several participants indicated they may be open to group psychological support following one-to-one appointments: *"if I found out that it was a group thing I wouldn't take part. Not immediately anyway"* (P109) and *"I think the one-to-one support was a good thing. If the sessions had continued maybe the next stage would have been meeting with other people"* (P101). Most participants also expressed a preference for face-to-face appointments over video or phone call, but again some participants were open to all formats.

Many participants indicated that shorter sessions would be better given the impact of PD on concentration: *"I mean it's about the concentration. And I know that's something that's altered for me, my spells of concentration have diminished a bit. So it would be... and I think thirty to forty-five minutes would be an ideal session"* (P110). However, others had a preference for sessions of up to an hour. A suggestion from some participants was to offer 30-minute sessions with the option of continuing for longer. This flexibility to the needs of each individual was again highlighted by participants as important for the format of support:

> *I think it's important for people to know that it would be tailored to their needs, you know it's not just one fits all.…People have to know that you know they'll be treated as an individual and the service will be as much as possible focused around their needs i.e. times, dates, even if they need help with transport or…* (P102).

Participants also expressed different preferences for the frequency of psychological support, from weekly sessions to once every few months. Similarly, participants had different preferences for the overall duration of psychological support. The key here appears to be flexibility to individual preference and need:

It depends on the patient really wouldn't it? I would imagine it might depend on how much the patient would need it. You know, so I think it would be good to let it roll until they say they don't want any more or they don't need any more, or you think they're maybe showing signs of improvement (P103).

Several participants indicated that the time of day of sessions would also need to be flexible, taking into account their medication and symptoms: *"I think Parkinson's people tend to have a wee bit of bother getting going in the morning. So I'd say mid-morning"* (P103) as well as their lifestyle and work: *"Well it needs to be evenings because I work. I suppose lunch times also a good time for it"* (P107).

Barriers to Accessing Support

Themes identified regarding barriers to accessing support are described below. Suggestions for strategies to overcome barriers derived from the barriers themselves and participant suggestions are summarised in Box 1.

Box 1

Suggestions for Overcoming Barriers to Accessing Psychological Support

Suggestions for overcoming barriers

Awareness

- Increasing awareness and information about available support

Resources and service access

- Improving communication between professionals involved in the care of people with PD
- Providing clarity on how to access psychological services
- Offering referral for psychological support at diagnosis
- Improving waiting times
- Increasing availability of psychological support

Attitudes of professionals

- Building rapport
- Respecting the patient and their decisions and preferences

Location and setting

- Local, easily accessible and non-stigmatised, neutral location e.g. GP surgery
- Comfortable and non-clinical setting
- Offering home visits

Stigma

- Increasing awareness and normalising psychological difficulties in PD

Confidentiality

- Providing clear information about confidentiality prior to accessing support and within both one-to-one and group support sessions

Covid-19

- Clinicians remaining accessible during lockdown periods
- Psychological services continuing to accept referrals during lockdown periods
- Respecting the preference of the patient for the format of support

Group support concerns

- Offering choice between one-to-one and group support
- Selecting group participants at similar stages of PD with similar levels of mental health difficulties
- Providing information about the characteristics of group members and what will be covered in the group in advance

Awareness

Participants spoke about the lack of awareness of psychological difficulties in PD:

> *Depression is a big part of this disease. People think they're going mad, they're not really going mad. It is an apathy, depression and apathy. People who don't- people seem to concentrate on the motor symptoms of the disease, not so much the psychological things* (P107).

*A*s well as the lack of awareness of psychological services: *"Well I actually haven't a clue about how... I don't know what functions you guys do or what's available or... how it would work or how it would happen. I'd need to be educated in that"* (P112). The need to make this information more widely available was mentioned by several participants: *"I would have to make an effort to try and do it so the more I know about it and how it works the more likely I am to actually access it"* (P111). This links to the informed decision-making subtheme; awareness needs to be increased about available supports and what they involve to allow people to make an informed decision.

Participants were asked about what would be helpful to include in an invitation letter for patients with PD about accessing psychological support. Participants' suggestions have been collated and summarised in Box 2. Participants also suggested psychological services could be advertised through other healthcare professionals, leaflets, posters (e.g., in GP surgeries), newsletters, phone calls, email, social media, at PD clinics, and by giving presentations at peer support groups.

Box 2

Suggestions for Content of an Invitation Letter to Attend Psychological Support

Suggestions for content of invitation letter

- Who has been sent the letter and why
- Normalising mental health difficulties in PD
- Explaining what psychological support is and what is being offered, making it clear that the patient can opt-in and attendance is not compulsory
- Aims of psychological support
- Information about the effectiveness of psychological support (e.g. research evidence or anonymous testimonials)
- What would be covered (e.g. content of sessions, type of approach), highlighting that this would be tailored to each individual's needs and preferences
- The format of support (e.g. one-to-one or group, face-to-face or video/phone call, time, day, session length, frequency, overall duration) and any flexibility within this to suit individual needs and preferences
- If group support is being offered, providing information about the characteristics of the group (e.g. people recently diagnosed with PD)
- Provision of any refreshments
- Information about confidentiality
- How to access the service (e.g. referral from GP or PD Nurse Specialist)
- Location of sessions and directions, information on public transport and parking

Resources and Service Access

An issue raised by some participants was difficulty accessing psychological services: *"You've got to know where to go to get help. If you don't know, that's you, you've had it. I think- I don't think that it's openly available"* (P106). A lack of resources was also highlighted by several participants: *"I know at times there's no availability for services because of the demand and finances so you've still got to be realistic"* (P102). Slow access to adult mental health services was also reported: *"People say there's all this help available, but if you try to get the help you find that it's not really available very quickly"* (P104). This was

in contrast to another participant who found that specialist psychological support for PD was available quickly, which may reflect differences in waiting times between services and areas:

> *Yes I was really surprised that I managed to... that I was seen so quickly. I can't remember how quickly it was but I imagined there would be a very long waiting list, but I think I was seen within a month* (P101).

Suggestions to improve service access included offering psychological support at PD clinics and routinely offering psychological support following PD diagnosis.

Many participants also raised a lack of coordination between services and the need to improve communication between different professionals involved in their care:

> *It's linkage between psychological services, my doctor and the Parkinson's specialists. ...I feel that my experience has been that it's difficult for them all to work in coordination. I'm sure that psychological services send reports to my doctor and the Parkinson's specialists but it's sometimes difficult to get things done and to know who the right person is to approach* (P101).

Attitudes of Professionals

Some participants described situations in which they were upset or annoyed by the manner or comments of healthcare professionals or group coordinators to the extent that they did not return to the service or group:

> *I think it's the people that take it. They either endear you to them or they don't. I think that can be off-putting right away if you go in and you get this don't care about you, don't care what you attitude. That's- that's the way I felt. Never went back* (P106).

Others described more positive experiences: *"[Name of clinician] was very... had a very good manner. I think she put me at my ease and I actually enjoyed the sessions"* (P101). Important qualities participants identified in a clinician included: rapport, openness, good

listening skills, easy to talk with, empathy, having a nice and calming manner, smiling, and the ability to make the patient laugh and put them at ease.

Location and Setting

Locations that are far away or difficult to get to were reported by some participants as off-putting: *"I suppose the only thing I could say that was unhelpful was I had to travel to get the support. ...And I wasnae always up for driving that distance. So that's the only difficulty though"* (P110). Additionally, hospital locations were reported to cause anxiety and some locations were viewed as having negative connotations:

> *It was quite intimidating going into that place the first time. …There's a lot of drug users and things as well that go to that place as well. So I'm there thinking do folk think I've got a drug problem or a drink problem?* (P107).

The setting of the room in which psychological support takes place was also noted to be important: *"Well it's where you are. Where are you going to be doing the talking to this person? You need somewhere that you feel at ease. Sitting in an office like room with a desk between is not good"* (P109).

When planning the location, participants' recommendations included: ensuring the location is accessible by public transport, car and taxi; considering patients' mobility and the building accessibility (e.g. stairs, lifts); offering home visits; and conducting sessions in a comfortable setting rather than office-like, clinical settings or locations with negative connotations.

Stigma

Some participants felt that stigma could impact on willingness to access psychological support: "*it's the stigma of going to a Psychologist for a lot of people that puts them off"* (P109). Others felt that stigma and acceptance of mental health issues is improving and more education about these issues is needed:

> *I think we're getting better at saying that mental health issues are just like- if somebody's got a broken leg we sign the plaster or whatever you know. If somebody's mind is broken we need to have that same acceptance. You know? It's a break, it's an illness. So we need to be educating folk that it's the same kind of thing. It's an illness, you know. So that I think- more education to acceptance. I think we're on- we're getting on that right road. We're certainly getting on that right road* (P110).

Confidentiality

Several participants mentioned the importance of confidentiality: *"I know it's all confidential and if you want it to be confidential then it's fine"* (P107). Confidentiality within group settings was also raised as a concern by one participant: *"with the confidentiality, you know that she had with us, you know, what happens in the group stays in the group. But then again you're going right would you keep that?"* (P103). Providing reassurance about confidentiality when offering psychological support was recognised as important: *"Well I think everybody knows about confidentiality but it doesn't harm to keep mentioning it because people don't like their so-called secrets let out"* (P109).

Covid-19

The impact of the Covid-19 pandemic on the provision of healthcare services was brought up by many participants. Participants advised that their usual contact with healthcare professionals had decreased, local peer support groups had stopped meeting face-to-face and NHS group support had been paused since the beginning of the pandemic.

As noted previously, most participants indicated a preference for face-to-face psychological support but many recognised this was not possible due to the pandemic. Some were willing to use video call as an alternative while others indicated this could be a barrier: *"other than the business about face-to-face really would be the only thing that would kind of put me off a wee bit"* (P111). Some felt the lack of face-to-face contact was impacting on their communication with healthcare professionals with potential knock-on impacts on their care:

> *It's difficult to at this particular time with the lockdown and that we've not had any specific person-to-person contact with the Parkinson's specialist. The most I've had is a phone call. So that's difficult to communicate what's really going on in a short phone call* (P101 member reflections).

Given this, it is important that the impact of the pandemic on access to psychological services is minimised as much as possible.

Group Support Concerns

Several concerns about group support were voiced during the interviews. Worries about meeting new people and not feeling comfortable with others in a group were raised: *"Well I get uptight meeting people so that would discourage me"* (P105) and *"I'd maybe feel a bit uncomfortable with people that I didn't know. …Aye. It would maybe make me… I know it would make me anxious"* (P112).

Concerns about the heterogeneity of group attendees were expressed by many participants. One aspect of this regarded differences in mental health needs: *"I think it's such a personal issue. And my mental health issues might be completely different from somebody else's in a group"* (P110) and worrying about others between sessions:

> *But I feel like going to a mixed one, a mixed bag of people, it's quite hard for you to understand and obviously you end up stressed going oh no, is he going to be ok? And you're going to the next meeting going how are you? You know and you're taking on somebody else's problems* (P103).

Similarly, heterogeneity in the PD stage of attendees was a concern for many participants:

> *Personally it's not for me because I just live a day at a time but I feel like if you go to these groups you might see people who are much more in advance and to me it's a bit scary because you think am I going to end up like that? So yeah, personally that's why I don't go to these groups* (P102).

A potential solution to this barrier can be found by looking to a local peer support group which was set up for younger people at similar stages of PD. It would also be important for group members to have similar mental health needs, and choice offered between one-to-one and group support.

Discussion

The interview data gave rise to a breadth of information not anticipated at the beginning of the project, and the final themes reflect a number of factors influencing people with PD when considering accessing psychological support. This was distilled down to three main themes: perceived need for support, choosing to engage in support, and the barriers to accessing support.

The perceived need for support appears to be driven by three subthemes. Participants indicated that symptoms would need to reach a certain level of severity before psychological support was accessed. The concept of resilience and reluctance to acknowledge the need for support were also discussed. The characteristic of "strength" has historically been regarded as an admirable quality in the geographical area in which the study was conducted. This may be underlying some participants' reluctance to seek help. It may be that the concepts of "needing support" and "resilience" act in opposition with one another, whereby it is felt that the characteristic of "strength" needs to be put aside or reduced in order for one to be able to seek support, leading to reluctance to seek support until eventually feeling that problems are "severe enough" that professional help is required.

Others' opinions were also found to be important in identifying the need for help, and at times others identified this need prior to the participant themselves. This idea was reflected in recruitment for the current study. Participants who were invited to take part were identified by a PD CNS as having had difficulties with mental health, while participants themselves did not all self-identify as having had mental health difficulties. Linking to the previous subtheme, it may be that participants did not feel their difficulties were "severe enough" to warrant a label of mental health difficulties, or these participants may be reluctant to apply

the label of "mental health difficulties" to themselves for the reasons discussed above, which may account for this difference.

The quality and utilisation of participants' support networks was also found to impact on the perceived need for support. Family, friends and local peer support groups were all identified as important sources of social support. However it was recognised that social support does not offset the need for psychological support when symptoms are more severe.

The second theme 'Choosing to engage in support' explored the factors influencing the choice to engage in support, given a need for support has been identified. In other words, what makes people want to engage in support? The subthemes 'Meaningful tailored content' and 'Flexible format' correspond to the first research question: 'What are the preferences of patients with PD for the content and format of support for psychological wellbeing?' The key messages of these subthemes were the differences between individuals and the need to tailor the content and format of psychological support to individual preference and need.

The third theme corresponds to the second research question: 'What views and experiences do patients have on the barriers to participation in psychological support and how these can be overcome?' Within the 'Awareness' subtheme, participants' suggestions for the content of an invitation letter to attend psychological support were collated, corresponding to the third research question: 'What are the opinions of patients on what would be helpful to include in an initial invitation letter to be sent to patients to provide more information about the services offered?' It is important to note that suggestions made regarding strategies to overcome barriers and content of an invitation letter need to be considered in the context of the current study, and readers must consider if these recommendations are appropriate for other settings and contexts.

Several of the subthemes identified in the current study correspond to barriers and issues identified in previous research. For example, the subtheme in the current study of 'Location and setting' corresponds to location and transport issues identified in previous research (Dobkin et al., 2013; Oehlberg et al., 2008; Sajatovic et al., 2017). In common with two previous studies, stigma was also identified as a barrier (Oehlberg et al., 2008; Troeung et al., 2015). Troeung et al. (2015) identified that younger age and expectations of the effectiveness of interventions predicted uptake of services. The current study also identified perceived effectiveness as a key consideration when choosing whether to access psychological services. Younger age was not identified as a factor in the current study however the age range of the sample was relatively young, and so the views of older patients with PD may have differed. Sajatovic et al. (2017) found that running sessions at fixed times made group participation more difficult, and the time of sessions was also identified in the current study within the subtheme 'Flexible format' as a consideration when deciding whether to access support. Other barriers identified by Dobkin et al. (2013) included the availability of services in the local community and lack of quality treatment options, which correspond with subthemes in the current study regarding location and setting, resources and service access, and meaningful tailored content. Dobkin et al. (2013) also report barriers such as "Anyone in my situation would be struggling" and "Doctors are not sensitive enough to PD related issues" which are reflected in the current study in discussions around perceived need for support, lack of awareness and issues regarding service access. Interestingly, another barrier identified by these authors was physical impairments, which was not found to be a barrier in the current study. This may be due to overlap with other subthemes such as 'Location and setting' which covered concerns about mobility and physical access. Another potential reason for this discrepancy may be differences in the severity of PD between participants in the two studies. In the current study only two participants identified the impact

of their PD as severe, with most reporting a moderate impact. The Dobkin et al. (2013) questionnaire study had a very large sample which may have included more individuals at advanced stages of PD. Finally, Oehlberg et al. (2008) found that some patients reported concerns around talking about personal problems to people they did not know. Similar topics arose in the current study within subthemes of 'Confidentiality' and 'Attitudes of professionals' in discussions around the importance of building rapport.

The current study mirrors previous findings and delineates the different factors associated with the perceived need for support, the choice to engage in psychological support, and barriers to accessing support. This study also expands on previous findings through the identification of barriers regarding group psychological support and the impact of the Covid-19 pandemic, as well as investigating preferences for the content and format of support, and exploring strategies to overcome barriers.

One potential limitation of the study pertains to the recruitment process and resulting sample. As noted previously, forty patients were sent invitation letters to participate and fourteen responses were received. Thus, it may be that the final sample were particularly proactive and had considerably positive or strong opinions regarding psychological support.

Another potential limitation is that participants may have been reluctant to share negative opinions of psychological services given the researcher's role within these services. However, participants were made aware at the stage of consent that their participation would not impact on their care and many participants offered constructive feedback during interviews. On a similar note, the lead researcher's role in these services may have influenced the co-constructed meanings produced from the interviews themselves as well as analysis and interpretation. Given the researcher's epistemological stance, this is not considered a limitation in itself but reinforces the contextual nature of the results.

Another limitation is that data on ethnicity and sexuality were not gathered during the project due to concerns regarding identification of individuals in a small sample. However, given the possibility for these factors to give rise to differences in meaning in qualitative research (Tracy, 2010), it would have been advantageous to gather this information.

Strengths of the study include its methodological rigour and use of reflective practices. The reflective log kept by the lead researcher throughout the project was used to document reflections and reflexivity, including the researcher's potential contextual influences on data collection, analysis and interpretation. A second researcher reviewed one full indexed interview transcript to enrich the analysis process and incorporate an additional perspective. Member reflections were also invited from two participants, and their clarifications and reflections were incorporated into the final results. The sample included participants who had previously sought psychological support and those who had not, which provided a more diverse perspective on the process of accessing services and potential barriers. Additionally, SIMD data suggested that the sample represented individuals from a range of socio-economic backgrounds.

The findings of the current study have clinical implications for promoting access to psychological services for individuals with PD and several suggestions are made throughout the paper regarding this. However, it must be noted that this was a qualitative study conducted with a small sample of individuals with PD in a specific geographical area within the UK NHS. Consequently, care must be taken when considering generalising findings to other contexts and populations. Nonetheless, this study provides a valuable insight into the preferences, opinions and experiences of individuals with PD regarding psychological support for wellbeing. Future research in this area could explore the opinions of older patients at later stages of PD regarding psychological support, as well as the opinions of carers and

family members. It would be interesting to note if the preferences and opinions of these groups differed and if so, how could psychological services be improved for these groups.

Conclusion

This study explored the preferences, opinions and experiences of patients with PD regarding psychological support for wellbeing. Three interlinked factors were identified which influence people with PD when accessing psychological support: perceived need for support, choosing to engage in support, and the barriers to accessing support. Participants expressed the importance of tailoring the content and format of support to individual need and preference. Other factors impacting access to psychological services were explored, with several barriers to accessing services identified and suggestions given on strategies to overcome these barriers. The findings demonstrate the importance of increasing awareness of psychological services, improving service accessibility, and identifying the individual needs of patients with PD when delivering psychological support for wellbeing.

References

Chen, J. J., & Marsh, L. (2014). Anxiety in Parkinson's disease: identification and management. *Therapeutic Advances in Neurological Disorders, 7*(1), 52-59.

Dobkin, R. D., Rubino, J. T., Friedman, J., Allen, L. A., Gara, M. A., & Menza, M. (2013). Barriers to mental health care utilization in Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology, 26*(2), 105-116.

Embi, P. J., Yackel, T. R., Logan, J. R., Bowen, J. L., Cooney, T. G., & Gorman, P. N. (2004). Impacts of computerized physician documentation in a teaching hospital: perceptions of faculty and resident physicians. *Journal of the American Medical Informatics Association, 11*(4), 300-309.

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology, 13*(1), 1-8.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82.

Hackett, A., & Strickland, K. (2018). Using the framework approach to analyse qualitative data: a worked example. *Nurse Researcher, 26*(3), 8-13.

Hadinia, A., Meyer, A., Bruegger, V., Hatz, F., Nowak, K., Taub, E., Nyberg, E., Stieglitz, R.-D., Fuhr, P., & Gschwandtner, U. (2017). Cognitive behavioral group therapy reduces stress and improves the quality of life in patients with Parkinson's disease. *Frontiers in Psychology, 7*, 1975.

Hennink, M. M., Kaiser, B. N., & Marconi, V. C. (2017). Code saturation versus meaning saturation: how many interviews are enough? *Qualitative Health Research, 27*(4), 591-608.

Krueger, R. A., Casey, M. A., Donner, J., Kirsch, S., & Maack, J. N. (2001). Social analysis: selected tools and techniques. *World Dev, 36*.

Letourneau, N., Tryphonopoulos, P. D., Duffett-Leger, L., Stewart, M., Benzies, K., Dennis, C.-L., & Joschko, J. (2012). Support intervention needs and preferences of fathers affected by postpartum depression. *The Journal of Perinatal & Neonatal Nursing, 26*(1), 69-80.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology, 91*(1), 1-20.

Oehlberg, K., Barg, F. K., Brown, G. K., Taraborelli, D., Stern, M. B., & Weintraub, D. (2008). Attitudes regarding the etiology and treatment of depression in Parkinson's disease: a qualitative study. *Journal of Geriatric Psychiatry and Neurology, 21*(2), 123-132.

Parkinson, S., Eatough, V., Holmes, J., Stapley, E., & Midgley, N. (2016). Framework analysis: a worked example of a study exploring young people's experiences of depression. *Qualitative Research in Psychology, 13*(2), 109-129.

Prediger, R. D., Matheus, F. C., Schwarzbold, M. L., Lima, M. M., & Vital, M. A. (2012). Anxiety in Parkinson's disease: a critical review of experimental and clinical studies. *Neuropharmacology, 62*(1), 115-124.

Rabiee, F. (2004). Focus-group interview and data analysis. *Proceedings of the Nutrition Society, 63*(4), 655-660.

Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research. In *Analyzing Qualitative Data* (pp. 187-208). Routledge.

Sajatovic, M., Ridgel, A. L., Walter, E. M., Tatsuoka, C. M., Colón-Zimmermann, K., Ramsey, R. K., Welter, E., Gunzler, S. A., Whitney, C. M., & Walter, B. L. (2017). A randomized trial of individual versus group-format exercise and self-management in individuals with Parkinson's disease and comorbid depression. *Patient Preference and Adherence, 11*, 965-973.

Swift, J. K., Callahan, J. L., Cooper, M., & Parkin, S. R. (2018). The impact of accommodating client preference in psychotherapy: A meta-analysis. *Journal of Clinical Psychology, 74*(11), 1924-1937.

The British Psychological Society. (2021). Psychological interventions for people with Huntington's disease, Parkinson's disease, motor neurone disease, and multiple sclerosis: Evidence-based guidance. https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Psychological%20interventions%20-%20Huntingtons%2C%20Parkinsons%2C%20motor%20neurone%20disease%2C%20multiple%20sclerosis.pdf

Todd, N. J., Jones, S. H., & Lobban, F. A. (2013). What do service users with bipolar disorder want from a web-based self-management intervention? A qualitative focus group study. *Clinical Psychology & Psychotherapy, 20*(6), 531-543.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357.

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry, 16*(10), 837-851.

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), 1-11.

Troeung, L., Gasson, N., & Egan, S. J. (2015). Patterns and predictors of mental health service utilization in people with Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology, 28*(1), 12-18.

Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology, 18*(1), 1-18.

Yamanishi, T., Tachibana, H., Oguru, M., Matsui, K., Toda, K., Okuda, B., & Oka, N. (2013). Anxiety and depression in patients with Parkinson's disease. *Internal Medicine, 52*(5), 539-545.

Young, D. S., & Casey, E. A. (2019). An examination of the sufficiency of small qualitative samples. *Social Work Research, 43*(1), 53-58.

Zarotti, N., Eccles, F. J., Foley, J. A., Paget, A., Gunn, S., Leroi, I., & Simpson, J. (2020). Psychological interventions for people with Parkinson's disease in the early 2020s: Where do we stand? *Psychology and Psychotherapy: Theory, Research and Practice*.

Zhang, Q., Yang, X., Song, H., & Jin, Y. (2020). Cognitive behavioral therapy for depression and anxiety of Parkinson's disease: A systematic review and meta-analysis. *Complementary Therapies in Clinical Practice, 39*, 101-111.

Appendices

Appendix 1.1 Relevant sections of author submission guidelines for Journal of Geriatric Psychiatry and Neurology

Available at: https://journals.sagepub.com/author-instructions/JGP

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Journal of Geriatric Psychiatry and Neurology, please ensure you have read the Aims & Scope.

1.2 General Instructions

Manuscripts should be submitted electronically to https://mc.manuscriptcentral.com/jgpn.

All material (abstracts, keywords, text, tables, and figure captions) should be typed double-spaced. Computer preparation is mandatory. Subheading should be used to designate the different sections of the text. References should be numbered consecutively throughout the text. Provide a list of three to six keywords to assist indexing of the article.

Articles of any length are considered.

Title page: The title should be brief and meaningful. The authors' first and last names, academic or medical degrees, and affiliations should follow the title. Authorship should be limited to direct participants, although technical assistance can be acknowledged as a footnote. A separate paragraph should identify where the work was done, if supported by a grant or otherwise, and the meeting, if any, at which the paper was presented.

Abstract: An abstract of approximately 150 words should be provided on. This abstract should be factual and should present the reason for the study, the main findings, and the principal conclusions.

Text: This should follow the usual format for scientific articles. Pages should be numbered consecutively. All abbreviations should be spelled out at first mention. Only generic names of drugs should be used.

Figures and tables: Special care should be given to the preparation of figures and tables, including captions and explanatory information. Technical excellence is stressed. Lettering and arrows, where applicable, should be done in a professional manner. Color illustrations are unacceptable for publication without prior permission of the publisher. Recognizable photographs of patients must be masked and must carry with them written permission for publication. Captions for all figures should be typewritten double-spaced, with numbers corresponding to those on the figures themselves.

Tables should be numbered consecutively according to their in-text citation. Each should be typed double-spaced and should be no larger than a single page. Include a brief descriptive title and an indication of its position in the text.

References: Authors are responsible for correctness and completeness of references. References should be typed double-spaced on separate pages. They should be arranged according to their order of appearance in the text, and indicated by superscript numbers. References should be typed in accordance with the style shown below for book and journal articles. Up to four authors should be listed; when there are more than four, only the first three should be listed, followed by "et al." Abbreviations of journal names should conform to the style in Index Medicus. Abstracts, editorials, and letters to the editor should be noted as such. Personal communications, unpublished manuscripts submitted but not yet accepted, and similar unpublished items should not appear in the reference list. Such citations may be noted in the text. Some basic information regarding references and the reference list has been listed below.

References List

Basic rules for the reference list:

- The title “References” is centered at the top of a separate page at the end of the document.
- Entries are preceded by their number and are given in numerical order.
- The reference list should be single-spaced. Single-space between entries.
- The second line and all subsequent lines of each item in the reference list should be indented (hanging indent).
- Do not use “et al.” in the Reference list at the end; names of all authors of a publication should be listed there.

Appendix 1.2 Search strategy for each database

Ovid Medline:

1	Randomized controlled trials as Topic/
2	Randomized controlled trial/
3	Random allocation/
4	Double blind method/
5	Single blind method/
6	Clinical trial/
7	exp Clinical Trials as Topic/
8	or/1-7
9	(clinic$ adj trial$1).tw.
10	((singl$ or doubl$ or treb$ or tripl$) adj (blind$3 or mask$3)).tw.
11	Placebos/
12	Placebo$.tw.
13	Randomly allocated.tw.
14	(allocated adj2 random).tw.
15	or/9-14
16	8 or 15
17	Case report.tw.
18	Letter/
19	Historical article/
20	Review of reported cases.pt.
21	Review, multicase.pt.
22	or/17-21
23	16 not 22
24	exp Parkinsonian Disorders/
25	parkinson*.tw.
26	24 or 25

27 exp Psychotherapy/

28 exp social support/

29 exp Self-Help Groups/

30 exp Adaptation, Psychological/

31 psychosocial intervention*.tw.

32 social support.tw.

33 social network*.tw.

34 support system*.tw.

35 self-help group*.tw.

36 support group*.tw.

37 educational therapy.tw.

38 psychotherapy.tw.

39 behavio* therapy.tw.

40 family therapy.tw.

41 group therapy.tw.

42 group intervention*.tw.

43 cogniti* therapy.tw.

44 psychological adjustment*.tw.

45 psychological adaptation.tw.

46 adaptive behavio*.tw.

47 coping behavio*.tw.

48 coping intervention*.tw.

49 coping strateg*.tw.

50 coping skill*.tw.

51 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50

52 23 and 26 and 51

Ovid Embase:

1 Clinical trial/

2 Randomized controlled trial/

3 Randomization/

4 Single blind procedure/

5 Double blind procedure/

6 Crossover procedure/

7 Placebo/

8 Randomi?ed controlled trial$.tw.

9 Rct.tw.

10 Random allocation.tw.

11 Randomly allocated.tw.

12 Allocated randomly.tw.

13 (allocated adj2 random).tw.

14 Single blind$.tw.

15 Double blind$.tw.

16 ((treble or triple) adj blind$).tw.

17 Placebo$.tw.

18 Prospective study/

19 or/1-18

20 Case study/

21 Case report.tw.

22 Abstract report/ or letter/

23 or/20-22

24 19 not 23

25 exp Parkinsonian Disorders/

26 parkinson*.tw.

27 25 or 26

28 exp Psychotherapy/

29 exp social support/

30 exp Self-Help Groups/

31 exp Adaptation, Psychological/

32 psychosocial intervention*.tw.

33 social support.tw.

34 social network*.tw.

35 support system*.tw.

36 self-help group*.tw.

37 support group*.tw.

38 educational therapy.tw.

39 psychotherapy.tw.

40 behavio* therapy.tw.

41 family therapy.tw.

42 group therapy.tw.

43 group intervention*.tw.

44 cogniti* therapy.tw.

45 psychological adjustment*.tw.

46 psychological adaptation.tw.

47 adaptive behavio*.tw.

48 coping behavio*.tw.

49 coping intervention*.tw.

50 coping strateg*.tw.

51 coping skill*.tw.

52 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51

53 24 and 27 and 52

EBSCOhost PsycINFO:

S22 S3 AND S21

S21 S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20

S20 TI ("psychosocial intervention*" or "social support" or (social n1 network*) or (support n1 system*) or (self-help n1 group*) or (support n1 group*) or “educational therapy*” or psychotherapy or "behavio* therapy" or "family therapy" or "group therapy" or "group intervention*" or "cognitive therapy" or "cognition therapy" or (psychological n1 adjustment) or "psychological adaptation" or "adaptive behavio*" or "coping behavio*" or "coping intervention" or "coping strateg*" or "coping skill*") OR AB ("psychosocial intervention*" or "social support" or (social n1 network*) or (support n1 system*) or (self-help n1 group*) or (support n1 group*) or “educational therapy*” or psychotherapy or "behavio* therapy" or "family therapy" or "group therapy" or "group intervention*" or "cognitive therapy" or "cognition therapy" or (psychological n1 adjustment) or "psychological adaptation" or "adaptive behavio*" or "coping behavio*" or "coping intervention" or "coping strateg*" or "coping skill*")

S19 DE "Psychoeducation"

S18 DE "Coping Behavior" OR DE "Coping Style"

S17 DE "Adaptive Behavior"

S16 DE "Group Intervention"

S15 DE "Family Therapy" OR DE "Conjoint Therapy" OR DE "Strategic Family Therapy" OR DE "Structural Family Therapy"

S14 DE "Educational Therapy"

S13 DE "Mindfulness-Based Interventions"

S12 DE "Behavior Therapy"

S11 DE "Anxiety Management"

S10 DE "Cognitive Therapy"

S9 DE "Cognitive Behavior Therapy" OR DE "Acceptance and Commitment Therapy" OR DE "Cognitive Processing Therapy" OR DE "Prolonged Exposure Therapy"

S8 DE "Emotional Adjustment"

S7 DE "Self-Help Techniques" OR DE "Self-Management"

S6 DE "Support Groups"

S5 DE "Social Support"

S4 DE "Psychotherapy" OR DE "Adlerian Psychotherapy" OR DE "Adolescent Psychotherapy" OR DE "Affirmative Therapy" OR DE "Analytical Psychotherapy" OR DE "Autogenic Training" OR DE "Brief Psychotherapy" OR DE "Brief Relational Therapy" OR

DE "Child Psychotherapy" OR DE "Client Centered Therapy" OR DE "Conversion Therapy" OR DE "Couples Therapy" OR DE "Eclectic Psychotherapy" OR DE "Emotion Focused Therapy" OR DE "Existential Therapy" OR DE "Experiential Psychotherapy" OR DE "Expressive Psychotherapy" OR DE "Eye Movement Desensitization Therapy" OR DE "Feminist Therapy" OR DE "Geriatric Psychotherapy" OR DE "Gestalt Therapy" OR DE "Group Psychotherapy" OR DE "Guided Imagery" OR DE "Humanistic Psychotherapy" OR DE "Hypnotherapy" OR DE "Individual Psychotherapy" OR DE "Insight Therapy" OR DE "Integrative Psychotherapy" OR DE "Interpersonal Psychotherapy" OR DE "Logotherapy" OR DE "Narrative Therapy" OR DE "Network Therapy" OR DE "Persuasion Therapy" OR DE "Primal Therapy" OR DE "Psychoanalysis" OR DE "Psychodrama" OR DE "Psychodynamic Psychotherapy" OR DE "Psychotherapeutic Counseling" OR DE "Psychotherapeutic Techniques" OR DE "Rational Emotive Behavior Therapy" OR DE "Reality Therapy" OR DE "Relationship Therapy" OR DE "Solution Focused Therapy" OR DE "Strategic Therapy" OR DE "Supportive Psychotherapy" OR DE "Transactional Analysis"

S3 S1 OR S2

S2 TI parkinson* OR AB parkinson*

S1 DE "Parkinson's Disease" OR DE "Parkinsonism"

CENTRAL database:

#1 MeSH descriptor: [Parkinson Disease] explode all trees

#2 parkinson*:ti,ab

#3 #1 or #2

#4 MeSH descriptor: [Social Support] explode all trees

#5 MeSH descriptor: [Self-Help Groups] explode all trees

#6 MeSH descriptor: [Psychotherapy] explode all trees

#7 MeSH descriptor: [Adaptation, Psychological] explode all trees

#8 "psychosocial intervention*":ti,ab or "social support":ti,ab or (social next network):ti,ab or (support next system*):ti,ab or (self-help next group*):ti,ab or (support next group*):ti,ab or "educational therapy*":ti,ab or psychotherapy:ti,ab or "behavio* therapy":ti,ab or "family therapy":ti,ab or "group therapy":ti,ab or "group intervention*":ti,ab or "cognitive therapy":ti,ab or "cognition therapy":ti,ab or (psychological next adjustment):ti,ab or "psychological adaptation":ti,ab or "adaptive behavio*":ti,ab or "coping behavio*":ti,ab or "coping intervention":ti,ab or "coping strateg*":ti,ab or "coping skill*":ti,ab

#9 #4 or #5 or #6 or #7 or #8

#10 #3 and #9

Appendix 2.1 Major research project revised proposal

Abstract

Background: Parkinson's disease is associated with high rates of depression and anxiety, for which group Cognitive Behavioural Therapy (CBT) may be an effective treatment. However, previous studies suggest that uptake of group CBT in this population is limited, and this was also the experience of the Neuropsychology and Older Adult services in NHS Ayrshire & Arran when these services offered a group CBT intervention to patients with Parkinson's disease.

Aims: The aim of this project is to gain a better understanding of the preferences of service users with Parkinson's disease for psychological support, and how barriers to participation can be overcome.

Methods: One-to-one semi-structured interviews will be conducted with 10-12 service users aged 18 or over with Parkinson's disease in the NHS Ayrshire & Arran health board, with questions covering topics such as content and format of psychological support, and barriers to participation. Framework analysis will be conducted on the resulting data to identify themes that emerge from the interviews, and member checks will be carried out to increase credibility of the results.

Applications: Results from the interviews will be used to develop recommendations for providing psychological support for people with Parkinson's disease, and will be used to guide the development and delivery of psychological support in a local service.

Introduction

Parkinson's disease is a neurodegenerative disorder characterised by both motor symptoms, such as a resting tremor and rigidity, and non-motor symptoms, such as cognitive and olfactory problems (Prediger et al., 2012). Parkinson's disease is also associated with high rates of depression and anxiety, with studies estimating the prevalence of depression at around 31% (Slaughter et al., 2001), and the prevalence of anxiety also at 31% (Broen et al., 2016). There are limited available treatments for mood disorders in Parkinson's disease (Chen & Marsh, 2014). However, there is some evidence to suggest that a Cognitive Behavioural Therapy (CBT) approach may be effective in reducing depression and anxiety symptoms in individuals with Parkinson's disease (Bomasang-Layno et al., 2015; Egan, Laidlaw & Starkstein, 2015).

A small number of studies have also investigated the efficacy of group interventions for mood, anxiety and wellbeing in Parkinson's disease. Group interventions may be more cost effective than one-to-one therapy (Brown, 2011; McDermut, Miller & Brown, 2001), and the group format may provide other benefits to participants (Whitfield, 2010), including a feeling of social cohesion that has been reported in some group interventions for Parkinson's disease (Fitzpatrick, Simpson & Smith, 2009; Pohl et al., 2020).

One study into group interventions from Hadinia et al. (2017) compared group CBT to a health enhancement programme for patients with Parkinson's disease, and found CBT to be more effective in reducing stress and improving quality of life. In another group intervention study, Troeung, Egan and Gasson (2014) found that group CBT reduced levels of depression and anxiety in comparison to a waitlist

control, and these effects were maintained at a 6-month follow-up. Similar results have also been reported in two small uncontrolled studies into group CBT for depression and anxiety in Parkinson's disease (Berardelli et al., 2015; Feeney, Egan & Gasson, 2005).

However, in two of these group intervention studies there was a notable dropout of participants from expression of interest in the study to participation. Hadinia et al. (2017) report recruiting 41 patients, 11 of whom dropped out. Reasons for drop out included: participants choosing not to continue, or missing two or more sessions, and health related problems. In addition, Troeung, Egan and Gasson (2014) noted dropout of individuals from expression of interest in the study to participation. They report that 45 people indicated their interest in taking part, 16 of whom later opted out after they were given more information about the study. Six participants indicated this was due to various practical reasons, while the remaining ten did not give a reason.

This experience of substantial drop-out rates has also been mirrored in a Psychological service setting. In NHS Scotland's Ayrshire & Arran health board, the Neuropsychology and Older Adult services developed a psychological wellbeing group for people with Parkinson's disease based on CBT approaches. The services gave a presentation to referring clinicians regarding the use of a "distress thermometer" tool to identify potential emotional problems, and some information about the group itself, so they would have a clear understanding of the group's purpose and content in order to inform patients. However, when the service offered the group intervention to patients with Parkinson's disease, patients either did not opt in, or agreed to be referred to the group but then opted out when they received a letter with more information, and so the group was not run. The service has identified

that the content or format of the intervention offered may not have been in line with the needs and wants of service users with Parkinson's disease for psychological support. Additionally some practical components of the group, such as time of day, may have created barriers for some service users accessing the group intervention.

The idea that practical issues may have been a barrier to participation is supported by findings from a study from Sajatovic et al. (2017) into group exercise interventions for people with Parkinson's disease. In this study participants reported that they enjoyed the social aspects of groups but found it difficult to attend group sessions at fixed times, and problems with transportation and getting to the locations for the groups made participation more difficult. Similarly, Dobkin et al. (2013) surveyed individuals with Parkinson's disease and found that issues with transport, availability of services and physical impairments were perceived as barriers to using mental health services.

Another survey study from Troeung et al. (2015) found that younger age and a belief that mental health interventions will be effective were significant predictors of uptake of mental health care, while stigma was reported as a concern for a small proportion of people with Parkinson's disease. A qualitative study from Oehlberg et al. (2008) also found that some participants with Parkinson's disease had concerns about engaging in psychotherapy due to stigma, as well as discomfort in talking about personal problems to people they did not know, and issues with transportation.

If stigma is a concern for some patients then a group format may help to overcome this barrier. It has been suggested that group CBT may help to decrease stigma due to the normalisation inherent in participating in a group with others experiencing

similar problems (Whitfield, 2010). However, the lack of engagement in the group intervention offered by NHS Ayrshire & Arran described above indicates that there may be other barriers preventing service users from engaging with this intervention. As negative expectations about group therapy may reduce its effectiveness and increase drop-out rates (Westra, Dozois, & Boardman, 2002), it is important to establish service users' initial engagement in support offered by Psychology services prior to commencement. Thus, a better understanding of service user preferences for psychological support, and the barriers to engaging in this support, is required. The previous research described above has mainly been quantitative, with a lack of scope for further exploration of participant views. Additionally, the one qualitative study from Oehlberg et al. (2008) touched on barriers to engaging in psychotherapy but did not explore service users' treatment preferences for psychological interventions.

Consequently, this study will aim to form a better understanding of the preferences of service users with Parkinson's disease for psychological support, and how barriers to participation can be overcome. The results will be used to guide recommendations for services for psychological support offered to patients with Parkinson's disease. This will inform the support offered by services in NHS Ayrshire & Arran, and can be utilised in other Neuropsychology and Older Adult services further afield. By developing psychological support for patients with Parkinson's disease driven by the preferences and experience of patients themselves, it is hoped that service user engagement in Psychology services will be increased.

Aims and Hypotheses

Aims

The aim of this project is to gain a better understanding of the preferences of service users with Parkinson's disease for psychological support, and how barriers to accessing this form of support can be overcome. This information will be used to inform recommendations for the adaptation of psychological support offered to patients with Parkinson's disease.

Research questions

1. What are the preferences of service users with Parkinson's disease for the content and format of support for psychological wellbeing?

2. What views and experiences do service users have on the barriers to participation in psychological support and how these can be overcome?

3. What are the opinions of service users on what would be helpful to include in an initial invitation letter to be sent to patients in NHS Ayrshire & Arran to provide more information about the services offered.

Plan of Investigation

Participants

Participants will be ten to twelve adults with a diagnosis of Parkinson's disease living within the NHS Ayrshire & Arran health board.

Inclusion and Exclusion Criteria

Inclusion criteria: Participants must have a clinical diagnosis of idiopathic Parkinson's disease, have experienced problems with their mental health, be aged 18 or over, be fluent in English, have the capacity to provide informed consent to take part in the interview, be able to contribute independently to the interview, and be able to take part in the interview either over the phone or using video conferencing software.

Exclusion criteria: Service users with a diagnosis of dementia will not be invited to participate in the interviews, as the needs of these service users may differ.

Recruitment Procedures

Participants will be recruited through NHS Ayrshire & Arran services, from the North, East and South Ayrshire Health and Social Care Partnerships. Parkinson's disease clinical nurse specialists working in the service have agreed to assist in recruitment. Parkinson's disease nurses will review their caseload and purposively select patients who would be suitable to participate in the interviews, based on the above inclusion and exclusion criteria. Participants selected will represent a mix of patients who were previously offered the group intervention described in the introduction and/or one-to-one support, and patients who have not previously received psychological support. After suitable patients have been identified, they will be sent an invitation letter by Parkinson's disease nurses, which will include an information sheet and pre-addressed and pre-paid reply slip. Patients will be asked to indicate on the reply slip whether or not they would like to participate in the interviews, and if they consent to be contacted by the researcher. If patients do not respond to the letter within two weeks, Parkinson's disease nurses may telephone call as a reminder to return the reply slip. Patients who express interest over the phone will be asked to confirm if they consent to being contacted by the researcher. Patients who indicate an interest

in participating will then be contacted by the researcher to provide the opportunity for patients to ask questions about the study, and to arrange a time for the interview if they would like to take part.

Measures

The interview schedule will be developed based on the research questions and previous literature. After the schedule has been drafted, local clinicians and members of the charity Parkinson's Disease UK will be asked to review the questions and provide feedback. This feedback will then be used to redraft the questions as necessary to create the final interview schedule.

The schedule will cover topics such as: content of psychological support, format and practicalities of the sessions, what participants would hope to gain from psychological support, barriers to participation and how these could be addressed (Krueger et al., 2013; Letourneau et al., 2012; Todd, Jones & Lobban, 2013). Participants will also be asked for their opinions on what would be helpful to include in an initial invitation letter sent to patients in NHS Ayrshire & Arran to provide more information about the psychological services offered.

Design

This study will employ a qualitative interview design.

Research Procedures

Parkinson's disease nurses will be asked to gather basic data from medical records on participant age, gender, and number of years since a diagnosis of Parkinson's disease was received. Participants will then be asked further demographic self-report questions, some of which are adapted from Dobkin et al. (2013), such as: marital

status; occupation or previous occupation; the type of accommodation the person is currently living in (e.g. rented, owned, supported accommodation); the extent to which PD symptoms affect the patient's ability to participate in activities of daily living (mildly, moderately, extremely); the number of other medical conditions the person is currently diagnosed with; if the patient has ever had any concerns about their mood or wellbeing, or felt they needed help managing their mood or wellbeing; and their postcode in order to calculate the SIMD (Scottish Index of Multiple Deprivation).

During the interviews, participants will be asked questions from the interview schedule, plus any clarifying questions as needed. Participants will also be asked if they would be willing to participate in member checks (discussed in more detail below), and if they consent to being re-contacted for this purpose at a later date.

Interviews will be recorded using audio recording software. The researcher will take notes during the data collection and analysis phases, to provide a reminder of issues not captured in the transcripts (such as contextual information) and to support the researcher's reflexivity. Following the interviews, participants will be debriefed and sent an information sheet detailing what to do if they are feeling distressed as a result of the interview. If a participant has given consent to be re-contacted, then they may be contacted by phone or email following the interview and subsequent analysis for member checking. This will involve the researcher providing the participant with a summary of the main themes, conclusions and interpretations of the data (Embi et al., 2004). Participants will be asked to check the accuracy of these interpretations, and to clarify or correct any misinterpretations or errors.

Data Analysis

Audio recordings from the interviews will first be transcribed by the researcher. NVivo software may be used to help organise the data. Framework analysis (Ritchie & Spencer, 2002) will then be conducted on the transcripts to identify key themes in the data. Framework analysis is type of thematic analysis that is a grounded and systematic approach to synthesising and interpreting qualitative data (Ritchie & Spencer, 2002). It was chosen as the analysis method for the current study as it is a thematic approach in which themes can be identified both from the data itself and from the original research questions (Rabiee, 2004), and it is regularly used for analysing data from semi-structured interviews (Gale et al., 2013). The researcher's theoretical stance is one of contextual constructionism. This epistemology posits that the analysis process and subsequent findings are subjective and dependent on the context of the participants and researcher, although still grounded in participant accounts. The goal of analysis is therefore to develop a richer understanding rather than to discover objective 'truths' (Madill, Jordan & Shirley, 2000).

Data will be organised and interpreted using the five-step approach proposed by Richie and Spencer (2002). The first stage will involve the researcher familiarising themselves with the data by listening to and reading interview transcripts, and noting any emerging themes. A combined inductive and deductive approach will then be taken to construct a thematic framework. This will be done by identifying themes driven by the interview schedule itself, issues expressed by participants, and concepts that emerge from patterns or repetitions in discussions with participants. The third stage will involve the researcher indexing the individual interview transcripts according to the framework, and the fourth will involve rearranging summarised versions of the data in a chart according to theme rather than individual.

The final stage will involve the researcher analytically studying the charted data to discover patterns and explanations, and using these findings to inform recommendations for improving psychological support for patients with Parkinson's disease. Coding will be carried out by the researcher, and two separate portions of the transcripts will also be coded by the Academic and Field Supervisors to provide additional perspectives and enrich the analysis. Member checks will also be carried out in order to increase the credibility of the findings and methodological rigour of the study. Any clarifications or corrections participants identify through member checking will be addressed and incorporated into the analysis.

Justification of sample size

The sample sizes detailed in previous qualitative interview studies utilizing the framework approach have varied substantially, from samples of 6 participants (Hackett & Strickland, 2018) through to samples as large as 77 participants (Parkinson et al., 2016). However, there often does not appear to be any clear theoretical justification for the choice of sample size, and this is a problem that has been reported in the wider field of qualitative health research (Vasileiou et al., 2018). The concept of theoretical saturation is used by some papers to justify sample size, and saturation has been reported by some researchers early in the process of thematic analysis of individual interviews. For example, Guest et al. (2006) reported that broad themes became apparent after analysis of just 6 interviews, and Hennink et al. (2017) reported discovering 84% of codes by the 6th interview they carried out. Given the possibility that saturation may require more interviews than in the above studies, and so that a representation of different participants can be included, this study will aim to recruit 10 participants. This number is also pragmatic for a doctorate project and should be achievable given the population the study will be recruiting

from. However, if data saturation has not been reached following the initial 10 interviews, the sample size may be increased to 12 participants. If saturation is reached prior to 10 interviews, all 10 interviews will still be carried out in order to determine if any new themes arise from the additional interviews.

Settings and Equipment

Interviews will be conducted either by telephone or using secure video conferencing software, such as Microsoft Teams. Audio recording software, such as the recording function in Microsoft Teams, will be used to record interviews. Interviews will then be transcribed, either using the transcript function in Microsoft Teams, or by a member of the research team. If needed, a laptop will be used to transcribe the audio recordings, and a transcription pedal will be used if available and required.

Health and Safety Issues

Researcher Safety Issues

Interviews will be conducted remotely, either by telephone or video conferencing software, so the researcher will not have any direct contact with patients.

Participant Safety Issues

Interviews will be conducted remotely so that participants will not need to have any direct contact with researchers. The researcher will check the local policy that is followed when service users become distressed during remote clinical contact, and what is done if a call with a service user is cut off while they are distressed. This

policy will then be followed in the event that any participant does become distressed and the call is cut off.

Ethical Issues

Approval will be sought from NHS R&D and NHS Ethics. Data will be stored and processed in line with GDPR guidelines. Notes from interviews and any written forms completed by participants will be stored in a locked cabinet at an NHS and/or University of Glasgow site. Personal data gathered during the study will be stored in a password protected file on a secure NHS and/or University of Glasgow drive. Audio recordings of interviews will also be uploaded to an NHS and/or University of Glasgow computer and saved on a secure NHS and/or University of Glasgow drive. Other ethical considerations such as confidentiality and informed consent will be considered and addressed in ethics applications. Participants will also be asked to consent in writing to participation in the interviews and to the interviews being recorded, transcribed, and selected quotations being used in published and disseminated reports. Participants will also be asked whether they consent to being contacted following the interview for member checking purposes, and it will be advised that this an optional addition to the main interview. It is not anticipated that the interview questions should cause distress, however if any participant should become distressed during the interviews then the researcher will follow relevant local policies regarding patient distress during remote contact.

Financial Issues

Costs to be covered will include: audio recording software to record interviews (if needed); stationery for taking notes during interviews; stationery for invitation letters, information sheets, consent forms, envelopes; postage.

Some previous research studies have reported difficulties with recruitment of service users with Parkinson's disease, and as such this population can be difficult to reach. Consequently, and if feasible, participants will be offered a £5 supermarket voucher as a thank you for their time. This may increase rates of participation and may help to ensure that participation in the interviews is not influenced by economic factors, and that the views of service users from different economic backgrounds are not precluded.

Timetable

Outline	30/09/2019
Draft proposal	09/12/2019
Proposal	27/01/2020
Revised proposal	Beginning of June 2020
Begin ethics application	June 2020
Final proposal	End of June 2020
Ethics approval (ideal scenario)	Summer - Autumn 2020
Recruitment	Autumn 2020
Data collection	September 2020 - January 2021

Analyses and possible member checking	September 2020 onwards
Initial report draft	May 2021
Final report	July 2021

Practical Applications

Results from the interviews will be used to guide recommendations to Psychological services for providing psychological well-being support for people with Parkinson's disease, as driven by service user perspectives and preferences. A future research project could then investigate the efficacy of the recommendations following implementation in NHS Ayrshire & Arran services.

References

Berardelli, I., Pasquini, M., Bloise, M., Tarsitani, L., Biondi, M., Berardelli, A., & Fabbrini, G. (2015). CBT group intervention for depression, anxiety, and motor symptoms in Parkinson's disease: preliminary findings. *International Journal of Cognitive Therapy*, *8*(1), 11-20.

Bomasang-Layno, E., Fadlon, I., Murray, A. N., & Himelhoch, S. (2015). Antidepressive treatments for Parkinson's disease: a systematic review and meta-analysis. *Parkinsonism & Related Disorders*, *21*(8), 833-842.

Broen, M. P., Narayen, N. E., Kuijf, M. L., Dissanayaka, N. N., & Leentjens, A. F. (2016). Prevalence of anxiety in Parkinson's disease: A systematic review and meta-analysis. *Movement Disorders*, *31*(8), 1125-1133.

Chen, J. J., & Marsh, L. (2014). Anxiety in Parkinson’s disease: identification and management. *Therapeutic Advances in Neurological Disorders*, *7*(1), 52-59.

Dobkin, R. D., Rubino, J. T., Friedman, J., Allen, L. A., Gara, M. A., & Menza, M. (2013). Barriers to mental health care utilization in Parkinson’s disease. *Journal of Geriatric Psychiatry and Neurology*, *26*(2), 105-116.

Egan, S. J., Laidlaw, K., & Starkstein, S. (2015). Cognitive behaviour therapy for depression and anxiety in Parkinson’s disease. *Journal of Parkinson's Disease*, *5*(3), 443-451.

Embi, P. J., Yackel, T. R., Logan, J. R., Bowen, J. L., Cooney, T. G., & Gorman, P. N. (2004). Impacts of computerized physician documentation in a teaching

hospital: perceptions of faculty and resident physicians. *Journal of the American Medical Informatics Association*, *11*(4), 300-309.

Feeney, F., Egan, S., & Gasson, N. (2005). Treatment of depression and anxiety in Parkinson's disease: a pilot study using group cognitive behavioural therapy. *Clinical Psychologist*, *9*(1), 31-38.

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.

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, *13*(1), 117.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, *18*(1), 59-82.

Hackett, A., & Strickland, K. (2018). Using the framework approach to analyse qualitative data: a worked example. *Nurse Researcher*, *26*(3).

Hadinia, A., Meyer, A., Bruegger, V., Hatz, F., Nowak, K., Taub, E., ... & Gschwandtner, U. (2017). Cognitive behavioral group therapy reduces stress and improves the quality of life in patients with Parkinson's disease. *Frontiers in Psychology*, *7*, 1975.

Hennink, M. M., Kaiser, B. N., & Marconi, V. C. (2017). Code saturation versus meaning saturation: how many interviews are enough?. *Qualitative health research*, *27*(4), 591-608.

Krueger, R. A., Casey, M. A., Donner, J., Kirsch, S., & Maack, J. N. (2001). Social analysis: selected tools and techniques. *Social Development Paper*, *36*.

Letourneau, N., Tryphonopoulos, P. D., Duffett-Leger, L., Stewart, M., Benzies, K., Dennis, C. L., & Joschko, J. (2012). Support intervention needs and preferences of fathers affected by postpartum depression. *The Journal of Perinatal & Neonatal Nursing*, *26*(1), 69-80.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British journal of psychology*, *91*(1), 1-20.

Oehlberg, K., Barg, F. K., Brown, G. K., Taraborelli, D., Stern, M. B., & Weintraub, D. (2008). Attitudes regarding the etiology and treatment of depression in Parkinson's disease: a qualitative study. *Journal of Geriatric Psychiatry and Neurology*, *21*(2), 123-132.

Pohl, P., Wressle, E., Lundin, F., Enthoven, P., & Dizdar, N. (2020). Group-based music intervention in Parkinson’s disease–findings from a mixed-methods study. *Clinical Rehabilitation*, *34*(4), 533-544.

Prediger, R. D., Matheus, F. C., Schwarzbold, M. L., Lima, M. M., & Vital, M. A. (2012). Anxiety in Parkinson’s disease: a critical review of experimental and clinical studies. *Neuropharmacology*, *62*(1), 115-124.

Rabiee, F. (2004). Focus-group interview and data analysis. *Proceedings of The Nutrition Society*, *63*(4), 655-660.

Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research. In Bryman, A., & R. G. Burgess (Eds.), *Analyzing Qualitative Data* (pp. 187-208). Routledge.

Sajatovic, M., Ridgel, A. L., Walter, E. M., Tatsuoka, C. M., Colon-Zimmermann, K., Ramsey, R. K., ... & Walter, B. L. (2017). A randomized trial of individual versus group-format exercise and self-management in individuals with Parkinson's disease and comorbid depression. *Patient Preference and Adherence*, *11*, 965.

Slaughter, J. R., Slaughter, K. A., Nichols, D., Holmes, S. E., & Martens, M. P. (2001). Prevalence, clinical manifestations, etiology, and treatment of depression in Parkinson's disease. *The Journal of Neuropsychiatry and Clinical Neurosciences*, *13*(2), 187-196.

Todd, N. J., Jones, S. H., & Lobban, F. A. (2013). What do service users with bipolar disorder want from a web-based self-management intervention? A qualitative focus group study. *Clinical Psychology & Psychotherapy*, *20*(6), 531-543.

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.

Troeung, L., Gasson, N., & Egan, S. J. (2015). Patterns and predictors of mental health service utilization in people with Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology*, *28*(1), 12-18.

Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*, *18*(1), 148.

Westra, H. A., Dozois, D. J., & Boardman, C. (2002). Predictors of treatment change and engagement in cognitive-behavioral group therapy for depression. *Journal of Cognitive Psychotherapy*, *16*(2), 227.

Whitfield, G. (2010). Group cognitive–behavioural therapy for anxiety and depression. *Advances in Psychiatric Treatment*, *16*(3), 219-227.

Appendix 2.2 COREQ checklist (Tong et al., 2007)

From: http://cdn.elsevier.com/promis_misc/ISSM_COREQ_Checklist.pdf

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	62
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	62
Occupation	3	What was their occupation at the time of the study?	62
Gender	4	Was the researcher male or female?	62
Experience and training	5	What experience or training did the researcher have?	62
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	62
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	62
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	62, 84
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	59, 61
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	57, 58
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	57, 58
Sample size	12	How many participants were in the study?	61, 62
Non-participation	13	How many people refused to participate or dropped out? Reasons?	62
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	58, 59
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	58
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	62, 63
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	57, 58, 138
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	59
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	58
Field notes	20	Were field notes made during and/or after the inter view or focus group?	58
Duration	21	What was the duration of the inter views or focus group?	62
Data saturation	22	Was data saturation discussed?	61, 63
Transcripts returned	23	Were transcripts returned to participants for comment and/or	59, 60

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	60, 62
Description of the coding tree	25	Did authors provide a description of the coding tree?	143
Derivation of themes	26	Were themes identified in advance or derived from the data?	59, 60
Software	27	What software, if applicable, was used to manage the data?	60
Participant checking	28	Did participants provide feedback on the findings?	59, 60
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	66-80
Data and findings consistent	30	Was there consistency between the data presented and the findings?	66-80
Clarity of major themes	31	Were major themes clearly presented in the findings?	66-80
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	66-80

Appendix 2.3 Ethical approval letter

WoSRES

West of Scotland Research Ethics Service

NHS Greater Glasgow and Clyde

Dr Breda Cullen
Senior Lecturer, Institute of Health and Wellbeing,
University of Glasgow
Mental Health and Wellbeing
Academic Centre, Gartnavel Royal Hospital
Glasgow
G12 0XH

West of Scotland REC 4
Research Ethics
Ward 11, Dykebar Hospital
Grahamston Road
Paisley
PA2 7DE

Date 18 January 2021
Direct line 0141 314 0213
E-mail WoSREC4@ggc.scot.nhs.uk

Dear Dr Cullen

Study title: **Developing psychological wellbeing support for patients with Parkinson's disease**
REC reference: **20/WS/0172**
IRAS project ID: **287012**

Thank you for your letter of 07 January 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:
https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at:
https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at
https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [PSBG MRP approval email 08.07.20]		08 July 2020

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Proceed to Ethics Letter 17.06.20]		17 June 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UoG Clinical Trials VOI 15.07.2020]		15 July 2020
Interview schedules or topic guides for participants [Interview schedule V1.3 18.12.20]	1.3	18 December 2020
IRAS Application Form [IRAS_Form_09112020]		09 November 2020
Letters of invitation to participant [Invitation letter and reply slip V1.4 07.01.21]	1.4	07 January 2021
Letters of invitation to participant [Address for return of pre-paid reply slips V1.1 18.12.20]	1.1	18 December 2020
Other [Neuropsychology Services Attend Anywhere Instructions V1.0 16.10.20]	1.0	16 October 2020
Other [Patient Information Proforma V1.3 07.01.21]	1.3	07 January 2021
Other [Interview confirmation V1.2 07.01.21]	1.2	07 January 2021
Other [Post-interview information V1.1 08.01.21]	1.1	08 January 2021
Other [Feedback from PDUK 22.10.20]		22 October 2020
Participant consent form [Consent form V1.5 07.01.21]	1.5	07 January 2021
Participant information sheet (PIS) [Information sheet V1.5 07.01.21]	1.5	07 January 2021
Research protocol or project proposal [Protocol V1.3 07.01.21]	1.3	07 January 2021
Response to Request for Further Information [Responses to REC V1.1 07.01.21]	1.1	07 January 2021
Summary CV for Chief Investigator (CI) [BCullen CV for R&D V1.0 31.07.20]		31 July 2020
Summary CV for student [JWhyte CV for R&D V1.0 04.08.20]		04 August 2020
Summary CV for supervisor (student research) [BCullen CV for R&D V1.0 31.07.20]		31 July 2020
Summary CV for supervisor (student research) [Susan O-CV-supervision V1.0 01.09.20]		01 September 2020

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 287012 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

On behalf of
Dr Ken James
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Dr Colette Montgomery Sardar

West of Scotland REC 4

Attendance at Sub-Committee of the REC meeting

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Wendy Cohen	Speech & Language Therapist	Yes	Chair of Meeting
Dr Rosemarie Davidson	Consultant in Clinical Genetics	Yes	
Ms Patricia Young	Retired Business Manager	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mrs Abibat Adewumi-Ogunjobi	REC Manager

Appendix 2.4 Consent form

Consent Form V1.5

Developing psychological wellbeing support for patients with Parkinson's disease

Contact details: Jessica Whyte
Email:

Please initial in box

1. I confirm that I have read and understand the information sheet dated 07.01.21 (Version 1.5) for the above study. ☐
2. I confirm that the researcher has answered any queries to my satisfaction. ☐
3. I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without my medical care or legal rights being affected, and that information I have provided up to that point may be included in the results of the study. ☐
4. I understand that any information collected about me in the study will remain confidential, and that no information which identifies me will be made publicly available. ☐
5. I give permission to the research team to audio record my interview, and for anonymous quotations from the interview to be used in reports. ☐
6. I give permission for Parkinson's disease Clinical Nurse Specialists to access my medical records to obtain information which is relevant to this study (date of birth, gender, name of diagnosis, date of diagnosis, if I have any history of mental health problems and if I have previously been offered support for my mental health) and pass this information on to the research team. ☐
7. I understand that my data (including personal information) may be accessed by authorised representatives of University of Glasgow and NHS Ayrshire & Arran for the purposes of audit only. ☐
8. I would like to be informed of the results of this research by email once the study is completed. This is an optional part of the study. ☐
9. I consent to being a participant in this study. ☐
10. I consent to taking part in member checks following the initial interview, and to being contacted by the researcher about taking part in these checks. This is an optional part of the study. ☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Appendix 2.5 Participant information sheet

Developing psychological wellbeing support for patients with Parkinson's disease

Patient information sheet

Version 1.5, 07/01/21

Chief Investigator: Dr Breda Cullen, Clinical Psychologist

Research Supervisors: Dr Breda Cullen and Dr Susan O'Connell

Trainee Clinical Psychologist: Jessica Whyte

You are being invited to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the research about?

This study is aiming to investigate how Psychology services can improve the support they offer to patients with Parkinson's disease to help improve their mental health, and how we can make Psychology services easier to access for people with Parkinson's disease. To do this, we will be interviewing people with Parkinson's disease over the phone or over video call. The results of the interviews will be used to help us improve the mental health support we offer to patients with Parkinson's disease in NHS Ayrshire and Arran and wider services.

Who is being asked to take part?

We are inviting people with a diagnosis of Idiopathic Parkinson's Disease to take part in the study. We are looking for 10-12 people to take part.

Why have I been invited?

You have been invited to take part in this research because you have a diagnosis of Idiopathic Parkinson's Disease, are registered with the Parkinson's disease team in NHS Ayrshire & Arran, are aged 18 years or over, and may have reported experiencing difficulties with your mental health.

Please return the reply slip to the researcher using the pre-addressed and pre-paid envelope provided if you are interested in taking part.

If you are interested in taking part, a researcher will telephone to give you the opportunity to ask any questions you may have about the study and to arrange a time for the interview if you would like to take part.

What will taking part involve?

Consenting to participate in this study means that you will be asked to take part in an interview with a researcher, either over the telephone or over video call. During the interview the researcher will ask you some general questions about yourself, followed by questions about your experiences of support for your mental health and how we can improve these. In total this should take 30-45 minutes and the interview will be audio recorded. At the end of the interview the researcher will ask if you would like to take part in checks of the study results. This is an optional part of the study and would involve the researcher sending you a summary of the study results by post and contacting you at a later date to ask for your opinion on the results.

As well as taking part in the interview, we will also request your permission for NHS Ayrshire & Arran Clinical Nurse Specialists to access details from your medical records to send to the research team at the University of Glasgow. This information would include your date of birth, gender, name of diagnosis, date of diagnosis, if you have a history of mental health problems and if you have previously been offered support for your mental health.

To thank you for your time taking part in the interview you will be given a £5 supermarket voucher.

If at any point you are no longer able to consent during the study, you would be withdrawn from the study and no new data would be collected. If you have already taken part in an interview we may keep recordings and transcripts of your interview and may use these as originally agreed in the consent form.

What are the possible benefits of taking part?

We do not expect there to be any particular benefits to yourself by taking part. Your participation will help us improve the mental health support we provide for people with Parkinson's disease.

Are there any disadvantages or risks to taking part?

Although we do not expect that participating in this study will cause you any distress, if you express distress when speaking to the researcher or through your responses to the interview questions, we will help you to access appropriate support if needed. Following the interview we will send you a post-interview sheet containing the details of individuals and organisations you can contact if you are feeling distressed. If you share information that makes the researcher concerned for your safety or the safety of other people, we may need to tell others involved in your care (e.g. your GP).

Do I have to take part?

No. It is up to you to decide whether to take part. This study is completely voluntary. You do not have to take part if you do not want to.

What happens if I decide not to take part?

Nothing. Taking part is entirely up to you. If you do not wish to take part, it will not affect any treatment that you currently receive and will not affect any future care you may need. Also, if you decide to take part, you can change your mind and withdraw from the study at any time, without giving a reason, and without it affecting your care either now or in the future.

What will happen to my data?

We will collect your basic personal data such as your name, contact details, date of birth and, limited special categories data (such as health data) in order to carry out the research study. We will only collect data that we need in order to conduct the research study.

Legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal basis is a task in the public interest and consent.

What we do with your data and who we share it with

All the personal data in the study is processed by staff at the University of Glasgow and NHS Ayrshire and Arran in the United Kingdom. Appropriate security measures will be in place such as encryption and pseudonymisation.

Will my information be kept confidential?

All the information you provide will be kept confidential and the recordings and transcripts of your interview will only be identified by code, not your name. The consent forms and study data will be stored on NHS Ayrshire and Arran and University of Glasgow premises and will be accessible only to researchers who are directly involved with the research, or other authorised staff for audit purposes.

Electronic information will be stored on secure NHS or University of Glasgow computer systems. When the study has finished the transcripts from your interview will continue to be stored anonymously, and the recording of your interview will be deleted.

If you share information that makes us concerned for your safety or the safety of other people, we may need to tell others involved in your care (e.g. your GP).

The University of Glasgow is the sponsor for this study based in Scotland. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Glasgow will keep identifiable information about you for 10 years after the study has finished. After this time, data will be securely deleted.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at https://www.nhsaaa.net/data-protection-notice/

What will happen to the results of the research study?

The results will be compiled in a report completed as part of an academic qualification (Doctorate in Clinical Psychology). They may later be published in a scientific journal and through other routes to ensure that the public are also aware of the findings. Some anonymised quotes from the interviews may be used in publications but you will not be identified in any report or publication arising from this study. During the interview the researcher will ask if you wish to be informed of results from the present study. If so, a summary of the results will be sent to you once the research is completed.

Who is organising the research?

The study is being undertaken in partial fulfilment of an academic qualification at the University of Glasgow and is organised by the Chief Investigator (Dr Breda Cullen) and research supervisor (Dr Susan O'Connell) and Trainee Clinical Psychologist (Jessica Whyte).

Who has reviewed the study?

The study has been reviewed by the University of Glasgow to ensure that it meets standards of scientific conduct. It has also been reviewed by an NHS Research

Ethics Committee, and the NHS Ayrshire and Arran Research and Development Department.

What will happen if there is a problem or if I want to make a complaint?

If you have any concerns about the study or the way it is conducted, or if you wish to complain about any aspect of this study, please contact Dr Breda Cullen, Mental Health and Wellbeing, Gartnavel Royal Hospital, Admin Building, 1st Floor, 1055 Great Western Road, Glasgow, G12 0XH, or the Research and Development Department, NHS Ayrshire and Arran on 01563 825850.

The normal NHS complaint mechanisms will also be available to you. NHS Ayrshire and Arran Complaints Team: 01292 513620

Contact for further information about the study

Jessica Whyte	Dr Breda Cullen	Dr Luke Williams
Mental Health and Wellbeing Admin Building, 1st Floor, Gartnavel Royal Hospital 1055 Great Western Road Glasgow G12 0XH 07583218206	Mental Health and Wellbeing Admin Building, 1st Floor, Gartnavel Royal Hospital 1055 Great Western Road Glasgow G12 0XH 0141 2113912	Psychology Department Horseshoe Building Ayrshire Central Hospital Kilwinning Rd, Irvine KA12 8SS 01294 322057

Other useful contacts

Nick Brydon & Paula Hewatt, Parkinson's Disease Clinical Nurse Specialists	Contact number: 01292 665628 Email: Clinical_Specialty_ParkinsonsService_BiggartHospital@aapct.scot.nhs.uk
Parkinson's Disease UK, Ayrshire branch contact: Gill MacGregor	Contact number: 0344 225 9836 Email: vc.scotland2@parkinsons.org.uk
Breathing Space telephone support line	Contact number: 0800 83 85 87
The Samaritans	Contact number: 116 123 Email: jo@samaritans.org

Thank you for reading this Participant Information Sheet

Appendix 2.6 Invitation letter and reply slip

Invitation letter: a research study on developing psychological wellbeing support for patients with Parkinson's disease

We are contacting you as we would like to hear your views on how Psychology services can best support the mental health of patients with Parkinson's disease. Psychology services offer support such as talking therapies to individuals who are having difficulties with their mental health. This support is provided by qualified Psychologists or other trained professionals, and is available to those who may be experiencing problems with their mental health, whether this is related or unrelated to their diagnosis of Parkinson's disease.

In the research study we are looking for volunteers to take part in interviews with a researcher from the University of Glasgow. In the interview we would ask you about your opinions and preferences on how Psychology services can best support people with Parkinson's disease. The interviews will help us develop the support that Psychology services offer to patients with Parkinson's disease in NHS Ayrshire and Arran.

The enclosed Participant Information Sheet provides more information about the study, and includes the contact details of the research team should you wish to contact them for more information about taking part. When you have read the information sheet, if you are interested in taking part in the study please complete the reply slip on page 2 of this invitation letter and send it back to the researcher using the pre-paid and pre-addressed envelope. The researcher will then contact you with further information about the study. If you are not interested in taking part in the study you do not need to do anything further. Thank you for taking the time to read this invitation letter. We look forward to hearing from you.

Yours sincerely,

Jessica Whyte

Trainee Clinical Psychologist

Reply Slip

If you are interested in taking part in the study please tick the box below and send this page back using the enclosed pre-paid and pre-addressed envelope.

I am interested in taking part in the study and would like to be contacted by the researcher to discuss the study. Please note, by returning the reply slip you are consenting to your contact details being passed on to the researcher. You will only be contacted by the researcher if you tick "YES" below. If you decide to take part in the study after speaking to the researcher, we will need to record your consent to take part verbally during the interview. If you tick "YES" you will also be confirming that if you decide to take part you will be happy for us to record your consent verbally just before the interview.

YES, I would like to be contacted by the researcher. I confirm that if I decide to take part I am happy for you to record my consent verbally and that this will be taken just before the interview. ☐

Your name _____

Your contact number _____

Appendix 2.7 Interview schedule

Interview Schedule

Recording:

As you know, I need to record this interview to help me in analysing the results later. This interview is now being recorded. Can you confirm that is OK with you?

RESEARCHER TO START RECORDING

Consent:

OK that's the recorder on now. First of all I wanted to thank you for agreeing to speak with me today. Can I check if you have had a chance to read over the Consent Form that was sent to you? What I'm going to do now is read through this with you and check that you consent to each of the points.

RESEARCHER TO READ THROUGH CONSENT FORM WITH PARTICIPANT AND CHECK THAT PARTICIPANT CONSENTS TO EACH NUMBERED POINT ON THE FORM. IF PARTICIPANT CONSENTS TO TAKE PART IN THE STUDY, TICK THE BOX BELOW. IF NOT, DO NOT PROCEED WITH THE INTERVIEW.

☐ *Consent given by participant*

Introduction:

Before we begin I just wanted to thank you for agreeing to take part in the interview today. Your answers will help us develop the support that Psychology services offer to patients with Parkinson's disease in NHS Ayrshire and Arran.

We'll start off with some quick questions about you, and then I'll ask some questions about your preferences and opinions on accessing support from Psychology services. If there are any questions you would rather not answer that is no problem at all, just let me know. And if at any time you would like to stop the interview or would like a break, just let me know and we can do this. If the call gets cut off I'll give you a ring back as soon as I can. Does that all sound OK?

To start off with I'm going to ask you a few quick questions about yourself, and then we'll move on to main interview questions.

Demographic questions:

(Adapted from Dobkin et al., 2013)

1. What is your current marital status?
    a. Single, married, separated, divorced, widowed, living with partner?
2. What is your employment status?
    a. Employed full time, employed part time, unemployed, retired?
    b. What is your occupation or previous occupation?
3. What type of accommodation are you currently living in?
    a. Rented, owned, supported accommodation?
4. To what extent do your Parkinson's disease symptoms affect your ability to participate in activities of daily living?
    a. Mildly, moderately, extremely?
5. How many medical conditions are you currently diagnosed with (not including Parkinson's disease)?
6. Have you ever had any concerns about your mood or wellbeing, or felt you needed help managing your mood or wellbeing?

Thank you for answering those questions for me. In this next part I will be asking you questions about your preferences and opinions for Psychological support for wellbeing. To provide a bit of background, Psychology services offer support such as talking therapies to individuals who are having difficulties with their mood or wellbeing. This support is provided by qualified Psychologists or other trained professionals, and is available to those who may be experiencing problems with their wellbeing, whether this is related or unrelated to their diagnosis of Parkinson's disease. We realise you may not necessarily choose to access support from Psychology services yourself, but we are interested in your thoughts about the idea of accessing support from Psychology, or other people with Parkinson's disease doing this. Do you have any questions about this?

Semi-structured interview:

Interview question ideas to address research questions and using the themes from Todd et al. (2013) (some adapted from Krueger et al., 2001 and Letourneau et al., 2012). Questions have been reviewed by Parkinson's disease UK.

1. How do you feel about accessing professional Psychological support?
    a. What makes you say this?
    b. Is there anything that would make you feel more or less comfortable accessing Psychological support?
2. How do you feel about group/individual Psychological support?

3. What experiences do you have of accessing psychological support?
    a. What was helpful?
    b. What was unhelpful?
4. If you could get one thing from Psychological support what would it be? / What would you most like to gain from Psychological support?
5. What would you like to see included/addressed in Psychological support?
    a. What do you think would be helpful?
    b. What do you think would be unhelpful?
6. What would encourage you to participate in Psychological support?
7. What would prevent you / discourage you from participating in Psychological support?
    a. Is there anything that you think would help overcome this?
8. Are there any practicalities you would want us to consider when planning Psychological support?
9. What would your preferences be for the following:
    a. Mode of support (e.g. one-to-one, group, telephone, video)?
    b. Location of support?
    c. Duration of support (e.g. duration of each session and overall number of sessions)?
    d. Frequency of support?
    e. Time of day of support?
10. In the future we are considering sending a letter to invite people to take part in psychological support. What do you think would be helpful for us to include in this letter?
11. Do you have any other comments?

Final question: When we have finished the interviews and have started to analyse the interview data, we are planning to contact some of the people who took part in the interviews to ask them to check the results and to give their opinions on the results. This is an optional addition to the study. Would you be interested in taking part in checking the results? If so, do you give your permission for us to contact you within the next few months to carry out these checks?

End:

That is the end of the interview. Thank you for taking part in the interview. We will send out a copy of our post-interview information sheet with details of individuals and organisations you can contact if you are feeling distressed in any way by the topics covered in the interview. Would you prefer us to send this to you by email or post?

When the study is finished we will send out a summary of the results to everyone who indicated they would like this in the consent form. Would you prefer us to send this to you by email or post? Thank you again for your participation in the study.

Appendix 2.8 Samples of reflections noted in the researcher's reflective log

Sample 1: 05/03/21 Personal reflections following interviews with P101 & 102:

Reflecting on the first two interviews I noticed I was incorporating my clinical skills into the interview with the aim of helping to make the participants feel heard, understood and validated. For example, I was acknowledging things that they found difficult, I was reflecting things back to the participants, and if the participants were struggling with words or to get something across, I checked in about what I had thought they meant to see if that was right.

I'm wondering if this could be introducing biases into the results. Although qualitative interviews can never be completely free from bias, even the questions themselves introduce some bias into the answers that are given. However, I wonder if I should be doing more to try to minimise these biases. On the other hand, I do think that using these clinical skills helped to maintain the engagement of participants and allowed them to feel comfortable speaking openly about difficult topics. Transcription will provide a good opportunity to listen back to the recordings and consider this in more detail. This will help me to consider whether I need to adjust my approach going forwards. It is also important for me to remember that my theoretical stance acknowledges these biases will be present but it is important to be aware of them.

I emailed my supervisor to discuss this concern. My supervisor advised that using active listening skills and reflecting things back to a participant is fine, if I am not talking too much or being too leading.

Sample 2: 22/03/21 Reflections following the first six interviews and a meeting with the field supervisor:

Participants who have had experience of mental health problems and who are able to view these problems as mental health problems appear to have been more readily able to reflect on their experiences and contribute more to the interviews, providing richer interview data. This is a consideration for future research focused on feedback and developing services.

Sample 3: 16/05/21 Personal reflections on the interviews:

- *The clarifying questions asked by the researcher in every interview following the first participant will inevitably have been influenced by all prior interviews and the answers given by previous participants.*
- *A potential limitation of the study may be that participants may have held back negative opinions of psychological services given that the researcher is part of these services. However, some participants did provide constructive feedback and so this may not be the case.*

Appendix 2.9 Initial framework used for indexing transcripts

1. Attitudes towards psychological support:
   1.1. Openness to support: readiness and perceived need for support
   1.2. Impact of Parkinson's on mental health (and life?)
   1.3. Importance of accepting help
   1.4. Positive experiences of individual support
   1.5. Negative experiences of group support
   1.6. Positive experiences of peer support
   1.7. Influence of media on perceptions of group support
2. Barriers to accessing psychological support:
   2.1. Lack of awareness of support
   2.2. Concerns about confidentiality
   2.3. Lack of joined up services and communication between services
   2.4. Lack of awareness of symptoms and mood difficulties in Parkinson's?
   2.5. Not feeling things are "bad" enough?
   2.6. Heterogeneity in groups: stage of disease, age, gender, preferences for approach
   2.7. Personal nature of difficulties
   2.8. Social anxiety / worry about meeting new people / discomfort with new people
   2.9. Stigma
   2.10. Attitudes of professionals
   2.11. Difficulties accessing support
   2.12. Practical barriers of location and setting
   2.13. Impact of COVID-19
3. Adaptations to psychological support for Parkinson's disease:
   3.1. Accessible language and breaking things down
   3.2. Providing written information
   3.3. Short sessions
   3.4. Considerations of the impact of symptoms and medication
   3.5. Support for families?
4. Preferences for aims and content:
   4.1. Achieving a sense of wellbeing and balance?
   4.2. Adjusting to life with Parkinson's
   4.3. Normalising mood difficulties in Parkinson's
   4.4. Practical advice and strategies
   4.5. Rapport: Attitude/manner of the clinician
   4.6. Being realistic but not confronting
   4.7. Learning from others with Parkinson's
   4.8. Providing choice
   4.9. Tailored to the individual
   4.10. Having a safe place to talk and be listened to
   4.11. Here and now focus
   4.12. Increasing confidence
5. Preferences for the format of support:
   5.1. Preference for one-to-one face-to-face support
   5.2. Openness to group support – potentially later on the journey?
   5.3. Importance of similarities between group participants
   5.4. Local, accessible and comfortable location
   5.5. Fast and easy to access

    5.6. Regular short sessions (30-60 mins)
    5.7. Time of day
    5.8. Resources
    5.9. Flexible duration
6. Preferences for content of the invitation letter:
    6.1. Increasing awareness of support
    6.2. Providing information
    6.3. Experiences of others

Appendix 2.10 Sample of indexing

Interview transcript ID109, phone call 26/03/21, duration: 52:52 14

R: And I guess I'm really glad that they were able to accommodate that kind of wanting to see someone out of your area. And is there anything else you found kind of helpful about accessing that support?

P109: Erm... the way... well we were talking a minute ago about being comfortable in the surroundings. I wouldn't have said where I was with that doctor was comfortable but his approach was good and I felt at ease and that's very important. And had- I was there for an hour and it was non-stop talk and you came out exhausted. But it was good in the end, it got a lot of it out and we talked it round and talked it through, turned it upside down and everywhere and it helped but it didn't make the problems go away, it never could. But it helps you think differently or it helps you deal a bit better with something.

2.12 & 5.4 Setting & comfort

4.5 Rapport

1.4 Experiences of support

4.10 Safe space to talk & be listened to

R: Brilliant. So it sounds like talking it through was helpful and having someone who had a good approach was helpful as well. Is there anything that was unhelpful about that?

P109: Erm... well I had a bit of a problem getting there. That doesn't help when you're up to your eyeballs in nerves anyway. Because my husband wasn't driving at that point and it meant bussing. That was a bit of a problem, not easy. I could have taxied but I didn't- well I did sometimes but it's a bit far. So something like that can put you off a bit.

2.12 & 5.4 Location as a barrier & preference for local location

R: Definitely. And I realise you hadn't wanted to speak to someone in South Ayrshire for the reason you gave before and I guess in general, what would your preference be for the location?

Appendix 2.11 R&D Management approval letter

Research & Development
56a Lister Street
University Hospital Crosshouse
Kilmarnock
KA2 0BB

Date 25 January 2021
Your Ref
Our Ref CM/KLB/CI R&D No 2020AA075

Dr Breda Cullen
University of Glasgow
Room 3, First Floor, Admin Building
Gartnavel Royal Hospital
Glasgow
G12 0XH

Enquiries to Karen Bell
Extension 25850
Direct line 01563 825850
Fax 01563 825806
Email Karen.Bell2@aapct.scot.nhs.uk

Dear Dr Cullen

Developing psychological wellbeing support for patients with Parkinson's disease

I confirm that NHS Ayrshire and Arran have reviewed the undernoted documents and grant R&D Management approval for the above study.

Documents received:

Document	Version	Date
Organisational Information Document	1.2	08.01.21
IRAS Form	5.17	09.11.20
Protocol	1.3	07.01.20
IRAS schedule of events	1.1	22.10.20
Interview schedule	1.3	18.12.20
Invitation letter and reply slip	1.4	07.01.20
Address for return of pre-paid reply slips	1.1	18.12.20
Patient Information Proforma	1.3	07.01.21
Interview confirmation	1.2	07.01.21
Neuropsychology Services AttendAnywhere Instructions	1.0	16.10.20
Post-interview information	1.1	08.01.21
Consent form	1.5	07.01.21
Information sheet	1.5	07.01.21

The terms of approval state that the investigator authorised to undertake this study within NHS Ayrshire & Arran is: -

- Jessica Whyte, NHS Ayrshire & Arran

With additional investigators:-

- Dr Breda Cullen, University of Glasgow
- Dr Susan O'Connell, NHS Ayrshire & Arran
- Dr Luke Williams, NHS Ayrshire & Arran

The sponsors for this study are University of Glasgow.

This approval letter is valid until 30 June 2022.

Regular reports of the study require to be submitted. Your first report should be submitted to Dr K Bell, Research & Development Manager in 12 months time and subsequently at yearly intervals until the work is completed.

Please note that as a requirement of this type of study your name, designation, work address, work telephone number, work e-mail address, work related qualifications and whole time equivalent will be held on the Scottish National Research Database so that NHS R&D staff in Scotland can access this information for purposes related to project management and report monitoring.

In addition approval is granted subject to the following conditions: -

- All research activity must comply with the standards detailed in the UK Policy Framework for Health and Social Care Research http://beta.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research and appropriate statutory legislation. It is your responsibility to ensure that you are familiar with these, however please do not hesitate to seek further advice if you are unsure.

- Recruitment figures must be submitted to R&D on a monthly basis. If recruitment figures are not received timeously you will be contacted by a member of the R&D team to provide this data.

- You are required to comply with Good Clinical Practice (ICH-GCP guidelines may be found at www.ich.org/LOB/media/MEDIA482.pdf), Ethics Guidelines, Health & Safety Act 1999, General Data Protection Regulation (GDPR) and Data Protection Act 2018.

- If any amendments are to be made to the study protocol and or the Research Team the Researcher must seek Ethical and Management Approval for the changes before they can be implemented.

- The Researcher and NHS Ayrshire and Arran must permit and assist with any monitoring, auditing or inspection of the project by the relevant authorities.

- The NHS Ayrshire and Arran Complaints Department should be informed if any complaints arise regarding the project and the R&D Department must be copied into this correspondence.

- The outcome and lessons learnt from complaints must be communicated to funders, sponsors and other partners associated with the project.

- As custodian of the information collated during this research project you are responsible at all times for ensuring the security of all personal information collated in line with NHS Scotland policies on information assurance and security, until the secure destruction of these data. The retention time periods for such data should comply with the requirements of the Scottish Government Records Management: NHS Code Of Practice. Under no circumstances should personal data be stored on any unencrypted removable media e.g. laptop, USB or mobile device (for further information and guidance please contact the Information Governance Team based at University Hospital Crosshouse 01563 825831 or 826813).

If I can be of any further assistance please do not hesitate to contact me. On behalf of the department, I wish you every success with the project.

Yours sincerely

Dr Crawford McGuffie
Medical Director

c.c. Dr Colette Montgomery Sardar, University of Glasgow (sponsor contact)
Lesley Douglas, Finance, Ailsa Hospital
Information Governance, NHS Ayrshire & Arran
Jessica Whyte, NHS Ayrshire & Arran
Dr Luke Williams, NHS Ayrshire & Arran
Dr Susan O'Connell, NHS Ayrshire & Arran

Appendix 2.12 Approval email from NHS Ayrshire & Arran Psychological Services Business Group

MRP

Mulhern, Sharon <Sharon.Mulhern@aapct.scot.nhs.uk>
Wed 08/07/2020 09:04

To: Jessica Whyte (PGR) [redacted]
Cc: marisa.forte <marisa.forte@aapct.scot.nhs.uk>; O'Connell, Susan <Susan.O'Connell@aapct.scot.nhs.uk>; Breda Cullen <Breda.Cullen@glasgow.ac.uk>

Dear Jessica
I have received your MRP for ratification. I have reviewed the proposal and I think it is excellent and very clinically useful. I will therefore be approving it at the business meeting this afternoon.
Well done!
Sharon

Dr Sharon Mulhern
Consultant Clinical Lead Neuropsychology & Neurorehabilitation
Honorary Clinical Lecturer, Medical, Veterinary and Life Sciences, University of Glasgow
Ayrshire Central Hospital
Administration Building
1st Floor, Room 439
Kilwinning Road
Irvine, KA12 8SS

Tel: 01294 322057
Page: 07623927934
sharon.mulhern@aapct.scot.nhs.uk