Awareness of Cognitive Abilities in People with Parkinson's Disease

And Clinical Research Portfolio

Volume 1

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Chapter 1: Systematic Review

A Systematic Review of Factors Associated with Depression and Awareness in People with Parkinson's Disease.

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Prepared in accordance with the instructions to authors for the Neuropsychological Rehabilitation: An International Journal (see Appendix 1.1)

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Chapter 1 - Systematic Review

A Systematic Review of Factors Associated with Depression and Awareness in People with Parkinson's Disease.

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Abstract

Background: People with Parkinson's disease (PD) are at an elevated risk of developing depression than the general population. Current literature suggests that there is a cross-over of phenomenology between these two conditions, however specific risk factors contributing to depression in PD remains unclear. Previous studies have also suggested that awareness of illness has an impact on emotional responses such as depression. However, the interaction between level of awareness and depression in PD has not been reviewed. **Aim:** To systematically review the evidence regarding risk factors for depression in PD and to examine the relationship between awareness and depression. **Methods:** A systematic literature search was conducted using Medline, Embase, Cinahl, Psychinfo and Psycharticles. Eligibility criteria were devised and included studies were assessed on methodological quality using the Crowe Critical Appraisal Tool (CCAT). **Results:** Nine articles met inclusion criteria. Four studies examined risk factors for depression in PD. Findings identified a total of 17 risk factors which were sub-typed into; clinical, motor, cognitive and physiological factors. The remaining five studies explored the association between awareness and depression. Results of these studies were mixed, with only two reporting a significant association between level of awareness and severity of depression. **Conclusions:** Data extracted highlighted that the majority of identified risk factors for depression were associated with PD symptoms. A relatively small evidence base exists in the association between awareness and severity of depressive symptoms in PD. Due to methodological factors such as utilized measures, limited conclusions were drawn from the findings of the included studies. Further high quality research is needed to clarify the relationship between awareness and depression in the PD population.

Keywords: Parkinson's disease, Depression, Awareness, Risk Factors

Introduction

Parkinson's disease (PD) is a neurodegenerative condition associated with a range of motor and cognitive symptoms (Peto, Jenkinson, Fitzpatrick & Greenhail, 1995; Muslimovic, Post, Speelman & Schmand, 2005). PD has a prevalence rate of 1 in 500, with an average age of onset around 60 years (Schrag and Schott, 2006). In addition to motor and cognitive symptoms, individuals with PD experience higher rates of depression than the general population. The estimated prevalence rate of depressive disorders in PD is approximately 40%, compared to 13.5% in the general population (Ishihara & Brayne, 2006; Schrag et al., 2007; Pachana et al., 2013). Despite the elevated risk of developing depression, fewer than 20% of depressed PD patients receive appropriate treatment (BPS, 2009). Under-diagnosis may be due to factors such as methodological differences in diagnosing depression and clinical features of mood disorders overlapping with the motor and non-motor symptoms of PD (Pachana et al, 2013).

Many depressive symptoms and PD symptoms (e.g. fatigue) overlap. This cross-over of phenomenology between these two conditions presents PD individuals with a barrier to diagnosis. Poewe (2008) stated that signs of depression may originate from the motor problems experienced by people with PD and not from mood. Gallagher, Lees, and Schrag (2010) suggested that individuals with PD without depression may also exhibit these 'depressed' symptoms due to their diagnosis of PD. This diagnostic overshadowing may also contribute to an under-diagnosis of depression in PD, due to similar characteristics of depression being wrongly diagnosed as part of motor problems (Fernandez, 2012).

Theories of Depression in PD and Associated Risk Factors

There are three competing theories of the association between PD and depression. Mayeux's (1990) 'serotonin hypothesis' stated that depression was intrinsic to PD and a direct result of underlying neuropathological changes to brain structure and function. Alternatively, Tandberg, Larsen, Aarsland, Laake and Cummings (1997) suggested that

environmental, situational and psychological factors may contribute to mood changes in PD and proposed that depressive symptoms in PD represented an understandable reaction to the diagnosis of a progressive impairment. Recently, Negre-Pages et al., (2010) stated that no clear unidirectional relationships existed between either theory, and proposed that a combination of biological and psychosocial factors influenced mood and exacerbated PD symptomology. In summary, three pathways between depression and PD have been proposed; 1. All biological; 2. All adjustment reaction; or 3. An interaction between biological and psychosocial factors.

Previous studies have described correlates of depression commonly found in people with PD, such as level of education, with more educated patients less likely to be depressed (Dissanayaka, et al., 2011). In their sample, depression was associated with younger age of onset, longer duration of PD, memory problems, hallucinations, sleep disturbances, postural hypotension and falls. Schrag, Jahanshahi and Quinn (2001) also suggested that impaired activities of daily living, high rates of apathy, PD severity and longer treatment duration were all associated with symptoms of depression. Sagna, Gallo and Pontone (2014) integrated these findings into a biopsychosocial framework in the development of depression in older adults with PD. This framework included sources of risk and resilience in PD patients; such as severity of motor symptoms, access to social support and family relationships, past psychiatric history, coping strategies and personality type.

Current literature suggests that individuals with PD and depression present clinicians with a complex presentation of intertwining symptoms. Evidence has suggested that depressive symptoms occur more frequently in patients with PD than in the general population, however specific risk factors contributing to depression in PD remain unclear (Dissanayaka et al, 2011). Rickards (2006) systematic review into factors associated with depression and neurological conditions, including PD, stated that altered mental states are an intrinsic part of neurological disorders and may influence the way patients experience their illnesses. This concept of perception of disability, how aware

the individual with PD is of their PD symptoms has recently received research attention. Of particular interest in this current systematic review is the possible association between awareness and depression in PD.

Awareness and Depression in Individuals with PD

Recognition of one's deficits varies along a continuum from complete unawareness (anosognosia) to full awareness (McGlynn & Schacter, 1989). Unawareness involves an inadequate evaluation of one's impairments with individuals often underestimating or denying their deficits, whereas individuals who are said to be aware are able to detect the presence of impairments associated with their disability (Clare, 2004). Awareness may also be described as a lack of insight or judgement. The ability to be aware of illness and associated deficits, allows individuals to recognize being ill and to assign a correct meaning to the symptoms they experience (Orfei et al, 2008). The phenomenon of awareness can be thought of as arising from interactions between different neuropsychosocial determinants, such as the patient's attitudes, beliefs, coping skills, and cultural social context (Halligan, 2006). Unawareness may originate from a person's behavioural reaction to a diagnosis of a serious or life-changing illness. This reactive mechanism may take the form of a process of adjustment, adaptation and accommodation to the changing physical, social and psychological needs associated with a neurological condition (Hurwitz & Calne, 2001). However, Klinowski and Paulsen, (2013) have proposed a different awareness pathway, suggesting that unawareness is intrinsic to the neurological condition, originating from the neuropathological changes in brain structure rather than the impact of adjustment reactions.

This lack of awareness can have significant impact on day to day functioning and emotional state of patients with chronic neurological conditions (Rosen, 2011). Schrag et al's (2001) regression analysis suggested that depression in Parkinson's disease was more strongly influenced by the patients' perceptions of illness than by their actual disability. Mediating factors, such as personality traits or social circumstances, may

increase disability or act as sources of resilience in patients with the same level of disease severity or impairment. The limited evidence base suggests that awareness of affective states, motor and cognitive abilities may be impaired in individuals with PD. Awareness is not an all-encompassing phenomenon as PD individuals can be differentially aware of deficits in various domains of functioning (Peto et al, 1995; Muslimovic et al, 2005).

Previous systematic reviews have focused on either prevalence rates of depression and/or correlates and risk factors of depression in PD (e.g. age of onset and duration of illness) rather than psychological variables (e.g. awareness of disability). Current research findings suggest that awareness of illness has an impact on emotional responses such as depression. However, the interaction between risk and awareness factors of depression in PD has not been reviewed.

Aims and Research Questions

This systematic review aims to highlight the most consistently reported factors (descriptive features and risk factors) and possible underlying psychological mechanisms (awareness) associated in the presence of depression in individuals with PD.

1. Determine the extent that current research into PD, awareness, depression and risk factors include standardised measures of mood and severity of PD.

2. What elevates the risk of depression in PD? Describe the most consistently reported risk factors of depression in PD.

3. Examine the association between awareness and depression in PD. In particular, does greater awareness of PD symptoms affect the likelihood of depression?

Methods

This systematic review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement guidelines (PRISMA; Moher et al., 2009; Liberati et al., 2009). A search of the Database of Abstracts of Reviews of Effects and the Cochrane Database of Systematic Reviews was completed. No existing or ongoing, literature reviews, systematic reviews or meta-analyses into this area were identified.

A systematic search of electronic databases was conducted to identify all existing research articles, assessing descriptive factors and risk factors of depression and aspects of awareness among adults with Parkinson's disease. The following databases and search platforms were used: Medline (via OVID Medline (R) 1946 to May week 1 2015.) Embase (via OVID Embase, 1947 to present, updated daily on 5th May 2015) CINAHL, PsycArticles and PsycInfo (via EBSCOhost 1987 until 5th May 2015). In addition to the database searches, a hand search was completed on the journal 'Movement Disorders', a key journal in the field of Parkinson's disease (for the last three years, from May 2012 – April 2015). In order to identify any articles of relevance which may not have been identified by the electronic searches, hand searches were completed on the reference lists of the key articles found in the database searches.

After considering previous systematic reviews of PD and depression (Sagna et al, 2014) and reviewing current literature, the following search terms were used:

(*Asterisk indicates truncation of words).

1. Parkinson's disease/ OR Parkinson disease/ OR Young Onset Parkinson's disease OR Parkinson*
2. Depressive Disorder/ OR Depressive Disorders OR Major Depressive Disorder/ OR Major Depression/ OR Depression/ OR Depress* OR Adjustment Disorder/ OR Adjustment Disorders/

3. Awareness/ OR Unawareness OR Insight; Judgement OR Judgment/ OR Anosognosia.
4. Risk Factor/ OR Risk Factors/ OR Risk factors for depression OR Predictor* OR Correlate* OR Association/ OR Associate* OR Descriptive* OR Descriptive feature* OR Descriptor*

All search terms were combined with the Boolean operator 'AND' (1 AND 2 AND 3 AND 4).

Date of publication limitations were specified to include all articles published until 5th May 2015. Articles were screened for eligibility through scrutiny of titles and abstracts, with a detailed review being conducted on those retrieved for inclusion against the following criteria: 1. Peer-reviewed articles published in the English language; limited to human studies with adult participants (over 18 years); 2. Studies were limited to original published research (Cohort studies, observational studies, intervention studies, randomised control trials, experimental studies, cross-sectional and descriptive studies) 3. Participants had a diagnosis of PD based on a standardised diagnostic measure. 4. Depressive symptoms were measured using a standardised instrument (e.g. Hospital Anxiety and Depressive Scale - HADS). 5. Risk factors or correlates of depression are reported. 6. Awareness of PD symptoms is reported or described.

Papers were excluded if they were: 1. Unpublished research, review articles, books, book reviews, poster presentations/ conference abstracts, Editorials; 2. Studies with no data or qualitative data; 3. Presence of neurological disorders other than PD (e.g. Traumatic Brain Injury; Dementia; Stroke or mixed neurological populations). 4. Participants with diagnosis of other mental health disorders. (Please see Appendix 1.2 for data extraction form).

Endnote was used to store and manage all references identified by the search. This reference manager also enabled duplicates to be removed. If eligibility for inclusion remained unclear, a researcher independent of the project reviewed the article.

Search Results

Electronic and hand searches identified 249 citations, which, once duplicates were removed left 196 unique citations to be screened for inclusion. Their titles and abstracts were assessed for their relevance to the review, resulting in 27 potential citations being retained. The full texts of these papers were obtained. After applying inclusion criteria to these full text papers, 18 papers were excluded. Therefore 9 papers were included in this systematic review. As stipulated in PRISMA, a four-phase flow diagram was produced to document the flow of information through the different phases of the systematic review (identification, screening, eligibility and included studies). Figure 1 illustrates the PRISMA Flowchart selection process.

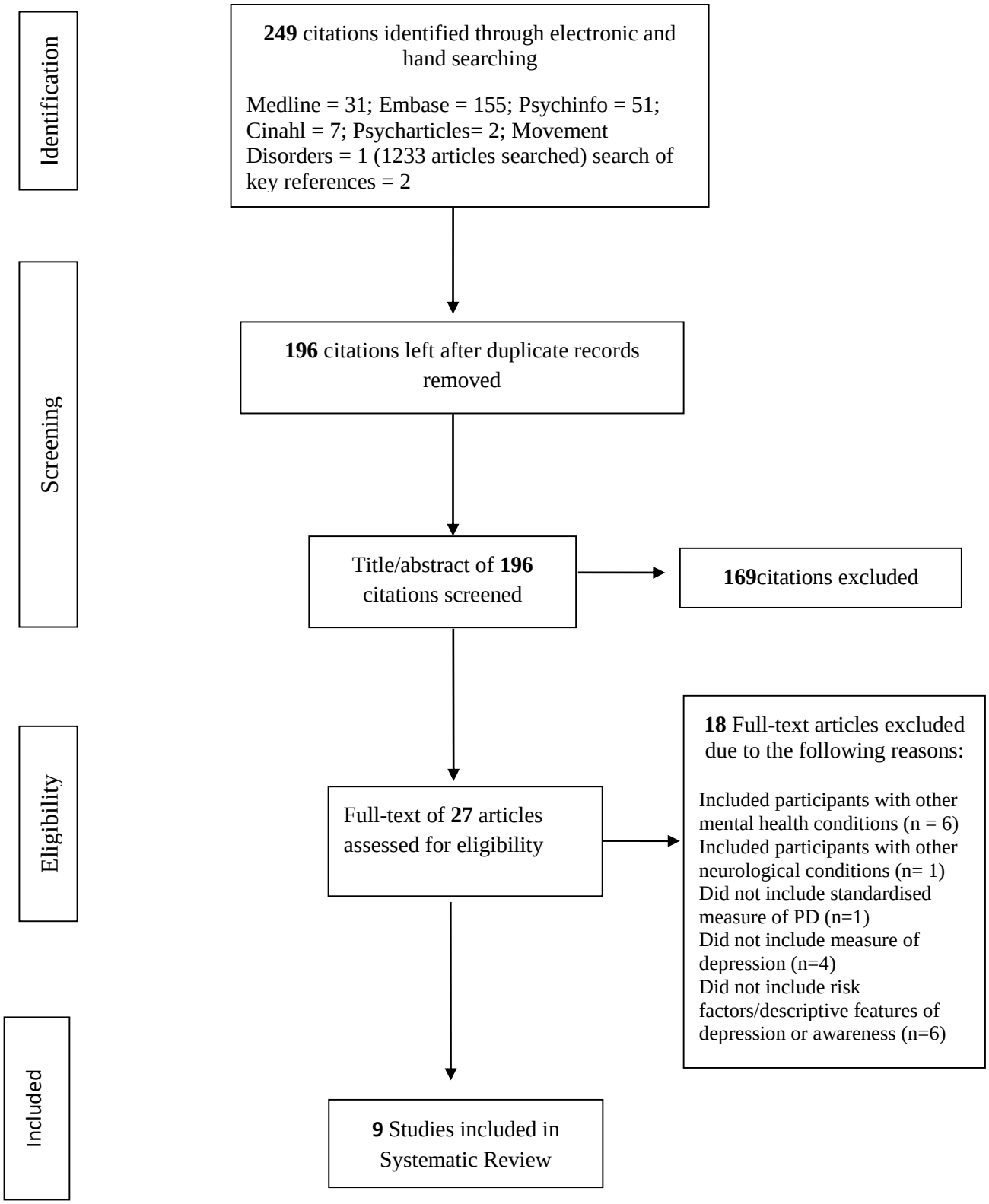

Figure1. PRISMA Flow diagram

Methodological Quality Rating

The Crowe Critical Appraisal Tool (CCAT; Crowe 2013) was used to quality rate studies. The CCAT consists of 22 items divided into eight categories reflecting the content of a typical research paper: Preliminaries, Introduction, Research Design, Sampling, Data Collection, Ethical Matters, Results and Discussion. Each category is scored on a 6 point scale, with the lowest score for each category being 0 and the highest score 5. The overall CCAT score for a single paper that can be achieved is expressed out of 40 and then converted to an overall percentage. The ratings for each of the studies in relation to the quality criteria are shown in Appendix 1.3.

In order to ensure reliability and increase confidence in quality rating, all identified papers were reviewed and co-rated by a fellow Trainee Clinical Psychologist, who was independent of the study. Quality rating process: each reviewer rated five papers, this was then followed by a discussion of individual ratings. Agreement (within two marks) of the total quality score was found in 4 of 5 (80%) co-rated papers, and agreement (within one mark) was found for the remaining article. Points of disagreement were resolved through discussions, with disagreed ratings amended to the consensus. The remaining four articles were then independently rated, following a second discussion all four papers received the same mark from both reviewers. Overall, quality rating agreement was high.

Results and Discussion

Data Synthesis

It is necessary to consider the overall findings of highlighted studies in respect of their collective methodological strengths and weaknesses. As the studies identified for inclusion in this systematic review varied in terms of their methodology, standardised measures and statistical analysis, it was decided that a narrative synthesis would be used. This is a textual approach to collating and appraising findings from multiple studies and allows for the analysis of relationships between them (Popay et al., 2006). For clarity of presentation, the evidence for each aim of the systematic review will be examined separately.

In order to gather the relevant data from each study for inclusion in the systematic review, a data extraction form was devised (Appendix 1.2). In regards to risk factors associated with depression in PD, a table was created based on key clinical and demographic features of depression, as stipulated in the criteria for Major Depressive Episode: DSM-V (American Psychiatric Association, 2013) and from the knowledge base of depression in PD (Dissanayaka et al, 2011, Sagna et al, 2014 & Schrag et al, 2001). Though the use of a vote counting procedure, each feature was allocated to a risk factor category: Behavioural, Clinical, Cognitive, Motor and Physiological.

General Characteristics of Studies

Based on the CCAT, the overall methodological quality of included studies had a mean total score of 29.1 (73.1%), with scores ranging from 27 - 31 (range of 68 - 78%). Four of the nine studies reported risk factors and correlates of depressive symptoms in individuals with PD. Table 1 summarises participant's characteristics of these four studies. The remaining five studies used a level of awareness measure and specifically explored the relationship between depression and level of awareness. Participant characteristics of these five studies are summarised in Table 2.

Table 1. Summary of participant's characteristic and measures - studies on risk factors and depression in PD.

Study	**Overall Quality Rating**		**Purpose**	**Sample Size and Characteristics**	**Standardised measure of PD**	**Standardised measure of Depression**	**Other Measures**	**Consideration of Pharmacological /Psychological Interventions**
	Total	%						
Farabaugh et al (2009)	29	73	Examined the frequency of risk factors specific to depressive symptoms in PD.	158 patients with PD (108 men and 50 women; mean age 66.82 years, range 39 – 74years. Mean disease duration 9.1 years, range 7-20 years. Mean age of onset 57.7 years	H&Y	HANDS	n/a	70 Participants currently prescribed Anti-depressant medication.
Saez-Francas et al (2013)	30	75	Evaluated the relationship between apathy and central fatigue in PD patients.	Total sample size of 90 PD patients. 60 male, 30 female. Mean age 61.44 years Fatigued group Gender 22 male to 15 female. Mean age 62.2 years Mean age of onset 58.3 years	H&Y UPDRS	HAM-D	**Cognitive** MMSE **Mood** LARS STAI **Other**	All PD participants were prescribed Anti-parkinsonian medication and were on the 'on state' of medication when tests were administered.

			Non-fatigued group Gender 38 males to 15 females. Mean age 62.8 years (9.6). Mean age of onset 58.5 years (10.2)			PFS	
Schrag et al (2001)	29 73	Investigated factors that may contribute to depression in PD.	97 PD individuals. Gender; 50 men and 47 women Mean age in years was 73 Mean disease duration 5.8 years Mean age of onset age 67.6 years.	H&Y UPDRS SE	BDI	**Cognitive** MMSE **Quality of Life** PDQ-39	All PD participants were prescribed Anti-parkinsonian medication.
Verbaan et al (2007)	28 70	1. Evaluated the occurrence of Autonomic Symptoms (AS) in PD, compared to the occurrence of AS in control subjects. 2. Explored the association between demographic, disease-related and clinical variables in this PD cohort.	420 patients with idiopathic PD (64% men and 36% female; mean age 61.1 yr; range 39 – 74yrs. Mean disease duration 10.5 years Mean age of onset 50.6 years Severity of PD 217 – mild PD 110 – moderate PD 82 severe PD (missing data 11 patients). 150 control participants of with 55% were male and 45% female. Mean age 60.9 years	Diagnosis based on the United Kingdom PD Society Brain Bank criteria for idiopathic PD. SCOPA-AUT H&Y	BDI	**Motor/movement** SPES/SCOPA-motor **Cognitive** SCOPA-COG **Mood** Modified-PPRS Other SCOPA-SLEEP	397 PD participants were prescribed Anti-parkinsonian medication and were on the 'on state' of medication when tests were administered. 23 PD participants were not prescribed Anti-parkinsonian medication.

Abbreviations: BDI = Beck Depression Inventory; HAM-D = Hamilton Depression scale; HANDS = Harvard Department of Psychiatry/National Depression Screening Day Scale; H&Y = Hoehn & Yahr Staging Score; LARS = The Lille Apathy Rating Scale; MMSE = Mini Mental State Examination; PDQ-39 = Parkinson's disease Questionnaire; PFS = The Parkinson Fatigue Scale; SE = Schwab-England Scale; SPES/SCOPA = Short Parkinson's Evaluation Scale/Scales for Outcomes in Parkinson's disease (SCOPA-AUT: autonomic function; SCOPA-COG; cognition; SCOPA-MOTOR: motor; SCOPA-SLEEP; sleep); STAI = State-Trait Anxiety Inventory State; UPDRS = Unified Parkinson's disease Rating Scale.

Table 2. Summary of participant's characteristic and measures - studies on depression and awareness in PD.

Study	Overall Quality Rating Total / %	Sample Size and Characteristics	Standardised measure of PD	Standardised measure of Depression	Measures of Awareness	Other Measures	Consideration of Pharmacological /Psychological Interventions
Amanzio et al (2010)	29 / 73	25 PD patients and observers (12 men and 13 women; mean age 59.12 yrs, range 39 – 74yrs. Mean disease duration 137.60 months, range 84-240.	H&Y UPDRS (Parts III & IV)	HAM-D	**Movement Disorders** GAM Dyskinesia Rating Scale Hypo-bradykinesia rating scale. **Awareness of disabilities in activities of daily living** NUDS	**Motor/movement** UPDRS Parts III & IV **Cognitive** MMSE WMS subtests IV & VII Claridge modified test WCST modified Phonemic Fluency Test **Mood** HAM-A BPRS	All PD participants were prescribed Anti-parkinsonian medication. Tests were administered on both the 'on state' and 'off state' of PD medication. PD participants were excluded if diagnosed with depression or if prescribed; Anti-depressant, Neuroleptics or Anxiolytic medication.
Brown et al (1989)	29 / 73	66 patients with PD (43 men and 23 women; mean age 58.6 yr, range 39 – 74yrs. Mean disease duration 10.7 years Mean age of onset 48.9	H&Y King's College London Parkinson's disease Rating Scale.	BDI	ADL	**Cognitive** MMSE	All PD participants were prescribed Anti-parkinsonian medication. 37 Participants were involved in an intervention study

		years					examining psychosocial function in PD. 29 participants were involved in a study examining sexual function in PD.
Lehrner et al (2015)	31 78	PD cognitively healthy group – 28 (17 men and 11 women) Mean age 67 yrs; range 52 – 81 yrs). Cognitively healthy Control Group – 211 (77 men and 134 women; mean age 66 yr; range 50 – 93yrs. Criteria for control: MMSE score ≥27 & MOCA score ≥26. No active neurological or psychiatric disease, no psychotropic medication and no medical disorder or treatment that negatively affects cognitive functioning.	Diagnosis based on the criteria of the UK Parkinson's disease Society Brain Bank. H & Y	BDI-II	VSRT (objective) FAI (subjective)	**Motor/movement** B-ADL **Cognitive** NTBV MMSE WST	Exclusion criteria: All individuals with a diagnosis of depression. Individuals prescribed psychotropic medication.
Sitek et al	30 75	45 PD patient – observer pairs (26 men and 19	H & Y UPDRS	BDI MADRS	SRSMF	**Motor/movement** UPDRS Parts III & IV	All PD participants were prescribed

(2011a)			women; observers included 33 spouses, 9 children and 3 patient friends) mean age 64.98 yr,) range 40 – 84yrs. Median disease duration in years 8 (range 2 – 24) Age of onset Mean 56.58 years, range 33 – 75	SE			**Cognitive** MMSE AVLT Stroop test	Anti-parkinsonian medication.
Sitek et al (2011b)	27	68	21 patients with idiopathic PD (10 men, 11 women) mean age: 63.29 years, range 40-78 years. Mean disease duration 12.19 years, range 5 – 24 years. Each PD individual was part of an observer partnership. (14 spouses and 7 children).	H & Y scale UPDRS parts II & IV SE	BDI	Questionnaires comprising of dyskinesia items from; UHDRS, UPDRS and SPDDS.	**Cognitive** MMSE Stroop Task	All PD participants were prescribed Anti-parkinsonian medication and were on the 'on state' of medication when tests were administered. PD participants were excluded if prescribed Anticholinergic medication.

Abbreviations: ADL = Activities of Daily Living; AVLT = Auditory Verbal Learning Test; B-ADL = Bayer Activities of Daily Living Scale; BDI = Beck Depression Inventory; BDI-II = Beck Depression Inventory-II; BPRS = Brief Psychiatric Rating Scale; FAI = The Forgetfulness Assessment Inventory; GAM = Global Awareness of Movement disorders scale;; HAM-A = Hamilton Anxiety Scale; HAM-D = Hamilton Depression scale; H&Y = Hoehn & Yahr Staging Score; MADRS = Montgomery – Asberg Depression Rating Scale; MMSE = Mini Mental State Examination; NTBV = The Neuropsychological Test Battery Vienna; NUDS = The North University Disability Scale; SE = Schwab-England Scale; SPDDS = Self-Assessment Parkinson's disease Disability Scale; SRSMF – Self-Rating Scale of Memory Functions; UHDRS = Unified Huntington's Disease Rating Scale; UPDRS = Unified Parkinson's disease Rating Scale; VSRT = The Verbal Selective Reminding Test; WCST = Wisconsin Card Sorting Test; WMS = Wechsler Memory Scale; WST = Wortschatztest.

Participants

The sample sizes of the experimental groups of all nine studies ranged from 21 to 420 participants. The mean age of the participants ranged from 58.6 years to 73.0 years. Mean age of onset ranged from 48.9 years to 67.6 years (documented in six studies) and mean duration of disease 5.8 years to 12.9 years (documented in seven studies). Information on the gender of participants was provided by all studies, with an overall sample of 595 Males to 355 Females.

Measurement of Depression

Eight studies measured depression by self-report measures (Amanzio et al, 2010; Brown et al, 1989; Farabaugh et al, 2009; Lehrner et al, 2015; Saez-Francas et al, 2013; Schrag et al, 2001; Sitek et al, 2011b & Verbaan et al, 2007). The most common self-report measure used was the Beck Depression Inventory I/II (BDI - six studies), followed by the Hamilton Depression Scale (HAM-D– two studies) and the Harvard Department of Psychiatry/National Depression Screening Day Scale (HANDS – one study). The remaining study by Sitek et al (2011a) utilized both clinician and self-report measures of depression using the BDI and the Montgomery – Asberg Depression Rating Scale (MADRS). All standardised depression measures utilized by the studies have been found to be reliable and valid scales of measurement in PD, especially the BDI (Sagna et al, 2014).

The results of the measurements of depression must be viewed in light of several limitations. The overwhelming reliance of self-report measures in all studies may give rise to subjective bias from the participants (Farabaugh et al, 2009). Due to differences between self-rating measures and clinician rated scales, in terms of mode of administration and symptoms assessed, Uher et al (2012) propose that a complete assessment of depression should include both clinician-rated scales and self-reported measures. Although, Sitek et al (2011a) utilised two methods of depression measurements (self-rating and clinician rating) they did not document who administered the MADRS or whether the objective rater was qualified to administer the measure.

In terms of pharmacological and/or psychological treatment, eight of the nine studies reported that PD individuals who were currently prescribed anti-Parkinsonian medication were involved in the studies. Of these eight studies, three (Saez-Francas et al, 2013; Sitek et al, 2011b; Verbaan et al, 2007) only administered tests when individuals were on the 'on state' of the anti-Parkinsonian medication and one study (Amanzio et al, 2010) compared PD individuals in both 'on and off state'. In terms of other pharmacological and psychological interventions, only two studies documented the exclusion criteria of anti-depressants/ psychotropic medication (Amanzio et al, 2010 & Lehrner et al, 2013). Brown et al (1989) was the only study to document whether PD individuals were receiving psychological interventions. Overall, conclusions of all nine studies must take into consideration the potentially confounding factors involved in either receiving/ not receiving additional interventions on the study outcomes.

Measurement of PD Severity

In terms of standardised measures of PD diagnosis/disease severity, all nine studies used the clinician rated Hoehn & Yahr Staging Scale of PD (H&Y). Seven studies provided supplementary standardised measures of PD severity; five studies used the UPDRS standardised scale of motor symptom severity. The Schwab – England Scale (SE) was used in three studies; Diagnosis based on criteria of the UK Parkinson's disease Society Brain Bank was used in two studies; The SCOPA-AUT was used in one study; The King's College London Parkinson's disease Rating Scale was used in one study.

What elevates the risk of depression in PD? Describe the most consistently reported risk factors of depression in PD.

Risk factors associated with depression in individuals with PD were examined in four of the nine included studies (Table 1). The majority of these studies used cross-sectional designs (Saez-Francas et al, 2013; Farabaugh et al, 2009; Verbaan et al (2007). The remaining study was a population based cohort study (Schrag et al, 2001). The sample sizes of these studies ranged from 90 – 420 and the mean ages of the samples ranged from 61.1 to 73.0 years. Through the vote counting procedure, 17 risk factors associated

with PD and depression were identified in these papers. These risk factors were divided into different sub-types: clinical (7), motor (5), cognitive (3) and physiological (2). (Table 3 - Summary of key descriptive features and risk factors of depression in PD).

Table 3. Summary of key descriptive features and risk factors of depression in PD

Risk Factor Subtype	Clinical-Demographic Correlate	Association with Depression	Study
Clinical Factors			
	Gender	No significant effect	Schrag et al (2001)
	Age	No significant difference with current age above or below 60 years.	Schrag et al (2001)
	Age of Onset	No significant difference between depression and age of onset (before or after 55 years).	Schrag et al (2001)
	Stage of Disease/ Severity of PD	Significant effect ($p<0.05$) Strong and significant positive effect was found between Hoehn & Yahr score and ratings of hopelessness ($p<0.0062$).	Farabaugh et al (2009)
		Significant correlation ($p<0.001$)	Schrag et al (2001)
	Duration of illness	No significant association	Farabaugh et al (2009) & Schrag et al (2001)
	Premorbid psychiatric Condition – depression	Significant association found between history of depression prior to PD diagnosis and severity of depressive symptoms (HANDS, $p<0.001$).	Farabaugh et al (2009)

	Suicidal Ideation	Strong association was shown between history of depression and suicidal ideation ($p<0.0001$)	Farabaugh et al (2009)
Physiological Factors			
	Autonomic Symptoms	Significant correlation ($p<0.01$)	Verbaan et al (2007)
	Fatigue	Significant difference in severity of depressive symptoms between PD patients with fatigue and PD without fatigue ($p<0.001$).	Saez-Francas et al (2013)
Cognitive Factors			
	Awareness	Significant difference ($p<0.001$).	Schrag et al (2001)
	Cognitive Impairment	Significant association between cognitive deterioration and severity of depression. ($p<0.0001$).	Schrag et al (2001)
		Strong association was shown between history of depression and poor concentration ($p<0.001$).	Farabaugh et al (2009)
	Hallucinations	Depression scores were significantly higher in individuals who self-reported hallucinations ($p<0.05$)	
Motor Factors			
	Balance/Falls	Depression scores were significantly higher in individuals who reported falls ($p<0.01$)	Schrag et al (2001)
	Dyskinesia	No significant association	
	Tremor	Correlation found between level of depression and higher tremor	

		scores ($p<0.05$)	
	Bradykinesia / Stiffness	Significant correlation between depression and higher akinesia scores ($p<0.01$) Depression scores were significantly higher in individuals who self-reported stiffness ($p<0.05$)	
	Dexterity or Speech	Depression scores were significantly higher in individuals who self-reported impairment of dexterity or speech ($p<0.05$)	

Through the application of vote-counting, seven clinical risk factors were identified in two studies (Farabaugh et al, 2009 & Schrag et al, 2001). Both studies found a significant positive association between severity of depression and stage of disease, with higher depression scores associated with advancing disease severity. Farabaugh et al, (2009) found a significant correlation between H&Y score and ratings of hopelessness, as PD individuals with higher H&Y scores exhibited higher ratings of hopelessness and were more likely to be diagnosed with depression. However, no association was found between duration of illness and level of depression (Farabaugh et al, 2009; Schrag et al, 2001). Schrag et al, 2001 examined the clinical factors of gender, current age and age of onset. No significant associations were found between depression scores and gender or between level of depression and current age above or below 60 years. No significant difference was found between depression and age of onset before or after 55 years.

Individuals with premorbid depression prior to PD diagnosis were significantly more depressed than those who had no previous psychiatric history (Farabaugh et al, 2009). Following on from this finding, Farabaugh et al (2009) found a strong association between history of depression and suicidal ideation, with individuals with premorbid depression reporting a significantly higher frequency of suicidal thoughts.

In regards to the motor category, one study identified five risk factors (Schrag et al, 2001). Significant correlations were found between PD patients with higher depression scores and who self- reported; the presence of falls, tremor, bradykinesia, stiffness or impairment of dexterity and/or speech. However, no significant association was found between level of depression and self-reported dyskinesia.

Cognitive risk factors were examined in two studies (Farabaugh et al, 2009 & Schrag et al, 2001). Schrag et al (2001) found a significant association between cognitive impairment and depression. With PD patients who scored >25 on the Mini-Mental

MMSE being more likely to have a diagnosis of depression. Farabaugh et al (2009) found a significant correlation between level of depression and poor concentration, and a significant relationship between numbers of self-reported hallucinations with higher depressive scores.

The cognitive risk factor of awareness was examined by Schrag et al (2001). This study compared PD participants self-rating of disability to that of clinician's objective ratings. Results suggested the level of depression in PD was strongly influenced by the patients' perceptions of disability rather than by their actual disability. PD patients with BDI scores of >18, rated their disability greater than the clinician. In comparison, PD patients with BDI scores <18 rated their level of disability similarly to clinicians. Over 90% of patients with depression scores >18, were rated on stages of 3, 4 or 5 of the H&Y Scale. This suggests that individuals with higher H&Y score perceived themselves to be more disabled and were at an increased likelihood of reporting symptoms of depression. However, a small proportion of patients with moderate to severe depression were found to be at the early stages of illness, lower staging on H&Y. These individuals may represent the subtype of depressed PD patients proposed by Tandberg et al (1997), who exhibit depressive symptoms as a reaction to diagnosis.

Physiological risk factors were examined in two studies (Verbaan, et al, 2007 & Saez-Francas et al, 2013). Verbaan et al (2007) found a significant correlation between autonomic dysfunction (symptoms that relate to cardiovascular, gastrointestinal, urinary, thermoregulatory, pupillomotor, and sexual functioning) and depressive symptoms. Suggesting that increasing severity of autonomic symptoms in PD individuals was associated with increasing severity of depressive symptoms. Saez-Francas et al (2013) found a significant association between depression and fatigue, as PD patients with fatigue showed a significantly higher score of depression than non-fatigued PD participants.

Methodological Limitations of Reviewed Literature

Methodological limitations of these studies, included a lack of psychiatric diagnosis of depression, as depression was measured using patient self-rating scores, such as the BDI. Therefore all analysis have been completed on a prevalence rate that relates to the proportion of patients scoring highly on that scale, rather than the presence of a depressive illness. This reliance on self-report measures may have an inherent subjective bias (Schrag et al, 2001).

Summary of Results

The majority of studies were cross-sectional studies that used standardised measures of depression and PD severity. Four research studies were identified that reported 17 risk factors of depression in PD. It must be noted that methodological issues were apparent in these studies. The finding of a discrepancy between subjective and objective clinician rating of disability by Schrag et al (2001), highlights the important role that awareness of abilities may play in PD and depression. Although, Schrag et al (2001) did not include a standardised measure of awareness, the findings from this article provide background to the association between awareness and depression.

The Association Between Awareness and Depression in PD.

The association between awareness and depressive symptoms in individuals with PD was examined in five of the nine studies. All five studies were observational in design; four cohort studies (Amanzio et al, 2010; Brown et al, 1989; Sitek et al, 2011a, & Sitek et al, 2011b) and one case-control study (Lehrner et al, 2015). Three of the studies focused on awareness of motor abilities and the remaining two studies focused on PD patient's awareness of their memory functioning (Lehrner et al, 2015; Sitek et al, 2011b). The sample sizes of these studies ranged from 21 – 60 and the mean age of samples ranged from 58.6 to 67.0 years.

Assessment of Awareness

All five studies applied a discrepancy method, whereby discrepancy ratings between self-reported levels of ability were compared against an objective rating. However, three methods of awareness measurement were utilized within the five studies. Two studies used PD patient - observer discrepancy ratings to produce a measure of awareness and compared these discrepancies against objective memory performance (actual performance) (Sitek et al, 2011a & Sitek et al, 2011b). Amanzio et al, (2010) and Brown et al, (1989) utilized two sources of objective discrepancy ratings, from observer and qualified clinicians, which were then compared to subjective ratings. The final study, (Lehrner et al, 2015) measured discrepancy ratings between PD patient's subjective memory appraisals (estimation of performance) and objective memory performance (actual performance). These results were then compared to the discrepancy ratings of a control group of healthy volunteers. Table 4 outlines the study rationale, awareness measure and key findings of the five included studies.

Table 4. Association between awareness of abilities and depression in PD

Study	Purpose	Awareness Method	Association
Amanzio et al (2010)	To analyse the presence of awareness of movement (dyskinesia and hypokinesia) and motor fluctuations with mood.	Discrepancy ratings between patients self-report of awareness of movement disorders and level of disability to observer evaluations.	Significant association ($p<0.001$).
Brown et al (1989)	Assessed the accuracy of self-reported disability in activities of daily living and explored the possible influence of depression on self-report.	Discrepancy ratings between PD individuals self-reported level of ability and observer (relative) judgements on ADL measure. And discrepancy scores between PD self-reported and clinician-rated ability on motor task and symptom severity.	BDI was unrelated to symptom severity or self-reported disability.
Lehrner et al (2015)	Explored correlates of awareness and compared frequencies of subjective over and under-estimations. Comparison between PD and control group of healthy volunteers.	Awareness of memory ability was measured as the difference between subjective memory appraisals and objective memory performance.	No correlation was found between PD patients level of awareness and BDI scores.
Sitek et al (2011a)	This study examined self-awareness of dyskinesia and motor symptoms in PD.	Discrepancy ratings were used by subtracting observer ratings from patient self-report on motor awareness questionnaire.	No significant associations were found between awareness of motor ability and depression.
Sitek et al (2011b)	Assessed self-awareness of memory in PD by comparing patients' and caregivers' questionnaire ratings of the patients' memory and by correlating subjective ratings with verbal learning results. Factors that could influence the self-awareness of symptoms, such as mood, general cognitive status and disease severity were also assessed.	Discrepancy ratings calculated by subtracting observer ratings from patients self-report on the adapted SRSMF (This study took place in Poland, the SRSMF was translated into Polish and demonstrated satisfactory consistency, Cronbach's alpha of 0.92 and validity. The SRSMF was adapted for use as an observer measure - satisfactory reliability (Cronbach's alpha=0.89)	Significant correlation were found between MADRS and ADS* ($p<0.05$), MADRS and OS** ($p<0.001$) and BDI and OS ($p<0.01$)

Abbreviations: BDI = Beck Depression Inventory; HAM-D = Hamilton Depression scale; MADRS = Montgomery – Asberg Depression Rating Scale;
* ADS = average difference score of the Self-Rating Scale of Memory Functions (SRSMF) 18 items between patient and observer recordings.
**OS = overestimation scores (patient rated their memory abilities as more severely impaired than did their observer).

Association between Motor Awareness and Depression

Awareness of motor symptoms was examined in three of the included studies (Amanzio et al, 2010; Brown et al 1989, & Sitek et al, 2011a).

Amanzio et al (2010) examined the 'on-off states' of motor fluctuations on awareness. The majority of PD individuals are prescribed dopaminergic medication, such as Levodopa, which alleviates the motor symptoms of PD. However, as the disease progresses research has been shown that this medication becomes less effective. As a result, individuals with PD are said to be in an 'on state' when the medication is effective. However, due to the medication 'wearing off' period, the person is then said to reach an 'off state', where they may exhibit an increase in motor symptoms, such as stiffness and rigidity (Lees, 1989).

Amanzio et al (2010) found a significant association between severity of motor impairment, level of awareness and severity of depression. PD patients who scored higher on levels of depressive symptoms in the 'off state', reported higher awareness of motor impairment. It was also found that individuals with higher levels of depressive symptoms scored higher in areas of apathetic behaviour, such as lack of interest and reduced emotional responsiveness. Neuropsychological test results indicated a difference between on and off state for cognitive performance. Results showed that when in the 'on state' PD patients performed better on tests of executive functioning and memory, suggesting a possible link between severity of motor impairment and cognitive functioning, however no comparison was made in relation to level of awareness.

Brown et al.'s (1989) study of self-rated disability of motor abilities, found that PD individuals provided accurate judgements of disability similar to those of observer ratings. Overall, PD patient's BDI scores were unrelated to self-ratings of symptom severity, suggesting that there was no independent contributory factor of level of

depression with accuracy of motor awareness. Sitek et al (2011a) found no significant associations between awareness of motor ability and level of depression in PD. Results of this study suggested that patient's perception of motor disability were consistent with observer ratings.

Association between Awareness of Memory Functioning and Depression

Awareness of memory functioning was examined in two studies (Sitek et al, 2011b& Lehrner et al, 2015).

Sitek et al (2011b) cohort study found that self-awareness of memory functioning was negatively affected by depressive symptoms, as PD patients who rated higher levels of memory dysfunction recorded higher depression scores. Results also suggested that PD patient's total subjective memory ratings and observer objective memory ratings did not differ significantly, suggesting that self-awareness of memory function is relatively preserved in PD. However, when individual domains were examined, better agreement was found in items of verbal recall and word finding difficulties. Whereas working memory ratings differed significantly, with PD participants rating these higher than observer. This may be due to these memory features being more implicit to the person.

In contrast, Lehrner et al (2015) reported no association between PD patient's awareness of memory ability and severity of depression. Findings also suggested relatively accurate self-appraisals in the PD group. This suggests that individuals who were less accurate at predicting memory functioning (either under or over estimating ability) were just as likely to report depressive symptoms as PD individuals with awareness. A particular strength of this study was the use of a healthy control group, however, no demographic or statistical data of the control group were presented. Lehrner et al (2015), also noted that inaccurate self-assessment can be observed in control participants, however no data was supplied on the actual frequency for this population.

Methodological Limitations of Reviewed Literature

There are a number of methodological limitations which must be taken into consideration when examining the results of these five studies. All five studies used various methods and designs, which led to difficulty in providing direct comparisons between studies. Of the five studies, Lehrner et al (2015) was the only study to include a control group. However, the authors stated this was a convenience sample of control participants recruited through an advertisement, which they argue may have led to selection bias.

Only Amanzio (2010) differentiated between patients with 'on - off' state motor fluctuations, which has been argued to be a significant contributor to depression in PD. However, this sample comprised of individuals with a higher degree of PD severity, therefore it may be difficult to generalise these results to PD patients at different stages of disease severity. None of the remaining four studies differentiated between the 'on – off state'. In fact, Sitek et al's (2011a) PD sample were only examined in the 'on state', suggesting that pharmalogical medication may have been alleviating the motor symptoms of PD, as no comparisons were made between awareness of disability and level of depression in the 'off state'.

Other limitations include no documentation of flow of participants or reasons why people did not participate in the research in any of the five studies. Therefore, it could be argued that non-participants may exhibit other symptoms than those displayed by the experimental groups. As no sample size calculations were documented it is unsure if statistical power was achieved for any of the five studies.

Summary of Results

In summary, results from the five papers exploring the relationship between awareness and depression in PD were mixed. All studies administered a discrepancy rating scale to compute level of awareness of either memory or motor abilities. Two studies outlined a significant association between level of awareness and severity of depression (Amanzio et al 2010 & Sitek et al 2011b), whereas the remaining three studies reported no relationship between these two conditions.

Conclusions

Our aim was to review current literature on aspects of awareness, depression and risk factors in PD. From the search strategy nine empirical studies were identified that met inclusion criteria for this systematic review. Although, this is a relatively small number of articles, to date the empirical research in this area has received little attention and as such, the available evidence is in its infancy. Nonetheless, supplementation of results with hand searching and searching reference lists of included papers provides confidence that all relevant research was included in this systematic review and that conclusions arising from this review can be based on the synthesis of all available evidence. Overall, all nine papers included standardised measures of PD severity/ diagnosis and depression.

What elevates the risk of depression in PD? Describe the most consistently reported risk factors of depression in PD.

Within the nine articles, four papers examined risk factors and descriptive features of depression in PD. Several risk factors were highlighted in the articles and these were divided into sub-domains of clinical, motor, physiological, cognitive and behavioural factors. Data extracted across all four studies suggested that the most commonly associated risk factors of depression in PD patients were related to PD symptoms rather than demographic characteristics (with the exception of dyskinesia, Schrag et al, 2001). Demographic characteristics such as age, gender and age of onset were not associated with depression in PD. Factors which elevated the risk of depression included: severity of disease, premorbid depression, motor and cognitive symptoms.

Due to many depressive and PD symptoms overlapping, the use of standardised measures of depression may present difficulties to PD individuals, as questions could relate to either condition. Difficulties in differentiating between PD symptomology and depressive symptoms, may result in PD patients receiving inappropriate treatment and under-diagnosis of depression (Pachana, 2013). Modifiable factors that could be targeted to reduce adverse outcome such as distress and suffering, could include the

development of specific tools sensitive to the unique characteristics demonstrated by this population. Through the application of standardised self-report measures, key depressive symptoms may be unrecognised due to their association with PD symptoms. It is hoped that findings from this review highlight the complex interaction between these two conditions and informs clinicians when assisting in the prevention and intervention of depression in PD patients. To summarise, previous literature (Sagna et al 2014) has stated the equivocal nature of risk factors in PD and findings from this current systematic review further highlight this.

Examine the association between awareness and depressive symptoms in PD. Does greater awareness of PD symptoms affect the likelihood of depression?

Five studies explored the relationship between awareness and depressive symptoms in PD. Overall findings were mixed, with only two articles reporting an association between level of awareness of motor/memory impairments and severity of depression. Findings from Sitek et al (2011b) and Amanzio et al (2010) suggested that PD patients who were more aware of PD symptoms (memory and motor) were more likely to be depressed. With higher scores on awareness associated with higher depressive scores. Results from this systematic review suggest that awareness of illness may have an impact on depression. This is consistent with previous research, which stated that perception of illness rather than actual disability was a mediating factor of depression (Schrag et al, 2001).

The mixed findings reported in this review may be due to a combination of study factors such as; different awareness measures, study design, sample size and characteristics of participants. For example, Amanzio et al (2010) was the only study to examine pharmalogical/medication factors. Results from this study suggested that when PD patients were experiencing motor fluctuations (‘off- state’) they were more aware of PD symptoms and self-reported higher depressive symptoms. However, when motor fluctuations were controlled through medication (‘on-state’) PD patients noted a reduction in depressive symptoms. The underlying mechanisms of unawareness

(intrinsic/reactive) still remains unclear and further research is needed into the possible relationship between awareness of PD symptoms and depression.

Strengths and Limitations of the current review

This is the first systematic review to be completed on PD, depression, awareness and risk factors. The results were limited to studies written in English. Parekh-Bhurke et al., (2011) suggested that an inherent publication bias is common when conducting a systematic review. However, the current review did include several quality rated papers which reported non-significant findings.

The method of narrative synthesis used to analyse the articles within this review is a subjective method that can be open to several criticisms. In comparison to meta-analysis, Popay et al (2006) stated that narrative synthesis could be regarded as the 'second best' approach to synthesising data but, as noted in the Cochrane handbook: 'systematic reviews adopting a narrative approach to synthesis will be prone to bias, and may generate unsound conclusions,' (2005; pg. 6). In order to reduce sources of subjective bias in this current review, both the inclusion/exclusion decisions and the quality ratings were subjected to independent review.

Although the reliability and validity of Critical Appraisal Tools (CAT's) have been questioned, such as arbitrary cut-off weightings of what constitutes good quality evidence from moderate and poor quality studies (Crowe & Sheppard, 2011). The CCAT utilized in the current review was devised from a systematic review of over 40 CAT's. A key strength of the CCAT was that scores were not converted into a scale/weighting, with each study evaluated on its own merit. This allowed for a narrative comparisons between scores rather than a numerical comparison, which may have masked methodological or design defects. Overall, applying a transparent and potentially replicable method of narrative synthesis to the current review allowed for the collation of evidence from several empirical studies, which highlighted a gap in the research knowledge base.

Clinical Implications & Future Research

Findings from the four studies examining risk factors and descriptive features of depression in PD, suggest that the most commonly associated risk factors of depression in PD patients were related to PD symptoms. Although some of the papers included in this review offered evidence of an association between level of awareness and depression, this relationship was not reported across the five studies. Results from this review have documented the methodological limitations within the existing evidence base which may inform the development of new studies examining associations between level of awareness and depression. It is suggested that additional research with higher degree of methodological rigour is needed to allow for more consistent conclusions to be drawn.

The majority of the included studies examining the relationship between awareness and depression either focused primarily on motor or memory abilities. As PD patients may experience impairments in both their motor and cognitive abilities it would be interesting to explore the differences of PD patient's level of awareness between these two domains. Moreover, it would be beneficial to explore the potential relationship between specific motor and cognitive domains. Results of this review highlighted that only the cognitive domain of memory was assessed. It is suggested that future studies examine other cognitive domains such as; attention, concentration, visuospatial abilities, problem solving and executive functioning. This may allow clinicians to further understand the impact of these cognitive domains on severity of depression in individuals with PD.

In terms of methodological limitations, it is proposed that future studies should be adequately powered and sample size calculations should be made available to aid cross study comparisons. In terms of impact of PD on depressive symptoms and level of awareness, the employment of a control group of healthy volunteers would allow for more robust comparisons to be examined.

Overall Conclusion

In summary, this systematic review extracted data from the available literature base of PD, depression, awareness and risk factors. A relatively small evidence base exists of the association between level of awareness and severity of depressive symptoms, with mixed results from the included studies. The available research has several methodological limitations and it is recommended that further good quality empirical research is needed in this area. Insight into this relationship between awareness and depression may have clinical implications in the assessment, diagnosis and treatment of depression in individuals with PD.

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Chapter 2: Major Research Project

Unawareness of Cognitive Abilities in People with Parkinson's Disease: A Case-Controlled Study.

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Prepared in accordance with the instructions to authors for the Journal of Neurology, Neurosurgery and Psychiatry (see Appendix 2.1)

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Chapter 2: Major Research Project

Unawareness of Cognitive Abilities in People with Parkinson's Disease:

A Case-Controlled Study

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Plain English Summary

Background: Awareness of our abilities is important in everyday life as it supports the ability to recognise our limits. This ability is commonly weakened in neurological diseases, such as Parkinson's disease (PD). Awareness is important in PD as it can impact on everyday functioning, ability to judge risks and may cause difficulties in relationships. Although several studies have examined level of unawareness of motor symptoms in people with PD, there has been limited research into PD people's unawareness of cognitive abilities; attention and memory.

Aims: The aim of this study was to explore unawareness of cognitive abilities in people with PD. This study also explored the differences between unawareness of cognitive abilities and motor abilities, and investigated how the person's unawareness of cognitive abilities might affect their caregivers.

Methods: This study comprised of two groups: an experimental group of people with PD and a control group of healthy volunteers (recruited from an advertisement in local GP surgeries). Participants included in the study had no history of learning disabilities; no current psychiatric disorder (e.g. depression); no substance misuse; nor previous neurological conditions (e.g. Traumatic Brain Injury; Stroke). Due to PD being a progressive illness, we decided not to include people at the more severe stages on the Hoehn and Yahr (1967) rating scale, as their motor and physical disabilities may be too severe for them to complete the tests.

Both groups were asked to predict their performance before completing the cognitive tests. After completing the tasks, all participants were asked to estimate their actual performance. This allowed us to calculate each participants level of unawareness by comparing their before and after ratings to their actual performance. The PD participants also completed an unawareness questionnaire and a motor test (finger tapping and heel lifts). 15 PD participants consented to having a family member complete a caregiver questionnaire.

Main Findings: We found that PD people overestimated their cognitive abilities compared to the healthy controls. PD people also showed a difference between their cognitive unawareness and motor unawareness. They tended to underestimate their motor abilities compared to their cognitive abilities. We also found a significant relationship between level of cognitive abilities and caregiver stress. This meant that PD people who were less aware of their cognitive abilities had carers who reported more stress.

Conclusions: Results from this study suggest that people with PD show unawareness of their cognitive abilities compared to the healthy controls. It is hoped this project will further our understanding of unawareness of cognitive abilities in PD and what this means for people with PD, their carers and clinicians in a practical and functional sense.

References: Hoehn, M.M., &Yahr, M.D. (1967) Parkinsonism: onset, progression and mortality. *Neurology*, 17 pp.427–442.

Abstract

Background: 'Anosognosia', or unawareness of ones deficits, is an important influence on behavioural functioning as it underpins the ability to recognise our limits. Anosognosia is common in neurological diseases, such as Parkinson's disease (PD). Although several studies have examined PD patient's level of unawareness of motor symptoms there has been no research into PD patient's unawareness of cognitive abilities. **Aims:** This study aimed to explore PD patient's unawareness of their cognitive abilities in comparison to a healthy control group. We also explored differences in level of unawareness of cognitive abilities versus motor abilities. Finally, we explored the relationship between level of unawareness of cognitive abilities and caregiver burden. **Methods**: 21 PD participants and 21 control participants, with similar demographic characteristics, participated in this study. All participants predicted their performance based on a normal distribution curve, prior to completing the RBANS assessment. Following task completion, participants were then asked to estimate their actual performance. This resulted in a pre and post discrepancy score of the differences between self-rated and actual performances. The PD participants completed additional measures, including the Awareness Questionnaire and MDS-UPDRS-Part 3 (pre and post discrepancy). Fifteen PD participants consented to a significant other completing the Zarit Burden Interview **Results:** PD participants overestimated their cognitive abilities in comparison to the control group. Comparisons between unawareness measures were not significant. PD participants were more accurate at estimating their motor abilities and a significant correlation was found between level of cognitive unawareness and caregiver burden. **Conclusion:** This is the first study to show that people with PD tend to over-estimate their cognitive abilities. Results from the percentile method could provide an alternative, more direct measure of assessing explicit processes related to unawareness in PD. PD patients may be differentially aware of deficits within and across various domains of functioning. Our preliminary data from carers suggests that unawareness of cognitive abilities is a correlate of caregiver burden.

Keywords: Unawareness, Cognitive abilities, Parkinson's disease, Motor abilities, Caregiver Burden.

Introduction

'Anosognosia' was first introduced by Babinski (1914; cited in Klinowski & Paulsen, 2013) to describe unawareness of one's disease or deficit. In this context, the ability to be aware has been defined as: 'a reasonable or realistic perception or appraisal of a given aspect of one's situation, functioning or performance, or the resulting implications' (Clare, Markova, Roth & Morris, 2011, p.936). Research on unawareness has shown that this function is commonly compromised in neurological diseases, such as dementia (Williamson, et al., 2010). In comparison, disturbances of awareness have not been extensively examined in the second most commonly diagnosed degenerative neurological condition, Parkinson's disease (PD).

PD was first described as the 'Shaking Palsy' by James Parkinson in 1817 and was initially characterized by motor symptoms such as rigidity, tremor of the limbs and bradykinesia (Schapira, 2010). However, PD patients may also experience changes in non-motor symptoms, such as impairments in attention, memory, executive functioning, slowing of mental processing, delayed response time and visuospatial defects (Peto, Jenkinson, Fitzpatrick & Greenhail, 1995; Muslimovic, Post, Speelman & Schmand, 2005). It is estimated that 85% of PD patients exhibit deficits in cognitive functioning at various stages of disease progression (McNamara, 2011). Cognitive disturbances in PD can be as disabling as the motor symptoms of the disease, typically with attention, complex decision making, and mental flexibility affected first (Schapira, 2010).

Several studies have examined PD individual's level of unawareness in terms of motor symptoms (Sitek, et al., 2011a), expressivity (Mikos, et al., 2009) and social deficits (Leritz, Loftis, Crucian, Friedman & Bowers, 2004). In contrast, there has been limited research into cognitive domains, with only two studies examining awareness of memory functioning (Lehrner et al., 2015; Sitek, Soltan, Wieczorek, Robowski & Slawek, 2011b). There has been no research examining PD patient's unawareness of cognitive

abilities and whether disturbances in cognitive awareness have similar repercussions for individuals with PD as those highlighted in dementia literature.

Methods of Assessing Unawareness

Methods of measuring unawareness have primarily compared questionnaires that ask patients about their current abilities and compare these responses to the objective perceptions of a close informant. These patient-proxy questionnaires produce a discrepancy rating which is then used to measure the patient's level of unawareness (Sherer, Bergloff, Boake, High & Levin, 1998). There are identified limitations with patient-proxy measures, such as informant bias (Clare, 2004b). It has been suggested that less biased methods should be developed, such as applying discrepancy scorings of objective self-ratings to patient's perceptions of their abilities (Eslinger et al., 2005). Eslinger et al (2005) propose that unawareness is a metacognitive process comprising of two components of self-prediction and self-monitoring. Self-predictions can be defined as awareness of cognitive ability through pre-test, whereby the patient derives self-knowledge of abilities, reflection and previous life experience. Self-monitoring can be thought of as awareness of cognitive performance through post-testing estimations, where the client judges their actual performance compared to their perceived performance.

Williamson et al (2010) devised an unawareness measure whereby dementia patients predicted their cognitive performance before and after administering a standardised neuropsychological assessment. These predictions were then rated on a percentile scale, represented by a normal distribution curve (illustrated in Figure 1). This allowed for direct comparison between pre and post estimates of cognitive performance against actual performance using the same scale. Several studies from the limited literature on unawareness in PD have applied patient-proxy questionnaires (Amanzio, et al. 2010; Sitek et al, 2011b). The percentile ranking method devised by Williamson et al (2010) has not been applied in the PD population.

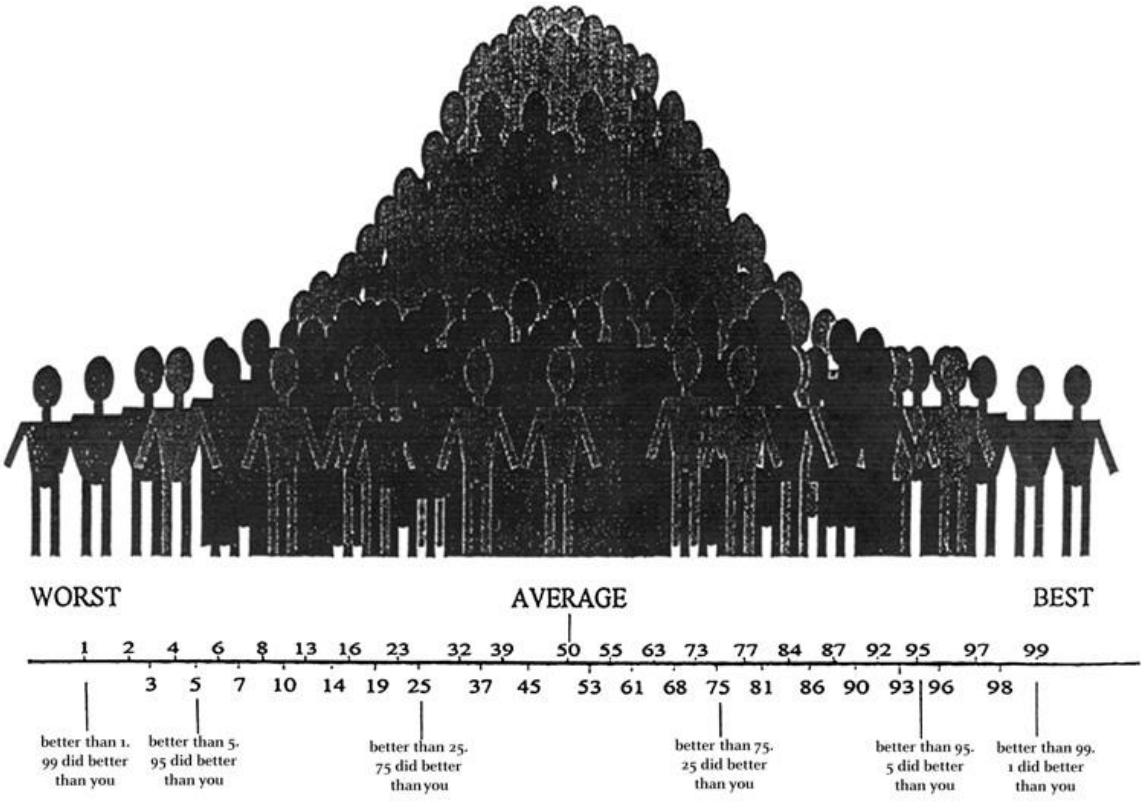

Figure 1. Bell shaped curve used as reference for pre and post-test performance predictions (Williamson et al, 2010, p. 142).

Factors Associated with Level of Unawareness

Clare, et al., (2012) proposed that a number of non-cognitive factors influence measures of unawareness in dementia. For example, psychosocial factors, such as psychological denial and mood may be important influences on reduced awareness (Ownsworth, Clare & Morris, 2006). Naylor and Clare (2008) state that unawareness may serve as a protective function against the threats to identity of self that follow the onset and progression of dementia. In regards to the impact of mood on level of unawareness of memory functioning, Sitek et al (2011b) found that self-awareness of memory functioning was negatively affected by depressive symptoms, as PD patients who overestimated their level of memory dysfunction recorded higher depression scores.

In terms of biological influences on unawareness, a correlational study has demonstrated a significant relationship between the degree of motor impairment and cognitive ability in individuals with PD (Murakami, et al., 2013). Amanzio et al's (2010) study of motor awareness suggested a possible link between severity of motor impairment and cognitive functioning, with PD patients performing poorer on tests of memory when ratings of motor impairment were high. Therefore, suggesting a possible link between motor and cognitive functioning, however no comparison was made in relation to level of unawareness.

It has also been shown that unawareness of deficit has significant impact on day to day functioning of the PD individual and on the affective state of their caregiver (Rosen, 2011). Due to PD being a degenerative disease, the task of supporting and caring for the individual usually falls to a spouse or family member. This can give rise to caregiver burden, the physical, mental, and socio-economic problems experienced by the caregivers of people with chronic diseases (Martinez-Martin, et al., 2007). Several studies have examined the impact of unawareness of motor abilities on caregiver burden in carers of individuals with PD. In their sample which included PD patients, Faison, Faria and Frank (1999) reported a positive correlation between level of care needed to perform activities of daily living and caregiver burden (r = 0.21; small effect) indicating that increases in motor deficits were associated with increases in caregiver burden. Schrag, Horvis, Morley, Quinn and Jahanshahi (2006) found that self-reported motor disability was associated with greater degree of caregiver burden in PD. Presently, no study has examined the relationship between unawareness of cognitive abilities in PD and caregiver burden.

As no research exists in relation to PD and cognitive unawareness, this study will examine whether people with PD are less accurate at estimating their cognitive abilities and monitoring their cognitive performance compared to a control of healthy participants. Previous research has shown significant association between PD patients motor and cognitive abilities and significant relationship between unawareness of motor

abilities and caregiver burden. However, no research has examined the relationship between unawareness of cognitive abilities and unawareness of motor abilities, or the association between cognitive unawareness and caregiver burden. It is hoped the results will further our understanding of unawareness of cognitive abilities in PD and what this means for patients, carers and clinicians in a practical and functional sense.

Hypotheses

1. a. The ability to be aware, as reflected by the ability to judge performances, varies within populations. It is predicted that PD patients will overestimate their cognitive abilities, as measured by discrepancies between estimated and perceived performance on neuropsychological tasks, in comparison to the control group.

   b. Does the method of assessing unawareness matter? As percentile measures of unawareness have not previously been deployed in PD patients, the relationship between percentile scale and questionnaire methods in the PD only group will be examined. PD patients who are less accurate at estimating cognitive abilities (pre and post-test discrepancies) will also demonstrate unawareness of abilities in general as shown through the patient – proxy discrepancy (concurrent validity).

2. Murakami et al.'s (2013) correlational study found a significant relationship between the PD participant's degree of motor impairment and cognitive problems, suggesting that deficits in both areas occur simultaneously. However, the difference in unawareness of motor and cognitive abilities has not been examined. Due to the salient feedback of motor deficits compared to the more discreet presentation of cognitive deficits in individuals with PD, it is predicted that self-ratings of their cognitive deficits will be less accurate (estimating and monitoring performance), than self-ratings of their motor deficits.

3. Based on Faison et al.'s (1999) significant correlational study of motor unawareness and caregiver burden, it is predicted that greater unawareness of cognitive abilities will also correlate with carer burden. This will further our understanding of the progressive changes in cognitive ability in individuals with PD and its possible implications on caregiver burden.

Method

Ethical Approval

Ethical approval was obtained from North of Scotland Research Ethics Committee (Appendix 2.1 & Appendix 2.2). Management approval for the protocol was granted by NHS Highlands Research and Development Department (Appendix 2.3). Participation in the study was voluntary and written informed consent was obtained from all participants.

Participants

PD participants were recruited from the NHS Highland Parkinson's disease Department. The inclusion criteria for PD participants: were adults over the age of 18 years, with a clinical diagnosis of PD and at disease stages 1 – 3, as specified by the Hoehn & Yahr (H&Y) Staging Scale (1967). Through consultations with the PD department it was agreed that due to increasing severity of motor control and physical disabilities as PD progresses, it was decided to exclude individuals at stages 4 and 5 on the H&Y (confinement to bed or wheelchair unless aided). Control participants were recruited through an advertisement in local GP surgeries. Exclusion criteria for all participants included a history of learning disabilities; current diagnosed psychiatric disorder (e.g. depression); current substance misuse disorder; or previous neurological conditions (e.g. Traumatic Brain Injury; Stroke).

Measures

Demographic information was collected from all participants (age, gender, marital status, education and occupation). Additional information regarding severity of disease and duration of illness for the PD participants was obtained through reviewing medical records.

Test of Global Cognitive Functioning - Repeatable Battery for Assessment of Neuropsychological Status (RBANS) (Randolph, 1998) (all participants)

The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) was developed for the dual purposes of identifying and characterizing cognitive decline in older adults and as a neuropsychological screening battery for younger patients (Randolph, 1998).

The RBANS consists of several subtests which assess the cognitive domains of Immediate Memory, Visuospatial/Construction, Language, Attention, and Delayed Memory. Scaled score norms for individual subtests and total summary score are grouped by decade of age for individuals from 20 to 89 years (Beatty, et al., 2003). RBANS Index scores demonstrate strong convergent validity with other neuropsychological measures and provide clinicians the ability to interpret individual subtests and make direct comparisons between subtests. The RBANS has been found to be useful in discriminating patterns of cognitive impairment in Parkinson's disease (Ryder, et al., 2002; Beatty et al 2003).

The Awareness Questionnaire (AQ) (Sherer et al, 1998). (PD patients only)

The AQ consists of 17 items (cognitive – seven items, motor/sensory – four items and behavioural/affective – six items). All items ask patients and their informant to rate their current level of functional abilities on a Likert scale ranging from 1 (much worse) to 5 (much better). Informant interviews for each PD participant was completed by the Specialist PD Nurse. Discrepancy scores were calculated through subtracting the informant ratings from the self-ratings. An overall discrepancy score >20 indicates clinically significant impairment of awareness.

The AQ has high reliability and internal consistencies (Sherer, Hart & Todd, 2003). Although initially devised as an awareness measure for brain injury, the AQ has been

recommended by The Parkinson Evidence Database to Guide Effectiveness (PDEDGE) task force (The Rehabilitation Measures Database, 2015).

Test of Global Motor Functioning: Part three - The Movement Disorder Society Unified Parkinson's disease Rating Scale (MDS-UPDRS) (Goetz, 2008) (PD patients only)

The MDS-UPDRS incorporates both motor and cognitive components and involves a self-administered questionnaire, informant interview and clinician judgement. The MDS-UPDRS consists of four subscales; 1- Non-motor Experiences of Daily Living; 2 - Motor Experiences of Daily Living; 3 - Motor Examination; where the client is given instructions by the clinician to complete (client section); 4 - Motor Complications. The MDS-UPDRS also incorporates the assessment of severity of motor deficits as outlined by the Hoehn and Yahr Scale (Stages 1 – 5).

Carer Burden: Zarit Caregiver Burden Inventory (ZCBI) (Carers only)

The ZCBI (Zarit, Reever & Bach-Peterson, 1980) is used to assess the distress experienced by caregivers of elderly or disabled persons. It consists of 22 questions which examine the impact of the client's disability on the caregiver's physical health, emotional well-being, social and financial issues. For each item, caregivers rate how often they have felt a suggested feeling or perception on a five-point scale (0 - never to 4- nearly always). The ZCBI is scored out of 88 with a higher score indicating higher perceived caregiver burden. Although, initially devised for use with caregivers of dementia patients, the ZCBI has been found to be feasible and acceptability measure for evaluating carer burden in PD patients (Martinez-Martin et al, 2007).

Mood State: Hospital Anxiety & Depression Scale (HADS) (all participants)

The HADS (Zigmond and Snaith, 1983) - consists of 14 items (7 items on Depression and 7 items on Anxiety) each rated from 0 to 3 according to severity of difficulty

experienced. Subscale totals for both Depression and Anxiety are calculated and an individual can score between 0 and 21 for either subscale. Scores of 0-7 indicate no Depression or Anxiety; scores between 8 – 10 indicate the Borderline presentation of Depression or Anxiety and scores of 11 and above indicate Depression or Anxiety. The HADS demonstrates good internal reliability and validity when assessing anxiety and depression in patients with PD (Marinus, Leentjens, Visser, Stiggelbout & Van Hilten, 2002).

Measure of Unawareness of Cognitive/ Motor Abilities - Percentile Scale

An assessment based on the designs of Williamson et al (2010) and Medin and McLeod (in preparation) was used to assess unawareness of abilities. Awareness as measured through pre-test predictions and post-test estimations of performance were assessed by asking participants to judge their performance based on a percentile scale, prior to and after the administration of the RBANS (both experimental and control groups) and the MDS-UPDRS (experimental group).

The percentile scale used for ratings was presented to the participant and explained as a normal distribution graph (Figure 1). Participants were informed that on a typical task, the majority of healthy age-matched peers would perform around the 50th percentile, with smaller numbers performing above or below average (as these principles were described the corresponding locations on the bell curve were pointed out by the researcher). All participants were then presented with a brief standardised description of the tests, as stated in the RBANS and MDS-UPDRS manual instructions. Based on the description of the task, participants were asked, 'How well do you think you will perform on the (test name)?' Participants then predicted their level of performance relative to the general population using the percentile scale. After completion of each test, the bell curve picture was presented again and the participant was asked to estimate how well they actually performed compared to general population. The prompt question was: 'Now that you have completed (test name), how well do you think you performed?' Results from performance pre-predictions and post reflections allowed for

differences between self-rated and actual performances to be calculated for the standardised tests in its entirety.

Procedure

During routine outpatient appointments, PD participants who were deemed by the PD department to be suitable to participate and had the capacity to provide informed consent, were informed of the study by their Consultant Geriatrician and/or Specialist PD Nurse. Those who expressed interest were provided with an information pack which included a patient information sheet (Appendix 2.5) and consent to contact form (Appendix 2.4). Once the signed consent to contact form was obtained, the researcher then contacted potential participants to provide further information regarding the study and answer any questions. Arrangements were then made for the testing session at a GP/Hospital closest to the person's home. In order to allow comparisons of awareness of abilities and caregiver burden, 15 of PD participants consented to a significant other being approached to complete the Zarit caregiver burden scale.

Administration of measures took an average of ninety minutes for the PD group. Due to potential confounding factors of fatigue and energy levels impacting on concentration levels and participant performance, all PD participants were given a 15 minute comfort break between the administration of the cognitive and motor tests. Administration of measures took on average sixty minutes for control group and ten minutes for the caregiver burden interview.

Once informed consent was obtained, measures were administered in the following order:

1. Demographic information (gathered from all participants).
2. HADS (all participants)
3. The Awareness Questionnaire (PD Patients only)

4. Test of Global Cognitive Ability – RBANS (all participants)

    a. Pre-Test prediction of performance score
    b. Post-Test estimation of performance score

    BREAK

5. Test of Global Motor Functioning – MDS-UPDRS – Part three (PD Patients only)

    c. Pre-Test prediction of performance score
    d. Post-Test estimation of performance score
6. The Zarit Caregiver Burden Inventory – (Carer only)

All PD participants were examined on the 'on state' of medication.

Design and Analysis

This was a cross-sectional study, consisting of between subjects comparison of PD and control participants objective self-ratings on pre-test predictions and post-test estimations of performance on tests of cognitive abilities. Within subjects comparisons compared PD participants' unawareness of motor and cognitive abilities. Correlations were calculated between the two measures of unawareness (percentile versus questionnaire) and caregiver burden.

Raw scores for the RBANS were converted into percentiles using the procedures outlined in the manual. As the RBANS is norm-referenced, this allowed for a direct comparison of participants' self-ratings of their cognitive abilities and performance. As pre and post predictions were based on a percentile scale this allowed for discrepancy scores to be calculated by subtracting pre and post scores from actual percentile scores. This resulted in pre and post-test prediction discrepancy scores for each of the 12 tests, which were then converted into an overall average percentile score, allowing for comparisons across domains for each participant. Negative scores indicated an

overestimation of abilities and a positive discrepancy score highlighted an underestimation of abilities.

Pre and post motor task discrepancy scores were also calculated for the MDS-UPDRS using the same method as the RBANS. The researcher was trained by the PD team on how to administer the MDS-UPDRS. The MDS-UPDRS part 3 consists of 33 items, all scored on a 5 point scale (with 0 being an absence of any impairment to 4 being unable to complete motor task due to motor impairment). As stipulated on the testing form, administration of the test involved the researcher either describing or demonstrating tasks to the PD patient. Immediately after the task was performed by the patient the researcher then rated the PD patient's motor abilities on the five point scale. For conversion purposes these scores were reversed in order to reflect more meaningful percentile ranks (0%, 25%, 50%, 75%, 100%). Participants could achieve a total score out of 132 (100%). In order to calculate an overall actual motor score and subsequent percentile ranking, the total of the participants score on the 33 items was divided by 132 and multiplied by 100.

Sample Size

No previous comparable studies exist from which an estimate of expected effect size could be obtained. Williamson et al, 2010, applied the same discrepancy method of objective self-rating when examining unawareness of cognitive abilities in people with Dementia versus healthy controls and found a large effect size (d = 0.79).

As the current study used similar methodology, participants with a neurological condition and measures, it is reasonable to assume that the present study will have a similar effect size, 0.8. As calculated by G* Power 3.1 (Faul, Erdfelder, Lang, and Buchner, 2009) it was estimated that to detect significant differences between groups this study would require 21 participants per group (N = 42) to allow for 0.8 power (α = 0.05, Effect Size (d) = 0.8).

Results

Data Analysis

Preliminary analyses were carried out to assess the normality of the distribution of data. Visual inspection of histograms and QQ plots were used to assess for skewness, kurtosis and outliers. Kolmogorov-Smirnov tests were conducted to assess for normality and Levene's test was used to assess for homogeneity of variance. Several variables were found to violate these assumptions of normality and were analysed using non-parametric tests.

Participant Characteristics

Recruitment was conducted between March 2015 – July 2015. During this time 42 participants were recruited to the study, 21 met criteria for the PD group and 21 control group participants. Independent sample t-test or non-parametric equivalent (Mann Whitney U test) and chi-squared tests were used to compare groups on demographic and clinical variables. The participant's characteristics of both groups are detailed in Table 1.

Table 1. Demographic and Clinical Characteristics of Sample

Characteristic	**PD (n=21)** **Mean (SD) or N(%)**	**Healthy Control (n=21)** **Mean (SD) or N(%)**	**t, z or χ^2**	***P* value**
Gender (Male: Female)	12:9	9:12	χ^2=0.857	0.538
Age (years)	64.33 (8.84)	55.43 (14.11)	t=2.44	0.019
PD Duration (years)	5.19 years (range: 1 – 13 years)			
Hoehn & Yahr Staging	**Stage 1**- 9 (42.86) **Stage 2**- 9 (42.86) **Stage 3**- 3 (14.28)			
Marital Status				
Single,	3 (14.3)	5 (23.8)	χ^2=3.976	0.278
Married,	13 (61.9)	15 (71.4)		
Divorced/separated	2 (9.5)	1 (4.8)		
Widowed	3 (14.3)	0 (0.0)		
Education				
High School	11 (52.4)	11 (52.4)	χ^2=1.818	0.438
College	4 (19.0)	7 (33.3)		
University	6 (28.6)	3 (14.3)		
Employment Status				
Employed	5 (23.8)	14 (66.7)	χ^2=7.785	0.012
Retired	16 (76.2)	7 (33.3)		
Mood				
HADS – Anxiety	6.14 (3.97)	3.86 (2.37)	t=2.261	0.029
HADS- Depression	4.33 (2.49)	2.09 (2.42)	z=-2.909	0.004
Neuropsychological				
RBANS Total Score (percentile)	36.52 (28.16)	69.14 (24.84)	t=-3.981	<0.005

As indicated in Table 1, there were no significant differences between groups in relation to gender (p>.05) or marital status (p>.05) or education level (p>.05). There was a significant group difference on the demographic variable of employment (p<.05). The mean age of the PD group was 64.33 years compared to the control group average age of 55.43 years, this difference was statistically significant (t(40)=2.44, p=0.019, *two-tailed*). Although neither group demonstrated relatively high levels of mood disturbance, the PD group had significantly higher scores than the control group on the HADS-Anxiety (t(40)= 2.261, p=0.029, *two-tailed*) and HADS- Depression (Mann Whitney U=106.500, z=-2.909, p=0.004, *two-tailed*). As expected, the PD group had significantly lower percentile ranks on the neuropsychological test (RBANS) than the control group (t(40)=-3.981, p=<0.005, *two-tailed*).

Hypothesis 1.a - *Are people with PD less accurate at estimating their cognitive abilities and monitoring their performance compared to healthy control participants.*

Change in predictions between pre and post estimations of performance for both groups were not significant; Pre-test (t(40)=-1.946, p=<0.059, *two-tailed*, r=0.29) and Post-test (z=-1.711, p=0.087, *two-tailed*, r= -0.26). Table 2. Documents the mean and range of percentile ranks of both groups on the RBANS.

Table 2. Mean and range of percentile ranks on the RBANS.

	RBANS Pre-test Predicted Percentile Rank	RBANS Actual Performance Percentile Rank	RBANS Post-test Estimated Percentile Rank
PD			
Mean (SD)	51.9 (13.06)	36.52 (28.16)	60.59 (16.38)
Range	24.25 – 74.50	1.00 – 94.00	31.75 – 87.25
Healthy Controls			
Mean (SD)	60.38 (16.07)	69.14 (24.84)	69.69 (15.67)
Range	20.25 – 89.65	9.00 – 98.00	28.70 – 94.70

Discrepancy scores

PD participants overestimated their cognitive abilities both when estimating their pre and post cognitive performance. Although control participants initially underestimated their abilities, their post-performance estimations were almost identical to their actual percentile rank performance. The average pre-test and post-test prediction discrepancies were significantly greater in PD than in controls; pre-test discrepancy measuring unawareness of cognitive performance ($z = -3.031$, $p = 0.002$, $r = -0.47$) and post-test discrepancies measuring unawareness of cognitive monitoring ($z = -3.157$, $p = 0.002$, $r = -0.49$). Overall, PD participants were less aware of their cognitive abilities and had poorer monitoring ability than control participants. Table 3 shows means and standard deviations, of pre and post discrepancy percentile ranks for both groups. Figure 2 displays the pre and post discrepancies between the groups self-estimates of cognitive functioning and neuropsychological test performance using percentile rank of test scores.

Table 3. Mean (SD) and range of pre and post discrepancy percentile ranks for cognitive abilities for both groups.

	Cognitive Pre-test Prediction Discrepancy Percentile Rank	Cognitive Post-test Prediction Discrepancy Percentile Rank
PD		
Mean (SD)	-15.06* (22.30)	-24.07* (22.75)
Range	-49.00* – 33.35	-58.25* – 24.60
Healthy Controls		
Mean (SD)	8.76 (25.90)	-0.55* (21.03)
Range	-65.75* – 47.00	-62.00* – 38.25

*Note: negative figures represent an overestimation and positive figures represent an underestimation of cognitive abilities.

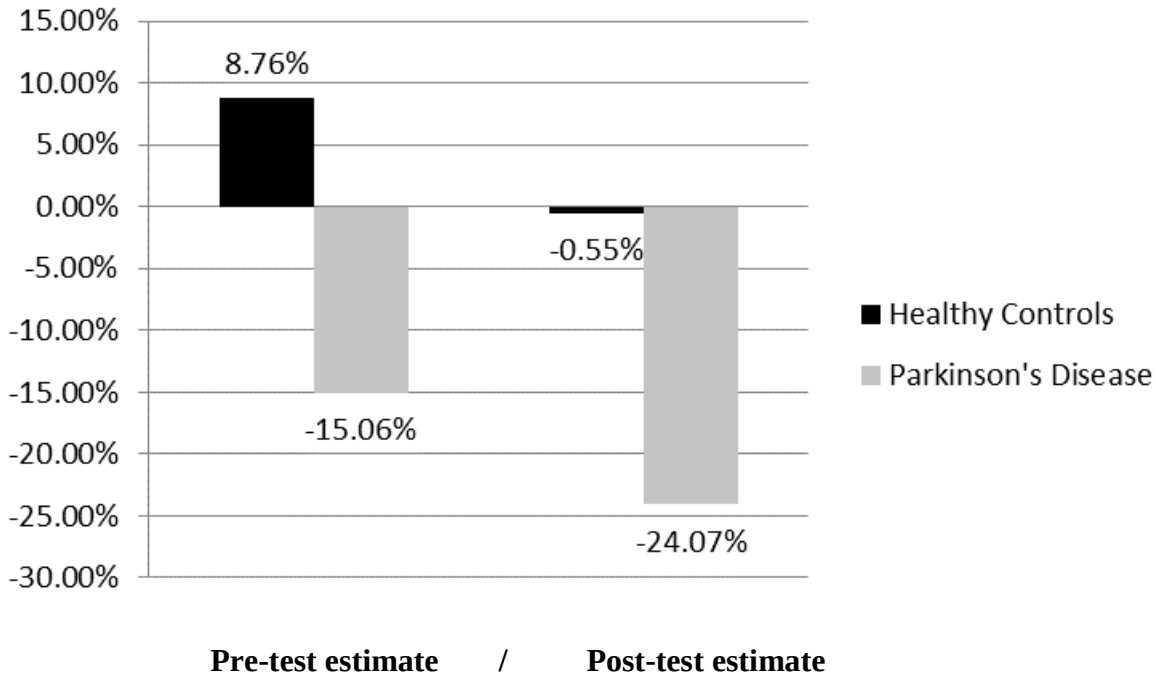

Figure 2. Unawareness discrepancies of self-estimates (pre and post-performance) and neuropsychological test performance using percentile rank of test scores.

Hypothesis 1.b. *Does the method of assessing unawareness matter? Examine PD participant's general unawareness of deficit.*

An analysis was calculated between the two methods of measuring unawareness of abilities in PD (percentile scale and questionnaire). Through the application of the Awareness Questionnaire (AQ) a general unawareness of deficit score was obtained for all PD participants. All 21 PD participants rated their general level of abilities (cognitive, motor and affective) to be poorer than before their PD diagnosis. Through discrepancy scores between self-rated and objective ratings completed by a clinician, no participant reached the >20 threshold of clinically significant impairment of awareness on the AQ (Mean= 0.81, SD = 4.77, range= -7 to 10). Table 4 shows means and standard deviations, of AQ discrepancy scores (Total and Cognitive Sub-Scale).

Table 4 Means (SD) and range of Awareness Questionnaire discrepancy scores (Total and Cognitive Sub-Scale) for PD participants.

	Awareness Questionnaire Total Discrepancy Score	Awareness Questionnaire Cognitive Sub-Scale Discrepancy Score
PD		
Mean (SD)	1.48 (4.60)	0.89 (2.71)
Range	-7.00 – 10.00	-5.00 – 8.00

The hypothesis that unawareness of cognitive abilities, as measured by percentile predictions of cognitive performance would be correlated with total score of AQ was not supported for pre-test (rho = -.23, p > .05) or post-test discrepancies (rho= -.065, p>.05). Further analysis of the relationships between AQ cognitive sub-scale with pre-test discrepancy (rho = -.25, p > .05) and post-test discrepancy (rho= .011, p>.05) were not significant.

Hypothesis 2 - *PD participants will be less accurate at estimating their pre and post-performance on tasks of cognitive abilities than tasks of motor abilities.*

Within subject comparison of change in predictions of pre–test estimations of performance for cognitive versus motor abilities was found to be significant (t(20)=-4.923, p=<0.05, *two-tailed*, r=0.74). However, change in predictions of post-test predictions between cognitive and motor abilities was not statistically significant (t(20)=-2.063, p=0.052, *two-tailed*, r=0.42).

Discrepancy scores

PD participants overestimated their cognitive abilities at both the pre and post ratings of cognitive performance. In comparison, they underestimated their motor abilities at both the pre and post performance time-points. The within groups differences in pre-test and post-test prediction discrepancies were significantly greater for cognitive abilities than motor abilities; unawareness of performance pre-test (z= - 2.972, p= 0.002, r= -0.46) and post-test (t(20)=-5.254, p=<0.05, *two-tailed*, r=0.76). Overall, PD participants were less aware and had poorer monitoring of their cognitive abilities than their motor abilities. The RBANS discrepancy scores in Table 3 and Table 5 outline the mean and standard deviations of percentile ranks predictions and actual score on the MDS-UPDRS, alongside pre and post discrepancy percentiles for PD participants. These results suggest that PD participants were more accurate in estimating pre and post-test performance of their motor abilities than their cognitive abilities. Figure 3 demonstrates the difference in the PD group's discrepancies between their actual performance and pre and post estimations of cognitive and motor abilities.

Table 5. Mean, standard deviations and range of percentile ranks on the MDS-UPDRS.

	MDS-UPDRS Pre-test Prediction Percentile Rank	MDS-UPDRS actual performance Percentile Rank	MDS-UPDRS Post-test estimation Percentile Rank	Motor Pre-test Prediction Discrepancy Percentile Rank	Motor Post-test Prediction Discrepancy Percentile Rank
PD					
Mean	67.44	71.93	68.06	4.49	3.87
(SD)	(17.51)	(16.11)	(19.14)	(5.27)	(6.36)
Range	35.88–93.24	36.47– 96.47	33.24– 95.29	-4.12– 15.88	-5.89– 18.52

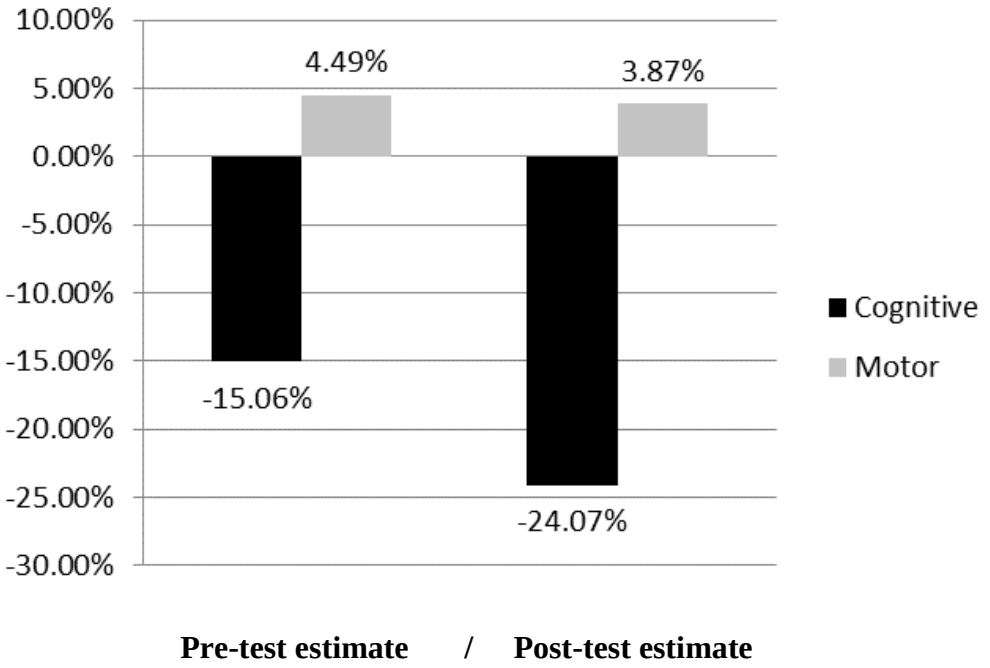

Figure 3. Unawareness of PD patient's discrepancies of pre and post-test estimations and actual test performance of cognitive and motor functioning using percentile ranks of standardisation test scores.

Hypothesis 3 *– Zarit Burden Interview: greater unawareness of cognitive abilities will be correlated with carer burden*

Zarit Burden Interviews were obtained from the significant other of 15 PD participants (13 - Spouses, 1 – Sibling and 1 – Daughter). Caregiver burden was rated by the significant other as; 'little or no burden' = 9, 'mild to moderate burden' = 5 and 'moderate to severe burden'= 1 (Mean =17.20, SD=13.32, range= 4 – 45).

The correlation between ratings of caregiver burden and level of cognitive unawareness (pre-test and post-test estimations) were examined. As several of the cognitive measures were not-normally distributed, non-parametric Spearman's rho correlations were conducted to explore the associations between caregiver burden with level of cognitive unawareness. Table 6 presents the correlation data examining the associations between ratings of caregiver burden and measures of cognitive abilities.

Table 6 Bivariate Spearman's rho correlations between caregiver burden and level of unawareness of cognitive abilities (pre and post-test estimations).

	Level of cognitive unawareness – Pre-test estimations.	Level of cognitive unawareness- Post-test estimations.
Zarit Caregiver Burden	-0.728**	-0.744**

** Significant at p <0.01

In line with the hypothesis that caregiver burden would be associated with unawareness of cognitive abilities, caregiver burden scores were significantly negatively correlated with level of cognitive unawareness, pre-test ($p < .01$) and post-test ($p < .01$). Therefore suggesting that an increase in carer burden was associated with unawareness of cognitive abilities, both in terms of pre and post-test estimations of performance.

Discussion

Are people with PD less accurate at estimating their cognitive abilities and monitoring their performance compared to healthy control participants?

The aim of the current study was to examine unawareness of cognitive abilities in a clinical sample of adults with PD. Although the groups differed in age, the age-standardised nature of the RBANS means that scores were age adjusted, which allowed for valid performance comparisons between groups. As hypothesised, PD participants were significantly less accurate at predicting their cognitive abilities and monitoring their performance compared to a control group of healthy participants. The participants with PD overestimated their cognitive abilities and performance on neuropsychological tests by 15-24%. In comparison, control participants initially underestimated their abilities by 9%, but were able to adjust their post-performance judgements to an almost identical percentile rank to that of their actual performance, over-estimating their cognitive performance by only 0.55%. These between group differences in pre and post percentile rank discrepancies, are comparable to studies which have applied similar methods to smaller samples of people with dementia (Williamson et al, 2010) and schizophrenia (Medin & McLeod, in.prep).

As this was the first study to assess unawareness of cognitive abilities in PD, it is difficult to draw comparisons to the limited knowledge base of unawareness in PD. Our results are inconsistent with the findings using patient-proxy discrepancies of memory functioning in PD, which observed relatively accurate self-appraisals of memory functioning in PD participants (Lehrner et al, 2015 & Sitek et al, 2011b). However, methodological limitations of previous research included lack of a control group (Sitek et al, 2011b). Clare, Whitaker & Nelis (2010) stated that it is unclear how much of the over-under estimation reported by people with neurological conditions was within the normal range and to what extent inaccuracy of ratings is a particular feature of the condition, rather than simply a reflection of the normal ageing process. Dunning,

Meyerowitz & Holzberg, (1989) state that when people (general population) are asked to estimate their abilities, the judgements they provide tend to be self-serving, usually resulting in an over-estimation.

These self-serving appraisals can take several biased forms. Miller and Ross (1975) outlined that people either self-protect, by underestimating their abilities or self-enhance through overestimation. Through comparisons with a control group we have found that PD participants less accurately judged their cognitive abilities and monitoring of performance. PD patients displayed inflated self-appraisals, as they tended to overestimate their cognitive abilities and performance. Whereas, healthy controls initially underestimated their abilities in a self-protecting way and were then able to accurately adjust their estimations through self-monitoring of performance. These findings are similar to Oyebode, Telling, Hardy and Austin (2007) who examined dementia patients estimations of unawareness compared to two control groups; young and older healthy volunteers. Results from their analysis also found a self-serving bias, with the dementia group overestimating, younger volunteers underestimating and the older group accurately predicting abilities. Due to the significant difference in age between our groups this may account for the initial underestimation found in our healthy volunteers.

Does the method of assessing unawareness matter? PD participant's general unawareness of deficit.

Results from the Awareness Questionnaire, suggested that none of our PD sample reached the clinical threshold of impairment of awareness in general or in the sub-domain of cognitive abilities. This is consistent with previous research findings in patient-proxy discrepancies, which have observed relatively accurate self-appraisals of memory functioning in PD participants (Lehrner et al., 2015; Sitek et al., 2011b). However, no association between the AQ and percentile estimates of performance methods was found in our PD sample, unlike Williamson et al. (2010) who found a

significant relationship between percentile based and questionnaire measures of unawareness.

This leads us to question the concurrent validity of the percentile based approach on measuring unawareness of abilities in PD. Williamson et al (2010) suggested that a potential limitation of the percentile measure was that it may reflect individual's deficits in estimation ability rather than awareness. However, Appollonio, et al., (2003) examined PD patient's estimation ability on several tests (Cognitive Estimation Task and The Time and Weight Estimation test). Results did not show a significant deficit of cognitive estimation ability, suggesting that PD patients do not show general problems with estimation. In relation to our findings, the non-significant difference of pre and post percentile predictions between the PD and control groups, suggests that both groups had interpreted the instructions regarding the percentile ranks correctly. In regards to the discrepancy scores, our finding that PD patient were more accurate with estimations of their motor abilities, suggests that there was not a general problem with ability estimation in our PD sample.

The findings from our study demonstrate that the questionnaire method of measuring unawareness has not detected the significant effects of the percentile based analysis. This may be due to measures assessing different components of awareness. Awareness of deficit is a dimensional construct comprising of a level of explicit and implicit awareness of functioning (Clare, 2004b). Explicit awareness is where the individual has the ability to verbally acknowledge their abilities, this may be influenced by social pressures and defensiveness (Oyebode et al, 2007). Implicit awareness is defined as when an individual has the ability to accurately judge the impact of their cognitive deficits and are able to modify their behaviours/actions accordingly. (Medin & McLeod, in.prep). Findings from our study may suggest that when completing the AQ measure, PD patients were more accurate, therefore more aware of their cognitive abilities. However, performance on the percentile measure suggested unawareness in our PD sample. This may suggest that PD patients in our sample, showed differential awareness within cognitive domains. Although they explicitly denied their cognitive deficits, as

measured through the percentile estimations, they were unintentionally processing components of their deficit implicitly through results of the AQ.

Are people with PD less accurate at estimating and monitoring their performance on tasks of cognitive abilities than tasks of motor abilities?

PD participants were significantly less accurate at estimating and self-monitoring their performance for cognitive abilities compared to motor abilities. Findings from our study suggested that PD patients tended to overestimate their pre and post-test performance of cognitive abilities. In comparison, although slightly under-estimated, predictions of their motor abilities were more accurate, with less discrepancy between self-ratings and actual performance. This is consistent with previous findings of motor awareness, which suggested that PD patient's provided accurate judgements of disability similar to those of observer ratings (Brown et al.'s, 1989 & Sitek et al, 2011a). Several studies have shown a link between severity of motor impairment and cognitive problems in PD with deficits occurring simultaneously (Murakami et al.'s, 2013; Amanzio et al, 2010). In term of unawareness, our study has found a difference between PD patients degree of motor and cognitive unawareness. This might suggest that awareness and self-monitoring are not part of a unitary ability, but may be dissociable capacities that are domain specific.

The effect of unawareness of cognitive abilities on carer burden.

Although, several studies have shown an association between unawareness of motor abilities and caregiver burden in PD, no previous literature exists in regards to unawareness of cognitive abilities. As expected, increased caregiver burden was correlated with unawareness of cognitive abilities, both in terms of predicting awareness and self-monitoring of performance. Our results suggest that PD patients who are unaware of their cognitive deficits seem to place greater burden on their carers. Previous literature highlighted a weak effect between awareness of motor deficits in PD and caregiver burden (Faison et al, 1999). In comparison, our sample demonstrated a strong association between cognitive awareness and caregiver burden. The potential

confounding factors of severity/duration of PD must be taken into account when discussing caregiver burden. Research with other dementia sufferers suggests that caregiver burden increases with increasing severity of illness (Mioshi et al, 2013). It is not possible to determine from our analysis whether individuals who exhibited greater unawareness of cognitive abilities were at a mild or moderate stage of disease severity or whether they had experienced a longer duration of PD. The impact of these variables should be examined in future studies.

Clinical Implications

Through the use of a percentile based approach, it was shown that PD individual's cognitive awareness was significantly poorer than the control group, as measured through predictions of pre and post- test performance. In comparison, between domains of functioning it was shown the PD patients were less accurate in their judgements of their own cognitive abilities compared to their motor abilities. These significant differences may have important implications for clinicians working with this population in terms of assessment and understanding of unawareness of deficits in PD.

The phenomenon of unawareness involves an inadequate evaluation of one's impairments (Clare, 2004a). Previous research in dementia suggested that unawareness of abilities could have serious implications for the individual, as it was found that people with dementia who overestimated their abilities were less likely to adhere to treatment and more likely to expose themselves to unnecessary risk. Individuals who underestimated their abilities were more likely to unnecessarily limit their activities and avoid situations they perceived as challenging (Clare et al, 2010). All these factors may be relevant to the PD population, as prevalence of dementia associated with PD (PDD) is estimated to be six times greater than in the general population (Kulisevsky & Pagonabarraga, 2009) and cognitive disturbances are common in PD at various stages of disease progression (Schapira, 2010). Findings from the differences between the domains of cognitive and motor deficits, highlights the importance of cognitive deficits in PD, which may be less salient than the motor symptoms. This may have implications

for clinicians in spotting early warning signs and detecting changes in less salient cognitive abilities.

At present, unawareness research is heavily reliant on using questionnaires to ascertain discrepancies between patient's subjective ratings and informant ratings of functioning. As shown in this study, no difference was found between patient-proxy ratings. However, through examining unawareness through judgments of ability based on percentiles, a significant difference was found between PD patient's ability to predict and monitor their cognitive abilities. This leads us to question whether current ways of assessing unawareness of cognitive deficits are insufficiently sensitive. As self-appraisal is reliant on explicit awareness, where the individual is able to verbally acknowledge their deficits, our results suggest that PD individuals may under-report cognitive difficulties. Employing a percentile based measure may remove the inherent perspective bias from confounding results obtained from patient-proxy discrepancy scores (Sitek et al, 2011b) and may expose different aspects of awareness (Medin & McLeod, in.prep).

The significant correlation between unawareness of cognitive abilities and Caregiver Burden, highlights the wider systemic impact of neurological conditions. Implementation of compensatory strategies (to reduce the impact of deficits on everyday functioning) is dependent on accurate appraisal of one's cognitive abilities (Clare, 2004b). Therefore unawareness may mean the PD patient is more likely to engage in behaviour that is beyond their abilities, which in turn increases caregiver burden (Faison et al, 1999). In conclusion, unawareness of cognitive abilities in PD may have several real life implications for the individual with PD, clinicians and carers.

Strengths and Limitations of Study

This is the first study to examine unawareness of cognitive abilities in PD, results have highlighted areas which need further exploration: differences between cognitive unawareness in PD patients and healthy volunteers, differential unawareness on domain

functioning in PD, impact on caregiver burden and clinical implications in methods of measuring unawareness. Other strengths of this study were that the majority of measures used have previously been administered on individuals with PD and demonstrate good psychometric properties and that the calculated sample size was achieved.

The results of the study must be considered in the context of several limitations. A significant difference was shown in the affect of the groups, with PD participants scoring significantly higher in depression and anxiety in the HADS. However, neither group included participants who reached the clinical threshold of >11 for depression. Within our PD sample the level of affective disturbance does not seem to explain an alternative explanation for the unawareness scores obtained, e.g. the overestimation of results are due to the presence of mild depressive symptoms (Sitek et al, 2011b).

Due to ethical reasons, PD participants were initially contacted by a member of the PD department during their routine outpatient appointment, this may have led to self-selection bias of the clinical team informing participants they felt would be more likely to engage in the research. A further limitation was that members of the PD department who acted as informant raters for AQ were not blind to hypotheses and this could have influenced objective ratings. Therefore, the samples in this study may not be an accurate representation of the clinical PD population.

Future Research

There is a need to replicate these findings, as further research exploring cognitive unawareness in this clinical population is needed. The results of this study apply mostly to PD patients with mild to moderate severity of disease, as measured by the Hoehn and Yahr staging scale. Due to the degenerative nature of PD, individuals progress through the Hoehn & Yahr stages at various rates. Although this study did not differentiate between individuals at stages 1, 2 and 3, it would be clinically and individually

beneficial to differentiate between the various stages of PD, in order to best facilitate the individual with PD and their care givers as they transition through the disease. The generalisability of the current findings to individuals in the later stages of the disease is also limited. In regards to dementia, Ecklund-Johnson & Torres (2005) state that awareness is a common clinical symptom at the earliest stages of the disease and that the frequency of unawareness increase with disease progression. Future research should consider the advantages of using a large, longitudinal research design examining the long-term impact of unawareness of cognitive abilities with increasing PD severity.

Further research is required to explore other variables in relation to unawareness of cognitive abilities in PD. Due to previous research stating that depression may impact on level of unawareness in PD, all individuals who met criteria for major depression were excluded from our study. Although anxiety was not deemed to be a mediating factor of unawareness in our study design, results from the HADS suggested that PD individuals were more likely rate their level of anxiety higher than control participants. Further research is needed to investigate the non-cognitive influencing factor of anxiety on level of unawareness.

As limited research has been conducted in this area of PD, it is uncertain whether these biopsychosocial factors of disease severity and anxiety have differing influences on PD individual's level of unawareness of their cognitive abilities. In order to examine these possible relationships, methodological limitations of this study must be taken into consideration when examining unawareness of cognitive abilities in PD.

Conclusion

The key findings of this study indicate that PD participants show unawareness of cognitive abilities relative to healthy controls, with PD individuals having a tendency to overestimate their abilities. Unawareness of cognitive abilities measured by percentile rank was not significantly associated with the standardised measure of the Awareness Questionnaire. Results may suggest that the percentile method could provide an alternative, more direct measure of assessing explicit processes related to unawareness in PD. Further comparisons across the domains of cognitive and motor abilities suggested that PD participants had greater unawareness on tasks examining their cognitive abilities. These results may suggest that PD individuals can be differentially aware of deficits within and across various domains of functioning. Finally, a significant correlation was found between level of cognitive unawareness and caregiver burden. These results highlight the need to detect and address unawareness in order to reduce carer burden.

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Chapter 3 - Advanced Clinical Practice I Reflective Account (Abstract Only)

My Clinical Psychology journey; 'naïve undergraduate to competent clinician'.

A reflective account of my personal and professional development in clinical practice.

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Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D.Clin.Psy)

Abstract

This reflective account described the importance of clinical supervision on my personal and professional development over the course of training. This account was structured using the Integrated Developmental Model (Stoltenberg, McNeill, and Delworth, 1998) and Gibbs' Model of Reflection (1988). This was done through charting different learning experiences of supervision and the impact it had on the development of my clinical skills and confidence in applying psychological methods and concepts, namely the unique skill of formulation. In doing so, I identified the thoughts and feelings I experienced during these learning experiences and evaluated these in the context of my development as a competent and confident clinician. This account also considered the ever changing political landscape and discussed the impact that governmental policies and guidelines had on the diverse and extended role of a clinical psychologist. Throughout the account I reflected on what this will mean for my future development and clinical practice when I become a qualified Clinical Psychologist.

Chapter 4 - Advanced Clinical Practice II Reflective Account (Abstract Only)

Being a Scientist Practitioner is at the heart of every Clinical Psychologist.

'So What?'

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Abstract

This reflective account charts the various research experiences I have had throughout my Doctoral training in Clinical Psychology and reflects on my experiences as an evolving scientist practitioner. Through the application of Rolfe, Freshwater and Jasper's (2001) model of reflection, this account documents three of my key research learning situations. First I reflect on the service-based evaluation project I completed in my first year. In this section I discuss the shift in attitude I had from initial trepidation of conducting an audit, to my greater appreciation of the clinical and service implications that can be brought about through service evaluation. I then reflect on my biggest research challenge to date, my Major Research Project (MRP). I then discuss the wider role of being a scientist practitioner, and reflect on the valuable application of routine outcome monitoring, which has the dual role of both informing clinical practice and service development. As I reflect on the differing roles of a scientist practitioner, I discuss the purpose and benefits of clinician-led research. I conclude with a reflection about the challenges that currently face qualified Clinical Psychologists and discuss the wider implications of being a scientist practitioner.

Reflecting on my research experiences throughout training has enabled me to explore and make sense of my learning, actions and reactions. These invaluable research skills have equipped me with a new found passion for conducting research and I look forward to transferring these skills to my new role as a post-qualified Clinical Psychologist. Being a scientist practitioner really is at the heart of every Clinical Psychologist.

APPENDICES

Appendix 1.1: Author Guidelines Neuropsychological Rehabilitation: An International Journal

1. Journal-specific guidelines

- This journal accepts original (regular) articles, scholarly reviews, and book reviews.
- The style and format of the typescripts should conform to the specifications given in the Publication Manual of the American Psychological Association (6th ed.).
- There is no word limit for manuscripts submitted to this journal. Authors should include a word count with their manuscript.

2. General guidelines

- Manuscripts are accepted in English. Oxford English Dictionary spelling and punctuation are preferred. Please use double quotation marks, except where "a quotation is 'within' a quotation". Long quotations of words or more should be indented without quotation marks.
- Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgements; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
- Abstracts of 150-200 words are required for all manuscripts submitted.
- Each manuscript should have up to 5 keywords.
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance here.
- Section headings should be concise.
- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.
- Biographical notes on contributors are not required for this journal.
- Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate paragraph, as follows:
  - *For single agency grants:* "This work was supported by the [Funding Agency] under Grant [number xxxx]."
  - *For multiple agency grants:* "This work was supported by the [Funding Agency 1] under Grant [number xxxx]; [Funding Agency 2] under Grant [number xxxx]; and [Funding Agency 3] under Grant [number xxxx]."

  Authors must also incorporate a Disclosure Statement which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.

  For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.

Authors must adhere to SI units. Units are not italicised.

When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.

2. Style guidelines

- Description of the Journal's reference style.
- Guide to using mathematical scripts and equations.
- Word templates are available for this journal. If you are not able to use the template via the links or if you have any other template queries, please contact authortemplate@tandf.co.uk.
- Authors must not embed equations or image files within their manuscript

3. Figures

- Please provide the highest quality figure format possible. Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.
- Figures must be saved separate to text. Please do not embed figures in the manuscript file.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).
- Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

Last updated 11/03/2014

Appendix 1.2: Data Extraction Form

Citation

Lead Author	
Year Published	
Title	
Journal	
Country of Origin	
Type of Study	

Screening and Selection:

Were participants diagnosed with Parkinson's disease? YES / NO

Did the study report standardised measure of PD? YES / NO

Were participants of the pre-specified age? YES / NO

Did the study report standardised measure of Depression? YES / NO

Did the study report on Risk factors/descriptive features associated Depression in PD?
YES / NO

OR

Did the study report on the association between Awareness and Depression in PD?
YES / NO

Notes / Short description of Study:

FINAL DECISION INCLUDED / EXCLUDED

REASONS FOR EXCLUSION OF STUDY FROM REVIEW:

Patients:

Different disease (Neurological disease / Mental Health Disorder)

Different Age.

Outcomes:

No clinically relevant outcomes assessed

Preliminary Date

Qualitative data.

Other:

Duplicate publication / Book Review / Conference abstract / Poster Presentation / Language / Thesis

INCLUDED STUDIES – DATA EXTRACTION.

Study Characteristics.

Study aims / purpose:

What are the eligibility criteria?

Inclusion:

Exclusion:

Participant characteristics

Age Range		
Mean Age		
Gender		
Age of Onset		
Disease stage/severity		

Recruitment

How were participants recruited?

Convenience sample / Geographic cohort / Highly selective sample

Number of participants recruited?

Was there a control group? Yes / NO

If Yes, what were control groups characteristics:

How were participants recruited in Control group?

Convenience sample / Geographic cohort / Highly selective sample

Risk factors and/or descriptive features associated with Depression in PD?

Clinical Factors	Severity of PD	
	Age of Onset	
	Stage of Disease	
	Duration of illness	
	Premorbid psychiatric Condition	
Behavioural Factors	Apathy	
	Motivation	
	Social Withdrawal	
Physiological Factors	Sleep Disturbance	
	Fatigue	
Cognitive Factors	Awareness	
	Cognitive impairment: Memory problems	
Motor Factors	Balance/Falls	
	Dyskinesia	
	Bradykinesia	

Outcome Measures:

Standardised Measure of PD Severity	
Standardised Measure of Depression	
Other Standardised Measures; Awareness	
Other Standardised Measures; Cognitive	
Other Standardised Measures; Motor	
Other Standardised Measures;	

Data Analysis

Type of analysis?

Conclusion

Awareness and Depression in PD.

Type of analysis?

Strength of Association between Awareness and PD:

Conclusion

Factors associated with Depression and Awareness in PD:

Methodological Quality of Paper - Crowe Critical Appraisal Tools (CCAT – Maximum score of 40 = 100%)

Appendix 1.3 Quality Ratings for Included Studies

Study	Preliminaries	Intro	Design	Sampling	Data Collection	Ethical Matters	Results	Discussion	Overall Quality Rating	
									Total	%
Amanzio, Monteverdi, Giordano, Soliveri, Filippi & Geminani, (2010)	4	5	3	3	4	3	3	4	29	73
Brown, MacCarthy, Jahanshahi & Marsden (1989)	3	5	3	4	5	0	5	4	29	73
Farabaugh, Locascio, Yap, Weintraub, McDonald, Agoston, Alpert, Growdon & Fava (2009)	5	5	3	3	4	1	4	4	29	73
Lehrner, Kogler, Lamm, Moser, Klug, Pusswald, Dal-Bianco, Pirker & Auff (2015)	5	5	3	5	3	3	3	4	31	78
Saez-Francas, Hernandez- Vara, Roso, Martin & Brugue (2013)	4	5	3	4	4	2	4	4	30	75
Schrag, Jahanshahi Quinn (2001)	5	5	3	4	4	1	4	3	29	73
Sitek, Soltan, Wieczorek, Schinwelski, Robowski, Reilmann, Guzinska, Harciarek, Krysa & Slawek (2011a)	5	3	3	4	3	2	3	4	27	68
Sitek, Soltan, Wieczorek, Robowski & Slawek (2011b)	5	5	3	4	3	3	3	4	30	75
Verbaan, Marinus, Visser, van Rooden, Stiggelbout & van Hilten (2007)	5	5	4	4	3	0	4	3	28	70

Appendix 2.1: Author Guidelines Journal of Neurology, Neurosurgery and Psychiatry

Preparing your manuscript

All material submitted is assumed to be submitted exclusively to the journal unless otherwise stated. Submissions may be returned to the author for amendment if presented in the incorrect format.

Manuscript documents are deleted from our systems 6 months after completion of the peer review process.

Cover letter

Your cover letter should inform the Editor of any special considerations regarding your submission, including but not limited to:

- Details of related papers by the same author(s) already published or under consideration for publication.
- Details of previous reviews of the submitted article.

Copies of related papers, previous Editors' and reviewers' comments, and responses to those comments can be submitted using the File Designation "Supplementary file for Editors only". Editors encourage authors to submit previous communications as doing so is likely to expedite the review process.

NIH Employees

Manuscripts authored or co-authored by one or more NIH employees must be submitted with a completed and signed NIH Publishing Agreement and Manuscript Cover Sheet according to NIH's Employee Procedures.

Title page

The title page must contain the following information:

- Title of the article.
- Full name, postal address, e-mail and telephone number of the corresponding author.
- Full name, department, institution, city and country of all co-authors.

- Up to five keywords relevant to the content of your manuscript. This will enable us to identify the most suitable reviewers for your manuscript.
- Word count, excluding title page, abstract, references, figures and tables.

Manuscript format

The manuscript must be submitted as a Word document. PDF is not accepted.

The manuscript should be presented in the following order:

- Title page.
- Abstract, or a summary for case reports (Note: references should not be included in abstracts or summaries).
- Main text separated under appropriate headings and subheadings using the following hierarchy: BOLD CAPS, bold lower case, Plain text, Italics.
- Tables should be in Word format and placed in the main text where the table is first cited.
- Tables must be cited in the main text in numerical order.
- Acknowledgments, Competing Interests, Funding and all other required statements. Reference list.

Images must be uploaded as separate files (view further details under the Figures/illustrations section). All images must be cited within the main text in numerical order and legends should be provided at the end of the manuscript.

Appendices should be uploaded using the File Designation "Supplementary File" and cited in the main text.

Please remove any hidden text headers or footers from your file before submission.

Style

Abbreviations and symbols must be standard. SI units should be used throughout, except for blood pressure values which should be reported in mm Hg.

Whenever possible, drugs should be given their approved generic name. Where a proprietary (brand) name is used, it should begin with a capital letter.

Acronyms should be used sparingly and fully explained when first used.

Figures/illustrations

Images must be uploaded as separate files. All images must be cited within the main text in numerical order and legends should be provided at the end of the manuscript.

Video: How to improve your graphs and tables >>

Colour images and charges

For certain journals, authors of unsolicited manuscripts that wish to publish colour figures in print will be charged a fee to cover the cost of printing. Refer to the specific journal's instructions for authors for more information.

Alternatively, authors are encouraged to supply colour illustrations for online publication and black and white versions for print publication. Colour publication online is offered at no charge, but the figure legend must not refer to the use of colours.

Detailed guidance on figure preparation >>

File types

Figures should be submitted in TIFF or EPS format. JPEG files are acceptable in some cases. A minimum resolution of 300 dpi is required, except for line art which should be 1200 dpi. Histograms should be presented in a simple, two-dimensional format, with no background grid.

During submission, ensure that the figure files are labelled with the correct File Designation of "Mono Image" for black and white figures and "Colour Image" for colour figures.

Figures are checked using automated quality control and if they are below the minimum standard you will be alerted and asked to resupply them.

Please ensure that any specific patient/hospital details are removed or blacked out (e.g. X-rays, MRI scans, etc). Figures that use a black bar to obscure a patient's identity are NOT accepted.

Tables

Tables should be in Word format and placed in the main text where the table is first cited. Tables must be cited in the main text in numerical order. Please note that tables embedded as Excel files within the manuscript are NOT accepted. Tables in Excel should be copied and pasted into the manuscript Word file.

Tables should be self-explanatory and the data they contain must not be duplicated in the text or figures. Any tables submitted that are longer/larger than 2 pages will be published as online only supplementary material.

Video: How to improve your graphs and tables >>

Multimedia files

You may submit multimedia files to enhance your article. Video files are preferred in .WMF or .AVI formats, but can also be supplied as .FLV, .Mov, and .MP4. When submitting, please ensure you upload them using the File Designation "Supplementary File - Video".

References

Authors are responsible for the accuracy of cited references and these should be checked before the manuscript is submitted.

Appendix 2.2: Ethical Approval Letter I

NRES Committees -
North of Scotland
Summerfield House

12 December 2014

Miss Kaye McKie
Department of
Clinical Psychology
New Craig's Hospital

Dear Miss McKie

Study Title: Awareness of Cognitive Abilities in People with Parkinson's disease

REC reference: IRAS project ID: 14/NS/1080 160843

The Research Ethics Committee reviewed the above application at the meeting held on 11 December 2014.

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Further information or clarification required

1 The Committee wonder whether you have missed out an important step, namely, how the cognitive problems limit the ability to perceive problems and ask for clarification on this.

2 A59 - please confirm whether it is possible to achieve the numbers required for the study.

3 A13 - the Committee note that additional information regarding disease, duration of illness etc will be obtained prior to participation in the study. However, this is not clear in the Patient Information Sheet. Please include this in the Information Sheet.

4 A13 – 4 - please provide details of who will carry out the motor examination and whether they are qualified to do so.

5 Please provide details of the recruitment process for control participants.

6 Please clarify how carers will be recruited into the study.

7 A17-2 - please confirm that participants presenting with depression or dementia will be excluded from the study as this is not clear.

8 A-22 – the Committee note that 'participation in the research might uncover a previously undiagnosed clinical problem' and wonder whether the healthy volunteers will also be advised to speak to their GP. If so, then this will need to be made clear in the Healthy Volunteer Information Sheet and Consent Form.

9 A13/53 – final paragraph - the Committee note that feedback will be provided to the clinical team however, this is not clear in the Information Sheet. Please include this in the Patient Information Sheet.

10 A53 – please clarify the feedback process as this differs within the paperwork.

Participant Information Sheet

11 A35 - the Committee note that data already collected will be kept if a participant loses capacity. This will need to be made clear in the Patient Information Sheet. Please insert a sentence to reflect this.

12 Please provide separate paperwork for the carers.

Response Slip

13 Please change 'envelop' to 'envelope'.

Poster

14 Please amend the Poster so that it is relevant for the intended audience.

15 Please amend the Poster using lay language.

16 Please remove the bracket from 'Stroke' and insert it after 'disorder'.

Burden Interview Questionnaire

17 The Committee ask whether it is possible to remove question 17 as it is not relevant to this study.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair, Vice-Chair and Alternate Vice-Chair.

When submitting a response to the Committee, the requested information should be electronically submitted from IRAS. A step-by-step guide on submitting your response to the REC provisional opinion is available on the HRA website using the following link: http://www.hra.nhs.uk/nhs-research-ethics-committee-rec-submitting-response-provisional-opinion/

Please submit revised documentation where appropriate underlining or otherwise highlighting the changes which have been made and giving revised version numbers and dates. You do not have to make any changes to the REC application form unless you have been specifically requested to do so by the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 10 January 2015.

Summary of the discussion at the meeting

Social or scientific value; scientific design and conduct of the study

On review of the application, the Committee wondered whether the researcher had missed out an important step, namely, how the cognitive problems limited the ability to perceive problems.

A59 - the Committee wondered whether it would be possible for the researcher to achieve the numbers required for the study.

A13 - the Committee noted that additional information regarding disease, duration of illness etc would be obtained prior to participation in the study. However, this was not made clear in the Patient Information Sheet.

A13 – 4 - the Committee noted that a motor examination would be carried out. It was not clear from the paperwork who would carry this out and whether they were qualified to do so.

Recruitment arrangements and access to health information, and fair participant selection

The Committee felt that the control recruitment was vague and required clarification.

The Committee asked for clarification on how carers would be recruited into the study.

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)

A-22 – the Committee noted that 'participation in the research might uncover a previously undiagnosed clinical problem' and wondered whether

the healthy volunteers would also be advised to speak to their GP. If so, then this would need to be made clear in the Healthy Volunteer Information Sheet and Consent Form.

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

A13/53 – final paragraph - the Committee noted that feedback would be provided to the clinical team however, this was not made clear in the Information Sheet.

A53 - the Committee required clarification on whether participants would be given feedback at the end of the study as this differed within the paperwork.

Participant Information Sheet
A35 - the Committee noted that data already collected would be kept if a participant lost capacity. This would need to be made clear in the Patient Information Sheet.

Informed consent process and the adequacy and completeness of participant information

The Committee noted that there was no paperwork for the carers and asked that separate paperwork be provided which was relevant to them.

Response Slip

The researcher was asked to change 'envelop' to 'envelope'.

Poster

The Committee felt that the Poster was only relevant to healthy volunteers and not for significant others or carers. The Poster would need to be changed to reflect the intended audience.

The Poster should be written in lay language as in its present format was too technical.

In the second paragraph, the bracket would need to be moved from 'Stroke' and inserted after 'disorder'.

Burden Interview Questionnaire

The Committee noted that question 17 made reference to death, however the participant would still be alive. The Committee asked whether it was possible to remove this question as it was not relevant to this study.

Documents reviewed

The documents reviewed at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants: Poster Advertisement	2	11 November 2014
Covering letter on headed paper		18 November 2014
GP/consultant information sheets or letters: GP Letter	2	17 November 2014
IRAS Checklist XML: Checklist 24112014		24 November 2014
Letter from Sponsor		4 November 2014
Letters of Invitation to Participant: Consent to Contact	2	17 November 2014
Non-validated questionnaire: Awareness Percentile Scale	2	17 November 2014
Non-validated questionnaire: Demographic Profile	2	17 November 2014
Participant Consent Form: PD Patient	2	17 November 2014
Participant Consent Form: HV Control	2	17 November 2014

Document	*Version*	*Date*
Participant Information Sheet (PIS): PD Patient	2	17 November 2014
Participant Information Sheet (PIS): HV Control	2	17 November 2014
REC Application Form: REC Form 24112014		24 November 2014
Referee's report or other scientific critique report: Proceed to Ethics Letter - University of Glasgow	1	26 September 2014
Referee's report or other scientific critique report: CUSP Feedback		20 June 2014
Research protocol or project proposal	2	17 October 2014
Summary CV for Chief Investigator (CI): Kaye McKie	1	15 October 2014
Summary CV for supervisor (student research): Hamish McLeod	1	12 August 2014
Validated questionnaire: Awareness Questionnaire Patient Form	1	13 October 2014
Validated questionnaire: RBANS	1	28 October 2014
Validated questionnaire: MDS-UPDRS part 3	1	13 October 2014
Validated questionnaire: HADS	1	13 October 2014
Validated questionnaire: Burden Interview	1	13 October 2014

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet

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.

14/NS/1080 Please quote this number on all correspondence

Yours sincerely

Dr Alex Johnstone (Chair)

Copy to: Ms Frances Hines, NHS Highland

NRES Committees - North of Scotland (2)

Attendance at Committee meeting on 11 December 2014

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Alex Johnstone	Chair & Senior Scientist in Human	Yes	
Dr Ruth Stephenson	Vice Chair and Consultant in Anaesthesia	Yes	
Mr Gary Cooper	Lay Member - Alternate Vice Chair and Quality Assurance Manager	Yes	
Mr Russell Brinklow	Community Psychiatric Nurse	Yes	
Dr Hanne Bruhn	Lay Member - Research Fellow -Psychology	Yes	
Dr Jennifer Caldwell	Senior Lecturer in Occupational Therapy	Yes	
Mrs Ann Conroy	Retired Midwife	Yes	
Dr Ian Fleming	Research Fellow	Yes	
Mrs Baljit Jagpal	MRI Lead Superintendent	Yes	
Dr Petr Kalous	Consultant Neonatologist	Yes	
Dr Kirsty Kiezebrink	Lecturer	No	
Mrs Kathryn McMullan	Retired Clinical Pharmacist	Yes	
Dr Jeremy Morse	Manager of Clinical Skills	Yes	
Mrs Sian Roughton	Practice Educator Intensive Care Unit/Honorary Lecturer Aberdeen	No	
Mrs Fiona Watson	Lay Member - Ex Company Director	No	
Mrs Sophie Welch	Coach Practitioner	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Karen Gauld	Ethics Administrator
Mrs Carol Irvine	Senior Ethics Co-ordinator

Written comments received from:

Name	*Position*
Mrs Sian Roughton	Practice Educator Intensive Care Unit/Honorary Lecturer Aberdeen

Appendix 2.3: Ethical Approval Letter II

NRES Committees -
North of Scotland
Summerfield House

23 December 2014

Miss Kaye McKie
Department of
Clinical Psychology
New Craig's Hospital

Dear Miss McKie

Study title: Awareness of Cognitive Abilities in People with Parkinson's disease
REC reference: IRAS project ID: 14/NS/1080 160843

Thank you for your letter of 22 December 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair, Vice-Chair and Alternate Vice-Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mrs Carol Irvine, nosres@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

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.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the
start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

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).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

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

Document	*Version*	*Date*
Copies of advertisement materials for research participants: Poster Advertisement	3	15 December 2014
Covering letter on headed paper		18 November 2014
Covering letter on headed paper: Response to Provisional Opinion		22 December 2014
Covering letter on headed paper: Cover Letter	3	22 December 2014
GP/consultant information sheets or letters: GP Letter	2	17 November 2014
IRAS Checklist XML: Checklist 22122014		22 December 2014
Document	*Version*	*Date*
Letter from Sponsor		4 November 2014
Letters of invitation to participant: Consent to Contact Form	3	15 December 2014
Non-validated questionnaire: Demographic Profile	2	17 November 2014
Non-validated questionnaire: Awareness Percentile Scale	2	17 November 2014
Participant Consent Form	3	15 December 2014
Participant Consent Form: Healthy Volunteer	3	15 December 2014
Participant Consent Form: Spouse/Carer	1	15 December 2014
Participant Information Sheet (PIS)	3	15 December 2014
Participant Information Sheet (PIS): Healthy Volunteers	3	15 December 2014
Participant Information Sheet (PIS): Spouses/Carers	1	14 December 2014
REC Application Form: REC Form 22122014		22 December 2014
Referee's report or other scientific critique report: Proceed to Ethics Letter - University of Glasgow	1	26 September 2014
Referee's report or other scientific critique report: CUSP Feedback		20 June 2014
Research protocol or project proposal	2	17 October 2014
Summary CV for Chief Investigator (CI): Kaye McKie	1	15 October 2014
Summary CV for supervisor (student research): Hamish McLeod	1	12 August 2014
Validated questionnaire: RBANS	1	28 October 2014
Validated questionnaire: Awareness Questionnaire Patient Form	1	13 October 2014
Validated questionnaire: MDS-UPDRS part 3	1	13 October 2014
Validated questionnaire: HADS	1	13 October 2014
Validated questionnaire: Zarit Caregiver Burden Inventory	1	15 December 2014

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.

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

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

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 Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

14/NS/1080 Please quote this number on all correspondence

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

Yours sincerely

Carol Irvine

pp'd behalf of Dr Alex Johnstone Chair

Appendix 2.4: Research and Development Approval Letter

Professor Angus Watson
Research & Development Director
NHS Highland Research & Development Office
Room S101
Centre for Health Science
Old Perth Road
Inverness
IV2 3JH

Tel: 01463 255822
Fax: 01463 255838
E-mail: angus.watson@nhs.net

NHS Highland

12 January 2015

NHS Highland R&D ID: **1056**
NRSPCC ID: **NA**

RECEIVED

Miss Kaye McKie
Trainee Clinical Psychologist
Department of Clinical Psychology
Drumossie Unit
New Craigs Hospital
Leachkin Road
Inverness
IV3 8NP

Dear Miss McKie,

Management Approval for Non-Commercial Research

I am pleased to tell you that you now have Management Approval for the research project entitled: **'Awareness of Cognitive Abilities in People with Parkinson's Disease'. [Protocol V2 17/10/14].** I acknowledge that:

- The project is sponsored by NHS Highland.
- The project does not require external funding.
- Research Ethics approval for the project has been obtained from the North of Scotland Research Ethics Committee, (Reference Number: 14/NS/1080).
- The project is Site-Specific Assessment exempt.

The following conditions apply:

- The responsibility for monitoring and auditing this project lies with NHS Highland.

- This study will be subject to ongoing monitoring for Research Governance purposes and may be audited to ensure compliance with the Research Governance Framework for Health and Community Care in Scotland (2006, 2nd Edition), however prior written notice of audit will be given.
- All amendments (minor or substantial) to the protocol or to the REC application should be copied to the NHS Highland Research and Development Office together with a copy of the corresponding approval letter.
- **It should be noted that a minor amendment submission will be required as Consent Form V3 15/12/14 references the wrong version and date of the PIS and PIS (Health Volunteer Control) (states V2 11/11/14 when it should be V3 15/12/14). Please submit minor amendment to the REC, and to NHS Highland R&D for approval.**
- The paperwork concerning all incidents, adverse events and serious adverse events, thought to be attributable to participant's involvement in this project should be copied to the NHS Highland R&D Office.
- Monthly recruitment rates should be notified to the NHS Highland Research and Development Office, detailing date of recruitment and the participant trial ID number. This should be done by e-mail on the first week of the following month.

Please report the information detailed above, or any other changes in resources used, or staff involved in the project, to the NHS Highland Research and Development Manager, Frances Hines (01463 255822, frances.hines@nhs.net).

Yours sincerely,

Frances Hines
R&D Manager

cc Frances Hines, R&D Manager, NHS Highland Research & Development Office, Room S101, The Centre for Health Science, Old Perth Road, Inverness, IV2 3JH

Appendix 2.5: Participant Consent to Contact Form

Study Title: Awareness of Cognitive Abilities in People with Parkinson's disease

Date

Dear

I am writing to let you know about some research that is being completed by a final year Trainee Clinical Psychologist, called Kaye McKie, working within NHS Highland. Kaye is completing the research study as part of her doctoral degree at the University of Glasgow.

Kaye is interested in investigating the impact Parkinson's disease may have on people's awareness of their cognitive abilities, such as, memory, attention and problem solving.

The enclosed patient information sheet (version number 2; 11/11/2014) describes the study. It also explains what will happen if you decide to participate. Please take your time reading the information, feel free to discuss it with friends and family, the research team or myself. Contact detail are listed on the participant information sheet.

If you decide that you would like to take part in this project, please let me know that you consent for your details to be passed to Kaye for her to contact you. You can do this by returning the attached response slip in the stamped addressed envelope provided or you can phone me and let me know. I will then pass your details to Kaye to make contact with you. Please return your slip within two weeks of the date at the top of the letter. If I do not hear from you by this time I will assume that you do not wish your details to be passed on, and do not wish to take part in the project.

Please feel free to contact me if you have any questions and please be aware that I am independent of the research team.

Address: Parkinson's disease Department, Raigmore Hospital, Old Perth Road, Inverness, IV2 3UJ

Tel: 01463 706378

Thanks you for taking the time to read this letter.

Yours sincerely,

Dr Martin Wilson/ Ms Sharon Sutherland

Parkinson's disease Team

Response Slip

Study Title: Awareness of Cognitive Abilities in People with Parkinson's disease

Please fill in this section and return using the self-addressed envelope if you consent for your contact details to be passed to Kaye McKie (Trainee Clinical Psychologist).

Name:……
……

Address:……
……
……

Telephone:……

Appendix 2.6: Participant Information Sheet

Study Title: Awareness of Cognitive Abilities in People with Parkinson's disease.

Participant Information Sheet

Invitation to Participate in a Research Project

We would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being carried out and what is involved. Please take time to read the following information carefully and discuss it with others if you wish. Please contact us if there is anything that is not clear or if you would like any further information.

Who is conducting the research?

The research is being carried out by Kaye McKie (Trainee Clinical Psychologist) and Dr Hamish McLeod from the Institute of Health and Wellbeing of the University of Glasgow. The study is being undertaken as part of the fulfilment for an academic qualification (Doctorate in Clinical Psychology).

What is the research about?

This study is designed to investigate the impact of Parkinson's disease on awareness of cognitive abilities, such as, memory, attention and problem solving. Awareness of our abilities is an important aspect of everyday life, as it provides us with the ability to recognise our limits, to judge risks and maintain relationships. Previous research has examined people with Parkinson's disease level of awareness of motor symptoms, but there has been no research into their awareness of cognitive abilities. It is hoped this project will further our understanding of cognitive awareness in Parkinson's disease and what this means for patients, carers and clinicians in a practical and functional sense.

Why have I been invited?

You have been invited to take part in this study as you have a diagnosis of Parkinson's disease and are over the age of 18 years.

Do I have to take part?

It is entirely up to you whether you take part or not. The research team will provide you with an information sheet and will give you at least 24 hours to decide whether you want to take part. If you still want to participate, then we will make arrangements to meet and you will be asked to sign a consent form to show you have agreed to take part in the study. If you decide to take part you are still free to withdraw at any time without giving a reason. In the (perhaps unlikely) event of a loss of capacity, the research team would retain personal data collected and continue to use it confidentially in connection with the purposes for which consent is being sought. A decision not to take part or a decision to withdraw from the study at any time will not affect the standard of care you receive now or in the future.

What does taking part involve?

If you decide to take part we will arrange a time convenient to you to come along and meet our researcher at your health centre. Taking part involves approximately 90 minutes of assessment. This will include a variety of tasks such as completing questionnaires (one asking about mood, one asking about motor features of your condition and one asking questions about how you make decisions) and paper and pen style tasks (for example completing puzzles, memory and language tasks). You can have a break half way through testing and at any other time if required. With your permission additional information regarding severity of disease, duration of illness and current medications will be obtained from medical staff already involved your care, will be recorded.

If you consent to the research team contacting a family member/carer, we will ask your family member or carer questions regarding your condition. This will consist of our researcher asking them to complete a short questionnaire, this will only take fifteen minutes.

What are the possible benefits of taking part?

In general, research improves our knowledge of what people's difficulties are and what we can do to help people overcome these and improve people's lives. Your participation will help increase our knowledge of awareness of cognitive deficits and potentially improve treatment for others in the future.

Are there any disadvantages or risks of taking part?

There are no significant risks or disadvantages for taking part. You may feel a little tired, but there will be regular breaks during the assessment session to minimise this. Although we do not anticipate that participating in this study will cause you any distress, if this did happen we would help you to access appropriate support if needed. With your permission we will inform your GP that you are taking part in the study.

Will my information be confidential?

All the information you provide will be treated confidentially and the research questionnaires will only be identified by a code, not your name. The anonymised questionnaires will then be analysed by the research team. The consent forms and study data will be stored on University of Glasgow premises and will be accessible to researchers who are directly involved with the research.

What happens to the information?

Your identity and personal information will be completely confidential and known only to the researcher. The information obtained will be stored in a locked filing cabinet. The data are held in accordance with the Data Protection Act (1998), which means that we keep it safely and cannot reveal it to other people, without your permission. If we publish any findings from the study, this will be in the form where your results are combined with those of many other people and average scores are presented.

What will happen to the results of the study?

Within two weeks of completing the assessments, feedback of your results will be passed to the Parkinson's disease team. You will then be able to collect your feedback at your next PD appointment.

On completion of the full research project the completed report will be submitted to the University of Glasgow as part fulfilment of the researcher's Doctorate in Clinical Psychology degree. It is hope that the results will also be published in a medical journal and through other routes to ensure that the general public are also aware of the findings. You will not be identified in any report/publication arising from this study.

Who is funding the research?

This research is being funded by the University of Glasgow, Doctorate in Clinical Psychology.

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 the North of Scotland Research Ethics Committee (NOSREC) to ensure that it meets standards of ethical conduct.

Who can I contact for further information?

If you require any further information or have any questions, please feel free to contact a member of the research team. Alternatively, you can speak to someone who is independent of the study who can answer questions or give advice.

Name	**Role**	**Contact**
Kaye McKie	Trainee Clinical Psychologist NHS Highland	Department of Psychology, New Craig's Hospital, Drumossie Unit, Leachkin Road, Inverness, IV3 8NP Telephone: 01463 253697
Dr Hamish McLeod	Academic Supervisor University of Glasgow	Academic Unit of Mental Health and Wellbeing, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH Telephone: 0141 211 3922
Dr Jim Law	Field Supervisor NHS Highland	Department of Psychology, New Craig's Hospital, Drumossie Unit, Leachkin Road, Inverness, IV3 8NP Telephone: 01463 253697
Prof. Jon Evans	Independent Contact University of Glasgow	Academic Unit of Mental Health and Wellbeing, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH Telephone: 0141 211 3978

Appendix 2.7: Participant Consent Form

Patient Identification Number:

PARTICIPANT CONSENT FORM

Awareness of Cognitive Abilities in People with Parkinson's disease.

Research Team: Researcher, Kaye McKie – Trainee Clinical Psychologist. Academic Supervisor, Dr Hamish McLeod - DClinPsy Programme Director. Local Field Supervisor, Dr Jim Law – Consultant Clinical Psychologist.

Please Initial the Box

1. I confirm that I have read and understand the information sheet dated (11/11/2014; version number 2) for the above study. ☐

2. I have had the opportunity to consider the information provided, ask questions and had these answered satisfactorily. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

4. I understand that sections of my medical notes may be looked at by the research team where it is relevant to my taking part in the research. I give my permission for the research team to access my records. ☐

5. I give permission for a family member to be asked questions regarding my Parkinson's disease and to complete a short questionnaire. ☐

6. I give permission for my GP to be informed that I am taking part in the current study. ☐

7. In the (perhaps unlikely) event of a loss of capacity, I consent to the research team retaining any personal data collected and allow them to continue to use it confidentially in connection with the purposes for which consent is being sought. ☐

8. I agree to take part in the above study. ☐

Participant signature: ..... Date: ……..

Researcher signature: ..... Date: ……

Appendix 2.8: Major Research Project Proposal

Title: Awareness of Cognitive Deficits in Parkinson's disease

Abstract

Background: 'Anosognosia' the awareness of ones deficits is an important aspect of functioning as it underpins the ability to recognise our limits. This function is commonly compromised in neurological diseases, such as Parkinson's disease (PD). Although several studies have examined PD client's level of awareness of motor symptoms there has been no research into PD patient's awareness of cognitive deficits. **Aims:** This study aims to explore PD patient's awareness of their cognitive deficits. In doing so, this study will also: explore perceived difference between clients level of awareness of cognitive deficit to that of their motor deficits and explore the relationship between clients level of awareness of cognitive deficit on caregiver burden. **Methods**: Participants with PD and a control group will predict their performance based on a percentile scale, prior to completing the global cognitive and global motor functioning assessment. Following task completion, participants will be asked to estimate their performance, therefore allowing for differences between self-rated and actual performances to be calculated. **Practical Applications:** The ability to recognize impairments and the capacity to self-monitor the impact on functioning is important in PD, as individual's level of awareness has implications for level of their perceived risk in tasks of everyday living, carer burden, therapeutic and rehabilitation gains, It is hoped this project will further our understanding of awareness of cognitive deficit in PD and what this means for patients, carers and clinicians in a practical and functional sense.

Introduction

The term anosognosia was introduced by Babinski (1914; cited in Klinowski & Paulsen, 2013) to describe a lack of awareness/insight of one's disease or deficit. Awareness of our deficits is an important aspect of everyday life which provides us with the ability to recognise our limits (Williamson, Alcantar, Rothlind, Cahn-Weiner, Miller & Rosen, 2010). However, this function is commonly compromised in neurological diseases, such as Parkinson's disease (PD). Although several studies have examined PD clients level of awareness in terms of motor symptoms (Sitek, Sołtan, Wieczorek, Schinwelski, Robowsk, Reilmann, Guzińska, Harciarek, Krysa & Sławek, 2011), expressivity (Mikos, Springer, Nisenzon, Kellison, Fernandez, Okun & Bowers, 2009) and social deficits (Leritz, Loftis, Crucian, Friedman & Bowers, 2004) there has been no research into PD patients awareness of cognitive deficits.

PD is the second most common degenerative neurological condition after Alzheimer's disease. PD has a prevalence rate of 1/500, with an average age of onset around 60 years. PD is initially characterized by motor symptoms such as rigidity and tremor of the limbs whilst at rest, bradykinesia and postural instability (Schapira, 2010). PD patients may also experience changes in non-motor symptoms, such as impairments in attention, memory, executive function (planning and mental flexibility), slowing of mental processing, delayed response time and visuospatial defects (Peto, Jenkinson, Fitzpatrick & Greenhail, 1995; Muslimovic, Post, Speelman & Schmand, 2005). It is estimated that 85% of PD patients exhibit deficits in cognitive functioning at various stages of disease progression (McNamara, 2011).

Cognitive disturbances in PD can be as disabling as the motor symptoms of the disease, typically with attention, complex decision making and mental flexibility affected first (Schapira, 2010). However, these cognitive deficits are only recently attracting research attention. Correlational research has led to the suggestion that motor and cognitive impairments share a common pathophysiology and emerge together (Murakami, Owan, Mori, Fujita, Futamura, Sugimoto, Kobayawa, Kezuka, Midorikawa & Kawamura,

2013). Through the administration of the Montreal Cognitive Assessment (MoCA) and measure of general motor function, as measured by the Parts II and III of the Unified Parkinson's disease Rating Scale (UPDRS) a significant relationship between the degree of motor impairment and cognitive ability was shown (r= -0.45 Medium Effect).

Awareness of deficit is a dimensional construct comprising of a level of explicit and implicit awareness of functioning, current situation, and of the disorder itself (Clare, 2004). Explicit awareness is where the individual has the ability to verbally acknowledge their deficit and implicit awareness where the individual has the ability to accurately judge the impact of their cognitive deficit (Medin & McLeod, in preparation). However, even when the patient explicitly denies the presence of cognitive deficits, implicit awareness may be evident. Methods of measuring insight have primarily compared questionnaires that ask patients about their current abilities and compare these responses to the subjective perceptions of a close informant (Sherer, Bergloff, Boake, High & Levin, 1998). Eslinger, Dennis, Moore, Antani, Hauck & Grossma (2005) proposed that an objective self-rating of awareness was needed in order to move away from the reliance of informant knowledge, which may pose a bias perspective. Eslinger et al (2005) devised a process of discrepancy scoring of objective self-ratings to indicate the patients perceptions of their own level of abilities and assess the two components of insight: self-awareness of the knowledge of ones abilities through pre-testing predictions, whereby the patient derives self-knowledge of abilities, reflection and previous life experience; self-monitoring of abilities through post-testing estimations, where the client judges their actual performance compared to their perceived performance. Williamson, Alcantar, Rothlind, Cahn-Weiner, Miller & Rosen (2010) devised an assessment strategy whereby the patient is asked to rate their performance on a percentile scale, represented as a bell shaped curve. This allows for a comparison between predicted and actual performance using the same percentile scale. However a potential concern for this measure is that it reflects overall estimation ability more than awareness of personal performance deficits. Due to the difficulties predicting percentile scores from poor estimation skills rather than poor insight, a further

comparison between two methods of assessing awareness of cognitive deficit will be completed (percentile vs questionnaire approach).

The phenomenon of impaired awareness involves an inadequate evaluation of one's impairments often underestimating the degree of their deficit, whereas their ability to rate others performing the same task remains intact (Clare, 2004). It has been suggested that several psychosocial factors, such as psychological denial, personal standards of success, compensatory strategies, and ageist preconceptions, might be important influences on reduced awareness (Ownsworth, Clare & Morris, 2006). In regards to dementia, Naylor & Clare (2008) state that reduced awareness may serve as a protective function against the threats to identity of self, by the onset and progression of the disease.

Unawareness of deficit has significant impact on day to day functioning and affective state for the PD patient and their caregivers (Rosen, 2011). Due to PD being a degenerative disease the task of supporting and caring for the individual with PD usually falls to a spouse or family member. This can give rise to caregiver burden, the physical, mental, and socio-economic problems experienced by the caregivers of people with chronic diseases (Martinez-Martin, Forjaz, Frades-Payo, Rusinol, Fernandez-Garcia, Benito-Leon, Arillo, Barbera, Sordo & Catalan, 2007). Predictors of caregiver burden in carers of PD patients include: time devoted to caring and strain deriving from the patient's condition; disability and disease severity; psychological well-being of caregivers; clinical aspects of disease and patients' mood (Martinez-Martin et al, 2007).

Several studies have examined the impact of awareness of deficit of motor abilities on caregiver burden in carers of individuals with PD. Faison, Faria and Frank (1999) reported a positive correlation between level of care needed to perform activities of daily living and caregiver burden, $r = 0.21$ (small effect) indicating that increases in

ADL were associated with increases in caregiver burden. De Bettigines, Mahurin & Pirozzolo (1990) found that level of insight was significantly correlated with the degree of caregiver burden, with higher levels of awareness of Independent Living Skills related to lower levels of caregiver burden. It would be interesting to examine awareness of cognitive deficit in PD in relation to caregiver burden as no previous research has been completed in this area. This would allow for real life implications of the impact of awareness and cognitive deficits to be better understand and enhance the literature.

In conclusion, awareness of cognitive deficits in PD may have several real life implications on the individual with PD and their carer/spouse. Previous research has shown significant association between PD clients motor and cognitive abilities and significant relationship between awareness of motor abilities and caregiver burden. However, no research has examined the relationship between awareness of cognitive abilities and motor abilities, or the association between cognitive awareness and caregiver burden. In order to examine theses factor the development of methods for examining awareness of cognitive deficits in PD is required.

Aims

The aim of the proposed study is to analyse PD patient's awareness of their cognitive deficits. It is hoped the results will further our understanding of awareness of cognitive deficit in PD and what this means for patients, carers and clinicians in a practical and functional sense.

In doing so, this study will also:

- Examine if there is a difference in magnitude between participants awareness of cognitive deficit to their awareness of motor deficits.
- Examine the extent to which awareness of cognitive deficit impacts on caregiver burden.

Hypotheses

1. The ability to judge awareness varies within populations. As no previous research exists in relation to PD and cognitive awareness it will be interesting to examine whether people with PD will be less accurate at predicting and monitoring their cognitive abilities and performance compared to healthy control participants. Specifically, PD participants will overestimate their cognitive abilities, as measured by discrepancies between estimated and perceived performance on neuropsychological tasks, in comparison to the control group. As previous research stated the limits of percentile scales measures may be result from poor estimation skills rather than poor insight, a further comparison between the two methods of measuring awareness of deficit (percentile scale and questionnaire) will be completed for PD patients.

2. Murakami et al.'s (2013) correlational study found a significant relationship between the PD participant's degree of motor impairment and cognitive problems, suggesting that deficits in both areas occur simultaneously. However, the difference in *awareness* of motor and cognitive abilities has not been examined. Due to the salient feedback of motor deficits compared to the more discreet presentation of cognitive deficits in individuals with PD, it is predicted that self-ratings by PD participants of their awareness of cognitive abilities would be less accurate at predicting and monitoring performance, than self-ratings of their awareness of motor deficit.

3. Based on Faison et al.'s (1999) significant positive correlational study of motor awareness and caregiver burden, it is predicted that greater unawareness of cognitive abilities will also correlate positively with carer burden. This will further our understanding of the progressive changes in cognitive ability in individuals with PD and its possible implications on caregiver burden.

Plan of Investigation

Participant Recruitment Procedures

Participants will be recruited from services at the Parkinson's disease Unit in NHS Highland. Suitable participants will initially be informed of the study at routine outpatient clinics by a Consultant Geriatrician who specialises in Parkinson's disease and/or a Specialist PD Nurse. Those who express interest will be provided with an information pack (which will include a participant information sheet, contact details of the researcher and a consent form). Potential participants will then be given an appointment or phone call with the researcher in order to answer any questions and provide further information. If informed consent is obtained, arrangements will be made for the testing session.

Recruitment of Control Group (two options).

1. In order to control for confounding variables such as demographic profiles it is planned that initial recruitment will be significant other/carers from the experimental participants. This would also allow for the comparison of awareness of deficit and caregiver burden.

2. If the PD participant consents to the study but does not have a suitable carer/ or if the significant other does not give consent, the control group will consist of a population of older adults attending a local NHS physiotherapy service.

   In regards to carer burden, if the experimental participant has a significant other who consents to completing a single measure of caregiver burden, this will allow for an analysis of caregiver burden.

Exclusion Criteria

- Due to increasing severity of motor control and physical disabilities as PD progresses, Individuals at Stage 5 of the Hoehn and Yahr (1967) rating scale (confinement to bed or wheelchair unless aided) will be excluded from the study.
- Participants who are deemed by the clinical team to lack capacity to provide informed consent.
- Participants should have no history of learning disabilities; no current psychiatric disorder (e.g. depression); Substance Misuse; or previous neurological conditions (e.g. Traumatic Brain Injury; Stroke).

Measures

Demographic information will be collected from all participants and a relative/carer (age, gender, marital status, relationship to the individual with PD (e.g. spouse), education and occupation). Additional information regarding severity of disease, duration of illness and current medications will be obtained from mental health staff involved in participants' care and/or by case note review.

List of standardised measures

(Outline of all measures can be found in Major Research Project Paper -Chapter 2,)

- Test of Global Cognitive Functioning percentile scale based approach: Repeatable Battery for Assessment of Neuropsychological Status (RBANS) (Randolph, 1998).
- Test of Global Cognitive Functioning questionnaire based assessment: The Awareness Questionnaire (Sherer, Bergloff, Boake, High & Levin, 1998).

- Test of Global Motor Functioning: The Movement Disorder Society (MDS)-sponsored revision of the Unified Parkinson's disease Rating Scale (MDS-UPDRS) (Goetz, 2008).
- Carer Burden: Zarit Caregiver Burden Inventory -ZCBI (Zarit, Reever & Bach-Peterson, 1980).
- Mood State: Hospital Anxiety & Depression Scale- HADS (Snaith and Zigmond, 1983).

Assessing Awareness of Cognitive and Motor Deficit.

In order to assess awareness of deficit, an assessment based on Medin and McLeod (in. prep) design will be used. This involves participants predicting their performance based on a percentile scale, prior to completing the cognitive assessment (RBANS) and motor functioning assessment (MDS-UPDRS). Following task completion, participants will be asked to estimate their performance on these assessments, therefore allowing for differences between self-rated and actual performances to be calculated. This analysis would assess the patient's ability to predict and reflect on their test performance, error processing and ability to self-monitor. A further analysis will be conducted in order to examine whether there are differences in self- awareness between cognitive domains, it is proposed that this current study will compare predicated/estimated and actual scores on individual cognitive domain sub-scales. Due to the difficulties predicting percentile scores from poor estimation skills rather than poor insight, a further comparison between two methods of assessing awareness of cognitive deficit will be completed (percentile vs questionnaire approach).

Design and Analysis

This will be a cross-sectional study consisting of individuals with PD with varying degrees of severity of disease. To control for biases and potential influences a control group will be used. Participants in both the experimental and control conditions will be administered all standardised assessments and tests of cognitive and motor awareness. This study will comprise of a mixed method design: Between subject's comparison of

PD and control participants objective self-ratings on pre-test predictions and post-test estimations of performance in tests of cognitive awareness.

Within subjects comparison of PD participants awareness and monitoring of motor and cognitive abilities. Within subjects comparisons of discrepancies in awareness of abilities in individual cognitive domains for each PD participant. A further comparison of PD patient discrepancies in cognitive deficit will be correlated with perceived carer burden.

Procedure

Once recruitment and consent processes have been complete, the measures along with practice items will be administered in the following order:

3. Demographic information (gathered from all participants).
4. HADS (all participants)
3. The Awareness Questionnaire (PD Patients only)
4. MD-UPDRS (PD Patients only)
5. Zarit Caregiver Burden Inventory (carers only)

BREAK

6. Test of Global Cognitive Ability – RBANS (all participants)

    a. Pre-Test prediction of performance score
    b. Post-Test estimation of performance score

BREAK

7. Test of Global Motor Functioning – MDS-UPDRS – section 3 (PD Patients only)

    c. Pre-Test prediction of performance score
    d. Post-Test estimation of performance score

DEBRIEF

It is estimated that this process will last 90 minutes including rest breaks for PD Patients and 60 minutes for control group. The Zarit Caregiver Burden Inventory Carer assessment will take 15 minutes to administer.

Sample Size*

Due to the exploratory nature of this research no previous comparable studies exist from which an estimate of expected effect size could be obtained. A recent study which applied the discrepancy method of objective self-rating in examining awareness of cognitive abilities in people with schizophrenia, recruited 9 clinical participants and 22 healthy controls (Medin & McLeod, in.prep) and found a statistically significant difference between the clinical and control group. Effect sizes were around 0.54 for awareness of cognitive abilities, 0.62 for awareness of cognitive performance, and 0.67 for monitoring of cognitive performance, as measured by between subject discrepancy data.

It is reasonable to assume that the present study will have a similar effect size, 0.6. It is estimated that 37 participants per group will be required to detect significant differences between groups with a significance level of alpha = 0.05, with a power of 0.8 (one tailed).

Please see MRP Addendum – Appendix 2.8

Health and Safety Issues

All Local and NHS health and safety procedures will be followed throughout the duration of this project.

Researcher safety – all participants will be seen in local NHS GP Surgery's or in Hospital clinics. NHS Highland protocol will be adhered to and a panic alarm is situated in all clinical rooms.

Participant safety – The testing session may be challenging for some adults with PD so frequent comfort breaks will be offered and participants can discontinue testing at any time without negative consequences.

Ethical Issues (including where submissions will be made)

Ethical applications will be submitted to the NHS Highland Research & Development Group and NHS ethics committee.

Participants will be asked if they wish to participate in the study. The length of the testing session and purpose of the study will be explained to all participants and written consent will be obtained prior to testing. Care will be taken throughout the study to ensure that the participants are fully informed of the research procedures and have the opportunity to refuse or withdraw consent at any stage. All participants will be offered a debriefing at the end of the testing session. Following completion of the study information regarding the study outcomes will be sent to participants.

All data sheets and database records will use a coding scheme to conceal the identity of participants. All raw data will be stored in a locked filing cabinet and analysis of this data will be completed on an encrypted laptop.

Financial Issues

Materials - printer paper, access to an encrypted laptop, photocopier and printer will be required.

Test materials: RBANS response sheets.

Transport costs: Travel to and from base to clinical sites current petrol cost £0.24 per mile. (Invergorden Community Hospital – 40miles return trip and Raigmore Hospital – 6miles return trip).

Timetable

- April 2014: Proposal submitted to University.
- July 2014: Prepare ethics application.
- September 2014: Application to NHS Highland Research & Development Group and ethical approval.
- October 2014 – March 2015: Begin recruitment and data collection.
- April – May 2015: Data analysis.
- June - July 2015: Write up.

Practical Applications

- Cognitive impairment is common in PD and it is hoped this study will increase clinicians understanding of cognitive awareness in PD. Understanding the difference of perceived awareness of motor vs non-motor deficits in clients with PD.
- Implications for the assessment and understanding of insight into cognitive deficits in people with Parkinson's disease.
- Implications in the medical and psychosocial management of Parkinsonian patients and useful for therapeutic intervention targeting PD cognitive decline at an earlier stage.
- Implications on Caregiver Burden and carer well-being.

References

Can be found in the Major Research Project Paper -Chapter 2 with the exception of:

Schacter, D. L. (1990). Toward a cognitive neuropsychology of awareness: Implicit knowledge and anosognosia. *Journal of Clinical and Experimental Neuropsychology*, 12, pp155–178.

Sitek, E.J., Sołtan, W., Wieczorek, D., Schinwelski, M, Robowski, P., Reilmann, R., Guzińska, K., Harciarek, M., Krysa, W., & Sławek, J. (2011). Self-awareness of Motor Dysfunction in Patients with Huntington's disease in Comparison to Parkinson's disease and Cervical Dystonia. Journal of the International Neuropsychological Society. 17. pp 788 – 795.

Appendix 2.9: Addendum to Major Research Project Proposal

Amendment to Sample Size Calculation

Through consultation with academic and field supervisors, it was decided that the initial sample size calculation based on Medin and McLeod (in.prep) was to be revised.

As the current study used similar methodology as the Williamson et al (2010) study, assessed participants with a neurological condition and applied the same discrepancy method of objective self-rating when examining awareness of cognitive abilities, it was decided that a new sample size calculation would be conducted on the results of this study.