

The University Of Hull

Parkinson's disease and the perception of body affect.

**Being a Thesis submitted in partial fulfilment of the requirements for the degree of
Doctor of Clinical Psychology**

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by

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Overview:

This portfolio has three parts:

Part one is a systematic literature review. The literature for the impact of Parkinson's disease on the spousal couple is reviewed.

Part two is an empirical paper. The effect of Parkinson's disease in recognising emotions expressed through body movements is investigated.

Part three contains the appendices. These provide further information regarding both parts one and two.

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Part One: Systematic Literature Review

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Abstract

Objective: Parkinson's disease (PD) is a degenerative neurological condition causing severe physical and cognitive impairments. Due to the severity of disability caused by PD, individuals are usually in need of long term care. Care is often provided by partners. This review aimed to discover the impact of PD upon the couple relationship.

Method: The search terms (Parkinson*) AND (Spous* OR Couple* OR Partner* OR Husband* OR Wife* OR Wive* OR Marital* OR Marriag* Or Relationship*) were entered into the PsycINFO, Scopus and PUBMED databases resulting in 12,810 papers. After assessments of suitability and the removal of duplicate papers 27 studies were included in this review.

Results: PD was shown to have negative impacts on spouses and the spousal relationship. Particular PD symptoms caused specific negative effects. Negative impacts of PD were found to be mediated by a variety of factors internal and external to the spousal relationship.

Discussion: Increased attention is needed into how negative outcomes of PD impact well partners and the partner relationship, in addition to factors which can mediate this. Clinical implications include areas for increased professional awareness and for targeted interventions. The findings also highlight possible further areas of research including; considering the effect of specific PD symptoms on the couple relationship and possible protective factors that minimise the effect of PD on well partners and couple dyads.

The Effect of Parkinson's Disease on the Couple Relationship:

A Systematic Review of the Literature

Introduction

Parkinson's disease (PD) is a neurodegenerative condition associated with "dopamine depletion in the Basal Ganglia and its connections from the Substantia Nigra" (Lezak, Howieson & Loring, 2004). This neurodegeneration causes severe motor and cognitive impairments. The average age of onset of PD is in the fifth and sixth decades of life with 1% of the world's population over 60 being affected (Schoenberg, 1987).

PD has been shown to negatively impact the individual in addition to the impairments of the motor modality. PD is associated with significant levels of depression (Richardson & Marshall, 2012) and anxiety (Forjaz et al., 2013). The mental health issues caused by PD have been found to be rarely recognised or treated effectively. This is attributed to individuals with PD not being aware that they have the above psychiatric conditions as well as poor access to services, poor screening and poor identification by health professionals (Dobkin et al., 2013). Furthermore these psychiatric conditions are correlated with lower quality of life (Yang, Sajatovic & Walter, 2012).

PD also severely impacts upon the sufferer's social functioning. This deficit is likely the result of the interaction of many different impairments, both cognitive and motor, caused by PD. For example, Theory of Mind is impaired in individuals with PD thus impairing the individual's ability to perspective take and empathise (Freedman & Stuss, 2011). Individuals with PD are also impaired on measures of social problem

solving, such as detecting sarcasm (Anderson, Simpson, Channon, Samuel & Brown, 2013).

Facial masking is a motor difficulty found in PD where impairment in the ability to move facial muscles causes the individual to have less expressive and spontaneously responsive facial expressions. Individuals with facial masking are perceived by others as less supportive, empathetic and less engaged in social interactions (Hemmesch, Tickle-Degnen & Zebrowitz, 2009).

Impairments in the recognition of emotion are also hypothesised to be a cause of impaired social functioning. Clark, Nearing and Cronin-Golomb (2008) demonstrated that PD patients showed significant deficits in the recognition of facial emotion when compared to a healthy control group. A meta-analysis of 34 different studies investigating PD and facial emotion recognition found “a robust link between PD and specific deficits in recognising emotion” “...particularly negative emotions” (Gray & Tickle-Degnen 2010). No research exists into the effect of impaired emotional perception on social communication with a PD population. However, Hooker and Park (2002) have shown that individuals with psychosis and impaired facial affect recognition scored significantly lower on a measure of social functioning, suggesting emotional perception plays some role in social functioning.

Additionally individuals with PD are perceived by others as being less polite than individuals without PD (Holtgraves & McNamara, 2010).

Individuals with PD themselves also experience difficulty in conversations, interacting with others and with making themselves understood (Miller, Noble, Jones & Burn, 2006). The affected individual’s impairments in communication, coupled with how these deficits are perceived by the recipient of the communication both contribute to the socio-communication deficits found in PD.

Due to the myriad of disabilities caused by PD, and the disorder's degenerative course, individuals with PD are usually in need of long term care. PD is responsible for large amounts of caregiver burden in both formal and informal carers. Levels of caregiver burden are proportional to the amount of disability caused by PD in both physical and cognitive functioning (Ozdilek & Gunal, 2012). Caregiver burden can cause reductions in the carer's quality of life, psychological well being and physical health. Some studies have suggested that good informal care giving is dependent on several factors partially good interpersonal relationships between carer and the recipient of care (Lau et al., 2010). The U.S. Administration on Aging (2000) found that 65% of older adults with long term health needs rely upon spouses, friends and other family members to be informal carers. Given the above findings showing the importance of interpersonal relationships in care giving and the fact that PD disrupts interpersonal relationships it could be argued that PD is likely to present difficulties in the caring relationship.

Further compounding difficulties experienced by partner caregivers, PD negatively impacts upon the dynamics of a couple where one member of the dyad has the disease. These couples report higher levels of relationship strain. This strain is present in the early stages of the disease and increases during its progression (Hemmesch et al., 2009). The cause for the negative impact on spouses has been attributed to a number of factors. The above factors regarding caregiver burden (Ozdilek & Gunal, 2012) and social difficulties (Anderson et al., 2013) may contribute to marital strain. Further explanation may come from PD disrupting mechanisms which are important in the maintenance of a relationship, such as communication, for example Hodgson, Garcia and Tyndall (2004) have demonstrated that couples in which one member has PD experience a great deal of verbal and nonverbal communication difficulties, which contribute to relationship strain.

Dementia, another degenerative chronic health condition in later life, has also been shown to have negative impacts on the couple relationship. The presence of dementia in a spousal relationship has been shown to cause depressive symptoms in the well spouse (Adams, 2008) and reduced couple activities (Baikie, 2002). Several systematic literature reviews have also focused upon the impact of dementia on spousal couples. These reviews have highlighted that the presence of dementia in a partner causes a number of negative experiences in the well spouse. Specific negative impacts include a sense of relationship loss (Evans & Lee, 2013) increased levels of mental health difficulties in the well spouse (Brodaty & Donkin, 2009), particularly depression (Cuijpers, 2005) and fear of social isolation (Stoltz, Uden & Willman, 2004). The results of these reviews have highlighted areas for further research in the hope of improving clinical outcomes.

Systematic literature reviews into other chronic degenerative health conditions, such as dementia, have aided in the development of clinical interventions to improve quality of life of couples affected by those conditions. The degenerative and chronic nature of PD together with the characteristics of the illness would suggest that similar issues that affect relationships in other conditions may also arise in PD. The experiences of partners in particular are important as they are likely to be providing care. At the time of writing there exists no literature review regarding the impact of PD on relationships.

The aim of the current review was therefore to examine the impact of PD on partners and the couple relationships in order to provide a greater understanding of this area that could be used to inform and develop interventions in the future.

Method

Search Strategy

The search terms (Parkinson*) AND (Spous* OR Couple* OR Partner* OR Husband* OR Wife* OR Wive* OR Marital* OR Marriag* Or Relationship*) were entered into the PsycINFO, Scopus and PUBMED databases. The terms were entered into the “All Fields” search field on the respective databases. These terms were selected to ensure that the search terms used were wide enough to identify studies detecting a wide range of effects of PD on partners and the couple relationship. Search limiters were applied to the literature search. These limiters were that the article had to be written in English and be from peer reviewed sources. No “from” date limiters were used during the literature review the search was conducted on 13/12/13 providing an “until” date.

This search yielded 419 papers from the PsycINFO database, 9586 papers from the SCOPUS database and 2805 papers from the PUBMED database. The abstracts of these papers were reviewed as an initial assessment of suitability to ensure they were applicable to the present literature review and in accordance with the inclusion and exclusion criteria below. This resulted in 17 papers from the PsycINFO database 27 from the SCOPUS database and 33 from the PUBMED database being included in this review. After the removal of duplicate papers 38 papers remained. Papers were then read in their entirety and following application of the inclusion and exclusion criteria 11 papers were removed leaving 27 papers that were included in the review. The article selection process is outlined in Figure 1.

Inclusion criteria

Peer reviewed sources.

Published in English.

Quantitative and qualitative methodologies. Both methodologies were included in order to obtain the fullest picture of the effect on partners.

One partner diagnosed with PD, here defined as a neurodegenerative condition due to dopamine depletion.

Exclusion criteria

Studies investigating other causes of Parkinsonism, such as brain injury as these cases follow a different neurodegenerative course.

Studies were excluded if their results were not attributed specifically to partners. This was done to ensure that it was the specific experiences of partners that were the focus of this review as, given previous research, the experiences of partners are likely to be unique.

Studies were also excluded if they investigated the impact of a number of neurological diseases on partners but the results did not specifically attribute findings to the impact of PD. This was done to ensure that the specific impacts of PD, as opposed to other neurological conditions with overlapping symptoms, such as dementia, were the focus of this review as this was an identified gap in the literature and is likely to be a unique experience.

Methodological quality assessment

After the initial assessment of suitability, retrieved papers were sorted into qualitative and quantitative categories based upon their methodology. Papers were then quality assessed.

Qualitative methodology papers were assessed using the Methodology Checklist: Qualitative studies (NICE, 2006) (Appendix 1.1). Quantitative methodology papers were quality assessed using the Methodology Checklist: Quantitative studies (NICE, 2006) (Appendix 1.3). These two quality measures assess a variety of different methodological domains, such as data collection and internal validity, and were used as they have similar construct validity for both qualitative and quantitative studies. However the item “Is the setting applicable to the UK” was not used as this would have resulted in multiple studies being negatively rated. The Methodology Checklist: Qualitative studies (NICE, 2006) uses descriptive data which is either positive e.g. “reliable” or negative e.g. “inappropriate” across a number of categories such as Participants and Data Collection. The Methodology Checklist: Quantitative studies (NICE, 2006) uses similar ratings, however rather than using descriptive words, categories are rated using ++, + or -. Quality assessment scores for qualitative papers can be found in Appendix 1.2. Quality scores for quantitative studies are contained in Appendix 1.4. No studies were excluded on the grounds of quality.

An independent rater was also used during the quality assessment stage. This independent rater was familiar with psychological research methodologies. The independent rater assessed all included papers using the above mentioned quality checklists. The percentage of inter-rater agreement was calculated. Inter rater reliability was 80.41% for quantitative papers and 89.29% for qualitative papers. The independent rater’s quality scores can be found in Appendix 1.3 and 1.6.

Where differences occurred between raters these were discussed with the independent rater. Many differences were around the magnitude of a rating i.e between ratings of ++ and+ . During discussion the context of the field of research was discussed to reach consensus between raters. Appendix 1.7 contains a table displaying the areas of disagreement between raters. As can be seen from the table common areas of disagreement between raters were in areas of data collection, particularly the controlling of any confound variables and methods of statistical reporting particularly around levels of precision. The paper with the highest variability between raters was Schrag et al. (2006). Items producing the highest levels of inter rater disagreement for qualitative papers were the context of the researcher. These disagreements may have arisen due to differing perspectives of research between the two raters. A table of agreed ratings can be found in Appendix 1.8.

Data analysis

Narrative Synthesis was used in the analysis of data. This approach was used for two reasons. Firstly due to the variety of methodologies used by papers in this review a quantitative analysis was not appropriate. Secondly Narrative Synthesis allows common elements and differences between retrieved papers to be reported.

Figure 1. Overview of selection of article process

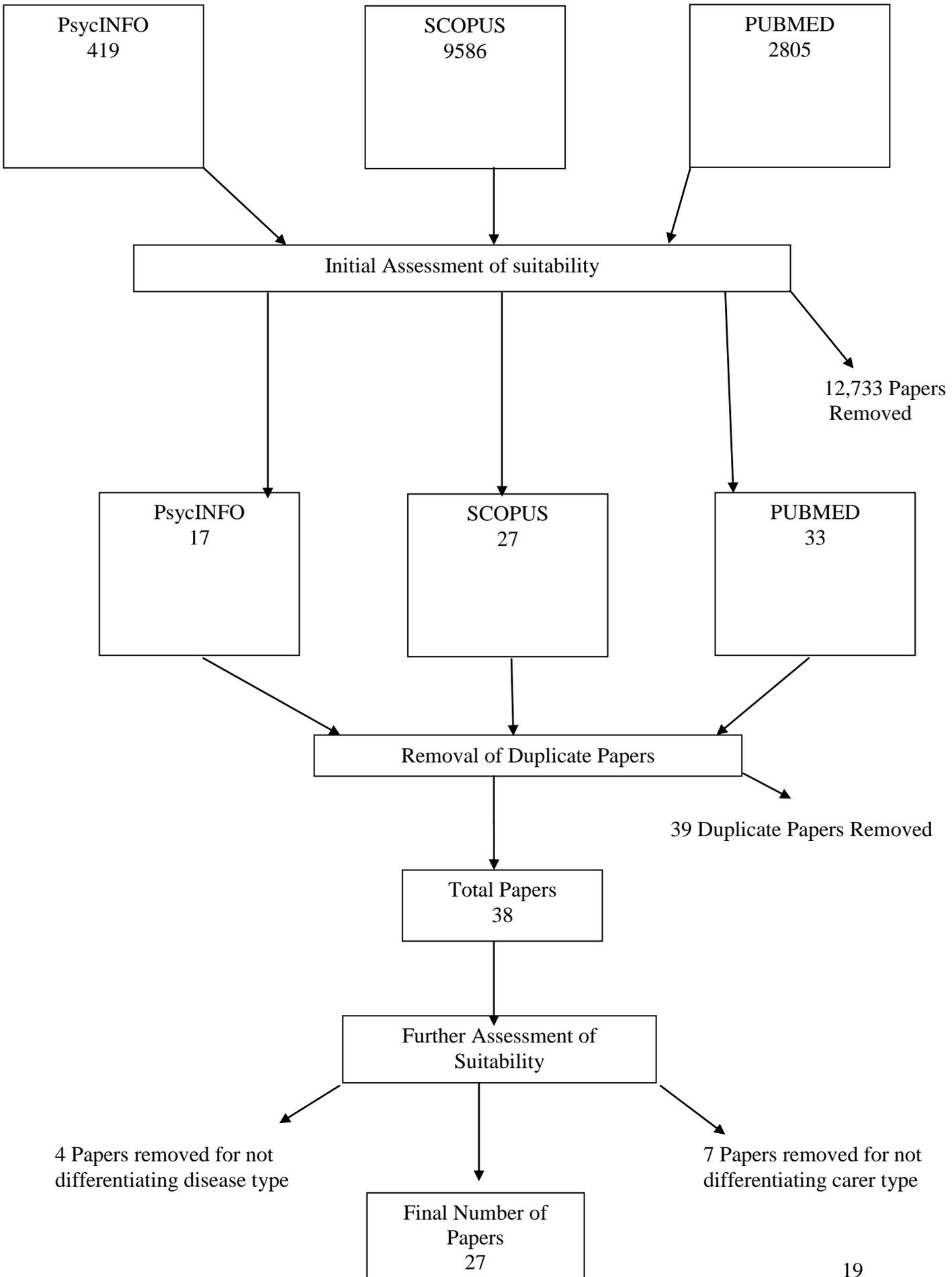


Table 1: Main characteristics of quantitative studies included in the review.

Author	Participants	Measures	Results
Miller, Berrios and Politynska (1996)	54 married couples, one spouse with PD.* 36 married control subjects (No PD).	General Health Questionnaire. Care Giver Inventory Geriatric Depression Scale. Beck Depression Inventory. Machin Strain Scale. Hamilton Depression Scale. Hamilton Anxiety Scale. Webster Scale. The North Western Scale. The Hoehn and Yahr Scale. The Karnofsky Performance Status Scale. The WHO Scale. Self developed measure of social contact in the last 2 weeks.	Significant differences between control group and PD group on all listed measures. Carer strain significantly correlated with levels of physical impairment within the sufferer. Sufferer's Geriatric depression scale score most key predictor of carer's level of anxiety, depression and general health. Number of individuals in social support network not a significant predictor of carer distress.

		<p>Schonell Graded Word Reading Test.</p> <p>Benton Line Orientation Test.</p>	
O'Connor, McCabe and Firth (2008)	<p>143 Couples, one with PD.*</p> <p>112 Couples, one with Multiple Sclerosis.</p> <p>120 Couples, one with Motor Neurone Disease.</p> <p>48 Couples one with Huntington's Disease.</p>	<p>Relationship Assessment Scale.</p> <p>World Health Organisation Quality of Life Questionnaire (sex questions).</p> <p>Social Supports Questionnaire.</p> <p>Self Designed Measure Assessing Illness Severity.</p> <p>Single Qualitative Question.</p>	<p>PD patients rated social support as significantly higher than PD carers.</p> <p>Sex life satisfaction and social support satisfaction significant contributors to marital relationship satisfaction.</p> <p>Physical changes the most difficult aspect for a spouse to adjust to.</p>
Schrag, Hovris, Morley, Quinn and Jahanshahi (2006)	116 Spouses of individuals with PD.	<p>Scale of Quality of Life of Care-Givers (SQLC).</p> <p>Caregiver-burden Inventory (CBI).</p> <p>Beck Depression Inventory (BDI).</p> <p>Marital Satisfaction Scale.</p>	<p>Poorer caregiver burden score significantly associated with disease duration, severity and disability.</p> <p>Patient falls, hallucinations, confusion and depression significantly correlated with low carer QoL scores.</p> <p>Patient falls, hallucinations and confusion significantly correlated with high care giver burden scores.</p> <p>Patient depression significantly correlated with carer depression.</p> <p>Carer depression significantly negatively correlated with marital and sexual satisfaction scores.</p>

		<p>The Short Social Support Questionnaire.</p> <p>Hoehn and Yahr scale.</p> <p>Schwab and England scale.</p> <p>Parkinson's disease-specific PDQ-39.</p>	<p>Measures of sexual relationship satisfaction scores significantly positively correlated with carer QoL and negatively correlated with carer burden scores.</p>
<p>Carter and Carter (1994)</p>	<p>20 Spousal pairs, One with PD the other with a chronic health condition.*</p> <p>26 Spousal pairs, One with PD the other well.</p>	<p>Dyadic Adjustment Scale (DAS).</p> <p>Projective Sentence Completion (PSC).</p> <p>Self completed Likert scale rating level of disability.</p>	<p>No significant difference between groups on the DAS.</p> <p>Both groups scored significantly above the norm on measures of Cohesion.</p> <p>Both groups scored significantly below the norm on measures of Consensus.</p> <p>Ill spouses feel more supported by spouse with PD and more positive relationship with physicians than ill spouses.</p> <p>More well spouses viewed PD as having a negative effect on marriage than ill spouses.</p>
<p>Hand, Grey, Chandler and Walker(2010).</p>	<p>88 Participants with PD.</p>	<p>Unified Parkinson's Disease Rating Scale (UPDRS).</p> <p>Hospital Anxiety Depression Scale.</p> <p>Mini Mental State Examination.</p> <p>The Parkinson's Disease</p>	<p>Younger males most likely to report sexual dysfunction.</p> <p>Gender and UPDRS scores significant predictors of relationship strain.</p>

		<p>Questionnaire (PDQ) 39.</p> <p>The Szasz sexual functioning scale.</p> <p>Golombok Rust Inventory of Marital State.</p>	
Carter et al.(1998)	306 Spousal carers of patients with PD	<p>Family Caregiver Inventory.</p> <p>Howen and Yahr Scale.</p>	<p>All scales on the FCI increased significantly over the course of PD including worry, economic burden and tension.</p> <p>Number of direct care activities increased significantly over the course of PD.</p> <p>Negative life style changes increased significantly over the course of PD.</p> <p>Cares received significantly more support over the course of PD.</p> <p>Caregiver depression did not increase over the course of PD.</p> <p>Caregiver health did not decrease over the course of PD.</p>
D'Amelio et al. (2009)	40 PD patients and their spousal care givers* 11 M with PD 29 F with PD	<p>Unified Parkinson's Disease rating scale</p> <p>Howen and Yarh scale</p> <p>Mini Mental State Examination</p> <p>Neuropsychiatric Inventory</p> <p>Geriatric Depression Scale</p>	Caregiver distress significantly associated with PD severity and mental symptoms.

		Caregiver Burden Inventory	
Tanji et al.(2008)	96 Spousal Pairs*	Mutuality Scale Care Giver Strain Index Breif Symptom Inventory-18 Cumulative illness Rating Scale SF-12v2 Unified Parkinson's Disease Rating Scale	Increased Mutuality associated with lower caregiver burden, depression of both spouse and patient and less PD severity. Mutuality inversely correlated with severity of motor symptom and disability. Greater Mutuality associated with higher spousal quality of life. Motor symptoms are particular marital stressors.
Carter, Lyons, Stewart, Archbold and Scobee, 2010	65 spousal PD caregivers 37 "Young" 28 "Old"(over 70 YO)	Author developed measure of caregiver strain	Younger spouses report significantly higher strain from lack of personal resources than older spouses. Younger spouses found caring significantly less rewarding than older spouses. Younger spouses reported significantly lower levels of relationship mutuality than older spouses.
Fernandez, Tabano, David and Friedman (2001)	45 PD patients and their spouses* 30 M with PD 15 F with PD	Unified Parkinson's Disease Rating Scale Howen and Yarh Mini Mental State Examination Beck Depression Inventory	Duration of PD strongest predictor of spouse depression.

		Hamilton Depression Scale	
Happe and Berger(2002)	106 spousal dyads one with PD*	Centre for Epidemiologic Studies Depression Scale Giessener Beschwerdebogen of psychometric complaints Caregiver burden inventory Unified Parkinson's disease rating scale Hoehn and Yahr scale	Depression scores of ill and well spouse strongly correlated. Bad night sleep of well spouse associated with ill spouse symptom severity, frequency of caregiving events and sleep in ill spouse. Frequency of caregiving was found to be mediated by caregiver burden. Motor symptom severity associated with bad sleep in well spouses.
Thommessen et al.(2002)	92 spousal carers of Alzheimer's disease. 58 spousal carers of PD 36 spousal cares of stroke	Relative's Stress Scale Mini mental State Examination Activities of Daily Living index Unified Parkinson's Disease Rating Scale Montgomery-Aasberg Depression Rating Scale	Similar levels of caregiver burden present in well spouse regardless of type of disease. Spouses reported constraints on social life and sleep distance regardless of disease type. Lower cognitive function associated with higher psychological burden of well spouse in PD and stroke. Caregiver burden associated with depression of ill spouse in PD.

<p>Brown, Jahanshahi, Quinn and Marsdan (1993)</p>	<p>33 couple dyads, one spouse wPD* 23 M, 10 F</p>	<p>Activities of Daily Living Scale Gollombock Rust Inventory of Sexual Satisfaction Gollombock Rust Inventory of Marital Satisfaction Beck Depression Inventory Spielberger Stait-Trait Anxiety Inventory (STAI). Care Giver Strain Index Acceptance of Illness Scale Assessment of autonomic responses</p>	<p>Lack of sexual satisfaction found to occur more in female well spouses. Sexual dysfunction reported more in ill male, well female dyads. Greater levels of marital satisfaction found in ill male, well female dyads. Marital satisfaction and sexual satisfaction strongly correlated.</p>
<p>Smith, Ellgring and Oertel (1997)</p>	<p>153 spousal dyads, one with PD* 103 control spousal dyads, no neurological conditions.</p>	<p>Zung Self Rating Depression Scale Author developed measures of sleep quality</p>	<p>PD spouse group reported significantly higher sleep disturbance than controls. Female ill and well spouses reported more sleep disturbance than male ill and well spouses. Disease severity strongest predictor of sleep disturbance in well spouse.</p>

<p>Petrican, Burris, Bielak, Schimmack, and Moscovitch (2011)</p>	<p>18 spousal dyads one spouse with PD*</p>	<p>Theory of Mind Test Working Memory Task False belief stories Gaze control measure Autobiographical memory measure Measure of relationship dynamics, intimacy and relationship satisfaction</p>	<p>Spouses reported higher levels of enmeshment if ill spouse PD prevented gaze control. This is related to gaze control being a predictor with the ability to differentiate “Self from Other”.</p> <p>Impairment in “Self Other” differentiation is a predictor of perceived lackof autonomy of ill spouse in late stage PD but not in early stage PD.</p> <p>Reduced relationship satisfaction associated with impairment in “Self Other” differentiation.</p> <p>Enmeshment related to poorer relationship satisfaction.</p>
<p>Shin, Lee, Youn, Kim and Cho (2012)</p>	<p>91 main caregivers of people with PD 50 Spouse 41 Adult child</p>	<p>Unified Parkinson’s Disease Rating Scale Beck Depression Inventory Mini Mental State Examination Hoehn and Yahr Scale Barthel Index of ADL Zarit Burden Inventory</p>	<p>No significant difference in burden between spouses and children.</p> <p>Burden in spouses and children associated with cognitive function and disease severity.</p> <p>Patient depression associated with burden in spouses but not children.</p>

<p>Aarsland, Larsen, Karlsen, Lim and Tandberd (1999)</p>	<p>94 carers of patients with PD (58 spouses) 100 patients with diabetes 98 healthy participants</p>	<p>Relative Stress Scale The General Health Questionnaire Beck Depression Inventory Activities of Daily Living Unified Parkinson Disease Rating Scale Hoehn and Yahr Scale Schwab and England ADL Scale Mini Mental State Examination Dementia Rating Scale Neuropsychiatric Inventory Montgomery-Asberg Depression Rating Scale</p>	<p>Spouses reported higher levels of caregiver stress and emotional distress than other caregivers. Patient duration of education inversely correlated with well spouse depression. Severity of patient motor and mental disturbances significantly correlated to all measures of carer distress. Mental disturbance of patient associated with well spouse emotional distress and caregiver stress. Ill spouse impairment of function associated with caregiver stress. Delusions, agitation and motor disturbance of ill spouse contributed to emotional distress in care giver. Ill spouse depression and cognitive impairment contributed to well spouse emotional distress.</p>
<p>Lyons, Stewart, Archbold and Carter (2009)</p>	<p>225 spouses of patients with PD</p>	<p>Hoehn and Yahr Scale Author developed measures of strain from worry, tension feeling manipulated and other global factors. Life Orientation Test Mutuality Scale</p>	<p>Well spouse strain on all measures increases over duration of PD. Increased marital strain over duration of PD. Husbands have significantly lower levels of strain over the course of PD than wives. Higher levels of mutuality associated with lower levels of well spouse tension strain over the course of PD. Spouses with higher levels of optimism reported lower levels of stain from tension and worry over the course of PD.</p>

			Spouses with higher levels of pessimism reported increased strain from worry over the course of PD
Soulas, Sultan, Gurruchaga, Palfi and Fenelon (2012)	26 Spouses of PD patients 7M, 19F	SF-36 Questionnaire for Quality of Life The Zarit Burden Inventory Beck Depression Scale Unified Parkinson's Disease Rating Scale Parkinson's Disease Questionnaire	Overall surgically induced reductions in PD severity were not associated with changes of well spouse depression, quality of life and care burden. Improvements in ill spouse quality of life not associated with improvements in well spouse quality of life, depression or burden. At the individual level well spouse responses to neurological interventions were more frequently negative. Younger spouses <63 YO had significant improvements in caregiver burden post surgery. Older spouses did not.

*Indicates ill and well spouses were interviewed together

Table 2: Main characteristics of qualitative studies included in the review

Authors	Method	Measures	Participants	Findings
Davey, Wiles, Ashburn and Murphy (2004)	Interpretative Phenomenological Analysis	Semi-Structured interview	14 spousal caregivers (11 F, 3 M)	<p>Falls occur often with people with PD.</p> <p>Falls due to PD symptoms but also occur when in medicated “on” phase.</p> <p>Caregivers did not receive much information or support regarding falls.</p> <p>Caregivers described the physical (injury when helping spouse up from fall), emotional (anxiety about spouse falling) and social (withdrawal from going out to avoid falls) impact of falling in PD.</p>
Birgersson and Edberg (2004)	Interpretative Phenomenological Analysis	Open Ended Interview	6 Spousal couples one spouse with PD (4 F, 2 M)	<p>Support mainly directed at the ill spouse.</p> <p>Supported ill spouse experienced solidarity community, satisfaction and confidence.</p> <p>Unsupported ill spouses experienced being humiliated, not receiving enough information and being misunderstood.</p> <p>Supported well spouse experienced freedom and being the focus of others’ concern and attention.</p> <p>Unsupported well spouse experienced feeling neglected, uncertain and isolated.</p> <p>Maintenance of closeness in the relationship due to equal support of ill and well spouse.</p> <p>Distancing in the relationship due to disparities in amount of support the ill and well spouse receive.</p>

Hodgson, Garcia and Tyndall (2004)	Phenomenological qualitative research	Interview based on the question “What impact has PD had on your couple relationship?”	10 Spousal couples one spouse with PD (6 M, 4F)*	<p>Transition from “well spouse” to “ill spouse” a period of heightened relationship strain.</p> <p>Anxiety when leaving ill spouse. Which causes tension as ill spouse feels infantilised.</p> <p>Difficulty maintaining employment for both ill and well spouse.</p> <p>Focus on the need for clear communication from health care professionals.</p> <p>Strategies deemed important for maintaining a marital relationship in the context of PD include, seeking outside support, neutralizing hostility before it escalates and maintaining a sense of humour.</p>
Williamson, Simpson and Murray (2008)	Interpretative Phenomenological Analysis	Semi-Structured Interview	10 wives of people with PD who had experienced psychotic symptoms	<p>Sense of confusion when spouse experienced psychotic symptoms due to lack of information.</p> <p>Well spouses adapted a management strategy of reducing agitation or distress.</p> <p>Psychosis perceived as “another thing” taking over the ill spouse and contributing to a further loss.</p> <p>Comparisons to more severe PD sufferers made by spouses. This helped bolster self esteem but also lead to some spouses catastrophizing and expecting the worse.</p>
Beaudet and Ducharme (2013)	Interpretative Phenomenological Analysis	Semi Structured Interview	10 couple dyads, one partner with PD*	<p>Six areas for intervention identified:</p> <ul style="list-style-type: none"> • Meeting future challenges • Develop strategies to stay healthy • Solving problems together • Access resources and plan for the future • Communicate better • Fine tune roles

Roland, Jenkins and Johnson (2010)	Interpretive Phenomenological Analysis	Semi Structured Interview	5 spousal caregivers to PD patients	<p>Well spouses reported high amounts of social isolation.</p> <p>Spouses reported hyper vigilance for the safety of ill spouse.</p> <p>Well spouses reported the importance of social support and education around PD in mediating factors of caregiver burden.</p>
Habermann (2000)	Interpretive Phenomenological Analysis	Semi Structured Interview	8 spouses with spouses with PD 5 F, 3M	<p>Spouses identified watching ill spouse struggle was the most challenging aspect of life.</p> <p>Spouses identified reduced shared activities with ill spouse.</p> <p>Spouses identified 3 main coping strategies; maintaining their own life, seeing challenges as secondary to those of their partner and encouraging ill partner to stay active.</p>
McLaughlin et al. (2011)	Interpretive Phenomenological Analysis	Semi Structured Interview	26 informal family caregivers 9M, 17F	<p>Spouses identified stress during diagnosis period as a time of stress.</p> <p>Lack of Co-ordinated health care.</p> <p>Struggle to initiate conversations regarding palliative care.</p> <p>Well spouse provide more physical emotional and social support over course of disease.</p> <p>Well spouses reported high levels of burden related to care.</p> <p>Well spouses did not feel that they could leave the ill spouse due to being depended on.</p> <p>All spouses reported lack of information during diagnostic period.</p> <p>Lack of information regarding progression of PD, medications treatment options and side effects identified by spouses.</p> <p>Spouses reported economic burden such as leaving work due to care and being unaware of benefits they could claim.</p>

Haahr, Kirkevold, Hall and Ostergaard (2013)	Hermeneutic phenomenological analysis	Longitudinal qualitative interview	10 spouses of individuals with PD	<p>Spouses identified solidarity, respect and responsibility as important values in their relationship.</p> <p>Spouses reported senses of loss of intimacy, social life and companionship.</p> <p>Spouses adapted by being more available to ill spouse.</p> <p>Spouses developed an increased awareness of ill spouses' body.</p> <p>Spouses reported maintaining an active life with ill spouse as being important.</p> <p>Following surgical improvements in ill spouse, well spouses reported an increased sense of freedom.</p> <p>Well spouses reported less worry following by surgical improvements.</p> <p>Growing partnership following surgical improvements.</p> <p>Difficult period of adjustment following surgical improvements due to side effects.</p>
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*Indicates ill and well spouses were interviewed together

Results

27 studies fulfilled the inclusion criteria. The main study characteristics are outlined in Tables 1 and 2.

Overview of papers

Of the 27 papers included in this review, 12 papers focussed on the negative impact PD had on the well spouse including reports of well spouse depression, general health, quality of life and caregiver burden. Nine papers focussed on the negative impact PD had upon the couple relationship. The impact of particular symptoms of PD on well spouses was a topic of eight papers. Well spouses' methods of coping were reported in four papers. External mediators were discussed in ten papers. Finally, well spouses experiences of PD over the course of the illness were a topic of four papers.

Papers were from a variety of countries however all but one paper were from the northern hemisphere with western populations. The majority of papers, 10, were from the USA. 7 papers were from the UK, 3 from Canada. All other papers but one were from western Europe, Germany, Sweden, Denmark, Italy Norway and France. Only one paper included an eastern, South Korean, population. The range of participant numbers across papers was 18-306. 13 papers interviewed well spouses alone, 13 interviewed well and ill spouses and 1 paper interviewed ill spouses alone

Methodological quality

The majority of papers included in this review were of a quantitative methodology (N=19). Most quantitative papers were cross sectional in design however

4 used a longitudinal design. All articles were exploratory in nature. Papers using quantitative methods presented with a number of limitations such as an increased likelihood of demand characteristics and a lack of depth in information which may be gained from qualitative methodologies. A common finding across the majority of quality reviews of papers was that the well spouses were not very well described. The length of marriage, frequency of care giving and type of care giving provided was rarely reported in depth in included papers. A variety of measures were used across papers however some of these were of varying quality. Some studies included author developed measures (Miller, Berrios & Politynska, 1996; Smith, Ellgring & Oertel, 1997). However the validation of these measures was not reported in the above studies. Finally all well partners and partner dyads were selected from a population who were interested in taking part in the study and therefore all included papers are subject to sample bias. Compared to quantitative papers, qualitative papers were rated by both raters as being generally higher in overall quality. However one area in which a number of qualitative papers were consistently rated negatively on was their methods of data analysis. Particularly due to their low number of researchers used in the analysis stage.

Effect of Parkinson's disease on the well spouse

PD was shown to have a number of negative effects on well spouses' physical health, mental health, quality of life and social functioning across a variety of different measures. Spouses living with partners with PD were shown to have significantly higher levels of depression, strain and lower levels of quality of life than a healthy control group of spousal dyads with no presence of PD.

Spouses living with a partner with PD were shown to have high levels of depression (Miller et al., 1996; Schrag, Hovris, Morley, Quinn & Jahanshahi,

2006;Happe & Berger, 2002;Aarsland et al., 1999;Fernandez, Tabano, David & Friedman, 2001). In Miller et al. (1996) these heightened depression levels were found to be significantly higher than a healthy control group

Levels of depression in the well spouse were found to be associated with a number of factors in the ill spouse. A constant finding across many papers was that the presence of depression in the ill spouse was found to predict the presence of depression in the well spouse (Aarsland et al., 1999;Miller et al., 1996). Indeed, ill spouse depression was shown to correlate positively with well spouse depression across numerous studies (Happe & Berger, 2002;Shrag et al., 2006). Other predictors of depression in the well spouse were specific to PD such as disease severity (D'Amelio et al., 2009), specific motor disturbances (Aarsland et al., 1999) and duration of PD (Fernandez et al.,2001). PD also caused anxiety in the well spouse, however this was reported in fewer studies. Anxiety in the well spouse was found to be predicted by ill spouse depression levels (Miller et al, 1996).

The presence of PD was also shown to affect the physical health, overall quality of life (QoL) and social aspects of the well spouse. Well spouses experienced lower levels of general health than a control group of well spousal couples (Miller et al., 1996). Well spouse general health was also negatively correlated with ill spouse depression levels (Miller et al, 1996). The well spouse's quality of life was also found to be negatively affected by the presence of PD (Schrag et al., 2006). Well spouse quality of life levels were negatively correlated with ill spouse depression levels (Schrag et al., 2006). Well spouses also reported high levels of social isolation (Roland, Jenkins & Johnson, 2010) and losses of social networks (Haahr, Kirkevold, Hall & Ostergaard, 2013; Thommessen et al., 2002).

Well spouses also exhibited high amounts of caregiver burden across a number of papers (Miller et al., 1996; Shrag et al., 2006;Tanji et al., 2008;Happe & Berger,

2002;Thommenson et al., 2002;Shin et al., 2002;Roland et al., 2010). As with other negative impacts on well spouses, caregiver burden was also predicted and associated with a number of factors in the ill spouse. The level of physical disability in the ill spouse (Miller et al., 1996;Shrag et al.,2006), level of depression (Thommenssen et al., 2002) cognitive impairment (D'Ameli et al., 2009) and frequency of care giving (Happe & Burger, 2002) were all positively correlated with well spouse caregiver burden. Caregiver burden appeared to be more pronounced in spousal caregivers with the study by Aarsland et al. (1999) demonstrating that spousal caregivers experienced higher levels of caregiver stress than other caregivers. Contradicting the Aarsland et al. (1999) study Shin et al. (2002) found no significant differences between spousal and adult child caregiver distress. However levels of caregiver distress had different correlates in spouses, with depression being a key predictor of caregiver stress in spousal caregivers but not adult children caregivers.

Well spouses were also found to have unique factors which influenced their levels of caregiver burden and strain. Spouses with high levels of optimism reported lower levels of strain than spouses with high levels of pessimism (Lyons et al., 2009). Well spouse age was also associated with levels of caregiver strain and worry with younger spouses (<70 YO) reporting higher levels of caregiver burden and lower levels of satisfaction when caring, than older spouses (Carter, Lyons, Stewart, Archbold & Scobee, 2010).

There were also certain periods and factors of PD that spouses identified as being particularly difficult. Spouses reported the period of initial diagnosis (McLaughlin et al. (2011) watching the ill spouse struggle (Habermann (2000) and adjusting to physical symptoms (O'Connor et al., 2008) as all being particularly difficult experiences.

The findings of Miller et al. (1996) are particularly noteworthy as they are derived from a study which used a control group of spousal couples where neither spouse had PD. Similarly the findings of O'Conner et al. (2008) were from a study with groups of spouses where one spouse had other chronic health conditions

Effect of PD on the spousal relationship

In a number of papers PD was shown to negatively affect the spousal relationship. Couple dyads with one partner with PD reported less shared activities (Habbermnan, 2000) less marital satisfaction (Schrag et al., 2006) greater levels of marital strain (Hodgson, Garcia & Tyndall, 2004;Lyons et al., 2009) and high levels of enmeshment (Petrican, Burris, Bielak, Schimmack & Moscovitch, 2011), However the Petrican et al. (2011) study used a relatively low number of participants, 18, which is the lowest number of participants used in any other study in this review. Specifically well spouses reported PD as having caused reductions in marital mutuality (Tanji et al., 2008) and difficulties reaching consensus in the marital relationship (Carter & Carter, 1996). Spouses also reported loss in intimacy and companionship (Haahr et al., 2013). Though none of these studies utilised control groups or comparison groups.

The negative impact of PD on spousal relationships was also found to cause secondary negative effects. Reductions in marital mutuality were shown to reduce well spouse quality of life (Tanji et al., 2008). Additionally marital satisfaction was shown to be negatively correlated with well spouse depression (Schrag et al., 2006).

Similar to the negative impact on spouses, the negative impact of PD on the spousal relationship was found to have a number of predictors across a number of papers. Level of social support was shown to be associated with marital satisfaction (O'Connor et al., 2008). Increases in marital strain were associated with PD severity

(Hand et al., 2010). In the Tanji et al. (2008) study, motor symptoms in particular were found to contribute to reductions in marital mutuality.

Transitions also caused relationship strain. The highest levels of relationship strain were found to be during the transition of one spouse from “well spouse” to “ill spouse” (Hodgson et al., 2004). This study also highlighted particular interactions between couples which specifically caused strain. For example the well spouse underestimating the abilities of the ill spouse thus “infantilising” them.

The impact of particular symptoms of PD

The impact of particular deficits caused by PD was a key focus of many included papers.

Williamson, Simpson and Murray (2008) highlighted the presence of psychotic symptoms as being a specific area of difficulty for well spouses. Due to the nature of medication psychotic symptoms are a common, if not fully expected, side effect of these medications. The presence of these symptoms caused negative effects in the well spouse and prompted adaptations being made in spousal interactions. Firstly, well spouses experienced high levels of confusion during the onset of psychotic symptoms due to a lack of information and preparation for these symptoms. Similar to other studies discussed here, lack of information is a detrimental factor when coping with PD. Another negative impact associated with the presence of psychotic symptoms is that it prompts a further sense of loss with one spouse reporting “it’s another thing” taking over the partner or reporting “sometimes it’s like living with a different person”.

Davey, Wiles, Ashburn and Murphy (2004) demonstrated that falls in particular reduce well spouse’s mental health, physical health and social functioning. Well spouses reported high levels of anxiety and vigilance around the possibilities of their

spouse falling; “While I was seeing to him I was alright but once I got back into bed I was shaking”. They also experienced physical injury whilst helping the ill spouse when falling; “I’ve found that catching him puts a strain on my arms and shoulders”. Finally due to the two factors above well spouses reported increased levels of social withdrawal; “I never like it. I never like to leave him on his own because if he falls no one’s here to help him”.

Impairment of sexual functioning caused by the motor deficits present in PD was also found to negatively impact spousal relationships (Hand et al., 2010), reduce the well spouses’ quality of life (Schrag et al., 2006) contribute to marital strain (O’Connor et al., 2008) and reduce marital satisfaction (Brown, Jahanshahi, Quinn & Marsdan, 1993). The study by Brown et al. (1993) also demonstrated the influence of gender on the impact of sexual impairment in PD. Female well spouses were more likely to report sexual dissatisfaction. However higher levels of marital satisfaction were found in ill male/well female spousal dyads.

Three papers also investigated the impact of sleep disturbance, a common symptom of PD, on the well spouse (Happe & Berger, 2002;Thommessen et al., 2002;Smith et al., 1997). Across all three papers ill spouse and well spouse sleep disturbance were highly correlated. Causes of sleep disturbance in the well spouse were found to be due to disease severity particularly in motor symptoms (Happe & Berger, 2002;Smith et al., 1997) and frequency of well spouse care giving (Happe & Berger, 2002). Female well spouses were also more likely to report sleep disturbances than male well spouses (Smith et al., 1997). However the Smith et al. (1997) study used an author developed measure to measure sleep disturbance whilst the Happe & Berger (2002) and Thommessen et al. (2002) studies used more established measures.

Spousal coping

Spousal methods of coping were a main feature of four papers. Many of these methods of coping were adaptations that the well spouse undertook (Hodgson et al., 2004; Habberman, 2000). In the study by Habberman (2000) spouses reported maintaining their own life, seeing challenges as secondary to those of their partner and encouraging the ill partner to stay active as being important coping strategies. Spouses in Haahr et al. (2013) reported that important coping strategies for them were being available to the ill spouse and being aware of the ill spouses' body and symptoms. Both ill and well spouses in this study also stated that solidarity, respect and responsibility were important factors in coping with, and maintaining a healthy relationship with PD in the spousal dyad. Hodgson et al. (2004) found that couples said that "knowing when to seek support", "maintaining a sense of humour", "clear communication" and "neutralising difficulties before they escalated" were helpful adaptations that a spousal couple could make. One paper also focused on spousal adaptations to particular PD symptoms. With regard to psychotic symptoms, well spouses were found to alter interactions with spouses to reduce irritation and anxiety with one spouse stating "you learn to take the fear away from them". Spouses also described comparing themselves to other couples experiencing PD as a way of coping. It was found that comparisons made to couples in a worse position were helpful for some couples though certain spouses discovered that this caused them to "fear for the worst" (Williamson et al., 2008). One paper involved partners identifying areas for intervention that would help with coping when living with PD (Beudet & Ducharme, 2013). These areas were "meeting future challenges, problem solving, strategies to maintain health, accessing resources, communication and redefining roles". Spouses also identified areas which felt they would further benefit from. In McLaughlin et al. (2011) spouses reported that there was

a lack of co-ordinated health care and difficulties in initiating discussions around palliative care with professionals. Whilst all these studies utilised a qualitative methodology, thus ensuring detailed results, all used a small number of researchers in the analysis stage of the study.

External mediators

Nine papers covered factors external to the spousal relationship which could reduce or increase the negative impacts of PD on the well spouse or spousal relationship.

Support was a factor many spouses felt was important when coping with PD. Spouses in papers by (Birgersson & Edberg, 2004; Davey et al., 2004; O'Connor et al., 2008; Hodgson et al., 2004; Roland et al., 2010) all highlighted the importance of support. In particular spouses reported that support was important for reducing their anxiety (Davey et al., 2004) and maintaining closeness in the spousal dyad (Hodgson et al., 2004). In two papers well spouses reported a lack of support (Birgersson & Edberg, 2004; O'Connor et al., 2008). Well spouses reported that lack of support led them to experience feelings of neglect and isolation (Birgersson & Edberg, 2004). A common theme of these papers was the well spouses reporting that their support needs were often overlooked due to the needs of the ill spouse (Birgersson & Edberg, 2004). Additionally, the study by Birgersson & Edberg (2004) demonstrated that differences in levels of support between well spouses and ill spouses lead to well spouses feeling neglected and alienated and this contributed to distancing in the spousal relationship.

Similarly information was identified by spouses as being important in coping with PD (Williamson et al., 2008; McLaughlin et al., 2010; Davey et al., 2004). Particular areas identified by spouses as needing more information were specific

symptoms of PD such as falls (Davey et al., 2004) or psychotic symptoms (Williamson et al., 2008) the progression of PD, medication side effects, diagnostic process and what economic support the couple could access (McLaughlin et al., 2010). A lack of information was shown to cause increases in well spouse confusion and anxiety (Williamson et al., 2008) and contribute to possible economic burden (McLaughlin et al., 2010)

Clinical interventions in PD were also external factors which mediated the negative effects of PD. Two papers investigated the effect of interventions for PD, specifically neurostimulation, on well spouses and spousal relationships. Though neurostimulation was shown to reduce PD severity and improve quality of life, this did not reduce well spouse depression, care burden or increase well spouse quality of life (Soulas et al., 2012). However, when spouses were split by age groups, younger spouses were found to benefit from neurostimulation in relationship to caregiver burden (Soulas et al., 2012). Further demonstrating the positive impacts of the intervention of neurostimulation was the study by Haahr et al. (2013). This study found that following surgical induced improvements in PD severity, well spouses reported less worry and increased closeness in the marital relationship and an increased sense of freedom though initial post surgery adjustment was difficult.

The course of PD

This review also highlighted the experiences of couples over the course of PD. Studies demonstrated that over the course of PD caregiver burden increases (Carter et al., 1998; Shrag et al., 2006) as does marital strain (Lyons et al., 2009) as does the amount of support well spouses provide (McLaughlin et al., 2011), The findings of Carter et al. (1998) are derived from a study using a large number of participants, 306.

However the study by Carter et al. (1998) discovered that an increase in caregiver tasks and strain did not increase the levels of depression in the well spouse, nor did it cause any reduction in the general health of the well spouse. The reason for this was that well spouses reported receiving an increase in support as the disease progressed. Again this highlights the importance of support for the well spouse as well as the person with PD. Protective factors for spouses over the course of PD were discovered in the study by Lyons et al. (2009). This study found that over the course of PD well husbands exhibited less of an increase in caregiver strain than well wives. This study also found that high levels of marital mutuality reduced the amount of caregiver strain experienced by well spouses over the course of PD.

Discussion

This review firstly demonstrated that PD in the couple relationship causes broad negative impacts on the well partner and the couple relationship. These negative impacts are across a variety of domains including social, physical and mood.

Related to this, this review also highlighted elements within the ill partner which can cause, exacerbate or reduce the negative impacts found in this review. For example a common finding in many studies was ill partner depression being a key predictor of well partner depression and caregiver burden. This demonstrated there are also other important factors in PD other than the more obvious motor symptoms which can impact on both the ill partner and the well partner.

The review also covered external factors which could increase or reduce the negative impacts of PD. External factors such as support, information and the impact of medical interventions were all found to effect the experience of PD for well partners and the couple dyad. This again gives further clear areas for possible interventions external to the spousal couple that require further attention.

The effect of specific symptoms of PD on well partners and the couple relationship, rather than the broader experiences of PD in general, were also highlighted in a number of papers. Falls, psychotic symptoms, sleep disturbance and sexual dysfunction were shown to have negative effects on the spousal relationship and well partner mood, physical health and social networks.

This review highlighted methods of coping that well partners and the couple dyad can undertake in order to reduce the above negative impacts of PD. These coping strategies involved changes in the well spouse such as being more aware of the ill partner's symptoms (Haahr et al., 2013) and changes in the couple dyad such as maintaining a sense of humour (Hodgson et al., 2004).

Finally the impact of PD on the couple relationship over the course of the disease was highlighted in a number of papers. A variety of negative impacts of PD increased over the course of PD including caregiver burden and marital strain. However there were a variety of different protective factors both in the well partner and in the couple dyad that could reduce the increase in negative factors over the course of PD, such as support.

These findings are congruent with literature reviews into the impact of dementia, another degenerative neurological condition of later life, on partner's and the partner relationship. Both dementia and PD show a variety of negative impacts on the well spouse and the spousal relationship across a number of different domains. Systematic literature reviews into dementia have shown depression to be a common reaction in well partners (Brodaty & Donkin, 2009; Cuijpers, 2005). Well spouses with spouses with dementia also report a sense of loss of the relationship (Evans & Lee, 2013). Social isolation was also a common experience of partners of people with dementia (Stoltz, Uden & Willman, 2004). Finally similar to the findings of this review, partners with dementia have also been found to have a number of factors which can mediate the negative effects on them (Cuijpers, 2005). For example male well partners experienced less negative effects when their partner had dementia than female well spouses. All of these findings were found in the current review to also be applicable to partners of individuals with PD.

The implications of these similarities between dementia partner caregivers and PD partner caregivers are twofold. Firstly it demonstrates there are common experiences of partners who have a partner with a neurodegenerative condition, such as depression, loss of social networks and sense of loss of relationship. This information can be used to possibly predict what partners of individuals with other neurodegenerative conditions may experience. Secondly the knowledge of particular common elements experienced

by partners of individuals with dementia or PD may allow targeted interventions to be developed that can be used on two populations, partners of individuals with PD and partners of individuals with dementia.

Limitations of findings

Of note within this review is that all couples were heterosexual. This may have been a result of the search terms used, however the search terms used such as Couple* and Relationship* would have yielded any papers concerning homosexual couples. One possible reason for this bias in reviewed papers may be related to the cohort of couples typically affected by PD. From a generational perspective it could be argued that older adults are historically unlikely to have expressed their homosexuality openly due to factors such as discrimination and stigmatisation. This may have led to individuals in this cohort not expressing their sexuality and thus not having the opportunity to be in a homosexual couple. Additionally many of the studies looked at spouses or spousal relationships. This may have been done as a measure of relationship quality. However, legally in certain locations homosexual couples cannot become spousal couples, thereby creating a heterocentric bias in the literature. Although there is no reason for homosexual couples to experience PD differently to heterosexual couples there does exist a gender difference in caring. Informal male caregivers have been shown to experience less caregiver burden than females in heterosexual couples (Gallicchio, Siddiqi, Langenberg, Baumgarten 2002). Given this, it is possible to expect that couples composed of the same gender may experience and adapt to one spouse becoming affected by PD differently.

This review also raises issues around generalisability. Most of the reviewed studies investigated an American population. Within this population it could be argued

that certain subtle cultural differences exist such as attitudes to family, the elderly and the additional economic impact of accessing health care in a privatised system. All these differences could play a role in how American couples experiencing PD have a very different and specific experience which is not generalisable to a wider population or to the UK based population where socialised healthcare is available through the NHS.

The majority of papers in this review focused solely on the impact of PD on spouses and spousal dyads without the use of a control group with other chronic health conditions. This leads to a reduction in the validity of the findings as the results of studies without these control groups, such as increased caregiver strain, may be due to other factors rather than the impact of PD specifically. Only studies by O'Connor et al. (2008), Thommensen et al. (2002) and Aarsland et al. (1999) used control groups with various other neurological and physical conditions. This means that the findings of these studies such as caregiver burden being associated with ill spouse depression (Thommensen et al., 2002) are more likely to be attributable to PD specifically rather than other chronic conditions of older life.

Within the studies reviewed there does exist the possible risk of demand characteristics. Demand characteristics refer to study participants altering their behaviour due to the presence of a researcher. Many of the measures used in studies had very negative connotations such as "caregiver burden" or "depression scale". This may have lead to well spouses minimising their responses due to not wishing to describe the ill partner in a negative light. This in turn may have lead to findings not being truly representative of the experiences of well partners.

Many of the studies reviewed also used a number of different outcome measures to assess the same variable. For example caregiver burden was measured using the Family Caregiver Inventory and the Care Giver Inventory by Carter et al. (1996) and Miller et al. (1998) respectively. A disadvantage of this is different measures have

different methods of administration, scoring and construct validity. This reduces the validity of findings based around a single factor which are drawn from a number of studies.

As mentioned above a number of papers included in the review contained certain methodological limitations which should be considered when viewing the findings of this review. Firstly some papers did not describe the well partners in depth. This may have lead to certain well partner groups in studies possessing certain factors which may be considered extraneous variables, such as pre-existing marital difficulties, pre existing mental health difficulties or the partner's social/familial situation. The addition of these extraneous variables could have caused some studies to produce findings which were due to these extraneous variables rather than purely due to the impact of PD on partners and the partner relationship.

Many of the findings of quantitative papers were correlations. These correlations were used to infer a variety of results such as ill spouse depression causing well spouse depression. However as correlation does not imply causation care must be taken when interpreting these findings.

Some studies used author developed measures. However the validation of these measures was not reported in many studies. This then reduces the validity of findings as measures used may not themselves have been valid tools of measurement whilst studies which employed standardised measures could be argued to have more valid and reliable findings.

Finally the presence of sampling bias may have reduced the validity of the review. Sampling bias may mean well spouses and spousal dyads willing to take part in a study may have possessed certain common attributes which in turn may reduce the validity of results gained from these papers as the sample has been skewed. This would

result in the experiences of spouses and spousal dyads without these attributes not being included in this review.

The use of only single or a low number of individuals during the analysis stage in some included qualitative papers may have reduced the validity of the findings from these papers. By using a single or low number of individuals during analysis it increases the likelihood of subjective bias in the analysis of collected data and thus the conclusions made from these studies.

Limitations of Review

A limitation of this review was that it only included articles from peer reviewed sources. Whilst only including peer reviewed sources is a method of ensuring quality it also causes any relevant information from other sources to be omitted.

Another quality issue to consider when using peer reviewed articles is publication bias. Publication bias is the tendency for only studies with significant findings to be published, again possibly leading to the omission of information in this review. However publication bias is unlikely to have affected this literature review as studies in this area mainly seek to discover the experience of couples and PD and are not seeking to find specific significant results. Therefore studies not finding significant results are still likely to be published as this is still a key finding in this area.

The assessment of suitability may have also influenced the papers included in this review. During this period papers were excluded if they included a mixed sample of caregivers and did not explicitly attribute findings to spouses or partners. This was done to ensure homogeneity of findings and to ensure all reported findings were indeed the experiences of spouses or partners. However a weakness of this approach is that it may have resulted in important findings that were those of spouses or partners being

excluded from this review simply because the paper in question did not explicitly state so.

Finally, though care was taken to ensure that the search terms used were wide enough to identify studies detecting a wide range of effects of PD on couple relationships, there is a possibility that some papers using specific terminology may have been overlooked by this search strategy.

Clinical Implications

Primarily this review highlighted that there are many factors in the ill partner, aside from motor deficits, which can negatively impact on the well partner and the couple relationship. The implications of these findings are multifaceted. Firstly on the individual level professionals working with individuals with PD should be aware of the multiple effects it has on the patient beyond impairment of motor function, especially their mental health. Secondly an awareness of how these factors in the ill partner negatively affect the well partner could help to produce targeted interventions for both the well partner and the couple. Professionals should also be aware of particular risk factors within the ill partner, such as depression, and particular areas of difficulty which can negatively affect the well partner. Finally well partners themselves should be supported by professionals given the wide range of negative experiences they can have.

Similar to the internal factors which this review highlighted, attention should be given to those external factors which can either aid or hinder partners and the couple dyad in PD. Professionals delivering care to couples with PD should be aware of the negative effects of lack of support and information. Awareness of these factors could be used to develop targeted interventions such as providing more information, particularly in highlighted neglected areas such as psychotic symptoms, and signposting couple

dyads with PD to relevant information. These findings could also be used to inform wider systemic interventions such as aiding couples to engage more in other support networks or gain financial support. Professionals should also be aware of the outcomes following standard interventions for PD. Neurostimulation which reduces symptom severity in PD did not produce positive outcomes in certain partners (Soulas et al., 2012). This again demonstrates the need for professionals to use a systemic framework and take into account experiences of the well partner when intervening in PD, even with individual based interventions such as neurostimulation.

This review highlighted particular areas of difficulty for couples with PD such as sexual dysfunction, sleep disturbance and psychotic symptoms. These specific areas of difficulty should be attended to and care should be taken to ensure they are not neglected due to the more obvious physical symptoms of PD being the focus of care particularly given the broad negative impacts these symptoms can have.

Finally this review also contained papers which addressed the course of PD and the impact of this on couples. Two of these papers also discussed protective factors which could reduce the negative impacts of PD over the course of the illness. This information may aid professionals as they can be aware of certain risk factors in the couple relationship which may increase the negative impacts of PD and implement interventions to address this.

Future research

An overarching finding across many papers is that the systemic impact of PD is not a well researched area when compared to the health, neurobiological and physical symptoms of the individual with PD. Further research in this area would produce a

greater breadth and depth of research to draw from. and allow a more detailed picture of the systemic impacts of PD to develop.

Given the wide range of physical, mental and social impairments that PD causes, further research into specific PD impairments and their effect on the couple dyad would be worthy of further investigation. Miller et al. (1996) demonstrated that physical impairments are responsible for increasing caregiver burden. However, there is no mention of specific physical impairments unique to PD such as tremor or facial masking and the effects these have upon partners and the couple relationship. This would allow a clearer picture of the unique experiences of living with the condition of PD to be gained. Research in this area would allow the impact of specific problematic symptoms of PD to be assessed, understood and may guide further focus for interventions.

Finally, research could focus on the positive and protective factors which help to maintain couple relationships in the presence of PD. Studies by Hodgson et al. (2004), Habberman et al. (2000) and Haahr et al. (2013) reported factors which spouses reported as being protective and reducing the negative impact of PD. Further research in this area may help find methods to reduce the multitude of negative effects caused by PD and help maintain couple relationships and these could be incorporated into interventions.

Conclusion

In summary this literature review has demonstrated the experiences of partner's of individuals with PD, in addition to the external factors which can mediate these and partner's methods of coping. A number of these findings are congruent with other neurodegenerative conditions. The findings of this review demonstrate possible areas for intervention in addition to areas of further clinical research.

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Part Two: Empirical Paper
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Abstract

Background: Parkinson's disease (PD) has been shown to impair the perception of facial emotions. Studies have demonstrated that neurologically healthy individuals are able to correctly perceive emotions expressed solely through body movements. The present study investigated if PD impaired the perception of body emotions.

Design: A mixed model design was used. Two groups took part in this study. An experimental group of participants with PD (n=15) and a control group of neurologically healthy control participants (n=15).

Method: Participants viewed a series of emotional stimuli blocks containing face photographs and videos of bodies presented for three seconds. The stimuli were displaying the 6 emotions of anger, disgust, happiness, sadness, fear and neutrality. After each stimuli had been presented, participants were asked to identify what emotion they had seen.

Results: Participants with PD scored significantly lower in the perception of emotion expressed through body movements. There was no significant difference in the perception of facial emotion between PD and control participants.

Conclusions: PD may cause deficits in body emotional perception. The results being divergent from other findings showing PD causes impairment in facial affect recognition may be due to facilitative factors in the perception of facial emotion which are not present in the perception of body emotion.

Introduction

Parkinson's disease (PD) is a progressive neurological condition caused by cell death in the Substantia Nigra which in turn leads to a reduction in dopamine production. The causes for this dopaminergic cell death are not fully understood, with a variety of hypotheses existing, including genetic mutation and environmental toxins (Davie, 2008). The average age of onset of PD is in the fifth to sixth decade of life. PD exists in 1% of the population over the age of 60 and 4% of the population over the age of 80 (de Lau & Breteler, 2006). There exist variations in prevalence between race and gender, with Caucasian males being the population with the highest percentage of PD (Van Den Eeden et al, 2003), though the cause for this variance remains unknown.

The symptoms of PD were first described in 1817 by James Parkinson as "involuntary tremulous motion, with lessened muscular power". Following its initial identification the physical symptoms of PD have been explained in greater detail. The symptoms of PD are now known to include "Cogwheel rigidity", slowness of movement, difficulties with sequential movement, motor freezing and difficulties initiating movement (Jankovic, 2008). PD can be separated into two distinct types based on the dominant symptoms. These types are tremor form and akinetic form (Van Rooden et al., 2011).

Though PD is commonly associated with physical symptoms, the deficits caused by the disease extend beyond that of the motor modality. In a systematic literature review of the prevalence of dementia in PD it was found that 24-31% of people with PD develop dementia (Aarsland, Zaccai & Brayne, 2005).

Cognitive deficits are also present in the absence of dementia. Cognitive processes shown to be impaired in PD include working memory (Thomas, Reymann, Lieury & Allain, 1996) attention (Sampaio et al., 2011) and perception. These cognitive

deficits have been observed as worsening with the progression of the disease and they may also precede the onset of psychological symptoms (Jankovic, 2008).

PD also causes deficits in the individual's social functioning. Individuals with PD are often perceived by others as being less polite (Holtgraves & McNamara, 2010) and less engaged in conversations (Hemmesch, Tickle-Degnen & Zebrowitz, 2009). Individuals with PD themselves also report difficulties with communication (Miller, Noble, Jones & Burn, 2006).

Possibly related to social impairments in PD, an area of specific research interest has been into the effect of PD on the perception of emotional stimuli. Clark, Nearing and Cronin-Golomb (2008) demonstrated that PD caused significant deficits in the recognition of facial emotions when compared to a healthy control group. Further studies have demonstrated that specific emotions are more difficult to identify for individuals with PD. In the above study it was found the recognition of anger and fear was significantly impaired. The recognition of disgust is also significantly impaired in PD when compared to the perception of other facial emotions (Suzuki, Hoshino, Shigemasu & Kawamura, 2006).

Deficits in emotional perception are also found in the auditory modality, with perception of emotional prosody being impaired (Ariatti, Benuzzi & Nichelli, 2008). This deficit also extends to the perception of emotion in music (van Tricht, Smeding, Speelman & Schmand, 2010).

The findings of these studies conform with many others in the same research area. Indeed, a meta-analysis of 34 different studies investigating PD and emotional perception with a total of 1,295 participants found "a robust link between Parkinson's disease and specific deficits in recognising emotion" "...particularly negative emotions" (Gray & Tickle-Degnen, 2010).

Studies suggest that this deficit in facial affect perception is only present after significant cognitive decline (Pell & Leonard, 2005). However, facial affect perception impairments have also been shown to be present in individuals with PD who do not have dementia (Herrera, Cuetos and Rodriguez-Ferreiro, 2011). Therefore the point at which facial affect perception becomes impaired in the progression of PD is still not fully understood.

One proposed theory for the cause of impairments in facial affect perception is that the co-morbid psychiatric conditions common in PD, such as anxiety and depression, are responsible. Anxiety has been shown to bias emotional perception towards identifying facial emotions as negative (Bouhuys, Bloem & Groothuis, 1995). However this seems unlikely as several studies have found these deficits to be present even after controlling for such psychiatric difficulties (Gray & Tickle-Degnen 2010).

Other theories suggest impairment in ocular motor functioning not allowing for sufficient scanning of faces (Clark et al., 2008), or amygdala dysfunction impairing perception of negative stimuli (Yoshimura, Kawamura, Masaoka, and Homma, 2005). However, neither of these theories explains impairment in either recognising positive emotions or in recognising emotion via the auditory sensory modality.

One theory that does explain emotional perception impairment in PD across sensory modalities is that of Sprengelmeyer et al. (2003). These authors suggest that it is a lack of dopamine which causes impairments in emotional perception. In this study un-medicated patients with PD displayed a significantly greater deficit in perception of all facial emotion than patients with PD who were on dopamine replacement medication. This study also found that medicated and un-medicated participants were still significantly impaired on facial affect perception when compared to a neurologically healthy control group.

Perception of another person's emotional state is facilitated via methods other than facial expression. Recognition of emotion has been shown to be facilitated when both the face and body are displaying the same emotion (App, Reed & McIntosh, 2012). This study found that participants took significantly longer to identify an emotion when the emotion being expressed by the face and the body were incongruent. This demonstrates that recognition of emotion is informed by body as well as facial expression. However more time and attention is spent focussing upon the emotional expression displayed by the face than the body (Shields, Engelhardt & Ietswaart, 2012). This suggests that emotional recognition employs a top down perceptual approach with the face being used as the key informer as to emotional expression and the body is used to facilitate this recognition.

Atkinson, Dittrich, Gemmell and Young (2004) have demonstrated that neurologically healthy individuals are able to accurately identify the 5 expressions of anger, disgust, happiness, sadness and fear when presented only through body posture and movement. Additionally the ability to identify emotions through body movement was evident even when participants were presented with minimal visual information. This finding was achieved by using videos where the actor's body was represented by a small number of illuminated dots which highlight the actor's body movement.

Individuals with PD have been shown to experience a high level of interpersonal distress (Clark et al., 2008). Interpersonal distress has been found to highly correlate with impairments in facial emotion recognition (Clark et al., 2008).

As body affect recognition has been shown to contribute to facial affect recognition, impairment in body affect recognition may explain some of the difficulties individuals with PD experience in emotional recognition. This in turn may also explain the social difficulties individuals with PD experience. Investigating the ability to recognise body affect could also guide interventions with individuals with PD such as

not relying on body movement to convey emotional content if an impairment were to be discovered. However if, unlike facial affect recognition, body affect recognition was shown to not be impaired this would also lead to possible interventions. For example, adaptations to communication could be made that convey emotional content through this spared domain when communicating with individuals with PD.

Given the possible global impairment of emotional recognition caused by dopamine depletion it was hypothesised that PD would cause impairment in the recognition of emotions represented through body movement, similar to that of faces, when compared to a control group.

At time of writing there had been no research investigating if PD causes deficits in perception of body affect similar to the deficits present in facial affect perception. The study detailed below sought to investigate this.

Materials and Method

Ethical approval for this study was gained from the Bradford Research and Ethics Committee (REC) on 30/01/2013.

Design

The study used a mixed model design as it incorporates elements of a repeated measures design (The different emotional stimuli blocks) and elements of a between groups design (The different participant groups taking part in the study).

Participants

After discussion with professionals in the field regarding the exclusion criteria that would be applied to the sample population, a sample size of 15 experimental and 15 control participants was deemed possible. Power calculations using G*Power found this number of participants had 80% power to detect an effect size of 0.24 for the group x stimuli interaction in a repeated measures ANOVA with an assumed within-subject correlation of 0.5 amongst the all pairs of the three repeated measures and using a 5% significance level.

Experimental participants had to score three or under on the Howen and Yahr PD scale, a measure of disability caused by PD (Hoehn & Yahr, 1967). Exclusion criteria for experimental participants were: unable to comprehend English to the levels necessary for the study; experiencing any neurological illness other than PD; having experienced any form of invasive neurological surgery; experiencing severe mood disorder; experiencing any form of visual disturbance. Experimental participants were

also excluded if their PD was of an early onset (before the age of 40). All experimental participants were on dopamine replacement medication.

Fifteen control participants were included in this study. The 15 control participants were comprised of three participants recruited through the Women's Institute (WI) and 12 participants recruited from spouses of experimental participants. Control participants were also subjected to the same above exclusion criteria with the difference being they would be excluded if there were experiencing any neurological illness including PD.

Materials

Mini Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975)

The MMSE was used to ensure that participants were not experiencing any form of gross cognitive impairment as this has been shown to impair emotional perception abilities (Hargrave, Maddock & Stone, 2002). The MMSE was chosen due to its short form so as to ensure that participants were not too fatigued before taking part in the experiment. A cut off score of 26 and lower was used when screening participants with the MMSE as scores at this level have been shown to be indicative of dementia or other gross cognitive impairment. No participants were screened out due to the presence of cognitive impairment.

Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)

The HADS was used to measure the participant's levels of depression and anxiety. This was deemed necessary as both depression (Leppanen, Milders, Bell, Terriere & Hietanen, 2004) and anxiety (Surcinelli, Codispoti, Montebanocci, Rossi & Baldaro, 2006) have been shown to influence facial emotional perception. The HADS was chosen as it controls for the more physical symptoms of anxiety and depression which may be present in an older adult population and avoids these being attributed to depression or anxiety. A cut off point of 11 and over was used as this indicates anxiety or depression symptoms are at a significant level and are outside of the "normal" range. Previous studies investigating PD and emotional perception have also excluded participants outside the "normal" ranges on measures of mood (Clark et al., 2008). The cut off point of 11 was chosen rather than 8-11 which indicates a borderline case of

anxiety or depression. This was to ensure that participants were screened out due to a clear case of mood disorder rather than screening out participants who may have been misidentified as having a mood disorder as this would have placed further limitations on an already small population. No participants were screened out due to the presence of mood disorder.

Visual Object and Perception Battery (VOSP) (Warrington & James, 1991)

The screening battery of the VOSP was used to measure the basic visual perceptual abilities of participants. This was deemed necessary to ensure that visual disturbance did not impair emotional perception. Due to the low floor of the VOSP screening battery, participants who did not attain an 8/8 score on the screening test were excluded from the study. No participants were screened out due to visual impairment.

STOIC facial expression database (Roy, et al 2007)

The STOIC facial expression database is composed of 60 grey scale static images of 10 actors' faces (five male/five female) expressing the 6 emotions of disgust, happiness, anger, sadness, fear and neutrality. These faces were used for the facial affect stimuli (Appendix 2.1). The 60 STOIC faces were validated on a population of 35 Canadian students and were found to be the most reliably correctly identified stimuli out of 7,000 faces. The STOIC faces were chosen over the more commonly used Ekman faces (Ekman & Friesen, 1971) due to their more recent creation and greater validity in controlling for confounding variables such as hair.

Dynamic stimuli (point light condition) (PL)

Sixty, three second long, black and white video clips of 10 actors displaying the emotions of disgust, happiness, anger, sadness, fear and neutrality were used as part of the body affect stimuli. The point light condition refers to the fact that the actors performing the emotions did so in a darkened room and were only visible due to bands of lights placed on their head, arms and legs (Appendix 2.2). These stimuli were taken from the study by Atkinson et al. (2004) and validated on a population of 36 students by Atkinson et al. (2004).

Dynamic stimuli (full light condition) (FL)

Sixty, three second long, black and white video clips of 10 actors displaying the emotions of disgust, happiness, anger, sadness, fear and neutrality were used as part of the body affect stimuli. The full light condition refers to the fact that actors were presented completely lit up. These stimuli were again taken from the study by Atkinson et al. (2004) and validated on a population of 36 students by Atkinson et al. (2004) (Appendix 2.3).

Three blocks of emotional stimuli were used one of faces and two of bodies. The reasons for this were 3 fold. Firstly to observe any difference between facial and body stimuli. Secondly using the two forms of body stimuli allowed this study to closer replicate the Atkinson et al. (2004) due to the body stimuli being from this study. More closely replicating the Atkinson study was done to ensure higher validity of the stimuli used. Finally two forms of body stimuli were used to allow any differences in emotional recognition acuity between fully visualised and partially visualised stimuli to be seen as these are theorised to utilise two different neurological systems.

OpenSesame Software

The OpenSesame computer software was used to present the experimental stimuli to the participants. Stimuli were grouped together based on type, i.e all facial stimuli were presented together forming a “Facial Stimuli Block”. These 3 groups of stimuli are referred to throughout the paper as “Stimuli Block”. The experiment was programmed to present the three blocks of experimental stimuli: one block containing 60 images of facial affect, one block containing 60 three second video clips of full light body affect and one block containing three second video clips of point light body affect. Stimuli block order was randomised in the experimental procedure as this would avoid any possible order effects. The order of stimuli within the stimuli block was also randomised, again to negate any order effects.

Procedure

Experimental participants were recruited over a three month period through local PD nurses using a self-selecting sampling method. Participants attending a PD clinic were informed about the study by a PD nurse. Those who expressed interest in taking part in the study were then approached by the researcher and provided with more details about the study. Those interested in the study were provided with an information sheet (Appendix 3.2, 3.3) and consent form (Appendix 3.4) which also contained contact details of the researcher for them to use should they wish to take part.

Control participants were recruited from participants' spouses or from local Women's Institutes (WI). Spouses were recruited using the same method described above. Participants recruited through the local WI were again recruited using a self selecting sampling method however they were approached at a WI meeting and provided with an information sheet.

The experimental procedure was conducted in participants' homes. Care was taken to ensure that distractions were minimised such as background noise. Participants completed the HADS, MMSE and VOSP. If the participant was within the predetermined cut off range (no higher than 11 on HADS, no lower than eight on VOSP and no lower than 27 on MMSE) they were then presented with the experimental stimuli. This was presented on a Sony VAIO laptop with a 15.5" screen. Participants sat roughly one and a half feet away from the screen. They were then presented with instructional information which told them to say aloud which emotion they had seen and that the administrator would press the button corresponding to that emotion.

Participants were then presented with a 60 item block of emotional stimuli (either facial, full light body or point light body). This stimulus was presented in the centre of the screen with a black background for three seconds. After this, participants

were presented with a screen with the question “What emotion did you see?” 1. Anger, 2. Disgust, 3. Happiness, 4 No emotion, 5 Sadness, 6 Fear. Participants then gave a response and the administrator entered this via the attached keyboard. Once this response was entered the next stimulus was presented. This process happened 60 times.

After the 60th stimulus was shown participants were presented with a screen displaying “Break”. Participants were asked if they had any questions and if they were happy to continue. If they replied yes the above routine was repeated but with a different block of stimuli. This block of stimuli lasted for 60 items before the participant was presented with another screen displaying “Break”. When the participant agreed to continue with the experiment they were presented with the final 60 stimuli and the above procedure was repeated.

After the final stimulus the participant was presented with a screen thanking them for their participation.

Statistical Analysis

In order to test the hypothesis that PD would cause impairment in the recognition of emotions represented through body movement, similar to that of faces, when compared to a control group, a Repeated Measures ANOVA was used.

In order to measure the effect of participant neurological status, PD or no PD, independent sample T-tests were used. Tests of normality were run on all collected data. Results for the Kolmogorov-Smirnov test (KS) for normality were: control faces ($KS=0.189$, $df = 15$, $p=0.158$), PD faces ($KS=0.125$, $df=15$ $p=0.200$), control full light ($KS=0.124$, $df=15$, $p=0.200$), PD full light ($KS=0.185$, $df=15$, $p=0.179$) and PD point light ($KS=0.127$, $df=15$, $p=0.200$) Therefore, all these scores were shown to be normally distributed.

However the scores of control point light could not be assumed to be normally distributed ($KS=0.237$, $df=15$, $p=0.024$). However the accompanying histogram demonstrated control point light data was not greatly skewed as it did not deviate hugely from a Gaussian bell shaped curve. Due to this and the KS value not being highly significant, normality for control point light data was assumed and was further analysed as such.

Results

Participant Demographics

Demographics of the participants who took part in this study are summarised in Table 1. All participants included in the study had attained a score of <11 on the HADS, >26 on the MMSE and eight on the VOSP.

Table 1: Participant demographic

	Male Controls (n=7)	Female Controls (n=8)	Total Controls (n=15)	Male PD (n=7)	Female PD (n=8)	Total PD (n=15)
Age in Years Mean (SD)	66.6 (7.72)	64.8 (10.54)	65.6 (9.05)	73 (6.81)	66.4 (5.42)	70 (6.91)
Length of diagnosis (Years) Mean (SD)	N/A	N/A	N/A	5.4 (2.91)	5.8 (4.31)	5.5 (4.58)

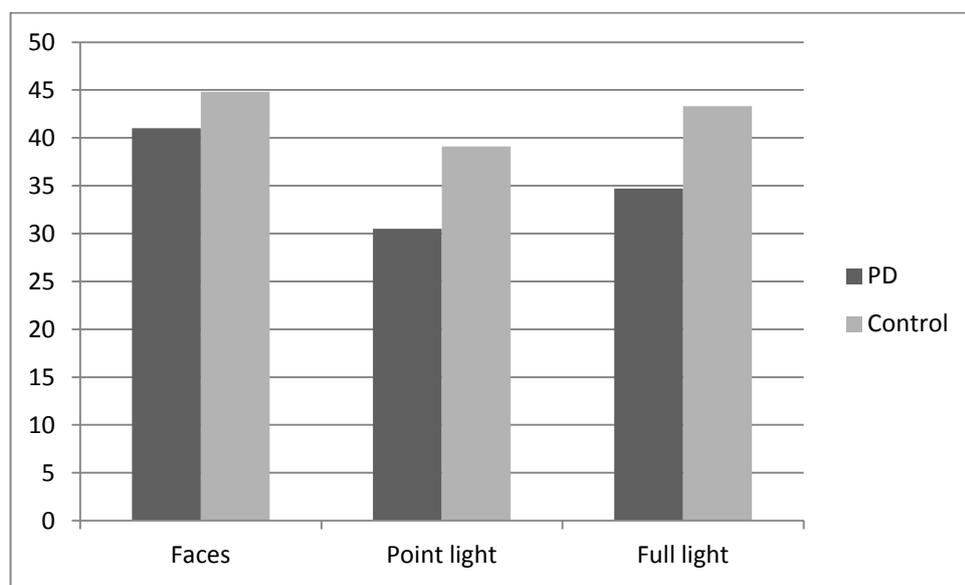
Table 2-Mean Participant psychometric results

	PD	Control
Mean MMSE Score (SD)	29.1 (0.74)	29.2 (0.77)
Mean HADS (Depression) Score (SD)	7.9 (1.75)	5.8 (1.70)
Mean HADS (Anxiety) Score (SD)	8.2 (2.02)	5.9 (1.77)
Mean VOSP Score (SD)	8 (0)	8 (0)

Descriptive Statistics

The mean scores of emotional perception for each experimental group and each stimuli block are displayed in Figure 1. The maximum possible score in each stimuli block was a score of 60.

Figure 1: Average scores for stimuli blocks



Hypothesis: PD would cause impairment in the recognition of emotions represented through body movement, similar to that of faces, when compared to a control group.

In order to test the hypothesis that emotional accuracy would be influenced by emotional stimuli, block collected data was subjected to a repeated measures ANOVA. This test was used to calculate the significance level between the different emotional stimuli blocks and participant groups. During this analysis Mauchly's Test of Sphericity indicated that the assumption of sphericity had not been violated, $\chi^2(2)=3.92, p=0.14$.

Stimuli block was shown to have a significant effect on level of accuracy $F(2,56)=40.46, p<0.0005$). Levels of accuracy were significantly lower for point light

videos than faces $F(1,28)=61.88, p<0.0005$) and significantly lower for point light than full light $F(1,28)=32.92, p<0.0005$).

A significant group X stimuli interaction was found for the difference in accuracy between faces and point light videos $F(1,28)=5.28, p=0.029$ but not between point light and full light videos $F(1,28)=0.002, p=0.96$.

The effect of neurological status on emotional recognition

Independent two tailed T-tests were used to measure the significance level of the difference between control and experimental participants on each of the stimuli blocks. For the analysis of point light scores Levene's test for equality of variance demonstrated that equal variance could be assumed $F(1, 28)=0.774, p=0.386$. A t-statistic assuming equal variances was then calculated. The results of this t-test demonstrated that the scores of individuals with PD ($M=30.53, SD=6.96$) differed significantly compared to the scores of controls ($M=39.01, SD=7.62$) in the perception body emotions when displayed in point light $t(28)=3.20, p=0.003$. The mean score difference was 8.48, 95% CI (3.08, 13.99).

In the analysis of full light scores Levene's test for equality of variance demonstrated that equal variance could be assumed $F(1, 28)=1.10, p=0.743$. Due to this result a t-statistic assuming equal variances was calculated. A significant difference was found in the scores of PD participants ($M=34.73, SD=6.00$) and control participants ($M=43.44, SD=5.97$) in the perception of emotion through full light videos, $t(28)=3.99, p<0.0005$. The mean difference of scores here was 8.71, 95% CI (4.19, 13.01).

In the analysis of facial stimuli Levene's test for equality of variance demonstrated that equal variance could be assumed $F(1, 28)=2.551, p=0.121$. Due to this result a t-statistic assuming equal variances was calculated. However the t-test

showed that there was no significant difference in the scores of facial emotional perception between PD ($M=41$, $SD=7.38$) and control participants ($M=44.8$, $SD=5.24$), $t(28)=1.63$, $p=0.115$. The mean difference was 3.80, 95% CI (-0.98, 8.58). A summary of the T-Tests can be found in Table 3.

Table 3, Summary of T-Tests

Stimuli Type	Mean Control Group Score	Mean Experimental Group Score	Difference In Scores	Degrees of Freedom	T-value	P Value
Faces	44.8	41	3.80	28	1.628	0.115
Point light	39.01	30.53	8.48	28	3.203	0.003
Full light	43.44	34.73	8.71	28	3.993	<0.0005

Discussion

This study sought to investigate whether PD significantly impaired accuracy of body emotion recognition similar to that of faces. The results of this study show individuals with PD scored significantly lower in the perception of emotion expressed through body movements. This was found to occur for both point light and full light videos; the difference was more pronounced when identifying emotions through full light videos. However, given the possible lack of normality in control point light data, care should be taken when interpreting this result. This lack of normal distribution may have been due to the high variability in recognising emotions expressed through partially visualised stimuli. Supporting this are the wide confidence intervals for the point light t-test, 95% CI (3.08, 13.99). The widest confidence intervals were also found in point light videos in the Atkinson et al. (2004) study. Wide confidence intervals suggest high variability. This lack of robust normality in point light data could be overcome by using a larger sample size in future studies.

The causes for such a finding may be linked to the similar deficits that have been found in facial emotional perception (Gray & Tickle-Degnen, 2010). However as the precise cause of facial emotional perception impairment in PD is unknown it cannot be stated whether the cause in body emotional perception impairment has the same neurological substrate as facial emotional perception impairment and is the result of global emotional perception impairment, or whether it has a separate cause. Further research would be needed in both the areas of facial and body emotional perception in order for the causes of these particular deficits to be ascertained.

An impairment in recognising emotions when expressed through bodies may produce several difficulties, for example in social functioning. The ability to accurately recognise emotions has been shown to be associated with higher quality of relationships

(Lopes, Salovey & Straus, 2003). Body movements also have a high emotional communicative role (Sinke, Kret & DeGelder, 2012) and body movements are used to facilitate facial emotional perception (App et al., 2012; Mondloch, 2012). It is quite possible that impairment in the ability to recognise emotions through bodies would contribute to difficulties in social functioning. This is also supported by the findings of Clarke et al. (2008) and Holtgraves and McNamara (2010) who have found that many people with PD do experience social difficulties.

The results from this study have shown that there were no significant differences in the perception of facial emotions between participants with PD and without PD. These findings are incongruent with many other studies which have repeatedly demonstrated that PD causes significant impairments in the perception of facial emotions (Gray & Tickle-Degnen, 2010). There are a number of possible explanations for this result.

Firstly, research into the area of facial affect perception has shown this to be a cognitive process with a wide variety of facilitators and inhibitors. Bate, Parris, Haslam and Kay (2010) have shown that levels of empathy significantly affect the accuracy of identifying facial emotions, with higher levels of empathy being associated with higher levels of acuity. Similarly Austin (2004) has shown that emotional intelligence also affects an individual's ability to perceive facial emotions. Higher levels of emotional intelligence were found to produce higher levels of accuracy. Meyer, Scholar and Levy (2010) demonstrated that an individual's attachment style can also significantly affect emotional perception. This study found that adults with an anxious attachment style had significantly higher levels of emotional perception accuracy. It is quite possible that the presence of any one of the above may be enough to decrease the negative impact of PD on emotional perception. Given the variety of possible facilitating factors it is highly likely that any number of them may have been present in PD participants used in this

study's sample. This may have produced a non-significant result in the difference in facial affect perception between PD participants and controls. Supporting this are studies by Adolphs, Schul and Tranel (1998) and Pell and Leonard (2005) which also found no significant difference in facial emotional perception between individuals with PD and individuals without. The authors of both studies cited numerous uncontrolled extraneous variables as being a possible reason for divergent results while stating that further research was needed to further discover the reasons for impaired and intact facial emotional perception in PD.

Additionally the role of dopaminergic medication may also have contributed to this divergent result. Dopamine medication has been shown to be associated with improving emotional perception (Sprengelmeyer et al., 2003). Though all experimental participants were on dopamine replacement medication the idiosyncratic nature of dopamine medication regimes may mean that a great number of PD participants taking part in this study were at the peak of their medication. This will have minimised the effect of PD on facial emotional perception and may have contributed to producing a non significant result. This is supported by the findings of Sprengelmeyer et al, (2003) who demonstrated that emotion perception impairment is more pronounced in un-medicated PD participants than PD participants who were taking dopamine replacing drugs.

Another possible explanation for not finding a significant result in facial emotional perception may be the nature of the facial stimuli used. The STOIC faces have not been used on a PD population before and the stimuli may not be as difficult for individuals with PD to recognise. However many other studies researching the area of PD and emotional perception have used many different forms of facial stimuli including the Ekman faces, the Benton Facial Recognition task, and own author developed and validated blocks of facial stimuli. Due to this, it would appear that impairment in facial

affect perception in PD is observed across many different forms of facial stimuli. It is therefore unlikely that impairment in emotional perception would not also be present when observing emotions displayed through the STOIC faces.

Finally, there also exists the possibility that participants with PD did not have impairment in the neurological processes involved in facial emotional perception. However this could not have been controlled for due to a number of reasons. Firstly there is no established point in the course of PD where facial emotional perception impairment begins. Additionally even if this point could be established there still remains the possibility of facial affect perception impairment occurring at different times and at different rates for each participant.

A possible explanation for this study finding a significant difference in body stimuli but not in facial stimuli is that there is little evidence that emotional perception through body movement, unlike faces, is facilitated by any additional factors. A study by Rozin, Taylor, Ross, Bennett and Hejmadi (2005) has demonstrated that individual differences such as trait anxiety do not significantly influence the ability to recognise emotions through body movement. Therefore if a deficit in emotional perception exists in PD it may be more observable through bodies as, unlike facial emotional perception, there are no known facilitative factors that may mask an impairment in emotional perception.

These results are also congruent with those of Atkinson et al. (2004) as participants were shown to have significantly higher accuracy scores when emotions were presented through full light rather than point light videos. This indicates that these stimuli are valid for use on an older adult population as they have produced the same results as the original study's sample of university students.

Limitations

The present study was subject to several methodological limitations. Firstly the materials used in the study. The tools used to screen for anxiety, depression, cognitive impairment and visual difficulties are all relatively insensitive and would only detect the most pronounced cases of mood, cognitive or visual impairment. These particular measures were chosen due to their short administration times and to avoid fatiguing participants before the emotional perception task. However, a disadvantage of this is more subtle cognitive, visual or mood difficulties may have not been detected and may have biased emotional perception particularly in the control group. In relation to the HADS specifically there exists the possibility of participants exhibiting demand characteristics. This may have been so as not to appear to be experiencing anxiety or depression due to possible perceived stigma. Further to this not every possible extraneous variable which could affect emotional recognition was screened and controlled for. For example psychosis, which has been established as impairing emotional recognition (Hooker and Park, 2002) and which is a common side effect of PD medication, was not screened for. Additionally the practice of screening out participants could be argued to have caused this study to not have a representative sample of the population. However screening out participants on the basis of mood, depression and cognitive abilities was necessary to ensure the scientific validity of this study.

As mentioned above, the STOIC facial database is arguably less well established as a collection of facial stimuli and it could be argued they have lower validity than other facial stimuli.

The study arguably did not employ standardised laboratory conditions. Due to the emotional perception task being undertaken in participants' homes it is likely there

were many extraneous variables which varied from experiment to experiment. However care was taken on behalf of the researcher to ensure experimental environments were as similar as possible.

The method of participant recruitment is also a limitation of this study. Due to utilising a self selecting sampling method there is a chance of bias in participants. It could be argued that individuals likely to sacrifice personal time to participate in a study are demonstrating some degree of empathy. This has been shown to facilitate emotional perception (Bate et al., 2010) and therefore it could be argued that the sample possessed characteristics which would facilitate their abilities of facial emotional perception.

Finally as this study utilises a cross-sectional design this also produced limitations. A cross sectional design would be unable to reliably demonstrate causality and opens up the possibility that participant results were a result of the particular day of testing rather than due to the independent variable thus possibly effecting the validity of this study. How due to time limitations and the very nature of this study a longitudinal design would not have been possible.

This study also highlights particular areas that may benefit from further research. The current study has raised the issue that the well established theory of PD causing deficits in emotional perception of faces may be mediated and indeed overcome by a number of other facilitators to facial emotional perception. The interaction of the facilitative effects on emotional perception and the emotional perception deficits caused by PD could be investigated. Further research may also be used to investigate the deficits in emotional perception of body movements identified by this study. Facial emotional impairment in PD has been shown to more frequently effect negative emotions (Gray & Tickle-Degnen, 2010). If these same emotions were found to be more significantly impaired in body emotion perception it may strengthen a hypothesis that deficits in facial emotional perception and body movement share the same neurological

substrate. Finally research into any possible facilitative factors in recognising emotions through body movements would also be beneficial and may support or refute to the findings of this study.

The clinical implications of these findings further demonstrate that care should be taken when communicating emotions to individuals with PD. This is due to a number of reasons. Firstly impairment in the perception of body emotions would make recognising emotions from further away more difficult, as bodily movements are employed more than faces in this process (Sinke et al., 2012). Secondly App et al. (2012) have shown that the body is used to facilitate facial emotional perception. Therefore impairment in recognising body emotions would also impair the ability to recognise facial emotions. This may also contribute to the social difficulties present in PD expressed by both the individual with PD (Clarke et al., 2008) and those communicating with them (Holtgraves & McNamara, 2010)

Clinically care should be taken when communicating with individuals with PD to ensure that emotions are clearly and concretely communicated without solely relying on body or facial expressions. Additionally spouses and those who work with PD may benefit from education around emotional perception impairment in PD. This may help further understand emotional perception impairment as part of PD and help it to be conceptualised as such, rather than in ways which may negatively impact on relationships. This may help reduce the interpersonal distress many individuals with PD experience (Clark et al, 2008).

In summary, the current study found evidence that individuals with PD do show impairment when recognising emotions expressed through body movements when compared to healthy controls. These findings may contribute to the established literature into social difficulties individuals with PD, and those living with individuals with PD, experience. The current study also demonstrated some divergent results by not finding a

significant difference in the perception of facial emotions between PD participants and controls. However there exist a number of facilitative factors in the perception of facial emotion that may have been present in the sample used in this study thus producing these results.

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Appendices

Appendix 1.1 Quality Appraisal Checklist – Qualitative Studies

Appendix 1.2 Table of Quality Assessment Scores for Qualitative Studies (Researcher)

Appendix 1.3 Table of Quality Assessment Scores for Qualitative Studies (Independent Rater)

Appendix 1.4 Quality appraisal checklist – Quantitative Studies

Appendix 1.5 Table of Quality Assessment Scores for Quantitative Studies (Researcher)

Appendix 1.6 Table of Quality Assessment Scores for Quantitative Studies (Independent Rater)

Appendix 1.7 Table showing areas of inter-rater agreement and disagreement (Quantitative Studies)

Appendix 1.8 Appendix 1.8 Table showing areas of inter-rater agreement and disagreement (Qualitative Studies)

Appendix 1.9 Appendix 1.9 Table of final agreed ratings

Appendix 2.1 Example of STOIC facial stimuli

Appendix 2.2 Example of Point Light dynamic body stimuli

Appendix 2.3 Example of Full Light dynamic body stimuli

Appendix 3.1 Participant Invitation Sheet

Appendix 3.2 Participant Information Sheet (Parkinson's disease group)

Appendix 3.3 Participant Information Sheet (Control group)

Appendix 3.4 Consent Form

Appendix 4.1 NHS Ethical Approval

Appendix 4.2 Research and Development Approval for HEY Trust

Appendix 4.3 Honorary Contract

Appendix 5.1 Reflective Statement

Appendix 6.1 Diagnostic Criteria for Parkinson's disease.

Appendix 7.1 Submission Guidelines Journal of Health and Aging

Appendix 7.2 Submission guidelines for Perception

Appendix 8.1 HADS

Appendix 8.2 MMSE

Appendix 1.1 Quality Appraisal Checklist – Qualitative Studies

Theoretical approach		
<p>1. Is a qualitative approach appropriate?</p> <p>For example:</p> <p>Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings?</p> <p>Could a quantitative approach better have addressed the research question?</p>	<p>Appropriate</p> <p>Inappropriate</p> <p>Not sure</p>	<p>Comments:</p>
<p>2. Is the study clear in what it seeks to do?</p> <p>For example:</p> <p>Is the purpose of the study discussed – aims/objectives/research question/s?</p> <p>Is there adequate/appropriate reference to the literature?</p> <p>Are underpinning values/assumptions/theory discussed?</p>	<p>Clear</p> <p>Unclear</p> <p>Mixed</p>	<p>Comments:</p>
Study design		
<p>3. How defensible/rigorous is the research design/methodology?</p> <p>For example:</p> <p>Is the design appropriate to the research question?</p> <p>Is a rationale given for using a</p>	<p>Defensible</p> <p>Indefensible</p> <p>Not sure</p>	<p>Comments:</p>

<p>qualitative approach?</p> <p>Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used?</p> <p>Is the selection of cases/sampling strategy theoretically justified?</p>		
Data collection		
<p>4. How well was the data collection carried out?</p> <p>For example:</p> <p>Are the data collection methods clearly described?</p> <p>Were the appropriate data collected to address the research question?</p> <p>Was the data collection and record keeping systematic?</p>	<p>Appropriately</p> <p>Inappropriately</p> <p>Not sure/inadequately reported</p>	<p>Comments:</p>
Trustworthiness		
<p>5. Is the role of the researcher clearly described?</p> <p>For example:</p> <p>Has the relationship between the researcher and the participants been adequately considered?</p> <p>Does the paper describe how the research was explained and presented</p>	<p>Clearly described</p> <p>Unclear</p> <p>Not described</p>	<p>Comments:</p>

to the participants?		
<p>6. Is the context clearly described?</p> <p>For example:</p> <p>Are the characteristics of the participants and settings clearly defined?</p> <p>Were observations made in a sufficient variety of circumstances</p> <p>Was context bias considered</p>	<p>Clear</p> <p>Unclear</p> <p>Not sure</p>	Comments:
<p>7. Were the methods reliable?</p> <p>For example:</p> <p>Was data collected by more than 1 method?</p> <p>Is there justification for triangulation, or for not triangulating?</p> <p>Do the methods investigate what they claim to?</p>	<p>Reliable</p> <p>Unreliable</p> <p>Not sure</p>	Comments:
Analysis		
<p>8. Is the data analysis sufficiently rigorous?</p> <p>For example:</p> <p>Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results?</p> <p>How systematic is the analysis, is the procedure reliable/dependable?</p>	<p>Rigorous</p> <p>Not rigorous</p> <p>Not sure/not reported</p>	Comments:

<p>Is it clear how the themes and concepts were derived from the data?</p>		
<p>9. Is the data 'rich'?</p> <p>For example:</p> <p>How well are the contexts of the data described?</p> <p>Has the diversity of perspective and content been explored?</p> <p>How well has the detail and depth been demonstrated?</p> <p>Are responses compared and contrasted across groups/sites?</p>	<p>Rich</p> <p>Poor</p> <p>Not sure/not reported</p>	<p>Comments:</p>
<p>10. Is the analysis reliable?</p> <p>For example:</p> <p>Did more than 1 researcher theme and code transcripts/data?</p> <p>If so, how were differences resolved?</p> <p>Did participants feed back on the transcripts/data if possible and relevant?</p> <p>Were negative/discrepant results addressed or ignored?</p>	<p>Reliable</p> <p>Unreliable</p> <p>Not sure/not reported</p>	<p>Comments:</p>
<p>11. Are the findings convincing?</p> <p>For example:</p> <p>Are the findings clearly presented?</p>	<p>Convincing</p> <p>Not convincing</p> <p>Not sure</p>	<p>Comments:</p>

<p>Are the findings internally coherent?</p> <p>Are extracts from the original data included?</p> <p>Are the data appropriately referenced?</p> <p>Is the reporting clear and coherent?</p>		
<p>12. Are the findings relevant to the aims of the study?</p>	<p>Relevant</p> <p>Irrelevant</p> <p>Partially relevant</p>	<p>Comments:</p>
<p>13. Conclusions</p> <p>For example:</p> <p>How clear are the links between data, interpretation and conclusions?</p> <p>Are the conclusions plausible and coherent?</p> <p>Have alternative explanations been explored and discounted?</p> <p>Does this enhance understanding of the research topic?</p> <p>Are the implications of the research clearly defined?</p> <p>Is there adequate discussion of any limitations encountered?</p>	<p>Adequate</p> <p>Inadequate</p> <p>Not sure</p>	<p>Comments:</p>
<p>Ethics</p>		
<p>14. How clear and coherent is the reporting of ethics?</p>	<p>Appropriate</p>	<p>Comments:</p>

<p>For example:</p> <p>Have ethical issues been taken into consideration?</p> <p>Are they adequately discussed e.g. do they address consent and anonymity?</p> <p>Have the consequences of the research been considered i.e. raising expectations, changing behaviour?</p> <p>Was the study approved by an ethics committee?</p>	<p>Inappropriate</p> <p>Not sure/not reported</p>	
Overall assessment		
<p>As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)</p>	<p>++</p> <p>+</p> <p>-</p>	<p>Comments:</p>

Appendix 1.2 Table of Quality Assessment Scores for Qualitative Studies (Researcher)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Williamson, Simpson and Murray	Appropriate	Clear	Defensible	Appropriate	Not described	Clear	Reliable	Rigorous	Not Sure	Reliable	Convincing	Relevant	Adequate	Clear
Birgersson & Edberg	Appropriate	Clear	Not defensible	Appropriate	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Clear
Davey, Wiles & Ashburn 1	Appropriate	Clear	Defensible	Appropriate	Not described	Clear	Reliable	Rigorous	Not Sure	Reliable	Convincing	Relevant	Adequate	Clear
Hodgson, J. H., Garcia, K., & Tyndall, L	Appropriate	Clear	Not Sure	Appropriate	Unclear	Clear	Reliable	Rigorous	Not sure	Not sure	Convincing	Relevant	Adequate	Clear
<i>Beaudet and Ducharme (2013)</i>	Appropriate	clear	Defensible	appropriate	Unclear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Clear
<i>Roland, Jenkins and Johnson (2010)</i>	Appropriate	Clear	Defensible	Appropriate	Unclear	Clear	Reliable	Rigorous	Rich	Not Sure	Convincing	Relevant	Adequate	Clear
<i>Habermann (2000)</i>	Appropriate	Clear	Defensible	Appropriate	Not described	Clear	Reliable	Rigorous	Rich	Not Sure	Convincing	Relevant	Adequate	Clear
<i>McLaughlin et al (2010)</i>	Appropriate	Clear	Defensible	Appropriate	Not described	Clear	Not Sure	Rigorous	Rich	Unreliable	Convincing	Relevant	Adequate	Clear

Appendix 1.3 Table of Quality Assessment Scores for Qualitative Studies (Independent rater)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Williamson, Simpson and Murray	Appropriate	Clear	Defensible	App	Unclear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Clear
Birgersson & Edberg	Appropriate	Clear	Defensible	App	clear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Clear
Davey, Wiles & Ashburn 1	Appropriate	Clear	Defensible	App	Not described	Clear	Reliable	Rigorous	Rich	Not Sure	Convincing	Relevant	Adequate	Clear
Hodgson, J. H., Garcia, K., & Tyndall, L	Appropriate	Clear	Defensible	App	Not described	Clear	Reliable	Rigorous	Not sure	Reliable	Convincing	Relevant	Adequate	Clear
<i>Beaudet and Ducharme (2013)</i>	Appropriate	clear	Defensible	App	Clear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Clear
<i>Roland, Jenkins and Johnson (2010)</i>	Appropriate	Clear	Defensible	App	Clear	Clear	Reliable	Rigorous	Rich	Not Sure	Convincing	Relevant	Adequate	Clear
<i>Habermann (2000)</i>	Appropriate	Clear	Defensible	App	Unclear	Clear	Reliable	Rigorous	Not sure	Not Sure	Convincing	Relevant	Adequate	Clear
<i>McLaughlin et al (2010)</i>	Appropriate	Clear	Defensible	Not Sure	Not described	Clear	Not Sure	Not Sure	Rich	Unreliable	Convincing	Relevant	Adequate	Clear

Appendix 1.4 Quality Appraisal Checklist – Quantitative Studies

Study identification: Include full citation details		
Study design: Refer to the glossary of study designs (appendix D) and the algorithm for classifying experimental and observational study designs (appendix E) to best describe the paper's underpinning study design		
Guidance topic:		
Assessed by:		
Section 1: Population		
1.1 Is the source population or source area well described? Was the country (e.g. developed or non-developed, type of health care system), setting (primary schools, community centres etc), location (urban, rural), population demographics etc adequately described?	++ + – NR NA	Comments:
1.2 Is the eligible population or area representative of the source population or area? Was the recruitment of individuals, clusters or areas well defined (e.g. advertisement, birth register)? Was the eligible population representative of the source? Were important groups underrepresented?	++ + – NR NA	Comments:
1.3 Do the selected participants or areas represent the eligible population or area? Was the method of selection of participants from the eligible population well described? What % of selected individuals or clusters agreed to participate? Were there any sources of bias? Were the inclusion or exclusion criteria explicit and appropriate?	++ + – NR NA	Comments:
Section 2: Method of selection of exposure (or comparison) group		

<p>2.1 Selection of exposure (and comparison) group. How was selection bias minimised?</p> <p>How was selection bias minimised?</p>	<p>++ + - NR NA</p>	<p>Comments:</p>
<p>2.2 Was the selection of explanatory variables based on a sound theoretical basis?</p> <p>How sound was the theoretical basis for selecting the explanatory variables?</p>	<p>++ + - NR NA</p>	<p>Comments:</p>
<p>2.3 Was the contamination acceptably low?</p> <p>Did any in the comparison group receive the exposure?</p> <p>If so, was it sufficient to cause important bias?</p>	<p>++ + - NR NA</p>	<p>Comments:</p>
<p>2.4 How well were likely confounding factors identified and controlled?</p> <p>Were there likely to be other confounding factors not considered or appropriately adjusted for?</p> <p>Was this sufficient to cause important bias?</p>	<p>++ + - NR NA</p>	<p>Comments:</p>
<p>2.5 Is the setting applicable to the UK?</p> <p>Did the setting differ significantly from the UK?</p>	<p>++ + - NR NA</p>	<p>Comments:</p>
<p>Section 3: Outcomes</p>		

<p>3.1 Were the outcome measures and procedures reliable?</p> <p>Were outcome measures subjective or objective (e.g. biochemically validated nicotine levels ++ vs self-reported smoking -)?</p> <p>How reliable were outcome measures (e.g. inter- or intra-rater reliability scores)?</p> <p>Was there any indication that measures had been validated (e.g. validated against a gold standard measure or assessed for content validity)?</p>	<p>++</p> <p>+</p> <p>-</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>3.2 Were the outcome measurements complete?</p> <p>Were all or most of the study participants who met the defined study outcome definitions likely to have been identified?</p>	<p>++</p> <p>+</p> <p>-</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>3.3 Were all the important outcomes assessed?</p> <p>Were all the important benefits and harms assessed?</p> <p>Was it possible to determine the overall balance of benefits and harms of the intervention versus comparison?</p>	<p>++</p> <p>+</p> <p>-</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>3.4 Was there a similar follow-up time in exposure and comparison groups?</p> <p>If groups are followed for different lengths of time, then more events are likely to occur in the group followed-up for longer distorting the comparison.</p> <p>Analyses can be adjusted to allow for differences in length of follow-up (e.g. using person-years).</p>	<p>++</p> <p>+</p> <p>-</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>3.5 Was follow-up time meaningful?</p> <p>Was follow-up long enough to assess long-term benefits and</p>	<p>++</p> <p>+</p>	<p>Comments:</p>

harms?	–	
Was it too long, e.g. participants lost to follow-up?	NR NA	
Section 4: Analyses		
<p>4.1 Was the study sufficiently powered to detect an intervention effect (if one exists)?</p> <p>A power of 0.8 (i.e. it is likely to see an effect of a given size if one exists, 80% of the time) is the conventionally accepted standard.</p> <p>Is a power calculation presented? If not, what is the expected effect size? Is the sample size adequate?</p>	++ + – NR NA	Comments:
<p>4.2 Were multiple explanatory variables considered in the analyses?</p> <p>Were there sufficient explanatory variables considered in the analysis?</p>	++ + – NR NA	Comments:
<p>4.3 Were the analytical methods appropriate?</p> <p>Were important differences in follow-up time and likely confounders adjusted for?</p>	++ + – NR NA	Comments:
<p>4.6 Was the precision of association given or calculable? Is association meaningful?</p> <p>Were confidence intervals or p values for effect estimates given or possible to calculate?</p> <p>Were CIs wide or were they sufficiently precise to aid decision-making? If precision is lacking, is this because the study is under-powered?</p>	++ + – NR NA	Comments:

Section 5: Summary		
<p>5.1 Are the study results internally valid (i.e. unbiased)?</p> <p>How well did the study minimise sources of bias (i.e. adjusting for potential confounders)?</p> <p>Were there significant flaws in the study design?</p>	<p>++</p> <p>+</p> <p>–</p>	<p>Comments:</p>
<p>5.2 Are the findings generalisable to the source population (i.e. externally valid)?</p> <p>Are there sufficient details given about the study to determine if the findings are generalisable to the source population?</p> <p>Consider: participants, interventions and comparisons, outcomes, resource and policy implications.</p>	<p>++</p> <p>+</p> <p>–</p>	<p>Comments:</p>

Appendix 1.5 Table of Quality Assessment Scores for Quantitative Studies (Researcher)

	1.1	1.2	1.3	2.1	2.2	2.3	2.4	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.4	5.1	5.2
<i>Hand, Grey, Chandler & Walker</i>	++	++	+	++	++	++	++	++	++	N/A	N/A	N/A	N/R	++	++	++	++	++
<i>Schrag, Hovris, Morley, Quinn & Jahanshahi</i>	++	++	+	++	++	++	+	+	++	N/A	N/A	N/A	N/R	+	+	+	+	++
<i>O'Connor, McCabe & Firth</i>	++	+	N/R	++	++	++	++	++	+	+	N/A	N/A	N/R	+	++	++	++	++
Carter, et al	++	++	++	++	+	++	-	+	++	N/R	N/A	N/A	N/R	++	++	+	-	+
Carter & Carter	++	++	+	+	+	++	+	+	+	++	N/A	N/A	N/R	++	+	++	+	++
<i>Miller, Berrios & Politynska</i>	++	++	+	-	++	++	-	+	+	++	N/A	N/A	N/R	+	+	+	+	++
<i>D'Amelio, et al</i>	+	++	+	+	++	++	++	++	++	++	N/A	N/A	N/R	++	++	+	++	++
<i>Tanji et al</i>	+	++	+	++	++	++	++	+	++	++	N/A	N/A	N/R	++	++	++	++	++

<i>Carter, Lyons, Stewart, Archbold and Scobee ,</i>	+	+	++	+	++	++	-	+	++	+	N/A	N/A	N/R	++	++	-	++	++
<i>Fernandez, Tabano, David and Friedman</i>	+	+	-	+	++	++	++	+	++	++	N/A	N/A	N/R	++	++	++	++	++
<i>Happe & Berger</i>	-	++	++	+	++	++	++	+	++	++	++	++	N/R	++	++	++	++	++
<i>Thommensen, et al</i>	+	++	+	+	++	++	++	++	++	++	++	N/A	N/R	++	++	++	++	++
<i>Brown, Jahanshahi, Quinn and Marsdan</i>	+	++	+	+	++	++	-	+	++	++	N/A	N/A	N/R	++	++	-	++	++
<i>Smith, Ellgring and Oertel</i>	+	++	+	+	++	++	+	++	++	+	+	N/A	N/R	++	++	++	++	++
<i>Petrican, Burris, Bielak, Schimmack & Moscovitch</i>	+	++	+	+	+	++	+	++	++	++	N/A	N/A	N/R	++	++	-	++	++
<i>Shin, Lee, Youn, Kim and Cho</i>	+	++	++	++	++	++	-	+	++	++	N/A	N/A	N/R	++	++	+	++	++
<i>Aarsland, Larsen, Karlsen, Lim and Tandberd</i>	+	++	+	+	++	++	+	+	++	++	N/A	N/A	N/R	+	++	+	++	++
<i>Lyons, Stewart, Archbold and</i>	+	+	+	++	++	++	-	+	++	++	N/A	N/A	N/R	++	++	+	++	++

<i>Carter</i>																			
<i>Soulas, Sultan, Gurruchaga, Palfi and Fenelon</i>	+	++	+	+	++	++	-	+	++	++	++	++	++	N/R	++	++	++	++	++

Appendix 1.6 Table of Quality Assessment Scores for Quantitative Studies (Independent rater)

	1.1	1.2	1.3	2.1	2.2	2.3	2.4	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.4	5.1	5.2
<i>Hand, Grey, Chandler & Walker1</i>	++	++	+	(++)	++	++	++	++	++	++	N/A	N/A	N/R	+	++	++	++	++
<i>Schrag2, Hovris, Morley, Quinn & Jahanshahi</i>	++	++	+	(++)	++	-	+	+	++	++	N/A	N/A	N/R	+	++	++	++	++
<i>O'Connor, McCabe & Firth 3</i>	++	++	+	(++)	++	++	++	+	++	++	N/A	N/A	N/R	+	++	++	++	++
Carter, et al	++	++	++	++	+	++	-	+	++	N/R	N/A	N/A	N/R	++	+	+	++	+
Carter & Carter	+	++	+	+	+	++	+	+	+	++	N/A	N/A	N/R	++	+	++	+	++
<i>Miller, Berrios & Politynska 4</i>	++	++	+	-	++	-	-	+	+	++	N/A	N/A	N/R	+	++	+	++	++
<i>D'Amelio, et al 5</i>	+	++	+	+	++	-	-	++	++	++	N/A	N/A	N/R	++	++	-	++	++
<i>Tanji et al 6</i>	+	+	+	-	++	++	-	+	++	++	N/A	N/A	N/R	++	++	++	++	++

<i>Carter, Lyons, Stewart, Archbold and Scobee 7,</i>	+	+	++	+	++	-	-	+	++	++	N/A	N/A	N/R	++	++	++	++	++
<i>Fernandez, Tabano, David and Friedman 8</i>	+	+	-	+	++	++	++	+	++	++	N/A	N/A	N/R	++	++	++	++	++
<i>Happe & Berger 9</i>	-	++	++	-	++	+	-	+	++	++	N/A	N/A	N/R	++	++	++	++	++
<i>Thommensen, et al 10</i>	+	++	+	-	++	++	-	++	++	++	++	N/A	N/R	+	++	++	++	++
<i>Brown, Jahanshahi, Quim and Marsdan15</i>	+	+	+	+	++	++	-	+	++	++	N/A	N/A	N/R	++	++	-	++	++
<i>Smith, Ellgring and Oertel</i>	+	++	+	+	++	++	+	++	++	+	+	N/A	N/R	++	++	++	++	++
<i>Petrican, Burris, Bielak, Schimmack & Moscovitch 14</i>	+	++	+	+	++	++	+	++	++	++	N/A	N/A	N/R	++	++		++	++
<i>Shin, Lee, Youn, Kim and Cho</i>	+	++	++	++	++	++	-	+	++	+	N/A	N/A	N/R	++	++	+	++	++
<i>Aarsland, Larsen, Karlsen, Lim and Tandberd 11</i>	++	+	+	+	++	++	+	+	+	++	N/A	N/A	N/R	+	++	++	++	++

<i>Lyons, Stewart, Archbold and Carter12</i>	+	+	+	++	++	++	-	++	++	++	N/A	N/A	N/R	++	++	+	++	++
<i>Soulas, Sultan, Gurruchaga, Palfi and Fenelon 13</i>	++	+	+	+	++	++	-	+	++	++	++	++	N/R	++	++	+	++	++

Appendix 1.7 Table showing areas of inter-rater agreement and disagreement
(Quantitative Studies)

Study																			Percentage Agreement
<i>Hand, Grey, Chandler & Walker</i>	1	1	1	1	1	0	1	1	1	0	1	1	1	1	0	0	0	0	12/18
<i>Schrag, Hovris, Morley, Quinn & Jahanshahi</i>	1	0	0	1	1	1	1	0	0	0	1	1	1	1	1	1	1	1	13/18
<i>O'Connor, McCabe & Firth</i>	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	1	0	1	16/18
<i>Carter, et al</i>	0	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	17/18
<i>Carter & Carter</i>	1	1	1	1	1	0	1	1	1	1	1	1	1	1	0	1	0	1	15/18
<i>Miller, Berrios & Politynska</i>	1	1	1	1	1	0	0	1	1	1	1	1	1	1	1	0	1	1	15/18
<i>D'Amelio, et al</i>	1	0	1	0	1	1	0	1	1	1	1	1	1	1	1	1	1	1	15/18
<i>Tanji et al</i>	1	1	1	1	1	0	1	1	1	0	1	1	1	1	1	0	1	1	15/18
<i>Carter, Lyons, Stewart, Archbold and Scobee ,</i>	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	18/18
<i>Fernandez, Tabano, David and Friedman</i>	1	1	1	0	1	0	0	1	1	1	0	0	1	1	1	1	1	1	13/18
<i>Happe & Berger</i>	1	1	1	0	1	1	0	1	1	1	1	1	1	0	1	1	1	1	15/18
<i>Thommensen, et al</i>	1	0	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	17/18
<i>Brown, Jahanshahi, Quinn and Marsdan</i>	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	18/18
<i>Smith, Ellgring and Oertel</i>	1	1	1	1	0	1	1	1	1	1	1	1	1	1	1	0	1	1	16/18
<i>Petrican, Burris, Bielak, Schimmack & Moscovitch</i>	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	17/18
<i>Shin, Lee, Youn, Kim and Cho</i>	0	0	1	1	1	1	1	1	0	1	1	1	1	1	1	0	1	1	14/18

<i>Aarland, Larsen, Karlsen, Lim and Tandberd</i>	1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	1	1	1	17/18
<i>Lyons, Stewart, Archbold and Carter</i>	0	0	1	1	1	1	1	1	1	1	1	1	1	1	1	0	1	1	15/18
<i>Soulas, Sultan, Gurruchaga, Palfi and Fenelon</i>	1	1	1	1	1	1	1	1	1	1	0	1	1	1	0	1	1	1	16/18

<p><u>Key</u> 1= Agreement 0= Disagreement</p>
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Appendix 1.8 Table showing areas of inter-rater agreement and disagreement (Qualitative Studies)

Study															Percentage Agreement
Williamson, Simpson and Murray	1	1	1	1	0	1	1	1	0	1	1	1	1	1	12/14
Birgersson & Edberg	1	1	0	1	0	1	1	1	1	1	1	1	1	1	12/14
Davey, Wiles & Ashburn 1	1	1	1	1	1	1	1	1	0	0	1	1	1	1	12/14
Hodgson, J. H., Garcia, K., & Tyndall, L	1	1	0	1	0	1	1	1	1	0	1	1	1	1	11/14
<i>Beaudet and Ducharme (2013)</i>	1	1	1	1	0	1	1	1	1	1	1	1	1	1	13/14
<i>Roland, Jenkins and Johnson (2010)</i>	1	1	1	1	0	1	1	1	1	1	1	1	1	1	13/14
<i>Habermann (2000)</i>	1	1	1	1	0	1	1	1	0	1	1	1	1	1	12/14
<i>McLaughlin et al (2010)</i>	1	1	1	0	1	1	1	0	1	1	1	1	1	1	12/14

Key
 1= Agreement
 0= Disagreement

Appendix 1.9 Table of final agreed ratings

	1.1	1.2	1.3	2.1	2.2	2.3	2.4	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.4	5.1	5.2
<i>Hand, Grey, Chandler & Walker</i>	++	++	+	++	++	++	++	++	++	N/A	N/A	N/A	N/R	++	++	++	++	++
<i>Schrag, Hovris, Morley, Quinn & Jahanshahi</i>	++	++	+	++	++	+	+	+	++	N/A	N/A	N/A	N/R	+	+	+	+	++
<i>O'Connor, McCabe & Firth</i>	++	+	N/R	++	++	++	++	++	+	+	N/A	N/A	N/R	+	++	++	++	++
Carter, et al	++	++	++	++	+	++	-	+	++	N/R	N/A	N/A	N/R	++	++	+	-	+
Carter & Carter	++	++	+	+	+	++	+	+	+	++	N/A	N/A	N/R	++	+	++	+	++
<i>Miller, Berrios & Politynska</i>	++	++	+	-	++	++	-	+	+	++	N/A	N/A	N/R	+	+	+	+	++
<i>D'Amelio, et al</i>	+	++	+	+	++	++	++	++	++	++	N/A	N/A	N/R	++	++	+	++	++
<i>Tanji et al</i>	+	+	+	++	++	++	++	+	++	++	N/A	N/A	N/R	++	++	++	++	++
<i>Carter, Lyons, Stewart, Archbold and Scobee,</i>	+	+	++	+	++	++	-	+	++	+	N/A	N/A	N/R	++	++	-	++	++

<i>Fernandez, Tabano, David and Friedman</i>	+	+	-	+	++	++	++	+	++	++	N/A	N/A	N/R	++	++	++	++	++
<i>Happe & Berger</i>	-	++	++	+	++	++	++	+	++	++	++	++	N/R	++	++	++	++	++
<i>Thommensen, et al</i>	+	++	+	+	++	++	++	++	++	++	++	N/A	N/R	++	++	++	++	++
<i>Brown, Jahanshahi, Quinn and Marsdan</i>	+	++	+	+	++	++	-	+	++	++	N/A	N/A	N/R	++	++	-	++	++
<i>Smith, Ellgring and Oertel</i>	+	++	+	+	++	++	+	++	++	+	+	N/A	N/R	++	++	++	++	++
<i>Petrican, Burris, Bielak, Schimmack & Moscovitch</i>	+	++	+	+	+	++	+	++	++	++	N/A	N/A	N/R	++	++	-+	++	++
<i>Shin, Lee, Youn, Kim and Cho</i>	+	++	++	++	++	++	-	+	++	++	N/A	N/A	N/R	++	++	+	++	++
<i>Aarmland, Larsen, Karlsen, Lim and Tandberd</i>	+	++	+	+	++	++	+	+	++	++	N/A	N/A	N/R	+	++	++	++	++
<i>Lyons, Stewart, Archbold and Carter</i>	+	+	+	++	++	++	-	+	++	++	N/A	N/A	N/R	++	++	+	++	++
<i>Soulas, Sultan, Gurruchaga,</i>	+	++	+	+	++	++	-	+	++	++	++	++	N/R	++	++	+	++	++

<i>Palfi and Fenelon</i>																		
------------------------------	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Williamson, Simpson and Murray	Appropriate	Clear	Defensible	Appropriate	Unclear	Clear	Reliable	Rigorous	Not Sure	Reliable	Convincing	Relevant	Adequate	Clear
Birgersson & Edberg	Appropriate	Clear	Not defensible	Appropriate	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Clear
Davey, Wiles & Ashburn 1	Appropriate	Clear	Defensible	Appropriate	Not described	Clear	Reliable	Rigorous	Not Sure	Not sure	Convincing	Relevant	Adequate	Clear
Hodgson, J. H., Garcia, K., & Tyndall, L	Appropriate	Clear	Not Sure	Appropriate	Unclear	Clear	Reliable	Rigorous	Not sure	Not sure	Convincing	Relevant	Adequate	Clear
<i>Beaudet and Ducharme (2013)</i>	Appropriate	clear	Defensible	appropriate	Unclear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Clear
<i>Roland, Jenkins and Johnson (2010)</i>	Appropriate	Clear	Defensible	Appropriate	Unclear	Clear	Reliable	Rigorous	Rich	Not Sure	Convincing	Relevant	Adequate	Clear
<i>Habermann (2000)</i>	Appropriate	Clear	Defensible	Appropriate	Not described	Clear	Reliable	Rigorous	Rich	Not Sure	Convincing	Relevant	Adequate	Clear
<i>McLaughlin et al (2010)</i>	Appropriate	Clear	Defensible	Appropriate	Not described	Clear	Not Sure	Rigorous	Rich	Unreliable	Convincing	Relevant	Adequate	Clear

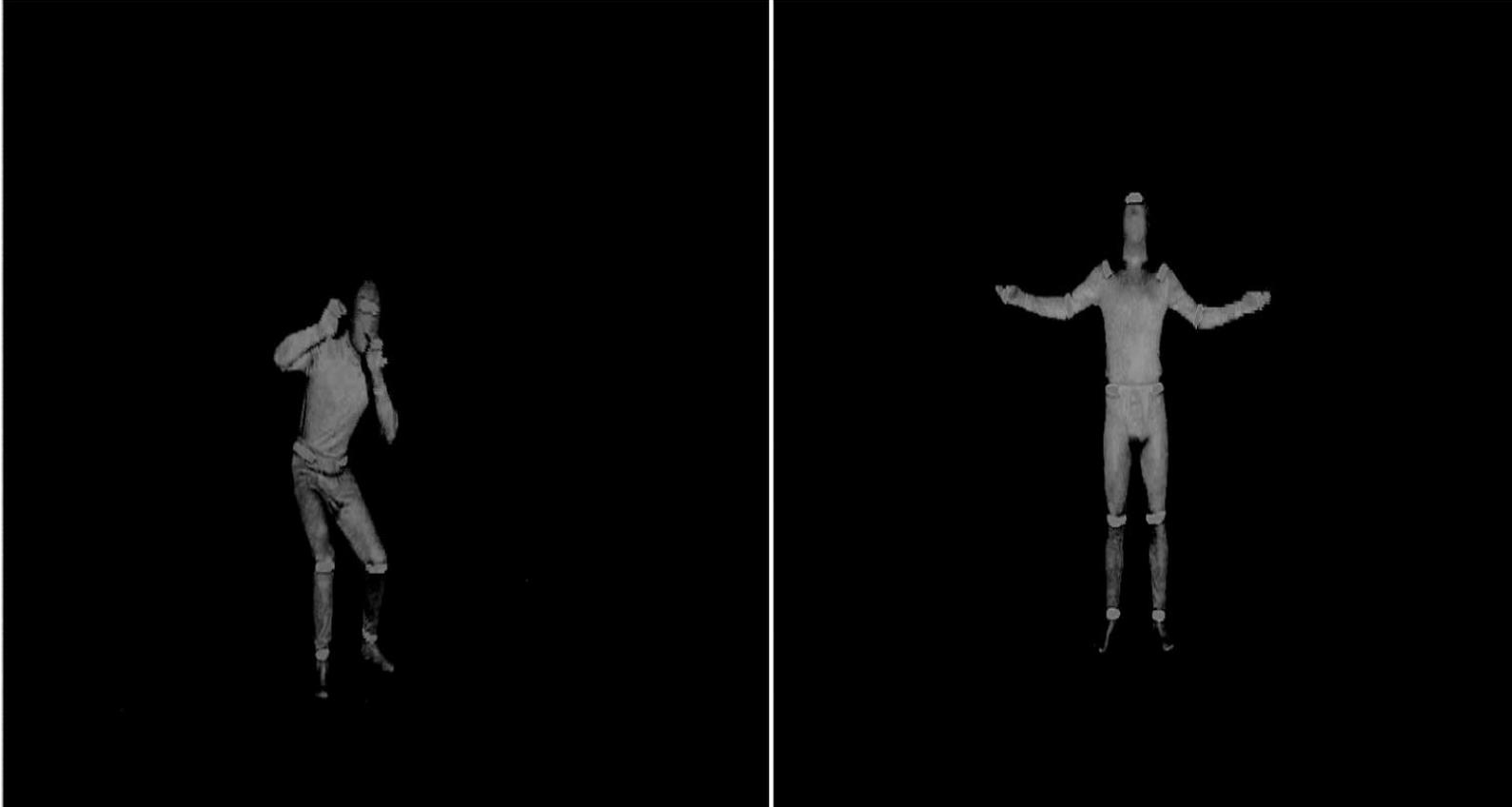
Appendix 2.1 Example of STOIC facial stimuli



Appendix 2.2 Example of point light stimuli



Appendix 2.3 Example of full light stimuli



Participant Invitation

Introduction

You are invited to take part in a study called "Parkinson's disease and the perception of body affect".

This study hopes to see if people with Parkinson's disease recognise emotions differently. This research is being done by Paul Hollett from the University of Hull.

The study requires a group of people with Parkinson's disease and a group of people without Parkinson's disease.

The Study

This study takes between an hour and an hour and a half. There are two parts to the study. In Part 1 you will be asked to complete 3 forms measuring mood, vision and memory.

Some participants will then be asked to complete part 2. In this part you will be shown videos on a computer of people showing emotion. You will be asked what emotion you think you saw.

Not everyone will be asked to complete both parts of the study.

Voluntary Participation

You are free to choose whether or not to complete the study. You can also decide during and after the study if you want me not to use your information.

Anonymity

Your name will not be recorded during this experiment (except on this consent form). At no point will your name or any other personal information be used.

Confidentiality

All information gained through this study will be kept confidential.

Risks and Benefits

This study involves little risk. You may experience some eye strain from looking at a computer screen for a long time. If you find that you get tired we can arrange to take breaks.

Contacts

I will be happy to answer questions that you may have about taking part in this study.

P.Hollett@2007.hull.ac.uk

07563615180

Paul Hollett

Trainee Clinical Psychologist

University of Hull

Under the supervision of

Dr Miles Rogish

M.Rogish@hull.ac.uk

01482 464106

Participant Information Sheet

Parkinson's Group

Hello,

My name is Paul Hollett and I am currently studying Clinical Psychology at the University of Hull. I am hoping to research how people with Parkinson's disease see emotions.

What is the research?

You have been invited to take part in this research as it requires a group of participants with Parkinson's disease. It is believed that people with Parkinson's disease find seeing other people's emotions difficult. This research will see if there is any difference between how people with Parkinson's disease recognise emotions and if people without Parkinson's disease see the same emotions differently.

What would I need to do?

You will not need to travel anywhere for this research. I will come to you.

If you agree to take part in this research you will first complete some forms which measure mood, memory and visual ability.

After completing these forms some participants may then

be asked to watch videos of people displaying emotions through both their faces and their body movement. I

will also ask you what emotion you saw. All of this should take around an hour and a half with breaks.

Not all participants will need to complete both stages of the research.

Do I have to take part?

No it is up to you to decide to take part in the research. If you agree to take part, you will then be asked to sign a consent form. You are free to withdraw at any time, without giving a reason. Withdrawing will not affect your care.

What will happen to the results I give?

The answers from this research may be used in published scientific reports, but at no point will your name or any other personal information be used. You will also be asked if you would like your G.P to be informed regarding your participation in the research.

Will my information be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Your name will not be recorded during this research. You will be given a code (e.g. AA), this will be used to show me which answers are yours. These results will also be kept secure at the researcher's base.

Voluntary Participation

You are free to choose whether or not to complete the research. You can stop the experiment at any time. You can also ask me to not use your results after you have completed the research.

Risks and Benefits

This research involves little risk. You may experience some eye strain from looking at a computer screen for a long time. If you find that you get tired we can arrange to take a break.

At the end of the experiment I will answer any questions you may have. By helping with this research you will help us learn more about the difficulties people with Parkinson's disease experience.

Who is organising the research?

The research is being completed as part of a university training programme with approval from the Humber NHS trust.

Who has reviewed the research?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This research has been reviewed and given favourable opinion by Bradford Research Ethics Committee. Reference number:12/YH/0553

Involvement of General Practitioner (G.P)

If you wish your G.P to be informed of your participation in this research and of your results you will be able to indicate this on the consent form.

If you wouldn't like this information to be shared you will also be able to request this.

What if I have any complaints?

Should you have any complaints during the research period please feel free to contact my supervisor Dr Miles Rogish at the University of Hull on 01482 464106.

What if I would like further information

Should you wish for any further information regarding the research feel free to contact me on the phone number and email address listed below.

What should I do next?

If you would like to take part in this research please ask the Parkinson's disease nurse to provide you with a consent form. Thank you for taking the time to read this letter. I look forward to hearing from you.

Yours Sincerely

Paul Hollett

P.Hollett@2007.hull.ac.uk

07563615180

Trainee Clinical Psychologist at the University of Hull

Under the supervision of

Dr Miles Rogish

M.Rogish@hull.ac.uk

01482 464106

Participant Information Sheet

Control Group

Hello,

My name is Paul Hollett and I am currently studying Clinical Psychology at the University of Hull. I am hoping to research how people with Parkinson's disease see emotions.

What is the research?

You have been invited to this research as it requires a group of participants without Parkinson's disease. It is believed that people with Parkinson's disease find seeing other people's emotions difficult. This research will see if there is any difference between how people with Parkinson's disease recognise emotions and if people without Parkinson's disease see the same emotions differently.

What would I need to do?

You will not need to travel anywhere for this research. I will come to you.

If you agree to take part in this research you will first complete some forms which measure mood, memory and visual ability.

After completing these forms some participants may then be asked to watch videos of people displaying emotions through both their faces and their body movement. I will also ask you what emotion you saw. All

of this should take around an hour and a half with breaks.

Not all participants will need to complete both stages of the research

Do I have to take part?

No, It is up to you to decide to take part in the research. If you agree to take part, you will then be asked to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to the results I give?

The answers from this research may be used in published scientific reports, but at no point will your name or any other personal information be used. You will also be asked if you would like your G.P to be informed regarding your participation in the research.

Will my information be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Your name will not be recorded during this research. You will be given a code (e.g. AA), this will be used to show me which answers are yours. These results will also be kept secure at the researcher's base.

Voluntary Participation

You are free to choose whether or not to complete the research. You can stop the experiment at any time. You can also ask me to not use your results after you have completed the research.

Risks and Benefits

This research involves little risk. You may experience some eye strain from looking at a computer screen for a long time. If you find that you get tired we can arrange to take a break.

At the end of the experiment I will answer any questions you may have. By helping with this research you will help us learn more about the difficulties people with Parkinson's disease experience.

Who is organising the research?

The research is being completed as part of a university training programme with approval from the Humber NHS trust.

Who has reviewed the research?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This research has been reviewed and given favourable opinion by Bradford Research Ethics Committee.

Reference number:12/YH/0553

Involvement of General Practitioner (G.P)

If you wish your G.P to be informed of your participation in this research and of your results you will be able to indicate this on the consent form.

If you wouldn't like this information to be shared you will also be able to request this.

What if I have any complaints?

Should you have any complaints during the research period please feel free to contact my supervisor Dr Miles Rogish at the University of Hull on 01482 464106.

What if I would like further information

Should you wish for any further information regarding the research feel free to contact me on the phone number and email address listed below.

What should I do next?

If you would like to take part in this research please ask the Parkinson's disease nurse to provide you with a consent form.

Thank you for taking the time to read this letter. I look forward to hearing from you.

Yours Sincerely

Paul Hollett

P.Hollett@2007.hull.ac.uk

07563615180

Trainee Clinical Psychologist at the University of Hull

Under the supervision of

Dr Miles Rogish

M.Rogish@hull.ac.uk

01482 464106

CONSENT FORM

Title of Project: Parkinson's disease and the perception of body affect

Name of Researcher: **Paul Hollett**

1. I confirm that I have read and understand the information sheet dated 18/2/13 (version 3.0) for the above research. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. 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.

3. I understand that data collected during the research may be looked at by individuals from the University of Hull, from regulatory authorities or from the Humber NHS Trust, where it is relevant to my taking part in this research..

4. I agree to my GP being informed of my participation in the research.

5. I agree to take part in the above research.

Name of Participant Date Signature

Name of Person Date Signature
taking consent.

Thank you for agreeing to help in completing this research.

Paul Hollett
P.Hollett@2007.hull.ac.uk

07563615180

Under the supervision of

Dr Miles Rogish
M.Rogish@hull.ac.uk

01482 464106

Appendix 4.1 REC Approval

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Appendix 4.2 R and D approval

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Appendix 4.3 Honorary Contract

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Appendix 5.1 Reflective Statement

Reflective statement

The single most important thing I will take away from this process is that the passion of conducting research and the practicalities of conducting research rarely complement each other. This research has been mired by delays in the practicalities of conducting research such as ethics, R and D and recruitment.

Firstly when experiencing these difficulties it was important to remember the positives of research. For me these positives were remembering that the research was developing new knowledge and the clinical applications which may arise from it. These positives were bolstered by the reactions participants had to my research and the questions they asked about it. Their fresh view on my research helped me stay attuned to the positive factors present in, what at some times, was a very difficult and demoralising experience. This has made me realise what parts of research are important to hold on to and to ensure full commitment to. I feel it reflects well on these positive factors of research that I look forward to developing and conducting research in the near future.

Secondly reflecting upon this process I have come to realise certain areas which are important to attend to during research in order to counter the difficulties experienced during this process. These have arisen from reflecting on the difficulties I have experienced in the course of this research. Namely taking every possible step to ensure a wide as possible pool of participants, ensuring the scientific process is explained clearly and that the rationale for conducting research is always at the fore front of my mind when conducting and reporting research.

Both the above reflections I feel will help in the conducting of further research both practically and personally.

Reflecting back now this project has ended I am also struck with how humbling it is for a project which has taken 3 years to accomplish to fit alongside other research in this area, and contribute to the ever growing area of emotional recognition in Parkinson's disease. And that has made it all feel worth it.

Appendix 6.1 Diagnostic Criteria for Parkinson's Disease

UK PARKINSON'S DISEASE SOCIETY BRAIN BANK CLINICAL DIAGNOSTIC CRITERIA*

Step 1. Diagnosis of Parkinsonian Syndrome

- Bradykinesia
- At least one of the following
 - Muscular rigidity
 - 4-6 Hz rest tremor
 - postural instability not caused by primary visual, vestibular, cerebellar, or proprioceptive dysfunction

Step 2 Exclusion criteria for Parkinson's disease

- history of repeated strokes with stepwise progression of parkinsonian features
- history of repeated head injury
- history of definite encephalitis
- oculogyric crises
- neuroleptic treatment at onset of symptoms
- more than one affected relative
- sustained remission
- strictly unilateral features after 3 years
- supranuclear gaze palsy
- cerebellar signs
- early severe autonomic involvement
- early severe dementia with disturbances of memory, language, and praxis
- Babinski sign
- presence of cerebral tumor or communication hydrocephalus on imaging study
- negative response to large doses of levodopa in absence of malabsorption
- MPTP exposure

Step 3 supportive prospective positive criteria for Parkinson's disease

Three or more required for diagnosis of definite Parkinson's disease in combination with step one

- Unilateral onset
- Rest tremor present
- Progressive disorder
- Persistent asymmetry affecting side of onset most
- Excellent response (70-100%) to levodopa
- Severe levodopa-induced chorea
- Levodopa response for 5 years or more
- Clinical course of ten years or more

**From: Hughes AJ, Daniel SE, Kilford L, Lees AJ. Accuracy of clinical diagnosis of idiopathic*

Parkinson's disease. A clinico-pathological study of 100 cases. JNNP 1992;55:181-184.

Appendix 7.1 Submission guidelines for Journal of Health and Aging

Manuscripts must be submitted for review via the *Journal of Aging and Health* SAGE Track website at <http://mc.manuscriptcentral.com/jah>. Manuscripts should be prepared in accordance with the 6th edition of the Publication Manual of the American Psychological Association. Double space all manuscripts, including references, notes, abstracts, quotations, and tables, on 8 1/2 x 11 paper. The title page should be a separate document and include all authors' names and affiliations and highest professional degrees, the corresponding author's address and telephone number, and a brief running headline. Place acknowledgments in a separate document under the heading AUTHOR'S NOTE. The title page should be followed by a structured abstract of 100 to 150 words that includes the following subheadings: Objectives, Methods, Results, and Discussion. On the abstract page include 3 to 5 words or short phrases for indexing purposes. The abstract page as well as the first page of the text should include the manuscript's title without the authors' names to facilitate blind review. Tables and references should follow APA style and be double-spaced throughout. Ordinarily manuscripts will not exceed 30 pages (double-spaced), including tables, figures, and references. Authors of accepted manuscripts will be asked to supply camera-ready figures. Submission of a manuscript implies commitment to publish in the journal. Authors submitting manuscripts to the journal should not simultaneously submit them to another journal, nor should manuscripts have been published elsewhere in substantially similar form or with substantially similar content. Authors in doubt about what constitutes prior publication should consult the editor.

Appendix 7.1 Submission guidelines for *Perception*

Regular papers. These form the bulk of the content in both journals. They are open submissions on any aspect of perception involving any one or more sensory modalities. Sections should usually include (in order): abstract, introduction, methods, results (and discussion), and (general) discussion. The abstract is limited to 200 words. There are no other limits, though authors are encouraged to aim for brevity and to write in a style that will be accessible to readers without expertise in the immediate subject area of the article.

Style. Authors are urged to write as clearly as possible, *in English* (either UK or US usage is acceptable), with emphasis on what they judge to be of greatest importance and interest, with, where possible, clearly stated theoretical implications. Experimental results should be presented in sufficient detail for replication to be possible. Statistical tests need not be given in full. Abbreviations should be used sparingly. Merriam–Webster's Collegiate Dictionary is recommended as the spelling reference.

Presentation. Great care should be taken in differentiating between capital and lowercase characters (s and S, c and C, p and P, etc), Latin and Greek characters (k and kappa, p and rho, w and omega, etc), and letters and numerals (l and 1, z and 2, etc).

Abstract. All papers should be preceded by a brief abstract (of about 200 words for regular articles, and no more than 150 words for Short and Sweet articles).

Nomenclature. It is recommended that the authors follow the Royal Society's latest publication 'Quantities, Units, and Symbols' and use the SI system of units.

Website. We encourage the submission of additional material relevant to the submitted manuscript, to be hosted on the Perception website—for example, the stimuli used in the published study, or material which cannot be represented in print, such as animations or colour images (see [above](#)).

References. References and in-text citations should be formatted according to APA style. The full list of all references cited in the paper should appear at the end of the text in alphabetical order by author and in ascending chronological order for each author. All references must be cited in the text, and all citations in the text must appear in the references. *All* authors and editors should be listed for each reference. First and last pages should be provided for all articles published in journals or books.

Appendix 8.1 HADS

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Appendix 8.2 MMSE
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