An exploration into the experiences of Parkinson’s disease and its relationship with emotional well-being

Thesis submitted to the University of Leicester
in partial fulfilment for the degree of
Doctorate in Clinical Psychology

Jodie Goddard
2014
Declaration

I confirm that the literature review and research contained within this thesis is my own and have not been submitted for any other academic award.
An exploration into the experiences of Parkinson’s disease and its relationship with emotional well-being

Jodie Goddard

Thesis Abstract

Parkinson’s disease (PD) is estimated to affect one person in every 800, it is a condition that affects physical appearance and individuals can experience a wide range of psychological symptoms. No previous research has directly explored visible difference or associated psychological difficulties within PD, despite research existing for other chronic health conditions.

Literature Review
Using a meta-ethnographic approach, the literature review examined twelve qualitative studies exploring individuals’ experiences of PD. Seven third order constructs, grouped under four overarching main themes were identified. Individuals experienced uncertainty in adjustment and coping, and associated emotional challenges of living with PD. A sense of being trapped was reported and living with the disease undermined spontaneity, as life was constrained by routines in drug regimens and relentlessly planned activities. The review demonstrated an understanding of the lived experience of PD and highlighted the psychological demands of living with the disease. The review also indicated that specific experiences of PD were under-reported and highlighted the need for further research.

Empirical study
The empirical study explored shame (general, external and body), psychological morbidity (anxiety, depression, social anxiety and fear of negative evaluation), quality of life and body image disturbance in individuals with PD. The findings demonstrated that participants experienced higher levels of general shame and body image disturbances compared to non-clinical populations and significant associations between shame and psychological morbidity were found. It was found that participants quantitatively reported low levels of shame (external and body), fear of negative evaluation and social anxiety but qualitatively expressed embarrassment, self-consciousness and associated concealment and avoidance behaviours in relation to PD symptoms. It was suggested that open-ended questions may have facilitated participants to share their experiences in comparison to responding to quantitative self-report measures alone. Interpretations of the findings, clinical implications and suggestions for future research were discussed.
Acknowledgements

I would like to start by thanking the participants for taking part in the study; I am very grateful for their time and contribution and I appreciate that without their participation, the study would not have been possible.

I would also like to express my gratitude to everyone at the outpatient clinic, especially the Consultant Physician, Parkinson’s Disease Specialist Nurses and clinic co-ordinators, you all played a part in recruitment and I thank you all for being so welcoming and helpful.

Sincere thanks go to Noelle Robertson and Steve Allan for their continued support during the research process. I am very grateful for their time, encouragement, feedback and guidance that they have given throughout. This thesis would not have been possible without them both.

Thank you to all of my friends who have been there for me throughout the ups and downs of clinical training. Last but by no means least, I would like to express my sincere appreciation to my parents, my grandad and to Martyn (absolute star), who have always believed in me and supported me throughout. I could not have completed this journey without them. Special thanks go to my parents, as without their unconditional love, encouragement, support and guidance I would not have reached this point in my career.

To my grandma, I miss you more than words can say and I am sad that you didn’t get to see me complete this journey, I know you would have been proud.
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Section 1

Literature Review
'Locked in confinement. No release’ A meta-synthesis of the lived experiences of Parkinson’s disease

Jodie Goddard

1.0 Abstract

Purpose: To date, there appears to be no systematic aggregation of studies which have focused on experiences of living with Parkinson’s disease (PD). The aim of this literature review was to synthesise qualitative studies exploring the lived experiences of PD to offer a comprehensive understanding to inform clinical practice and research.

Methods: A meta-ethnographic approach (Noblit & Hare, 1988) was incorporated into the methods used for this review, involving a systematic search of seven databases and selection procedures to identify and critically appraise relevant research papers. An iterative process enabled a list of key themes, metaphors and concepts from each study to be constructed and allowed the author to determine how the papers were related.

Results: A total of twelve articles exploring individual’s experience of living with PD were identified as appropriate for review. Interpretations of the original authors’ interpretations (second order constructs) were made to develop seven third order constructs, grouped under four overarching main themes. Individuals experienced uncertainty in adjustment and coping, and associated emotional challenges of living with PD. A sense of being trapped was reported and living with the disease undermined spontaneity, as life was constrained by routines in drug regimens and relentlessly planned activities.

Conclusions: The review demonstrated an understanding of the lived experience of PD and highlighted the psychological demands of living with the disease. Areas for psychological intervention were identified; however, it was evident from guidance to health professionals that a lack of psychological support was available for individuals with PD. This synthesis highlighted that specific experiences of PD were under-reported and highlighted the need for further research.
2.0 Introduction

Parkinson’s disease (PD) is a chronic, progressive neurodegenerative condition predominately affecting those over the age of 50, and estimated to affect 1% of the population aged 65 and over (NHS Choices, 2012). In the UK currently there are approximately 127,000 people with PD (NHS Choices, 2012). The disorder is principally one of movement resulting from loss of dopaminergic neurons in the substantia nigra, (National Institute for Health and Clinical Excellence; NICE, 2006), but with cell death aetiology unknown (Parkinsons UK, 2013).

The dominant symptoms of PD tend to be tremor, rigidity, hypokinesia (poverty of movement) and bradykinesia (slowness of movement), however sleep problems, cognitive decline, speech and communication problems, and swallowing difficulties may also be prominent (Parkinson’s UK, 2011). Symptoms may be multifaceted with individuals experiencing a range of biological, psychological, and social symptoms (Parkinson’s UK, 2013), and progression of PD is unpredictable, with fluctuations in the rate of decline and severity of symptoms (Holloway, 2007).

Life expectancy for those with PD is little shorter than that of the general population; and the disease may thus be lived with for many years (Eccles, Murray & Simpson, 2011). Primary treatment is pharmacological and directed at symptom reduction and maintenance of independent functioning (Olanow, 2004), although progressive disability is usual (Suchowersky et al., 2006). However over time, increase in medication dose is often needed to control symptoms (Parkinson’s UK, 2013) with potential to induce further uncontrollable movements (dyskinesia).

Research in PD has been largely biomedical in orientation in efforts to understand aetiology and develop treatments to ease symptoms (Abudi et al., 1997). Within this paradigm, substantial research has explored psychiatric symptomatology in PD with claims that such symptoms are manifestations of underlying neuropathology (Brod, Mandelson & Roberts, 1998) rather than a reaction to psychosocial stress and disability (McDonald, Richard & DeLong, 2003). However, putative mechanisms are underdeveloped (Schrag, Jahanshahi & Quinn, 2000) and research findings equivocal.
Where studies have focused on broader life impacts, consistent negative impacts are reported, (Schenkman et al., 2002) with very few areas of life unaffected (Brod et al., 1998; Dakof & Mendelsohn, 1989). Furthermore, with disease progression, individuals may experience difficulties in completing fundamental activities of daily living (NICE, 2006), requiring considerable social and physical adjustments (Playfer, 2002) and adversely affecting quality of life (Adler, 2002; Leonardi et al., 2012).

Within more psychological research, evidence of affective problems is notable. Depression is commonly reported in people with PD, with 20-40% of individuals experiencing major depression (Lieberman, 2006). Although less researched anxiety rates are reported as high as 40% (Walsh & Bennett, 2001). Albeit quantitatively assessed and part of larger studies, there is evidence that individuals living with PD experience challenges to body image, mobility, social role, and independence (Abudi et al., 1997) with particularly adverse consequences for social interactions (Schrag et al., 2000; Schreurs, De Ridder & Bensing, 2000).

To date, assessment of the impact of PD has focused largely on defining, measuring and categorising symptoms (Schreurs et al., 2000). Whilst enlightening, such numerically-driven studies often diminish the meaning of the subjective experience of living with PD. By contrast, qualitative approaches may capture what it is to live with PD by exploring and evaluating personal experiences (Moon et al., 2013). Such research exploring the lived experience of PD is circumscribed (Hudson, Toye & Kristjanson, 2006; Schenkman et al., 2002) and has tended to focus on particular aspects or consequences of the condition, rather than its overall impact (Hammarlund, Nilsson & Hagell, 2012). Yet although underrepresented, research exploring more broad ranging experiences of PD has become increasingly prominent (Bramley & Eatough, 2005).

To date, there appears to be no systematic aggregation of studies which have focused on living with PD. Synthesis of the literature to date permits existing research to be contextualised and understood in a more comprehensive manner. It can also allow for more complete knowledge of disease phenomenology and conclusions to be drawn from research that might not be apparent from studies examined in isolation. There is opportunity to strengthen a cumulative evidence base (Britten, 2011; Campbell et al., 2011) and inform service policy and clinical practice (Mays, Pope & Popay, 2005). Synthesising qualitative studies of PD may help to provide healthcare professionals with a better awareness and
understanding of individual experiences of living with PD and inform and shape treatment approaches (Hodgson, Garcia & Tyndall, 2004).

2.1 Aims
Since the experience of living with PD has been increasingly explored by qualitative means over the last decade and no previous reviews exist; the aim of this literature review was to integrate identified studies to offer a comprehensive understanding to inform clinical practice and research. A meta-ethnographic approach was used to synthesise the qualitative research.
Debate continues about what constitutes effective synthesis (see Appendix A for discussion). However, interpretive synthesis has been advocated as a preferred approach to the synthesis of qualitative research, with the findings from different studies being brought together by interpretation to achieve a deeper understanding (Campbell et al., 2011). Meta-ethnography, as a highly interpretative method of synthesis that offers an alternative to aggregative methods of synthesis (Britten et al., 2002), has received the most attention to date (Campbell et al., 2011; Dixon-Woods, Booth & Sutton, 2007) and is arguably the best developed method for synthesising qualitative data (Britten et al., 2002; Campbell et al., 2011).

Synthesis in meta-ethnography is achieved from the translation of studies into one another (Noblit & Hare, 1988), by relating findings of different studies to each other, in order to determine new relationships between concepts (Campbell et al., 2011). It enables those engaged in synthesis to understand and transfer ideas, concepts and metaphors between the various studies (Britten et al., 2002) and has been effectively used for synthesis of research in healthcare, specifically for questions pertinent to patient experiences of chronic illness (Atkins et al., 2008). Published examples include patient experiences of rheumatoid arthritis (Campbell et al., 2011), diabetes (Campbell et al., 2011), back pain (Snelgrove & Liossi, 2013) and cancer (Smith, Pope & Botha, 2005) and the approach was therefore deemed appropriate to focus on the experiences of individuals living with PD.

Noblit and Hare (1988) identified seven phases when completing a meta-ethnography, these have been incorporated into the methods used for this review; 1) developing a research question; 2) identifying relevant studies (including use of an appropriate search strategy and inclusion and exclusion criteria); 3) reading the studies; 4) deciding how the studies are related; 5) translating the studies in relation to one another; 6) synthesising the translations and 7) presenting the synthesis. A more comprehensive explanation of these seven phases can be found in the Appendices (Appendix B).

3.1 Meta-ethnography; phases one to three

3.1.1 Search Strategy

A systematic search of seven databases (CINAHL, Web of Science, Psychinfo, Medline, Scopus, Pubmed and The Cochrane Library) was conducted in September 2013 and again in
March 2014. Searches were carried with no time limits to ensure diverse psychological literature was included (qualitative research within this area also appeared to be limited) and was confined to peer-reviewed papers in English. Broad search terms such as *Parkinson*, *experience* and *qualitative* were used to find as many pertinent studies as possible (see Appendix C). To ensure search focus and improve identification of qualitative studies, search terms specifically concerning qualitative methodology (such as phenomenology) were used (Dixon-Woods et al., 2007).

The search strategy was devised using the CHIP (Context, How, Issue of interest, Population) search strategy tool (Shaw, 2010), deemed suitable since the purpose of the review was to explore individuals’ experiences. The Context was not limited and was open to those living with PD in any context. Qualitative methodology was specified for this review, allowing exploration of rich and varied accounts of an individuals’ experience of PD. The Issue of interest was PD and the Population was individuals with PD.

3.1.2 Inclusion and exclusion criteria
To enable selection of relevant papers, inclusion criteria for papers were that they:

1) Used qualitative framing, methodologies and analysis (all qualitative methodologies were included to permit a wider range of papers) to explore individuals’ experiences of PD;

2) Employed single case study designs (meta-ethnography recognises the value of the uniqueness of individual cases and collectives and does not theoretically dismiss single case studies as locally bound; Doyle, 2003);

3) Published multiple papers from the same study (as long as they provided new data).

Papers were excluded if they:

1) Focused on an intervention, or a specific symptom of PD;

2) Combined results from individuals’, carers and health-care professionals, preventing separate and distinct examination of individuals’ experiences;

3) Comprised editorials, books or literature reviews.

3.1.3 Selection of papers
A total of 369 titles and abstracts were found during the initial search. After duplicates were removed, 170 were available for further scrutiny. Titles and abstracts were screened for
relevance according to three screening questions (Is the study qualitative research? Is the study about PD? Does the study report individuals’ experiences of having PD?), prompting removal of a further 154 articles. Reasons for omission included use of quantitative methodology, a circumscribed focus on a particular aspect of PD (e.g. a particular symptom) or a sole focus on intervention.

Sixteen full text articles that met the inclusion criteria were therefore obtained and assessed for eligibility. Reference lists of all sixteen articles were searched to identify any further relevant articles and contact was made with known authors in the field, yielding no further articles. Following assessment for eligibility, four articles were further excluded. One because it focused on individuals’ experiences of PD prior to Deep Brain Stimulation (Haahr et al., 2010) and a second because the study focused uniquely on palliative care (Hudson et al., 2006). The final two studies were excluded because they examined frequent practices and factors that were important for quality of life, using specific quality of life facets (in association with quantitative measures for example) but not lived experiences more generally (Den Oudsten et al., 2011; Whitney, 2004). A total of twelve articles were therefore identified as appropriate for review (see Appendix D for a summary table of the study characteristics). A flowchart showing the identification of papers can be seen in the Appendices (Appendix E).

3.1.4 Quality Appraisal
The Critical Appraisal Skills Programme (CASP, 2010) is an appraisal tool regularly used to assess quality and methodological robustness of qualitative research (Campbell et al., 2003). For the purpose of this review the CASP was used as a guide and to aid interpretation of papers. No papers were excluded on the basis of quality (see Appendix F for discussion about quality appraisal tools in qualitative research).

3.1.5 Study Characteristics
A summary of the studies using the CASP checklist as guidance is provided below in a tabular format (Table 1). A description of this information is available in the Appendices (Appendix G)
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3.2 Meta-ethnography; phases four and five

3.2.1 Translating the studies in relation to one another; first and second order constructs

Each of the twelve papers were thoroughly read so that the author became as familiar as possible with the content and details of each of the studies. A data extraction form (see Appendix H) was used to help extract key information and summarise the main themes. From completing the data extraction form, closely examining each of the papers in detail and keeping in mind the aims of the synthesis, a list of key themes, metaphors and concepts from each study were constructed. This was an iterative process, enabling the development of first and second order constructs (presented in Table 2) and allowed the author to determine how the studies were related. It was apparent that there were similar themes across the different studies that could be incorporated into one another; studies therefore appeared to be related by reciprocal translations (explained in Appendix B).
<table>
<thead>
<tr>
<th>Paper</th>
<th>Themes</th>
<th>Author’s comments</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Building on the past (life history, significant events, relationships, identity).</td>
<td>• Need to feel a sense of control over PD. Meaning constantly challenged by changes in symptoms. Routines evolved as symptoms changed.</td>
<td>• Stability, maintaining a sense of control, routines and medicine management - key dimensions.</td>
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<td></td>
<td>• Bridging the present (Managing meaning, managing medication, maintaining stability, protecting routines)</td>
<td>• Future not given centre stage, until stability in medication and routines began to crumble.</td>
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<td></td>
<td>• Broaching the future (Coping fatigue, cracks in relationship, managing strategies and routines)</td>
<td>• Importance of biography in the process of accommodation/shaping identity.</td>
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<tr>
<td>2. Habermann (1999)</td>
<td>• Maintaining An Intact Self by Sustaining A Sense of Continuity - Strive to be in control of body and situations. Planning around medications.</td>
<td>• Intact self and a continuity with pre-Parkinson’s self. Shaped by background, meanings and concerns.</td>
<td>• Meaning of bodily experiences and responses shaped by self and illness understandings.</td>
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<td></td>
<td>• Coping with Limited Horizons: Keeping Possibilities Open - Living in the present.</td>
<td>• Symptoms experienced as a way of staying engaged and connected</td>
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<td>3. Habermann (1996)</td>
<td>• Dealing With Emotional Responses</td>
<td>• Automaticity was lost. Mind/brain unaffected</td>
<td>• Adaptive challenge was dealing with emotional responses and integrating PD into daily lives and self-understanding.</td>
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<td></td>
<td>• Dealing with a Changing Body - Instruct ‘uncooperative’ body. Abilities are questioned.</td>
<td>• As PD progressed individuals had to find new ways of doing activities.</td>
<td>• Becoming skilled expert of medication dosing, timing and sequencing required intense bodily monitoring.</td>
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<td></td>
<td>• Gaining Formal and Practical Knowledge - Becoming skilled.</td>
<td>• Movement that once was pre-reflective required conscious effort.</td>
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<td></td>
<td>• Dealing with Unpredictability: Day-to-day and hour-to-hour. Ongoing bodily monitoring.</td>
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<td>Paper</td>
<td>Themes</td>
<td>Author’s comments</td>
<td>Conclusions</td>
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<tr>
<td>4. Charlton and Barrow (2002)</td>
<td>• Experiences associated with the illness (Progressive loss of functions, loss of identity, loss of future)</td>
<td>• Fears in relation to progressive loss. Awareness is less affected than physical activity.</td>
<td>• Most coping strategies are cognitively orientated to psychological distress.</td>
</tr>
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<td></td>
<td>• Ways of coping (social comparison, fighting spirit, not thinking about the illness, positive outlook, hope and acceptance)</td>
<td>• Threat to identity by being labelled as a person with disabilities/sufferer of a disease.</td>
<td>• Coping focused on maintaining a normal life as possible and denying the condition a central role.</td>
</tr>
<tr>
<td>5. Wressle et al. (2007)</td>
<td>• Consequences on daily living (activity restrictions, habits changes, decreased socialisation, worries and fears)</td>
<td>• Activities taking more time, or impossible to perform. Interaction with stress. Individuals experienced frustration and limited freedom. Avoidance associated with embarrassment and unpredictability.</td>
<td>• Even when not in an advanced stage, PD has a great impact on the daily lives of individuals</td>
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<td></td>
<td>• Facilitating factors (accessibility of health care, coping strategies, psychological support)</td>
<td></td>
<td>• Planning difficult, but necessary to reduce stress.</td>
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<td>6. Caap-Ahlgren, Lannerheim and Dehlin (2002)</td>
<td>• Wish for a stable body image: important to the identity. Women felt conspicuous and avoided activities.</td>
<td>• Symptoms can be seen by anyone. Fear of symptoms, not being in control and unpredictable fluctuation in physical competence. Movement pattern changed as PD progressed.</td>
<td>• PD dominated the women’s daily living and made life embarrassing.</td>
</tr>
<tr>
<td></td>
<td>• Wish to keep traditional female competence: Painful apprehension regarding future and use of a wheelchair.</td>
<td>• On/off periods make it difficult to plan. Interaction with stress.</td>
<td>• The body and environment form an interwoven whole.</td>
</tr>
<tr>
<td></td>
<td>• Need to feel accepted for the person she is: Social contact was difficult and troublesome</td>
<td>• Loss of independence, self-confidence and self-esteem.</td>
<td>• The women’s wish to be looked at as normal healthy persons, to be independent and live as normally as possible is not fulfilled.</td>
</tr>
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<td></td>
<td>• Perceived stigmatisation: feelings of shame. Social withdrawal as the women were afraid of negative evaluation</td>
<td>• Feelings that a person with PD is considered an idiot, incompetent and stupid.</td>
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<tr>
<td>Paper</td>
<td>Themes</td>
<td>Author’s comments</td>
<td>Conclusions</td>
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- **Daily negotiations in the midst of uncertainty:** No consistent days, PD dictates individuals’ day. Individuals engaged in holistic self-assessment. Dependent on timing, medication and symptoms.  
- **Imprisonment:** Locked in confinement  
- **Reconstruction of the self:** Continual effort of examining the former self, attaching meaning to revised self-perceptions of the self with PD.  
- **Reflections on the voyage of reconstruction of the self:** I’m still me. Feeling watched, criticised and judged. Individuals hide symptoms. | • Daily living was challenging and each day required them to battle the unpredictable storm, daily but also minute-to-minute. Integration of PD on a daily basis.  
• Desire to be seen as a person, not as a disease.  
• Isolation - Awareness that life will never be the same, and stigmatization associated with being different.  
• World became more narrow. | • People with PD experience integration on daily basis.  
• “Knowing, acknowledging, seeing, and remembering the person” was the predominant idea.  
• Struggle with dealing with uncertainties and fluctuations of PD while reconstructing their perceptions of themselves. |
**PD Challenges to the Maintenance of Masculine Identity:** Feelings of shame at changing appearance and concerns about others’ perception. Their bodies become unreliable.  
**Gender and Tremor** – Embarrassment and hiding of symptoms | • Women’s commentary on symptoms emphasised activities that connected them to others.  
• Men’s narratives characterised by attention to appearance and strength. | • Experience of impairments is gendered.  
• Importance of role continuity.  
• Men; withdraw from social arenas. Women; become distressed when unable to fulfil their domestic responsibilities. |
<table>
<thead>
<tr>
<th>Paper</th>
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<th>Author’s comments</th>
<th>Conclusions</th>
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</thead>
</table>
| 9. Sunvisson (2006) | **Changing habitual skilfulness:** Individuals ‘know-how’ no longer works and movements have to be broken down. Conscious structuring and planning of activities. Unreliable body becomes the foreground of actions.  
**Striving for involvement:** Embracing personal challenges involves never ending effort.  
**A changing horizon:** Strive to cope with the changed circumstances of life. Discrepancy between the mind and body. Future visions become limited to life here and now and the world is experienced more intensely. | • Thoughts and actions impossible to unite. Demands concentration.  
• As the illness forced her to change the way in which she manages, it also changed the way of living during this time.  
• Incorporated symptoms of PD into life world.  
• Transformation of the way time and space was lived and experienced. Strategies become less reliable.  
• Self-image altered. | • PD is manifested as a sense of lost control over daily life and as a life with unpredictable bodily reactions.  
• Intimate connection between experience of environmental and social influences.  
• Help individuals to elicit potential situations that would solicit a reintegrated healthy understanding of the self in the situation. |
| 10. Marr (1991) | **Impact of the disease:** Diagnosis, physical and social activity loss and emotional loss.  
**Dealing with the Disease:** social comparison, support, medication. Carrying on as usual. Live one day at a time.  
**Maintaining Independence and Normality** No choice but to persevere.  
**Effort** - Increased effort required in all aspects of experiences of living with PD. Associated fatigue. | • Losses resulted in a changed self-concept, self-esteem because individuals felt less capable than before.  
• Visible changes and unwanted attention was embarrassing.  
• Frustration arose because of the individual’s inability to easily or normally perform activities. | • Overriding theme was effort  
• The need to be as close as normal as possible was a desirable goal.  
• Adjusting routines and lifestyle to meet the demands of PD.  
• Individuals chose to persevere because they had no choice. |
<table>
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<tr>
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<th>Author’s comments</th>
<th>Conclusions</th>
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</table>
| 11. Bramley and Eatough (2005) | • **Mind and body**: The challenge of movement: loss of control over taken-for-granted basic functions and thinking. The cyclical experience: little physical and mental consistency and pressure in social situation. Medication: Dependent on, also created feelings of being powerless.  
• **Self and agency** – Misrepresentation of the body creates a new self which causes conflicts. Conscious of appearance and fear of negative evaluation. Stable, inner self unaffected by PD. Thoughts of the future are avoided and life is planned around physical symptoms and medication. | • Body as alien; constantly tormenting and plaguing the sense of oneself. Can’t make it behave.  
• Self-instruction for loss of movement.  
• Fear that strangers will make identity assumptions based on physical symptoms. Negative self-image. PD inconsistent with feminine persona.  
• Trapped in a body. Attempt to hide physical symptoms and project a normal body to others. | • Living with PD engenders a complex relationship between mind and body, and has a profound effect on the sense of self.  
• ‘Thoughtful attendance’ the loss of unity between mind and body and the effort required to achieve a level of control.  
• Inner self as imprisoned by an unreliable and unresponsive outer self.  
• Dynamic process of coping. |
| 12. Fleming, Tolson and Schartau (2004) | • **Labile Emotions**  
• **Body image**: Feeling self conscious and embarrassed about tremor.  
• **Dependence**: Fear of future.  
• **Lifestyle**: Changes in lives, work, hobbies, driving.  
• **Isolation**: Social isolation. Being in touch with own bodies and taking control of medication. | • Shock, horror and disbelief of the diagnosis.  
• Medication as their “only weapon” Individuals self-regulated.  
• Sense of loss experienced.  
• View of PD as an “old persons” condition. | • All participants acknowledged dread of the future through concerns at their increasing dependence.  
• For the women who are having to make major changes to their lifestyles the seemingly trivial becomes vitally important. |
4.0 Results

4.1 Meta-ethnography; phases six and seven: Synthesising the translations and presenting the synthesis and third order constructs

Interpretations of the original authors’ interpretations (second order constructs) were made to develop seven third order constructs, grouped under four overarching main themes (see Table 3). The reviewer ensured that new interpretations were derived from the original data by constantly examining the table of first and second order constructs and each of the original papers throughout the synthesis. The presence of third order constructs / themes in each study can also be seen in Table 3.
Table 3: Presence of third order constructs / themes

<table>
<thead>
<tr>
<th>Third order constructs</th>
<th>1. Uncertainty of adjustment</th>
<th>2. Emotional challenges</th>
<th>3. Trapped</th>
<th>4. Losing predictability yet imposing regimes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Body as incompetent</td>
<td>My mind tells my body to go</td>
<td>I look different</td>
<td>Loss of spontaneity</td>
</tr>
<tr>
<td>1. Williams, 2008</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>2. Habermann, 1999</td>
<td>✓</td>
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<td>✓</td>
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<tr>
<td>3. Habermann, 1996</td>
<td>✓</td>
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<td>✓</td>
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<tr>
<td>4. Charlton, 2002</td>
<td>✓</td>
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</tr>
<tr>
<td>5. Wressle, 2007</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
</tr>
<tr>
<td>6. Caap-Ahlgren, 2002</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>7. Stanley-Hermans, 2010</td>
<td>✓</td>
<td>✓</td>
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<td>8. Solimeo, 2008</td>
<td>✓</td>
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<td>✓</td>
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<tr>
<td>10. Marr, 1991</td>
<td>✓</td>
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<tr>
<td>11. Bramley, 2005</td>
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<tr>
<td>12. Fleming, 2004</td>
<td>✓</td>
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</table>
4.2 Third order constructs

1. Uncertainty of adjustment and coping

The experience of PD was consistently emphasised as unpredictable in nature. Respondents described active attempts to manage symptoms and maximise functioning (Bramley & Eatough, 2005; Habermann, 1999; Sunvisson, 2006) but felt they were continuously reminded about the uncertainties of the condition (Williams & Keady, 2008), and that coping “could never be the same” (Stanley-Hermanns & Engebretson, 2010, p.352). Respondents emphasised the struggle to live in the present and not worry about the future (Charlton & Barrow, 2002; Habermann, 1996; Habermann, 1999; Marr, 1991; Sunvisson, 2006; Williams & Keady, 2008), whilst maintaining a consistent approach to daily management. Unpredictable symptoms magnified these challenges requiring continued flexibility and resourcefulness in adapting coping strategies (Bramley & Eatough, 2005).

“Well I try not to worry about the future. I try to live one day at a time. I just cope with it that way” (Marr, 1991, p.327).

With disease progression, respondents expressed the need to re-appraise their situation contingent on erratic and additional symptoms, loss of mobility and the inability to undertake previously achievable tasks (Habermann, 1996; Stanley-Hermanns & Engebretson, 2010; Wressle, Engstrand & Granérus, 2007).

“Everything that I go to do is hard to do. Getting the lids off of jars or opening a box or trying to read or anything I do is more difficult…Things you just take for granted until you can’t do it” (Stanley-Hermanns & Engebretson, 2010, p.353).

This was reported as destabilising and distressing as medication efficacy reduced and previous coping strategies became less effective (Habermann, 1996; Williams & Keady, 2008). Such losses forced respondents to face a diminished future, further deterioration and death (Charlton & Barrow, 2002; Habermann, 1999; Sunvisson, 2006) as their social, temporal and physical world shrank (Charlton & Barrow, 2002; Stanley-Hermanns & Engebretson, 2010; Sunvisson, 2006).
“Now, my world has shrunk, and my perspective has gotten a little bit deeper. I don’t have to go so far away for experiences anymore” (Sunvisson, 2006, p.97).

Unstable symptoms and general health appeared to emphasise the necessity of medication. Essential to control symptoms, many respondents perceived it as “their only weapon which kicked in and did battle with the disease” (Fleming et al., 2004, p.517) “flicking on a switch” (Bramley & Eatough, 2005, p.227), allowing the individual to function again (Habermann, 1996; Sunvisson, 2006). Experimenting with medication and dose could offer a sense of control and hope (Bramley & Eatough, 2005; Fleming et al., 2004; Habermann, 1996; Habermann, 1999; Sunvisson, 2006; Williams & Keady, 2008). However, some individuals also expressed how medication could itself be unreliable. Despite increased mobility the movement felt ‘false’ and itself a problem if becoming ‘too much’ (Bramley & Eatough, 2005; Habermann, 1999) and engendering further problems, such as dyskinesia and a feeling of being controlled (Fleming et al., 2004; Sunvisson, 2006).

“......I add some more medicine and suddenly, I become so over-mobile that I can’t, I can’t manage. It’s terrible” (Sunvisson, 2006, p.95).

Although less frequently noted, individuals expressed hope around the progression of the disease and their future (Charlton & Barrow, 2002; Habermann, 1999). Some individuals expressed gratitude for their current situation and compared themselves to others who were less fortunate (Bramley & Eatough, 2005; Charlton & Barrow, 2002; Fleming et al., 2004; Marr, 1991; Stanley-Hermanns & Engebretson, 2010).

“You don’t think you’ll end up like this and yet I’m grateful to be like this because I could be a lot worse” (Charlton & Barrow, 2002, p.476).

“Hopefully it’s a slow process and that’s basically what I hope for, that I can go on without it getting much worse quickly” (Charlton & Barrow, 2002, p.476).

Individuals described how being with others who had PD enabled them to share their stories of dealing with the disease and develop a sense of connection, which appeared to provide a valuable source of strength in being able to manage the effects of PD (Bramley & Eatough, 2005; Charlton & Barrow, 2002; Marr, 1991; Williams & Keady, 2008). Alternatively,
some avoided seeing others with the disease for fear of what their future might hold (Charlton & Barrow, 2002; Williams & Keady, 2008; Wressle et al., 2007).

“And then when you find other people have it you feel a little bond with them. They are coping with the same thing” (Marr, 1991, p.328).

2. Emotional challenges to daily living
After initially reporting shock and anger, the majority of respondents disclosed emotional lability associated with disease management and real and perceived losses, particularly relating to mood, anxiety, self-confidence, self-esteem and self-concept. It was apparent throughout all the papers that progressive impairments of physical and mental functioning affected individuals’ sense of independence and freedom. Furthermore, as activities became complicated, time consuming or impossible, increased effort and exhaustion permeated all aspects of life, both emotionally and physically and created frustration, magnified by failure to control the body.

“Living with PD is very frustrating…sheer frustration…you can’t do anything…I live a life of frustration” (Stanley-Hermanns & Engebretson, 2010, p.356).

Unpredictability of symptoms seemed to engender fear as well as challenge future existence (Charlton & Barrow, 2002; Fleming et al., 2004; Habermann, 1999; Stanley-Hermanns & Engebretson, 2010; Sunvisson, 2006; Williams & Keady, 2008; Wressle et al., 2007). Cumulatively, these experiences appeared to erode the self as competent and having agency.

“........I can picture myself sitting paralysed in a wheelchair unable to communicate, in pain because my back is hurting and no one knows that I need to lie down. Or unable to watch television because no one knows they have given me the wrong spectacles and I cannot tell them” (Charlton & Barrow, 2002, p.475).

3. Trapped
3.1 Body as incompetent
Experiences of freezing, tremor, ‘off’ states and dyskinesia were commonly expressed, meaning a “smoothly functioning body ceased to be” along with limited actual and appraised control (Habermann, 1996, p.403). Daily, hourly and minute-by-minute fluctuations in
symptoms and ability were frequently described, with little consistency in ability to execute a movement, “I could a moment ago, why not now?” (Caap-Ahlgren et al., 2002, p.91). Individuals experienced oscillations in perceived competence as their symptoms fluctuated, particularly between ‘on’ and ‘off’ periods (Caap-Ahlgren et al., 2002; Habermann, 1999; Marr, 1991; Solimeo, 2008; Sunvisson, 2006), during which fluctuations became more pronounced and threatening.

“Very fluctuating – fluctuating quite a lot…..from being off to being on. In the middle of doing things I sort of fade away……just like a rag doll and won’t be able even to get out of the chair or….reach a drink or….anything, not even to speak sometimes” (Williams & Keady, 2008, p.382).

Individuals viewed their body as unreliable, sabotaging their ability to do the things they wanted to do (Bramley & Eatough, 2005; Fleming et al., 2004; Solimeo, 2008; Stanley-Hermanns & Engebretson, 2010; Sunvisson, 2006; Wressle et al., 2007).

‘Cleaning is almost the worst. When you have to use your arms, it doesn’t work, as I can’t lift.’ (Wressle et al., 2007, p.134).

During ‘off’ periods an individual experienced a complete loss of physical competence (Habermann, 1999) and was described by some as a “painful experience” (Caap-Ahlgren et al., 2002, p.91). Fluctuations and uncertainty in certain abilities appeared privileged, notably the core functions of feeding and dressing (Caap-Ahlgren et al., 2002; Marr, 1991; Stanley-Hermanns & Engebretson, 2010; Wressle et al., 2007). Women felt anxious about their inability to complete everyday household tasks (Caap-Ahlgren et al., 2002; Solimeo, 2008). Furthermore, tremor precluded certain tasks leaving them to feel “worthless and stupid” (Stanley-Hermanns & Engebretson, 2010, p.357). Despite these difficulties, some individuals expressed their desire to do things independently (Caap-Ahlgren et al., 2002; Habermann, 1996; Marr, 1991; Williams & Keady, 2008), since accomplishing tasks produced a sense of worth and competence.

“You persevere...You don’t want someone to go ahead and do everything for you...You need to do it for yourself” (Marr, 1991, p.328).
The transient nature of competence appeared to markedly affect self-confidence, self-esteem and perceived inferiority (Caap-Ahlgren et al., 2002; Marr, 1991). Some respondents alluded to a constant sense of uncontrollability in relation to unpredictable fluctuations in physical competence and sustained ‘off’ periods, underpinned by ruminative worry (Caap-Ahlgren et al., 2002). The knowledge of symptom unpredictability that intention might not permit action was associated with anticipatory fear and avoidance (Bramley & Eatough, 2005; Caap-Ahlgren et al., 2002; Charlton & Barrow, 2002; Sunvisson, 2006).

3.2 “My mind tells my body to go but it doesn’t listen”
Fundamental movements and activities previously undertaken without conscious effort now required enormous focus (Habermann, 1996; Marr, 1991; Sunvisson, 2006). Automaticity of movement was lost as the mind and body became separated and seemed impossible to unite (Bramley & Eatough; Solimeo, 2008; Stanley-Hermanss & Engebretson, 2010; Sunvisson, 2006). The former tried to control and consciously instruct an uncooperative and unresponsive body (Habermann, 1996). Individuals expressed a need to thoroughly consider and deconstruct each sequence of action to initiate and maintain a series of movements (Habermann, 1996; Sunvisson, 2006), described as ‘thoughtful attendance’ (Bramley & Eatough, 2005).

“I would put my hand up to wave good-bye and I’d put it up and it wouldn't wave. And that was a peculiar feeling. I could lift it and it wouldn't be automatic-and I'd think wave. Oh yeah, I had to consciously do it” (Habermann, 1996, p.403).

Movements that had appeared unconscious such as sitting or standing straight required conscious attention to achieve, since failure to do so increased the risk of falling or injury (Sunvisson, 2006). Intensified awareness and inability to make their bodies act as desired, left them to feel incarcerated in a body wilfully disobeying (Solimeo, 2008; Stanley-Hermanss & Engebretson, 2010; Sunvisson, 2006; Wressle et al., 2007).

“I feel like I am locked in confinement…I can’t do things that I want to do” (Stanley-Hermanss & Engebretson, 2010, p.352).

“I am a prisoner of my own house and a prisoner in my own body” (Stanley-Hermanss & Engebretson, 2010, p.353).
3.3 “I look different, I walk different, and shake a bit but it’s still me....”

Individuals expressed a desire to retain their individual self and not be defined by disease (Stanley-Hermanns & Engebretson, 2010), however, some felt the condition created a self in conflict with perception of a real inner self, notably an unresponsive and unreliable external self (Bramley & Eatough, 2005). Individuals were aware that their changing bodies and symptoms were visible; and described feeling self-conscious of being flawed and incapable, ‘demented’, ‘senile’, ‘cripple’, ‘freak’, ‘incompetent’ or an ‘invalid’ (Bramley & Eatough, 2005; Caap-Ahlgren et al., 2002; Fleming et al., 2004; Habermann, 1996; Marr, 1991; Solimeo, 2008; Stanley-Hermanns & Engebretson, 2010; Sunvisson, 2006). Individuals described shame (Caap-Ahlgren et al., 2002; Habermann, 1999; Solimeo, 2008), embarrassment (Bramley & Eatough, 2005; Fleming et al., 2004; Marr, 1991; Wressle et al., 2007), fearing negative evaluation of their physical symptoms and being vulnerable to unwanted scrutiny and criticism (Bramley & Eatough, 2005; Caap-Ahlgren et al., 2002; Marr, 1991; Solimeo, 2008; Stanley-Hermanns & Engebretson, 2010). Communication difficulties (particularly of facial and vocal expression) and the inability to complete basic tasks appeared to magnify these feelings (Caap-Ahlgren et al., 2002; Solimeo, 2008; Stanley-Hermanns & Engebretson, 2010).

Individuals described their avoidance of social situations where visible differences could be observed by others (Caap-Ahlgren et al., 2002; Habermann, 1999) and become a source of embarrassment such as eating difficulties (Solimeo, 2008; Wressle et al., 2007). Some respondents disclosed that social anxiety concerned them more than functional limitations (Solimeo, 2008).

“I just don’t like [how I look]. Well, I am bent over. I walk downtown and in those big store windows I see that guy in there and I don’t know him. ‘Who the hell is that?’ Bent over. That really hurts” (Solimeo, 2008, p.46).

Maintaining a stable body image appeared important to individual identity (Caap-Ahlgren et al., 2002). Living with PD appeared to create discordance on the basis of age (with descriptions of a vital, young mind trapped within a frail, old body) (Bramley & Eatough, 2005; Stanley-Hermanns & Engebretson, 2010) and gender (women expressed how they felt physically undesirable and unsexy due to the symptoms they experienced (Bramley &
Eatough, 2005; Caap-Ahlgren et al., 2002; Fleming et al., 2004). Men expressed dissonance with regard to ambition and body strength; “Well, I don’t have ambition and I don’t have the strength and I don’t have the balance. Those are the three main things...” (Solimeo, 2008, p.45). Individuals resisted being constructed as incapacitated and endeavoured to present a normal body by refusing disability aids and attempting to conceal their symptoms (for example by putting a hand in a pocket or holding onto something to hide tremor) (Bramley & Eatough, 2005; Charlton & Barrow, 2002; Solimeo, 2008; Stanley-Hermanns & Engebretson, 2010; Sunvisson, 2006).

“I try and stop myself from moving. So I hold my arm or I put my arms to the back and clasp my fist like this, so my fingers aren’t moving and my hands aren’t moving and I try and disguise it but I look worse when I disguise it because I’m doing contortions” (Bramley & Eatough, 2005, p.230).

4. Losing predictability yet imposing regimes

4.1 Loss of spontaneity

In an attempt to manage the disease and maximise functioning, individuals were forced to live their lives by carefully constructed routines, planning and adjusting their daily activities in relation to symptoms and medication. They described becoming skilled monitors of timing, sequencing, bodily functioning and medication dosing (Bramley & Eatough, 2005; Habermann, 1996; Habermann, 1999; Stanley-Hermanns & Engebretson, 2010; Sunvisson, 2006; Williams & Keady, 2008).

“So I live with Parkinson’s on a daily basis…I have to adjust my times…do it [daily activities] slowly or do it differently…” (Stanley-Hermanns & Engebretson, 2010, p.352).

However, a life of structure and regimes removed spontaneity (Bramley & Eatough, 2005), leaving respondents to feel ‘locked up’ with little freedom (Wressle et al., 2007).

“You have to plan it by tablets, not by life and clocks and you know what I mean, you can’t just say ‘Oh I’ll get up at six o’clock and I’ll be straight out that door’ because I couldn’t do it” (Bramley & Eatough, 2005, p.230).
Furthermore, although planning around medication and timing was essential, it was difficult due to the frequent changes in level of function and unpredictability of symptoms (Caap-Ahlgren et al., 2002; Wressle et al., 2007). Despite rigorous structures and routines, there appeared to be limits to the amount of control achieved (Habermann, 1999; Habermann, 1999). Some avoided planning altogether (Stanley-Hermanns & Engebretson, 2010).

“On and off periods make it difficult to make plans” (Caap-Ahlgren et al., 2002, p.90).

“.....It does me no good to plan things, because I never know what I am physically going to be able to do on any given day” (Stanley-Hermanns & Engebretson, 2010, p.351).

Failure to adhere to routines and timing of medication had adverse consequences for the individual, reinforcing their importance (Stanley-Hermanns & Engebretson, 2010; Williams & Keady, 2008; Wressle et al., 2007).

“But once this prescription wears, this medication wears off if I don’t take the tablets in good time I’m absolutely stuck, you know I’m like a pillar of salt really.....” (Williams & Keady, 2008, p.383).

4.2 “If I get stressed everything is locked”
Symptoms of PD also appeared to fluctuate and interact with certain environmental situations. Individuals described how symptoms increased when they felt pressured or stressed (Bramley & Eatough, 2005; Caap-Ahlgren et al., 2002; Habermann, 1996; Sunvisson, 2006) and an inability to function and a feeling of becoming ‘locked’ was expressed (Wressle et al., 2007).

“.....I was shaking, I had a terrible tremor.... So I have to learn how to adjust this when I'm under pressure. I have to figure how it works with stress and anxiety” (Habermann, 1996, p.405).

“Stress I can’t stand at all. I have to be ready in good time with everything. Because, if I get stressed everything is locked, nothing works” (Wressle et al., 2007, p.134).
Unexpected interruptions, surprises and pressure in social situations precipitated ‘off’ periods and freezing, particularly if individuals had to walk through crowds of people, if they were rushed or if they had to cross a road, for example and was associated with anticipatory fear of freezing and humiliation (Bramley & Eatough, 2005; Caap-Ahlgren et al., 2002). As a consequence, stress avoidance such as eschewing pressured social situations (crowds for example) was reported and planning for all contingencies to reduce feeling harried (Sunvisson, 2006; Wressle et al., 2007).

By contrast, in certain emotional and environmental contexts (feeling happy and well, being with family, enjoyment at social gatherings), in which respondents felt ‘at one’, respondents reported fewer symptoms or seemed less conscious of how their physical body behaved (Bramley & Eatough, 2005; Caap-Ahlgren et al., 2002; Sunvisson, 2006).

“It’s fantastic when I walk in the forest. I get quite a different posture, totally relaxed. You should see me when I’m out shopping. People probably think that I’m really drunk. I have no steadiness when I walk” (Sunvisson, 2006, p.95).
5.0 Discussion

This meta-ethnographic synthesis was the first to integrate qualitative studies exploring the lived experiences of PD. Despite studies using different populations, locations and qualitative methodologies, the meta-synthesis enabled identification of themes across the papers pertinent to the research aim. Seven third order constructs, grouped under four overarching main themes were identified. Individuals experienced uncertainty in adjustment and coping, and associated emotional challenges of living with PD. A sense of being trapped was reported and living with the disease undermined spontaneity, as life was constrained by routines in drug regimens and relentlessly planned activities.

5.1 Summary of findings and clinical implications

5.1.1 Uncertainty of adjustment and coping

The experience of PD was consistently emphasised as unpredictable in nature, causing progressive uncertainty of adjustment and coping, requiring individuals to continually and independently discover ways of adapting to the disease. Respondents’ sense of isolation in this process was interesting given explicit guidance to health professionals that therapy can enable individuals with PD to enhance existing abilities, and develop their own coping strategies to manage future difficulties (NICE, 2006). Clearly the impact of instability exists despite treatments shown to be effective in improving motor adaptation and performance, and reducing tremor (Macht, Pasqualin & Taba, 2007; Mohr et al., 1996). And those with the disease report any enhanced capacity as temporary, consistent with a trajectory of deterioration.

Discussion of effective interventions focused almost exclusively on medication, with little discussion of alternatives. Medication was experienced with ambivalence offering ability to function and a sense of control, consistent with benefits accrued in other chronic conditions such as diabetes (Georfd & Thomas, 2010). However, for those with PD strict compliance was necessary to avoid adverse consequences, which was demanding and relentless. The ambiguities of medication use (its simultaneous benefits and constraints) could be more often discussed in professional consultations with discussions facilitated to enable negotiation, respecting the individual’s wishes and beliefs in order to support medication taking and maximum treatment benefit (Department of Health; DoH, 2001). Furthermore, self-management programmes could be more readily available, given that in some NHS Trusts
this service is limited to newly diagnosed individuals. These programmes could improve confidence, ingenuity and self-efficacy, as effectiveness has been demonstrated in other chronic health conditions such as Arthritis and MS (DoH, 2001).

A valuable source of support described by individuals was meeting others with PD, although this was difficult for some since exposure to others with advanced disease evoked fear and avoidance. Some of these fearful appraisals and concerns could be addressed by improving understanding of the very individual and idiosyncratic experiences of PD, particularly of symptoms and rate of decline. However, it is acknowledged that tailoring such care can pose significant challenges in the current health system.

Furthermore, as internet use increases, online support groups have become progressively available for people with diverse health conditions and research has demonstrated effectiveness in enabling individuals with PD to cope with the challenges of the disease and improve quality of life (Attard & Coulson, 2012; Lieberman et al., 2006). Although not routinely offered, online support groups could be a useful adjunct or alternative to traditional forms of support, particularly for individuals who cannot (due to mobility difficulties) or choose not to attend face-to-face groups (due to being concerned about encountering others more debilitated than themselves). Further exploration is needed however, to determine the need and efficacy of such a service for individuals with PD.

5.1.2 Trapped
A sense of being trapped in an unreliable body, described in relation to fluctuating perceived and actual competence due to rapid oscillations in symptoms, appeared uniformly distressing. Although other neurodegenerative conditions confer motor uncertainty and failure, such rapid fluctuations in competence are not encountered (NICE, 2003). Furthermore, physical symptoms of PD and aging effects are likely to create further difficulties for individuals with PD as they are likely to experience comorbid physical health problems. Feelings of incompetence generated in this way may compromise self-confidence and self-efficacy detracting from willingness to undertake tasks (McAuley & Rudolph, 1995). Alternatively, a strong desire to perform a functional task but low self-efficacy to act upon it may cause conflict in the form of adjustment difficulties such as anxiety and/or depression (Rejeski et al., 2006). This could be more routinely assessed rather than assuming psychological morbidity as an inevitable but non-specific consequence of the condition. Psychological
intervention to address feelings of low efficacy and competence may increase an individual’s confidence in their ability to perform tasks, prevent active avoidance and potentially reduce the risk of anxiety and depression.

Anticipatory fear of experiencing an ‘off state’, rendering an individual immobile and vulnerable, may engender avoidance of activities and development of safety behaviours. Individuals described how they avoided social situations fearing potential negative evaluation, increased stress and exacerbation of symptoms. Such disclosures are consistent with aetiology and experience of social phobia (Clark, 2001). For those with PD there may be dual benefits to intervening using Cognitive Behavioural Therapy, addressing avoidance and safety behaviours: this therapeutic approach could mitigate the distress of aversive symptoms which might aggravate motor difficulties, and may also reduce withdrawal acknowledged by numerous respondents. It may also reduce potential isolation, explicitly referred to in one study (Stanley-Hermanns & Engebretson, 2010), but a frequent correlate of negative evaluations (Schneider & Conrad, 1981).

Individuals’ descriptions of fear and humiliation when freezing, and others’ judgements of their symptoms revealed sensitivity to negative evaluation. Individuals resisted being constructed as incapacitated and endeavoured to present a normal body by refusing physical aids and concealing symptoms. Such rejection of identity rooted in invalidism is consistent with other research in chronic illness (Charmaz, 1987) and in PD (Burgener & Berger, 2008; Nijhof, 1995; Posen et al., 2000). Yet PD appeared to create an external vulnerable self which could be potentially shaming for individuals, indeed, individuals referred to shame and embarrassment of the disease. Shame is a complex and painful emotion (Goss & Allan, 2009), underpinning vulnerability (Brown, 2010) and has been associated with lower quality of life (Moreira & Canavarro, 2010), anxiety and depression (Averill et al., 2002). This synthesis suggests that professionals should be aware of the potential psychological consequences of vulnerability and the importance of assessing for such self-conscious emotions. Compassion-focussed therapy has been shown to be beneficial in developing self-compassion to act as an antidote to shame (Gilbert & Irons, 2005).

5.1.3 Loss of spontaneity
Individuals described how experience and management of PD sapped life’s spontaneity and freedom through need for routines in drug regimens and relentlessly planned activities to
ensure their bodies could act, and avoid adverse consequences. Such reduction in autonomy and choice, particularly when accompanied by routines of variable effectiveness, may increase vulnerability to depression via learned helplessness. A loss of perceived and actual competence was frequently expressed, associated with rumination about inabilities to undertake previously achievable tasks, and frustration and fear of a diminished future. These findings suggest that interventions such as mindfulness may be beneficial, given their focus on non-judgmental awareness and acceptance of the present to enable disengagement from potentially unhelpful rumination, emotions and bodily sensations. Optimistic findings in a range of chronic health conditions have been reported, including PD where individuals expressed an ability to make positive changes to coping responses (Fitzpatrick, Simpson & Smith, 2010).

5.2 Strengths and Limitations
This synthesis included studies reporting on a range of ages (young and old), disease severity, gender and contexts, providing greater opportunity to identify themes capturing the breadth and depth of living with PD.

It is acknowledged that this synthesis only included published peer reviewed studies, excluding book chapters and ‘grey literature’. Furthermore, papers were excluded from the synthesis if they combined results from individual’s, carers and health-care professionals therefore, precluding a systemic understanding of the disease. The majority of the papers included in the synthesis were conducted in nursing contexts and only two were psychologically based, potentially limiting psycho-social constructs elicited and analysed in the studies. This synthesis included studies that ranged across approximately twenty years, it is recognised that individuals experiences over this time may have changed given advancements in medication and services provided. It is also acknowledged that several studies explored the experiences of women living with PD and no studies explored men’s experiences alone. However, the majority of studies included both men and women’s experiences.

The author acknowledged that the findings of this meta-ethnography were further removed from the original data of participant’s experiences of PD, as the findings reflect interpretations of the original author’s interpretations. However, to ensure that themes
stemmed from the findings of the original studies, an iterative process of returning to the
details and findings from the original studies was adopted.

This synthesis sought to minimise problems in identifying qualitative studies by using search
terms specifically concerning qualitative methodology (such as phenomenology; Dixon-
Woods et al., 2007) and a systematic search strategy using several comprehensive search
terms across seven databases. Furthermore, the search terms used have been clearly listed in
the Appendices to enhance transparency.

5.3 Absences
Most of the studies included in the synthesis adopted a cross-sectional design, yet adjustment
to a chronic illness like PD is complex, can be enduring and is often dynamic in nature.
Cross-sectional design use to explore PD phenomena may constrain what information is
captured. From extant quantitative literature, albeit assumptive, experiences of lowered
mood, dementia, hallucinations and impulse control behaviours were under-reported in this
review of qualitatively assessed experiences. Furthermore, there was a lack of discourse
surrounding impact of the disease systemically; particularly trust and satisfaction regarding
carers and care, surprising given that some papers included spousal perspectives. A dearth of
discussion around medication efficacy was also found, somewhat unexpected when
medication effectiveness is limited over time.

Broad psychosocial research exploring PD is less developed in comparison to other chronic
illness such as asthma and diabetes. It has been suggested that diseases affecting verbal
communication such as amyotrophic lateral disease, stroke or PD are unduly unpopular
research topics and qualitative researchers may have a preference to carry out studies with
verbal, articulate and competent adults (Thorne et al., 2002). Indeed, PD has been described
as the ‘Cinderella of brain conditions’ (Hill, 2012), although it is not clear as to why this
might be.

5.4 Future Research
Future exploration of lived experiences of PD from a psychological perspective may provide
opportunities to comprehensively understand the meaning of living with the condition and
potentially gain insight into some of the absent concepts identified in this synthesis. Future
research would benefit from adopting a longitudinal design, as living with a chronic illness is
a complex and often dynamic experience unlikely to be fully captured by cross-sectional studies. This synthesis has highlighted that lived experiences of men with PD is limited (explored in only one study), and future research would benefit from exploring men’s experiences.

To date, no research has attempted to understand the role of self-management in PD, despite its manifest importance in maintaining health (Stanley-Hermanns & Engebretson, 2010) and exploration in other chronic illnesses (Krlaik et al., 2004). Given the findings of the current synthesis, exploration of self-management in PD would be valuable.

5.5 Conclusion
This meta-synthesis has highlighted that individuals with PD experience significant and detrimental physical, psychological and social difficulties associated with living with the disease, and may require additional support to medication alone. However, psychological issues and provision of emotional support is neglected within PD NICE (2006) guidance, in marked contrast guidance for MS (NICE, 2003), in which psychologically-based treatments are recommended to address the emotional distress arising from the experiences of cumulative loss, loss of control, unpredictability and uncertainty. Interestingly, these are also experienced by people living with PD. This review has demonstrated that an increase in provision of Clinical Psychology to specialist PD services is needed, consistent with guidance from The British Psychological Society (BPS; 2009). Specific experiences of PD were under-reported in this review of qualitatively assessed experiences which highlighted the need for further research.
6.0 References

*indicates studies included in the synthesis


Section 2

Empirical study
An exploration into the experiences of Parkinson’s disease and its relationship with emotional well-being

Jodie Goddard

1.0 Abstract

Background: Parkinson’s disease is estimated to affect one person in every 800, it is a condition that affects physical appearance and individuals can experience a wide range of psychological symptoms. No previous research has directly explored visible difference within Parkinson’s disease, despite research existing for other chronic health conditions.

Objectives: This study explored experiences of shame (general, external and body), psychological morbidity (anxiety, depression, social anxiety and fear of negative evaluation), quality of life and body image disturbances in individuals with Parkinson’s disease.

Methods: A total of 81 participants with a diagnosis of Parkinson’s disease were recruited from three outpatient clinics. Participants completed several self-report questionnaires exploring the constructs of interest. Levels of shame, psychological morbidity, body image disturbances and quality of life were compared with other groups (similar and non-clinical populations). Correlation analyses were used to explore relationships between the variables and multiple regression analyses were used to determine the relative importance of shame in individuals with Parkinson’s disease.

Results: The findings demonstrated that participants experienced higher levels of general shame and body image disturbances compared to non-clinical populations and significant associations between shame and psychological morbidity were found. It was found that participants quantitatively reported low levels of shame (external and body), fear of negative evaluation and social anxiety but qualitatively expressed embarrassment, self-consciousness and associated concealment and avoidance behaviours in relation to Parkinson’s disease symptoms. It was suggested that open-ended questions may have facilitated participants to share their experiences in comparison to responding to quantitative self-report measures alone.

Conclusions: This study aimed to explore experiences of shame, psychological morbidity, quality of life and body image disturbance in individuals with Parkinson’s disease. It was found that participants reported low levels of these constructs quantitatively but verbally expressed emotional distress in response to open-ended questions.
2.0 Introduction

Parkinson’s disease (PD) is a progressive neurodegenerative condition in which there is significant depletion of dopamine producing cells in the substantia nigra; an area of the brain involved in movement control (National Institute for Health and Clinical Excellence; NICE, 2006). Cause of cell loss remains unknown however, symptom presentation is thought to arise when cell loss exceeds 80 percent (Parkinson’s UK, 2013). PD prevalence in the UK is 127,000 (Parkinson’s UK, 2013), is estimated to affect one person in every 800 and due to the ageing of Western populations, is likely to increase (Lees, Hardy & Revesv, 2009).

Each individual’s experience of PD differs, however prominent symptoms include tremor, bradykinesia (slowness of movement), rigidity (muscle stiffness) and hypokinesia (poverty of movement). A variety of non-movement symptoms such as difficulties with sleep, speech and communication, dysphagia (swallowing difficulties) and cognitive impairments may also be experienced (Parkinson’s UK, 2013). Very few areas of life are unaffected by PD (Brod, Mandelson & Roberts, 1998), as life can become constricted to planning and routines. To try and manage symptoms and maximise functioning individuals engage in daily physical and social adjustment (Playfer, 2002), in relation to symptoms and medication (Habermann, 1999; Williams & Keady, 1999). However, as yet PD is incurable and medication such as Levodopa (L-dopa) is used to mitigate symptoms, yet with potential side effects accumulating over time, worsening the appearance of motoric deficits (NICE, 2006). Dyskinesia is one such side effect whereby the individual presents with involuntary muscle movements and spasms.

The overt physical consequences of PD have been extensively researched, but psychosocial consequences less so, with evidence to suggest that physicians may overlook lowered mood and anxiety in older individuals (Quelhas & Costa, 2009). Yet individuals can experience a wide range of psychological, and social symptoms (Parkinson’s UK, 2013) with adverse impacts on quality of life (Adler, 2002; Caap-Ahlgren, Lannerheim & Dehlin, 2002; Chapuis et al., 2005; Frazier, 2000; Hirayama et al., 2008; Leonardi et al., 2012; Schenkman et al., 2002), notably psychological difficulties can compound the pathological effects of PD (Suzukamo et al., 2006).
Prevalence data for depression in PD, even in the absence of a clear relationship between the two entities, is significant (NICE, 2006). Mean prevalence, derived from a review of 26 studies (Cummings, 1992), was reported at approximately 40%, with a range of 4-70%. More recent data is supportive with 65% of individuals with PD reporting lowered affect (Suzuki et al., 2009), and is of significant concern given depression is a main predictor of suicidal ideation in people with PD (Kummer, Cardoso & Teixeira, 2009).

Anxiety also appears common amongst individuals with PD with prevalence rates from 25% (Dissanayaka et al., 2010), to 50% (Marinus et al., 2002). Furthermore, anxiety and depression often coexist (Dissanayaka et al., 2010; Marinus et al., 2002; Pontone et al., 2011; Quelhas & Costa, 2009) which may reflect temporary cessation of motor function potentiating embarrassment, further exacerbating anxiety and promoting more withdrawal, inactivity and depression (Adler, 2002).

Whilst depression and anxiety in PD are often argued to be a consequence of underlying neuroanatomical degeneration (Cummings, 1992; McDonald, Richard & DeLong, 2003), the mechanisms are inadequately understood (Schrag, Jahanshahi & Quinn, 2001) and research is contradictory. Although biochemical changes may be associated with depression in PD, an individual’s perception and appraisal of the condition and symptom impact may be more important for adjustment than objective severity and impairment (Schrag et al., 2001). Some research in PD has sought to examine psychological phenomena such as social anxiety in which appraisals figure more prominently (Crippa et al., 2008; Macht, Pasqualini & Taba, 2007; Solimeo, 2008), although such research is both scarce (Bolluk et al., 2010) and variable in focus and quality. A fundamental feature of social anxiety is thought to be fear of negative evaluation (FNE; Rapee & Heimber, 1997; Weeks et al., 2005). Indeed, Crippa et al. (2008) suggest that high rates of social anxiety among PD individuals reflect FNE and appearing different rather than a particular neurobiological process taking place. Social anxiety and distress in social interactions may occur as a consequence of living with a medical condition that affects physical appearance (Bolluk et al., 2010).

2.1 Visible difference

Individuals with visible differences may be hypersensitive to others looking at or distancing themselves (Gilbert, 2002) and may fear adverse evaluation from others, potentially magnifying adjustment reactions in chronic disease (Thompson & Kent, 2001). A limited
literature suggests those with PD are concerned that their diagnosis will be revealed to others (Fitzpatrick et al., 2010) and fear public exposure (Caap-Ahlgren et al., 2002; Macht et al., 2007). Visible symptoms such as tremor, stooped posture and shuffling gait may prompt embarrassment and avoidance of social situations because of evaluative fears (Quelhas & Costa, 2009). Given the condition affects physical appearance, including overt motor changes, on-off presentations and tremor (which are likely to become more obvious with progression), it is surprising that experience of visible difference has not been more explored within PD. Although indirectly expressed, individuals with PD have reported feelings of self-consciousness (Bramley & Eatough, 2005; Caap-Ahlgren et al., 2002; Fitzpatrick, Simpson & Smith, 2010; Fleming, Tolson & Schartau, 2004) particularly in relation to symptoms such as tremor (Calne, 2003; Fleming et al., 2004; Velickovic & Gracies, 2002), with the potential to undermine self-esteem and confidence, and cause individuals to isolate themselves (Calne, 2003).

Certainly for other conditions in which visible difference figures prominently, self-esteem appears diminished and depression and anxiety elevated (Thompson & Kent, 2001). Individuals with visible difference may experience social awkwardness and great distress, which may increase feelings of dislike of the self (Gilbert, 2002). In those who are particularly appearance-conscious and socially anxious, concerns with evaluation, interpretive biases, sensitivity to threat and an inadequate sense of self are likely to be magnified (Rapee & Heinberg, 1997). Evaluating the self as defective may be associated with a sense of shame and it has been suggested that individuals living with psoriasis (Gilbert & Miles, 2002), acne (Kellett & Gilbert, 2001), obesity (Malterud & Ulriksen, 2010), women following breast cancer surgery (Moreira & Canavarro, 2010) and disfiguring conditions more generally (Rumsey et al., 2004) experience high levels of shame.

2.2 Shame
Shame is an intricate, self-conscious and painful emotion encompassing affective, cognitive, behavioural, social and physiological domains (Goss & Allan, 2009), and focusing on several aspects of the self, including physical appearance (Gilbert, 2002). It is a socially contextualised experience that involves social comparison, and can engender emotions such as anxiety, anger and disgust that undermine positive emotions (Gilbert, 2002). Gilbert (1997) suggested that shame arises in response to threat of, or experience of social rejection or devaluation, based on what others will find as unattractive or undesirable.
Facets of shame include internal shame, relating to an individual’s cognitions and affects about their own attributes, personality characteristics or behaviours (Gilbert, 2002; Goss, Gilbert & Allan, 1994) and external shame, which relates to how individuals think others perceive the self (Allan, Gilbert & Goss, 1994). Significant positive correlations between measures of internal and external shame have been regularly demonstrated (Allan et al., 1994; Goss et al., 1994). Therefore, individuals who think of themselves as inadequate may assume others think of the self in the same way. An individual may however, feel sensitive to how others judge the self without feeling internal shame (Gilbert, 2002).

2.3 Shame and psychological morbidity
Shame-prone individuals report lower quality of life (Moreira & Canavarro, 2010; Persons et al., 2010; Rumsey et al., 2004; Rüscher et al., 2007), feelings of self-consciousness (Magin et al., 2009; Tangney et al., 1996) and appear susceptible to elevated anxiety and depression with positive correlations observed between shame and measures of depression (Andrews Qian & Valentine, 2002; Averill et al., 2002; Cheung, Gilbert & Irons, 2004; Gilbert, 2000; Gilbert & Miles, 2000; Matos & Pinto-Gouveia, 2010; Moreira & Canavarro, 2010; Orth, Berking & Burkhardt, 2006; Rumsey et al., 2004). For individuals experiencing depression, shame may function largely though social anxiety (Gilbert, 2000), and there is evidence that the latter constructs are significantly associated (Fergus et al., 2010; Zhong et al., 2008).

2.4 Shame in PD
Despite research suggesting individuals with disfiguring conditions experience high levels of shame, and circumscribed findings suggesting people with PD experience self-consciousness and social anxiety, there has been little research into the role, experiences and consequences of shame in people with PD. PD is associated with significant psychological morbidity, some of which may derive from how the self is constructed when living with a chronic illness that confers visible difference. Furthermore, tentative data suggests people with PD experience shame and embarrassment as a consequence of PD symptoms and / or perceived reactions from others (Burgener & Berger, 2008; Caap-Ahlgren et al., 2002; Nijhof, 1995; Parkinson’s UK, 2011; Posen et al., 2000), particularly in younger individuals (Schrag et al., 2003), as it is considered to be an age-related disease (Bramley & Eatough, 2007). Avoidance of social situations, concealment of symptoms and avoidance of disease disclosure has been reported by individuals (Bramley & Eatough, 2005; Burgener & Berger, 2008; Caap-Ahlgren et al.,
Some may also fear and avoid eating, drinking and writing in public, due to tremor (Chen & Swope 2007; Lorenz et al., 2011) and may feel conspicuous and embarrassed for themselves, their friends and family and consequently withdraw from society (Parkinson’s UK, 2011). Furthermore, individuals may frequently experience symptoms such as freezing and ‘off’ states where a total loss of movement is temporarily experienced. It has been suggested that a loss of body control can be deeply shaming (Gilbert, 2002).

Despite these findings, study of shame experienced in PD has been limited to only one previous study (Nijhof, 1995), in which an imprecise definition of shame was inferred within a circumscribed qualitative study. To date, no previous studies have directly examined shame in PD, with brief allusion offered to the experience in small, predominantly female samples (Caap-Ahlgren et al., 2002; Posen et al., 2000; Solimeo, 2008).

2.5 Body image and body shame

Like shame, little attention has been paid to individual experiences of body image in people with PD, despite limited evidence of concerns about changed appearance and body image (Caap-Ahlgren et al., 2002; Gamarra et al., 2009; Hirayama et al., 2008; Posen et al., 2000; Schartau, Tolson & Fleming, 2003; Solimeo, 2008; Welsh, Hung & Waters, 1997). Furthermore, body image disturbances have been observed in other visible difference populations, including individuals with physical disabilities (Moin, Duvdevany & Mazor, 2009), acne (Bow et al., 2011), patients undergoing dialysis treatment (Partridge & Robertson, 2011), individuals with Multiple Sclerosis (MS; Pfaffenberger et al., 2011), Motor Neurone Disease (MND; Wasner et al., 2004) and spasmodic torticollis (Jahanshahi, 1991).

Concerns about appearance and body control arising from unpredictable and uncontrollable motor symptoms may be experienced by individuals with PD. Women with PD have described feeling increasingly self-conscious and negative about their changing bodies (Fleming et al., 2004). Self-consciousness about appearance and body image disturbance has been suggested to be closely comparable to body shame (Carr, 2002). Individuals living with disfiguring conditions experience higher levels of body shame than those who are able to conceal their condition (Kent & Keohane, 2001) and may therefore be liable to experience increased levels of distress (Thompson & Kent, 2001). Furthermore, body shame has been identified as an important aspect of adjustment to living with visible difference (Kent &
Thompson, 2002) and has been associated with psychological morbidity (FNE, social anxiety and depression; Gilbert, 2002) and lower quality of life (Moreira & Canavarro, 2010). However, body image disturbance and shame experiences in individuals with PD are unknown and therefore exploration is required.

2.6 Summary and rationale
Whilst the physical consequences of PD have been extensively researched, there is a growing literature on psychosocial impacts. PD appears to be associated with a range of psychological morbidities. However, no one psychosocial variable has shown particular predictive power for psychological wellbeing and little theory-driven research to date has focused on constructs of shame in people with PD. This is despite limited research suggesting individuals with PD experience shame, and a more extensive literature base suggesting that shame has been associated with psychological symptoms in others whose condition confers visible difference.

Given the existing literature base has neglected the role of shame in people with PD; research in this area will explore shame in people with PD and its relationship to psychological status. The current study may help explain whether there are associations between severity of PD, shame, psychological morbidity (anxiety, depression, FNE and social anxiety), body image disturbances and quality of life. Exploring the role of shame in those living with PD could lead to a better understanding of the presence of shame in this population and possible relationships between PD and psychological difficulties.

Although this study is exploratory in nature, if shame and/or severity of PD are predictive of psychological difficulties this would provide greater understanding to suggest that clinicians need to be more aware of possible experiences of psychosocial difficulties. This could enable interventions to be implemented before an individual experiences significant psychological distress and becomes socially withdrawn.

2.7 Research aims
The aim of this study was to explore shame, psychological morbidity, quality of life and body image disturbances in individuals with PD. Specific research aims were as follows:

- To examine the prevalence and extent of experiences of shame (general, external and body), psychological morbidity (encompassing anxiety, depression, FNE and social
anxiety), quality of life and body image disturbances amongst people with PD.

- To determine the extent to which experiences of shame and severity of PD are associated with psychological morbidity, quality of life and body image disturbances in individuals with PD.
- To determine the relative importance of shame and severity of PD for psychological morbidity, quality of life and body image disturbances in people with PD.
3.0 Method

3.1 Design
The study utilised a cross-sectional, quantitative survey design to examine independent variables of shame (general, external and body) and severity of PD and dependent variables of psychological morbidity (anxiety, depression, FNE and social anxiety), quality of life and body image disturbance. Adults with PD were invited to complete eight measures during attendance at a routine outpatient clinic.

3.2 Participants
The sample of participants consisted of individuals diagnosed with PD, attending routine follow-up outpatient clinic appointments (weekly with 4-8 appointments per clinic) at an acute teaching hospital in the East Midlands. All individuals attending the clinic were invited to take part according to inclusion and exclusion criteria. Eligibility required participants to be over 18 years of age and diagnosed with PD by their Consultant Physician. An understanding of English was required, as the majority of the measures had not been validated in or translated into other languages. Individuals were excluded if they had received their diagnosis of PD within the last twelve months (given adjustment reactions may confound the data) or had defined cognitive impairment. All participants invited to take part were screened for dementia and were excluded if there were indications of cognitive impairment.

An *a priori* power analysis was conducted to determine an adequate sample size for this study. A commonly used power value of 0.80 was utilised for this study and is considered to be an acceptable level of power (Cohen, 1988). Given that no studies have previously been conducted in this area it was not possible to ascertain the effect size based on earlier research. Therefore, standardised effect sizes as determined by Cohen (1988) were consulted and a medium effect size was assumed. Pearson’s correlation and multiple regression were planned for analyses. Consequently, for Pearson’s correlation to achieve a power of 0.80 based on a medium effect size (0.3; Cohen, 1988), a minimum of 84 participants were required. For multiple regression to achieve a power of 0.80 based on a medium effect size (0.13; Cohen, 1988) a minimum of 105 participants were required. A significance level of 0.05 was used.
3.3 Procedure and Ethical Considerations

The research was conducted following ethical approval from the local Research Ethics Committee (Appendix I) and the host NHS Trust Research and Development department (Appendix J). The Consultant Physician and PD Nurse Specialist (clinicians) identified eligible participants (according to inclusion and exclusion criteria) from their forthcoming clinic lists by screening the individual’s medical records. Suitable individuals were sent a participant information sheet (Appendix K) and covering letter (Appendix L), inviting them to take part in the study, a week prior to their routine follow-up appointment at the outpatient clinic, ensuring they had more than 24 hours to consider participation in the research.

Individuals were informed via the participation information sheet that they could discuss details of the study with their clinician during their outpatient appointment. During this appointment individuals were able to convey their decision about participation without the presence of the researcher. Individuals were made aware that they were entitled to refuse to take part in the study and that by doing so their care would not be affected in any way.

If individuals agreed to participate, the researcher met with the participant in a separate room to discuss the study and answer any additional questions. A screening tool for cognitive impairment (Clock Drawing Test) and the consent form (Appendix M) were then completed. Participants provided written consent to say that they understood if the study highlighted additional difficulties (cognitive impairment), this would be discussed with their Consultant Physician and unfortunately they would be unable to continue with the study. The consent form also highlighted that talking about personal experiences of PD may be a sensitive topic, it was emphasised that participants were able to ask for a break or stop completing the questionnaires at any time and without giving reason. If participants did become upset during the meeting, the researcher offered support and ensured participants were content to continue. Participants were aware that their participation would remain anonymous and confidential throughout the study and that they could withdraw at any time, without giving reason.

Contact details for the researcher and the Patient Advice and Liaison Service were provided so that participants could ask further questions, request to withdraw or express their concerns about the study. In the event of a participant wanting to withdraw from the study, each participants name was linked to their data by a participant number (no participant requested to be withdrawn). This information was stored separately and only seen by the researcher so that participant’s anonymity and confidentiality was adhered to throughout.
The researcher assisted the participant with completing the measures (by reading the questions to participants and marking their responses on the questionnaires) and asked open-ended questions on two of the measures: completion time varied between 30 and 70 minutes, with the majority of participants taking between 45 and 60 minutes to complete the measures. The severity of PD (Hoehn & Yahr stage) for each participant was obtained from the clinician at the end of each clinic.

3.4 Measures
Measures were chosen based on previous studies’ methodologies, including suitability for the target population, good reliability and validity. Demographic information (age, gender, ethnicity, relationship status and employment status) was collected when the researcher met with the participants to complete the measures (Appendix N).

3.4.1 Measures of Shame

The ESS contains four body shame items selected for this study to measure body shame experiences over the past year in people with PD. These four items ask questions such as; “have you felt ashamed of your body or any part of it?” and uses a four point rating scale, from 1 (not at all) to 4 (very much). Scores are summed to give a total score (minimum of 4 and maximum of 16) with higher scores indicating higher levels of experienced body shame. Andrews et al. (2002) reported high internal consistency (0.92), high test-retest reliability and good construct validity.

*Other As Shamer Scale* (OAS; Goss et al., 1994) (Appendix P).

The OAS comprises an 18-item self-report measure of external shame, exploring overall judgements of how others see the self (Goss et al., 1994), for example; “I feel other people see me as not good enough”. Participants are asked to rate items according to the frequency with which they find themselves feeling or experiencing what is described in the statement. Items are rated using a 5 point Likert scale, from 0 (never) to 4 (almost always). Scores are summed to give a total score (minimum of 0 and maximum of 72) with higher scores indicating higher levels of external shame. Previous research has indicated satisfactory internal consistency (0.92; Goss et al., 1994).
The Derriford Appearance Scale-Short Form (DAS-24; Carr, Moss & Harris, 2005) (Appendix Q).

The DAS-24 is a 24 item self-report measure that assesses distress and dysfunction to problems of appearance; comprising fear, negative affect, shame, social anxiety and behavioural responses of withdrawal and avoidance (Carr et al., 2005). It also allows participants to provide qualitative information about any aspect of appearance about which they are sensitive, self-conscious or ashamed. The DAS-24 asks questions such as; “How distressed do you get when going to social events?” Each item is scored between either 0 and 4 (where a ‘not applicable’ option is given) or 1 and 4. Scores are summed to provide a total score (minimum of 10 and maximum of 96) with higher scores indicating higher levels of distress and greater appearance concerns. Carr et al. (2005) developed clinical and non clinical population norms across several demographic categories. The DAS-24 has good internal consistency (0.92), good test-retest reliability over six months (0.82), good construct validity and has been validated in numerous clinical populations, including cancer, acne, cosmetic surgery and scarring from trauma and burns (Carr et al., 2005).

3.4.2 Measures of Psychological Morbidity

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) (Appendix R).

The HADS is a 14-item self report measure of psychological distress; seven items each address anxiety and depression. It has been used in diverse chronic illness populations and designed to be less affected by confounding presentations of illness (Snaith & Zigmond, 1994). Each item has four potential responses and is scored from 0 to 3. Scores are summed to give an overall total score (minimum of 0 and maximum of 42), a total score for anxiety (0-21) and a total score for depression (0-21). Higher scores indicate higher levels of psychological distress. Scores of 7 or below are deemed to be in the normal range, scores of 8 to 10 are considered to be borderline and scores of 11 or above are regarded as being in the clinical range (Snaith, 2003). The HADS has previously been used with participants with PD, showing adequate internal consistency (0.88), reliability and construct validity that correspond with findings in other populations (Marinus et al., 2002). Other scales frequently contain somatic items that are similar to features intrinsic to PD, therefore, an overestimation of anxiety and depression may occur, however the HADS is a scale that lacks somatic items (Marinus et al., 2002).
**Self-consciousness Scale, Social Anxiety Items** (SCS; Fenigstein, Scheier & Buss, 1975) (Appendix S).

The SCS contains six social anxiety items; these were selected for the purpose of this study to measure social anxiety in people with PD. These six items ask questions such as; “large groups make me nervous” and uses a 5 point Likert scale, from 0 (not at all like me) to 4 (very much like me). One of the items is reverse scored before all of the scores are summed to give a total score (minimum of 0 and maximum of 32), with higher scores indicating higher levels of social anxiety. Satisfactory levels of internal reliability (Nystedt & Ljungberg, 2002) and adequate levels of concurrent and discriminate validity (Carver & Glass, 1976) have been reported.

**Fear of Negative Evaluation Scale** (FNE; Watson & Friend, 1969) (Appendix T).

The FNE is a 30-item self report measure that assesses cognitive aspects of social anxiety. It explores the participant’s avoidance, apprehension, expectation and distress about negative evaluation from others (Watson & Friend, 1969). Participants rate items such as; “I am afraid people will find fault with me” using a true or false response. Items are scored as 0 or 1 and all scores are summed to give a total score (minimum score of 0 and maximum score of 30), with higher scores indicating higher levels of FNE. The FNE has been tested in clinical samples and has demonstrated good internal consistency (0.94; Oei, Kenna & Williams, 1991). Watson and Friend (1969) reported significant correlations of the FNE with other tests of anxiety, test-retest reliability (0.78), internal consistency (0.72) and acceptable criterion validity.

**3.4.3 Quality of life and Body Image Disturbance measures**

*Parkinson’s Disease Questionnaire* (PDQ-39; Peto et al., 1995) (Appendix U).

The PDQ-39 is the most commonly used disease-specific quality-of-life instrument for PD (Siderowf, Ravina & Glick, 2002) and has been extensively validated for use within the UK (Marinus et al., 2002). It is a 39-item self-report measure that assesses eight domains including; Mobility (10 items), Activities of Daily Living (6 items), Emotional Well-being (6 items), Stigma (4 items), Social Support (3 items), Cognition (4 items), Communication (3 items) and Bodily Discomfort (3 items). Each item is rated using a 5 point Likert scale, from 0 (never) to 4 (always or cannot do at all). Scores are calculated to give a single index score for each domain, with scores ranging from 0 (no problem at all) to 100 (maximum level of problem). An overall single index score can also be calculated by dividing the total
dimension scores by eight. Higher scores are indicative of lower quality of life. Peto et al. (1995) reported adequate internal reliability, test-retest reliability, and construct validity in relation to other measures reported by respondents with PD.

*Body Image Disturbance Questionnaire* (BIDQ; Cash et al., 2004) (Appendix V). The BIDQ is a seven-item self report measure that asks participants about body appearance concerns. It also assesses the participant’s preoccupation, experiences of emotional distress, social and occupational functioning and behavioural avoidance (Cash et al., 2004). Each item is rated on a 5-point Likert scale from 1 (no distress or impairment) to 5 (high levels of distress or impairment). A mean score is calculated with higher scores indicating higher levels of body image disturbance. The BIDQ also includes five open-ended follow up questions that allow participants to provide qualitative information in addition to the scaled responses. The BIDQ has been shown to be internally consistent (.89; Cash et al., 2004) with strong test-retest reliability (Cash & Grasso, 2005). Normative data for males and females have been reported by Cash and Grasso (2005).

### 3.4.4 Severity and stage of PD

*Hoehn and Yahr Scale* (Hoehn & Yahr, 1967) (Appendix W). The Hoehn and Yahr (H&Y) Scale is a clinical measure of PD progression and provides a global assessment of severity in PD. The scale assesses signs and symptoms of functional impairment, incorporating postural instability, rigidity, tremor, and bradykinesia (Quelhas & Costa, 2009). The stage of PD ranges from 0 (no signs of the disease) to 5 (severe symptoms, where the individual is restricted to a wheelchair or confined to a bed, unless aided) with intermediate stages across an eight point scale. The H&Y was completed for every participant by the clinician at the end of each clinic.

### 3.4.5 Dementia screening tool

*Clock Drawing Test* (CDT; Strauss, Sherman & Spreen, 2006). The CDT is a screening tool to assess for cognitive impairment (Pinto & Peters, 2009). Participants are asked to draw the face of a clock, with the time showing ten past eleven. It is a screening tool that has been shown to be highly correlated with the Mini Mental Status Examination (MMSE) and other tests of cognitive dysfunction (Agrell & Dehlin, 1998). In comparison to the MMSE, the CDT has been considered as simple and quick to administer and less threatening to participants (Agrell & Dehlin, 1998; Pinto & Peters, 2009). It has been
shown to have good inter-rater reliability, test-retest reliability, good concurrent validity and predictive validity (Pinto & Peters, 2009; Schulman, 2000). Schulman (2000) reviewed the literature and found that that the full range of published scoring systems all had excellent psychometric properties. A five point scoring system was used for the current study as it has been shown to be more predictive of dementia. Scores of three or above demonstrate cognitive impairment (Strauss et al., 2006).

3.5 Data Analysis
Data for each of the measures were coded and entered into Statistics for the Social Sciences (SPSS) version 20. Subscale scores for each of the measures were then calculated. Preliminary, descriptive and reliability analyses were conducted before inferential statistical analysis was undertaken to determine statistical significance. Statistical analyses (Pearson’s correlation and regression analysis) was used to analyse the quantitative data. Qualitative data collected from the BIDQ and DAS-24 were used to determine further exploration of shame in participants with PD. This data were subject to thematic analysis.
4.0 Results

4.1 Participants
The sampling frame comprised a six month period from September 2013 to March 2014. The researcher attended three clinics every week, with 56 clinics being attended in total. Each clinic was attended by four to six patients and on average two to three patients in each clinic were eligible to take part. Fifty-four potential participants declined to take part citing; time constraints, not wanting to take part in research and not wanting to talk about their experiences because of emotional difficulties. Three participants were excluded from the study because of indications of cognitive difficulties, resulting in a total sample size of 81 participants. The majority of participants were male (61.7%), white (95%) and retired (90%). Severity of PD according to the H&Y was similar to other UK outpatient samples (Schrag, Jahanshahi & Quinn, 2000; Simpson, Lekwuwa & Crawford, 2013). Table 4 shows the demographics for all 81 participants.

Table 4: Participant demographic information

<table>
<thead>
<tr>
<th>All participants (N = 81)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (N)</strong></td>
</tr>
<tr>
<td>Age range (years)</td>
</tr>
<tr>
<td>Mean age (SD)</td>
</tr>
<tr>
<td><strong>Sex N (%)</strong></td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td><strong>Ethnicity N (%)</strong></td>
</tr>
<tr>
<td>White</td>
</tr>
<tr>
<td>Black</td>
</tr>
<tr>
<td>Asian</td>
</tr>
<tr>
<td><strong>Employment status N (%)</strong></td>
</tr>
<tr>
<td>Retired</td>
</tr>
<tr>
<td>Unemployed</td>
</tr>
<tr>
<td>In employment</td>
</tr>
<tr>
<td><strong>Duration of PD</strong></td>
</tr>
<tr>
<td>Range</td>
</tr>
<tr>
<td>Mean (SD)</td>
</tr>
<tr>
<td><strong>Hoehn &amp; Yahr Stage</strong></td>
</tr>
<tr>
<td>Mean (SD)</td>
</tr>
</tbody>
</table>
4.2 Data preparation and preliminary checks
Preliminary analyses were conducted to inspect data before statistical analyses were carried out. All data was screened using various methods (histograms, Normal Q-Q Plot, Detrended Normal Q-Q Plots, 5% Trimmed Mean, skewness and kurtosis values) to examine outliers and distribution of data to determine which statistical technique was most appropriate. All data were positively skewed therefore, logarithm and square root transformations of data were conducted with transformations improving levels of normality. It was decided that transformations would be performed in order for parametric tests to be carried out over non-parametric alternatives, as they are more powerful and sensitive (Pallant, 2013). It has been reported that parametric tests can be used for non-normally distributed data with large enough sample sizes (above 30). However, multiple regression analysis is sensitive to a number of assumptions, including normality of data (Pallant, 2013) and there is no non-parametric alternative. Significant results are reported at $p < .05$ level (two tailed).

4.3 Internal reliability of measures
The internal consistency for each measure was assessed using Cronbach’s $\alpha$ coefficient, the results are presented in Table 5 with comparisons to alpha values reported in other studies.
Table 5: Cronbach α values

<table>
<thead>
<tr>
<th>Measure</th>
<th>Cronbach α</th>
<th>Comparative Cronbach α</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCS (Social Anxiety)</td>
<td>0.81</td>
<td>0.75&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>FNE</td>
<td>0.93</td>
<td>0.93&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>OAS</td>
<td>0.96</td>
<td>0.92&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>ESS (Body Shame)</td>
<td>0.65</td>
<td>0.86&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
<tr>
<td>BIDQ</td>
<td>0.83</td>
<td>0.89&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>HADS Total</td>
<td>0.87</td>
<td>0.88&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>HADS Anxiety</td>
<td>0.83</td>
<td>0.86&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>HADS Depression</td>
<td>0.78</td>
<td>0.78&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>DAS-24</td>
<td>0.87</td>
<td>0.92&lt;sup&gt;g&lt;/sup&gt;</td>
</tr>
<tr>
<td>PDQ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PDQ-39 Mobility</td>
<td>0.92</td>
<td>0.94&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>PDQ-39 ADL</td>
<td>0.83</td>
<td>0.89&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>PDQ-39 EWB</td>
<td>0.85</td>
<td>0.83&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>PDQ-39 Stigma</td>
<td>0.88</td>
<td>0.80&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>PDQ-39 Social</td>
<td>0.81</td>
<td>0.69&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>PDQ-39 Cognition</td>
<td>0.59</td>
<td>0.70&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>PDQ-39 Communication</td>
<td>0.71</td>
<td>0.79&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>PDQ-39 BD</td>
<td>0.76</td>
<td>0.75&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>Single Index</td>
<td>0.95</td>
<td>-</td>
</tr>
</tbody>
</table>

<sup>a</sup>Nystedt & Ljungberg, 2002; <sup>b</sup>Watson & Friend, 1969; <sup>c</sup>Goss et al., 1994; <sup>d</sup>Andrews et al., 2002; <sup>e</sup>Cash et al., 2004; <sup>f</sup>Marinus et al., 2002; <sup>g</sup>Carr et al., 2005; <sup>h</sup>Peto et al., 1995.

All but two scales demonstrated values above 0.7, indicating suitable internal consistency (Pallant, 2013). Cronbach alpha values were also similar to values demonstrated in previous studies. The ESS body shame items and Cognition subscale of the PDQ-39 were below the 0.7 cut off, although this is not uncommon for scales with a small number of items (Pallant, 2013).

4.4 Means and standard deviations of all measures and comparisons with other groups

The first part of the study sought to examine experiences of shame (general, external and body), psychological morbidity (anxiety, depression, social anxiety and FNE), quality of life and body image disturbances among individuals with PD. Means and standard deviations for
each of the measures have been provided and were compared to similar populations (participants with visible difference) and non-clinical populations using z-tests (see Tables 6 to 11). Significant differences ($p < .05$) are indicated with an asterisk (*). Means and standard deviations for all measures for this study can be seen in the Appendices (Appendix X).

**Psychological Morbidity**

To explore psychological morbidity in the current sample, the HADS anxiety and depression mean scores were examined and compared with means from a similar population (Partridge & Robertson, 2011), a non-clinical sample (Crawford et al., 2001) and a sample of individuals with PD (Hurt et al., 2011). Anxiety and depression scores reported in the current sample were higher than non-clinical sample means (but were not significantly different), and were significantly lower than means from a similar and PD population. In this sample, 34.5% of participants reported scores indicative of borderline or definite clinical “caseness” (scores of 8 or above) for anxiety and 21% for depression. The percentage of clinical range scores (scores of 11 or above) for anxiety and depression were also compared and are presented in Table 6.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sample M(SD)</th>
<th>Non-clinical M(SD)</th>
<th>z</th>
<th>Comparative M(SD)</th>
<th>z</th>
<th>PD M(SD)</th>
<th>z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>6.27 (4.36)</td>
<td>6.14 (3.76)</td>
<td>.31</td>
<td>7.06 (5.18)</td>
<td>-1.37</td>
<td>7.3 (4.5)</td>
<td>-2.06*</td>
</tr>
<tr>
<td>Clinical range</td>
<td>19.7%</td>
<td>12.6%</td>
<td>-</td>
<td>24.7%</td>
<td>-</td>
<td>19.1%</td>
<td>-</td>
</tr>
<tr>
<td>Depression</td>
<td>4.30 (3.43)</td>
<td>3.68 (3.07)</td>
<td>1.82</td>
<td>6.5 (4.09)</td>
<td>-4.84*</td>
<td>6.3 (3.7)</td>
<td>-4.86*</td>
</tr>
<tr>
<td>Clinical range</td>
<td>7%</td>
<td>3.6%</td>
<td>-</td>
<td>18.6%</td>
<td>-</td>
<td>8.8%</td>
<td>-</td>
</tr>
</tbody>
</table>

Psychological morbidity was also examined in the current sample by exploring social anxiety (SCS) and FNE mean scores. Compared to non-clinical means (SCS; Fenigstein et al., 1975; FNE; Stopa & Clark, 2001) and means from similar populations (SCS; Partridge & Robertson, 2011; FNE; Richards et al., 2004), the current sample demonstrated significantly lower mean scores of social anxiety and FNE (see Table 7).
Table 7: SCS (social anxiety) and FNE sample and population means

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sample</th>
<th>Non-clinical</th>
<th>z</th>
<th>Comparative</th>
<th>z</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M(SD)</td>
<td>M(SD)</td>
<td></td>
<td>M(SD)</td>
<td></td>
</tr>
<tr>
<td>SCS</td>
<td>7.54 (6.78)</td>
<td>12.65 (4.3)</td>
<td>-10.70*</td>
<td>14.47 (4.24)</td>
<td>-14.71*</td>
</tr>
<tr>
<td>FNE</td>
<td>8.89 (7.72)</td>
<td>14.26 (7.72)</td>
<td>-06.26*</td>
<td>14.1 (8.4)</td>
<td>-5.58*</td>
</tr>
</tbody>
</table>

Shame

Mean scores for the shame measures were compared to non-clinical and similar population means (see Table 8). The mean scores for the ESS body shame items were significantly lower than those reported in a non-clinical sample (Andrews et al., 2002). Scores were not compared to similar population means, as no comparative data was found from scoping the literature. The OAS mean sample scores were significantly lower than non-clinical (Cheung et al., 2004) and similar population mean scores (Norberg et al., 2007), indicating lower levels of external shame in the current sample.

Table 8: ESS and OAS sample and population means

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sample</th>
<th>Non-clinical</th>
<th>z</th>
<th>Comparative</th>
<th>z</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M(SD)</td>
<td>M(SD)</td>
<td></td>
<td>M(SD)</td>
<td></td>
</tr>
<tr>
<td>ESS Body Shame</td>
<td>5.91 (1.92)</td>
<td>9.82 (3.40)</td>
<td>-10.35*</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>OAS</td>
<td>10.14 (10.38)</td>
<td>21.73 (10.96)</td>
<td>-9.52*</td>
<td>29.5 (13.11)</td>
<td>-16.48*</td>
</tr>
</tbody>
</table>

The mean scores for the DAS-24 were compared to non-clinical (Carr et al., 2005) and similar population (Carr et al., 2005) mean scores according to age categories (as reported in the DAS-24 manual). Mean scores for both age categories were significantly higher than non-clinical means indicating higher levels of general shame and appearance concerns for the current sample. Mean scores for the current sample were significantly lower than those obtained in similar populations for both age categories, demonstrating lower general shame and appearance concerns in the current sample (see Table 9).

Table 9: DAS-24 sample and population means

<table>
<thead>
<tr>
<th>Variable (by age)</th>
<th>Sample</th>
<th>Non-clinical</th>
<th>z</th>
<th>Comparative</th>
<th>z</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M(SD)</td>
<td>M(SD)</td>
<td></td>
<td>M(SD)</td>
<td></td>
</tr>
<tr>
<td>DAS-24 (31-60)</td>
<td>37.00 (12.46)</td>
<td>31.3 (12.9)</td>
<td>3.98*</td>
<td>47.2 (17.9)</td>
<td>-5.13*</td>
</tr>
<tr>
<td>DAS-24 (61+)</td>
<td>28.77 (10.0)</td>
<td>23.8 (10.5)</td>
<td>4.26*</td>
<td>32.6 (12.7)</td>
<td>-2.71*</td>
</tr>
</tbody>
</table>
**BID**

Mean scores from the BIDQ (male and female) for the current sample were compared to non-clinical (Cash & Grosso, 2005) and similar population (Partridge & Robertson, 2011) mean scores to ascertain differences in BID (see Table 10). Respondents in the current sample scored significantly higher than non-clinical samples for both males and females, indicating greater levels of BID. Mean BIDQ scores were slightly lower than those obtained from a similar population, although significance was not demonstrated.

### Table 10: BIDQ sample and population means

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sample (by gender)</th>
<th>Non-clinical</th>
<th>z</th>
<th>Comparative</th>
<th>z</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M(SD)</td>
<td>M(SD)</td>
<td></td>
<td>M(SD)</td>
<td></td>
</tr>
<tr>
<td><strong>BIDQ Male</strong></td>
<td>2.10 (.75)</td>
<td>1.57 (.60)</td>
<td>7.95*</td>
<td>2.17 (1.01)</td>
<td>-.62</td>
</tr>
<tr>
<td><strong>BIDQ Female</strong></td>
<td>1.98 (.80)</td>
<td>1.81 (.67)</td>
<td>2.28*</td>
<td>2.22 (1.12)</td>
<td>-1.93</td>
</tr>
</tbody>
</table>

**Quality of life**

Mean scores for each of the eight PDQ-39 dimensions were compared to two other studies who had utilised the PDQ-39 to examine quality of life in individuals with PD (see Table 11). The single index mean score was also compared to the single index mean score reported in a study by Chapuis et al. (2005). Higher scores on the PDQ-39 were inversely related to quality of life. Compared to a study by Bucks et al. (2011), it was found that the current sample scored significantly higher on the dimensions of Mobility, Activities of Daily Living and Cognition, indicating more problems and therefore lower quality of life for these domains in the current sample. Mean scores were also slightly higher on the Emotional Well-being and Bodily Discomfort dimensions, however these were not significant. The current sample scored significantly lower on the Social Support dimension and lower, (but not significant) on the Stigma and Communication dimensions, indicating fewer problems and better quality of life within these domains.

Compared to a study by Chapuis et al. (2005) it was found that the current sample scored significantly lower on all dimensions of the PDQ-39, demonstrating fewer problems and better quality of life. Exploration of the different samples within the two comparative studies indicated that participants in a study by Chapuis et al. (2005) had longer disease duration than...
those in a study by Bucks et al. (2011), which may have contributed to participants having greater problems and lower quality of life.

**Table 11: PDQ-39 sample and population means**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sample M(SD)</th>
<th>Bucks 2011 M(SD)</th>
<th>z</th>
<th>Chapuis 2005 M(SD)</th>
<th>z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>38.43 (30.15)</td>
<td>22.05 (21.43)</td>
<td>6.88*</td>
<td>45.8 (25.6)</td>
<td>-2.59*</td>
</tr>
<tr>
<td>ADL</td>
<td>34.88 (26.40)</td>
<td>20.76 (17.90)</td>
<td>7.10*</td>
<td>41.5 (25.2)</td>
<td>-2.36*</td>
</tr>
<tr>
<td>EWB</td>
<td>23.56 (18.80)</td>
<td>22.17 (18.12)</td>
<td>0.69</td>
<td>43.6 (18.6)</td>
<td>-9.69*</td>
</tr>
<tr>
<td>Stigma</td>
<td>13.04 (16.63)</td>
<td>15.55 (20.55)</td>
<td>-1.10</td>
<td>36.9 (24.8)</td>
<td>-8.66*</td>
</tr>
<tr>
<td>Social Support</td>
<td>8.74 (15.25)</td>
<td>13.44 (17.66)</td>
<td>-2.4*</td>
<td>13.5 (18.1)</td>
<td>-2.37*</td>
</tr>
<tr>
<td>Cognition</td>
<td>30.02 (20.19)</td>
<td>22.54 (17.33)</td>
<td>3.88*</td>
<td>34.7 (18.2)</td>
<td>-2.32*</td>
</tr>
<tr>
<td>Communication</td>
<td>18.21 (19.73)</td>
<td>19.44 (18.40)</td>
<td>-0.60</td>
<td>30.03 (21.2)</td>
<td>-5.13*</td>
</tr>
<tr>
<td>Bodily Discomfort</td>
<td>34.57 (26.06)</td>
<td>33.63 (22.29)</td>
<td>0.38</td>
<td>47.1 (20)</td>
<td>-5.34*</td>
</tr>
<tr>
<td>Single Index</td>
<td>24.75 (14.17)</td>
<td>-</td>
<td>-</td>
<td>36.5 (14.2)</td>
<td>-7.45*</td>
</tr>
</tbody>
</table>

To summarise, comparison of means and standard deviations with other groups indicated significantly lower scores for body shame, external shame, FNE and social anxiety and significantly higher scores for general shame and BIDQ in comparison to other non-clinical mean scores. When data was compared with similar populations, significantly lower scores were obtained for all measures apart from BIDQ and HADS anxiety scores (lower but not significant).

### 4.5 Correlation Analyses

The second part of the study sought to examine associations between shame (general, external and body), severity of PD, psychological morbidity, quality of life and body image disturbances. Associations between these constructs are shown in tables 12 to 15. Significance at .05 level (*) and significance at .01 level (**) are reported (two tailed).

**Shame and severity of PD**

Associations between shame and severity of PD were examined (see Table 12). A small, significant positive relationship between severity of PD and general shame was found, indicating greater severity of PD was associated with higher levels of general shame. There
were no significant relationships between severity of PD, external shame and body shame. All measures of shame were associated with one another.

**Table 12: Correlation Analyses: Shame and severity**

<table>
<thead>
<tr>
<th></th>
<th>H&amp;Y</th>
<th>OAS</th>
<th>ESS</th>
<th>DAS-24</th>
</tr>
</thead>
<tbody>
<tr>
<td>H&amp;Y</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OAS</td>
<td>.10</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ESS</td>
<td>.09</td>
<td>.46**</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>DAS-24</td>
<td>.22*</td>
<td>.56**</td>
<td>.53**</td>
<td>-</td>
</tr>
</tbody>
</table>

*Shame, severity and psychological morbidity*

Associations were examined between severity of PD, shame and psychological morbidity (see Table 13). A medium, significant positive relationship between severity of PD and depression was found; indicating greater severity of PD was associated with higher levels of depression.

Significant positive relationships between all measures of shame (general, external and body) and anxiety, depression, FNE and social anxiety were identified, therefore higher levels of shame were associated with higher levels of psychological morbidity. Strong relationships were observed between all measures of shame and FNE and also between general shame, anxiety and depression.

**Table 13: Correlation Analyses: Shame, severity of PD and psychological morbidity**

<table>
<thead>
<tr>
<th></th>
<th>H&amp;Y</th>
<th>OAS</th>
<th>ESS</th>
<th>DAS-24</th>
<th>HADS-A</th>
<th>HADS-D</th>
<th>FNE</th>
<th>SCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS-A</td>
<td>.21</td>
<td>.42**</td>
<td>.46**</td>
<td>.68**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HADS-D</td>
<td>.31**</td>
<td>.35**</td>
<td>.28*</td>
<td>.62**</td>
<td>.59**</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FNE</td>
<td>.09</td>
<td>.53**</td>
<td>.58**</td>
<td>.56**</td>
<td>.55**</td>
<td>.17</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>SCS</td>
<td>.16</td>
<td>.38**</td>
<td>.40**</td>
<td>.49**</td>
<td>.43**</td>
<td>.22*</td>
<td>.52**</td>
<td>-</td>
</tr>
</tbody>
</table>

*Shame, severity and BID*

Associations were examined between severity of PD, shame and BID (see Table 14). There was a medium significant positive relationship between severity of PD and BID. Medium significant positive associations were demonstrated between external shame, body shame and...
BID. There was a large positive association between general shame and BID. These associations indicated that higher levels of shame were associated with greater BID.

Table 14: Correlation Analyses: Shame, severity and BID

<table>
<thead>
<tr>
<th></th>
<th>H&amp;Y</th>
<th>OAS</th>
<th>ESS</th>
<th>DAS-24</th>
</tr>
</thead>
<tbody>
<tr>
<td>BIDQ</td>
<td>.35**</td>
<td>.31**</td>
<td>.41**</td>
<td>.63**</td>
</tr>
</tbody>
</table>

Quality of life

Associations were examined between severity of PD, shame and quality of life (see Table 15). Severity of PD was significantly related to dimensions of Mobility, Emotional Well-being, Communication and Bodily Discomfort, including the single PDQ-39 index score (overall quality of life). These correlations suggest that greater severity of PD was associated with higher levels of problems and therefore lower quality of life.

External and body shame were significantly related to all dimensions of the PDQ-39, apart from the Mobility and Emotional Well-being dimensions (also Cognitive dimension for body shame). There were significant positive relationships between general shame and all eight dimensions of the PDQ-39, including the single index score. These results suggest higher levels of general shame were associated with greater problems and therefore indicative of lower quality of life.

Table 15: Correlation Analyses: Severity of PD, shame and quality of life

<table>
<thead>
<tr>
<th></th>
<th>H&amp;Y</th>
<th>OAS</th>
<th>ESS</th>
<th>DAS-24</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>.30**</td>
<td>.16</td>
<td>.14</td>
<td>.39**</td>
</tr>
<tr>
<td>ADL</td>
<td>.21</td>
<td>.12</td>
<td>.11</td>
<td>.38**</td>
</tr>
<tr>
<td>Emotional Well-being</td>
<td>.30**</td>
<td>.45**</td>
<td>.41**</td>
<td>.64**</td>
</tr>
<tr>
<td>Stigma</td>
<td>.15</td>
<td>.42**</td>
<td>.47**</td>
<td>.65**</td>
</tr>
<tr>
<td>Social Support</td>
<td>.21</td>
<td>.49**</td>
<td>.37**</td>
<td>.53**</td>
</tr>
<tr>
<td>Cognition</td>
<td>.21</td>
<td>.38**</td>
<td>.12</td>
<td>.33**</td>
</tr>
<tr>
<td>Communication</td>
<td>.25*</td>
<td>.49**</td>
<td>.35**</td>
<td>.57**</td>
</tr>
<tr>
<td>Bodily Discomfort</td>
<td>.34**</td>
<td>.30**</td>
<td>.28*</td>
<td>.41**</td>
</tr>
<tr>
<td>Single Index</td>
<td>.35**</td>
<td>.42**</td>
<td>.35*</td>
<td>.63**</td>
</tr>
</tbody>
</table>
To summarise, correlation analyses indicated all measures of shame were positively associated with anxiety, depression, FNE, social anxiety, BID and lower quality of life. Severity of PD was significantly positively associated with general shame, BID and quality of life (Mobility, Emotional Well-being, Communication and Bodily Discomfort).

4.6 Multiple Regression Analyses
The third part of the study sought to determine the relative importance of shame (general, external and body) and severity of PD for psychological morbidity, quality of life and body image disturbances. Significant correlations between these constructs were examined further by conducting multiple regression analyses.

Preliminary analyses were conducted to ensure assumptions of normality, linearity, multicollinearity and homoscedasticity were met. Indeterminate assumptions of homoscedasticity were found for PDQ-39 subscales of Stigma, Social Support and Communication; these results should therefore be treated with caution.

For multiple regression to achieve a power of 0.80 based on a medium effect size (0.13) (Cohen, 1988) a minimum of 105 participants was required. Although the current sample was underpowered, Tabachnick and Fidell (2007) recommended 82 participants for four independent variables. The current sample was therefore deemed adequate (N = 81).

Multiple regression analyses are summarised in Table 16 and 17. Each table shows $R^2$ standardised beta values ($\beta$) and significance (* $p < .05$). The percentage of variance accounted for by independent variables for each dependent variable is also included. $F$ values are included to indicate statistical significance of each regression model. Where a missing value is present, the variable was not entered into the regression model as there were no significant correlations.

**Psychological morbidity and BID**
Multiple regression analyses were used to determine whether severity of PD, external, general and body shame would predict psychological morbidity (anxiety, depression, social anxiety and FNE) and BID. Results are presented in Table 16. All multiple regression models were significant, except that for social anxiety. It was found that severity of PD significantly predicted BID only. External and body shame significantly predicted FNE alone and general
shame significantly predicted anxiety, depression, FNE and BID. No independent variables significantly predicted social anxiety. Independent variables explained between 41% and 48% of the variance in dependent variables of psychological morbidity (excluding SCS). According to beta values general shame made the strongest unique contributions for anxiety, depression and BID. Body shame made the strongest unique contributions for FNE.

Table 16: Multiple Regression Analyses: Psychological morbidity and BID

<table>
<thead>
<tr>
<th>Dependent Variables – β values</th>
<th>HADS-A</th>
<th>HADS-D</th>
<th>SCS</th>
<th>FNE</th>
<th>BIDQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>H&amp;Y</td>
<td>-</td>
<td>.18</td>
<td>-</td>
<td>-</td>
<td>.22*</td>
</tr>
<tr>
<td>OAS</td>
<td>.03</td>
<td>.03</td>
<td>.15</td>
<td>.24*</td>
<td>-.09</td>
</tr>
<tr>
<td>ESS</td>
<td>.14</td>
<td>-.06</td>
<td>-.16</td>
<td>.33*</td>
<td>.13</td>
</tr>
<tr>
<td>DAS-24</td>
<td>.59*</td>
<td>.59*</td>
<td>.05</td>
<td>.25*</td>
<td>.57*</td>
</tr>
<tr>
<td>$R^2$</td>
<td>.48</td>
<td>.41</td>
<td>.03</td>
<td>.46</td>
<td>.46</td>
</tr>
<tr>
<td>Variance</td>
<td>48%</td>
<td>41%</td>
<td>3%</td>
<td>46%</td>
<td>46%</td>
</tr>
<tr>
<td>$F$</td>
<td>23.22*</td>
<td>13.33*</td>
<td>.78</td>
<td>22.12*</td>
<td>16.30*</td>
</tr>
</tbody>
</table>

Quality of life

Multiple regression analyses were used to determine whether severity of PD and shame predicted PDQ-39 quality of life dimensions (see Table 17). The Activities of Daily Living dimension was not included as only one significant association was found between the independent variables. It was found that all models of regression were significant. Severity of PD significantly predicted Mobility, Bodily Discomfort and overall quality of life scores (single index). External shame significantly predicted Social Support, Communication and Cognition scores. None of the quality of life dimensions were predicted by body shame. General shame, however significantly predicted all dimensions of quality life, apart from Cognition and made the largest unique contributions (apart from Bodily Discomfort) according to beta values. Independent variables explained between 17% and 46% of the variance in quality of life.
Table 17: Multiple Regression Analyses: Quality of life

<table>
<thead>
<tr>
<th>Dependent Variables – β values</th>
<th>M</th>
<th>EWB</th>
<th>Stigma</th>
<th>SS</th>
<th>Com</th>
<th>Cog</th>
<th>BD</th>
<th>SI</th>
</tr>
</thead>
<tbody>
<tr>
<td>H&amp;Y</td>
<td>.23*</td>
<td>.17</td>
<td>-</td>
<td>-</td>
<td>.14</td>
<td>-</td>
<td>.27*</td>
<td>.23*</td>
</tr>
<tr>
<td>OAS</td>
<td>-</td>
<td>.13</td>
<td>.04</td>
<td>.26*</td>
<td>.25*</td>
<td>.29*</td>
<td>.09</td>
<td>.10</td>
</tr>
<tr>
<td>ESS</td>
<td>-</td>
<td>.07</td>
<td>.17</td>
<td>.06</td>
<td>.03</td>
<td>-</td>
<td>.08</td>
<td>.01</td>
</tr>
<tr>
<td>DAS-24</td>
<td>.24*</td>
<td>.49*</td>
<td>.54*</td>
<td>.36*</td>
<td>.38*</td>
<td>.16</td>
<td>.26*</td>
<td>.52*</td>
</tr>
<tr>
<td>( R^2 )</td>
<td>.20</td>
<td>.45</td>
<td>.45</td>
<td>.34</td>
<td>.38</td>
<td>.17</td>
<td>.25</td>
<td>.46</td>
</tr>
<tr>
<td>Variance</td>
<td>20%</td>
<td>45%</td>
<td>45%</td>
<td>34%</td>
<td>38%</td>
<td>17%</td>
<td>25%</td>
<td>46%</td>
</tr>
<tr>
<td>( F )</td>
<td>9.77*</td>
<td>15.52*</td>
<td>3.77*</td>
<td>13.14*</td>
<td>7.76*</td>
<td>7.76*</td>
<td>6.25*</td>
<td>15.89*</td>
</tr>
</tbody>
</table>

*M (Mobility) EWB (Emotional Well-being), SS (Social Support), Com (Communication), BD (Bodily Discomfort), SI (Single Index)

To summarise, multiple regression analyses indicated that for psychological morbidity, severity of PD provided significant contributions to BID only (although general shame was the strongest predictor). General shame was the only independent variable that contributed significant variance to anxiety and depression. When FNE was examined, all measures of shame contributed significant variance; however, body shame was the strongest predictor. External shame and general shame, contributed significantly to quality of life domains. It was found that general shame had a unique contribution to all domains of quality of life (except Cognition) and provided the strongest predictor for all domains except Bodily Discomfort, where severity of PD was shown to be strongest predictor (although the difference in beta values was very small; .01).

4.7 Qualitative Analysis

Open-ended questions in the BIDQ and DAS-24 allowed participants to provide qualitative responses regarding concerns about their appearance, including preoccupation associated with these concerns, experiences of emotional distress, interference in social and occupational functioning, and behavioural avoidance related to appearance concerns. Fifty-four percent of participants expressed at least one concern with their appearance in relation to PD. Participant responses were analysed using thematic analysis with four themes identified, namely; **self consciousness, negative self-image, avoidance and physical limitations**. The most frequent and problematic aspect of appearance reported by participants was tremor,
followed by difficulties in walking, including shuffling, slowness of movement and posture. Less frequently expressed was weight gain (from reduced activity) and facial masking.

*Self-consciousness*

Self-consciousness and embarrassment was frequently noted by participants, they described being aware of others looking at them when their symptoms were apparent. Concerns about others’ perceptions were particularly present when describing eating and drinking in public. Participants reported being constantly aware of their symptoms; particularly tremor (expressed as being the most noticeable) and shuffling, and described how increased awareness exacerbated tremor. Participants also described how anxious they felt in novel situations and on meeting strangers, also increasing consciousness and exacerbation of tremor. In addition, concerns about the impact of symptoms on others and not wanting to cause embarrassment were reported by participants. Quotes referring to self-consciousness can be seen in Table 18.

**Table 18: Self-consciousness quotes**

<table>
<thead>
<tr>
<th>Self-consciousness quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Tremor.... I daren't stand in a crowd, I'm embarrassed. Shaking... people seeing it. They look and you wonder what they are thinking”</td>
</tr>
<tr>
<td>“Tremor.... eating and drinking in public, people looking at me if I spill it”</td>
</tr>
<tr>
<td>“I have a bent back. I don't like walking with my head down, I’m a little self-conscious”</td>
</tr>
<tr>
<td>“Tremor is unsightly, I’m conscious of it”</td>
</tr>
<tr>
<td>“Tremor..... a bit embarrassing.... I’d rather it not be there”</td>
</tr>
<tr>
<td>“Tremor... I feel self-conscious, normally when I meet someone new. Initial response is that I feel nervous, I worry about what they might think”</td>
</tr>
<tr>
<td>“Shuffling is the most problematic. I’m self-conscious of it, I get frustrated and try to walk properly”</td>
</tr>
<tr>
<td>“I can't walk the same. I’m worried about what people will think”</td>
</tr>
<tr>
<td>“Feeling self conscious of it (tremor) always being aware of it no matter how nice people are”</td>
</tr>
<tr>
<td>“When tremoring I think about it quite a lot”</td>
</tr>
<tr>
<td>“Tremor.... How it will impact on other people, will it disturb them”</td>
</tr>
</tbody>
</table>
Negative self-image

Participants expressed concerns about how their symptoms of PD marked them as ‘different’ and descriptions of the self were frequently negative. Participants described how they felt their symptoms portrayed them as ‘old’, ‘ancient’, ‘not normal’, ‘deformed’, ‘silly’, ‘drunk’, ‘clumsy’, ‘batty’, ‘invalid’ and ‘disabled’. Participants felt that use of physical aids reinforced their perception as disabled and was age-inappropriate. They described feeling disadvantaged, with people ignoring them and choosing to associate with others who were not disabled, one participant described feeling like a ‘second class citizen’. Concerns about appearing ‘old’ were particularly prominent, distressing if they did not feel old, “if you think you are old the problem doesn’t matter, if you don’t then it is distressing”. Participants felt misunderstood because of a self-image PD tends to create; “People don’t understand what Parkinson’s disease is, they expect a jibbering wreck”. Quotes referring to negative self-image can be seen in Table 19.

Table 19: Negative self-image quotes

<table>
<thead>
<tr>
<th>Negative self-image quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Walking – looking ancient, not looking like I used to. I hate using the wheelchair if we are local, it makes me look old and ill”</td>
</tr>
<tr>
<td>“I don't want to look old and disabled.... not what I used to be”</td>
</tr>
<tr>
<td>“Makes me feel like an invalid, I don’t like it. It makes me old”</td>
</tr>
<tr>
<td>“Appearing as clumsy, people see you as different and I don’t want to be different”</td>
</tr>
<tr>
<td>“Shoulders..... deformed state.... makes you look old.... puts 10 years on you”</td>
</tr>
<tr>
<td>“I don’t go out in a wheelchair because I wonder what people will think. I’m too young for that”</td>
</tr>
<tr>
<td>“…What other people might think.... I’ve got a physical disability or with my movement that I am drunk”</td>
</tr>
<tr>
<td>“Appearing as clumsy, people see you as different and I don’t want to be different”</td>
</tr>
<tr>
<td>“My walking is affected. Makes me feel stupid. With the shakes sometimes I feel a bit silly and I can’t sit still”</td>
</tr>
<tr>
<td>“Tremor identifies me as someone as not normal”</td>
</tr>
</tbody>
</table>
Avoidance

Participants described avoidance at social events, making efforts to be away from others to avoid embarrassment. Avoidance of restaurants and social situations was frequently reported, not merely because of practicalities and mobility concerns, but because of fear of being viewed as flawed. Participants were aware that social life had declined and that they were withdrawing. They avoided disclosing their condition due to perceived and actual negative reactions and attempted to conceal symptoms such as tremor. Quotes referring to avoidance can be seen in Table 20.

Table 20: Avoidance quotes

<table>
<thead>
<tr>
<th>Avoidance quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>“If I go to the theatre and plays, I don’t want to go to the front because of embarrassment”</td>
</tr>
<tr>
<td>“...going into a room full of people, I tend to find a corner”</td>
</tr>
<tr>
<td>“I’m withdrawing” “I avoid social situations”</td>
</tr>
<tr>
<td>“I have no social life”</td>
</tr>
<tr>
<td>“I have stopped engaging with others, I’m worried about what other people might think”</td>
</tr>
<tr>
<td>“I don’t tell people I have got Parkinson’s disease. Sometimes I have and you get looked at as if you’re unclean / different. It makes you feel withdrawn, I don’t want to mix”</td>
</tr>
<tr>
<td>“Try to hide tremor, when I’m talking it does what it wants unless I’m concentrating”</td>
</tr>
<tr>
<td>“Tremor.... I’d rather it not be there... I try and put my hand in my pocket”</td>
</tr>
<tr>
<td>“Having to look for clothes that draw attention from these faults”</td>
</tr>
<tr>
<td>“Sometimes I feel like I don’t want to bother going somewhere if I feel nervous (because of self-consciousness)”</td>
</tr>
</tbody>
</table>

Physical limitations

Participants expressed concerns about how PD affected their ability to do the things they were once able to do. Apprehension about their efficiency, concerns about slowness, control of symptoms in public and what others may think as a consequence were described. Participants described feeling upset, embarrassed, angry, frustrated, depressed and miserable when they compared themselves to how they were previously and expressed concerns about losing independence and becoming a hindrance. An inability to take part in activities that
were once previously enjoyed (including employment) was commonly expressed. Participants also described how their confidence was affected, engendering further avoidance of some activities. Quotes referring to physical limitations can be seen in Table 21.

**Table 21: Physical limitation quotes**

<table>
<thead>
<tr>
<th>Physical limitation quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>“In general people like to get things done efficiently and on time and I can be slower”</td>
</tr>
<tr>
<td>“I get embarrassed if I can’t do it”</td>
</tr>
<tr>
<td>“It makes me miserable, I can’t do what I used to do”</td>
</tr>
<tr>
<td>“Shaking, I haven’t got control, it has stopped me from mixing”</td>
</tr>
<tr>
<td>“My confidence is affected. When I go into a shop it is confusing with the money, I worry about holding the queue up. I work it out before I go in now”</td>
</tr>
<tr>
<td>“Not what I used to be. I lived a pretty full life. I used to be pretty fit”</td>
</tr>
<tr>
<td>“Takes me a long of time to do things. Both with Parkinson’s disease and thinking about it. I like to get things right. I feel anxious, embarrassed, upset and angry if I’m hindering somebody”</td>
</tr>
<tr>
<td>“Slowness.... My hand won’t do what the brain tells it to do”</td>
</tr>
<tr>
<td>“It’s the way you speak and walk and shaking. The fact you cannot do things as you’d wish to do them e.g. picking up a glass shaking and spilling it”</td>
</tr>
<tr>
<td>“Movement in my hands when they need to be used to do something. I’m not able to do as much as I used to, I get frustrated. People know that I can’t put it right”</td>
</tr>
<tr>
<td>“Can’t do the things like I used to. Worried about what people might think of my abilities”</td>
</tr>
</tbody>
</table>

These findings indicated inconsistencies with the quantitative data, as over half of the sample reported concern(s) about their appearance in relation to PD, particularly in relation to self-consciousness, embarrassment, negative self-image and social avoidance.
5.0 Discussion

To date, circumscribed research has suggested individuals with PD experience shame; however, no previous studies have directly explored the role of shame in individuals with PD, despite associations with shame and psychological morbidity in other chronic health conditions. The purpose of this study was therefore to explore shame (general, external and body) and its relationship to psychological morbidity (anxiety, depression, FNE and social anxiety), quality of life and BID amongst individuals with PD. A summary and discussion of the findings is presented, followed by interpretations of the findings, consideration of limitations, future research and clinical implications.

5.1 Summary and Discussion of Findings

5.1.1 Levels of shame, psychological morbidity, BID and quality of life in comparison with other groups

Findings from the present study suggest that participants in the current sample reported lower levels of shame (general, external and body), psychological morbidity (depression, FNE and social anxiety) and BID compared to similar populations. When compared with non-clinical populations, participants in the current sample demonstrated higher levels of general shame and BID, indicating individuals with PD may be concerned with the physical appearance of overt motor changes, on-off presentations and tremor. Findings were consistent with previous studies indicating appearance concerns in PD (Caap-Ahlgren et al., 2002; Gamarra et al., 2009; Hirayama et al., 2008; Posen et al., 2000; Schartau et al., 2003) and other neurodegenerative conditions (Pfaffenberger et al., 2011; Wasner et al., 2004).

Although levels of distress in the current sample were not comparable with similar populations or within clinical ranges (i.e. mean scores on the HADS), a proportion of respondents did report elevated distress, akin to other studies exploring appearance concerns (Amin, 2011; James et al., 2011; McBain et al., 2014; Rumsey et al., 2004) and of a clinical range similar to those found in a study of individuals with PD (Hurt et al., 2011). Therefore, although mean scores were indicative of non-clinical ranges, a proportion of participants demonstrated greater levels of distress. This suggests that health care professions should be aware of potential signs and symptoms indicative of anxiety or depression in individuals with PD, particularly as clinicians tend to focus on physical complaints (Quelhas & Costa, 2009).
5.1.2 Associations and importance of shame with other measures

Associations between variables suggested that levels of general, external and body shame were significantly positively associated with levels of psychological morbidity, BID and greater problems, indicating lower quality of life, comparable to previous findings in other populations demonstrating higher levels of general shame (Rumsey et al., 2004), body shame (Moreira & Canavarro, 2010) and external shame (Matos & Pinto-Gouveia, 2010) associated with greater anxiety, depression and poorer quality of life (Moreira & Canavarro, 2010). Gilbert (2000) also demonstrated significant associations between shame, FNE, social anxiety and depression. As the strongest predictor of variance for nearly all of the dependent variables, general shame provided the strongest predictors of variance in psychological morbidity (anxiety and depression), BID and quality of life.

It was found that severity of PD was significantly associated with several variables, although of these, general shame was the strongest. The relationship between severity of PD and psychological difficulties is unclear (Menza & Mark, 1994) and previous research appears contradictory. Given that appraisals of condition and symptom impact may predict adjustment better than objective severity and impairment (Schrag et al., 2001), and subjective appearance of a condition is more strongly associated with poor adjustment than objective severity (Moss, 2005), future research should look at perception of severity in PD.

5.1.3 Qualitative data

Verbal self-report data indicated that participants felt self-conscious and embarrassed about symptoms and were apprehensive about being perceived as ‘old’ or ‘disabled’, consistent with previous qualitative studies (Bramley & Eatough, 2005; Caap-Ahlgren et al., 2002; Nijhof, 1995). It was evident that there was a clear disparity between quantitative and qualitative data, as over half of the sample expressed concerns about some aspect of their appearance associated with PD. Numerous participants verbally reported concerns about others’ perceptions and consequent social avoidance, yet levels of external shame, body shame, FNE and social anxiety were lower than those demonstrated in non-clinical populations. Inconsistencies have also been indicated in previous research with older adults exploring pain, whereby participants’ denial of pain in response to direct questions was incongruent with their verbal or nonverbal behaviour (Bergh et al., 2005; Spiers, 2006).
5.2 Interpretations of the findings

Interpretations were made complicated by inconsistencies between qualitative and quantitative findings. It may be that high levels of negative affect (body shame, external shame, anxiety, depression, FNE and social anxiety) were not experienced by participants in the present sample, certainly in comparison to levels anticipated with clinical (psychiatric) populations. However, such apparently low negative affect demurs from previous studies despite significant associations found between shame and psychological morbidity, more consistent with previous research. It may be that these issues were not a primary source of concern for participants, as they may have been focusing more on the disease and ways of managing it. Furthermore, participants met with the researcher following their appointment with their clinician, a context in which the prime focus was on symptom and medication monitoring. Indeed, research has suggested that individuals with PD report emphasis on living in the present, managing symptoms and maximise functioning (Bramley & Eatough, 2005; Williams & Keady, 2008). It may also be that low levels of distress in the current sample occurred due to selection bias, as a number of participants expressed their reluctance to talk about their emotions when they refused to participate (this is discussed further in the limitations section).

By contrast, participants did express concerns about body image and general shame, as reflected by higher responses on the BIDQ and DAS-24. Higher levels of BID and general shame have been demonstrated in other conditions that render an individual visibly different. Individuals with acne (Bowe et al., 2011) and patients undergoing dialysis treatment (Partridge & Robertson, 2011) have demonstrated similar levels of BID to the current sample. General shame has also been identified in women following breast cancer surgery (Moreira & Canavarro, 2010) and amongst a sample of 458 participants with a range of disfiguring conditions (Rusmey et al., 2004). Each of these studies found significant associations between general shame or BID and anxiety, depression, FNE, social anxiety and lower quality of life.

Interestingly, it was these measures that participants provided qualitative information for and findings may therefore indicate that the BIDQ and DAS-24 may have been more appropriate measures to capture appearance concerns of the current sample compared to other measures such as the OAS (external shame), which have predominately been used with clinical
(psychiatric) populations. It may be that measures such as the OAS were not suitable to capture shame experiences of individuals with PD.

It may also be that the open-ended questions facilitated participants to share their experiences of shame and BID by enabling them to explicitly think about their self-conscious emotions in relation to PD, both qualitatively and quantitatively. It was noted that when asked, participants merely stated an aspect of appearance they were concerned about (for example, tremor) without indicating further details about why they were concerned. It may be that participants had limited opportunities prior to meeting with the researcher to discuss emotional experiences of their condition. Indeed, research has indicated that older adults may be unacquainted with expressing emotions with regards to their medical condition (Hiskey & McPherson, 2013). However, the presence of the researcher in the current study allowed exploration of participants responses by asking follow up questions. The researcher also refrained from using ‘physical defect’ when asking questions from the BIDQ and alternatively referred to appearance concerns associated with PD. Research has suggested that the impact of negatively focused questionnaires that are pathologising in nature and use negative terminology (for example, defect) may have a negative influence for participants completing the measures (Rumsey & Harcourt, 2004). Therefore, it may be that refraining from using negative terminology within the BIDQ facilitated participants to respond to questions about appearance concerns.

The above mentioned interpretations appear plausible, however inconsistencies remained notably, qualitative responses obtained from the BIDQ and DAS-24 and some of the PDQ-39 responses. Participants expressed embarrassment, self-consciousness, FNE and social avoidance in response to open-ended questions (as noted above), but reported ‘never’ to PDQ-39 items concerning concealment, avoidance and embarrassment associated with PD, and reflected in low scores on the stigma dimension. The PDQ-39 is a problem-focused measure and participants may have been reluctant to endorse such items. It is also possible that several demand conditions were present: participants may not have wished to appear to complain, given their relationship and reliance on long-familiar staff within the outpatient clinic. Stoicism has frequently been reported in older adults within medical contexts (Bhar & Silver, 2014; Cairncross, Magee & Askham, 2007; Spiers, 2006) and has been implicated in an individual’s readiness to report symptoms (Helme & Gibson, 2001; Yong et al., 2003). Furthermore, it has been suggested older adults may be reluctant to ‘bother’ or ‘complain’
(Spiers, 2006) and desire to be a ‘good’ patient, not wanting to be a burden or a ‘nuisance’,
which may play a factor in participants under-reporting (Cairncross et al., 2007; Gagliese,
2009). Therefore, indicating individuals may be less inclined to seek help from health care
professionals (Cornally & McCarthy, 2011) which may have important physical and mental
health implications, particularly when not given the chance to further explore their
experiences with follow-up questions (see above).

Overall, it appeared that participants may have felt more comfortable engaging in
conversation to disclose their difficulties and the act of doing so also enabled them to relate
their experiences to subsequent quantitative items within the same questionnaire, i.e. on the
BIDQ and DAS-24. It may have been difficult for participants to relate their experiences to
questions on those measures that did not have the preceding qualitative aspect or those that
were negative in nature or problem focused. Thus it may be that when participants responded
to the quantitative measures there was a slightly different psychological orientation than
when discussing personal experience. It may also explain why scores on some of the
measures were lower than those demonstrated in non-clinical samples. Furthermore, items on
the BIDQ and DAS-24 appeared to be somewhat less direct and less definitive in comparison
to measures such as the OAS and FNE. Research has also found that older adults’ responses
to direct questions were inconsistent with verbal and nonverbal behaviour (Bergh et al.,
2005). Furthermore, it has been suggested that when eliciting responses from older adults
(exploring pain) a number of approaches to therapeutic questioning is required that is
respectful to the individuals’ stoicism (Spiers, 2006).

5.3 Limitations and suggestions for improvements to the current study
The cross-sectional design of this study provided a limited representation of participant
experiences of shame. Furthermore, the current sample was recruited from a clinic where
participants frequently expressed a positive relationship with their clinician, therefore
demand conditions may have impacted on how participants’ responded.

A large proportion of individuals refused to take part in the study; it may be that selection
bias was present in the current sample due to reluctance to discuss emotions given its explicit
aims. Shame-prone individuals may have been particularly reluctant to disclose potentially
shameful experiences (Matos & Pinto-Gouveia, 2010). Providing assistance with completion
of the measures may have been considered as a limitation to the study, as the presence of the
researcher may have impacted on participant’s responses, potentially making it difficult for them to reveal personal experiences such as shame. Shame can be a painful emotion, and revealing shame itself can become a further source of shame (Scheff, 1988). However, it was deemed necessary to support participants with completion given difficulties associated with PD symptoms.

It was not possible to determine whether psychological difficulties were experienced prior to the participants’ diagnosis and whether medication was taken by participants to help with any distress. For individuals who did report significant levels of distress, it was not known whether these difficulties were present prior to their diagnosis of PD or as a consequence. A more comprehensive experience of psychological difficulties in individuals with PD could be explored in future research.

The current study used the H&Y as the only measure of severity of PD. Although the H&Y has been widely used and accepted, the scale does not capture the complete range of motor impairments and does not give information on non-motor difficulties (Goetz et al., 2001). The Unified Parkinson’s Disease Rating Scale (UPDRS) provides a more comprehensive assessment of severity of PD. Although previous research has been contradictory with regards to severity of PD and psychological morbidity, the UPDRS could be used to explore whether a more comprehensive measure of severity is associated with self-conscious emotions. In addition, research has suggested that an individuals’ perception of PD severity may be more important than objective severity, this finding has also been replicated in visible difference research (Moss, 2005). It was also observed from meeting with participants that there was often a lack of correlation between the participant’s perception of severity and the clinician’s severity rating (according to the H&Y). Future research could include a more comprehensive measure of severity, but could also explore subjective perceptions of severity too.

Although it was possible to explore relationships between variables in the current study and significant associations were found between shame, psychological morbidity, quality of life and BID, causality cannot be inferred. Furthermore, the results of the current sample should be interpreted with caution as the sample achieved was underpowered. Tabachnick and Fidell (2007) recommended 82 participants for multiple regression analysis with four independent variables; however, according to Cohen (1988) a minimum of 105 participants were required.
to achieve adequate power. Another limitation of the present study was that the current sample was not representative on the basis of ethnicity (majority of participants were Caucasian) and severity of PD (there was a low proportion of participants with severe stages of PD). A larger and more representative sample could be obtained, so that power is achieved and a more inclusive range of participants are included.

The current study excluded individuals who did not use English as their first language, as questionnaires were not validated in or translated into other languages. A number of participants were therefore unable to participate in the research as they had difficulties in understanding English. In addition, a significant proportion of individuals with PD had a co-morbid diagnosis of dementia and were excluded due to exclusion criteria. The current study was therefore unable to determine shame experiences and psychological difficulties amongst these individuals. So as to not exclude significant proportions of individuals with PD, future research could include participants with cognitive impairment to explore experiences of shame, appearance concerns and psychological difficulties.

5.4 Future Research

The findings of this current study were ambiguous, given the low levels of self-reported shame, significant associations between the variables and inconsistent verbal information. Future research is necessary to allow for further understanding of the current findings.

Given the possibility of demand conditions, a suggestion for future research could be to recruit from several hospital sites, however the medically-orientated nature of outpatient clinics may influence demand conditions. It was suggested as a possible hypothesis for interpreting the current findings that qualitative methods may have enabled participants to share their experiences. However, as mentioned in the limitations section, the presence of the researcher may have affected participant’s responses. Given that assistance with completion of the measures was deemed necessary for a large proportion of individuals with PD, individuals may need to feel comfortable with the researcher before sharing personal experiences and emotions. Gilbert (2002) suggested that when assessing body image disturbance and shame, effective interview formats need to engage and reassure patients, while providing some structured evaluation of relevant domains. Furthermore, older adults research in pain (Bhar & Silver, 2014) and trauma (Hiskey & McPherson, 2013) has demonstrated that trust enabled participants to express themselves openly and disclose levels
of distress or difficulty. Future research could adopt more of a community based approach using a longitudinal design in an attempt to aid participants’ disclosure and overcome some of the demand conditions presented in the current study.

As previously mentioned, some of the measures were negative and pathologising in nature and given the potential difficulty of measures to accurately capture experiences of individuals with PD, a mixed methods design could be adopted, with a particular qualitative emphasis on exploring an individuals’ experience of self-conscious emotions. Also, utilising a measure that establishes an individual’s strengths and abilities in addition to distress and difficulties would permit a more balanced view of appearance related concerns (Rumsey & Harcourt, 2004). Including elements of resilience to help protect against psychological distress has also been demonstrated in other chronic health conditions (Mednick et al., 2007). Alternatively, designing a measure to specifically examine potential shameful experiences of living with PD may be deemed more clinically relevant than a generic measure of shame. It has been suggested in eating disorders research that shame around specific behaviours related to eating was more clinically appropriate than global shame (Burney & Irwin, 2000).

The current sample consisted of a limited number of participants who were younger than 60 years of age. Research has suggested that individuals with PD fear being perceived as ‘old’ or ‘demented’, given that PD is regarded as an age related disease (Bramley & Eatough, 2005). Furthermore, it has been demonstrated that perceived stigmatization is greater among younger individuals with PD (Schrag et al., 2003). Future research could examine self-conscious emotions among a younger cohort of participants to explore whether higher levels of self-conscious emotions are apparent. Interestingly, participants in the current sample frequently expressed their concerns about being perceived as old, yet the average age of participants was 74 years of age. Future research could explore the psychological meaning of being ‘old’ and associations with self-conscious emotions.

5.5 Clinical Implications

It is not known whether participants were forthcoming about some of their experiences on particular measures. Findings demonstrated that some of the responses on the PDQ-39 were not comparable to qualitative responses, and could indicate the importance of healthcare professionals to acknowledge that patients may be reluctant to disclose personal information. There is a need for health care professionals to carefully assess psychosocial issues with
It was evident that levels of general shame and BID were greater than non-clinical populations, indicating health care professionals should be aware that individuals with PD may have concerns about their appearance. This is of particular concern given that both BID and general shame have been associated with psychological difficulties. If patients deny when directly asked by their clinician and do not complain or disclose difficulties, one might assume they are coping relatively well, which could potentially lead to a worsening of difficulties and related problems (Moore et al., 2012). Furthermore, it has been suggested that experiences of anxiety and depression may increase levels of shame in older adults, possibly causing further difficulties (Crossley & Rockett, 2005). Individuals could be referred to psychology services for therapy, so as to try and prevent further psychological distress and social isolation. Compassion focussed therapy has been shown to be beneficial in developing self-compassion to act as an antidote to shame (Gilbert & Irons, 2005) and mindfulness based approaches have also been found to be positive in individuals with PD (Fitzpatrick et al., 2010).

It may be necessary for health care professionals to sensitively communicate with patients about their potential difficulties, so as to acknowledge possible stoicism but continue to persist in cautiously exploring any psychological difficulties. Healthcare professionals could ensure that time is spent in each follow up appointment attending to psychosocial issues, to avoid a sole focus on medical complaints and to allow the patient to become more acquainted with such discussions. Clinical Psychologists could play a role in supporting and training clinicians and increasing their psychological awareness of potential difficulties experienced by patients with PD.

5.6 Conclusion
This study was the first to directly explore experiences of shame and associated psychological morbidity among individuals with PD. The findings demonstrated that participants experienced higher levels of general shame and body image disturbances compared to non-clinical populations and significant associations between shame and psychological morbidity were found. It was found that participants quantitatively reported
low levels of shame (external and body), fear of negative evaluation and social anxiety but qualitatively expressed embarrassment, self-consciousness and associated concealment and avoidance behaviours in relation to Parkinson’s disease symptoms. It was suggested that open-ended questions may have facilitated participants to share their experiences in comparison to responding to quantitative self-report measures alone.
6.0 References


Section 3

Critical Appraisal
Critical Appraisal

Throughout the research process I reflected on each stage, noting the lessons I have learned, the challenges and opportunities which I encountered, and the skills I have developed. These issues were recorded in a diary throughout my research journey and have been used to reflect and appraise the research process.

Developing the Research Idea

At the beginning of clinical training I generated potential project ideas after staff had presented their research interests. One area of interest was to explore appearance-related schema and fear of negative evaluation in people with Parkinson’s disease (PD). My priority was to undertake a piece of research that I was interested in, as previously it had been challenging trying to sustain interest in certain research projects.

My first year literature review explored experiences of one of the most predominant symptoms of PD (tremor). It was apparent that several studies made indirect references to self-conscious emotions and behaviours because of symptoms that appeared visible to others. Furthermore, studies in other populations with visible difference suggested positive associations between shame and psychological morbidity. However, there was a dearth of research looking at the psychological impact of symptoms from an appearance-related perspective in PD and no quantitative studies had been conducted exploring the prevalence of these phenomena.

My preference was to conduct a project parallel to my research epistemology (positivist / post-positivist), strengths and experiences. I believed that phenomena such as shame could be objectively quantifiable using valid quantitative methods to determine relationships with other phenomena. Scoping previous literature that had examined shame confirmed my view that shame is a construct that can be objectively measured. Based on previous research in other populations, it was therefore decided that quantitative methodology would be used to examine experiences of shame, psychological morbidity, quality of life and body image disturbances amongst people with PD.
Designing the project
One of my supervisors had developed research collaborations with a Consultant Physician (CP) at a neurology outpatient department, and a previous trainee had undertaken research in this context. I was fortunate in that the CP valued psychological research and was keen to assist, as I learned from liaising with fellow trainees and understanding their difficulties in obtaining a sample, commitment and facilitation from clinical staff is essential. Involving the hospital staff (CP and specialist nurses) throughout various stages of the study was invaluable to reveal dimensions to the project not previously considered and in helping to shape the design of the project. I felt that it also encouraged an invested interest in the study.

The project was discussed over several meetings with the CP who expressed their concerns about using ‘shame’ in the project title and felt that an alternative word should be used. As a consequence, ‘shame’ was removed (also discussed below). It was agreed that I could attend the CP’s clinic and two nurse-led clinics every week to obtain my participant numbers. There were concerns about whether it would be possible to meet with all eligible patients in a clinic, as it was estimated to take between 45 and 60 minutes to meet with each patient. It was deemed ethically unfair not to invite all suitable participants to take part, but equally unfair to turn patients away. Fewer patients attended the nurse-led clinics therefore this issue did not apply.

As data collection commenced, the CP revealed difficulties in completing measures of severity due to service re-structuring, time constraints and increase in workload. Additional concerns were also raised about the robustness of the study, as it was felt I would not obtain sufficient participant numbers. I gave my reassurances that I would exert my best efforts and I suggested a meeting with one of my supervisors to discuss and resolve these concerns. As a consequence it was agreed that only one measure of severity would be completed and one of my supervisors would assist with data collection when several eligible patients had been identified (known a week in advance).

The research revealed the challenges of NHS research – that dominance of clinical activity, in an age of fiscal constraint and prioritising direct patient contact leaves clinicians with little time to commit to research. I discovered that by discussing and working through concerns and achieving a compromise, issues can be addressed and overcome. On reflection, it was positive that the CP felt so strongly about the study that they were concerned about the
logistics of the research. Furthermore, I was fortunate and grateful that the hospital staff were willing to assist with my study. However, for future projects I will not assume that clinicians can fully commit to research (despite their best intentions) and I will be mindful of placing additional demands upon clinicians.

**Literature Review**

From completing the literature review in the first year, I developed a wider interest in exploring self-conscious emotions in PD. My preference was to conduct a systematic literature review parallel to my research epistemology, strengths and experiences. However, scoping searches indicated that research was too limited to warrant a literature review in this area. My interest in developing further understanding of PD and developing my competencies took precedence over conducting a systematic review in a similar condition, so I chose to undertake a meta-synthesis in PD.

From scoping the literature it was evident that lived experiences of PD had been increasingly explored by qualitative means over the last decade, highlighting the need to integrate identified studies. I decided to use a meta-ethnographic approach as it has received the most attention and explication to date (Campbell et al., 2011) and has been effectively used for synthesis of research in healthcare, particularly for questions pertinent to patient experiences of illness.

Significant effort was put into careful reading around meta-ethnography to gain a thorough understanding of the approach and to develop my confidence in conducting the synthesis. I learnt the importance of engaging in rigorous procedures involving several stages to identify relevant research papers. Using a meta-ethnographic approach enabled me to develop my skills and knowledge in interpreting and synthesising concepts within studies. It also helped to challenge my epistemological stance, as I became increasingly interested in the information elicited from utilising qualitative methodology.

**Peer and Ethical Review**

**Peer Review**

My research proposal was submitted for peer review at the Clinical Psychology Department. The feedback received was useful in being able to attend to some important considerations and in developing a sound research proposal with my supervisors.
**Integrated Research Application System (IRAS)**

In order to obtain NHS ethical approval from the local Research Ethics Committee (REC), it was necessary to complete the IRAS form. This form was lengthy, repetitive and confusing in places. I learnt that it was important to seek advice from relevant professionals who had knowledge of the ethics procedure to avoid unnecessary mistakes and time delays.

**REC Meeting**

Upon completion of the IRAS form there was a five week wait to attend the next available REC meeting. The committee was attended by 10 members consisting of various professionals and lay members, but no psychologists.

The panel at the REC meeting were apprehensive about participants becoming upset due to ‘shame’ being mentioned in the Participant Information Sheet and requested it to be replaced with self-consciousness. Personally, this reaction emphasised a pertinent difference in how difficult emotions are appraised and approached within professions outside of psychology. I thought it was not conducive to mask over concerns of shame by referring to it as self-consciousness. The panel acknowledged that some measures had shame in their title and suggested that this could be discussed with patients upon meeting them. I believed that patients should have obtained this information beforehand, as it may have affected their decision to meet with me.

Upon reflection, I felt that the panel did not understand or take into account our role as Clinical Psychologists or the importance of talking about shame in what could be shaming experiences of having a chronic condition. I felt that had a psychologist been present on the panel, a different outcome may have been achieved. In experiencing people’s reaction to the word ‘shame’ it highlighted a particular area of interest to explore upon completion of my clinical training.

**Local Research and Development (R&D)**

Completion of consent training and Good Clinical Practice training was necessary before R&D ethical approval was granted. After a frustrating eight week wait for training I reflected on why it was necessary to take such precautionary actions, I learnt how the NHS is rigorous in protecting patients and in producing good quality research. However, the relevance of the
process seemed debatable given its emphasis on clinical trials, rather than small questionnaire studies.

After an unanticipated six month period to gain ethical approval, I learnt that it was paramount to overestimate the amount of time required for NHS ethics, including allowance for potential obstacles. This will be an integral part of planning and timing for any further research I conduct.

**Data Collection**

*Pilot study and number of measures*

My original plan was to administer a pilot sample of questionnaires to determine the suitability of length and completion time. Unfortunately, due to time constraints and the delay in getting ethical approval I decided not to prolong data collection.

Completing the measures with patients took longer than anticipated, as the majority of patients were slow to process information. I naively assumed that this would be mitigated as I was assisting patients with completion. Although time consuming, it was the best method of data collection, as patients would have encountered difficulties (due to tremor and other symptoms). Furthermore, it enabled a full dataset to be obtained, preventing difficulties with data analyses and it also provided opportunities to ask follow up questions to the qualitative aspects of the questionnaires.

In hindsight, I would have conducted a pilot study and consequently reduced the number of questionnaires to decrease the burden and length of time to administer, as on occasion completion took over an hour.

*Obtaining participants*

Initiating data collection at the nurse-led clinics was delayed, as a function of service restructuring, transfer to community and insufficient office space. This was testing as I felt I was unable to control events, as numerous clinics were cancelled, and a limited number of eligible patients were identified to participate (according to exclusion criteria). Only seven patients were obtained after six weeks of data collection and I learned the need for flexible thinking and clarity when under pressure.
I now understand the inadvertent delays that can occur in process if clinic staff are so pressured that information sheets are not issued. I also considered the impact of clinic busyness of potential respondents. Some appeared to decline because clinics were already running late and they needed to see multiple staff. In an attempt to overcome these problems, I took letters and stamps on a weekly basis to act as a gentle reminder and I spoke to clinicians before each clinic commenced. The burden on myself as a researcher was greater than anticipated as I needed to attend for as long as possible, yet there could be lengthy gaps between meetings with respondents. I became adept at fitting in reading and/or inputting data into SPSS.

Due to low participant numbers I considered alternative options with my supervisors as part of a contingency plan to maximise numbers. Additional support with data collection was considered; however, it was apparent that there were requirements for ethical approval. Although one of my supervisors agreed to assist, it wasn’t deemed to be an efficient use of their time as clinics did not always go to plan and there was limited room availability. Developing contacts with CP’s at another hospital site was also another option; however, this required additional ethical approval and planning. It was therefore decided that it would be more appropriate to review how participant numbers developed before considering further options.

I learnt that it was important to develop a good rapport with hospital staff which allowed us to work together to complete tasks. Although this placed extra demands on my time, I felt my engagement with them was reciprocated. On reflection, I felt the competencies I had developed throughout my clinical psychology training enabled me to utilise my interpersonal skills and ability to work in multidisciplinary teams.

My experience has enabled me to learn that in order to ensure efficient data collection in a busy, demanding and stressful NHS environment, it is necessary to be effectively organised and to work with staff to put systems into place and adapt them accordingly. I have learned that despite best efforts, there will always be factors out of the researchers’ control that impede smooth data collection. Therefore, it is necessary to be flexible and have good problem solving skills when difficulties arise. For future research I will ensure that I spend time getting to know how clinics operate in an attempt to increase awareness of potential difficulties that may arise, so that proactive planning can take place over reactive planning.
However, I have learned that research will always require a degree of flexibility regardless of the amount of planning that takes place.

**Personal reflections**

By liaising with clinicians I was able to provide psychological information and understanding about how some patients may experience PD and for them to consider referrals to psychological services. It was encouraging that clinicians were interested in developing their psychological awareness and I plan to discuss this further in the future. I hope that this would encourage clinicians to hold clinical psychology in mind in their multi-disciplinary working, especially for patients experiencing significant psychological difficulties. This experience has enabled me not to assume that medical staff would have psychological awareness of mental health difficulties.

I did not anticipate that data collection would be so slow, time consuming and demanding. Due to time constraints and attending three clinics per week (approximately 56 clinics attended in total) it was necessary to use evenings and weekends to work on my thesis. I learnt that it was imperative to have good time management skills and to be organised throughout the research process. I used a schedule to prioritise tasks and to effectively manage my time to ensure tasks were completed. The importance of self-care was paramount and I scheduled time off. On reflection, I believe this method of organisation enabled me to stay focused on the task at hand, prevented burnout and enabled me to stay determined.

As previously mentioned, I found that patients were slow to process information and although I wanted to spend time with them, not discredit their experiences and not pressure them, I was conscious of time constraints and missing out on opportunities to see other patients. I was also mindful of not rushing patients, as stress can exacerbate symptoms. It was difficult trying to balance the different roles of being a researcher and a clinician, especially when patients became emotionally upset. As a clinician, I would have preferred to have spent more time with them talking through their experiences; however, I had to remind myself that I was meeting with patients as a researcher and I had to be aware of boundaries. It was helpful to discuss and reflect on these concerns with my clinical supervisor on placement.

It was apparent that patients appeared to give mixed messages about their experiences via different modes of communication. For example, in response to certain scaled questions
patients did not feel they were concerned about their appearance, yet during conversations and qualitative responses to the Body Image Disturbance Questionnaire (BIDQ) and Derriford Appearance Scale-24 (DAS-24) they referred to feelings of self-consciousness and embarrassment about symptoms such as tremor. Some did not mention concerns at all, yet were observed trying to hide tremor (by sitting on their hand or putting their hand in their coat pocket). On occasions, when patients’ became aware that I had noticed, it opened up a dialogue and patients expressed concerns of self-consciousness and embarrassment.

On reflection I questioned the authenticity of the measures and queried what factors may have contributed to the mixed responses. I also speculated about whether there may have been an impact of an essentially medical context, very clinically orientated setting (medical rooms, clinical waiting room) on patient responses. Furthermore, I met with patients after their outpatient appointment where the prime focus had been on symptom and medication monitoring with little, if any discussion around their emotional experiences of PD.

I also considered whether directly asking or talking about difficult emotions such as shame could have inhibited responses, as shame has been considered to be an unspoken emotion that underpins vulnerability (Brown, 2010). It might have been easier for patients to talk about self-consciousness and embarrassment and when it felt comfortable to do so, rather than responding to a brief question with limited response formats. Admitting to experiences of shame can be shaming in itself and having to give responses in a clinical setting with a stranger may have influenced how patients responded. Cumulatively these factors could have potentially impacted on the quantitative results. However, I felt that open-ended questions facilitated participants to share their experiences by enabling them to explicitly think about their self-conscious emotions in relation to PD.

Conducting the literature review enabled me to develop links between the themes apparent in the literature and patient responses to the qualitative questions. Previously, I had acknowledged the limitations of quantitative methodology; however, I remained sceptical about the use of qualitative methods, as I felt they were too subjective and offered little to the research base. My experience of conducting the literature review and meeting with participants to administer measures enabled me to challenge my epistemological position and appreciate the value of qualitative methodology. I previously assumed that shame was a construct that could be objectively measured and its relationships with other phenomena
could be examined using quantitative methodology. However, I have discovered that this assumption is not without limitation as shame is a complex, subjective emotion and as previously mentioned it can be a difficult emotion to identify and admit to and consequently challenging to measure. I also felt that some of the quantitative measures were too abrupt and did not allow the patient to feel safe enough to disclose such private emotions. I have become aware of how quantitative measures provide limited opportunities for individuals to discuss their experiences and measures reduce experiences down to specific constructs. Furthermore, the presence of the researcher was likely to heavily influence individual’s responses to quantitative measures, in particular shaming experiences. According to positivist paradigms the study is not affected by the researcher and objectivity is strived for.

Despite these concerns I continued to assume that associations between shame, PD and psychological morbidity existed, given some of the information I obtained from meeting with participants. However, I questioned whether shame could be objectively measured using the present design/procedure and paradigm. I was able to gain some rich (although limited) information from discussions with participants; information that was not reflected in the measures. These discussions allowed me to discover how shameful experiences are unique (like experiences of PD) and need to be considered within different social contexts, something that isn’t taken into account in an empiricist paradigm, as objectivity is reduced. Furthermore, conducting the literature review allowed to me to discover how quantitative methodologies provided little information with limited meaning in comparison to qualitative data, a method that permits a real understanding of the phenomena. My experiences have enabled me to develop more of an understanding of the limits of an empiricist paradigm and I recognise that quantitative methodology is not appropriate for all forms of research.

I was (and still am) very grateful for the fact patients agreed to participate in the research and I valued listening to their experiences. However, I felt increasingly frustrated and saddened that patients had little, if any, psychological support. This made me determined to obtain as many participants as possible to ensure that my research was robust, in the hope that it would be published and hopefully increase awareness of peoples’ experiences of PD. I will definitely ensure a summary of the research will be made available to patients, as I am grateful for their time and effort and believe they should be given feedback about what they contributed to.
Research supervision

I was fortunate to have two research supervisors who provided support with the development of the research proposal and useful feedback on my written work, enabling me to improve my writing style. I found supervision useful to alleviate some of my anxieties around data collection, especially in the early stages.

I was advised by both supervisors to start my literature review over the summer for completion in September 2013. I found this difficult to achieve after a busy second year of training and consequently didn’t start the literature review until September. In hindsight, I would have started the review when advised to do so, as it was difficult trying to complete the literature review whilst attending three clinics per week to collect data.

Limitations and suggestions for future research

I acknowledged several limitations to the study and if I were to carry out this research again, I would make several modifications (in addition to the suggestions I have previously mentioned) in an attempt to improve the study:

- I would reconsider some of the measures/items used, in particular the Other As Shamer Scale and the BIDQ, as I felt uncomfortable with the words “defect” and “defective” being used. Furthermore, some participants expressed comments about the negative language used. However, the BIDQ was helpful in that the qualitative aspects enabled participants to share their experiences and I was able to replace “physical defect” with appearance concerns associated with PD.
- I am now more sceptical of exclusively using quantitative methods to explore patients’ experiences, as the meaning of phenomena can be diminished, it would be interesting to adopt more of a mixed methods design, with a particular qualitative focus on exploring patients’ subjective experience of shame. However, in an attempt to overcome potential under responding, a longitudinal type of approach may be more appropriate, in the hope that participants feel safe enough to disclose feelings of shame.
- A setting other than an outpatient clinic may be more appropriate and as such, meeting with patients in the community may be more effective.
- The current study failed to take into account whether experiences of psychological morbidity and shame were experienced prior to a diagnosis of PD and whether individuals were taking medication for psychological difficulties. These factors may
have affected the data and it may be important to take these into consideration for future research. Furthermore, future research could focus specifically on shame experiences of living with PD, rather than relying on generic shame measures.

- It was originally planned for the Unified Parkinson’s Disease Rating Scale (UPDRS) to be used in addition to the Hoehn and Yahr (H&Y) to measure severity of PD. However, due to clinician workload demands it was decided to use the H&Y only. The UPDRS provides a more comprehensive assessment of severity of PD, as the H&Y merely focuses on motor symptoms. Further research would benefit from using the UPDRS, but it would also be beneficial to explore patient’s perception of severity, as individual’s perception and appraisal of the condition and symptom impact may be more important than objective severity (Schrag, Jahanshahi & Quinn, 2001).
- A larger and more representative sample could be achieved, so that power is attained and a more inclusive range of participants are included, for example on the basis of ethnicity (95% of the sample were White), severity of PD (94% of the sample were of H&Y stages 1-3) and age (mean age of the sample was 74 years of age).

Conclusion
Overall, I am more aware of the research process and I have developed skills and confidence throughout. I have learned that planning, organisation, overestimating the length of time for various stages, good time management, team working, problem solving and good communication skills are all needed throughout the research process. Although it was a quantitative study, I enjoyed meeting with patients and learning about their experiences. Meeting with older adults (the majority of patients were) in a clinical setting was a novel experience for me, but one that I found rewarding. I feel passionate about clinical psychology having more of a presence within such settings. Finally, I have learned that all research has limitations and despite rigorous planning and organisation, in reality there will always be unexpected obstacles that occur outside of the researcher’s control. Research is a dynamic process that requires a degree of flexibility throughout.
References


Appendices
Appendix A: Effective synthesis

It has been suggested that the diversity of qualitative methods with varying epistemological positions, aims, theoretical premises and methodological approaches may prevent effective synthesis (Snelgrove & Liossi 2013). Embarking on synthesis of qualitative research must therefore grapple with differing epistemologies and must also include contending theoretical approaches that reflect different kinds of reality (Gomersall, Madill & Summers, 2011). These differences have prompted debates about suitable methods for study selection, appraisal and synthesis involved in qualitative synthesis (Campbell et al., 2011) and whether qualitative synthesis encourages a ‘positivist approach’ (Barbour, 2001). Yet, whilst disparities can create challenges, effective synthesis is possible, given most qualitative research has a mutual concern with understanding and challenge positivist approaches (Ring, Jepson & Ritchie, 2011). Furthermore, methods of synthesis have been developed that remain true to epistemological origins (Barnett-Page & Thomas, 2009).
Appendix B: Meta-ethnography

Meta-ethnography is a method of synthesis that is applicable to qualitative research generally; it can be used for any set of ethnographic or interpretive studies (Noblit & Hare, 1988) using different methodologies (Barnett-Page & Thomas, 2009). Synthesis is attained from the translation of studies into one another (Noblit & Hare, 1988). This involves relating findings of different studies to each other, in order to determine new relationships between concepts (Campbell et al., 2011). It enables the synthesiser to understand and transfer ideas, concepts and metaphors between the various studies (Britten et al., 2002). Noblit and Hare (1988) identified seven phases when completing a meta-ethnography:

**Phases one to three**

The initial two phases involves developing a research question and conducting a thorough search of the literature using an appropriate search strategy, to identify relevant studies according to inclusion and exclusion criteria and quality appraisal. The third phase involves repeated reading of the studies, including data extraction and noting concepts throughout the development of the synthesis.

**Phases four and five**

Meta-ethnography is an interpretative method of synthesis that can develop new insights and interpretations that go beyond those identified in the original studies (Campbell et al., 2011). These new interpretations are developed through the synthesisers’ engagement and position to become third order constructs (Campbell et al., 2011), themselves based on first and second constructs provided in the identified studies. The participants’ accounts and understanding of a particular phenomenon in the identified studies are first order constructs. And second order constructs are formed through the authors’ interpretations of these accounts (Campbell et al., 2011). The interpretations and explanations provided in the original studies are treated as data in the meta-ethnography (Britten et al., 2002).

Phases four and five of a meta-ethnography involve determining how the studies are related and then translating them into one another. This involves identifying and comparing key concepts, phrases and metaphors across the different studies to determine how they are related. The translation of studies focuses on translating the meaning of the text and aims to maintain the original meanings and contextualisation (Campbell et al., 2011). Noblit and Hare (1988) referred to this process as Reciprocal Translational Analysis. They identified
three possible types of relationship that can guide translation and synthesis (Campbell et al., 2011). Studies can be related by reciprocal translations; when there are similar themes across the different studies. Alternatively, if themes across the studies conflict with each other, a refutational relationship may be present. The third type of relationship is line of argument; when studies suggest inference and a new interpretative context about some greater issue or phenomenon that may not have been evident in the individual studies (Campbell et al., 2011).

**Phases six and seven**

The sixth and seventh phases involved synthesising translations and expressing the synthesis. An iterative process of closely examining the table of first and second order constructs, along with each of the papers, enables the development of new interpretations (third order constructs).
### Appendix C: Search Terms

<table>
<thead>
<tr>
<th>Database</th>
<th>Search Terms</th>
<th>Number of Articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>PsychINFO</td>
<td>Parkinson* AND (qualitative OR interview OR phenomenology OR discourse OR interpretive) AND (experience* OR feeling OR emotion* OR perception OR perceive* OR cop* OR manag* OR apprais* OR narrative*)</td>
<td>99</td>
</tr>
<tr>
<td></td>
<td>Limiters - Peer reviewed and Qualitative Methodology</td>
<td></td>
</tr>
<tr>
<td>Web of Science</td>
<td>Topic=(parkinson*) AND Topic=(qualitative OR interview* OR phenomenolog* OR discourse* OR interpretive) AND Topic=(experience* OR feeling* OR emotion* OR perception* OR perceive* OR cop* OR manag* OR apprais* OR narrative*)</td>
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</tr>
<tr>
<td>Scopus</td>
<td>(TITLE-ABS-KEY(parkinson*) AND TITLE-ABS-KEY(qualitative OR interview* OR phenomenolog* OR discourse* OR interpretive) AND TITLE-ABS-KEY(experience* OR feeling* OR emotion* OR perception* OR perceive* OR cop* OR manag* OR apprais* OR narrative*))</td>
<td>617</td>
</tr>
<tr>
<td>Medline</td>
<td>Parkinson* AND (qualitative study) AND (experience* OR feeling* OR emotion* OR perception* OR perceive* OR cop* OR manag* OR apprais* OR narrative*))</td>
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</tr>
<tr>
<td>CINAHL</td>
<td>Parkinson* AND (qualitative OR interview* OR phenomenolog* OR discourse* OR interpretive) AND (experience* OR feeling* OR emotion* OR perception* OR perceive* OR cop* OR manag* OR apprais* OR narrative*)</td>
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</tr>
<tr>
<td></td>
<td>Refine – Peer review and English</td>
<td></td>
</tr>
<tr>
<td>PudMed</td>
<td>((parkinson*) AND (qualitative OR interview* OR phenomenolog* OR discourse* OR interpretive)) AND (experience* OR feeling* OR emotion* OR perception* OR perceive* OR cope OR coping OR manag* OR apprais* OR narrative*)</td>
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</tr>
<tr>
<td>The Cochrane Library</td>
<td>Parkinson’s disease</td>
<td>133</td>
</tr>
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</table>
## Appendix D: Study Characteristics

<table>
<thead>
<tr>
<th>Paper</th>
<th>Aims of study</th>
<th>Country / Setting</th>
<th>Sample details</th>
<th>Method of Data Collection</th>
<th>Method of Data Analysis</th>
</tr>
</thead>
</table>
| ‘A stony road… a 19 year journey’: ‘Bridging’ through late-stage Parkinson’s disease (Williams & Keady, 2008) | • To understand the experiences of patients with PD and their families as they manage and adjust to living with late-stage PD | North Wales | **Population:** 13 people with late-stage PD  
**Age:** 65-89  
**Gender:** 3 Female, 10 male  
**Duration of PD:** Range 6-19 years (8 people 6-10, 5 people 11-19)  
**Stage of PD:** Assessed as having late-stage disease using the Hoehn and Yahr scale | 2 year longitudinal study. Repeated interviews conducted between 2007-2008 | Grounded Theory (Strauss & Corbin, 1990) |
| Continuity Challenges of PD in Middle Life (Habermann, 1999) | • To explore the experience of having PD in middle life. How people cope with challenges and threats to their sense of self and future limited horizons. | Various neurology practices, San Francisco Bay | **Population:** 16 middle aged participants with PD  
**Age:** 42-59 years ($M = 48$ years)  
**Gender:** 7 Female, 9 Male  
**Duration of PD:** 70% diagnosed less than 5 years. Range of 1-16 years, 11 (<5 years), 4 (5-10 years) and one had been diagnosed 16 years.  
**Stage of PD:** 75% Hoehn & Yahr 2-3 | Three in-depth interviews were conducted over a 3 month period. | Interpretative approach. Three interrelated interpretive strategies (thematic analysis, analysis of exemplars, and search for paradigm cases) |
<p>| Day-to-Day Demands of Parkinson’s Disease (Habermann, 1996) | • To explore the day-to-day demands experienced by those living with PD in middle life. | | | | |</p>
<table>
<thead>
<tr>
<th>Paper</th>
<th>Aims of study</th>
<th>Country / Setting</th>
<th>Sample details</th>
<th>Method of Data Collection</th>
<th>Method of Data Analysis</th>
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</thead>
</table>
| Coping and self-help group membership in Parkinson’s disease: an exploratory qualitative study (Charlton & Barrow, 2002) | • To investigate the consequences of living PD.  
• To identify the coping methods used to alleviate psychological distress, and to see whether coping methods are related to self-help group membership. | UK | **Population:** 8 people with PD  
**Age:** All participants were over 62 years of age (range = 62-86 years).  
**Gender:** 5 Females and 3 Males  
**Duration of PD:** All participants had been diagnosed with PD for over 3 years (range 3-8 years)  
**Stage of PD:** Not known | Semi-structured interviews. | Thematic analysis |
| Living with Parkinson’s disease: Elderly patients’ and relatives’ perspective on daily living (Wressle, Engstrand & Granérus, 2007) | • To study how PD affects daily living from the perspective of both patient and relative. | Sweden | **Population:** 7 people with PD  
**Age:** 64 - 77 years of age  
**Gender:** 4 Females and 3 Males  
**Duration of PD:** Range of 2 to 5 years.  
**Stage of PD:** Patients were categorised into stages 1–2, and 5 according to Hoehn and Yahr (1967). | Qualitative interviews | Grounded Theory (Strauss & Corbin, 1990) |
<table>
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<tr>
<th>Paper</th>
<th>Aims of study</th>
<th>Country / Setting</th>
<th>Sample details</th>
<th>Method of Data Collection</th>
<th>Method of Data Analysis</th>
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</table>
| Older Swedish women’s experiences of living with symptoms related to Parkinson’s disease (Caap-Ahlgren, Lannerheim & Dehlin, 2002) | • To explore women’s experiences of living with symptoms related to PD, and to analyse how the symptoms influence their quality of life. | Outpatient clinic, neurology department. Sweden. | **Population:** 8 women with PD  
**Age:** 63 - 80 years of age \( (M = 70 \text{ years}) \)  
**Gender:** 8 Females  
**Duration of PD:** Range of 5 - 15 years.  
**Stage of PD:** Hoehn & Yahr  
Stage 1 \((n=1)\), Stage 2 \((n=2)\), Stage 3 \((n=3)\), Stage 4 \((n=1)\), and Stage 5 \((n=1)\). | Qualitative, informal, conversational interviews | A phenomenologic al-hermeneutic method, inspired by the philosophy of Ricoeur was used. |
| Sailing the Stormy Seas: The Illness Experience of Persons with Parkinson’s Disease (Stanley-Hermanns & Engebretson, 2010) | • To understand how people with PD construct their illness experience and manage living with the disease on a daily basis. | East Texas | **Population:** 14 people with PD  
**Age:** 38 – 82 years of age \( (M= 68.4 \text{ years}) \)  
**Gender:** 7 Females and 7 Males  
**Duration of PD:** Not known  
**Stage of PD:** Hoehn and Yahr  
Stage 1 \((n=2)\), Stage 2 \((n=2)\), Stage 3 \((n=3)\), Stage 4 \((n=6)\), and Stage 5 \((n=1)\). | Ethnography over two years. Observations and discussions at support group meetings. Individual semi-structured interviews. | Thematic analysis |
<table>
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<tr>
<th>Paper</th>
<th>Aims of study</th>
<th>Country / Setting</th>
<th>Sample details</th>
<th>Method of Data Collection</th>
<th>Method of Data Analysis</th>
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<tbody>
<tr>
<td>Sex and Gender in Older Adults’ Experience of Parkinson’s Disease (Solimeo, 2008)</td>
<td>• To explore sex differences in symptomatology. How male and female gender identity may influence the interpretation of somatic phenomena in PD.</td>
<td>USA, State of Iowa</td>
<td>Population: A total of 171 PD participants in the study (PD support groups and interviews n=70). &lt;br&gt;Age: Mean age 72.68 years. Females $M = 72.68$ years and Males $M = 73.27$ years &lt;br&gt;Gender: 35 Females and 35 Males &lt;br&gt;Duration of PD: Females $M = 8.63$ years and Males $M = 7.97$ years</td>
<td>Ethnography over 15 months. Majority of data derived from field notes, interview transcripts, and open-ended questionnaire items.</td>
<td>Narrative analysis</td>
</tr>
<tr>
<td>Stopped within a track: embodied experiences of late-stage Parkinson’s Disease (Sunvisson, 2006)</td>
<td>• To explore the lived experience of late-stage Parkinson’s disease.</td>
<td>Sweden</td>
<td>Population: Female patient with PD &lt;br&gt;Age: 72 years &lt;br&gt;Gender: Female &lt;br&gt;Duration of PD: 15 years before the study commenced</td>
<td>Interview with no guide. &lt;br&gt;Frequent conversations (almost one each month) with the patient over a five year period.</td>
<td>Phenomenologic method developed by Karlsson (1995).</td>
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<tr>
<td>Paper</td>
<td>Aims of study</td>
<td>Country / Setting</td>
<td>Sample details</td>
<td>Method of Data Collection</td>
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<tr>
<td>The experience of living with Parkinson's disease (Marr, 1991)</td>
<td>To explore what it is like to live with PD.</td>
<td>Outpatient movement disorder clinic. Canada</td>
<td>Population: 6 people with PD</td>
<td>Unstructured interviews</td>
<td>Content analysis</td>
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<td></td>
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<td>Age: 53 – 79 years</td>
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<td>Gender: 3 Females and 3 Males</td>
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<td>Duration of PD: 2 - 5 years</td>
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<td></td>
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<td></td>
<td>Stage of PD: Hoehn &amp; Yahr stages 1 - 4</td>
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<tr>
<td>The experience of living with Parkinson's disease (Bramley &amp; Eatough, 2005)</td>
<td>What are the lived experiences of an individual with a chronic degenerative disorder?</td>
<td>UK</td>
<td>Population: Female patients with PD</td>
<td>Semi-structured interviews</td>
<td>Interpretative phenomenologic al analysis (IPA)</td>
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<td></td>
<td></td>
<td></td>
<td>Age: 62 years</td>
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<td></td>
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<td></td>
<td>Duration of PD: 18 years</td>
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<td></td>
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<td></td>
<td>Stage of PD: Stage 4 (UPDRS)</td>
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<tr>
<td>Changing perceptions of womanhood: living with Parkinson’s Disease (Fleming, Tolson &amp; Schartau, 2004)</td>
<td>To develop an understanding of the experiences and adjustments made by women with PD in relation to womanhood</td>
<td>Scotland, UK</td>
<td>Population: 19 female patients with PD</td>
<td>Descriptive case studies through individual and group interviews, reflective diaries, reflective tapes, creative writing.</td>
<td>Data analysed using framework of Intrapersonal, Interpersonal, Extrapersonal Metapersonal health - Boddy &amp; Rice</td>
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<td></td>
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<td></td>
<td>Age: 34 – 56 years of age (M= 44 years)</td>
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<td></td>
<td></td>
<td></td>
<td>Gender: Female</td>
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<td></td>
<td></td>
<td></td>
<td>Duration of PD: 18 months – 27 years</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Stage of PD: Not known</td>
<td></td>
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</tr>
</tbody>
</table>
Appendix E: Identification of papers flow chart

Identification

Records identified through database search
\( N = 369 \)

Records after duplicates removed
\( N = 170 \)

Screening

Records screened
\( N = 170 \)

Records excluded
\( N = 154 \)

Eligibility

Full text articles assessed for eligibility
\( N = 16 \)

Articles included for qualitative review
\( N = 12 \)

Included

Full text articles excluded
\( N = 4 \)

\( N = 1 \) Focus on experiences prior to Deep Brain Stimulation
\( N = 1 \) Focus on palliative care
\( N = 2 \) Focus on quality of life aspects
Appendix F: Justification of not excluding papers on the basis of quality

There is much disagreement about whether quality appraisal in qualitative research should exist given that there are ongoing debates about what characteristics define good quality research (Dixon-Woods et al., 2004) and whether there is a credible philosophical rationale for carrying out appraisals (Campbell et al., 2003). Dixon-Woods et al. (2004) suggested that methods of appraising qualitative research are necessary if it is to contribute appropriately to systematic reviews; however, there is no agreement about the function of quality criteria and how they should be applied. A wide range of criteria and checklists are available to help assess quality of qualitative research and although their use continues to be contentious, (Chapple & Rogers, 1998) it has been reported that quality criteria are guides to good practice rather than strict requirements when appraising papers (Henwood & Pidgeon, 1992).

The Critical Appraisal Skills Programme (CASP, 2010) is a quality appraisal tool that has been frequently used in the assessment of qualitative research; it is a tool that has encouraged synthesisers to justify their reasons (Campbell et al., 2003; Dixon-Woods et al., 2007). Campbell et al. (2011) reported that an important benefit of using criteria to quality appraise studies was to encourage the careful reading of studies that aided interpretation. Interestingly, Noblit and Hare (1988) and others (Campbell et al., 2011; Smith et al., 2005) have suggested that including poorer quality of studies would contribute minimally to the synthesis and it was improbable that they would have an extremely distorting impact on the synthesis (Campbell et al., 2011). The synthesis therefore becomes “weighted” towards the findings of the better quality studies (Munro et al., 2007). Furthermore, only slight difference was found when comparing quality appraisal tools with researcher judgements (Dixon-Woods et al., 2007). Noblit and Hare (1988) did not encourage any method of quality appraisal before synthesis.
Appendix G: CASP Checklist – Study Characteristics

Research Aims and Design: The aims of the research for all of the studies were explicitly reported and all papers aimed to explore the experiences of PD. Although research design was deemed appropriate to address research aims, very few papers justified their research design or epistemological stance.

Sampling: Sampling methods were adequately described in majority of the studies; with purposive sampling being the most frequently used method. Very few studies provided discussion around recruitment, for example, why some participants chose not to take part and very few provided a rationale for their sampling method.

Data Collection: Methods of data collection were clearly stated in all of the studies, however, the level of detail varied. Very few studies provided a rationale for their method of data collection and in only two studies (Stanley-Hermanns & Engebretson, 2010; Sunvisson, 2006) did authors critically examine their own role and potential bias and influence during the research. Reflexivity was discussed in only one study (Stanley-Hermanns & Engebretson, 2010) and in the majority of studies data saturation was not reported.

Ethics: Eight studies stated they had gained ethical approval from ethics committees; four studies made no reference to ethics (Bramley & Eatough, 2005; Habermann, 1996; Habermann, 1999; Marr, 1991). Details provided regarding incorporation of ethical considerations and how the research was explained to participants varied markedly, making it difficult to assess the extent to which ethical standards were maintained throughout the study. A small number of studies (Charlton & Barrow, 2002; Wressle, Engstrand & Granérus, 2007) considered the potential impact of respondents’ participation.

Data Analysis: All studies described the process of data analysis; however, only a minority of studies provided in-depth descriptions and three studies provided minimal details (Fleming, Tolson & Schartau, 2004; Marr, 1991; Solimeo, 2008). Some studies reported attempts to ensure rigour and some referred to validation criteria, only one study commented on the use of a reflexive journal (Stanley-Hermanns & Engebretson, 2010). All studies provided sufficient data to support their findings; however, only some reported extensive quotations so that credibility of the analysis could be determined.

Findings: Explicit findings were reported in all of the studies and were discussed in relation to the original research question. Discussions about the meaning of themes were present in all of the studies and were reported in reference to clinical implications in the majority of studies.
Appendix H: Data Extraction Form

Study:

Eligibility

<table>
<thead>
<tr>
<th>Question</th>
<th>If yes</th>
<th>If no</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Is the study qualitative research?</td>
<td>Continue</td>
</tr>
<tr>
<td>2</td>
<td>Is the study about Parkinson’s Disease?</td>
<td>Continue</td>
</tr>
<tr>
<td>3</td>
<td>Does the study report patient’s experiences of having Parkinson’s Disease</td>
<td>Continue</td>
</tr>
</tbody>
</table>

Study Characteristics:

<table>
<thead>
<tr>
<th>Study details</th>
<th>Research question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location and Setting</td>
<td></td>
</tr>
<tr>
<td>Theoretical Framework</td>
<td></td>
</tr>
<tr>
<td>Participants</td>
<td>Population</td>
</tr>
<tr>
<td></td>
<td>Age (range, mean)</td>
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<tr>
<td></td>
<td>Gender</td>
</tr>
<tr>
<td></td>
<td>Ethnicity</td>
</tr>
<tr>
<td></td>
<td>Duration of PD</td>
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<tr>
<td></td>
<td>Staging of PD</td>
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<tr>
<td></td>
<td>Recruitment/sampling method</td>
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<tr>
<td>Data collection</td>
<td>Method</td>
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<td></td>
<td>Who?</td>
</tr>
<tr>
<td></td>
<td>Data analysis preparation (e.g. interviews transcribed)</td>
</tr>
<tr>
<td>Analysis</td>
<td>Method</td>
</tr>
<tr>
<td>Validity</td>
<td>What validation methods were used?</td>
</tr>
<tr>
<td>Reflexivity</td>
<td>Did the study report engaging in reflexivity?</td>
</tr>
<tr>
<td>Findings</td>
<td>How are the results presented?</td>
</tr>
<tr>
<td>Category 1 (including title, description)</td>
<td></td>
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DESCRIPTION
<table>
<thead>
<tr>
<th>Description, verbatim extracts of data and/or author’s analytic commentary of the data</th>
<th>Category 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category 3</td>
<td></td>
</tr>
<tr>
<td>Category 4</td>
<td>Key significant findings</td>
</tr>
<tr>
<td>Authors conclusions</td>
<td>Conclusion (author’s remarks, key findings)</td>
</tr>
<tr>
<td></td>
<td>Limitations (identified by authors)</td>
</tr>
<tr>
<td></td>
<td>Implications (identified by authors)</td>
</tr>
<tr>
<td></td>
<td>Key references (not identified by search strategies)</td>
</tr>
<tr>
<td>Comments</td>
<td></td>
</tr>
</tbody>
</table>
Appendix I: REC final decision letter

Health Research Authority

NRES Committee East Midlands - Northampton

09 May 2013

Miss Jodie Goddard
Trainee Clinical Psychologist
Leicestershire Partnership NHS Trust
104 Regent Road
Leicester LE1 7LT

Dear Miss Goddard,

Study title: An exploration into the experiences of Parkinson’s disease and its relationship with psychological outcomes
REC reference: 13/EM/0110
IRAS project ID: 120755

Thank you for your letter of 01 May 2013, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator [REDACTED] NRESCommittee.EastMidlands-Northampton@nhs.net.

Confirmation of ethical opinion

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

Ethical review of research sites

NHS sites

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

Non-NHS sites

Conditions of the favourable opinion

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

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

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

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

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

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

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

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

Approved documents

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

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering Letter</td>
<td></td>
<td>14 February 2013</td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td>04 February 2013</td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td>2</td>
<td>22 January 2013</td>
</tr>
<tr>
<td>Other: Unified Parkinson's Disease rating scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other: Internal peer review form</td>
<td></td>
<td>12 November 2012</td>
</tr>
<tr>
<td>Other: Service user reference group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other: Covering letter to participants</td>
<td>3</td>
<td>17 April 2013</td>
</tr>
<tr>
<td>Other: Confirmation of pre-engagement checks</td>
<td>1</td>
<td>30 April 2013</td>
</tr>
<tr>
<td>Participant Consent Form</td>
<td>3</td>
<td>17 April 2013</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>3</td>
<td>17 April 2013</td>
</tr>
<tr>
<td>Protocol</td>
<td>4</td>
<td>16 January 2013</td>
</tr>
</tbody>
</table>
Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
Further information is available at National Research Ethics Service website > After Review

13/EM/0110
Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at [http://www.hra.nhs.uk/hra-training/](http://www.hra.nhs.uk/hra-training/).

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

Yours sincerely

pp

Mr [Name]
Chair

Email:NRESCommittee.EastMidlands-Northampton@nhs.net

Enclosures: “After ethical review – guidance for rsearchers”

Copy to: Sponsor - [Name]
R&D [Name]
Appendix J: R&D study approval letter

DIRECTORATE OF RESEARCH & DEVELOPMENT

Director: [Redacted]
Assistant Director: [Redacted]
R&D Manager: [Redacted]

Direct Dial: [Redacted]
Fax No: [Redacted]

31/07/2013 - Re-issued: 23/08/2013

Dear Dr [Redacted]

Ref: Title: 11259
An exploration into the experiences of Parkinson's disease and its relationship with psychological outcomes
Project Status: Project Approved
End Date: 01/05/2014

I am pleased to confirm that with effect from the date of this letter, the above study has Trust Research & Development permission to commence at [Redacted]. The research must be conducted in line with the Protocol and fulfil any contractual obligations agreed with the Sponsor. If you identify any issues during the course of your research that are likely to affect these obligations you must contact the R&D Office.

In order for the [Redacted] to comply with targets set by the Department of Health through the 'Plan for Growth', there is an expectation that the first patient will be recruited within 30 days of the date of this letter. If there is likely to be a problem achieving this target, please contact the office as soon as possible. You will be asked to provide the date of the first patient recruited in due course. In addition, the Title, REC Reference number, local target recruitment and actual recruitment...
for this study will be published on a quarterly basis on the [redacted] external website.

All documents received by this office have been reviewed and form part of the approval. The documents received and approved are as follows:

Please note: Dr Noelle Robertson is not approved to carry out consent assessments on this study until, [redacted] consent assessment training has been completed.

<table>
<thead>
<tr>
<th>Description</th>
<th>Version</th>
</tr>
</thead>
<tbody>
<tr>
<td>Letter of invitation to participant</td>
<td>V2 Dated: 22 January 2013</td>
</tr>
<tr>
<td>Covering letter to participants</td>
<td>V3 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Participant Consent Form</td>
<td>V4 Dated: 17 June 2013</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>V3 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Protocol</td>
<td>V4 Dated: 16 January 2013</td>
</tr>
<tr>
<td>Questionnaire: The experience of shame scale - body shame items</td>
<td>V2 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Questionnaire: Hoehn and Yahr</td>
<td>V2 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Questionnaire: Demographic Information</td>
<td>V2 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Questionnaire: Fear or negative evaluation scale</td>
<td>V2 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Questionnaire: HADS</td>
<td>V2 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Questionnaire: OAS Scale</td>
<td>V2 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Questionnaire: PDQ-39</td>
<td>V2 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Questionnaire: Self Consciousness Scale - Social Anxiety Items</td>
<td>V2 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Questionnaire: ESS</td>
<td>V2 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Questionnaire: DAS-24</td>
<td>V2 Dated: 17 April 2013</td>
</tr>
<tr>
<td>Questionnaire: UPDRS</td>
<td>V2 Dated: 17 April 2013</td>
</tr>
</tbody>
</table>

Please be aware that any changes to these documents after approval may constitute an amendment. The process of approval for amendments should be followed. Failure to do so may invalidate the approval of the study at this trust.

Undertaking research in the NHS comes with a range of regulatory responsibilities. Please ensure that you and your research team are familiar with, and understand the roles and responsibilities both collectively and individually.
Documents listing the roles and responsibilities for all individuals involved in research can be found on the R&D pages of the Public Website. It is important that you familiarise yourself with the Standard Operating Procedures, Policies and all other relevant documents which can be located by visiting

The R&D Office is keen to support and facilitate research where ever possible. If you have any questions regarding this or other research you wish to undertake in the Trust, please contact this office. Our contact details are provided on the attached sheet.

We wish you every success with your research.

Encs: .R&D Office Contact Information
Appendix K: Participant Information Sheet

Patient Information Sheet
An exploration into the experiences of Parkinson’s disease and its relationship with emotional well-being

We would like to invite you to take part in this research study. Before you decide whether or not you wish to participate, it is important for you to understand why the study is being done and what it will involve. Please take the time to read the following information carefully. If you have any queries after reading this document you will be able to discuss them with the Consultant Physician or the researchers when attending the clinic for your next outpatient appointment. Thank you for taking the time to read this.

What is the purpose of the study?
People with Parkinson’s disease may experience many different factors that can affect their lives. Some of these factors may be physical factors such as specific symptoms of Parkinson’s disease and others may be emotional factors for example, anxiety, low mood and self-consciousness. This study aims to ask you about some of these experiences of Parkinson’s disease to gain a better understanding of how they may be related to some of these emotional factors. This study also aims to identify the emotional needs of individuals with Parkinson’s disease and to help drive future developments for interventions and support programmes.

Why have I been chosen?
Everyone who has a diagnosis of Parkinson’s disease and attends the outpatient clinic at the [insert location] will be invited to take part in the study. You will have received this information sheet approximately a week prior to your routine outpatient appointment.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be asked to give your written consent after your outpatient appointment to show you agree to be involved in the study. After your outpatient appointment, myself or another co-researcher (Dr Noelle Robertson) will meet with you to describe the study in more detail and answer any questions you may have. If you decide to take part you are free to withdraw at any time without giving a reason. Any information or responses you may have already given will be destroyed. A decision not to take part or to withdraw at any time will not affect the standard of care you will receive.

What will happen to me if I take part?
During your outpatient appointment, you will have the opportunity to ask any questions and discuss the study with your Consultant Physician who will invite you to take part. If you agree to take part in the study you will meet with me or Noelle after your appointment with your Consultant Physician. This is an opportunity for you to ask any further questions. If you require more time to consider whether or not to take part in the study, you are more than welcome to contact the clinic / researchers to arrange an alternative meeting.

If you agree to take part in the study you will need to sign a written consent form before completing a set of questionnaires. If you require support in filling in the questionnaires myself and Noelle are available throughout the meeting to assist you. Only one meeting will be required, which should take no longer than an hour. However, if it is not possible to complete the questionnaires in one appointment, we will be happy to make arrangements to meet again. You can take breaks at any time throughout the meeting and there will be an opportunity after the meeting to ask any questions or to discuss any concerns you may have.
The questionnaires will be kept in a secure location by the main researcher (Jodie Goddard) and will remain anonymous and confidential.

**What do I have to do?**
Taking part in this study means that you will be asked to respond to some questionnaires that the researchers will administer. One of these is a questionnaires is called the Clock Drawing Test and involves you drawing a clock. This is a routinely used memory assessment tool. You do not have to do anything else. Your regular activities and day-to-day routines will not be affected as much as possible.

**What are the possible risks or disadvantages of taking part?**
There are no risks involved in taking part but it is possible that the study could be a sensitive topic for some and talking about your experiences may cause you to feel upset. The researchers will therefore always offer the opportunity after the meeting to discuss this with you and support will be provided if you have found it distressing in any way. You can stop completing the questionnaires at any time during the appointment.

The study may highlight additional difficulties that can be associated with Parkinson’s disease. If such difficulties are identified, the Consultant Physician will be made aware of these. Unfortunately, it would mean that you are not able to continue with the study.

**What are the possible benefits of taking part?**
We cannot promise that involvement in the study will directly help you, but we are hopeful that findings from the research may be used to help services be more sensitive to the needs of people with Parkinson’s disease to help determine the type of support that will be beneficial.

**What if something goes wrong?**
If you wish to complain or have any concerns about any aspect of the study, you are able to contact the Patient Information and Liaison Service who will do their best to deal with any complaints or questions you may have. The contact details are provided below.

**Will my taking part in this study be kept confidential and anonymous?**
All information which is collected from you during the course of the study will be kept strictly confidential; it will have no information attached to it that you could be recognised from. All data will be kept on encrypted computer hardware (a method of storage that prevents unauthorised access to any data stored) and hardcopies of questionnaires will be securely kept at the University of Leicester. All data will be destroyed five years following the study. Should information be disclosed during the course of the research which causes the researchers to believe either you or anyone else is at serious risk of harm, the researchers have a professional duty to break confidentiality and pass this information on to the Consultant Physician. In the event of this occurring, wherever possible the researchers will discuss that your confidentiality will be broken.

**What will happen to the results of the study?**
The results of this study will be available in 2014-2015. The results will form the researcher’s (Jodie Goddard) doctoral thesis and is expected to be published in a peer-reviewed journal. You will not be identifiable throughout any of these processes. A copy of the collected results will be sent to the outpatient service at the [Leicester General Hospital](#). A copy of the final report can also be made available in Autumn 2014. You can request a copy from either the researchers during the meeting or from your Consultant Physician, a copy will then be posted to the clinic and the clinic team will pass this on to you.

**Who is organising the study**
The research is organised by the University of Leicester and Leicestershire Partnership NHS Trust. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by a Research Ethics Committee.

**Contact for further information**
If you have any questions or would like more information about the study please contact the researcher (Jodie Goddard, Trainee Clinical Psychologist) or the co-researcher (Dr Noelle Robertson, Consultant Clinical Psychologist) on 01162231639.

Patient Information and Liaison Service Contact details:

Patient Advice & Liaison Service

Telephone:

Email:

Thank you for taking the time to consider taking part in this study.
Appendix L: Covering letter to participant

Date:

Dear Sir/Madam,

Re: “An exploration into the experiences of Parkinson’s disease and its relationship with emotional well-being”

You are invited to take part in a research study on emotional well-being and Parkinson’s disease, which is being undertaken by a Trainee Clinical Psychologist from the University of Leicester.

If you are interested in taking part, please read the enclosed information sheet, which will tell you in more detail what the study is about and answers some of the questions you may have. Please take your time to decide whether you wish to take part and feel free to contact the researcher, Jodie Goddard, using the contact details on the information sheet should you require any further information. Alternatively, if you have any queries after reading the information sheet you will be able to discuss them with the Consultant Physician or the researcher when attending the clinic for your next outpatient appointment.

Thank you for taking the time to read this.

Yours faithfully,

[Name]
Consultant Physician

Jodie Goddard
Trainee Clinical Psychologist
Appendix M: Participant Consent Form

Participant Consent Form

An exploration into the experiences of Parkinson's disease and its relationship with emotional well-being

I, ________________________, the undersigned, hereby consent to participate as a volunteer in the above named research project and consent to my responses being documented as part of this research project conducted by Jodie Goddard, Trainee Clinical Psychologist.

Consent Statements:

<table>
<thead>
<tr>
<th>Consent Statements</th>
<th>Initial to show consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The nature of the research project has been fully explained to me and I am aware of what my participation will involve. I have been provided with a detailed participant information sheet (dated 17.04.13 version 3) for the above study.</td>
<td></td>
</tr>
<tr>
<td>2. I have been given the opportunity to ask questions about the research project and these questions have been satisfactorily answered.</td>
<td></td>
</tr>
<tr>
<td>3. I understand that I will be required to complete various questionnaires that will only be seen by the researcher and that all data will be kept completely confidential.</td>
<td></td>
</tr>
<tr>
<td>4. I understand that data will be kept on encrypted computer hardware during the study and hardcopies of questionnaires will be securely kept in a locked room at the Clinical Psychology Base at the University of Leicester after the study. All data will be destroyed five years following the study.</td>
<td></td>
</tr>
<tr>
<td>5. I understand that my identity will remain anonymous throughout the study.</td>
<td></td>
</tr>
<tr>
<td>6. I understand that if the researcher is concerned about my safety or the safety of anyone I mention, that the researcher has a professional duty to break confidentiality and pass the information on to the Consultant Physician.</td>
<td></td>
</tr>
<tr>
<td>7. I understand that my participation is voluntary and that I can withdraw from the research project at any time, without giving reason. In doing so, I understand that any data will be destroyed and my future care will not be affected in any way.</td>
<td></td>
</tr>
<tr>
<td>8. I understand that the research project could be a sensitive topic and I may become upset or distressed through speaking about my experiences. I understand that I can ask for a break and I can stop completing the questionnaires at any time and without giving reason.</td>
<td></td>
</tr>
<tr>
<td>9. I understand that the study may highlight additional difficulties that can be associated with Parkinson’s disease and that, if identified, the Consultant Physician would be made aware of these and I would not be able to continue with the study.</td>
<td></td>
</tr>
<tr>
<td>10. I have been provided with the researchers contact details.</td>
<td></td>
</tr>
<tr>
<td>11. I understand that relevant sections of my medical notes (including personal data) and data collected during the study, may be looked at by individuals from the University of Leicester, from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.</td>
<td></td>
</tr>
</tbody>
</table>

I am agreeing to participate in this study with the full knowledge and understanding of the nature of the study and of what will be expected of me. I agree to all of the consent statements detailed above.

Participant Signature: ___________________  Researcher Signature: ___________________
Name in Block Capitals: ________________  Name in Block Capitals: ________________
Date: ________________________________  Date: ________________________________
Appendix N: Demographic Information

Demographic Information

Age:

Gender:

Relationship Status:

What is your ethnic group?

Employment Status:

Duration of Parkinson’s disease:
Appendix O: The Experience of Shame Scale – Body Shame Items

N.B. For copyright reasons copies of questionnaires are not included
Appendix P: Other As Shamer Scale
Appendix Q: Derriford Appearance Scale (DAS-24)
Appendix R: The Hospital Anxiety and Depression Scale
Appendix S: Self Consciousness Scale – Social Anxiety Items
Appendix T: Fear of Negative Evaluation Scale
Appendix U: PDQ-39
Appendix V: BIDQ
Appendix W: Hoehn and Yahr Scale

Hoehn & Yahr Staging

- **Stage 0**: no sign of disease
- **Stage 1**: symptoms are very mild and appear only on one side of the body
- **Stage 1.5**: symptoms appear only on one side of the body but with axial involvement
- **Stage 2**: symptoms appear on both sides without impairment of balance
- **Stage 2.5**: symptoms appear on both sides and still mild, with recovery on pull test
- **Stage 3**: symptoms are mild to moderate, some postural instability occurs, but patients are physically independent
- **Stage 4**: symptoms are severe, the patient is severely debilitated and needs some assistance, but can still walk or stand unassisted
- **Stage 5**: symptoms are very severe, the patient is typically wheelchair-bound or confined to a bed, unless aided
## Appendix X: Range, mean and standard deviation for each scale and subscale

<table>
<thead>
<tr>
<th>Scale</th>
<th>Range</th>
<th>M(SD)</th>
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<tbody>
<tr>
<td><strong>H&amp;Y</strong></td>
<td>0 - 1</td>
<td>2.04 (.89)</td>
</tr>
<tr>
<td><strong>HADS Total</strong></td>
<td>0 - 35</td>
<td>10.65 (7.25)</td>
</tr>
<tr>
<td>HADS Anxiety</td>
<td>0 - 15</td>
<td>6.27 (4.36)</td>
</tr>
<tr>
<td>HADS Depression</td>
<td>0 - 13</td>
<td>4.30 (3.43)</td>
</tr>
<tr>
<td><strong>SCS</strong></td>
<td>0 - 24</td>
<td>7.54 (6.78)</td>
</tr>
<tr>
<td><strong>FNE</strong></td>
<td>0 - 30</td>
<td>8.89 (7.72)</td>
</tr>
<tr>
<td><strong>OAS</strong></td>
<td>0 - 33</td>
<td>10.14 (10.38)</td>
</tr>
<tr>
<td><strong>ESS</strong></td>
<td>4 - 11</td>
<td>5.91 (1.92)</td>
</tr>
<tr>
<td><strong>DAS-24 Total</strong></td>
<td>11 - 52</td>
<td>29.38 (10.34)</td>
</tr>
<tr>
<td>DAS-24 (31-60)</td>
<td>21 - 52</td>
<td>37.00 (12.46)</td>
</tr>
<tr>
<td>DAS-24 (61+)</td>
<td>11 - 52</td>
<td>28.77 (10.0)</td>
</tr>
<tr>
<td><strong>BIDQ Total</strong></td>
<td>1 - 4</td>
<td>2.05 (.77)</td>
</tr>
<tr>
<td>Male</td>
<td>1 - 4</td>
<td>2.10 (.75)</td>
</tr>
<tr>
<td>Female</td>
<td>1 - 4</td>
<td>1.98 (.80)</td>
</tr>
<tr>
<td><strong>PDQ Single Index</strong></td>
<td>0 - 53</td>
<td>24.75 (14.17)</td>
</tr>
<tr>
<td>PDQ-39 Mobility</td>
<td>0 - 100</td>
<td>38.43 (30.15)</td>
</tr>
<tr>
<td>PDQ-39 ADL</td>
<td>0 - 100</td>
<td>34.88 (26.40)</td>
</tr>
<tr>
<td>PDQ-39 EWB</td>
<td>0 - 63</td>
<td>23.56 (18.80)</td>
</tr>
<tr>
<td>PDQ-39 Stigma</td>
<td>0 - 50</td>
<td>13.04 (16.63)</td>
</tr>
<tr>
<td>PDQ-39 Social</td>
<td>0 - 50</td>
<td>8.74 (15.25)</td>
</tr>
<tr>
<td>PDQ-39 Cognition</td>
<td>0 - 81</td>
<td>30.02 (20.19)</td>
</tr>
<tr>
<td>PDQ-39 Communication</td>
<td>0 - 75</td>
<td>18.21 (19.73)</td>
</tr>
<tr>
<td>PDQ-39 BD</td>
<td>0 - 100</td>
<td>34.57 (26.06)</td>
</tr>
</tbody>
</table>
Appendix Y: Statement of Epistemological Position

The current research project was conducted from a positivist standpoint. This approach assumed constructs of shame, body image disturbance, psychological morbidity and quality of life can be measured objectively using reliable and valid quantitative measures. The research methodology adopted these assumptions and predominantly utilised quantitative methodology to investigate these constructs within a sample of Parkinson’s disease patients.
# Appendix Z: Chronology of Research Process

## Chronology of Research Process

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>May 2012</td>
<td>Draft research proposal submitted for peer review</td>
</tr>
<tr>
<td>November 2012</td>
<td>Final research proposal submitted for peer review</td>
</tr>
<tr>
<td>January 2013</td>
<td>Research proposal reviewed by Service User Reference Group</td>
</tr>
<tr>
<td></td>
<td>Meeting with Consultant Physician to discuss research proposal</td>
</tr>
<tr>
<td>February 2013</td>
<td>Integrated Research Application System (IRAS) form submitted</td>
</tr>
<tr>
<td>March 2013</td>
<td>Research Ethics Committee (REC) panel meeting</td>
</tr>
<tr>
<td>May 2013</td>
<td>Ethical approval received following minor amendments</td>
</tr>
<tr>
<td>June 2013</td>
<td>Applied for Research &amp; Development (R&amp;D) ethical approval</td>
</tr>
<tr>
<td>August 2013</td>
<td>R&amp;D ethical approval received. Data collection (August – March)</td>
</tr>
<tr>
<td>September 2013</td>
<td>Literature review started</td>
</tr>
<tr>
<td>Jan-March 2014</td>
<td>Data entry (ongoing)</td>
</tr>
<tr>
<td>February 2014</td>
<td>Write up of research project started</td>
</tr>
<tr>
<td>March 2014</td>
<td>Data analysis. Critical appraisal completed</td>
</tr>
<tr>
<td>March-April 2014</td>
<td>Write up of research project completed. Literature review completed</td>
</tr>
<tr>
<td>April 2014</td>
<td>Submission of thesis</td>
</tr>
</tbody>
</table>
Disability and Rehabilitation
Instructions for Authors

*Disability and Rehabilitation* is an international interdisciplinary journal and particularly welcomes contributions from a wide range of professional groups, including medical practitioners, occupational therapists, physiotherapists, speech and language therapists, clinical psychologists and those involved in nursing, education and engineering.

*Disability and Rehabilitation* is organised into sections: Reviews; Research Papers; Case Studies; Perspectives on Rehabilitation; reports on Rehabilitation in Practice, Education and Training and Correspondence.

Special Issues and specific sections on contemporary themes of interest to the Journal's readership are published. Please contact the Editor for more information.

**Submissions and Peer Review**

All submissions should be made online at *Disability and Rehabilitation* ScholarOne Manuscripts site: [http://mc.manuscriptcentral.com/dandr](http://mc.manuscriptcentral.com/dandr).

Authors are given the option to remain anonymous during the peer-review process. Authors will be able to indicate whether their paper is 'Anonymous' or 'Not Anonymous' during manuscript submission, and should pay particular attention to the below:

**Authors who wish to remain anonymous** should prepare a complete text with information identifying the author(s) removed. This should be uploaded as the “Main Document” and will be sent to the referees. A separate title page should be included providing the full affiliations of all authors. Any acknowledgements and the Declaration of Interest statement must be included but should be worded mindful that these sections will be made available to referees.

**Authors who wish to be indentified** should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. The complete text should be uploaded as the “Main Document”.

**All submissions** should include a separate title page that contains contact information for the authors(s). This should be uploaded as a “Title Page” and will not be sent to referees.

If a paper is deemed to be acceptable for publication pending minor revision, the author(s) names may be disclosed to the referees when the Editor’s decision is made, irrespective of whether the authors names(s) were included as part of the original
submission. Every effort will be made to keep the author(s) name(s) anonymous, if required, should the paper require extensive revision and further peer-review. If authors wish to remain anonymous throughout the second round of peer-review, they are reminded not to include identifying information in the „Authors’ Response” section during the upload of their revised paper.

Every paper that is revised and resubmitted must clearly indicate the parts of the manuscript that contain amendments, by highlighting the revised text in a different colour or by using ‘Track Changes’ (for minor revisions).

Systematic Reviews should be submitted as a “Review” and Narrative Reviews should be submitted as “Perspectives in Rehabilitation”. All Systematic Reviews will be automatically submitted for the annual Best Review Paper competition.

Education and Training

This is a new section for the journal. It will publish papers relating to the education and professional training of those working in the field of rehabilitation. Papers are encouraged which develop innovatory approaches to this process and provide multi-disciplinary and international comparisons for those working in the field. Through this new section it is intended to contribute towards the development of education and training within these professional groupings.

Papers should be submitted with any tables, figures, or photographs, all of which should be of high quality suitable for reproduction. Submissions should be in English presented in double line spacing.

Submissions should include, where appropriate, a formal statement that ethical consent for the work to be carried out has been given. Photographs of patients should be avoided, but if essential, patients’ consent in writing must accompany manuscript. It is not sufficient to mask identity by covering the patients’ eyes.

Word Limit

There is no stated word limit to papers submitted to Disability and Rehabilitation. It should however be noted that space is at a premium and therefore succinct and well-constructed papers are more likely to be reviewed positively. However, the key to evaluating a paper will be the quality of the work along with the methodology adopted particularly for qualitative studies which do tend to be longer.

Disability and Rehabilitation considers all manuscripts at the Editor’s discretion; the Editor’s decision is final. Please see below for information on the Journal’s Appeal Procedure.

Disability and Rehabilitation considers all manuscripts on the strict condition that they are the property (copyright) of the submitting author(s), have been submitted only to Disability and Rehabilitation, that they have not been published already, nor are they under consideration for publication, nor in press elsewhere. Authors who fail to adhere to this condition will be charged all costs which Disability and Rehabilitation incurs, and their
papers will not be published. Copyright will be transferred to \textit{Disability and Rehabilitation} and Informa UK Ltd., if the paper is accepted.

\textbf{IMPLICATIONS FOR REHABILITATION}

A feature of the Journal is a boxed insert on „Implications for Rehabilitation“. This box should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. \textbf{All papers including reviews, research, rehabilitation in practice, perspectives on rehabilitation, case studies and a new section on education and training for rehabilitation professionals must include this feature.} This should be uploaded as a separate document through Manuscript Central as a single side of A4 during submission.

Included below are examples. If you have any questions, please contact the Editor. \textbf{Example 1: Leprosy}

\begin{itemize}
  \item Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
  \item Reconstructive surgery is a technique available to this group.
  \item In a relatively small sample this study shows participation and social functioning improved after surgery.
\end{itemize}

\textbf{Example 2: Multiple Sclerosis}

\begin{itemize}
  \item Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
  \item People with MS have complex reasons for choosing to exercise or not.
  \item Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.
\end{itemize}

\textbf{Example 3: Community Based Rehabilitation}

\begin{itemize}
  \item Community Based Rehabilitation (CBR) is a Western concept that may not readily fit other cultures.
  \item CBR needs to be „owned“ by those involved and subject to re-interpretation to be effective in other cultures.
\end{itemize}

\textbf{Standardised Reporting Guidelines}

We encourage Authors to be aware of, and to take into account standardised reporting guidelines when preparing their manuscripts.

The table below provides information about guidelines for different study types:

\begin{table}[h]
\centering
\begin{tabular}{|l|l|l|}
\hline
Study Type & Name & Source                               \\
\hline
Case reports & CARE & www.care-statement.org/                 \\
\hline
Diagnostic accuracy & STARD & www.stard-statement.org/               \\
\hline
Observational studies & STROBE & http://strobe-statement.org/           \\
\hline
Randomized controlled trial & CONSORT & www.consort-statement.org      \\
\hline
Systematic reviews, meta-analyses & PRISMA & www.prisma-statement.org/            \\
\hline
\end{tabular}
\end{table}

Whilst the use of such guidelines is supported, given the multi-disciplinary nature of the Journal, it is not compulsory.
Manuscript Preparation

In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.

File preparation and types

Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon submission. These should be submitted as “Image” files during submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see References section for examples).

Structure of Paper

Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (uploaded as separate files); figures with captions (uploaded as separate files).

An introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation; standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section. Extensive tabulations will not be accepted unless their inclusion is essential.

Title Page

A title page should be provided comprising the manuscript title plus the full names and affiliations of all authors involved in the preparation of the manuscript. One author should be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing the article. The title page should be uploaded separately to the main manuscript and designated as “title page” on ScholarOne Manuscripts. This will not get sent to referees.

Abstracts

Structured abstracts are required for all papers, and should be submitted as detailed below, following the title page, preceding the main text.

Purpose State the main aims and objectives of the paper.
Method Describe the design, and methodological procedures adopted.
**Results** Present the main results.

**Conclusions** State the conclusions that have been drawn and their relevance to the study of disability and rehabilitation.

The abstract should not exceed 200 words.

**Nomenclature and Units**

All abbreviations and units should conform to SI practice. Drugs should be referred to by generic names; trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

**Copyright Permission**

Contributors are required to secure permission for the reproduction of any figure, table, or extensive (more than fifty word) extract from the text, from a source which is copyrighted - or owned - by a party other than Informa UK Ltd or the contributor. This applies both to direct reproduction or 'derivative reproduction' - when the contributor has created a new figure or table which derives substantially from a copyrighted source.

**Code of Experimental Ethics and Practice**

Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human or animal subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.

**Tables, figures and illustrations**

The same data should not be reproduced in both tables and figures. The usual statistical conventions should be used: a value written 10.0 ± 0.25 indicates the estimate for a statistic a mean) followed by its standard error. A mean with an estimate of the standard deviation will be written 10.0 SD 2.65.

Contributors reporting ages of subjects should specify carefully the age groupings: a group of children of ages e.g. 4.0 to 4.99 years may be designated 4 +; a group aged 3.50 to 4.49 years 4 ± and a group all precisely 4.0 years, 4.0.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. 'As seen in table [or figure] 1 ..' (not Tab., fig. or Fig).

The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript:

Insert table 2 about here

Each table and/or figure must have a title that explains its purpose without reference to the text. The filename for the tables and/or figures should be descriptive of the graphic, e.g. table 1, figure 2a.

**Tables**
Tables should be used only when they can present information more efficiently than running text.

Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text.

Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

**Figures and illustrations**

Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible.

Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher.

Please note that it is in the author’s interest to provide the highest quality figure format possible.

**Acknowledgments and Declaration of Interest sections**

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose.

The Acknowledgments section details special thanks, personal assistance, and dedications. Contributions from individuals who do not qualify for authorship should also be acknowledged here.

Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance writer), grant support and numbers, and statements of employment, if applicable.

**Acknowledgments section**

Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

**Declaration of Interest section**

All declarations of interest must be outlined under the subheading “Declaration of interest”. If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: *The authors report*
declarations of interest. When submitting a paper via ScholarOne Manuscripts, the “Declaration of interest” field is compulsory (authors must either state the disclosures or report that there are none). If this section is left empty authors will not be able to progress with the submission.

Please note: for NIH/Wellcome-funded papers, the grant number(s) must be included in the Declaration of Interest statement.

Mathematics
Click for more information on the presentation of mathematical text.

References

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in The CSE Manual for Authors, Editors, and Publishers, Seventh Edition. Periodical abbreviations should follow the style given by Index Medicus.

Examples are provided as follows:


Internet databases: [7] Prevention News Update Database [Internet]. Rockville (MD):
APPEAL PROCEDURE

Disability and Rehabilitation and Disability and Rehabilitation: Assistive Technology The Editors of both Journals will respond to appeals from Authors relating to papers which have been rejected.

The Author(s) should email the Editor outlining the concerns and making a case for why their paper should not have been rejected. The Editor will undertake one of two courses of action:

1: The Editor Accepts the Appeal
   I. In this case the Editor will secure a further review making available confidentially the relevant information for the reviewer
   II. The Editor on receiving the review will either accept the appeal and therefore invite a resubmission for further review; or reject the appeal and no further action will be taken.
   III. If an appeal is rejected there will be no further right of appeal within the jurisdiction of the Journal.

2: The Editor does not uphold the Appeal
   I. If the Editor does not accept the appeal and is not prepared to secure further review the decision will be referred to the Editor of the relevant affiliated Journal for independent consideration. In the case of Disability and Rehabilitation, the Editor of Disability and Rehabilitation: Assistive Technology will be contacted, and if an appeal is not upheld by the Editor of Disability and Rehabilitation: Assistive Technology, the Editor of Disability and Rehabilitation will be consulted.
   II. The Editor will either confirm the decision or recommend that a further review be obtained.
   III. Therefore, if both Editors agree that the appeal should not be upheld there will be no further right of appeal within the jurisdiction of the Journal.

Dave Muller, Editor in Chief, Disability and Rehabilitation
Marcia Scherer, Editor, Disability and Rehabilitation: Assistive Technology