Quality of Life and Caregiver Burden in Parkinson's Disease: The Role of Patients' and Carers' Illness Appraisals

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By

Sarah Simms

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Declaration

I confirm that this thesis is my own work and has not been submitted for any other academic award.

Thesis abstract

Parkinson's disease is common in older adult populations, with an increasing prevalence with age. Many psychosocial factors have been shown to be associated with quality of life, however there has been limited research investigating the role of illness appraisals, despite this existing for other chronic health conditions.

The literature review examined experiences of caring for a spouse with Parkinson's disease. A critical thematic synthesis of qualitative research was conducted with rigorous quality appraisal. Negative consequences to caring were evident with social restrictions and loss of previous identities and a shared future identified. However, a sense of resilience emanated throughout the studies. Ambivalence was an emergent theme, with spouses reporting a need for increased professional support but stated difficulties discussing issues, particularly those regarding end of life. Increased community support and resource is required with a dyadic focus, including both spouse and patient.

The empirical study focussed on quality of life and caregiver burden in Parkinson's disease and the role of patients' and carers' illness appraisals. A cross-sectional self-report design was utilised. Illness appraisals were demonstrated to be key predictors of quality of life and burden, after controlling for biomedical variables, and the importance of consideration of both patient and carer appraisals for these outcome measures was highlighted. Clinical implications of the findings are discussed with suggestions for future research.

The critical appraisal discussed reflections on the research process addressing key areas, including origins of the project and development of research ideas, ethical submission, data collection and analyses, whilst making reference to specific learning points.

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Section 1

Literature Review

The experience of caring for a spouse with Parkinson's disease:

A Critical Qualitative Synthesis

Sarah Simms

1.0 Abstract

Purpose: This systematic literature review sought to determine the experiences of caring for a spouse with Parkinson's disease.

Method: A systematic search of five electronic databases was conducted to obtain relevant articles. A data extraction form was used to retrieve relevant information about potential studies for review. Due to similar methodological approaches being adopted across studies, a qualitative critical synthesis was conducted using thematic analysis.

Results: Nine articles were deemed eligible for inclusion in the review. The findings revealed numerous negative consequences on quality of life, psychological well-being and marital relationships. A loss of previous identities and a shared future emerged along with social restrictions. Despite challenges imposed, resilience was evident throughout the studies. Ambivalence also emerged from carers with regards to information about the condition. A need for more information about disease progression and increased professional support was reported, but simultaneously spouses expressed the difficulties experienced when discussing the illness with others, particularly for end of life issues.

Conclusion: Provision of care is a complex and challenging task and requires greater recognition and support from services. Care should be tailored to each couple with a dyadic focus, incorporating the spouse. Community resource and professional support need to be increased to ensure spouses are not experiencing high levels of burden, which can hinder the standard of care provided.

Target journal: Disability and Rehabilitation (Appendix A)

2.0 Introduction

2.1 Parkinson's disease

Parkinson's disease (PD) is a chronic, progressive, neurodegenerative condition characterised by resting tremor, rigidity and bradykinesia (slowness of movement). Within the United Kingdom approximately 120, 000 people are currently diagnosed with Parkinson's disease, with 10,000 new cases presenting each year (National Collaborating Centre for Chronic Conditions, 2006). The incidence rate is highest for individuals over the age of 50, with a median age of onset of 60 years (Lees, Hardy & Revesz, 2009). Mean duration of the disease from diagnosis to death is approximately 15 years (Lees, Hardy & Revesz, 2009) and reduction in life expectancy appears associated with earlier onset of the disease (Ishihara, Cheesbrough, Brayne & Schrag, 2007).

The depletion of dopamine-producing neurons in the substantia nigra has been implicated in the onset of the disease and the difficulties that ensue. Once diagnosed, level of disability is classified using the Hoehn and Yahr Scale and can range from stage 0 to 5; stage 0 describing asymptomatic disease and stage 5 encompassing those with severe symptoms, typically dependent on aids or confined to a bed, unless assisted (Hoehn & Yahr, 1967).

Diagnosis of Parkinson's disease confers an increased risk of cognitive decline and dementia, which may increase mortality (Forsaa, Larsen, Wentzel-Larsen & Alves, 2010). Newly diagnosed patients are twice as likely to develop mild cognitive impairment than healthy individuals, and between 20% and 57% of patients with PD show mild cognitive impairment within five years of diagnosis (Kehagia, Barker &

Robbins, 2010). Individuals with PD are three to five times more likely to develop dementia compared with healthy individuals, with a prevalence of PD dementia in the general population between 2% and 3% (Kehagia, Barker & Robbins, 2010).

2.2 Impact of Parkinson's disease

2.2.1 Impact on the patient

The impact on individuals living with Parkinson's disease has been increasingly documented over the last ten years, with predominantly a biomedical focus. Prevalence studies have revealed elevated levels of psychological co-morbidity. Major depression is reported in 20% to 40% of Parkinson's disease patients; several times the prevalence in the general population (Lieberman, 2006). The rate of minor depression in community samples is reported at approximately 30% to 40 %, with only 3% to 8% fulfilling the Diagnostic and Statistical Manual (DSM) criteria for depression (Schrag, 2006). This highlights the presence of psychological morbidity that may go undiagnosed. Prevalence rates of anxiety in Parkinson's disease appear more variable, with figures ranging from 5% (Lauterbach & Duvoisin, 1991) to 40% (Walsh & Bennett, 2001).

Various quality of life indicators, including emotional well-being, social support and cognition, have been shown to be lower in individuals with the condition (Schrag, Jahanshahi & Quinn, 2000) and a reduction in social activities (Schrag, Hovris, Morley, Quinn & Jahanshahi, 2006) and decreased marital and sexual satisfaction (Hand, Gray, Chandler & Walk, 2010) have also been reported. Elevated levels of unemployment, marital dissatisfaction and disruption of family life (Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2003) are more frequently reported for those individuals

whose PD is of earlier onset, emphasising a need to address these issues for patients who develop the condition earlier (Schrag et al., 2003).

2.2.2 Impact on family members

As with other forms of ill health, Parkinson's disease affects not only those diagnosed with the condition but also those around them, predominantly family members. Research examining extended impacts for other chronic conditions, such as diabetes, has demonstrated poorer psychological well-being reported by carers, notably depression and distress (Franks, Lucas, Stephens, Rook & Gonzalez, 2010).

The effects upon family members of those with PD appears to have received less specific research scrutiny. However, responding to increasing understanding that care delivery can be multifaceted and complex, research has evolved. To date this has predominantly been assumptive using quantitative evaluation of the impact of care provision on family members, applying well operationalised constructs utilised in assessing the impact of other chronic conditions, with a focus predominantly on caregiver burden, strain and well-being (Berry & Murphy, 1995; O'Reilly, Finnan, Allwright, Smith & Ben-Shlomo, 1996; Wallhagen & Brod, 1997).

More specifically, carers of those with PD are increasingly shown to present with lowered mood and stress (Kristjanson, Anoun & Oldham, 2005), increased anxiety (Gilbar & Harel, 2000) and fatigue (Teel & Press, 1999). Carers report fewer social contacts and social activities and are shown to have poorer health outcomes (O'Reilly, Finnan, Allwright, Smith & Ben-Shlomo, 1996). Such evidence clearly demonstrates some of the negative effects of care-giving and indicates a need for carer recognition

and support. However, this focus on quantifiable dimensions of care effects appears to have neglected how care is constructed by those providing it and has rather neglected care as a process. In utilising well established measures of carer strain and burden the discourse has been one of adversity, diminishing potentially positive and rewarding dimensions of care. An examination of richer and more complex accounts of the care process would complement this approach.

2.3 Provision of care by family members

Family members who provide care and support for a relative with a chronic illness, in addition to the formal care provided by health professionals, are often referred to as 'informal carers'. Individuals with Parkinson's disease are often provided with support and care within the community by a relative, irrespective of the stage of the condition. Even when profoundly debilitated, with constrained movement, balance, speech and feeding, family members are reported to provide over 50 hours caring per week (Parkinson's UK, 2008). This care may encompass intimate personal care, support with basic daily activities and involve undertaking responsibilities not previously required, such as domestic tasks (O'Reilly, Finnan, Allwright, Smith & Ben-Shlomo, 1996).

Most carers express a wish to keep their relative at home for as long as possible even at the later stages of the condition, when palliative care may be required, emphasising the length of time care may be provided. Research across other chronic health conditions (Zauszniewski, Bekhet & Suresky, 2009) consistently identifies that provision of care can have deleterious effects on carers' physical and emotional health, with adverse consequences for the ability to provide care over a substantial timeframe.

2.4 Rationale for current review

Investigation of the research base relating to family members' experiences of Parkinson's disease revealed no reviews focussing on the experiences of family members caring for a relative with Parkinson's disease. This may reflect a developing literature and a previous focus on quantifying the impact on families.

Consequently this review will focus on current qualitative literature investigating experiences of caring for a relative with Parkinson's disease. Qualitative research enables quantitative findings to be contextualised, interpreted and can consider process of care at divergent time points, stages of diagnosis and life stage at which Parkinson's disease is diagnosed. Synthesising available qualitative accounts permits more complete knowledge than that which emerges from individual studies. Synthesis may also permit more grounded understanding of any variations or ambiguities in research, and may identify gaps in research about care of those with Parkinson's disease.

3.0 Method

The review process comprised three stages:

(1) Systematic literature search (search strategy and study selection)

(2) Quality appraisal of elicited papers

(3) Synthesis of themes using thematic analysis

Systematic search

Search strategy

Electronic searches of the following five electronic databases were undertaken in November 2011 and again in March 2012: PsychINFO, Medline, Web of Science, Cochrane Review Library and Pubmed. No time limit was applied to the searches. The review search strategy was defined using Shaw's (2010) CHIP (Context, How, Issue of interest, Population) tool for qualitative studies. Search terms included different combinations of: Parkinson*, Parkinson's, Care*, Carer, Spouse, Partner, Couple and Psychol* using the Boolean logic term "AND". Search terms remained broad in order to ensure full identification of potential articles, given the area had not been subject to previous review.

Selection criteria

(1) Reported in English Language

(2) Published peer reviewed articles to ensure rigorous scrutiny of research

(3) **C**ONTEXT: Family member caring for their relative with diagnosed Parkinson's disease

(4) **H**OW: Utilised qualitative design methodology

(5) **I**SSUE OF INTEREST: The experience of caring for a relative with Parkinson's disease

(6) **P**OPULATION: Patients with Parkinson's disease and their informal family carer

Study Selection

The article selection process involved the stages of identification, screening and eligibility (See Appendix B for flowchart). For each search, titles were initially scrutinised for relevance according to the selection criteria. All identified titles (n=224) from the five databases were then collated and duplicates removed (n=112). Abstracts were then screened for relevance by SS and NR and discarded if failing to meet inclusion criteria. Most articles discarded at this juncture were omitted because they used exclusively quantitative methodology.

Seventeen articles thus remained, were obtained in full text and were assessed for eligibility for the review. Reference lists from these articles were also hand searched to identify additional studies for inclusion and contacts were made with authors identified as working in the field, however no additional articles were elicited. Of eight articles excluded at this stage, six articles focused only on a circumscribed facet rather than a broad experience of care (e.g. decisions to relinquish care and seek residential support, the impact of falls and care-giving at night). One article focused exclusively on the impact of co-morbid psychotic symptoms and further only described carer experience tangentially to a focus on care. The remaining article was considered poor in quality, being notably short, with impoverished data and insufficient information to judge

adequacy of the research process. Thus nine articles remained for inclusion in the review (See Appendix C for study characteristics).

Papers forming basis for synthesis

Of the nine articles selected for inclusion in the review one study was based in Canada, two in Northern Ireland, one in North Wales, three based in the U.S.A and two in Sweden. The studies explored spousal experiences of caring for individuals with Parkinson's disease at different stages across the disease trajectory from point of diagnosis to palliative care and end of life. The Hoehn and Yahr disability assessment is a clinician based objective measure frequently used to determine the stage of Parkinson's disease, in contrast to subjective perceptions of patients. Articles varied in their focus on disease trajectory; some opting for breadth and examining spousal experiences for those in differing stages of the condition, although six of the studies reported experiences of care for those presenting within stages 2 to 4 of the Hoehn and Yahr scale (Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011; Habermann, 2000; Hodgson, Garcia & Tyndall, 2004; McLaughlin et al., 2010; Roger & Medved, 2010; Wressle, Engstrand & Granérus, 2007). Another two studies focused on spousal experiences whilst providing care for late-stage PD patients (Williams & Keady, 2008) and end of life care (Hasson et al., 2010). All the studies related to experiences of older adult spouses, with the exception of Habermann (2000), who focussed on spousal experiences in middle life.

Data extraction

Data was then extracted using the extraction form (See Appendix D) for all nine articles and information obtained regarding study details, participant characteristics, recruitment strategies, data collection, analysis, findings, limitations and implications.

Quality considerations

Meyrick's (2006) comprehensive overview for assessing the rigour of qualitative research was used to assess the quality of the studies. Transparency and systematicity are considered to be key principles for quality. The Critical Appraisal Skills Programme (CASP) checklist (Public Health Resource Unit, 1998) (See Appendix E) was also used as a further quality appraisal tool. All nine papers were appraised by two reviewers (SS and NR) and the results of the appraisal were used to determine the quality of the papers and their importance and content regarding their contribution to final synthesis. The quality of the papers was also considered for weighting the findings from the review in terms of their robustness.

Synthesis

Given that no previous reviews of this area had been identified, this novel review sought to identify and describe current evidence, and an aggregative synthesis was felt most valuable to inform current practice. As the evidence base examining the impact on spouses for PD becomes more extensive a more interpretive approach may be useful to begin developing a theoretical understanding of the literature. Thematic synthesis of the qualitative studies was conducted to identify, analyse and report patterns or themes within and across the studies. The analysis followed the six phases outlined by Braun and Clarke (2006) which involved familiarisation with the studies via reading and re-

reading, generation of initial codes, searching for themes, reviewing themes, defining and naming the themes and finally producing the report of the themes constructed. Table one presents the themes elicited by the reviewers (SS and NR) via this method.

Table 1: Aims, themes and conclusions of studies reviewed

Authors	Aims	Themes	Conclusions
1. Birgersson & Edberg (2004) Southern Sweden	To describe persons with PD and their partner's experience of support	**Support from others:** 1. Being in the light of support: receiving attention, experiencing solidarity/sense of community, freedom, focus of others' concern 2. Being in the shade of support; being neglected, being isolated 3. Support in the frame of the relationship; transitions from unity to unity **(**relationship intact**)**, unity towards distance (grief, loss), from distance towards unity (increased satisfaction)	1. Support mainly offered to those with the condition 2. Partners central but vulnerable with sparse support 3. A need for informative, practical, social and emotional support for partners
2. Davis, Gillis, Deshefy-Longhi, Chestnutt & Molloy (2011) U.S.A	To provide a contextual understanding of the link between care relationship quality and caregivers' depressive affect and burden	**1. Loss of the relationship:** loss of uniqueness of the cared for, loss of intimacy, loss of shared future **2. Tension within the relationship:** recurrent friction/disagreements **3. Care decision conflicts within the relationship:** interpersonal conflict from changed roles	Loss is dominant. Spouses who experienced relational losses were more burdened, more depressed and perceived themselves as being less prepared to provide care
3. Habermann (2000) Western U.S.A	To explore the challenges faced, and coping strategies used, by middle-aged spouses	**Challenges experienced:** 1. Watching relative struggle 2. Renegotiating how to spend time together **Coping strategies** 1. Maintaining their own life 2. Seeing challenges they experience as secondary	1. Spouses did not see themselves as caregivers but provided a supportive role 2. The support was an extension and further development of the relationship – did not require a new

		3. Encouraging their partner to stay active and involved	role acquisition 3. Spousal experience of PD is both positive and negative
4. Hasson et al. (2010) Northern Ireland	To understand experiences of family carers who cared for someone with PD so that their role might be recognised and supported	**1. Carers' role and burden** Adjustment to multiple roles, psychological impact of the disease, unwilling to relinquish carer role **2. Palliative Care** Distress in watching physical deterioration, lack of access and knowledge of palliative services, speed of decline surprising **3. Bereavement** Felt abandoned and unsupported, change in role, dealing with sudden end **4. Access to health and social care services** Uncoordinated and patchy, lack of signposting, variable access and interactions with specialists	Breadth of impact of palliative stage of PD on carers' daily lives. Reality of unmet need around impending death. Continuation of emotional and physical need beyond bereavement
5. Hodgson, Garcia & Tyndall (2004) South-eastern U.S.A	To determine the impact that PD has on a couple relationship	**1. Relationship and disease history** Diagnosis experience, early onset more fragmented diagnosis, family history of PD caused fear for children's vulnerability **2. Impact on the couple relationship** Strain and a blessing, struggle reassigning duties and leaving relative alone, affirmed commitment to one another, typical couple grievances magnified by disease, caregivers reporting less support than patients	Impact on partner and couple openly discussed regarding physical, psychological and social worlds of patient but also of the partner. Better understanding of whole couple biography to support coherent clinical support

		3. Impact on self and others Overwhelmed in competing roles, health anxious, parenting demands, losses (physical, financial and cognitive) **4. Connecting with resources** Positive and negative, knowledge/compassion of medical providers, transportation, support groups **5. Strategies for survival** Talking to one another, living in moment, offer reassurance/patience, extend trust, importance of thankfulness	
6. McLaughlin et al. (2010) Northern Ireland	To explore the experience of informal carers of people with PD	**1. Medical support** - Diagnosis - Coordinated and continuing medical care - Meaning and timing of palliative care **2. Burdens related to care-giving** Disease progression demanding increased physical, emotional and social support, stoicism in the face of burden, carers' frustration with relentless need **3. Information needs** Lack of information at diagnosis, importance of timing of this information regarding progression **4. Economic implications** Relinquishing employment, difficulty accessing information about benefits	Carers significantly burdened. Many elderly spouses caring over long periods often feeling unprepared

7. Roger & Medved (2010) Canada	1.To analyse how partners perceive their roles in communication 2. To examine meanings partners assign to communication experiences 3. To identify how experiences of communication changed over time	**Managing identity together** 1. The first moments of change in relation to each other after diagnosis, affected by life and relationship stage 2. Managing change as an on-going daily experience, 'rollercoaster', new ways of communicating, accepting 3. Assisting others, sharing experiences	1. Aim to continue to find meaning in their lives and relationships following diagnosis 2. Form cooperative identities rather than autonomous realities 3. Communication is central in order to manage identity together
8. Williams & Keady (2008) North Wales	1.To map the experiences of people with PD and their families as they manage and adjust to living with late-stage PD 2. To identify coping and decision-making strategies and how these change over time; 3. To explore how therapeutic strategies used by multidisciplinary professionals may support people with late-stage PD and their families;	**Bridging** **1. Building on the past** (life history, significant events, relationships, identity) **2. Bridging the present** (managing meaning, managing medication, maintaining stability, protecting routines) **3. Broaching the future** (Coping fatigue, cracks in relationship, managing strategies and routines)	Stages and properties of bridging have important implications for the understanding of PD and informing the nursing role to develop supportive interventions

9. Wressle, Engstrand & Granérus (2007) Sweden	To examine how PD affects daily living from both patients' and relatives' perspectives	**Consequences on daily living:** Changes to role, routines/habit, decreased socialisation, constraint (could be positive), worries about capacity for future care **Facilitating factors:** Accessibility of health care, coping strategies, psychological support	Burden of care even when PD not advanced. Client-centred support key, delivered by staff experienced with PD

4.0 Results

4.1 Methodological quality of studies

The methodological quality of studies is considered below using Meyrick's (2006) overview and a summary of results from the CASP checklist is provided in Table 2, before presenting a synthesis of the findings.

Epistemological/theoretical stance and reflexivity

None of the studies overtly stated their epistemological/theoretical stance; however one paper (Hodgson, Garcia & Tyndall, 2004) explicitly stated their use of a phenomenological framework.

Only two studies considered the influence of the researcher. Hodgson, Garcia and Tyndall (2004) considered the issue of reflexivity extensively and included bias statements before commencement of the study in order to own and monitor their biases throughout the study, arguably increasing the quality and application of the research (Lincoln & Guba, 1985). A verification process was also conducted to support trustworthiness and researchers noted their personal reactions to the interviews in a reflective journal. Member checking was also undertaken with transcripts being read through by each participant to ensure the integrity of the data. Birgersson and Edberg (2004) also considered the influence of the researcher on conversations within the interview and attempted to strengthen their validity of interpretations by using several researchers to limit the subjectivity of interpretations.

Methods

All papers explicitly stated aims or objectives, with all methodology being deemed appropriate to the aims of the studies.

Sampling

All papers provided circumscribed description of how they recruited their sample, yet all but one of the papers (Hodgson, Garcia & Tyndall, 2004) failed to provide a rationale for the sampling technique. Purposive sampling was the most commonly cited method for participant recruitment, with five papers adopting this technique (Birgersson & Edberg, 2004; Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011; Habermann, 2000; Hodgson, Garcia & Tyndall, 2004 & Williams & Keady, 2008). Two papers used convenience sampling (Hasson et al., 2010; McLaughlin et al., 2010), one study used strategic sampling (Wressle, Engstrand & Granérus, 2007), and one study explicitly stated their use of theoretical sampling (Roger & Medved, 2010). Hodgson, Garcia and Tyndall (2004) and Roger and Medved (2010) were the only papers to discuss saturation of data.

Data Collection

All studies used qualitative interviews for data collection. Varying level of detail was provided for the studies regarding specific process giving rise to varying degrees of systematicity. Six studies described the location of data collection (occurring in either the participants' home environment, the outpatient clinic, or that selected by participant) (Birgersson & Edberg, 2004; Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011; Hasson et al., 2010; Hodgson, Garcia & Tyndall, 2004; McLaughlin et al., 2010 & Wressle, Engstrand & Granérus, 2007). All studies but one (Williams &

Keady, 2008) explicitly noted their use of interview guides with the majority providing examples of questions and probes used, increasing transparency.

Analysis

Studies varied in transparency and systematicity of data analysis compromising appraisal of epistemological coherence. Most studies used thematic or content analysis (Birgersson & Edberg, 2004; Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011; Hasson et al., 2010; McLaughlin et al., 2010); however in most papers the precise details of process were vague. Other analyses included grounded theory or interpretive phenomenological analysis (Habermann, 2000; Roger & Medved, 2010; Williams & Keady, 2008; Wressle, Engstrand & Granérus, 2007). One study (Hodgson, Garcia & Tyndall, 2004) used Colaizzi's phenomenological data analysis. Details of analysis were provided for all studies but varied in depth. Attempts to ensure rigour were evident in some studies with the majority of papers using more than one researcher to analyse the data, yet only Hodgson, Garcia and Tyndall (2004) used reflective journals to ensure trustworthiness.

Results and Conclusions

All studies used quotes to demonstrate themes and underpin conclusions, and contextualised findings within previous literature. Habermann (2000) shared transcripts with three spouses for validation purposes, as did Hodgson, Garcia and Tyndall (2004). Studies varied in reporting the path pursued from collecting data to results, with none outlining this comprehensively. Most studies considered issues of generalisability, with caution expressed about sample size, homogeneity and contextual constraints. One study (Roger & Medved, 2010) did not consider such limitations to the study yet stated

the applicability and transferability of the findings to other health conditions such as Alzheimer's disease.

Quality of the papers

All of the papers were considered to be of satisfactory quality for inclusion in the review. Birgersson and Edberg (2004), Habermann (2000) and Hodgson, Garcia & Tyndall (2004) were deemed the three papers of highest quality due to additional extensive consideration of the influence of the researcher and methods of validation.

Table 2: Quality appraisal using the CASP checklist

First Author	*Aims*	*Method*	*Design*	*Recruitment*	*Data collection*	*Relationships*	*Ethical issues*	*Analysis*	*Findings*	*Value of research*
1. Birgersson (2004)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2. Davis, (2011)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
3. Habermann (2000)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
4. Hasson (2010)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
5. Hodgson (2004)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
6.McLaughlin (2010)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
7. Roger (2010)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
8. Williams (2008)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
9. Wressle (2007)	✓	✓	✓	✓	✓	X	X	✓	✓	✓

4.2 Findings

4.2.1 Challenges of care-giving

Generic and specific consequences of caring for a spouse with Parkinson's disease were consistently articulated within all studies reviewed. Negative discourses appeared to be privileged in all papers, with a consistent challenge for spouses to see their loved one struggle to manage symptoms, limitations and physical decline, and witness their frustration (irrespective of disease stage). The increasing provision of physical, social and emotional support as the disease progressed, involving assisting with medication, transport and mobility as well as help with personal care, was reported as burdensome (Hasson et al., 2010; McLaughlin et al., 2010). The burden was not described solely in physical terms but as often an emotional burden given spouses' difficulty coping with relatives' mood change and anger (Hasson et al., 2010). Spouses also noted being particularly challenged by their loved ones' lack of motivation which they ascribed to the disease process as often as to loss of agency (Hasson et al., 2010; Williams & Keady, 2008).

Tensions within the relationship were reported and appeared magnified when spouses attempted to assist and enable those with PD to undertake routine daily activities (Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011). Adopting new roles could offer a means of coping (Roger & Medved, 2010) and were not necessarily unwelcome albeit unfamiliar, specifically driving and managing accounts (Wressle, Engstrand & Granérus, 2007). However undertaking such tasks might require spouses to make decisions on their own, without any consultation; a source of friction with their relative (Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011; Hodgson, Garcia & Tyndall, 2004) and understood as stressful when undertaken without guidance from

health care professionals (Hasson et al., 2010). Discussion of future events and planning for potential disability tended to be avoided until spouses became unable to manage the difficulties arising from their loved ones' failing health, memory or movement, often potentiating crisis (Hasson et al., 2010; Williams & Keady, 2008). Clear communication between couples to determine when and what type of support may be needed in different circumstances seemed to mitigate distress as did explicitly informing the other of mutual need (Hodgson, Garcia & Tyndall, 2004; Wressle, Engstrand & Granérus, 2007). Renegotiation of tasks since diagnosis of PD and how families spent time together appeared to be a pervasive issue (Habermann, 2000).

Increasing dependency of a relative was consistently emphasised (Hasson et al., 2010; Hodgson, Garcia & Tyndall, 2004; McLaughlin et al., 2010) as was constraint. Many spouses felt unable to leave the house for long periods of time, especially at night (Birgersson & Edberg, 2004; Wressle, Engstrand & Granérus, 2007). Spouses were often unwilling to relinquish the care-giving role despite respite opportunities being available (Hasson et al., 2010). Strength of feeling about relinquishing a caring role appeared to intensify as end of life drew near (McLaughlin et al., 2010).

4.2.2 Perceived losses and gains

Spouses reported various and numerous losses. Economic loss and reduced financial circumstances featured prominently with difficulties in accessing information on benefits to address reduced income and availability for paid employment (Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011; McLaughlin et al., 2010). For those spouses still in employment, they reported stress generated whilst balancing caring and employment responsibilities (Hodgson, Garcia & Tyndall, 2004).

Also prominent was loss of previously valued activities (McLaughlin et al., 2010; Wressle, Engstrand & Granérus, 2007) and restorative time for themselves, along with much reduced communal activities and contacts (Birgersson & Edberg, 2004; Habermann, 2000) often resulting in social isolation (Hasson et al., 2010). Increased care responsibilities and neglect of own needs could lead to physical, mental and emotional exhaustion, with spouses postponing meeting their own needs until a crisis situation occurred (Birgersson & Edberg, 2004).

Alongside more tangible losses, studies described loss of identity (Birgersson & Edberg, 2004; Roger & Medved, 2010). This was articulated as evolving, dynamic although not uniformly negative and descriptions emphasised the interplay between an old self, prior to diagnosis of PD, and anticipated future change. Whilst altered self-identity was prominent (Hasson et al., 2010) and grieved for, negative descriptions were also embedded in loss of the unique selves to carer and cared-for, as illness identities came to dominate (Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011; Hodgson, Garcia & Tyndall, 2004). This change of identities extended in time such that loss of the shared future planned by the couple was curtailed with nostalgia expressed for joint enterprises (Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011).

Spouses described loss of the intimate connection within their relationship (Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011) and impact on their physical relationship was evident (Habermann, 2000). Of the eight studies reviewed, three contained explicit comment on adverse changes to their sexual relationship. Separate rooms/beds for sleeping were reported in response to symptoms and medication side-

effects (Habermann, 2000). Others, whilst remaining sexually active, felt a reduced physical relationship altered the nature of being close (Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011; Habermann, 2000; Hodgson, Garcia & Tyndall, 2004).

Impact of care was not solely described as loss. Indeed, spouses reported numerous positive impacts on their relationships as a couple (Habermann, 2000; Roger & Medved, 2010; Wressle, Engstrand & Granérus, 2007) and found the illness had brought them closer together and deepened the relationship (Birgersson & Edberg, 2004), affirmed commitment to one another and in some cases saved their relationship (Hodgson, Garcia & Tyndall, 2004). Some spouses described the illness as a catalyst for attempting things they had previously dismissed, increasing self-confidence and financial stability (Habermann, 2000).

Stoicism and burden were clearly evident, and caring was often accepted as a spousal duty with a need to incorporate the disease and its demands (McLaughlin et al., 2010; Wressle, Engstrand & Granérus, 2007). However adjustment was also construed in more active terms and spouses supported a positive embodiment of love (Birgersson & Edberg, 2004; Habermann, 2000).

4.2.3 Resilience

Despite the undoubted physical and psychological burden articulated by spouses, adjustments could be framed positively and resilience was evident. For the purpose of this review resilience was defined as the ability of a spouse to use various strategies to continue with daily life and cope, despite challenges presented by the disease. Resilience was underpinned by spouses perceiving challenges of care-giving as

secondary rather than allowing them to become the primary focus in their lives (Habermann, 2000). This was further achieved through spouses maintaining their own lives and activities (Habermann, 2000; Williams & Keady, 2008), whilst simultaneously encouraging relatives to continue engaging in meaningful activities.

Resilience could be effected through review of past, present and future events. 'Bridging' was described by Williams & Keady (2008) as central to adjustment to Parkinson's disease and described how couples sought to build on past experiences. By talking through their life history together, and reviewing significant events experienced, it provided both parties with a supportive, mutual narrative. Through such review processes a sense of closeness was achieved and maintained helping individuals shape their identities following the introduction of Parkinson's disease (Roger & Medved, 2010). The protection of current shared daily routines, with an agreed set of priorities, provided couples with a sense of control over the condition (Williams & Keady, 2008), however this was acknowledged to be difficult to sustain when medication became ineffectual.

Outside agencies and involvement with them could bolster or detract from resilience. Support groups were seen as valuable, external resources for accessing information about Parkinson's disease (Hodgson, Garcia & Tyndall, 2004), as well as validating through being the focus of others' concern (Birgersson & Edberg, 2004). Practical discussion of helpful strategies via support groups and the opportunity to share what had been learned through caring enabled spouses to derive greater meaning from their roles which seemed to mitigate distress (Roger & Medved, 2010). However carers' involvement in such groups was tempered by needs to protect patients - fearing the

impact of witnessing the more advanced stages of Parkinson's disease and their own future (Williams & Keady, 2008).

Family support also appeared central to building resilience (Birgersson & Edberg, 2004; Williams & Keady, 2008; Wressle, Engstrand & Granérus, 2007) particularly for support following bereavement (Hasson et al., 2010), with spiritual advisors and political outlets (Hodgson, Garcia & Tyndall, 2004) accorded similar importance. Hodgson, Garcia and Tyndall (2004) also highlighted the unique contribution of 'thankfulness' for resilience, with spouses utilising various forms of positive reframing (noting that disease progression was slow, other terminal conditions had not been diagnosed, their spouse remained independent).

4.2.4 Professional support

Lack of knowledge of, and circumscribed access to health, social care and palliative services was commonly expressed (Williams & Keady, 2008; Wressle, Engstrand & Granérus, 2007). Frustration was reported that services were not identified or made available at diagnosis, that signposting to services was limited (Hasson et al., 2010) with liaison between primary and secondary services and voluntary and statutory services poor (McLaughlin et al., 2010). As end of life issues became prominent, access to hospice care was underutilised due to incorrect beliefs that availability was solely for those with cancer (McLaughlin et al, 2010). Continued social isolation was magnified after spouses' death by a sense of loss and purpose, which had been implicit in caring, intensified further by feeling abandoned by services. There was little evidence of spouse referral for additional support from bereavement counselling (Hasson, et al., 2010).

Spouses expressed ambivalence about engagement with professionals. The high regard expressed about primary care professionals and reliance upon them to provide home visits and access information on the spouse's behalf was contrasted with criticism describing lack of detailed knowledge of Parkinson's disease (Hasson et al., 2010; Hodgson, Garcia & Tyndall, 2004; McLaughlin et al., 2010). Extensive difficulties receiving the initial diagnosis, with increasingly fragmented paths to diagnosis and misdiagnoses if the disease was of early onset (Hodgson, Garcia & Tyndall, 2004) was attributed to absence of sufficiently early specialist care. A need for a broader range of professionals, with training specific to Parkinson's disease was argued for (McLaughlin et al., 2010; Wressle, Engstrand & Granérus, 2007).

Process of care, particularly communication, was also described with ambivalence and tailoring of messages to spouses appeared to be absent. Appointments were described as brief, predominantly focused on biomedical dimensions of the disease and irregular, with professionals often not addressing spouses directly and failing to keep them appropriately informed, leading them to feel not respected or unheard (Birgersson & Edberg, 2004; Wressle, Engstrand & Granérus, 2007). Limited time was available for spouses to enquire about the condition resulting in limited understanding, encouraging information to be sought from other sources, predominantly the internet (McLaughlin et al., 2010).

There was little acknowledgement of individual differences in type and volume of information to be shared, with some spouses seeking full responses about prognosis and others reluctant to seek specialist knowledge due to fears of relatives becoming depressed (Hasson et al., 2010). Delivery of diagnosis was described negatively often

due to the stark or indirect manner in which information was conveyed, leading to anger and shock (McLaughlin et al., 2010). These experiences were not confined to diagnosis with many interactions with professionals described as poor (Hasson et al., 2010) and professionals reluctant to discuss other issues other than Parkinson's disease, leaving spouses feeling unsupported (Birgersson & Edberg, 2004).

5.0 Discussion

5.1 Summary of findings and clinical utility

The findings from the review indicate that, as with other chronic debilitating conditions such as Multiple Sclerosis (McKeown, Porter-Armstrong & Baxter, 2003), spouses report significant negative consequences to themselves on quality of life and psychological well-being and on their spouse and the marital relationship, as a consequence of caring. Loss of identity, a shared anticipated future, fiscal and social restrictions were prominent as were isolation and the constraints placed on an intimate sexual relationship. Yet resilience and adjustment/accommodation to Parkinson's disease was certainly evident despite the challenges imposed in the wake of a chronic health condition (physical, emotional and social). Despite ambivalence in obtaining information about the condition, spouses clearly stated a need for increased communication from professionals about the condition and its progression, with more support systems available for spouses, particularly at palliative stages of the condition and following bereavement.

Previous research also evidences spouses to be at greatest risk of negative consequences when providing care as opposed to children or other family members, due to their intense involvement (Dupuis, Epp & Smale, 2004). Spousal relationships are forced to adapt when a chronic condition is introduced and spouses have been shown to adopt the role as carer as opposed to a wife or husband, often impacting negatively on relationships (Eriksson & Svedlund, 2006). This was only partially evidenced in the studies reviewed with many spouses considering care-giving as a deepening of the spousal role as opposed to requiring the acquisition of new roles. In studies of

traumatic brain injury (Jumisko, Lexell & Söderberg, 2007) spouses adjusted their lives accordingly through a natural love and had no doubt in taking up the challenge of caring for their relative with a brain injury, which is certainly demonstrated in this review. In the studies reviewed, identities were forced to adapt to the introduction of Parkinson's disease. Spouses constructed caring as an act of love rather than a duty and built cooperative and shared identities as a couple with a chronic health condition, as opposed to adopting separate identities and taking on new disparate roles as carer and patient.

Sexual intimacy is a core component of a spousal relationship with chronic health conditions having significant influences on sexual intimacy, with couples experiencing a reduction in sexual activity (Dalteg, Benzein, Fridlund & Malm, 2011). In this review a reduction in sexual activity was evident but the focus was predominantly on its relationship with intimacy within the relationship as opposed to a focus on sexual dysfunction or apprehension at resuming sexual activities. A reduction in sexual intimacy caused spouses to perceive lower levels of intimacy and a lack of closeness with their relative that was previously evident prior to Parkinson's disease. Sexual concerns for couples are often dismissed and not discussed as part of care, despite this being explicitly highlighted as an area for assessment (National Collaborating Centre for Chronic Health Conditions, 2006). Screening for sexual concerns should be included within assessments with couples and appropriate support provided for individuals to be able to discuss concerns with relevant health professionals, with further avenues for referral available, if deemed necessary.

It is important to consider that the studies included in this review focussed on an older adult population, in which perceptions and importance of sexual activities and intimacy may be different to those of a younger population experiencing chronic health conditions. As couples age sexual expression may become less integral to a relationship. This may explain reports of lower intimacy levels due to reduced sexual activity in this population as opposed to younger populations reporting difficulties with resuming and continuing with sexual activities. There is a clear need for further research on younger populations, diagnosed with early-onset PD, and their view of sexual intimacy and its impact on the couple relationship.

The ability for adaptation to the condition, that was evident in these studies, may also be explained by Parkinson's disease predominantly occurring in later life and in predominantly an older adult population, when a sense of history and survivorship may prevail and couples have experienced a relationship without the intrusion of a chronic condition. For those chronic conditions, such as Multiple Sclerosis, which typically have an onset in early adulthood, relationships are often premature which may make adaptation to a chronic condition more difficult to bear for some couples (Speziale, 1997).

Professional support has been highlighted as an area requiring improvement with regards to increased liaison with carers and support during palliative stages of the condition and following bereavement. Furthermore, professional support should be tailored and individualised to couples, to ensure information about the condition is conveyed at a time when couples feel ready.

Carers are considered within the National Institute for Health and Clinical Excellence (NICE) guidance for Parkinson's disease (2006) with statements regarding inclusion of carers in decisions of care and provision of information; however these statements are limited in detail. Within the dementia field, policy documents such as the NICE Social Care Institute for Excellence (2006) document now exists, which explicitly references the support that should be made available for carers of those with dementia. Support highlighted includes an initial carer's assessment as set out in the Carers (Equal Opportunities) Act (2004) and suggests interventions including psycho-education, peer support groups and training courses and psychological therapy, with the provision of transport and short breaks, to enable carers to take advantage of these support systems.

Bereavement support appeared sub-optimal for spouses following the death of their relative. Reports of connections with professionals being suddenly lost left spouses feeling abandoned and alone, with limited spouse referral to bereavement counselling, leaving spouses to identify these services themselves. This has been further evidenced by families following the death of a child through cancer (deCinque et al., 2006) demonstrating a need for more supportive contact from hospital professionals during palliative stages and following bereavement and earlier provision of information to help prepare families emotionally and practically.

The NICE Quality Standards for End of Life Care for Adults (2011) explicitly highlight the importance of bereavement support and state immediate and on-going bereavement support should be provided. A stepped approach is suggested which may include the provision of information about local support services, practical support such as support with funeral arrangements, supportive conversations from health professionals or

support from voluntary or community organisations and an option of a referral to more specialist support from trained bereavement counsellors or mental health workers. All of these could be usefully incorporated into the package of care provided to families managing a chronic health condition such as Parkinson's disease.

These areas for improvement need to be considered in light of the new Health and Social Care Bill (2011). With the restructuring of the National Health Service (NHS) giving GP Consortia and Foundation Trusts more freedom as to how to spend NHS funds, health care may become dependent on the area in which individuals reside, resulting in different levels of care available for spouses caring for a relative with Parkinson's disease. The variability of views regarding general practitioners was highlighted throughout the studies. Evidence of general practitioners demonstrating varying depths of specific knowledge regarding Parkinson's disease and its impact is of key significance and concern if these professionals will have the power to decide on the services required, and simultaneously funded, in local areas. However, a multi-disciplinary systems approach to care tailored to the management of Parkinson's disease, along the full disease trajectory and beyond, would be of great value.

5.2 Strengths and limitations of the review

Whilst all articles were considered to be of satisfactory quality for inclusion in the review, some articles were deemed more rigorous and trustworthy. All findings generated from the review can be considered to add further contributions to the Parkinson's disease literature. However, themes including challenges to care-giving, perceived losses and gains and resilience may be considered to be more robust and trustworthy due to being supported by papers demonstrating higher quality. The theme

of professional support, though adding important insights, may be considered less robust due to solely being supported by two lower quality papers.

All studies reviewed, with the exception of Habermann (2000), focused on the experiences of older adults, unsurprising given when the disease most commonly presents (Lees, Hardy & Revesz, 2009). This clearly limits the generalisability of findings to younger adults, given that the review revealed only one study examining the impact of earlier onset Parkinson's disease.

Whilst articles are all broadly Western, there is potential for cultural differences to have an effect across the papers with regards to differences in health care contexts and service provision. In Western and developed countries there may also be a greater understanding of neurological processes of such conditions. Knowledge of the understanding and management of Parkinson's disease in developing countries would be an area for future research.

Respondents and the resultant narratives may only represent those patient and spouse dyads prepared to discuss the impact of Parkinson's disease on their lives. It may be that these individuals are extremely robust, coping well and feel able to discuss these issues or conversely they may be more vulnerable. Either perspective may result in biased findings with the omission of those unwilling to discuss their experiences.

The majority of studies interviewed each member of the couple separately resulting in an absence of a dyadic focus and the interplay that exists between couples with a chronic condition. Furthermore, studies were cross-sectional in design limiting

information obtained from a specific point in time. Adjustment to a chronic illness is often dynamic in nature, requiring a longitudinal design to capture how experiences of living with Parkinson's disease may change over time.

Despite limitations, there can be confidence in the conclusions drawn from the review due to the rigour of the approach adopted and the retrieval of common themes across studies reviewed.

6.0 Conclusions

Data synthesis indicates that spouses are experiencing many challenges to caring for a relative with Parkinson's disease with varying experiences of professional support. The theme of loss was dominant in spousal narratives but resilience also emanated, with evidence of the condition having some positive influences for spouses.

These findings have important clinical implications. Individualised care is important to ensure information about the disease and its progression is given at an appropriate time, and this should be carried out with a dyadic focus, incorporating the spouse. Due to numerous challenges that spouses face when providing care, more professional support and community resource should be available to reduce burden that spouses may experience at times during the caring role, which is a role with longstanding responsibilities. This is particularly important for palliative stages of the condition and following bereavement.

This review highlights provision of care as complex and multifaceted that requires greater recognition and support from services, for spouses to continue in the demanding role of caring for a relative with Parkinson's disease, over a substantial timeframe, within the community.

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Section 2:

Research report

Quality of life and caregiver burden in Parkinson's disease: the role of patients' and carers' illness appraisals

Sarah Simms

1.0 Abstract

Purpose: Parkinson's disease is common in older adult populations, with an increasing prevalence with age and requires substantial support and care from family. Psychological factors have increasingly begun to be a focus of research due to biomedical factors alone not providing sufficient explanation for patient outcome. The role of illness appraisals has been shown to provide some explanation of patient outcome in other chronic health conditions, but has been minimally investigated in Parkinson's disease. Furthermore, despite the extensive caring role often adopted by family members, limited research has focussed on the impact of this care on relatives.

Methods: A cross-sectional design was utilised. Participants were recruited from two outpatient clinics within one teaching hospital in the East Midlands. Self-report questionnaires were administered to patients and carers in order to investigate the role of patients' and carers' illness appraisals for quality of life and caregiver burden. Correlation and regression analyses were used to analyse results.

Results: A total of 59 patients and 62 carers were recruited. Illness appraisals were demonstrated to be key predictors of quality of life and burden, after controlling for biomedical variables, and the importance of both patient and carer appraisals for these outcome measures was highlighted.

Conclusion: This is the first study to investigate the role of patients' and carers' illness appraisals in Parkinson's disease. Illness appraisals have been shown to be a key factor for patient and carer outcome, demonstrating the importance and utility of Leventhal's Common Sense Model in predicting health outcome. A strong belief in treatment efficacy and fewer negative emotional representations were demonstrated as the illness appraisals most predictive of quality of life and caregiver burden for both patients and carers. Clinical implications include the routine assessment of carers with care tailored to individual needs and increased liaison across services. There is a need for bereavement support and screening for issues regarding intimacy, particularly for younger patients.

2.0 Introduction

2.1 Parkinson's disease

Parkinson's disease is a progressive, neurological condition affecting the coordination of movement. Its primary cause is thought to be the loss of neurons within the substantia nigra that produce the neurotransmitter, dopamine. The main motor symptoms include hypokinesia (poverty of movement), bradykinesia (slowness of movement), rigidity of muscles and resting tremor (NICE, 2006). Parkinson's disease affects approximately 120 000 people within the UK, with 10 000 new cases each year. There is a higher incidence of Parkinson's disease in males and a rising prevalence with age (National Collaborating Centre for Chronic Conditions, 2006). The mean duration of the disease from diagnosis to death is approximately 15 years (Lees, Hardy & Revesz, 2009), resulting in an explicit and increasing need for care, within the community, over a substantial timeframe.

2.2 Adjustment to Parkinson's disease

Although the disease predominantly affects movement, numerous studies have shown clear associations with elevated levels of psychological morbidity; with prevalence of major depression as high as 42% (dos Anjos et al., 2009), and generalised anxiety over 30% (Kummer, Cardoso & Teixeira, 2009). The rate of minor depression in community samples is reported at approximately 30% to 40% with only 3% to 8% of these fulfilling the Diagnostic Statistical Manual (DSM) criteria for depression (Schrag, 2006), highlighting the presence of psychological difficulties that may go undiagnosed. Recognition of psychological morbidity associated with Parkinson's disease appears sub-optimal, may remain untreated and more adversely affect quality of life than motor symptoms (Parkinson's Disease Society, 2008).

Quality of life has been extensively used as an outcome measure when assessing psychological morbidity, with both elevated anxiety and depression shown to be associated with reduced quality of life (Carod-Artal, Ziomkowski, Mourao Mesquita & Martinez-Martin, 2008). Cognitive decline and dementia are also both reported as the disease progresses (Forsaa, Larsen, Wentzel-Larsen & Alves, 2010). Where cognitive domains of Parkinson's disease have been assessed, higher scores on visual attention/memory, visuo-spatial and executive functioning are associated with enhanced quality of life (Klepac, Trkulja, Relja & Babic, 2008), whereas poorer quality of life has been associated with cognitive impairment (Klepac, Trkulja, Relja & Babic, 2008) and the experience of hallucinations (McKinlay et al., 2008).

The progressive deterioration in Parkinson's disease often results in a considerable loss of autonomy and an increased need for care and support, which is usually provided by family members (Williamson, Simpson & Murray, 2008). This provision of care can have deleterious effects on carers' health, with greater perceived caregiver burden creating considerable effects on depressive symptoms, personal resourcefulness and quality of life (Zauszniewski, Bekhet & Suresky, 2009) and physical health (Chang, Chiou & Chien, 2010); all of which may influence the standard of care-giving.

Research to date has primarily focused on identifying which symptoms are related to increased caregiver burden. Associations relating to severity of the disease (D'Amelio et al., 2009), and presence of depression and dementia (Stella, Banzato, Barasnevicius Quagliato, Viana & Christofoletti, 2009) underscore dementia as the strongest predictor of burden. However, greater understanding of carers' responses to Parkinson's disease and the relationships to caregiver burden is required to extend knowledge in this area.

Much of the impetus to understand the psychological dimensions and consequences of the disease has been driven by recognition that patient outcomes are not adequately explained by physical status and biomedical variables alone. Improving patient outcome may not only require a more nuanced understanding of mood but also of how the condition and its manifestations are understood, attributed and evaluated by those with the disease and those who care for them.

2.3 Illness appraisals

Understanding professional response to and management of chronic illnesses such as Parkinson's disease has been facilitated over the last two decades by an increasing focus on patients' own illness appraisals. Prominent in directing this has been Leventhal's Common Sense Model (CSM) of illness appraisal, which has considerable empirical support in predicting patient outcomes across various health conditions (Hagger & Orbell, 2003). It proposes that individuals construct their own cognitive appraisals of their condition in response to a health threat. Together with emotional responses, these act to determine health-oriented behaviours.

The model consists of five core cognitive dimensions including:

- Identity (The label given to the illness and the symptoms experienced);
- The perceived cause of the illness;
- Time line (The individual's belief regarding the duration of the illness);
- Consequences (The effects of the illness on the individual's social life);
- Curability and Controllability (The extent to which the individual believes their illness can be cured and how much it is controllable by themselves or others).

The model has now been through further revisions to include a timeline cyclical subscale to determine beliefs regarding the variability of a health condition. The curability and controllability subscale has been separated into personal control and treatment control to determine how much control individuals feel over the condition and their beliefs in the effectiveness of treatment, respectively. Emotional representation has been included to determine individuals' emotions regarding their health condition (Moss-Morris et al., 2002).

The association of illness appraisals with patient outcomes has been demonstrated across a number of chronic health conditions including Multiple Sclerosis (Spain, Tubridy, Kilpatrick, Adams & Holmes, 2007), Chronic Obstructive Pulmonary Disease (Scharloo et al., 2007) and Diabetes (Ponzo et al., 2006). Patients' own illness appraisals were shown to be the most significant predictors across outcomes of social dysfunction, fatigue, anxiety, depression, self-management and self-esteem, after controlling for illness severity.

The importance of appraisals for other neurological diseases has also been revealed by Helder et al. (2002), demonstrating that individuals who attributed many of their symptoms to their diagnosis of Huntington's disease, who believed in a sustained duration of the disease, who perceived adverse consequences for daily lives and little hope for improvement or cure were more likely to report poorer outcomes. Scores on the identity and cure dimensions were key predictors of quality of life, with identity being the strongest predictor of physical functioning, bodily pain, general health, vitality and mental health.

Establishing and addressing less helpful illness appraisals for chronic health conditions has been associated with greater attendance at rehabilitation programmes (French, Cooper & Weinman, 2006) and with better recovery and reduced disability for cardiac patients (Petrie, Cameron, Ellis, Buick & Weinman, 2002). Assessing patient appraisals can permit the tailoring and focusing of effective interventions and can be introduced to discussion in early consultations from diagnosis onwards. It allows interventions to be targeted at the appraisals predictive of poorer patient outcomes to improve quality of life and minimise distress.

To date research examining illness appraisals for those living with Parkinson's disease is circumscribed. Some literature is emerging examining illness appraisals, coping style and their relationship to psychological adjustment to the disease (Evans & Norman, 2009), revealing that patients' perceived low personal control and serious consequences were predictive of anxiety and depression. Through gaining a deeper understanding of the types of illness appraisals held by patients with Parkinson's disease, it may be possible to determine unhelpful appraisals adversely affecting patient outcome. This identification may lead to earlier intervention to adapt these appraisals to improve patient outcome and general quality of life.

2.4 Illness appraisals of family members

Health outcome appears not only affected by patients' own appraisals of their condition. Increasingly the influence of significant others has also become a key focus of research. Psychological morbidity of those with Parkinson's disease, revealed positive associations between psychological distress and dissatisfaction with social support, demonstrating satisfaction with support as key in psychological outcome (Simpson,

Haines, Lekwuwa, Wardle & Crawford, 2006). Social support can be beneficial to patients but family interactions can also compromise psychological wellbeing. Overprotectiveness of spouses with cardiac disease, driven by fear for a loved one, has been shown to result in resentment and frustration in patients (Dalteg, Benzein, Fridlund & Malm, 2011). This raises the question of how exactly significant others, who adopt a caring role, may influence outcomes of patients with chronic health conditions.

One proposed mechanism by which significant others may exert influence is through the illness appraisals they themselves construct. Dempster et al., (2011) studied the illness appraisals of carers and the relationship with psychological distress of patients following oesophageal cancer. Perceptions by carers of severe consequences of the cancer for the patient and beliefs that medical staff had minimal control over the cancer led to reports of higher psychological distress in patients, suggesting a potential mediating role of carers' perceptions.

More recently, studies have begun to shift their focus from the impact solely on patient outcomes to investigate how illness appraisals may affect the health outcomes of carers themselves. Kaptein et al. (2007) examined how patients' and partners' illness appraisals of Huntington's disease appeared to affect quality of life. Patients' and partners' own illness appraisals accounted for most of the variance in their own quality of life but this was also influenced by the appraisals of their relative. Enhanced patient quality of life was associated with patient appraisals of a weaker illness identity, lengthy illness duration, fewer perceived consequences, greater control and less belief in treatment and partner's appraisals involving weak illness identity and belief in cure

through treatment. A higher quality of life of partners was highly associated with partner's beliefs in a longer duration of the illness and fewer perceived consequences and patient beliefs in control over the illness and less serious perceived consequences.

Barrowclough, Lobban, Hatton & Quinn (2001) investigated illness beliefs of carers of schizophrenia patients with a primary focus on the impact on carer outcomes and investigated beliefs in consequences and control from their own perspective as opposed to their perceptions of patient beliefs for these subscales. A reduction in carer well-being was predominantly related to perceptions of numerous consequences of schizophrenia for themselves and their daily lives. A further study by Lobban, Barrowclough & Jones (2005) demonstrated that relatives who believed they had some control over schizophrenia and its related symptoms felt optimistic about the impact of treatment. Relatives with a coherent understanding of the mental health problems also felt more able to control them.

Whilst appraisals of those with chronic illness and carers have been studied separately, the extent to which appraisals are discrepant has also been examined as predictive of health outcomes.

Studies examining patients with Chronic Fatigue and Addison's disease, demonstrated couples generally held congruent views with regards to illness identity and cause but showed dissimilarities concerning timeline, cure/control and consequences of the illness (Heijmans, De Ridder & Bensing, 1999). These dissimilarities had a strong impact on the psychological adaptation of the patient. Minimisation of the illness by the partner resulted in a strong negative impact on patients' psychological outcome and appeared to

be more detrimental to patient quality of life. In addition, spousal congruence for personal control and cyclicity predicted better psychological adjustment in women with rheumatoid arthritis (Sterba et al., 2008), with better psychological adjustment when beliefs regarding personal control, illness coherence and consequences were positively rather than negatively congruent.

Identifying and therapeutic targeting of unhelpful illness appraisals of patients and carers, and understanding the role that convergence and divergence in appraisals can have may improve quality of life and adjustment. That carers' perspectives and outcomes are also addressed seems key given the central role they have in delivering best care (Zauszniewski, Bekhet & Suresky, 2009) and supporting those with Parkinson's disease.

2.5 Aims of the study

This study will aim to explore whether specific illness appraisals are significant predictors of quality of life and caregiver burden in patients with Parkinson's disease and their carers and determine the relative importance of congruence between patient and carer appraisals.

Specific research aims are as follows:

- To determine how patients with Parkinson's disease appraise their condition.
- To determine how carers of patients with Parkinson's disease appraise the condition.
- To determine to what extent patient and carer appraisals demonstrate convergence/divergence

- To determine if patient and/or carer appraisals are predictive of quality of life.
- To determine if patient and/or carer appraisals are predictive of caregiver burden.

3.0 Method

3.1 Design

A cross-sectional, quantitative study of illness appraisals of patients with Parkinson's disease and their carers was conducted. Data was gathered using eight measures. Predictor variables included stage of disease, motor ability and illness appraisals and outcome variables included quality of life and caregiver burden. An empirical, positivist position was adopted, assuming that the topics of interest could be objectively measured in a reliable and valid way.

3.2 Participants

The sample comprised patients with a diagnosis of Parkinson's disease and their carers. Both patient and carer had to consent to take part in the study in order to be included. . A six month sampling frame was negotiated in August 2011 between the researcher, Consultant and PD nurse specialist, and all patients attending an outpatient appointment at a teaching hospital at an Acute Trust in the East Midlands were eligible to take part. No time frame for time of diagnosis was imposed. Inclusion criteria dictated they were over 18 years of age, could read and understand written English, had no other physical health condition diagnosed within the last two years and did not have diagnosed cognitive impairment. All carers were also invited to take part providing they could read and understand written English, were over 18 years of age and were not formally paid. A total of 62 carers and 59 patients were recruited.

An a priori power calculation was conducted to determine a sample size required to achieve sufficient level of power. Given circumscribed research in this area a medium effect size was assumed. A power of 0.8 (Field, 2009) and statistical significance of

0.05 was utilised for purposes of the power analysis. For Pearson correlations, 85 participants per group would be required. A maximum of eight predictor variables was anticipated to be used in the hierarchical regression analyses, requiring a sample size of 108 participants per group. It was decided to attempt to recruit 108 participants per group.

3.3 Research Procedure

3.3.1 Ethical Approval

Ethical approval was sought and obtained from the local ethics research committee (See Appendix F). Permission was granted from the research and development department of the host trust (See Appendix G). It was not anticipated that participants would suffer distress through participation; however there was recognition that questions may be sensitive for some participants. All participants were encouraged to take a break or withdraw from the study if feeling distressed at any point. Contact details were provided for the Patient Advice and Liaison Service (PALS) and for the Consultant in Elderly and Geriatric Medicine attached to the clinic, should they wish to ask further questions or share concerns about the study. Confidentiality was ensured as all questionnaires were anonymous and identified by an identity number. A measure to screen for cognitive impairment was administered to patients. Patients provided written consent for any cognitive difficulties identified through completion of this measure to be passed on to the Consultant or PD nurse specialist for discussion, if these professionals deemed this necessary.

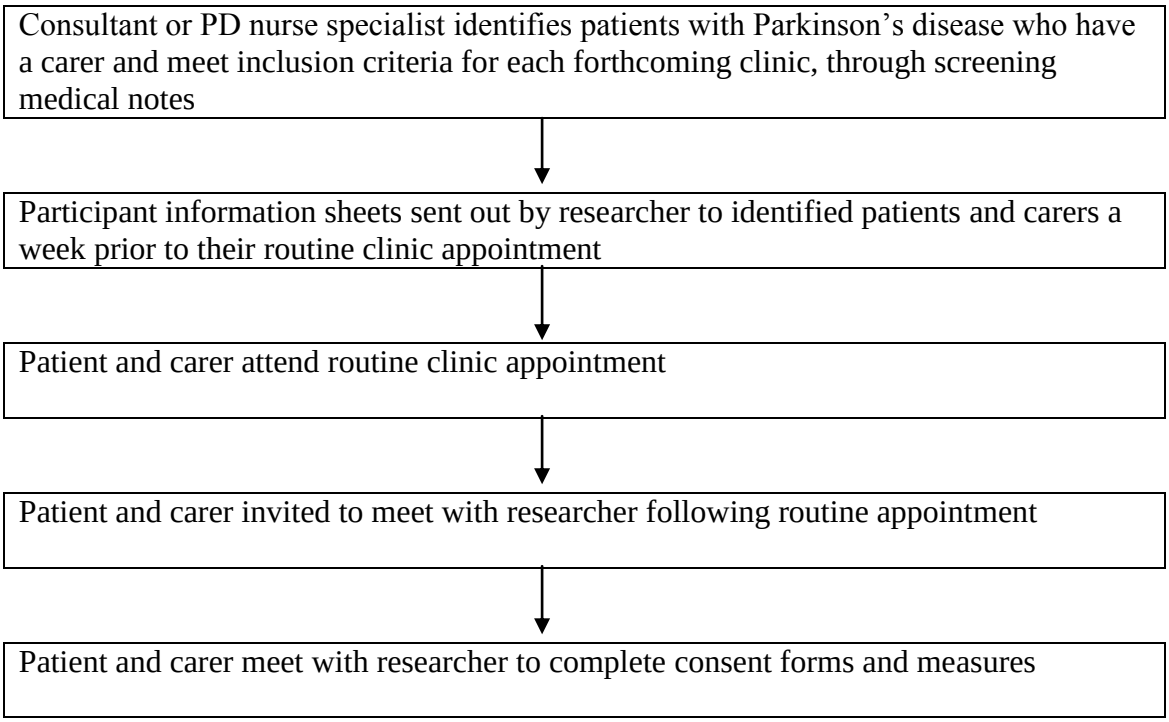
3.3.2 Obtaining the sample

All patients with a diagnosis of Parkinson's disease attend an outpatient clinic for follow up appointments with a Consultant in Geriatric and Elderly Medicine or a PD Nurse Specialist on a regular basis. A week prior to a routine clinic appointment, participant information sheets were distributed to eligible patients attending the forthcoming clinic. Two separate information sheets were sent out; one for the patient (See Appendix H) and one for the carer (See Appendix I). These were sent by the researcher following screening of medical records of potential participants by the Consultant or specialist nurse to determine eligibility.

Following consultation with either the Consultant or PD Nurse Specialist participants were invited to meet with the researcher. In order for patients and carers not to feel under pressure to agree to participate in the study, they were able to consent to the study whilst with the Consultant or PD nurse specialist, and therefore were able to leave the clinic without meeting with the researcher if one or both parties were unwilling to take part. For those that agreed, a consent form was then completed by both the patient (See Appendix J) and carer (See Appendix K) and measures completed.

Procedure to obtain sample is outlined in Figure 1.

Figure 1. Procedure to obtain sample



3.3.3 Data Collection

Patients and carers both completed four questionnaires. The researcher met with the patient separately to complete the measures and was able to provide assistance with reading and writing responses, if necessary. During this time the carer also completed measures in the waiting room and joined the patient at the end to ask any further questions about the measures or the study. The researcher also met with the carer if assistance was required with reading and writing responses. Questionnaire completion took between 30 minutes and one hour.

3.4 Measures

The following measures were used to collect data for predictor and outcome variables:

3.4.1 Demographic information. (Appendix L)

The following information was obtained for the patient:

Age

Gender

Employment status

Duration of Parkinson's disease

The following information was obtained for the carer:

Age

Gender

Relationship to patient

Employment status

In addition the following biomedical indices were obtained:

3.4.2 Stage of Parkinson's disease (Appendix M)

The severity and stage of Parkinson's disease was assessed using the Hoehn and Yahr Staging measure. This comprises an eight point scale (0, 1, 1.5, 2, 2.5, 3, 4, and 5) ranging from 0 (no signs of the disease) to 5 (symptoms are very severe, with patient typically wheelchair-bound). The stage of Parkinson's disease was determined by the Consultant in Elderly and Geriatric Medicine or the PD Nurse Specialist during their outpatient appointment.

3.4.3 Motor ability (Appendix N)

To assess a patient's motor ability the motor section of the Unified Parkinson's Disease Rating Scale (UPDRS) was completed by the Consultant or the PD Nurse Specialist. The motor section comprises 14 items rating ocular motor function, dysarthria, chorea, dystonia, gait and postural stability. The total motor score is the sum of all the items with higher scores indicating poorer motor performance with a maximum score of 56.

3.4.4 Dementia screening tool

The Clock Drawing Test (Strauss, Sherman & Spreen, 2006) was used as a guide to assess for cognitive impairment and dementia in patients. As the second most frequently used instrument for dementia screening (Aprahamian, Martinelli, Neri & Yassuda, 2010), after the Mini Mental Status Examination (MMSE), it is deemed easier and quicker to administer and reported to be less threatening to patients than the MMSE (Agrell & Dehlin, 1998).

The task requires a respondent to draw the face of a clock with all the numbers in it and to then draw the hands of the clock set to a specific time usually ten past eleven. Despite many different scoring systems, the five point scoring system has been shown to be more predictive of dementia than other systems and therefore was used as a guide for the purposes of this study. Higher scores reflect a greater number of errors and greater impairment, with a score of three or greater indicating cognitive deficit (Strauss, Sherman & Spreen, 2006).

In addition the following psychological variables were obtained:

3.4.5 Illness Appraisals – Patient (Appendix O) and Carer (Appendix P)

The Illness Perception Questionnaire – Revised (Moss-Morris et al., 2002) was used to determine patient and carer illness appraisals regarding Parkinson's disease. It is recommended that the original validated questionnaire be adapted for use with carers and questions re-phrased to ensure wording is appropriate to gather carers' beliefs about Parkinson's disease. This is evident in previous studies assessing partner's illness appraisals for patients with rheumatoid arthritis (Sterba & DeVellis, 2009) and for schizophrenia (Barrowclough, Lobban, Hatton & Quinn, 2001), where they also adapted the wording to obtain beliefs regarding the impact on their own lives, as this perspective had been disregarded in other studies (Heijmans, deRidder & Bensing, 1999).

The questionnaire comprises nine subscales including *Identity* (the description or view of symptoms associated with the illness), *Cause* (ideas about what caused the illness), *Timeline Acute/Chronic* (beliefs about how long the illness will last), *Timeline Cyclical* (beliefs about the predictability or cyclic nature of the illness), *Personal Control* (extent to which an individual has control over illness), *Treatment Control* (beliefs about treatment effectiveness), *Illness Coherence* (extent to which an individual has a clear understanding of the illness), *Consequences* (the expected effects of the illness) and *Emotional representation* (the emotional reactions to the illness). It uses a five-point Likert scale ranging from 1 – 5 indicating level of agreement, with some items requiring reverse scoring, with higher total scores indicating greater agreement.

The revised illness perception questionnaire was used rather than the original, given the latter's minor psychometric problems with two of the subscales, improved upon in the revised version. The revised version now demonstrates good internal reliabilities for all the subscales (Moss-Morris et al., 2002). Furthermore, the current questionnaire also includes questions focusing on illness coherence and emotional representation. The illness coherence dimension allows researchers to determine how a patient 'makes sense' of their condition and its impact on adjustment and response to symptoms. The addition of an emotional representation domain allows researchers to determine how emotional representations can influence health outcome.

3.4.6 Patient Quality of Life (Appendix Q)

The Parkinson's Disease Questionnaire (PDQ-39) was used to assess disease-specific quality of life. Internal reliability of the subscales is acceptable, with a minimum value of 0.69 (Peto, Jenkinson, Fitzpatrick & Greenhall, 1995). Furthermore, when compared with other quality of life instruments for Parkinson's disease, it is seen to be the most appropriate instrument, given questions relating specifically to Parkinson's disease rather than general questions regarding quality of life. It has been widely validated for use within the UK (Marinus, Ramaker, van Hilton & Stigglebout, 2002).

The questionnaire comprises 39 questions covering eight domains including *Mobility* (ten items), *Activities of Daily Living* (six items), *Emotional Well-Being* (six items), *Stigma* (four items), *Social Support* (three items), *Cognition* (four items), *Communication* (three items) and *Bodily Discomfort* (three items). A single index score can be calculated for each domain with scores ranging from 0 – 100, with increased scores inversely related to quality of life.

3.4.7 Carer Quality of Life (Appendix R)

The Short Form Health Survey version 2 (SF-36v2) was used to determine carer quality of life. It has been widely used across various conditions to assess quality of life of carers and significant others (Kaptein et al., 2007; Heijmans, deRidder & Bensing. 1999). It comprises eight domains including physical functioning, role functioning-physical, role functioning – emotional, general health, vitality, social functioning, mental health and bodily pain. The raw scores are transformed in order to obtain a 0 – 100 scale, with higher scores indicating a better outcome.

3.4.8 Caregiver Burden (Appendix S)

The Brief Zarit Burden Interview (Bédard et al., 2001) was used to determine carer perception of burden. This 12-item scale was employed rather than the 22-item full version, given similar psychometric properties and brevity of administration. It assesses role strain (relating to the demands of the care-giving role) and personal strain (relating to the caregiver's sense of adequacy about being a carer). It uses a five-point Likert scale ranging from 0 - 4 with higher scores indicating greater burden.

3.4.9 Anxiety and Depression (Appendix T)

The Hospital Anxiety and Depression Scale (HADS) was used to measure the presence and severity of anxious and depressive symptoms. It utilises seven items for anxiety and seven depressive items, each scored 0 – 3 and with total scores for each of 21. This measure has been found to be reliable in assessing for clinically significant anxiety and depression in outpatient settings (Zigmond & Snaith, 1983). In a review of its psychometric properties by Herrmann (1997) the HADS demonstrated good reliability

and validity and was sensitive to changes in emotional state over time. Scores of eight or more have been shown to be the optimal cut-off scores for indicators of both anxiety and depression (Bjelland, Dahl, Haug & Neckleman, 2002).

4.0 Results

4.1 Data analysis

Data were analysed using the Statistics for the Social Sciences (SPSS) version 18.0. All scores for individual items were entered into the database. Descriptive statistics are presented in Table 3 to describe the demographics of the two groups. Cronbach's Alpha was used to undertake reliability analysis for all measures used.

4.2 Statistical Procedures for data analysis

Prior to data analysis the data set was examined to determine appropriate application of tests. Parametric tests are considered more powerful and sensitive and are considered initially for inferential statistical analyses. Parametric tests require three criteria to be met in order to be applied to data. These include homogeneity of variance, normal distribution of scores and level of measurement should be interval or ratio (Pallant, 2010). However, if assumptions are not fully met, these tests still appear robust (Field, 2000).

Visual distributions of data (histograms) and z scores were inspected to assess normality and the Kolmogorov-Smirnov statistic was considered to determine if scores deviated significantly from a normal distribution. Outliers were treated as missing data and data was re-examined. Scores for all measures were derived from various Likert-type scales and considered as interval data. Although distances between these scales cannot be assumed, this restriction is often waived in psychological research to optimise power (Bryman & Cramer, 1997).

Paired samples t-tests were used to test for differences between illness appraisals of patient and carer. Some data were not normally distributed, however parametric tests were still utilised since with sample sizes of over 30, violation of this assumption is unlikely to cause any serious problems (Pallant, 2010). Correlational analyses were used to determine whether patient and carer illness appraisals were associated with patient and carer quality of life and caregiver burden. The non-parametric, Spearman's Rho statistical test was used as variables tended to be positively or negatively skewed. Transformations were not performed due to the high number of variables demonstrating skew. Multiple hierarchical regression analyses were used to determine if patient and carer illness appraisals were predictive of quality of life and burden. No transformations were performed as standardised residuals all met the assumption of normality.

4.3 Descriptive data

One hundred and twenty four participants (sixty two carers and sixty two patients) agreed to take part in the study. Three patients were excluded due to demonstrating signs of cognitive impairment resulting in 59 patients participating in the study. There was an acceptance rate of approximately 30% from the outpatient clinics. For those who declined to take part in the study or could not be included, reasons comprised time constraints, not wishing to discuss the condition in depth, diagnosis of dementia or an additional physical health problem or patients turning up to appointments without a carer. Table 3 shows demographic details of the two groups.

Table 3. Demographic details of patients and carers

Variable	Patient (N = 59)	Carer (N = 62)
Mean age (SD) in yrs	72.9 (9.4)	65.5 (12.3)
Gender (%)		
Male	36 (61)	18 (29)
Female	23 (39)	44 (71)
Work status (%)		
Retired	55 (89)	41 (69)
Employed	7 (11)	16 (27)
Unemployed	0	2 (4)

Fifty nine patients (36 males, 23 females) and their carers (18 males and 44 females) took part in the study. The mean age of patients and carers was 72.9 years and 65.5 years, respectively, and the majority of patients (n = 55) and carers (n = 41) were retired.

Table 4. Relationship of carer to the patient

Carers' relationship to patient (%)	
Spouse	50 (80)
Son/daughter	9 (14)
Sibling	1 (2)
Other	3 (4)

The majority of carers (n = 50) had a spousal relationship with the patient with Parkinson's disease, with other carers being children (n = 9) or siblings (n = 1).

The mean duration of PD was 6 years (SD = 5.7; range: 0.5 - 30). Patients' mean total motor score was 17.1 (SD = 8.2; range: 3 – 36) and mean stage of PD at 2.3 (SD = .86; range: 1 – 5) and modal value for stage of disease of 2.5.

For levels of depression patients scored a mean of 5.2 (SD = 3.6; range: 0 - 16) and carers a mean of 3.9 (SD = 3.3; range: 0 - 16), with 36% of patients and 15% of carers scoring within the clinical range. For levels of anxiety patients scored a mean of 6.4 (SD = 4.1; range: 0 - 21) and carers a mean of 6 (SD = 4.1; range: 0 - 18), with 27% of patients and 30% of carers scoring within the clinical range. These results suggest patients to be more likely to present with co-morbid depression and carers with co-morbid anxiety within the clinical range.

4.4 Reliability analysis

Internal consistency was calculated using Cronbach's alpha (α) for all outcome measures as none had been previously applied to this population. Summaries of these are shown in Tables 5 to 7.

Table 5. Summary of reliability analysis for the measure of illness appraisals for patient and carer

Measures	Cronbach's α	
	Patient	**Carer**
IPQ – Timeline	0.87	0.70
IPQ – Consequences	0.82	0.74
IPQ – Personal Control	0.67	0.75
IPQ – Treatment Control	0.55	0.57
IPQ – Illness Coherence	0.88	0.77
IPQ – Timeline Cyclical	0.81	0.85
IPQ – Emotional Representation	0.78	0.80

The analysis suggested that internal reliability of the measures exceeded an acceptable minimum of 0.7 (Kline, 1997) for all subscales on the IPQ-R except the treatment control subscale for both the patient and carer illness appraisal questionnaire. The treatment control subscale demonstrated relatively poor reliability in comparison to the other subscales.

Table 6. Summary of reliability analysis for the measure of patient quality of life

Measures	Cronbach's α
PDQ-39 – Mobility	0.91
PDQ-39 – Activities of Daily Living	0.81
PDQ-39 – Emotional Well-Being	0.75
PDQ-39 – Stigma	0.83
PDQ-39 – Social Support	0.69
PDQ-39 – Cognitive Impairment	0.68
PDQ-39 – Communication	0.77
PDQ-39 – Bodily Discomfort	0.72

The analysis showed that internal reliability of all the subscales for patient quality of life exceeded an accepted minimum of 0.7 (Kline, 1997).

Table 7. Summary of reliability analysis for measures of carer quality of life and burden

Measures	**Cronbach's α**
SF-36 – Physical Functioning	0.90
SF-36 – Role Limitations (Physical Health)	0.95
SF-36 – Role Limitations (Emotional Health)	0.95
SF-36 – Vitality	0.89
SF-36 – Mental Health	0.85
SF-36 – Social Functioning	0.86
SF-36 – Bodily Pain	0.88
SF- 36 – General Health	0.79
Burden	0.93

The analysis showed that internal reliability of all the subscales for carer quality of life and burden exceeded an accepted minimum of 0.7 (Kline, 1997).

4.5 Addressing research questions

Tests of difference

4.5.1 What is the extent of congruence between patients' and carers' illness appraisals?

Table 8. Patient-carer differences in illness appraisals

IPQ subscale	Possible scoring range	PD Patients Mean (SD)	Carers Mean (SD)	Patient-Carer difference T
Identity	0 – 14	4.1 (2.8)	5.1 (2.8)	2.83**
Timeline	6 – 30	26.3 (2.7)	26.5 (3.8)	-.33
Timeline Cyclical	4 – 20	12.4 (3.6)	11.9 (3.9)	1.02
Consequences	6 – 30	20.6 (4.6)	19.8 (3.8)	1.05
Personal Control	6 – 30	20.4 (3.3)	15.9 (4.3)	7.84***
Treatment Control	5 – 25	15.9 (2.9)	16.6 (2.5)	-1.65
Illness Coherence	5 – 25	15.9 (4.8)	17.5 (3.3)	-2.18*
Emotional Representation	6 – 30	18.4 (4.5)	19.4 (4.3)	-1.39

*P < .05; **P < .01; ***P < .001

PD patients and their carers did not differ significantly on the "timeline", "timeline cyclical", "consequences", "treatment control" or "emotional representation" subscales of the IPQ. Both groups reported perceiving PD as having a long duration with some variability, with many consequences for their daily lives, positive beliefs regarding treatment efficacy and negative emotional representations of the condition. Patients and carers did differ on the "identity", "personal control" and "illness coherence" subscales. Patients attributed fewer symptoms to the condition and showed a more limited understanding than did carers. Patients did report perceiving greater personal control over Parkinson's disease than did carers.

Patients and carers both attributed Parkinson's disease predominantly to chance/bad luck, ageing or stress/worry. Chance/bad luck was reported as a cause of the condition by 40 patients (64.5%) and 35 carers (56.5%), ageing was reported by 33 patients (53.3%) and 28 carers (45.1%) and stress/worry was reported as a possible cause by 24 patients (38.7%) and 17 carers (27.4%).

Correlational analyses

Bivariate correlations were used to explore the possible relationships between illness appraisals of both patient and carer (measured by the IPQ-R) with quality of life (measured by the PDQ-39) and burden (measured by the Zarit Burden Questionnaire). Significant relationships are displayed in tabular form.

4.5.2 What relationships exist between patients' illness appraisals and patients' quality of life?

Table 9. Relationships between patients' illness appraisals and patients' quality of life: Spearman's Rho

	Illness Identity	**Consequences**	**Treatment Control**	**Illness Coherence**	**Timeline Cyclical**	**Emotional Representations**
Mobility		.431**	-.449**			.328*
Activities of Daily Living	.315*	.276*	-.352**	.275*		
Emotional Well-being	.332*	.489**			.392**	.758**
Stigma						.370**
Social Support	.270*	.417**				
Cognitive Impairment	.310*	.266*	-.285*			
Communication	.432**	.392**				
Bodily Discomfort	.648**	.523**			.365**	

Note: * $p < 0.05$ (two tailed) ** $p < 0.005$ (two tailed)

Correlational analyses revealed that all domains of illness appraisals showed associations with at least one of the domains of quality of life. Stronger illness identity and higher perceived consequences on patients' lives demonstrated significant negative associations with multiple domains of quality of life. A weaker illness identity, fewer perceived consequences, more belief in treatment control, a more predictable and stable condition and fewer negative emotional representations were demonstrated in the study to contribute to a higher quality of life for patients. Low illness coherence was also significantly related to higher quality of life. This has also been demonstrated in studies of patients with cardiac disease, where congruence of low illness coherence between patients and carers predicted higher palliative coping. However, contradictory evidence also exists (Sterba et al., 2008) demonstrating congruent high illness coherence for patients with rheumatoid arthritis is predictive of psychological adaptation to the condition.

4.5.3 What relationships exist between patients' illness appraisals and carers' quality of life and burden?

Table 10. Relationships between patients' illness appraisals and carers' quality of life and burden: Spearman's Rho.

	Illness Identity	**Consequences**	**Treatment Control**	**Illness Coherence**	**Emotional Representation**
Role Limitations – Physical Health	-.294*		.272*		-.267*
Role Limitations – Emotional Health				-.305*	
Vitality					-.381**
Bodily Pain					-.307*
General Health	-.254*				-.264*
Burden		.363**	-.417**	.262*	.289*

Note: * $p < 0.05$ (two tailed) ** $p < 0.005$ (two tailed)

Correlational analyses revealed that all illness appraisal subscales showed significant association with at least one domain of carer quality of life. However, emotional representation showed multiple associations with role limitations (physical health), vitality, bodily pain, general health and burden. Consequences, illness coherence and emotional representation demonstrated positive associations with burden and treatment control showed a negative association with burden.

Higher quality of life of carers was associated with patient appraisals of a weaker illness identity, more belief in treatment efficacy, lower illness coherence and fewer negative emotional representations. Furthermore low perceived burden by carers was associated with fewer perceived consequences, more belief in treatment efficacy, lower illness coherence and fewer perceived negative emotional representations of patients. Not only has lower illness coherence of patients been shown to relate to a higher quality of life for patients but results also suggest that lower illness coherence is also significantly related to higher quality of life and lower burden for carers.

4.5.4 What relationships exist between carers' illness appraisals and carers' quality of life and burden?

Table 11. Relationships between carers' illness appraisals and carers' quality of life and burden: Spearman's Rho.

	Illness Identity	Consequences	Treatment Control	Timeline Cyclical	Emotional Representations
Physical Functioning					-.290*
Role Limitations – Physical Health					-.287*
Role Limitations – Emotional Health		-.294*			-.436**
Vitality		-.325**	.270*	-.280*	-.432**
Mental Health		-.268*			-.514**
Social Functioning					-.406**
Bodily Pain		-.320*			-.450**
General Health		-.388**			-.439**
Burden	.393*	.474**		.344**	.400**

Note: * $p < 0.05$ (two tailed) ** $p < 0.005$ (two tailed)

Correlational analyses revealed that higher perceived consequences and higher negative emotional representations of the carer were negatively associated with multiple domains of quality of life, with emotional representation demonstrating negative association with all domains of quality of life. Higher negative consequences were negatively associated with role limitations (emotional health), vitality and mental health; treatment control was positively associated with vitality whereas timeline cyclical was negatively associated with vitality. All illness appraisal sub-scales, with the exception of treatment control, demonstrated positive association with burden.

Carers endorsing appraisals including fewer perceived negative consequences, more belief in treatment efficacy, and perceptions of a more predictable and stable condition and fewer negative emotional representations reported a higher quality of life. Low

burden was also reported for those carers demonstrating a weaker illness identity, fewer negative consequences, a more predictable and stable condition and fewer negative emotional representations.

4.5.5 What relationships exist between carers' illness appraisals and patients' quality of life?

Table 12. Relationships between carers' illness appraisals and patients' quality of life: Spearman's Rho.

	Illness Identity	**Consequences**	**Personal Control**	**Treatment Control**	**Illness Coherence**	**Timeline Cyclical**
Mobility			-.271*	-.417**		.318*
Activities of Daily Living		.309*	-.269*	-.422**		
Emotional Well-being	.328*					.368**
Stigma	.470**					.401**
Cognitive Impairment	.261*					
Communication	.363**	.305*			.377**	.319*
Bodily Discomfort	.410**	.335*				.430**

Note: * $p < 0.05$ (two tailed) ** $p < 0.005$ (two tailed)

Correlational analyses revealed the majority of illness appraisals demonstrated significant relationships with at least one domain of quality of life. Illness identity and timeline cyclical were the appraisals positively associated with multiple domains of quality of life.

Carers' appraisals of a weaker illness identity, fewer negative consequences, more personal control, and more belief in treatment efficacy, low illness coherence and more beliefs in a predictable and stable condition were significantly related to a higher quality of life of patients.

However a strong illness identity, more perceived negative consequences and beliefs in the illness being unpredictable were significantly associated with a lower quality of life across multiple domains.

Regression Analyses

Multiple hierarchical regression analyses were conducted to determine the contribution of patients' and carers' illness appraisals to quality of life and caregiver burden. Regression analyses were conducted for those outcome variables that had demonstrated correlation with patient or carer illness appraisals at the bivariate level. The required assumptions for regression analyses were met for all variables. The standardised residuals were all normally distributed by visual inspection of normal P-P plots and variables did not demonstrate homoscedasticity. No multi-collinearity between variables was identified through inspection of the variance inflation factor (VIF) statistic.

In the regression analyses block 1 consisted of control variables (stage of disease and motor ability), block 2 consisted of patients' illness appraisals and block 3 consisted of carers' illness appraisals.

4.5.6 Are illness appraisals of patients and carers predictive of patient quality of life?

Table 13. Regression analysis for patients' and carers' illness appraisals on patient quality of life

Steps and Variables	**Adj. R^2**	**R^2Change**	**F Change**
PDQ-39: Mobility			
1.Control variables[a]	.50	.086	2.40
2.Illness appraisals (patient): consequences, treatment control, emotional representation	.29	.27	6.82**
3.Illness appraisals (carer): personal control, treatment control, timeline cyclical	.41	.14	4.12*
PDQ-39: Activities of Daily Living			
1.Control variables[a]	.09	.13	3.70*
2.Illness appraisals (patient): identity, consequences, treatment control, illness coherence	.25	.21	3.82**
3.Illness appraisals (carer): consequences, personal control, treatment control	.47	.22	7.54***
PDQ-39: Emotional Well-being			
1.Control variables[a]	-.04	.01	.12
2.Illness appraisals (patient): identity, consequences, timeline cyclical, emotional representation	.50	.55	14.32***
3.Illness appraisal (carer): identity, timeline cyclical	.52	.04	1.89
PDQ-39: Stigma			
1.Control variables[a]	-.04	.00	.01
2.Illness appraisals (patient): emotional representation	.12	.17	9.92**
3.Illness appraisals (carer): identity, timeline cyclical	.25	.15	5.00*
PDQ-39: Social Support			
1.Control variables[a]	.10	.13	3.83*
2.Illness appraisals (patient): identity, consequences	.19	.12	4.02*
PDQ-39: Cognitive Impairment			
1.Control variables[a]	.01	.05	1.37
2.Illness appraisals (patient): identity, consequences, treatment control	.08	.12	2.26
3.Illness appraisals (carer): identity	.08	.02	1.09

PDQ-30: Communication			
1.Control variables[a]	.12	.15	4.64*
2.Illness appraisals (patient): identity, consequences	.16	.07	2.25
3.Illness appraisals (carer): identity, consequences, illness coherence, timeline cyclical	.17	.07	1.16
PDQ-39: Bodily Discomfort			
1.Control variables[a]	.13	.16	4.92*
2.Illness appraisals (patient): identity, consequences, timeline cyclical	.48	.37	12.63***
3.Illness appraisals (carer): identity, consequences, timeline cyclical	.51	.05	1.77

[a]Stage of Parkinson's disease and Motor ability scores *P < .05; **P < .01; ***P < .001

After controlling for control variables of stage of PD and motor ability scores, patients' own illness appraisals explained additional variance for all subscales of patient quality of life, with the exception of cognitive impairment and communication. A strong belief in treatment efficacy added to the prediction of higher mobility (β -.35, P < .01), low illness coherence and strong identity added to the prediction of higher activities of daily living (β .27, P < .05; β .37, P < .01) and fewer perceived negative consequences added to the prediction of increased satisfaction with social support (β .34, P < .05). Emotional representation demonstrated the highest unique contributions to emotional well-being and stigma (β .62, P < .001; β .43, P < .01).

After controlling for patients' illness appraisals, carers' appraisals explained additional amounts of variance to patient scores on the mobility (14%), activities of daily living (22%) and stigma (15%). A stronger carer belief in treatment control added to the prediction of higher mobility (β -.28, P < .05) and activities of daily living (β -.41, P < .01).

4.5.7 Are illness appraisals of patients and carers predictive of carer quality of life and burden?

Table 14. Regression analysis for patients' and carers' illness appraisals on carer quality of life

Steps and Variables	**Adj. R^2**	**R^2Change**	**F Change**
SF-36: Physical Functioning			
1.Control variables[a]	-.037	.001	.026
2.Illness appraisals (carer): emotional representation	.025	.08	4.36*
SF-36: Role Limitations (physical)			
1.Control variables[a]	-.04	.003	.09
2.Illness appraisals (carer): emotional representation	.07	.12	6.99*
3.Illness appraisals (patient): identity, treatment control, emotional representation	.21	.17	3.98*
SF-36: Role Limitations (emotional)			
1.Control variables[a]	.01	.05	1.25
2.Illness appraisals (carer): consequences, emotional representation	.25	.26	9.37***
3.Illness appraisals (patient): illness coherence	.31	.07	5.02*
SF-36: Vitality			
1.Control variables[a]	-.002	.04	.94
2.Illness appraisals (carer): consequences, treatment control, timeline cyclical, emotional representation	.25	.30	5.44**
3.Illness appraisals (patient): emotional representation	.35	.10	7.99**
SF-36: Mental Health			
1.Control variables[a]	-.03	.01	.18
2.Illness appraisals (carer): consequences, emotional representation	.22	.27	9.59***
SF-36: Social Functioning			
1.Control variables[a]	-.01	.03	.71
2.Illness appraisals (carer): emotional representation	.17	.19	11.95**
SF-36: Bodily Pain			
1.Control variables[a]	.03	.06	1.71

2.Illness appraisals (carer): consequences, emotional representation	.21	.20	6.87**
3.Illness appraisals (patient): emotional representation	.23	.04	2.51
SF-36: General Health			
1.Control variables[a]	.00	.04	1.01
2.Illness appraisals (carer): consequences, emotional representation	.21	.23	7.70**
3.Illness appraisals (patient): identity, emotional representation	.25	.07	2.38
Burden			
1.Control variables[a]	.10	.14	4.14*
2.Illness appraisals (carer): identity, consequences, timeline cyclical, emotional representation	.30	.24	4.65**
3.Illness appraisals (patient): consequences, treatment control, illness coherence, emotional representation	.54	.25	7.23***

[a]Stage of Parkinson's disease and Motor ability scores *P < .05; **P < .01; ***P < .001

After controlling for control variables of stage of PD and motor ability scores, carers' own illness appraisals explained additional variance for all subscales of carer quality of life. Fewer perceived emotional representations by carers contributed to all dimensions of quality of life and burden with emotional representations contributing the most to mental health (β -.47, P < .001). More belief in treatment efficacy also contributed to higher carer vitality (β -.26, P < .05).

After controlling for carers' illness appraisals, patients' appraisals explained an additional amount of variance to carer scores on the role limitations - physical (17%) and role limitations – emotional (7%), vitality (10%) and burden (25%). A weaker illness identity of patients contributed to the prediction of fewer role limitations due to difficulties with physical health (β -.28, P <.05) and lower illness coherence contributed to fewer role limitations due to difficulties with emotional health (β - .26, P < .05). Fewer patient negative emotional representations contributed to higher carer vitality (β - .34, P < .01) and more beliefs in treatment efficacy contributed to less burden perceived by carers (β - .43, P < .001).

5.0 Discussion

This study examined the role of patients' and carers' illness appraisals for outcomes of quality of life and caregiver burden. Despite previous research examining the impact of illness appraisals for both patients and carers in other chronic health conditions (Kaptein et al., 2007); those living with Parkinson's disease have not been similarly explored. Emerging research within the Parkinson's disease field (Evans & Norman, 2009) has highlighted the importance of illness appraisals for understanding patient outcome, supporting the utility of Leventhal's Common Sense Model, and going beyond merely biomedical explanations for health outcomes. Research focus to date has predominantly considered the impact of the disease from the patient's perspective, thus it is timely to consider carers' appraisals and their impact.

A cross-sectional self-report questionnaire study was utilised recruiting patients and carers from one NHS teaching hospital in the East Midlands. A total of 121 participants were recruited with 59 patients with Parkinson's disease and 62 carers. The findings will be discussed with reference to the research questions developed from the aims posed in the introduction. Clinical implications will be discussed with consideration of methodological strengths and weaknesses and implications and suggestions for future research for Parkinson's disease.

Psychological morbidity

Anxiety and depression levels of both patients and carers were assessed to determine levels of psychological morbidity in the sample, in relation to community norms (Crawford, Henry, Crombie & Taylor, 2001). Community norms refer to the mean scores of depression and anxiety within the general population. For depression 58% of patients and 47% of carers scored above community norms and for anxiety 42% of patients and 35% of carers scored higher than community norms. Proportion of patients reporting depression caseness, (36%), was similar to other studies assessing psychological morbidity in Parkinson's disease patients (dos Anjos et al., 2009).

These results highlight the presence of co-morbid depression and anxiety for this sample of patients with Parkinson's disease and have also demonstrated the existence of depression for those caring for a relative with the condition in relation to community norms. Awareness of these psychological difficulties that exist for patients and carers by health professionals is a prerequisite for any morbidity to be addressed and managed appropriately within services.

5.1 Research question 1

What is the extent of congruence between patients' and carers' illness appraisals?

The results indicate that patients and their carers differed significantly regarding appraisals of *identity*, *personal control* and *illness coherence* and patients felt greater personal control, perceived a poorer understanding than demonstrated by carers and attributed fewer symptoms to the condition.

The latter has been evidenced in other chronic health conditions (Kaptein et al., 2007) and patients have demonstrated a greater understanding and less personal control than their partners in previous research (Karademas, Zarogiannos & Nikolaoset, 2010). That carers reported a better understanding of the condition than patients but felt less control over the disease, suggests carers appear to be more knowledgeable but simultaneously feel more powerless. It is important to consider if enhanced knowledge yet powerlessness may result in learned helplessness amongst carers. This may result in a higher propensity for reduced confidence and low mood, known to significantly impact on the standard of caregiving (Zauszniewski, Bekhet & Suresky, 2009). Assessing for positive strategies to empower carers may be advisable.

It is important to establish if these differences between patient and carer and these specific illness appraisals are beneficial to our understanding of the factors that contribute to decreased quality of life and burden for carers. This increased awareness will allow clinicians to tailor assessment and intervention to foster beliefs found to be associated with an increased quality of life.

Despite divergent beliefs argued to affect patient outcome adversely (Heijmans, deRidder & Bensing, 1999), there is more equivocal evidence of weak relationships found between extent of dissimilarity of illness appraisals and patients' reported self-rated health and coping (Karademas, Zarogiannos & Nikolaoset, 2010). Thus research focusing solely on dissonant beliefs may be of limited value (Kaptein et al., 2007), and appears evidenced in the correlation and regression analyses that follow. An exclusive

focus on consonance or dissonance of beliefs disregards the importance of particular appraisal patterns of patients and carers that may be key determinants of outcome.

5.2 Research question 2

What relationships exist between patients' illness appraisals and patients' quality of life?

Positive relationships between patient *identity*, *consequences*, *illness coherence*, *timeline cyclical* and *emotional representation* and patient quality of life were identified. Findings for identity and consequences are consistent with a similar study with patients with Huntington's disease and their partners (Kaptein et al., 2007), but the current study also included timeline cyclical and emotional representations; appraisals unexamined previously.

Findings suggest the attribution of fewer symptoms to the condition, fewer perceptions of negative consequences, less understanding, more belief in the predictability of the condition and fewer negative emotional representations are associated with a higher quality of life. A negative relationship between *treatment control* and patient quality was identified, suggesting more belief in treatment efficacy is associated with a higher quality of life of patients, consistent with previous research (Alsén, Brink, Persson, Brändström & Karlsen, 2010). A stronger belief in treatment has been shown to be constructive for adherence to medication (Bucks et al., 2009) and attendance at rehabilitation programmes (French, Cooper & Weinman, 2006) and suggests

interventions to address and enhance efficacy beliefs might more routinely be focused on interactions with health professionals.

Personal control and *timeline* were not found to relate to patient quality of life, consonant with work conducted by Kaptein et al. (2007). This lack of relationship between personal control and quality of life may be underpinned by patients' adopting a more external locus of control. From dialogue with patients in clinic, for those who did evidence a certain level of personal and internal locus of control over their Parkinson's disease, reference was made predominantly to their control with regard to treatment and medication adherence, supported by their strong belief in treatment efficacy and external sources supporting the management of the condition. The absence of relationship between timeline and patient quality of life is echoed in previous studies (Moss-Morris, Petrie & Weinman, 1996; Robertson, 2003) but may also be attributed to patients' strong beliefs in treatment efficacy. Despite patients' perceiving a lengthy disease duration, quality of life may not be compromised, as evidenced in previous studies (Searle, Norman, Thompson & Vedhara, 2007), if treatment is believed to be successful in management and stabilisation of the condition, reducing its interference in daily living.

5.3 Research question 3

What relationships exist between patients' illness appraisals and carers' quality of life and burden?

Positive relationships between *treatment control* and carer quality of life were identified, suggesting more belief in treatment efficacy by patients is associated with higher quality of life of carers, which may be suggestive that patient optimism may play a part in carer outcome. Negative relationships existed between *identity*, *illness coherence* and *emotional representation*. This suggests that the attribution of fewer symptoms to Parkinson's disease, less understanding of the condition and perceptions of fewer negative emotional representations by patients are associated with a poorer quality of life for carers.

Caregiver burden was associated with *consequences*, *treatment control*, *illness coherence* and *emotional representation*. Perceptions of patients expressing fewer negative consequences due to the condition, more belief in treatment efficacy, less understanding of the condition and fewer negative emotional representations demonstrated a relationship with increased quality of life of carers. These appraisals are all entirely psychologically consistent with the exception of a lack of disease understanding contributing to a higher quality of life. Despite this, patient appraisals are demonstrated herein to be key cognitive factors in explaining quality of life and perceived burden amongst carers.

Emotional representation was revealed as a patient appraisal that demonstrated significant associations with multiple domains of carer quality of life and perceived burden. Measurement of the domain incorporates questions tapping affect (feelings of depression, anxiety and worry) as a result of attempting to cope with a chronic condition such as Parkinson's disease. Previous research has revealed relationships between emotional representation and psychological morbidity (Evans & Norman, 2009; Lancastle, Brain & Phelps, 2011). In the latter study, extensive multi-collinearity was found between emotional representation and measures of anxiety and depression, suggesting that emotional representation may be a proxy for psychological morbidity.

Psychological co-morbidity is a common adjunct to chronic illness (Maurer et al., 2008, Pearlstein, 2002) and is well documented in Parkinson's disease (Lees, Hardy & Revesz, 2009). It may be speculated that greater psychological morbidity amongst patients, may increase their need for support and care, thus reducing carer quality of life and increasing sense of burden. Psychological morbidity in patients has demonstrated associations with increased physical disability for patients with chronic obstructive pulmonary disease (Maurer et al., 2008), poorer self-management of diabetes (Wu et al., 2011) and poorer daily function for patients with Parkinson's disease (Tan, 2012). If emotional representation acts as a proxy for psychological morbidity and appears to reinforce links with poorer quality of life it emphasises a need to assess emotional reactions rather than assume they are normal to adjustment and have no longer term implications for carer functioning.

5.4 Research question 4

What relationships exist between carers' illness appraisals and carers' quality of life and burden?

Positive relationships between *treatment control* and carer quality of life and negative relationships between *consequences*, *timeline cyclical* and *emotional representation* and carer quality of life were identified, similar to previous correlations. Carers who perceived fewer negative consequences from Parkinson's disease, had more belief in treatment efficacy, believed Parkinson's disease to be predictable and stable and perceived fewer negative emotional representations reported a higher quality of life.

Positive relationships were evident between *identity*, *consequences*, *timeline cyclical* and *emotional representation* and carer burden. Lower burden was associated with carers who attributed fewer symptoms to Parkinson's disease, perceived fewer negative consequences, believed the condition to be predictable and stable and perceived fewer negative emotional representations.

These findings are consistent with other studies of carers of patients with schizophrenia (Barrowclough, Lobban, Hatton & Quinn, 2001) and eating disorders (Whitney, Haigh, Weinman & Treasure, 2007), where greater perceived consequences for the carer were related to adverse carer outcomes, including higher levels of depression and subjective burden. Given the significant findings evidenced here through developing Barrowclough, Lobban, Hatton & Quinn's (2001) focus on carers' appraisals with regards to the relationships with their own lives, this extends previous studies

(Heijmans, deRidder & Bensing, 1999) whereby carers were primarily included to assess their perceptions of patient appraisals. The findings emphasise a need to assess carers' perceptions of the impact of Parkinson's disease on their own lives and not assume it is only the patients' lives that are adversely affected.

5.5 Research question 5

What relationships exist between carers' illness appraisals and patients' quality of life?

Positive relationships between *identity*, *consequences*, *illness coherence* and *timeline cyclical* and patient quality of life were evident. Negative relationships between *personal control* and *treatment control* and patient quality of life were also evident. Carers' appraisals, including the attribution of fewer symptoms to Parkinson's disease, fewer negative perceived consequences, more belief in treatment efficacy, less understanding of the condition and more belief in the predictability of the condition were associated with a better quality of life of patients.

No relationship between *emotional representation* of carers and patient quality of life was identified, which is an interesting finding and was a dimension unexamined in other studies of illness appraisals (Kaptein et al., 2007). With the notion of emotional representation acting as a proxy for psychological morbidity, it would be anticipated that this dimension would show an association with quality of life. Previous research highlights substantial psychological morbidity amongst carers of patients with Parkinson's disease frequently presenting with lowered mood and stress (Kristjanson,

Anoun & Oldham, 2005) and increased anxiety (Gilbar & Harel, 2000), which can impact on standard of care-giving and ultimately patient quality of life (Zauszniewski, Bekhet & Suresky, 2009). However, as noted with regard to caseness of the carer sample, depression and anxiety did not generally exceed community norms (Crawford, Henry, Crombie & Taylor, 2001).

Alternatively, the minority of carers who were exhibiting psychological morbidity may not wish to openly show or discuss this with their relative to prevent causing the patient from further upset and wish to act in a protective manner. Carers often report adopting a new role as a 'carer' as opposed to their previous role as a husband or wife, and may believe it is their duty to provide support to the patient rather than be the recipient, and ultimately rely less on their relative for emotional support (Eriksson & Svedlund, 2006). Carers may either deny their emotionality due to not wishing to express it towards the patient or may express emotionality towards other family members in order to gain support without burdening the patient. Less reliance upon patients by carers has been documented in studies of male spouses of patients with breast cancer, who reported family support to be most predictive of reduced psychological distress, as opposed to support of their partner (Hasson-Ohayon, Goldzweig, Braun & Galinsky, 2010), which is in contrast to the source of support prior to diagnosis.

An interesting finding, and one that has consistently arisen throughout the analyses, is that of a lower illness coherence of carers demonstrating an association with higher quality of life of patients. More specifically, the higher quality of life reported was related to the communication domain of the Parkinson's Disease Questionnaire -39,

with improved communication of the patient in terms of their speech and with more satisfaction of feeling connected to their carer and not overlooked. Carers' less developed understanding of Parkinson's disease may reflect living with a partner whose health and abilities are as yet not too compromised. Carers may find it easier to ignore the illness and its implications when at this stage of the condition and choose not to pursue information or simply ignore full information to cope.

5.6 Research question 6

Are illness appraisals of patients and carers predictive of patient quality of life?

Multiple regression analyses showed that illness appraisals of patients and carers each explained significant proportions of variance for the quality of life of patients. Patient appraisals added significantly to the model after controlling for stage of Parkinson's disease and motor ability, and carer appraisals added significantly beyond the impact of these control variables and patient appraisals.

Patient illness appraisals showing significant and unique contributions to the model included *identity, treatment control, illness coherence* and *consequences* and *emotional representation*. More specifically, it is more beneficial to patient quality of life for patients to attribute fewer symptoms to their condition, have a stronger belief in treatment efficacy, less understanding of the condition, and perceive fewer negative consequences and fewer negative emotional representations. Carer illness appraisals showing significant and unique contributions to the model included *treatment control*,

with a stronger belief in treatment efficacy contributing to a higher quality of life of patients.

Interesting findings relate to illness coherence and treatment control dimensions. Less understanding of the condition by patients was shown to be predictive of higher quality of life of patients, in contrast to previous research demonstrating a better understanding of the condition improves patient well-being (Karademas, Zarogiannos & Nikolaoset, 2010). The sample predominantly comprised patients in the middle stages of Parkinson's disease (stage 2.5) in which arguably an objectively higher standard of life could still be maintained, with the patient sample not predominantly exceeding community norms for anxiety and depression. It may be speculated that patients are reluctant to obtain information about the implications of Parkinson's disease at this stage, when fewer negative effects are being experienced, and are using denial as a defence mechanism. Denial has been shown in studies of lung cancer patients to be a normal phenomenon following diagnosis of a major health condition (Vos, Putter, van Houwelingen & de Haes, 2008). As patients progress to the more severe stages of the disease, they may become more aware of the effects of the condition, consequently increasing their understanding. Denial may only begin to become a maladaptive coping style once the severity of the disease has progressed and requires the patient to be aware of the implications of the disease (Klein, Turvey & Pies, 2007).

Stronger beliefs in treatment efficacy of patients and carers contributed to a higher quality of life of patients, as has been consistent with other studies of illness appraisals (Alsén, Brink, Persson, Brändström & Karlsen, 2010). The findings from the current

study suggest patients' well-being may be supported through patients and carers maintaining optimism about slow progression of Parkinson's disease with beliefs in a lack of deterioration or stabilisation and use of relativism, with regards to comparisons to those less well off than the self and through utilising the notion of thankfulness (Hodgson, Garcia & Tyndall, 2004).

Optimism has been shown in the Parkinson's disease literature to be predictive of a higher quality of life of patients (Gruber-Baldini, Ye, Anderson & Shulman, 2009). Despite numerous implications to a disease such as this, many couples remain positive and are thankful that the condition is not terminal or at more severe stages (Hodgson, Garcia & Tyndall, 2004). Furthermore, research has shown that by examining past and current life-events with a thankfulness, people may become less fearful of death due to a sense that life has been well-lived (Lau & Cheng, 2011). Positive framing of the condition by both patients and carers may be extremely influential in enhancing patient outcome.

5.7 Research Question 7

Are illness appraisals of patients and carers predictive of carer quality of life?

Multiple regression analyses showed that illness appraisals of patients and carers each explained significant proportions of variance for the quality of life and burden of carers. Carer appraisals added significantly to the model, after controlling for stage of Parkinson's disease and motor ability, and patient appraisals added significantly beyond the impact of these control variables and carer appraisals.

Carer illness appraisals showing significant and unique contributions to the model included *treatment control* and *emotional representation*. A higher belief in treatment efficacy contributed to higher quality of life of carers. Fewer negative emotional representations was also found to contribute to a higher quality of life for all dimensions and significantly contributed to reduced burden.

Patient illness appraisals that demonstrated significant and unique contributions to the model included *identity, illness coherence, emotional representation* and *treatment* control. The attribution of fewer symptoms to the condition, less understanding and perception of fewer negative emotional representations by carers contributed to a higher quality of life of carers. Furthermore, stronger beliefs in treatment efficacy of patients were found to contribute to reduced burden in carers.

In the previous study by Kaptein et al. (2007) only *personal control* of patients was found to contribute to a higher quality of life of carers. This was not replicated in the current study, which may reflect patients demonstrating more beliefs in external sources of control, specifically the success of treatment. More belief in treatment efficacy of patients and carers was shown to be a key predictor for carer quality of life and burden. The importance of strong beliefs in treatment has further supported the notion that optimism and hope may play a key role for well-being. It may also be a facet of the sample source and an artefact of a consultant selecting better functioning respondents who engage with treatment and thus have investment in its success

Emotional representation was shown to predict higher quality of life across all domains and less burden. A higher emotional representation of chronic conditions has shown positive relationships with anxiety and depression levels (Sampaio, Pereira & Winck, 2012) supporting the notion of emotional representation as a proxy for psychological morbidity. Increased psychological morbidity in carers of patients with brain tumours has been shown to be detrimental to quality of life (Janda et al., 2007), suggesting that our emotional representations of a condition are important facets to consider for well-being.

The relationship between illness coherence and quality of life revealed less understanding of the condition by patients associated with carers reporting fewer limitations to daily roles and activities as a consequence of any personal emotional difficulties. This may imply that disease has not progressed sufficiently to be overly intrusive and that patients have had no great need to immerse themselves in understanding it. As disease progression occurs patients may simultaneously increase their understanding of the disease as implications may become more obvious and intrusive

5.8 Clinical implications

This study has provided valuable insight into the important role of illness appraisals for quality of life of patients with Parkinson's disease and their carers. As evidenced in previous studies examining patient appraisals for chronic illness, diverse beliefs about the condition relate to outcome of both patient and carer, beyond physical status of the patient. Best practice in managing those with PD, and their carers, should be more

routinely alert to how the disease and its consequences are understood to optimise outcomes.

5.8.1 Dyadic focus for assessment and follow up appointments

Illness appraisals of patient and carer have not only been shown to be important for their own quality of lives but also for each other's. It is integral to clinical practice to begin to consider both patient and carer constructions of Parkinson's disease within assessments as opposed to solely patients themselves, as well-being is a function of a relationship and not solely patient appraisals. Consultations with patients should be more inclusive of carer perspectives; however difficulties need to be acknowledged for professionals when aiming to be both patient and carer centred, whilst simultaneously respecting confidentiality and working within limited clinic appointment times.

Routine outpatient assessments and follow-up appointments may seek to assess for appraisals predictive of a poorer quality life of patients and carers, and high burden for carers, with a view to identifying those at most risk. Clinical Psychologists could be involved in training of professionals to increase knowledge of the beliefs indicative of poorer quality of life and to aid with detection and management. Clinical psychologists have key skills in intervention and the use of cognitive behavioural therapy has been recommended to modify and address unhelpful appraisals (Weinman & Petrie, 1997), with interventions being affected for a couple. Furthermore, with greater attribution of symptoms related to decreased quality of life, psycho-education work may be warranted to ensure Parkinson's disease is not being perceived to impact on other unrelated

symptoms, thereby increasing quality of life. Perceptions of treatment control and consequences could also be addressed with cognitive techniques with interventions also warranted for work regarding acceptance. It is important to acknowledge which findings may be most suitable to inform these possible interventions. Appraisals relating to incurability of the disease and long duration may have ethical implications for their modification and professionals must consider if it is ethical for them to be altered.

5.8.2 Screening for psychological morbidity

Negative emotional representations of both patients and carers have been shown to be key appraisals relating to quality of life, particularly for carers. With relationships between emotional representations of chronic health conditions and psychological morbidity, this study suggests that emotional representation may be acting as a proxy for morbidity and psychological distress. Higher levels of worry, anxiety and depression in patients and carers have been shown to relate to poorer quality of life of carers and higher perceived burden, with patients' own emotional representations also impacting negatively on their own quality of lives. Psychological morbidity in carers and higher perceived burden has been linked with poorer standards of caregiving, limiting the length of time care can be provided (Zauszniewski, Bekhet & Suresky, 2009). This emphasises the need for increased vigilance amongst health professionals and argues for the development of routine psychological screening.

Guidance incorporating psychological screening and intervention for psychological morbidity is sparse for Parkinson's disease (NICE, 2006), with an exclusively pharmacological emphasis on intervention, if psychological morbidity is evident. Reference to carers is minimal, focuses nebulously on the need to involve carers in the care process and decision making, with no reference to their own psychological status (NICE, 2006). Reference to an evidence base demonstrating carer needs seems warranted. Routine outpatient appointments would be an appropriate time to screen for psychological morbidity of patients and carers and would allow this to be monitored over time. They could serve to prevent psychological deterioration, dependency and reduce burden amongst carers, supporting care, maintaining family relationships and enabling independence for as long as is feasible. A challenge for professionals incorporating this screening would be ensuring provision of services and referral pathways to treat those displaying high levels of psychological morbidity.

5.8.3 Delivery of information regarding Parkinson's disease

Low illness coherence was shown throughout the analyses to be associated with higher quality of life for patients and carers. Increased knowledge of Parkinson's disease may have significant negative impacts on both parties. How then should information giving be most effectively timed and expanded upon with patients and their carers to mitigate any adverse impacts? If remaining hopeful and optimistic can enhance wellbeing (Gruber-Baldini, Ye, Anderson & Shulman, 2009) how can information giving harness these coping styles? Tailoring is clearly necessary (McLaughlin et al., 2010) and could be more effectively delivered with greater insight to appraisals revealed here. Sensitivity to patient beliefs should therefore more routinely feature in all health

professional care to ensure a truly client-centred consultation respecting desire for knowledge (Stajduhar, Thorne, McGuiness & Kim-Sing, 2010). Furthermore, it is essential to ensure appropriate support structures are in place and referral pathways to other services to support patients and carers with managing this new information and minimising its impact. Increasing professional's knowledge of support groups for patients and carers would be key and other relevant professionals for referral for support and counselling, if individuals are struggling to manage following provision of information.

5.9 Strengths and Limitations

5.9.1 Strengths

The present study is the first of its kind in Parkinson's disease investigating both patients' and carers' illness appraisals and the associations with quality of life and burden. To date, examination of specific illness appraisals is limited. This study increases knowledge of illness appraisals permitting unhelpful beliefs to be identified and addressed by professionals within consultations to enhance care and outcomes. The study also provides greater knowledge of the impact of carer appraisals; an area previously neglected, and determines these illness appraisals from the perspective of the carer, increasing the focus on the impact on carers' lives. With carers being a significant figure in the lives of patients and with demonstrated influence on patients' lives, unhelpful beliefs of carers can also be targeted, with an aim for a dyadic focus to care.

Despite studies for other chronic conditions (Kaptein et al., 2007) adopting a similar methodological focus, the current study went beyond a focus solely on quality of life of patients and carers but also included the notion of caregiver burden; a concept not routinely focussed upon in illness appraisal literature. High perceived burden by carers has been shown to impact negatively on standards of care-giving and longevity of care (Zauszniewski, Bekhet & Suresky, 2009). Through obtaining knowledge of the appraisals significant for high perceived burden for carers, these can be identified and addressed, reducing burden. This will ensure carers are able to continue in their caring role for the substantial timeframe required for Parkinson's disease and within the home environment; a concern voiced by numerous carers (McLaughlin et al., 2010).

The sample size of the study was predicted on medium effect, however the study showed some evidence of medium and large effect sizes when conducting statistical correlational analyses. This may enhance the power of the study to that previously considered, however a larger sample could still be warranted.

The demography of participants reflected those with PD and the study was able to recruit patients with PD of varying duration and severity; however inclusion of patients with severe PD was limited, with only one patient classified as stage 5 of the Hoehn and Yahr Scale. Participants from different ethnic backgrounds were also recruited, but this was also limited due to the requirement of participants to speak and understand written English.

5.9.2 Limitations

A limitation to the study was that of the underlying epistemology. An empirical positivist position was adopted to investigate illness appraisals, quality of life and burden, using quantitative methodology. This approach reduced quality of life to specific constructs precluding exploration of specific experiences that were patient and carer defined. Future qualitative work within Parkinson's disease would certainly be warranted with a focus on appraisals to gain more in depth knowledge of beliefs, allowing quantitative findings to be contextualised.

Access to participants was limited to one site as opposed to multiple sites, limiting the diversity of the sample. Sample size was limited due to patients and carers both being required to attend for the outpatient appointment to participate and if the patient attended alone they were thus ineligible given the need for a dyad. Time taken to complete measures was increased due to patients and carers requiring a great deal of assistance with reading and writing in order to complete the questionnaires. This further reduced the number of participants who could be seen from each clinic.

The illness perception questionnaire used in the study is designed for use with patients with single conditions; however it is often the case that patients demonstrate multi-morbidity. There is a need for further research with illness appraisals for patients demonstrating multi-morbidity, which also identifies a need to extend the illness perception model to accommodate this (Bower et al., 2012).

The study deliberately excluded those patients with dementia or cognitive impairment, however these co-morbid difficulties are present for a substantial number of patients and future research investigating the effect of illness appraisals on those with Parkinson's disease and co-morbid dementia could be warranted. It could be argued that this group of patients may be more demanding for carers, given the burdens of cognitive decline highlighted in other pathologies (Stella et al., 2009). Furthermore, some patients with additional physical health conditions were also excluded and carers' own physical health status was not assessed. This did not allow investigation of the possible impact of co-morbidities in both patients and carers and is an area for future research. Qualitative research would be an approach most appropriate to capture both patients' and carers' complex experiences.

5.10 Future research

A cross-sectional design permitted illness appraisals and their relationship with outcomes to be accessed from only one point in time precluding causal inference. Longitudinal research would allow the exploration of the impact of illness appraisals over time and their meditational effect over biomedical variables, particularly necessary with a chronic condition, such as Parkinson's disease, as a dynamic and evolving process. Furthermore, extending the methodology beyond correlational and regression analyses to include cluster analyses would also add value. Cluster analyses have been utilised in other chronic conditions (Clatworthy, Hankins, Buick, Weinman & Horne, 2007; Hobro, Weinman & Hankins, 2003) to begin to determine particular groupings or "clusters" of appraisals that may be associated with poorer well-being and go beyond solely identifying independent appraisals.

The current study has highlighted the potential role of hope and optimism in disease management and quality of life for both patients and carers, specifically with regards to positive beliefs for treatment efficacy. Studies have predominantly focussed on a deficit model of patients' and carers' experiences within Parkinson's disease and further research exploring resilience factors that help to protect against the experience of psychological distress would be valuable to the field, as has been demonstrated in other chronic health conditions (Mednick et al., 2007).

The absence of detail regarding psychological assessment and interventions within policy for Parkinson's disease (NICE, 2006), suggests a need to enhance awareness and to suggest what might be translated from psychological interventions in other chronic diseases. With evidence to support psychological assessment and intervention, updates of policies may begin to include psychological dimensions and may begin to be included in standard practice.

6.0 Conclusions

Whilst acknowledging the methodological limitations of the study, it has developed the research base of illness appraisals in a highly neglected field, whilst simultaneously enhancing research with the inclusion of carers. It is the first study to investigate the role of illness appraisals for both patient and carer for quality of life and burden in Parkinson's disease and has demonstrated their importance and the utility of Leventhal's Common Sense Model in predicting health outcome. Hopefully this research will act as a stimulus for further examination of psychological processes underpinning quality of life in Parkinson's disease and provide evidence for these psychological processes to be considered during outpatient care.

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Section 3

Critical Appraisal

Critical Appraisal

Throughout the research process a reflective diary was maintained to record the research journey, noting reflections at different stages of the research process from development of the research idea, through data collection to analysis and dissemination.

Origins of the project

Not long before commencing clinical training, a close family member was diagnosed with Parkinson's disease offering some insight into the difficulties, not least uncertainty, shock and struggle with acceptance, that may be experienced by families prior to and following a diagnosis. Observing these processes within the family provoked an interest in Parkinson's disease and the way in which patients and families come to terms with such a life altering chronic condition. Discussions within the family revealed that a biomedical focus was prominent within hospital appointments with minimal consideration of the psychological impact of the diagnosis. Due to my existing knowledge of certain health conditions, through completing an undergraduate psychology degree and corresponding clinical modules, information regarding the condition had already been obtained. However, information was minimal for other family members with limited information on cause, disease trajectory and prognosis.

Given this family experience I felt I might like to explore how PD was experienced but I had no strong preconceptions of how I might study this. Various research ideas had been generated including examining psychosocial predictors of quality of life for patients and impact of tremor on patient self-image. However I was particularly drawn to impacts beyond the self, given the effects on my family members as well as the

individual diagnosed and labelled. Through discussions with my supervisor I became aware of a literature examining patient and carer appraisals of chronic conditions. Further literature searches, revealed minimal research existed focussing on the impact of beliefs held for patients with Parkinson's disease and that no research to date had investigated how the beliefs of partners or other family members may have an impact on management of the condition. At this point the decision was made to investigate the role of illness appraisals for patients with Parkinson's disease and their partners on quality of life and burden. Burden was also included at this stage, as evidence suggested that partners play a key role in care-giving, but limited research had investigated how burdensome this role may become.

Literature Review

The review produced as part of the doctoral thesis has been an evolving piece of work requiring systematic searches of the Parkinson's disease literature and a need to develop my skills in synthesising research. I have learned the importance of clear search strategies to maintain a concise focus on relevant research papers. It was often difficult to strike the correct balance between conducting a specific search whilst simultaneously maintaining breadth, to not overlook potentially relevant articles. As minimal research was elucidated incorporating family members, a broader topic for review was chosen investigating spousal experiences of caring for a relative with Parkinson's disease using qualitative methodology. I have developed competencies in appraising qualitative literature and have developed knowledge of various appraisal tools. The synthesis of themes was a particular challenge, due to this being a novel area and I found the initial development of themes particularly challenging, however I have developed a sound understanding of the processes of thematic synthesis.

Development of the research idea

Reading of studies examining appraisal across other diseases suggested how to conduct the study. Initially the aim was to conduct a multi-centre study across three different outpatient clinics within the East Midlands, given generalisability would be reduced through use of a single site, due to decreasing diversity of the population recruited. However co-ordination and differential organisation of other potential sites, their geographical spread, and my need to be present to facilitate data collection, precluded their use.

At the chosen site the recruitment of participants was discussed at length to determine if the required sample size would be achievable within the sampling frame available within a DClin Psy. It was agreed with the relevant professionals that this would be attainable with this site alone and there would be the opportunity to recruit from two outpatient clinics on this single site. My early work to establish links and scope feasibility enabled me to gather an adequate sample, however further exploration of clinic operation and staffing levels would have enabled more comprehensive assessment of what could be achieved. I was reliant on a team in which I did not work and this liaison added to time involved in planning, and a recognition that I was asking for significant commitment from NHS staff who could be less invested as a researcher, given they had not generated the ideas.

Meetings with professionals from outpatient clinics were paramount to the project and valuable information was gained to modify the design and ensure a valuable and achievable study. I decided to broaden the study beyond partners to carers, which may

include a range of family members, a decision aided by discussion with the consultant physician familiar with his patients and circumstances. Due to being predominantly an older adult population many partners were managing their own health condition and could not attend clinic or had deceased. In both cases, the provision of care was carried out by other family members, namely siblings or children.

The conduct of NHS research requires flexibility and good communication skills when working in environments where you are dependent on other peoples' schedules. It was of paramount importance to ensure stakeholder commitment and enthusiasm in order to begin the project and to maintain it. Good time management, planning and organisational skills were key to ensure the study was kept to task, when often working within time constraints.

Ethics submission

Following modification to the original research protocol, submission was made to the local ethics committee and the first available meeting was May 2011. Permission from the relevant research and development department was also sought and additional training attended including consent training and Good Clinical Practice training. This provided me with valuable insight into the various policies and legislation to ensure conduction of ethical research within the National Health Service and ensured my consent procedures were appropriate for the study.

The research process was, at times, time consuming and frustrating. Consideration of ethical issues including capacity to consent and confidentiality are paramount for patient safety and quality of research; however the systems do appear tailored towards

medical trials rather than smaller psychological empirical studies. A key issue identified through the ethical process was managing the detection of dementia or cognitive impairment in patients during the completion of measures. Consideration of this with the committee deemed it necessary to incorporate a statement into the patient consent form to state that if cognitive difficulties were identified, the relevant professional, would be informed following. It was important for the professional in charge of the patient's care to be informed and they would be the most appropriate person to discuss with the patient and monitor, due to regular appointments with the patients. It is important to allow more time to consider more deeply the ethical issues that may arise during a study, in order to identify ways to manage these most effectively.

Data Collection

I feel myself and my supervisor worked hard to achieve a sound working relationship with our medical colleagues and to gain credibility with them. This facilitated frank and involved discussion about how to approach potential respondents which eased access and recruitment. It was agreed that I would collect the data myself on the day of the clinic and the Consultant would be involved with ensuring participants met the inclusion criteria, prior to sending out initial information letters, and also at their routine outpatient appointment.

As data collection began it was clear that completing questionnaires and consent forms with participants was taking substantially longer than originally envisaged, reducing the number of participants being seen in a clinic, and ultimately circumscribing the sample size given the constraints of time to submission. The majority of patients were

very slow at processing the information in the questionnaires and required great support from myself with reading and writing, due to problems with vision and tremors. It was originally thought that the majority of carers would be able to complete questionnaires independently, however many also required great support with reading and writing, increasing the time taken for data collection. The number of patients able to be seen within a clinic was also substantially reduced due to the need for them to come with a carer. Despite this being stated within the information sheet sent out to them prior to the clinic, many arrived to the appointment alone.

Statistical analysis

My statistical knowledge, from undergraduate training required refreshment! I had to re-acquaint myself with the parameters of SPSS and, since using much smaller data sets previously, became aware of the numerous stages required before results are obtained. I dramatically underestimated the time taken to enter all the data onto a spread sheet and to conduct procedures to clean and screen data. Furthermore, extensive reading was undertaken in order to recode and total up scores for all variables, all of which was required before analysis could be undertaken. It made me reflect on the real resource difficulties of conducting research as a clinician and that research appears far easier when working in systems fully focused on research. I hope that my familiarity with statistics and their limitations has been enhanced by the analyses I have conducted.

Writing up

An attempt to begin write up early was made, however time taken for me to complete sections was underestimated and adequate time needed to be allowed for drafts of sections to be read through by my research supervisor. Feelings of doubt certainly

emerged during this stage, but with determination and moments of progress emerging the write up continued and I have learnt that research can be an incremental grind, which requires patience and reflection. Writing a piece of work such as this, and being fortunate to have valuable feedback from my supervisor, I have been able to improve my writing style and feel more confident about writing research pieces in the future.

Dissemination of findings

I am committed to disseminating the findings of the study to participants, the outpatient clinics from which recruitment was undertaken and to all relevant professionals through presentations, journal submission and conferences. Summary sheets of results will be provided to the outpatient clinics for all patients and their carers who volunteered for the study. Following submission, I will be preparing my literature review for publication the Disability and Rehabilitation journal and also aim to submit my research piece for publication. I hope to add to the evidence base the importance of psychological factors, namely illness appraisals, for the management of a chronic condition and to encourage services, through dissemination of the findings, to think more widely than the patient alone and adopt a more dyadic focus to care.

Conclusions and Learning Outcomes

Through conducting this research project I have been able to hone and develop my research skills. I have been able to:

- Increase my knowledge of the Parkinson's disease literature specifically relating to the experience of caring for a spouse and the role of illness appraisals in the management of the condition. It has been interesting and rewarding to be able to gain a deeper understanding in one particular area.

- Increase my critical appraisal skills and feel able to use these confidently in future literature reviews I may undertake. The qualitative literature reviewed has also increased my interest in the use of qualitative methodology and the breadth and depth of information on individuals' experiences this can elicit.
- Increase my knowledge of epistemological positions and methodological strengths and weaknesses of both methodologies that the two positions would adopt. Through this current study my scepticism has increased regarding the sole use of quantitative methodology and how this can reduce experiences down to specific constructs.
- Achieve greater confidence in myself as a researcher. I have deepened my knowledge of the research process, specifically with regards to ethical submission and analysis, and have been able to demonstrate complex skills of project management and liaison in a rapidly moving acute trust to deliver a creditable sample size. I have reflected that I prefer conducting research in a team and found my role as a lone researcher in a new setting somewhat isolating. I have however enjoyed sharing ideas and debating and I would enjoy future research projects involving teamwork and the opportunity to share ideas with others.
- Increase my awareness of the ethical issues surrounding the dissemination of research. After the help and support from participants and health professionals it is important to disseminate findings to those involved and to present the results to wider populations.
- Increase my awareness of the research process as a whole from research design, selection of measures, data collection, and analysis through to dissemination. Furthermore, it has highlighted the challenges that can arise during the process

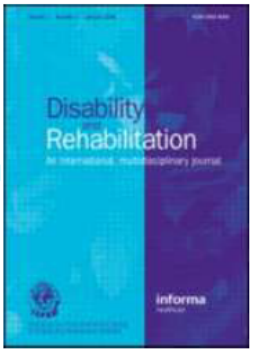
and the importance of organisational and planning skills tailored with effective team working and communication.

Finally the production of this thesis has been a rewarding learning experience and the enthusiasm of participants to take part in the study has been immensely gratifying and I would be eager to conduct research in the future.

Appendices

Appendix A - Disability and Rehabilitation Journal (Author Guidelines)

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 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***'s ScholarOne Manuscripts site: 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. 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).

Please contact the Editor if you require more information.

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.

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.

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 ***Disability and Rehabilitation*** and Informa UK Ltd., if the paper is accepted.

NEW FEATURE

IMPLICATIONS FOR REHABILITATION

A new feature of the Journal will be 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. **All papers including reviews, research, rehabilitation in practice, perspectives on rehabilitation, case studies and a new section education and training for rehabilitation professionals must include this additional feature**. This should be submitted separately through Manuscript Central as a 'Supplemental File' on a single side of A4 at the time of submission.

Included below are examples. If you have any questions, please contact the Editor.

Example 1: Leprosy
• Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
• Reconstructive surgery is a technique available to this group.
• In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis
• Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
• People with MS have complex reasons for choosing to exercise or not.
• Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

Example 3: Community Based Rehabilitation
• Community Based Rehabilitation (CBR) is a Western concept that may not readily fit other cultures.
• CBR needs to be 'owned' by those involved and subject to re-interpretation to be effective in other cultures.

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 (e.g. 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. Please do not hesitate to contact our Production Department if you have any queries.

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 no 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.

Click here to view our full Declaration of Interest Policy.

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:

Journal article: [1] Steiner U, Klein J, Eiser E, Budkowski A, Fetters LJ. Complete wetting from polymer mixtures. Science 1992;258:1122-9.

Book chapter: [2] Kuret JA, Murad F. Adenohypophyseal hormones and related substances. In: Gilman AG, Rall TW, Nies AS, Taylor P, editors. The pharmacological basis of therapeutics. 8th ed. New York: Pergamon; 1990. p 1334-60.

Conference proceedings: [3] Irvin AD, Cunningham MP, Young AS, editors. Advances in the control of Theileriosis. International Conference held at the International Laboratory for Research on Animal Diseases; 1981 Feb 9-13; Nairobi. Boston: Martinus Nijhoff Publishers; 1981. 427 p.

Dissertations or Thesis: [4] Mangie ED. A comparative study of the perceptions of illness in New Kingdom Egypt and Mesopotamia of the early first millennium [dissertation]. Akron (OH): University of Akron; 1991. 160 p. Available from: University Microfilms, Ann Arbor MI; AAG9203425.

Journal article on internet: [5] De Guise E, Leblanc J, Dagher J, Lamoureux J, Jishi A, Maleki M, Marcoux J, Feyz M. 2009. Early outcome in patients with traumatic brain injury, pre-injury alcohol abuse and intoxication at time of injury. Brain Injury 23(11):853-865. http://www.informaworld.com/10.1080/02699050903283221. Accessed 2009 Oct 06

Webpage: [6] British Medical Journal [Internet]. Stanford, CA: Stanford Univ; 2004 July 10 - [cited 2004 Aug 12]; Available from: http://bmj.bmjjournals.com

Internet databases: [7] Prevention News Update Database [Internet]. Rockville (MD): Centers for Disease Control and Prevention (US), National Prevention Information Network. 1988 Jun - [cited 2001 Apr 12]. Available from: http://www.cdcnpin.org/

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

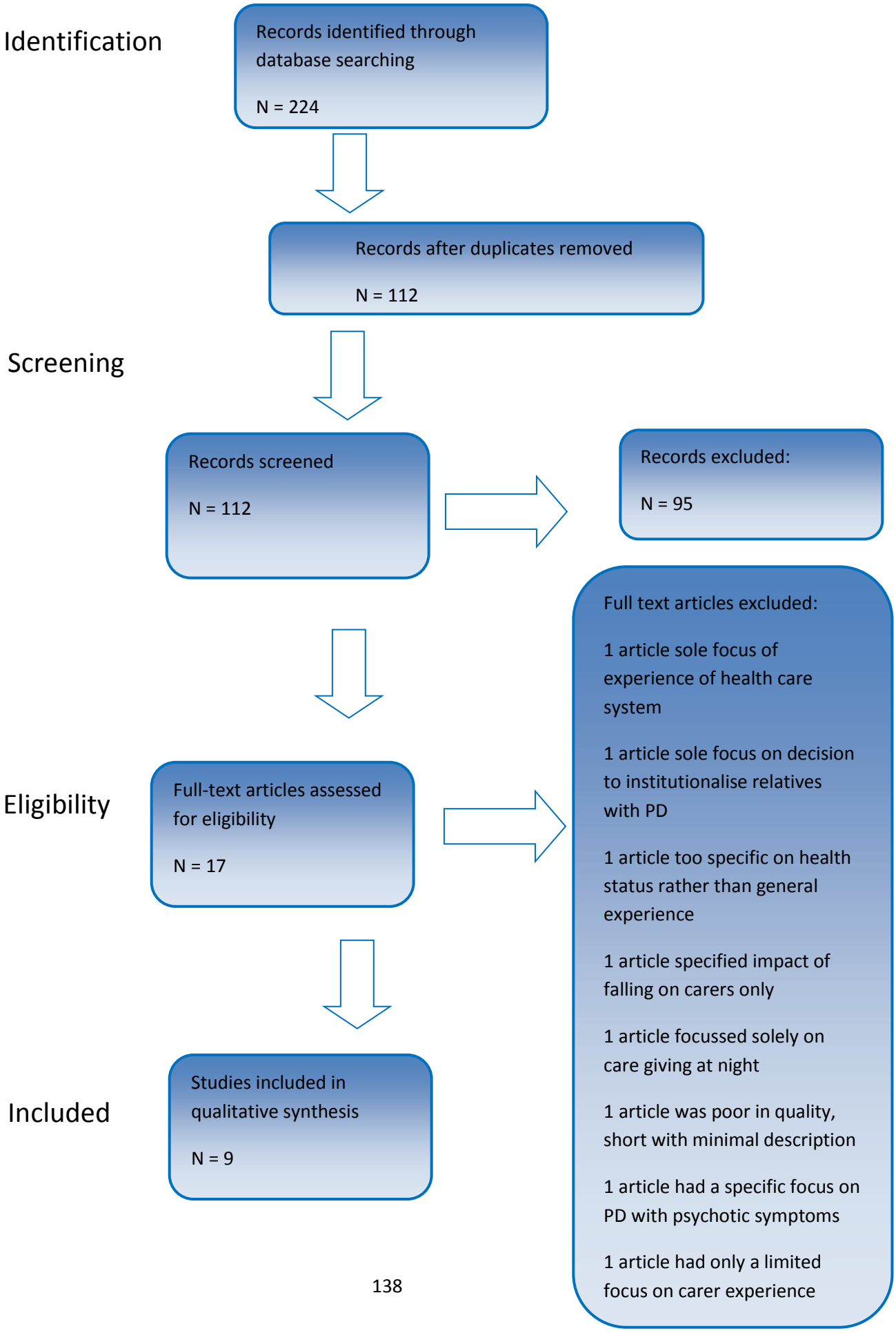
I. If the Editor does not accept the appeal and is not prepared to secure further review the decision will be referred to the Editor of the relevant affiliated Journal for independent consideration. In the case of *Disability and Rehabilitation*, the Editor of *Disability and Rehabilitation: Assistive 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*

Appendix B - Flowchart for article selection

Flowchart for article selection process



Appendix C - Study characteristics

Study characteristics

Title	First author and date	Aims of study	Setting	Sample	Method of data collection	Method of data analysis
Being in the light or in the shade: person's with Parkinson's disease and their partner's experience of support	Birgersson (2004)	To describe persons with Parkinson's disease and their partner's experience of support received	Southern Sweden	6 couples – patients with PD and their partners	Open ended interviews using a semi-structured guide	Qualitative content analysis
The nature and scope of stressful spousal care-giving relationships	Davis (2011)	To provide a contextual understanding of the link between care relationship quality and caregivers' depressive affect and burden	Alabama and North Carolina	22 spouses	Semi-structured interviews	Thematic analysis
Spousal perspective of Parkinson's disease in middle life	Habermann (2000)	To explore the challenges faced by middle aged spouses and the coping strategies used by these spouses	Western United States	8 spouses (five wives and three husbands)	Semi-structured interview	Interpretive phenomenological analysis
An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease	Hasson (2010)	To explore former carers' lived experiences of palliative and end-of-life care	Northern Ireland	15 former caregivers	Qualitative semi-structured interviews using a semi-structured topic list	Content analysis
Parkinson's Disease and the Couple Relationship: A Qualitative Analysis	Hodgson (2004)	To explore the impact of PD on the couple relationship.	South eastern United States	10 couples	Phenomenological interviews	Colaizzi's (1978) phenomenological data analysis method
Living and coping with Parkinson's disease: Perceptions of informal carers	McLaughlin (2010)	To explore the experience of informal carers of people with PD	Northern Ireland	26 informal family caregivers (9 male and 17 female)	Semi-structured interviews	Content analysis

Living with Parkinson's – Managing identity together	Roger (2010)	-To analyze how partners perceive their roles in communication. -To examine the meanings partners assign to communication experiences. -To identify how experiences of communication changed over time.	Canada	3 spousal couples and 1 female/male sibling pair	Semi-structured interviews	Grounded theory
'A stony road… a 19 year journey': 'Bridging' through late-stage Parkinson's disease	Williams (2008)	To attempt to understand the transitions experienced by patients and their families as they encounter greater disability	North Wales	13 people with late-stage PD and their close family supporters, usually a spouse	2 year longitudinal study Repeated interviews conducted between 2007-2008	Grounded theory
Living with Parkinson's disease: Elderly patients' and relatives' perspective on daily living	Wressle (2007)	To examine how Parkinson's disease affects daily living from the perspective of both patients and relatives	Sweden	Nine carers (Four women and five men)	Qualitative interviews	Strauss and Corbin (1990) Grounded theory

Appendix D - Data extraction form

Data Extraction Form

Study Title:
Date:
Author:

Eligibility

Question		If YES	If NO
1	Is the study about Parkinson's Disease?	Continue	Exclude
2	Does the study include informal carers of individuals with Parkinson's Disease?	Continue	Exclude
3	Does the study discuss the experience of caring for someone with Parkinson's Disease?	Continue	Exclude

Study Characteristics

Study details	Location	
	Research question	
	Theoretical Framework	
Participants	Population	
	Age (range, mean)	
	Gender	
	Ethnicity	
	Recruitment/sampling method	

Data collection	Method (interviews, focus groups)	
	Who collected the data?	
	How were the data prepared for analysis? (e.g. interviews transcribed)	
Analysis	Method (thematic analysis, interpretative phenomenological analysis, grounded theory)	
Validity	What validation methods were used?	
Reflexivity	Did the study report engaging in reflexivity?	

Findings	How are results presented?	
Category 1 (including title, description as given, verbatim extracts of data and/or author's analytic commentary of the data	Title:	

Category 2	Title:	
Category 3	Title:	

Author's conclusions	Conclusion (author's concluding remarks, key findings)	
	Limitations identified by authors	
	Implications identified by authors	
	Key references (not identified by search strategy)	
Comments	Anything of note about his study not covered already	

Appendix E - Critical Appraisal Skills Programme Checklist

Critical Appraisal Skills Programme

Screening Questions

1. Was there a clear statement of the aims of the research? ❑ Yes ❑ No

Consider:

– what the goal of the research was

– why it is important

– its relevance

2. Is a qualitative methodology appropriate? ❑ Yes ❑ No

Consider:

– if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants

Is it worth continuing?

Detailed questions

Appropriate research design

3. Was the research design appropriate to address the aims of the research? Write comments here

Consider:

– if the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)

Sampling

4. Was the recruitment strategy appropriate to the aims of the research? Write comments here

Consider:

– if the researcher has explained how the participants were selected

– if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study

– if there are any discussions around recruitment (e.g. why some people chose not to take part)

Data collection

5. Were the data collected in a way that addressed the research issue?

Write comments here

Consider:

- *if the setting for data collection was justified*
- *if it is clear how data were collected (e.g. focus group, semi-structured interview etc)*
- *if the researcher has justified the methods chosen*
- *if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they used a topic guide?)*
- *if methods were modified during the study. If so, has the researcher explained how and why?*
- *if the form of data is clear (e.g. tape recordings, video material, notes etc)*
- *if the researcher has discussed saturation of data*

Reflexivity (research partnership relations/recognition of researcher bias)

6. Has the relationship between researcher and participants been adequately considered?

Write comments here

Consider whether it is clear:

- *if the researcher critically examined their own role, potential bias and influence during:*
  - *formulation of research questions*
  - *data collection, including sample recruitment and choice of location*
- *how the researcher responded to events during the study and whether they considered the implications of any changes in the research design*

Ethical Issues

7. Have ethical issues been taken into consideration?

Write comments here

Consider:

- *if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained*
- *if the researcher has discussed issues raised by the study (e. g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)*
- *if approval has been sought from the ethics committee*

Data Analysis

8. Was the data analysis sufficiently rigorous? Write comments here

Consider:

- *if there is an in-depth description of the analysis process*
- *if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?*
- *whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process*
- *if sufficient data are presented to support the findings*
- *to what extent contradictory data are taken into account*
- *whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*

Findings

9. Is there a clear statement of findings? Write comments here

Consider:

- *if the findings are explicit*
- *if there is adequate discussion of the evidence both for and against the researcher's arguments*
- *if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)*
- *if the findings are discussed in relation to the original research questions*

Value of the research

10. How valuable is the research? Write comments here

Consider:

- *if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)*
- *if they identify new areas where research is necessary*
- *if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*

Appendix F – Research Ethics Committee approval letter

NHS
Health Research Authority

NRES Committee East Midlands - Leicester
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839368
Facsimile: 0115 8839294

27 June 2011

Miss Sarah Simms
Trainee Clinical Psychologist
Leicestershire Partnership NHS Trust
c/o Clinical Psychology
104 Regent Road
Leicester
LE1 7LT

Dear Miss Simms

Study title:	**Quality of life and caregiver burden in Parkinson's Disease: the role of patients' and carers' illness appraisals.**
REC reference:	**11/EM/0133**

Thank you for your letter of 21 June 2011, 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.

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:

Document	*Version*	*Date*
Covering Letter		28 March 2011
Investigator CV		
Other: CV - Academic Supervisor		28 March 2011
Other: Internal Peer Review Form		25 November 2010
Participant Consent Form: Carer	2	28 March 2011
Participant Consent Form: Patient	2	28 March 2011
Participant Information Sheet: Carer	2	28 March 2011
Participant Information Sheet: Patient	2	28 March 2011
Protocol	4	28 March 2011
Questionnaire: Unified Parkinsons Disease Rating Scale (UPDRS)		
Questionnaire: SF-36		
Questionnaire: PDQ - 39		
Questionnaire: Hoehn & Yahr staging		
Questionnaire: Hospital Anxiety and Depression Scale (HADS)		
Questionnaire: Illness Perception - Patient	1	28 March 2011
Questionnaire: Illness Perception - Carer	1	28 March 2011
Questionnaire: The Zarit Burden Interview		
REC application	69282/203043/1/546	01 April 2011
Response to Request for Further Information		21 June 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

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.

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
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.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/EM/0133	**Please quote this number on all correspondence**

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

Yours sincerely

pp.

Dr Carl Edwards
Chair

Email: jessica.parfrement@nottspct.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Dr David Clarke*
Carolyn Maloney, University Hospitals Leicester NHS Trust

Appendix G – Research and Development approval letter

University Hospitals of Leicester NHS
NHS Trust

DIRECTORATE OF RESEARCH & DEVELOPMENT

Director: **Professor D Rowbotham**

Assistant Director: **Dr David Hetmanski**

R&D Manager: **Carolyn Maloney**

Direct Dial: (0116) 258 8351
Fax No: (0116) 258 4226

Research & Development Office
Leicester General Hospital
Gwendolen Road
Leicester
LE5 4PW

27/07/2011

Miss Sarah Simms
c/o Clinical Psychology
104 Regent Road
Leicester
Leicester
LE1 7LT

Dear Miss Sarah Simms

Ref: UHL 11053
Title: Quality of life and caregiver burden in Parkinson's Disease: the role of patients' and carers' illness appraisals.
Project Status: Project Approved
End Date: 27/04/2012

I am pleased to confirm that with effect from the date of this letter, the above study now has Trust Research & Development permission to commence at University Hospitals of Leicester NHS Trust.

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

Document Name	Version Number	Date
REC Approval Letter	11/EM/0133	27/06/11
Internal Peer Review Form		25/11/10
Participant Consent Form: Carer	V2	28/03/11
Participant Consent Form: Patient	V2	28/03/11
Participant Information Sheet: Carer	V2	28/03/11
Participant Information Sheet: Patient	V2	28/03/11
Protocol	V4	28/03/11
Questionnaire: Unified Parkinsons Disease Rating Scale (UPDRS)		
Questionnaire: SF – 36		
Questionnaire: PDQ – 39		
Questionnaire: Hoehn & Yahr Staging		
Questionnaire: Hospital Anxiety and Depression Scale (HADS)		

Version 5, 20.04.10

Questionnaire: Illness Perception – Patient	V1	28/03/11
Questionnaire: Illness Perception – Carer	V1	28/03/11
Questionnaire: The Zarit Burden interview		
REC application	69282/203043/1/546	01/04/11
Response to request for further information		21/06/11

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.

We are aware that undertaking research in the NHS comes with a range of regulatory responsibilities. Attached to this letter is a reminder of your responsibilities during the course of the research. Please ensure that you and the research team are familiar with and understand the roles and responsibilities both collectively and individually.

You are required to submit an annual progress report to the R&D Office and to the Research Ethics Committee. We will remind you when this is due.

The R&D Office is keen to support research, researchers and to facilitate approval. If you have any questions regarding this or other research you wish to undertake in the Trust, please contact this office.

We wish you every success with your research.

Yours sincerely

Carolyn Maloney
R&D Manager

Encs: .Researcher Information Sheet

Please note that some of the documents may not apply to your study.

Appendix H - Participant information sheet (patient)

TO BE PRINTED ON LETTER HEADED PAPER

Participant Information Sheet – Patient

1. Study Title

'The role of illness appraisals on outcomes in Parkinson's Disease'

2. Invitation to participate

I would like to invite you to take part in this research study. The following information will explain why the research is being done and will help you to decide whether you would like to take part. If you have any queries after reading this document you will be able to discuss them with the Consultant Physician or the researcher when attending the clinic for your next outpatient appointment.

3. What is the purpose of the study?

There are many factors that can impact on the lives of people with Parkinson's disease and their carers. Some of these may be physical factors and others may be psychological factors. Therefore it is important to understand how all these factors may influence people's lives in order to provide the support they may need. This study focuses on the psychological factors and more specifically how people with Parkinson's disease and their carers view the condition and how this may impact on quality of life.

4. Why have you been invited to take part in the study?

All patients with a diagnosis of Parkinson's disease and their carers, who attend the clinic for their outpatient appointment, will be invited to take part in the study.

5. Inclusion/Exclusion criteria

All patients with a diagnosis of Parkinson's disease, who are over 18, will be able to take part in the study. However, patients experiencing additional, physical or cognitive difficulties that may also impact on their quality of life may not be able to be involved in the study.

6. Do you have to take part in the study?

It is up to you to decide whether or not to join the study. In order to take part both you and your carer will need to agree to be involved. When attending for your next appointment, I will meet with you and your carer to describe the study in more detail and go through this information sheet. If you did agree to be involved you are free to withdraw at any time, without giving a reason. If you decide to withdraw from the study or decide not to take part at all this will not affect the standard of care you receive.

7. What will happen if I agree to take part?

If you and your carer agree to take part I will then meet with you both separately in order for you to each sign a consent form and complete a set of different questionnaires, taking between half an hour and an hour. This will be the only time you and your carer will need to meet with the researcher. The questionnaires will then be kept in a secure location by the researcher and will remain confidential. There will also be the opportunity for you and your carer to meet together with the researcher following this if you would like to discuss any issues that may have arisen whilst completing the questionnaires.

8. Are there any risks in taking part?

No significant risks have been identified in this study. If, however, you become distressed whilst completing the questionnaires, the researcher will be prepared to take action and ensure you get the support you need.

9. What are the potential benefits of taking part?

I cannot promise that involvement in the study will directly help you but the information that would be gained will help to determine the type of support that will be beneficial for people with Parkinson's disease.

10. Confidentiality and Anonymity

All questionnaires will remain anonymous and will not be shared with anyone else. However, if the researcher was concerned about the safety of you, or anyone else that is mentioned, the researcher has a professional duty to break confidentiality and pass this information on to the Consultant Physician.

11. How will the findings of the study be used?

The results will be presented to the clinic team. The study will also be submitted for publication to selected journals in Autumn 2012. You will not be identifiable throughout any of these processes. A copy of the final report will be available from the researcher in Autumn 2012 if you request it.

12. Who is funding the research?

The research is being funded by the University of Leicester and is sponsored by the relevant NHS Trust.

13. Who has reviewed the study?

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.

14. Complaints

If you have a concern about any aspect of the study, you are able to contact the Patient Information and Liaison Service:

Patient Information and Liaison Service
Patient Advice and Liaison Services
Hospital Address
Telephone number

They will do their best to deal with any complaints or questions you may have.

15. Further information

If you require any more information now or in the future you may contact the researcher, Sarah Simms (Email: ses28@le.ac.uk).

THANK YOU FOR TAKING THE TIME TO CONSIDER PARTICIPATING.

Appendix I - Participant information sheet (carer)

TO BE PRINTED ON LETTER HEADED PAPER

Participant Information Sheet – Carer

1. **Study Title**

'The role of illness appraisals on outcomes in Parkinson's Disease'

2. **Invitation to participate**

I would like to invite you to take part in this research study. The following information will explain why the research is being done and will help you to decide whether you would like to take part. If you have any queries after reading this document you will be able to discuss them with the Consultant Physician or the researcher at the Parkinson's disease outpatient clinic at future appointments you may attend with the person you care for.

3. **What is the purpose of the study?**

There are many factors that can impact on the lives of people with Parkinson's disease and their carers. Some of these may be physical factors and others may be psychological factors. Therefore it is important to understand how all these factors may influence people's lives in order to provide the support they may need. This study focuses on the psychological factors and more specifically how people with Parkinson's disease and their carers view the condition and how this may impact on quality of life.

4. **Why have you been invited to take part in the study?**

All patients with a diagnosis of Parkinson's disease and their carers, who attend the clinic for their outpatient appointment, will be invited to take part in the study.

5. **Inclusion/Exclusion criteria**

All carers of patients with a diagnosis of Parkinson's disease will be able to take part in the study. Formally paid carers, such as those from social services, will not be able to take part in the study.

6. **Do you have to take part in the study?**

It is up to you to decide whether or not to join the study. In order to take part both you and the person you care for will need to agree to be involved. When attending for the next appointment, I will meet with you both to describe the study in more detail and go through this information sheet. If you did agree to be involved you are free to withdraw at any time, without giving a reason. If you decide to withdraw from the study or decide not to take part at all this will not affect the standard of care you receive.

7. What will happen if I agree to take part?

If you and the person you care for agree to take part I will then meet with you both separately in order for you to each sign a consent form and complete a set of different questionnaires, taking between half an hour and an hour. This will be the only time you and the person you care for will need to meet with the researcher. The questionnaires will then be kept in a secure location by the researcher and will remain confidential. There will also be the opportunity for you both to meet together with the researcher following this if you would like to discuss any issues that may have arisen whilst completing the questionnaires.

8. Are there any risks in taking part?

No significant risks have been identified in this study. If, however, you become distressed whilst completing the questionnaires, the researcher will be prepared to take action and ensure you get the support you need.

9. What are the potential benefits of taking part?

I cannot promise that involvement in the study will directly help you but the information that would be gained will help to determine the type of support that will be beneficial for people with Parkinson's disease and their carers.

10. Confidentiality and Anonymity

All questionnaires will remain anonymous and will not be shared with anyone else. However, if the researcher was concerned about the safety of you, or anyone else that is mentioned, the researcher has a professional duty to break confidentiality and pass the information on to the Consultant Physician.

11. How will the findings of the study be used?

The results will be presented to the clinic team. The study will also be submitted for publication to selected journals in autumn 2012. You will not be identifiable throughout any of these processes. A copy of the final report will be available from the researcher in autumn 2012 if you request it.

12. Who is funding the research?

The research is being funded by the University of Leicester and is sponsored by the relevant NHS Trust.

13. Who has reviewed the study?

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 Leicester Research Ethics Committee.

14. Complaints

If you have a concern about any aspect of the study, you are able to contact the Patient Information and Liaison Service:

Patient Information and Liaison Service
Hospital Name
Hospital Address
Hospital Telephone Number

They will do their best to deal with any complaints or questions you may have.

15. Further information

If you require any more information now or in the future you may contact the researcher, Sarah Simms (Email: ses28@le.ac.uk).

THANK YOU FOR TAKING THE TIME TO CONSIDER PARTICIPATING.

Appendix J - Consent form (patient)

CONSENT FORM - Patient

Title of Project: The role of illness appraisals on outcomes in Parkinson's disease

Name of Researcher: Sarah Simms, Trainee Clinical Psychologist, University of Leicester

Please initial box

1. I confirm that I have read and understood the information sheet dated 28th March 2011 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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

3. I understand that I will be required to complete various questionnaires that will only be seen by the researcher. ☐

4. I understand that my identity will remain anonymous throughout the study. ☐

5. 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. ☐

6. 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. ☐

7. I understand that the data collected will be kept securely at the University of Leicester and destroyed after seven years. ☐

8. I understand that the data collected will be included as part of a Doctoral thesis and that results will be published in academic journals and fed back to outpatient clinics. ☐

9. I agree to take part in the above study.

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix K - Consent form (carer)

CONSENT FORM - Carer

Title of Project: The role of illness appraisals on outcomes in Parkinson's disease

Name of Researcher: Sarah Simms, Trainee Clinical Psychologist, University of Leicester

Please initial box

1.I confirm that I have read and understood the information sheet dated 28th March 2011 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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

3. I understand that I will be required to complete various questionnaires that will only be seen by the researcher. ☐

4. I understand that my identity will remain anonymous throughout the study. ☐

5. 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. ☐

6. I understand that the data collected will be kept securely at the University of Leicester and destroyed after seven years. ☐

7. I understand that the data collected will be included as part of a Doctoral thesis, and that results will be published in academic journals and fed back to outpatient clinics. ☐

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

_____	_____	_____
Name of Carer	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix L - Demographic form

Demographic Information

Age

Sex

Relationship Status

Employment Status

Duration of Parkinson's disease (Patients only)

Appendix M – Stage of Parkinson's disease

Hoehn & Yahr staging

The simplest and most popular scale to establish the severity of PD is the Hoehn & Yahr Stage scale (source: Hoehn & Yahr, 1967) while this scale is useful for rough classification of the disease, it lacks sensitivity to changes in the patient's functional condition (source: Jankovic, 2003). The disease process is divided into the following stages: (source: Hoehn & Yahr, 1967; Jankovic, 2003)

- Stage 0: no signs 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 N – Motor ability

III. MOTOR EXAMINATION

18. Speech
0 = Normal.
1 = Slight loss of expression, diction and/or volume.
2 = Monotone, slurred but understandable; moderately impaired.
3 = Marked impairment, difficult to understand.
4 = Unintelligible.

19. Facial Expression
0 = Normal.
1 = Minimal hypomimia, could be normal "Poker Face".
2 = Slight but definitely abnormal diminution of facial expression.
3 = Moderate hypomimia; lips parted some of the time.
4 = Masked or fixed facies with severe or complete loss of facial expression; lips parted 1/4 inch or more.

20. Tremor at rest (head, upper and lower extremities)
0 = Absent.
1 = Slight and infrequently present.
2 = Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present.
3 = Moderate in amplitude and present most of the time.
4 = Marked in amplitude and present most of the time.

21. Action or Postural Tremor of hands
0 = Absent.
1 = Slight; present with action.
2 = Moderate in amplitude, present with action.
3 = Moderate in amplitude with posture holding as well as action.
4 = Marked in amplitude; interferes with feeding.

22. Rigidity (Judged on passive movement of major joints with patient relaxed in sitting position. Cogwheeling to be ignored.)
0 = Absent.
1 = Slight or detectable only when activated by mirror or other movements.
2 = Mild to moderate.
3 = Marked, but full range of motion easily achieved.
4 = Severe, range of motion achieved with difficulty.

23. Finger Taps (Patient taps thumb with index finger in rapid succession.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

24. Hand Movements (Patient opens and closes hands in rapid succesion.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

25. Rapid Alternating Movements of Hands (Pronation-supination movements of hands, vertically and horizontally, with as large an amplitude as possible, both hands simultaneously.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

26. Leg Agility (Patient taps heel on the ground in rapid succession picking up entire leg. Amplitude should be at least 3 inches.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

27. Arising from Chair
(Patient attempts to rise from a straightbacked chair, with arms folded across chest.)
0 = Normal.
1 = Slow; or may need more than one attempt.
2 = Pushes self up from arms of seat.
3 = Tends to fall back and may have to try more than one time, but can get up without help.
4 = Unable to arise without help.

28. Posture
0 = Normal erect.
1 = Not quite erect, slightly stooped posture; could be normal for older person.
2 = Moderately stooped posture, definitely abnormal; can be slightly leaning to one side.
3 = Severely stooped posture with kyphosis; can be moderately leaning to one side.
4 = Marked flexion with extreme abnormality of posture.

29. Gait
0 = Normal.
1 = Walks slowly, may shuffle with short steps, but no festination (hastening steps) or propulsion.
2 = Walks with difficulty, but requires little or no assistance; may have some festination, short steps, or propulsion.
3 = Severe disturbance of gait, requiring assistance.
4 = Cannot walk at all, even with assistance.

30. Postural Stability (Response to sudden, strong posterior displacement produced by pull on shoulders while patient erect with eyes open and feet slightly apart. Patient is prepared.)
0 = Normal.
1 = Retropulsion, but recovers unaided.
2 = Absence of postural response; would fall if not caught by examiner.
3 = Very unstable, tends to lose balance spontaneously.
4 = Unable to stand without assistance.

31. Body Bradykinesia and Hypokinesia (Combining slowness, hesitancy, decreased armswing, small amplitude, and poverty of movement in general.)
0 = None.
1 = Minimal slowness, giving movement a deliberate character; could be normal for some persons. Possibly reduced amplitude.
2 = Mild degree of slowness and poverty of movement which is definitely abnormal. Alternatively, some reduced amplitude.
3 = Moderate slowness, poverty or small amplitude of movement.
4 = Marked slowness, poverty or small amplitude of movement.

Appendix O - Illness Perception Questionnaire (patient)

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Patient

Name……. Date……

YOUR VIEWS ABOUT YOUR PARKINSON'S DISEASE

Listed below are a number of symptoms that you may or may not have experienced since your Parkinson's Disease. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your Parkinson's Disease, and whether you believe that these symptoms are related to the Parkinson's Disease.

	I have experienced this symptom since my Parkinson's Disease		**This symptom is related to my Parkinson's Disease**	
Pain	**Yes**	**No**	**Yes**	**No**
Sore Throat	**Yes**	**No**	**Yes**	**No**
Nausea	**Yes**	**No**	**Yes**	**No**
Breathlessness	**Yes**	**No**	**Yes**	**No**
Weight Loss	**Yes**	**No**	**Yes**	**No**
Fatigue	**Yes**	**No**	**Yes**	**No**
Stiff Joints	**Yes**	**No**	**Yes**	**No**
Sore Eyes	**Yes**	**No**	**Yes**	**No**
Wheeziness	**Yes**	**No**	**Yes**	**No**
Headaches	**Yes**	**No**	**Yes**	**No**
Upset Stomach	**Yes**	**No**	**Yes**	**No**
Sleep Difficulties	**Yes**	**No**	**Yes**	**No**
Dizziness	**Yes**	**No**	**Yes**	**No**
Loss of Strength	**Yes**	**No**	**Yes**	**No**

We are interested in your own personal views of how you now see your Parkinson's Disease.

	VIEWS ABOUT YOUR PARKINSON'S DISEASE	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
IP1	My illness will last a short time					
IP2	My illness is likely to be permanent rather than temporary					
IP3	My illness will last for a long time					
IP4	This illness will pass quickly					
IP5	I expect to have this illness for the rest of my life					
IP6	My illness is a serious condition					
IP7	My illness has major consequences on my life					
IP8	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					
IP10	My illness has serious financial consequences					
IP11	My illness causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my illness gets better or worse					
IP14	The course of my illness depends on me					
IP15	Nothing I do will affect my illness					
IP16	I have the power to influence my illness					
IP17	My actions will have no effect on the outcome of my illness					
IP18	My illness will improve in time					
IP19	There is very little that can be done to improve my illness					
IP20	My treatment will be effective in curing my illness					
IP21	The negative effects of my illness can be prevented (avoided) by my treatment					
IP22	My treatment can control my illness					
IP23	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My illness is a mystery to me					
IP26	I don't understand my illness					

IP27	My illness doesn't make any sense to me					
IP28	I have a clear picture or understanding of my illness					
IP29	The symptoms of my illness change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My illness is very unpredictable					
IP32	I go through cycles in which my illness gets better and worse					
IP33	I get depressed when I think about my illness					
IP34	When I think about my illness I get upset					
IP35	My illness makes me feel angry					
IP36	My illness does not worry me					
IP37	Having this illness makes me feel anxious					
IP38	My illness makes me feel afraid					

CAUSES OF MY PARKINSON'S DISEASE

We are interested in what you consider may have been the cause of your Parkinson's Disease. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your Parkinson's Disease rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your Parkinson's Disease. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
C1	Stress or worry					
C2	Hereditary – it runs in the family					
C3	A germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in the past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					
C12	My emotional state e.g feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused your Parkinson's Disease. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me are:-

1. _____
2. _____
3. _____

Appendix P - Illness Perception Questionnaire (carer)

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Carer

Name……. Date……

YOUR VIEWS ABOUT THE PERSON YOU CARE FOR AND PARKINSON'S DISEASE

Listed below are a number of symptoms that the person you care for may or may not have experienced since their Parkinson's Disease. Please indicate by circling *Yes* or *No*, whether the person you care for has experienced any of these symptoms since their Parkinson's Disease, and whether you believe that these symptoms are related to the Parkinson's Disease.

	The person I care for has experienced this to since their Parkinson's Disease		**This symptom is related Parkinson's Disease**	
Pain	**Yes**	**No**	**Yes**	**No**
Sore Throat	**Yes**	**No**	**Yes**	**No**
Nausea	**Yes**	**No**	**Yes**	**No**
Breathlessness	**Yes**	**No**	**Yes**	**No**
Weight Loss	**Yes**	**No**	**Yes**	**No**
Fatigue	**Yes**	**No**	**Yes**	**No**
Stiff Joints	**Yes**	**No**	**Yes**	**No**
Sore Eyes	**Yes**	**No**	**Yes**	**No**
Wheeziness	**Yes**	**No**	**Yes**	**No**
Headaches	**Yes**	**No**	**Yes**	**No**
Upset Stomach	**Yes**	**No**	**Yes**	**No**
Sleep Difficulties	**Yes**	**No**	**Yes**	**No**
Dizziness	**Yes**	**No**	**Yes**	**No**
Loss of Strength	**Yes**	**No**	**Yes**	**No**

We are interested in your own personal views of how you now see the person you care for's Parkinson's Disease.
Please indicate how much you agree or disagree with the following statements about their Parkinson's Disease by ticking the appropriate box.

	VIEWS ABOUT THEIR PARKINSON'S DISEASE	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
IP1	Their illness will last a short time					
IP2	Their illness is likely to be permanent rather than temporary					
IP3	Their illness will last for a long time					
IP4	Their illness will pass quickly					
IP5	I expect they will have their illness for the rest of their life					
IP6	Their illness is a serious condition					
IP7	Their illness has major consequences on my life					
IP8	Their illness does not have much effect on my life					
IP9	Their illness strongly affects the way others see me					
IP10	Their illness has serious financial consequences					
IP11	Their illness causes difficulties for those that are close to me					
IP12	There is a lot which I can do to control their symptoms					
IP13	What I do can determine whether their illness gets better or worse					
IP14	The course of their illness depends on me					
IP15	Nothing I do will affect their illness					
IP16	I have the power to influence their illness					
IP17	My actions will have no effect on the outcome of their illness					
IP18	Their illness will improve in time					
IP19	There is very little that can be done to improve their illness					
IP20	Their treatment will be effective in curing their illness					
IP21	The negative effects of their illness can be prevented (avoided) by their treatment					
IP22	Their treatment can control their illness					
IP23	There is nothing which can help their condition					
IP24	The symptoms of their condition are puzzling to me					
IP25	Their illness is a mystery to me					

IP26	I don't understand their illness					
IP27	Their illness doesn't make any sense to me					
IP28	I have a clear picture or understanding of their illness					
IP29	The symptoms of their illness change a great deal from day to day					
IP30	Their symptoms come and go in cycles					
IP31	Their illness is very unpredictable					
IP32	They go through cycles in which their illness gets better and worse					
IP33	I get depressed when I think about their illness					
IP34	When I think about their illness I get upset					
IP35	Their illness makes me feel angry					
IP36	Their illness does not worry me					
IP37	Their illness makes me feel anxious					
IP38	Their illness makes me feel afraid					

CAUSES OF THEIR PARKINSON'S DISEASE

We are interested in what you consider may have been the cause of the person you care for's Parkinson's Disease. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused their Parkinson's Disease rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for their Parkinson's Disease. Please indicate how much you agree or disagree that they were causes by ticking the appropriate box.

	POSSIBLE CAUSES	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
C1	Stress or worry					
C2	Hereditary – it runs in the family					
C3	A germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in their past					
C7	Pollution in the environment					
C8	Their own behaviour					
C9	Their mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused their illness					
C11	Overwork					
C12	Their emotional state e.g feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	Their personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused their Parkinson's Disease. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes are:-

1. _____
2. _____
3. _____

Appendix Q - Quality of life (PDQ-39)

PDQ-39 QUESTIONNAIRE

Please complete the following

Please tick <u>one</u> box for each question

Due to having Parkinson's disease, how often <u>during the last month</u> have you....		**Never**	**Occasionally**	**Sometimes**	**Often**	**Always** or cannot do at all
1	Had difficulty doing the leisure activities which you would like to do?	☐	☐	☐	☐	☐
2	Had difficulty looking after your home, e.g. DIY, housework, cooking?	☐	☐	☐	☐	☐
3	Had difficulty carrying bags of shopping?	☐	☐	☐	☐	☐
4	Had problems walking half a mile?	☐	☐	☐	☐	☐
5	Had problems walking 100 yards?	☐	☐	☐	☐	☐
6	Had problems getting around the house as easily as you would like?	☐	☐	☐	☐	☐
7	Had difficulty getting around in public?	☐	☐	☐	☐	☐
8	Needed someone else to accompany you when you went out?	☐	☐	☐	☐	☐
9	Felt frightened or worried about falling over in public?	☐	☐	☐	☐	☐
10	Been confined to the house more than you would like?	☐	☐	☐	☐	☐
11	Had difficulty washing yourself?	☐	☐	☐	☐	☐
12	Had difficulty dressing yourself?	☐	☐	☐	☐	☐
13	Had problems doing up your shoe laces?	☐	☐	☐	☐	☐

*Please check that you have ticked **one box for each question** before going on to the next page*

Due to having Parkinson's disease, how often <u>during the last month</u> have you....		***Please tick <u>one</u> box for each question***				
		Never	**Occasionally**	**Sometimes**	**Often**	**Always** or cannot do at all
14	Had problems writing clearly?	☐	☐	☐	☐	☐
15	Had difficulty cutting up your food?	☐	☐	☐	☐	☐
16	Had difficulty holding a drink without spilling it?	☐	☐	☐	☐	☐
17	Felt depressed?	☐	☐	☐	☐	☐
18	Felt isolated and lonely?	☐	☐	☐	☐	☐
19	Felt weepy or tearful?	☐	☐	☐	☐	☐
20	Felt angry or bitter?	☐	☐	☐	☐	☐
21	Felt anxious?	☐	☐	☐	☐	☐
22	Felt worried about your future?	☐	☐	☐	☐	☐
23	Felt you had to conceal your Parkinson's from people?	☐	☐	☐	☐	☐
24	Avoided situations which involve eating or drinking in public?	☐	☐	☐	☐	☐
25	Felt embarrassed in public due to having Parkinson's disease?	☐	☐	☐	☐	☐
26	Felt worried by other people's reaction to you?	☐	☐	☐	☐	☐
27	Had problems with your close personal relationships?	☐	☐	☐	☐	☐
28	Lacked support in the ways you need from your spouse or partner?	☐	☐	☐	☐	☐
	If you do not have a spouse or partner tick here		☐			
29	Lacked support in the ways you need from your family or close friends?	☐	☐	☐	☐	☐

*Please check that you have ticked **one box for each question** before going on to the next page*

Due to having Parkinson's disease, how often <u>during the last month</u> have you....		***Please tick <u>one</u> box for each question***				
		Never	**Occasionally**	**Sometimes**	**Often**	**Always**
30	Unexpectedly fallen asleep during the day?	☐	☐	☐	☐	☐
31	Had problems with your concentration, e.g. when reading or watching TV?	☐	☐	☐	☐	☐
32	Felt your memory was bad?	☐	☐	☐	☐	☐
33	Had distressing dreams or hallucinations?	☐	☐	☐	☐	☐
34	Had difficulty with your speech?	☐	☐	☐	☐	☐
35	Felt unable to communicate with people properly?	☐	☐	☐	☐	☐
36	Felt ignored by people?	☐	☐	☐	☐	☐
37	Had painful muscle cramps or spasms?	☐	☐	☐	☐	☐
38	Had aches and pains in your joints or body?	☐	☐	☐	☐	☐
39	Felt unpleasantly hot or cold?	☐	☐	☐	☐	☐

*Please check that you have ticked **one box for each question** before going on to the next page*

Thank you for completing the PDQ 39 questionnaire

Appendix R – Carer quality of life (SF-36)

SF-36v2™ Health Survey

This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities.

1. **In general, would you say your health is**

Excellent	Very Good	Good	Fair	Poor
☐	☐	☐	☐	☐

2. ***Compared to one year ago,* how would you rate your health in general now?**

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
☐	☐	☐	☐	☐

3. **The following questions are about activities you might do during a typical day. *Does your health now limit* you in these activities? If so, how much?**

		Yes, limited a lot	Yes, limited a little	No, not limited at all
a.	*Vigorous Activities,* such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
b.	*Moderate Activities,* such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐	☐	☐
c.	Lifting or carrying groceries	☐	☐	☐
d.	Climbing *several* flights of stairs	☐	☐	☐
e.	Climbing *one* flight of stairs	☐	☐	☐
f.	Bending, kneeling, or stooping	☐	☐	☐
g.	Walking *more than a mile*	☐	☐	☐
h.	Walking *several hundred yards*	☐	☐	☐
i.	Walking *one hundred yards*	☐	☐	☐
j.	Bathing or dressing yourself	☐	☐	☐

4. **During the *past 4 weeks,* how much of the time have you had any of the following problems with your work or other regular daily activities *as a result of your physical health?***

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a.	Cut down on the *amount of time* you spent on work or other activities	☐	☐	☐	☐	☐
b.	*Accomplished* less than you would like	☐	☐	☐	☐	☐
c.	Were limited in the *kind* of work or other activities	☐	☐	☐	☐	☐
d.	Had *difficulty* performing the work or other activities (for example, it took extra effort)	☐	☐	☐	☐	☐

5. **During the *past 4 weeks,* how much of the time have you had any of the following problems with your work or other regular daily activities *as a result of any emotional problems* (such as feeling depressed or anxious)?**

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a.	Cut down on the *amount of time* you spent on work or other activities	☐	☐	☐	☐	☐
b.	*Accomplished less* than you would like	☐	☐	☐	☐	☐
c.	Did work or activities *less carefully than usual*	☐	☐	☐	☐	☐

6. **During the *past 4 weeks,* to what *extent* has your *physical health or emotional problems* interfered with your normal social activities with family, friends, neighbors, or groups?**

Not at all	Slightly	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

7. **How much *bodily* pain have you had during the *past 4 weeks*?**

None	Very Mild	Mild	Moderate	Severe	Very Severe
☐	☐	☐	☐	☐	☐

8. **During the *past 4 weeks,* how much did *pain* interfere with your normal work (including both work outside the home and housework)?**

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

9. **These questions are about how you feel and how things have been with you *during the past 4 weeks*. For each question, please give the one answer that comes closest to the way you have been feeling.**

How much of the time during the *past 4 weeks*...

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a.	Did you feel full of life?	☐	☐	☐	☐	☐
b.	Have you been very nervous?	☐	☐	☐	☐	☐
c.	Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐
d.	Have you felt calm and peaceful?	☐	☐	☐	☐	☐
e.	Did you have a lot of energy?	☐	☐	☐	☐	☐
f.	Have you felt downhearted and depressed?	☐	☐	☐	☐	☐
g.	Did you feel worn out?	☐	☐	☐	☐	☐
h.	Have you been happy?	☐	☐	☐	☐	☐
i.	Did you feel tired?	☐	☐	☐	☐	☐

10. **During the *past 4 weeks,* how much of the time has your *physical health or emotional problems* interfered with your social activities (like visiting friends, relatives, etc.)?**

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

11. **How TRUE or FALSE is *each* of the following statements for you?**

		Definitely true	Mostly true	Don't Know	Mostly false	Definitely false
a.	I seem to get sick a little easier than other people	☐	☐	☐	☐	☐

	other people					
b.	I am as healthy as anybody I know	☐	☐	☐	☐	☐
c.	I expect my health to get worse	☐	☐	☐	☐	☐
d.	My health is excellent	☐	☐	☐	☐	☐

Appendix S – Zarit caregiver burden questionnaire

THE ZARIT BURDEN INTERVIEW

Please circle the response the best describes how you feel.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	Score
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4	
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4	
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4	
5. Do you feel angry when you are around your relative?	0	1	2	3	4	
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4	
7. Are you afraid what the future holds for your relative?	0	1	2	3	4	
8. Do you feel your relative is dependent on you?	0	1	2	3	4	
9. Do you feel strained when you are around your relative?	0	1	2	3	4	
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4	
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4	
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4	

14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4	
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4	
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4	
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4	
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4	
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
20. Do you feel you should be doing more for your relative?	0	1	2	3	4	
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4	
Total Score (out of 88)						

Interpretation of Score:	
0 – 21	little or no burden
21 – 40	mild to moderate burden
41 – 60	moderate to severe burden
61 – 88	severe burden

Score values and interpretation are guidelines only, as discussed in:
Hebert R, Bravo G, and Preville M (2000). *Canadian J Aging* 19: 494-507.

Appendix T – Hospital Anxiety and Depression Scale

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			**I feel as if I am slowed down:**
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			**I get a sort of frightened feeling like 'butterflies' in the stomach:**
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			**I have lost interest in my appearance:**
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			**I feel restless as I have to be on the move:**
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			**I look forward with enjoyment to things:**
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			**I get sudden feelings of panic:**
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			**I can enjoy a good book or radio or TV program:**
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:
Total score: Depression (D) _____ Anxiety (A) _____
0-7 = Normal
8-10 = Borderline abnormal (borderline case)
11-21 = Abnormal (case)

Appendix U – Epistemological position

Statement of epistemological position

For the current research study an empirical positivist position was adopted. This approach assumes variables can be measured objectively and reliably, and result in meaningful findings. A range of measures were available for use for predictor and outcome variables. Numerous studies have previously adopted this approach when investigating the role of psychological factors in chronic health conditions for patient and carer outcome, allowing for some comparison across studies.

Appendix V - Chronology of research process

Chronology of research process

June 2011	Research proposal submitted
Dec 2011	Peer review process
May 2011	Ethical submission
Aug 2011 – Feb 2012	Data collection
Dec 2012	Literature review
March 2012	Analysis of data
April 2012	Thesis write-up