

THE UNIVERSITY OF HULL

The Impact of Specialist Palliative Care on Coping in Parkinson's Disease:
the Experiences of Patients and Carers

being a Thesis submitted in partial fulfillment of the requirements for the
Degree of Doctor of Clinical Psychology

in the University of Hull

by

Nathan James Badger, BSc (Hons.) Psychology

June 2014

Total word count (parts one and two; excluding appendices): 18,481

Dedication

This thesis is dedicated to the memory of Daisy Hazel Wright.

Acknowledgements

I would like to thank my research supervisors Dr Dorothy Frizelle and Professor Miriam Johnson for their support and advice throughout the research process. I would also like to thank Dr Eric Gardiner for his statistical advice and Dr Ed Richfield for his assistance with the systematic literature review.

Thanks also to the clinical nurse specialists at the specialist palliative care service for their ongoing interest in this research and their crucial support in recruiting participants, and to the members of the Hull and East Yorkshire branch of Parkinson's UK and Pete Haslam for their advice regarding the design of the empirical study.

Thanks to my fellow trainees who have helped make the previous three years such a valuable and enjoyable experience.

I would like to thank my family for their love and support, without which none of this would have been possible. Huge thanks and love to Lauren for her reassurance, support, and love, and for being here with me through everything.

Finally, my sincere thanks to the patients and carers who so generously gave their time to take part in this research.

Overview

This portfolio thesis consists of three parts; a systematic literature review, an empirical study, and a set of appendices.

Part one is a systematic literature review, reviewing literature regarding the relationship between the way patients with Parkinson's Disease cope with their illness and the degree of depressive symptoms they experience. This review was undertaken as it has been suggested that psychological variables may influence the presence of depressive symptoms in Parkinson's Disease, and coping may be one such variable. Identification of adaptive or maladaptive ways of coping could potentially aid effective targeting of psychological interventions for depressive symptoms in Parkinson's Disease.

Part two of this portfolio is an empirical study exploring the impact of specialist palliative care on coping for patients with Parkinson's Disease and their carers. Despite recommendations that palliative needs are considered throughout the course of Parkinson's Disease, referral to specialist palliative care is less common for this population than in other illnesses such as cancer, despite these illnesses being associated with similar challenges. Specialist palliative care appears to be beneficial in helping patients with other illnesses and their carers cope, however there is a lack of research exploring the impact of such services in Parkinson's Disease. This study aimed to contribute to the discussion regarding whether such services should be developed and made more accessible for patients with Parkinson's Disease and their carers.

Part three consists of a set of appendices relating to both parts one and two.

Table of Contents

Section	Subsection	Page
<u>List of tables</u>		p8
<u>List of figures</u>		p10
<u>Part one: Systematic literature review</u>		p12
	<i>Title page</i>	p13
	<i>Abstract</i>	p14
	<i>Introduction</i>	p15
	<i>Method</i>	p18
	<i>Results</i>	p22
	<i>Discussion</i>	p43
	<i>References</i>	p54
<u>Part two: Empirical study</u>		p62
	<i>Title page</i>	p63
	<i>Abstract</i>	p64
	<i>Introduction</i>	p65
	<i>Method</i>	p71
	<i>Results</i>	p75
	<i>Discussion</i>	p86
	<i>References</i>	p95

<u>Part three: Appendices</u>	p102
<i>Appendix A- Author guidelines for British Journal of Health Psychology</i>	p103
<i>Appendix B- References for studies excluded at full-text review stage</i>	p111
<i>Appendix C- Quality assessment information</i>	p113
<i>Appendix D- Participant selection tool used by recruiters</i>	p117
<i>Appendix E- Participant information leaflet</i>	p120
<i>Appendix F- Confirmation of ethical approval</i>	p123

<i>Appendix G- Confirmation of sponsor approval</i>	p124
<i>Appendix H- Non-NHS SSI confirmation</i>	p125
<i>Appendix I- Consent form</i>	p126
<i>Appendix J- Interview schedule</i>	p127
<i>Appendix K- Data regarding participants' understanding of coping and the impact of PD on participants' lives</i>	p128
<i>Appendix L- Worked example of IPA analysis</i>	p129

Appendix M- Epistemological statement **p145**

*Appendix N- Reflective
statement* **p149**

List of Tables

Section	Title	Page
<u>Part one: Systematic literature review</u>	<i>Table 1.0. Search terms used in database search</i>	p19
	<i>Table 2.0. Inclusion criteria for inclusion in review</i>	p19
	<i>Table 3.0. Details of reviewed studies</i>	p24
	<i>Table 4.0. Coping measures used in reviewed studies</i>	p31

*Table 5.0. Depressive
symptom measures used
in reviewed studies* **p37**

Part two: Empirical study *Table 6.0. Participant
details* **p73**

*Table 7.0. Super-
ordinate and sub-
ordinate themes from
interview transcripts* **p76**

*Table 8.0. 'Managing
Uncertainty' sub-ordinate
themes and supporting
quotes* **p77**

*Table 9.0. 'Impacts on
the Self' sub-ordinate
themes and supporting
quotes* **p81**

*Table 10.0. 'SPC
maintaining a positive
outlook' sub-ordinate
themes and supporting
quotes* **p85**

Part three: Appendices *Table 11.0. Quality
assessment scores* **p115**

List of Figures

Section	Title	Page
<u>Part one: Systematic literature review</u>	<i>Figure 1.0. Process of study selection</i>	p21
	<i>Figure 2.0. Data extracted from included studies</i>	p22
	<i>Figure 3.0. Distinction between simple, complex, and chaotic systems</i>	p52

Part two: Empirical study

Figure 4.0. Distinction

p90

*between simple,
complex, and chaotic
systems*

Part one: Systematic Literature Review

The relationship between coping with Parkinson's disease and depressive symptoms

Nathan J. Badger¹, Dr Dorothy Frizelle¹, Dr Ed W. Richfield²
and Prof Miriam Johnson²

¹Department of Psychological Health and Wellbeing,
University of Hull

²Hull York Medical School, University of Hull

This paper is prepared for submission to the British Journal of Health Psychology, as per the author guidelines (Appendix A).

Total word count (exc. appendices): 9,140

Word count (exc. abstract, figures/tables, references as per author guidelines, and appendices): 5,280

*Requests for reprints should be addressed to Nathan Badger, Department of Psychological Health and Wellbeing, Hertford Building, University of Hull, Cottingham Road, Hull, HU6 7RX, United Kingdom (e-mail: Nathan.badger@nhs.net).

Abstract

Purpose: This article reviewed literature regarding the relationship between the way patients cope with Parkinson's Disease (PD) and the presence of depressive symptoms (DS). As disease-related factors may be insufficient to explain DS in PD, psychological factors such as coping may be relevant. Identified relationships could indicate appropriate psychological interventions for DS in PD.

Methods: This systematic review utilised narrative synthesis to review seven studies, obtained by searching PsycInfo, PsycArticles, CINAHL Plus, MEDLINE and Academic Search Premier databases.

Results: Some emotion-focused coping variables and cognitive coping were related to the presence of greater DS, whilst active cognitive coping and behavioural coping were related to lower DS. Many non-significant relationships were reported. Use of different coping measures led to a lack of replication, limiting ability to draw conclusions regarding whether particular coping variables are related to DS.

Conclusions: Conclusions were limited by lack of replication, predominance of cross-sectional designs, and a lack of consideration of wider influencing variables in analyses. Future studies might consider: prospective and/or longitudinal designs; using consistent, valid and reliable coping and DS measures; accounting for other potential influencing variables in analyses; studying specific PD-related stressors rather than 'PD' more generally; and considering the role of coping appraisal. The findings of such research should

be seen as indications of factors to consider in planning interventions for DS in PD, rather than as contributing to the development of full understanding and prescriptive treatments for DS in PD, which are likely unattainable for a complex problem such as DS.

Introduction

Parkinson's Disease (PD) is a progressive neurological condition, affecting an estimated 127,000 people in the United Kingdom (UK) (Parkinson's UK, 2009). PD is characterised by motor symptoms, particularly 'tremor at rest, rigidity, akinesia¹ (or bradykinesia²) and postural instability' (Jankovic, 2008, p368). These result from impaired dopamine functioning in Nigrostriatal regions of the brain (Dauer & Przedborski, 2003). Non-motor features of PD include erectile dysfunction, bladder dysfunction, excessive sweating (Magerkurth, Schnitzer & Braune, 2005), cognitive impairment/dementia (Hely, Morris, Reid & Trafficante, 2005) and excessive daytime sleepiness (Gjerstad, Alves, Wentzel-Larsen, Aarsland & Larsen, 2006).

Approximately 35% of patients with PD (PWPD) experience clinically relevant depressive symptoms (DS) (Reijnders, Ehrt, Weber, Aarsland & Leentjens, 2008), though study setting and methodology may influence reported prevalence. In addition to the DS themselves, DS (in this review defined as elements of a depressed presentation, rather than symptoms of underlying pathology) in PD are correlated with poorer quality of life (Schrag, Jahanshahi & Quinn, 2000; Karlsen, Larsen, Tandberg & Mæland, 1999), and greater functional disability (Weintraub, Moberg, Duda, Katz & Stern, 2004), whilst a

¹ 'Loss of movement' (Jankovic, 2008, p371).

² 'Slowness of movement' (Jankovic, 2008, p 369).

'depressed' group of PWPd showed greater cognitive decline than a 'non-depressed' group (Starkstein, Bolduc, Mayberg, Preziosi & Robinson, 1990). Those with a clinical depression diagnosis may also show more rapid disease progression (Starkstein, Mayberg, Leiguarda, Preziosi & Robinson, 1992). DS thus seem to be associated with negative effects for PWPd.

Explanations for 'depression' in PD, usually assessed using rating scales of DS, include it resulting from neurological changes, or being a reaction to disease-related variables such as duration and severity (Frisina, Borod, Foldi & Tenenbaum, 2008). Frisina et al (2008) note that findings exist to support both explanations. DS and disease-related variables may share only a small amount of variance, however other variables may affect this relationship and/or account for variability in DS, including psychological variables (Gotham, Brown & Marsden, 1986; Menza & Mark, 1994). Together with evidence that psychological intervention can reduce DS in PD (Yang, Sajatovic & Walter, 2012), it seems psychological variables may be influential.

Coping may be one such variable (Gotham et al, 1986). Crisis Theory (Moos & Schaefer, 1984, as cited in Ogden, 2007) postulates that coping may influence outcomes following illness, such as wellbeing or psychological adjustment (Ogden, 2007). Lazarus and Folkman (1984, p141) define coping as 'constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the person'. Successful coping may lead to better adaptation, for example higher morale (Lazarus & Folkman, 1984), though success may not entail overcoming a stressor, but may involve 'minimizing, avoiding, tolerating and accepting' (Lazarus & Folkman, 1984, p142).

One categorisation of coping is between problem-focused and emotion-focused coping. Emotion-focused strategies may aim to reduce emotional distress, for example 'avoidance, minimization, distancing, selective attention, positive comparisons, and wresting positive value from negative events' (Lazarus & Folkman, 1984, p150), or, in some cases, increase emotional distress (e.g. self-blame) to enable individuals to feel relief later, or to 'mobilize themselves for action' (Lazarus & Folkman, 1984, p150). In contrast, problem-focused coping involves environmental and internal strategies directed at the problem, i.e. aiming to change the problem in some way e.g. making environmental changes or problem-directed cognitive reappraisal (Lazarus & Folkman, 1984; Kahn, Wolfe, Quinn, Snoek & Rosenthal, 1964, as cited in Lazarus & Folkman, 1984). Using one type of coping might affect the other, for example using emotion-focused coping in some situations may lead to poor problem management, whilst focusing on a stressor may increase distress. Roth and Cohen (1986) distinguished between approach coping (approaching stressors) and avoidance coping (avoiding stressors), suggesting that both have advantages and disadvantages, and that adaptiveness may depend on the controllability of the stressor, with avoidance more appropriate for unchangeable stressors than changeable ones. Coping adaptiveness may then be dependent to some degree on the stressor being managed.

The way patients cope with chronic illness may affect emotional outcomes (e.g. Felton & Revenson, 1984), whilst beneficial psychological intervention for DS in PD also seemed to affect use of positive reframing coping strategies (Dobkin et al, 2011a; Dobkin et al, 2011b). Consequently, coping may affect emotional outcome in chronic illness and be related to effects of psychological intervention for DS in PD.

In summary, DS are common in PD and are associated with negative outcomes. Disease-related variables alone may be insufficient to explain their prevalence. The apparent effectiveness of psychological intervention for DS in PD suggests psychological variables may be relevant. Theories of coping, the Crisis Theory of Illness, and research into psychological intervention for DS in PD, suggest coping could be a variable of interest. Consequently, this review aimed to explore the relationship between the way PWPD cope with PD and DS. Identification of possible influencing coping variables could facilitate targeting of psychological interventions, aiming to prevent DS developing and/or reduce DS when they occur, and ultimately lessen the negative impact DS may have for PWPD.

Method

The databases Academic Search Premier, the Cumulative Index to Nursing and Allied Health (CINAHL) Plus database, MEDLINE, PsycArticles and PsycInfo were searched (April 2014), in order to cover both psychological and medical disciplines.

Search Terms

The search terms used are shown in table 1.0.

Table 1.0. Search terms used in database search.

Search Term	Rationale
Parkinson*	The population under consideration; to include 'Parkinson' and 'Parkinson's' results.
Cope* OR coping	To return studies investigating coping.
Depress* OR low mood OR sad*	To return studies investigating depression/depressed mood/DS.

Databases were searched concurrently using the EBSCOHost platform. To increase likelihood of research included in the review being of high quality, the peer review limiter was applied.

Inclusion Criteria

Studies were required to fulfil the criteria in table 2.0 for inclusion.

Table 2.0. Inclusion criteria for inclusion in review.

Criterion	Rationale
Sample of PWPD, or a mixed sample where PWPD could be analysed independently.	PWPD were the population under consideration.
Quantitative design.	Focus was on understanding strength and direction of relationships rather than individuals' experiences of such relationships.

Included statistical analyses directly testing relationships between coping variables and DS.	To enable the specific contribution of coping variables to DS to be assessed.
Coping measure was completed with regards to the way participants coped with PD or PD-related stressors (or used coping with illness measure assumed to be applied to PD by participants).	Conceptualisations of coping and the findings of Frazier (2000) suggest that outcome of coping may be stressor-dependent, therefore studies assessing coping with other situations were not considered relevant to the review question.
Not a case study or literature review.	Case studies excluded due to inability to generalise findings. Literature reviews excluded as present review aimed to review original studies and findings.
Available in English.	To enable understanding and analysis by researchers.
Peer reviewed.	To increase likelihood of included studies being of a high quality.

Study Selection

The search of the selected databases produced ninety-five articles following the removal of duplicates. As the databases were searched concurrently the number of articles retrieved from each database is not reported. Study selection was conducted by the first author. Titles and abstracts from the initial search were reviewed, with full texts obtained for those which fulfilled the inclusion criteria, or where there was insufficient information from the title and abstract to determine this. Full texts were assessed against the

inclusion criteria (see appendix B for studies excluded at full-text stage).

References of included studies were hand-searched for other relevant studies.

Following these stages of selection, seven studies were included in the final review. Figure 1.0 shows the study selection process.

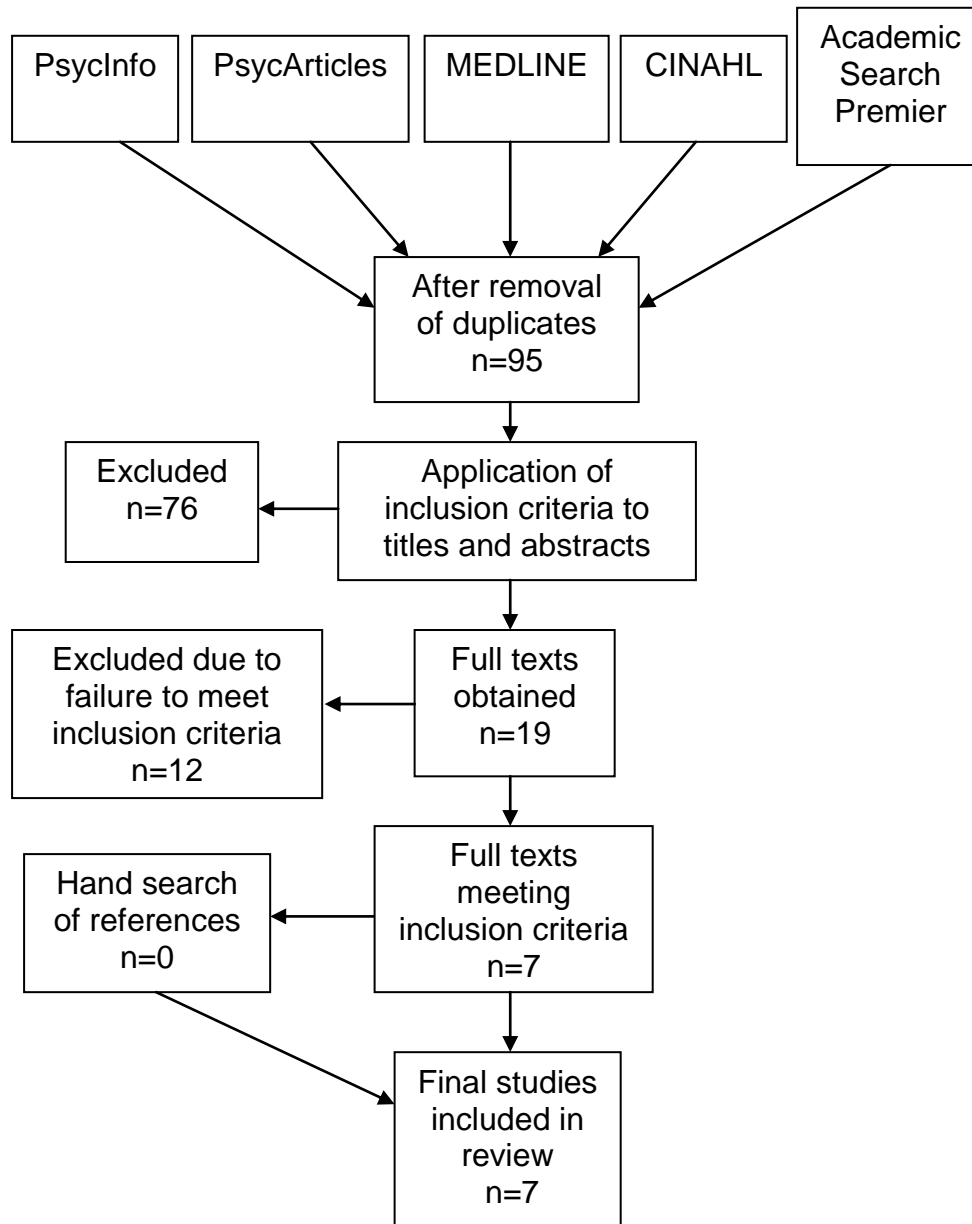


Figure 1.0. Process of study selection.

Data Extraction

Figure 2.0 lists the information extracted from included studies.

Data Analysis

All included studies were quantitative. However, several different measures of DS and coping were used, making it difficult to examine relationships between specific types of coping and DS using a meta-analysis, as efforts to group coping variables (e.g. problem-focused vs. emotion-focused) may be unreliable.

Furthermore, one included study did not present data necessary for a meta-analysis.

Consequently, narrative synthesis was chosen as the method of data analysis.

Quality Assessment

Quality of included studies was assessed using a custom checklist, to ensure that criteria were relevant to the studies and topic under review. This was based on criteria assessed by the Downs and Black (1998) checklist. A sample of the included studies were also quality assessed by the third author (see appendix C).

Results

Table 3.0 shows selected data extracted from reviewed studies.

Study Characteristics

All reviewed studies were cross-sectional, whilst one additionally presented longitudinal findings (Evans & Norman, 2009). All studies presented

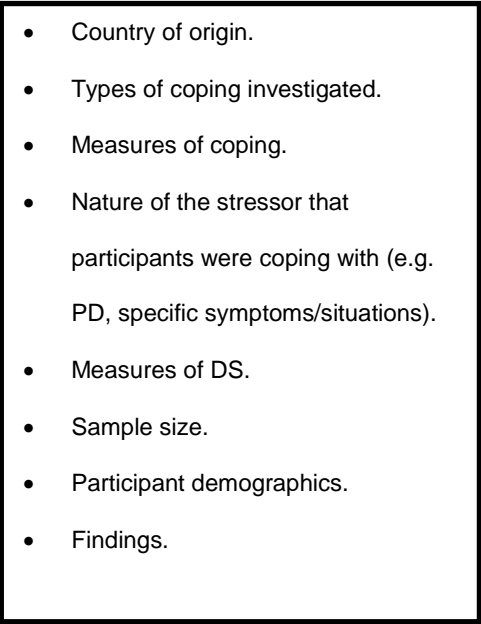
- 
- Country of origin.
 - Types of coping investigated.
 - Measures of coping.
 - Nature of the stressor that participants were coping with (e.g. PD, specific symptoms/situations).
 - Measures of DS.
 - Sample size.
 - Participant demographics.
 - Findings.

Figure 2.0. Data extracted from included studies.

bivariate correlational findings, with four additionally undertaking regression analyses. Sample size ranged from 45 (Ehmann, Beninger, Gawel & Riopelle, 1990; Krakow, Haltenhof & Bühler, 1999) to 136 (MacCarthy & Brown, 1989), (mean= 71.4, SD=32.2). Regarding gender, the most uneven sample was 69.5% male (Moore & Seeney, 2007); the most balanced was 48.9% male (Ehmann et al, 1990). Mean gender composition was 58.3% male (SD=7.9%) and 41.7% female (SD=7.9%), reflecting the higher prevalence of PD in males (e.g. Wooten, Currie, Bovbjerg, Lee & Patrie, 2004). Four studies' participants completed coping measures with regards to their coping with 'PD', whilst two used coping with illness questionnaires which are assumed to have been completed by participants with regards to PD. One study's participants (Croyle et al, 2003) responded specifically with regards to the stressor of potential upcoming surgical intervention for PD.

Table 3.0. Details of reviewed studies.

Key: BDI (Beck Depression Inventory); CDS (Cornell Depression Scale); CRI (Coping Responses Inventory); DS (Depressive Symptoms); FKV-Lis (Freiburg Coping with Illness Questionnaire); HADS (Hospital Anxiety and Depression Scale); H&Y (Hoehn and Yahr Scale (Hoehn & Yahr, 1967) (n.b. staging tool, higher stage indicates greater progression, max = 5)); MCMQ (Medical Coping Modes Questionnaire); PD (Parkinson's Disease); POMS (Profile of Mood States); SD (Standard Deviation); UPDRS (Unified Parkinson's Disease Rating Scale (Fahn, Elton & UPDRS Development Committee, 1987) (n.b. measure of motor symptom severity); WCC (Ways of Coping Checklist); WCC-R (Ways of Coping Checklist Revised).

Study (Location)	Sample description (selected variables)	Coping measure	Stressor	DS measures	Findings
Croyle et al, 2003 (USA)	52 males, 28 females. Mean age 61.7 years (\pm 10.1 years). Estimated age at diagnosis mean 50.6 years (\pm 9.5 years) (based on 78/80). Mean BDI 11.94 (max 63) (\pm 7.23). 61 patients assessed with motor UPDRS, mean 41.92 (\pm 15.13).	CRI.	Upcoming possible neurosurgery for PD.	BDI.	<ul style="list-style-type: none"> Summary measure of coping ($r=-.05$), cognitive coping ($r=-.11$), approach coping ($r=-.03$), avoidance ($r=-.07$) and behavioural coping ($r=-.21$) not significantly correlated with DS. When the effects of cognitive and behavioural coping were considered together in a hierarchical regression predicting DS, greater DS were predicted by use of cognitive coping ($\beta=.52$, $p<.001$) and lower DS by use of behavioural coping ($\beta=-.58$, $p<.001$). Further steps showed approach coping did not contribute ($\beta=.043$), avoidance was not tested.

Ehmann et al, 1990 <i>(Canada)</i>	22 males, 23 females. Mean age 67.35 years (range 51-85 years). 'Average' disease duration approx 3.5 years (no SD provided). H&Y mean 2.25 (no SD provided).	Billings and Moos Coping Questionnaire.	PD over recent months.	BDI.	<ul style="list-style-type: none"> • Active cognitive coping was significantly correlated with lower DS ($r=-.31$, $p<.05$). • Specific active cognitive coping strategies of 'tried to see the positive side' and 'drew on past experiences' significantly correlated with lower DS (no statistics provided). • Avoidance coping ($r=.29$) and active behavioural coping ($r=-.12$) did not significantly correlate with DS.
Evans & Norman, 2009 <i>(UK)</i>	At baseline, 28 males, 30 females. Mean age 58.64 years (SD=5.01 years). Mean length of diagnosis 6.73 years (SD=5.65 years). Mean HADS depression subscale 7.09 (max 21) (SD=3.32). H&Y mean 2.65 (SD=0.97). One drop-out at follow-up, no revised sample characteristics reported.	MCMQ.	PD.	HADS.	<ul style="list-style-type: none"> • Baseline confrontation not significantly correlated with DS at baseline ($r=-0.08$) or six month follow-up ($r=0.05$). • Baseline avoidance significantly correlated with greater DS at baseline ($r=.32$, $p<.05$) but not at six month follow-up ($r=0.18$). • Baseline acceptance-resignation (tendency towards resignation) significantly correlated with greater DS at baseline ($r=.56$, $p<.001$) and six month follow-up ($r=.31$, $p<.05$).

-
- A hierarchical regression analysis predicting baseline DS, with various illness representations entered at step 1 and avoidance and acceptance-resignation entered at step 2, showed that acceptance-resignation (tendency towards resignation) was a significant independent predictor ($\beta=.28$, $p<.05$) though avoidance was not ($\beta=.11$). Both coping measures together explained 6% (sig $p<.05$) of variance in baseline DS. Acceptance-resignation also significantly mediated the relationship between both consequences and emotional representations on DS at baseline.
 - Hierarchical regression predicting follow-up DS, baseline acceptance-resignation entered at step 3, baseline DS at step 1, baseline 'consequences' and 'personal control' illness representations at step 2, acceptance-resignation not a significant independent predictor ($\beta=-.17$) accounting for 2% (n.s.) variance. No evidence of acceptance-resignation mediating other relationships.

Herrmann et al, 1997 <i>(Germany)</i>	<p>33 males, 21 females. Median age 64 years (range 47-75 years). Median age at onset 56 years (range 32-73 years). Median months post onset 96 months (range 6-288 months). CDS informant-report median score 15 (max 38) (range 2-29). H&Y: 20% S1, 43% S2, 7% S3, 26% S4, 4% S5.</p>	FKV-Lis.	<p>Unspecified, assumed PD due to use of coping with illness questionnaire.</p>	<p>CDS (informant-report); BDI (self-report).</p>	<ul style="list-style-type: none"> No significant correlations between DS measured with either DS measure and any of the coping variables measured by the FKV-Lis. No statistics provided.
Krakow et al, 1999 <i>(Germany)</i>	<p>27 males, 18 females. Mean age 55.8 years (SD=8.4 years). Mean age at onset 47.1 years (SD=6.5 years). Mean disease duration 8.9 years (SD=5.5 years). Mean DS score = 12 (max 48) (SD=7.6). Mean H&Y 3.0 (\pm0.9).</p>	FKV-Lis.	<p>Unspecified, assumed PD due to use of coping with illness questionnaire.</p>	<p>Depression Scale of Von Zerrsen.</p>	<ul style="list-style-type: none"> Depressive coping ($r=.61$, $p<.01$) and dissimulating and wishful thinking ($r=.41$, $p<.01$) significantly correlated with greater DS. No findings were presented regarding the other coping variables measured by the FKV-Lis. An integrated scale of 'uneffective coping' significantly correlated with greater DS but it is not specified which scales contributed to this.

MacCarthy & Brown, 1989 (UK)	55% male, 45% female (n=136). Mean age 64.5 years (SD=9.5 years). Median illness duration 9.4 years (range 2.5-32.2 years). Mean BDI 13.98 (max 63) (range 1-36). H&Y (best) 37% S1 or S2, 50% S3, 13% S4 or S5.	WCC (adapted).	Effects of having PD over previous six months.	BDI.	<ul style="list-style-type: none"> • Maladaptive coping significantly correlated ($r=.52$, $p<.001$) with greater DS. • Positive coping did not significantly correlate with DS ($r=-.10$). • In a hierarchical regression predicting DS, when entered at step 2 together with self esteem, with functional disability at step 1, maladaptive coping was a significant independent predictor ($\beta=.36$, $p<.001$).
Moore & Seeney, 2007 (Australia)	57 males, 25 females. Mean age 68 years (SD=9.4 years). Mean length of illness 19.58 years (SD=12.97). Mean POMS 11.08 (max 60) (SD= 11.81).	WCC-R.	PD.	POMS.	<ul style="list-style-type: none"> • Blames self ($r=.50$, $p<.01$), avoidance ($r=.64$, $p<.01$) and wishful thinking ($r=.64$, $p<.01$) were all significantly correlated with greater DS (depressed mood). • Problem-focused coping ($r=.20$) and seeking social support ($r=.14$) were not significantly correlated with DS (depressed mood). • In a regression model accounting for 64% of variance in DS (depressed mood), blames self

($\beta=.41$, $p<.001$) and avoidance ($\beta=.33$, $p<.001$) were significant independent predictors. Wishful thinking ($\beta=.06$) was not.

Coping Measures

Table 4.0 shows the six coping measures used in reviewed studies. Only the Freiburg Coping with Illness Questionnaire (FKV-Lis) was used by more than one study (Herrmann, Freyholdt, Fuchs & Wallesch, 1997; Krakow et al, 1999). Only three studies reported the internal consistency of utilised measures. These were acceptable ($\alpha > .70$) for both subscales used by Moore and Seeney (2007), and for one subscale used by MacCarthy and Brown (1989) with the other being $\alpha = .69$. Evans and Norman's (2009) subscales were between $\alpha = .60$ and $\alpha = .64$.

DS Measures

Table 5.0 shows the five measures of DS used in reviewed studies. All studies used self-report measures, most commonly the Beck Depression Inventory (BDI) (four studies). Herrmann et al (1997) also used the Cornell Depression Scale (CDS) as an informant measure. Moore and Seeney (2007) used a measure exclusively measuring depressed mood, rather than DS more generally. Only two studies reported the internal consistency of their DS measures, both of which reported acceptable or better internal consistencies.

Table 4.0. Coping measures used in reviewed studies.

Measure	No. items	Subscales	Studies using measure	Details of alterations	Internal consistency in studies (Cronbach's alpha (α) unless otherwise stated)
Billings and Moos Coping Questionnaire <i>(Billings & Moos, 1981)</i>	19.	Active-cognitive coping; Active-behavioural coping; Avoidance.	Ehmann et al, 1990.	No alterations reported.	Not reported for study sample. Billings and Moos (1981) in the original development of the measure reported the following α : active-cognitive coping (.72); active-behavioural coping (.80); avoidance coping (.44).

Coping Responses Inventory (Moos, 1993)	48 (n.b. Croyle et al (2003) stated the CRI consisted of 58 items).	Eight subscales combining to produce four coping scale scores as outlined below: Approach scale (seeking guidance and support; problem solving; logical analysis; positive reappraisal); Avoidance scale (emotional discharge; seeking alternative rewards; cognitive avoidance; acceptance or resignation); Behavioural scale (emotional discharge; seeking alternative rewards; seeking guidance and support; problem solving); Cognitive scale (logical analysis; positive reappraisal; cognitive avoidance; acceptance or resignation).	Croyle et al, 2003.	The mean of the four subscales was computed to give a total score.	Not reported for the study sample. The test manual (Moos, 1993) reports α for the eight subscales separately for males and females. For males the following α are reported: logical analysis (.67); positive reappraisal (.74); seeking guidance and support (.61); problem solving (.68); cognitive avoidance (.72); acceptance or resignation (.64); seeking alternative
--	---	--	---------------------	--	--

rewards (.68);
emotional discharge
(.62). For females
the following α were
reported: logical
analysis (.64);
positive reappraisal
(.71); seeking
guidance and
support (.60);
problem solving
(.63); cognitive
avoidance (.70);
acceptance or
resignation (.60);
seeking alternative
rewards (.71);
emotional discharge
(.58).

Freiburg Coping with Illness Questionnaire (FKV-Lis) (Muthny, 1989)	35.	Depressive coping; Active problem-oriented coping; Distraction and self-reorganization (Herrmann et al, 1997) (distraction and self-affirmation (Krakow et al, 1999)); Religious relief/quest for sense (Herrmann et al, 1997) (religiousness and search for meaning (Krakow et al, 1999)); Minimization and wishful thinking (Herrmann et al, 1997) (dissimulation and wishful thinking (Krakow et al, 1999)).	Herrmann et al, 1997. Krakow et al, 1999.	None reported. Created two integrating scales, 'effective' and 'uneffective' coping but not specified which subscales these included.	Not reported for either study's sample. The original manual (Muthny, 1989) is produced in German, and was unobtainable, therefore it was not possible to ascertain the developmental internal consistency data.
Medical Coping Modes Questionnaire (Feifel, Strack & Nagy, 1987a; 1987b)	19.	Confrontation; Avoidance; Acceptance-Resignation.	Evans & Norman, 2009.	None reported.	For the study sample: confrontation (.64), avoidance (.64 after removing one item), acceptance-

					resignation (.60). Original scale development reported by Feifel et al (1987a): confrontation (.70); avoidance (.66); acceptance-resignation (.67).
Ways of Coping Checklist-Revised <i>(Vitaliano et al, 1985)</i>	42.	Problem-focused coping; Blaming self; Wishful thinking; Avoidance; Seeking social support.	Moore & Seeney, 2007.	None reported.	Reports all >.71 for study sample. Original scale development reported by Vitaliano et al (1985) reports all subscales above .73 for all three samples studied in development.

Adapted Revised	28 in	Following principal components analysis, 26	MacCarthy & Brown,	Based on principal components	For study sample,
Ways of Coping	adapted	items were retained and four factors	1989.	analysis, combined 'Problem-	positive coping (.79),
Checklist (<i>Folkman</i>	form used.	identified:		solving and reorientation' and	maladaptive coping
& <i>Lazarus, 1985</i>)		Problem-solving and reorientation; Acting		'Distancing' factors into 'Positive	(.69). The scale
		out and distraction; Distancing; Wishful		coping'. Re-labelled 'Acting out	used was adapted
		thinking and denial.		and distraction' factor 'Maladaptive	following principal
				coping'. Excluded 'Wishful thinking	components analysis
				and denial' factor.	so original measure
					development
					reliabilities are not
					applicable.

Table 5.0. DS measures used in reviewed studies.

Measure	No. items	Studies using measure	Internal consistency in studies (Cronbach's alpha (α) unless otherwise stated)
<p>Beck Depression Inventory (<i>Beck, Wards, Mendelson, Mock & Erbaugh, 1961; Beck, Rush, Shaw & Emery, 1979; Beck & Beamesderfer, 1974</i>)</p>	21.	<p>Croyle et al, 2003; Ehmann et al, 1990; Herrmann et al, 1997; MacCarthy & Brown, 1989.</p>	<p>Not reported for any of the four study samples. Original development paper (Beck et al, 1961) reported split-half reliability of $r=0.86$, $r=0.93$ after Spearman-Brown correction.</p>
<p>Cornell Depression Scale (<i>Alexopoulos et al, 1988a</i>)</p>	<p>19 informant-report items, 19 self-report items.</p>	<p>Herrmann et al, 1997 (used informant-report form).</p>	<p>Not reported for study sample. Original development internal consistencies presented by Alexopoulos et al (1988a; 1988b) are for the full measure (informant-report + self-report followed by clinician's judgement), rather than only the informant-report used by</p>

			Herrmann et al (1997). As such, this data is not applicable to the measure used in the study.
The Depression Scale of Von Zerssen <i>(Von Zerssen, 1976)</i>	16.	Krakov et al, 1999.	Not reported for study sample. The developmental internal consistency data for this measure was unobtainable.
Hospital Anxiety & Depression Scale <i>(Zigmond & Snaith, 1983)</i>	7 anxiety questions and 7 depression questions.	Evans & Norman, 2009.	For the study sample, (Depression scale) baseline, $\alpha=.79$, follow-up, $\alpha=.80$. Original development internal consistency data presented by Zigmond & Snaith (1983) was obtained by correlating (Spearman) each item score with the other item scores. They report that for the depression scale used by Evans & Norman

Profile of Mood States (<i>McNair et al, 1971</i>) 65.	Moore & Seeney, 2007 (used 15-item depression subscale).	(2009), all correlations were between .60 and .30, all statistically significant ($p < .02$).
		For study sample, (Depression subscale) $\alpha = .93$. Test manual (McNair et al, 1971) reports that in two normative samples, internal consistency was .95, measured using the Kuder-Richardson Formula 20.

Quality Assessment

The first author assessed the quality of all seven included studies, whilst a subsample of four studies were also assessed by the third author. The final quality assessment scores reported in this section are those of the first author. The highest quality score was 13/16 (Moore & Seeney, 2007). The lowest score was 6/16 (Krakow et al, 1999). The mean quality score was 9.85 (SD=2.41). Criteria not attained by at least 50% (i.e. four studies) were: clearly stating process of recruitment; reporting reliability of/using coping measures demonstrated to be reliable for the study sample; reporting reliability of/ using DS measures demonstrated to be reliable for the study sample; including all coping subscales in all analyses; reporting actual probability values; and accounting for non-coping variables alongside coping variables. Inter-rater agreement on the quality of the subsample of four double-reviewed studies was good ($\kappa=0.78$). Full quality assessment scores are shown in appendix C.

The Relationship between Coping with PD and DS

Ehmann et al (1990) studied coping behaviours over recent months to cope with PD in a group of forty-five participants with idiopathic PD³. Greater BDI scores were significantly correlated with less use of active cognitive coping, characterised by cognitive processes targeted at the stressor, though this correlation was weak. Correlations between BDI score and both active behavioural coping and avoidance were non-significant.

Two studies measured coping using the FKV-Lis. Herrmann et al (1997) recruited participants via an outpatient department, PD centre and patients' associations, and found no significant relationships between FKV-Lis coping

³ PD with an unknown cause (Parkinson's UK, n.d.)

variables and either self- or informant-reported DS. In contrast, Krakow et al (1999) found greater DS moderately and significantly correlated with use of both depressive coping and dissimulating/wishful thinking. Correlations between DS and other FKV-Lis coping subscales were not presented; it is unclear if this is due to non-significance. This study's sample were PD inpatients, whereas most other studies' samples appear to consist largely of outpatients. Consequently, stressors facing this population and other samples may differ.

Similarly, Croyle et al's (2003) stressor is perhaps different to those faced in other studies, possibly upcoming deep brain stimulation (DBS) due to motor symptoms. Neither Coping Responses Inventory (CRI) summary score, nor any of the CRI's four subscales, significantly correlated with BDI score. A strength of this study is the undertaking of a hierarchical regression analysis, to consider interactions between coping subscales that may have obscured significant relationships with DS. Within this regression analysis⁴, behavioural coping alone did not significantly predict DS, however adding cognitive coping at step two led to behavioural coping predicting lower DS and cognitive coping predicting greater DS. Approach coping made no contribution whilst avoidance was not tested for statistical reasons. This study did not however attempt to account for non-coping variables.

The above studies did not report internal consistency data for the utilised DS and coping measures with regards to their study samples. MacCarthy and Brown (1989) similarly did not report the internal consistency of the BDI in their sample, however following a principal components analysis on the Ways of Coping Checklist (WCC) they used two coping subscales, one with acceptable

⁴ Apart from the second regression analysis conducted by Evans and Norman (2009) predicting follow-up DS, the discussions of reviewed studies' regression analyses refer to the extent to which scores on a given coping variable predict scores on a given DS measure cross-sectionally, as opposed to predicting future DS.

internal consistency and the other approaching acceptability at $\alpha=.69$. The first scale combined two factors, 'problem solving and reorientation' and 'distancing', labelled 'positive coping'. The second was labelled 'maladaptive coping' and reflected a factor called 'acting out and distraction'. DS significantly moderately correlated with use of maladaptive coping, but were unrelated to positive coping. Unlike Croyle et al (2003), MacCarthy and Brown (1989) included the influence of functional disability, a non-coping variable, in a hierarchical regression. With this added at step one, and maladaptive coping added with self-esteem at step two, maladaptive coping was a significant independent predictor of greater DS. However, the concurrent addition of maladaptive coping and self-esteem renders the variance contribution of maladaptive coping specifically indeterminable.

Specific variance contributions were also not discernible in the findings of Moore and Seeney (2007). Prior to developing a regression model, depressed mood measured with the Profile of Mood States (POMS) did not significantly correlate with problem-focused coping or seeking social support, but greater depressed mood was significantly and moderately correlated with the use of the strategies 'blames self', 'avoidance' and 'wishful thinking'. These significant coping types were entered into a regression model along with social impairments and disease-related variables, which explained 64% of the variance in depressed mood. Blaming self and avoidance were significant independent predictors of greater depressed mood, though wishful thinking was not a significant independent predictor. This study benefited from assessing the internal consistency of all coping subscales and the POMS, finding all $\alpha>.71$.

Evans and Norman (2009) also presented the internal consistency of their measures. The HADS depression subscale showed acceptable levels,

however all coping subscales had $\alpha < .70$, a limitation the authors acknowledge. Significant positive correlations between DS and both avoidance and acceptance-resignation (tendency to resignation) were reported. There was no correlation with confrontation coping. In a regression analysis, both avoidance and acceptance-resignation were entered at step two, with step one consisting of illness representations (e.g. identity, personal control) that also significantly correlated with DS. Together, the coping variables accounted for a significant amount of variance (6%) in DS; acceptance-resignation was a significant independent predictor (of greater DS), though avoidance was not. Acceptance-resignation also significantly mediated the relationships between two types of illness representation and DS. Evans and Norman (2009) was the only reviewed study to examine coping longitudinally. Higher scores on acceptance-resignation (reflecting resignation) at baseline were significantly correlated with greater DS measured six months later, though neither baseline avoidance nor confrontation coping correlated with DS at follow-up. A regression analysis with baseline DS at step one, baseline consequences and personal control illness representations at step two, and baseline acceptance-resignation at step three found that acceptance-resignation was not a significant independent predictor of DS at follow-up, and that its addition contributed only 2% of variance.

Discussion

The Relationship between Coping with PD and DS

Findings suggest there may be a relationship between the way PWPD cope with PD and DS. Cross-sectional findings showed only active cognitive coping (Ehmann et al, 1990) correlated with lower DS, whilst depressive coping, dissimulation and wishful thinking (Krakow et al, 1999), blaming self, wishful

thinking (Moore & Seeney, 2007), avoidance (Moore & Seeney, 2007; Evans & Norman, 2009), resignation (Evans & Norman, 2009) and maladaptive coping (MacCarthy & Brown, 1989) correlated with greater DS. Regression analyses taking into account other variables also identified relationships, with behavioral coping related to lower DS and cognitive coping related to greater DS when both types of coping were accounted for (Croyle et al, 2003). Maladaptive coping still significantly predicted greater DS when functional disability and self-esteem were accounted for (MacCarthy & Brown, 1989), whilst blaming self and avoidance were significant independent predictors of greater DS when selected disease-related and social variables were also considered in a regression analysis, though wishful thinking's bivariate relationship with DS was reduced to non-significance in this path analysis model (Moore & Seeney, 2007). Evans and Norman (2009) found that accounting for the effect of various illness representations and resignation reduced the relationship between avoidance and DS to non-significance, but resignation remained an independent predictor of greater DS; both coping variables together predicted 6% of variance in DS.

Due to the correlational nature of these findings, the direction of identified relationships is unclear. For example, active cognitive coping may correlate with lower DS because it enables positive efforts to manage emotions and change stressors. Conversely, given the relationship between DS and cognition (e.g. Starkstein et al, 1990), DS could inhibit the use of active cognitive coping. However, Ehmann et al (1990) suggested that their PWPD sample had significantly greater DS than control participants, but did not differ on usage of most specific coping strategies, whilst Croyle et al (2003) showed comparable mean usage of coping strategies in high and low BDI groups. In contrast, cognitive coping was related to elevated DS in Croyle et al's (2003) findings,

with behavioural coping related to lower DS, when both types of coping were considered together; these variables consisted of various coping types, both approach and avoidance, therefore it is difficult to relate these specifically to outcomes. The other variables related to elevated DS seem to broadly reflect emotion-focused coping, since these variables, and the items contributing to them in the studies' coping measures, typically reflected strategies targeted at managing emotions, rather than managing the stressor itself. According to Lazarus and Folkman (1984), such a focus is characteristic of emotion-focused coping. These strategies could lead to greater DS because emotion-focused coping does not resolve stressors, such that negative effects of stressors continue. Alternatively, these emotion-focused strategies could deliberately increase distress, to enable relief to be felt later or to motivate remedying action (Lazarus & Folkman, 1984). However, due to the progressive and uncontrollable nature of PD, such relief may never be attained, and motivated action may be futile, such that negative emotional coping, and DS, continue. On the other hand, these variables could be associated with long-term benefit even in PD. However, the only longitudinal findings in this review (Evans & Norman, 2009) showed that baseline avoidance, though cross-sectionally related to elevated DS, was not longitudinally related to DS, whilst baseline resignation correlated with greater DS in the future, suggesting resignation was not associated with long-term benefits. It is interesting to note however that in a regression analysis taking into account other variables, although baseline resignation did not significantly predict DS at follow-up, the relationship direction suggested that greater use of resignation at baseline might be related to lower DS at follow-up i.e. that this form of coping could have longitudinal benefits. As such, further longitudinal studies might be beneficial to explore this possibility.

Again, however, the correlational nature of these findings means that the relationships may operate in the opposite direction. DS might lead to patients having more emotions to cope with, leading to use of emotion-focused coping. It could also be argued that some of these emotion-focused variables, and items contributing to them in coping measures (e.g. resignation; hopelessness; self-pity; brooding; wishful thinking; preparing for the worst) are DS themselves, and are simply another aspect of a depressed presentation, resulting from some other variable.

Though correlational research leaves relationship direction indiscernible, it may be that relationships between coping variables and DS are bi-directional, interacting with a range of other relationships. Cognitive-behavioural therapy (CBT), a model of therapy seemingly beneficial in PD for DS (e.g. Dobkin et al, 2011a; 2011b), highlights bi-directional links between emotions (e.g. depressed mood), physiology, thoughts and behaviours (Westbrook, Kennerley & Kirk, 2011), in a complex multi-factorial system as opposed to a system based on simple cause and effect relationships. Coping, given it is conceptualised by Lazarus and Folkman (1984) as either cognitive or behavioural, may fit within this system. Some aspects of DS within this model could develop independently of coping (e.g. biologically), which then influences the way PWPD cope with PD (contained within their thoughts and behaviours). These ways of coping may then further influence other DS in a maintaining cycle of inter-connections. Alternatively, use of maladaptive coping strategies could influence the initial development of other DS, which then influence coping in turn. In such a conceptualisation of DS and coping in PD, the absence of causal inference would not preclude identification of coping variables of interest from the reviewed studies, as these relationships would be hypothesised to operate in

both directions. The largely cross-sectional nature of reviewed studies does however inhibit determination of whether coping variables have an initial causal influence on the development of other DS, or whether they only maintain other DS following the development of DS due to other factors; longitudinal and prospective studies would better enable this to be studied, which might enable more effective targeting of interventions (i.e. whether coping interventions could be pre-emptive to prevent DS developing, or whether such interventions would be beneficial only after DS development).

Unfortunately, there are other methodological issues that limit the ability to draw conclusions regarding relationships between the way PWPD cope with PD and DS. Firstly, since only two studies used the same coping measure, direct replication of method and findings is largely absent. The only measure used by more than one study was the FKV-Lis (Herrmann et al, 1997; Krakow et al, 1999). However, their findings were inconsistent, possibly related to sample characteristics (e.g. inpatient vs. outpatient; participant age). Though similar conceptualisations of coping were measured in reviewed studies, subscales typically included different items, or multiple coping behaviours were measured in one subscale, making it difficult to reliably compare and categorise studied coping variables. Some inconsistencies in results whereby similar coping variables are significantly related to DS in one study and not others may be contributed to by this, and also by use of different DS measures.

Non-significant relationships between coping variables and DS were also reported. This may reflect the absence of a relationship between that particular variable and DS. Alternatively, it could be that an existent relationship is obscured by other variables, as in Croyle et al's (2003) study. A further issue, highlighted by the quality assessment, was lack of reporting of/inadequate

internal consistencies of utilised coping and DS measures for the study samples. Some measures for which sample-specific data was not presented in studies have been reported to be measures with adequate reliability during development (e.g. BDI; some subscales of the CRI and Billings and Moos coping questionnaire), and therefore it is likely that these were also reliable in the study samples despite the absence of this information. However, other subscales of the CRI and Billings and Moos coping questionnaire were reported to have inadequate reliability during development ($\alpha < .70$), whilst some measures were unobtainable, therefore developmental internal consistency data for these measures is unknown (e.g. FKV-Lis; Depression Scale of von Zerssen). Additionally, the use of the CDS by Herrmann et al (1997) deviated from that for which internal consistency was reported in the measure's development, making comparisons difficult. As such, the reliability and validity of many utilised coping and DS measures, and therefore many of the studies' findings, is uncertain. In the absence of sample-specific internal consistency data, and considering the mixed internal consistency of measures during their development, it is possible that some measures had inadequate internal consistencies which made it more difficult to find significant relationships.

The validity of DS measures is also questioned by the possible overlap between DS and PD. Some DS measures used (e.g. BDI, HADS, CDS) include items that could be related to PD rather than being a DS, such as physical problems, tiredness and not enjoying previously enjoyed activities. It may be that when measuring DS in PD (as opposed to clinically diagnosing depression), depressed mood should be the variable of interest, measured with tools exclusively measuring depressed mood as opposed to DS more widely. Alternatively, measuring aspects of DS that are less likely to be confounded by

PD itself (such as general thoughts of guilt and self-blame (as opposed to these being used as coping strategies)) may be beneficial.

One of the key limits on drawing conclusions regarding relationships between coping with PD and DS is the failure to acknowledge the potential influence of wider variables in the reviewed studies. Weak-moderate bivariate correlations and small variance contributions of coping variables in regression analyses suggest sizeable portions of variance in DS was unexplained in reviewed studies, whilst other studies (e.g. Gotham et al, 1986; Tandberg, Larsen, Aarsland, Laake & Cummings, 1997) suggest other variables such as symptom severity, functional disability and medication dosage may be related to DS in PD. Furthermore, the regression analyses undertaken in some studies showed that when other variables were accounted for, the relationships between coping variables and DS were often altered, and in some cases other influencing variables also affected usage of coping strategies. As such, it seems unlikely that bivariate correlations are an adequate way of representing the reality of the relationships between coping variables and DS, as bivariate correlations assess this relationship in isolation. Though the regression analyses did account for the influence of other variables in reviewed studies, sizeable variance remained unexplained, suggesting there are likely to be other influencing variables that were not considered, which might also affect coping-DS relationships. It seems important then that future studies investigating the relationship between coping variables and DS consider a wider range of potentially influencing variables to better reflect reality, and, as noted by Croyle et al (2003), the effect of coping variables on each other. Given the number of potential variables that might influence DS, the size of relationships between DS and coping variables may be relatively small when other variables are

accounted for. Larger sample sizes may be necessary if wider variables are taken into consideration to ensure adequate power.

Frazier's (2000) findings suggest that the outcome of some coping strategies may be stressor-dependent. Apart from the study by Croyle et al (2003), participants seem to have responded regarding their coping with 'PD' in the reviewed studies. This question may lack reliability and have led to some of the inconsistent and non-significant relationships, since, as PD is associated with a range of impacts, both motor and non-motor, physical and psychological, it may be that 'PD' is too general, and is associated with such breadth of stressors that each individual may have responded with different stressors in mind. This would inevitably impact on the strength of any relationships found, since the coping measures are not necessarily measuring the same thing for each participant, meaning there may be high levels of variance due to these differences. Examining the relationships between stressor-specific coping and DS in future studies may more accurately reflect reality for PWPD, improve reliability of findings, and facilitate more beneficial targeting of interventions.

A further topic that might be considered is appraisal. The Common Sense Model of Illness Representations (Leventhal, Meyer & Nerenz, 1980) suggests that individuals appraise their coping efforts. None of the reviewed studies included this factor. In contrast, Brod et al (1998) reported that PWPD's attempts to avoid both worrying about the future and dwelling on impairment were correlated with increased psychological and cognitive symptom severity; however avoidance attempts considered successful were related to lower severity in these domains. The appraisal of coping may then influence whether a coping variable is related to positive or negative outcomes, as opposed to the coping variable per se; this may have influenced some of the non-significant

and inconsistent findings. Considering the possible role of appraisal, it may be that psychological intervention for DS in PD need not focus on facilitating specific coping styles, but rather exploring with PWPD what they think would be helpful, and supporting them to achieve and test this.

Recommendations

Multiple factors likely influence DS, therefore studying coping-DS relationships in isolation perhaps lacks ecological validity. Consequently, future research should explore relationships between coping variables and DS in a context of other influencing relationships, rather than isolating the relationship between a coping variable and DS. However, these multiple influences (including coping variables), as in a CBT model, may have bi-directional and unpredictable relationships with DS, and with each other. Such features suggest DS may be a complex system (or problem). The unpredictability and lack of independence of any individual factor or relationship in such a complex system means agreement and certainty regarding intervention is often not total (figure 3.0). It is unlikely therefore that a simple intervention (i.e. one or more interventions with predictable cause and effect outcome) is possible. As such, findings from future studies should not be interpreted as moving towards 'knowing' exactly which variables influence DS in order to develop a prescriptive, predictably beneficial treatment. Such an interpretation would be based on the notion that 'big problems can be broken down into smaller ones, analysed, and solved by rational deduction' (Plsek & Greenhalgh, 2001, p625).

In any case, such research could never fully reflect reality.

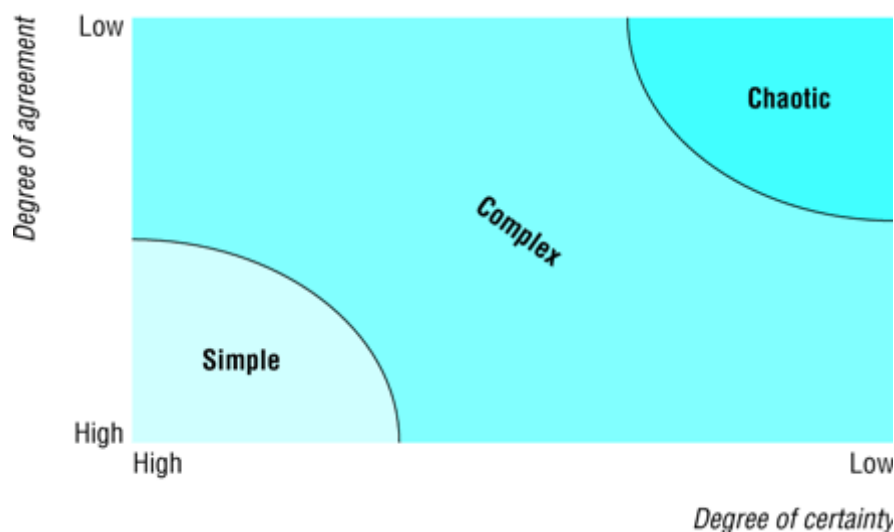


Figure 3.0. Distinction between simple, complex, and chaotic systems (from Plsek & Greenhalgh, 2001)

Instead, future findings should be interpreted as indicating variables that might influence DS in PD (allowing some degree of certainty and agreement, avoiding chaos), which clinicians might consider when planning interventions in this context, taking into account what is appropriate for the specific individual and acknowledging the complexity of the problem. Future research might also consider using prospective and longitudinal designs to better study the nature of coping-DS relationships; using reliable, valid, consistent methods of measurement; studying the effect of stressor-specific coping; and considering coping appraisal.

Critique of Review

The use of a customised quality checklist means the reliability and validity of this assessment is unknown. However, a second reviewer assessed a subsample of studies in an effort to assess this procedure's reliability.

Furthermore, including only peer-reviewed papers means this review may suffer from publication bias. Study selection was conducted by only one reviewer;

reliability could have been measured and improved by having a second reviewer. The conceptualisation of coping used in this review assumed that coping outcome is stressor-dependent, therefore only studies assessing coping in a PD-specific context were included. Other authors (e.g. Hurt et al, 2011) have measured coping more generally, perhaps reflecting a conceptualisation of coping characterised by stability across stressors. Other authors may not consider the distinction between these two conceptualisations necessary and wish to examine both types of coping conceptualisations concurrently, however it was felt that this was an appropriate distinction in the present review to answer the review question.

Conclusions

Findings suggest there are some relationships between the way PWPD cope with PD and DS. Such relationships may be bi-directional, therefore findings from correlational research would still be useful. Unfortunately, usage of different coping measures impeded replication of findings, whilst utilised measures have uncertain reliability. Studies also did not adequately account for the context within which coping-DS relationships occur. DS are likely to be a complex problem, influenced by multiple factors with bi-directional and inter-connected relationships. Future research findings should not be seen as the basis of prescriptive, simple interventions, but rather as suggesting variables to consider when planning multi-factorial interventions for DS in PD, acknowledging the person and their context.

References

- Alexopoulos, G.S., Abrams, R.C., Young, R.C. & Shamoian, C.A. (1988a). Cornell scale for depression in dementia. *Biological Psychiatry*, 23, 271-284. doi: 10.1016/0006-3223(88)90038-8.
- Alexopoulos, G.S., Abrams, R.C., Young, R.C. & Shamoian, C.A. (1988b). Use of the Cornell scale in nondemented patients. *Journal of the American Geriatrics Society*, 36 (3), 230-236.
- Beck, A.T., Wards, C.H., Mendelson, M., Mock, J. & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4, 561-571. doi:10.1001/archpsyc.1961.01710120031004.
- Beck, A.T. & Beamesderfer, A. (1974). Assessment of depression: the depression inventory. In P. Pichot (Ed.), *Psychological measurements in psychopharmacology, vol 7*. Paris: Karger-Basel.
- Beck, A.T., Rush, A.J., Shaw, B.F. & Emery, G. (1979). *Cognitive therapy of depression*. New York: The Guildford Press.
- Billings, A.G. & Moos, R.H. (1981). The role of coping responses and social resources in attenuating the stress of life events. *Journal of Behavioral Medicine*, 4 (2), 139-157. doi: 10.1007/BF00844267.
- Brod, M., Mendelsohn, G.A. & Roberts, B. (1998). Patients' experience of Parkinson's disease. *Journal of Gerontology*, 53B (4), 213-222. doi: 10.1093/geronb/ 53B.4.P21.
- Croyle, K.L., Tröster, A.I., Fields, J.A., Straits-Tröster, K.A., Lyons, K.E. & Pahwa, R. (2003). Presurgical coping, depression, and quality of life in persons with Parkinson's disease. *Journal of Clinical Psychology in Medical Settings*, 10 (2), 101-107. doi: 10.1023/A:1023342021244.

- Dauer, W. & Przedborski, S. (2003). Parkinson's disease: mechanisms and models. *Neuron*, 39, 889-909. doi: 10.1016/S0896-6273(03)00568-3.
- Dobkin, R.D., Menza, M., Allen, L.A., Gara, M.A., Mark, M.H., Tiu, J. & Bienfait, K.L. et al (2011a). Cognitive-behavioural therapy for depression in Parkinson's disease: a randomized, controlled trial. *American Journal of Psychiatry*, 168, 1066-1074. doi: 10.1002/mds.21455.
- Dobkin, R.D., Menza, M., Allen, L.A., Tiu, J., Friedman, J., Bienfait, K.L. & Gara, M.A. et al (2011b). Telephone-based cognitive-behavioural therapy for depression in Parkinson disease. *Journal of Geriatric Psychiatry and Neurology*, 24 (4), 206-214. doi: 10.1177/0891988711422529.
- Downs, S.H. & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology & Community Health*, 52, 377-384. doi: 10.1136/jech.52.6.377.
- Ehmann, T.S., Beninger, R.J., Gawel, M.J. & Riopelle, R.J. (1990). Coping, social support, and depressive symptoms in Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology*, 3, 85-90. doi: 10.1177/089198879000300206.
- Evans, D. & Norman, P. (2009). Illness representations, coping and psychological adjustment to Parkinson's disease. *Psychology & Health*, 24 (10), 1181-1196. doi: 10.1080/08870440802398188.
- Fahn, S., Elton, R.L. & UPDRS Development Committee (1987). Unified Parkinson's disease rating scale. In S. Fahn, C.D. Marsden, D.B. Calne & M. Goldstein (Eds.), *Recent developments in Parkinson's disease (vol 2)*. New Jersey: Macmillan Healthcare Information.

- Feifel, H., Strack, S. & Nagy, V.T. (1987a). Coping strategies and associated features of medically ill patients. *Psychosomatic Medicine*, *49*, 616-625.
- Feifel, H., Strack, S. & Nagy, V.T. (1987b). Degree of life-threat and differential use of coping modes. *Journal of Psychosomatic Research*, *31* (1), 91-99. doi: 10.1016/0022-3999(87)90103-6.
- Felton, B.J. & Revenson, T.A. (1984). Coping with chronic illness: a study of illness controllability and the influence of coping strategies on psychological adjustment. *Journal of Consulting and Clinical Psychology*, *52* (3), 343-353.
- Folkman, S. & Lazarus, R.S. (1985). If it changes it must be a process: study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology*, *48*, 150-170. doi: 10.1037/0022-3514.48.1.150.
- Frazier, L.D. (2000). Coping with disease-related stressor in Parkinson's disease. *The Gerontologist*, *40* (1), 53-63. doi: 10.1093/geront/40.1.53.
- Frisina, P.G., Borod, J.C., Foldi, N.S. & Tenenbaum, H.R. (2008). Depression in Parkinson's disease: health risks, etiology, and treatment options. *Neuropsychiatric Disease and Treatment*, *4* (1), 81-91.
- Gjerstad, M.D., Alves, G., Wentzel-Larsen, T., Aarmland, D. & Larsen, J.P. (2006). Excessive daytime sleepiness in Parkinson disease: is it the drugs or the disease? *Neurology*, *67* (5), 853-858. doi: 10.1212/01.wnl.0000233980.25978.9d.
- Gotham, A.M., Brown, R.G. & Marsden, C.D. (1986). Depression in Parkinson's disease: a quantitative and qualitative analysis. *Journal of Neurology, Neurosurgery and Psychiatry*, *49*, 381-389. doi: 10.1136/jnnp.49.4.381.

- Hely, M.A., Morris, J.G., Reid, W.G. & Trafficante, R. (2005). Sydney multicenter study of Parkinson's disease: non-L-dopa-responsive problems dominate at 15 years. *Movement Disorders, 20* (2), 190-199. doi: 10.1002/mds.20324.
- Herrmann, M., Freyholdt, U., Fuchs, G. & Wallesch, C.W. (1997). Coping with chronic neurological impairment: a contrastive analysis of Parkinson's disease and stroke. *Disability and Rehabilitation, 19* (1), 6-12. doi: 10.3109/09638289709166439.
- Hoehn, M.M.J. & Yahr, M.D. (1967). Parkinsonism: onset, progression, and mortality. *Neurology, 17*, 427-442. doi: 10.1212/WNL.17.5.427.
- Hurt, C.S., Thomas, B.A., Burn, D.J., Hindle, J.V., Landau, S., Samuel, M., Wilson, K.C.M. & Brown, R.G. (2011). Coping in Parkinson's disease: an examination of the coping inventory for stressful situations. *International Journal of Geriatric Psychiatry, 26*, 1030-1037. doi: 10.1002/gps.2634.
- Jankovic, J. (2008). Parkinson's disease: clinical features and diagnosis. *Journal of Neurology, Neurosurgery, and Psychiatry, 79*, 368-376. doi: 10.1136/jnnp.2007.131045.
- Karlsen, K.H., Larsen, J., Tandberg, E. & Maland, J. (1999). Influence of clinical and demographic variables on quality of life in patients with Parkinson's disease. *Journal of Neurology, Neurosurgery, and Psychiatry, 66* (4), 431-435. doi: 10.1136/jnnp.66.4.431.
- Krakow, K., Haltenhof, H. & Bühler, K.E. (1999). Coping with Parkinson's disease and refractory epilepsy. *The Journal of Nervous and Mental Disease, 187* (8), 503-508. doi: 10.1097/00005053-199908000-0000.
- Lazarus, R.S. & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.

- Leventhal, H., Meyer, D. & Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Medical Psychology*, p7-30. Oxford: Pergamon Press.
- MacCarthy, B. & Brown, R. (1989). Psychosocial factors in Parkinson's disease. *British Journal of Clinical Psychology*, 28, 41-52. doi: 10.1111/j.2044-8260.1989.tb00810.x.
- Magerkurth, C., Schnitzer, R. & Braune, S. (2005). Symptoms of autonomic failure in Parkinson's disease: prevalence and impact on daily life. *Clinical Autonomic Research*, 15, 76-82. doi: 10.1007/s10286-005-0253-z.
- McNair, D.M., Lorr, M. & Droppleman, L.F. (1971). *Manual: Profile of Mood States*. San Diego: Educational and Industrial Testing Service.
- Menza, M.A. & Mark, M.H. (1994). Parkinson's disease and depression: the relationship to disability and personality. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 6, 165-169.
- Moore, K.A. & Seeney, F. (2007). Biopsychosocial predictors of depressive mood in people with Parkinson's disease. *Behavioral Medicine*, 33, 29-37. doi: 10.3200/BMED.33.1.29-38.
- Moos, R.H. (1993). *Coping Responses Inventory: CRI – Adult Form*. Odessa: Psychological Assessment Resources.
- Muthny, F.A. (1989). *Freiburger Fragebogen zur Krankheitsverarbeitung*. Weinheim: Beltz.
- Ogden, J. (2007). *Health psychology: a textbook*. Maidenhead: Open University Press.

- Parkinson's UK (2009). *Parkinson's prevalence in the United Kingdom*. London: Author. Retrieved from <http://www.edinburghparkinsons.org/wp-content/uploads/import/ParkinsonsprevalenceUK.pdf> on 10/05/14.
- Parkinson's UK (n.d.). *Types of Parkinson's and Parkinsonism*. Retrieved from <http://www.parkinsons.org.uk/content/types-parkinsons-and-parkinsonism> on 10/05/14.
- Plsek, P.E. & Greenhalgh, T. (2001). The challenge of complexity in health care. *British Medical Journal*, *323*, doi: 10.1136/bmj.323.7313.625.
- Reijnders, J.S.A.M., Ehrt, U., Weber, W.E.J., Aarsland, D. & Leentjens, A.F.G. (2008). A systematic review of prevalence studies of depression in Parkinson's disease. *Movement Disorders*, *23* (2), 183-189. doi: 10.1002/mds.21803.
- Roth, S. & Cohen, L.J. (1986). Approach, avoidance and coping with stress. *American Psychologist*, *41* (7), 813-819. doi: 10.1037/0003-066X.41.7.813.
- Schrag, A., Jahanshahi, M. & Quinn, N. (2000). What contributes to quality of life in patients with Parkinson's disease? *Journal of Neurology, Neurosurgery and Psychiatry*, *69*, 308-312. doi: 10.1136/jnnp.69.3.308.
- Starkstein, S.E., Bolduc, P.L., Mayberg, H.S., Preziosi, T.J. & Robinson, R.G. (1990). Cognitive impairments and depression in Parkinson's disease: a follow up study. *Journal of Neurology, Neurosurgery, and Psychiatry*, *53*, 597-602. doi: 10.1136/jnnp.53.7.597.
- Starkstein, S.E., Mayberg, H.S., Leiguarda, R., Preziosi, T.J. & Robinson, R.G. (1992). A prospective longitudinal study of depression, cognitive decline, and physical impairments in patients with Parkinson's disease. *Journal of*

Neurology, Neurosurgery and Psychiatry, 55, 377-382. doi:
10.1136/jnnp.55.5.377.

Tandberg, E., Larsen, J.P., Aarsland, D., Laake, K. & Cummings, J.L. (1997).

Risk factors for depression in Parkinson disease. *Archives of Neurology*, 54, 625-630. doi: 10.1001/archneur.1997.00550170097020.

Vitaliano, P.P, Russo, J., Carr, J.E., Maiuro, R.D. & Becker, J. (1985). The ways of coping checklist: revision and psychometric properties. *Multivariate Behavioral Research*, 20, 3-26. doi: 10.1207/s15327906mbr2001_1.

Von Zerssen, D. (1976). *Paranoid-Depressivitäts-Skala. Depressivitäts Skala*. Weinheim:Beltz.

Weintraub, D., Moberg, P.J., Duda, J.E., Katz, I.R. & Stern, M.B. (2004). Effect of psychiatric and other nonmotor symptoms on disability in Parkinson's disease. *Journal of the American Geriatrics Society*, 52, 784-788. doi: 10.1111/j.1532-5415.2004.52219.x.

Westbrook, D., Kennerley, H. & Kirk, J. (2011). *An introduction to cognitive behaviour therapy: skills and applications (2nd edition)*. London:Sage.

Wooten, G.F., Currie, L.J., Bovbjerg, V.E., Lee, J.K. & Patrie, J. (2004). Are men at greater risk for Parkinson's disease than women? *Journal of Neurology, Neurosurgery, and Psychiatry*, 75 (4), 637-639. doi: 10.1136/jnnp.2003.020982.

Yang, S., Sajatovic, M. & Walter, B.L. (2012). Psychosocial interventions for depression and anxiety in Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology*, 25, 113-121. doi: 10.1177/0891988712445096.

Zigmond, A.S. & Snaith, R.P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67, 361-370. doi: 10.1111/j.1600-0447.1983.tb09716.

Part two: Empirical Study

The impact of specialist palliative care on coping in Parkinson's disease: the experiences of patients and carers

Nathan J. Badger¹, Dr Dorothy Frizelle¹ and Prof Miriam Johnson²

¹Department of Psychological Health and Wellbeing,
University of Hull

²Hull York Medical School, University of Hull

This paper is prepared for submission to the British Journal of Health Psychology, as per the author guidelines (Appendix A).

Word count (exc. appendices): 9,341

Word count (exc. abstract, figures/tables, and references as per author guidelines, and appendices): 5,284

*Requests for reprints should be addressed to Nathan Badger, Department of Psychological Health and Wellbeing, Hertford Building, University of Hull, Cottingham Road, Hull, HU6 7RX, United Kingdom (e-mail: Nathan.badger@nhs.net).

Abstract

Objectives: Despite recommendations that patients with Parkinson's disease (PD) have access to a palliative approach to care, provision is poor, and the impact of specialist palliative care (SPC) for this population is unknown. This study explored the experiences of patients with PD and their carers referred to a SPC service, with particular attention to the effect of SPC on their ability to cope with effects of PD.

Design: Research in this area is lacking, therefore a qualitative design facilitating exploration was used, focusing on participants' lived experience.

Methods: Eight semi-structured interviews were conducted, three with patients with PD and five with carers. Data was analysed using Interpretative Phenomenological Analysis (IPA).

Results: Participants reported that access to SPC services helped them cope with the impact of PD. Three super-ordinate themes were developed: managing uncertainty; impacts on the self; and SPC maintaining a positive outlook.

Conclusions: SPC helped participants cope with PD, in similar ways to SPC's impact in other conditions. The SPC team seemed to acknowledge the complex and holistic nature of PD and cared for patients and carers with this in mind. This enabled health in some aspects for patients and carers despite the continued presence of PD pathology. These findings support the utility of such approaches in both non-SPC and SPC services. Consideration of palliative need in PD may be limited by a fear of acknowledging death, however these

data suggest that such an approach and refocus can be a beneficial rather than negative experience.

Introduction

Parkinson's Disease: Characteristics and Management

Parkinson's disease (PD) is a progressive neurological condition affecting approximately 127,000 people in the United Kingdom (UK) (Parkinson's UK, 2009), with prevalence increasing with age (National Institute for Health and Care Excellence (NICE), 2006). PD is characterised by motor impairment, such as 'tremor at rest, rigidity, akinesia⁵ (or bradykinesia⁶) and postural instability' (Jankovic, 2008, p368), resulting from dopaminergic neuronal death and the presence of protein aggregates called Lewy Bodies in Nigrostriatal regions of the brain (Dauer & Przedborski, 2003). In addition to these hallmark motor features, non-motor effects of PD include erectile and bladder dysfunction, excessive sweating (Magerkurth, Schnitzer & Braune, 2005), cognitive impairment/dementia (Hely, Morris, Reid & Trafficante, 2005), depressive symptoms (Reijnders, Ehrt, Weber, Aarsland & Leentjens, 2008), and excessive daytime sleepiness (Gjerstad, Alves, Wentzel-Larsen, Aarsland & Larsen, 2006). Informal carers of those with PD are typically the patients' spouse, and PD can have substantial impact for them also, including needing to take on responsibilities previously those of the patient, effects on mood and sleep, social life restriction, loss of future plans, financial impact, helplessness, loss of control and self-identity, and emotional exhaustion (McLaughlin et al, 2011; Hasson et al, 2010).

⁵ 'Loss of movement' (Jankovic, 2008, p371).

⁶ 'Slowness of movement' (Jankovic, 2008, p369).

Dopamine-increasing pharmacological treatment is the mainstay of PD management and is recommended by NICE, though further side-effects can become problematic (NICE, 2006). Some patients may also be eligible for surgical stimulation of specific brain regions. All patients with PD should be managed by a multi-disciplinary team including specialist PD nursing, physiotherapy, occupational therapy, and speech and language therapy (NICE, 2006). Furthermore, it is recommended that 'palliative care (PC) requirements of people with PD should be considered throughout all phases of the disease' with '[patients] and their carers...given the opportunity to discuss end-of-life issues' (NICE, 2006, p25).

Palliative Care and Specialist Palliative Care in PD

The World Health Organization (WHO) define PC as 'an approach that improves the quality of life (QoL) of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual...[which] intends neither to hasten or postpone death' (WHO, 2002, p84). Domains contributing to QoL include: physical health; psychological aspects (e.g. emotions and self-esteem); independence; social relationships; environment (e.g. leisure, safety); and spirituality/religion/ personal beliefs (WHO, 1997).

QoL domains (WHO, 1997) seem to overlap considerably with areas impacted by PD for patients and carers, therefore an approach focused on improving QoL such as PC would seem appropriate for a PD population. PC needs are present in PD and related conditions (Saleem et al, 2012) whilst the

challenges of PD (e.g. loss; uncertainty; isolation) are similar to those experienced by patients for whom PC approaches are common (Hudson, Toye & Kristjanson, 2006). One way of meeting PC need is referral to specialist palliative care (SPC) services, which specialise in PC 'provided by a multi-professional team who have undergone recognised SPC training' (Tebbit, 1999, as cited in Association for Palliative Medicine of Great Britain & Ireland (APMGBI), 2012, p6). Tasks undertaken by SPC include symptom management, emotional support, and advice and information provision. Whilst PC can be provided by non-specialist professionals, referral to SPC might be more appropriate where patient need exceeds the non-SPC professional's capabilities, and where needs are particularly complex (APMGBI, 2012). PC and SPC need not be confined to the end-of-life stage, but can be appropriate at any point in the disease process (APMGBI, 2012; Department of Health, 2010), distinguishing PC from end-of-life care which is typically concentrated in the last year of life (APMGBI, 2012).

Despite the apparent relevance of SPC to PD, and presence of PC need in this population, PD patients and carers often do not access SPC services (Hudson et al, 2006; Kristjanson, Aoun & Oldham, 2006); indeed, 'SPC services for PD have been slow to develop' (Richfield, Jones & Alty, 2013, p805). PC and SPC may be limited in PD due to a perceived 'lack of experience of PD in [SPC], lack of available resources to provide such a service and...[health and social care professionals'] own lack of knowledge' (Northern Ireland Hospice & University of Ulster Research Committee (NIHUURC), 2010, p2). Further possible limitations include PC being seen as synonymous with end-of-life care (NIHUURC, 2010) and as exclusively for cancer patients (McLaughlin et al, 2011), the long disease course of PD, and a possible unwillingness for PD

patients and carers to identify PD as a terminal illness (Hudson et al, 2006), particularly as patients and carers may attempt to maintain a positive attitude to cope with PD (NIHUURC, 2010).

SPC has been demonstrated to be beneficial in previous studies, typically with a focus on cancer patients, though some studies have also included other non-PD conditions. SPC may improve symptom and pain management, and reduce hospitalisation (Hearn & Higginson, 1998), increase feelings of security for both patients and carers, and provide a feeling of relief for carers due to being able to attain support if required (Milberg, Strang, Carlsson & Borjesson, 2003). SPC may also improve quality of life for both patients and carers, and for carers reduce anxiety, depression and feelings related to the burden of caring (Groh, Vyhnalek, Feddersen, Fuhrer & Borasio, 2013). A literature review by Bradley, Frizelle and Johnson (2010a, p226) suggested specialist palliative day care (SPDC) 'reduces isolation, increases social support, encourages communication and provides activities', whilst a further qualitative study proposed that SPDC helped patients cope with illness in a variety of ways, including by making them feel cared for, enabling downward comparison, and enabling a focus on other activities rather than illness (Bradley, Frizelle & Johnson, 2010b). Low, Perry and Wilkinson (2005), studying patients with unspecified conditions, reported SPDC was considered a trusted service, leading to feelings of security, and which improved patients' self-esteem. By providing respite, SPDC also allowed carers to relax, whilst patients may feel more able to discuss some issues with SPDC staff than other professionals. Leung et al (2010) suggest that holistic care, as provided by the inpatient SPC service they studied, incorporating psychological, social and spiritual aspects alongside physical intervention, is important.

Coping

From these studies, SPC clearly helped patients and carers manage the impact of illness. Given Lazarus and Folkman's (1984, p141) definition of coping as 'constantly changing cognitive and behavioral efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the person', it might be suggested that SPC helps patients and carers cope. The use of 'manage' in this definition acknowledges that coping does not necessarily involve mastery, but may involve 'minimizing, avoiding, tolerating and accepting' (Lazarus & Folkman, 1984, p142). Lazarus and Folkman (1984) suggested one type of coping is emotion-focused, involving cognitive processes to change emotional distress associated with a stressor, attempting to either reduce it (e.g. avoidance and minimization) or increase it (e.g. self-blame), which may lead to feelings of relief over time. Alternatively, problem-focused coping attempts to change the stressor, either environmentally (i.e. altering the environment to manage a problem) or internally (e.g. learning new skills or problem-focused cognitive reappraisals) (Lazarus & Folkman, 1984; Kahn, Wolfe, Quinn, Snoek & Rosenthal, 1964, as cited in Lazarus & Folkman, 1984). SPC may facilitate individuals' ability to engage in coping efforts themselves, or in some cases provide coping resources, for example directly reducing a stressor such as pain. Sometimes these coping approaches may be mutually facilitative, for example directly targeting a stressor may also lead to distress reduction, or reducing distress may better enable problem-management. However, each may also have negative effects on the other, for example focusing on the problem might lead to elevated distress, whilst focusing on emotions may impede problem-management (Lazarus & Folkman, 1984).

A further conceptualisation of coping is that of Roth and Cohen (1986) who distinguished between directing attention towards a problem (approach coping) or away from it (avoidance coping). Given the relative advantages and disadvantages of both aspects of these two coping conceptualisations, the adaptiveness of a particular type of coping might depend to some extent on the stressor being dealt with, for example the degree to which the stressor is controllable (Roth & Cohen, 1986).

Several studies have investigated the coping methods of PD patients and their relation to outcomes such as mood and QoL. PD patients seem to use similar coping strategies to patients with other neurological conditions, for example distraction, minimization and wishful thinking, and active problem-oriented coping (Herrmann et al, 2000). Avoidance coping may be related to poorer overall and psychosocial health status (Backer, 2000), whilst some types of emotion-focused coping strategies may relate to elevated depressive symptoms (e.g. Moore & Seeney, 2007; Krakow, Haltenhof & Bühler, 1999), though conclusions from this literature may be limited by methodological issues (Badger, Frizelle, Richfield & Johnson, in preparation (part one)). The Common Sense Model (Leventhal, Meyer & Nerenz, 1980) suggests individuals appraise the success of their coping efforts. Brod et al (1998) found that attempting avoidance as a coping strategy was related to negative outcomes, however, if avoidance attempts were appraised as successful, they were related to positive outcomes. It may therefore be that the adaptiveness of coping depends to some extent on the appraisal of its success. The coping of carers of those with PD seems to be much less researched, though Hobson, Leeds and Meara (2001) reported that carers' use of cognitive coping (such as trying to see the positive side; stepping back from the situation) was related to lower levels of depression.

Present Study's Objectives

Bradley et al (2010b) suggested that SPDC positively affects coping, whilst findings discussed above suggest SPC more widely might help patients and carers cope with the impact of illness. However, these studies did not present data specifically regarding the impact of SPC in PD. Consequently, the present study explored the experiences of patients with PD and their carers receiving SPC from a service which offered community, day, and inpatient care. The research questions were:

1. Does SPC affect the ability of patients with PD and their carers to cope with the impact of PD on their lives?
2. If so, what effects does SPC have on their coping?

Method

Design

A qualitative design was employed, analysing data from semi-structured interviews by Interpretative Phenomenological Analysis (IPA), since the focus of IPA, exploration of individuals' experiences and the meaning they ascribe to these (Smith & Osborn, 2008) fitted well with the exploratory aims of this study.

Participants

Participants were recruited from a SPC service in North East England. The inclusion criteria for either member of a patient-carer dyad were i) patient has a primary diagnosis of idiopathic PD⁷; ii) patient had received at least two face-to-face SPC contacts (one contact defined as one community visit (often simultaneous patient and carer contacts); or one day in day hospice; or one night inpatient admission); iii) ability to communicate in English (see appendix

⁷ PD with an unknown cause (Parkinson's UK, n.d.)

D). Patients meeting inclusion criteria and not consistently lacking capacity to consent, as determined by two clinical nurse specialists (CNS) from the SPC service, were invited to participate by being provided with an information leaflet by their CNS (see appendix E, based on Bradley et al, 2010b). Carers were provided with an information leaflet if the patient consented to this, or if the patient consistently lacked capacity. Those interested in participating gave their CNS permission to pass their contact details to the researcher, who made telephone contact to provide further information on the study, answer any questions, initially assess capacity, and arrange an interview appointment if appropriate.

Eight individuals participated in the study. Five female carers participated, each caring for a male patient. Three patients participated, two males and one female. Their details are shown in table 6.0.

Data Collection

Ethical approval was obtained from NRES Committee East Midlands-Derby (see appendix F), sponsor approval was granted (see appendix G) and site approval obtained from the SPC service (see appendix H). Capacity to consent was re-assessed by the researcher immediately prior to the interview, and consent obtained using a standard consent form (see appendix I). A copy of the signed consent form, a cover letter thanking participants for their participation, and the researcher's contact details in case of participant queries, were sent to participants following the interview. Audio recordings and documentation containing identifiable information were kept in accordance with ethical guidelines.

Table 6.0. Participant details.

Pseudonym	Patient/ carer	Gender	Age at interview (years)	Approximate duration of illness at interview	Notes
Susan	Carer	F	79	5 years	Participant's husband's diagnosis was unclear, initially idiopathic PD, but reviewed to 'probable vascular parkinsonism' prior to participation.
Michael	Patient	M	64	28 years	Husband of Barbara.
Carol	Carer	F	66	26 years	
Barbara	Carer	F	64	28 years	Wife of Michael.
Mary	Carer	F	70	10 years	
Elizabeth	Patient	F	65	20-25 years	
Catherine	Carer	F	61	21 years	
Thomas	Patient	M	66	5 years	

The interview schedule (appendix J) was adapted from a schedule used in previous SPC research (Bradley et al, 2010b). The schedule consisted of three main sections. The schedule initially asked participants about their understanding of coping, which was included as an introduction to the topic of coping for the participant, and to help the researcher understand how the

participants conceptualised coping, which might have affected their answers to subsequent questions regarding the impact of SPC on coping. Subsequently participants were asked about the impact of PD on their lives, to bring to mind the PD-related stressors that they were required to cope with, to better enable participants to reflect on how SPC had affected their coping with regards to these stressors. Data obtained from these two sections of the interview schedule was not used to answer the research questions of this study, and is summarised in appendix K. The final section of the interview schedule consisted of questions exploring the impact of SPC on coping, answers to which were used to answer the research questions. Peer and service-user feedback on this adapted schedule was obtained prior to data collection. All interviews were audio recorded and transcribed by the first author.

Data Analysis

Data was analysed in accordance with IPA methodology as described by Smith and Osborn (2008), involving five stages of analysis:

- Initial reading and re-reading of individual transcripts, annotating points of interest.
- Designation of emerging theme titles for individual transcripts.
- Connecting and clustering the themes identified in individual transcripts.
- Repeating these three steps with other transcripts.
- Connecting and clustering themes across cases.

This analysis was iterative, with quotations referred to throughout the process to ensure themes reflected the words of participants and vice versa.

The first stage of analysis was also conducted by the second and/or third author

for three transcripts, with comments informing the overall analysis. In addition, the third author reviewed the themes and supporting quotes for agreement.

Results

Following data analysis using IPA, three super-ordinate themes were identified, which reflected the ways in which SPC had affected participants' ability to cope, or method of coping, with PD and its impacts. These super-ordinate themes each consisted of a number of sub-ordinate themes, which are shown in table 7.0 below.

Referral to SPC often seemed to occur at a time when participants were at the limit of their personal resources:

"P- if it hadn't been for going in there that would have been wipeout.

I- for you?

P- for me yeah cos I was very very unsettled at that I couldn't er cope with cope with life round then" (Thomas).

Table 7.0. Super-ordinate and sub-ordinate themes from interview transcripts.

Managing uncertainty	Impacts on the self	SPC maintaining a positive outlook
Knowing SPC is there to help	Facilitating expression of other aspects of the self	Appraisal of SPC
SPC sharing the caring role	Impacting self-esteem	SPC as a positive service
The competence of SPC	Freedom of choice	
Reassuring that situations are manageable		

The following sections describe the super-ordinate themes, and illustrate each sub-ordinate theme with quotations from the participants. For each sub-ordinate theme, the relative contribution of patients and carers is indicated adjacent to the theme title in the tables below.

Super-ordinate theme: Managing Uncertainty

PD led to situations with which participants were unfamiliar, whilst they were often faced with an uncertain future, regarding what would happen and whether they would be able to manage. Worry and vigilance were frequently described by participants, and these behaviours can be conceptualised as coping efforts, for example Borkovec, Alcaine and Behar (2004, p78) suggest that worry can be used in an attempt to ‘solve the problem of possible future danger’. Similarly vigilance can be used with the aim of reducing uncertainty (Hock & Krohne, 2004). However, use of worry in ambiguous situations may

increase expectation of negative outcomes, maintaining anxiety (Yook, Kim, Suh & Lee, 2010) whilst vigilance may increase negative emotional arousal (Hock & Krohne, 2004). As such, both worry and vigilance may be coping efforts that are related to maladaptive outcomes. By being available and competent, sharing caring with carers, and providing support, advice and interventions for the future, SPC seemed to help participants manage uncertainty, apparently reducing participants' need to engage in worry and vigilance as methods of coping, and therefore potentially protecting them from some of the negative emotions associated with these behaviours. The subordinate themes for this super-ordinate theme are shown in table 8.0, together with supporting quotations from participants.

Table 8.0. Managing uncertainty sub-ordinate themes and supporting quotes.

Knowing SPC is there to help	<i>Approximately 69% of supporting quotes for this theme were provided by carers, 31% by patients.</i>
Participants seemed to value SPC being involved as they knew that they were not alone and there was a service they could go to if they needed support.	<i>"It's made me realise that if I'm struggling I can go in and have some time there, it's made me less anxious I think about the future" (Elizabeth).</i>
The provision of a direct telephone contact that could be used if necessary was particularly important for some carers.	<i>"She's come hasn't she and given me this lifeline this support line to ring her if there's anything that I need but up to that I was ringing anyone I could find there and asking what I had to do, there was no direct sort of thing" (Susan).</i>

SPC sharing the caring role	<i>All supporting quotes (100%) for this theme were provided by carers.</i>
<p>By sharing caring with carers in the form of respite or day hospice care, SPC seemed to allow carers to relax and have some time when they did not have to be vigilant for danger.</p>	<p><i>“It feels lovely...relaxed you know it just relaxes you knowing you’re not worrying about things just for a few hours you’re like free” (Mary).</i></p>
<p>For Carol, it was difficult to separate entirely from the caring role and relax, even when her husband was in respite.</p>	<p><i>“P- Even when he’s in respite and that’s when it clicked I’m thinking after two or three days I should be relaxing and I just couldn’t it’s funny isn’t it I just couldn’t.</i></p> <p><i>I- so really on your mind how he was was it?</i></p> <p><i>P- yeah I was thinking I wonder if he’s alright I know and they kept saying don’t go in every day I won’t I won’t but then you know I were glad I had to see him you know I did go in twice a week” (Carol).</i></p>
The competence of SPC	<i>Approximately 83% of supporting quotes for this theme were provided by carers, 17% by patients.</i>
<p>Relaxation as opposed to being on alert and worrying was often facilitated by the knowledge that SPC was able to care for patients when they were at the day hospice or in respite.</p>	<p><i>“It’s nice to know you’ve got that one day where you know he’s well looked after and I’ve got from say half past nine till half past three where I can do what I want [laugh] yeah yeah so and I know he’s looked after” (Catherine).</i></p>
<p>This was sometimes in contrast to participants’ experience of non-SPC inpatient services.</p>	<p><i>“At the beginning of the year he had to go into hospital and er erm he came out in a worse state than he went in and it was heartbreaking because they knew he couldn’t feed himself but quite often when we went to visit his food had just be there and no-one had but I know that’s</i></p>

not gonna happen at the hospice I know that someone's going to make sure that he's been fed that he's clean that he's had a drink you know so I had absolutely no qualms at all with that that you know he's well looked after yeah" (Mary).

For others, SPC's competence was helpful in managing uncertainty because SPC could raise and resolve issues that participants themselves and others could not.

"Someone somewhere would have had to broach this subject [advance decision], somebody has to make the first move, the CNS made it because I don't know if I would have...I don't know if I'd have really known how to, but with her help..." (Susan)

Knowing SPC had expertise also seemed to benefit participants because they knew SPC could be trusted to know how to help, and that it would be able to.

"I could call erm, ring the hospice and somebody would sort of talk to me...if he's having problems do I ring doctor, that out of hours thing, and they don't know what they're talking about, or do I ring the hospice, I'd ring the hospice you see, say 'I've got a worry about my husband, do you think I should', and you see if they thought that he needed an ambulance or something they'd get it wouldn't they for me, I know they would, so I'm not, there's that worry gone sort of thing" (Barbara).

Reassuring that situations are manageable

Approximately 83% of supporting quotes for this theme were provided by carers, 17% by patients.

SPC seemed to help participants feel that difficulties would be manageable. For Susan, SPC facilitated an advance decision for her husband, meaning she did not need to worry as much about whether she would be able to cope

"Knowing that that's what he wants yeah but if he hadn't had wanted that and he'd wanted this PEG erm and then he had to go back into hospital and they're doing all these things his choking gets worse and he can't cough now and

when her husband approached the end of his life.

it's oh that would have been awful I would not have wanted that...I'm much more at ease because I know he doesn't want that and I won't have to watch him going through anything else I don't think I can cope with because I can't, dying to me and things like that, I don't, I don't like" (Susan).

For others, future situations were made more manageable by providing practical adaptations.

*"P- this blow up sort of thing puts me up and then if we put this in front of me I can generally get back up onto my feet so in the space of time to get it blown up and me instead of being on the floor but sat up at this height.
I- a better height?
P- yeah yeah for standing up it's a lot quicker and steadier you know" (Michael).*

For some, contacting SPC was itself the management plan for future difficulties.

"Now I know that that number's there, the nurse has told me, she's given it me and I know I can ring her so if I get in that panic situation I would ring her so I won't worry about that" (Susan).

Super-ordinate theme: Impacts on the Self

An individual's self-concept consists of their self-definitions (Larsen & Buss, 2008). Caring seemed to reduce carers' opportunities to express other aspects of their self-concept outside of that role. PD also seemed to impact the self-concept by reducing the control and freedom that patients and carers had over their lives. This may be related to locus of control, and there is evidence that perceiving low personal control may be related to depression in PD (Zampieri & de Souza, 2011) and non-PD samples (Presson & Benassi, 1996).

Losing roles and independence, and taking on new uncertain responsibilities, may reduce patients' and carers' self-esteem, their evaluation of themselves, for example whether they are worthwhile or good (Larsen & Buss, 2008). This super-ordinate theme, and the sub-ordinate themes contributing to it, represent the ways SPC helped participants cope with these self-related stressors. In some instances, SPC seemed to enable participants to engage in coping efforts themselves that would not have been accessible without the intervention of SPC (e.g. overcoming lack of freedom of choice; expressing other aspects of self-concept). In other cases, SPC provided coping resources itself by managing a stressor directly, for example impacting self-esteem through the dedicated and compassionate care delivered. The sub-ordinate themes contributing to this super-ordinate theme are shown in table 9.0.

Table 9.0. Impacts on the self sub-ordinate themes and supporting quotes.

<p>Facilitating expression of other aspects of the self</p>	<p><i>Approximately 74% of supporting quotes for this theme were provided by carers, 26% by patients.</i></p>
<p>SPC respite and day hospice services allowed carers to break free of their carer role and express other aspects of their self concept.</p>	<p><i>"it varies yeah I might go and have a cup of coffee with a friend or I might just go in the car and go to the shopping centre or go to the next town make sure I do something" (Catherine).</i></p>
<p>For patients, SPC seemed to support them in doing things that were not illness-related, or to overcome the limitations of PD to express aspects of their self-concept.</p>	<p><i>"I never have been one for games as such you know, sport yeah but not games, but er since I've been there you know I've got involved with er the dominos and things there, and found it quite refreshing in a way" (Michael).</i></p>

Impacting self-esteem	<i>Approximately 55% of supporting quotes for this theme were provided by carers, 45% by patients.</i>
<p>SPC appeared to have effects on the way participants felt about themselves. For Elizabeth, SPC encouraged her to find things she could do in her life.</p>	<p><i>“Encouraging me to sort of follow what I wanted to do erm and er find ways of finding some purpose in life, things I can do from home er that I was very happy to do” (Elizabeth).</i></p>
<p>For Catherine, SPC helped her preserve her self-esteem in the face of making decisions about her husband’s care.</p>	<p><i>“P- You feel as though she doesn’t judge you, you know like I can, I can say ‘well look I’m not taking his independence away I’m letting him do things for himself” and she understands that, yeah, er cos I mean sometimes I think people think you’re maybe being a bit harsh but I don’t mean to be harsh...the nurse has helped with all that..</i></p> <p><i>I- so helped you in kind of</i></p> <p><i>P- Making me realise I’m not being selfish” (Catherine).</i></p>
<p>SPC may also impact on self-esteem by providing a comfortable, dedicated, and compassionate environment and service, that makes patients and carers feel worthy of attention and well cared for.</p>	<p><i>“She’s absolutely wonderful, and I think she’s erm found so many other things than we could ever, or we thought we’d got everything you know cos the times that the hospital had been or the physio would say ‘we’ll send somebody out, see if they can do anything for you’ and er er and yet when she came [from the hospice] she said ‘oh we’ve got this and we’ve got that and we’ll do this’, and yeah been wonderful” (Mary).</i></p>

“She’s so nice, kind, and she’ll listen to anything you say” (Carol).

SPC also helped some patients and carers feel good about themselves by giving them the opportunity to engage in activities related to self-care, and things that made them feel good.

“We used one session, we had a back massage, erm had our feet done er...hands, so it’s absolutely brilliant” (Mary).

“P- also the fact that the hospice you can do normal things having your hair done and all the rest of it

I- having your hair done

P- yes [inaudible] make you feel good about yourself” (Elizabeth).

Elizabeth did note however that she felt guilty about being part of SPC.

“P- I feel I feel guilty really that they could be seeing somebody else

I- what is it you feel guilty about?

P- that I’m taking a space up for someone else who needs to be there [inaudible]” (Elizabeth).

Freedom of Choice

Approximately 65% of supporting quotes for this theme were provided by carers, 35% by patients.

SPC allowed both patients and carers to regain some control over their life by enabling them to make choices for themselves. Just having SPC available as an option was beneficial for Elizabeth in being able to make choices.

“P- I was also quite pleased because a [inaudible] doctor I saw at the time, I was depressed, I had some antidepressants [inaudible] not to take them and this [SPC] was like a compromise

I- so it helped you, so you didn’t want the antidepressants?

P- that’s right yes

I-so it helped you come off of those did it or avoid those?

P- [inaudible] but it made me feel just that I was being awkward you know, it was a positive alternative" (Elizabeth).

Thomas did feel some loss of control however when he went into respite.

"P- I couldn't go for a walk or anything you always had to have somebody with you and you just feel as though you're like a little doggy on a chain but I see their point

I- so they've got to keep you safe?

P- everybody well you see I didn't realise these things it er

I- but that was a bit difficult

P- at that present moment" (Thomas).

By exploring end-of-life issues, SPC can help patients exercise choice about life and death.

"[The CNS] came because we had to put into place with the doctors and other people that he, he never wanted any resuscitation at all because he, he was asked to have this PEG feed, he refused it in April in hospital and the doctors tried to talk him into it" (Susan).

Though Elizabeth ultimately found it beneficial to explore these issues, she was initially unsure.

"Thought it was a bit ambitious really...to make all these plans for the future" (Elizabeth).

Similarly for Michael, practical adaptations provided by SPC seemed to help him make choices about what he wanted to do.

"Oh ye well the beauty of it is that if I'm if we're out somewhere like this last weekend was the regatta well I never went down there I can't do with it there's too many people you know but with the walking frame if you if I wanted to stop or just look admire the view or whatever I I have this seat on it with me so I can just steady it up put the brakes on and just go round it sort of

thing holding onto it and sit on the seat so that's been a big help" (Michael).

Super-ordinate theme: SPC maintaining a positive outlook

Due to PD being a progressive illness, patients and carers are faced with inevitable decline and loss, however The Crisis Theory of Illness suggests one important aspect of coping with illness is preserving emotional balance by continuing to experience positive emotions (Moos & Schaeffer, 1984, as cited in Ogden, 2007). This super-ordinate theme reflects the way SPC seemed to directly help participants maintain this emotional balance, by providing positive experiences, in contrast to the negative emotions and experiences resulting from PD and its impact. Table 10.0 shows the sub-ordinate themes for this super-ordinate theme.

Table 10.0. SPC maintaining a positive outlook sub-ordinate themes and supporting quotes.

Appraisal of SPC	<i>Approximately 46% of supporting quotes for this theme were provided by carers, 54% by patients.</i>
Participants had a strong positive evaluation of the care they received from SPC. This in itself may contribute to the maintenance of positive emotions for participants.	<i>"Like I say, anybody anywhere given the same sort of set up, can't help but come out of it feeling grateful" (Michael).</i>
SPC as a positive service	<i>53% of supporting quotes for this theme were provided by carers, 47% by patients.</i>
Rather than being associated with negativity	<i>"P- It seems very pleasant [inaudible], smiling</i>

and death, SPC seemed to be a service associated with positivity, that participants wanted to be involved in.

I- so they have a good attitude and feeling aswell

P- exactly yes [inaudible] people didn't look to be on death's door [inaudible], people were jolly" (Elizabeth).

"[The carer's group] was more about being relaxed and erm you know, not worrying about what you're doing at home, having a laugh and er you know people telling jokes" (Mary).

For others, SPC provided something to look forward to in the future, against a backdrop of ongoing caring and loss.

"He's going for a week's respite into the hospice, July, August, I've forgotten, I've got it down but I don't remember, and she's arranged that and that is quite, I'm really looking forward to a whole week nearly, you know" (Susan).

However, for Carol SPC did not help with her feelings about the loss of future plans.

"Well put it like this my husband is 72 and I'm 66 and we can't do, you've seen other people retired we can't do what we would have liked to have done because of the PD and it's so, a bit sad really" (Carol).

Discussion

The Impact of SPC on Coping in PD

Findings suggest SPC is beneficial for patients with PD and their carers, and that SPC does affect their ability to cope with the impacts of PD. SPC often seemed to intervene at a point where situational demands were becoming more difficult for participants to manage independently; the actions of SPC then seemed to affect coping, by reducing those demands or helping participants manage them. Importantly, these actions were appraised as beneficial by

participants. These findings seem to fit with the process of coping discussed by Lazarus and Folkman (1984). The impact of SPC on coping does not however seem to fit easily into the two most common coping conceptualisations, the dichotomies of emotion-focused and problem-focused coping (Lazarus & Folkman, 1984), and of approach and avoidance coping (Roth & Cohen, 1986). Many of the effects of SPC could be categorised as either type of coping in these dichotomies. For example, knowledge that SPC is there if needed could be seen as facilitating avoidant coping, enabling participants to think and worry less about the future, but conversely as approach coping, in that it involves acknowledging that there may be difficulties in the future for which they may require support. Similarly, being able to express other aspects of their self-concept could be seen as emotion-focused coping on the one hand, in that it involves a separation from the truth of illness, but problem-focused coping if the problem is seen as a restriction in social life. Imposing such a dichotomy would perhaps oversimplify the impact of SPC on coping. Instead, the ways SPC affected participants' coping with PD seemed to be organised around three super-ordinate themes; managing uncertainty; impacts on the self; and maintaining a positive outlook. These themes are similar to the findings of previous studies investigating SPC in other illness groups (e.g. Low et al, 2005; Milberg et al, 2003; Groh et al, 2013), suggesting that SPC can have similar benefits and impacts for those with PD and their carers as it does for patients and carers facing other illnesses such as cancer. Although all but one of the themes (SPC sharing the caring role) was discussed by at least one patient, it should be noted that the majority of supporting quotes across the three super-ordinate themes were provided by carers (approximately 70%). As a result, the

findings of the present study perhaps reflect the impact of SPC on the coping of carers to a greater extent than the impact of SPC on the coping of patients.

The Role of Holism and Complexity

The benefits SPC had for participants, and the ways SPC led to these benefits, were varied, with a range of professionals involved, and different settings (e.g. community, day hospice, inpatient) and interventions being provided, with regards to both patient and carer. This perhaps reflects a holistic model of care. Such a model considers the broad experience of illness in the context of the whole person and system (Wade, 2009). This approach is in contrast to the biomedical model of illness, which perhaps remains the dominant model of illness in healthcare, whereby illness is conceptualised as arising from underlying pathology, and some separation between the physical and mental is maintained (Wade & Halligan, 2004). Such a model purports that 'disease (pathology) is always the single cause [of illness] and removal or attenuation of the disease will result in a return to health' (Wade & Halligan, 2004, p1398). As such, treatment based on such a model may focus predominantly on pathology, at the expense of other aspects. Previous research suggests some carers of patients with PD may have experienced care characterised by such issues; for example, carers were not included in appointments and felt a lack of opportunity to express their feelings (McLaughlin et al, 2011), whilst meetings with specialists, though considered beneficial, often involved 'lengthy waiting times...with meetings brief, focusing on medication, with little or no psychological support' (Hasson et al, 2010, p734). This study's findings suggest that focusing solely on the pathology of PD (i.e. dopaminergic impairment) may be an inadequate way of caring for and managing PD.

Instead, SPC, by taking a holistic view of the patient and system (e.g. patient-carer dyad), was able to return health to some aspects of the system, benefiting participants' ability to cope with a range of impacts of PD, in spite of the continued presence of pathology. As reflected in the proportion of supporting quotes attributed to carers, SPC has a clear impact on the coping of carers. Care based on the biomedical model rather than a holistic approach is unlikely to adequately address the concerns of carers. Taken together, these findings reinforce the utility of a holistic approach to care in PD that does not focus solely on pathology.

Viewing PD holistically also highlights elements of complexity; for example, PD is associated with a range of stressors, physical and non-physical, which are likely to interact unpredictably. The PD patient therefore shares some features of a complex system. Notably, the complex PD patient also exists within other systems, for example the family system and patient-carer dyad; this embedding of systems is also characteristic of complexity (Plsek & Greenhalgh, 2001). When complex problems (as PD might be conceptualised) present, there may be a tendency to try and impose simplicity by employing unambiguous solutions, where the next intervention is clear, with high agreement and certainty (Plsek & Greenhalgh, 2001) (figure 4.0).

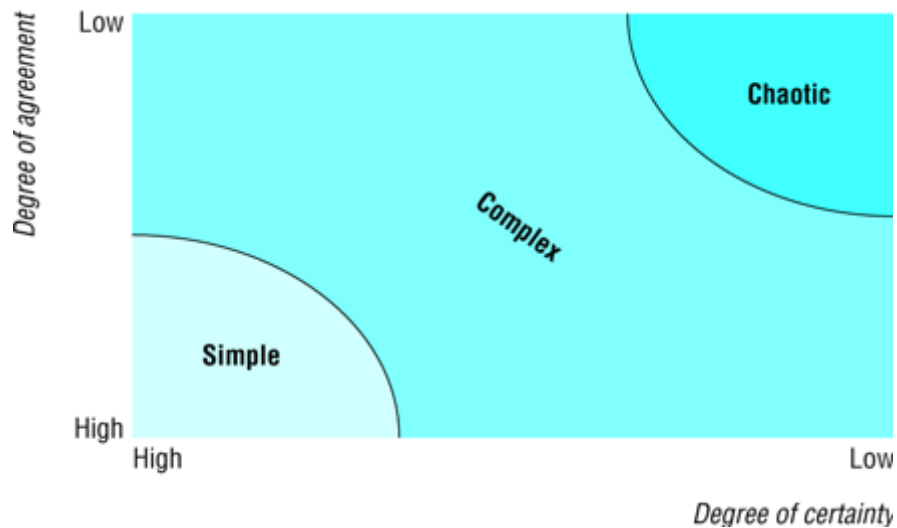


Figure 4.0. The distinction between simple, complex, and chaotic systems (from Plsek & Greenhalgh, 2001)

Focusing on pathology in PD, for example pharmacological intervention within the biomedical model, may represent an attempt at reducing a complex problem to simplicity, applying a high certainty and high agreement intervention targeted at a part of the problem (the pathology) that is relatively well understood. However, due to the complexity and unpredictability of the 'PD system', such conceptualisations and solutions are unlikely to be adequate ways of intervening. Though such interventions will have benefits, the complexity of PD may necessitate a range of interventions, as are offered by SPC, targeted at many aspects of PD, including carers. This multiple-intervention approach may be beneficial when working with complexity, allowing professionals to offer interventions that fit most appropriately for the person. They may then 'gradually [shift] time and attention towards those things that seem to be working best' (Plsek & Greenhalgh, 2001, p627; Zimmermann, Lindberg & Plsek, 1998, as cited in Plsek & Greenhalgh, 2001), rather than knowing beforehand exactly which interventions will be beneficial and should be offered, which is likely impossible to know as a result of PD's complexity. SPC

intervention might itself share elements of complexity; for example, SPC interventions, and the effects of those interventions, consisted of multiple elements, and showed some interconnections e.g. carers may only have felt able to express other aspects of their self if SPC took on the caring role so that they could relax, which may only have been possible because SPC was trusted to be competent and caring. As such, this study's findings demonstrate how certain aspects of SPC combine to have positive effects for patients' and carers' coping with PD, which could be beneficial for SPC services working with PD to possess and engage in (i.e. there are some suggestions for intervention, to avoid chaos due to complete lack of agreement and certainty), but it is not possible to explain exactly how these elements interact in order to predict precise outcomes, which would risk imposing simplicity on what appears to be a complex intervention.

A Fear of Acknowledging Death?

Addressing palliative needs by taking a holistic and complex view of PD may be challenging for a number of reasons, for example PD's long disease course and a lack of identification of PD as a terminal illness (Hudson et al, 2006). The perceived relationship between SPC and end-of-life care may also limit palliative conversations (NIHUURC, 2010). Improving access to PC and SPC for this population may mean that such difficulties have to be addressed. It might be that reticence regarding discussion of PC and SPC need in PD is related to a fear of acknowledging death. Kübler-Ross (1973) postulated that scientific advances have elevated a cultural fear, and denial of, death. She suggested that even where acknowledging the reality of death may ultimately be better for the patient, the drive remains to fix and save the person; 'he [the

patient] will get a dozen people around the clock, all busily preoccupied with his heart rate, pulse, electrocardiogram or pulmonary functions, his secretions or extractions, but not with him as a human being” (Kübler-Ross, 1973, p8). By refocusing away from pathology and cure and acknowledging complex, holistic, palliative issues related to improving QoL, death may be acknowledged.

However, rather than taking away hope and increasing anxiety, referral to SPC, and receiving care which acknowledged the holistic and complex nature of PD, benefited this study’s participants, helping them cope with some of the impacts of PD on their lives. This suggests that the process of refocusing from cure to QoL, by either discussing palliative needs or referring to SPC, need not be feared. One factor that may be important in this refocus is information provision, as participants often seemed to benefit from having information, and conversations with professionals, about the distinction between SPC and end-of-life care, which helped reduce any distress upon referral.

The Future Role of SPC in PD

Taking a holistic view and providing a palliative approach to care in PD need not be exclusive to SPC services, and some of the SPC activities that led to benefits for participants could be provided in non-SPC services. In this case, SPC could act as a consultant to non-SPC professionals, to encourage holistic and palliative approaches to care in wider services. Some aspects of SPC may be best, or more realistically provided, in a SPC setting, such as inpatient respite and day hospice services. Joint-working between SPC and non-SPC services could therefore facilitate a joined up holistic, complex and palliative approach to care. In some cases, non-SPC professionals may feel unable to manage the complex needs of patients and carers, and in these circumstances

referral to SPC may be appropriate (APMGBI, 2012). As such, the continued development of SPC services, as both a consultant and partner to non-SPC services, and as a provider of direct care, would be beneficial.

Study Limitations and Future Research

It is important to acknowledge limitations of this study. Recruitment was undertaken by SPC staff, and participants with negative experiences of SPC may have felt less able to participate. As more becomes known about SPC in PD, anonymous data collection e.g. postal questionnaires could be utilised, however due to the paucity of current research in this area, it was felt qualitative methods using semi-structured interviews were most appropriate. Although patients' and carers' experiences seemed similar, it must be acknowledged that approximately 70% of supporting quotes were provided by carers. This may be a result of there being fewer patients in the sample, possibly reflecting the degree of dementia in patients in this service, resulting in a lack of mental capacity to consent; this again points to the importance of exploring palliative issues before dementia prevents patients from contributing to advance care planning. It may also be related to the necessity to undertake shorter interviews with patients due to their health condition and associated impairments, for example concentration difficulties and fatigue, which meant that less data was gathered from patients than carers. Due to the study timescale it was not possible to prolong recruitment to include more patients, however future research may consider ways of obtaining a broader view of patients' experiences. One carer's spouse's diagnosis had been revised to 'probable vascular parkinsonism', meaning the sample was not homogenous with regards to diagnosis, however the challenges for this participant, and impacts of SPC,

were similar to those for other participants. As is common with qualitative methodologies, the findings of the study cannot, and are not intended to, be generalised, since IPA aims to examine individual experiences rather than make broad generalisations (Smith & Osborn, 2008).

Further research continuing to explore the effects of SPC in PD would be of benefit. The experience of referral to SPC for this population might be explored, whilst it might also be beneficial to consider research on patients' and carers' perceptions of the focus of non-SPC services and SPC with regards to the concepts of complexity and holism, and whether there is any difference between these two types of service from the perspective of patients and carers.

Conclusions

The findings of this study address a gap in the literature regarding the impact of SPC for a PD population. These data suggest that such services are beneficial in PD, and help patients and carers cope with the impact of PD on their lives. These findings represent one way of understanding the experiences of participants receiving SPC in the context of PD, acknowledging that the way different aspects of SPC affect coping is complex. Nevertheless, the benefits described by these participants of being in a SPC service that acknowledges death and the complex, holistic nature of PD, supports increased consideration of palliative need in this population and further developments in SPC provision for people with PD and their carers.

References

- Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care & Palliative Care Section of the Royal Society of Medicine (2012). *Commissioning guidance for specialist palliative care: helping to deliver commissioning objectives*. Southampton: Association for Palliative Medicine of Great Britain and Ireland.
- Backer, J.H. (2000). Stressors, social support, coping, and health dysfunction in individuals with Parkinson's disease. *Journal of Gerontological Nursing*, 26 (11), 6-16.
- Badger, N.J., Frizelle, D., Richfield, E.W. & Johnson, M. (in preparation). The relationship between coping with Parkinson's disease and depressive symptoms.
- Borkovec, T.D., Alcaine, O.M. & Behar, E. (2004). Avoidance theory of worry and generalized anxiety disorder. In R.G. Heimberg, C.L. Turk & D.S. Mennin (Eds.), *Generalized Anxiety Disorder: Advances in Research and Practice* (p77-108). New York: Guildford Press.
- Bradley, S.E., Frizelle, D. & Johnson, M. (2010a). Patients' psychosocial experiences of attending specialist palliative day care: a systematic review. *Palliative Medicine*, 25 (3), 210-228. doi: 10.1177/0269216310389222.
- Bradley, S.E., Frizelle, D. & Johnson, M. (2010b). Coping with terminal illness: the experience of attending specialist palliative day care. *Journal of Palliative Medicine*, 13 (10), 1211-1218. doi: 10.1089/jpm.2010.0131.

- Brod, M., Mendelsohn, G.A. & Roberts, B. (1998). Patients' experiences of Parkinson's disease. *Journal of Gerontology*, 53B (4), 213-222.
- Dauer, W. & Przedborski, S. (2003). Parkinson's Disease: mechanisms and models. *Neuron*, 39, 889-909. doi: 10.1016/S0896-6273(03)00568-3.
- DoH (2010). *End of life care in long term neurological conditions: a framework for implementation*. London: Author.
- Gjerstad, M.D., Alves, G., Wentzel-Larsen, T., Aarsland, D. & Larsen, J.P. (2006). Excessive daytime sleepiness in Parkinson disease: is it the drugs or the disease? *Neurology*, 67 (5), 853-858. doi: 10.1212/01.wnl.0000233980.25978.9d.
- Groh, G., Vyhnalek, B., Feddersen, B., Fuhrer, M. & Borasio, G.D. (2013). Effectiveness of a specialized outpatient palliative care service as experienced by patients and caregivers. *Journal of Palliative Medicine*, 16 (8), 848-856. doi: 10.1089/jpm.2012.0491.
- Hasson, F., Kernohan, W.G., McLaughlin, M., Waldron, M., McLaughlin, D., Chambers, H. et al (2010). An exploration into palliative and end-of-life experiences of carers of people with Parkinson's disease. *Palliative Medicine*, 24 (7), 731-736. doi: 10.1177/0269216310371414.
- Hearn, J. & Higginson, I.J. (1998). Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliative Medicine*, 12, 317-332.
- Hely, M.A., Morris, J.G., Reid, W.G. & Trafficante, R. (2005). Sydney multicenter study of Parkinson's disease: non-L-dopa-responsive problems dominate at 15 years. *Movement Disorders*, 20 (2), 190-199. doi: 10.1002/mds.20324.

- Herrmann, M., Curio, N., Petz, T., Synowitz, H., Wagner, S., Bartels, C. & Wallesch, C. (2000). Coping with illness after brain disease- a comparison between patients with malignant brain tumors, stroke, Parkinson's disease and traumatic brain injury. *Disability and Rehabilitation, 22* (12), 539-546.
- Hobson, P., Leeds, L. & Meara, J. (2001). The coping methods of patients with Parkinson's disease their carers and the associations between health-related quality of life and depression. *Quality in Ageing, 2* (4), 12-19.
- Hock, M. & Krohne, H.W. (2004). Coping with threat and memory for ambiguous information: testing the repressive discontinuity hypothesis. *Emotion, 4* (1), 65-86.
- Hudson, P.L., Toyne, C. & Kristjanson, L.J. (2006). Would people with Parkinson's disease benefit from palliative care? *Palliative Medicine, 20*, 87-94.
- Jankovic, J. (2008). Parkinson's disease: clinical features and diagnosis. *Journal of Neurology, Neurosurgery and Psychiatry, 79*, 368-376. doi: 10.1136/jnnp. 2007.131045.
- Krakow, K., Haltenhof, H. & Bühler, K.E. (1999). Coping with Parkinson's disease and refractory epilepsy. *The Journal of Nervous and Mental Disease, 187* (8), 503-508. doi: 10.1097/00005053-199908000-0000.
- Kristjanson, L.J., Aoun, S.M. & Oldham, L. (2006). Palliative care and support for people with neurodegenerative conditions and their carers. *International Journal of Palliative Nursing, 12* (8), 368-377.
- Kübler-Ross, E (1973). *On Death and Dying*. London:Routledge.
- Larsen, R.J. & Buss, D.M. (2008). *Personality psychology*. New York: McGraw-Hill.

- Lazarus, R.S. & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Leung, K., Tsai, J., Cheng, S., Liu, W., Chiu, T., Wu, C. & Chen, C. (2010). Can a good death and quality of life be achieved for patients with terminal cancer in a palliative care unit? *Journal of Palliative Medicine*, 13 (12), 1433-1438. doi: 10.1089/jpm.2010.0240.
- Leventhal, H., Meyer, D. & Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Medical Psychology*, p7-30. Oxford: Pergamon Press.
- Low, J., Perry, R. & Wilkinson, S. (2005). A qualitative evaluation of the impact of palliative care day services: the experiences of patients, informal carers, day unit managers and volunteer staff. *Palliative Medicine*, 19, 65-70.
- Magerkurth, C., Schnitzer, R. & Braune, S. (2005). Symptoms of autonomic failure in Parkinson's disease: prevalence and impact on daily life. *Clinical Autonomic Research*, 15, 76-82. doi: 10.1007/s10286-005-0253-z.
- McLaughlin, D., Hasson, F., Kernohan, W.G., Waldron, M., McLaughlin, M., Cochrane, B. et al. (2011). Living and coping with Parkinson's disease: perceptions of informal carers. *Palliative Medicine*, 25 (2), 177-182. doi: 10.1177/0269216310385604.
- Milberg, A., Strang, P., Carlsson, M. & Borjesson, S. (2003). Advanced palliative home care: next-of-kin's perspective. *Journal of Palliative Medicine*, 6 (5), 749-756.

- Moore, K.A. & Seeney, F. (2007). Biopsychosocial predictors of depressive mood in people with Parkinson's disease. *Behavioural Medicine*, 33, 29-37.
- NICE (2006). *Parkinson's disease: diagnosis and management in primary and secondary care*. London: Author.
- NIHUURC (2010). Palliative care needs of people with Parkinson's disease. *Newsletter of the Northern Ireland Hospice & University of Ulster Research Committee*, 2 (1), 2.
- Ogden, J. (2007). *Health psychology: a textbook (4th edition)*. Maidenhead: Open University Press.
- Parkinson's UK (2009). *Parkinson's prevalence in the United Kingdom*. London: Author.
- Parkinson's UK (n.d.). *Types of Parkinson's and parkinsonism*. Retrieved from [http:// www.parkinsons.org.uk/content/types-parkinsons-and-parkinsonism](http://www.parkinsons.org.uk/content/types-parkinsons-and-parkinsonism) on 27/5/14.
- Plsek, P.E. & Greenhalgh, T. (2001). The challenge of complexity in health care. *British Medical Journal*, 323, doi: 10.1136/bmj.323.7313.625.
- Presson, P.K. & Benassi, V.A. (1996). Locus of control orientation and depressive symptomology: a meta-analysis. *Journal of Social Behavior & Personality*, 11 (1), 201-212.
- Reijnders, J.S.A.M., Ehrt, U., Weber, W.E.J., Aarsland, D. & Leentjens, A.F.G. (2008). A systematic review of prevalence studies of depression in Parkinson's disease. *Movement Disorders*, 23 (2), 183-189. doi: 10.1002/mds.21803.

- Richfield, E.W., Jones, E.J.S. & Alty, J.E. (2013). Palliative care for Parkinson's disease: a summary of the evidence and future directions. *Palliative Medicine*, 27 (9), 805-810. doi: 10.1177/0269216313495287.
- Roth, S. & Cohen, L.J. (1986). Approach, avoidance and coping with stress. *American Psychologist*, 41 (7), 813-819.
- Saleem, T.Z., Higginson, I.J., Chaudhuri, K.R., Martin, A., Burman, R. & Leigh, P.N. (2012). Symptom prevalence, severity and palliative care needs assessment using the palliative outcome scale: a cross-sectional study of patients with Parkinson's disease and related neurological conditions. *Palliative Medicine*, 27 (8), 722-731. doi: 10.1177/0269216312465783.
- Smith, J.A. & Osborn, M. (2008). Interpretative phenomenological analysis. In J.A. Smith (Ed), *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage.
- Wade, D.T. & Halligan, P.W. (2004). Do biomedical models of illness make for good healthcare systems? *British Medical Journal*, 329, 1398-1401.
- Wade, D.T. (2009). *Holistic health care: what is it, and how can we achieve it?* Retrieved from <http://www.ouh.nhs.uk/oce/research-education/documents/HolisticHealthCare09-11-15.pdf> on 8/5/14.
- WHO (1997). *Measuring quality of life: the world health organization quality of life instruments*. Geneva: Author.
- WHO (2002). *National cancer control programmes: policies and managerial guidelines, 2nd edition*. Geneva: Author.
- Yook, K., Kim, K.H., Suh, S.Y. & Lee, K.S. (2010). Intolerance of uncertainty, worry and rumination in major depressive disorder and generalized anxiety disorder. *Journal of Anxiety Disorders*, 24, 623-628. doi: 10.1016/j.janxdis.2010.04.003.

Zampieri, M. & de Souza, E.A. (2011). Locus of control, depression, and quality of life in Parkinson's disease. *Journal of Health Psychology, 16* (6), 980-987. doi: 10.1177/1359105310397220.

Part three: Appendices

Appendix A- Author guidelines for British Journal of Health Psychology

The British Journal of Health Psychology was chosen as the journal for submission for both the systematic literature review and empirical paper. The rationale for this was that both papers relate to the interaction between physical illness, psychological processes, and intervention, which are types of research topic typically published by this journal.

Author guidelines:

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations, using either quantitative or qualitative methods;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via [Editorial Manager](#). You may like to use the [Submission Checklist](#) to help you prepare your manuscript. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper. Before submitting, please read the [terms and conditions of submission](#) and the [declaration of competing interests](#).

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from [here](#).
- Statement of Contribution: All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results,

Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:

Author, A., Author, B., & Author, C. (1995). *Title of book*. City, Country: Publisher.

Author, A. (2013). Title of journal article. *Name of journal*, 1, 1-16. doi:
10.1111/bjep.12031

- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the [APA Publication Manual](#) published by the American Psychological Association.
- Manuscripts describing clinical trials are encouraged to submit in accordance with the [CONSORT statement](#) on reporting randomised controlled trials.

6. Supporting information

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files. Supporting Information should be cited within the article text, and a descriptive legend should be included. Please

indicate clearly on submission which material is for online only publication. It is published as supplied by the author, and a proof is not made available prior to publication; for these reasons, authors should provide any Supporting Information in the desired final format.

For further information on recommended file types and requirements for submission, please visit the [Supporting Information page](#) on Author Services.

7. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive. A full list of [terms and conditions](#) is available on Wiley Online Library.

Any authors wishing to send their paper OnlineOpen will be required to complete the payment.

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

8. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key

stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript.

Visit [Author Services](#) for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

9. Copyright and licences

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services, where via the Wiley Author Licensing Service (WALS) they will be able to complete the licence agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the [Copyright FAQs](#) .

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons Licence Open Access Agreements (OAA):

- Creative Commons Attribution Non-Commercial Licence (CC-BY-NC)
- Creative Commons Attribution Non-Commercial -NoDerivs Licence (CC-BY-NC-ND)

To preview the terms and conditions of these open access agreements please visit the [Copyright FAQs](#) and you may also like to visit the [Wiley Open Access Copyright and Licence](#) page.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY licence supporting you in complying

with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit our [Funder Policy](#) page.

10. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a [Colour Work Agreement](#) form upon acceptance of the paper.

11. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found in [Author Services](#). All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

12. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from [Adobe's web site](#). This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Hard copy proofs will be posted if no e-mail address is available. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

13. Early View

British Journal of Health Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. Eg Jones, A.B. (2010). Human rights Issues. *Journal of Human Rights*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x.

Appendix B- References for studies excluded at full-text review stage

The following studies were excluded at the full-text review stage due to failure to meet the inclusion criteria for the systematic literature review.

Barnes, J., Connelly, V., Boubert, L. & Maravic, K. (2013). Behavioural coping patterns in Parkinson's patients with visual hallucinations. *Journal of Neuropsychology*, 7, 326-334. doi: 10.1111/jnp.12016.

Bucks, R.S., Cruise, K.E., Skinner, T.C., Loftus, A.M., Barker, R.A. & Thomas, M.G. (2011). Coping processes and health-related quality of life in Parkinson's disease. *International Journal of Geriatric Psychiatry*, 26 (3), 247-255. doi: 10.1002/gps.2520.

Caap-Ahlgren, M. & Dehlin, O. (2004). Sense of coherence is a sensitive measure for changes in subjects with Parkinson's disease during 1 year. *Scandinavian Journal of Caring Science*, 18, 154-159. doi: 10.1111/j.1471-6712.2004.00248.x.

Giaquinto, S., Bruti, L., Dall'Armi, V., Palma, E. & Spiridigliozzi, C. (2011). Religious and spiritual beliefs in outpatients suffering from Parkinson disease. *International Journal of Geriatric Psychiatry*, 26, 916-922. doi: 10.1002/gps.2624.

Hobson, P., Leeds, L. & Meara, J. (2001). The coping methods of patients with Parkinson's disease, their carers, and the associations between health-related quality of life and depression. *Quality in Ageing*, 2 (4), 12-19. doi: 10.1108/14717794200100025.

Hurt, C.S., Thomas, B.A., Burn, D.J., Hindle, J.V., Landau, S., Samuel, M. & Wilson, K.C.M. et al (2011). Coping in Parkinson's disease: an examination of the coping inventory for stressful situations. *International Journal of Geriatric Psychiatry*, 26, 1030-1037. doi: 10.1002/gps.2634.

- Hurt, C.S., Landau, S., Burn, D.J., Hindle, J.V., Samuel, M. & Wilson, K. & Brown, R.G. (2012). Cognition, coping, and outcome in Parkinson's disease. *International Psychogeriatrics*, 24 (10), 1656-1663. doi: 10.1017/S1041610212000749.
- Montel, S., Bonnet, A-M. & Bungener, C. (2009). Quality of life in relation to mood, coping strategies, and dyskinesia in Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology*, 22 (2), 95-102. doi: 10.1177/0891988708328219.
- Naber, D., Weinberger, D.R., Bullinger, M. & Polsby, M. (1988). Personality variables, neurological and psychopathological symptoms in patients suffering from spasmodic torticollis. *Comprehensive Psychiatry*, 29 (2), 182-187. doi: 10.1016/0010-440X(88)90012-0.
- Pusswald, G., Fleck, M., Lehrner, J., Haubenberger, D., Weber, G. & Auff, E. (2012). The "sense of coherence" and the coping capacity of patients with Parkinson disease. *International Psychogeriatrics*, 24 (12), 1972-1979. doi: 10.1017/S1041610212001330.
- Rod, N.H., Bordelon, Y., Thompson, A., Marcotte, E. & Ritz, B. (2013). Major life events and development of major depression in Parkinson's disease patients. *European Journal of Neurology*, 20, 683-670. doi: 10.1111/ene.12019.
- Whitworth, S.R., Loftus, A.M., Skinner, T.C., Gasson, N., Barker, R.A., Bucks, R.S. & Thomas, M.G. (2013). Personality affects aspects of health-related quality of life in Parkinson's disease via psychological coping strategies. *Journal of Parkinson's Disease*, 3 (1), 45-53. doi: 10.3233/JPD-120149.

Appendix C- Quality assessment information

Following consultation of the Downs and Black (1998) and CONSORT (2010) checklists for quantitative studies, it was decided that a custom quality assessment tool would be devised to ensure relevance to the studies and topic being reviewed. Two items were taken directly from the Downs and Black checklist, with minor changes in wording (items 1 and 13 in review quality assessment) whilst other items were either devised independently or based on the Downs and Black criteria and item descriptions considered most relevant to the review topic. Whilst this ensured that the assessed criteria were most relevant to the reviewed studies, this meant that the quality assessment tool had not been assessed for validity and reliability. Table 11.0 shows the quality assessment scores and criteria for the reviewed studies. The second reviewer's scores for the subsample of four double-reviewed papers are shown in parentheses alongside the first author's scores. This double-review process was used in an attempt to ascertain an estimate of reliability of the quality assessment, therefore disagreements in scoring were not discussed to obtain consensus. Instead, the quality scores reported in the main body of the article are those of the first author. The inter-rater agreement was good, assessed using Cohen's Kappa as $\kappa=0.78$. Disagreement occurred on half of the double-reviewed studies (two), for the criteria 'Is it clearly stated in text/measure description that the measure of coping was applied to PD or its impact?' and 'Was the stressor the participants were asked to respond regarding representative of the experience of the majority of patients?'. These disagreements may have occurred as a result of the subjective nature of the words 'clearly' and 'representative', however the reasons for disagreement were not discussed between reviewers.

References

Schulz, K.F., Altman, D.G. & Moher, D. (2010). CONSORT 2010 statement:

updated guidelines for reporting parallel group randomised trials. *British Medical Journal*, 340, 698-702. doi: 10.1136/bmj.c332.

Downs, S.H. & Black, N. (1998). The feasibility of creating a checklist for the

assessment of the methodological quality both of randomised and non-

randomised studies of health care interventions. *Journal of Epidemiology*

& Community Health, 52, 377-384. doi: 10.1136/jech.52.6.377.

Table 11.0. Quality assessment scores.

Criterion	Croyle et al, 2003	Ehmann et al, 1990	Evans & Norman, 2009	Herrmann et al, 1997	Krakow et al, 1999	MacCarthy & Brown, 1989	Moore & Seeney, 2007	Total Item Score
1. Is the hypothesis/aim clearly described?	1 (1)	1 (1)	1	1	1	1 (1)	1 (1)	7 (4)
2. Are inclusion and exclusion criteria clearly stated?	1 (1)	0 (0)	1	1	1	0 (0)	0 (0)	4 (1)
3. Is the process of recruitment and refused participation clearly stated?	0 (0)	0 (0)	1	0	0	1 (1)	1 (1)	3 (2)
4. Is it clear where participants were recruited from? (e.g. inpatient, newsletter)	1 (1)	0 (0)	1	1	1	0 (0)	1 (1)	5 (2)
5. Is the sample clearly described?	1 (1)	1 (1)	1	1	1	1 (1)	1 (1)	7 (4)
6. Are the types of coping to be measured clearly defined in the introduction/method? (i.e. content of subscales explained/described or presented in full)	1 (1)	1 (1)	1	1	0	1 (1)	1 (1)	6 (4)
7. Were all subscales used to measure coping reliable in the study? (Cronbach's Alpha >.70)	0 (0)	0 (0)	0	0	0	1 (1)	2 (1)	3 (2)
8. Were all measures of depression reliable in the study? (Cronbach's Alpha >.70)	0 (0)	0 (0)	1	0	0	0 (0)	1 (1)	2 (1)

9. Is it clearly stated in text/measure description that the measure of coping was applied to PD or its impact?	1 (1)	1 (0)	1	0	0	1 (1)	1 (0)	5 (2)
10. Are the statistics for all reported relevant significant relationships presented? (for no sig results score yes)	1 (1)	1 (1)	1	1	1	1 (1)	1 (1)	7 (4)
11. Are the statistics for all reported relevant non-significant relationships presented? (for no non-sig results score yes)	1 (1)	1 (1)	1	0	1	1 (1)	1 (1)	6 (4)
12. Are relationships between depression and all coping subscales measured by the coping measure reported in all analyses unless reported as statistically inappropriate?	1 (1)	1 (1)	0	1	0	0 (0)	0 (0)	3 (2)
13. Have actual probability values been reported for all relevant significant results except for those <.001? (if no sig results score yes, if no sig results above p<.001 score yes)	1 (1)	0 (0)	0	1	0	1 (0)	0 (0)	3 (1)
14. Was the stressor the participants were asked to respond regarding representative of the experience of the majority of patients?	0 (0)	1 (0)	1	1	0	1 (1)	1 (0)	5 (1)
15. Was any effort made to account for the effects of other potential influencing non-coping variables on the relationship between coping and depression?	0 (0)	0 (0)	1	0	0	1 (1)	1 (1)	3 (2)
Total Quality Score /16	10 (10)	8 (6)	12	9	6	11 (10)	13 (10)	

Scoring key: study meets criteria =1; study does not meet criteria/unable to determine based on information presented=0. Item 7, none=0, some=1, all=2.

Participant Selection Protocol- Patients

The following four criteria are the selection criteria for this study:

1. The patient has a primary diagnosis of Idiopathic Parkinson's Disease (as opposed to other syndromes of which Parkinsonism is a symptom).
2. The patient has received at least two face-to-face contacts from the Palliative Care service at the hospice. (One contact= one community visit OR one day in day hospice OR one day inpatient stay).
3. The patient communicates in English.
4. The patient DOES NOT consistently lack capacity (e.g. the patient is not in the late stages of a dementia where consent is consistently lacking).

If the patient meets these four criteria, they should be provided with a participant information sheet, which serves as an invitation to participate in the study.

Capacity ordinarily fluctuates and fluctuating capacity on the part of the patient should not be used to exclude them from being approached. To protect this group of patients in particular, in all cases, patients who express an interest in taking part in the study will have their capacity to consent to participate assessed twice by the researcher, first in the initial telephone contact to discuss and arrange the interview, and again on the day of the interview prior to any data being collected. If it is determined that a potential participant lacks capacity to consent the interview will not continue as planned and will be re-arranged for another day at a time when the patient has capacity.

Patients should not be excluded based on the clarity of their communication and speech, this will be assessed by the researcher due to its subjective nature.

Participant Selection Protocol- Carers

The following four criteria are the selection criteria for this study:

1. The patient for whom the carer is the primary carer for has a primary diagnosis of Idiopathic Parkinson's Disease (as opposed to other syndromes of which Parkinsonism is a symptom).
2. The patient for whom the carer cares for has received at least two face-to-face contacts from the Palliative Care service at the hospice. (One contact= one community visit OR one day in day hospice OR one day inpatient stay).
3. The carer communicates in English.
4. The carer DOES NOT consistently lack capacity.

If the carer meets these four criteria, then the following procedures should be followed:

If the patient DOES NOT consistently lack capacity:

- The patient should be asked, at a time when capacity is present, for permission to provide their primary carer with a participant information sheet. If the patient gives their consent, the carer should then be provided with a participant information sheet. If the patient does not give their consent, the carer should not be approached.

If the patient DOES consistently lack capacity (e.g. they are in an advanced stage of dementia):

- The carer should be provided with a participant information sheet.

Capacity ordinarily fluctuates and fluctuating capacity on the part of the carer should not be used to exclude them from being approached. To protect this group in particular, in all cases, carers who express an interest in taking part in the study

will have their capacity to consent to participate assessed twice by the researcher, first in the initial telephone contact to discuss and arrange the interview, and again on the day of the interview prior to any data being collected. If it is determined that a potential participant lacks capacity to consent the interview will not continue as planned and will be re-arranged for another day at a time when the carer has capacity.

Carers should not be excluded based on the clarity of their communication and speech, this will be assessed by the researcher due to its subjective nature.

Logo removed for hard-binding

The Impact of Specialist Palliative Care on Coping in Parkinson's Disease: The Experiences of Patients and Carers

Research Study Information Leaflet

What is this study about?

This study is investigating the experiences of people with Parkinson's Disease and their family members/carers of receiving palliative care from [removed for hard-binding]. This includes what might have been beneficial, what might have been difficult or unhelpful, and how the service has affected people's ability to cope with the challenges of Parkinson's Disease.

Why are you studying this?

People with Parkinson's Disease are less likely than people with other health problems to be referred to the type of service that [removed for hard-binding] provides. [Removed for hard-binding] is one of few providers of this type of care to people with Parkinson's Disease in the UK. By exploring patients' and carers' experiences of receiving such a service, we can determine whether, how, and why such care is beneficial in Parkinson's Disease, and provide suggestions as to how services can improve their care for people with Parkinson's Disease and their carers.

Who is organising and funding the study?

The researcher is employed by Humber NHS Foundation Trust. Research expenses are being provided by the University of Hull.

How can I help?

We are asking people with Parkinson's Disease and their carers who receive care from [removed for hard-binding] to share their experiences of those services with us.

What will I have to do?

If you are interested in sharing your experiences of [removed for hard-binding]care with us, you will be invited to participate in a one-to-one interview with the researcher. This interview would be arranged for a time and place that is convenient for you, and could take place over two separate appointments if you wish.

During the interview, the researcher will ask you questions about the effect Parkinson's Disease has had on you/your relative, what services you receive from the team at [removed for hard-binding] and how this has affected your ability to cope with Parkinson's Disease. The questions will be very broad to enable you to talk about anything that is important to you.

The interview would last for between 60 and 90 minutes (though this could be done over two separate appointments). The interview would be audio taped by the researcher.

What will happen to the tape?

The audio recording will be securely stored electronically. This means that only the researcher will have access to it. The researcher will listen to the tape recording of the interview and transcribe it. This transcript will be anonymous (people will not be able to identify you from it) and securely stored. The researchers will then read through this transcript of the interview in order to better understand your experiences. An anonymous summary of the main experiences from all of the interviews in the study will also be reviewed by one of our study advisors who themselves is a carer of someone with Parkinson's Disease, to check we have included all of the areas that are important to people with experience of Parkinson's Disease.

What if I change my mind?

You are under no obligation to participate in this study. Even if you give consent to participate, you can still ask to withdraw at any time without giving a reason for doing so. Deciding not to participate, or withdrawing your consent later, will have no impact on the care you receive from the hospice or other services.

Who has reviewed the study?

The study has been reviewed within the researcher's department at the University of Hull, and has been reviewed by Derby-East Midlands Research Ethics Proportionate Review Sub-Committee.

What if there is a problem?

If you have any concerns about the study, it might be helpful to discuss these with the researcher who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can contact the field supervisor for this study, Prof Miriam Johnson on [removed for hard-binding], or the hospice complaints system [removed for hard-binding]. Any complaints will be addressed and will not affect your care either now or in the future.

I am interested in participating and would like further information.

If you are interested in participating, you can:

- ask the clinician who gave you this leaflet to pass on any questions to the researcher.
- ask the clinician to pass on your contact details to the researcher so they may contact you and discuss the study.
- contact the researcher via the details at the bottom of this page.

Will other people know what I have said?

During the interview, you may speak about things which you do not want others to know e.g. family, nurses. Everything you discuss in the interview will remain anonymous and confidential. Non-anonymised information (e.g. signed consent forms and your personal information) will only be accessible to the researchers.

Confidentiality may have to be broken if you tell the researcher something which gives us concern for your own or someone else's safety. In these cases we would discuss this with you before any action was taken. Occasionally the researcher may be concerned about you or people you know. In these cases the researcher may need to tell someone about their concerns without asking you first.

Researcher Contact Details

Nathan Badger

Department of Clinical Psychology and Psychological Therapies
Hertford Building
University of Hull
Cottingham Road
Hull
HU6 7RX

Telephone: Removed for hard-binding (please leave a message if the call is not answered and the researcher will get back to you)

Email: Removed for hard-binding

Thank you for taking the time to read this information leaflet.

Appendix F- Confirmation of ethical approval

Removed for hard-binding

Appendix G- Confirmation of sponsor approval

Removed for hard-binding

Appendix H- Non-NHS SSI confirmation

Removed for hard-binding

Logo removed for hard-binding

Centre Number:

Study Number:

Patient Identification Number for this trial:

CONSENT FORM

Title of Project: **The Impact of Specialist Palliative Care on Coping in Parkinson's Disease: The Experiences of Patients and Carers**

Name of Researcher: **Nathan Badger**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 02.04.13 (version 2.0) 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, without my medical care or legal rights being affected.
3. I agree that any quotes I provide during the interview may be used anonymously in future publications by the study group.
4. I agree that if I lose capacity to consent during the study then information already collected from the interview may be retained and used by the researcher in line with point 3.
5. I give my permission for the interview to be audio recorded.
6. I agree to take part in the above study.

Name of Participant/Witness

Date

Signature

Name of Person taking consent

Date

Signature

Appendix J- Interview schedule

Interview Schedule

Thank you for consenting to participate in this study. As I've explained, the study is looking at the impact of the service you receive from the hospice on your coping with Parkinson's Disease and the changes it has had on your life. I'm going to ask you some questions about these types of issues, but we can speak about whatever is important to you.

1. **Understanding of coping** e.g. could you explain to me what coping means to you?

2. **The impact of Parkinson's Disease** e.g. how has Parkinson's Disease changed your life? Are there things you have to consider/think about/do now that you did not have to before you were diagnosed with Parkinson's Disease? Are there any things in particular that have been particularly difficult about Parkinson's Disease that you have had to cope with?

3. **Impact of PC on coping with those aspects**
 - a. How did you feel when you were first told about and referred to the PC service?
 - b. What aspects of the PC service have you accessed?
 - c. How have those services impacted on your coping with the changes Parkinson's Disease has led to?
 - d. How do you think life would be different for you without the PC service?
 - e. Is there anything about the PC service that has made it more difficult to cope with the changes Parkinson's Disease has led to?

Appendix K- Data regarding participants' understanding of coping and the impact of PD on participants' lives

Patients identified a range of changes since their diagnosis of PD including: the uncertain nature of their symptoms and future; loss of competencies and roles; social life changes; loss of independence; mobility impairment and pain; and the impact of PD on their spouse. Carers also highlighted a range of impacts including: the demands of being alert in caring; the burden of having multiple tasks to complete; lost roles and relationship change; worry due to uncertainty; tiredness; social and everyday life restriction; embarrassment due to personal care tasks; needing to learn new skills and roles; frustration and stress; loss of future hopes; and the difficulties of caring in the context of their own aging.

Participants typically showed elements of stoicism in their understanding of coping, often saying that coping meant getting on with things. Throughout the interviews, other aspects of participants' coping were alluded to through their comments, for example aspects of focusing on the present, minimisation, optimism, avoiding thinking about emotions or the future, finding new avenues for enjoyment and competence, acceptance, humour, planning ahead, looking for positives, taking a step back to calm down, and being alert.

Appendix L - Worked example of IPA analysis

Below is an extract from one of the participants' interviews (Mary), to demonstrate the process of data analysis that was undertaken. In the first instance, transcripts were read several times, with points of interest noted in the margin (left-hand column):

	I- what was so helpful about the carers group what kind of things made that helpful for you
<p>Getting knowledge.</p> <p>Simple, 'just have a coffee'.</p> <p>Crucial support.</p> <p>Others feel the same; not alone.</p> <p>Self care and feeling good.</p> <p>Getting advice.</p>	<p>P- oh it was brilliant because they had people that come erm to to discuss things with you erm you know different people erm and we'd just have a chat a coffee and erm er I don't think I could have coped really at the beginning without it because erm you realise that you're not on your own erm and you've got people to talk to and erm and we used one session we had a back massage erm had our feet done er fin er hands so it's absolutely brilliant erm because they'd have erm as I said different you know people'd come in and discuss things with you</p>
	I- so would they be like medical

	professionals were they or
Getting advice. Financial aspects. Professional knowledge?	P- oh yeah they'd had oh not all the the last one one session they had someone came in from erm citizen's advice bureau on benefits and you know things erm and and someone from the hospice erm you know about things for mobility and you know all different things
	I- so it was useful to hear that information was it
Others feel the same as me. Enjoyment- positivity.	P- oh yes yeah yeah very good yeah yeah yeah I've really enjoyed going there and then you know there is other people in the same you know same situation as what you're in
	I- so were they having similar difficulties similar erm feelings to you were they in terms of the erm carer role that they were in
Positives in life; enjoyment. Free from caring.	P- oh yes yeah but we didn't like er we didn't go into things really I mean you'd be chatting to people near you and we all knew that we were all you know caring but it was

	<p>more about being relaxed and erm you know not worrying about what you're doing at home having a laugh and er you know people telling jokes and they'd get onto one subject and and might discuss something and then something you never finished anything cos it all just went from like what you'd watched on television and things you know so</p>
	<p>I- so it sounds like it was a place where what you were all used to doing at home was parked off for a little bit and you just enjoyed yourselves as a group of people</p>
<p>Hospice was facilitative of the group keeping going.</p> <p>Together with professionals- cared for?</p>	<p>P- yes yeah yeah and it was so useful that's why they'd asked if we could just do it on our own you know just all just meet up which we thought they might not let us cos there's always some staff members I think she's a nurse there they were always with us so when we did it on our own we just by ourselves but we'd just chat and</p>

<p>Able to forget what is happening at home. Denial?</p>	<p>they let us make coffee and things just the same so it's brilliant you just forget about things at home yeah yeah it's really good</p>
	<p>I- and I guess you said there about feeling like you weren't the only one or you weren't alone there were people in the same boat as you so even though you weren't talking about the boat you were all you all felt that there was something there did you</p>
	<p>P- yes yeah yeah</p>
	<p>I- ok great was there any other that the carers group helped you cope it sounds like it had quite a strong social and kind of a social enjoyment function for you</p>
	<p>P- yes yeah</p>
	<p>I- was there any other way it helped you cope can you think</p>
<p>Trust that the hospice can solve problems. They make things happen- they're available for this.</p>	<p>P- well I can't think but I know if I'd whilst I was there if I'd got a problem if I told the staff members they'd they'd sort sort something out for me you know</p>

	<p>I- so quite a a trust in the people that work there that they were if you did have a problem they could sort that they would help</p>
	<p>P- yes yes yeah</p>
	<p>I- is that something that goes across the hospice more generally or was it specific to the group do you think</p>
	<p>P- well I would imagine it's for the hospice all together</p>
	<p>I- yeah</p>
<p>Accessible- they do everything.</p> <p>Brilliant- positive experience of service.</p> <p>Husband enjoys it there- positive.</p>	<p>P- I don't really know much about the hospice apart from going there and then when my husband's been in twice erm and the day centre I mean that when my husband's gone to the day centre they're brilliant aswell you know there's someone picks him up and and you know brings him back home and he's really enjoyed well I think he's enjoyed going there</p>

Following this stage of analysis, the transcripts were re-read, with emerging themes noted (right-hand column):

	I- what was so helpful about the carers group what kind of things made that helpful for you	
Getting knowledge. Simple, 'just have a coffee'. Crucial support. Others feel the same; not alone. Self care and feeling good. Getting advice.	P- oh it was brilliant because they had people that come erm to to discuss things with you erm you know different people erm and we'd just have a chat a coffee and erm er I don't think I could have coped really at the beginning without it because erm you realise that you're not on your own erm and you've got people to talk to and erm and we used one session we had a back massage erm had our feet done er fin er hands so it's	Giving knowledge. Important positive. Not alone. Self-care.

	<p>absolutely brilliant erm because they'd have erm as I said different you know people'd come in and discuss things with you</p>	
	<p>I- so would they be like medical professionals were they or</p>	
<p>Getting advice. Financial aspects. Professional knowledge?</p>	<p>P- oh yeah they'd had oh not all the the last one one session they had someone came in from erm citizen's advice bureau on benefits and you know things erm and and someone from the hospice erm you know about things for mobility and you know all different things</p>	<p>Giving knowledge.</p>
	<p>I- so it was useful to hear that information was it</p>	
<p>Others feel the same as</p>	<p>P- oh yes yeah yeah</p>	<p>Not alone.</p>

<p>me.</p> <p>Enjoyment.</p>	<p>very good yeah yeah yeah I've really enjoyed going there and then you know there is other people in the same you know same situation as what you're in</p>	
	<p>I- so were they having similar difficulties similar erm feelings to you were they in terms of the erm carer role that they were in</p>	
<p>Positives in life; enjoyment. Free from caring.</p>	<p>P- oh yes yeah but we didn't like er we didn't go into things really I mean you'd be chatting to people near you and we all knew that we were all you know caring but it was more about being relaxed and erm you know not worrying about what you're doing at home having a laugh and er</p>	<p>A break from illness.</p> <p>Social.</p>

	<p>you know people telling jokes and they'd get onto one subject and and might discuss something and then something you never finished anything cos it all just went from like what you'd watched on television and things you know so</p>	
	<p>I- so it sounds like it was a place where what you were all used to doing at home was parked off for a little bit and you just enjoyed yourselves as a group of people</p>	
<p>Hospice was facilitative of the group keeping going.</p> <p>Together with</p>	<p>P- yes yeah yeah and it was so useful that's why they'd asked if we could just do it on our own you know just all just meet up which we thought they might not let us cos there's always some</p>	

<p>professionals- cared for?</p> <p>Able to forget what is happening at home.</p> <p>Denial?</p>	<p>staff members I think she's a nurse there they were always with us so when we did it on our own we just by ourselves but we'd just chat and they let us make coffee and things just the same so it's brilliant you just forget about things at home yeah yeah it's really good</p>	<p>Social.</p> <p>Forgetting illness.</p>
	<p>I- and I guess you said there about feeling like you weren't the only one or you weren't alone there were people in the same boat as you so even though you weren't talking about the boat you were all you all felt that there was something there did you</p>	
	<p>P- yes yeah yeah</p>	
	<p>I- ok great was there</p>	

	<p>any other that the carers group helped you cope</p> <p>it sounds like it had quite a strong social and kind of a social enjoyment function for you</p>	
	P- yes yeah	
	I- was there any other way it helped you cope can you think	
<p>Trust that the hospice can solve problems.</p> <p>They make things happen- they're available for this.</p>	<p>P- well I can't think but I know if I'd whilst I was there if I'd got a problem if I told the staff members they'd they'd sort sort something out for me you know</p>	Trust in competence.
	I- so quite a a trust in the people that work there that they were if you did have a problem they could sort that they would help	
	P- yes yes yeah	
	I- is that something that	

	<p>goes across the hospice more generally or was it specific to the group do you think</p>	
	<p>P- well I would imagine it's for the hospice all together</p>	
	<p>I- yeah</p>	
<p>Accessible- they do everything.</p> <p>Brilliant- positive experience of service.</p> <p>Husband enjoys it there- positive.</p>	<p>P- I don't really know much about the hospice apart from going there and then when my husband's been in twice erm and the day centre I mean that when my husband's gone to the day centre they're brilliant aswell you know there's someone picks him up and and you know brings him back home and he's really enjoyed well I think he's enjoyed going there</p>	<p>Positive appraisal.</p>

After this level of analysis, emerging themes from each individual transcript were grouped into sub-ordinate themes. For the excerpt above, the following quotes were organised into the following sub-ordinate themes:

Not feeling alone

- P- oh it was brilliant because they had people that come erm to to discuss things with you erm you know different people erm and we'd just have a chat a coffee and erm er I don't think I could have coped really at the beginning without it because erm you realise that you're not on your own erm and you've got people to talk to and erm and

Enhancing self-esteem

- P- we used one session we had a back massage erm had our feet done er fin er hands so it's absolutely brilliant

Having someone knowledgeable involved:

- P- as I said different you know people'd come in and discuss things with you
- P- someone from the hospice erm you know about things for mobility and you know all different things
- P- well I can't think but I know if I'd whilst I was there if I'd got a problem if I told the staff members they'd they'd sort sort something out for me you know
I- so quite a a trust in the people that work there that they were if you did have a problem they could sort that they would help
P- yes yes yeah

I- is that something that goes across the hospice more generally or was it specific to the group do you think

P- well I would imagine it's for the hospice all together

Being part of a well appraised service:

- P- oh it was brilliant because they had people that come erm to to discuss things with you erm you know different people erm and we'd just have a chat a coffee and erm er I don't think I could have coped really at the beginning without it
- P- oh yes yeah yeah very good yeah yeah yeah I've really enjoyed going there and then you know there is other people in the same you know same situation as what you're in
- P- when my husband's gone to the day centre they're brilliant aswell you know there's someone picks him up and and you know brings him back home and he's really enjoyed well I think he's enjoyed going there

Engaging in different selves:

- P- oh it was brilliant because they had people that come erm to to discuss things with you erm you know different people erm and we'd just have a chat a coffee
- P- oh yes yeah but we didn't like er we didn't go into things really I mean you'd be chatting to people near you and we all knew that we were all you know caring but it was more about being relaxed and erm you know not worrying about what you're doing at home having a laugh and er you know people telling jokes and they'd get onto one subject and and might discuss something and then something you never finished anything cos

it all just went from like what you'd watched on television and things you know so

- P- yes yeah yeah and it was so useful that's why they'd asked if we could just do it on our own you know just all just meet up which we thought they might not let us cos there's always some staff members I think she's a nurse there they were always with us so when we did it on our own we just by ourselves but we'd just chat and they let us make coffee and things just the same so it's brilliant you just forget about things at home yeah yeah it's really good

Retaining enjoyment:

- P- oh yes yeah but we didn't like er we didn't go into things really I mean you'd be chatting to people near you and we all knew that we were all you know caring but it was more about being relaxed and erm you know not worrying about what you're doing at home having a laugh and er you know people telling jokes and they'd get onto one subject and and might discuss something and then something you never finished anything cos it all just went from like what you'd watched on television and things you know so
- P- when my husband's gone to the day centre they're brilliant aswell you know there's someone picks him up and and you know brings him back home and he's really enjoyed well I think he's enjoyed going there

Following this level of analysis, sub-ordinate themes from each participant were grouped across cases according to super-ordinate concepts as described in the results section, with constant review of the degree to which the data supported

the emerging cross-case sub-ordinate and super-ordinate themes and vice versa, with analysis developing in an iterative manner. Sub-ordinate themes not supported to a large extent by the data and/or not supported across cases were not included in the final super-ordinate and sub-ordinate themes.

Appendix M- Epistemological statement

Epistemology is a 'theory of knowledge' (Carter & Little, 2007, p1317), which provides a justification for the knowledge that results from particular research methods (Carter & Little, 2007). Epistemologies affect methodologies, which are the theoretical bases which guide the choice, and justification, of research methods (i.e. the way the question is studied) (Carter & Little, 2007).

In choosing a research method for the empirical paper in this thesis, the nature of the question and topic area were considered. Research methods are often broadly categorised as either quantitative or qualitative. Quantitative research is typically based on the philosophy of positivism, which advocates a research approach akin to that used by physical scientists, that reality is determined by the object being studied, with little influence of the person observing (Onwuegbuzie, 2000; Willig, 2001). Quantitative research is typically focused on testing pre-existing theory (Johnson & Onwuegbuzie, 2004) rather than developing new theory, and therefore it was felt such methodologies and research methods were inappropriate for the empirical paper regarding the impact of specialist palliative care in Parkinson's disease, as this topic had not been previously studied and therefore there was an absence of pre-existing theory or hypotheses to test.

Instead, the aim of this research was to explore something new to obtain some understanding of how specialist palliative care impacted coping in Parkinson's disease. A qualitative approach was considered most appropriate. In contrast to quantitative research where obtained data can be restricted (e.g. to the questions asked on a questionnaire), qualitative research produces data 'based on the participants' own categories of meaning' (Johnson & Onwuegbuzie, 2004, p20). Qualitative research consists of a range of

methodologies and methods, but broadly reflect an epistemological stance that rejects positivist principles, and instead are more likely to subscribe to have 'a concern with people's grasp of their world' (Ashworth, 2008, p5), and 'contend that multiple-constructed realities abound' (Johnson & Onwuegbuzie, 2004, p14).

The chosen method of data analysis for the empirical paper was Interpretative Phenomenological Analysis (IPA). Methodological assumptions underlying IPA include phenomenology; hermeneutics; and idiography (Birkbeck, 2011). Phenomenology refers to the 'systematic study of people's experiences and ways of viewing the world' (Barker, Pistrang & Elliott, 2002, p76); this seemed to fit well with the aims of the study. Hermeneutics involves interpretation, a key foundation of IPA (Birkbeck, 2011). In the first instance, the way individuals describe their perspective involves them 'trying to make sense of their world' (Smith & Osborn, 2008, p55). In trying to access this account, the researcher must interpret the individual's own efforts to make sense, which necessarily involves 'the researcher's own conceptions' (Smith & Osborn, 2008, p55). As such, a double-hermeneutic is evident in IPA, whereby 'the participants are trying to make sense of their world [and] the researcher is trying to make sense of the participants trying to make sense of their world' (Smith & Osborn, 2008, p55). Finally, idiography refers to the focus on the individual (Birkbeck, 2011).

In contrast, the systematic literature review included only quantitative papers, underlain by the principles of positivism. As with the choice of methodology and method for the empirical paper, this choice of methodology focus for the systematic literature review was made based on the question for which an answer was being sought. The aim of exploring the nature of the

relationship between coping and depressive symptoms seemed to be best achieved using quantitative research which can enable strength and direction of relationships to be studied, and which would better enable generalisations.

As such, the methodologies and epistemologies on which the empirical paper and systematic literature review are based are apparently contradictory. As noted by Johnson and Onwuegbuzie (2004, p14) in their discussion of mixed methods research, 'some graduate students who graduate from educational institutions with an aspiration to gain employment in the world of academia or research are left with the impression that they have to pledge allegiance to one research school of thought or the other' (i.e. quantitative or qualitative). However, Johnson and Onwuegbuzie (2004) go on to suggest that epistemological belief should not limit the use of research methods, and that some previous philosophical conflicts between quantitative and qualitative researchers have been largely resolved. Instead, the philosophical position of pragmatism can be applied, which considers knowledge to be of value if it has useful practical consequences. Such a philosophy suggests that method selection should be 'needs-based' (Johnson & Onwuegbuzie, 2004, p17), giving the best opportunity to attain findings that will be useful. It is this principle that guided the choice of methodology and research methods for the two papers in this portfolio.

References

Ashworth, P. (2008). Conceptual foundations of qualitative psychology. In J.A. Smith (Ed.), *Qualitative psychology: a practical guide to research methods* (2nd ed). London:Sage Publications.

- Barker, C., Pistrang, N. & Elliott, R. (2002). *Research methods in clinical psychology* (2nd ed). Chichester: John Wiley & Sons.
- Birkbeck (2011). *IPA*. Retrieved from <http://www.ipa.bbk.ac.uk/about-ipa> on 25/5/14.
- Carter, S.M. & Little, M. (2007). Justifying knowledge, justifying method, taking action: epistemologies, methodologies, and methods in qualitative research. *Qualitative Health Research*, 17 (10), 1316-1328.
- Johnson, R.B. & Onwuegbuzie, A.J. (2004). Mixed methods research: a research paradigm whose time has come. *Educational Researcher*, 33 (7), 14-26.
- Onwuegbuzie, A.J. (2000). *Positivists, post-positivists, post-structuralists, and post-modernists: why can't we all get along? Towards a framework for unifying research paradigms*. Paper presented at the annual meeting of the Association for the Advancement of Educational Research (AAER), Ponte Vedra, Florida.
- Smith, J.A. & Osborn, M. (2008). Interpretative Phenomenological Analysis. In J.A. Smith (Ed.), *Qualitative psychology: a practical guide to research methods* (2nd ed). London: Sage Publications.
- Willig, C. (2001). *Introducing qualitative research in psychology: adventures in theory and method*. Buckingham: Open University Press.

Appendix N- Reflective statement

Empirical Paper

In choosing the topic of my empirical paper, at first I had absolutely no idea what I wanted to study. After thinking about this topic and another, I decided to study specialist palliative care in Parkinson's disease. I had no personal reasons for my interest in this topic, and I knew next to nothing about both palliative care and Parkinson's before I began putting my research proposal together. I think what grabbed me about this topic was the real life relevance of it, the fact that the findings would (hopefully) directly impact service development and delivery. It also appealed to me that this would be a completely new area of research, since specialist palliative care had not been studied in Parkinson's disease before.

Since I had no prior knowledge, I put a lot of effort into the research proposals. Even though these seem quite unimportant, not being marked and being only a prelude to bigger proposals, it was really useful to attempt to be as thorough as possible even at this early stage, helping to focus my mind on the topic and issues, and reducing stress later, as these earlier proposals directly informed both my ethics submission and final write-up. I spent time with the nurses who would be recruiting on my behalf, and tried to learn as much about the service as I could; this groundwork was really beneficial in getting the context right in my head. I was lucky that the team were on board with the research from day one, but having regular contact was beneficial, and might help keep your research on the agenda, as it might be the most important thing to you, but people recruiting on your behalf have their own job to do as well and are often under pressure themselves.

Given the lack of research in this area, it seemed that quantitative methods would be restrictive of the research, particularly as it did not seek to confirm existing theory but rather find new knowledge. Instead, it seemed an appropriate area and question for qualitative methodology, and Interpretative Phenomenological Analysis (IPA) was chosen due to its focus on individuals' experiences. This was something very different for me, having had an undergraduate thesis focused entirely on numbers.

Many of my peers had a hard time going through ethical approval, but I was relatively lucky to get through proportionate review first time, which was also contributed to by writing a clear and concise ethics proposal, pre-empting possible objections. It's probably dependent to some extent on the committee your proposal is reviewed by, however trying to submit as early as possible is probably a good insurance against any hurdles put up in the process, so that there is time to make any adjustments. I had a time-scale that I was trying to work to, and submitted my ethical proposal in April of 5th year, which was a great time to get it signed off as it allowed the summer when there was no teaching to begin recruitment.

My hope, perhaps naively, had been to finish recruitment over the summer of 5th year, giving me a whole year to do analysis and write-up. Unfortunately, that didn't happen, with data collection not ending until February of 6th year. I had been concerned at the very beginning of the research, after discussions with the nurses recruiting on my behalf, that I would find it impossible to recruit patients. It definitely was more difficult to recruit patients than carers, with two of the patients not being recruited until near the end of recruitment. This might have been contributed to by some patients having developed dementia, such that fewer patients were able to be approached than

carers. This perhaps speaks to the importance of considering palliative care at an earlier stage so that aspects of such services such as advance care planning can be undertaken in a timely manner. Two patients who had been interested in participating also chose to not participate when I discussed the study further with them. As one of their spouses mentioned, there may have been an element of embarrassment, and not wanting to talk. Given I was still, at this point, worried that I wouldn't be able to get as many patients as I wanted to include in my sample, I was disappointed by this. However, reflecting on how these patients' lives had changed, what they had lost, and how difficult I myself would find it to discuss my own death and illness, helped me to keep in touch with the people rather than the numbers, particularly when recruitment was slow, remembering what I was asking participants to do.

In the interviews I was struck by the openness and willingness of participants to discuss what appeared to be some of the most difficult aspects of their lives. I was extremely grateful for this, but I was always aware of the possibility that interviews can stray to places that participants do not want to go. I reflected on how the researcher-participant relationship differs from the therapeutic relationships I was engaged in on placements, where as a therapist I may continue to 'dig' down to the root of an issue where clients show avoidance. It was important to recognise the difference, that the participants were not coming for therapy, and therefore being attentive to signs that participants did not want to go further into some issues was important.

In noting reflections throughout the interview process, there were some issues that I would like to note as being potential influences on the research, as is common when working with IPA. As a psychologist I had belief in the interactions between the physical and psychological. However, I did wonder

initially whether the main benefit of specialist palliative care for participants would be medication and symptom management. I was surprised in interviews that participants rarely mentioned this, however having a pre-existing theoretical view of the links between physical and psychological may have influenced the direction of interviews and data analysis, leading to a focus on such issues; professionals with a more physical focus may interpret the data differently.

Hearing the benefits that specialist palliative care had for participants made me reflect on my own view of death. I initially expected that participants might find referral to specialist palliative care, in conceding cure is not possible and acknowledging the inevitability of death, to be upsetting, however this did not seem to be the case. I perhaps held a view related to my own culture that death is something to be feared and avoided; indeed the interviews occurred at a time when for the first time a close relative of mine passed away, reinforcing further the fear of and upset at death. Seeing how participants benefited from the refocus from cure to quality of life with referral to specialist palliative care has challenged some of my own views on the appropriateness of unremitting medical intervention.

As a researcher in my early twenties, there may have been some aspects of their experiences that participants were not comfortable with exploring due to the large age difference between researcher and participant, which could have affected the data collected. Similarly, there may have been areas that I did not focus on because of my age. Some participants discussed relationship change, however I wonder if at times the age gap and similarity of some participants to my own grandparents limited exploration of this, particularly regarding emotional and sexual aspects of these relationships. As a

more experienced and/or older therapist and researcher, I may have explored these issues in more detail.

On reflection, I think from the first interview it was apparent that specialist palliative care was associated with benefits, and I perhaps had an initial expectation that many participants would find such a service beneficial once they had been referred. Most of the interviews focused on positives, and I noticed later how my questioning was often geared towards whether aspects of specialist palliative care had been helpful or had benefits. Although all participants were asked about any negative or unhelpful aspects of specialist palliative care, saying there were none, these expectations may have influenced my questioning and affected the balance of positive and negative aspects of specialist palliative care discussed by participants.

After the excitement of interviews, I was ready to get into the data analysis, and was a bit disappointed that transcription stood in the way. I soon realised that I had misjudged the value of transcription, and I noticed many parts of the conversations that I had forgotten. I came to see transcription as the first stage in data analysis rather than as the precursor to it. Don't be tempted to use shortcuts to transcription, as it was so beneficial to become immersed in the data from the beginning.

After transcription, I perhaps rushed a bit too quickly into trying to find themes. I think this came from a position of wanting to make some sense of the information in front of me, to feel that I knew what I was doing in this role in which I was inexperienced. On reflection, I can see these feelings parallel those of many of the participants, living with uncertainty and striving to reduce it. Refocusing and taking my time was beneficial, as was remembering that the interpretative nature of IPA means you cannot really be 'wrong'.

Systematic Literature Review

In contrast to my time-line and pro-activeness with the empirical paper, I think I always considered the systematic literature review (SLR) the poor relation. I expected it to be quite quick and simple, after all, there's no recruitment. As such the SLR began in fits and starts, with bits being done then put on the backburner as other pieces of work took precedence. When I finally did devote some time specifically to it, the piecemeal nature of the earlier stages meant having to start again. I've definitely realised through doing my SLR that this can be just as complex a piece of work as an empirical paper, and keeping better track of work done earlier if it does have to be done in stages would have been beneficial.

I initially had a different SLR question to the one submitted. I had all of my papers together and was happy with them, however as I began to write about them I realised that the high variability between studies made it difficult for me to manage them in the timescale and word limit available; it would have been beneficial to have thought about this in more detail earlier on. Instead, I chose to change the question to the one submitted. Once I got the papers together for this new question, there appeared to be a lot of variability in conceptualisations and methods of measuring coping. This confusion in the literature was reflected in me, as I struggled to balance these different conceptualisations and findings into a coherent narrative and discussion.

Studying an area in detail was rewarding, enabling me to go beyond findings of individual studies but thinking more broadly about conceptual and methodological issues. This highlighted elements that I would and would not want to replicate in my own write-ups. I also valued the quantitative focus of the SLR, enabling me to consider research from different perspectives in contrast to

the empirical paper, highlighting the different uses of these methodologies and knowledge gained through their usage.

Overall Reflections

The overall thesis experience had gone very well until about two months before hand in when the stress that I had been told to expect finally arrived. Having a clear timescale and being generally proactive definitely helped stave off this feeling until this late in the day. The thesis has reaffirmed my belief that research is an important aspect of our role that should not be underestimated or ignored, and I hope to be able to continue with research following qualification. As the deadline loomed the thesis completely took over my life, and I look forward to a time in the near future when the balance between work and life is restored. At the same time, handing in this thesis will represent a big change, as I will find myself outside of full-time education for the first time since I was four years old. In one way this is an exciting prospect however it is also tinged with sadness that this stage is over.