

The Relationships between Executive Functions, Coping, and
Quality of Life in Parkinson's Disease.

Elise M. Duncan

School of Psychology

Curtin University, Bentley

This thesis is presented in partial fulfilment of the requirements of the Master of Psychology
(Clinical Psychology) degree at Curtin University, Bentley.

November 2013

This thesis is my own composition, all sources have been acknowledged and my contribution is clearly identified in the thesis. This thesis has been completed during the course of enrolment in this degree at Curtin University and has not previously been accepted for a degree at this or another institution.

Abstract

Executive functions (EF) are often impaired in Parkinson's disease (PD). Research suggests that EF deficits are associated with reduced quality of life (QOL), reduced planful problem solving (PPS) coping and increased escape-avoidance (EA) coping. Increased use of EA coping is associated with reduced QOL, whereas increased PPS is associated with increased QOL. The current study examined whether the relationship between EF and QOL is mediated by coping in a sample of 148 older adults with PD. It was predicted that the EF-QOL relationship would be strengthened by the increased use of EA, and would be weakened by the increased use of PPS. Participants completed the Ways of Coping Questionnaire (WCQ), the Parkinsons Disease Questionnaire-39 (PDQ-39), and two assessments of EF. There was no significant mediation effect of coping on the relationship between EF and QOL. However, significant relationships between EF and QOL, and between EA coping and QOL, were evident. Further analysis examined whether the EF-QOL relationship depended on whether EF deficits were present. It was found that the EF-QOL relationship was no longer significant for the EF-deficit and non-deficit groups. However, QOL was significantly reduced when EF-deficits were present. Implications of these findings and future directions are discussed.

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Acknowledgements

This thesis has resulted from not only many months of dedicated work, but from continued support, encouragement and wisdom offered by certain individuals involved. Thank you to my wonderful supervisor, Andrea Loftus. Your incredible mind and your passion for this research allowed me to have the confidence to think critically and become immersed in the findings of this study in order to put together the pieces of the puzzle. Thank you to the team at ParkC for allowing me access to the ParkC dataset and the opportunity to be a part of cutting-edge research into the psychological processes taking place in PD. I am also eternally grateful to my fellow Masters travellers whose support and advice has meant the world this year. Finally, to Jaz; I could not have done this without your unwavering love and support. Thank you for putting up with my mess (both physical and mental).

The Relationships between Executive Functions, Coping, and Quality of Life in Parkinson's Disease.

Parkinson's Disease (PD) is a neurodegenerative disease with symptoms and secondary effects that have a significant impact on quality of life (Karlsen, Larsen, Tandberg, & Maeland, 1998; Karlsen, Tandberg, Arslan, & Larsen, 2000; Schrag, Jahanshahi, & Quinn, 2000). PD is characterised by motor symptoms such as tremor, rigidity, akinesia/bradykinesia, and postural instability (Foltynie, Brayne, & Barker, 2002). Cognitive symptoms such as impaired executive functioning (EF), memory, visuo-spatial, and speech and language are also key features of PD (Martinez-Martin, 2011; Owen, 2004). The presentation of physical and cognitive symptoms varies between patients with PD; however, some specific factors are known predictors of quality of life (QOL) in PD. These include the presence of co-morbid depression (Schrag et al., 2000; Soh, Morris, & McGinley, 2011), physical disability (Karlsen et al., 2000; Schrag et al., 2000), and cognitive impairment (Leroi, McDonald, Pantula, & Harbishettar, 2012; Schrag et al., 2000). Cognitive impairment predicts reduced QOL in PD even in the absence of depression and dementia (Klepac, Trkulja, Relja, & Babic, 2008; Schiehser et al., 2009; Schrag et al., 2000). EF is integral to overall cognitive functioning. Reduced EF is associated with reduced QOL in healthy older women (Davis, Marra, Najafzadeh, & Liu-Ambrose, 2010), adults with attention deficit/hyperactivity disorder (Brown & Landgraf, 2010) and adults with schizophrenia (Tyson, Laws, Flowers, Mortimer, & Schulz, 2008). In light of these findings, it is unsurprising that EF is a significant predictor of QOL in PD.

EF impairments predict coping strategy use in various clinical populations (Goretti et al., 2010; Krpan, 2007; Krpan, Stuss, & Anderson, 2011; Wilder-Willis, Shear, Steffen, & Borkin, 2002). Coping strategies are cognitive-behavioural responses applied to manage

internal and external demands raised by challenging situations. Coping strategies may be emotion-focused, whereby individuals aim to reduce emotional distress; or problem-focused, whereby individuals seek solutions to a problem (Lazarus & Folkman, 1984). Research suggests that individuals are more likely to use emotion-focused coping strategies, such as escape-avoidance (EA), when their EFs are impaired as EA is less cognitively demanding (Goretti et al., 2010; Krpan, 2007; Krpan et al., 2011; Wilder-Willis et al., 2002). Research suggests that PPS requires intact EF (Krpan, 2007; Krpan et al., 2011). PPS requires EF skills such as problem appraisal, generation and consideration of alternative solutions, planning, purposive-action, and self- and environmental-monitoring. Therefore, those with intact EF are more likely to use PPS than EA coping (Krpan, 2007; Krpan et al., 2011). Montel & Bungener (2008) suggested that EF impairment does not limit strategy use in PD. There is substantial evidence, however, that EF deficits are associated with reduced PPS and increased EA coping.

Coping is also associated with QOL. In adults with PD, Bucks and colleagues (2011) found that increased PPS was significantly associated with increased QOL, whereas increased EA was associated with reduced QOL. This relationship has also been reported for brain-injured adults (Wolters, Stapert, Brands, & Van Heugten, 2010). The study found that coping strategy use changed from active problem-focused to more passive emotion-focused over 5 months of rehabilitation. Greater use of problem-focused coping and reduced use of emotion-focused coping predicted increased long-term QOL (Wolters et al., 2010).

A recent PD study investigated the relationships between cognitive function, coping, and outcome in terms of mood and QOL (Hurt et al., 2012). Cognitive function was assessed using the Addenbrooke's Cognitive Examination Revised (ACE-R; Hodges, 2005), coping was assessed using the Coping Inventory for Stressful Situations (CISS; Endler & Parker, 1999), and outcome was assessed using both the Hospital Anxiety and Depression Scale

(HADS; Zigmond & Snaith, 1983) and the Parkinson's Disease Questionnaire (PDQ; Jenkinson, Fitzpatrick, Petrone, Greenhall, & Hyman, 1997). Hurt and colleagues found a small mediating effect of coping on the relationship between general cognition and outcome (mood and QOL). The authors reported that emotion-focused coping (such as EA) was associated with both poorer cognitive functioning and poorer mood and QOL. In contrast, task-oriented behaviour (such as PPS) was associated with improved mood and QOL. This is consistent with research suggesting a relationship between coping and QOL (Bucks et al., 2011).

Hurt et al. (2012) also considered the specific contribution of EF (rather than general cognitive functioning). They selected three components of the ACE-R that they judged to be indicative of EF skills. These were: orientation, attention/concentration, and visuo-spatial subtasks. The combined score from these components (the author's measure of EF) was less strongly associated with coping and outcome than the overall ACE-R score. Hurt et al. (2012) therefore concluded that a global index of cognition (total ACE-R score) was more reliably associated with task-focused coping than a representative measure of EF (total score from the three components). However, this study was limited by a fundamental methodological flaw. The ACE-R was designed as a general measure of cognitive function; it was never intended to be analysed in terms of its component tasks. Furthermore, the ACE-R components used by Hurt et al. as specific measures of EF are actually more general tests of cognitive function. These components assessed orientation (naming the day, date, season, and where they are located in a building and in the world); attention/concentration (counting back from 100 in lots of seven, and spelling forward and backward), and visuo-spatial (copy two diagrams and clock-drawing). These are not established measures of specific components of EF. It is therefore reasonable to suggest that the findings of Hurt et al. (2012) are hindered by the lack of established measures of EF. The current study will address this by using established

measures known to target EF from the Cambridge Neuropsychological Test Automated Battery (CANTAB).

The current study examined the relationships between EF, coping, and QOL in older adults with PD. The study used a sample of 148 male and female adults aged 37 to 85 years with confirmed diagnoses of PD. EF was assessed using two CANTAB tests: The Stockings of Cambridge test (SOC) and the Spatial Working Memory test (SWM). PPS and EA were assessed using the Ways of Coping Questionnaire (WCQ) and QOL was assessed using the Parkinson's Disease Questionnaire-39 (PDQ-39). Based on the current research, it was predicted that coping strategy use would significantly mediate the relationship between EF and QOL. Specifically, EF would predict the coping strategy used (PPS or EA) which in turn would impact QOL (see Figure 1). Within this mediated regression model, the following specific hypotheses were addressed:

- 1) SWM scores will significantly predict QOL scores, such that lower SWM ability will be associated with poorer QOL
- 2) SOC (planning) scores will significantly predict QOL scores, such that lower SOC ability will be associated with poorer QOL.
- 3) EA will mediate the relationship between EF and QOL. EA strategies will be used more by those with poorer EF and increased use of EA will be associated with poorer QOL. This was predicted for both SOC and SWM measures of EF.
- 4) PPS will mediate the relationship between EF and QOL. PPS strategies will be used less by those with poorer EF and decreased use of PPS will be associated with poorer QOL. This was predicted for both SOC and SWM measures of EF.

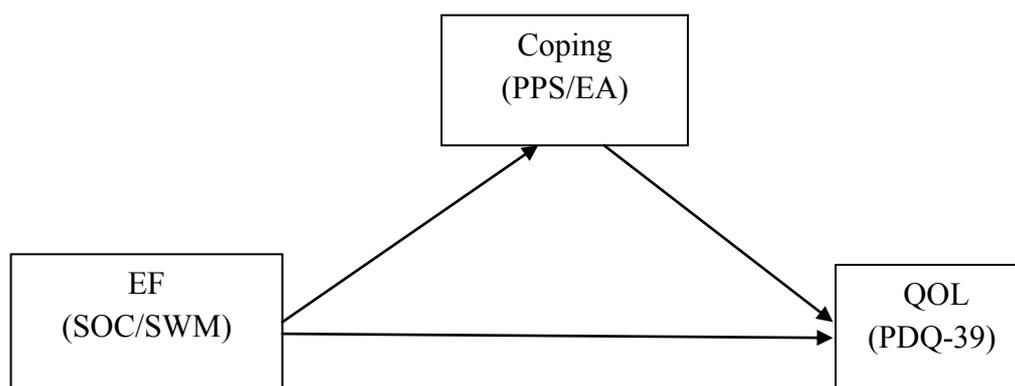


Figure 1. Proposed mediation model executive function (EF), coping, and quality of life (QOL). SOC: Stockings of Cambridge; SWM: Spatial Working Memory; PPS: Planful problem solving; EA: Escape-avoidance; PDQ-39: Parkinson’s Disease Questionnaire-39.

Method

The current study was conducted as part of a larger, ongoing, community-based research project run by a multidisciplinary team of researchers at the Parkinson’s Centre (ParkC), Edith Cowan University. The current researcher (Elise Duncan) is in the process of contributing to ParkC in the form of testing and data entry to gain access to the data set. This study has been granted ethical approval by the Edith Cowan University Human Research Ethics Committee (Reference code 08-106-THOMAS). The following sections outline information relevant to the current study only.

Participants

Participants of this data set had initially contacted ParkC after reading an advertisement in the Parkinson’s Association of Western Australia (PWA) newsletter. Informed consent was obtained prior to participation in any ParkC research. All diagnoses of PD were verified by a ParkC neurologist or geriatrician. Individuals with a history of other

significant neurological disorders (e.g. cerebrovascular accident, stroke) or possible dementia (Mini Mental State Examination; MMSE score < 24) were excluded from the study.

The original sample consisted of 244 male (165; 67.6%) and female participants aged 37-87 years old ($M = 66.01$, $SD = 9.78$). Following data-screening (see Results section of this report), the final data set consisted of 148 participants who had mild to moderate PD (Hoehn and Yahr < 4). The average age of the final sample was 63.96 ($SD = 9.27$) with ages ranging 37-85 years. The majority of the final sample was male (92; 64.2%). All participants in the final data set had completed all measures required for the analyses with no mean substitutions necessary.

Measures and Procedure

Demographic information and screening. Demographic data for each participant was obtained through a semi-structured interview and included information on each participant's current age, age at diagnosis with PD, gender, disease duration, and years of education.

The MMSE was used to assess general cognitive function and assessed orientation, immediate recall, attention/calculation, delayed recall, naming an object, repeating a sentence, completing a 3-stage command, writing, copying, and reading and acting out written instructions. MMSE scores below 24 indicated possible dementia; participants scoring below 24 were excluded from analysis. The MMSE is a well-established measure of cognitive functioning.

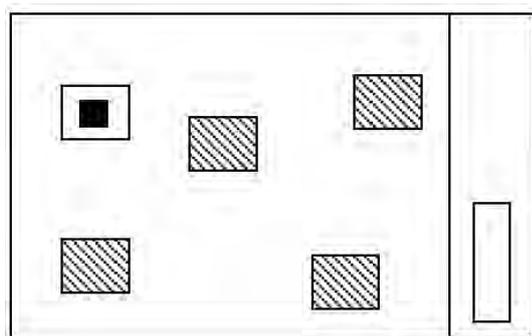
The Geriatric Depression Scale short-form (GDS-15) assessed symptoms of depression in older adults. This was to be used as a control variable as depression is a known predictor of QOL in PD (Schrag, et al., 2000). The GDS-15 is a 15-item self-report

questionnaire with Yes/No responses to various questions about mood. One point is assigned to each item that indicates the presence of the symptom. As this is a short-form scale, scores are doubled upon calculation. Higher scores indicate higher levels of depression. The GDS-15 is a more sensitive measure of depression in PD for two reasons: i) it is designed to measure depression in older adults (the dominant demographic for PD), yet is appropriate for use in adults from 17 years and ii) it assesses affective and behavioural aspects of depression, avoiding confusion between somatic symptoms of depression and PD (Strauss et al., 2006). The GDS-15 demonstrated good internal consistency in the current study ($\alpha = .81$).

Executive functions. Two tests from the Cambridge Neuropsychological Test Automated Battery (CANTAB) were used to measure EF: a measure of spatial working memory (SWM) and a measure of planning called the Stockings of Cambridge test (SOC). For both measures, participants were seated comfortably and responded to visual stimuli on a touch-screen computer.

The SWM test assessed participants' ability to retain and manipulate spatial information using spatial working memory skills. Participants used a process of elimination to locate a 'token' hidden in one of a selection of 'boxes', then drag the token to fill the column on the right of the screen (see Figure 2a). The token did not appear in the same box in consecutive trials and task complexity increased with number of boxes presented (up to eight). To avoid errors, participants remembered which box previously contained the token and which boxes they already checked. The task ended when the column on the right was filled (approximately eight minutes). SWM scores were calculated as the total number of errors made (number of times a box was checked that was known not to contain the token). Higher SWM total error scores indicate poorer SWM.

a) SWM



b) SOC

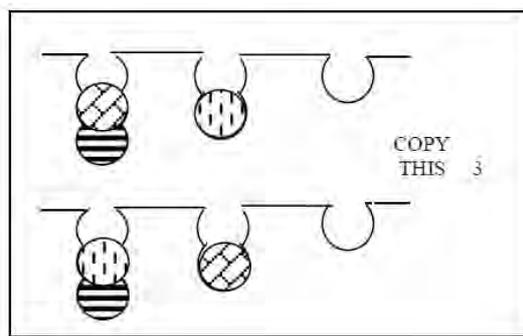


Figure 2. CANTAB executive function tasks: a) Spatial working memory (SWM); b) Stockings of Cambridge (SOC). SWM total errors and SOC accuracy scores were calculated.

The SOC test assessed participants' spatial planning and problem solving skills. Participants rearranged three coloured balls within three pockets/stockings on the lower half of the screen to match a target arrangement on the upper half of the screen (see Figure 2b). The balls were moved one-by-one by touching the ball to be moved, then the target location. Certain rules apply, such as only one ball can be moved at a time, balls underneath other balls cannot be moved, and the arrangement should be completed in the minimum amount of moves possible. Task complexity increased with increased minimum number of moves required to achieve the target arrangement. The task took approximately ten minutes to complete. SOC accuracy scores were calculated as the total number of problems solved in the minimum number of moves specified. Higher SOC accuracy scores indicate greater spatial planning ability.

Quality of life. The Parkinson's Disease Questionnaire (PDQ-39) assessed the impact of PD on QOL. The PDQ-39 is a 39-item self-report questionnaire with each item rated on a five-point Likert scale (0 = never, to 4 = always). This assesses eight domains of QOL including Mobility, Activities of Daily Living, Emotional Well-being, Stigma, Social Support, Cognitive Impairment, Communication, and Bodily Discomfort. The PDQ-39 single

index score was calculated as the mean of the total sum score of the domains, divided by the number of domains. Scores ranged from 0 to 100, with higher scores indicating poorer QOL. The PDQ-39 single index measure demonstrated excellent internal consistency for this study ($\alpha = .94$).

Coping processes. The Ways of Coping Questionnaire (WCQ; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986) assessed participants' coping processes. The WCQ is a 66-item self-report questionnaire with items rated on a four-point Likert scale (0 = not used, to 3 = used a great deal). Raw scores for eight coping processes were generated from the WCQ. These are Confrontive Coping, Distancing, Self-Controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance (EA), Planful Problem Solving (PPS), and Positive Reappraisal. Total raw scores were obtained from each subscale. EA and PPS were of particular interest in this study as evidence suggests that these specific coping strategies may be associated with EF and QOL in PD (Bucks et al., 2011; Hurt et al., 2012). Therefore, total raw scores from the EA and PPS subscales only were used in the current analyses. Raw scores were the sum of items for each subscale, with higher scores representing higher use of that coping strategy. Good internal consistency was demonstrated for EA ($\alpha = .71$) and PPS subscales in this study ($\alpha = .79$).

Results

Data Screening

The initial data set was screened for missing and problematic data. Data from 95 participants was removed. Fourteen were removed for medical reasons (e.g. stroke history). One was removed due to high severity PD (Hoehn and Yahr = 4 - outlier) and two were removed due to possible dementia (MMSE <24). Two participants' data were removed due to missing data for the measure of the outcome variable (PDQ-39). On measures of EF (SOC

and SWM), 18 were removed as they had not completed any of the tests ($N = 13$) or the test was aborted ($N = 5$). On the measure of coping (WCQ) 59 participants' data were removed from the data set due to missing data ($N = 40$), declined responses ($N = 1$), or inability to provide a response or "not applicable" ($N = 18$).

Sample Characteristics

The sample had an average age of 63.96 ($SD = 9.27$) and the majority were males (92; 64.2%). Table 1 displays descriptive statistics for coping, QOL, EF, and depression scores for the current sample. The current sample made more SWM errors than an age-matched normative sample ($M = 29.74$, $SD = 22.74$). The current sample's average SOC accuracy score was less than that for the age-matched normative sample ($M = 8.12$, $SD = 2.03$). There was no normative data available for EA and PPS. The EA and PPS score ranges were similar; therefore the two means can be meaningfully compared without standardisation. The mean PPS raw score was greater than the EA mean raw score, indicating the sample were more likely to use PPS than EA.

Table 1.

Descriptive statistics for executive functions, coping, health-related quality of life and depression measures in the PD sample.

| | Mean (<i>SD</i>) | Range |
|--|--------------------|-------|
| Executive Functions | | |
| SWM total errors | 42.20 (21.51) | 0-95 |
| SOC problems solved in minimum number of moves | 7.38 (2.10) | 2-12 |
| Coping (WCQ) | | |
| Escape-Avoidance | 4.32 (4.07) | 0-19 |
| Planful problem solving | 8.21 (4.31) | 0-18 |
| Health-related quality of life | | |
| PDQ-39 Single index score | 21.00 (13.33) | 1-71 |
| Depression | | |
| GDS-15 total score | 3.56 (3.12) | 0-13 |

Note. SWM: Spatial Working Memory. Higher scores indicate poorer performance. SOC: Stockings of Cambridge. Higher scores indicate better performance. WCQ: Ways of Coping Questionnaire. Higher scores indicate more use of strategy. PDQ-39: Parkinson's Disease Questionnaire. Higher scores indicate poorer HRQoL. GDS-15: Geriatric Depression Scale. Higher scores indicate higher depression levels.

Assumptions of Regression

Four mediated regression analyses were planned according to Baron and Kenney's (1986) criteria (see Figure 3). Assumption testing was conducted prior to the regression analyses. First, it was required that data be normally distributed without significant outliers. All distributions were approximately normal with no outliers removed. Second, for regression assumptions of linearity and multicollinearity to be met there must be significant, linear

relationships between the variables of the proposed mediated relationship. Correlations between variables were assessed to verify the presence of these relationships. The significance level was set at $\alpha = .05$ for all analyses.

Age at participation had significant, moderate inverse relationships with both SOC, $r(147) = -.41, p < .001$, and SWM, $r(147) = .45, p < .001$, whereby poorer EF (higher SWM total error scores, lower SOC accuracy scores) was associated with older age. GDS-15 score had a significant, strong positive relationship with both EA, $r(147) = .50, p < .001$, and PDQ-39, $r(147) = .64, p < .001$, whereby higher depression scores were associated with both increased use of EA and poorer QOL. SOC score had a significant, moderate inverse relationship with SWM score, $r(147) = -.50, p < .001$, and EA had a significant, weak positive relationship with PPS, $r(147) = .19, p = .01$.

Bivariate correlations between the key variables are shown in Figure 3. SWM had a significant, weak positive relationship with PDQ-39 scores, whereby poorer SWM (higher SWM total error scores) was associated with higher PDQ-39 scores (poorer QOL). EA scores had a significant, moderate positive correlation to PDQ-39 scores, whereby increased EA was associated with higher PDQ-39 scores (poorer QOL). There was a trend towards significance for the weak, inverse relationship between SOC and PDQ-39 ($p = .07$), whereby lower SOC (lower planning score) was associated with higher PDQ-39 scores (poorer QOL). SOC was not significantly related to PPS or EA. PPS was not significantly related to SWM, SOC or PDQ-39.

The SWM-QOL relationship, coupled with the trend towards a SOC-QOL relationship, indicate a general EF-QOL relationship. The results also highlight a strong relationship between EA and PDQ-39. Given that there were not significant linear relationships between *all* variables for any of the mediated regression models, the data did not

meet the simple assumptions of regression and the more complex assumptions which would result from the regression output were not conducted. As the criteria outlined by Baron and Kenney (1986) were not met, the planned multiple regression analyses could not be conducted.

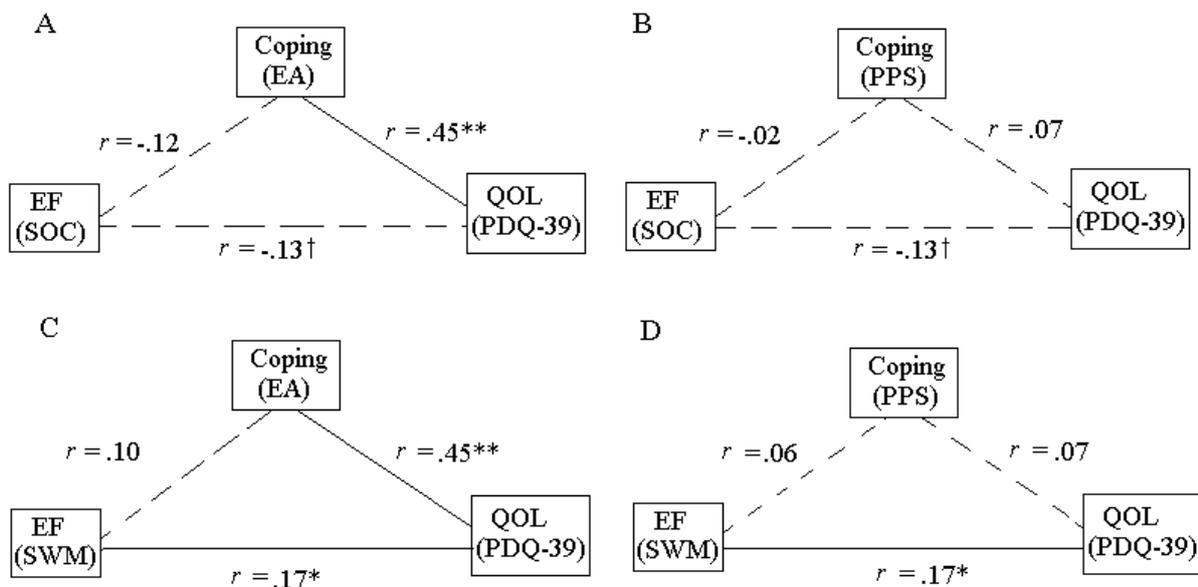


Figure 3. Proposed mediation models of the relationships between coping, executive function (EF) and quality of life (QOL) with correlations. **A:** Escape-avoidance (EA) mediates the EF-QOL relationship (EF measured using SOC); **B:** Planful problem solving (PPS) mediates the EF-QOL relationship (using SOC); **C:** EA mediates the between EF-QOL relationship (using SWM); **D:** PPS mediates the EF-QOL relationship (using SWM). Significant (solid lines) and non-significant (dashed lines) relationships between variables are shown. Note: * $p < .05$, ** $p < .001$. † $p = .07$ (trend).

Follow-Up Exploratory Analyses

As the planned regression models could not be tested, exploratory analyses were considered. It was proposed that the relationships required for regression may only manifest when an EF deficit is present. Therefore, the data set was divided into those with an EF deficit

and those without by applying age and gender-appropriate norms. Individuals were identified as having an EF deficit if they scored $> 1 SD$ below the appropriate norm for either SOC or SWM. Three groups were identified: i) SOC-deficit, ii) SWM-deficit and, iii) non-deficit. Descriptive statistics for each of these groups are presented in Table 4. EA use was higher in the SWM and SOC-deficit groups, compared to the non-deficit group. The SWM-deficit group used more PPS than both the SOC-deficit and non-deficit groups. PDQ-39 scores were higher (poorer QOL) for both EF-deficit groups than the non-deficit group. GDS-15 scores were comparable between groups.

Table 4.

Descriptive statistics for the two executive-function deficit groups and the non-deficit group.

| Measure | SOC-deficit group ($N = 30$) Mean (SD) | SWM-deficit group ($N = 43$) Mean (SD) | Non-deficit control group ($N = 91$) Mean (SD) |
|---------------------------|--|--|--|
| Age at participation | 66.23 (9.68) | 65.14 (8.85) | 63.45 (9.57) |
| Gender (% Male) | 70.0 | 69.8 | 59.3 |
| Executive Functions | | | |
| SWM total errors | 52.77 (17.85) | 64.26 (12.33) | 32.12 (17.94) |
| SOC accuracy | 4.40 (1.33) | 6.49 (2.36) | 8.20 (1.52) |
| Coping (WCQ) | | | |
| Escape-Avoidance | 5.20 (4.33) | 4.93 (4.49) | 3.86 (3.74) |
| Planful problem solving | 7.57 (4.59) | 8.65 (4.58) | 7.95 (4.04) |
| Quality of life | | | |
| PDQ-39 Single index score | 25.14 (15.00) | 24.99 (15.81) | 19.07 (11.78) |
| Depression | | | |
| GDS-15 total score | 4.23 (3.82) | 3.77 (3.66) | 3.45 (2.79) |

SOC-deficit group. Bivariate correlations established the relationships between variables (Figure 4). A significant, strong positive relationship was found between EA and PDQ-39. SOC was not significantly related to PDQ-39. There were no significant

relationships involving PPS. As the data did not meet the assumptions, the mediated regression analysis could not be conducted.

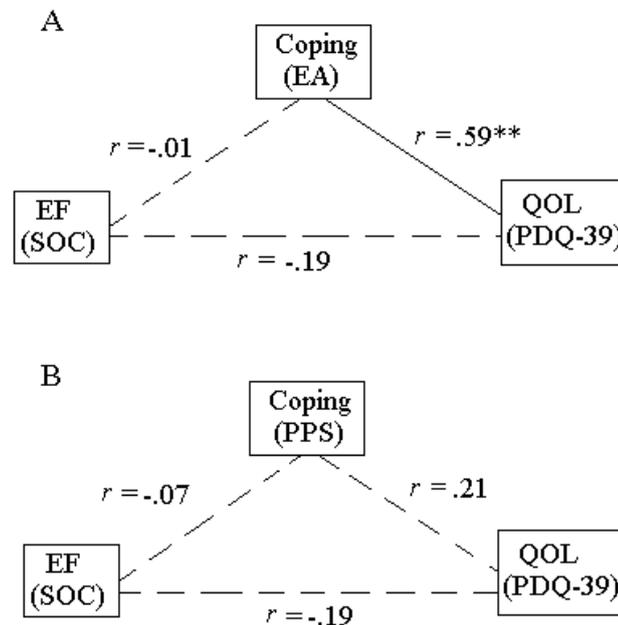


Figure 4. Bivariate correlations between coping, executive function (EF), and quality of life (QOL) for those with a deficit in the Stockings of Cambridge (SOC) task. **A:** SOC-QOL relationship mediated by escape-avoidance coping; **B:** SOC-QOL relationship mediated by planful problem solving. Significant (solid lines) and non-significant (dashed lines) relationships between variables are shown. Note: * $p < .05$, ** $p < .001$.

SWM-deficit group. Bivariate correlations established the relationships between variables (Figure 5). A significant, strong positive relationship was found between EA and PDQ-39. The previously significant SWM-QOL relationship was no longer present. There were no significant relationships involving PPS. As the data did not meet the assumptions, the mediated regression analysis could not be conducted.

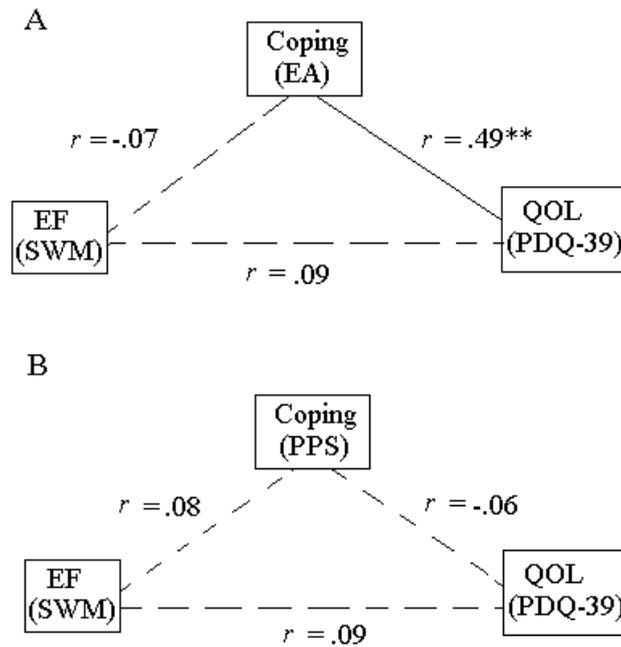


Figure 5. Bivariate correlations between coping, executive function (EF), and quality of life (QOL) for those with a deficit in the Spatial Working Memory (SWM) task. **A:** SWM-QOL relationship mediated by escape-avoidance coping; **B:** SWM-QOL relationship mediated by planful problem solving. Significant (solid lines) and non-significant (dashed lines) relationships between variables are shown. Note: * $p < .05$, ** $p < .001$.

Non-deficit group. Bivariate correlations established the relationships between variables (Figure 6). A significant, moderate positive correlation between EA and PDQ-39 was found. There were no other significant relationships. Therefore, no mediated regression analyses were conducted.

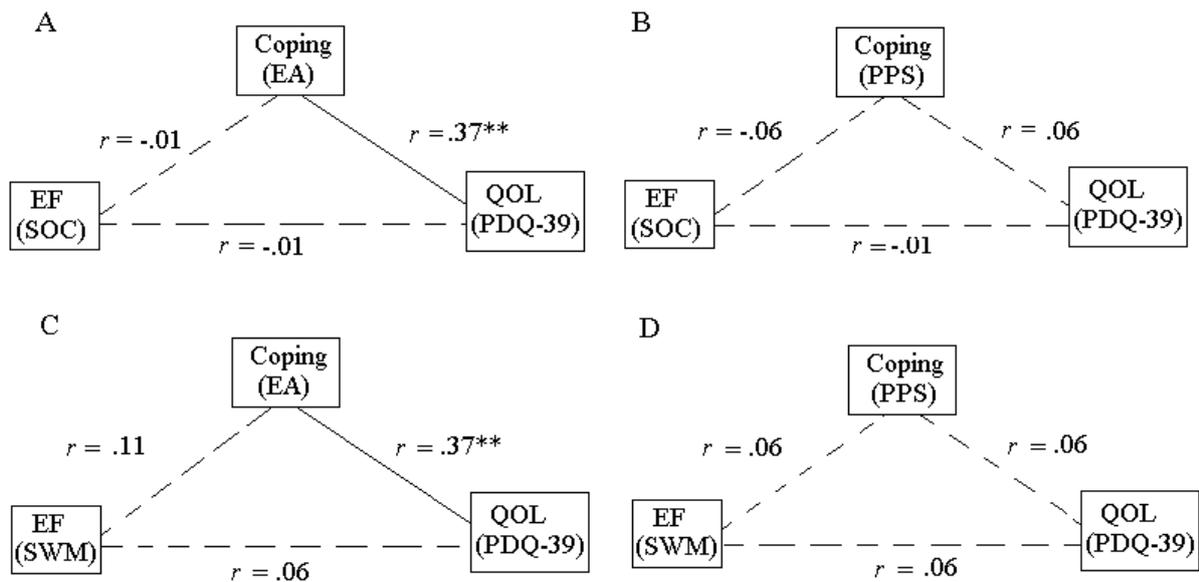


Figure 6. Bivariate correlations between coping, executive function (EF), and quality of life (QOL) for the non-deficit sample. **A:** Escape-avoidance (EA) mediates the EF-QOL relationship (using SOC); **B:** Planful problem solving (PPS) mediates the EF-QOL relationship (using SOC); **C:** EA mediates the between EF-QOL relationship (using SWM); **D:** PPS mediates the EF-QOL relationship (using SWM). Significant (solid lines) and non-significant (dashed lines) relationships are shown. Note: * $p < .05$, ** $p < .001$.

Examination of group differences. It was noted that the previously significant relationship between SWM and PDQ-39 (and trend towards a significant relationship between SOC and PDQ-39) was no longer present within the EF-deficit and non-deficit groups. However, the relationship between EA and PDQ-39 became stronger when EF-deficits were present. The deficit and non-deficit groups were therefore compared to establish the differences between these groups in terms of coping, QOL and depression. Only the SOC-deficit group was compared to the non-deficit group for this analysis as SOC is considered a more holistic measure of EF than SWM. The results of this analysis are displayed in Table 5. SOC accuracy scores were significantly lower for the deficit than the non-deficit group. PDQ-

39 scores were significantly higher (lower QOL) for the deficit group than the non-deficit group. There were no other significant differences.

Table 5.

Comparisons between the SOC-deficit group and the non-deficit group on measures of coping, executive functioning, quality of life and depression.

| Measure | SOC-deficit group ($N = 30$) | Non-deficit control group ($N = 91$) | Group difference (t -test) |
|--------------------------------------|--------------------------------|--|---|
| | Mean (SD) | Mean (SD) | |
| Age at participation | 66.23 (9.68) | 63.45 (9.57) | $t(119) = -1.38, p = .17$ |
| Gender (% Male) | 70.0 | 59.3 | $t(119) = 1.04, p = .30$ |
| Executive Functioning | | | |
| SOC problems solved in minimum moves | 4.40 (1.33) | 8.2 (1.52) | $t(119) = 12.21, p < .001$ |
| Coping (WCQ) | | | |
| Escape-Avoidance | 5.20 (4.33) | 3.86 (3.74) | $t(119) = -1.64, p = .10$ |
| Planful problem solving | 7.57 (4.59) | 7.95 (4.04) | $t(119) = 0.43, p = .67$ |
| Health-related quality of life | | | |
| PDQ-39 Single index score | 25.14 (15.00) | 19.07 (11.78) | $t(119) = -2.28, p = .02$ |
| Depression | | | |
| GDS-15 total score | 4.23 (3.82) | 3.45 (2.79) | $t(119) = -1.04, p = .30$ |

Note: Bolded t -tests indicate statistical significance ($p < .05$)

Discussion

The current study investigated whether coping mediates the relationship between EF and QOL in a PD sample. It was expected that poorer EF would be related to poorer QOL for both SOC and SWM. It was also expected that coping (EA and PPS) would mediate this relationship. The EF-QOL relationship was supported by the current results; however, the mediated regression models could not be tested. Findings suggest that those with poorer EF are more likely to have poorer QOL and those using EA coping are similarly likely to have poorer QOL. However, the expected EF-coping relationship was not found. Analyses examining EF-deficit and non-deficit groups did not support the hypothesised relationship between EF, coping, and QOL. The loss of the EF-QOL relationship for EF-deficit and non-deficit groups can be explained in terms of reduced variance in SWM and SOC scores. The reduced QOL seen for the EF-deficit compared to the non-deficit group provides evidence that EF-deficits negatively impact QOL in PD.

The results are consistent with previous findings that EA use is related to poorer QOL in a PD sample (Bucks et al., 2011) and that those with poorer EF are more likely to have poorer QOL (Brown & Landgraf, 2010; Davis et al., 2010; Tyson et al., 2008). These findings indicate that impaired EF negatively impacts QOL in PD and that attempts to avoid problems and associated emotional distress will be detrimental to QOL. The results were inconsistent with previous findings that suggested intact EF is required for PPS coping use (Krpan, 2007; Krpan et al., 2011) and that poorer EF necessitates the use of less cognitively-demanding strategies such as EA (Goretti et al., 2010; Krpan, 2007; Krpan et al., 2011; Wilder-Willis et al., 2002). The results also contrast with research suggesting that increased PPS use is related to improved QOL in a PD sample (Bucks et al., 2011). The current findings resemble those by Montel and Bungener (2008) who suggested that EF impairments do not limit coping strategy selection in a PD sample. However this is not believed to be the case for the current study as

certain issues were identified that may have prevented the emergence of the expected results. Three key issues were explored: The differential relationships that SOC and SWM had with QOL; difficulties with the coping measure; and the PD sample's potential simultaneous use of EA and PPS strategies.

The current findings revealed a significant EF-QOL relationship for one measure of EF (SWM) and only a trend towards significance for the other (SOC). This may suggest that SWM and SOC differentially influence QOL or are differentially impaired in PD. Mattay et al. (2002) demonstrated that older adults recruit more areas of the brain for use even in simple tasks than do younger adults. This is thought to be a compensatory mechanism as the aging brain reorganises and recruits additional networks to compensate for loss of structure and function. It has been suggested that planning tasks (such as SOC) are more holistic measures of EF and require recruitment of more cortical areas for successful completion compared to more specific EF tasks such as the SWM error-monitoring (Mattay et al., 2002). If compensatory mechanisms are used for the SOC task, white and grey matter atrophy in the frontal areas would have less impact on the task and may explain the non-significant SOC-QOL relationship. On the other hand, SWM requires input from parietal areas. If atrophy of frontal or parietal areas or white matter connecting these areas occurred, the options for other areas that could compensate are limited. With limited compensatory mechanisms, the neurological atrophy occurring in PD may have had a greater impact on the SWM task and therefore on QOL. This possibility could be examined in future fMRI studies of cortical activation. An SOC-QOL relationship may therefore be identified in a sample with greater PD symptom severity where neurodegeneration may exceed the capacity of compensatory mechanisms. The current sample performed comparatively to a normative sample for the SOC task. The SOC variance was small which may have limited establishing a relationship between EF and coping. This may also indicate that, as suggested by Lewis et al. (2003), there

may be EF subtypes of PD in the current sample. There may have been groups of individuals affected by EF deficits and others who are not, or groups with specific planning (SOC) or error-monitoring (SWM) deficits. Future cluster analyses could examine EF subtypes and other specific characteristics of individuals with PD.

Another issue was the apparent incompatibility between sample characteristics and the coping measurement. Researchers observed that participants had difficulty completing the WCQ with 24% of the original sample's data removed due to missing responses. Participants were often unable to bring to mind "the most stressful situation that you have experienced in the *past week*" (p. 1), the fundamental instruction of the WCQ questionnaire. Additionally, participants needed to remember their chosen situation for subsequent questions. The WCQ may therefore have been contaminated by memory deficits. It is also difficult to ascertain whether the measured coping strategy reflects the individual's response to the particular situation or their more general disposition when facing stressors. Parker and Endler (1992) suggested that the number of extracted factors in coping measures changes depending on the sample studied and the stressor chosen. They highlighted that the WCQ items were grouped into the eight coping processes through exploratory factor analysis and are highly subjective, conceptually heterogeneous items. The WCQ is therefore unable to provide a stable factor structure (Parker & Endler, 1992). Difficulties with this measure would have impacted all expected relationships between coping (EA and PPS) and other variables. Adjustments to the wording of the WCQ are required to improve its relevance and suitability to the situation of those with PD.

The significant positive relationship between EA and PPS (unexpected based on the literature) indicates that the individuals of this study were using both strategies simultaneously. This highlights the inadequacy of the WCQ for a PD sample as the intended factor structure may not be supported for this population. Multiple studies have found

alternative factor structures of the WCQ for clinical samples (see Lundqvist & Ahlstrom, 2006 for a review). Coping constructs may not be as clear-cut in clinical populations as Folkman et al.'s (1986) eight-factor model based on a healthy sample. Individuals with chronic illness may use which ever coping resources they have available, some simultaneously. A study examining coping in individuals with heart failure identified that the chronic, challenging nature of the illness necessitated delivery of interventions to improve both emotion-focused and problem-focused coping (Vollman, LaMontagne, & Hepworth, 2007). The authors stated that effective emotion and problem-focused strategy use would be beneficial, suggesting the population currently engaged in both types simultaneously (although ineffectively). Another study by Sorlie and Sexton (2001) extracted five factors from the WCQ relevant to surgical patients: Wishful Thinking, Avoidance, Thinking it Over, Goal-Oriented Coping and Seeking Support. Some previous EA items became Wishful Thinking items (e.g. "I hoped a miracle would happen"), whereas others became Avoidance (e.g. "I avoided people in general"). In Sorlie and Sexton's (2001) study, some items of the avoidance factor (keeping feelings to themselves, preserving pride and not letting feelings interfere) had a low loading (0.3-0.4) on the goal-oriented factor. Together with goal-oriented behaviour, these items could be interpreted as a "just get on with it" attitude; problem solve where possible and make the most of a bad situation without complaining. This attitude seems likely to occur in a clinical population such as PD. This possibility, that simultaneous goal-oriented/avoidant coping occurs in clinical samples, clarifies the current sample's EA-PPS relationship. However, Sorlie and Sexton's (2001) it may not be possible to generalise results from surgical patients to other clinical samples. Research on this issue is lacking and could provide insight into the different coping processes of healthy and clinical samples.

Both methodological and sample-based limitations may have affected the current findings. The WCQ may require adjustment to detect the expected EF – coping – QOL

relationship. The limited sample variability (mild-moderate symptom severity) may have limited the study. It may be that the expected relationship only occurs when EF is considerably impaired, which may occur more in severe PD. Adding cases of severe PD is recommended if this research is replicated. The construction and application of a more appropriate measure of coping for PD is recommended for use in future research. Future studies may also consider a qualitative research design to determine whether EA and PPS strategies are being used simultaneously and for what purpose. Finally, future research could focus on methods for improving EA coping in PD in an effort to improve QOL. Interventions could include mindfulness-based training to encourage awareness and acceptance of emotional distress rather than relying on potentially harmful EA strategies such suppression of thoughts and feelings and behavioural avoidance.

Conclusion

This study investigated the relationship between EF, coping, and QOL. The hypothesised mediation effect of coping on the relationship between EF and QOL could not be tested due to regression criteria not being met. However, several conclusions can be made from these results. It is apparent that a relationship between EF and QOL exists in the current PD sample. This relationship may depend on the brain's ability to use compensatory mechanisms given the nature of the EF task. Furthermore, coping strategy selection is influenced by sample characteristics and the chosen stressor. As such, coping measures based on healthy samples are not suited to clinical samples and adjustments to the WCQ need to be made in order for it to reflect the coping styles of individuals with PD given their unique situation and stressors. Coping also may not be clear cut and individuals may use multiple strategies to tackle the challenges of PD. Overall, both poorer EF and use of EA have negative influences on QOL. Therefore, any strategies to reduce detrimental EA use in PD and teach more useful approaches to coping with problems and distress (e.g. problem solving and

mindfulness) are likely to improve QOL. It is important that future research continues to investigate these relationships in order to achieve a greater understanding of the underlying processes of PD and to optimize preventative and treatment interventions.

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Appendix A

Participant Information Sheet

**INFORMATION SHEET**

**Project titled: COGNITIVE AND MOTOR HETEROGENEITY
IN IDIOPATHIC PARKINSON'S DISEASE.**

JOONDALUP CAMPUS
270 Joondalup Drive, Building 21, Level 5
Joondalup, Western Australia 6027
☎ (08) 6304 3560
ParkC@ecu.edu.au
www.ParkC.org.au
MANAGED BY WESTERN CIVILIS (P) 001/158

Chief Investigator(s): Dr Meghan Thomas, PhD (*Director and Postdoctoral Research Fellow, ParkC, Edith Cowan Health and Wellness Institute, Edith Cowan University*), Miss Caitlin Timms (*Research Assistant, ParkC, Edith Cowan Health and Wellness Institute, Edith Cowan University*). **Co-Investigator(s):** Dr Romola Bucks, PhD (*UK Trained Clinical Neuropsychologist and Lecturer, School of Psychology, University of Western Australia*), Dr Andrea Loftus, PhD (*Lecturer, School of Psychology, University of Western Australia*), Dr Natalie Gasson, PhD (*Undergraduate co-ordinator, Lecturer, School of Psychology, Curtin University*).

We would like to invite you to participate in the following research which will investigate the relationship between motor (i.e. balance, walking, tremor, rigidity), and non-motor (i.e., problems with memory, thinking, and mood) symptoms of Parkinson's disease (PD). Information regarding the relationship between the motor and non-motor symptoms will to be used to identify subtypes of PD.

Currently, the cause of PD is unknown. It is possible that some (but not all) individuals may have a genetic predisposition to developing PD and the current research aims to explore this further.

Please take time to read the following information carefully and discuss it with others if you wish.

What are the possible benefits of taking part?

The information we gain from your participation will help us better to understand the motor (balance, walking, tremor, rigidity) cognitive (thinking and memory) and affective (mood) problems that can occur as a result of PD. The information we gain from your participation will help us to identify subtypes of PD and the identification of subtypes will have implications for the clinical management of future patients with PD.

Why have I been invited to participate in this research?

You have been invited to participate in this research because you have been diagnosed with PD or Parkinsonism.

What will I be asked to do?

There are three parts to this study: Part 1) involves the completion of questionnaires or surveys; Part 2) involves some computer and paper-based assessments; and Part 3) involves an assessment of motor (i.e. balance, walking, tremor, rigidity) symptoms.

Part 1: We will provide you with a questionnaire package via post and ask that you complete some surveys regarding your mood, memory, and personality, how sleepy you are during the day and possible sleep difficulties, how your Parkinson's symptoms influence your everyday life, and how you cope with things in general. All of these surveys are designed to be self-completed; therefore, you may complete the surveys at

home and bring them with you to your appointment at ParkC, if you decide to participate in Part 2 of the study. You are also free to complete all or part of the questionnaires at the end of your appointment at ParkC if you wish. A research staff member from ParkC will sit with you and discuss any questions you may have regarding the questionnaires. If you do not wish to take part in Part 2 of this research, you may still complete the questionnaires and we will provide you with a reply paid envelope to return your questionnaires.

Part 2: If you are happy to participate in Part 2 of this research, we will go over the information sheet with you when you arrive at ParkC, explain what is going to happen during the appointment, and answer any questions you might have. You will then be asked to participate in some tasks that are designed to look at your memory and thinking skills. These will be both paper-based and computer-based tasks. The session will be made as enjoyable as possible for you; however some of these tasks can be challenging. If you feel at any point during the assessment that you would like to stop, please tell the research staff and they will end the session immediately. You do not have to give a reason why and you will not be asked any further questions.

Part 3: Lastly, you will be asked to perform some simple motor (i.e. balance, walking, tremor, rigidity) tasks as part of the Unified Parkinson's Disease Rating Scale (UPDRS), a standardised assessment for the motor symptoms of PD. These motor tasks will include: finger tapping, hand rotations, fist clenching/opening, finger to nose movements, leg and toe tapping, rising from a chair, and a 10 meter walk. The investigator will also give you a slight pull on the shoulders to assess your balance and will stand behind you to provide support should you become unbalanced. Assessments of speech, facial expression, rigidity (stiffness of neck, arms and legs), and tremor will be made via observation during this assessment period. You will also be asked some questions regarding dyskinesias (involuntary movements), fluctuations in functioning due to medications cycles and dystonia (painful cramps and/or muscle spasms) which you may or may not experience. **All of these assessments will be videotaped to allow for independent review and rating by experts in the field of Parkinson's, although you can decline to have the session videotaped.** We will also take a measurement of your height, weight and waist circumference.

The motor assessment requires manipulation of the hips and legs. Please wear comfortable clothing; trousers are preferred.

Throughout the appointment you will be encouraged to ask questions and while the testing is anticipated to take no more than 2 hours, you will be given regular breaks.

Blood sample for Genetic Analysis

There is a fourth optional part of this project. As part of the appointment at ParkC, we ask participants if they would be happy to donate a small sample of blood so that we can look at genetic make-up (i.e. your DNA). **Please note that the decision to have a blood sample taken is completely optional and forms a different part of the study. You can decide not to have a blood sample without affecting any other data we collect about you for the study. Your participation will be of equal value, with or without the blood sample.**

Blood and DNA samples will be stored for the length of this research project and will be analysed for a range of DNA markers.

Initially we will screen for the known genetic mutations that cause familial PD. These mutations occur in the SNCA, LRRK2, Parkin, PINK1, DJ-1 and Parkin 9 genes. Familial PD occurs in only 10% of PD cases so is uncommon. If we find a known genetic cause of PD we will (with your consent) inform your treating physician who will be able to arrange appropriate Genetic Screening to confirm our research findings.

We also intend to screen for a range of genetic measures that may be associated with the various aspects of PD. The technology for genotyping DNA is changing rapidly and is producing more and more complex data. Further the known genetic influences that may affect different aspects of PD are still unclear. Therefore we

would like to screen for a range of as yet unspecified markers, with your consent. In the short term this research is more about trying to find associations between your DNA and your PD symptoms. It is very experimental and at this stage not able to influence any treatment approaches although we hope that in the future it will have clear treatment implications.

If you provide written consent, indicating that you are happy to provide a blood sample, a qualified phlebotomist will take your blood sample. We are grateful to everyone who agrees to give a sample.

What about my medication?

We would ask you to take your medication as normal. No changes will be made to your medication and you will not be asked to stop taking your current medication at any point during this study.

What will happen when the research study stops?

This is a longitudinal study and so it does not have a specific end date. At the end of your appointment, we will ask whether you might like to participate in a further follow-up appointment scheduled for approximately two years later.

What are the possible disadvantages and risks of taking part in this research?

There are no foreseeable risks or disadvantages associated with taking part in this study, aside from the possibility of becoming a little tired as a result of undertaking these assessments. However, you will be provided with regular breaks to help avoid becoming fatigued.

There are no foreseeable risks or disadvantages associated with Part 3 (motor assessment), aside from the minimal risk of a fall during the balance assessment. However, at least two investigators will be present during this assessment and the investigator conducting the balance assessment will stand behind you to support you in the case that you become unbalanced. The balance assessment conducted as part of the UPDRS is standard in clinical practice for PD.

The discomforts associated with taking a blood sample are minimal. There is a risk that sometimes bruising and minor infection may occur and the arm might become sore. Risk of bruising or infection will be minimised because all blood samples will be performed by an experienced phlebotomist (lab technician). The total amount of blood we need is small (10-40ml).

Confidentiality – who will have access to the data?

ParkC complies with the requirements of the National Health and Medical Research Council (NHMRC) guidelines with regard to collection, storage, processing, and disclosure of personal information and is committed to upholding the Act's core data protection principles. All information that is collected about you during the course of the research will be kept strictly confidential. Some of your data may include personal information such as your name, date of birth and/or a reference number. This information will be held in secure, locked filing cabinets at ParkC, or on a password protected computer database held on a secure system, which allows access to authorized individuals only. On completion of the study, all data will be stored for a period of 5 years before being destroyed by secure shredding facilities and permanent deletion of video files.

The video files and data collected during Part 3 of the research may be used in future research projects conducted at ParkC which are in the same general area of research interest, if you agree. These data will only be accessed by research staff and individuals affiliated with ParkC, Edith Cowan University.

Although the researchers at ParkC are not qualified to comment on the clinical implications of individual test performance, we are able to forward the results of your assessment to your treating specialist, with your consent.

Do I have to take part?

Participation in this study is completely voluntary. We will describe the study and go through this information sheet with you. If you do decide to take part you will be given this information sheet to keep

and will be asked to sign a consent form, of which you will get a copy. If you decide to take part you are still free to withdraw at any time and you do not need to give a reason. A decision to withdraw from this research will not affect the standard of care you receive and there will be no effect on your legal rights, medical care, or your relationship with the hospital or your doctors. You are also welcome to participate in other research projects conducted by ParkC if you decide to withdraw from this particular study.

If you do decide to withdraw, we will ask you whether you are happy for us to use the data that we might have already collected from you. If you are not happy for us to use any of the data collected from you, any data relating to your participation in this study will be destroyed.

Who is organising and funding the research?

ParkC is funded by Edith Cowan University (ECU), donations from the McCusker Foundation, the Rotary Club of Morley, and donations from members of the public and Parkinson's community.

Who has approved the study?

This research has been approved by Edith Cowan University's Human Research Ethics Committee, Parkinson's Western Australia (PWA) Inc., and Joondalup Health Campus Human Research Ethics Committee.

Who can I contact about this study?

If you have any questions about this study or would like more information, please contact either Miss Caitlin Timms or Dr Meghan Thomas on (08) 6304 3560 or email ParkC@ecu.edu.au

What if there is a problem and I want to make a complaint?

If you have any concerns of an ethical nature or complaints about the manner in which the research is conducted, please contact (Kim Gifkins: Research Ethics Officer) of ECU's Human Research Ethics Committee on: (08) 6304 2170 or email research.ethics@ecu.edu.au. Additionally, you can contact the Joondalup Health Campus Human Research Ethics Committee through the Executive Office on (08) 9400 9404. Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

What will happen to the study results?

We will let you know the results of the study in our annual newsletter which will be posted via mail and on the ParkC website (www.ParkC.org.au). However, if you would like to know anything further please feel free to contact the research team at ParkC before then and we will be happy to share the findings with you. The results of this study will also be communicated via presentations at National and International conferences as well as being written into manuscripts which will be submitted to peer-reviewed journals. All of your identifying features will be removed in such cases.

Do I get to keep a copy of the Information Sheet and Consent form?

You will be given a copy of this Information Sheet to keep. If you decide to take part in this research and sign the consent form, you will be given a copy of this signed consent form for your records also.



Dr Meghan Thomas
 Director, Postdoctoral Research Fellow
 Parkinson's Centre (ParkC)
 Edith Cowan University
 Phone: (08) 6304 3560
 Fax: (08) 6304 2499
 Email: m.thomas@ecu.edu.au



Caitlin Timms
 Research Assistant
 Parkinson's Centre (ParkC)
 Edith Cowan University
 Phone: (08) 6304 3560
 Fax: (08) 6304 2499
 Email: caitlin.timms@ecu.edu.au

Appendix B

Consent Form



CONSENT FORM

**Project titled: COGNITIVE AND MOTOR HETEROGENEITY
IN IDIOPATHIC PARKINSON'S DISEASE.**

JOONDALUP CAMPUS
7700 Mowlem Drive, Building 20, Level 5
Joondalup, Western Australia 6107
☎ (08) 9361 3540
ParkC@ecu.edu.au
www.ParkC.org.au
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Please tick box

1. I have read and understood the 'Information Sheet' for this study.
2. The nature and the possible effects of this study have been explained to me.
3. Any questions that I have asked have been answered to my satisfaction.
4. I understand that this research involves a number of computer and paper-based tasks.
5. I understand that the UPDRS, a standardised assessment of the motor symptoms of Parkinson's will be administered and that this assessment involves a number of simple motor tasks, an assessment of balance, and various observations of speech, tremor, rigidity, and posture.
6. I understand that I will be videotaped undertaking the assessment of motor (i.e. balance, walking, tremor, rigidity) symptoms
 - a. I consent for the video files of my UPDRS assessment to only be used in this study for the purposes of confirming my diagnosis of Parkinson's and that the recording will be deleted upon completion of the study.
 - b. I consent for the video file of my UPDRS assessment to be used in future approved research projects conducted at ParkC which are in the same general area of Parkinson's research.
7. I consent to my results being released to my treating physician/neurologist if requested.
8. I understand that all research data will be securely stored at ParkC, Edith Cowan University, for a minimum period of five years following the study end date. I also understand that the data will be securely stored on password protected computers and locked cabinets at ParkC until no longer required, at which time it will be destroyed.
9. I understand that there are no foreseeable risks associated with this research, aside from the possibility of fatigue and minimal risk of falls associated with the balance assessment conducted in Part 3 of the research.



- 10. I agree that research data for the study may be published and that I will not be identified as a participant.
- 11. I understand that my identity will be kept confidential and that any information I supply to the researchers will be used only for the purposes of this research and/or research in the same general area.
- 12. I agree to participate in this investigation and understand that I may withdraw at anytime without giving a reason, and without my medical care or legal rights being affected. I also understand that if I so wish, I may request that any personal data gathered be withdrawn from the research.
- 13. I agree to donate a sample of blood for research purposes. I understand that this sample will be used for the purpose of genetic tests.
 - a. I consent for my blood samples to only be used in this study and that they will be destroyed at the completion of the study
 - b. I consent for my blood sample to be used as explained so far and for any other analysis that may arise during the course of the study.
 - c. I consent for my blood samples to be held for future studies that may or may not be related to Parkinson's but that have received ethics approval from a recognised institution.
 - d. I consent for ParkC to inform my treating physician if a mutation in a known familial PD gene is found

Name of Participant _____

Signature of Participant _____ Date _____

For the Investigator

I have explained this project and the implications of participation to this volunteer and believe that the consent is informed and that he/she understands the implications of participation.

Name of Investigator _____

Signature of Investigator _____ Date _____



Appendix C

Mini Mental State Exam

MMSE

Participant ID _____ Date _____

| Orientation | Response | Score |
|---|--|--------------|
| 1. What is today's date? | Date (day/month/year). 1 point for each correct OR | /3 OR |
| (if participant does not answer question 1 correctly e.g., only responds 21 st ask 1a,b) 1a What is the year? 1b What is the month? | 1 point each for year, month, date (e.g., 21 st) | /3 |
| 2. What day is today? | e.g., Monday | /1 |
| 3. Can you tell me what season it is? Allow 2 weeks flexibility | Summer= 1 st Dec-28 th Feb; Autumn= 1 st March-31 st May; Winter= 1 st June-30 th Aug; Spring= 1 st Sep-30 th Nov | /1 |
| | Total | /5 |
| 4. Can you tell me the name of the Institution we are in? Can you name the Department we are in? If participant responds ParkC, you can prompt "can you tell me the institution?" e.g., ECU to get the full points. | 2 points= ECU and/or ParkC 1 point= ECU or ParkC, Parkinsons, School of Medical Sciences. If conducting at nursing home take name of nursing home. If conducting at home, take name of street and house number. | /2 |
| 5. What City/Suburb are we in? | Joondalup | /1 |
| 6. What State are we in? | Western Australia | /1 |
| 7. What Country are we in? | Australia | /1 |
| | Total | /5 |

| Immediate Recall | | Response | Score |
|---|------------------------|--|-----------------|
| <p>"I'm going to say some words. Listen carefully and when I have said all the words, please repeat them to me. So I say the words and then you say them".</p> <p>BALL (pause) FLAG (pause) TREE</p> <p>1 point for each correct response</p> | "Ball" | | /1 |
| | "Flag" | | /1 |
| | "Tree" | | /1 |
| | Number of trials _____ | | Total /3 |
| | | <p>This first repetition determines the participants score (0-3) but keep saying them until the participant can repeat all 3. Up to 6 trials- but use judgement.</p> | |

| Attention/Calculation | Response | | Response |
|---|----------|---|-----------|
| <p>"I've got some mental arithmetic for you. Starting with 100 take away 7, then take away 7 from that number, and keep taking away by 7 until I tell you to stop."</p> <p><i>continue for 5 subtractions.</i></p> <p>AND Word Backwards. No need to get them to spell it forward</p> <p>"Spell the word "WORLD" as in the world that we live in" backwards,</p> <p><i>This may be accompanied by a physical prompt as to what the word is.</i></p> <p>When scoring, count an error as the number of moves the word is out of order. E.g., DRLOW is only 1 move from being correct, so only 1 error 4 points.</p> <p>(Score both of these tests)</p> | 93 | <p>If asked, you may prompt with the previous answer they gave. However, note the prompt and do not score the response as correct even if calculation is correct.</p> | D |
| | 86 | | L |
| | 79 | | R |
| | 72 | | O |
| | 65 | | W |
| Total | | /5 | /5 |

| Recall | | Response | Score |
|--|--------|----------|--------------------|
| <p>I asked you to repeat some words earlier. Can you tell me what they were?</p> <p><i>You may tell the participant that you did not ask them to remember the words at the time.</i></p> | "BALL" | | /1 |
| | "FLAG" | | /1 |
| | "TREE" | | /1 |
| | | | Total /3 |

| | | Response | Score |
|---|---|----------|-------|
| <p>NAMING</p> <p>"What is this called?" <i>Show wrist watch</i></p> <p>"And this?" <i>show a pencil</i></p> | Watch | | /1 |
| | Pencil | | /1 |
| | <i>(do not let the participant touch the objects)</i> | | |
| <p>REPETITION</p> <p>"I'm going to say a sentence to you. It's an unusual one. Please listen carefully and then repeat after me. So I say the sentence and then you say it" (pause)</p> <p>"NO IFS, ANDS, OR BUTS"</p> | "No ifs, and or buts" is not acceptable | | /1 |
| <p>3-STAGE COMMAND</p> <p>Hold blank paper close to yourself with both hands. Give instructions then present the paper with <u>both hands</u> to the person's midline</p> <p>"I want you to listen carefully and then do what I say".</p> <p>"Take this piece of paper in your right hand (pause) fold it in half (pause) and place it on your knee".</p> | Takes paper in right hand | | /1 |
| | Folds it in half | | /1 |
| | Puts paper on knee | | /1 |
| | | | |

| | | | |
|---|--|---|--------------------------------------|
| <p>WRITING</p> <p>Give the participant a blank piece of paper. Say to participant:</p> <p>“Now I would like you to write a sentence (<i>pause</i>). “Write anything you like as long as it make sense.” You may also say “It doesn’t have to be long”.</p> <p>If you are unsure what the sentence says, ask the participant to read it aloud.</p> | <p>The sentence has to be written spontaneously. It must contain a subject and a verb and be sensible. Correct grammar and pronunciation are not necessary. (Go away!= pass; Happy Birthday=Fail).</p> | | <p>/1</p> |
| <p>COPYING</p> <p>Show participant the pentagons.</p> <p>“Now I would like you to copy this picture exactly as it is. It doesn’t have to be a work of art, just get all the corners in”.</p> | <p>All 10 angles must be present and 2 must intersect to form a four sided figure to score 1 point. Tremor and rotation are ignored.</p> | | <p>/1</p> |
| <p>READING COMMAND</p> <p>“I’m going to show you a sentence and I want you to read and do what it says.”</p> <p>Show participant the piece of paper with the sentence “CLOSE YOUR EYES”.</p> <p>If there is uncertainty, ask the participant to read it out loud. If they read it but don’t do it, prompt the person and score as zero.</p> <p>Prompt: “Please do as it says”.</p> | <p>Score correct only if the participant actually closes their eyes.</p> <p>You may prompt to establish whether the participant has forgotten the command.</p> | | <p>/1</p> <p>Total /9</p> |
| <p>TOTAL SCORE SERIAL 7S</p> | | <p>TOTAL SCORE WORLD BACKWARDS</p> | |
| <p>TOTAL SCORE (maximum score is 30)</p> | | | |

Appendix D

Geriatric Depression Scale

Participant ID _____ **GDS** _____ **Date** _____

Please circle yes or no for each of the following statements to indicate how you have felt over the **past week**.

- | | |
|--|----------|
| 1. Are you basically satisfied with your life? | Yes / No |
| 2. Have you dropped many of your activities and interests? | Yes / No |
| 3. Do you feel that your life is empty? | Yes / No |
| 4. Do you often get bored? | Yes / No |
| 5. Are you in good spirits most of the time? | Yes / No |
| 6. Are you afraid that something bad is going to happen to you? | Yes / No |
| 7. Do you feel happy most of the time? | Yes / No |
| 8. Do you feel helpless? | Yes / No |
| 9. Do you prefer to stay at home rather than going out and doing new things? | Yes / No |
| 10. Do you feel you have more problems with memory than most? | Yes / No |
| 11. Do you think it is wonderful to be alive? | Yes / No |
| 12. Do you feel pretty worthless the way you are now? | Yes / No |
| 13. Do you feel full of energy? | Yes / No |
| 14. Do you feel that your situation is hopeless? | Yes / No |
| 15. Do you think that most people are better off than you are? | Yes / No |

Appendix E

Parkinson's Disease Questionnaire -39



PDQ-39 QUESTIONNAIRE

Please complete the following

Please tick one box for each question

Due to having Parkinson's disease, how often during the last month have you....

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

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

Due to having Parkinson's disease, how often during the last month have you....

Please tick one box for each question

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

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

Due to having Parkinson's disease, how often during the last month have you....

Please tick one box for each question

| | Never | Occasionally | Sometimes | Often | Always |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 30 Unexpectedly fallen asleep during the day? | <input type="checkbox"/> |
| 31 Had problems with your concentration, e.g. when reading or watching TV? | <input type="checkbox"/> |
| 32 Felt your memory was bad? | <input type="checkbox"/> |
| 33 Had distressing dreams or hallucinations? | <input type="checkbox"/> |
| 34 Had difficulty with your speech? | <input type="checkbox"/> |
| 35 Felt unable to communicate with people properly? | <input type="checkbox"/> |
| 36 Felt ignored by people? | <input type="checkbox"/> |
| 37 Had painful muscle cramps or spasms? | <input type="checkbox"/> |
| 38 Had aches and pains in your joints or body? | <input type="checkbox"/> |
| 39 Felt unpleasantly hot or cold? | <input type="checkbox"/> |

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

Thank you for completing the PDQ 39 questionnaire

Appendix F

Ways of Coping Questionnaire

Please provide the following information:

Name: _____ Date: _____
Month / Day / Year

Identification Number (optional): _____ Gender (Circle): **M** **F** Age: _____

Marital Status (check): Single Married Widowed Separate/Divorced

Instructions

To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. Take a few moments and think about the most stressful situation that you have experienced in the *past week*.

By "stressful" we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation. The situation may have involved your family, your job, your friends, or something else important to you. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that you experienced during the week.

As you respond to each of the statements, please keep this stressful situation in mind. **Read each statement carefully and indicate, by circling 0, 1, 2 or 3, to what extent you used it in the situation.**

Key: 0 = Does not apply or not used 1 = Used somewhat
 2 = Used quite a bit 3 = Used a great deal

Please try to respond to every question.

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

1. I just concentrated on what I had to do next – the next step. 0 1 2 3
2. I tried to analyze the problem in order to understand it better. 0 1 2 3
3. I turned to work or another activity to take my mind off things. 0 1 2 3
4. I felt that time would have made a difference –
the only thing was to wait. 0 1 2 3
5. I bargained or compromised to get something positive
from the situation. 0 1 2 3
6. I did something that I didn't think would work,
but at least I was doing something. 0 1 2 3
7. I tried to get the person responsible to change his or her mind. 0 1 2 3
8. I talked to someone to find out more about the situation. 0 1 2 3
9. I criticized or lectured myself. 0 1 2 3
10. I tried not to burn my bridges, but leave things open somewhat. 0 1 2 3
11. I hoped for a miracle. 0 1 2 3
12. I went along with fate; sometimes I just have bad luck. 0 1 2 3
13. I went on as if nothing had happened. 0 1 2 3
14. I tried to keep my feelings to myself. 0 1 2 3
15. I looked for the silver lining, so to speak;
I tried to look on the bright side of things. 0 1 2 3
16. I slept more than usual. 0 1 2 3
17. I expressed anger to the person(s) who caused the problem. 0 1 2 3
18. I accepted sympathy and understanding from someone. 0 1 2 3
19. I told myself things that helped me feel better. 0 1 2 3
20. I was inspired to do something creative about the problem. 0 1 2 3
21. I tried to forget the whole thing. 0 1 2 3
22. I got professional help. 0 1 2 3

Go on to next page

Received from Mind Garden, Inc. on June 11, 2008

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

- 23. I changed or grew as a person. 0 1 2 3
- 24. I waited to see what would happen before doing anything. 0 1 2 3
- 25. I apologized or did something to make up. 0 1 2 3
- 26. I made a plan of action and followed it. 0 1 2 3
- 27. I accepted the next best thing to what I wanted. 0 1 2 3
- 28. I let my feelings out somehow. 0 1 2 3
- 29. I realized that I had brought the problem on myself. 0 1 2 3
- 30. I came out of the experience better than when I went in. 0 1 2 3
- 31. I talked to someone who could do something concrete
about the problem. 0 1 2 3
- 32. I tried to get away from it for a while by resting or taking a vacation. 0 1 2 3
- 33. I tried to make myself feel better by eating, drinking,
smoking, using drugs, or medications, etc. 0 1 2 3
- 34. I took a big chance or did something very risky
to solve the problem. 0 1 2 3
- 35. I tried not to act too hastily or follow my first hunch. 0 1 2 3
- 36. I found new faith. 0 1 2 3
- 37. I maintained my pride and kept a stiff upper lip. 0 1 2 3
- 38. I rediscovered what is important in life. 0 1 2 3
- 39. I changed something so things would turn out all right. 0 1 2 3
- 40. I generally avoided being with people. 0 1 2 3
- 41. I didn't let it get to me; I refused to think too much about it. 0 1 2 3
- 42. I asked advice from a relative or friend I respected. 0 1 2 3
- 43. I kept others from knowing how bad things were. 0 1 2 3
- 44. I made light of the situation; I refused to get too serious about it. 0 1 2 3

Go on to next page

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

- | | | | | |
|--|---|---|---|---|
| 45. I talked to someone about how I was feeling..... | 0 | 1 | 2 | 3 |
| 46. I stood my ground and fought for what I wanted. | 0 | 1 | 2 | 3 |
| 47. I took it out on other people..... | 0 | 1 | 2 | 3 |
| 48. I drew on my past experiences; I was in a similar situation before.... | 0 | 1 | 2 | 3 |
| 49. I knew what had to be done, so I doubled my efforts to make things work..... | 0 | 1 | 2 | 3 |
| 50. I refused to believe that it had happened | 0 | 1 | 2 | 3 |
| 51. I promised myself that things would be different next time..... | 0 | 1 | 2 | 3 |
| 52. I came up with a couple of different solutions to the problem..... | 0 | 1 | 2 | 3 |
| 53. I accepted the situation, since nothing could be done..... | 0 | 1 | 2 | 3 |
| 54. I tried to keep my feeling about the problem from interfering with other things. | 0 | 1 | 2 | 3 |
| 55. I wished that I could change what had happened or how I felt..... | 0 | 1 | 2 | 3 |
| 56. I changed something about myself..... | 0 | 1 | 2 | 3 |
| 57. I daydreamed or imagined a better time or place than the one I was in. | 0 | 1 | 2 | 3 |
| 58. I wished that the situation would go away or somehow be over with. | 0 | 1 | 2 | 3 |
| 59. I had fantasies or wishes about how things might turn out..... | 0 | 1 | 2 | 3 |
| 60. I prayed. | 0 | 1 | 2 | 3 |
| 61. I prepared myself for the worst..... | 0 | 1 | 2 | 3 |
| 62. I went over in my mind what I would say or do..... | 0 | 1 | 2 | 3 |
| 63. I thought about how a person I admire would handle this situation and used that as a model..... | 0 | 1 | 2 | 3 |
| 64. I tried to see things from the other person's point of view. | 0 | 1 | 2 | 3 |
| 65. I reminded myself how much worse things could be..... | 0 | 1 | 2 | 3 |
| 66. I jogged or exercised..... | 0 | 1 | 2 | 3 |

Stop Here.

Extended Literature Review

The Relationship between Executive Functioning, Coping, and
Quality Of Life in Parkinson's Disease

Elise M. Duncan

Curtin University, Bentley

2013

The Relationship between Executive Functioning, Coping, and Quality Of Life in Parkinson's Disease

Parkinson's disease (PD) is one of the most prevalent diseases of the older population (Jankovic, 2008). PD is a progressive, neurodegenerative condition which is characterised by both motor and non-motor symptoms (Jankovic, 2008). These symptoms significantly impact on the individual's quality of life (QOL), including aspects of physical independence, psychological wellbeing, and social functioning (Karlsen, Larsen, Tandberg, & Maeland, 1998; Karlsen, Tandberg, Arslan, & Larsen, 2000; Schrag, Jahanshahi, & Quinn, 2000). To date, research has been focused on investigating the motor deficits of PD and the development of treatment interventions to improve motor function (Baatile, Langbein, Weaver, Maloney, & Jost, 2000; Schrag, et al., 2000; Tamir, Dickstein, & Huberman, 2007). It is increasingly acknowledged that it is important to include cognitive rehabilitation alongside strategies focused on the recovery of movement (Sammer, Reuter, Hullmann, Kaps, & Vaitl, 2006; Schrag et al., 2000). In order to develop rehabilitative interventions that optimise QOL for those with PD, continued research into various factors that influence QOL is required. One area of PD literature that is currently deficient is that which investigates the impact of mild executive impairments on QOL and the factors that affect this relationship.

As PD is a complex illness with multiple motor and non-motor symptoms, a thorough understanding of all aspects of PD is necessary if treatment interventions are to be optimised. The characteristic motor symptoms of PD are well-known and include akinesia/ bradykinesia, tremor, rigidity, and postural instability (Foltynie, Brayne, & Barker, 2002; Jankovic, 2008). More recent studies have highlighted the presence and impact of cognitive impairments such as a memory, speech and language, and executive function (EF) deficits that often accompany motor symptoms (Leroi, McDonald, Pantula, & Harbisetar, 2012; Martinez-Martin, 2011;

Owen, 2004; Zgaljardic, Foldi, & Borod, 2004). Both motor and non-motor symptoms of PD diminish QOL for those with the illness (Karlsen et al., 2000; Leonardi et al., 2012; Muslimovic et al., 2008; Schrag et al., 2000). It is widely accepted that disruptions to dopaminergic pathways in the midbrain underlie the characteristic motor impairments observed in PD, although the involvement of nondopaminergic neurotransmitter systems such as serotonergic, noradrenergic, and cholinergic pathways have recently been suggested to underlie non-motor symptoms of PD (Zgaljardic et al., 2006; Zgaljardic et al., 2004). PD can be genetic in origin, triggered by insults such as traumatic brain injury or substance abuse. The most common diagnosis, however, is one of Idiopathic Parkinson's disease (IPD). IPD refers to instances of the disease occurring in the absence of a specific known cause or trigger (Jankovic, 2008). Researchers have reported a high degree of variation in symptom presentation of IPD.

The variations in symptom presentation for those with IPD have led to studies into the heterogeneity of the disease. Cluster analysis studies have reported that IPD subtypes can be defined by characteristics such as age at diagnosis, age at testing, and severity of depressive symptoms (Graham & Sagar, 1999; Lewis, Foltynie, Blackwell, Robbins, & Owen, 2005; Post, Speelman, & de Haan, 2008). Post et al. (2008) completed a cluster analysis on a sample of 133 patients with newly-diagnosed Parkinson's disease, where age of onset and emotional functioning were determining variables. The results indicated three distinct subgroups; a younger onset group, an intermediate onset group with higher anxiety and depression, and an older onset group characterised by higher motor impairment and faster progression. However, another study conducted further analyses controlling for these individual characteristics and revealed EF deficits as the *only* significant feature that distinguished the IPD subtypes (Lewis, Cools, Robbins, Dove, & Barker, 2003). Lewis and colleagues (2003) controlled for individual characteristics through matching participants in terms of current age, age at onset,

disease duration, stage of illness, motor latency, cognitive ability, and emotional functioning. They then demonstrated that a visuo-spatial measure of EF, The Tower of London Task, could be used to discriminate between subtypes of IPD. These findings indicate that EF deficits are a key determining feature of IPD, which may have important implications for rehabilitation. More tailored interventions may be constructed for individuals according to their symptom presentation, enabling optimal improvements in health and overall QOL.

Health-Related Quality of Life in IPD

IPD has negative impacts on multiple areas of an individual's life, including their mood, physical health and wellbeing, independence, social functioning, and cognitive ability. The impact of IPD on an individual's life is typically examined in terms of health-related QOL (HRQOL). HRQOL refers to an individual's perception of their own physical, psychological, social, and somatic aspects of health and is often reduced in those with PD compared to healthy older adult populations (Karlsen et al., 1998; Karlsen et al., 2000). Although treatment interventions for IPD largely focus on improving motor function, research suggests that non-motor aspects of PD (medications, falls, depression, and dementia) can have equal or greater impact upon HRQOL (Schrag et al., 2000). The key factors which impact upon HRQOL in IPD include depression (Schrag et al., 2000; Soh, Morris, & McGinley, 2011), physical disability (Karlsen et al., 2000; Leonardi et al., 2012; Muslimovic et al., 2008; Schrag et al., 2000), and cognitive impairment (Leroi et al., 2012; Schrag et al., 2000). Depression is considered one of the strongest predictors of HRQOL of life in IPD (Martinez-Martin, 2011; Schrag et al., 2000). One study found a diagnosis of Major Depression in 24% of those with PD, whereas the prevalence was 11% and 4% for an age-matched diabetic group and a control group, respectively (Tandberg, Larsen, Aarsland, & Cummings, 1996). Others have found depression to account for up to 60% of impairment as measured by the Parkinson's Disease Questionnaire (PDQ-39), an assessment of HRQOL in PD (Jenkinson,

Fitzpatrick, Petrone, Greenhall, & Hyman, 1997). Physical disability and postural instability in PD often lead to reduced independence and dramatic lifestyle changes that have a significant effects on HRQOL for those with PD (Karlsen et al., 1998; Schrag et al., 2000).

Cognitive deficits are one of the key features of PD, with approximately one third of individuals with the illness developing dementia (Zgaljardic et al., 2004). It has recently been suggested that the mild cognitive impairments occurring in PD are just as clinically relevant as dementia for HRQOL (Leroi et al., 2012). Cognitive impairments such as attention, memory, and speech and language impairments are negatively associated with HRQOL (Hurt et al., 2012; Leroi et al., 2012; Muslimovic et al., 2008; Schrag et al., 2000). Furthermore, in the absence of depression and dementia, cognitive impairment remains a strong predictor of HRQOL (Klepac, Trkulja, Relja, & Babic, 2008; Schiehser et al., 2009). It has been suggested that executive dysfunction underlies the general cognitive deficits seen in IPD (Lewis, Slabosz, Robbins, Barker, & Owen, 2005).

EF and HRQOL

EF deficits have also been suggested to have a negative impact upon HRQOL for those with PD (Lewis et al., 2003; Rae et al., 2012; Uekermann et al., 2004; Zgaljardic et al., 2006). EFs are the higher-level cognitive functions of the dorsolateral frontal cortex (Uekermann et al., 2004). EF deficits are common in early PD and may progress to dementia later in the disease (Muslimovic et al., 2008; Uekermann et al., 2004). EFs such as planning, complex problem-solving, self and environmental-monitoring, abstract reasoning, visuo-spatial working memory, and inhibition are necessary for many day-to-day functions, including appropriate social interaction, successful adaptation to environmental demands, and for converting intent to purposeful action (Smith & Jonides, 1999). Such skills are also prerequisites for achieving many every-day tasks and challenges (Pirogovsky, Woods,

Filoteo, & Gilbert, 2012; Smith & Jonides, 1999; Uc & Rizzo, 2008). For example, those with PD have reduced driving ability compared to healthy, age-matched controls in both simulated and real-life driving assessments (Cordell, Lee, Granger, Vieira, & Lee, 2008; Ranchet, Paire-Ficout, Marin-Lamellet, Laurent, & Broussolle, 2011; Uc & Rizzo, 2008). It has been suggested that EF deficits in PD, such as the reduced ability to update information in working memory (Ranchet et al., 2011) and make appropriate decisions (Cordell et al., 2008) may underlie reduced driving ability. Kramberger et al. (2012) found that EFs predict activities of daily living in people with PD and comorbid dementia. This indicates the importance of executive function integrity to the successful completion of every-day tasks for those with PD dementia. However, the importance of EF impairments in those who have PD without dementia has not been formally quantified.

The relationship between EF and QOL has been demonstrated in non-PD samples (Brown & Landgraf, 2010; Davis, Marra, Najafzadeh, & Liu-Ambrose, 2010; Tyson, Laws, Flowers, Mortimer, & Schulz, 2008). Davis et al. (2010) found a significant relationship between EF and HRQOL in a sample of healthy older women. The authors assessed EF in their sample using the Trail-Making B test, the Verbal Digits Backward test, and the Stroop Colour-Word test. HRQOL was assessed as Quality Adjusted Life Years (QUALYs) calculated from the EuroQuol EQ-5D. Davis et al. highlighted that set-shifting and working memory accounted for a significant amount of variance in HRQOL. The authors also suggested that such deficits in these areas of EF may underlie other factors that affect HRQOL, such as reduced mobility, noncompliance with medication, reduced driving performance, and difficulties with emotion regulation. The sample studied by Davis et al. (2010) were healthy adults without mild cognitive impairment, therefore these results cannot be generalised to a PD sample. However, the findings demonstrate a relationship between EF and HRQOL that requires further investigation. Furthermore, EF deficits have also been

shown to predict HRQOL in clinical samples (Brown & Landgraf, 2010; Tyson et al., 2008). Brown and Landgraf (2010) examined the relationship between EF and HRQOL in adults with attention deficit/ hyperactivity disorder (ADHD). In two placebo-controlled clinical trials, the authors found that improvements in EF, measured using the Brown Attention-Deficit Disorder Scale (BADDS), were reliably associated with improvements in HRQOL, measured using the ADHD Impact Module-Adult (AIM-A). Although these measures were specific to ADHD and the findings cannot be generalised to a PD sample, these results provide further evidence for the predictive relationship between executive function and HRQOL. Tyson et al. (2008) found a similar trend in a sample of adults with schizophrenia. The study found that executive dysfunction, as measured by the Behavioural Assessment of the Dysexecutive Syndrome (BADS), predicted both poorer social functioning and QOL. Social functioning was assessed using the Multnomah Community Ability Scale, and QOL was assessed using the Quality of Life Self Assessment Inventory. This further supports that executive function abilities are necessary for social functioning and successful completion of tasks of every-day living.

EF and Coping Strategy Use

As well as having an over-all impact on HRQOL, mild executive deficits may impair an individual's ability to cope with the multiple stressors associated with having PD. EF impairments have been shown to predict coping strategy use in various clinical populations such as schizophrenia (Wilder-Willis, Shear, Steffen, & Borkin, 2002), traumatic brain injury (Krpan, 2007; Krpan, Stuss, & Anderson, 2011a, 2011b), and multiple sclerosis (Goretti et al., 2010b). Coping strategies are cognitive-behavioural responses that individuals employ to manage internal and external demands that arise when faced with a challenging situation. In their Transactional Model, Lazarus and Folkman (1984) suggested that the way an individual appraises a situation can change the effect the situation has on them. Lazarus and Folkman

suggested that those who see stress as something positive or as a challenge to overcome, rather than as a threat, are better able to manage situations of stress.

Two key classes of coping strategies include emotion-focused coping, whereby emotional responses are employed to cope with stressors; and problem-focused coping, whereby responses are focused on finding a solution to the problem (Lazarus & Folkman, 1984). Planful problem solving (a problem-focused strategy) requires the use of skills such as problem appraisal, generation and consideration of alternative solutions, planning, purposive action, monitoring of self and environment, and updating information in the working memory; all of which are considered to be executive-based skills (Krpan, 2007; Krpan et al., 2011b; Lazarus & Folkman, 1984). It has therefore been suggested that intact EFs are required in order to successfully adopt a planful problem solving coping style. Escape-avoidance (an emotion-focused strategy) is generally considered to be a maladaptive coping strategy, as those using escape-avoidance coping behave in a way to avoid triggers of distress. As such, they tend to disengage from relationships, social activities and other events/activities and tend to engage in thought suppression and over-use of distraction tools. Escape-avoidance often results in physical, cognitive, and emotional withdrawal, leading to poor self-esteem and other associated difficulties (Lazarus & Folkman, 1984).

Research suggests that when EFs are impaired, individuals are more likely to use coping strategies of lesser cognitive demand (such as escape-avoidance) rather than using planful problem solving (Goretti et al., 2010a; Krpan, 2007; Krpan et al., 2011b). Conversely, when EFs are intact, individuals are more able to adopt a planful problem solving approach to stress. However, Montel and Bungener (2008) suggested that EF impairments do not limit coping strategy use in those with PD. Montel and Bungener examined coping styles in a large sample of PD patients who had EF impairments but who did not have dementia. They found that the PD group with EF impairments were no less able to adopt various coping strategies

(including planful problem solving) than a PD control group who did not have EF impairments. Of note, however, was the greater age and disease duration of the executive-impaired group. As those with executive impairments were older and had had PD for longer, it is possible that they had adapted to their impairments over time and had learned to use the coping strategies effectively despite their impairments. A follow-up study comparing groups matched on age and disease duration is required to clarify this. The majority of evidence suggests that EF deficits predict reduced planful problem solving and increased escape-avoidance coping styles. However, this relationship has yet to be examined in PD.

Coping Strategy Use and HRQOL

Coping strategy use has been suggested to predict HRQOL in various studies. Although coping strategies are differentially suited to certain situations, it is generally accepted that emotion-focused strategies (such as escape-avoidance) lead to poorer outcome in terms of mood and overall HRQOL when compared to problem-focused strategies (such as planful problem solving; Bucks et al., 2011). Bucks and colleagues (2011) examined the relationship between coping strategy use and HRQOL in a sample of adults with IPD. The authors assessed coping strategy use with the Ways of Coping Questionnaire (WCQ), and mood-related HRQOL with the Depression, Anxiety, and Stress Scale (DASS-21), and PD-specific health-related HRQOL with the Parkinson's Disease Questionnaire (PDQ-39). They found that both planful problem solving and escape-avoidance were key predictors of HRQOL (for both mood and PD-specific HRQOL measures). Greater use of planful problem solving was associated with improved HRQOL measures of cognitive function, communication, and bodily discomfort. Greater use of escape-avoidance was associated with reduced emotional wellbeing, mood, and social support. These findings indicate that greater use of planful problem solving and reduced use of escape-avoidance coping was associated with improved emotional and health-related HRQOL in IPD. Furthermore, this relationship

has been reported in a sample of brain-injured adults (Wolters, Stapert, Brands, & Van Heugten, 2010; 2011). Wolters and colleagues (2010) found that, over a 5-month period of rehabilitation, patients with traumatic brain injury (TBI) tended to replace active, problem-focused coping strategies with more passive, emotion-focused coping strategies. They also found that greater use of problem-focused coping and reduced use of emotion-focused coping predicted increased long-term QOL in these patients. The authors extended these findings with a second study the following year (Wolters et al., 2011). These findings indicate that, as participants' cognitive condition worsened following TBI, they were less able to adopt the more cognitively-demanding problem-focused strategies and instead adopted less cognitively-demanding emotion-focused strategies. The result of this, as indicated in Wolter et al.'s (2011) study, was reduced QOL. Together, these findings indicate that greater playful problem solving and reduced escape-avoidance are commensurate with improved HRQOL. The findings may also indicate a possible mediating effect of coping on the relationship between cognitive function and QOL.

EF, Coping, and HRQOL

Recent evidence suggests a mediating effect of coping on the relationship between cognitive function and HRQOL in PD (Hurt et al., 2012; Krpan et al., 2011a, 2011b). Krpan and colleagues conducted two studies examining coping strategy use in participants with TBI during a psychosocial stress test. The authors recorded coping behaviour and physiological responses during the Baycrest Psychosocial Stress Test (BPST), and participants completed a self-report coping measure; the Ways of Coping Questionnaire (WOC). Krpan et al. (2011a) found there were two distinct groups based on coping style in TBI; "planners" and "avoiders". avoidance coping predicted poorer long term outcomes for the participants in the study. Krpan et al. also highlighted the importance of investigating the predictors of coping strategy selection (such as cognitive functioning) and the role that coping strategies play in

determining QOL. Such investigations, it was argued, would lead to the establishment of more effective rehabilitative interventions.

In their follow-up study, Krpan et al. (2011b) investigated predictors of coping style in those with TBI using additional neuropsychological tests. They found that “planners” displayed improved EFs, higher estimated premorbid intelligence, higher psychological and physiological reactivity, and superior speech performance compared to “avoiders”. Using multiple regression, they also found that executive dysfunction was the strongest predictor of avoidant coping. Krpan et al. suggested this indicates that in the absence of adequate EFs needed for planful problem solving, individuals default to escape-avoidance coping. Psychological and physiological reactivity was the strongest predictor of planful coping. Krpan et al. suggested that this indicates that individuals require an ability to be sensitive to negative emotions and other stimuli, and require the cognitive control to regulate their behaviour and apply effort to use planful strategies. They also found that those who used planful coping had better outcomes in terms speech performance (a short oral presentation), but they did not include an assessment of HRQOL. These findings suggest a link between EF, coping, and outcome (in terms of oral presentation performance). However, the relationship between EF, coping, and HRQOL remains unclear and it is also unclear whether this relationship is also present in IPD.

Hurt et al. (2012) examined the relationship between cognitive function, coping strategy use, and outcome (mood and HRQOL) in a sample of 347 patients with PD. Cognitive function was assessed using the Addenbrooke’s Cognitive Examination Revised (ACE-R; Hodges, 2005) and coping was assessed using the Coping Inventory for Stressful Situations (CISS; Endler & Parker, 1999). Outcome was assessed using both the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and the Parkinson’s Disease Questionnaire (PDQ; Jenkinson, Fitzpatrick, Petrone, Greenhall, & Hyman, 1997).

The author's measures of task-oriented and emotion-oriented coping obtained from the CISS are comparable to Lazarus Folkman's (1984) coping categories of problem-focused and emotion-focused coping respectively. As such, task-oriented coping can be considered comparable to the problem-focused strategy of planful problem solving, and emotion-oriented coping to the emotion-focused strategy of escape-avoidance. The authors reported that emotion-oriented behaviour was associated with poorer cognitive functioning and poorer outcome (depression, anxiety, and HRQOL). In contrast, task-oriented behaviour was associated with better cognitive function and better outcomes. This is consistent with past research suggesting an association between coping and HRQOL (Bucks et al., 2011).

Hurt et al. (2012) used structural equation modelling to test whether there was an indirect association between global cognition and outcome that was mediated by coping (Figure 1). The analysis included data from those with mild cognitive impairment but not dementia. Hurt et al. found a significant, small, mediating effect of coping on the relationship between global cognition and outcome, in which lower ACE-R score was associated with less task-oriented coping, and less task-oriented coping was associated with poorer outcome scores. These results indicate that global cognition affected coping strategy selection, which in turn affected outcome (mood and QOL). Those with reduced global cognitive function were less able to engage in more cognitively-demanding strategies (task-oriented coping). Instead, less cognitively-demanding strategies were selected (emotion-oriented coping) which resulted in reduced outcome.

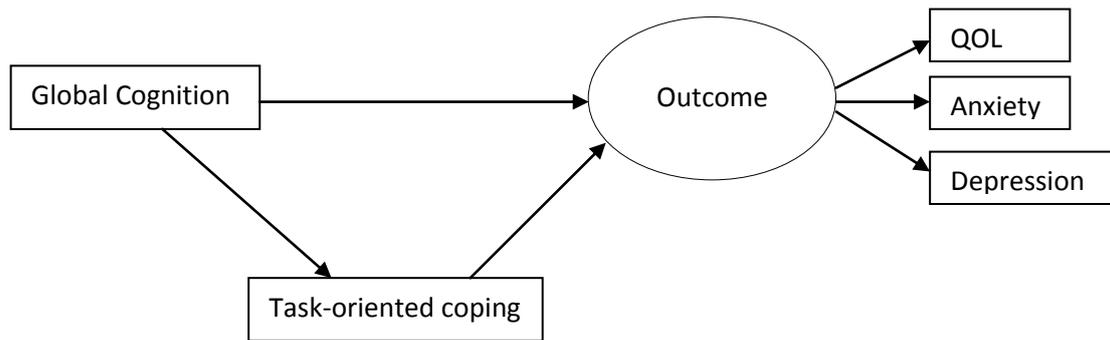


Figure 1. Hurt and colleagues’ theoretical model of the mediating effect of coping on the relationship between cognition and outcome in Parkinson’s disease. Adapted from Hurt et al. (2012) p. 1659.

Hurt et al. (2012) also considered the possible contributions of EF in their analyses. The authors selected three components of the ACE-R that they judged to be EFs; (i) orientation, (ii) attention/concentration, and (iii) visuo-spatial subtasks. Whereas the overall ACE-R score represented “global cognition”, scores for these three components were combined to create a measure of EF for each participant. Hurt et al. found that EF was less strongly associated with coping and outcome than overall ACE-R score. Therefore, they concluded that global cognition is a more reliable predictor of task-focused coping than EF. However, this study was limited by a fundamental methodological flaw. The ACE-R was designed as a general measure of cognitive function; it was never intended to be analysed in terms of its component tasks. Furthermore, the ACE-R components used by Hurt et al. as measures of EF are tests of more general cognitive function and are not considered to be specific measures of EF. The “orientation” component involved naming the day, date, season, and where they are located in a building and in the world. Such skills require general attention and short term memory skills, not higher-order EFs. The “attention/concentration” component involved counting back from 100 in lots of seven, and spelling the word “WORLD” forward and backward. Although this requires some working memory, it is mostly an assessment of general attention and number and word knowledge. Finally, the “visuo-spatial” component

involved copying two simple diagrams and clock-drawing. This is a broad psychomotor task and does not require EFs such as spatial working memory, planning, decision-making, or reasoning. These are all general measures of cognitive function and are not established measures of EF. It is therefore reasonable to suggest that the findings of Hurt et al. (2012) are hindered by the lack of established measures of EF. Additionally, Hurt et al.'s participants reported using task-oriented coping significantly more frequently than emotion oriented coping. Past evidence by Krpan (2011b) suggests that executive dysfunction is a strong predictor of escape-avoidance (an emotion-oriented coping style). Hurt et al.'s sample may not have been diverse enough, in terms of coping strategy selection, for this relationship to be examined. Therefore, even if an established measure of EF had been used, Hurt et al. may not have found a significant relationship due to low number of "escape-avoiders".

The current study addressed these and other issues in the research by examining the relationship between EFs, coping, and HRQOL in IPD. To address methodological flaws and build on findings by Hurt et al. (2012), the current study targeted EFs using well-established measures from the Cambridge Neuropsychological Test Automated Battery (CANTAB). EF Skills assessed by these measures included planning, complex problem solving, spatial working memory, and task-oriented strategy use. The study examined the mediating effects of planful problem solving and escape-avoidance separately, as literature suggests these strategies may be differentially related to EF and HRQOL. Participants in this study were screened for dementia and depression as the literature also suggests these are strong predictors of HRQOL that need to be measured to avoid them confounding the data. Those with mild executive impairments were included in the study, whereas those with clinical levels of dementia were excluded. Depression scores were controlled for in analyses. The overarching hypothesis for the current study was that an individual's executive functioning predicts the coping strategy they use (planful problem solving or escape-avoidance), which will, in turn,

impact upon HRQOL. Therefore, it was expected that there would be a significant relationship between executive functioning and HRQOL, mediated by coping (Figure 2). The following specific hypotheses were addressed:

- 1) Executive functioning will be significantly related to HRQOL, whereby poorer executive functioning will be associated with poorer HRQOL.
- 2) Executive functioning will be significantly related to coping strategy use, whereby poorer executive functioning will be associated with reduced planful problem solving and increased escape-avoidance strategy use.
- 3) Coping strategy use will mediate the relationship between executive functioning and HRQOL.

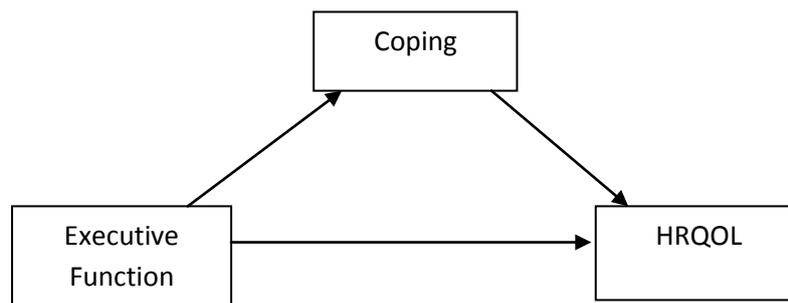


Figure 2. A theoretical model of the relationship between executive function and health-related quality of life (HRQOL) mediated by coping strategy use (planful problem solving or escape-avoidance coping). Executive function deficits are proposed to result in reduced HRQOL due to reduced planful problem solving and increased escape-avoidance coping strategy use.

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