

# Coping processes and health-related quality of life in Parkinson's disease<sup>†</sup>

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**Objective:** This study investigated the predictive value of various coping processes for the psychological and disease specific aspects of health-related quality of life (HRQoL) in Parkinson's disease (PD).

**Method:** Cross-sectional study of 85 participants with PD using the Ways of Coping Questionnaire (WCQ), Depression, Anxiety, and Stress Scale (DASS-21), quality of life (PDQ-39), and socio-demographic and clinical variables.

**Results:** Greater use of planful problem solving coping was found to be significantly associated with better HRQoL in relation to cognitive impairment, communication and bodily discomfort. In addition to greater disease duration, greater use of escape-avoidance coping processes were identified as significant predictors of poorer HRQoL outcomes in the domains of mood and emotional well-being.

**Conclusion:** Psychological interventions such as mindfulness training, aimed at reducing the use of escape-avoidance coping, may help to improve HRQoL in PD. Copyright © 2010 John Wiley & Sons, Ltd.

**Key words:** coping; health-related quality of life (HRQoL); mood; Parkinson's disease

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## Introduction

Parkinson's disease (PD) is a progressive neurodegenerative disorder classically defined as a disorder of movement (Pearce and Jones, 1994). However, it also leads to significant cognitive and psychiatric features (Barbas, 2006). These include difficulties with attention and memory, as well as anxiety and depression (Alder, 2005; Gotham *et al.*, 1986; Menza, 2002; Walsh and Bennett, 2001; Zgaljardic *et al.*, 2004). These symptoms have been shown to reduce quality of life (QoL) above and beyond the impact of physical features (Cubo *et al.*, 2002; The Global Parkinson's Disease Survey, 2002).

QoL is an 'individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (WHO, 1993). This encompasses: *physical health* (activities of daily living, medication, pain, fatigue, sleep and mobility), *psychological well-being* (mood, spirituality and cognition), *social aspects* (social relationships and support), and *environment* (finances, accessibility of services/transport, participation).

Typically, research into PD QoL reports *health-related quality of life* (HRQoL). This is an individual's perception of how a chronic health condition, its management and treatment, impact on their QoL

(Patrick and Erickson, 1988). Health status is important to HRQoL: worsening disease severity, assessed in terms of motor symptoms and medication use, has been shown to lead to lower HRQoL (Kuopio *et al.*, 2000; Schrag *et al.*, 2000). However, patients with similar PD severity can report very different HRQoL (Gotham *et al.*, 1986). For example, whilst some view depression as a consequence of the hallucinations, cognitive impairment and disability experienced in PD (Tandberg *et al.*, 1997), psychological well-being seems only modestly related to such factors (Gotham *et al.*, 1986; MacCarthy and Brown, 1989). As PD is a progressive disease, a greater understanding of what influences HRQoL in people with PD is important for better disease management. Arguably, the way in which an individual copes with PD specific (Ehmann *et al.*, 1990; Frazier, 2000, 2002; Schreurs *et al.*, 2000) and stressful life events more generally (Montel *et al.*, 2009; Sanders-Dewey *et al.*, 2001), may mediate the negative impact of disease severity on HRQoL in general and mood-related HRQoL specifically.

Coping as a process is defined as the cognitive and behavioural efforts to manage psychological stress (Lazarus, 1993). Early conceptualizations distinguished two dimensions: problem *versus* emotion-focussed, and active/approach *versus* avoidant (Roth and Cohen, 1986). Problem-focussed strategies focus on changing aspects of the environment and the person's relationship to it. Emotion-focussed strategies focus on managing one's emotional responses to stressors (Folkman and Lazarus, 1980; Lazarus 1993). Active coping strategies are psychological/behavioural attempts to change the nature of a stressor or one's thoughts about it (and may be problem or emotion-focussed). Avoidant strategies are behavioural/psychological approaches that prevent people from directly engaging with a stressor (e.g. withdrawing from a situation/emotion).

Most PD-related coping research has concentrated on the problem- and emotion-focussed distinction (e.g. Moore and Seoney, 2007; Sanders-Dewey *et al.*, 2001), usually investigating emotion-focused coping by averaging subscales (e.g. Frazier, 2000, 2002; Herrmann *et al.*, 2000; Sanders-Dewey *et al.*, 2001). Studies have revealed that higher emotion-focussed coping scores are associated with worse mood-related HRQoL (Moore and Seoney, 2007; Schreurs *et al.*, 2003), greater symptom-related distress (Sanders-Dewey *et al.*, 2001), poorer physical health (Frazier, 2000, 2002) and poorer HRQoL more generally, assessed with the Parkinson's Disease Questionnaire (PDQ-39) summary index (Montel *et al.*, 2009). In

contrast, active coping strategies have been associated with better HRQoL (Backer, 2000; Schreurs *et al.*, 2003). Except for Frazier (2000), no studies have considered the importance of the perceived controllability of the stressor for the person with PD, and she used a general, rather than a PD-specific HRQoL measure.

The type of coping strategy employed may depend on the stressful event experienced (Maes *et al.*, 1996). That is, stressors which are potentially controllable/manageable (such as bodily discomfort or cognitive and communication difficulties) are more likely to be addressed successfully using problem-focussed strategies. In contrast, stressors which are perceived to be less controllable (such as social stigma) are more likely to prompt emotion-focussed coping (Christensen *et al.*, 1990; Folkman and Lazarus, 1980). This has been termed the 'matching hypothesis' (Christensen *et al.*, 1995; Lazarus, 1993).

This study tested the relationships between specific coping processes and disease-specific and mood-related HRQoL<sup>1</sup> in PD participants without dementia, over and above the impact of disease-severity, age or other confounding variables. We predicted that:

- (1) Better HRQoL in domains perceived as manageable, such as difficulties with cognition, communication and bodily discomfort, would be associated with greater use of problem-focussed coping processes, in particular planful problem solving, seeking social support and positive reappraisal.
- (2) Aspects of the disease perceived as less controllable, can be managed using active or passive emotion-focussed coping strategies which affect HRQoL either positive or negatively. Thus, greater use of escape-avoidance, self-controlling and distancing coping would be negatively related to well-being, stigma and social support HRQoL, whilst greater use of seeking social support and positive reappraisal coping would be predictive of better emotional well-being and mood, stigma and social support HRQoL.

## Methods

Between September 2008 and June 2009, 97 participants with idiopathic PD (diagnosed by a neurologist or geriatrician) were recruited to the Cognitive and Motor Heterogeneity in Idiopathic PD research project

<sup>1</sup>Whilst previous studies have used depression as a predictor of disease-specific QoL (e.g. The Global Parkinson's Disease Survey, 2002) we would argue that this is circular, since mood is defined as an aspect of QoL (WHO, 1993).

(Edith Cowan University). Approval was obtained from the Human Research Ethics Committee, Edith Cowan University. All participants provided written informed consent to participate. Participants not available to complete cognitive screening, or presenting with significant cognitive impairment were excluded ( $N = 12$ ).

#### Cognitive screening

Global cognitive functioning was assessed using the Mini-Mental State Examination (MMSE; Folstein *et al.*, 1975). Participants scoring below 24 were excluded, as cognitive impairment may influence the coping processes adopted during stressful events, with a bias against strategies requiring greater mental flexibility such as problem-solving (Lysaker *et al.*, 2004).

#### Socio-demographic and clinical variables

Age, sex, employment status, marital status, level of education, age of disease onset, disease duration and medication use were collected *via* self-report questionnaire.

#### Mood and PD specific aspects of HRQoL

PD-specific aspects of HRQoL were assessed using the PDQ-39 (Jenkinson *et al.*, 1997), which has 39 items rated on a scale from never (0) to always (4). The scale assesses HRQoL in mobility (10 items; Cronbach's  $\alpha$  in this study = 0.92), activities of daily living (6 items; ADL;  $\alpha = 0.80$ ), emotional well-being (6 items;  $\alpha = 0.86$ ), stigma (4 items;  $\alpha = 0.79$ ), social support (3 items;  $\alpha = 0.79$ ), cognitive impairment (4 items;  $\alpha = 0.64$ ), communication (3 items;  $\alpha = 0.80$ ) and bodily discomfort (3 items;  $\alpha = 0.75$ ).

The shortened version of the Depression, Anxiety and Stress Scale (DASS-21; Lovibond and Lovibond, 1995) was used to evaluate mood-related HRQoL. The scale assesses depression (7 items;  $\alpha = 0.89$ ), anxiety (7 items;  $\alpha = 0.76$ ) and stress (7 items;  $\alpha = 0.86$ ). The DASS-21 is suitable for participants with limited concentration, whilst retaining reliability (Henry and Crawford, 2005; McNamara *et al.*, 2006; Simpson *et al.*, 2006).

#### Coping

Coping processes were assessed using the Revised Ways of Coping Questionnaire (WCQ; Folkman and

Lazarus, 1988), which assesses the thoughts and behaviours individuals use to cope with everyday stressful encounters. Participants are asked to think about the most stressful situation they have experienced in the past week. 'Stressful' means a situation that was difficult or troubling, because of the distress it caused or the effort required to deal with it. Participants indicate how much each of 66 statements applied to them (e.g. 'I tried to analyze the problem in order to understand it better'). Items are rated from never (0; does not apply to me) to always (3; used a great deal), such that higher scores indicate greater use of that strategy. The WCQ has eight domains: 'confrontative coping' (6 items;  $\alpha = 0.71$ ), describing more aggressive strategies to change the situation; 'distancing' (6 items;  $\alpha = 0.71$ ), describing cognitive approaches to finding distance from a situation so reducing its significance; 'self-controlling' (7 items;  $\alpha = 0.73$ ), describing attempts to regulate actions and feelings; 'seeking social support' (6 items;  $\alpha = 0.78$ ), assessing attempts to seek emotional, information or tangible support; 'accepting responsibility' (4 items;  $\alpha = 0.54$ ), assessing the degree to which the person acknowledges their own role in creating a problem situation and attempts to resolve this; 'escape-avoidance' (8 items;  $\alpha = 0.79$ ), assessing cognitive and behavioural attempts to avoid a problem or situation; 'planful problem-solving' (6 items;  $\alpha = 0.84$ ), assessing explicit efforts to improve a situation based on logical problem-solving strategies and 'positive reappraisal' (7 items;  $\alpha = 0.68$ ), assessing the degree to which an individual seeks positive meaning/personal growth within the situation. Internal reliability was generally good except for 'accepting responsibility', which was excluded from further analysis.

#### Statistical analysis

Mean substitution was used to impute missing values when calculating subscale scores. The total scores for subscales involving more than one missing value were excluded from further analysis. PDQ-39 subscale scores range from 0 to 100 (maximum problem), and are calculated as the sum of the items, divided by 4 (maximum per item) times the number of items in the subscale, then multiplied by 100. The WCQ can be scored using raw scores (the frequency of effort used on a specific process) or relative scores (the proportion of effort represented by each coping process *in relation* to all scales combined). The relative scoring method controls for unequal numbers of items within scales and differences in the degree to which individuals

report using coping across all the strategies (Folkman and Lazarus, 1988; Vitaliano *et al.*, 1987). Of interest to this study was the *relative* use of a particular type of coping strategy and its relationship to specific aspects of HRQoL. Therefore, the relative scoring method was used.

Given that the DASS depression, anxiety and stress subscales were all significantly correlated (depression with anxiety,  $r = 0.75$ , with stress,  $r = 0.73$ , anxiety with stress,  $r = 0.79$ ) and to reduce the risk of multiple comparisons, subsequent analyses were conducted on the DASS total score, which is a valid measure of negative affect (Henry and Crawford, 2005). Internal consistency for the total score was excellent,  $\alpha = 0.93$ . Correlation analyses (Pearson's) were performed to assess the predicted relationships between each demographic/clinical variable, coping process and the HRQoL outcome measures (see Table 2). However, all correlations are provided.

In order to examine the relative contribution of demographic/clinical variables and coping processes to the prediction of mood and PD-specific HRQoL, separate, hierarchical multiple regression analyses were conducted. Demographic/clinical variables which correlated significantly with HRQoL scores, or for which there were significant group differences, were selected for entry into Step 1 of each model, so as to control for their contribution to HRQoL. Coping processes which were (a) predicted to be related to HRQoL scores and (b) significantly correlated with those measures were entered into Step 2. For ease of interpretation, final models containing only significant predictors were also generated. Statistical significance was set at 0.05. Given that the relationships between coping and HRQoL were predicted *a priori*, no adjustments were made for multiple comparisons.

## Results

The majority of the sample was male (53; 63%), retired (66; 78%), married/in long-term relationship (62; 73%) and had completed high school (60; 71%). Many had completed tertiary (13; 15%) or post graduate qualifications (14; 17%) or a trade certificate (10; 12%). Most were 55+ years of age when tested ( $M = 62.79 \pm 9.26$ , range 37–82), were diagnosed within 1–2 years of the study (age at diagnosis,  $M = 58.39 \pm 10.03$ , range 26–81), were currently under the care of a neurologist (90; 95%) and on dopaminergic medications (68; 80%). Disease duration ranged from 0 to 16 years ( $M = 4.40 \pm 4.03$ ). MMSE ranged from 24–30 ( $M = 27.92 \pm 1.56$ ). Over half had

Table 1 Descriptive statistics for each HRQoL and coping variables

Variable	M (SD)	Range
Mood-related HRQoL (DASS)		
Total score	9.99 (11.97)	0–53
PD Specific HRQoL (PDQ-39)		
Mobility	22.05 (21.43)	0–83
ADL	20.76 (17.90)	0–84
Emotional Well-Being	22.17 (18.12)	0–84
Stigma	15.55 (20.55)	0–84
Social Support	13.44 (17.66)	0–84
Cognitive impairment	22.54 (17.33)	0–84
Communication	19.44 (18.40)	0–84
Bodily Discomfort	33.63 (22.29)	0–83
Coping (WCQ)		
Confrontative	0.08 (0.06)	0–0.25
Distancing	0.15 (0.08)	0.02–0.42
Self-controlling	0.18 (0.07)	0–0.36
Seeking social support	0.14 (0.08)	0–0.43
Escape-avoidance	0.09 (0.08)	0–0.40
Planful problem solving	0.17 (0.08)	0–0.33
Positive reappraisal	0.12 (0.07)	0–0.42

Note: DASS, Depression, Anxiety and Stress Scale, Lovibond and Lovibond, 1995, higher scores indicate worse HRQoL; PDQ-39, Parkinson's Disease Questionnaire, Jenkinson *et al.*, 1997, higher scores indicate worse HRQoL; ADL, activities of daily living; WCQ, Ways of Coping Questionnaire, Folkman and Lazarus, 1988, higher scores indicate more use of that coping process.

clinically significant anxiety (mild to extremely severe, 51; 60%), with more than a third reporting clinically significant depression (33; 39%) and/or mild to extremely severe stress (28; 33%).<sup>2</sup> Ten (11.36%) were taking medications for anxiety and/or depression.

Descriptive statistics for coping, and mood and PD-specific HRQoL measures are given in Table 1. There were significant sex differences in PDQ-39 emotional well-being, males =  $18.6 \pm 16.3$ , females =  $28.0 \pm 19.6$ ,  $t(82) = 2.37$ ,  $p = 0.020$ , and bodily discomfort, males =  $29.8 \pm 20.1$ , females =  $40.1 \pm 24.6$ ,  $t(81) = 2.07$ ,  $p = 0.042$  scores. There were also significant differences between those taking medication for their PD and those not on medication in PDQ-39 cognitive impairment (meds =  $24.3 \pm 18.3$ , no-meds =  $15.8 \pm 10.6$ ),  $t(43.28) = 2.47$ ,  $p = 0.017$ ; communication (meds =  $21.6 \pm 16.3$ , no-meds =  $10.8 \pm 10.9$ ),  $t(44.58) = 3.06$ ,  $p = 0.004$  and bodily discomfort (meds =  $23.1 \pm 22.5$ , no-meds =  $24.0 \pm 19.3$ ),  $t(81) = 2.03$ ,  $p = 0.045$  scores. There were no medication or sex differences in DASS scores.

Participants who were older at diagnosis reported better emotional well-being, better social support, less

<sup>2</sup>Individuals' total scores for depression, anxiety and stress were classified in terms of severity using Lovibond and Lovibond's (1995) percentile cut off scores: 0–78 'normal'; 78–87 'mild'; 87–95 'moderate'; 95–98 'severe' and 98–100 'extremely severe'.

Table 2 Correlation matrix for predicted relationships between demographic/clinical variables, coping process, and HRQoL outcome measures

	Health-related Quality of Life (PDQ-39)								
	Mood-related HRQoL	Mobility	ADL	Emotional well-being	Stigma	Social support	Cognitive impairment	Communication	Bodily iscomfort
DASS total									
Demographic/clinical	-0.15	0.07	-0.03	-0.19	-0.31	-0.15	-0.07	-0.16	-0.08
Age at testing	-0.21	-0.09	-0.17	<b>-0.24</b>	-0.32	<b>-0.23</b>	-0.15	<b>-0.27</b>	-0.18
Age at diagnosis	0.20	0.38	0.35	0.15	0.09	<b>0.23</b>	0.21	<b>0.29</b>	<b>0.25</b>
Disease duration	-0.16	0.06	-0.10	0.04	0.05	0.03	<b>-0.22</b>	-0.17	0.01
MMSE									
Coping Processes (WCQ)									
Confrontative	0.06	0.10	0.18	0.09	0.02	0.24	-0.04	0.11	0.20
Distancing	-0.06	0	-0.11	-0.05	0	-0.09	-0.03	-0.01	-0.12
Self-controlling	-0.05	0.07	0.11	0.07	0.13	-0.03	0.03	0.20	0.04
Social support	-0.14	-0.11	-0.06	0.03	-0.19	0	-0.17	-0.21	0.01
Escape-avoid	0.41	0.19	0.11	0.39	<b>0.24</b>	0.34	0.40	0.27	0.22
Problem solving	<b>-0.24</b>	0.15	-0.15	-0.22	0.05	-0.17	<b>-0.24</b>	<b>-0.29</b>	-0.33
Positive reappraisal	-0.11	-0.12	-0.14	-0.13	-0.13	-0.14	-0.08	-0.16	-0.04

Note: DASS, Depression, Anxiety and Stress Scale, Lovibond and Lovibond, 1995; PDQ-39, Parkinson's Disease Questionnaire, Jenkinson et al., 1997, higher scores indicate worse HRQoL; ADL, activities of daily living; WCQ, Ways of Coping Questionnaire, Folkman and Lazarus, 1988, higher scores indicate more use of that coping process. All significant correlations are in bold. Correlations significant at  $p < 0.01$  (two tailed) are also in italics.

stigma, and better communication HRQoL (Table 2). Likewise, older age at testing was significantly associated with lower reported stigma. In contrast, participants with longer disease duration reported poorer mobility and ADL-related HRQoL, social support, communication and bodily discomfort. Lower MMSE scores were significantly correlated with worse cognitive impairment HRQoL. As predicted, greater use of planful problem-solving was significantly associated with better HRQoL in terms of cognitive impairment, communication and bodily dysfunction. However, seeking social support and positive reappraisal coping were not related to cognitive impairment, communication or bodily dysfunction HRQoL. As predicted, worse mood-related and emotional well-being HRQoL were significantly associated with greater use of escape-avoidance coping. Also as predicted, greater use of escape-avoidance coping was related to greater complaints of stigma and poorer social support HRQoL, albeit no other hypothesized coping processes (positive reappraisal, distancing, self-controlling or seeking social support) were significantly associated with HRQoL.

Predictors of HRQoL

Aspects of HRQoL amenable to control/management. In the prediction of cognitive impairment HRQoL (Table 3), MMSE was entered first and was not significant,  $F(1,68) = 3.37, p = 0.071, R^2 = 0.05$ . When planful problem-solving scores were added, the model became significant,  $F(2,67) = 3.94, p = 0.024, R^2$  change = 0.06,  $p = 0.041$ . Only problem-solving coping was a significant predictor of PDQ-39 cognitive impairment scores, as shown in the final model,  $F(1,68) = 4.30, p = 0.042, R^2 = 0.06$ . A greater tendency to use planful problem-solving coping was significantly associated with better cognitive-impairment-related HRQoL.

In the prediction of communication HRQoL, age at diagnosis and disease duration were entered first, and were significant predictors,  $F(2,67) = 4.14, p = 0.020, R^2 = 0.11$  (Table 3). When planful problem-solving coping scores were added, the significance of the model improved,  $F(3,66) = 4.47, p = 0.006, R^2$  change = 0.06,  $p = 0.034$ . Only problem-solving coping was a significant predictor of PDQ-39 communication scores, final model,  $F(1,68) = 6.04, p = 0.017, R^2 = 0.08$ . A greater tendency to use planful problem-solving coping was significantly associated with better communication related HRQoL.

Table 3 Hierarchical multiple regression analysis examining the contribution of demographic/clinical variables and coping processes to the prediction of HRQoL outcomes

Predictors		<i>B</i>	SE ( <i>B</i> )	$\beta$	Sig.	CI upper	CI lower
Cognitive impairment							
Step 1	MMSE	2.42	1.32	-0.22	0.071	5.04	0.21
Step 2	MMSE	2.38	1.28	0.21	0.069	4.94	0.19
	WCQ-Planful problem-solving	50.24	24.12	0.24	<b>0.041</b>	98.38	2.11
Cognitive impairment Final model	WCQ-Planful problem-solving	-50.89	24.54	-0.24	<b>0.042</b>	-99.86	-1.92
Communication							
Step 1	Age at diagnosis	-0.34	0.23	-0.18	0.146	-0.79	0.12
	Disease duration	0.98	0.57	0.21	0.091	-0.16	2.12
Step 2	Age at diagnosis	-0.33	0.22	-0.18	0.142	-0.78	0.11
	Disease duration	0.81	0.56	0.18	0.152	-0.31	1.93
	WCQ-Planful problem-solving	-54.46	25.16	-0.25	<b>0.034</b>	-104.708	-4.22
Communication Final model	WCQ-Planful problem-solving	-63.29	25.75	-0.29	<b>.017</b>	-114.68	-11.90
Bodily discomfort							
Step 1	Disease duration	1.40	0.65	0.25	<b>0.034</b>	0.11	2.67
Step 2	Disease duration	1.15	0.63	0.21	0.072	-0.11	2.41
	WCQ-Planful problem-solving	-78.81	30.63	-0.29	<b>0.012</b>	-139.94	-17.68
Bodily discomfort Final model	WCQ-Planful problem-solving	-87.39	30.78	-0.33	<b>0.006</b>	-148.82	-25.96
Mood (DASS)							
	WCQ-Escape-avoidance	50.37	13.68	0.41	<b>&lt;0.001</b>	23.08	77.66
Emotional well-being							
Step 1	Age at diagnosis	-0.38	0.21	-0.21	0.074	-0.80	17.09
	Gender (categorical)	8.46	4.32	0.23	<b>0.004</b>	-0.17	17.09
Step 2	Age at diagnosis	-0.30	0.20	-0.17	0.142	0.70	0.10
	Gender (categorical)	6.91	4.12	0.19	0.098	1.32	15.13
	WCQ-Escape-avoidance	75.25	25.08	0.33	<b>0.004</b>	25.18	125.32
Emotional well-being Final model	WCQ-Escape-avoidance	86.93	25.22	0.39	<b>0.001</b>	36.60	137.27
Stigma							
Step 1	Age at testing	-0.21	0.64	-0.09	0.744	-1.48	1.06
	Age at diagnosis	-0.49	0.59	-0.24	0.412	-1.66	0.69
Step 2	Age at testing	-0.24	0.63	-0.11	0.710	-1.49	1.02
	Age at diagnosis	-0.40	0.58	-0.20	0.492	-1.57	0.76
	WCQ-Escape-avoidance	49.99	29.47	0.20	0.095	-8.85	108.84
Social support							
Step 1	Age at diagnosis	-0.29	0.22	-0.16	0.203	-0.74	0.16
	Disease duration	0.72	0.56	0.17	0.200	-0.39	1.84
Step 2	Age at diagnosis	-0.21	0.22	-0.12	0.340	-0.64	0.22
	Disease duration	0.70	0.53	0.16	0.192	-0.36	1.77
	WCQ-Escape-avoidance	67.79	24.97	0.31	<b>0.008</b>	17.95	117.64
Social support Final model	WCQ-Escape-avoidance	74.30	25.07	0.34	<b>0.004</b>	24.28	124.32

Note: DASS, Depression, Anxiety and Stress Scale, Lovibond and Lovibond, 1995; PDQ-39, Parkinson's Disease Questionnaire, Jenkinson et al., 1997, higher scores indicate worse HRQoL; WCQ, Ways of Coping Questionnaire, Folkman and Lazarus, 1988, higher scores indicate more use of that coping process.

In the prediction of bodily discomfort HRQoL, disease duration was entered first, and was significant,  $F(1,68) = 4.67$ ,  $p = 0.034$ ,  $R^2 = 0.06$  (Table 3). When planful problem-solving coping scores were added, the significance of the model improved,  $F(2,67) = 5.84$ ,  $p = 0.005$ ,  $R^2$  change = 0.08,  $p = 0.012$ , but disease duration was no longer a significant predictor. Only planful problem-solving coping remained, as reflected in the final model,  $F(1,68) = 8.06$ ,  $p = 0.006$ ,  $R^2 = 0.11$ . A greater tendency to use planful problem-solving coping was significantly associated with better bodily discomfort-related HRQoL.

Aspects of HRQoL less amenable to control/management. Only escape-avoidance scores were entered as a

predictor of mood HRQoL (DASS total score), and were significant,  $F(1,69) = 13.56$ ,  $p < 0.001$ ,  $R^2 = 0.16$ , with a greater tendency to use the coping strategy of seeking to escape from or avoid stressful situations or emotions significantly associated with worse mood (Table 3).

In the prediction of emotional well-being HRQoL, age at diagnosis was entered first. Although the model was significant,  $F(2,67) = 4.06$ ,  $p = 0.022$ ,  $R^2 = 0.11$ , age at diagnosis was not a significant predictor (Table 3). When escape-avoidance coping scores were added, the significance of the model improved,  $F(3,66) = 6.03$ ,  $p = 0.001$ ,  $R^2$  change = 0.11,  $p = 0.004$ . Only escape-avoidance coping was a significant predictor of PDQ-39 emotional well-being scores, as

shown in the final model,  $F(1,68) = 11.88$ ,  $p = 0.001$ ,  $R^2 = 0.15$ . A greater tendency to use escape-avoidance coping strategies to escape from or avoid stressful situations or emotions was significantly associated with poorer emotional well-being.

In the prediction of stigma HRQoL, age at diagnosis and at testing were entered first. The model was significant,  $F(2,67) = 3.98$ ,  $p = 0.023$ ,  $R^2 = 0.11$ , although neither predictor was significant in its own right (Table 3). When escape-avoidance coping scores were added, the model did not improve,  $F(3,66) = 3.69$ ,  $p = 0.016$ ,  $R^2$  change = 0.04,  $p = 0.095$ . That is, no variable was a significant predictor of PDQ-39 stigma scores.

In the prediction of social support HRQoL, age at diagnosis and disease duration were entered first, and were not significant,  $F(2,67) = 2.71$ ,  $p = 0.074$ ,  $R^2 = 0.08$  (Table 3). When escape-avoidance coping scores were added, the model became significant,  $F(3,66) = 4.43$ ,  $p = 0.007$ ,  $R^2$  change = 0.09,  $p = 0.008$ . Only escape-avoidance coping was a significant predictor of social support HRQoL, as shown in the final model,  $F(1,68) = 8.79$ ,  $p = 0.004$ ,  $R^2 = 0.11$ . A greater tendency to use escape-avoidance coping was significantly associated with worse social support HRQoL.

## Discussion

Two coping processes, planful problem-solving and escape-avoidance, were the main predictors of HRQoL, whether mood or PD-specific in nature. As predicted, aspects of HRQoL that might be experienced by people with PD as amenable to management (cognitive impairment, communication and bodily discomfort) were significantly improved by greater use of active, planful problem-solving coping. Aspects of HRQoL that might be experienced by people with PD as being less controllable (emotional well-being, mood and social support) were significantly worsened by greater use of escape-avoidance coping. Given that self-criticism and blame, wishful thinking, behavioural avoidance, increased sleep and avoidance of social interaction characterize this type of coping (Folkman and Lazarus, 1988), this is not surprising.

Only Frazier (2000) has previously offered evidence in PD consistent with this view, but used a non PD-specific HRQoL measure. Additionally, this was the first study to report individual subscale data from the WCQ in PD (Sanders-Dewey *et al.*, 2001 combined all scores). Our finding, that the use of avoidant coping behaviours is related to mood-related HRQoL is

confirmed in many other conditions, including cardiac disease (Murberg *et al.*, 2004), cancer (Ho *et al.*, 2004), spinal cord injury (Pollard and Kennedy 2007), multiple sclerosis (Montel and Bungener, 2007) and kidney disease (Pucheu *et al.*, 2004). Whilst active coping has previously been shown to be associated with better overall HRQoL in PD (Backer, 2000; Schreurs *et al.*, 2003), this study demonstrates that active coping, in particular planful problem-solving, is important for some aspects of HRQoL in PD, whereas escape-avoidance is detrimental to others.

Cross-sectional studies cannot confirm causal relationships: as HRQoL worsens with increase in disease severity this *could* lead to a change in the coping processes available. Although longitudinal studies of coping have been conducted (e.g. Frazier, 2002), a prospective study of both coping *and* HRQoL is needed to determine whether coping styles at baseline are predictive of future HRQoL. To date, one study has shown that active coping was significantly predictive of psychological functioning and communication after 1 year (Schreurs *et al.*, 2000), although non PD-specific HRQoL and coping measures were used.

A minor modification to the use of the WCQ could be helpful: namely, modifying the scale so participants identify a disease-specific situation, so as to control for heterogeneity in situations selected. This might strengthen associations between coping strategies and HRQoL. Alternatively, given that lack of flexibility in coping processes has been associated with poorer mental and physical health outcomes (Frazier, 2002), measuring coping processes over a number of stressful events (which may or may not be disease specific) might also be informative.

There is growing evidence that avoiding the emotional consequences of daily-life stressors reduces HRQoL and may even make the emotions worse (Wenzlaff and Wegner, 2000). Most psychological interventions aimed at improving mood-related HRQoL (such as cognitive behavioural therapy; CBT) are predicated on the view that strengthening strategies for managing negative thoughts, feelings and behaviours associated with a condition can improve well-being (Feeney *et al.*, 2005; Kortte *et al.*, 2009). The unanticipated association between planful problem-solving coping and mood supports the use of CBT in PD. Whilst excellent for helping people to improve their use of active coping, CBT may be less appropriate for stresses perceived as less changeable. Therefore, working with people to help them engage in less escape-avoidance coping may improve their HRQoL in these areas. Accordingly, we need interventions that promote a positive and accepting

### Key points

- Greater use of planful problem-solving is associated with better health-related quality of life in terms of cognitive impairment, communication and bodily discomfort.
- Greater use of escape-avoidance coping is associated with poorer mood-related and emotional well-being health-related quality of life.
- Clinical interventions aimed at reducing avoidant behaviours, perhaps using such interventions as mindfulness training, may help improve health-related quality of life in people with Parkinson's disease.

approach to aspects of PD that are perceived as unchangeable.

Acceptance based interventions, such as acceptance and commitment therapy and group mindfulness programs, may be fruitful. There is evidence that interventions which promote mindfulness,<sup>3</sup> have positive effects for psychological and physical health (Baer, 2003; Grossman *et al.*, 2004). Furthermore, mindfulness is increasingly incorporated into mainstream psychological interventions (e.g. Dialectical Behaviour Therapy, Linehan, 1993; Acceptance and Commitment Therapy, Segal *et al.*, 2002), which holds promise in PD.

This study emphasises the need to conduct longitudinal research and to evaluate the impact of interventions designed to reduce avoidant coping such as mindfulness, on HRQoL in PD.

### Conflict of interest

The sponsoring bodies had no role in any aspect of this study including design, data collection, analysis and interpretation of data, or report writing.

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<sup>3</sup>Such as the Mindfulness-Based Stress Reduction program (which combines formal exercises: mediation, thought watching; and informal practices: deliberate attempts to complete everyday activities, such as the washing up, with full attention; Kabat-Zinn, 1982).

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