

**Care burden and mental ill health in spouses of people with  
Parkinson disease dementia and Lewy body dementia**

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## **ABSTRACT**

**Objectives:** To explore and compare levels of mental health, care burden and relationship satisfaction among caregiving spouses of people with mild cognitive impairment or dementia in Parkinson disease (PD-MCI or PDD), or dementia with Lewy bodies (DLB).

**Methods:** Spouses (n = 136) completed measures of mood, stress, resilience, general health, quality of life, care burden, and relationship satisfaction, as well as socio-demographic factors. Additionally, data on motor and neuropsychiatric symptom severity of people with PD-MCI, PDD or DLB was obtained in a sub-sample.

**Results:** Most spouses were married women (> 85%) who provided a median of 4 years of care and 84 hours of weekly care. Among these, relationship dissatisfaction, stress, anxiety, care burden, and feelings of resentment were common. Spouses of people with PDD and DLB had significantly higher rates of burden, resentment and depression compared to spouses of people with PD-MCI. Furthermore, unique group differences emerged whereby spouses of people with PDD had significantly longer duration of care provision, higher stress, more relationship dissatisfaction, and fewer positive interactions, compared to PD-MCI group, whereas anxiety and lower levels of mental health were prominent in spouses of people with DLB, compared to PD-MCI group. Despite this, the majority of spouses reported good quality of life, resilience, and satisfaction with the caring role.

**Conclusion:** PDD and DLB significantly contribute to poorer mental health and higher levels of care burden in spouses. Clinicians should actively screen the risk of burden, stress, depression and anxiety among caregiving spouses of people with these conditions.

**Keywords:** informal caregiving; spouses; Parkinson disease dementia (PDD); dementia with Lewy bodies (DLB); Parkinson disease and mild cognitive impairment (PD-MCI); burden

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## INTRODUCTION

Worldwide approximately 10 million people have Parkinson disease<sup>1</sup> and 47 million people have dementia<sup>2</sup>, of whom majority are cared by spouses and long-term partners. The characteristics of carers of people with Parkinson disease (PD) and non-PD dementias have already been well described.<sup>3</sup> However, there is little understanding of the characteristics of caregiving spouses in the context of mild cognitive impairment or dementia in PD (PD-MCI or PDD), or in dementia with Lewy bodies (DLB). A deeper understanding of the emotional, psychological and relationship patterns of carers of people with these conditions is crucial so that the care and quality of life of those with PD-MCI, PDD and DLB can be optimised.

PD is a complex movement disorder which is characterised by a myriad of motor and non-motor symptoms, including neuropsychiatric and cognitive abnormalities, autonomic dysfunction, sleep disturbances and sensory abnormalities.<sup>4-5</sup> As the motor and non-motor symptoms are common amongst people with PD, Langston (2006)<sup>6</sup> highlighted that parkinsonism is just 'tip of the iceberg' and should rather be seen as the 'Parkinson's complex'. Approximately 25% of people with PD present with MCI at the point of PD diagnosis<sup>7</sup>. PD-MCI is characterised by impairment in at least two cognitive domains, but which is not severe enough to significantly impact on an individual's functional ability.<sup>7</sup> Up to 80% of people develop dementia in PD (PDD) within 10 to 20 years following the onset of motor symptoms.<sup>8,9</sup> PDD is diagnosed when cognitive impairments are severe enough to affect functional ability, and PDD is associated with a significant drop in quality of life, an increase in level of disability and carer burden.<sup>10</sup> The prevalence of PDD is predicted to rise threefold by 2060,<sup>11</sup> underscoring the need to recognise and manage this stage of PD in an

optimal way. DLB is the second most common type of dementia<sup>12</sup> and often presents with cognitive changes before, or simultaneously with, typical parkinsonian motor changes. DLB is characterised by fluctuating levels of consciousness, frequent visual hallucinations, and an array of other neuropsychiatric symptoms.<sup>13,14</sup> PD-MCI, PDD and DLB are all part of the Lewy body spectrum of disorders, and while PDD and DLB share many underlying pathological changes and certain cognitive and neuropsychiatric features, their course and prognosis may differ.<sup>12,15-18</sup> Thus, comparing and contrasting key aspects of these clinical presentations, such as the impact on spousal carers, is important.

PD-MCI, PDD and DLB are all progressive neurodegenerative conditions characterised by cognitive, neuropsychiatric and motor changes. As these conditions progress, the support of a carer becomes necessary, and this role is most frequently filled by spouses or life partners, adult children or other family members. Carers are important in supporting disease management and activities of daily living of people with PD-MCI, PDD or DLB; however, providing care may lead to challenges in balancing personal and care-related responsibilities, and may increase burden and stress.<sup>19-25</sup> Providing care may also result in depression and anxiety in carers.<sup>22,26</sup> With the progression of cognitive impairment in PD and DLB, burden<sup>9,23,27-30</sup> and emotional stress<sup>31-33</sup> intensify in carers, and their quality of life drops.<sup>9,34</sup> This suggests that the stage of cognitive impairment in the care recipient significantly affects carer well-being. Consequently, caring may lead to neglect of carers' own health and needs,<sup>35,36</sup> carer burnout,<sup>24</sup> and institutionalisation of care recipients,<sup>11,37-41</sup> all of which have long-term cost implications.

Studies have explored the impact of PD without cognitive impairment to PD-MCI and PDD<sup>9,34</sup> on carer burden and quality of life, but earlier studies did not include carers of people with DLB. Thus, the current study aimed to describe and compare the sociodemographic and clinical characteristics of caregiving spouses according to the clinical syndrome of care recipients (i.e. PD-MCI, PDD or DLB). We hypothesized that, since the rate of decline and neuropsychiatric burden of people with DLB may be greater than in PD-MCI or PDD, the spouses of people with DLB would experience higher levels of mental health problems, care burden and relationship dissatisfaction.

## **METHODS**

### **Sample and setting**

This cross-sectional study was nested within the INVEST (INdiVidualised cognitive Stimulation Therapy) study. INVEST is a pilot feasibility randomised controlled trial of individualised cognitive stimulation therapy adapted for people with PD-MCI, PDD or DLB ('CST-PD'), and their study partners.<sup>42</sup> Participants were eligible if they were a caregiving spouse of a person with PD-MCI, PDD, or DLB. We applied the term 'spouse' in a broad sense to include married partners as well as 'life partners' or people who lived with the person PD-MCI, PDD or DLB in an intimate way. Individuals who were in a non-intimate relationship with the person with PD-MCI, PDD or DLB, whose spouse with one of these conditions had passed away, or who lacked capacity to consent were excluded from the study.

### **Recruitment and procedure**

We recruited the spouses of people with PD-MCI, PDD OR DLB via two routes: (1) baseline assessments in the INVEST study undertaken in a home-based interview between the researcher and the couple (April 2016 – July 2017), and (2) a postal questionnaire for spouses only (July 2017 – January 2018).

In route one, participant-dyads for the INVEST study were identified through memory or movement disorder clinics in four locations in England (Greater Manchester, Derbyshire, North East London and Warrington). People with PD-MCI, PDD and DLB were diagnosed by the referring PD specialists who were geriatricians, neurologists, and PD specialist nurses with expertise in the diagnosis and management of PD and working in movement disorder clinics. They all followed accepted diagnostic criteria for possible or probable PD-MCI<sup>43</sup>/PDD<sup>44</sup> and DLB<sup>45</sup>, and undertook validated cognitive screening tests (i.e. such as the Addenbrooke's Cognitive Evaluation rating scale)<sup>46</sup> to ascertain the presence of dementia or MCI. In some cases, neuroimaging (i.e. dopamine transporter SPECT imaging or 'DaT scan') was used by the referrers to support the diagnosis. Following referral, we screened participants at their first visit using the Montreal Cognitive Assessment (MOCA)<sup>47</sup> to verify and document the extent of cognitive impairment, as well as taking a history to verify the referral diagnosis as PD-MCI or PDD or DLB.

In route two, potential participants for the postal questionnaire study were identified through: (a) the 'screen-failed' participant list of the INVEST study, who were unable to participate in the INVEST study due to distance from the research centre, high presence of care burden or lack of interest in participating in an interventional study; and (b) patient databases held by the Greater Manchester Mental Health and North West Boroughs

Healthcare National Health Service (NHS) Trusts. In this route, spouses self-reported the diagnosis of the care recipient. As majority of spouses in the postal questionnaire were recruited via the INVEST screen-failed list and NHS patient databases, the diagnosis of care recipients could be verified and it was therefore not considered a major concern of the study. The postal questionnaire, together with an invitation letter, a participant information sheet, a consent form and a pre-paid envelope were posted out to potential participants. We also utilised UK-based charity and research websites (e.g. Parkinson's UK, Join Dementia Research, the UK's Lewy Body Society) as recruitment methods for route one and two.

The data of 57 spouses were extracted from the INVEST study, which represented all those eligible from this dataset. Additionally, 79 spouses participated in the postal questionnaire study. People with PD-MCI, PDD or DLB did not participate in the current study.

### **Ethics**

The INVEST study and the postal questionnaire received ethical approval from the Yorkshire & The Humber – Bradford Leeds Research Ethics Committee (reference number: 15/YH/0531). All spouses who were eligible to participate in the study provided written informed consent. Additionally, people with PD-MCI, PDD or DLB recruited via route 1 provided written informed consent through the INVEST study and all had the capacity to consent to participation.

### **Measures**

To gain a comprehensive overview of the emotional, psychological and relationship factors among caregiving spouses of the three groups, we administered a battery of validated rating

scales, several of which are novel in this population. The included scales are described below.

*Burden, stress and resilience:* The *Zarit Burden Interview (ZBI)*<sup>48</sup>, a 22-item scale, assesses spouses' degree of burden on a 5-point Likert scale (0 = never to 4 = nearly always). The *Relatives' Stress Scale (Rel.SS)*<sup>49</sup> consists of 15 items on a 5-point scale from 0 (never/not at all) to 4 (always/considerably), measuring the amount of stress and upset experienced by the spouse as a result of providing care. The *Dyadic Relationship Scale (DRS)*<sup>50</sup> assesses positive interaction (6 items) and negative strain (5 items) with the care recipient on a 4-point Likert scale ranging from 0 (strongly disagree) to 3 (strongly agree). The *Family Caregiving Role scale (FCR)*<sup>51</sup> consists of 16 items on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree), which are divided into 3 sub-scales: (1) satisfaction with the caring role, (2) resentment and (3) anger. The *Brief Resilience Scale (BRS)*<sup>52</sup> explores the ability to bounce back from stress with 6 items on a 5-point Likert scale varying from 1 (strongly disagree) to 5 (strongly agree). Higher scores on the ZBI, Rel.SS, DRS-negative strain, FCR-resentment and FCR-anger indicate higher levels of burden, stress, strain and negative feelings, whereas higher scores on DRS-positive interaction, FCR-satisfaction and BRS show greater positive interaction, satisfaction with the caring role and higher resilience.

*Relationship satisfaction:* The *Relationship Satisfaction Scale (RSS)*<sup>53</sup> explores relationship satisfaction with regards to communication and openness, conflict resolution, degree of affection/caring, intimacy/closeness, as well as overall satisfaction with the relationship with 7 items on a 7-point Likert scale (0 = very dissatisfied to 6 = very satisfied). Higher score on the RSS indicate higher relationship satisfaction.



*Health and quality of life:* The *Short Form 12 Health Survey (SF-12)*<sup>54</sup> evaluates spouses' physical and mental health separately in 12 yes/no or Likert-type questions. The *Hospital Anxiety and Depression Scale (HADS)*<sup>55</sup> consists of 14 items measuring anxiety and depression on a 4-point Likert scale ranging between 0 and 3. The *EuroQoL-5D-3L (EQ-5D)*<sup>56</sup> assesses health-related quality of life with an index score consisting of five indices (i.e. mobility, self-care, usual activities, pain/discomfort, anxiety/depression), and a visual analogue scale (VAS) rating spouses' health today on a scale between 0 and 100%. Higher scores on the SF-12 and the EQ-5D indicate better physical/mental well-being and quality of life, whereas higher scores on the HADS indicate higher anxiety/depression.

*PD-related symptoms* (elicited from the home-based assessments in route 1): The *Hoehn and Yahr stage (H&Y)*<sup>57</sup> (range I to V) and *Unified Parkinson's disease Rating Scale part III (UPDRS-III)*<sup>58</sup> (range 0 to 100) measure the severity of care recipients' PD. The *Schwab & England Activities of Daily Living scale (SE-ADL)*<sup>59</sup> (range 0 to 100%) assesses care recipients' functional ability. The *MoCA*<sup>47</sup> evaluates the cognitive status of the person with PD-MCI, PDD OR DLB, which can range between 0 and 30, and the *Neuropsychiatric Inventory (NPI)*<sup>60</sup> measures the frequency and severity of 12 neuropsychiatric symptoms of the care recipients, which were rated by spouses. For H&Y, UPDRS-III and NPI, higher scores indicate a more advanced disease stage and more frequent and severe neuropsychiatric symptoms.

*Demographic information:* Age, gender, education, ethnicity, marital status, relationship duration and living status were collected about both partners. In addition, spouses provided details of care recipients' diagnosis, year of onset of PD or DLB symptoms and degree of

cognitive impairment as well as regarding spouses' duration of care provision in years and weekly hours.

Several scales of this study, such as the ZBI, Rel.SS, SF-12, EQ-5D, HADS, have been widely used with carers and spouses of people with PD-MCI, PDD, DLB; however, the remaining scales (i.e. RSS, DRS, BRS; FCR) appear to be novel in this population and their psychometric properties in this sample are described elsewhere (Vatter et al., in submission).

## **Analyses**

Descriptive variables are presented as percentages (categorical variables), means and standard deviations [SD] (normally distributed continuous variables), or medians and interquartile ranges [IQR] (non-normally distributed continuous variables). Parametric tests (i.e. t-test, ANOVA) and non-parametric tests (i.e. Spearman correlation coefficient, Mann-Whitney U-test and Kruskal-Wallis H test) were undertaken, as appropriate. Due to the use of several tests and several groups, post hoc tests (i.e. Bonferroni, Hochberg or Games-Howell) were applied. Missing data were imputed with the expectation-maximization method. Outliers were transformed with winsorization, whereby the outliers were assigned the highest or the lowest value found in the sample that was not an outlier. All analyses were conducted in SPSS version 23 and the significance level for the results was set at  $p < .05$ .

## **RESULTS**

### **Sample characteristics**

Participants were spouses of people with PD-MCI, PDD or DLB ( $n = 136$ ), all of whom lived together with the care recipient. Most participants (94.9%) were married (Table 1). The median relationship duration was 46.5 years (IQR = 34.75, 53.00). The majority of couples comprised a male with PD-MCI, PDD or DLB and a female spouse (85.3%) and most were white British. The mean age of spouses was 69.44 years ( $SD = 7.62$ ) and of care recipients, 73.51 years ( $SD = 6.48$ ). Thirty-seven people had a diagnosis of PD-MCI, 50 of PDD and 49 of DLB. The median disease duration of PD (including DLB diagnosis in the absence of PD diagnosis) was 5 years (IQR = 3, 10) and of cognitive impairment, 4 years (IQR = 2, 6). The median duration of PD and cognitive impairment amongst people with PD-MCI was 6 (IQR = 3.00, 7.64) years and 3 (IQR = 1.00, 5.00) years, respectively; amongst people with PDD 10 (IQR = 5.00, 16.25) years and 4.5 (IQR = 2.00, 7.25) years, respectively, and amongst people with DLB 3 (IQR = 1.00, 5.50) years and 4 (IQR = 2.00, 6.00) years, respectively. Spouses had provided care for between 0 and 20 years (median = 4; IQR = 2, 7) and at the time of the study were providing between 0 and 168 hours of care per week (median = 84; IQR = 38.5, 168). Nearly half of the spouses (46.0%) provided over 100 hours of care per week. The median care provision duration among spouses of people with PD-MCI was 4 (IQR = 2.00, 7.00) years and 56 (IQR = 28.00, 168.00) weekly hours, among spouses of people with PDD 7 (IQR = 3.00, 10.25) years and 126 (IQR = 42.00, 168.00) weekly hours, and among spouses of people with DLB 2.5 (IQR = 2.00, 6.00) years and 98 (IQR = 42.00, 168.00) weekly hours. In the sub-sample of care recipients recruited via Route 1, 50.9% had a H&Y stage of 2 (Table 2). We have outlined the scores of the MoCA, UPDRS-III, SE-ADL and NPI, according to PD-MCI, PDD or DLB grouping, in Table 2.

Table 1 Participant characteristics (n = 136 spouses)

	Spouses	People with PD-MCI, PDD or DLB
<b><u>Categorical variables, N (%)</u></b>		
Gender, female	116 (85.3)	20 (14.7)
Ethnicity, white British	122 (89.7)	123 (90.4)
Relationship status		
Married	129 (94.9)	
Cohabiting	7 (5.1)	
Living with spouse	136 (100)	
Education		
Left school aged 14-16 years	41 (30.1)	54 (39.7)
Left school aged 17-18 years	11 (8.1)	6 (4.4)
Further education	34 (25.0)	36 (26.5)
Higher education (university degree)	50 (36.8)	40 (29.4)
Clinical diagnosis		
PD-MCI		37 (27.2)
PDD		50 (36.8)
DLB		49 (36.0)
<b><u>Continuous variables, Mean (SD); range</u></b>		
Age, years	69.44 (7.62); 48-85	73.51 (6.48); 49-90
<b><u>Continuous variables, Median (IQR); range</u></b>		
Relationship duration, years	46.5 (34.75, 53.00); 5-68	
Age left full-time education	17 (16.00,20.00); 14-53	16 (15.00, 20.75); 14-46
Duration of PD, years		5 (3.00, 10.00); 0-37
Duration of cognitive impairment, years		4 (2.00, 6.00); 0.2-22
Care provision duration, years	4 (2.00, 7.75); 0-20	
Care provision hours/week	84 (38.50, 168.00); 0-168	

Abbreviations: DLB – Dementia with Lewy bodies; IQR – interquartile range; PD – Parkinson disease; PDD – Parkinson disease dementia; PD-MCI – Parkinson disease and mild cognitive impairment; SD – standard deviation.

Table 2 Disease variables of 57 care recipients

	Spouses n = 57	Care recipients n = 57	People with:		
			PD-MCI n = 18	PDD n = 25	DLB n = 14
<b><u>Categorical variables, n (%)</u></b>					
Retired, 'yes'	47 (82.5)	57 (100)			
H&Y stage					
I		9 (16.4)			
II		28 (50.9)			
III		6 (10.9)			
IV		10 (18.2)			
V		2 (3.6)			
<b><u>Continuous variables, Median (IQR); range</u></b>					
MoCA score (max 30)			22.00 (19.00, 25.25); 13-30	16.50 (13.00, 21.00); 7-26	17.00 (14.50, 19.50); 8-24
UPDRS-III (max 100)			20.00 (15.00, 26.50); 10-47	37.50 (23.75, 41.50); 13-53	35.00 (32.00, 45.00); 10-58
SE-ADL (max 100)			80.00 (50.00, 90.00); 30-90	40.00 (25.00, 65.00); 20-90	50.00 (27.50, 60.00); 10-80
NPI (max 120)			5.00 (2.00, 11.50); 0-42	14.00 (4.00-24.00); 0-58	12.00 (7.75, 38.25); 0-53
NPI – carer distress (max 50)			3.50 (1.50, 6.00); 0-17	6.00 (2.00, 11.75); 0-31	5 (3.50, 14.50); 0-30

Abbreviations: DLB – Dementia with Lewy bodies; H&Y – Hoehn & Yahr scale; IQR – interquartile range; MoCA – Montreal Cognitive Assessment; NPI – the Neuropsychiatric Inventory; PD – Parkinson disease; PDD – Parkinson disease dementia; PD-MCI – Parkinson disease and mild cognitive impairment; SD – standard deviation; SE-ADL – Schwab & England Activities of Daily Living scale; UPDRS-III – Unified Parkinson’s disease Rating Scale part III.

Table 3 Participant measures (n = 136 spouses)

Measures	Mean (SD)	n (%)
<b>RSS</b>	<b>24.97 (11.94)</b>	
Very dissatisfied (0-20)		18 (35.29)
Moderately dissatisfied (21-30)		31 (22.79)
Moderately satisfied (31-40)		36 (26.47)
Very satisfied (41-42)		18 (13.24)
<b>ZBI</b>	<b>36.83 (16.31)</b>	
Little or no burden (0-20)		19 (13.97)
Mild to moderate burden (21-40)		57 (41.91)
Moderate to severe burden (41-60)		41 (30.15)
Severe burden (61-88)		10 (7.35)
<b>BRS</b>	<b>3.52 (0.80)</b>	
Low resilience (1.00-2.99)		30 (22.06)
High resilience (3.00-5.00)		106 (77.94)
<b>HADS-anxiety</b>	<b>7.56 (4.54)</b>	
Normal (0-7)		68 (50.00)
Mild anxiety (8-10)		31 (22.79)
Moderate anxiety (11-14)		23 (16.91)
Severe anxiety (15-21)		12 (8.82)
<b>HADS-depression</b>	<b>5.78 (4.07)</b>	
Normal (0-7)		85 (62.50)
Mild depression (8-10)		33 (24.26)
Moderate depression (11-14)		13 (9.56)
Severe depression (15-21)		3 (2.21)
<b>SF-12-PCS</b>	<b>50.38 (10.80)</b>	
<b>SF-12-MCS</b>	<b>44.86 (10.50)</b>	
<b>EQ5D-Index</b>	<b>0.770 (0.236)</b>	
Low quality of life (-1.000...0.799)		69 (50.74)
High quality of life (0.800...+1.000)		67 (49.26)
<b>EQ5D-VAS</b>	<b>75.20 (17.30)</b>	
Low quality of life (0-79)		63 (46.32)
High quality of life (80-100)		71 (52.21)
<b>Rel.SS</b>	<b>25.74 (10.83)</b>	
Little or no stress (0-22)		52 (38.24)
Mild to moderate stress (23-29)		26 (19.12)
Moderate to severe stress (30-60)		55 (40.44)
<b>DRS-positive interaction</b>	<b>9.33 (3.25)</b>	
<b>DRS-negative strain</b>	<b>5.32 (3.37)</b>	
<b>FCR-satisfaction</b>	<b>4.04 (0.51)</b>	
Low satisfaction with caring role (1.00-2.49)		2 (1.47)
High satisfaction with caring role (2.50-5.00)		132 (97.06)
<b>FCR-resentment</b>	<b>2.77 (0.97)</b>	
Low feelings of resentment (1.00-2.49)		51 (37.50)
High feelings of resentment (2.50-5.00)		85 (62.50)
<b>FCR-anger</b>	<b>1.98 (0.83)</b>	
Low feelings of anger (1.00-2.49)		92 (67.65)
High feelings of anger (2.50-5.00)		43 (31.62)

Abbreviations: BRS – Brief Resilience Scale; DRS – Dyadic Relationship Scale, positive interaction or negative strain sub-scale; EQ-5D – EuroQoL-5D index; EQ5D VAS – EurQoL-5D visual analogue scale; FCR – Family Caregiving Role scale; HADS – Hospital Anxiety and Depression Scale; Rel.SS – Relatives' Stress Scale; RSS – Relationship Satisfaction Scale; SD – standard deviation; SF-12 – Short Form 12 Health Survey, physical health (PCS) or mental health (MCS) sub-scale; ZBI – Zarit Burden Interview.

## Characteristics of spouses

In Table 1 we present the descriptive values of spouses' characteristics and in Table 3 we outline the cut-off scores of each measure. In Tables 4 and 5 we report associations among spousal and care recipient variables, respectively, with the Spearman rank correlation analyses (with Bonferroni adjusted alpha levels of .003). A separate Spearman rank correlation analysis between the participants recruited via route one and route two was conducted which revealed no significant differences; thus, we only present merged data in Table 4.

### *Burden, stress and resilience*

Nearly 60% of spouses experienced stress ( $n = 81$ ; Rel.SS) and 36% burden ( $n = 49$ ; ZBI); however, over 75% of respondents ( $n = 106$ ) reported good resilience (BRS), highlighting that spouses could adapt well to stressful situations. A large proportion of spouses displayed resentment ( $n = 85$ ; 62.50%; FCR-resentment) and a smaller proportion of the sample ( $n = 43$ , 31.6%) reported feeling anger due to their caring role (FCR-anger). In contrast, nearly all ( $n = 132$ , 97.1%) reported feeling satisfied with their caring role (FCR-satisfaction). Burden (ZBI) significantly correlated with stress (Rel.SS), strain (DRS), depression (HADS), anxiety (HADS), mental health (SF-12), quality of life (EuroQoL), resilience (BRS), resentment and anger (FCR).

### *Relationship satisfaction*

Almost 60% of participants ( $n = 79$ ; RSS) were dissatisfied with the relationship. Lower relationship satisfaction (RSS) in spouses was associated with higher burden (ZBI), stress (Rel.SS), anxiety and depression (HADS), negative strain (DRS), feelings of resentment and

anger (FCR), and lower mental health (SF-12), quality of life (EuroQoL), lower resilience (BRS) and fewer positive interactions with one's partner (DRS).

#### *Health and quality of life*

Clinically significant anxiety and depression was reported by 25.7% (n = 35) and 11.8% (n = 16) of participants, respectively. About half of spouses reported relatively good quality of life according to the EQ-5D-index scores (n = 67, 49.3%) and visual analogue scale (n = 71, 52.2%). Lower spouses' mental health (SF-12) was related to intrapersonal aspects (i.e. own anxiety, depression, quality of life, resilience) as well as interpersonal aspects (i.e. burden, stress, strain, resentment and anger related to care provision).

#### *PD symptoms*

For the sub-sample of 57 spouses and people with PD-MCI, PDD OR DLB, Spearman rank correlation analyses were performed using a Bonferroni adjusted alpha level of .005 (.05/10). The duration of caregiving years correlated with care recipients' PD and cognitive impairment duration (both  $p < .001$ ), H&Y stage ( $p = .001$ ), SE-ADL ( $p < .001$ ) and weekly care provision hours ( $p = .002$ ), but not with UPDRS-III ( $p = .109$ ) (Table 4). There was also a significant negative association between weekly care provision hours and SE-ADL ( $p < .001$ ), but this was not related to PD motor symptom severity.



Table 4 Spearman correlation analyses among spousal characteristics (n = 136 spouses)

	<b>RSS</b>	<b>ZBI</b>	<b>BRS</b>	<b>HADS- anx.</b>	<b>HADS- depr.</b>	<b>SF-12- PCS</b>	<b>SF-12- MCS</b>	<b>EQ5D- index</b>	<b>EQ5D- VAS</b>	<b>Rel.SS</b>	<b>DRS- inter.</b>	<b>DRS- strain</b>	<b>FCR- satisf.</b>	<b>FCR- resent.</b>
<b>ZBI</b>	<b>-.712***</b>													
<b>BRS</b>	<b>.359***</b>	<b>-.487***</b>												
<b>HADS-Anxiety</b>	<b>-.432***</b>	<b>.689***</b>	<b>-.594***</b>											
<b>HADS-Depression</b>	<b>-.553***</b>	<b>.681***</b>	<b>-.547***</b>	<b>.760***</b>										
<b>SF-12-PCS</b>	.030	-.019	.128	-.054	-.162									
<b>SF-12-MCS</b>	<b>.494***</b>	<b>-.635***</b>	<b>.599***</b>	<b>-.742***</b>	<b>-.662***</b>	-.157								
<b>EQ5D-index</b>	<b>.281**</b>	<b>-.286**</b>	<b>.350***</b>	<b>-.448***</b>	<b>-.468***</b>	<b>.597***</b>	<b>.345***</b>							
<b>EQ5D-VAS</b>	<b>.266**</b>	<b>-.279**</b>	<b>.345***</b>	<b>-.374***</b>	<b>-.391***</b>	<b>.591***</b>	<b>.299***</b>	<b>.511***</b>						
<b>Rel.SS</b>	<b>-.624***</b>	<b>.872***</b>	<b>-.505***</b>	<b>.672***</b>	<b>.694***</b>	<b>-.014</b>	<b>-.671***</b>	<b>-.387***</b>	<b>-.266**</b>					
<b>DRS-interaction</b>	<b>.351***</b>	-.209	.122	-.126	-.177	-.093	.145	.096	.001	-.153				
<b>DRS-strain</b>	<b>-.636***</b>	<b>.710***</b>	<b>-.330***</b>	<b>.441***</b>	<b>.487***</b>	.055	<b>-.455***</b>	<b>-.225</b>	<b>-.272**</b>	<b>.639***</b>	<b>-.314***</b>			
<b>FCR-satisfaction</b>	.216	-.210	.077	-.042	-.103	-.121	.005	-.128	-.066	-.112	<b>.387***</b>	<b>-.369***</b>		
<b>FCR-resentment</b>	<b>-.612***</b>	<b>.752***</b>	<b>-.427***</b>	<b>.605***</b>	<b>.701***</b>	.112	<b>-.578***</b>	<b>-.258**</b>	-.184	<b>.748***</b>	-.201	<b>.569***</b>	-.123	
<b>FCR-anger</b>	<b>-.571***</b>	<b>.598***</b>	<b>-.320**</b>	<b>.464***</b>	<b>.383***</b>	.102	<b>-.463***</b>	<b>-.266**</b>	-.212	<b>.584***</b>	<b>-.428***</b>	<b>.659***</b>	<b>-.346***</b>	<b>.546***</b>

Notes: \*\* p < .003, \*\*\* p < .001 (Bonferroni adjustment applied)

Abbreviations: BRS – Brief Resilience Scale; DRS – Dyadic Relationship Scale, positive interaction or negative strain sub-scale; EQ-5D – EuroQoL-5D index score or visual analogue scale (VAS); FCR – Family Caregiving Role scale, caregiving satisfaction, resentment or anger sub-scale; HADS – Hospital Anxiety and Depression Scale, anxiety or depression sub-scale; Rel.SS – Relatives’ Stress Scale; RSS – Relationship Satisfaction Scale; SF-12 – Short Form 12 Health Survey, physical health (PCS) or mental health (MCS) sub-scale; ZBI – Zarit Burden Interview.

Table 5 Spearman correlation analyses among Parkinson symptoms and care provision aspects (n = 57 couples)

	Caring duration (y)	Weekly caring (h)	PD duration	Cognitive impairment duration	MoCA	H&Y	UPDRS- III	SE-ADL	NPI- total
Weekly caring (h)	<b>.261**</b>								
PD duration	<b>.673***</b>	.236							
Cogn. Imp. Duration	<b>.411***</b>	.123	<b>.309***</b>						
MoCA	.081	-.264	-.028	.059					
H&Y	<b>.449**</b>	.284	<b>.415**</b>	.265	-.203				
UPDRS-III	.230	.328	.298	.165	-.298	<b>.662***</b>			
SE-ADL	<b>-.551***</b>	<b>-.443**</b>	-.340	-.361	.330	<b>-.636***</b>	<b>-.657***</b>		
NPI-total	.194	.314	.232	.297	-.029	.241	.300	-.359	
NPI-carer distress	.084	.175	.185	.164	-.055	.341	.349	-.236	<b>.830***</b>

Notes: \*\* p < .005, \*\*\* p < .001

Abbreviations: H&Y – Hoehn & Yahr scale; MoCA – Montreal Cognitive Assessment; NPI – Neuropsychiatric Inventory; PD – Parkinson disease; SE-ADL – Schwab & England Activities of Daily Living scale; UPDRS-III – Unified Parkinson’s disease Rating Scale part III.

## **Group comparisons**

We conducted two sets of group comparisons: (1) a pooled analysis with 136 life partners, which is presented below, and (2) separate analyses with participants recruited via route 1 (n = 57 spouses) and route 2 (n = 79), which is available as a supplementary file.

### *Burden, stress and resilience*

A one-way ANOVA revealed that spouses of people with PDD and DLB experienced more burden and resentment than spouses of people with PD-MCI (both  $p < .05$ ) (Table 6). In addition, spouses of people with PDD experienced, higher stress levels ( $p = .019$ ), and less positive interaction with the care recipient ( $p = .018$ ) compared to spouses of people with PD-MCI, but these variables did not differ between DLB and PD-MCI groups. The FCR-satisfaction sub-scale failed the assumptions of ANOVA, thus we applied a Kruskal-Wallis H test, which revealed no statistical differences between the disease groups ( $p > .05$ ).

Weekly care provision hours did not differ among PD-MCI, PDD and DLB ( $p > .05$ ); however, when PD-MCI was compared with the two dementia groups combined, spouses of people with PDD and DLB devoted more hours to caregiving each week ( $m = 102.59$ ,  $SD = 60.72$ ) than spouses of people with PD-MCI ( $m = 76.74$ ,  $SD = 64.03$ ) [ $t(133) = -2.16$ ,  $p = .033$ ]. Spouses of people with PDD provided care for longer than spouses of people with PD-MCI ( $p = .006$ ) and DLB ( $p < .001$ ), as determined by the Games-Howell post hoc test.

### *Relationship satisfaction*

Spouses of people with PDD had lower relationship satisfaction ( $p = .047$ ) than spouses of people with PD-MCI, but we did not observe any statistically significant difference in relationship satisfaction between the PD-MCI and DLB groups.

#### *Health and quality of life*

Spouses of people with DLB had higher levels of anxiety ( $p = .010$ ) and lower levels of mental health ( $p = .024$ ) than spouses of people with PD-MCI but no difference was found between PDD and PD-MCI groups on these variables. Using a one-way ANOVA, we found a statistically significant difference in the HADS-depression scores among spouses of people with PD-MCI, PDD or DLB [ $F(2,133) = 9.94, p < .001$ ]. Spouses of people with PDD and DLB had significantly higher depression scores than those caring for people with PD-MCI (both  $p < .001$ ), as determined by the Games-Howell post hoc test. Finally, we found no statistically significant differences between PDD and DLB groups on any of the variables examined ( $p > .05$ ).

Table 6 Spousal characteristics (n = 136) according to PD-MCI, PDD and DLB

Diagnosis	ANOVA					Post hoc test	
	m (SD)			F	P	p	
	PD-MCI (n = 37)	PDD (n = 50)	DLB (n = 49)	df (2,133)		PD-MCI vs PDD	PD-MCI vs DLB
Years caring	4.68 (3.35)	7.74 (5.62)	3.68 (3.43)	11.53	<b>.000</b>	<b>.006</b> ‡	n.s.
Hours caring pw	76.74 (64.03)	106.77 (63.15)	98.32 (58.48)	2.55	.082	n.s.	n.s.
<b>RSS</b>	28.68 (10.61)	22.48 (12.16)	24.22 (12.03)	3.07	<b>.050</b>	<b>.047</b> †	n.s.
<b>ZBI</b>	28.16 (14.19)	38.06 (14.00)	37.99 (16.78)	5.68	<b>.004</b>	<b>.009</b> †	<b>.011</b> †
<b>BRS</b>	3.60 (0.76)	3.51 (0.78)	3.47 (0.86)	0.31	.732	n.s.	n.s.
<b>HADS-anxiety</b>	5.73 (3.83)	7.88 (4.33)	8.65 (5.03)	4.69	<b>.011</b>	n.s.	<b>.010</b> †
<b>HADS-depress.</b>	3.46 (2.52)	6.46 (3.95)	6.96 (4.45)	9.94	<b>.000</b>	<b>.000</b> ‡	<b>.000</b> ‡
<b>SF-12-PCS</b>	51.96 (10.23)	49.10 (10.62)	50.49 (11.23)	0.76	.471	n.s.	n.s.
<b>SF-12-MCS</b>	48.28 (10.42)	44.87 (9.16)	42.28 (11.06)	3.63	<b>.029</b>	n.s.	<b>.024</b> †
<b>EQ5D-index §</b>	0.83 (0.19)	0.76 (0.24)	0.77 (0.19)	1.39	.253	n.s.	n.s.
<b>EQ5D-VAS §</b>	78.03 (14.97)	75.22 (17.95)	73.54 (16.39)	0.77	.465	n.s.	n.s.
<b>Rel.SS</b>	21.65 (9.59)	27.94 (10.85)	26.80 (10.77)	4.15	<b>.018</b>	<b>.019</b> †	n.s.
<b>DRS-interaction</b>	10.36 (3.57)	8.46 (3.03)	9.54 (2.87)	4.03	<b>.020</b>	<b>.018</b> †	n.s.
<b>DRS-strain</b>	4.38 (3.23)	6.04 (3.50)	5.64 (3.13)	2.85	.061	n.s.	n.s.
<b>FCR-resentment</b>	2.38 (0.80)	2.92 (0.97)	2.91 (1.03)	4.25	<b>.016</b>	<b>.029</b> †	<b>.035</b> †
<b>FCR-anger</b>	1.69 (0.73)	2.11 (0.86)	2.06 (0.83)	3.26	<b>.042</b>	n.s.	n.s.

Notes: † - Hockberg's GT2 post hoc test; ‡ - Games-Howell post hoc test; §- winsorized.

Abbreviations: ANOVA – analysis of variance; BRS – Brief Resilience Scale; df – degrees of freedom; DLB – Dementia with Lewy bodies; DRS – Dyadic Relationship Scale, positive interaction or negative strain sub-scale; EQ5D – EuroQoL-5D index or visual analogue scale (VAS); FCR – Family Caregiving Role scale; HADS – Hospital Anxiety and Depression Scale; IQR – interquartile range; n.s. – not significant; PDD – Parkinson disease dementia; PD-MCI – Parkinson disease and mild cognitive impairment; pw – per week; Rel.SS – Relatives' Stress Scale; RSS – Relationship Satisfaction Scale; SD – standard deviation; SF-12 – Short Form 12 Health Survey, physical health (PCS) or mental health (MCS) sub-scale; ZBI – Zarit Burden Interview.

## DISCUSSION

Our study demonstrated that burden, stress, relationship dissatisfaction and feelings of resentment are common among spouses of people with PD-MCI, PDD or DLB. We also found that spouses of people with PDD and DLB have higher rates of burden, depression and feelings of resentment, compared to spouses of people with PD-MCI. Furthermore, spouses of people with PDD report higher levels of stress and lower levels of relationship satisfaction, whereas spouses of people with DLB exhibit higher levels of anxiety and lower levels of mental health, in comparison to PD-MCI. The daily care provision hours exceeded 14 hours for over half of spouses in the current study, which is significantly higher than the level found in carers of people with dementia (i.e. between 3 and 11 hours per day).<sup>61</sup> This finding highlights the complexity of PD-related dementias as well as an immense commitment by carers in taking care of their relatives.

Several findings resonate with previous studies in terms of high levels of burden and stress,<sup>9,23,24,31,62</sup> but relationship dissatisfaction, perceived negative feelings (resentment) and resilience are new findings emerging from this study, despite being well-researched constructs in carers of people with non-PD type dementia.<sup>63-67</sup> This could be explained by a number of reasons. Firstly, people with PD-MCI, PDD or DLB have higher rates of burden,<sup>30,68</sup> stress,<sup>32,33</sup> depression,<sup>69</sup> lower ability to live well,<sup>70</sup> and more tension and arguments in the dyadic relationship<sup>71</sup> compared to carers of people with Alzheimer disease and/or vascular dementia. Secondly, most carers are older adults themselves and many have physical or mental health problems,<sup>2</sup> which makes caring for a relative increasingly demanding whilst also taking care of oneself. Thirdly, the new findings in regards to relationship dissatisfaction, feelings of resentment, and resilience in this study could be

explained by the use of the scales (i.e. RSS, FCR and BRS, respectively), which were generic, condition-neutral and which have not been used in this population before. For this reason we undertook psychometric property testing of these scales, which would act as a guidance to future studies in regards to selecting an appropriate measure in this population (reported in Vatter et al., in submission). Furthermore, the constructs of relationship satisfaction and resilience are both multi-faceted, complex and lack clear definitions which add additional complexities into the measurement process. Future studies should focus on examining the constituent parts, either through factors derived from a factor/cluster analysis of the measurements, or develop validated condition-specific scales *de novo*.

Notwithstanding the high prevalence of burden, stress and low levels of mental health, many spouses in the current study had good quality of life and resilience, emphasising their ability to cope and adjust to the challenging nature of the care recipients' condition. These findings are consistent with a recent qualitative study of spouses of people with PD-MCI, PDD or DLB<sup>72</sup> where spouses had learned to accept and adapt to their partners' condition despite the demands and stresses they faced. Importantly, however, in this study female spouses reported that they cherished their marital vows and exhibited commitment to support their partners 'in health and in sickness'.<sup>72</sup> Care provision frequently takes place within a long-term intimate relationship, and having a good relationship quality is important as it can protect against stressors and support carers' quality of life,<sup>32,73</sup> therefore, strengthening and supporting interpersonal relationships is crucial and should be a focus of future studies.

The finding that spouses of people with DLB had high levels of anxiety and poor mental health is novel despite comparative studies demonstrating that these carers have significantly more burden<sup>30</sup> and stress<sup>32,33</sup> compared to carers of people with other types of dementia. The impact of DLB on spouses may be more profound as the speed of onset of the condition is faster, the intensity of symptoms and levels of fluctuation are often higher, and impairments in certain areas of cognitive functioning greater than in PDD.<sup>74,75</sup> Interestingly, our study found that burden, stress, resilience, relationship satisfaction, quality of life, anxiety, depression and mental health levels did not differ between spouses of people with PDD and DLB. These findings suggest that both PDD and DLB appear to have a similar effect on spouses, which could be due to the two syndromes having a clinically similar symptom presentation in terms of cognitive, psychiatric and motor symptoms as well as share underlying pathology.<sup>11,13-18</sup> However, further studies are required to determine the impact of PDD and DLB on spouses.

The limitations of the study should be acknowledged. We were unable to elicit the disease-specific aspects, such as motor, psychiatric and cognitive symptoms of PD for all care recipients due to the nature of the postal questionnaire, which precluded a wider exploration of the impact of disease-specific aspects on spouses. We were also not able to capture spouses' health history and these data could have expanded our knowledge regarding the role that their physical and mental health needs played in their ability to provide care to their relatives. We also acknowledge the two different modes of administering the questionnaires as the data were combined from participants recruited through the INVEST study, where a researcher was present to help with any queries, and the postal questionnaire study, where participants self-completed the measures. This may have



influenced our results to a small extent. Furthermore, participants in the postal questionnaire had a self-selection bias as they chose whether to take part in the study or not. This bias would not have been as marked had we recruited all participants through a single route. Lastly, all information provided by spouses was subjective in nature and could have been biased or over-/underestimated depending on how spouses felt at the time of the assessments. Applying a longitudinal design could potentially extend our knowledge regarding spousal characteristics.

## **CONCLUSION**

This is the first and largest study to date describing and comparing the characteristics of spouses of people with PD-MCI, PDD or DLB. Importantly, our study highlighted that spouses of people with PDD and DLB have high rates of burden, stress, relationship dissatisfaction and resentment as well as poor levels of mental health. A diagnosis of PDD and DLB should alert the clinician to the risk of carer burden, strain and stress and clinical symptoms, such as depression and anxiety, which will have implications for patient outcomes.

## **Authors' notes**

I.L. conceived the INVEST study and received ethical approval. S.V. was responsible for data collection, statistical analyses and writing up the study. All authors critically revised drafts of the paper and approved the final version of the manuscript.

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## **Conflict of interest**

None declared.

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### **Ethical approval**

Ethical approval for this study was granted by Yorkshire & The Humber – Bradford Leeds Research Ethics Committee on 18/01/16, reference number 15/YH/0531.

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