

# A qualitative study of female caregiving spouses' experiences of intimate relationships as cognition declines in Parkinson's disease

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## Abstract

**Background:** the complex and progressive nature of Parkinson's disease (PD) and cognitive impairment may necessitate a care provider, a role which is frequently undertaken by a spouse. Providing and receiving care related to dementia impacts on a couple's partnership and may result in decreased intimacy and relationship satisfaction.

**Objective:** to explore the changes in long-term intimate relationships in Parkinson's-related dementia, as perceived by spouses providing care to their partners.

**Methods:** participants were identified using purposive sampling. Twelve female spouses whose partners had PD and mild cognitive impairment (PD-MCI), PD dementia (PDD) or dementia with Lewy bodies (DLB) completed semi-structured face-to-face interviews. Transcribed data were analysed using inductive thematic analysis. The consolidated criteria for reporting qualitative research (COREQ) were applied.

**Results:** couples' relationship satisfaction, intimacy and communication had already reduced in the mild cognitive impairment stage of PD, but the decline in these domains was markedly greater with the emergence of dementia. Increased spousal care responsibilities resulted in partners spending more time together, but feeling emotionally more distanced. Several participants' roles transitioned from spouse to caregiver and they reported feelings of frustration, resentment, anger, sadness and a worry for the future. Cognitive impairment was significantly harder to accept, manage and cope with than the motor symptoms of PD. Spouses acknowledged their marital commitments and exhibited acceptance, adjustment, resilience and various coping strategies.

**Conclusion:** this is the first study exploring relationship satisfaction in Parkinson's-related dementia and has provided valuable insight into the changing patterns of intimate relationships.

**Keywords:** *spouses, informal caregiving, Parkinson's disease dementia, Dementia with Lewy bodies, qualitative research, older people*

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## Introduction

Parkinson's disease (PD) is a complex neurodegenerative disorder characterised by multiple motor and non-motor features. Approximately, 20–50% of people develop mild cognitive impairment (PD-MCI) [1] and nearly 80% develop dementia (PDD) within first two decades of their PD diagnosis [2]. Dementia with Lewy Bodies (DLB) is considered to be the second most common type of dementia with a prevalence representing 10–20% of all dementia cases [3]. Evidence suggests that PD-MCI is a precursor to dementia [4–7] and occurrence and severity of cognitive, neuropsychiatric and physical symptoms intensifies with the emergence of dementia in PD [8], highlighting the needs of this population. Health and support care costs and frequency and length of hospital admissions increases in PDD and DLB [3, 9–11], compared to PD without cognitive impairment, but the costs are largely saved by the care provided by family members and spouses [12]. Thus, these care partnerships are vital to preserve to limit the increasing costs of health care.

The progressive nature of PD raises the need for care. In the majority of the cases, this role is fulfilled by a spouse or a life partner (subsequently referred to as a spouse); however, multiple studies have shown that this may have a profound negative impact on the spouse's quality of life [13, 14] and mental, emotional and physical well-being [15], and consequently increase burden and strain [16, 17]. In recent years, the literature has referred to caregiving spouses as 'hidden or invisible patients' [18]; their caregiving role and increased responsibilities may lead to neglect of their own health and care needs.

Long-term intimate partnerships have been a topic of interest in the neurodegenerative literature and findings suggest that emergence of the neurodegenerative condition is associated with significant changes in couples' intimate relationships [19–21]. Premorbid relationship quality can be predictive of future relationships for both the person with dementia and the partner [22]. In particular, poor quality of the prior relationship can lead to depression, lower quality of life, less satisfaction from caregiving and higher burden in the caregiving spouse [23, 24]. To our knowledge, transitions in intimate relationships in the context of one partner developing Parkinson's-related dementia have not yet been investigated qualitatively. The aim of this study was to explore the changes in long-term intimate relationships in PD-MCI, PDD and DLB through the perspective of spouses. The research question for this study was: How have intimate relationships change as a result of one partner developing PD-MCI, PDD or DLB?

## Method

This cross-sectional qualitative study is part of the 'Individualised cognitive Stimulation Therapy' project (INVEST), a pilot feasibility study of a novel psychosocial therapy for people with Parkinson's-related dementia and their study partners [25] for which ethical approval was granted (Yorkshire & The Humber—Bradford Leeds REC 15/YH/0531). Participants were recruited through memory or movement disorder clinics

in Greater Manchester and through UK-based charity websites (e.g. Parkinson's UK, Join Dementia Research). Purposive selection of participants, in particular criterion sampling, was used to ensure diversity of partners' diagnoses. The inclusion criteria for the participants were the following: currently providing care to a partner who has a diagnosis of PD-MCI, PDD or DLB (based on the standard clinical diagnostic criteria and verified by the referring clinician and on screening visit), being in a long-term relationship and living together with their spouse. Participants who did not meet the inclusion criteria were not invited to take part. All participants in the INVEST study had provided written informed consent agreeing to be approached for the interviews and participate in audio-recorded interviews; therefore, for the purposes of this study only verbal consent was sought from the participants. The majority of spouses and partners in the INVEST study were female participants; thus, all potential participants who were invited to participate in the current study were also women. It was estimated that 6–12 interviews were sufficient to reach saturation within the sample [26], therefore a maximum of 12 interviews was planned. Thirteen participants were contacted by telephone and the study was explained in detail by the first author. Twelve participants agreed to take part in the interviews, and one participant refused due to personal reasons.

All in-depth one-to-one interviews were conducted once by one white female PhD candidate (S.V.), who had three years of qualitative research experience. Eleven interviews took place in a participants' home and one in a café. Rapport between the interviewer and participants was easily formed as interviewees were known to the first author through their participation in the INVEST study. Acquaintance with participants was deemed beneficial as it allowed the establishment of a safe and supportive environment for the interview to take place. The researcher had experience working within neurodegenerative conditions and researching intimate relationships quantitatively. Participants were informed about the purpose of the interviews. A semi-structured topic guide, used in all interviews, was informed by the Personal Assessment of Intimacy in Relationships (PAIR) [27] scale and reviewed by the Patient and Public Involvement representatives of the INVEST study (Supplementary data, Appendix 1, available online in *Age and Ageing*). Following the first five interviews, a researcher (K.R.M.) suggested asking subsequent participants to rate their current and premorbid relationship satisfaction quantitatively as it appeared to be an important and clear indicator of change in the relationship satisfaction. Thus, at the start of the interview, seven participants were asked to rate their current and premorbid relationship satisfaction on a horizontal visual analogue scale [28] ranging from zero (very dissatisfied) to ten (very satisfied).

Interviews were audio-recorded and lasted between 35 and 97 min. During the interviews field-notes were made to record observations and reflections of the interviews. Verbatim transcripts were analysed by one researcher (S.V.) in MSOffice Word (Microsoft Corp.) using an inductive thematic analysis approach, whereby the codes and themes were identified from within the data [29]. The transcripts were read and re-read multiple times to facilitate familiarisation with the text, which

was followed by initial code-searching and analysis. After coding each transcript the codes were merged into one file and arranged into possible themes. To ascertain clarity and coherence, the emerging themes were discussed with two other researchers (K.R.M. and E.S.). Discussions continued until consensus was reached within all themes and sub-themes. As no new themes emerged after the tenth transcript analysis, it was deemed that the data saturation had been reached within the sample. To maximise the transparency of the methods and results sections, the consolidated criteria for reporting qualitative research (COREQ) were utilised [30].

## Results

### Participant characteristics

Twelve individual semi-structured interviews were carried out with spouses between November 2016 and March 2017 by the first author. All participants were white British females with an average age of 69.3 years (SD = 4.8). All but one interviewee were married and all couples lived together. Four of the participants' partners had PD-MCI, five had PDD and three had DLB. The mean scores of the visual analogue scale [28] for premorbid and current relationship satisfaction for spouses of people with PD-MCI were 8.8 (SD = 1.04) and 5.5 (SD = 3.28), respectively, and for spouses of people with PDD/DLB 8.8 (SD = 0.96) and 2.1 (SD = 1.65), respectively. A summary of participant characteristics is provided in Table 1.

### Key findings

Three themes and ten sub-themes were identified from the data analysis. The three key themes were the following: (i) altered relationship; (ii) care partner challenges; and (iii) acceptance and adjustment. The themes and sub-themes are described and presented in Tables 2 and 3 with illustrative data excerpts. Additionally, a table with frequency of quotes

is Supplementary data, Appendix 2, available in Age and Ageing online.

### Altered relationship

The sub-themes of 'Altered relationship' were emotional distance, role transition and communication. Ten participants reported that their satisfaction with the relationship had decreased compared with the early stage of their partner's illness but the decrease was larger in the dementia group, which was also supported by the mean scores of the visual analogue scale [28] between current and premorbid relationship satisfaction. Overall intimacy remained largely unchanged for couples in the mild cognitive impairment group but was either diminished or non-existent following the emergence of dementia. Multiple intimacies, including emotional, physical, sexual, recreational and intellectual, were significantly reduced in comparison to the premorbid stage. The presence of Parkinson's disease and cognitive impairment resulted in a practical need for couples to spend more time together to enable the spouses to support their husbands in managing activities of daily living and provide physical care but in contrast the spouses felt emotionally more distanced, disconnected and separated from their husbands and longed for closeness and mutual companionship. Eight spouses reported sleeping in separate bedrooms to their husband due to motor and non-motor symptoms of PD and noted that the level of physical closeness and intimacy with their partner, including hugs, holding hands, caresses, cuddles and sex, had decreased. Spouses were divided in their opinion as to how they viewed their current role: two participants felt that their role as a wife had not changed, six participants saw themselves as in both a marital and a caregiving role and remaining four felt they only had a caregiving role. Partners of husbands with mild cognitive impairment noted a somewhat decreased level of communication and fewer conversations. However, once dementia had developed, communication

Table 1. Characteristics of participants

Participant ID	Participant age (years)	Partner's diagnosis	Partner's MoCA score (at baseline)	Partner's age (years)	Disease duration (years)	H&Y stage	Type of relationship	Relationship duration (years)	Duration of care provision (years)	Weekly care provision (hours)	Premorbid relationship satisfaction (VAS)	Current relationship satisfaction (VAS)
P01	64	PDD	19	67	18	2.0	Marriage	44	8	72	NR	NR
P02	78	PDD	16	77	8	4.0	Marriage	56	7	168	NR	NR
P03	65	PDD	25	68	12	2.0	Marriage <sup>a</sup>	20	10	168	NR	NR
P04	69	PD-MCI	26	77	5	2.0	Marriage	50	3.5	49	NR	NR
P05	63	DLB	24	64	7	3.0	Marriage	37	6	84	NR	NR
P06	67	DLB	14	76	6	2.0	Marriage	46	5	140	8	2
P07	75	PDD	7	77	3	2.0	Marriage	58	2	168	10	0
P08	73	PD-MCI	19	78	3	1.5	Marriage	50	1	7	8	5
P09	72	PD-MCI	26	74	3	1.5	Marriage	50	4	168	10	9
P10	72	PDD	13	74	17	3.0	Co-habitation <sup>a</sup>	40	11	140	9	2.5
P11	64	PD-MCI	23	67	4	1.0	Marriage	45	4	168	8.5	2.5
P12	69	DLB	12	73	10	2.5	Marriage	43	2	168	8	4

Key: MoCA, Montreal Cognitive Assessment (Nasreddine *et al.* 2005); NR, not reported; VAS, visual analogue scale; PD-MCI, Parkinson's disease and mild cognitive impairment; PDD, Parkinson's disease dementia; DLB, Dementia with Lewy Bodies; H&Y, Hoehn & Yahr stage.

<sup>a</sup>Second long-term relationship indicated.

Table 2. 'Altered relationship' sub-themes and sample quotes

Sub-themes	Quotes
Emotional distance	<ul style="list-style-type: none"> <li>• He is sort of emotionless, you know, so where you could have a kiss and a cuddle he is not up for a kiss and a cuddle. [...] There is just no intimacy [in tears] and it's difficult. [P09, PD-MCI]</li> <li>• Um, I don't think we have a relationship. Um, we live together as man and wife, but there is no sexual, there hasn't been for... 13 years. [...] And there's no intimacy of any other sort. [...] Um, he, he doesn't even hold my hand, you know, if you're walking, or put his arm around, there is nothing... nothing at all. [P11, PD-MCI]</li> <li>• I wouldn't say [the relationship] was any the less strong. I suppose you could say he relies on me more strongly now than ever he has done but I haven't got him to rely on, you know. [P02, PDD]</li> <li>• There cannot be closeness when he doesn't know who you are. [P07, PDD]</li> </ul>
Role transition	<ul style="list-style-type: none"> <li>• I just see myself very much as on my own but within a relationship where I can't do much because I'm not on my own. [P06, DLB]</li> <li>• Somebody has got to take care of him, I'm his only carer really. [P01, PDD]</li> </ul>
Communication	<ul style="list-style-type: none"> <li>• I miss the conversations, the natters, the chatters, the just saying, 'Ooo did you enjoy that?' and talking about summat [something] you've watched, seen or done. [...] We'll talk, but it's not a conversation. It's sort of 'yes, no'. [P11, PD-MCI]</li> <li>• You can't have a proper conversation, you might be saying something to him and then he'll answer you with something that's nothing to do with what you are talking about. [P10, PDD]</li> <li>• My children have commented that he's very quiet, he is going quieter as time goes by. [P12, DLB]</li> </ul>

in couples was predominantly absent leading to feelings of loneliness in the spouses.

### Care partner challenges

This theme consisted of four sub-themes: responsibilities, negative feelings, motor and non-motor manifestations and worry for future. As a result of their husbands' neurodegenerative condition, wives felt a significant increase in their responsibilities. In addition to continuing their regular everyday tasks, spouses also had to take over husbands' previous obligations, such as managing the household, finances, transport and maintenance. In the mild cognitive impairment stage, husbands' independence and ability to do things was largely preserved, as they were able to drive, self-care, administer medication and deal with paperwork, but their spouses were beginning to check medication adherence and accuracy of completed paperwork. However, the husbands with dementia had become more co-dependent and less able to do things they were once capable of doing, meaning their partners had to take over most of the activities of daily living, such as driving, dressing, washing, cooking, managing household and finances and administering medication. Consequently, participants felt their time, freedom and ability to plan for the future had become more restricted as they had to spend a large proportion of their day providing care and surveillance, supporting with day-to-day tasks and maintaining security and safety for their partners. Thus, spouses spoke of increased negative feelings such as frustration, resentment, annoyance, anger, sadness, disappointment, irritation, guilt, distress, fear as well as worry about the future regarding what might happen to their husbands if they were unable to provide care. Seven participants whose husband had dementia noted their life had changed to the point where they feel they have lost their own life, freedom and independence as a result of providing continuous care for their loved one.

Furthermore, the analysis revealed that cognitive impairment and neuropsychiatric disturbances, regardless of disease

severity and duration were significantly more difficult to accept, manage and cope with than the motor symptoms of Parkinson's disease. Many spouses also feared the inevitable progression of dementia and recognised that their husbands have become more self-absorbed as a result of their disease. All participants commented that they were constantly involved with the management of their partners' motor and non-motor symptoms, but challenges in dealing with cognitive and neuropsychiatric symptoms were more pronounced in spouses whose husband had PDD and DLB.

### Acceptance and adjustment

The final emerging theme referred to spouses' acceptance of the current situation and adjustment to it. They acknowledged their inability to change the situation and recognised awareness, acceptance, coping and moving on as their strategies for continuation. Several spouses reported specific coping methods such as laughter, separating the illness from the person and applying learnt coping techniques to their lives, and most spouses displayed great resilience. Many couples received informal social support from their adult children, other family members and friends and many husbands attended local voluntary sector group either alone or with their partner which was supportive. Only a few participants ( $N = 4$ ) were receiving support from formal paid carers or respite care.

Caring for one's husband was perceived as a fundamental part of the marital contract and commitment, which wives embraced. Throughout the marriage, husbands had cared for their spouses and women felt they ought to return the favour. Despite the challenges of providing care, spouses continued to support their husbands and several participants exhibited feelings of love, commitment, empathy, sympathy and altruism. Finally, most participants believed accepting the situation and adjusting to each day was the only way forward and without it they would 'go down with it' and 'lose the battle'.

**Table 3.** Sub-themes and quotes for ‘Care partner challenges’ and ‘Acceptance and adjustment’ themes

Themes	Sub-themes	Quotes
Care partner challenges	Responsibilities	<ul style="list-style-type: none"> <li>• I’ve had to take on all the responsibility, money, power of attorney, I have to do the maintenance. [P01, PDD]</li> <li>• You will look around and whatever you see, I do. Everything. I move the furniture, I, I cook, I, everything. He can’t make a cup of tea, he can’t switch the television on, he can’t answer the phone, he can’t clean himself up when he goes to the toilet. I do everything. [P07, PDD]</li> </ul>
	Negative feelings	<ul style="list-style-type: none"> <li>• I... have these times where I get so frustrated with him, I just want to walk out and go, become somebody nobody knows, nobody, you know... [P11, PD-MCI]</li> <li>• I want to run away sometimes [cries]. Um... I cope better with it now, ‘cause I’m sort of getting a bit more used to it, but I feel sick [voice breaks with emotion], I feel resentment, I feel lost... It’s just everything. And [clears throat]... It’s like having a child, but, it’s a grown man and he’s my other half. He’s not a child, you know... Sometimes, in the morning I get in a panic ‘cause I think I can’t do this. [...] I have no, no life and I have no future, I can’t do anything. [P07, PDD]</li> <li>• I do feel resentful sometimes when I think he’s taking me for granted and I know I shouldn’t do but I do [...] because I know if it was me he wouldn’t feel like that [cries]. [P02, PDD]</li> <li>• I got to the point where I wasn’t sleeping, I wasn’t eating, I was crying, because I can’t go out and leave him. I’ve got no freedom. And the doctors put me on some tablets for stress and they are helping. But it affects your whole life, all my freedom has been taken away from me. [P12, DLB]</li> </ul>
	Motor & non-motor manifestations	<ul style="list-style-type: none"> <li>• Dementia is very much more worrying. I mean with Parkinson’s there’s always the possibility of drug therapy to make that symptom better but there’s nothing for dementia. [P01, PDD]</li> <li>• Once dementia’s there, you’re lost. If [my husband] was in a wheelchair I would cope admirably. If I had to bathe him, wash him, dress him whatever. Whatever physically I would cope. [...] I’m used to caring, you know, but not the dementia it’s, it’s evil. And there is no joy at all with dementia, there just isn’t. [P07, PDD]</li> <li>• I’ve coped with the Parkinson’s fine but it’s the dementia side of it which is the thing that gets me more than anything. [...] If it was just Parkinson’s we could carry on but the Lewy Body is the main hurdle for us. [P12, DLB]</li> </ul>
	Worry for future	<ul style="list-style-type: none"> <li>• I worry if he gets much worse I’ve got to look after him. I’m worried about that, I wouldn’t like that, you know. [P04, PD-MCI]</li> <li>• I do worry about the future, I do worry that what, what will become of us in the future because I can’t ever see us not being together but I worry what would happen if I went first. Who would look after him then? [P05, DLB]</li> </ul>
Acceptance & adjustment	Marital contract	<ul style="list-style-type: none"> <li>• He’d looked after me, so it’s my turn now, I have to be the one for him. [P11, PD-MCI]</li> <li>• When we got married you got married forever, you know. And that was it, for better, for worse and I always think you know, well you say in sickness and in health, well we’ve had the health bit and now we’re on the sickness bit you know. It’s just inevitable and you just have to accept it. [...] And I’ve got to look after him because it’s what I signed up to do all those years ago you know [laughs]. [P02, PDD]</li> </ul>
	Social support	<ul style="list-style-type: none"> <li>• I’ve not had a time where I’ve needed support [...] but if I did need help then I would go to our children and they would [help]. [P08, PD-MCI]</li> <li>• If I searched for the help I probably would get some and I could pay privately for somebody to come in. [P01, PDD]</li> <li>• I’ve got a lot of friends that will say ‘Oh you’ve only got to ask’ and they will come. [P06, DLB]</li> <li>• My children always say to me ‘There’s three of us looking after the dad, you are not on your own’, so I find that very re-assuring, they are very good. [P12, DLB]</li> </ul>
	Resilience & coping	<ul style="list-style-type: none"> <li>• One of the things that I was taught to do was to analyse myself every night, so I would say ‘What can I do about that?’ Can’t do anything about it, what’s the point worrying about it. Cast it aside. And I do that you see, I am in a different position perhaps to a lot of wives, who’ve got husbands with Parkinson’s because I have lots of methods of coping. [P09, PD-MCI]</li> <li>• Sometimes I do feel a bit hopeless but I tend to bounce back again... [I] might wallow in self-pity [laughs] for a couple of hours or so and then think oh well you know, I get on with it each day you know. [P02, PDD]</li> <li>• I am quite positive really with regards to the illness because to me you either fight it or you go down with it and both of us we’ll go down with it, so you’ve got no alternative but to fight it. And to look at things we can do, not things we can’t do, you can’t dwell on the past. [P12, DLB]</li> </ul>

## Discussion

To our knowledge, this is the first qualitative study investigating changes in long-term intimate relationships in Parkinson’s-related dementia from the perspective of caregiving wives. Analysis revealed three major themes illustrating changes in the marital relationship, challenges in providing care as well as accepting and adjusting to the situation. The findings indicated that satisfaction with the intimate relationship had decreased more at the advanced cognitive impairment stage in comparison to the early stages of cognitive decline in PD.

By the time dementia had emerged, the role of spouses had transitioned into that of caregiver accompanied by feelings of frustration, anger, sadness, resentment, worry for the future as well as loss of own freedom and independence. Despite the fact that cognitive impairment and neuropsychiatric symptoms were difficult to manage, spouses did not renounce their marital vows and exhibited acceptance and resilience towards the situation they were in.

The results are consistent with earlier studies with spouses of people with neurodegenerative conditions [19–21], highlighting

the losses of dyadic interaction, intimacy, relationship and loss of a partner, the challenges of providing care as well as acceptance, adaptation and coping by the spouses. However, qualitative studies with caregiving spouses of people with dementia and people with PD have not collectively explored the combination of motor, psychiatric and cognitive symptoms and compared different stages of the cognitive decline. Current work demonstrates the contrast between mild and advanced stages of cognitive impairment and illustrates that dementia has a stronger impact on spouses' lives and well-being. This goes hand in hand with the length of the disease as caregiving spouses of people with PDD and DLB have often provided care for longer than those providing care to partners with other types of dementia.

We acknowledge the limitations of the current study. Firstly, the interviews were undertaken solely with female caregiving spouses and did not include male spouses, which limits our understanding of the role that the gender may play in long-term intimate relationships. Secondly, the relatively low sample of each of the disease groups should not be disregarded as increasing the number of spouses of people with PD-MCI, PDD and DLB may grant a deeper understanding of the experiences of spouses. Thirdly, the cross-sectional nature of the study did not compare the current and premorbid relationship satisfaction nor observe relationships longitudinally. Finally, the chosen analysis was driven by the data and arranging data into themes but thematic analysis lacks the capacity to interpret data beyond the quotations and analyse nuances of language use which should be recognised. Notwithstanding the limitations, the current study has provided valuable insight into the changing patterns of long-term intimate relationships in Parkinson's-related dementia.

## Key points

- Relationship satisfaction, intimacy and communication decreased as a result of Parkinson's-related dementia.
- Providing and maintaining care for a loved one brought couples physically closer but emotionally further apart.
- Transitioning from spouse to care provider led to decreased own health, independence and freedom.
- Motor symptoms of Parkinson's disease were easier to handle and tolerate than cognitive impairment.
- The marital contract remained important, supporting feelings of acceptance, resilience and coping.

## Supplementary Data

Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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## Conflict of interest

None.

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## Ethical approval

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