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Long-Term Partnerships in Lewy Body Dementias

Sabina Vatter and Iracema Leroi

Abstract

Long-term partnerships are important as they can determine happiness, influence physical and mental health and lengthen one's lifespan. However, complex neurodegenerative conditions, such as Parkinson's disease dementia (PDD) and dementia with Lewy bodies (DLB), can disrupt long-term relationships and even lead to dissolution of the partnership. The majority of studies in this field have focused on exploring the effect of PDD and DLB on care partners' outcomes but the impact of these conditions on dyadic, long term relationships is less well understood. We conducted a series of studies with people with PDD or DLB and their caregiving life partners using quantitative and qualitative methods. We demonstrated that PDD and DLB has a tremendous impact on the caregiving life partners and reduces relationship satisfaction. We argue for more studies in this field and recommend that future research focuses on strengthening dyadic relationships, which can ultimately preserve relationships and delay institutionalisation of the person with PDD and DLB, which has cost saving implications.

Keywords: long-term relationships, Parkinson's disease dementia, dementia with Lewy bodies, spouse, carer, caregiver, stress-appraisal model

1. Introduction

The prevalence of neurodegenerative conditions, such as Parkinson's disease (PD), Alzheimer's disease (AD) and dementia with Lewy Bodies (DLB) is rapidly growing due to an ageing population. Of the people living with PD, the majority will develop cognitive impairment (PD-MCI) or dementia (PDD) within 20 years of their PD diagnosis. This has implications for the person with the condition, their care partner as well as the wider health and social care economy. Cognitive impairment and dementia are key factors contributing to increases in health care costs, admission to care homes and early mortality. Importantly, these costs can be significantly reduced by the care provided by an informal care partner, usually a family member or a spouse. Such informal care accounts for over £11.6 billion in the United Kingdom (UK) per year [1]. Care partners support the person with a neurodegenerative condition with managing their daily activities as well as their physical and neuropsychiatric symptoms; however, this can impact their mental, emotional, social, financial and physical health.

In this chapter we will examine the nature of the care relationship of long-term partners of people with PDD or DLB, including a theoretical basis for this relationship. We will also outline the impact of the care role with a focus on care burden, quality of life and relationship satisfaction. A deeper understanding of the complex

issues surrounding long term care relationships in neurodegenerative conditions such as PDD and DLB is essential in ensuring appropriate support can be put in place.

2. Lewy body dementias (LBD)

PD is a complex progressive neurodegenerative disorder characterised by multiple motor and non-motor symptoms. It affects about 10 million people worldwide and is the second most common neurodegenerative condition after AD [2]. A recent 'Global Burden of Disease Study' found that PD is one of the most rapidly growing neurological conditions for which the number of deaths, prevalent cases and disability-adjusted life years have doubled between 1990 and 2015 [3]. As a result, PD has now been termed 'The Parkinson Pandemic' [4].

While the primary clinical presentation of PD includes a number of motor symptoms including slowness of movement (i.e. bradykinesia), muscular rigidity, rest tremor, or postural instability, a variety of other 'non-motor' symptoms may also manifest. Predominant among these is cognitive impairment and other neuropsychiatric symptoms such as apathy and psychosis which can often be precursors to the onset of PDD [5].

In contrast to PDD, DLB initially presents with cognitive and behavioural symptoms and motor symptoms may not emerge until later in the course of the condition, or in some cases, not at all. PDD and DLB are jointly referred to as 'Lewy body spectrum disorders' [6, 7] or 'Lewy body dementia' (LBD), which is the term we use in this chapter.

2.1 Dementia in PD (PDD)

Dementia in PD (PDD) has become increasingly prevalent with nearly 80% of people with PD developing dementia within 20 years after receiving the diagnosis of PD [8]. PDD is characterised by deterioration in memory, attention, visuospatial functions, executive functions and occurrence of behavioural and psychiatric symptoms, such as apathy and hallucinations [9]. Low cognitive reserve, mild cognitive impairment at baseline, hallucinations and older age, and older age at onset, and the akinetic-rigid motor phenotype are among the main risk factors for developing PDD [9–11].

2.2 Dementia with Lewy bodies (DLB)

DLB is the second most common type of neurodegenerative dementia following AD with a prevalence of 5% of all dementia cases [12]. Pathologically, the distinctive feature of DLB is the appearance of the thread-like protein deposits containing pathologic alpha-synuclein (known as the Lewy bodies) which occur in the central, peripheral, and autonomic nervous system [13]. Symptoms of DLB include cognitive impairment (especially in visuospatial domains and executive function), fluctuating confusion, parkinsonism, visual hallucinations, sleep disturbances and apathy [14]. Recent evidence suggests that 'pure DLB' is less common than 'DLB with concurrent Alzheimer's pathology' due to the overlap of Lewy bodies and neurofibrillary tangles specific to AD [15]. However, cognitive decline is generally faster in DLB than in AD [16] supporting the notion that DLB is an independent disease entity. In 2017, the international clinical diagnostic criteria for DLB were updated and now include guidelines for differentiating between clinical features and diagnostic biomarkers [14].

2.3 Comparison of PDD and DLB

Although PDD and DLB are generally considered part of the same disease spectrum, the initial clinical presentation may differ, due to the timing of the onset of cognitive impairment. However, this view has been challenged [17] and some scholars have concluded that PDD and DLB do not differ with regards to cognitive and neuropsychiatric profile, sleep and autonomic dysfunction, PD type and severity, neuroleptic sensitivity, and responsivity to cholinesterase inhibitors [18–22]. Nonetheless, further studies have demonstrated that significant differences exist between PDD and DLB such as in age of onset (PDD < DLB) [23], levodopa responsiveness (DLB < PDD) [24], neuropsychological test performance (DLB < PDD) [25], and neuropsychiatric presentation [26]. This supports the notion that PDD and DLB are separate clinical conditions but share a common underlying pathology and a distinction should be made on diagnosis.

3. Wider impact of LBD

Both PD and LBD have a significant impact on the person with the condition, their life partner, and family, as well as on society, due to higher needs and dependency as a result of developing the illness. For the person with the condition, the progression of PD can worsen their health-related quality [27], particularly physical and social functioning, cognition, communication and emotional well-being [28]. The notion of adverse impact of PD on physical, social and role functioning is corroborated by a qualitative study which found that PD brings about many changes in emotions and feelings, including fears and uncertainty about the future but also highlights some benefits that PD may bring [29]. Despite the well-established association between subjective well-being and motor impairment, there is a growing literature suggesting that more emphasis should be paid to the positive aspects of well-being, specifically endorsing social support, socialising with other people with PD, engaging in physical activities and maintaining motor skills can contribute to life satisfaction, sense of accomplishment, autonomy and positive emotions in people with PD [27]. This suggests that future studies could focus on life satisfaction and psychological well-being, which could potentially diminish the negative impact of PD on the person.

In terms of the wider impact of PD on society, the disease places a major socioeconomic burden with an estimated annual cost of £2 billion in the UK [30]. A recent report on the impact of living with PD revealed that the total financial costs per household exceeded £16,000 per year due to increase in health and social care costs and reduction in income [31]. Many care partners of people with PD also had to give up employment to be able to provide care for their partner, which led to loss of income [32]. As the severity of PD increases, the costs also rise and can be up to six times higher at the advanced stage (i.e. H&Y stage 5) compared to the initial stage (H&Y stage 1) [33]. These costs likely increase with disease progression due to the complexity of concomitant symptoms of PD, the increasing need for a care partner, and increased rate of admission to residential care homes. However, some of the costs could be partially saved by the help, care and support that family care partners provide to people with PD and LBD. Prince and colleagues [1] estimated that care providers save about £11.6 billion in the UK each year, which is increasing faster than the corresponding increase in formal health and social care costs [1].

Cognitive impairment in PD significantly increases the frequency of institutionalisation [34, 35] and increases healthcare costs even more than PD without cognitive impairment [36, 37]. Furthermore, mortality, which is already increased among

people with PD compared to the rest of the population [38], increases with the emergence of dementia, which is one of the key predictors of PD-related mortality [36, 37]. The emergence of cognitive impairment can also significantly decrease quality of life of people with PD and increase emotional stress [39].

Similarly to PD and PDD, a diagnosis of DLB can also escalate healthcare costs [7], shorten time to death [7, 40, 41], and accelerate the rate of admission to residential care homes and hospitals [7, 42]. A DLB diagnosis can also lengthen hospital stay and increase hospitalisation costs [43, 44] compared to AD. Mueller et al. [43] explain that this is due to deteriorated physical health and increased neuropsychiatric symptoms in DLB and they conclude that overall people with DLB have a worse prognosis compared to people with AD [15]. Mueller and colleagues [43] estimate that approximately 80,000 people with DLB in the UK will incur over 27,000 hospital admissions, and spend over 300,000 days in hospital that will exceed £35 million in hospitalisation costs in just 1 year, which is higher compared to the equal number of people with AD.

4. Overview of care partners

Around the world, one person in ten is a care partner [45]. In the UK, there are currently 6.5 million people who provide care and each day 6000 people in addition take on the caring role [46]. Of all the care partners in Great Britain, approximately 11% provide care to someone with dementia in a home setting [47]. Financially, the contribution that care partners make exceeds £132 billion per annum, which surpasses the annual budget of the National Health Service (NHS) in England [48], showing that the help and support that care partners provide is invaluable and has cost saving implications for the health and social care system.

A care partner is an individual, usually a spouse or an adult child, who has taken on the responsibility to help, support and assist a family member who cannot take care of themselves, and to assure they are safe and well [49, 50]. Care provision helps the person with the condition to reach the highest possible functioning in their daily life [49]. Often, the care partner of a person with PD supports with personal, psychological and medical care, assisting with mental and physical exercising, maintaining good nutrition, arranging living conditions and helping with housework [32, 51]. Care partners also coordinate, plan and manage care and look for various interventions and treatments that could potentially alleviate the symptoms of the care recipients [49, 52]. Notably, in addition to providing care, a proportion of care partners may be in part-time or full-time employment [53], which raises complex issues around managing their work and care commitments and may diminish their time and energy to provide care. In addition, care partners may also be older adults themselves and have physical and mental health issues which may limit their capabilities to provide care [51]. As a consequence, care partners, particularly within dementia, may have increased negative feelings, depression, diminished well-being, and neglect their own health [54]. Thus, they become 'the invisible or hidden patients' [52].

Caring and caregiving are considered to be different. Namely, caring is the affective component of 'one's commitment to the welfare of another', whereas caregiving is 'the behavioural expression of this commitment' ([50], p. 583). Likewise, caring has been described as the interplay between emotion and action involving endearing feelings such as love as well as activities involving labour [55]. Caregiving, however, has even been named as the 'unexpected career' due to the sudden onset of this role [56].

The shift into taking on care responsibilities may either be gradual or sudden, although in the case of neurodegenerative conditions such as PDD and DLB, this transition usually occurs gradually. The presenting symptoms of PDD and DLB may be so subtle that care partners may not notice a visible change in their

responsibilities, even though they may have started to help and support the care recipients. Thus, in early stages of the disease, care partners may not identify themselves as carers and may even dislike being called a 'carer' [57–59]. Instead, many people prefer to be acknowledged as a 'spouse', 'partner' or 'support person' [58], highlighting the importance of endorsing the relationship between the person receiving care and the person providing it.

The involvement of a care partner in the care of their family member is advantageous because they have a unique perspective on the care recipient's condition and thus, can provide a more precise and detailed description of their symptoms [60]. However, the State of Caring 2018 survey in the UK [48] found that 72% of care partners experienced worsening of their mental health and 61% in their physical health due to their caring role. Furthermore, over half of care partners anticipated that both physical and mental health would continue to deteriorate over the coming years, and a third of participants predicted that a decline in their mental and physical health would prevent them from being able to provide care to the care recipients in the future [48]. Brodaty and Donkin [52] contended that including care partners is so imperative that without their help, the quality of life of people with neurodegenerative conditions would drop so much that it would increase admissions to institutional care. However, this comes at the cost of care partners' own quality of life [52] and raises an important question about how to maintain the well-being of both partners when facing a neurodegenerative condition.

5. Theoretical models of dyadic care relationships in PD

To understand the impact of PD factors on care partners and how they affect care partner well-being and the dyadic relationship, a theoretical framework is required. Such a framework also helps to understand the connections between the variables and to determine the direction of predictors. In the context of dementia, a number of multi-component models have been developed evaluating the factors contributing to caregiving-related stressors [61]. The most common care partner stress models in dementia [61] are:

1. the transactional model of stress and coping [62];
2. the two-dimensional model of psychosocial morbidity [63];
3. the stress process and coping model [64]; and
4. the stress process model [50].

These four preceding models take into account the characteristics of each member of the dyad as well as the care recipient's disease symptomatology and care partner's reactions and outcomes. In PD, the Stress Process Model [50] and the PD-specific Stress-Appraisal Model [65] are most applied by scholars. The Stress-Appraisal model [65] has been built on previous similar models [50, 66–69] and has since been developed further following a systematic review which evaluated burden, mental health and quality of life among care partners of people with PD [70]. The proposed adaptations by Greenwell and colleagues [70] are depicted in **Figure 1**.

The adapted PD-specific Stress-Appraisal model [70], which is derived from the Stress-Appraisal model by Goldsworthy and Knowles [65], captures care partners' experiences of care provision in PD (see **Figure 1**) and consists of four main domains [65, 70]:

1. *Stressors*: care partner well-being is affected by the person with PD factors (= primary stressors), such as neuropsychiatric and cognitive symptoms, their quality of life, their ability to perform activities of daily living and functional dependency (but not motor symptoms), which decreases physical health and increases depression in the care partner (= secondary stressors),
2. *Stress appraisals*: how care partners experience the disease can influence whether they make primary appraisals (i.e. seeing the disease as threatening and thus care partner becomes more involved in care provision by providing more hours of care) or ‘secondary appraisals’ (i.e. increase of burden and potentially developing coping strategies). Greenwell et al. [43] proposed that tertiary appraisals, which are affected by primary and secondary stressors, secondary appraisal and protective factors, also have a role in determining perceived burden and perceived uplifts by care partner, although burden was seen as a secondary appraisal in Goldsworthy and Knowles’ [53] model.
3. *Protective factors (or mediators)*: an important predictor of burden is perceived social support, which can promote well-being or protect from negative consequences of stress. In Goldsworthy and Knowles’ [53] model, quality of dyadic relationship, frequency of breaks, formal service hours as well as care partner self-esteem were important mediators in the process of care partner stress appraisal. Greenwell and colleagues [43] suggested that other predictors may include care partner personality traits, sense of coherence and self-efficacy, which require further investigation.
4. *Outcomes*: the impact of primary and secondary stressors; primary, secondary and tertiary appraisals, and protective factors have a direct or indirect impact on care partner outcomes, such as determining their quality of life and depression.

The Stress-Appraisal model is useful in understanding the experiences of care partners in the context of PD and can appropriately be applied to PDD and DLB as well.

Although the Stress-Appraisal model is comprehensive, it does not incorporate the dyadic relationship as an important factor in the context of caregiving relationship. Townsend and Franks [71] proposed the *Binding Ties Theory*, which was designed to

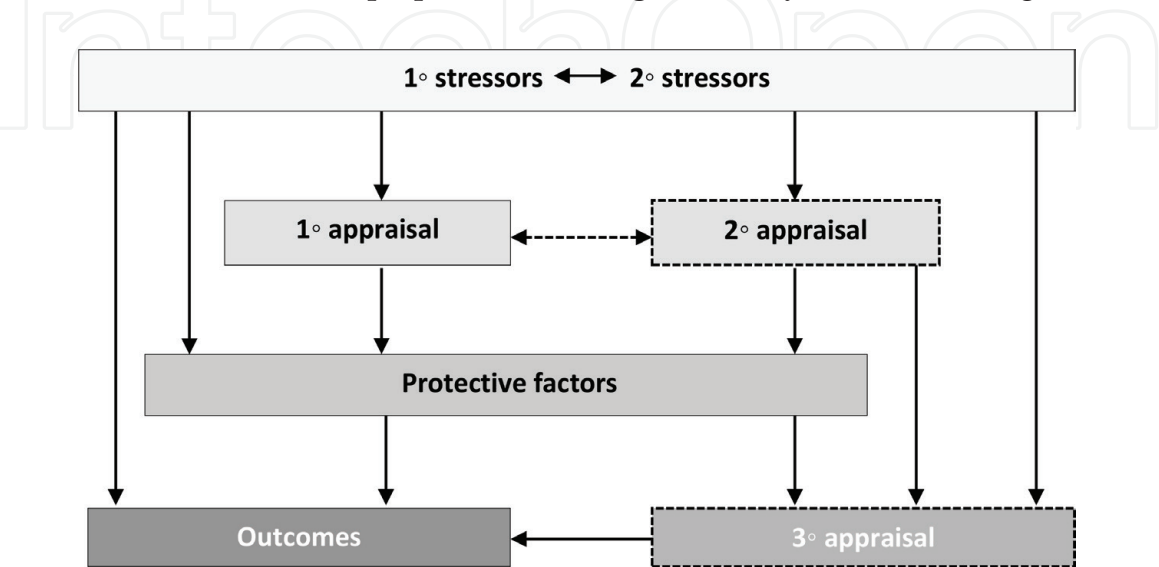


Figure 1. The stress-appraisal model adapted from Greenwell et al. [70]. The dash line needs further examination. The dash boxes depict alterations to Goldsworthy and Knowles [65] model by Greenwell et al. [70].

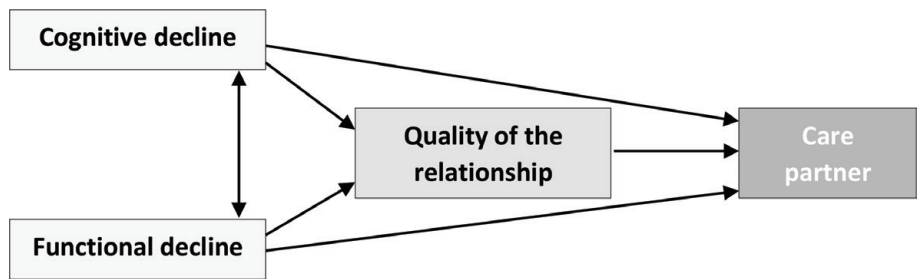


Figure 2.
The binding ties theory [71].

describe the quality of the relationship between adult children and their parents with cognitive impairment (see **Figure 2**). The authors considered the quality of the dyadic relationship to be crucial in care provision and an important determinant in the caregiving experience [71]. The model describes the associations between cognitive and functional impairment, closeness (positive), conflict (negative) and care partner well-being through measures of subjective caregiving stress, subjective caregiving effectiveness and depression. The findings suggest that negative ties were more predictive of care partner well-being than positive ties [71]. Furthermore, the pathway of ‘cognitive decline → relationship quality → care partner well-being’ was stronger than the ‘functional decline → relationship quality → care partner well-being’ pathway and advancing cognitive impairment led to less closeness and more conflict in the dyadic relationship [71]. This highlights that studies should evaluate both positive and negative interactions in the context of caregiving relationships.

With regards to the intimate dyadic relationship in PDD and DLB, the Townsend and Franks’ [71] model could be incorporated in the Stress-Appraisal model [65, 70] by considering ‘cognitive and functional decline’ as primary stressors, ‘quality of the relationship’ as a protective factor and ‘care partner well-being’ as an outcome.

6. Care provision in LBD

A growing body of research spanning several decades has drawn attention to the impact that LBD has on care partners [70, 72]. The progressive and complex nature of the motor, psychiatric and cognitive symptoms of LBD [73] can reduce one’s ability to carry out everyday activities and take care of oneself, thus increasing the need of a care partner. Care partners have a substantial role to play in the lives of people with PDD or DLB as they support and assist with activities of daily living, personal care, medication, feeding, housework, attending specialists’ appointments, maintenance of the person’s quality of life and independence, and being there as a partner and friend [51, 60, 74, 75]. Commonly, a care partner of a person with PD is a female spouse, aged around 70 years, living with her partner, having provided care for an average of 5 years and currently providing up to 16 hours of care per day [33, 76–79]. Although these descriptions are comparable to those providing care to someone with dementia, the care provision hours in dementia are notably lower than in PD (i.e. 6–9 hours per day) [52].

A recent qualitative meta-synthesis summarised the experiences of PD care partners into four interrelated themes describing (1) the need to carry on as usual, (2) the importance of support in facilitating coping, (3) the difficult balancing act between caregiving and caregiver needs, and (4) conflicts in seeking information and knowledge [80]. Thus, care provision within PD has been considered unique and complex in comparison to other neurodegenerative conditions but to date, little is known about the profile of care partners of people with PDD or DLB.

Studies have evaluated which aspects of PD (in the absence of cognitive impairment) have the highest impact on care partners. Findings suggest that both motor and non-motor symptoms of PD affect care partners' well-being, quality of life and burden but non-motor domains, particularly psychiatric manifestations such as apathy, psychosis, depression and cognitive impairment, tend to have a stronger effect [70, 72, 78, 81–85]. Similarly, the notion that caring for someone with mental illness is emotionally harder, more complex and taxing, as opposed to caring for someone with a physical illness, has been previously posited. This may be due to the changeable, unstable and erratic symptom presentation in mental health conditions, which disrupts 'the coherence of everyday life' ([86], p. 7). This is in line with literature on care partners of people with dementia [52, 87], PD [39, 70] and DLB [74], confirming the complexity of non-motor symptoms in PDD and DLB.

Providing care to a person with PD can be emotionally draining, physically challenging and mentally exhausting for care partners [75, 88]. The impact of PD on care partners is multifaceted, including social, financial, physical, emotional, mental and cognitive aspects. Socially, care partners of people with PD may not be able to go out as much as before, struggle to get away on holidays and have fewer social interactions with their friends, family and neighbours [74, 89–91]. In addition, due to care provision many care partners may be unable to do their usual daily tasks, activities and hobbies, and may receive insufficient social support from friends and family. Having hobbies, being socially active and receiving social support are important because they could protect against worsening of health and well-being [66, 70, 92]. Physically, care partners may experience deterioration in health [90], health-related quality of life [5, 93, 94] and greater fatigue [79].

In terms of mental–emotional aspects, care partners may encounter negative feelings, such as frustration, sadness, anger, resentment, guilt, worry [75, 95], and feel overwhelmed, stressed, strained and burdened [72, 74, 77, 78, 83, 84, 92, 96–98]. Care provision may significantly increase anxiety and depression [89, 93, 95] and lower care partners' mental health [93]. As a consequence, PD care partners' life satisfaction may reduce [95]. Furthermore, in non-PD care partners, the rates of mortality [98], cognitive impairment [99] and relationship dissatisfaction [100] may increase. All of these factors can be escalated with the progression of cognitive impairment in PD [101], which suggests that focusing on the care partners of people with LBD is crucial.

6.1 Physical and mental health

Several studies have found that care provision within PD can worsen mental health and result in distress in care partners [89, 93, 95] compared to the general population. Nearly 50% of care partners of people with PD may experience clinically significant anxiety and depression [72]. Among PD care partners, over a third experienced a deterioration of their health due to care provision [85]. Lack of sleep, fatigue, high blood pressure, muscle strain, headaches and gastrointestinal problems were also common in this group [77] and likely a direct result of providing care. Poor mental health in care partners is directly linked to duration of care provision in years and proportion of hours devoted to caring each day [79]. Moreover, lower levels of mental health are also predicted by care recipients' motor, psychiatric and cognitive symptoms, although drawing definite conclusions about what predicts mental health remains difficult due to the variability of the measures, inconsistent findings and lack of evidence [70]. Importantly, despite the care partners' own health needs, they felt they had to stay healthy as long as possible to be

able to care for and support the care recipients [75, 92]. This presents major physical, financial, emotional, mental and social challenges for care partners to continue in their role whilst taking care of themselves.

6.2 Quality of life

Providing care to a person with PD can have a direct effect on care partners' well-being and quality of life. In the literature, quality of life has been synonymously used with other terms such as health, health status, perceived health, functional status, and health-related quality of life although these terms are independent of one another [102]. The concepts of quality of life are wide incorporating economic, environmental, cultural, social, spiritual and personal aspects [103, 104], whereas health-related quality of life specifically focuses on individual's physical, mental and social aspects and the perceptions of their global health [103, 104]. Health-related quality of life has been found to be lower among care partners of people with PD compared to general population [92] and decreases with the emergence and development of cognitive impairment in PD [5, 105, 106].

Quality of life is associated with several factors. Lower quality of life in care partners was predicted by the care recipients' disease-related factors (i.e. motor, cognitive and neuropsychiatric symptom severity, poorer quality of life, higher need for care, greater dependency in activities of daily living), personal aspects (i.e. higher age, depression) and care-related variables (i.e. longer duration of care provision in years and hours per day) [51, 70, 105, 107]. Well-being of care partners is important because lower strain and 'caregiving load' reduces the risk of institutionalising persons with PD [108], which has long-term implications for the future.

6.3 Care burden

As PD progresses, the cognitive impairment advances leading to higher strain [83], burden [5, 76, 78, 106, 109] and stress [82] in care partners. The main contributors to care partner burden and stress in people with PDD were the person's neuropsychiatric symptoms (i.e. depression, psychotic symptoms) [78, 82] and cognitive decline [5, 76, 109, 110]. Apathy, a common and often under-recognised neuropsychiatric complication of PDD and DLB, is strongly associated with care burden [111], in part due to emotional blunting that is one of the dimensions of the apathy syndrome [112].

6.3.1 What exactly is 'care burden': a dimensional perspective

One of the most researched constructs in care partner research is 'caregiver burden' [49]. Several different definitions have been proposed but two interwoven descriptions from the 1980s are used concurrently to this day. George and Gwyther [113], p. 253, define burden as 'the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults'. The same year, Zarit et al. [87], p. 261, proposed a very similar explanation adding that burden is 'the extent to which caregivers perceive their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative'. Even though both explanations encompass the multifaceted impact on care partners, the definitions of burden are still diverse, incoherent and vague in many research studies making measuring 'burden' ambiguous [102, 114]. The authors recommend that burden should be defined clearly, researched using mixed methods (i.e. both quantitatively and qualitatively) and evaluated as specific dimensions of burden [102, 114].

In PD, several different terms exist to refer to burden, for instance *strain* [77, 96, 115, 116], *stress* [117] and *distress* [96, 118]. Despite the fact that these terms have been used instead of burden or in conjunction with burden [84], recent studies have determined that these constructs are independent from burden and are evaluated as separate constructs [72, 76, 84, 119].

One of the most frequently used validated measures of care partner burden is the ZBI [87] which considers 'burden' as a unitary concept. However, burden is highly complex and most likely comprises several dimensions, which have been explored in DLB [120] but not in PDD and DLB jointly. Thus, we undertook a study to explore the factor structure of the ZBI, specifically in life partners of people with PDD or DLB, and to examine the relationships among the emerging factors and the demographic and clinical features in this sample.

In this study [121], we undertook an exploratory factor analysis of the ZBI (principal axis factoring) with 127 life partners. This revealed five burden dimensions: social and psychological constraints, personal strain, interference with personal life, concerns about future, and guilt. These burden factors were associated with lower relationship satisfaction, mental health, and resilience, and higher stress, anxiety, depression, resentment, negative strain and people with PDD/DLB motor severity. In multiple linear regression analyses, where each factor score was the dependent variable, stress, negative strain and resentment emerged as significant predictors of specific burden dimensions. We concluded that burden in PDD and DLB, like in PD in general, is a complex and multidimensional construct and interventions supporting care partners should address specific types of burden to optimise outcomes such as quality of life.

6.3.2 What exactly is 'care burden: life partners' perspectives

To fully explore the meaning of 'care burden' experienced by life partners in the context of PDD and DLB, it is important to go beyond quantitative ratings of burden with typical rating scales such as the ZBI. To address this, we undertook a qualitative study of 12 female life partners of people with PDD and DLB to understand more fully how relationships change as cognition declines in PD [122].

In this study, we undertook semi-structured interviews using a face-to-face format and analysed the outputs using the thematic analysis approach. Our analysis revealed three important, and interlinked, themes: changes in the marital relationship, challenges in providing care, and acceptance and adjustment of the situation, which are discussed below. This study has provided key insights into the changes in long-term marital relationships as dementia progresses in Parkinson's disease.

The theme of 'altered relationship' revealed that the female life partners felt that their relationship satisfaction had decreased as a result of progression in their partners' condition. This was closely linked with partners' reduced ability to communicate and the transition in role for the life partners. Alongside reduced relationship satisfaction, global intimacy as well as emotional, social, recreational, intellectual, physical and sexual intimacies had altered and resulted in life partners feeling emotionally distanced from their partner despite spending more time together. The notion of being physically closer but feeling emotionally further away from their partner was recognised by most life partners in the interviews. This 'emotional disconnection' has been described in the field of dementia [123], as well as the term 'married widowhood' [124, 125]; however, the 'physical closeness' due to day-to-day management of the condition was a finding that emerged in this study, which illustrated the unique challenges that LBD poses in this population.

The second theme, 'care partner challenges' emerged from the complex nature of the motor and non-motor symptoms of LBD as care recipients had lost skills and

abilities to do things they were once capable of doing, which in turn increased life partners' responsibilities. Some life partners described they had a dual role in the marriage by being both the man and the woman in the relationship and managing the household, finances, maintenance, car which used to be their spouses' duty. These findings are consistent with previous studies with life partners of people with dementia where life partners took on additional responsibilities while providing care to their partners [123, 126–128]. The increase of care-related responsibilities due to the care recipients' condition was accompanied with an increase in negative feelings and took its toll on life partners. In particular, the time, freedom and independence of wives had reduced to the point of 'losing own life' and becoming mentally and physically weary. As a result of regular care provision, support and surveillance to their partners, wives felt a myriad of feelings such as resentment, frustration, annoyance, sadness, grief, despair, disappointment, guilt, distress and worry.

Finally, the third theme to emerge, 'acceptance and adjustment', captured life partners' acceptance of care provision as part of their marital contract and saw it inseparable from their commitments to the relationship with their partner. In spite of the challenges, difficulties and negative feelings that wives experienced and confronted with due to providing care, they revealed feelings of love, compassion, empathy and sympathy towards their partner. People with DLB had cared for their wives throughout their married life when they needed help due to health ailments and this reciprocity was acknowledged by life partners who felt they had to reciprocate the care for as long as they could. Life partners in this study and in other qualitative studies were committed to their marital vows and held onto the 'in sickness and in health, till death do us apart' but there was also some confusion whether the marriage still existed as dementia progressed [129–132]. Notwithstanding the conflict between existence and loss of relationship, life partners felt committed to their partners and were willing to continue providing care to their spouse in the future.

6.4 The influence of LBD on care partner outcomes

Comparative studies between care partners of people with different neurodegenerative conditions have shown important distinctions. In one study, burden in care partners was higher in PDD compared to AD, with neuropsychiatric disturbances fundamentally contributing to burden in care partners of people with PDD [133]. Another study supported these findings and added that care partners of people with PDD experienced more depression, lower satisfaction with life and needed more help and assistance compared to care partners of people with PD and AD [101]. Similarly, care partners of people with DLB had higher burden [134] and distress [135, 136] compared to care partners of people with AD and frontotemporal lobar degeneration [137] due to more prominent neuropsychiatric symptoms in DLB. Care partners of both people with PDD and DLB also experienced higher levels of stress compared to AD and vascular dementia [138]. To examine this issue further, we undertook a study comparing the characteristics of care partners in three groups of people with different clinical profiles of Parkinson's-related cognitive impairment: PD-MCI, PDD and DLB.

6.4.1 Study of care partner characteristics in LBD

In our study [139] we aimed to describe the sociodemographic and clinical profile of life partners of people with different cognitive syndromes in LBD, including physical and mental health, burden, stress, quality of life and feelings related to care provision, and compare life partners' outcomes according to the clinical syndrome (PD-MCI, PDD or DLB). The study involved a cross-sectional assessment battery

undertaken by 136 co-resident life partners who completed ratings of overall mental well-being, anxiety, depression, burden, stress and aspects of the relationship such as satisfaction. We found that the majority of participants were women (85%), with a mean age of 69 years (SD = 7.62; range 48–85 years) who had been in an intimate relationship for a median of 45 years. Life partners had provided care for between 0 and 20 years (median = 4; IQR = 2–7) and at the time of the study, were currently providing care between 0 and 168 hours per week (median = 84; IQR = 38.5–168). Nearly half of the participants (46.0%) provided over 100 hours of care per week.

Our assessments revealed that over 25% of the life partners were experiencing clinically significant anxiety and over 10% were experiencing significant depression, as per cut-off scores on the Hospital Anxiety and Depression Scale [140]. Findings on the Relatives' Stress scale [141] and the Zarit Burden Interview (ZBI) [87] revealed that nearly 60% of participants were experiencing significant stress and over 30% were experiencing significant burden. About 60% of life partners reported dissatisfaction with the relationship, as determined by the Relationship Satisfaction Scale [142] and slightly fewer than half reported quality of life that was lower than 'good', as per the EQ-5D index scores and visual analogue scale [143]. Overall, the majority of caregiving life partners reported satisfaction with their caring role; however, over 60% of life partners displayed resentment (63%) and over 30% anger in relation to this role (measured with the Family Caregiving Role Scale, [144]).

These findings of high levels of burden, stress and feelings of resentment and anger among life partners resonated with earlier findings of high levels of stress, burden and quality of life among care partners of people with PD, PDD, and DLB [5, 39, 72, 78, 145]. However, relationship dissatisfaction, perceived negative feelings, such as resentment, and resilience are new findings emerging from this study and appear to be under-researched in the field of LBD, despite numerous studies evaluating these constructs in other types of dementia [129, 146, 147]. This is important as it could be hypothesised that care partner outcomes could be similar in LBD and other types of dementia, but evidence suggests that rates of burden, stress, depression, as well as physical health outcomes are worse in partners of people with PDD and DLB compared to other forms of dementia [101, 133, 134, 136, 138]. Furthermore, tensions and arguments in the dyadic relationship [126] and lower abilities to live well [148] appear in PDD and DLB care partners, compared to care partners of people with AD and/or vascular dementia. This suggests that care partners of people with PDD or DLB may require more support. Importantly, our finding that care provision by over half of life partners exceeded 14 hours each day and over 100 hours each week, which is significantly higher compared to the rest of care partners in the UK [149], emphasised the complexity of providing care for a person with PDD or DLB as well as the immense commitment by life partners in providing the care.

Furthermore, we found that characteristics of life partners differed according to the clinical profile of the care recipient [139]. As expected, life partners of people with PDD had provided care for more years than life partners of people with PD-MCI, and life partners of people with PDD and DLB were providing more hours of care each week than life partners of people with PD-MCI. A linear relationship was found between several variables and progression of cognitive impairment in PD. Once dementia in PD had emerged, life partners were more burdened, stressed, depressed, resentful, dissatisfied with the relationship and experienced fewer positive interactions with their partner compared to those whose partner had PD-MCI. Similarly to PDD, life partners of people with DLB had higher rates of depression, burden and feelings of resentment in comparison to life partners of people with PD-MCI. Importantly, life partners of people with DLB had higher

anxiety levels and reported lower levels of mental health compared to life partners of people with PD-MCI, whereas these outcomes did not differ between PD-MCI and PDD groups, suggesting that specific clinical syndrome plays an important role in determining life partner outcomes.

7. Overview of dyadic relationships

Relationship quality is a multifactorial construct and can be broken down into overall satisfaction, commitment, closeness or intimacy, passion, trust and love [150]. Spanier [151], p. 290, defined relationship quality as ‘a subjective evaluation of a married couple’s relationship with the range of evaluations constituting a continuum reflecting numerous characteristics of marital interaction and marital functioning’. In the context of marriage, relationship quality encompasses adjustment, satisfaction, integration and happiness and can be seen in terms of its functionality and how the partners are affected by its functioning [151].

Relationship satisfaction is one of the key components of relationship quality. It has been defined in the context of interdependence theory [152, 153], which sees the interaction between partners, dependence and satisfaction as the core elements in close intimate relationships [154]. The dyadic *interaction* consists of rewards (i.e. pleasure, enjoyment, fulfilment) as well as costs (i.e. stress, pain, shame) that each partner may receive in the relationship. The goal is to minimise costs and maximise rewards [154]. Relationship satisfaction is affected by the level of one partner fulfilling the most significant needs of the other partner [155]. Each individual assesses the gains and benefits in their relationship as well as outputs they give to their partner. Relationship satisfaction is higher when the input-outcome ratio equates with that of the partner, whereas an imbalance in the ratio leads to dissatisfaction with the relationship [154].

8. Dyadic relationships in LBD

Both dementia and PD have a profound effect on the person, the care partner and their relationship [156]. People with PD have reported significant reduction in sexual functions, although the non-sexual relationship aspects, for example talking about one’s feelings or tenderness, increased with the duration of the disease [157]. Men with PD tend to withdraw from the relationship, may have had increased thoughts of divorce and may have reported dissatisfaction with the relationship and sexuality since the onset of PD, more so than women with PD [157]. Mutuality, defined as the positive quality of a partnership consisting of love and affection, reciprocity, shared values and shared pleasurable activities [158], remains relatively high at mild to moderate stages of PD but can be significantly lower at an advanced stage of PD [83, 159]. Likewise, in another study, both partners’ mutuality levels were similar but people with PD reported higher reciprocity than their partners [159]. Mutuality, alongside with non-motor symptoms, was also found to be a predictor of health-related quality of life for people with PD, whereas mutuality and cognition were the main predictors of burden in life partners [159]. These studies highlight that the impact of PD on the couple is substantial.

The advancing nature of dementia increases the person’s memory loss, confusion, agitation and inability to communicate, which may lead them to not recognising one’s partner and forgetting that they are married [129]. As a consequence, the life partner might start to doubt whether the marriage still exists [129]. Thus, the central theme describing relationships within dementia is often ‘loss’—loss of a

person, relationship, mutual companionship and connectedness [123, 129]. This theme also applies in PD as life partners of people with PD experienced feelings of loss and helplessness and felt overwhelmed and unable to cope with the cognitive impairment of the care recipient [39], highlighting that once cognition has started to decline, the impact is more profound compared to intact PD.

Neurodegenerative conditions, such as PDD and DLB, can challenge a couple and impact negatively on relationship quality and lead to dissatisfaction even more than other diseases due to its incurable and progressive nature. Evidence outside of PD has revealed that one partners' depression can contribute to relationship dissatisfaction, lower levels of communication and problem-solving abilities as well as difficulties maintaining intimacy [160]. In turn, higher loss of intimacy can lead to higher levels of depression [161]. Similarly, lower marital quality in people with PD can contribute to higher anxiety in life partners [162]. In cognitively intact people with PD, the motor symptoms had a significant impact on the relationship [163] but when cognitive decline had emerged, non-motor symptoms were the most prominent stressors on couples' relationships [159]. In order to overcome the challenges and sustain relationships, efficient and effective coping strategies are required. Lack of these strategies can lead to increased burden and health issues in the care partner, institutionalisation of the person with LBD and eventually relationship breakdown [164].

Importantly, having a close relationship with one's partner can be protective. More satisfaction with intimacy was associated with less stress and fewer depressive symptoms, particularly in female care partners [165]. In PD, higher mutuality was related to better mental health outcomes for partners, lower PD severity as well as lower burden and higher quality of life in the care partner [163]. The ability to remain positive when having PD or living with a care recipient who has PD has been found to contribute to higher marital quality for the couple [162]. These findings resonate with Habermann's [166] study who stated that PD affected couples' closeness and communication positively. Despite these encouraging findings, PD has been found to have a detrimental effect on the relationship and lead to poor marital adjustment [167]. Thus, further research is required to explore the consequences of PD and LBD on the person, life partner and their relationship.

9. Conclusion

This chapter has highlighted the profound impact of LBD on life partners, in particular due to psychiatric and cognitive symptoms of people with PDD and DLB which intensify with the progression of cognitive impairment in PD. As a result of providing care to people with LBD, life partners experience burden, stress, poor mental health, negative feelings and relationship dissatisfaction, and for many life partners their life had changed as a result of becoming a care partner. There is currently minimal targeted support available to couples within LBD but in light of the protective nature of good relationships, future studies should focus on supporting intimate relationships resulting in more positive outcomes for both partners.

Conflict of interest

The authors have no financial conflicts.

This chapter is based on a doctoral thesis [168].

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