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Exploring Caregiver Burden in Parkinson's Disease: A Qualitative Investigation of the Differing Experiences of Parkinson's Carers Who Experience Lower and Higher Burden

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ABSTRACT

Objectives: This study aimed to explore levels of caregiver burden in unpaid carers of people with Parkinson's disease and explore the factors which contribute to and ease burden, with a focus on the differences of experience between higher- and lower-burdened carers.

Methods: Opportunity sampling was used to recruit six participants, who were organised into lower and higher burden groups (three lower burden and three higher burden). Individual semistructured interviews with carers focused on caregiving experiences. Interviews were analysed using reflexive thematic analysis, paying particular attention to the groups of 'lower' or 'higher' burden, to determine whether or not themes were consistent within and across groups.

Results: Participants had a mean score of mild–moderate burden. From the interviews, three themes were identified: 'Everything's a fight or feeling supported', 'Everything you don't know' and 'Everything for the family'.

Conclusion: The study supported previous research in establishing some of the key themes associated with caregiver burden, and how these present differently across differing levels of that burden. The findings of this, and similar research, should now be used to tailor support to caregivers, ensuring help is provided where it is most needed, to limit the risk of caregiver burden and associated health complications.

1 | Introduction

As the life expectancy of the population of the United Kingdom (UK) increases, so too does the number of people living with, and requiring care for, a neurodegenerative disease [1]. With the continued strain on the U.K.'s health services, the shift from professional to familial care has become more apparent, with an estimated 10.6 million 'unpaid' carers (UCs) now in the UK alone [2]. This is often a family member who does not receive financial aid or training for the care they provide. As such, UCs are often ill-equipped to cope with the strain the responsibility can induce [3]. UCs contribute approximately £162 billion per year to the U.K. economy, a figure comparable to the £164 billion per year spent by the government to fund the NHS, and yet the well-being of UCs is often ignored [4, 5]. As a result, the term 'caregiver burden' (CB) has emerged [6].

CB describes the physical, emotional, social and financial stress that occurs when providing care for a patient with a chronic

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illness [7, 8]. The concept has been largely associated with an increased incidence of depression, potentially due to a lack of support and an inability to maintain adaptive coping mechanisms [9]. Worryingly, CB in UCs of those with neurodegenerative diseases has also been linked to a marked deterioration of their own cognitive ability [10]. Despite this it is often overlooked, particularly in carers of people with Parkinson's disease (PWP) despite research indicating that providing UC for PWP often causes great strain on many aspects of the carer's life [8, 11, 12].

Parkinson's disease (PD) is a progressive neurodegenerative disease affecting more than 8 million people worldwide, making it the second most prevalent neurodegenerative disease, behind Alzheimer's disease [12, 13]. PD is typically characterised by impaired motor functioning (bradykinesia, tremor and rigidity) and neuropsychiatric symptoms (anxiety, depression, insomnia and dementia) [14]. However, it is important to note that PD presents differently in every case, with patients also reporting pain, loss of senses, medication complications and constipation [15–17]. Due to the complexity of this disease, the vast majority of those living with PD will, at some point, require assistance in their daily lives, and this assistance often comes in the form of an UC [18, 19].

Much like CB for other chronic conditions, research suggests that the length of time served as a caregiver and the severity of PD is linked to higher burden [20–22]. This is likely due to its degenerative nature making it harder for the caregiver to manage as it progresses [23]. The advancement of PD can manifest as both increased physical and neuropsychiatric symptoms [24]. However there appears to be no clear consensus regarding what symptoms carers find hardest to manage. Some suggest hallucinations, confusion and falls are the most burdensome [25], while others argue that motor impairments cause the most strain due to the increased dependency they bring on the carer [19]. Anxiety, depression and impaired cognitive functioning have all also been shown to have significant correlations to increased CB [26]. The contradictions found in research highlighting the most burdensome symptoms of PD leave room for the assumption that factors outside of PD's symptomology contribute to the development of CB and the severity to which it is felt.

The extent to which one's family duties and social activities are impacted, combined with the amount of support they receive has also been shown to largely impact the severity of CB [26]. Caring for a PWP significantly alters the everyday life of the carer, with changes being seen in their daily routines and freedom to meet their own needs [12]. In some cases, this can lead to social isolation due to reduced ability to visit friends and family [27]. This is not only cause for concern for burden levels but also presents a risk factor for depression and all-cause mortality [28, 29]. Furthermore, the loss of social contact experienced by some removes a layer of social support that has often been shown as a protective factor in the occurrence of CB [30].

Notably, the experience of CB does not only have a detrimental effect on the caregiver, but it can also significantly impact the PWP. Research has shown that the PWP's ability to manage their illness and their quality of life is significantly associated with the levels of burden their caregiver feels [31]. UCs are imperative for allowing PWP to keep the independence and freedom they would lose were they to enter care homes and hospices [32].

It is also important to note that CB does not dissipate when the caregiving ends; the death of the person requiring care does not reverse the health deterioration of the caregiver, highlighting the long-term impact of CB [10]. It is therefore important to understand the differences in experience of those who express lower burden versus higher burden to determine what contributes to burden, and ultimately what support can be provided to manage or prevent it.

Factors affecting the development of CB have been explored quantitatively. However, few studies have utilised a qualitative design to develop a more complete understanding of the phenomenon. The use of the qualitative design, alongside the Caregiver Burden Scale [33] allows us to both quantify the burden levels felt by carers and understand why they are so, as told by the carers themselves [34]. Furthermore, conducting qualitative interviews with those experiencing lower versus higher burden may uncover the key differences that determine how burden is felt and how best to support those experiencing higher burden. It is hoped that findings will aid in the development of policies and interventions to reduce and prevent CB.

The aim of this study was therefore, to explore CB in UCs of PWP, with a focus on understanding what differentiates the experiences of carers who report lower versus higher burden.

2 | Method

2.1 | Ethics

The study received full ethical approval (ref:-PsyREC-RA-142-23/24).

2.2 | Theoretical Approach

In line with Braun and Clarke [35], data were analysed from a social constructionist epistemological position, to unearth the meaning behind the text via active involvement with the data. We followed a phenomenological ontology whereby contextual factors were also incorporated through participants narratives to give rise to meaning.

With respect to reflexive judgement, we adopted a relative stance whereby experiences are lensed through the values of the current sociopolitical landscape. Our position within the data was both subjective spectator (LEH; Health Psychology Postgraduate Student) who had experience of relatives with PD and those who care for them, and objective outsider (KA; Health Psychology Academic). Whilst direct experience of PD and people who care for PWP may have provided additional insight outside of that gleaned within interviews, the close supervision of the student collecting data and frequent scrutiny of the students reflective diary meant that these biases were frequently caught early and expelled from the analysis. However, thematic analysis practitioners value personal insight as a contributor to meaning making and therefore should not be problematised [36].

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2.3 | Design and Materials

A qualitative research design was utilised, using individual semistructured interviews. Interviews were conducted online (Microsoft Teams) or face to face between March–April 2024. The semistructured interviews asked open-ended questions regarding the type of support they received, the aspects of caring they found the most challenging and their experience as a caregiver (see supporting file 1).

Prior to taking part in the interviews, caregivers completed The Zarit Caregiver Burden Scale [33]. This scale determines overall burden scores for each participant, using 22-items, on which participants rated themselves on a 5-point Likert scale, with 0 being *never* and 4 being *nearly always*. The use of this scale allowed for a general understanding of burden levels in UCs of PWP and enabled the researchers to categorise participants into lower and higher burden groups for interview analysis with excellent internal reliability ($a = 0.93$) [37]. Overall burden ratings can include *little–none* (0–20), *mild–moderate* (21–40), *moderate–severe* (41–60), *severe* (> 61).

2.4 | Participants

UCs for PWP were invited to take part in the study, providing they were aged 18 and over, and provided UC to a person clinically diagnosed with PD. Six participants were recruited to take part in the study via an advert placed on social media. Participants completed the Caregiver Burden Scale and were grouped into lowest (CB score: 16–37, $n = 3$) and highest (CB score: 39–66, $n = 3$) burden. Participants thereafter completed an individual semistructured interview to explore CB further. All participants were over the age of 18. There was a range of 44–79 years ($M = 57.17$, $SD = 11.69$), most of participants were female ($n = 5$) and all participants were White. When split into their respective groups, there was an age range of 44–79 years ($M = 59.33$, SD = 17.90) for lower burden participants, with a gender split of two females and one male. For higher burden there was an age range of 52–57 years ($M = 55$, SD = 2.65) and all participants were female. Pseudonyms were provided to participants and to anyone whose name appeared in the interview transcripts. Lower burden participants were Andrew, Linda and Sarah and higher burden participants were Katherine, Ruth and Patricia. Between the six participants there were three PWP. Andrew, Linda and Sarah cared for the same PWP. Katherine and Ruth cared for the same PWP. Patricia cared for the remaining PWP.

2.5 | Procedure

Questionnaires were distributed online via QuestionPro. Participants were provided with the participant information sheet (PIS), and an online consent form. They were then asked to provide a unique ID to match questionnaire responses with interview data. Questionnaires were then presented to participants. Following this, participants took part in a 45–60-min interview.

Face-to-face interviews have been widely deemed the most beneficial to elicit rich data [38] as such five of the interviews were conducted this way. One interview was conducted via Microsoft Teams for convenience of the participant. Participants were provided with a second qualitative-specific PIS and a summary of the research prior to the interview, along with the chance to ask questions before providing written consent.

2.6 | Data Analysis

Total burden scores were calculated for all participants, along with descriptive information of the sample to identify trends in the data. Subsequently, interviews were transcribed verbatim and reflexive thematic analysis [39] was used to generate themes from the data. The data were analysed inductively, meaning themes were derived directly from the data with no preconceived opinions on the topic [40]. Semantic codes were used to gain a clear understanding of the carers views, while latent codes captured implied views.

Records of initial codes were kept along with detailed notes on their grouping into themes and potential subthemes. To ensure reliability and validity throughout, methods of data triangulation were utilised. The grouping of codes into themes and subthemes was discussed within the research team to avoid researcher bias, and a reflective diary was kept throughout. Results of the thematic analysis have been analysed and reported as one data set to first understand the shared experience, and to then uncover the differences between high and low burden carers. Comparisons of the lower versus higher burden experience have been clearly marked throughout.

Data saturation was deemed to be reached by the end of the analysis despite the small number of participants; however, this is not so uncommon given the specific nature of the research question and the interrelatedness of the participants [41]. However, increasingly proponents of thematic analysis have queried the relevance of the necessity of data saturation when deriving meaning from individuals' experiences [42].

3 | Results

3.1 | Descriptive Statistics

Participants experienced an average score within the range for mild–moderate burden (see Tables 1 and 2). Notably, the score range for this was 16–62, therefore there was a wide range of burden scores across the group.

3.2 | Qualitative Analysis

Thematic analysis generated three themes which are laid out below with corresponding subthemes (see Table 3; see Figure 1 for depiction of low vs. high experience).

3.3 | Theme 1: Everything's a Fight or Feeling Supported

Participants highlighted differences in care and support, and how these differences contributed to, or eased burden. The theme included three subthemes: 'getting a diagnosis', 'hospital care' and 'professional support'.

3.4 | Getting a Diagnosis

The process of getting a diagnosis came up frequently, interestingly those reporting lower burden experienced greater difficulty in getting a diagnosis than those reporting higher burden. Despite the PWP exhibiting clear signs of PD, and the

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TABLE 1 | Descriptive statistics for interview participant's caregiver burden scores.

Caregiver Burden Scale	Mean	Std. deviation	Minimum	Maximum
All participants	38.00	16.53	16.00	62.00
'Lower' burden	25.67	10.60	16.00	37.00
'Higher' burden	50.33	10.69	41.00	62.00

TABLE 2 | Descriptive statistics broken down for each participant.

	Age	Gender	Caregiver Burden Score	Time spent as caregiver (years)
Patricia	57	Female	62	10
Linda	44	Female	16	7
Sarah	55	Female	24	7
Ruth	52	Female	48	5
Andrew	79	Male	37	7
Katherine	56	Female	41	5

TABLE 3 | Depiction of themes and subthemes.

Themes	Subthemes
Everything's a fight or feeling supported	Getting a diagnosis. Hospital care. Professional support.
Everything you don't know	Managing Parkinson's disease. Managing life.
Everything for the family	Providing respite. Changing relationships. Time for reflection.

UCs concern that PD might be the cause, healthcare professionals remained adamant that other issues were at play, in one case resulting in the most advanced, undiagnosed, case of PD one Parkinson's nurse had ever encountered.

> "She said it's one of the latest diagnosis's she's seen, if that makes sense. She's not seen someone be that far advanced without being diagnosed". (Linda)

The delay of this diagnosis seemingly produced two responses, anger and relief. There was a sense of anger at how long it had taken to get a diagnosis, but also a relief that they now knew what it was, which eased the burden they were feeling at the time.

> "I think it was more of a relief because we knew what it was. We knew that she wasn't going mad, and I think she felt better because it was like, at least we know what it is now". (Sarah)

While the fight for a diagnosis appeared more prevalent in those experiencing lower burden, not all higher burden carers experienced a seamless diagnosis process. One higher burden carer also reported a lengthy diagnosis process with the symptoms of the PWP again being put down to alternative illnesses.

> "he was seen by a couple of doctors actually and they said, they thought it was a virus because it was his speech at first...then he finally got diagnosed with Parkinson's." (Patricia)

3.5 | Hospital Care

A clear distinction could be made between the hospital care received by the PWP cared for by lower burden carers compared to higher burden carers. When in hospital, all higher burden carers reported that the care the PWP received was inadequate, and in some cases bordered on medical negligence.

> "so he'd put his hand up and they'd just walk past him so he couldn't pick his own drink up to drink, he couldn't cut his food and feed himself. So, he was just left, and he was left in his own dirt" (Katherine)

This in turn, meant that when out of hospital, participants had to provide an even greater level of care due to the deterioration of the PWP when in hospital.

> "he didn't get basic care and because he was left there, his muscle wastage had gone. So it makes it harder again when he comes out" (Katherine)

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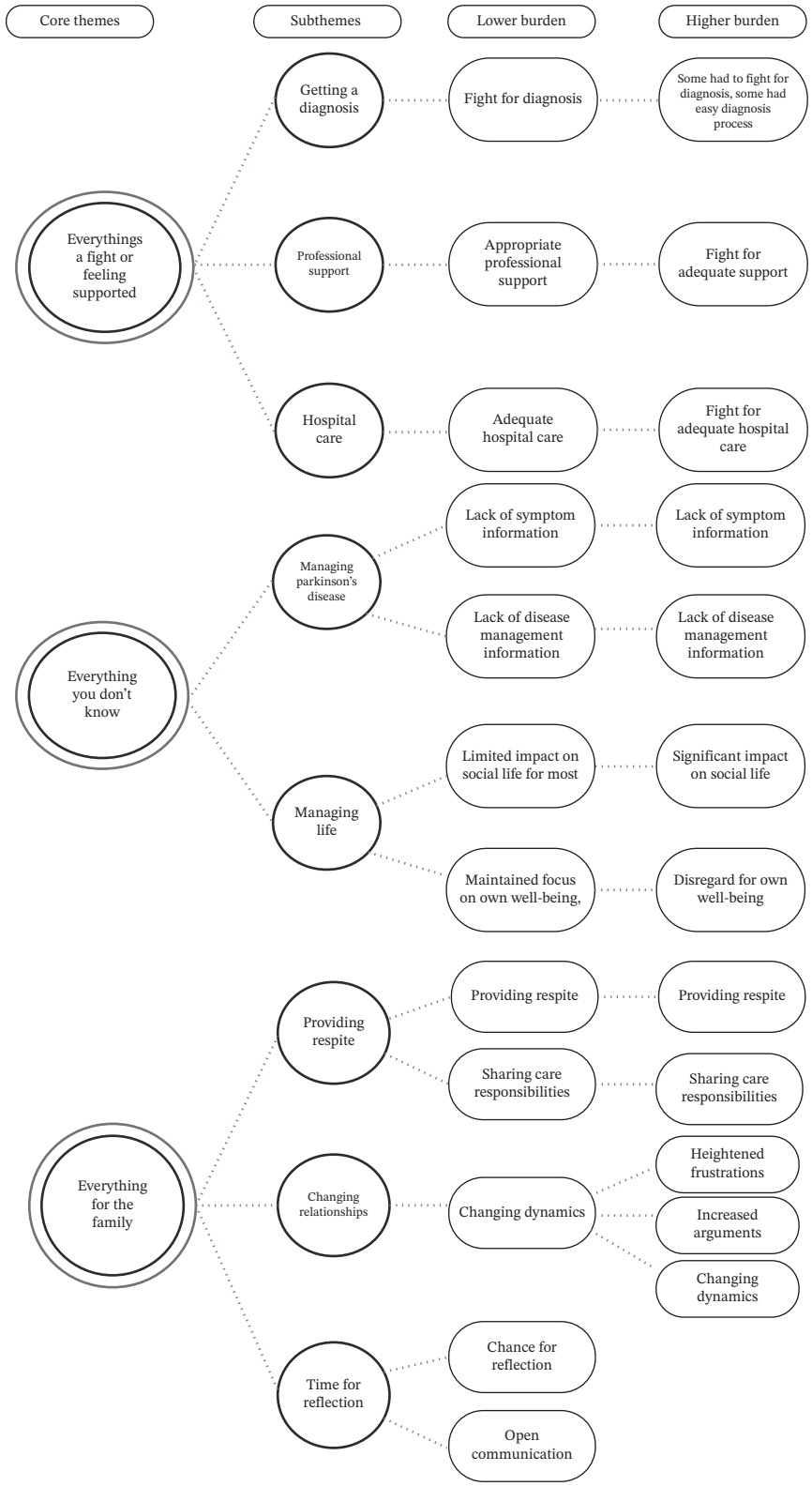


FIGURE 1 | Depiction of the similarities and differences in the lower/higher burden experience in relation to the three major themes and corresponding subthemes of the study.

Conversely, those reporting lower burden experienced fewer hospital visits with the PWP they were caring for. When they did, they mentioned that the PD was considered to ensure they maintained their current level of ability.

> "they were talking about the Parkinson's then because they said they needed to get an idea of where she was as to see what she might potentially get back to" (Linda)

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3.6 | Professional Support

The degree to which professional support was viewed favourably, and the ease of accessing that support, differed between groups. Those experiencing higher burden utilised professional support to a greater extent due to the severity of the symptoms the PWP was presenting. However, this did not always ease the burden they experienced due to the lengths they had to fight to receive adequate support.

> "we got the rehab team from [redacted] who got as far as the front door, seen me dad in the bed and said there's nothing we can do for him" (Ruth)

Not only did this add to the physical burden of being a carer, but it also impacted the carer mentally, leaving them with the realisation that this was a battle they would have to continue fighting. In cases where appropriate support was eventually provided, it often came too late.

> "once we have them in place, although it was too late it was a lot easier for us as a family" (Patricia)

In contrast, those experiencing lower burden had greater access to consistent, positive professional support in the form of a Parkinson's nurse. This allowed them to address concerns and have a point of contact should they have needed further support.

> "An the Parkinsons Nurse was outstanding, Elizabeth she were called she was, she was absolutely outstanding" (Andrew)

Lower burden participants also received more opportunities for carer support in the form of support groups. However, they were not always utilised due to the inability of the carer to leave the PWP unattended, highlighting the need for greater accessibility to carer support.

> "if somebody could have come to him because he didn't want to leave me mum for a bit of counselling or something like that" (Sarah).

3.7 | Theme 2: Everything You Don't Know

Split into two subthemes of 'managing Parkinsons Disease' and 'managing life' the theme 'everything you don't know' details the unexpected side of caring for a PWP.

3.8 | Managing PD

The greatest differences in management of PD were seen in the severity of the PD symptoms, with those experiencing higher burden taking on a more physical and constant carer role. However, both lower and higher burden carers expressed feeling ill-informed about the symptoms of PD and felt therefore, that they were unprepared to cope with the full extent of the illness.

> "I mean everybody knows what Parkinson's is. You've heard of it in some form haven't you but until know somebody who actually gets it, you don't actually know the full ins and outs of it". (Linda)

The idea that most people typically associate PD with a tremor was highlighted by many, however, a lack of awareness surrounding cognitive symptoms of PD was most prominently mentioned by higher burden carers. Symptoms such as paranoia, hallucinations and delirium were not initially explained as symptoms of PD and its medication leaving the carers unaware that this was a common development.

> "nobody explained any of that to me at all. Naively, I didn't link any of it to Parkinson's" (Patricia).

With regards to pharmacological treatment, those experiencing lower burden, overall received more information regarding medication and its side-effects, although, it is worth noting that more information did not necessarily ease the burden of managing the medication.

> "she were on about 10 pills at the end...so it were take one of them out, check that off, it were a nightmare to be honest with you" (Andrew)

3.9 | Managing Life

When thinking about the impact caring had on their lives, there was a relatively clear distinction between lower and higher burden carers. The majority of those experiencing lower burden reported very limited interference with their own social and work lives, and their ability to care for themselves. However, they noted that this is likely because they were not the primary carer of the PWP.

> "there was times where I had to take some time out for appointments and things from work... but it didn't really affect anything on my part" (Linda)

The only low burden carer who did provide primary care, reported a complete change to his social life, and daily routine due to the PWP increased dependence on him and notably, did report higher burden than other lower burden carers. Similarly, those experiencing higher burden, also reported a complete change to their daily lives; with significant disruptions to their social lives and an expectation to provide 24/7 care. Worryingly, all higher burden carers reported that their caring responsibilities also significantly impacted their sleep, with the change in the PWP waking hours impacting their ability to rest. This ultimately affected their ability to continue their caring responsibilities effectively the next day.

> "if you've had a good night sleep you can take on the world, when you are absolutely knackered and drained, everything's heightened" (Katherine)

Those experiencing higher burden appeared to neglect their own well-being, opting to focus their care on the PWP. Conversely, those experiencing lower burden made a point to prioritise their own well-being so that they could better look after the PWP.

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> "it no, its not, I wasn't interested in it" (Patricia)

> "I did...because I have to look after myself, look after the home and look after the garden for Jean." (Andrew)

3.10 | Theme 3: Everything for the Family

Many participants spoke of the role of other family members, highlighting the benefits of family support and the impact caring for a PWP had on the family as a whole. The theme encompassed three subthemes of 'providing respite', 'changing relationships' and 'time for reflection'.

3.11 | Providing Respite

The ability to share care responsibilities, and as such provide, or receive a break from caregiving was one benefit of family support that eased burden in both lower and higher burden participants. For higher burden carers, this respite typically came in the form of secondary UCs staying with the PWP for a few days. The primary carers typically noted that while this did give them a break, it did not ease the social isolation they felt as the build-up of exhaustion meant they preferred to use their breaks to be alone and relax.

> "but most of the time those breaks are just lounging on the couch and, like I do now actually, lounging on the couch and watching the telly." (Ruth)

For those experiencing lower burden, there was a greater emphasis on providing respite outside of the house particularly as the primary carer was reluctant to admit that they needed the help. As such family support during trips out, and holidays, gave the primary carer a break from completing care responsibilities alone without them having to ask for help.

> "it was hard to support me my dad because then he said he didn't need the help because he wanted to look after me mum" (Sarah)

3.12 | Changing Relationships

The subtheme changing relationships encompassed the frustrations and disagreements, but also the changes in role and communication, that occurred as a result of caring for a PWP. Such topics appear consistent among all carers. When taking on a role as intense as an UC, participants spoke of heightened frustrations and increased arguments. However, when considering the family approach to care seen within all participants, the impact arguments had on relationships seem negligible.

> "it was mainly conflict between me and me brother, but it was only, it was niggles, really, more than anything, you know, they thought one thing I thought another" (Ruth)

The loss of communication with the PWP due to the conditions impact on their speech, and watching the relationship between their parent's change, were highlighted as two of the hardest aspects of caring for a PWP, regardless of burden level.

> "it was hard seeing the dynamic change between them because like you said, they were husband and wife always, it was always them for like 50 years and then all of a sudden he's doing everything." (Linda)

3.13 | Time for Reflection

All participants expressed moments of great concern for the condition of their loved one. However, for lower burden participants, family support helped them reflect and plan the best course of action going forward. When addressing concerns they knew would not be well received by the PWP, the ability to discuss with their siblings eased burden as they could decide together how to approach the topic without responsibility being put on one carer.

> "being able to say things that you couldn't necessarily say to dad, we could, I could say to Sarah or to John. So in that support definitely helped" (Linda)

For others, the ability to access a voice of reason who could provide clarity over their concerns provided comfort and reassurance particularly when new symptoms emerged.

> "you just build everything up in your head...especially with me, Sarah's like me. Linda's, Linda's a lot calmer...Linda's dead calm like oh give over" (Andrew)

4 | Discussion

The current study aimed to explore CB in UCs of PWP, with a particular focus on the compared experience of lower versus higher burden carers. Three major themes were identified, 'Everything's a fight or feeling supported', 'Everything you don't know' and 'Everything for the family', each with corresponding subthemes. These three themes were present across both lower and higher burden participants, however the way in which they were felt differed, shedding light on the burden-inducing and burden-easing aspects of being an UC.

All carers disclosed feeling that they had to fight for support during their time as an UC. For low burden carers, this was a fight for diagnosis. Interestingly, all lower burden carers were providing care for a female relative, though it is important to note all lower burden carers cared for the same PWP and thus any apparent gender pattern must be interpreted with considerable caution. Despite women having a higher mortality rate, and faster progression of disease [43] it has been suggested that women are less likely to receive care from a Parkinson's specialist, and this may increase the time to diagnosis [44]. A delayed diagnosis may lead to a faster decline due to poor symptom management [45] and thus turn caregiving to a more burdensome responsibility for the carer, as appears to be reflected in the current study. The lower burden participants however, commented that once they received a diagnosis, they experienced exceptional professional support, and this support may have buffered the burdensome effects of a delayed diagnosis.

For higher burden carers, accessing this support was a challenge, with the poor care the PWP received in hospital or, in the care of

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a health professional being reported as increasing dependence on the carer when out of hospital. Amongst all high burden participants there seems a consistent issue among carers that within PD there is a lack of continued and co-ordinated care, the deterioration of the individual and an increased dependence on the carer [46]. The results of the current study, along with wider research [47] show that when PD is considered alongside pre-existing or additional illnesses patient outcomes improve and consequently so does CB.

The idea that so much of PD is unknown due to a lack of information ran continuously throughout the study. Both lower and higher burden participants expressed being unaware of the extent of the symptoms of PD. However, higher burden participants in particular felt uneducated in regard to its cognitive symptoms and this has been mirrored in wider research [48]. Furthermore, higher burden carers also stated a lack of information when thinking about medication complications and the progression of the disease. Importantly, previous research into CB in Alzheimer's disease has identified disease information as a protective factor for CB [49] highlighting the need for tailored information from professionals.

Family support eased burden allowing for respite and help with care for all participants and open communication regarding difficult conversations eased burden for lower burden participants. This support is crucial as previous research has shown that the amount of support received impacts the severity of the burden that is felt [26]. Family support eases burden by reducing the impact caregiving has on the ability of the carer to meet their own needs [12]. This is vital as research into caregiver well-being in dementia, has shown that the carers inability to prioritise their own health, particularly their own mental health, led to feelings of social isolation [50]. Social isolation has also been independently linked to an increased risk of cardiovascular disease and poor mental health [51]. However, the presence of family support mitigates this, providing the social contact necessary to avoid excess risk of mental ill-health [28]. For those without family support, disease specific carer support groups have proven valuable in easing the effects of solo caregiving [52].

A further interpretive consideration relates to the distinction between primary and secondary caregiver. Within the lower burden group, two participants identify as secondary carers, while one was the primary carer living with the PWP. Conversely, in the higher burden group, two participants identified as primary caregivers (one co-residing and one living separately), and the remaining participant identified as a secondary carer. This pattern may suggest that caregiving role influences perceived burden; a comparison of burden in primary versus secondary caregivers of the same person with dementia found that primary caregivers experienced significantly higher subjective burden [53]. However, both groups experienced clinically high levels of psychological distress with no statistically significant difference between primary and secondary caregivers suggesting caregiving role alone does not solely impact the effects of caregiving. This is mirrored in the current study in which role alone does not appear to fully account for the thematic differences observed; not all primary caregivers reported higher burden, and not all secondary caregivers reported lower burden, indicating that caregiving role and burden level do not map neatly onto one another. Given the small sample and the heterogeneity of carer role in both groups it is not possible to determine the independent contribution of caregiving role to burden in this study. Future research with larger samples may wish to examine how caregiving role interacts with burden level to clarify their respective explanatory value.

4.1 | Strengths, Limitations and Future Directions

Although a small sample of six carers connected to three PWP, this study shows novel insight into the enormity of the role a carer has for their family, themselves and for the PWP for whom they provide care; and the associated burden. Whilst this may mean that experiences overlap, research suggests that the way in which burden is felt can differ across different individuals caring for the same PWP [53]. It is important to acknowledge that UCs caring for the same person may, by virtue of the fact they are one of multiple carers, have a reduced burden simply due to the reduced number of hours they are providing care. However, providing care in a nonprofessional capacity is known to be burdensome irrespective of support and whilst three out of the six participants in this study cared for the same person, their burden should not be diminished due to their extended familial support. In future research, it may be beneficial to conduct family studies to explore the individual differences that caused such varying levels of burden among carers of the same PWP. Similarly, it is important to acknowledge the homogeneous sample with respect to gender and ethnicity, gender norms, ethnic-cultural caregiving expectations and access to formal services vary substantially and therefore the all-white, and predominately female nature of the sample may limit the transferability of findings to other cultures. It is worth noting the Zarit Burden Scale has established and validated cutoffs as follows, 0–20 (*little or no burden*) 21–40 (*mild–moderate*) 41–60 (*moderate to severe*) 61+ (*severe*). As such, we appreciate amongst our participants one scoring 24 and another scoring of 37 would be grouped in the same category and may appear to have vastly different levels of burden however, we have had to remain faithful to the original scale and therefore both of these UCs are correct in their same group placement. The use of Patient and Public Involvement and Engagement may serve to alter the study to better suit the needs of higher burden participants and therefore increase uptake [54]. The current findings highlighted some of the key factors that contribute to, or ease burden in UCs of PWP. Promisingly, some of the most burdensome aspects of caregiving such as the lack of information and inadequate professional care, are things that can be actively worked on to improve. Research has shown that due to the complexity of the disease, multidisciplinary care should be utilised in PD [47]. Not only would this benefit the PWP, but the improved care and team approach may ease the burden currently felt by carers who have only experienced inadequate care and received limited information. Importantly, the results of the current study support this, as those carers who experienced positive professional support exhibited lower signs of burden. When considering the differences in care experienced, future research may wish to explore the topic of regional differences in PD care and support.

5 | Conclusion

Overall, the current study has contributed to the existing literature by further establishing some of the key themes associated with CB in PD

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using a qualitative design. Interviews identified professional support and hospital care as factors influencing burden with appropriate support and hospital care easing burden, and poor support and hospital care contributing to burden. Concern for the future was also identified as a factor influencing burden and appeared evident in both lower and higher burden carers. By exploring burden in both lower and higher burden carers a better understanding into why burden is felt differently is gained. It is hoped that these findings will go on to inform changes in healthcare and interventions that will ultimately reduce the burden felt by these UC.

Author Contributions

Conceptualisation: Lauren E. Heywood and Kate Atherton. Methodology: Lauren E. Heywood and Kate Atherton. Software: Lauren E. Heywood. Validation: Lauren E. Heywood and Kate Atherton. Formal analysis: Lauren E. Heywood, Investigation: Lauren E. Heywood, Resources: Lauren E. Heywood. Data curation: Lauren E. Heywood. Visualization: Lauren E. Heywood, Supervision: Kate Atherton. Project administration: Lauren E. Heywood. Writing–original draft: Lauren E. Heywood. Writing–review and editing: Kate Atherton.

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Disclosure

All authors have read and approved the final manuscript. All authors agreed to be accountable for the content and conclusions of the article.

Ethics Statement

The study received full ethical approval from Liverpool John Moores University Psychology Research Ethics Committee: PsyREC-RA-142-23/24.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of the study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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