

Northumbria Research Link

Citation: Hand, Annette, Oates, Lloyd L., Gray, William K., Dismore, Lorelle L., Baker, Katherine, Naisby, Jenni and Walker, Richard W. (2021) Understanding Caregiver Strain in Parkinsonism—A Mixed Methods Approach. *Journal of Geriatric Psychiatry and Neurology*. 089198872199681. ISSN 0891-9887 (In Press)

Published by: SAGE

URL: <https://doi.org/10.1177/0891988721996819> <<https://doi.org/10.1177/0891988721996819>>

This version was downloaded from Northumbria Research Link:
<http://nrl.northumbria.ac.uk/id/eprint/45743/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)



UniversityLibrary



Northumbria
University
NEWCASTLE

Understanding Caregiver Strain in Parkinsonism – A Mixed Methods Approach

Annette Hand, DHealth^{1,2}, Lloyd L. Oates, MSc¹, William K. Gray, PhD¹, Lorelle L Dismore¹, Katherine Baker, PhD³, Jenni Naisby, PhD³, and Richard W. Walker, MD^{1,4}

1. Northumbria Healthcare NHS Foundation Trust, North Tyneside General Hospital, Rake Lane, North Shields, Tyne and Wear, UK
2. Northumbria University, Department of Nursing, Midwifery and Health, Newcastle-upon-Tyne, UK
3. Northumbria University, Department of Sport, Exercise and Rehabilitation, Newcastle-upon-Tyne, UK
4. Institute of Health and Society, Newcastle University, Newcastle-upon-Tyne, UK

Correspondence to: Annette Hand, Room H005, Coach Lane Campus (East), Northumbria University, Newcastle upon Tyne, NE7 7XA, United Kingdom

a.hand@northumbria.ac.uk

Word count: Main text words 5027, abstract words 228, references 63, tables 4, figures 2.

Running Title: Caregiver Strain in Parkinsonism

Key Words: Parkinson's disease, caregiver, caregiver strain,

Conflicts of interest statement: None declared.

Ethical Compliance Statement

Ethical approval for this study was granted by the Newcastle and North Tyneside 1 research ethics committee (ref: 14/NE/1093). National Health Service (NHS) Trust and Caldicott approval was also sought and granted for the project.

All participants gave written informed consent prior to study inclusion and all participants had the capacity to give informed consent.

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

Declaration of sources of funding: This study was part funded by a grant from Parkinson's UK (Ref: G-1310). Northumbria Healthcare NHS Foundation Trust acknowledges the support of the National Institute of Health Research Clinical Research Network (NIHR CRN).

Abstract

Background

Parkinsonism, including Parkinson's disease (PD) are progressive neurological conditions. As these condition progress, individuals will need more support with their care needs to maintain independent community-living. Care needs are mainly met by unpaid, informal caregivers, usually close family members or friends. Caregiver strain is thought to lead to the need for care home placement when the caregiver can no longer cope.

Objective

To understand predictors of caregiver strain and its influence on care home placement for people with moderate to advanced Parkinsonism.

Methods

This is a convergent mixed methods study. Quantitative data, following an adapted stress-appraisal model, were collected on caregiver profile, tasks performed and causes of caregiver strain. Semi-structured, in-depth interviews were conducted with caregivers of people with PD (PwP) who went into a care home during the study period, to develop a deeper understanding of the caregiver role and the factors influencing caregiver strain.

Results

Quantitative data were collected from 115 patient caregiver dyads. Interviews were conducted with 10 caregivers. A model to predict caregiver strain was developed and predictors of caregiver strain were identified, such as functional disability and poor caregiver sleep.

Conclusion

Our findings further demonstrate the complexity of carer strain. Particular dimensions are identified that need to be addressed within clinical practice to reduce carer strain and support people with Parkinsonism to remain within their own home for as long as possible.

Introduction

Parkinson's disease (PD) is the second most common neurodegenerative condition, currently affecting an estimated 145,519 people in the United Kingdom [1]. The prevalence of PD in the UK is expected to rise by 18% between 2018 and 2025 to over 168,000 [1]. PD is a complex condition that results in motor impairments (movement and mobility problems) and non-motor symptoms (sleep problems, cognitive impairment, depression and behavioural changes) [2].

As the condition progresses the person with PD (PwP) usually requires more support and informal caregivers can find themselves taking on increasing physical, economic and emotional support tasks, which can result in reduced quality of life (QoL) for the caregiver [3]. Previous studies have found that family members are the main providers of informal care [4, 5]. Previous work by our team revealed that for people in mid- to late-stage PD, 80.2% received informal care [6]. For these caregivers, the average age was 70.7 years old and 44.3% had at least one health condition which limited their caring role [6]. Caregivers save the healthcare system over £70 000 per person annually in health and social care costs [7]. Caregiver strain has been linked to PwP having increased hospital admissions and length of stay [8] and also to permanent care home placement [9, 10].

There have been two systematic reviews, one examining predictors of psychological impact of being a caregiver and the other examining the influence of demographic and clinical characteristics of PwP on caregiver strain [11, 12]. Interpreting the results of studies that employ a range of different clinical assessment scales and strain instruments makes it challenging to provide a valid summary of caregiver strain in PD [13].

There are multiple factors that may influence levels of caregiver strain, as a consequence this is a complex issue to examine. Caregiver strain stress models have been developed to gain a deeper understanding of the influences of intra-personal and inter-personal variables including stress moderators [14]. Goldsworthy

and Knowles [15] believed these theoretically based stress models did not take into account the unique factors related to caregivers of PwP. As a result Goldsworthy and Knowles [15] developed a model that acknowledged that individuals respond to disease differently and examined primary stressors (functional ability, cognition and behavioural problems of the person with PD), primary appraisal (assessment of the threat and seriousness of the stressor in relation to wellbeing), for example the task that the carer undertook (i.e. hours of care giving) and secondary appraisal (assessment of coping resources to manage the threat), in relation to strategies that carers used in response to stress (i.e. coping style) and protective factors (i.e. perceived social support, quality of relationship, frequency of breaks) to determine caregiver outcome (quality of life). Greenwell et al [11], as part of a systematic review, reviewed the Goldsworthy and Knowles [12] model, and identified important factors that were not taken into account so further adapted the model to include the quality of life for the PwP, caregivers physical health, personality and coping styles. This is the most contemporary model in this area, but required exploration in clinical research.

Previous studies have identified that factors influencing caregiver strain are related to caregiver and patient characteristics, including PD manifestations and consequences [11, 13], PwP alexithymia [16] and the vast array and complexity of motor and non-motor symptoms can have a profound effect on the informal caregiver [17, 18]. Reduced social activities, financial strain, perceived strain, emotional health and physical health associated with PD were related to reduced QoL in caregivers [19-21]. To benefit both patients and their informal caregivers pharmacological and nonpharmacological PD therapy is important to adequately treat motor and non-motor symptoms, in order to improve depressive symptoms of patients and promote patient independence in activities of daily living [22]. As well as interventions targeting perceived burden and family cohesion to improve mental health related QoL among family caregivers [23]. Psychological strain and depression among caregivers become more relevant in the late stages of idiopathic PD [24]. There is an unmet need in supporting geriatric patients suffering from advanced PD [25] and recognition is growing that a multidisciplinary team approach should address palliative care issues to optimise QoL for PwP and family caregivers [26].

Due to the complex nature of caregiver strain recommendations for future studies were: a) a better use of theoretical models in study design and data analysis and b) a better understanding of the areas that cause the greatest levels of caregiver strain [11, 27]. This mixed methods study aimed to explore the factors that cause the greatest levels of caregiver strain, for people caring for an individual with moderate to advanced PD and the influence of caregiver strain on the decision-making process of care home placement. This paper will focus on the factors causing the greatest level of caregiver strain.

Methods

Ethical approval for this study was granted by the Newcastle and North Tyneside 1 research ethics committee (ref: 14/NE/1093). National Health Service (NHS) Trust and Caldicott approval was also sought and granted for the project. All participants gave written informed consent prior to study inclusion and all participants had the capacity to give informed consent.

The Northumbria Healthcare NHS Foundation Trust PD service manages around 1400 people with PD and related conditions. All people known to the service, with a diagnosis of idiopathic PD (IPD) or PD dementia (PDD) at Hoehn and Yahr (HY) stage III-V, and those with Cortico-Basal Degeneration (CBD), Multiple System Atrophy (MSA) or Progressive Supranuclear Palsy (PSP) on 1st January 2015 were invited to participate in the study. People with a diagnosis of vascular Parkinsonism, drug induced Parkinsonism were excluded due to the differing aetiology and pattern of progression of these conditions.

Informal caregivers of all study participants (where available) were invited to participate. An informal caregiver was described as anyone, either family or friend, who supported the PwP with any activity including personal, emotional, financial or household tasks, as per the standard definition within the Informal Care in England Report [28]. By including all informal caregivers, rather than only the spouse, it was hoped to provide a greater understanding of the different informal caregivers involved, and their perspectives on the caregiver role.

Data collection ran from 1st October 2014 until 31st December 2015. Quantitative data including demographics for patients and caregivers were collected during a visit

to the PwP's home. Caregivers were asked how many years they had acted as a carer for the PwP, about any care tasks they undertook, the duration of these tasks, and current health problems they had which they felt negatively affected their ability to fulfil their caring role. To obtain data on factors related to caregiver strain, the stress-appraisal model by Greenwell, Gray [11] was further adapted and used (Figure 1).

To measure functional ability PwP were assessed using the Movement Disorder Society Modified Unified Parkinson's Disease Rating Scale (MDS UPDRS) [29], the Barthel Index (BI) [30], while non-motor aspects were assessed using the Montreal Cognitive Assessment (MoCA) [31], Hospital Anxiety and Depression Scale [32], Scale for Outcomes in Parkinson's Disease – Sleep (SCOPA-Sleep) [33], Non-motor Symptom Scale (NMS) [34] and Parkinson's Disease Questionnaire 39 – quality of life (PDQ-39) [35]. Following the adapted stress-appraisal model caregivers completed the Neuropsychiatric Inventory (NPI) [36], Revised Memory and Behaviour Problem Checklist (RMBPC) [37], to assess primary stressors, the PD Quality of Life – Carers PDQ – C [38] and SCOPA-sleep [39] for secondary stressors, Brief COPE [40] for secondary appraisal, Interpersonal Support Evaluation List (ISEL) [41], Relationship Assessment Scale (RAS) [42], Rosenberg Self-esteem scale [43], Life Orientation Test – Revised (LOT-R) [44] for protective factors and the Carer Burden Inventory (CBI) [45] and The Modified Caregiver Strain Index (MCSI) [46] for tertiary appraisal. The CBI was the primary outcome variable for the current study. The CBI is a 24-item multi-dimensional questionnaire measuring caregiver burden with five subscales, including, Time Dependency, Emotional Health, Development, Social Relationships and Physical Health. Scores for each item are rated on a five-point Likert scale ranging from 0 (never) to 4 (nearly always) with higher scores indicated higher caregiver burden. Caregivers also provided information on their role as an informal caregiver. While PwP data were collected by the nurse researcher (AH) or a trained research nurse, the caregiver complete the self-completion questionnaires. In-depth, semi-structured interviews were conducted by AH with caregivers of PwP admitted to long-term care home placement during the study period. Interviews were conducted using a semi-structured interview guide and were audio-recorded and transcribed verbatim. A guide was chosen to be flexible to allow new areas of interest to be explored whilst retaining focus on the aims and

themes related to carer strain. More detailed information about the caregiver role, tasks undertaken, symptom burden and consequences of caring was probed depending on the responses given. These quantitative data enabled us to investigate factors associated with the greatest levels of caregiver strain whilst the semi-structured interviews provided deeper understanding regarding the influence of these factors on caregiver strain.

Following a convergent mixed methods design [47] the qualitative and quantitative datasets were analysed separately and then merged to provide a comprehensive analysis. Quantitative data analysis was supported by the statistical software package IBM SPSS (version 21; IBM, Armonk, NY, USA). Parametric data were summarised in terms of mean and standard deviation and parametric tests applied (e.g., t-test). Some data collected on ordinal scales were normally distributed and so treated as parametric. Ordinal, non-parametric data were summarised in terms of median and inter-quartile range (IQR) and non-parametric tests applied (e.g., Mann-Whitney U test). All other data were summarised by frequency and tests appropriate to categorical data (e.g., Chi-square test) used to assess significance. These tests were applied during bivariate exploratory analysis as an initial examination of the data prior to model building.

CBI data met parametric assumptions and was used as the outcome variable with multivariable linear regression modelling used to identify variables independently associated with carer strain. Model building used stepwise methods and was based on the adapted theoretical framework of carer burden and carer quality of life, as originally proposed by Goldsworthy and Knowles [15] and further developed by Greenwell, Gray [11]. For each outcome, five separate models were developed for primary stressors, secondary stressors, primary appraisal variables, secondary appraisal variables and protective factors with a total of 110 variables examined. Backward and forward model building techniques were used during initial model building and the models refined manually by adding and removing variables which approached significance ($p < 0.1$). Models were compared using the Akaike Information Criterion (AIC). The final model was one where all variables were significant, and the AIC was minimised. Finally, all significant variables from the five models were combined into a single model using the stepwise methods described

above, until an overall model was created. Model fit, and robustness were assessed with reference to the distribution of residuals, eigenvalues and tolerance. Auto-correlation was assessed using the Durbin-Watson statistic and overall model fit using the adjusted R^2 statistic. Where care giving was split between two people, data from only the main care was included during model building. Two-tailed tests were used throughout and the threshold for statistical significance set at 5%.

For the qualitative data, a thematic coding approach was adopted and transcripts were analysed using thematic analysis, as described by Braun and Clarke [48]. Data analysis was conducted by two researchers, AH and an assistant psychologist (LO). The analysis began with each researcher familiarising themselves with the transcripts before coding the data separately. The researchers then met to discuss and compare the codes identified based on the emerging information. The researchers then refined the codes before grouping them into categories and determining the overarching themes. AH met with KB and JN for peer debriefing to discuss themes that had emerged. This ensured different perspectives throughout the analysis from nursing (AH), physiotherapy (KB and JN) and psychology (LO).

Results

On 1st January 2015, 286 PwP met the inclusion criteria of whom 162 (56.6%) consented to participate in the study. Of these, 30 did not identify a caregiver and nine caregivers declined to participate in the study. Reasons for declining have been previously published [49]. For two PwP, care tasks were split between two main caregivers (the spouse and a daughter in both cases) and both agreed to participate, with the spouse taken as the main caregiver as they had a greater involvement in care tasks. Of the 123 caregivers included eight had substantial amounts of data missing and were therefore excluded. Thus, quantitative data were available for 115 patient-caregiver dyads (Table 1). Further detailed demographic details for patients-caregivers have been previously published [50]. Ten caregivers (6 wives, 1 husband, 1 sister, 1 son and 1 daughter) took part in the qualitative interviews. The findings from the thematic analysis are presented in Figure 2.

Following the convergent mixed methods design the results are presented below.

Demographic data along with duration of caring and caring roles have previously been published [6] along with the demographics and care needs of PwP [50].

Overall levels of caregiver strain

A total of 107 caregivers fully completed the CBI with 74 (69.2%) scoring ≥ 24 , and 35 (32.7%) scoring ≥ 36 . Within the five domains of the CBI there were particular domains that appeared to show greater levels of strain and there was also evidence of increasing strain across the disease stages (Table 2). Time dependency, which included items such as having to perform many daily tasks along with having to watch the person constantly, which was often described, was found to have the greatest median score across all H&Y stages. The development items domain also scored highly with comments such as 'I feel that I am missing out on life' and '*I wish I could escape from this situation*'. Two caregivers described how they would try and literally 'escape' at times. For one lady this meant sleeping in her car. Another caregiver rented a house so she and her family could get a break and paid for formal carers for the PwP.

Issues that caused the greatest levels of caregiver strain within each domain of the theoretical framework were examined. Table 3 details significant independent predictors of caregiver strain within individual domains of the stress appraisal model. The final model summary with an adjusted R^2 of 0.69 demonstrates this model to be very predictive of caregiver strain.

Predictors of caregiver strain

Primary Stressors (PwP related factors): Functional ability, measured by the MDS UPDRS, was impaired across the cohort with only six (5.2%) participants reporting normal mobility and balance and 66 (57.4%) reporting moderate to severe mobility and balance issues. Only 23 (20%) reported eating tasks were normal with 11 (9.6%) moderate assistance and 6 (5.2%) needing total assistance. Aberrant motor behaviour was present in 12 (18.8%) participants. Interviewees described assisting with personal hygiene and three carers described support with eating tasks that enabled the researcher to understand the distress associated with this activity.

“Then it is left to me to get him in to his bedroom,... get him on the bed, strip him and get him back in here and then you know at meal times even I had, I didn’t mind cutting his food up for him, I used to cut his food up, it was all over, sit at the table..., it was all messed..., it was hard, really really hard, seeing the man you fell in love with all those years ago, you know a lovely strong... we had our own business, we had a lovely life... not nice but you have got to rise above it and I try.” (C5)

Secondary stressors (caregiver related factors): Issues related to caregiver health were a significant predictor of caregiver strain. Fifty-one (44.3%) caregivers identified at least one health condition that impacted on their ability to perform their caring role. During interviews, caregivers described three main effects on their health due to their caregiving role; worsening of an existing health condition, developing a new health condition or neglecting their own health needs. Several caregivers talked about how their health condition had been exacerbated or how they were experiencing increased levels of pain due to the physical demands of performing personal care tasks such as bathing or lifting the PwP. Not only did their caring role have a negative impact on their physical health but also to mental health with low mood and depression frequently reported.

Caregivers provided assistance overnight with 38 (33.7%) PwP requiring assistance turning over in bed, and 37 (32.2%) needed assistance to the toilet. Thirty-seven (32.2%) PwP had sleep and night-time behaviour disorders present according to the NPI. Caregivers reported problematic night-time behaviours such as Rapid Eye Movement (REM) sleep behaviour disorder, hallucinations, delusions, agitation and unsettled behaviour. Caregivers living with the PwP described one or multiple types of sleep disturbance and found this very disruptive.

“Most nights it was at least once, a lot of nights it was 2, 3 and 4 times ... and you’d go in and it would be like ‘What’ and there had usually not been much or she was hallucinating with the Parkinson’s ... when you were awoken for the third time day after day...it was just like ‘WHAT?’” (C9)

The symptoms displayed by the PwP that caused the greatest carer strain were disinhibition, aberrant motor behaviour, agitation and delusions, as identified by the NPI.

Many caregivers reflected on the impact of not getting a full night's sleep, describing how tired they felt all the time and how they were not coping very well. Several also described getting frustrated and agitated overnight and snapping at the PwP, for which they often felt guilty afterwards.

“I found his behaviour the most difficult to deal with, the agitation and paranoia. He used to shout and swear, he never used to, and he would throw things. I would often get upset with him and go upstairs to my room out of the way.” (C3)

Primary Appraisal (What tasks need to be done?): Changes to, and support needed for, personal hygiene were identified by 100 (87.7%) PwP with 90 (78.9%) of caregivers providing assistance with these tasks. Thirteen PwP (11.3%) identified that they needed moderate help and 19 (16.5%) full assistance to meet their hygiene needs. Only 23 (20%) PwP reported that eating tasks were normal with 11 (9.6%) needing moderate and 6 (5.2%) total assistance, while 56 (48.7%) caregivers reported helping with feeding tasks. Interviewees described assisting with personal hygiene and three carers described support with eating tasks that enabled the researcher to understand the distress associated with this activity.

Secondary Appraisal (What can I do to cope?): Out of the 14 different types of coping behaviours only active coping was found to be significant. Caregivers confirmed this coping behaviour as they had identified that the situation at home could not continue and had actively looked at ways to try and improve the situation. Caregivers described arranging extra formal care support so the PwP could be supervised enabling the caregiver to engage in other activities to support their coping behaviours. Maturation within this role was also influenced by previous care experiences and carers described the differences they felt supporting the PwP compared to their previous caring role. Carers also described expectations of the role, the level of time as a carer and for some, the acceptance of the role.

Protective Factors (strong relationship with the PwP): A better quality of relationship, as measured by the RAS was found to be protective against caregiver strain. During the interviews relationship changes were frequently reported to have occurred and caregivers described how they often no longer liked the person they were supporting or how the quality of the relationship had changed to the negative. This no longer

'liking' the person they cared for made their caring role more difficult to cope with and because they no longer had a supportive and loving relationship with the PwP this increased their levels of carer strain.

An overview of significant independent predictors of caregiver strain for the combined stress appraisal model (Table 4), supported with quotations from caregivers, illustrates the complex nature of these motor and non-motor symptoms and the impact they can have on the caregiver.

Discussion

This is the first study to use a stress appraisal model to determine predictors of caregiver strain with informal caregivers. Using a mixed methods approach enabled the researcher to fully appreciate symptoms described. The study by Goldsworthy and Knowles [15] examined 136 caregivers, although 30 (22.1%) were formal paid carers. This study recruited a more representative sample of caregivers for PwP (n = 115) but only focused on those caring for someone with moderate to advanced PD, rather than at all stages of the condition. Goldsworthy and Knowles [15] found that the square multiple correlation indicated that 64.2% and 68.9% of the variance in QoL and strain, respectively, were explained by this model. Greenwell, Gray [11] identified further variables that needed to be examined and suggested an adapted model, which has not been tested. This study combined both stress-appraisal models with further amendments, guided by previous research findings and experience from clinical practice.

Summary of the Quantitative Findings

In the final quantitative model, both motor and non-motor symptoms were identified as predictors of caregiver strain. Neuropsychiatric motor behaviours, issues around eating and mobility were significant primary stressors predicting carer strain, both were related to disease progression. Tasks around bathing and mealtimes were primary appraisal factors associated with strain. All the issues related to motor symptoms, which consequently meant the caregiver having to provide support to the PwP, were described as repetitive and time consuming, physically demanding and but also psychologically wearing. When combined with the significant secondary

stressors of poorer carer night-time sleep and carer health problems a picture of steadily increasing need but reduced physical and psychological ability on the part of the carer to meet these needs emerges. Nevertheless, an active coping style and a strong relationship appeared to be mediating factors.

Summary of the Qualitative Findings

The qualitative analysis revealed three/four key themes that were related to issues of caring for a PwP at home and provide detailed information about the carer role and tasks undertaken but also describe the distressing and troublesome symptoms that they had to deal with and the consequences of caring. 'The trouble with Parkinson's' theme is embedded throughout the quantitative findings, as symptoms, carer role, the impact of support including family and friends and healthcare professionals each provide richer context to understanding the stressors and appraisal of being an informal caregiver. 'How we coped with the changing face of Parkinson's' provided depth of understanding into how symptoms changed and the transition of the role into a carer. 'The consequences of caring' encapsulated the impact on the carer. The impact of caring led to frustration, helplessness and resentment, and the physical demands, combined with disturbed nights, affected their own health.

Comparison of the Findings with Existing Literature

Caregiver strain has been reported at all stages of PD [51] and it has been demonstrated that strain scores increase significantly with advancing H&Y stage [52-54]. In previous studies [55, 56], H&Y stage was found to be an important predictor of caregiver burden in multivariate analysis. In this study H&Y stage was not found to be significant in multivariate analysis, which is possibly because only those of a higher disease stage (H&Y ≥ 3) were included and scores were generally high across all participants. Also due to the number of variables analysed H&Y stage was not significant ($p = 0.696$), but other more specific determinants of caregiver strain were identified.

Previous studies have reported the effect of functional disability on caregiver strain, based on multivariate analysis, with scores of functional scales given as a whole [13, 57-60]. By examining the subscales within the functional scales, it has been possible to determine functional issues that are more predictive of caregiver strain, with the subscales of eating and hygiene (UPDRS II) being the most significant. Issues with

hygiene were often reported by interviewees due to their own health issues. Assisting the PwP to wash and bath was very uncomfortable or painful for some caregivers. PwP and caregivers often describe, in the clinic setting, difficulty with eating, but it was not fully appreciated, how stressful this was for caregivers. There are multiple issues to consider when eating, both from the perspective of the PwP, but now also their caregiver. Some of the eating issues described during the interviews included the PwP having difficulty feeding, being slow to eat, and not wanting to go out to eat due to embarrassment or making a mess whilst eating. For caregivers it was the challenge of preparing something the PwP would enjoy eating, the time it took to prepare meals and eating alone, as they often had to assist with feeding.

Previous studies have reported that depression (most commonly), anxiety and apathy have positive correlations with caregiver strain [13, 21, 60]. These areas were examined, from the PwP and caregiver perspective, but were not significant independent predictors of caregiver strain in multivariable analysis. It is clear from previous studies, and from the interviews, that these symptoms do increase caregiver strain.

Multiple studies examining caregiver strain [53, 60, 61] have shown in regression analysis that neuropsychiatric symptoms have a stronger impact than motor symptoms or functional impairment. One symptom that caregivers did not find particularly distressing, but it is often reported as such, was hallucinations. Forty-two (36.5%) PwP were experiencing hallucinations regularly, with caregivers talking openly about them. This is possibly due to better understanding and management of this symptom [19]. Lawson, Collerton [62] suggested that caregivers of PwP with cognitive impairment may experience an increase in burden as these caregivers, as they may acquire additional and unfamiliar household responsibilities. Female interviewees confirmed taking on additional household responsibilities that require executive function processes, particularly finances and decision making, supporting these previous findings. They also had to cope with watching their partner or relative decline, both physically and mentally, and described how upsetting they found this process. Carter, Lyons [63] revealed that pre-death grief is a significant finding in caregivers of PwP, with the severity of symptoms and the presence of non-motor symptoms, especially cognitive decline, predicting caregivers who are at greatest

risk of prolonged grief. Only a small number of PwP had been formally diagnosed with PDD (n = 10). Examining the MoCA scores, 55 (47.8%) PwP scored 22 or below, of whom ten (8.7%) had a diagnosis of PDD, signifying 45 (39.13%) PwP had cognitive changes that could warrant further investigation. The interviewees described changes to cognition and difficult behaviours displayed by the PwP, as the most challenging symptoms to cope and deal with. The subscales within the NPI of disinhibition, motor behaviour, agitation and delusions were all found to be significant in predicting caregiver strain in agreement with previous studies [63-65].

Caregivers were often spouses who were themselves elderly and had their own health problems. Caregivers' physical health is consistently associated with psychosocial outcomes [11]. Greenwell, Gray [11] suggested caregiver health should be included as a variable within the secondary stressors due to its potential impact on caregiver strain. Caregivers' health conditions were found to be significant within multivariate analysis which confirms its place within the model and during the interviews caregivers clearly articulated the impact of caring on their own health, describing worsening of current health problems, development of other conditions due to their caring role and also neglecting their own health needs.

Previous studies have already identified that the prevalence of sleep disturbances in PwP is high, with estimates from 74% - 98% [66, 67]. As a direct result, caregivers of PwP also have issues with sleep disturbances [68, 69] directly increasing levels of caregiver strain. Caregiver sleep had not previously been included within a stress-appraisal model in PD [11, 15] but from clinical experience was felt to be an important variable to examine. Poor night-time caregiver sleep was found to be significant following multivariate analysis. Many caregivers described night after night of disturbed sleep, during which they often had to cope with difficult behaviours. The majority had no night-time support with the only chance of a 'proper' night's sleep being when the PwP was either in respite or hospital.

Strength and Limitations

Strength includes the mixed methodology of this study. The caregiver tasks of bathing and mealtimes were being predictive of caregiver strain have not previously been reported and merit further exploration. Other important factors that were not measured in the current study may impact caregiver strain, such as treatment with

non-oral options, also need to be explored. The methodology included the use of a cross-sectional design as opposed to longitudinal and the use of the CBI, whereas the Parkinson's Disease Caregiver Burden tool, has been suggested as containing more relevant items for this population when compared with the CBI, and may be a valuable tool in the setting of PD. Other limitations include the over fitting in the multivariate analyse model and in conducting a large number of bivariate tests of association, we have not adjusted for the family-wise error rate. Furthermore, PD plus conditions were included i.e. PSP is associated with poor balance and falls, which may elevate the impact of motor symptoms in this analysis. Finally we acknowledge that our findings are an exploratory analysis and should be seen as a precursor to more detailed model building. Further studies are required to ensure generalisability and external validity.

Conclusion

With the prevalence of PD on the increase, and the increasing demands and restrictions in accessing formal care the majority of care support for PwP will continue to be met by informal caregivers. There is a growing body of evidence to demonstrate the impact of caregiver strain on carers' health and wellbeing, and the impact on PwP with increased hospital admissions and permanent placements within care homes. If health and social care professionals are able to focus interventions and support for factors that are most likely to cause caregiver strain, then caregiver strain may be improved with improved outcomes for all. Further research is needed to determine the most appropriate caregiver interventions but clinical studies examining outcomes for PwP should also include caregiver outcomes to realise the full benefit of current and future treatments.

Acknowledgements

We thank all PwP and their carers who participated in this study. We would like to thank Steve Dodds and Tina Mahan for support with data collection and Victoria Ferguson for assisting with data input.

References

1. Parkinson's UK. *The incidence and prevalence of Parkinson's in the UK*. 2018 [12th November]; Available from: <https://www.parkinsons.org.uk/professionals/resources/incidence-and-prevalence-parkinsons-uk-report>.
2. Chaudhuri, K., L. Yates, and P. Martinez-Martin, *The non-motor symptom complex of Parkinson's disease: a comprehensive assessment is essential*. *Current Neurology and Neuroscience Reports*, 2005. **5**: p. 275-283.
3. Martinez-Martin, P., et al., *Quality of life of caregivers in Parkinson's disease*. *Quality of Life Research*, 2005. **14**(2): p. 463-472.
4. O'Reilly, F., et al., *The effects of caring for a spouse with Parkinson's disease on social, psychological and physical well-being*. *Br J Gen Pract*, 1996. **46**(410): p. 507-12.
5. Martinez-Martin, P., C. Rodriguez-Blazquez, and M.J. Forjaz, *Quality of life and burden in caregivers for patients with Parkinson's disease: concepts, assessment and related factors*. *Expert Rev Pharmacoecon Outcomes Res*, 2012. **12**(2): p. 221-30.
6. Hand, A., et al., *The role and profile of the informal carer in meeting the needs of people with advancing Parkinson's disease*. *Aging Ment Health*, 2018: p. 1-8.
7. Jackson, D., P. McCrone, and L. Turner-Stokes, *Costs of caring for adults with long-term neurological conditions*. *Journal of rehabilitation medicine*, 2013. **45**(7): p. 653-661.
8. Klapotocz, J., et al., *The Pattern of Hospital Admissions Prior to Care Home Placement in People With Parkinson's Disease: Evidence of a Period of Crisis for Patients and Carers*. *J Aging Health*, 2018: p. 898264318786125.
9. Abendroth, M., B.J. Lutz, and M.E. Young, *Family caregivers' decision process to institutionalize persons with Parkinson's disease: a grounded theory study*. *Int J Nurs Stud*, 2012. **49**(4): p. 445-54.
10. Donnelly, N.-A., et al., *Systematic review and meta-analysis of the impact of carer stress on subsequent institutionalisation of community-dwelling older people*. *PloS one*, 2015. **10**(6): p. e0128213.
11. Greenwell, K., et al., *Predictors of the psychosocial impact of being a carer of people living with Parkinson's disease: a systematic review*. *Parkinsonism Relat Disord*, 2015. **21**(1): p. 1-11.
12. Leiknes, I., U. Lien, and E. Severinsson, *The Relationship among Caregiver Burden, Demographic Variables, and the clinical characteristics of Patients with Parkinson's Disease - A systematic Review of Studies Using Various Caregiver Burden Instruments*. *Open Journal of Nursing*, 2015. **5**: p. 855-877.
13. Martinez-Martin, P., et al., *Caregiver burden in Parkinson's disease*. *Mov Disord*, 2007. **22**(7): p. 924-31; quiz 1060.
14. Van Wersch, A., *Complementary medicine and health psychology*. 2009: McGraw-Hill Education (UK).
15. Goldsworthy, B. and S. Knowles, *Caregiving for Parkinson's disease patients: an exploration of a stress-appraisal model for quality of life and burden*. *J Gerontol B Psychol Sci Soc Sci*, 2008. **63**(6): p. P372-6.
16. Kliez, M., et al., *Validating the Parkinson's disease caregiver burden questionnaire (PDCB) in German caregivers of advanced Parkinson's disease patients*. *International Psychogeriatrics*, 2019. **31**(12): p. 1791-1800
17. Alves, G., et al., *Epidemiology of Parkinson's disease*. *J Neurol*, 2008. **255** Suppl 5: p. 18-32.
18. Tew, E.H., et al., *Quality of life in Parkinson's disease caregivers: the contribution of personality traits*. *Biomed Res Int*, 2013. **2013**: p. 151872.
19. Aarsland, D., et al., *Mental symptoms in Parkinson's disease are important contributors to caregiver distress*. *International Journal of Geriatric Psychiatry*, 1999. **14**(10): p. 866-874.

20. Schrag, A., et al., *Caregiver-burden in parkinson's disease is closely associated with psychiatric symptoms, falls, and disability*. *Parkinsonism Relat Disord*, 2006. **12**(1): p. 35-41.
21. Leiknes, I., et al., *Caregiver distress associated with neuropsychiatric problems in patients with early Parkinson's disease: the Norwegian ParkWest study*. *Acta Neurol Scand*, 2010. **122**(6): p. 418-24.
22. Rosqvist, K., *Satisfaction with Care in Late Stage Parkinson's Disease*. *Parkinson's Disease*, 2019.
23. Trapp, S., *Family cohesion, burden, and health-related quality of life among Parkinson's disease caregivers in Mexico*. *International Psychogeriatrics*, 2019. **31**(7): p. 1039-1045
24. Schmotz, C., Richinger, C., & Lorenzl, S. *High burden and depression among late-stage idiopathic Parkinson disease and progressive supranuclear palsy caregivers*. *Journal of Geriatric Psychiatry and Neurology*, 2017. **30**(5): p. 267-272
25. Klietz, M., et al., *Impaired quality of life and need for palliative care in a German cohort of advanced Parkinson's disease patients*. *Frontiers in neurology*, 2018. 9: p. 120
26. van der Steen, J. T., et al., *Dementia and Parkinson's disease: similar and divergent challenges in providing palliative care*, 2019. 10: p. 54
27. Leiknes, I., U. Lien, and E. Severinsson, *The Relationship among Caregiver Burden, Demographic Variables, and the Clinical Characteristics of Patients with Parkinson's Disease: A Systematic Review of Studies Using Various Caregiver Burden Instruments*. *Open Journal of Nursing*, 2015. **5**: p. 855-877.
28. Wanless, D., et al., *Wanless social care review: securing good care for older people, taking a long-term view*. 2006: King's Fund.
29. Goetz, C.G., et al., *Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS): process, format, and clinimetric testing plan*. *Movement Disorders*, 2007. **22**(1): p. 41-47.
30. Mahoney, F. and D. Barthel, *Functional evaluation: The Barthel Index*. *Maryland State Medical Journal*, 1965. **14**: p. 61-65.
31. Nasreddine, Z.S., et al., *The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment*. *Journal of the American Geriatrics Society*, 2005. **53**(4): p. 695-699.
32. Zigmond, A. and R. Snaith, *The Hospital Anxiety and Depression Scale*. *Acta Neurologica Scandinavica*, 1983. **67**: p. 361-370.
33. Marinus, J., et al., *Development of a questionnaire for sleep and sleepiness in Parkinson's disease*. *Sleep*, 2003. **26**: p. 1049-1054.
34. Chaudhuri, K.R., et al., *The metric properties of a novel non-motor symptoms scale for Parkinson's disease: Results from an international pilot study*. *Mov Disord*, 2007. **22**(13): p. 1901-11.
35. Jenkinson, C., et al., *The Parkinson's Disease Questionnaire (PDQ-39): development and validation of a Parkinson's disease summary index score*. *Age and Ageing*, 1997. **26**(5): p. 353-357.
36. Cummings, J.L., et al., *The Neuropsychiatric Inventory - Comprehensive Assessment of Psychopathology in Dementia*. *Neurology*, 1994. **44**(12): p. 2308-2314.
37. Teri, L., et al., *Assessment of Behavioral-Problems in Dementia - the Revised Memory and Behavior Problems Checklist*. *Psychology and Aging*, 1992. **7**(4): p. 622-631.
38. Jenkinson, C., et al., *The development and validation of a quality of life measure for the carers of people with Parkinson's disease (the PDQ-Carer)*. *Parkinsonism Relat Disord*, 2012. **18**(5): p. 483-7.
39. Marinus, J., et al., *Development of a questionnaire for sleep and sleepiness in Parkinson's disease*. *Sleep*, 2003. **26**: p. 1049-1054.
40. Carver, C.S., *You want to measure coping but your protocol's too long: consider the brief COPE*. *Int J Behav Med*, 1997. **4**(1): p. 92-100.

41. Cohen, S. and H.M. Hoberman, *Positive Events and Social Supports as Buffers of Life Change Stress*. Journal of Applied Social Psychology, 1983. **13**(2): p. 99-125.
42. Hendrick, S.S., *A Generic Measure of Relationship Satisfaction*. Journal of Marriage and the Family, 1988. **50**(1): p. 93-98.. Journal of Applied Social Psychology, 1983. **13**(2): p. 99-125.
43. Rosenberg, M., *Rosenberg self-esteem scale (SES)*. Society and the adolescent self-image, 1965.
44. Scheier, M.F., C.S. Carver, and M.W. Bridges, *Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a reevaluation of the Life Orientation Test*. Journal of personality and social psychology, 1994. **67**(6): p. 1063.
45. Novak, M. and C. Guest, *Application of a multidimensional caregiver burden inventory*. Gerontologist, 1989. **29**(6): p. 798-803.
46. Thornton, M. and S.S. Travis, *Analysis of the reliability of the modified caregiver strain index*. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 2003. **58**(2): p. S127-S132.
47. Creswell, J.W., *Research design: qualitative, quantitative, and mixed methods approaches*. 2014.
48. Braun, V. and V. Clarke, *Using thematic analysis in psychology*. Qualitative research in psychology, 2006. **3**(2): p. 77-101.
49. Hand, A., Oates, L. L, Gray, W. K., & Walker, R. W. *The role and profile of the informal carer in meeting the needs of people with advancing Parkinson's disease*. Aging & Mental Health, 2018. **23**(3): p. 337-344
50. Hand, A., et al., *Understanding the care needs and profile of people living at home with moderate to advanced stage Parkinson disease*. Journal of geriatric psychiatry and neurology, 2018. **31**(5): p. 237-247.
51. Carter, J.H., et al., *Living with a person who has Parkinson's disease: the spouse's perspective by stage of disease*. Movement disorders: official journal of the Movement Disorder Society, 1998. **13**(1): p. 20-28.
52. Carod-Artal, F.J., et al., *Burden and health-related quality of life among caregivers of Brazilian Parkinson's disease patients*. Parkinsonism & related disorders, 2013. **19**(11): p. 943-948.
53. Agrawal, V., et al., *Predictors of caregivers' burden of Parkinson's disease in India: experience of a tertiary care center in India*. Journal of Parkinsonism & Restless Legs Syndrome, 2012. **2**: p. 59.
54. Schmotz, C., C. Richinger, and S. Lorenzl, *High burden and depression among late-stage idiopathic Parkinson disease and progressive supranuclear palsy caregivers*. Journal of Geriatric Psychiatry and Neurology, 2017. **30**(5): p. 267-272.
55. Kudlicka, A., L. Clare, and J.V. Hindle, *Quality of life, health status and caregiver burden in Parkinson's disease: relationship to executive functioning*. International Journal of Geriatric Psychiatry, 2014. **29**(1): p. 68-76.
56. Oguh, O., et al., *Caregiver strain in Parkinson's disease: national Parkinson Foundation Quality Initiative study*. Parkinsonism & related disorders, 2013. **19**(11): p. 975-979.
57. Shin, H., et al., *Factors contributing to spousal and offspring caregiver burden in Parkinson's disease*. European neurology, 2012. **67**(5): p. 292-296.
58. Kim, K.S., et al., *Subjective and objective caregiver burden in Parkinson's disease*. Journal of Korean Academy of Nursing, 2007. **37**(2): p. 242-248.
59. Schrag, A., et al., *Caregiver-burden in Parkinson's disease is closely associated with psychiatric symptoms, falls, and disability*. Parkinsonism & related disorders, 2006. **12**(1): p. 35-41.
60. Thommessen, B., et al., *The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease*. International journal of geriatric psychiatry, 2002. **17**(1): p. 78-84.

61. Sarandol, A., et al., *Behavioral Disturbances and Depression of Patients with Parkinson's Disease have Significant Impact on Caregivers' Burden and Depression*. *Neurology Psychiatry and Brain Research*, 2010. **16**(3-4): p. 91-96.
62. Lawson, R.A., et al., *Coping with cognitive impairment in people with Parkinson's disease and their carers: a qualitative study*. *Parkinson's Disease*, 2018. **2018**.
63. Carter, J., et al., *Pre-death grief in Parkinson's caregivers: a pilot survey-based study*. *Parkinsonism & related disorders*, 2012. **18**: p. S15-S18.
64. Martinez-Martin, P., et al., *Neuropsychiatric symptoms and caregiver's burden in Parkinson's disease*. *Parkinsonism & related disorders*, 2015. **21**(6): p. 629-634.
65. Stella, F., et al., *Psychopathological features in patients with Parkinson's disease and related caregivers' burden*. *International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences*, 2009. **24**(10): p. 1158-1165.
66. Lees, A.J., N.A. Blackburn, and V.L. Campbell, *The Nighttime Problems of Parkinsons-Disease*. *Clinical Neuropharmacology*, 1988. **11**(6): p. 512-519.
67. Tandberg, E., J.P. Larsen, and K. Karlsen, *A community-based study of sleep disorders in patients with Parkinson's disease*. *Movement Disorders*, 1998. **13**(6): p. 895-899.
68. Happe, S., et al., *Sleep disorders and depression in patients with Parkinson's disease*. *Acta Neurol Scand*, 2001. **104**(5): p. 275-80.
69. Smith, M.C., H. Ellgring, and W.H. Oertel, *Sleep disturbances in Parkinson's disease patients and spouses*. *Journal of the American Geriatrics Society*, 1997. **45**(2): p. 194-199.