**Doctoral Thesis**

Submitted in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology

# Self-Compassion, Social Support, and Wellbeing in Carers of People with Neurodegenerative Motor Conditions

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**Statement of Word Count**

| Section | Main Text | Appendices, Including References, Figures, and Tables | Total |
|---|---|---|---|
| Abstract | 300 | - | 300 |
| Systematic Literature Review | 7,983 | 13,009 | 20,992 |
| Empirical Paper | 7,999 | 8,910 | 16,909 |
| Critical Appraisal | 3,837 | 1,695 | 5,532 |
| Ethics Section | 5,074 | 5,557 | 10,631 |
| Total | 25,193 | 29,171 | 54,364 |

# Abstract

Section one of this thesis comprises a systematic literature review of quantitative studies assessing the predictive role of social support on the wellbeing of carers of people with Parkinson’s, Huntington’s disease, multiple sclerosis, and motor neurone disease. A systematic search was conducted on four databases: PsycINFO, MEDLINE, CINAHL, and Scopus. Following the application of inclusion and exclusion criteria, then quality appraisal, 26 studies were analysed and presented using narrative synthesis. Generally, greater social support was associated with increased positive and reduced negative wellbeing. Findings were broadly consistent across conditions, suggesting a commonality to carer experiences. However, the diverse range of social support measures used presented barriers to further comparisons between studies, highlighting a need for clarity in how social support is conceptualised in future research.

Section two presents an empirical study examining the roles of self-compassion and social support in the wellbeing of carers of people with Parkinson’s. Self-identified carers of people with Parkinson’s completed an online survey which collected data regarding carer demographics, care-related tasks, carer burden, self-compassion, social support, and wellbeing. Greater carer stressors (carer burden and care tasks) were associated with lower wellbeing, and higher self-compassion and social support with higher wellbeing. Self-compassion and social support were significant independent predictors of wellbeing, controlling for carer stressors and demographics. Furthermore, self-compassion was a significant moderator in the relationship between care tasks and wellbeing, and approaching significance in the relationship between carer burden and wellbeing. Social support was not a significant moderator. Findings demonstrated that self-compassion and social support play an important role in carer wellbeing, and that self-compassion functions as both a predictor of wellbeing and a protective factor against the impact of stressors.

Section three presents a critical appraisal of the project, including discussion of key concepts and reflections arising from communication with carers throughout the research.

# Declaration

This thesis documents research undertaken for the Doctorate in Clinical Psychology at the Division for Health Research, Lancaster University. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Katy Brooks
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Date: 26th April 2024

# Acknowledgements

Firstly, I would like to thank everyone who participated in this research. Thank you for giving up your valuable time to be a part of this project. It would not have been possible without you. Thank you also to everyone who got in touch to share your thoughts, reflections, and experiences with me. It was a privilege to hear your stories. Special thanks go to the experts by experience who were so generous with their time and knowledge during the planning stages of this project. Your contribution to this research was invaluable.

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Thank you to my supervisors, Fiona Eccles and Jane Simpson. Thank you for your support, your encouragement, and your kindness. Thank you for your patience when things were hard, and your enthusiasm when things were going well. Thank you for always finding time for me, and for providing calm in response to every panicked email I sent you. You have been wonderful supervisors.

Finally, I would like to say a sincere and heartfelt thank you to the friends and family who have supported me over the course of this project and throughout my training journey. In some ways, you are the hardest people to thank, because I am so grateful to so many of you for so many different reasons. Thank you for being there, even when my mind was probably not. I look forward to being able to offer you more than one topic of conversation again very soon.

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# Section one: Systematic Literature Review

# Social Support as a Predictor of Psychological Wellbeing in Carers of People with Neurodegenerative Motor Conditions: A Systematic Review

Word count (excluding references, tables, and appendices): 7,999

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## Abstract

**Objectives**

Social support plays an important role in the wellbeing of carers. This paper reviewed quantitative studies assessing the predictive role of social support on psychological wellbeing in informal carers of people with Parkinson's, Huntington's disease (HD), motor neurone disease (MND), and multiple sclerosis (MS).

**Methods**

A systematic search was conducted on four databases: PsycINFO, CINAHL, MEDLINE, and Scopus. Search terms related to informal carers, Parkinson's, HD, MND, MS, and social support. Positive and negative wellbeing outcomes were both considered for inclusion. Studies were screened for relevance to the inclusion criteria, and quality appraisal was conducted. A narrative approach to synthesis was taken.

**Results**

Of 2,753 retrieved papers, 26 were included. Conceptualisations and measures of social support varied substantially. Use of psychological theory was limited, and negative outcomes were more commonly investigated than positive outcomes. Generally, greater social support was associated with increased positive and reduced negative wellbeing outcomes.

**Conclusion**

Social support has the potential to play an important role in the psychological outcomes of carers. Future research should focus on increasing clarity around how social support is defined and operationalised. This is necessary to increase understanding of this important concept and its role in carer wellbeing.

**Keywords:** social support, psychological wellbeing, informal carers, neurodegenerative motor conditions

## Introduction

As the population ages, the need for long-term care is increasing across many groups (Lindt et al., 2020). Much of this care is delivered informally by friends and family members, sometimes called ‘informal carers;’ a term used to refer to individuals who provide unpaid support due to someone’s physical or psychological health needs. In some societies, as much as 95% of care needs are met by informal carers (United Nations Economic Commission for Europe [UNECE], 2019). Caring roles are disproportionately held by women, who generally experience greater disadvantages associated with caregiving than male carers (Bhan et al., 2020; Sharma et al., 2016; Xiong et al., 2020). The support provided by informal carers is wide-ranging, and may encompass support with activities of daily living, emotional or financial support, and support with accessing healthcare and medication (D. Sherman, 2019). Perspectives and needs of informal carers are often underrepresented and overlooked in healthcare settings (Maybery et al., 2021).

Informal carers often experience reduced wellbeing, elevated risk of burnout, and psychological distress (Gilsenan et al., 2022; Tuncay & Fertelli, 2019). Quality of life is lower in carers than in the general population, and levels of depression are higher (Hlabangana & Hearn, 2020). In the UK, challenges faced by informal carers are often exacerbated by difficulties accessing support from health and social care services (Aubeeluck et al., 2012), and the importance of carer access to services has been identified across cultures (Bressan et al., 2020). In economically developed countries, several areas have been identified where additional support would benefit carers, including financial support, increased flexibility in healthcare services, and access to respite (Cottagiri & Sykes, 2019; Hall et al., 2022; Price et al., 2020).

One area which has received attention is social support (Liu et al., 2021; Roth, 2020; Teahan et al., 2021). Social support can be understood as structural (the composition and complexity of social links), and functional (the extent to which a person can depend on others around them) (del-Pino-Casado et al., 2022). While loneliness and social isolation are often discussed alongside social support (Akkus, 2011; Speelberg et al., 2023), these are subtly different concepts; social support can be considered in terms of a person's connection to and reliance on those around them, whereas loneliness and isolation are concerned with the size, frequency of contacts, and perceived presence of a social network (Leigh-Hunt et al., 2017). Furthermore, it is important to distinguish between formal support, provided by commissioned services, and informal support, provided by friends and family, both of which affect carer experiences (Shiba et al., 2016). Therefore, this review will focus on informal social support, understood as the practical and emotional help a person draws from their immediate network, outside of formal care agencies (George et al., 2020).

One group for whom social support could be important is carers of people with neurodegenerative motor conditions, such as Parkinson's[1], multiple sclerosis (MS), Huntington's disease (HD), and motor neurone disease (MND). The diverse and unpredictable range of symptoms associated with these conditions, in addition to common experiences of psychological distress, present unique challenges in management and adjustment (Gil-González et al., 2020; Radakovic et al., 2024; Sokol et al., 2021). Moreover, for carers supporting these individuals, a number of challenges have been reported. For example, carers can experience a sense of loss as difficulties progress, and must frequently adapt to the changing needs of the person receiving care (Appleton et al., 2018; Leidl et al., 2023; Trucco et al., 2024). Furthermore, carers often encounter a lack of knowledge in healthcare staff, placing them in the position of having to educate professionals and advocate for the needs of their loved ones (Flemming et al., 2020).

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[1] The preferred term for Parkinson's disease used by the charity Parkinson's UK.

Parkinson’s affects approximately 1% of people aged over 60 (Hawley et al., 2014), and is associated with tremors, rigidity, bradykinesia, and cognitive decline (Choi et al., 2020). HD is an inherited condition which can have a profound impact on families (Mand et al., 2015). Symptoms commonly develop between the ages of 30 and 50, and include chorea, bradykinesia, dystonia and ataxia, cognitive changes, and ultimately dementia (Wyant et al., 2017). MND typically affects people aged over 50, and is characterised by a degeneration of motor neurons, resulting in muscle weakness and atrophy, severely limiting movement over time, and often leading to respiratory failure (Oh & Kim, 2017). Additionally, MND can cause cognitive changes (Schrempf et al., 2022). MS is a demyelinating condition affecting the central nervous system, which can lead to sensory changes, blurred vision, changes in gait, and cognitive difficulties (Planche et al., 2016; Schapiro, 2003). Age of onset is typically between 20 and 40, although this is thought to be increasing (Romero-Pinel et al., 2022).

Differences between these conditions could lead to differences in carer experiences. For example, the relatively short duration and need to plan for palliative care in MND may create a more acute caregiving experience, while the genetic nature of HD means that family carers may also be at risk of developing the condition. However, despite these differences, research suggests that carer experiences transcend neurodegenerative diagnostic groups, as carer needs and stressors also differ within diagnostic groups (Roland & Chappell, 2017). Furthermore, there are many similarities across conditions such as the combined degeneration of cognitive and physical abilities, unpredictable condition progression, and the lack of a known cure, often resulting in psychological distress across conditions (Ghielen et al., 2019). Cognitive changes arising from these conditions have been linked to increased carer strain and communication difficulties between family members and the person receiving care (Hartelius et al., 2010; Martinez et al., 2018). Additionally, the physical demands of caregiving can increase carer distress and contribute to physical difficulties in carers managing their own health challenges (Trucco et al., 2024). Carers of people with neurodegenerative motor conditions have identified similar requirements from services, particularly home support and access to respite (McCabe et al., 2008). Furthermore, qualitative research has identified challenges facing carers across conditions, including lack of understanding from others, inadequate support, and high demands on family members (Bužgová et al., 2019). Thus, for the purposes of this review, carers of people with Parkinson's, HD, MS, and MND have been considered together; an approach adopted by other reviews in the field of neurodegenerative motor conditions (Boyt et al., 2022; Eccles & Simpson, 2011; Ghielen et al., 2019).

Given the challenges faced by carers of people with neurodegenerative motor conditions, one concept which deserves consideration is wellbeing. It has been argued that mental health and mental ill-health are distinct concepts which should be considered separately, and that wellbeing should be used solely to refer to concepts related to positive psychology, as opposed to as part of a spectrum including factors such as distress and illness (Iasiello et al., 2022; Westerhof & Keyes, 2010). However, research has typically considered caring experiences from a 'burden' perspective, through concepts such as carer burden, strain, and distress (Hand et al., 2022; Lau & Au, 2011; Mosley et al., 2017). While a positive psychology approach is growing (Prado et al., 2020; Al-Janabiet al., 2019), such approaches are in the minority. Therefore, this review will use a broad conceptualisation of wellbeing, including both positive and negative constructs which could be considered as having a role in overall psychological wellbeing (Quinn & Toms, 2018; Robertson et al., 2023).

Research has highlighted the important role that social support may play in the wellbeing of carers of people with other long-term conditions (Gibson et al., 2019; Giebel et al., 2021). Systematic reviews considering social support have typically focused on intervention studies, primarily with carers of people with dementia (Carter et al., 2020; Dam et al., 2016; Thompson et al., 2007). One meta-analysis considered the effectiveness of internet-based interventions, including social support interventions, for carers of people with neurodegenerative conditions (Boyt et al., 2022). However, the majority of reviewed studies pertained to carers of people with dementia, and no results were returned regarding carers of people with Parkinson's or HD. There is currently no systematic review focusing on social support as a predictor of psychological wellbeing in carers of people with neurodegenerative motor conditions. Improving understanding of predictors allows services to be proactive and responsive to factors which may jeopardise wellbeing (Tan et al., 2023). Psychological factors related to carer wellbeing have been associated with quality of life in individuals receiving care (Perepezko et al., 2023), indicating that carer and care receiver outcomes are closely related. Thus, improving understanding of the links between social support and wellbeing could improve outcomes for both carers and people living with neurodegenerative motor conditions.

Consequently, this review will focus on empirical studies reporting quantitative data from informal carers of people with Parkinson's, HD, MND or MS. The review will concentrate on adult carers, as it is likely that challenges faced by young carers may be less generalisable to carers as a whole (Fleitas Alfonzo et al., 2022). The review will provide a narrative synthesis addressing the following question: does social support have a predictive relationship with psychological wellbeing in carers of people with neurodegenerative motor conditions?

## Methods

This review was conducted following the Preferred Reporting Items for Systematic reviews and Meta-analyses (PRISMA) framework (Page et al., 2021), and was preregistered with PROSPERO registry of systematic reviews (CRD42023425171).

## Eligibility Criteria

Included papers were peer-reviewed empirical studies, employing quantitative methodology and reported in English. Samples needed to include adult (aged 18 or older) informal carers of people living with HD, MS, MND, or Parkinson's. Only studies in which carer data were extractable from care recipient data were included. If studies reported data related to other neurological conditions (e.g., dementia), these were included if the data related to Parkinson's, HD, MS, or MND were extractable from data related to other conditions.

Included studies used cross-sectional and/or longitudinal designs. Intervention and feasibility studies were excluded (i.e. where social support was investigated as the focus for or outcome from an intervention). Studies were required to report validated measures of both predictor (social support) and outcome (psychological wellbeing) variables to promote confidence in the robustness of the findings. Positive (quality of life, life satisfaction) and negative (carer burden, depression) interpretations of wellbeing were included. Studies reporting hours of support or number of social contacts without the addition of a validated scale were excluded. Where researchers created their own measures, these were considered providing sufficient detail was given regarding internal validity and reliability.

## Search Strategy

A systematic search of four electronic databases (PsycINFO, CINAHL, MEDLINE, and Scopus) was conducted in May 2023. PsycINFO, CINAHL and MEDLINE offered access to studies across medical, nursing, and psychological professions. Scopus was included as a multidisciplinary database to maximise the scope of results. A robust search strategy was developed with input from an academic librarian. Search terms were generated through engagement with relevant papers (McKeown et al., 2003; Ovaska-Stafford et al., 2021; Theed et al., 2017), database thesauruses, and Medical Search History (MeSH) terms.

MeSH headings and free text terms were combined using Boolean operators. The search combined terms related to carers (e.g., ‘carer’, ‘caregiver’), with terms related to Parkinson’s, MND, HD and MS, and terms related to social support (e.g., ‘social support’, ‘social inclusion’). No date modifiers were used, and no terms included for outcomes (See Tables 1.1-4 for search strings).

[Insert Tables 1.1-4]

## Selection Process

The search returned 2,753 results across the four databases (PsycINFO: 364, CINAHL: 516, MEDLINE: 672, Scopus: 1201). Results were imported into Rayyan systematic review management platform for screening. Following duplicate removal, 1,547 results remained. Titles and abstracts were screened according to the eligibility criteria. Following screening, 57 papers remained and were examined in full. Further exclusions were made based on the full text reading, resulting in 26 individual studies eligible for inclusion. Reference lists of included papers were hand-searched for further relevant studies, yielding no additional papers. In total, 26 papers were included (see Figure 1.1 for PRISMA diagram).

[Insert Figure 1.1]

## Quality Appraisal

As this review primarily included cross-sectional studies, the Appraisal tool for Cross-Sectional Studies (AXIS) was chosen to assess the quality and bias of selected papers (Downes et al., 2016). This 20-item tool is answered in a yes/no/don’t know format, offering a qualitative impression of study quality. An additional item was added to the AXIS to identify the small number of studies using longitudinal designs. While the AXIS does not provide a total score or cut-offs for exclusion, it is useful for identifying trends. Studies identified clear aims, were broadly strong when describing statistical approaches, and recruitment strategies were targeted to desired populations. However, of the 26 studies, only three justified their sample size, only one of which reported an *a priori* power calculation. While no studies were excluded on the basis of quality appraisal, these insights were considered during the analysis process, particularly regarding the impact of sample size on statistical significance. Key issues from quality appraisal are represented in Table 1.6. A random selection of six studies was reviewed by a peer to examine consistency and reliability of rating. Discrepancies were discussed until a conclusion was reached (see Table 1.5 for quality appraisal matrix).

[Insert Table 1.5]

## Data Extraction and Synthesis

Data were extracted and collated using Microsoft Excel (see Table 1.6). Extracted data included country of origin, sample size, condition, age and gender of participants, relationship of the carer to the care recipient, and recruitment method. Data related to predictor and outcome variables, methodology, and key findings were extracted. Where available, correlation coefficients were extracted to indicate effect sizes (Funder & Ozer, 2019), interpreted thus: $r = .10$ was a small effect, $r = .30$ a medium effect, and $r = .50$ a large effect (Rosnow & Rosenthal, 2003).

Due to the homogeneity of predictors, a meta-analysis was not appropriate. Studies were grouped based on outcome variables. A narrative approach to synthesis was applied (Popay et al., 2006).

[Insert Table 1.6]

# Results

## Study Characteristics

Publication dates ranged from 1995 (O'Brien et al., 1995) to 2023 (Bayen et al., 2023; Tülek et al., 2023). Two studies used the same data set, but as different measures of social support were used, both were included (Perrin et al., 2019; Tyler et al., 2020), resulting in 25 independent samples. Of these 25 samples, two focused on carers of people with HD, eleven on carers of people with MS, five on carers of people with MND, and six on carers of people with Parkinson's. One study included participants caring for people with any of the four conditions (O'Connor & McCabe, 2011).

Carer participants included spousal or romantic partners, adult children, siblings, parents, cousins, aunts/uncles, unspecified relatives, and friends or neighbours. Women represented the majority of participants in studies featuring carers of people with Parkinson's, HD, and MND. In studies featuring carers of people with MS, the gender balance was more even. Sample sizes ranged from 17 to 253, with a total of 2,350 participants represented across the 25 samples. Participants were aged between 16 and 90. Although one study (Pakenham, 2001) included participants younger than 18, this was included as those participants aged between 16 and 18 represented a very small proportion of the study's sample. Similarly, one study included a single paid carer (Mickens et al., 2018), but was included due to the small proportion of the study sample this represented.

## Key Findings

### *Measures of Social Support*

Across the 26 studies, 22 different measures of social support were used. Only four measures were used by more than one study: the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1990); the Social Support Rating Scale (SSRS) (Xiao, 1994); the Social Support Questionnaire (SSQ) (Sarason et al., 1987); and the Social Provisions Scale (SPS) (Cutrona & Russell, 1987). In four cases, social support appeared in subscales of other measures (e.g. QoL)  rather than specific social support measures (Mickens et al., 2018; Pagnini et al., 2010; Perrin et al., 2019; Rivera-Navarro et al., 2003). Measures generally focused on carers' perceptions of social support, rather than objective measures of support received. Nevertheless, the focus varied between measures. Measures such as the Social

Support Measurement Tool (J. Lee et al., 2019) considered support from different sources (e.g. family support, physician support), while other measures, such as the Close Persons Questionnaire (CPQ) (S. Stansfeld, 1992), focused on the nature of support received (e.g. emotional or practical support). Some measures were concerned with carers' satisfaction with support (Sarason et al., 1987), while others focused on perceptions of the availability of support (Zich & Temoshok, 1987). (See Table 1.6 for conceptualisations of social support.)

### *Outcome Measures*

Outcome measures were divided into positive, negative, and composite measures, generated by combining two or more measures. Positive measures included quality of life (QoL), satisfaction with life (SwL), wellbeing, and family adaptation, which assesses resources, function, and fulfilment within a family (Smilkstein, 1978).

Papers reporting negative outcomes were more numerous than those reporting positive outcomes. Carer burden and depression were the most commonly investigated (*n* = 10 and 8 respectively). Other negative outcomes included anxiety, carer distress, and mood, which was categorised as negative due to the measure's focus on unpleasant mood states such as anger and tension (Petrowski et al., 2021).

Three studies used a composite outcome measure: two used a composite measure of 'mental health' (Mickens et al., 2018; Tyler et al., 2020), and a third combined measures related to anxiety, depression, strain, and burden, to create a composite 'carer outcome' (Goldstein et al., 2006).

### *Positive Wellbeing Outcomes*

**Quality of Life (QoL).** Three of the 26 studies investigated QoL as an outcome (E. J. Lee et al., 2015; J. Lee et al., 2019; O'Connor & McCabe, 2011). One reported an association between unmet emotional, instrumental, and professional support needs and reduced QoL in carers of people with MS (E. J. Lee et al., 2015). Another reported a correlation between greater social support and increased QoL in carers of people with Parkinson's (J. Lee et al., 2019). Small to medium effect sizes were identified.

Two studies used regression analysis to explore social support as a predictor of QoL (E. J. Lee et al., 2015; O'Connor & McCabe, 2011). O'Connor and McCabe (2011) analysed change over time for carers of people with all four conditions. T-tests revealed no significant change in social support over time for any of the carer groups. Using a regression model which also featured income, economic pressure, and marital satisfaction, social support at time one was a significant predictor of QoL at time two for carers of people with HD and MS, but not carers of people with Parkinson's or MND (QoL at time one was not controlled). E. J. Lee et al.'s (2015) cross-sectional study of carers of people with MS used a model with greater emphasis on emotional as opposed to financial stressors, but found similarly that social support was a significant positive predictor of QoL in male and female carers.

One study used structural equation modelling (SEM) to explore the relationship between social support and QoL in carers of people with Parkinson's (J. Lee et al., 2019). In a model including carer characteristics, relationship with the care receiver, and care receiver activities, a direct effect of social support on QoL was observed, such that greater social support was associated with higher QoL.

**Satisfaction with Life (SwL).** Four studies investigated SwL as an outcome (O'Brien et al., 1995; Roscoe et al., 2009; T.E. Sherman et al., 2007; Waldron-Perrine et al., 2009). Three focused on carers of people with MS and one on carers of people with HD (Roscoe et al., 2009). Effect sizes ranged from small to large. Waldron-Perrine et al. (2009) and T.E. Sherman et al. (2007) reported significant associations between greater social support and increased SwL. Waldron-Perrine et al. (2009) and T.E. Sherman et al. (2009) used the same measures of social support and SwL, and reported very similar (large) effect sizes. In contrast, O'Brien et al. (1995) reported no association between social support and SwL. In carers of people with HD, Roscoe et al. (2009) reported a significant association with SwL for emotional support, with a large effect size, but no significant association for tangible or informational support. While the small sample size ($n = 17$) may have precluded finding weaker effects, the effect sizes for tangible and informational were notably smaller ($r \leq .13$ for both).

Three studies reported regression analyses with social support as a predictor of SwL for carers of people with MS (O'Brien et al., 1995; T.E. Sherman et al., 2007; Waldron-Perrine et al., 2009). T.E. Sherman et al.'s (2007) model accounted for 43% of the variance in SwL, and social support was a significant predictor when controlling for illness severity, carer psychological distress, and cognitive, functional, and behavioural difficulties in the person with MS. However, social support did not act as a significant predictor of SwL in Waldron-Perrine et al.'s (2009) or O'Brien et al.'s (1995) regression models. As well as social support, Waldron-Perrine et al.'s (2009) model included carer income, illness severity, carer uncertainty, patient awareness of deficit, and neuropsychological functioning. O'Brien et al.'s (1995) model also included measures of uncertainty and neuropsychological functioning, as well as coping, objective burden, and subjective burden, although the majority of variance in this model was accounted for by the burden measures (49% out of a total 51%). The fact that burden accounted for so much of the variance in this model provides some explanation for social support not acting as a significant predictor.

**Family Adaptation.** One study (E. J. Lee et al., 2013) found an association between greater social support and increased family adaptation in carers of people with MS, demonstrating a medium effect. The study used path analysis to explore the relationships between strain, coping, perceived control, social support, and family adaptation. The model accounted for 37.8% of the variance, with social support acting as a significant direct predictor.

**Positive Wellbeing.** One study included wellbeing in their analysis, focusing on positive aspects of mental health in carers of people with Parkinson's (Hooker et al., 1998). The study found a significant association between higher social support and greater wellbeing, demonstrating a medium effect.

### *Negative Wellbeing Outcomes*

**Carer Burden.** Seven of the ten studies measuring carer burden reported correlational analyses (Dayapoğlu & Tan, 2017; Edwards & Scheetz, 2002; Knight et al., 1997; Lian et al., 2022; Pagnini et al., 2010; Rivera-Navarro et al., 2003; Tülek et al., 2023). Higher social support was consistently associated with lower burden[2] in carers of people with MND and MS. Effect sizes ranged from medium to large.

Higher social support was a significant predictor of lower burden across carers of people with HD, MS, and Parkinson's in most of the regression studies (Bayen et al., 2023; Edwards & Scheetz, 2002; Knight et al., 1997; Shin et al., 2012), despite differences in variables included in the models (e.g. depression, symptom distress, coping, patient characteristics, income, duration of illness). Similarly, social support acted as a weighted variable within a Least Absolute Shrinkage and Selection Operator (LASSO) regression model, which included physical health and fatigue of the carer, depression, anxiety, gender, age, and economic and household variables (Lian et al., 2022). One study with carers of people with MS found social support was not a significant predictor (Rivera-Navarro et al., 2003) when controlling for years spent caring, work-related changes, scale of disability, and duration of MS. This may be due to the use of a social wellbeing subscale to assess social support, which is a slightly different conceptualisation of social support to that used by other studies, and may therefore have influenced the results.

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[2] There appeared to be errors reported in Edwards & Scheetz (2002). All correlations were reported as positive, but this was contradicted in the report. Clarification was sought from the study authors. However, no response was received. For the purposes of this review, correlations have been interpreted as implied by the report and subsequent analyses.

One study explored the relationship between social support and burden using a structural equation model (SEM) (Yang et al., 2019). Alongside self-efficacy, social support acted as a mediator between motor function in people with Parkinson's and carer burden, accounting for 76.8% of the variance.

**Depression.** Eight of the 26 studies investigated depression across the four conditions, seven of which reported correlation analysis (Bambara et al., 2014; Hooker et al., 1998; Pagnini et al., 2010; Pakenham, 2001; Perrin et al., 2019; Roscoe et al., 2009; Tyler et al., 2020). Four reported significant associations between greater social support and lower depression for carers of people with Parkinson's, MS, and MND (Bambara et al., 2014; Pagnini et al., 2010; Perrin et al., 2019; Tyler et al., 2020), all reporting medium to large effect sizes. In contrast, three studies reported no significant association between social support and depression for carers of people with Parkinson's, MS, and HD (Hooker et al., 1998; Pakenham, 2001; Roscoe et al., 2009).

Three studies used regression analysis to explore social support as a predictor of depression (Bambara et al., 2014; Pakenham, 2001; Perrin et al., 2019). Two of these (Bambara et al., 2014; Pakenham, 2001), both looking at carers of people with MS, found greater social support significantly predicted lower depression. Both controlled for condition severity, while Pakenham (2001) also controlled for carer gender, caregiving appraisal, and coping. One study compared results for carers of people with Parkinson's across two samples, one from the USA and one from Mexico (Perrin et al., 2019). Unmet emotional, instrumental, and community support needs were significant predictors of depression in the US sample, but only unmet instrumental support was a significant predictor in the Mexican sample.

One study used SEM to explore the relationship between social support and depression (Yang et al., 2019). In this study, social support, along with self-efficacy, was significant within the analysis, accounting for 51% of the variance as a mediator between motor function in people with Parkinson's and carer depression.

**Anxiety.** Three of the 26 studies explored the relationship between social support and anxiety in carers of people with Parkinson's (Hooker et al., 1998; Perrin et al., 2019; Tyler et al., 2020). Tyler et al. (2020) reported significant correlations between higher social support and lower anxiety for all social support subscales (appraisal, belonging, and tangible), with small to medium effect sizes. Hooker et al. (1998) reported a similar effect size, but this was not significant. Perrin et al. (2019) also reported similar correlations in size and direction for the US sample (i.e. increased unmet need was associated with higher anxiety), but only instrumental support was significant. In the Mexican sample, effect sizes were more widely spread ($r = .19$ for professional support to $r = .47$ for emotional support). In this case, only professional support was not significant.

One study used regression analysis to examine social support as a predictor of anxiety (Perrin et al., 2019). In the US sample, unmet emotional and instrumental support needs significantly predicted greater anxiety. In the Mexican sample, only unmet instrumental support needs was a significant predictor, and the model as a whole was not significant.

**Distress.** Two studies explored carer distress in carers of people with MS (Pakenham, 2001; T.E. Sherman et al., 2007). T.E. Sherman et al. (2007) reported a significant association between higher social support and lower distress in carers of people with MS, indicating a medium-large effect size. In contrast, Pakenham's (2001) longitudinal study, also focusing on carers of people with MS, found only very small, non-significant effects at two time points, twelve months apart.

In a regression model including patient variables, condition severity, awareness of deficits, and executive and behavioural difficulties, increased social support significantly predicted lower distress (T.E. Sherman et al., 2007). However, Pakenham's (2001) regression model, including characteristics of the person with MS, carer gender, caregiving appraisal, and coping, did not significantly predict distress, and social support was not a significant predictor within it.

**Mood.** One study found no association between social support and mood in carers of people with MS (O'Brien et al., 1995). However, social support was a significant predictor of mood when controlling for neuropsychological functioning in the person with MS, objective and subjective burden, uncertainty, and coping. Nevertheless, social support accounted for only 3% of the total 49% variance accounted for by the model.

### ***Composite Measures.***

Three studies utilised composite outcome measures (Goldstein et al., 2006; Mickens et al., 2018; Tyler et al., 2020), two of which reported correlation analyses (Goldstein et al., 2006; Mickens et al., 2018). Mickens et al. (2018) reported an association between unmet family needs and poor mental health in carers of people with MS, where mental health was comprised of depression, anxiety, carer burden, and SwL. Although a large effect size was observed ($r = -.55$), this correlation was not significant, despite their sample size ($n = 81$) being sufficient to detect large effect sizes in correlation analysis (Bujang et al., 2016). In contrast, Goldstein et al.'s (2006) composite 'carer outcome' measure, comprised of anxiety and depression, carer strain, and carer burden, was significantly correlated with negative social support (inadequate or worsening support) in carers of people with MND at an initial time point. Social support at time one was significantly correlated with carer outcome at time two, and approaching significance at time three (each time point approximately 5-6 months later). Sample size could be a factor in this change of significance, as the data showed attrition of participants over time ($n = 36$ at time one, 23 at time two, 19 at time three). The correlations showed medium to large effects of negative social support on carer outcomes.

One study used regression analysis to explore the relationship between social support and carer outcome (Goldstein et al., 2006). Caregiving variables at time one were used as predictor variables for three time points. Controlling for satisfaction with relationships, marital intimacy, number of dependants, and carer ratings of their partner’s functional limitations, negative social support was not a significant predictor of carer outcome at baseline, but it became the most significant predictor at time two. At time three, negative social support was not significant.

Two studies used SEM to explore the role of social support in carer mental health (Mickens et al., 2018; Tyler et al., 2020). Using a composite measure of depression and anxiety, Tyler et al. (2020) reported a significant indirect effect of social support on the mental health of carers of people with Parkinson’s, with resilience as a mediator. They also reported a significant direct effect of increased social support on improved mental health. In contrast, Mickens et al. (2018) found that unmet family needs was not significantly associated with mental health. However, it did act as a mediator between greater MS impairments and poorer mental health.

## Discussion

### Summary of findings

This review retrieved and synthesised 26 quantitative studies relating to whether social support acted as a predictor of psychological wellbeing in carers of people with Parkinson’s, MS, MND and HD. One study included a sample of carers of people with any of the four conditions; all other studies focused on carers of people with one of the four conditions specifically. Broadly, greater social support correlated with increased positive and reduced negative wellbeing outcomes. Results from the regression analyses were less consistent; social support acted as a significant direct predictor in some studies but not all, and regression models varied in terms of sample size and covariates. Effect sizes across the studies were also varied, but direct comparisons were challenging due to the breadth of measures used to conceptualise social support. While efforts were made to capture both positive and negative wellbeing outcomes, negative outcomes far outweighed positive.

### Social Support Across Conditions

This review found that the impact of social support on wellbeing was similar across carers of people living with the four different conditions, with only minor differences. Effect sizes were more diverse in studies relating to Parkinson's (ranging from small to large) compared to other conditions (medium to large). Studies relating to MND were more likely to focus on negative outcomes, and reported slightly less consistent findings. Two (Love et al., 2005; O'Connor & McCabe, 2011) of the six MND studies reported no significant associations between social support and wellbeing outcomes, which is a slightly larger proportion of non-significant results relative to the number of studies than seen in other conditions. The small number of HD studies (*n* = 3) made it difficult to draw definitive comparisons with other conditions, and conclusions should therefore be applied more tentatively to this condition.

Nonetheless, despite these differences, social support was more often associated with wellbeing than not in all conditions, suggesting commonalities in the factors influencing carer wellbeing. For example, difficulties with sleep, financial barriers, challenges with employment, and experiences of loss and grief may affect a range of carers (Toze et al., 2021; Wang et al., 2020), and difficulties associated with caring are likely to be multidimensional, regardless of the condition in question (Larkin et al., 2019). It is perhaps not surprising, therefore, that social support was found to have similar importance across carers. This speaks to a wider carer experience, in which the wellbeing of carers is consistently shaped by a similar range of factors, social support being one of them.

### Conceptualising Social Support

Twenty-two social support measures were used across the 26 studies. Some measures contained subscales, offering further division in the way in which social support was conceptualised, and studies varied in whether they reported subscale or total scores. This breadth in conceptualisation has been highlighted elsewhere (Mantri-Langeveldt et al., 2019; Perkins & Lamartin, 2012; Priego-Cubero et al., 2023). One critical appraisal identified 25 definitions of social support across disciplines (Williams et al., 2004). In the present review, conceptualisations of social support spanned availability of support (Pakenham, 2001), inadequacy of support (Goldstein et al., 2006), and satisfaction with support (O'Connor & McCabe, 2011). Where multidimensional measures of social support were used, dimensions covered both the source (e.g. community, professional, family) (J. Lee et al., 2019; Perrin et al., 2019), and the nature of support received (e.g. tangible, informational, emotional) (Roscoe et al., 2009; Tyler et al., 2020). This range of conceptualisation presents barriers to drawing comparisons, and conclusions must be tentative. For example, where studies reported subscales, emotional support was more often associated with wellbeing outcomes than tangible or informational support (E. J. Lee et al., 2015; Roscoe et al., 2009). However, there was variation in this: one study found that unmet emotional support needs significantly predicted carer depression in a sample from the US, but not in a sample from Mexico (Perrin et al., 2019), suggesting a cultural element to the way in which social support functions. However, although the retrieved studies presented data from a range of countries, the inconsistency of measures used made it impossible to explore this cultural element further. Greater consistency in the conceptualisation of social support would enable future research to explore the associations between culture, emotional support, and carer wellbeing in greater depth.

## Use of Theory

Social support was broadly associated with wellbeing outcomes in correlation analyses. However, as an independent predictor within regression analyses, its function was varied. In some cases, this could be attributed to sample size (Goldstein et al., 2006; O'Brien et al., 1995; Waldron-Perrine et al., 2009). However, another explanation is the diversity of covariates used across regression models, which included demographics, disease characteristics, economic factors, marital satisfaction, and psychological variables. This highlights a weakness in the literature: the lack of theoretical underpinning to model design (see Table 1.6). Of the 26 studies, only seven referred to a theoretical framework in their design (E. J. Lee et al., 2013; Mickens et al., 2018; O'Brien et al., 1995; O'Connor & McCabe, 2011; Pakenham, 2001; Roscoe et al., 2009; Waldron-Perrine, 2009). These studies predominantly used a stress process model as the basis for their hypotheses (Lazarus & Folkman, 1984), in which individuals' wellbeing is contingent on their appraisal of their resources and ability to cope with stressors. However, few studies overtly stated the theoretical underpinning to the construction of regression models, possibly accounting for the lack of consistency in the covariates selected. Where variation in findings was observed, it was therefore difficult to ascertain whether this resulted from different conceptualisations of social support, a different range of covariates, or a robust statistical finding. This emphasises the importance of improving the utilisation of psychological theory in social support research (Lakey & Cohen, 2000).

## Applying Theory to the Findings

The two continua model of mental health argues that positive and negative wellbeing should be considered separately, rather than as two ends of the same spectrum (Westerhof & Keyes, 2010). To some extent, the findings of this review are supported by the two continua model. Considering individual outcomes, social support was most consistently associated with burden (greater social support was associated with lower burden), while the association between social support and SwL was less consistent. This could indicate that social support functions differently in relation to negative wellbeing outcomes (i.e. burden) than it does in relation to positive ones (i.e. SwL), thus acting in line with the two continua model.

However, despite variation at an individual outcome level, on a broader scale, greater social support was associated with increased positive and reduced negative outcomes overall, suggesting that they may indeed be operating on the same spectrum. From this perspective, social support appeared to act in line with a bipolar model of mental health, in which mental health is understood as the absence of mental illness (Iasiello et al., 2020), and positive psychological wellbeing is achieved through the absence of negative constructs such as burden. Indeed, some studies included in this review operationalised the positive concept of wellbeing through the use of negative outcome measures (Bayen et al., 2023; Love et al., 2005), thereby presumably endorsing this position.

The fact that social support was associated with both positive and negative outcomes may therefore support the use of the bipolar model of mental health with carers. However, there was insufficient evidence to draw definitive conclusions, due to the high proportion of studies investigating negative outcomes in comparison to those investigating positive ones. Studies investigating the single concept of burden exceeded the number of studies investigating all positive outcomes combined. One systematic review assessing the psychometric properties of positive psychology measures attributed this lack of focus in part to the poor quality of measures available (J. Stansfeld et al., 2017). However, in the present review, the majority of studies investigating positive psychology concepts used well-validated scales (DelVecchio Good et al., 1979; López-Ortega et al., 2016; Morley et al., 2022; Vahedi, 2010), indicating that this lack of attention is not a result of inadequate measures to assess positive psychology concepts. While research continues to focus on negative outcomes at the expense of increasing understanding of positive outcomes, it will continue to be challenging to draw conclusions around the best model through which to interpret carer mental health.

## Limitations of the Literature

Quality appraisal revealed limitations in the included studies. Justification of sample size was limited. Only one study reported an *a priori* power calculation (O’Connor & McCabe, 2011). Two gave some justification of sample size but did not provide power analyses (J. Lee et al., 2019; Yang et al., 2019), and six noted the limitations of their sample size, either as a risk factor for poor model fit, or as a barrier to conducting more detailed analysis (Bambara et al., 2014; E. J. Lee et al., 2015; Mickens et al., 2018; O’Brien et al., 1995; Pakenham, 2001; Roscoe et al., 2009). The majority of samples were recruited through specialist medical settings or outpatient clinics. While this aligned the sample frame closely to the target population, it also meant that those not accessing professional support were excluded from many of the studies.

Many studies did not report ethnicity. Among those which did, the majority of samples were composed predominantly of White participants. It is therefore difficult to know the extent to which findings can be generalised to other populations. As discussed, few studies explicitly referred to a theoretical model underpinning their analysis. The majority of studies ($n$ = 23) were cross-sectional, meaning directional relationships should be interpreted with caution. Of those studies reporting longitudinal data ($n$ = 3), one was precluded from conducting full analysis of subsequent data (12 months later) due to the impact of attrition on sample size (Pakenham, 2001). This is indicative of some of the difficulties of conducting longitudinal research with groups affected by neurodegenerative motor conditions, where worsening symptoms and rapid deterioration present barriers to research participation (Garcia & Marder, 2017).

## Strengths and Limitations of the Review

This review brings together research on two important but poorly understood concepts: social support and wellbeing. In the case of social support, the review highlights the lack of clarity and consistency in how this concept is defined, and emphasises the importance of increasing understanding of how different facets of social support operate. The review illustrates that research into positive psychology outcomes, particularly wellbeing, is vastly overshadowed by research investigating negative outcomes. As caregiving is often comprised of both positive and negative experiences (Theed et al., 2017), the overfocus on negative outcomes risks the evidence base not reflecting the complete caregiving experience. Given the similarities noted between conditions (Ghielen et al., 2019), as well as the limited research in this area, combining findings relating to four neurodegenerative conditions enabled this review to give attention to carers of people with conditions which are less commonly featured in research, such as HD and MND (Zarotti et al., 2021), and to offer preliminary findings regarding social support and carer wellbeing. Further condition-specific research is needed, particularly regarding HD; nevertheless, in the present review, few differences between groups were identified.

Regarding limitations, only peer-reviewed studies were included to establish a baseline of quality for the reviewed studies. Grey literature, including theses, were excluded. Only papers published in English were considered for inclusion, meaning that findings from non-English speaking researchers have been excluded. Given the possible link identified between culture and experiences of social support, the inclusion of research from non-English speaking researchers would have been a valuable addition to this review. Finally, the majority of this review was conducted by a single researcher, raising the risk of bias. However, steps were taken to attempts to address this, including blind review by a peer of a selection of studies for quality appraisal, and discussions among the research team throughout the exclusion process.

## Clinical Implications

The findings suggest that social support may play an important role in supporting carer wellbeing, and should be considered by professionals working with carers of people with neurodegenerative motor conditions. Social support was found to be of value across carers of people with all four neurodegenerative motor conditions. This has important implications for carers of people with conditions such as HD and MND, where barriers to research participation limit the availability of studies focusing on these groups (Musson et al., 2019; Parekh et al., 2018; Steinhauser et al., 2006). Therefore, this review indicates that other research findings related to carers of people with Parkinson's and MS could be applicable to carers less often featured in research, offering new avenues to improving wellbeing in these groups.

While guidance differs internationally, in the UK, NICE guidance recommends that carers are informed about community support services they can access (National Institute for Health and Care Excellence [NICE], 2020). However, reports from the charity Parkinson's UK have found that not only are individuals not routinely informed about support following diagnosis (Mcdonnell et al., 2014), but the majority of carers do not receive the social care assessment to which they are entitled (Parkinson's UK, 2020). Additionally, no guidance is provided as to how practitioners can identify those in need of social support, and recommendations for practitioners assessing risk do not include measures assessing social support (Department of Health, 2009). Further guidance is therefore needed around how professionals can assess and respond to poor levels of social support in carers. Peer support interventions have been suggested as beneficial to the wellbeing of carers of people with dementia (Carter et al., 2020), but only a small number of studies have considered the effect of peer support interventions for carers of people with other neurodegenerative conditions (Clare et al., 2018). The findings of the current review would suggest that such interventions could be beneficial to carers of people with neurodegenerative motor conditions, and are worthy of further investigation.

## Direction for Future Research

A consistent theme across this review has been the lack of conceptual clarity around social support. Future research would benefit from better defining social support and increasing clarity around what aspect of social support measures are assessing. Consistency would aid understanding around aspects such as emotional, tangible, and informational support, and enable interventions to be tailored to the needs of carers (Nurullah, 2012). Furthermore, this review highlights a need for more robust use of psychological theory in social support research (Lakey & Cohen, 2000). Increased consistency in theoretical approach would improve insight into how social support functions, and allow for more definitive conclusions to be drawn.

Research has highlighted difficulties in accessing carers who do not identify with the term ‘carer,’ because they view the support they provide as one aspect of a relationship, rather than through the discourse of burden with which it is often associated (Henderson, 2001; Hughes et al., 2013; Molyneaux et al., 2011). As discussed, studies focusing on positive psychology outcomes, such as wellbeing, are still in the minority. Therefore, in addition to broadening understanding of an important psychological concept, redirecting the focus of carer research away from burden and towards wellbeing may help to access carers who object to the negative lens through which carer identities are often viewed, and offer a more holistic and nuanced picture of carers’ mental health.

## Conclusion

This review aimed to synthesise quantitative studies investigating the role of social support in the wellbeing of carers of people with Parkinson’s, MS, HD, and MND. Findings were broadly consistent across carers of people with all four conditions. Increased social support was generally associated with greater positive outcomes, such as wellbeing and quality of life, and with reduced negative outcomes, such as burden and mental health difficulties. Conceptualisations of social support were inconsistent, and future research would benefit from refining this concept. This has clinical implications in highlighting the importance of social support in carer wellbeing. The value of the contribution made to individuals and society by carers cannot be overstated. Findings such as these should therefore be used to transform the potential aims of interventions, such as improving social support, into testable, co-produced methods to help relieve distress and enhance wellbeing for informal carers.

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**Table 1.1**

*CINAHL Search Strategy*

| Search Number | Search Type | Terms |
|---|---|---|
| S1: Carers | Mesh | (MH "Caregivers") OR (MH "Caregiver Burden") OR (MH "Caregiver Support") |
| | Key words | Carer* OR caregiv* OR “care partner”<br>OR<br>((famil* OR spous* OR partner* OR husband* OR wife OR wives OR child* OR parent* OR mother* OR father* OR son* OR daughter* OR sibling* OR brother* OR sister OR friend* OR neighbour* OR neighbor* OR relat* OR informal OR unpaid) N3 (care* OR “caregiv*” OR “care partner” OR dyad)) |
| S2: Social support | Mesh | (MH "Support, Social+") OR (MH "Social Inclusion") OR (MH "Social Isolation") |
| | Key words | “social support” OR “social inclu*” OR “social exclu*” OR “social* isolat*” OR “social connect*” OR “social interaction*” OR “social ties” or “social contact*” OR “social capital”<br>OR<br>(social* N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties OR contact*))<br>OR (fami* N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties OR contact*))<br>OR (communit* N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties OR contact*)) |

| | | |
|---|---|---|
| | | OR (psychosocial N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties or contact*)) |
| S3: PD | Mesh | (MH "Parkinson Disease") OR (MH "Parkinsonian Disorders+") |
| | Key words | Parkinson* OR "lewy body" |
| S4: HD | Mesh | (MH "Huntington's Disease") |
| | Key words | Huntington* OR Chorea |
| S5: MS | Mesh | (MH "Multiple Sclerosis+") |
| | Key words | “multiple sclerosis” OR “multiple-sclerosis” OR MS |
| S6: MND | Mesh | (MH "Amyotrophic Lateral Sclerosis") OR (MH "Motor Neuron Diseases+") |
| | Key words | “motor neuron*” OR “Amyotrophic lateral sclerosis” OR ALS OR MND |
| S7 | PD OR HD OR MS OR MND (S3 OR S4 OR S5 OR S6) | |
| Total CINAHL | (S1 AND S2 AND S7): 516 | |

**Table 1.2**

*MEDLINE Search Strategy*

| Search Number | Search Type | Terms |
|---|---|---|
| S1: Carers | Mesh | (MH "Caregivers") OR (MH “Caregiver Burden”) |
| | Key words | Carer* OR caregiv* OR “care partner”<br>OR<br>((famil* OR spous* OR partner* OR husband* OR wife OR wives OR child* OR parent* OR mother* OR father* OR son* OR daughter* OR sibling* OR brother* OR sister OR friend* OR neighbour* OR neighbor* OR relat* OR informal OR unpaid) N3 (care* OR “caregiv*” OR “care partner” OR dyad)) |
| S2: Social support | Mesh | (MH "Social Support+") |
| | Key words | “social support” OR “social inclu*” OR “social exclu*” OR “social* isolat*” OR “social connect*” OR “social interaction*” OR “social ties” or “social contact*” OR “social capital”<br>OR<br>(social* N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties OR contact*))<br>OR (fami* N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties OR contact*))<br>OR (communit* N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties OR contact*))<br>OR (psychosocial N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties or contact*)) |
| S3: PD | Mesh | (MH "Parkinsonian Disorders+") |
| | Key words | Parkinson* OR "lewy body" |

| | | |
|---|---|---|
| S4: HD | Mesh | (MH "Huntington Disease") |
| | Key words | Huntington* OR Chorea |
| S5: MS | Mesh | (MH "Multiple Sclerosis+") |
| | Key words | “multiple sclerosis” OR “multiple-sclerosis” OR MS |
| S6: MND | Mesh | (MH "Motor Neuron Disease+") OR (MH "Amyotrophic Lateral Sclerosis") |
| | Key words | “motor neuron*” OR “Amyotrophic lateral sclerosis” OR ALS OR MND |
| S7 | PD OR HD OR MS OR MND (S3 OR S4 OR S5 OR S6) | |
| Total MEDLINE (S1 AND S2 AND S7): 672 | | |

**Table 1.3**

*PsycINFO Search Strategy*

| Search Number | Search Type | Terms |
|---|---|---|
| S1: Carers | Mesh | (DE “Caregiving”) OR (DE “Caregiving Burden”) |
|  | Key words | Carer* OR caregiv* OR “care partner”<br>OR<br>((famil* OR spous* OR partner* OR husband* OR wife OR wives OR child* OR parent* OR mother* OR father* OR son* OR daughter* OR sibling* OR brother* OR sister OR friend* OR neighbour* OR neighbor* OR relat* OR informal OR unpaid) N3 (care* OR “caregiv*” OR “care partner” OR dyad)) |
| S2: Social support | Mesh | DE "Social Support" OR DE "Perceived Social Support" OR DE "Social Connectedness" OR DE "Social Interaction" |
|  | Key words | “social support” OR “social inclu*” OR “social exclu*” OR “social* isolat*” OR “social connect*” OR “social interaction*” OR “social ties” or “social contact*” OR “social capital”<br>OR<br>(social* N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties OR contact*))<br>OR (fami* N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties OR contact*))<br>OR (communit* N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties OR contact*))<br>OR (psychosocial N3 (support OR network* OR relation* OR inclu* OR exclu* OR isolat* OR connect* OR interact* OR ties or contact*)) |
| S3: PD | Mesh | DE "Parkinson's Disease" OR DE "Parkinsonism" |

| | | |
|---|---|---|
| | Key words | Parkinson* OR "lewy body" |
| S4: HD | Mesh | DE "Huntingtons Disease" |
| | Key words | Huntington* OR Chorea |
| S5: MS | Mesh | DE "Multiple Sclerosis" |
| | Key words | "multiple sclerosis" OR "multiple-sclerosis" OR MS |
| S6: MND | Mesh | DE "Amyotrophic Lateral Sclerosis" |
| | Key words | "motor neuron*" OR "Amyotrophic lateral sclerosis" OR ALS OR MND |
| S7 | PD OR HD OR MS OR MND (S3 OR S4 OR S5 OR S6) | |
| Total PsycInfo (S1 AND S2 AND S7): 364 | | |

**Table 1.4**

*Scopus Search Strategy*

| Search Number | Terms |
|---|---|
| S1: Carers | Carer* OR caregiv* OR “care partner”<br>OR<br>(famil* w/3 care*) OR (spous* w/3 care*) OR (partner* w/3 care*) OR (wife w/3 care*) OR (wives w/3 care*) OR (child* w/3 care*) OR (parent* w/3 care*) OR (mother w/3 care*) OR (father* w/3 care*) OR (son* w/3 care*) OR (daughter* w/3 care*) OR (sibling* w/3 care*) OR (brother* w/3 care*) OR (sister* w/3 care*) OR (friend* w/3 care*) OR (neighbour* w/3 care*) OR (neighbor* w/3 care*) OR (relat* w/3 care*) OR (informal w/3 care*) OR (unpaid w/3 care*)<br>OR<br>(spous* w/3 dyad) OR (partner* w/3 dyad) OR (wife w/3 dyad) OR (wives w/3 dyad) OR (child* w/3 dyad) OR (parent* w/3 dyad) OR (mother w/3 dyad) OR (father* w/3 dyad) OR (son* w/3 dyad) OR (daughter* w/3 dyad) OR (sibling* w/3 dyad) OR (brother* w/3 dyad) OR (sister* w/3 dyad) OR (friend* w/3 dyad) OR (neighbour* w/3 dyad) OR (neighbor* w/3 dyad) OR (relat* w/3 dyad) OR (informal w/3 dyad) OR (unpaid w/3 dyad) |
| S2: Social support | “social support” OR “social inclu*” OR “social exclu*” OR “social* isolat*” OR “social connect*” OR “social interaction*” OR “social ties” or “social contact*”<br>OR<br>(social* w/3 support) OR (social* w/3 network*) OR (social* w/3 relation*) OR (social* w/3 inclu*) OR (social* w/3 exclu*) OR (social* w/3 isolat*) OR (social* w/3 connect*) OR (social* w/3 interact*) OR (social* w/3 ties) OR (social w/3 contact*)<br>OR (famil* w/3 support) OR (famil* w/3 network*) OR (famil* w/3 relation*) OR (famil* w/3 inclu*) OR (famil* w/3 exclu*) OR (famil* |

| | |
|---|---|
| | w/3 isolat*) OR (famil* w/3 connect*) OR (famil* w/3 interact*) OR (famil* w/3 ties) OR (famil* w/3 contact*)<br>OR (communit* w/3 support) OR (communit* w/3 network*) OR (communit* w/3 relation*) OR (communit* w/3 inclu*) OR (communit* w/3 exclu*) OR (communit* w/3 isolat*) OR (communit* w/3 connect*) OR (communit* w/3 interact*) OR (communit* w/3 ties) OR (communit* w/3 contact*)<br>OR (psychosocial w/3 support) OR (psychosocial w/3 network*) OR (psychosocial w/3 relation*) OR (psychosocial w/3 inclu*) OR (psychosocial w/3 exclu*) OR (psychosocial w/3 isolat*) OR (psychosocial w/3 connect*) OR (psychosocial w/3 interact*) OR (psychosocial w/3 ties) or (psychosocial w/3 contact*) |
| S3: PD | Parkinson* OR "lewy body" |
| S4: HD | Huntington* OR Chorea |
| S5: MS | “multiple sclerosis” OR “multiple-sclerosis” OR MS |
| S6: MND | “motor neuron*” OR “Amyotrophic lateral sclerosis” OR ALS OR MND |
| S7 | PD OR HD OR MS OR MND (S3 OR S4 OR S5 OR S6) |
| Total Scopus (S1 AND S2 AND S7): 235,474 | |

**Table 1.5**

*Quality Appraisal*

| Study | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21* |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Bambara et al. (2014) | Y | Y | N | Y | Y | DK | N | Y | Y | Y | Y | N | Y | N | Y | N | Y | Y | DK | Y | N |
| Bayen et al. (2023) | Y | Y | N | Y | Y | Y | N | Y | Y | Y | Y | N | DK | N | Y | Y | Y | Y | Y | Y | N |
| Dayapoğlu & Tan (2017) | Y | Y | N | Y | Y | N | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | N | Y | N |
| Edwards & Scheetz (2002) | Y | Y | N | Y | Y | N | Y | Y | Y | Y | N | N | Y | N | N | N | DK | Y | DK | Y | N |
| Goldstein et al. (2006) | Y | Y | N | Y | Y | N | N | Y | Y | Y | Y | Y | DK | N | Y | Y | Y | Y | Y | Y | Y |
| Hooker et al. (1998) | Y | Y | N | Y | Y | N | N | Y | Y | Y | Y | Y | DK | N | Y | Y | Y | Y | Y | DK | N |
| Knight et al. (1997) | Y | Y | N | Y | Y | N | DK | Y | N | Y | Y | Y | DK | N | Y | Y | Y | Y | DK | Y | N |
| E.J Lee et al. (2013) | Y | Y | N | Y | Y | N | N | Y | Y | Y | Y | Y | DK | N | Y | Y | Y | Y | DK | Y | N |
| E.J Lee et al. (2015) | Y | Y | N | Y | Y | N | Y | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | DK | Y | N |
| J. Lee et al. (2019) | Y | Y | Y | Y | Y | DK | Y | Y | Y | Y | Y | Y | N | N | Y | Y | Y | Y | N | Y | N |
| Lian et al. (2022) | Y | Y | N | Y | Y | DK | Y | Y | Y | Y | Y | Y | N | N | Y | Y | Y | Y | N | Y | N |
| Love et al. (2005) | Y | Y | N | Y | Y | N | N | Y | Y | Y | N | Y | Y | N | Y | Y | Y | N | DK | Y | N |
| Mickens et al. (2018) | Y | Y | N | Y | Y | N | Y | Y | Y | Y | N | N | N | N | Y | Y | Y | Y | N | Y | N |
| O'Brien et al. (1995) | Y | Y | N | Y | Y | DK | DK | Y | Y | Y | Y | Y | N | N | Y | Y | Y | Y | Y | Y | N |
| O'Connor & McCabe (2011) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | DK | Y | Y |

| | | | | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Pagnini et al. (2010) | Y | Y | N | Y | Y | DK | N | Y | Y | Y | Y | Y | DK | Y | Y | Y | Y | Y | Y | Y | N |
| Pakenham (2001) | Y | Y | N | Y | Y | N | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | DK | DK | Y |
| Perrin et al. (2019) | Y | Y | N | Y | Y | N | N | Y | Y | Y | Y | Y | DK | N | Y | Y | Y | Y | N | Y | N |
| Rivera-Navarro (2003) | Y | Y | N | Y | Y | DK | DK | Y | Y | Y | Y | N | DK | N | Y | N | Y | N | N | Y | N |
| Roscoe et al. (2009) | Y | Y | N | Y | Y | N | Y | Y | Y | Y | Y | N | N | N | DK | N | Y | N | DK | Y | N |
| Sherman (2007) | Y | Y | N | Y | Y | N | N | Y | Y | Y | Y | Y | DK | N | Y | Y | Y | N | Y | Y | N |
| Shin et al. (2012) | Y | Y | N | Y | Y | DK | N | Y | Y | Y | N | N | DK | N | N | Y | Y | Y | N | DK | N |
| Tülek et al. (2023) | Y | Y | N | Y | Y | N | N | Y | Y | Y | Y | Y | DK | N | N | Y | Y | Y | N | Y | N |
| Tyler et al. (2020) | Y | Y | N | Y | Y | N | N | Y | Y | Y | Y | Y | DK | N | Y | Y | Y | Y | N | Y | N |
| Waldron-Perrine (2009) | Y | Y | N | Y | Y | N | N | Y | Y | Y | Y | Y | DK | N | Y | Y | Y | Y | Y | Y | N |
| Yang et al. (2019) | Y | Y | Y | Y | Y | N | N | Y | Y | Y | Y | Y | DK | N | Y | Y | Y | Y | N | Y | N |

Y = yes, N = no, DK = don’t know

Full details of quality appraisal tool provided in appendix 1.1

* Additional item added: Did this study use a longitudinal design?

**Table 1.6**

*Characteristics of included studies, ordered by condition.*

| Study (year) Country | Condition of person cared for | Carer N (mean age) | Recruitment | Design | Analysis | Measure of social support | Outcome variables | Quality Appraisal* | Findings |
|---|---|---|---|---|---|---|---|---|---|
| HD | | | | | | | | | |
| Bayen et al. (2023), France | HD | 80 (57) | French national reference centre of HD | Cross-sectional | Multivariate regression, linear regression | Oslo Social Support Scale | RUD, ZBI, European Working Condition Survey | Theoretical approach not stated. Small sample for model. Social support not clearly defined. | Social support not significantly associated with objective burden (*p* = .25) but significantly negatively predicted subjective burden (β = -0.26, *p* = .025). |
| Roscoe et al. (2009), USA | HD | 17 (54) | Huntington's Disease Centres of Excellence | Cross-sectional | Correlation | SSI | LSI-Z, CES-D | Theoretical approach: stress process model. Model underpowered. Social support definition: tangible, informational, emotional. | Emotional support significantly correlated with SwL (*r* = .522, *p* < .05). Social support, tangible support, and informational support not correlated with SwL. No significant correlations between social support and depression. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| MND | | | | | | | | | |
| Goldstein et al. (2006), UK | MND | 50 (61.59) | King’s MND Care and Research Centre | Longitudinal | Linear mixed regression | CPQ | HADS, Strain Scale, CBI | Participants purposefully selected based on participating in other projects. Theoretical approach not stated. Statistical power not addressed; likelihood model underpowered. Social support definition covers emotional, practical and negative (worsening) support. | Negative social support significantly correlated with carer outcome at times 1 and 2 ($r = .352$, $p = .036$, and $r = .611$, $p = .002$ respectively) but not time 3 ($r = .436$, $p = .062$). Negative social support significantly predicted outcome at time 2 only ($t(19) = 3.29$, $p= 0.004$, $R^2 = 0.36$). |
| Lian et al. (2022), China | MND | 57 (45.32) | Via hospital | Cross-sectional | Correlation, Least absolute | SSRS | ZBI, HAMA, | Theoretical approach not stated. Model appears | Social support significantly correlated with burden ($r = -.41$, $p < .05$) and depression ($r$ |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | shrinkage and selection operator (LASSO) regression | | HAMD-17 | underpowered but not discussed. Refers to satisfaction with social support but no further definition given. Carers with physical or mental health issues excluded. | = .037, *p* < .05), but not anxiety. Ten variables predicted carer burden, including social support (variable weight = -0.455). |
| Love et al. (2005), Australia | MND | 75 (Range = 15 – 75, mean not reported) | Motor Neurone Disease Association of Victoria | Cross-sectional | Multiple Linear Regression | Caregiver Network Scale | GHQ-12 | 33% response rate. Theoretical approach not stated. Model adequately powered. Social support defined as received support, self-care, satisfaction, and stress on relationships. | Carer network scale subscales accounted for 39% of the variance in QoL, and the model was significant (*F*(4,70) = 11.17, *p* < 0.001). Only the stress on relationships subscale was a significant predictor (β = -0.37, *p* = 0.013). All other subscales were not significant (*p* > .05). |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Pagnini et al. (2010), Italy | MND | 40 (55.64) | NEuroMuscular Omnicentre Hospital | Cross-sectional | Correlation | Social support subscale from McGill QoL Questionnaire | ZBI, BDI | Theoretical approach not stated. Small sample size noted in limitations. Social support defined as perceived but no further definition. | Social support significantly correlated with carer burden ($\rho = -0.729$, $p < 0.001$), and depression ($\rho = -0.609$, $p$ 0.01). |
| Tülek et al. (2023), Turkey | MND | 108 (48.1) | ALS-MND Association | Cross-sectional | Correlation | MSPSS | ZBI | Theoretical approach not stated. Model adequately powered. Social support not clearly defined. | Perceived social support significantly correlated with carer burden ($r = -.28$, $p = .004$). |
| MS | | | | | | | | | |
| Bambara et al. (2014), USA | MS (veterans) | 42 (51.6) | Outpatient clinic | Cross-sectional | Hierarchical regression | SSSI | PHQ-9 | Theoretical approach not stated. Small sample but adequate model power. Social support definition: | Social support significantly negatively correlated with depression ($r = -.45$, $p < .01$) and significantly predicted depression ($\beta = -0.4$, $p < .01$). |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | ‘perceived availability of support across multiple domains.’ | |
| Dayapoğlu & Tan (2017), Turkey | MS | 98 (36.72) | Hospital admissions | Cross-sectional | Correlation | MSPSS | ZBI | Theoretical approach not stated. Model adequately powered. Perceived social support assessed but not defined. | Social support significantly negatively correlated with carer burden ($r = -.38$, $p < .01$). |
| Knight et al. (1997), New Zealand | MS | 55 (range = 29 – 74. Mean not reported) | Support groups, MS society, national carer’s network | Cross-sectional | Correlation, Hierarchical multiple regression analysis | Four items from SSQ | CBS, QLS | ‘No attempt made’ to ensure representativeness of sample. Approach based on previous stress theory research. Model underpowered. Satisfaction with | Social support significantly correlated with carer burden ($r = -.44$, $p < .05$), but not quality of life ($r = -.10$). Social support was a significant predictor of burden ($\beta = -.43$, $p = .002$) but not QoL ($p = .823$). The regression model ($F(7, 30) = 10.36$, $p < .0001$) predicted 61% of the variance in burden. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | social support measured but not clearly defined. | |
| E. J. Lee et al. (2013), USA | MS | 90 (49) | Caregiving or MS support websites | Cross-sectional | Path analysis, mediation | SSQ | APGAR | Theoretical approach: stress process theory. Model appears to be minimally powered but not discussed. Social support assessed as perceived quantity and satisfaction with support. | Social support significantly correlated with family adaptation (*r* = .35, *p* = .001). Social support, strain, and control of internal states all directly predicted family adaptation, accounting for 37.8% of the variance. Social support was a mediator between internal states and family adaptation. |
| E. J. Lee et al. (2015), USA | MS | 106 (52.87) | Caregiving or MS support websites | Cross-sectional | Correlation, t-tests, multiple regression | NNSQ | WHOQOL | Theoretical approach not stated. Bonferroni correction applied due to relatively small sample size. Assesses emotional, | Emotional support (*r* = -.25, *p* < .01), instrumental support (*r* = -.28, *p* < .01), professional support (*r* = -.37, *p* < .001) significantly correlated with QoL. Community support not significant. In men, QoL was |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | instrumental, and appraisal of social support. | significantly predicted by carer strain, needs for emotional support, and social support ($F(3, 43) = 10.20$, $p < 0.001$), accounting for 39% of the variance. In women, only strain and social support were significant ($F(3,54) = 14.53$, $p < 0.001$,). The model accounted for 43% of the variance. |
| Mickens et al. (2018), Mexico | MS | 81 (43.37) | Mexican Foundation of Multiple-sclerosis | Cross-sectional | Correlation, SEM | FNAT | ZBI,<br>SWLS,<br>PHQ-9,<br>STAI | Theoretical approach: stress appraisal model. Model underpowered. Unmet social support need represented by 2-item subscale of | Social support not significantly correlated with mental health ($r = -.55$, $p = .37$). Unmet family needs not significantly associated with mental health ($\beta = -0.38$, $p = 0.39$). However, a significant effect was observed when unmet family needs acted as a mediator between MS |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | FNAT. No definition given. | impairments and mental health ($\beta$ =0.13, $p$ = 0.008). |
| O'Brien et al. (1995), USA | MS | 61 (55.2) | Membership of an MS society chapter | Cross-sectional | Correlation, Hierarchical regression, mediation | SNLSSS | GHQ, Profile of Mood States – Bipolar Form, FSS, LSI-Z | Theoretical approach: stress process model. Model underpowered. Social support defined as perceived 'socialisation, tangible assistance, advice and guidance, social reinforcement, and emotional sustenance'. | Social support not significantly correlated with objective burden, subjective burden, life satisfaction, or mood ($r$ = -.18, .01, .19, and .23 respectively). Social support was a significant predictor of mood ($\beta$ = 0.179, $R^2$ = .480, $p$ = .05) and family satisfaction ($\beta$ = 0.242, $R^2$ = .343, $p$ = .001), but not life satisfaction. |
| Pakenham (2001), Australia | MS | 89 (49.87) | Hospital outpatient department, MS society adverts | Longitudinal | Correlation, Hierarchical | SSS | BSI, BDI, CRA | High number declined to participate. Theoretical approach: stress and | Social support significantly correlated with caregiving impact at times 1 and 2 ($r$ = -.27 and $r$ = -.34 respectively, $p$ < .001 for both), but not with |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | regression | | | coping theory. Attrition in sample prevented full analysis of longitudinal data. Social support availability assessed as emotional, problem-solving, physical, and indirect. | carer distress or depression. Social support was a significant predictor of depression (β = -0.21, $\Delta R^2 = 0.04$, $p < 0.05$) and caregiving impact (β = -0.25, $\Delta R^2 = 0.06$, $p < 0.05$), but not of distress (β = -0.11). |
| Rivera-Navarro et al (2003), Spain | MS | 91 (51.5) | Neurology Outpatient Clinic | Cross-sectional | Correlation, Regression | Social/family wellbeing subscale on FAMS | ZBI | Full regression data not reported. Theoretic approach not stated. Modal underpowered. Social support assessed as social/family wellbeing. | Family/social wellbeing significantly correlated with burden ($r = -.353$, $p = .001$). The regression model was not significant. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Sherman et al. (2007), USA | MS | 74 (49.1) | Tertiary care teaching hospital | Cross-sectional | Correlation, Multiple regression | SPS | GSI, SWLS | Theoretical approach not stated. Models underpowered. Social support not clearly defined. | Social support significantly correlated with distress ($r$ = -.40, $p < .001$) and SwL ($r$ = .44, $p < .001$). Social support significantly predicted distress (β = -0.38, $R^2$= 0.12, $p < 0.01$). The total model accounted for 43% of the variance. Social support significantly predicted SwL (β = 0.040, $R^2$= 0.14, $p$ <0.001.). The total model accounted for 37% of the variance. |
| Waldron-Perrine (2009), USA | MS | 64 (50.7) | Tertiary care neurology clinic | Cross-sectional | Correlation, ANCOVA, Multiple Regression | SPS | SWLS | Theoretical approach: buffer hypothesis. Number of predictors limited due to insufficient power. Social support definition: perceived | Social support significantly correlated with SwL ($r$ = .38, $p$ < .01). ANCOVA revealed a significant main effect of social support on SwL ($F$(1,58 = 4.81, $p$ = 0.032). Social support was not a significant predictor |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | availability of ‘attachment, social integration, reassurance of worth, reliable alliance, guidance, opportunity of nurturance’. | in regression analysis ($p$ = .104). |
| Parkinson’s | | | | | | | | | |
| Edwards & Scheetz (2002), USA | Parkinson’s | 41 (66.8) | Support groups, physician referrals, educational conferences | Cross-sectional | Stepwise multiple regression | PSS-Fa | ZBI | Possible errors in correlation reporting. Large percentage of non-respondents (40%). Stress process models referenced but not explicitly drawn on. Small sample size for model. Social support definition: | Social support reported as significantly positively correlated with burden ($r$ = .56, $p$ < .0002). However, social support reported as a significant negative predictor of burden in regression analysis (β = -0.348, $p$ = .037). Social support and activities of daily living accounted for 44.3% of the variance. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | extent to which family fulfils an individual's support needs. | |
| Hooker et al. (1998), USA | Parkinson's | 87 (67.1) | Hospital and neurology outpatients, support groups, newspaper and local adverts | Cross-sectional | Correlation | SSA | CES-D, BABS, STAI | Theoretical approach not stated. Adequate model power. Social support definition: subjective extent to which one feels 'loved, respected, and involved.' | Social support significantly correlated with wellbeing ($r$ = .26, $p < .05$), but not depression ($r$ = -.18) or anxiety ($r$ = -.19). |
| J. Lee et al. (2019), South Korea | Parkinson's | 208 (56.20) | Hospital neurology outpatients | Cross-sectional | SEM | Social Support Measurement Tool | PDQ-carer | SEM 'based on literature' (specific references not given). Social support assessed as family or physician support. Model slightly | Social support significantly correlated with QoL ($r$ = -.18, $p < .01$). There was a direct effect of social support on QoL ($\beta$ = -0.53, $p$ = 0.011), (low PDQ-carer scores indicate higher QoL). Within the SEM model, social support, |

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| | | | | | | | | underpowered (208 out of 220). | caregiving appraisal, and education programme needs had a significant effect on QoL. |
| Perrin et al. (2019), Mexico and USA | Parkinson's | 253, (USA: 68.73), Mexico: 53.66) | Speciality Parkinson's clinics | Cross-sectional | Correlation, Multiple Regression | Support subscales on FNQ | PHQ-9, GAD-7 | Theoretical approach not stated. Model adequately powered. Social support defined as emotional, instrumental, professional and community. | US sample: unmet needs for emotional support ($r = .431$, $p < .01$), instrumental support ($r = .466$, $p < .01$), professional support ($r = .316$, $p < .01$), and community network support ($r = .195$, $p = .05$) significantly correlated with depression. Unmet family needs explained 30.4% of the variance in depression, ($F(6, 104) = 7.12$, $p < 0.001$). Emotional support, instrumental support, and community support network were significant predictors. Unmet needs explained 29.5% of the variance in anxiety ($F$(6, |

104) = 6.82, $p < 0.001$). Emotional support ($\beta = 0.39$, $p = 0.010$) and instrumental support ($\beta = 0.44$, $p = 0.001$) were significant predictors. Mexico sample: unmet emotional support ($r = .271$, $p < .01$), instrumental support ($r = .358$, $p < .01$), professional support ($r = .219$, $p < .01$), and community support network ($r = .306$, $p < .01$) significantly correlated with depression. Unmet family needs explained 14.0% of the variance in depression, ($F(6, 147) = 3.83$, $p = 0.001$). Only instrumental support was a significant predictor. Unmet needs did not significantly predict anxiety.

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Shin et al. (2012), South Korea | Parkinson's | 91 (66.4) | Hospital outpatients | Cross-sectional | Multiple Linear Regression | SSI | ZBI | Theoretical approach not stated. Model adequately powered. Social support divided into private and community relationships. | Community relationships significantly predicted burden ($B$ = -0.318, $p$ = 0.034, $R^2$ = 0.462), accounting for 46.2% of the variance. |
| Tyler et al. (2020), USA and Mexico | Parkinson's | 253 (59.92) | Specialist Parkinson's clinics | Cross-sectional | Correlation, SEM | ISEL-12 | PHQ-9,<br>GAD-7 | Theoretical approach not stated. Model adequately powered. Social support definition: appraisal, belonging, tangible. | Social support appraisal significantly correlated with depression ($r$ = -.23, $p$ < .01), and anxiety ($r$ = -.15, $p$ < .05). Social support belonging significantly correlated with depression ($r$ = -.25, $p$ < .01) and anxiety ($r$ = -.13, $p$ < .05). Social support tangible significantly correlated with depression ($r$ = -.33, $p$ < .01) and anxiety ($r$ = -.28, $p$ < .01). A significant effect of social |

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| | | | | | | | | | support on mental health was reported ($\beta = -0.40$, $b = -0.69$, $p < 0.001$). |
| Yang et al. (2019), China | Parkinson’s | 112 (52.33) | Hospital outpatients | Cross-sectional | SEM | SSRS | ZBI, HADS | Theoretical approach not stated. Sample met minimum acceptable power. Social support defined as objective or subjective. | As a mediator, social support and self-efficacy accounted for 76.8% of the variance in burden and 51.0% of the variance in depression. |
| Multiple Conditions | | | | | | | | | |
| O’Connor & McMabe (2011), Australia | ALS (25.5%),<br>MS (20.8%),<br>Huntington's (22.4%),<br>Parkinson's (31.3%) | 192 (62) | National associations for each of the four conditions under investigation | Longitudinal | t-tests, regression | SSQ | WHOQOL | Theoretical approach: stress and coping model. *A Priori* power calculation reported. Total sample met power requirements, but individual condition samples | No significant difference in social support over time. Social support was a significant predictor of QoL for carers of people with HD ($\beta = 0.47$, $p = 0.01$), explaining 15% of the variance, and MS ($\beta = 0.50$, $p < 0.01$), explaining 23% of the variance, but not MND ($\beta =$ |

| | |
|---|---|
| were underpowered. Social support not clearly defined. | 0.04, $p = 0.76$) or Parkinson's ($\beta = 0.9$, $p = 0.48$). |

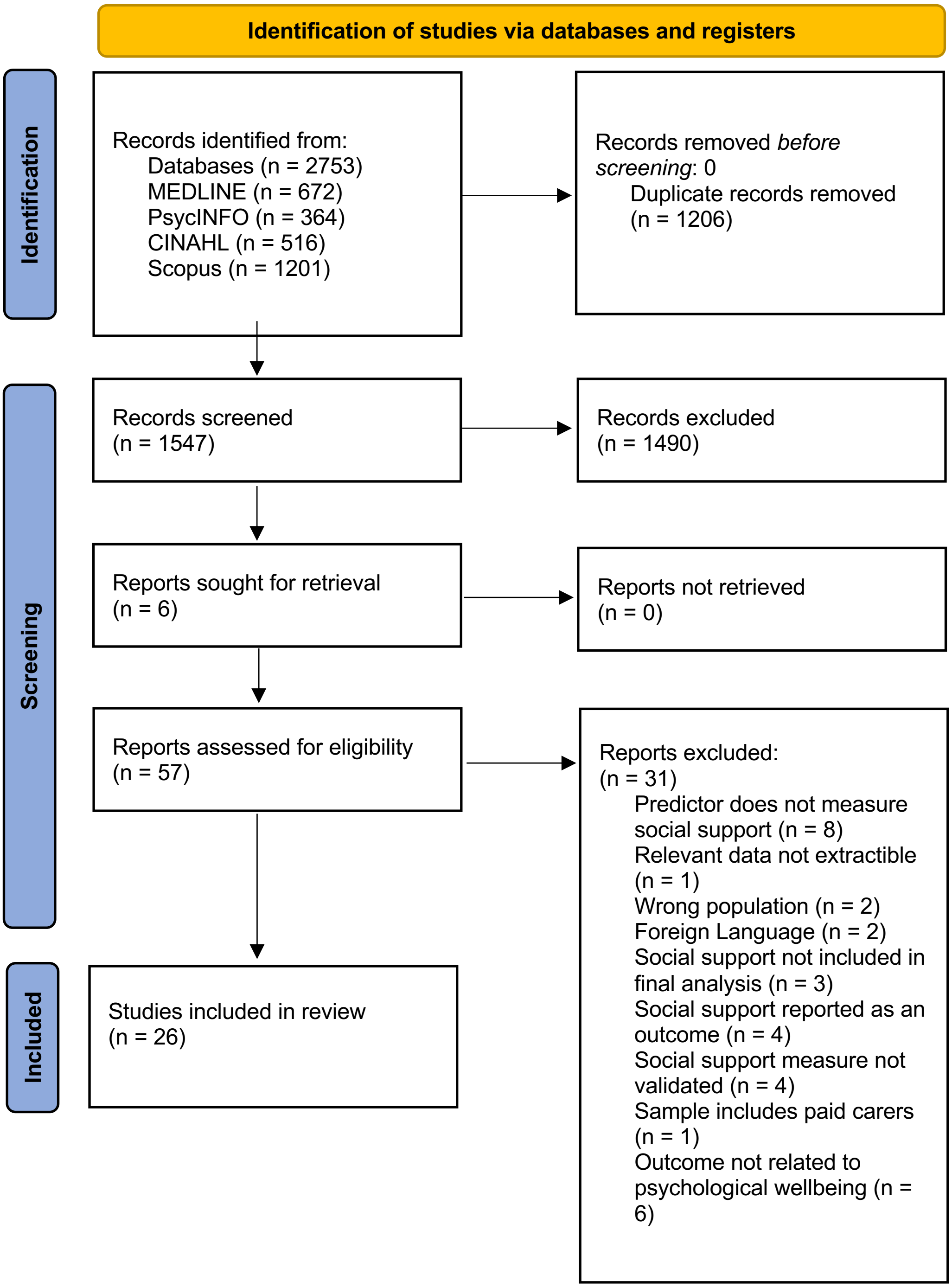
SSSI: Social stress and social support interview; MSPSS: Multidimensional scale of perceived social support; PSS-Fa: Perceived social support – family scale; CPQ: Close person's questionnaire; SSA: Social support appraisals scale; SSQ: Social support questionnaire; NNSQ: Norbeck social support questionnaire; SSRS: Social support rating scale; FNAT: Family needs assessment tool; SNLSSS: Social network list and support system scale; SSS: Social support scale; FNQ: Family needs questionnaire; FAMS: Functional assessment of MS; SSI: Social support index; SPS: Social provision scale; ISEL-12: Interpersonal support evaluation list

PHQ-9: Patient health questionnaire; RUDS: Resource utilization in Dementia; ZBI: Zarit Burden Interview; HADS: Hospital anxiety and depression scale; CBI: Carer burden inventory;  CES-D: Centre for epidemiological studies depression index; BABS: Bradburn affect balance scale; STAI: Strait trait anxiety inventory; CBS: Care burden scale; QLS: Quality of life Score; PDQ-Carer; Parkinson's disease questionnaire – carer; APGAR: Family adaptability, partnership, growth, affection and resolve; WHOQoL: World health organisation quality of life; HAMA: Hamilton anxiety scale; HAMD-17: Hamilton depression scale; GHQ-12: General health questionnaire; SWLS: Satisfaction with life scale; FSS: Family satisfaction scale; LSI-Z: Life satisfaction index-Z; BDI: Beck depression inventory; BSI: Brief symptom inventory; CRA: Caregiver reaction assessment; GAD-7: Generalised anxiety disorder; GSI: Global symptom index;

* Includes issues relating to statistical power, theoretical approach, and definition of social support used, in addition to any other relevant details arising from quality appraisal assessment.

**Figure 1.1**

*Prisma Diagram*



## Appendix 1.1: Quality Appraisal Tool

*Appraisal Tool for Cross-Sectional Studies (AXIS)*

| | Question |
|---|---|
| Introduction | |
| 1. | Were the aims/objectives of the study clear? |
| Methods | |
| 2. | Was the study design appropriate for the stated aim(s)? |
| 3. | Was the sample size justified? |
| 4. | Was the target/reference population clearly defined? (Is it clear who the research was about?) |
| 5. | Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation? |
| 6. | Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation? |
| 7. | Were measures undertaken to address and categorise non-responders? |
| 8. | Were the risk factor and outcome variables measured appropriate to the aims of the study? |
| 9. | Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously? |
| 10. | Is it clear what was used to determine statistical significance and/or precision estimates? (e.g. *p*-values, confidence intervals) |
| 11. | Were the methods (including statistical methods) sufficiently described to enable them to be repeated? |
| Results | |
| 12. | Were the basic data adequately described? |
| 13. | Does the response rate raise concerns about non-response bias? |
| 14. | If appropriate, was information about non-responders described? |
| 15. | Were the results internally consistent? |
| 16. | Were the results presented for all the analyses described in the methods? |
| Discussion | |
| 17. | Were the authors' discussions and conclusions justified by the results? |
| 18. | Were the limitations of the study discussed? |

| | |
|---|---|
| Other | |
| 19. | Were there any funding sources or conflicts of interest that may affect the authors’ interpretation of the results? |
| 20. | Was ethical approval or consent of participants attained? |
| 21.* | Did this study use a longitudinal design? |

* Additional question added to capture longitudinal studies

## Appendix 1.2: Author Guidelines for *Psychology and Health*

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*Updated 28th February 2024*

## Section Two: Empirical Paper

# How do Self-Compassion and Social Support Predict Wellbeing in Carers of People with Parkinson's?

Word count (excluding references, tables, and appendices): 7,952

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April 2024

Prepared in accordance with author guidelines for *Aging and Mental Health* (appendix 2.2)

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## Abstract

### Objectives

This was the first study to investigate the role of self-compassion in the wellbeing of carers of people with Parkinson's. The study aimed to investigate whether self-compassion and social support predicted carer wellbeing, and to explore whether self-compassion and/or social support moderated the relationship between carer stressors and wellbeing.

### Methods

A quantitative, cross-sectional, online survey design was used. Participants were 332 self-identified carers of people with Parkinson's. Data were collected regarding participant demographics, care-related tasks, and via validated measures of key variables. Data were analysed using hierarchical multiple regression and moderation analyses.

### Results

Self-compassion and social support were both significant independent predictors of wellbeing when controlling for carer stressors and demographics. Self-compassion was a significant moderator of the relationship between care tasks and wellbeing, and approaching significance in the relationship between carer burden and wellbeing. Social support was not a significant moderator.

### Conclusion

This study makes a unique contribution to knowledge in demonstrating that self-compassion and social support predicted wellbeing even accounting for the impact of carer stressors. Furthermore, self-compassion may protect against the impact of carer stressors, but this finding would require replication. Clinically, this demonstrates the need for individual and systemic approaches to promote wellbeing in carers of people with Parkinson's.

**Keywords:** Parkinson's, informal carers, self-compassion, social support, psychological wellbeing

## Introduction

Informal carers, the term used to describe those who provide support to friends or relatives who would otherwise struggle to meet their own needs (International Alliance of Carer Organizations [IACO], 2018), offer a substantial proportion of the care accessed by people with long-term physical or mental health difficulties. In Europe, research suggests that 12.7% of the population provide care informally to friends, relatives, or neighbours, representing approximately 576,000 million euros in unpaid labour and loss of paid employment (Peña-Longobardo & Oliva-Moreno, 2022). Definitions of informal carers vary between individual organisations and researchers, with some conceptualisations including requirements around the nature of the relationship with the person receiving care, the types of tasks undertaken, or the number of care hours provided (Tur-Sinai et al., 2020). In research, informal carers are generally defined as those who are not formally employed, in either a paid or voluntary capacity, to carry out the care they provide (Crawford et al., 2023; Hlabangana & Hearn, 2020; Qureshi et al., 2023). Informal carers face increased risk of physical and mental health difficulties (Cottagiri & Sykes, 2019), and research from the UK suggests that carers often feel their needs are not adequately met by health and social care services (Laparidou et al., 2019).

One group which faces significant and long-term challenges is carers of people with Parkinson's[1]. Parkinson's is a neurodegenerative condition, most prevalent in people aged over 60 (Mehanna et al., 2014), caused by a deficit of dopaminergic neurons in the substantia nigra (Hawley et al., 2014). Symptoms can include bradykinesia (slowness of movement), tremor, rigidity, sleep difficulties, fatigue, and decline in cognitive function (Heisters, 2011; Politis et al., 2010). Additionally, experiences of depression and anxiety are common (Khedr et al., 2020; Lubomski et al., 2020). Difficulties worsen with disease progression; those in the

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[1] The preferred term for Parkinson's disease used by the charity Parkinson's UK.

late stages of Parkinson’s are more likely to experience falls, insomnia, hallucinations, difficulty swallowing, and, in many cases, dementia (Fabbri et al., 2020; Oxtoby et al., 2021). There is currently no known cure for Parkinson’s, and while treatments such as dopaminergic medications and deep brain stimulation (DBS) can reduce bradykinesia and rigidity, they do not improve cognitive difficulties and effects diminish over time (T. K. Lee & Yankee, 2022; Nemade et al., 2021).

The degenerative nature of Parkinson’s, complex range of symptoms, and the lack of effective long-term treatment present significant difficulties for carers, who respond to the physical, cognitive, and psychological needs of the person they care for in the context of limited information, poor access to support, high treatment burden, and the limitations of their own emotional and physical response to caregiving (Chen et al., 2022; Tan et al., 2021; Theed et al., 2017). Unsurprisingly, therefore, caring for someone with Parkinson’s has frequently been associated with negative psychological outcomes (Aamodt et al., 2024; Bhimani, 2014; Lau & Au, 2011; Mosley et al., 2017). Research has typically explored factors affecting carers of people with Parkinson’s in relation to outcomes such as carer burden and mental health difficulties (Greenwell et al., 2015), and reviews focusing on seemingly positive outcomes, such as quality of life, often include studies assessing negative outcomes, such as depression and stress, in their analysis (Gumber et al., 2019). Although carers of people with Parkinson’s face many challenges, caregiving has been identified as encompassing both positive and negative elements (Walker et al., 2016). It is therefore important to consider positive psychological outcomes as well as negative ones when discussing carer experiences.

One positive outcome which is worthy of consideration in carers of people with Parkinson’s is psychological wellbeing. Wellbeing is related to, but distinct from, mental ill-health (Westerhof & Keyes, 2010), being primarily concerned with happiness, life satisfaction, and thriving (Tennant et al., 2007). Wellbeing is a holistic concept which, rather than depending solely on the absence of illness or distress, is influenced by a range of individual and social factors affecting a person's perceived potential to flourish (Simons & Baldwin, 2021). Carer wellbeing is influenced by a range of factors, including sense of purpose, optimism, appraisal of caregiving, and autonomy (Maguire et al., 2019). Furthermore, carers of people with Parkinson's have been found to report lower wellbeing than carers of adults with other age-related health difficulties (Vescovelli & Ruini, 2022), suggesting that this is a concept worthy of attention in carers of people with Parkinson's specifically.

Previous research has linked the stressors associated with caregiving, such as the nature of difficulties of the care receiver, the number of care-related tasks undertaken, and the hours of care provided, with poor carer wellbeing (Chappell & Reid, 2002; Drutyte et al., 2014; Peters et al., 2011). However, it is also important to consider factors which may promote greater wellbeing, such as social support (Siedlecki et al., 2014). Social support is understood as the perceived social resources an individual is able to access from those around them (Gottlieb & Bergen, 2010), and has been identified as a predictor of a range of outcomes for carers of people with Parkinson's, including burden, quality of life, depression, and anxiety (Edwards & Scheetz, 2002; J. Lee et al., 2019; Perrin et al., 2019; Tyler et al., 2020). Moreover, social support has been found to be predictive of wellbeing in other carer groups (A. Hayes et al., 2023; Orgeta et al., 2013). Although greater social support has been found to be significantly correlated with wellbeing in carers of people with Parkinson's, it has previously only been explored as a predictor of wellbeing within a combined sample including carers of people with Alzheimer's and Parkinson's (Hooker et al., 1998), and has not been investigated as a predictor of wellbeing in carers of people with Parkinson's specifically.

Another concept which may be important for carers of people with Parkinson's is self-compassion. Self-compassion can be understood as an ability to recognise and respond kindly to one's own suffering, and to see suffering as part of a universal human experience (Neff, 2003). Further theoretical development has suggested that self-compassion goes beyond this, and has placed increased emphasis on self-compassion requiring an active component, constituting a motivation to alleviate and prevent one's own suffering (Gilbert et al., 2017). In the current study, self-compassion was conceptualised using the multifactorial model proposed by Strauss et al. (2016), which encompasses elements of self-compassion related to positive psychological functioning. Empirical research has found low self-compassion to be a direct predictor of negative outcomes in carers of people with dementia and neurological conditions (Hlabangana & Hearn, 2020; Lloyd et al., 2019). However, although the role of self-compassion in carers of people with Parkinson's has been considered in grey literature (Hodge, 2019), there is currently no peer-reviewed study exploring the effect of self-compassion in this group. Moreover, no empirical study has previously investigated the effect of self-compassion on wellbeing for carers of people with Parkinson's.

In addition to establishing whether social support and self-compassion may have a beneficial effect on the wellbeing of carers of people with Parkinson's, it is also important to understand the mechanisms through which this may occur. The buffer hypothesis (Cohen & Wills, 1985) proposes that social support improves wellbeing through two processes: firstly, through a direct effect, in which greater social support is directly associated with greater wellbeing; secondly, through a 'buffering' model, in which social support improves wellbeing by protecting against the negative influence of stressors. The buffer hypothesis has been supported in carers of people with dementia, where increased social support reduced the strength of the relationship between perceived stress and quality of life (Gellert et al., 2018). Similarly, social support has been identified as a moderator in the relationship between care-related stressors and negative outcomes such as distress and burden (George et al., 2020; L. Xu et al., 2021). While social support has been found to moderate the relationship between stressors and negative outcomes in a combined sample comprised of carers of people with Alzheimer's, Parkinson's, and Parkinson's with dementia (Roland & Chappell, 2019), it has previously not been explored as a moderator between stressors and wellbeing within carers of people with Parkinson's.

In line with the buffer hypothesis, self-compassion acted as a buffer between specific stressors, such as stigma and the COVID-19 pandemic, and mental health difficulties in the general population (Beshai et al., 2022; Chan et al., 2020). In parents of children with emotional and behavioural difficulties, self-compassion moderated the relationship between emotional regulation difficulties and wellbeing (Shenaar-Golan et al., 2023). Additionally, self-compassion has been found to act as a moderator between stressors and negative psychological outcomes in carers generally (Wong et al., 2016; S. Xu et al., 2020). However, no study has previously considered the potential moderating function of self-compassion in carers of people with Parkinson's, nor has self-compassion been investigated as a moderator between stressors and wellbeing in carers of people with other long-term health conditions.

Consequently, the aim of this study was, firstly, to investigate whether self-compassion and social support directly predicted wellbeing in carers of people with Parkinson's, with their strength as predictors assessed against established predictors such as age and gender (Morley et al., 2012). Secondly, to explore whether self-compassion and social support acted as moderators in the relationship between carer stressors and wellbeing. The following hypotheses were investigated:

(1) Carer stressors would be negatively associated with wellbeing, and self-compassion and social support would be positively associated with wellbeing.

(2) Self-compassion and social support would be independent predictors of wellbeing when controlling for demographic factors and carer stressors.

(3) Self-compassion would moderate the relationship between carer stressors and wellbeing.

(4) Social support would moderate the relationship between carer stressors and wellbeing.

## Methods

### Design

This quantitative, cross-sectional study used online, self-report measures to collect data. Carer stressors were operationalised using two metrics to reflect the broad impact of caregiving: a validated measure of carer burden assessed carers' experiences of caregiving, and an assessment of care tasks, created for this study, captured the number and nature of care-related tasks carers were undertaking (see Materials section for details).

### Participants

Participants were adults (aged 18 and over) who self-identified as a carer of an individual with a diagnosis of Parkinson's, and who had been providing care (broadly defined as emotional or practical support) for at least 12 months. As the participant documents and questionnaires were not made available in other languages, participants were required to have good English comprehension.

In total, 332 participants were included in the analysis. An *a priori* power analysis, conducted using G*power, suggested that for multiple regression with three to six predictors, a sample size of between 77 and 98 participants was required to detect a medium effect size with 80% power ($p \leq .05$) (Faul et al., 2009). Small, medium, and large effect sizes in moderation analysis are considered to be 0.005, 0.01, and 0.025 respectively. Consequently, sample sizes of 200 or higher are generally required to detect noticeable effect sizes

(Whisman & McClelland, 2005). Large effects sizes have been reported for the interaction between self-compassion and stress when predicting depression in carers of people with cancer (Hsieh et al., 2019). In the current study, an *a priori* power calculation using G*power suggested that a sample size of 316 participants would be required to detect a large effect size ($f^2 = 0.025$) with 80% power ($p \leq .05$). Therefore, the current sample of 332 participants was sufficient for the proposed regression and moderation analyses.

## Procedure

The study was designed in consultation with four experts by experience, recruited through the charity Parkinson's UK. Experts met with the researcher via video call (https://zoom.us) to discuss their experiences, and provided email feedback on the content and useability of the participant documents. Participant materials were amended in response to the feedback.

Ethical approval was granted by the Lancaster University Faculty of Health and Medicine Research Ethics Committee (FHM-2022-0941-RECR-2).

The study was advertised online through Parkinson's UK's Take Part Hub (a database of research opportunities) and equivalent international organisations providing support to people affected by Parkinson's (e.g. Parkinson's Ireland, Parkinson's Europe, Parkinson's Australia etc.). The study was also advertised on Facebook and X (formerly Twitter). Physical copies of the advert were displayed in community and health venues such as libraries, town halls, and GP waiting rooms.

The advert directed people to the survey, hosted on a Qualtrics survey platform, via a link or QR code. Participants who wished to complete a paper version could request a postal copy via email or telephone. Participants were presented with the participant information sheet, followed by a consent form asking them to confirm they met the inclusion criteria and consented to be included in the study. Participants who did not answer 'Yes' to all consent and inclusion questions were not able to proceed to the survey. Those who answered ‘Yes’ to all consent questions were directed to the survey questions, which ended with a debrief sheet signposting to support resources (see ethics section for study adverts and participant materials).

All data were securely stored electronically. Returned paper questionnaires were manually entered into Qualtrics by the researcher and physical copies were securely destroyed.

## Materials

Information was collected pertaining to participant demographics, including age, gender, country of residence, employment, and ethnicity. Data were collected regarding participants’ relationship to the person receiving care, hours of care provided per week, whether they lived with the person with Parkinson’s, and whether the person with Parkinson’s lived in a residential support setting. These factors were included due to their potential to influence carer experiences and psychological outcomes (Armitage et al., 2009; Drutyte et al., 2014).

### *Predictor Variables*

**Carer Stressors.** Carer stressors were operationalised through the use of two metrics: the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989), which aimed to capture the emotional impact of caregiving, and an assessment of care tasks, which aimed to capture the practical impact.

The CBI (Novak & Guest, 1989) is a 24-item measure, which uses a Likert scale to assess the extent to which providing support to a close person due to illness or long-term condition negatively affects the person providing support. The measure has a total score and five subscales: Time-Dependence Burden, Developmental Burden, Physical Burden, Social Burden, and Emotional Burden. Both the total and the subscale scores have been found to be reliable and appropriate for use (Mecocci et al., 2005). The total score was used in this analysis. Total scores range from 0 to 96, where higher scores denote increased carer burden. This study used adaptations to the CBI recommended by  Caserta et al. (1996) in which the item '*I do not do as good a job at work as I used to*' is replaced by '*I do not get along as well as I used to with others*', and the item '*I've had problems with my marriage'* is expanded to include other relationships (Valer et al., 2015). Caserta et al. (1996) found that the original items jeopardised the reliability of the social burden subscale ($\alpha$ = .58 when included), and researchers have found that questions related to work are frequently not applicable for carers who may have retired or left work due to the demands of their caring responsibilities (Mecocci et al., 2005). The CBI has been found to be amenable to adaptation in other groups without detriment to its reliability (Conti et al., 2019; Farmer et al., 2018; Hassan & Najam, 2022). In carers of people with Parkinson's, the CBI has been found to have excellent internal consistency ($\alpha$ = .94) (Goldsworthy & Knowles, 2008), and has been used successfully online (Chahine et al., 2021).

The Care Tasks (CT) assessment () was created for the purposes of the study to understand the practical impact of caregiving. Previous research has attempted to capture caregiving intensity using the number of hours a person devotes to caregiving (L. Xu et al., 2021). However, no measure was found which assesses both the extent and the nature of caregiving tasks. Therefore, the CT assessment was created, through conversations with experts by experience, to capture the kind of tasks most relevant to carers of people with Parkinson's. Participants were presented with a 12-item list of possible tasks they might perform as a carer and asked to select those which applied to them. Item 12 was 'Other', with a free text space for participants to provide additional information about the care tasks they performed. Answers were scored as either one, if the task did apply to the participant, or zero, if it did not. Individual scores were combined to create a total score ranging from zero to twelve.

### *Moderator Variables*

**Self-Compassion.** The Sussex-Oxford Compassion for the Self scale (SOC-S) (Gu et al., 2020) was used to measure self-compassion. This is a 20-item Likert scale with a total score and five subscales: Recognising Suffering, Understanding the Universality of Suffering, Feeling for the Person Suffering, Tolerating Uncomfortable Feelings, and Acting or Motivation to Act to Relieve Suffering. Participants were asked to indicate the extent to which a list of given statements regarding self-compassion were true for them (‘Not at all true’ to ‘Always True’). The total score was used for this analysis, which has been found to be reliable (de Krijger et al., 2022; Meng et al., 2023). Possible total scores ranged from 20 to 100, with higher scores indicating greater self-compassion. As a relatively new instrument, the SOC-S has yet to be used with informal carers, but it has been found to be a reliable instrument with a range of populations, including working age and older adults (Schmidt et al., 2023; Shreffler et al., 2022; Strauss et al., 2021). The SOC-S has been found to have good internal consistency (Cronbach’s $\alpha = .86$) when used online as a total score (Halamová et al., 2023).

**Social Support.** Social support was measured using the Support for Caring subscale of the Adult Carer Quality of Life Questionnaire (AC-QoL(SS)) (Joseph et al., 2012). This was chosen because it assesses social support specifically within the context of caring, rather than in a more general sense. The subscale consists of five statements related to perceived support. Participants used a Likert scale to indicate how often given statements applied to them (‘Never’ to ‘Always’). Possible scores ranged from zero to fifteen, with higher scores indicating greater levels of support. Although not previously used specifically with carers of people with Parkinson’s, the AC-QoL has been used successfully with carers of people with dementia (Brooks et al., 2022), and the Support for caring subscale has been found to have good internal consistency (Cronbach's $\alpha$ = .87) (Negri et al., 2019).

### *Outcome Variable*

**Wellbeing.** The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) (Tennant et al., 2007) was used to assess psychological wellbeing in carers. The WEMWBS uses a 14-item Likert scale, and takes a positive psychology approach to mental health (García-Campayo et al., 2023). Participants were asked to indicate how often given statements could be applied to them over the past two weeks ('None of the time' to 'All of the time'). Possible total scores range from 14 to 70, with higher scores indicating greater wellbeing. The WEMWBS has been shown to have good to excellent internal consistency (Cronbach's $\alpha$ = .89 to 0.91) (Tennant et al., 2007), and has been successfully used with carers of people with Parkinson's (Simpson et al., 2022).

## Data Analysis

The information sheet was accessed 465 times between January and November 2023. Four people requested paper copies of the questionnaires, two of which were returned and manually inputted into Qualtrics. Of those who accessed the information sheet, 372 people indicated that they met the inclusion criteria and completed the consent form. Of those, four did not complete any further questions, 18 completed only the demographic questions, two completed the care tasks questions but did not attempt the questionnaires, and 16 missed full scales or large proportions of full scales which were essential to the analysis (CBI: $n$ = 10; SOC-S: $n$ = 3; AC-QoL(SS): $n$ = 3). The data from these participants ($n$ = 40) were excluded.

Thirteen participants completed the majority of questions but missed individual items. Where missing items accounted for no more than 20% of the total or subscale score, items were prorated using mean substitution (Peng et al., 2006). No more than two items across all measures were prorated for any individual participant. Missing data analysis was performed to investigate differences between those who completed all measures and those who did not. Little’s MCAR test was used to identify differences between the expected and observed means in the data (Little, 1988). No significant differences were identified ($p$ = .338), suggesting that there was no significant pattern in missed responses. Data were also visually inspected for patterns in missing items. Some attrition was seen as participants progressed through the survey, although the majority of participants completed all questionnaires.

Descriptive analyses were performed. Histograms were generated for key demographic data and questionnaire scores, and visually inspected for normality of distribution. Kolmogorov-Smirnov tests, considered an appropriate assessment of normality in sample sizes greater than 50 (Mishra et al., 2019), suggested that scores for the AC-QoL(SS), WEMWBS, and CT assessment were not normally distributed. P-P plots were examined for skewedness and kurtosis.

As the data were not normally distributed in all scales, correlation analysis using Spearman’s rho correlation coefficients was conducted to explore the relationships between variables. Hierarchical multiple regression was used to investigate whether self-compassion and social support predicted wellbeing when controlling for carer stressors and demographics. The model used was similar to one used by Maguire et al. (2019), in which carer demographics were entered into the model first, followed by burden related factors, followed by psychological variables. Age and gender were selected as demographic variables which have previously been associated with carer quality of life (Morley et al., 2012). This was followed by the carer stressor variables (carer burden or care tasks) due to their prior association with quality of life and wellbeing in carers of people with Parkinson’s (Rosqvist et al., 2022; Vescovelli & Ruini, 2022). Finally, self-compassion and social support were entered to test the extent to which these variables acted as predictors. Scatterplots were generated to examine linearity, homoscedasticity, and normality of residuals. Durbin-Watson tests were examined for autocorrelation, with values between 1.5 and 2.5 considered acceptable (Turner, 2020). In the present study, these were acceptable.

Moderation analyses were conducted using model one of Hayes PROCESS Tool (A. F. Hayes, 2022) within IBM SPSS Statistics (version 28). Self-compassion and social support were tested separately as moderating variables. Analyses examined whether either variable moderated the relationship between the predictors (carer burden or care tasks) and the outcome (wellbeing) (See Figure 2.1).

Cronbach's alpha was calculated for each scale. Views on what should be considered an acceptable alpha value vary (Charter, 2003). In this study, values of .80 and higher were considered good, and .90 and higher were considered excellent (Nunnally & Bernstein, 1994). *P* values of $\leq .05$ were considered statistically significant.

[Insert Figure 2.1]

## Results

### Demographics

Data from 332 participants were analysed. Of those, 297 identified their gender as female (89.5%), 34 as male (10.2%), and one selected 'prefer to self-identify' (0.3%), providing no further information. Ages ranged from 21 to 67, with a mean age of 47.04 (*SD* = 9.43). Most participants were living in the UK or Ireland (*n* = 297, 89.5%), although participants also responded from North America, wider Europe, and Australia (see Table 2.1). The majority of the sample identified as White (*n* = 235, 70.8%). Most participants were married or had a long-term partner (*n* = 318, 95.8%), and the majority were married to, or the partner of, the person for whom they were caring (*n* = 285, 85.8%). Most participants lived with the care receiver (*n* = 292, 88.0%). A small number cared for someone living in a supported living setting (*n* = 17, 5.1%). One hundred and seventy-eight participants (53.6%) provided more than 30 hours of care per week.

[Insert Table 2.1]

### Descriptive Statistics

Means, standard deviations, and Cronbach's alphas can be viewed in Table 2.2. Reliability analysis found good or excellent internal consistency for all scales ($\alpha \geq .81$ for all).

The CBI mean was high ($M = 43.72$) compared to studies drawing from similar populations (Bartolomei et al., 2018; Chahine et al., 2021; Goldsworthy & Knowles, 2008), indicating that levels of burden were relatively high in the current sample. Although not previously used with a comparable sample, the SOC-S mean indicated that reported self-compassion was lower in this sample ($M = 64.04$) than in the normative data (provided by students and healthcare staff) used in the measure's development (Gu et al., 2020). Similarly, the AC-QoL(SS) mean was noticeably lower in the present sample ($M = 4.19$) than in the normative data provided by a sample of carers (Joseph et al., 2012). For the WEMWBS, the mean ($M = 41.52$) was similar to that found in a Parkinson's UK report considering the impact of COVID-19 restrictions on people with Parkinson's and their carers (Simpson et al., 2022). A histogram of the care tasks assessment indicated that participants tended to undertake a high number of tasks ($M = 7.76$) as part of their caregiving role.

[Insert Table 2.2]

### Correlation Analyses

Nonparametric bivariate correlations were conducted to explore relationships between variables. In support of hypothesis one, carer burden, care tasks, self-compassion, and social support were all associated with wellbeing. Large effect sizes were found for all variables, with the exception of care tasks, which had a small-medium effect size. Specifically, significant correlations were found between higher carer burden and lower wellbeing ($r_s = -.58$, $p < .001$), and between greater number of care tasks and lower wellbeing ($r_s = -.20$, $p <$

.001). Significant correlations were found between higher levels of self-compassion and greater wellbeing ($r_s = .68, p < .001$), and between higher levels of social support and greater wellbeing ($r_s = .43, p < .001$) Carer age and gender were also significantly associated with wellbeing ($r_s = .21, p < .001$, and $r_s = .13, p = .022$ respectively). Hours spent caregiving, whether carers lived with the care recipient, and whether the care recipient lived in a supported living environment were not associated with wellbeing (see Table 2.3).

[Insert Table 2.3]

## Regression Analyses

Hierarchical multiple regression analyses were conducted to investigate hypothesis two: that self-compassion and social support would be significant independent predictors of wellbeing when controlling for carer stressors and demographics. Due to the high collinearity between carer burden and care tasks ($r_s = .56$), these variables were investigated separately using two distinct models. Variables were entered into the models in the following order: demographic variables (age and gender) in block one; carer stressors (either carer burden or care tasks) in block two; psychological variables (self-compassion and social support) in block three. In both models, wellbeing was the outcome variable (See Table 2.4).

[Insert Table 2.4]

### *Model One: Carer Burden, Self-Compassion, and Social Support*

In support of hypothesis two, self-compassion and social support were significant independent predictors of carer wellbeing when controlling for carer burden, age, and gender. The overall model was significant ($F(2,318) = 131.78$, $R^2 = .65$, $R^2\_adj = .64$, $p < .001$), as was each step of the model ($p < .001$ for all). At step 3, age, carer burden, self-compassion, and social support were all significant independent predictors of wellbeing ($\beta = .09, p = .010$; $\beta = -.37, p < .001$; $\beta = .49, p < .001$; and $\beta = .18$ $p < .001$ respectively). The addition of self-compassion and social support to the model at step 3 accounted for an additional 29.2% of variance beyond that accounted for by carer burden and demographics.

### *Model Two: Care Tasks, Self-compassion, and Social Support*

Also in support of hypothesis two, self-compassion and social support were significant independent predictors of carer wellbeing when controlling for care tasks, age, and gender. The overall model was significant ($F(2,318) = 162.87$, $R^2 = .56$, $R^2\_adj = .55$, $p < .001$), as was each step of the model ($p < .001$ for all). At step 3, age, care tasks, self-compassion, and social support were all significant independent predictors of wellbeing ($\beta = .13$, $p = .001$; $\beta = -.16$, $p < .001$; $\beta = .53$, $p < .001$; and $\beta = .30$, $p < .001$ respectively). The addition of self-compassion and social support to the model accounted for an additional 45.4% of variance beyond that accounted for by care tasks and demographics.

## Moderation Analyses

Four moderation analyses were undertaken to investigate hypotheses three and four: that self-compassion and social support would moderate the relationship between carer stressors and wellbeing. As with the regression analyses, carer burden and care tasks were explored using separate models. In model one, carer burden was the predictor variable and self-compassion was the moderating variable. In model two, care tasks was the predictor variable and self-compassion was the moderating variable. In model three, carer burden was the predictor variable and social support was the moderating variable. In model four, care tasks was the predictor variable and social support was the moderating variable. Wellbeing was the outcome variable in all models.

The moderation analyses were repeated controlling for age and gender. No change in significance/non-significance was noted in any of the models. Therefore, the original, non-controlled for models are presented. Full details are reported in Table 2.5.

[Insert Table 2.5]

### *Model One: Carer Burden, Self-compassion, and Wellbeing*

Contrary to hypothesis three, with self-compassion acting as the moderating variable, the moderating effect on the relationship between carer burden and wellbeing was not significant ($p = .082$). However, this effect was approaching significance.

### *Model Two: Care Tasks, Self-compassion, and Wellbeing*

In support of hypothesis three, with self-compassion acting as the moderating variable, a significant moderating effect was found on the relationship between care tasks and wellbeing ($F(1,328) = 4.44$, $\Delta R^2 = .007$, $p = .036$), meaning that the strength of relationship between care tasks and wellbeing was affected by participants' levels of self-compassion.

An interaction plot (Figure 2.2) indicated that when self-compassion was low (1 SD below the mean) there was a significant negative relationship between care tasks and wellbeing ($b = -.76$, $SE = .18$, $t = -4.29$, $p < .001$). At mean values of self-compassion, the relationship between care tasks and wellbeing was reduced, although it remained significant ($b = -.49$, $SE = .13$, $t = -3.86$, $p = .001$). At high values of self-compassion (1 SD above the mean), the relationship between care tasks and wellbeing was not significant ($b = -.23$, $SE = .18$, $t = -1.30$, $p = .196$).

Using a Johnson-Neyman approach to probe the interaction (A. F. Hayes, 2022), the relationship between care tasks and wellbeing was significant for self-compassion scores of 72.53 and lower. In the current sample, 76.20% of the sample scored below this cut off for significance. This suggests the relationship between care tasks and wellbeing was significant for approximately three quarters of the sample. Conversely, the relationship between care tasks and wellbeing was not significant for values of self-compassion higher than 72.53 (approximately a quarter of the sample).

[Insert Figure 2.2]

### *Model Three: Carer Burden, Social Support, and Wellbeing*

Contrary to hypothesis four, with social support as the moderating variable, no significant moderating effect was found on the relationship between carer burden and wellbeing ($p = .730$).

### *Model Four: Care Tasks, Social Support, and Wellbeing*

Contrary to hypothesis four, with social support as the moderating variable, no significant moderating effect was found on the relationship between care tasks and wellbeing ($p = .283$).

## Discussion

This cross-sectional study used data collected online to examine the relationships between carer stressors, self-compassion, social support, and wellbeing in carers of people with Parkinson's. In support of hypothesis one, increased carer burden and care tasks were associated with reduced wellbeing, while higher self-compassion and social support were associated with higher wellbeing. In support of hypothesis two, regression analyses revealed that self-compassion and social support significantly predicted wellbeing when controlling for carer stressors and demographics. Hypothesis three, that self-compassion would moderate the relationship between carer stressors and wellbeing, was partially supported. Self-compassion was a significant moderator in the relationship between care tasks and wellbeing, and approaching significance as a moderator in the relationship between carer burden and wellbeing. Hypothesis four, that social support would moderate the relationship between carer stressors and wellbeing, was not supported. Social support did not act as a moderator in the relationship between carer stressors and wellbeing.

### Regression Findings

In support of the first hypothesis, carer burden, care tasks, self-compassion, and social support were all significantly correlated with wellbeing. Each of these variables continued to be an independent predictor in the regression models when controlling for demographics.

Furthermore, in support of the second hypothesis, self-compassion and social support contributed a substantial portion of variance in both regression models when controlling for carer stressors and demographics. Higher levels of self-compassion have previously been associated with increased wellbeing across populations (Zessin et al., 2015), and with reduced burden in carers of older adults (Murfield, Moyle, Jones, et al., 2020). Low levels of self-compassion have been found to be predictive of depression in carers of people with neurological conditions (Hlabangana & Hearn, 2020). However, this is the first study to investigate self-compassion as a predictor of wellbeing in carers of people with Parkinson's. Social support has received slightly more attention in this group, although primarily in relation to negative psychological outcomes, such as depression and anxiety (Perrin et al., 2019; Tyler et al., 2020). The current findings demonstrate that, in addition to a lack of social support and self-compassion contributing to negative outcomes for carers, increased self-compassion and social support can be predictive of positive outcomes, such as wellbeing.

Of particular importance in the regression findings is the fact that not only were self-compassion and social support predictive of wellbeing, but that they accounted for a large proportion of variance beyond that accounted for by carer stressors and demographics. This study used two metrics to conceptualise carer stressors. The assessment of care tasks was intended to offer an objective assessment of the kinds of tasks most pertinent to carers of people with Parkinson's. Carer burden was assessed as a multifaceted concept related to a range of carer and care receiver needs, coping styles, and emotional responses (Hulshoff et al., 2021). Both were included to enable a broad range of stressors to be assessed and controlled for. Given that self-compassion and social support accounted for a large amount of variance in wellbeing beyond that contributed by these stressors, this suggests that supporting carers to increase their self-compassion and social support could improve their wellbeing even in the presence of considerable stressors. In the case of Parkinson's, where the neurodegenerative nature of the condition is likely to lead to an increase in carer stressors over time (Geerlings et al., 2023), the prospect of an avenue through which wellbeing may be improved despite the presence of mounting stressors is particularly valuable.

### Moderation Findings

Hypotheses three and four concerned whether self-compassion and/or social support would moderate the relationship between carer stressors and wellbeing. Self-compassion was a significant moderator in the relationship between care tasks and wellbeing, and approaching significance as a moderator in the relationship between carer burden and wellbeing. The relationship between undertaking more care tasks and lower wellbeing was strongest when levels of self-compassion were low. As levels of self-compassion increased, the relationship between care tasks and wellbeing became progressively weaker, ultimately becoming non-significant for those scoring in the top 23.8% for self-compassion. The fact that self-compassion moderates the relationship between care tasks and wellbeing in this way would suggest that self-compassion acts in line with the buffer hypothesis (Cohen & Wills, 1985). In the present study, self-compassion both directly predicted wellbeing, and reduced the impact of care tasks on wellbeing. Self-compassion has previously been considered as a moderator between carer stress and depression in carers of people with cancer (Hsieh et al., 2019), but this is the first study to investigate the interaction effect of self-compassion and carer stressors in carers of people with Parkinson's.

While the interaction effect between self-compassion and care tasks was significant, it was only approaching significance between self-compassion and carer burden. This was surprising, particularly as self-compassion has been found to act as a moderator between difficulties and responses to them in other populations (Abdollahi et al., 2020; Adams et al., 2023; Dev et al., 2020). One explanation may be that there is overlap between experiences of burden and the extent to which carers experience self-compassion. In the present study, analysis revealed a significant correlation between carer burden and self-compassion. Therefore, it may be that carers with higher self-compassion experienced lower burden in the first place. Thus, the relationship between burden and wellbeing was less affected because some of the effect of self-compassion was accounted for in the degree of burden experienced. In contrast, the objective assessment of care tasks enabled the moderating effect of self-compassion to be observed more clearly. Moreover, given that self-compassion was approaching significance as a moderator, the impact of power should be considered. The study was powered to detect large effect sizes in moderation analyses (Whisman & McClelland, 2005). In order to detect statistical significance in the interaction effect size observed between self-compassion and carer burden, retrospective power analysis revealed that a much larger sample size would be needed ($n = 2{,}183$). Recruitment of this scale was beyond the scope of this study. However, further investigation with a larger sample size would be valuable to offer insight into the types of stressors against which self-compassion may protect.

In contrast to self-compassion, social support was not a significant moderator in the relationship between carer stressors and wellbeing for either stressor variable. Social support has been identified as a moderator of stressors in other carer groups (Gellert et al., 2018; George et al., 2020), and the fact that it did not act in line with the buffer hypothesis in the current study is worthy of consideration. This may be related to the way in which social support was assessed in the current study. The support for caring subscale of the AC-QoL was chosen because it focuses on social support specifically in a caring context, rather than on a more generic level. The AC-QoL(SS) covers emotional, professional, and practical support (Joseph et al., 2012). However, in this sample, rates of professional support were low, with many carers receiving no professional support. This may in part have accounted for the data skew towards low levels of social support, particularly as two of the five questions concerned professional support. Furthermore, one study found that expressive support, but not instrumental support, moderated the relationship between care-related work interruptions and carer depression (Ang & Malhotra, 2018), suggesting that the type of social support affects its impact on the relationship between carer stressors and outcomes. Given that the measure used in the current study was weighted towards practical rather than emotional or expressive support, it may be that this influenced the lack of interaction effect. The findings of the current study would suggest that all types of social support are associated with, and predictive of, carer wellbeing, but that when considered as a buffer, some types of support may have a greater impact than others on the relationship between carer stressors and wellbeing.

## Limitations

This was a cross-sectional study, meaning that it is not possible to draw conclusions as to the direction of relationships. The study was powered to detect large effects in moderation analysis. However, a larger sample may have detected statistical significance in the smaller effect sizes observed in this study.

In order to explore carer stressors, a care tasks assessment was developed in response to a lack of appropriate validated measures available to assess this concept. There are limitations associated with this approach. Firstly, the assessment was not validated outside the present sample and no replication has taken place (Frost et al., 2007), meaning that its generalisability cannot be determined. Secondly, only a small number ($n = 4$) of experts by experience were involved in the creation of the assessment. It is possible that additional contributors may have identified further items for inclusion, meaning that it may not represent the complete range of care-related tasks. Thirdly, the use of a non-standardised assessment presents barriers to direct comparisons between the present findings and wider literature. Fourthly, a number of additional validation steps would have been necessary for this to be considered a reliable and valid psychometric measure (Boateng et al., 2018). Conclusions relating to this assessment must therefore be extremely tentative.

Although various recruitment strategies were used, the majority of recruitment took place online. This may have restricted access for those with lower computer literacy or reduced access to technology. Furthermore, use of technology has been found to have beneficial effects on social support for carers who use internet-based platforms to access support or connect with other carers (Newman et al., 2019). Given that carers with higher internet usage may therefore be accessing more social support, it is possible that carers with lower social support were less likely to encounter the study. However, the low reported social support in the sample would suggest that, to some extent, carers with poor social support were reached. The mean participant age was 47.04, which is relatively young compared to other studies focusing on carers of people with Parkinson's (Speelberg et al., 2023; Yang et al., 2019). As a result, findings may be less applicable to older carers.

## Clinical Implications

This study demonstrated that both self-compassion and social support promote wellbeing in carers of people with Parkinson's, even in the presence of carer stressors. Furthermore, it found that self-compassion acts as a buffer against the impact of carer stressors on wellbeing, suggesting that it may have a dual benefit for carers. On an individual level, therefore, interventions to support carers to increase their levels of self-compassion and social support may have a beneficial impact on wellbeing. Although relatively under-researched, emerging evidence has been optimistic about the potential benefits of self-compassion interventions for informal carers (Murfield et al., 2021; Murfield, Moyle, & O'Donovan, 2020). Interventions aimed at improving self-compassion have been found to be effective at increasing positive psychological outcomes and reducing distress in other carer groups (Diggory & Reeves, 2022; Noei et al., 2022; Spigelmyer et al., 2023). Similarly, peer support interventions have been found to be highly valued by carers when they included other support components, such as professional input (Carter et al., 2020). Further research is needed on the effect of such interventions for carers of people with Parkinson’s, but the findings of the current study suggest that interventions targeting self-compassion and social support could be of value to this group.

However, while individual interventions may be beneficial, it is important to consider wider contextual elements when considering the implications of the findings. The social relational model of disability argues that it is the barriers presented by environments and the impact of stigma which are detrimental to wellbeing for people with disabilities (Thomas, 2004). While this study focused on carers rather than people with Parkinson’s, research suggests that carers face many of the same societal barriers as the people they support, including barriers to accessing care services (Maybery et al., 2021), social exclusion (Greenwood et al., 2018), and stigma (Shi et al., 2019). It has been argued that individualised interventions are insufficient to address the difficulties experienced by those disadvantaged by such factors (Leigh et al., 2021), and that wider societal change, such as changing public perceptions around Parkinson’s, is necessary (Simpson et al., 2013). In demonstrating the importance of both intrapersonal (self-compassion) and interpersonal (social support) factors in the wellbeing of carers of people with Parkinson’s, the findings suggest that both individual and systemic approaches are necessary to support the wellbeing of carers.

## Directions for Future Research

In the current study, carer stressors were operationalised using two metrics due to the lack of a single appropriate measure. Development and validation of such a measure would be valuable to enable the buffer hypothesis to be further explored in relation to carer stressors and wellbeing. Replication of the analyses using a larger sample would enable the moderating role of self-compassion to be explored in relation to stressors beyond those captured by the care tasks assessment. Furthermore, as a preliminary investigation, this study considered the moderating roles of social support and self-compassion using two separate models. However, as both of these concepts occur together, (i.e. carers may experience self-compassion and social support naturally throughout their daily lives), these concepts would benefit from exploration using a dual moderation model. This study was not sufficiently powered for dual moderation, but exploration of this in future research would further understanding of the extent to which these factors may work together to reduce the impact of carer stressors on wellbeing.

The findings suggest that interventions targeted towards increasing self-compassion and social support in carers of people with Parkinson's may have a positive impact on carer wellbeing on an individual level. However, research into these interventions has typically focused on other carer groups, most prominently carers of people with dementia (Carter et al., 2020; Dam et al., 2016; Murfield et al., 2022). Development of self-compassion and social support interventions specifically targeted towards and sensitive to the needs of carers of people with Parkinson's would be a valuable direction for future research.

## Conclusion

This study aimed to explore how self-compassion and social support predict wellbeing in carers of people with Parkinson's. Self-compassion and social support were both significant independent predictors of wellbeing, and accounted for a large proportion of variance in wellbeing beyond that contributed by carer stressors and demographics. Additionally, self-compassion was a significant moderator in the relationship between carer stressors and wellbeing, although this will need further replication given the use of a non-validated assessment to measure carer tasks. The findings demonstrated that self-compassion and social support promoted carer wellbeing even in the presence of care-related stressors. Self-compassion was identified as having a dual benefit to carers, as both a predictor of wellbeing and as a protective factor against the impact of stressors. This was the first study to explore the role of self-compassion in the wellbeing of carers of people with Parkinson's. As such, this study makes a unique contribution to the current knowledge base around how self-compassion and wellbeing function in the lives of carers. By investigating the predictive roles of both an intrapersonal (self-compassion) and an interpersonal (social support) concept, the findings have important clinical implications in demonstrating the need for both individual and systemic approaches to supporting carers. Finally, the original findings regarding the positive impact of self-compassion and social support on wellbeing, even in the presence of significant stressors, demonstrate that these are concepts worthy of further exploration in future research.

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**Table 2.1**

*Sample Demographics*

| n = 332 | | Mean (range) | SD |
|---|---|---|---|
| Age* | | 47.04 (21 – 67) | 9.44 |
| | | N | % |
| Gender | Female | 297 | 89.5 |
| | Male | 34 | 10.2 |
| | Prefer to self-identify | 1 | 0.3 |
| Country | England | 234 | 70.5 |
| | Northern Ireland | 5 | 1.5 |
| | Scotland | 38 | 11.4 |
| | Wales | 14 | 4.2 |
| | Republic of Ireland | 6 | 1.8 |
| | Canada | 13 | 3.9 |
| | USA | 12 | 3.6 |
| | Spain | 4 | 1.2 |
| | Malta | 1 | 0.3 |
| | Portugal | 1 | 0.3 |
| | Italy | 1 | 0.3 |
| | France | 1 | 0.3 |
| | Australia | 2 | 0.6 |
| Ethnicity* | White UK or Irish | 147 | 44.3 |
| | Other UK or Irish | 66 | 19.9 |
| | Other North American | 4 | 1.2 |
| | White European | 2 | 0.6 |
| | Other European | 4 | 1.2 |
| | White/Caucasian | 84 | 25.3 |
| | South Asian or Indian | 2 | 0.6 |
| | Hispanic | 1 | 0.3 |
| | South American | 1 | 0.3 |
| | Mixed Heritage | 5 | 1.5 |

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| | | | |
|---|---|---|---|
| | Greek Cypriot | 1 | 0.3 |
| | Indigenous American | 1 | 0.3 |
| | Jewish/Ashkenazi | 5 | 1.5 |
| | Other | 3 | 0.9 |
| | White South African | 1 | 0.3 |
| | White Other | 1 | 0.3 |
| Employment | Full-time employment | 45 | 13.6 |
| | Part-time employment | 51 | 15.4 |
| | Unable to work due to caring responsibilities | 39 | 11.7 |
| | Retired | 171 | 51.5 |
| | Full-time education | 2 | 0.6 |
| | Part-time education | 1 | 0.3 |
| | Other | 21 | 6.3 |
| | Prefer not to say | 2 | 0.6 |
| Relationship to person with Parkinson's | Child | 41 | 12.3 |
| | Friend | 2 | 0.6 |
| | Sibling | 1 | 0.3 |
| | Spouse/Partner | 284 | 85.5 |
| | Other relationship | 4 | 1.2 |
| Partnership status | Married or have a partner | 318 | 95.8 |
| | Single | 11 | 3.3 |
| | Widowed | 2 | 0.6 |
| | Other | 1 | 0.3 |
| Living with the person with Parkinson's* | Yes | 292 | 88.0 |
| | No | 39 | 11.7 |
| Does the person with Parkinson's live in a supported living setting | Yes | 17 | 5.1 |
| | No | 315 | 94.9 |
| Hours of care* | 1 – 5 Hours | 21 | 6.3 |

| | | | |
|---|---|---|---|
| | 6 – 10 Hours | 37 | 11.1 |
| | 11 – 15 Hours | 35 | 10.5 |
| | 16 – 20 Hours | 23 | 6.9 |
| | 21 – 25 Hours | 29 | 8.7 |
| | 26 – 30 Hours | 8 | 2.4 |
| | More than 30 hours | 178 | 53.6 |

*Missing data: Age *n* = 7; Ethnicity *n* = 4; Living with the person with Parkinson's *n* = 1; Hours of Care *n* = 1.

**Table 2.2**

*Descriptive statistics*

| Measure | Mean | SD | Range | Cronbach's alpha |
|---|---|---|---|---|
| CBI total score | 43.73 | 17.35 | 2 - 92 | .94 |
| SOC-S total score | 64.04 | 11.83 | 30 - 96 | .93 |
| AC-QoL(SS) subscale score | 4.19 | 2.78 | 0 - 14 | .81 |
| WEMWBS total score | 41.52 | 9.44 | 15 - 69 | .93 |
| Care Tasks total score | 7.76 | 2.98 | 0 - 12 | NA |

**Table 2.3**

*Spearman's Rho Correlation Coefficients*

*n* = 332

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|---|
| 1. Age ^ | 1 | .147** | .179** | -.297** | .063 | -.081 | .182** | .185** | .059 | .209** |
| 2. Gender^ | | 1 | .158** | .057 | -.186** | -.153** | -.151** | .090 | .083 | .126* |
| 3. Hours spent caring | | | 1 | -.253** | .105 | .367** | .502** | .051 | -.016 | -.092 |
| 4. Living with care recipient | | | | 1 | -.509** | -.033 | -.172** | -.066 | .064 | -.055 |
| 5.Care recipient in supported living | | | | | 1 | -.035 | .121* | .025 | -.104 | .014 |
| 6. CBI | | | | | | 1 | .560** | -.290** | -.360** | -.577** |
| 7. CT | | | | | | | 1 | -.082 | -.062 | -.202** |
| 8. SOC-S | | | | | | | | 1 | .309** | .676** |
| 9. AC-QoL(SS) | | | | | | | | | 1 | .430** |
| 10. WEMWBS | | | | | | | | | | 1 |

CBI: Caregiver Burden Inventory; CT: Care Tasks; SOC-S: Sussex-Oxford Compassion for the Self Scale; AC-QoL(SS): Adult Carer Quality of Life Questionnaire (support for caring subscale); WEMWBS: Warwick Edinburgh Mental Wellbeing Scale.

^ Due to missing data, *n* = 325 for Age; *n* = 331 for Gender, Hours spent caring and Living with care recipient.

* p < .05, ** p < .01

**Table 2.4**

*Regression Models Predicting Wellbeing*

*n* = 324

| | | | Unstandardised Coefficients | | Standardised Coefficients | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Independent Variable | *B* | *SE* | Beta | *t* | p | $R^2$ | Adjusted $R^2$ | $\Delta R^2$ | F Change | Sig. F Change |
| Model One | Step 1. | | | | | | | .060 | .054 | .060 | 10.173 | <.001 |
| | | Age | 0.22 | 0.06 | .22 | 4.07 | <.001 | | | | | |
| | | Gender | 2.39 | 1.70 | .08 | 1.40 | .162 | | | | | |
| | Step 2. | | | | | | | .356 | .350 | .297 | 147.398 | <.001 |
| | | Age | 0.19 | 0.05 | .19 | 4.07 | <.001 | | | | | |
| | | Gender | -0.16 | 1.43 | -.01 | -0.11 | .912 | | | | | |
| | | CBI | -0.30 | 0.03 | -.55 | -12.14 | <.001 | | | | | |
| | Step 3. | | | | | | | .648 | .643 | .292 | 131.782 | <.001 |
| | | Age | 0.09 | 0.03 | .09 | 2.58 | .010 | | | | | |
| | | Gender | -0.51 | 1.06 | -0.2 | 0.48 | .631 | | | | | |
| | | CBI | -0.21 | 0.02 | -.37 | -10.23 | <.001 | | | | | |
| | | SOC-S | 0.39 | 0.03 | .49 | 13.56 | <.001 | | | | | |
| | | AC-QoL(SS) | 0.63 | 0.13 | .18 | 4.94 | <.001 | | | | | |
| | Step 1. | | | | | | | .060 | .054 | .060 | 10.173 | <.001 |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Model Two | | Age | 0.22 | 0.06 | .22 | 4.07 | <.001 | | | | | |
| | | Gender | 2.39 | 1.70 | .08 | 1.40 | .162 | | | | | |
| | Step 2. | | | | | | | .103 | .095 | .043 | 15.487 | <.001 |
| | | Age | 0.27 | 0.06 | .26 | 4.85 | <.001 | | | | | |
| | | Gender | 1.12 | 1.70 | .04 | 0.66 | .511 | | | | | |
| | | CT | -0.69 | 0.17 | -.22 | -3.94 | <.001 | | | | | |
| | Step 3. | | | | | | | .557 | .550 | .454 | 162.871 | <.001 |
| | | Age | 0.13 | 0.04 | .13 | 3.30 | .001 | | | | | |
| | | Gender | -0.04 | 1.20 | -.00 | -0.03 | .973 | | | | | |
| | | CT | -0.52 | 0.12 | -.16 | -4.21 | <.001 | | | | | |
| | | SOC-S | 0.42 | 0.03 | .53 | 13.12 | <.001 | | | | | |
| | | AC-QoL(SS) | 1.02 | 0.14 | .30 | 7.48 | <.001 | | | | | |

CBI: Caregiver Burden Inventory; CT: Care Tasks; SOC-S: Sussex-Oxford Compassion to the Self Scale; AC-QoL(SS): Adult Carer Quality of Life Questionnaire (support for caring subscale)

**Table 2.5**

*Moderation Models Predicting Wellbeing*

*n* = 332

| | | *b* | SE | *t* | $\Delta R^2$ | p |
|---|---|---|---|---|---|---|
| Model One | Constant | 41.658 | .332 | 125.615 | | <.001 |
| | CBI (centred) | -0.242 | .019 | -12.585 | | <.001 |
| | SOC-S (centred) | 0.437 | .028 | 15.505 | | <.001 |
| | CBI x SOC-S | 0.003 | .002 | 1.747 | .0036 | .082 |
| Model Two | Constant | 41.554 | .381 | 108.995 | | <.001 |
| | CT (centred) | -0.494 | .128 | -3.856 | | <.001 |
| | SOC-S (centred) | 0.523 | .032 | 16.159 | | <.001 |
| | CT x SOC-S | .022 | .010 | 2.108 | .0073 | .036 |
| Model Three | Constant | 41.571 | .422 | 98.562 | | <.001 |
| | CBI (centred) | -0.244 | .025 | -9.839 | | <.001 |
| | AC-QoL(SS) (centred) | 1.127 | .159 | 7.113 | | <.001 |
| | CBI x AC-QoL(SS) | 0.003 | .008 | 0.346 | .0002 | .730 |
| Model Four | Constant | 41.548 | .444 | 93.642 | | <.001 |
| | CT (centred) | -0.515 | .149 | -3.454 | | <.001 |
| | AC-QoL(SS) (centred) | 1.652 | .160 | 10.330 | | <.001 |
| | CT x AC-QoL(SS) | 0.061 | .056 | 1.076 | .0026 | .283 |

---

CBI: Caregiver Burden Inventory; CT: Care Tasks; SOC-S: Sussex-Oxford Compassion for the Self Scale; AC-QoL(SS): Adult Carer Quality of Life Scale (support for caring subscale)

Model One $R^2 = .617, p =.082$

Model Two $R^2 = .464, p = .036$

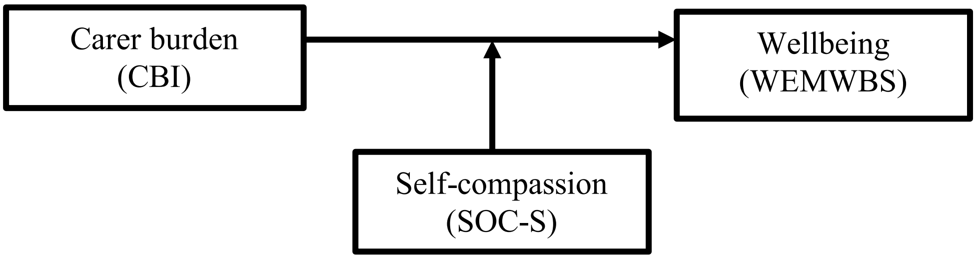
Model Three $R^2 = .421, p = .730$

Model Four $R^2 = .275, p = .283$

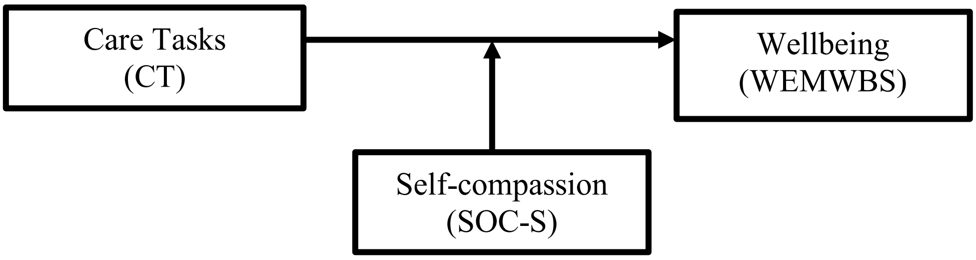
**Figure 2.1**

*Diagrams of moderation models*

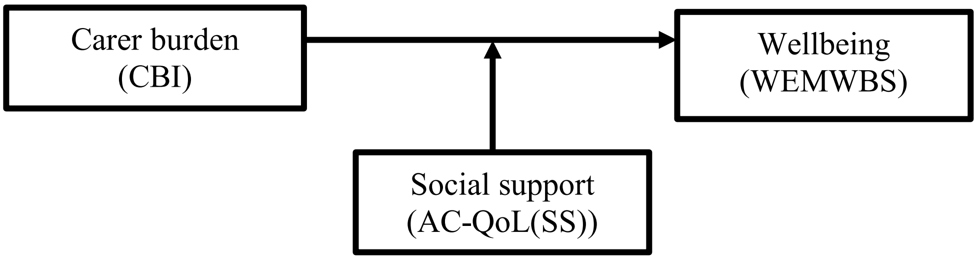
*Moderation Model 1.*



*Moderation Model 2.*



*Moderation Model 3.*



*Moderation Model 4.*

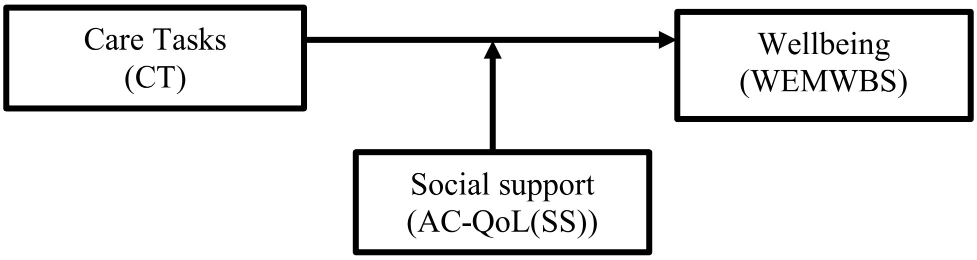
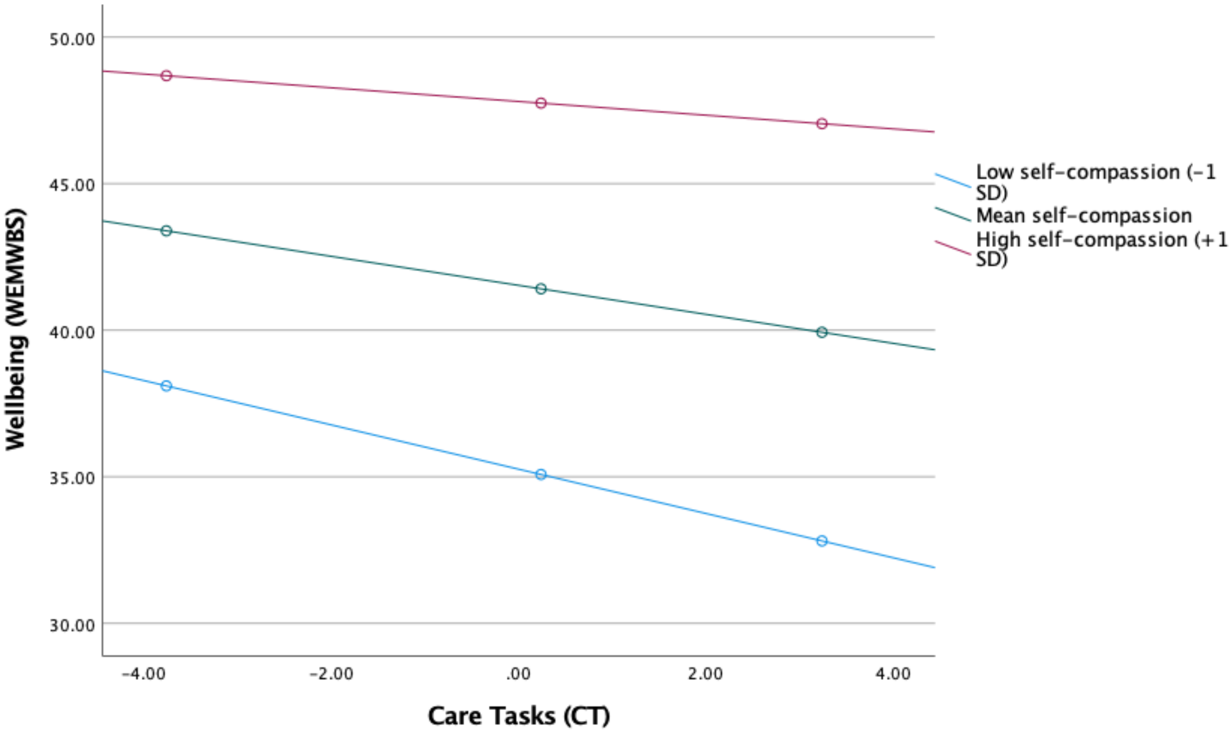


**Figure 2.2**

*Self-Compassion Moderating the Relationship Between Care Tasks and Wellbeing Using Mean Centred Values*



# Appendix 2.1: Development of the Care Tasks (CT) Assessment

The CT assessment aimed to provide an assessment of the nature of tasks carers were undertaking as part of their caregiving role. It was developed in collaboration with four experts by experience recruited through Parkinson's UK.

## Carer Collaborators

The collaborators included one male and three female carers. Two were spousal carers and two cared for a parent with Parkinson's. One collaborator was a bereaved carer and had provided support to a parent up until their death. Time caregiving ranged from three to ten years. One collaborator cared for someone who received a diagnosis of dementia subsequent to their Parkinson's diagnosis.

## Process

Collaborators were asked to think about their key roles and responsibilities as a carers. Specifically, they were asked to consider what tasks they might undertake in an average week to support the person to whom they provided care.

Themes from these discussions were collated to form the items in the CT assessment. Items were then shared with the carer collaborators for review and feedback. No items were added or removed as part of this process, but it was suggested that examples were provided with each item to aid clarity (e.g. 'Support with personal care (e.g. washing, dressing, going to the toilet')). The final version was reviewed by the research team.

## Validity

Correlation analysis was conducted  between the CT scores and Carer Burden Inventory (CBI) subscales: Time-dependence Burden (the extent to which carers' time is impacted by caregiving responsibilities), Developmental Burden (the extent to which carers feels their life stage deviates from their peers), Physical Burden (experiences of fatigue or physical ill-health resulting from caregiving), Social Burden (the extent to which carers feel their relationships are impacted by their role as a carer), and Emotional Burden (carers' experience of negative feelings towards the person receiving care).

*Spearman's Rho Correlation Coefficients for CBI Subscales*

| | CBI Total | Time Dependence | Developmental | Physical | Social | Emotional |
|---|---|---|---|---|---|---|
| CT | .560** | .796** | .422** | .490** | .171** | .231** |

** $p < .001$

The CT assessment was significantly correlated with all CBI subscales. A strong correlation was reported with the time dependence subscale, aligning with the premise that increased carer responsibilities would require greater time commitment. In contrast, weaker correlations were seen between the CT assessment and social and emotional subscales as might be expected as the CT assessment captures a more practical, as opposed to psychological or interpersonal, aspect of caregiving.

Additionally, a significant correlation was seen between the CT assessment and hours spent caregiving ($r_s = .502$, $p <$ 001), further suggesting that those spending more time caregiving undertake more caregiving tasks.

Cronbach's alpha was calculated ($\alpha = .80$), suggesting good internal consistency.

While not a formal test of the validity of the assessment, this provides some indication that the assessment is performing as required in that it correlates more highly with practical elements of caregiving, such as time required, physical effort, and types of tasks involved in caregiving. This aligns with its purpose as an objective assessment of caregiving responsibilities, indicating that it captures something different to the CBI, which focuses primarily on subjective carer experiences, including the emotional and psychosocial impact of caregiving.

**Assessment Items**

Items are scored as ‘one’ if the item does apply, or ‘zero’ if it does not apply.

1) Support with household jobs or tasks (e.g. cleaning, cooking)
2) Support with jobs or tasks outside the home (e.g. food shopping, attending GP or hospital appointments)
3) Support with movement (e.g. getting in or out of a chair, climbing stairs, crossing a road)
4) Support with personal care (e.g. washing, dressing, going to the toilet)
5) Support with meals (e.g. prompts to eat or drink, physical support with feeding)
6) Support with psychological difficulties (e.g. mood changes, hallucinations, disinhibited behaviour, memory difficulties)
7) Support to access benefits or formal care services
8) Support to source mobility aids or home adaptations (e.g. grab rails, commodes, walking frames)
9) Support to manage personal finances (e.g. paying bills, managing bank accounts)
10) Support to manage medication
11) Support in medical appointments (e.g. explaining medical information or advice, advocating for the needs of someone with Parkinson's to medical staff)
12) Other support (please give details if you wish)

# Appendix 2.2: Author Guidelines for *Aging and Mental Health*

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- Should be between 7,000 and 8,000 words, inclusive of:
    - Tables
    - References
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- Should contain a structured abstract of 200 words.

  Objectives, Methods, Results, Conclusion

- Should contain between 5 and 7 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

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*Updated 4th March 2024*

# Section Three: Critical Appraisal

Word count (excluding references): 3,837

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April 2024

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## Aims

This paper aims to consider some of the strengths, challenges, and reflections which have arisen during the course of this project. Firstly, I present an overview of the findings from the systematic literature review and empirical paper. Secondly, I discuss aspects of the decision-making process. Finally, I give my reflections on engagement with carers and experts by experience throughout the project.

## Overview of the Findings

### Systematic Literature Review

The systematic literature review aimed to explore the predictive role of social support in the psychological wellbeing of carers of people with Huntington's disease (HD), Parkinson's, multiple sclerosis (MS) and motor neurone disease (MND). Twenty-six quantitative studies were analysed. A range of wellbeing outcomes were considered, including quality of life, life satisfaction, carer burden, depression, and anxiety. Increased social support was broadly associated with increased positive and reduced negative wellbeing outcomes. However, there was variation within this, and further exploration was made challenging by the diversity of measures used to assess social support. Use of psychological theory was limited in the studies, as was investigation of positive wellbeing outcomes. Clinical implications included demonstrating that greater social support was generally associated with improved wellbeing in carers of people with neurodegenerative motor conditions. Furthermore, findings were broadly consistent across all four conditions, suggesting a commonality to carer experiences which could be important for carers of individuals with conditions less often featured in research, such as HD and MND (Zarotti et al., 2021). This suggests that other findings from carers of people with conditions more frequently included in research (e.g. Parkinson's, MS), may be applicable to less frequently included carer groups, broadening the avenues for intervention for these populations. The review highlighted the need for more robust use of theory and consistency in the conceptualisation of social support in future research.

## Empirical Paper

The empirical paper explored how self-compassion and social support predicted wellbeing in carers of people with Parkinson's. I hypothesised that carer stressors, self-compassion, and social support would be associated with wellbeing, and that self-compassion and social support would be significant independent predictors of wellbeing when controlling for carer stressors and demographics. Additionally, I hypothesised that self-compassion and social support would moderate the relationship between carer stressors and wellbeing. 'Carer stressors' was operationalised using the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989) and a care tasks assessment created for the study. As hypothesised, greater carer stressors were associated with reduced wellbeing, while higher self-compassion and social support were associated with increased wellbeing. Carer burden, care tasks, self-compassion, and social support all remained significant independent predictors of wellbeing in the regression models. Furthermore, self-compassion and social support contributed a large proportion of variance beyond that accounted for by carer stressors or demographics. Self-compassion was a significant moderator of the relationship between care tasks and wellbeing, and approaching significance as a moderator of the relationship between burden and wellbeing. However, contrary to the initial hypothesis, social support was not a significant moderator of these relationships.

The findings suggest that self-compassion and social support have a direct effect on the wellbeing of carers of people with Parkinson's. Furthermore, self-compassion also plays a protective role, acting as a buffer against the impact of carer stressors on wellbeing. This has clinical implications in demonstrating that both self-compassion and social support were beneficial to carer wellbeing even accounting for the impact of carer stressors. Identifying ways in which self-compassion and social support can be developed is therefore likely to improve carer wellbeing. Currently, there are no studies investigating the effectiveness of self-compassion interventions in carers of people with Parkinson's. The development and implementation of such interventions would be a valuable subject for future research. However, while individual interventions may be beneficial, the findings demonstrate that both intrapersonal (self-compassion) and interpersonal (social support) factors influence carer wellbeing. It is therefore important to consider systemic as well as individual approaches to supporting carers.

## Decisions, Strengths, and Challenges

Throughout this process, decisions arose which had a bearing on the direction of the work. Many of these decisions were related to the conceptualisation and measurement of core constructs. Some key decisions and their impact on the research are outlined below.

### Wellbeing

When I began this thesis, I was struck by the focus on deficit I encountered in much of the literature regarding carer experiences. Burden and Strain are prevalent concepts in carer literature (Aubeeluck et al., 2012; Carter et al., 2010; Giordano et al., 2016; Hand et al., 2022), but investigation into positive psychology concepts, such as wellbeing, is relatively limited (Hendriks et al., 2018). Drawing on my own experiences and values, I wanted to conduct this research with a focus towards 'living well' in the face of challenges presented by caregiving, rather than continue the pattern of previous research by exploring only negative concepts. Previous research has highlighted a need for increased focus on positive psychology concepts (Maguire et al., 2019), and in the UK, greater attention to carer wellbeing is a key component of NHS policy (NHS England, 2014). Responding to the need for increased research into positive psychological wellbeing in carers, and working in line with wider health policy, was therefore a strength of this research.

However, despite intending to focus on positive wellbeing, this was not always easy to achieve. During the preliminary searches to refine the focus of the systematic review, the extent to which research focusing on negative outcomes outweighed research focusing on positive outcomes became clear. Additionally, some studies stated they were investigating the positive concept of 'wellbeing,' but did so through the use of negative psychometric measures such as psychological distress (Bayen et al., 2023; Love et al., 2005). Theoretical understandings of wellbeing differ; some researchers argue for a dual-continua model of wellbeing, in which mental health and mental ill-health are considered as two distinct concepts (Iasiello et al., 2020), while others argue for a bipolar model, in which wellbeing and ill-being exist as opposite ends of the same spectrum (Zhao & Tay, 2023). Due to the lack of empirical studies considering wellbeing as a positive concept, the scope of the review was widened to include studies investigating negative psychological outcomes. This approach has been taken elsewhere in reviews concerning wellbeing (Robertson et al., 2023; Zhang & Chen, 2019). However, a systematic review focused solely on positive wellbeing would be a valuable addition to carer literature, and it is hoped that increased attention to positive psychology concepts makes this possible in the future. The use of a positive measure of wellbeing (the Warwick Edinburgh mental wellbeing scale (Tennant et al., 2007)) was therefore a strength of the empirical paper, in that it responded to one of the limitations found in the literature retrieved for review: the scarcity of carer research considering positive psychology outcomes.

## Carer Stressors

The buffer hypothesis (S. Cohen & Wills, 1985), drawn on in the empirical paper, argues that concepts such as social support and self-compassion can reduce the impact of carer stressors on wellbeing. In S. Cohen and Wills' (1985) original review, stressors were predominantly operationalised as undesirable life events, such as marital, financial, or legal difficulties. While carers are not immune to these stressors, this conceptualisation was not reflective of specific care-related stressors. Subsequent research (Gellert et al., 2018) has made use of measures of stress, such as the Perceived Stress Scale (S. Cohen et al., 1983). However, this is again a generic measure of stress, and not necessarily reflective of the specific stressors carers may face. It was therefore necessary to look beyond measures of stress to operationalise this concept. Literature searches revealed a lack of validated measures to assess the concept of carer stressors. Similar studies used measures of carer burden to assess carer stressors (Ong et al., 2018; Trapp et al., 2019), or hours spent caregiving as a measure of caregiving intensity (Xu et al., 2021). However, beyond carer burden, examples of validated measures to assess stressors were lacking. I therefore made the difficult decision to incorporate a measure of carer burden into the stressor component of the model.

While this approach was consistent with previous research (Ong et al., 2018; Trapp et al., 2019), it presented its own challenges. Critiques of the term ‘carer burden’ argue that many driving factors behind carer burden are not related to the act of caregiving, but to external pressures, such as insufficient financial and social resources (Liu et al., 2020). Despite this, measures of carer burden locate difficulties within the person receiving care, reducing them to a problem source, rather than an equal contributor to a relationship (Molyneaux et al., 2011). While it would have been preferable to avoid using this concept, the lack of appropriate alternatives made its inclusion necessary. I also included the care tasks assessment in the operationalisation of carer stressors, created through conversations with experts by experience, which aimed to assess the nature and number of tasks carers were undertaking. Although not validated, this was a useful addition to the analysis, as it allowed exploration of a more objective measure of stressors. Nonetheless, the lack of validated assessments of carer stressors, beyond measures of burden, is a gap in the literature. Development of such a measure would be a useful addition to future research.

**Social Support**

As a concept, social support presented challenges for both the systematic review and the empirical paper. In the review, the full breadth of social support as a concept became clear, presenting challenges as to which definition was most appropriate for use. Due to the lack of clarity around this concept, search terms for social support were intentionally overinclusive, and covered terms related to social isolation and social network, despite these being slightly different concepts from social support (Leigh-Hunt et al., 2017; Roth, 2020). This was a strength of the review, as titles and abstracts did not always specify how researchers were conceptualising social support, and a less inclusive search strategy may have resulted in papers being missed. However, this also presented dilemmas in the exclusion process, as full text reads revealed studies assessing social support through metrics such as number of social contacts (Miller et al., 1996), participation in support groups (Hecht et al., 2003), and experiences with health and social care services (Peters et al., 2012). Ultimately these examples were excluded on the basis that they were not assessing social support using the definition selected for the review. Clarity on the definition of social support for the purposes of the review was essential to aid decisions around inclusion and exclusion. However, while the review defined social support as the extent to which a person could rely on and derive support from those around them (del-Pino-Casado et al., 2018), applying this definition was rarely straightforward, due to the large range of measures used to operationalise the concept.

This breadth of measures for assessing social support also presented a challenge for the empirical paper. Identifying an appropriate measure of social support was a long and difficult process, which was to some extent corroborated by the diversity of measures found in the systematic review. One of the few measures which was used by more than one study in the review, the Multidimensional Scale of Perceived Social Support (Zimet et al., 1990), offered potential, but this measure focused on identifying a ‘special person’ from whom one derives support. This raised the question as to what the effect would be if your ‘special person’ was also the person for whom you were providing care. For example, the item ‘*There is a special person who is around when I am in need’* may not capture the availability of social support accurately if the source of need is a difficulty related to caring for someone with Parkinson’s, and your ‘special person’ is the person for whom you are caring. Alternative measures included items related to feeling valued at work (e.g. ‘*Others let me know that they enjoy working with me’*) (Weinert, 1981), which were likely to be less relevant to full-time carers. These examples highlighted the need for a measure of social support which was tailored towards a caregiving context. Therefore, I decided to use a social support subscale from the Adult Carer Quality of Life Questionnaire (AC-QoL(SS)) (Joseph et al., 2012).

This scale was both caring specific, and covered dimensions of emotional, practical, and professional support, which aligned with conceptualisations of social support as tangible, informational, and emotional (Östberg & Lennartsson, 2007). However, one finding to emerge from the systematic review was that emotional support appeared to be more often associated with wellbeing than practical or professional support. A limitation of the AC-QoL(SS) was that only one of the five items focused on emotional support. This may have influenced the non-significance of social support within the moderation analysis. On reflection, a measure more focused on emotional support would have been preferable for the study, although no carer specific measure with this focus was found. Given the breadth of conceptualisations of social support, the development of a validated measure to assess carer social support could offer much needed clarity and consistency around this concept, and would be a valuable addition to future research.

## Self-Compassion

Surprisingly, given that it is a relatively under-researched concept (Murfield et al., 2024), self-compassion presented the least difficulty in conceptualisation and measurement. Despite this, disagreement exists around its assessment. Previously, self-compassion has commonly been measured using Neff's Self-Compassion Scale (SCS) (Neff, 2003). However, critiques have grown regarding the use of a total score which includes both positive (self-kindness) and negative (self-coldness) aspects, suggesting instead that these concepts are separate, with self-coldness more related to psychopathology, and self-kindness to positive psychological functioning (Muris & Otgaar, 2020). Given the positive psychology approach taken in the empirical paper, I decided that a scale aligned with the position that mental health and mental illness are distinct concepts (Westerhof & Keyes, 2010) was more appropriate for the study. The Sussex-Oxford Compassion for Self Scale (SOC-S) was a strong candidate in terms of factor structure and reliability (Gu et al., 2020). However, as a relatively new scale, this came with the limitation that it has not previously been used with carers. A measure which had previously been validated within the target sample would have been preferable, but I felt that the benefits offered by the SOC-S outweighed these limitations.

## Carer Voices in Quantitative Research

A strength of this project was the inclusion of experts by experience from an early point in the planning process. The value of seeking the views and expertise of carers has been highlighted in research and NHS guidance (Bradley, 2015; NHS England, 2022), and the need for carer involvement in research design is gaining attention (Groot et al., 2022). The feedback provided by experts by experience was an invaluable aspect of this research, and the engagement of carers and experts by experience gave rise to important reflections.

### Terminology

In the early stages of the project, I met remotely with four carers individually, recruited through the charity Parkinson’s UK. Each had agreed to share their experiences and offer their thoughts on some of the research issues I was considering, one of which was how to refer to the people taking part in the study. The terms ‘carer,’ ‘caregiver,’ and more recently, ‘care partner’ are used interchangeably across the literature. Much has been written about the term ‘carer’ and how best to refer to people who provide support to others (Z. Hughes & O’Sullivan, 2017; Molyneaux et al., 2011). The term ‘carer’ was adopted throughout this research because this was the term preferred by the experts by experience involved in the project. Carer identities have been found to be fluid and subject to context (N. Hughes et al., 2013), and it seemed appropriate to use the term preferred by those whose context was most reflective of those taking part in the study.

However, when it came to advertising for recruitment, I noticed that this decision was not necessarily accepted by those promoting the study. Throughout the recruitment process, Parkinson’s charities, both nationally and internationally, were exceptionally supportive in promoting the study via newsletters, websites, and social media. However, although I used the term ‘carer’ in the study adverts, I noticed that several organisations altered this to ‘caregiver’ or ‘care partner’ in their own text introducing the advert. This raised a dilemma as to whether to address the mismatch of language between my advert and their text. Out of respect for the values of the organisations supporting my recruitment, I decided not to challenge their chosen language, although the subtle ‘correction’ of my use of ‘carer’ made me reflect on the difficulty of identifying language which feels representative to all members of such a diverse group. One expert who contributed to my study, for example, spoke passionately against the use of the term ‘care partner.’ Nevertheless, ‘care partner’ was frequently substituted for ‘carer’ by organisations promoting the study. Sensitive and inclusive language is hugely important for both organisations and researchers (Abbott, 2022;

NHS England, 2023), and while ‘carer’ was the preferred term of the experts who contributed to my study, critiques of this term also exist (Molyneaux et al., 2011), and there are undoubtedly others with caregiving responsibilities who would have identified with a different term.

## Positive Psychology or Positive Aspects of Caregiving

Another reflection related to research regarding positive aspects of caregiving (C. A. Cohen et al., 2002; Lee & Li, 2022). Throughout this project, I aimed to take a positive psychology approach, and to avoid the focus on burden and strain which characterises much of carer research. However, this was a position I questioned following my conversations with experts by experience. Much has been written about the challenges facing informal carers (Care Quality Commission, 2023; Read et al., 2023; Seshadri et al., 2023). Even so, the scale of difficulty facing some of those with whom I spoke was striking. The conversations prompted me to reflect on my own experiences of caregiving, and consider whether approaching caregiving from a lens of ‘positive aspects of caregiving’ would feel like a true reflection of both the experts’ and my own experiences. This led me to reflect on the difference between research with a positive psychology approach, and research focusing on the positive aspects of caregiving. While research has identified some positives associated with caregiving (Theed et al., 2017), I found myself wondering about the motivation behind, and implications of, a ‘positive aspects of caregiving’ approach, particularly when carers’ responses to caregiving are both context specific and systemically influenced (Brown & Brown, 2014). It was this which ultimately led me to choose an outcome measure which considered wellbeing generally, rather than one which considered wellbeing specifically in a caregiving context. It felt important to draw a distinction between having high wellbeing relative to being a carer, and having high wellbeing irrespective of caregiving responsibilities. As a result, the empirical study focused on maintaining wellbeing despite caregiving, rather than seeking to identify positives within caregiving. This placed carer wellbeing within the context of the general population, as opposed to considering wellbeing relative only to other carers and the caregiving role.

## Listening to Carer Voices

A final reflection relates to the contact I had with carers throughout the process. At all stages, I was struck by the willingness of carers to share their experiences. For example, when I initially approached Parkinson's UK to speak to experts by experience, I aimed to speak to approximately four carers and anticipated needing several weeks to recruit this number. In practice, twelve carers contacted me within twenty-four hours. Due to other commitments, it was not possible to speak to all of them. Therefore, after confirming with the first four volunteers, I contacted the other carers to thank them and politely explain that I was not in need of their support at this time. Even so, many of those with whom I was unable to speak replied with lengthy emails detailing their experiences. Some noted that, as active members of Parkinson's UK, they frequently saw invitations to participate in research for people with Parkinson's, but rarely encountered opportunities to participate as carers. The sense that carers felt their own experiences were overlooked was both implicit and explicit in the contacts I received over the following weeks. Although there were initial challenges reaching participants for the finished survey, once the study began to be publicised more widely, this level of engagement continued. Numerous carers used the contact email provided on the advert to tell me that they either had completed, or intended to complete the questionnaires. Some asked questions about the concepts within the survey, particularly self-compassion, which appeared to be largely unfamiliar to those getting in touch. Many sent long emails detailing the difficulties they faced providing care, liaising with professionals, and accessing support. A common theme across all who got in touch was the observation that their experiences as carers were rarely sought. Several even expressed gratitude for the carer-focused nature of the research.

The level of engagement from carers throughout this project was humbling, and it was validating to see that the research had resonated with carers. However, the extent to which carers were eager to share their experiences made me reflect on the use of quantitative methodology in this thesis. The positivist epistemological position I had taken in relation to this research was suited to furthering understanding into the mechanisms of several poorly understood concepts, and to refining their position within psychological theory (Park et al., 2020). However, it was less suited to capturing the nuances of the experiences carers were anxious to share with me. Furthermore, given the number of carers who contacted me, even after completing the survey, to share their experiences, I wondered whether the use of multiple-choice questionnaires felt adequate to carers who were telling me that their voices were so rarely heard. It was clear that among the carers who contacted me there was a need to share their experiences. Therefore, if I were to conduct more research in this area, I would consider a qualitative methodology, such as interpretive phenomenological analysis, which is particularly suited to accessing and communicating the lived experience of participants (Smith, 2011), in order to explore carer experiences in greater depth.

## Conclusion

I began this thesis knowing that I wanted to focus on carer experiences. I was confident that this was an area worthy of exploration, but I did not expect to be reminded so frequently of how closely this issue touched people's lives. Quantitative methodology has drawn criticism for lacking reflexivity (Jamieson et al., 2023). The generosity of carers who took the time to share elements of their stories with me has, in contrast, made this a highly reflective process, in which I have frequently had to consider my own position in relation to the research, the concepts under investigation, and how best to honour the experiences of the carers who participated in and contributed towards the research. It has been a privilege to conduct a quantitative project which has prompted so much engagement from a group who not only want, but clearly need, to be heard.

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# Section Four: Ethics Section

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# Ethics Application Form

## Research Ethics Application Form v1.9.6

## Research Ethics Application Form v1.9.6 RECR

## Self-compassion and social support in the wellbeing of carers of people with Parkinson's. - Approved

### Information Regarding this Research Project

Are you conducting a research project?

(for more information on research projects please see our ethics pages)

● Yes ○ No

Does your research only involve animals?

○ Yes ● No

Are you undertaking this research as/are you filling this form out as:

○ Academic/Research Staff
○ Non Academic Staff
○ Staff Undertaking a Programme of Study
● PhD or DClinPsy student
○ Undergraduate, Masters, Master by Research, MPhil or other taught postgraduate programme

Which Faculty are you in?

Faculty of Health and Medicine

Which department are you in?

Health Research

Will your project require NHS REC approval? (If you are not sure please read the guidance in the information button)

○ Yes ● No

Do you need Health Research Authority (HRA) approval? (Please read the guidance in the information button)

○ Yes ● No

Have you already obtained, or will you be applying for ethical approval, from another institution outside of Lancaster University? (For example, an external institution such as: another University's Research Ethics Committee, the NHS or an institution abroad (eg an IRB in the USA)? Please select one of the following:

● No, I do not need ethical approval from an external institution.
○ Yes, I have already received ethical approval from an external institution.
○ Yes, I will be applying for ethical approval from an external institution after I have received confirmation of ethical approval from my Faculty Research Ethics Committee (FREC) at Lancaster University, if the FREC grants approval.

Is this an amendment to a project previously approved by Lancaster University?

○ Yes ● No

Will your research involve any of the following? (Multiple selections are possible, please see i icon for details)

☑ Human Participants
☐ Data relating to humans (Secondary/Pre-existing data only)
☐ Data collection from online sources such as social media platforms, discussion forums, online chat-rooms
☐ Human Tissue
☐ None of the above

## Project Information

Please confirm/amend the title of this project.

Self-compassion and social support in the wellbeing of carers of people with Parkinson’s.

Estimated Project Start Date 05/12/2022

| | |
|---|---|
| Estimated End Date | 15/03/2024 |

Is this a funded Project?

○ Yes ● No

## Research Site(s) Information

Will you be recruiting participants from research sites outside of Lancaster University? *(E.g. Schools, workplaces, etc; please read the guidance in the information button for more information)*

○ Yes ● No

## Applicant Details

Are you the named Principal Investigator at Lancaster University?

● Yes ○ No

Please check your contact details are correct. You can update these fields via the personal details section located in the top right of the screen. Click on your name and email address in the top right to access "Personal details". For more details on how to do this, please read the guidance in the information button.

First Name

Katy

Surname

Brooks

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

k.brooks2@lancaster.ac.uk

## Principal Investigator

You have stated that you are the Principal Investigator for this project.

First Name

Katy

Surname

Brooks

Department

Health Research

Email

k.brooks2@lancaster.ac.uk

## Supervisor Details

Search for your supervisor's name. *If you cannot find your supervisor in the system please contact rso-systems@lancaster.ac.uk to have them added.*

First Name

Fiona

Surname

Eccles

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

f.eccles@lancaster.ac.uk

Do you need to add a second supervisor to sign off on this project?

● Yes ○ No

Search for your secondary supervisor's name. *If you cannot find your supervisor in the system please contact rso-systems@lancaster.ac.uk to have them added.*

First Name

Jane

Surname

Simpson

Department

Health Research

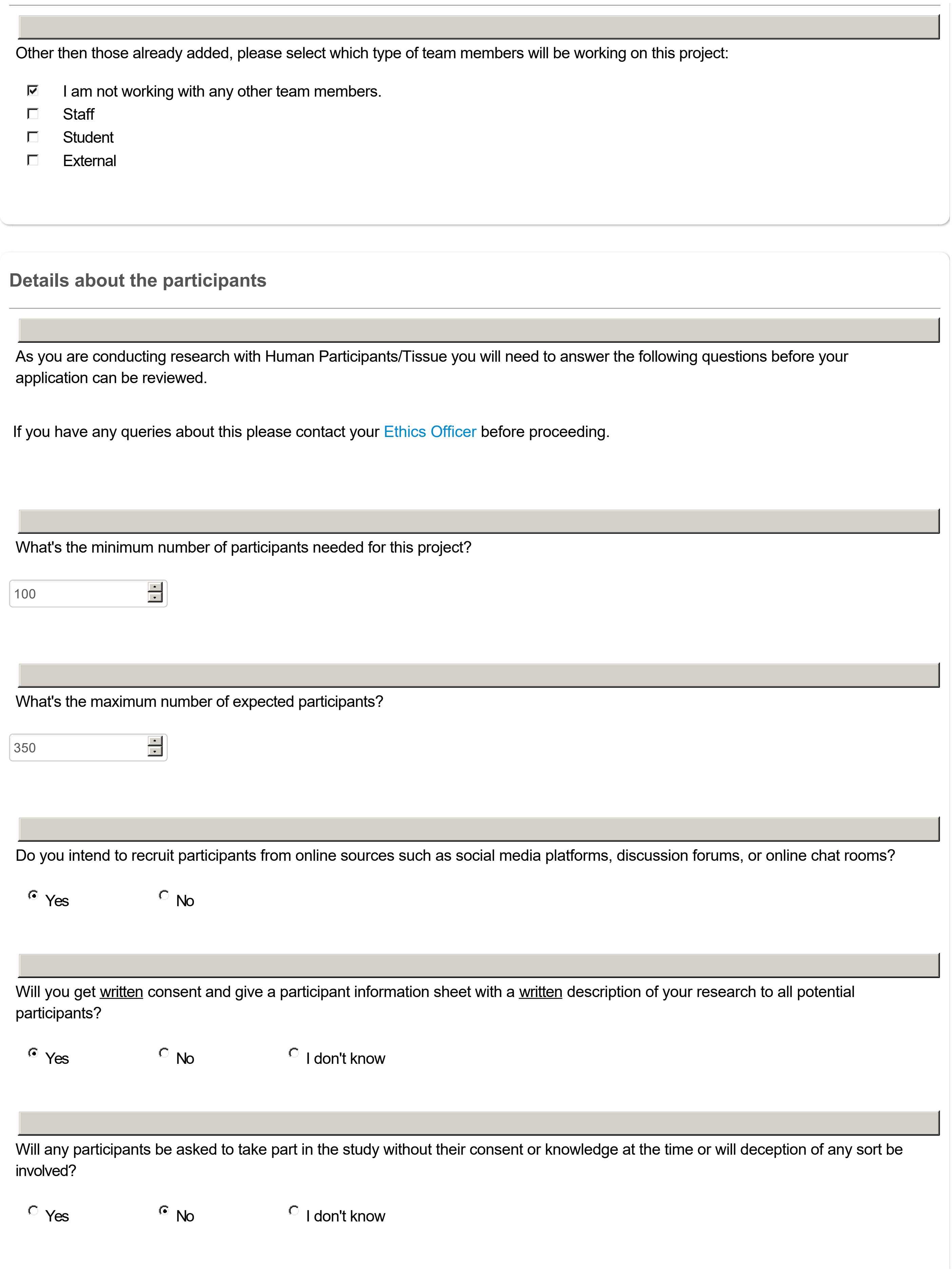
Faculty

Faculty of Health and Medicine

Email

j.simpson2@lancaster.ac.uk

## Additional Team Members



Other then those already added, please select which type of team members will be working on this project:

☑ I am not working with any other team members.
☐ Staff
☐ Student
☐ External

## Details about the participants

As you are conducting research with Human Participants/Tissue you will need to answer the following questions before your application can be reviewed.

If you have any queries about this please contact your Ethics Officer before proceeding.

What's the minimum number of participants needed for this project?

100

What's the maximum number of expected participants?

350

Do you intend to recruit participants from online sources such as social media platforms, discussion forums, or online chat rooms?

● Yes ○ No

Will you get written consent and give a participant information sheet with a written description of your research to all potential participants?

● Yes ○ No ○ I don't know

Will any participants be asked to take part in the study without their consent or knowledge at the time or will deception of any sort be involved?

○ Yes ● No ○ I don't know

Is your research with any vulnerable groups?

(Vulnerable group as defined by Lancaster University Guidelines)

○ Yes ● No ○ I don't know

Is your research with any adults (aged 18 or older)?

● Yes ○ No

Is your research data collected with completely anonymous adult (aged 18 or older) participants, with no contact details or other uniquely identifying information (e.g. date of birth) being recorded?

● Yes ○ No

Is your research with adult participants (aged 18 years, or older) in private interactions (for example, one to one interviews, online questionnaires)?

● Yes ○ No

Is your research with any young people (under 18 years old)?

○ Yes ● No ○ I don't know

Does your research involve discussion of personally sensitive subjects which the participant might not be willing to otherwise talk about in public (e.g. medical conditions)?

● Yes ○ No ○ I don't know

Could the study induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant’s usual, everyday life?

● Yes ○ No ○ I don't know

Is there a risk that the nature of the research topic might lead to disclosures from the participant concerning either:

- Their own or others involvement in illegal activities
- Other activities that represent a threat to themselves or others (e.g. sexual activity, drug use, or professional misconduct)?

○ Yes ● No ○ I don't know

Does the study involve any of the following:

- Physically intrusive procedures including touching or attaching equipment to participants
- Administration of substances
- Ultrasound or sources of non-ionising radiation (e.g. lasers)
- Sources of ionising radiation, (e.g. X-rays)
- Collection or use of samples of Human Tissue (e.g. Saliva, skin cells, blood etc.)

○ Yes ● No ○ I don't know

## Details about Participant relationships

Do you have a current or prior relationship with potential participants? For example, teaching or assessing students or managing or influencing staff (this list is not exhaustive).

○ Yes ● No ○ I don't know

If you need written permission from a senior manager in an organisation where research will take place (e.g. school, business) will you gain this in advance of undertaking your research?

○ Yes ○ No ○ I don't know ● N/A

Will you be using a gatekeeper to access participants?

● Yes ○ No ○ I don't know if I will be using a gatekeeper

The gatekeeper will be in a position of authority or have influence over potential participants (e.g., a teacher or manager). However, I will take the gatekeeper's assurance that they will stay completely impartial and that I will ensure that there is no perceived pressure to participate, and I will explain to participants that their decision on whether to participate or not will have no effect on their treatment or rights (e.g., learning or assessment).

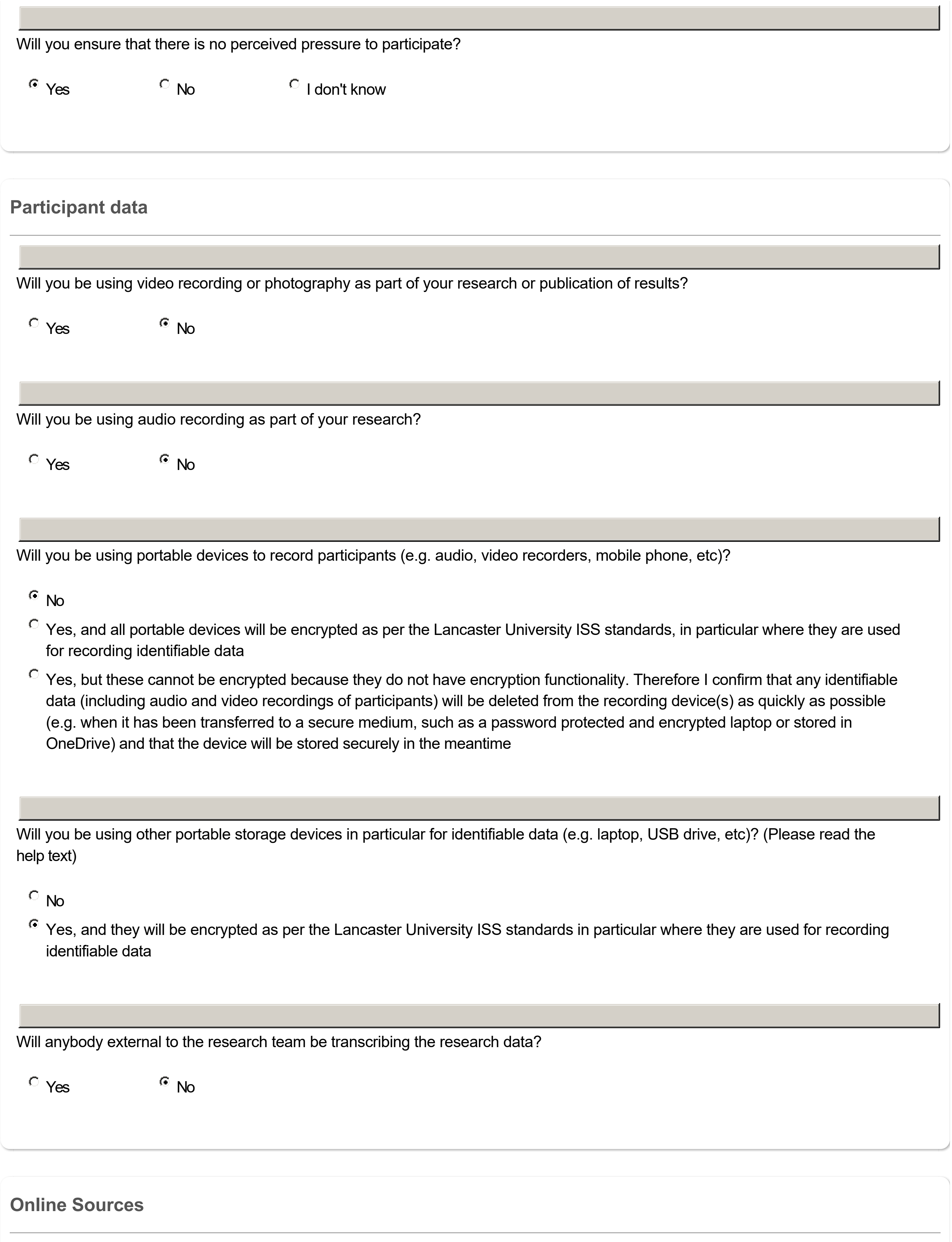
○ Yes ● No ○ I don't know

The gatekeeper will be able to tell who has participated (e.g., participants' responses will be made directly to the gatekeeper or if the researcher will inform the gatekeeper of who has participated), but I have assurance that they will not use this knowledge to treat participants differently.

○ Yes ● No ○ I don't know

Will participants be subjected to any undue incentives to participate?

○ Yes ● No ○ I don't know



Will you ensure that there is no perceived pressure to participate?

● Yes ○ No ○ I don't know

**Participant data**

Will you be using video recording or photography as part of your research or publication of results?

○ Yes ● No

Will you be using audio recording as part of your research?

○ Yes ● No

Will you be using portable devices to record participants (e.g. audio, video recorders, mobile phone, etc)?

● No

○ Yes, and all portable devices will be encrypted as per the Lancaster University ISS standards, in particular where they are used for recording identifiable data

○ Yes, but these cannot be encrypted because they do not have encryption functionality. Therefore I confirm that any identifiable data (including audio and video recordings of participants) will be deleted from the recording device(s) as quickly as possible (e.g. when it has been transferred to a secure medium, such as a password protected and encrypted laptop or stored in OneDrive) and that the device will be stored securely in the meantime

Will you be using other portable storage devices in particular for identifiable data (e.g. laptop, USB drive, etc)? (Please read the help text)

○ No

● Yes, and they will be encrypted as per the Lancaster University ISS standards in particular where they are used for recording identifiable data

Will anybody external to the research team be transcribing the research data?

○ Yes ● No

**Online Sources**

Does your research comply with the site(s) terms and conditions? Before completing the section below please read the 'Social Media Guidance for Researchers'

● Yes ○ No ○ It's unclear in the terms and conditions

Is there a reasonable expectation of privacy?

● Yes ○ No

**Because there is a reasonable expectation of privacy, you must obtain consent from site users. Therefore you will need to upload a copy of the Participant Information Sheet & Consent form that you intend to use to obtain their informed consent.**

## General Queries

Does the funder or any organisations involved in the research have a vested interest in specific research outcomes that would affect the independence of the research?

○ Yes ● No ○ I don't know

Does any member of the research team, or their families and friends, have any links to the funder or organisations involved in the research?

○ Yes ● No ○ I don't know

Can the research results be freely disseminated?

● Yes ○ No ○ I don't know

Will you use data from potentially illicit, illegal, or unethical sources (e.g. pornography, related to terrorism, dark web, leaked information)?

○ Yes ● No ○ I don't know

Will you be gathering/working with any special category personal data?

● Yes ○ No ○ I don't know

Are there any other ethical considerations which haven’t been covered?

○ Yes ● No ○ I don't know

## REC Review Details

Based on the answers you have given so far you will need to answer some additional questions to allow reviewers to assess your application.

It is recommended that you do not proceed until you have completed **all of the previous questions**.

Please confirm that you have finished answering the previous questions and are happy to proceed.

☑ I confirm that I have answered all of the previous questions, and am happy to proceed with the application.

## Questions for REC Review

Summarise your research protocol in lay terms (indicative maximum length 150 words).

Note: The summary of the protocol should concisely but clearly tell the Ethics Committee (in simple terms and in a way which would be understandable to a general audience) what you are broadly planning to do in your study. Your study will be reviewed by colleagues from different disciplines who will not be familiar with your specific field of research and it may also be reviewed by the lay members of the Research Ethics Committee; therefore avoid jargon and use simple terms. A helpful format may include a sentence or two about the background/ “problem” the research is addressing, why it is important, followed by a description of the basic design and target population. Think of it as a snapshot of your study.

The study will explore the roles that self-compassion and social support play in the wellbeing of carers of people with Parkinson's. Parkinson's is a degenerative neurological condition which can have a significant impact on people's physical and emotional wellbeing. People living with Parkinson's typically require additional support as the condition progresses. This support is often provided by informal family carers such as spouses, siblings and adult children. The wellbeing of informal carers is often overlooked, by both carers themselves and by services. The study will recruit people who identify as carers of people with Parkinson's. Participants will complete a series of online questionnaires related to the care they provide, and their levels of social support, self-compassion, and wellbeing. Some demographic data will be collected. All data will be anonymous. Data will be analysed to explore the impact of self-compassion and social support on the relationship between carer stressors and wellbeing. Experts by experience (recruited through Parkinson's UK) have been involved in the design of the project. Conversations with the experts by experience around elements of their caring role which they felt it was important to capture in the research has shaped the direction of the project, and the feedback on the participant information documents and questionnaires has also been incorporated into the survey design.

State the Aims and Objectives of the project in Lay persons' language.

The study will aim to explore factors which may have an impact on the wellbeing of carers of people with Parkinson's. In particular, the study will explore whether carer stressors, social support, and self-compassion predict wellbeing. The study will also consider the extent to which either self-compassion or social support influence the relationship between stressors and wellbeing.

The study will aim answer the following research question: to what extent do self-compassion and social support effect the relationship between carer stressors and carer wellbeing?

## Participant Information

Please explain the number of participants you intend to include in your study and explain your rationale in detail (eg who will be recruited, how, where from; and expected availability of participants). If your study contains multiple parts eg interviews, focus groups, online questionnaires) please clearly explain the numbers and recruitment details for each of these cohorts (see help text).

Participants will be recruited through Parkinson's UK's Take Part Hub. Parkinson's UK have already been contacted and have agreed to promote the study. Depending on recruitment success, other organisations providing support to people with Parkinson's may also be approached, including, but not limited to, Parkinson’s New Zealand, Parkinson’s Australia, and Parkinson’s Association of Ireland. Lancaster University’s Psychology Department also holds a list of people interested in Parkinson’s research and this may be utilised for recruitment. The study will also be promoted on Twitter where it is anticipated it will be retweeted by other users. Participants will be adults (aged 18 or over) who identify as carers of people with Parkinson's. There will be no upper age limit to be eligible for the study. Participants can be any gender.

Interested participants will see an advert displaying the title of the study followed by a short description of the project. At the end of the description, interested participants will have the option to follow a link (https://lancasteruni.eu.qualtrics.com/jfe/form/SV_0TUiioW0WfoveEC) which will direct them to a Qualtrics landing page containing the participant information, consent form, and questionnaires.

Participants will also be informed that they can request a paper copy of the survey by emailing the researcher. A paper copy will then be posted to an address they provide, including a stamped envelope in which to return it. Participants accessing the study from outside the UK will not be able to request hard copies of the survey. Any addresses provided by participants will be stored for the minimum length of time possible to send out the pack of questionnaires, and will then be destroyed.

For multiple regression analysis using 3 to 6 predictors, a priori power analysis suggests a sample size of between 77 and 98 participants. A larger sample size of 316 participants is necessary for moderation analysis. This study will therefore aim to recruit between 100 and 350 participants.

You have selected that the research may involve personal sensitive topics that participants may not be willing to otherwise talk about. Please indicate what discomfort, inconvenience or harm could be caused to the participant and what steps you will take to mitigate or manage these situations.

Participants will answer questions which will ask them to reflect on the nature of care they provide to someone with Parkinson's. They will also be asked to answer questions about the social support they receive, their levels of self-compassion, and their wellbeing. It is unlikely that these topics will cause discomfort, inconvenience or harm to participants. However, there is a small possibility that reflecting on their experiences could cause some discomfort. Relevant support services will be highlighted at the beginning of the questionnaires in the participant information sheet, and at the end of the questionnaires in the participant debrief sheet. Participants will be able to end their participation, without giving a reason, at any time, by closing the online window. The full questionnaire and participant information documents has also been reviewed by experts by experience (recruited through Parkinson's UK) prior to launch, in the interests of addressing any elements with the potential to cause distress prior to the study's launch. No elements with the potential to cause distress were identified by the experts by experience.

You stated that the study could induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant’s usual, everyday life. Please describe the question(s) and situation(s) that could lead to these outcomes and explain how you will mitigate this.

Participants will be asked to answer questions related to their caring role, their social support, self-compassion and wellbeing. It is not anticipated that these questions should cause stress or anxiety, but there is a small possibility that reflecting on these topics could cause cause distress for some participants. Some examples of questions which have the potential to cause distress are: (Participants are asked to what extent the following statements apply to them) "I feel like I am missing out on life"; "I resent the person I care for"; "I feel emotionally drained due to caring". Relevant support services will be highlighted in the participant information sheet and debrief sheet, and participants will be invited to contact the researchers should they experience any distress as a result of taking part. Participants will be informed of their right to end their participation at any time without providing a reason, and they can do this by closing the questionnaire window. Questionnaires and participant information documents have been reviewed by experts by experience (recruited via Parkinson's UK) in an effort to identify and address any potentially distressing elements which may not have been considered by the researchers. No such distressing elements were identified either by the researchers or by the experts by experience.

## Participant Relationships

Your answers about gatekeepers has indicated that there is a power imbalance due to there being no precautions to prevent undue pressure. Please explain the situation and how you plan to mitigate and manage the effects of this.

Gatekeepers will not be in a position to apply undue pressure to participants. Parkinson's UK will act as gatekeepers in that they will promote the study through their Take Part hub, where interested parties can access information about range of research projects. Parkinson's UK will not be made aware of whether individuals take part or not, and prospective participants will access the study through a Qualtrics link rather than via application to Parkinson's UK. There will be no incentives or penalties made to individuals regardless of whether or not they decide to take part.

## Information about the Research

What are your dissemination plans? E.g publishing in PhD thesis, publishing in academic journal, presenting in a conference (talk or poster).

The research will be presented as part of my DClinPsy thesis and may be submitted for publication in an academic journal or presented at a conference. A summary of the findings will also be shared with any organisations which support with recruitment for further dissemination.

## Online Sources

You have indicated site users have a reasonable expectation of privacy and therefore you will need to obtain consent to use their data for this project. Please explain how you propose to obtain consent.

Prior to beginning the questionnaires, participants will be asked to read an information sheet detailing the project and to complete a consent form. Participants will be asked to indicate whether they understand the information provided, whether they consent to take part, and whether they consent to their data being used for the project. Participants who indicate they do not consent will not be able to proceed to the online questionnaires to take part in the study. Participants who receive hard copies of the questionnaires will be informed that if they answer 'no' to any of the consent questions, they should not complete the questionnaires.

## General Queries

You have indicated that you will be gathering/working with special category data. Please confirm here how you will comply with data protection law (GDPR) for use of special category personal data.

Participants will be asked to provide a small amount of demographic information which will include some special category data (eg. gender, ethnicity). This data will used for the purposes of descriptive statistics and may be discussed in the research paper if it is felt that this data is relevant to the findings. All participant data will be anonymous and participants will not be personally identifiable from the data they provide. The data will be stored securely in line with GDPR and university guidelines, and only the researcher and research supervisors will have access to the raw data.

## Data Storage

How long will you retain the research data?

All electronic data will be securely stored in a password protected file, and only the researcher and research supervisors will have access to the raw data, in line with university policy on data storage. Once the project is complete and the project has been examined, the SPSS file containing the data will be sent securely to the research coordinator of the DClinPsy who will store it for 10 years. It will then be securely destroyed, under the supervision of the research supervisor, Fiona Eccles.

How long and where will you store any personal and/or sensitive data?

All data, including special category data, will be securely stored in a password protected University Onedrive for ten years, in line with University policy, after which it will be destroyed. All data will be stored anonymously.

Any names and addresses provided for the purposes of providing physical copies of the questionnaires will be saved in a password protected file only until the questionnaires have been posted, which will take place at the earliest opportunity. After the questionnaires have been posted, this information will be destroyed.

Please explain when and how you will anonymise data and delete any identifiable record?

Participants will not be asked for their name at any point during the data collection process, and no information which could make participants personally identifiable will be collected. If any participants provide their name and address in order to receive paper copies of the questionnaires, these will be saved in a password protected file only until the requested questionnaires have been posted, which will be at the earliest opportunity. After posting, the provided name and address will be destroyed and will not be retained for any other purpose.

## Project Documentation*

***Important Notice about uploaded documents:***

When your application has been reviewed if you are asked to make any changes to your uploaded documents please highlight the changes on the updated document(s) using the highlighter so that they are easy to see.

Please confirm that you have read and applied, where appropriate, the guidance on completing the Participant Information Sheet, Consent Form, and other related documents and that you followed the guidance in the help button for a quality check of these documents. For information and guidance, please use the relevant link below:

FST Ethics Webpage

FHM Ethics Webpage

FASS-LUMS Ethics Webpage

REAMS Webpage

☑ I confirm that I have followed the guidance.

In addition to completing this form you must submit all supporting materials.

Please indicate which of the following documents are appropriate for your project:

☑ Research Proposal (DClinPsy)
☑ Advertising materials (posters, emails)
☐ Letters/emails of invitation to participate
☑ Consent forms
☑ Participant information sheet(s)
☐ Interview question guides
☐ Focus group scripts
☑ Questionnaires, surveys, demographic sheets
☐ Workshop guide(s)
☑ Debrief sheet(s)
☐ Transcription (confidentiality) agreement
☐ Other
☐ None of the above.

Please upload the documents in the correct sections below:

Please ensure these are the latest version of the documents to prevent the application being returned for corrections you have already made.

As you are in a DClinPsy course please upload your Research Proposal for this project.

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Research Proposal | Research Protocol | Research Protocol.pdf | 28/10/2022 | 1 | 202.9 KB |

Please upload all consent forms to be used in this project.

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Consent Form | Consent form - online version | Consent form - online version.docx | 28/10/2022 | 1 | 35.2 KB |
| Consent Form | Consent form - hard copy version | Consent form - hard copy version.docx | 28/10/2022 | 1 | 35.7 KB |

Please upload all Participant Information Sheets:

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Participant Information Sheet | Information Sheet V2 (online version) | Information Sheet V2 (online version).pdf | 28/11/2022 | 2 | 126.3 KB |
| Participant Information Sheet | Information Sheet V2 (hard copy version) | Information Sheet V2 (hard copy version).pdf | 28/11/2022 | 2 | 127.7 KB |

Please upload all advertising materials (posters, emails)

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Advertising materials | Advert | Advert.docx | 28/10/2022 | 1 | 25.5 KB |

Please upload all Questionnaires, surveys, demographic sheets

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Questionnaires, surveys, demographic sheets | Questionnaires (Hard Copy Version) | Questionnaires (Hard Copy Version).pdf | 28/10/2022 | 1 | 79.1 KB |

Please upload a copy of your Debrief sheet.

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Debrief sheet | Debrief Sheet (Online Version) | Debrief Sheet (Online Version).pdf | 28/10/2022 | 1 | 98.5 KB |
| Debrief sheet | Debrief Sheet (Hard Copy Version) | Debrief Sheet (Hard Copy Version).pdf | 28/10/2022 | 1 | 92.2 KB |

## Declaration

***Please Note***

Research Services monitors projects entered into the online system, and may select projects for quality control.

All research at Lancaster university must comply with the LU data storage and governance guidance as well as the General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018. (Data Protection Guidance webpage)

☑ I confirm that I have read and will comply with the LU Data Storage and Governance guidance and that my data use and storage plans comply with the General data Protection Regulation (GDPR) and the UK Data Protection Act 2018.

Have you that you have undertaken a health and safety risk assessment for your project through your departmental process? (Health and Safety Guidance)

☑ I have undertaken a health and safety assesment for your project through my departmental process, and where required will follow the appropriate guidance for the control and management of any foreseeable risks.

When you are satisfied that this application has been completed please click "Request" below to send this application to your supervisor for approval.

**Signed:** This form was signed by Dr Fiona Eccles (f.eccles@lancaster.ac.uk) on 29/11/2022 11:00

Please press "Request" to send this application to your second supervisor.

**Signed:** This form was signed by Professor Jane Simpson (j.simpson2@lancaster.ac.uk) on 29/11/2022 12:13

Please read the terms and conditions below:

- You have read and will abide by Lancaster University's Code of Practice and will ensure that all staff and students involved in the project will also abide by it.
- If appropriate a confidentiality agreement will be used.
- You will complete a data management plan with the Library if appropriate. Guidance from Library.
- You will provide your contact details, as well as those of either your supervisor (for students) or an appropriate person for complaints (such as HoD) to any participants with whom you interact, so they know whom to contact in case of questions or complaints?
- That University policy will be followed for secure storage of identifiable data on all portable devices and if necessary you will seek guidance from ISS.
- That you have completed the ISS Information Security training and passed the assessment.
- That you will abide by Lancaster University's lone working policy for field work if appropriate.
- On behalf of the institution you accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).
- To the best of your knowledge the information you have provided is correct at the time of submission.
- If anything changes in your research project you will submit an amendment.

**Applicant Only: To complete and submit this application please click "Sign" below:**

**Signed:** This form was signed by Katy Brooks (k.brooks2@lancaster.ac.uk) on 29/11/2022 10:28

# Research Protocol

# Self-Compassion and Social Support in the Wellbeing of Carers of People with Parkinson's.

**Researcher:** Katy Brooks k.brooks2@lancaster.ac.uk
**DClinPsy Research Supervisor:** Fiona Eccles f.eccles@lancaster.ac.uk
**Field Supervisor:** Jane Simpson j.simpson2@lancaster.ac.uk

## Introduction

Parkinson's (Parkinson's UK's preferred term for Parkinson's disease) is a degenerative neurological condition characterised by a deficit of dopaminergic activity in an area of the brain called the substantia nigra (Hawley et al., 2014). Approximately 1% of the population aged over 60 are affected, with greater prevalence in older populations (Laux, 2021; Elbaz et al., 2016). Parkinson's presents with a range of motor and nonmotor symptoms, including tremor, bradykinesia, sleep difficulties, changes in cognitive function, and fatigue (Choi et al., 2020; Zafar & Yaddanapudi, 2021). Psychological difficulties are also common; rates of depression and anxiety are high in people with Parkinson's and have been associated with increased cognitive decline (Landau et al., 2015). Symptoms worsen over time, and people living with Parkinson's often require support with daily living as the condition progresses.

Despite the complex challenges experienced by people living with Parkinson's, a high proportion of care is provided informally by family or friends, and support for carers is often difficult to access (Toze et al., 2021). Research suggests that fewer than 50% of carers for people with Parkinson's receive any assistance from professional care services (Kalampokini et al., 2022). Carers of people with Parkinson's experience higher levels of depression, lower wellbeing, and lower life satisfaction than carers of people living with non-neurological conditions (Peters et al., 2011; Vescovelli & Ruini, 2019). Informal carers represent a substantial and often unacknowledged asset to society. In the UK, for example, there are currently an estimated 6.5 million unpaid carers, saving the UK government the equivalent of £530 million per day (Carers UK, 2021). It is therefore essential that those working in healthcare services have an understanding of the challenges faced by this group in order to adequately meet their needs.

In addition to understanding the factors negatively influencing carer wellbeing, it is also important to understand the protective factors. One such factor is perceived social support, which has been associated with psychological health in carers of older adults: those reporting higher perceived social support experienced reduced psychological distress in comparison to those with lower perceived social support (del-Pino-Casado, 2022). Carer stressors have been found to negatively impact carer burden, although the impact of carer burden on quality of life has been found to be reduced in carers with greater perceived social support (Goldsworthy & Knowles, 2008).

Another concept which may be important in carer wellbeing is self-compassion. Self-compassion has been found to be a significant protective factor against carer burden in the carers of people with dementia (Lloyd et al., 2019) and positively correlated with wellbeing in the parents of children with autistic spectrum conditions (Torbet et al., 2019). Interventions focused on fostering self-compassion in family carers have been found to be effective at reducing burden and promoting emotional regulation (Murfield, 2019), and both lack of self-compassion and hours spent caring have been found to be significant predictors of depression in carers of people with long term neurological conditions (Hlabangana, 2020).

To date, research exploring on carer experience has typically focused on negative outcomes, such as distress, burden and strain (Mosley et al., 2017; Lau & Au, 2011; Hand et al., 2021). While it is important to understand where carers are experiencing negative outcomes as a result of the pressures of caregiving, it is also important to understand factors which contribute to positive outcomes for carers. Reducing strain and burden in carers is one aspect of promoting carer quality of life; understanding the factors which promote wellbeing and flourishing is another. In order to address this relative gap in the literature, this study will therefore focus on carer wellbeing as its outcome measure.

Given the high proportion of informal care provided by the families of people with Parkinson's (Morley et al., 2012), and the prevalence of psychological distress meeting or exceeding diagnostic threshold in this group (Mosley et al., 2017) increasing understanding of the factors associated with carer wellbeing has important implications for healthcare practitioners including clinical psychologists. Improved understanding of the factors influencing carer wellbeing in this group will support the development of appropriate and tailored interventions which are better suited to meet the needs of carers of people with Parkinson's.

While families living with Parkinson's have been included in studies exploring self-compassion in carers of people with neurological conditions (Murfield et al., 2020), there is a lack of literature focusing explicitly on self-compassion in carers of people with Parkinson's. As both self-compassion and social support have been found to act as protective factors in carers, this research will therefore consider the impact that self-compassion and social support have on the relationship between carer stressors and carer wellbeing. This study will aim to address the research question, to what extent do self-compassion and social support moderate the relationship between carer stressors and carer wellbeing. In particular it is hypothesised that:

1. Carer stressors, social support, and self-compassion will act as independent predictors of carer wellbeing.

2. Self-compassion will moderate the relationship between carer stressors and carer wellbeing.
3. Social support will moderate the relationship between carer stressors and carer wellbeing.

## Method

### Participants

Participants will be people who self-identify as current informal carers of someone with Parkinson's. In order to avoid excluding certain caring groups, restrictions will not be placed on the nature of participants' relationship to the person they are caring for; this could be a spouse, sibling, parent, friend, or neighbour. People providing paid care or care in a registered voluntary capacity will not be included. Further information about the nature of the caring relationship and duration of time spent caring will be collected to enable the impact of different carer demographics to be explored as part of the data analysis. In addition to information about the nature of the caring relationship, demographic information collected will include the age, ethnicity, and gender of participants.

Participants will be recruited through Parkinson's UK Take Part Hub and via social media, using accounts belonging to Katy Brooks and set up for the sole and exclusive purposes of promoting the research. Social media platforms used will include Twitter, Facebook, Instagram, and Reddit, and any other relevant platforms. Other organisations which provide support to people with Parkinson's and their carers, including, but not limited to, Parkinson's New Zealand, Parkinson's Australia, Parkinson's Association of Ireland, and Carers UK may also be approached if required in order to reach the required number of participants. The study will also be promoted in community or health venues where it might be accessed by carers of people with Parkinson's, such as community centres, GP surgeries, hospital waiting rooms (with the consent of the relevant trust) or libraries. As participants are being recruited in their role as carers and not as patients, they are considered "healthy volunteers." Because of this, and in addition to the fact that the recruitment strategy is passive (copies of the advert will be displayed but healthcare professionals will not direct people towards the study), this approach does not require HRA or NHS REC approval.

Where appropriate, the researcher may attend relevant community groups or events for people with Parkinson's and their carers to discuss the study and provide further information. Interested parties will have the option to complete the study at the time, or to take away details of the study or copies of the questionnaires to complete on their own. No pressure or expectation will be placed on group members to complete the study, and all group members will be informed that participation is voluntary. If people do decide to complete the questionnaires while the researcher is present, a box will be provided for people to post their responses into so that it is not possible to see who has completed which questionnaires. Group members will be informed that, as the questionnaires are anonymous and no identifying data will be collected, it will not be possible to withdraw their responses after they have been submitted. Group members will be given the opportunity to ask questions as part of the group, and will also be provided with contact details (university email address and research phone number) so that if they have questions they would prefer not to raise in front of the other group members, they have the option to do so privately.

Lancaster University's Psychology Department also holds a list of people interested in Parkinson's research and this may also be utilised for recruitment.

Participants will be required to be aged 18 or older. There will be no upper age limit to be eligible for the study. Participants can be any gender. In order to meet inclusion criteria, participants must have been providing care or support to someone with Parkinson's for at least one year.

An a priori power analysis, conducted using G*power, suggests that for a multiple regression with 3 to 6 predictors, a sample size of between 77 and 98 participants is required in order to detect a medium effect size with 80% power ($p<0.05$) (Faul et al., 2009). Standard small, medium and large effect sizes in moderation analysis may be typically considered to be 0.005, 0.01, and 0.025 respectively, and as a result, larger sample sizes of 200 or higher are generally required in order to detect adequate effect sizes (Whisman & McClelland, 2005). In order to detect a large effect size ($f^2=0.025$), an a priori power calculations using G*power suggest that for 80% power ($p<0.05$) would require a sample size of 316 participants. The target sample size of this study will therefore be 316. Recruitment will continue until approximately 350 participants have been recruited or until it is no longer practical to collect further data (e.g. all recruitment avenues have been exhausted and the time constraints of the thesis mean recruitment cannot continue). In all events, at least 100 participants will be recruited to ensure the regression analysis (for hypothesis 1) is adequately powered.

## Design

The study will use a quantitative, cross-sectional design. Data will be collected via a series of online questionnaires constructed using Qualtrics software. Multiple regression analysis will be used to investigate whether stressors, social support and self-compassion predict wellbeing. Then moderation analysis will be used to explore the extent to which self-compassion and social support moderate the relationship between the predictor variable (carer stressors) and the outcome variable (wellbeing).

The design of the project has been shaped by contributions from experts by experience recruited through Parkinson's UK. Experts by experience have given feedback on the direction of the project and areas they feel are important based on their own experience of caring for someone with Parkinson's. They have also offered feedback on the participant information documents and questionnaires and amendments have been made in response to this.

**Materials**

Participant materials will be available via Qualtrics and in hard copies by request. The Qualtrics version can be accessed here: https://lancasteruni.eu.qualtrics.com/jfe/form/SV_0TUiioW0WfoveEC

Participants will be asked to provide a small amount of demographic information, including their age, ethnicity, gender, and country of residence. Participants will then be asked to provide some information on the care they provide, including the length of time since the person they support received a diagnosis of Parkinson's, the length of time the participant has been providing care or support, the type of support provided, and the average number of hours per week the participant spends carrying out caring duties.

The following validated measures will be used to collect data:

1. *The Carer Burden Inventory (CBI)* (Novak and Guest, 1989). This is a 24-item measure using a 5-point Likert scale with good internal consistency (Cronbach's α = 0.73 to 0.86). Participants are asked to rate how often (never; rarely; sometimes; quite frequently; always) a series of given statements represent their feelings. The measure has five subscales: Time Dependency; Developmental Burden; Physical Burden; Social Burden; and Emotional Burden. Although traditionally conceptualised as a measure of burden, this study will use the CBI subscales to measure the concept of carer stressors.

2. *The Sussex-Oxford Compassion for Self Scale (SOCS-S)* (Gu et al., 2019). This is a 20-item measure using a 5-point Likert scale used to measure self-compassion. For

the total score and subscales, Cronbach's α = 0.75 to 0.93. Participants are presented with a series of statements and asked to rate the extent to which they are true (not at all true; rarely true; sometimes true; often true; always true). The SOCS-S has five subscales: Recognising Suffering; Understanding the Universality of Suffering; Feeling for the Person Suffering; Tolerating Uncomfortable Feelings; and Acting or Being Motivated to Act to Alleviate Suffering.

3. *Adult Carer Quality of Life Questionnaire (AC-QoL)* (Joseph et al., 2012). This measure uses a 4-part Likert scale and asks participants to consider how often over the last two weeks (never; some of the time; a lot; always) a list of statements applies to them. This study will use the Support for Caring subscale (Cronbach's α = 0.87) (Negri et al., 2018) of the measure, which consists of five statements relating to the level of support received by the carer. This measure will be used to assess participant social support.

4. *The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)* (Tennant et al., 2007). This is a 14-item measure using a 5-part Likert scale with excellent validity (Cronbach's α = 0.91). Participants are asked to consider how often (none of the time; rarely; some of the time; often; all of the time) a list of statements have best reflected their thoughts and feelings over the past two weeks.

## Procedure

Participants will be recruited through Parkinson's UK Take Part Hub and the study will also promoted on social media. Depending on the success of recruitment, other organisations providing support to people with Parkinson's and their carers may be approached to promote the study. Organisations will only be approached in countries which use English as a main language as translations of the study will not be provided. However, if English speaking participants from other countries see the advert on social media or elsewhere they will be welcome to participate. Interested participants will see the title of the study followed by a short description of the project. At the end of the description, interested participants will have the option to follow a link which will direct them to a Qualtrics landing page.

Paper copies of the advert will be shared with community venues or health venues where they might be seen by carers of people with Parkinson’s, such as community centres, GP surgeries (with the consent of the relevant trust) or libraries. Where appropriate, physical copies of the questionnaires and participant documents may also be shared with these venues to make the study more accessible for people who are not confident with, or do not have access to, technology. The researcher may also attend relevant groups or events for people with Parkinson’s and their carers to discuss the study and provide information on how to participate.

Participants will be informed that they can request a paper copy of the survey by contacting the researcher. A paper copy will then be posted to an address they provide, including a stamped envelope in which to return it. Participants accessing the study from outside the UK will not be able to request hard copies of the survey. Any addresses provided by participants will be stored for the minimum length of time possible to send out the pack of questionnaires, and will then be destroyed.

Having followed the provided link, participants will first view the participant information sheet, which will provide further detail about the study. Participants will then be directed to a consent form which establish that participants are willing to take part in the study and meet necessary inclusion criteria (aged 18 or over, currently providing care to someone with a diagnosis of Parkinson’s). Only participants who answer ‘yes’ to all of the questions asked on the consent form will be able to proceed to the survey. If paper copies of the questionnaires are returned in which ‘yes’ has not been answered for all of the questions on the consent form, or the consent form has not been included with the questionnaires, it will be concluded that the respondent does not meet inclusion criteria for the study. In this case, their data will not be included in the analysis and their questionnaire will be destroyed. Paper copies sent out to prospective participants will clearly state the inclusion criteria for the study, and participants will be asked not to proceed with the study if they do not meet the specified criteria.

Participants who answer ‘yes’ to all of the questions on the consent form will then be directed to the survey. After answering all of the questions, participants will be presented with a debrief sheet which will provide further detail about the project aims, and restate the researcher contact details and details of support organisations.

Data will be stored on the researcher’s password protected Qualtrics account during data collection, which will be accessible only to the researcher and research supervisors. When the study is closed, the data will then be imported into SPSS Statistics for analysis. During this process, the data will only be accessible by the researcher and the research supervisors.

Following completion of the research, the results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal and presented at conferences. The results will also be given to the organisations that help with recruitment, so they can disseminate them to their members.

## Proposed Analysis

The software package SPSS, including the add-on Hayes PROCESS tool, will be used to analyse the data. Data will be exported from Qualtrics to SPSS, where data cleaning and error checking will be carried out. Descriptive statistics will be produced for the demographic data and predictor variables.

Multiple linear regression analysis will be conducted to establish the extent to which carer stressors, social support, and self-compassion predict wellbeing. Moderation analysis will then be conducted to establish whether self-compassion has a significant interaction on the relationship between carer stressors and wellbeing (see Figure 1). This analysis will then be repeated using social support as the moderating variable (see Figure 2). The significance and direction of any relationships will then be explored.

**Figure 1.**

*Moderation model using self-compassion as the moderating variable*

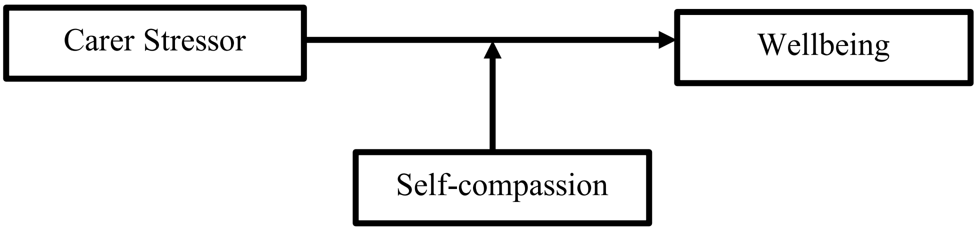
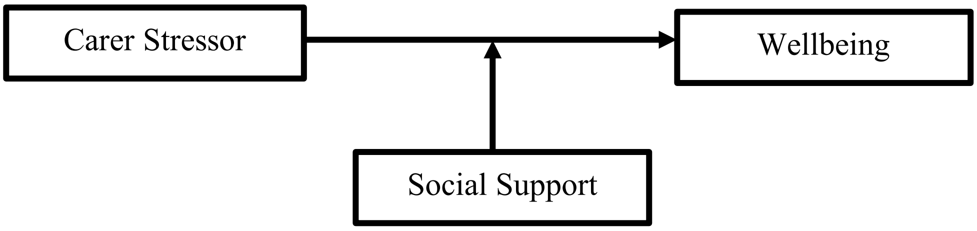


**Figure 2.**

*Moderation model using social support as the moderating variable*



## Practical Issues

It is possible that technology barriers could pose challenges to some participants. Interested parties who are not able to complete the surveys online will have the option of requesting physical copies of the questionnaires to ensure that they are not unintentionally excluded from the study. Costs for the printing and posting of physical questionnaires have been factored into the thesis proposal and will be met by the university. Any physical copies of questionnaires will be inputted directly into Qualtrics, after which physical copies will be destroyed. All electronic data will be securely stored in a password protected file, and only the researcher and research supervisors will have access to the raw data, in line with university policy on data storage. Once the project is complete and the project has been examined, the SPSS file containing the data will be sent securely to the research coordinator of the DClinPsy who will store it for 10 years. It will then be securely destroyed, under the supervision of the research supervisor, Fiona Eccles.

## Ethical Concerns

As the study will be conducted online, monitoring and responding to any participant distress will not be possible. While it is not expected that taking part in the study would cause undue distress, comprehensive participant information and debrief sheets will be provided in order to minimise any risk from this. Contact details for relevant support services will be included in the participant information sheet.

Participants will be asked to indicate their informed consent to take part in the study after reading the participant information sheet. Participants will be asked to provide demographic data but a ‘Prefer not to say’ option will be included with each demographic question should participants not feel comfortable providing this information. All data will be collected anonymously and participants will not be personally identifiable from the information they provide.

## Timescale

Pending ethical approval, recruitment will aim to start between December 2022 and January 2023. Data collection will last for approximately 6 months, although this may be reviewed and revised depending on the pace of recruitment. If suitable participant numbers are achieved before this point, recruitment may be closed early. Equally, if recruitment is slower than expected, this period may be extended. It is anticipated that data analysis will be conducted between September 2023 and November 2023, after which the research paper will be completed. The project will end in March 2024, at which point results will shared with Parkinson’s UK and any other organisations which have been involved in the promotion of the study, where it will be accessible to participants.

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## Appendix 4.1: Ethics Approval Letter

**Name:** Katy Brooks

**Supervisor:** Fiona Eccles

**Department:** Health Research

FHM **REC Reference:** FHM-2022-0941-RECR-2

**Title:** Self-compassion and social support in the wellbeing of carers of people with Parkinson's.

Dear Katy Brooks,

Thank you for submitting your ethics application in REAMS, Lancaster University's online ethics review system for research. The application was recommended for approval by the FHM Research Ethics Committee, and on behalf of the Committee, I can confirm that approval has been granted for this application.

As Principal Investigator/Co-Investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licences and approvals have been obtained.

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress).

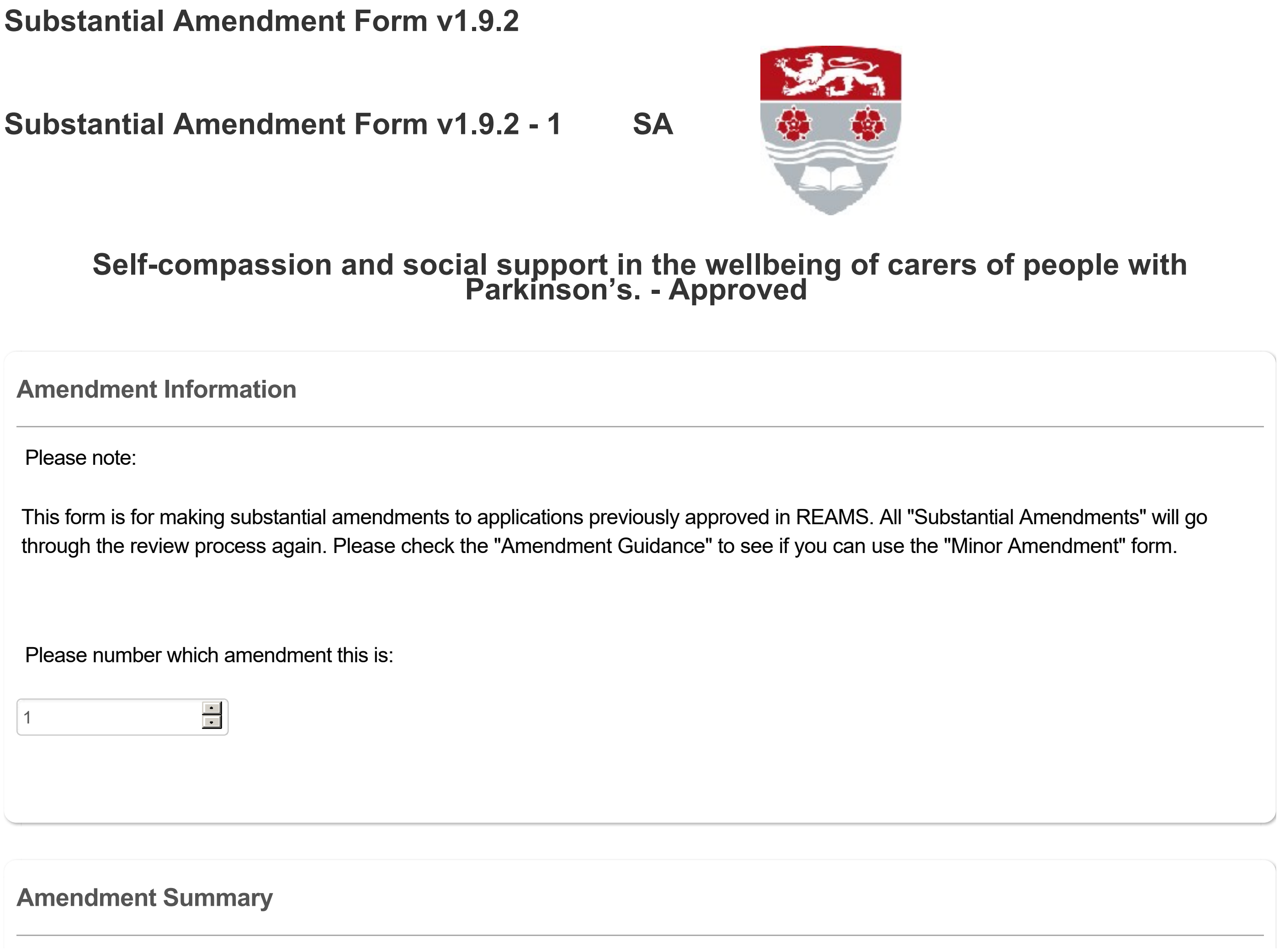
- submitting any changes to your application, including in your participant facing materials (see attached amendment guidance).

Please keep a copy of this email for your records. Please contact me if you have any queries or require further information.

Yours sincerely,

Dr Laura Machin
Chair of the Faculty of Health and Medicine Research Ethics Committee
fhmresearchsupport@lancaster.ac.uk

## Appendix 4.2: Ethics Amendment Application



### Substantial Amendment Form v1.9.2

### Substantial Amendment Form v1.9.2 - 1 SA

### Self-compassion and social support in the wellbeing of carers of people with Parkinson’s. - Approved

#### Amendment Information

Please note:

This form is for making substantial amendments to applications previously approved in REAMS. All "Substantial Amendments" will go through the review process again. Please check the "Amendment Guidance" to see if you can use the "Minor Amendment" form.

Please number which amendment this is:

1

#### Amendment Summary

Please summarise your changes and the reasons why you are making them. Ensure that you indicate which parts of the form have been altered.

Due to slow recruitment, I would like to extend the recruitment sites for this project to reach more people and encourage engagement. I would like to include additional social media platforms in the study advertising (currently only Twitter is used) to include Facebook, Instagram, Reddit, and other relevant platforms. Only professional accounts, set up specifically for the purpose of promoting the study, will be used. It is anticipated that the study will be shared further by other users, but the initial accounts used to display the advert will be created and maintained solely for the purpose of this research.

The study is currently only advertised online. I would like to amend this to include that physical copies of the advert will also be shared at community and health venues where carers of people with Parkinson's might access them, such as community centres, GP surgeries, hospital waiting rooms (with the consent of the relevant trust) or libraries. This will only be done with the consent of management at the venues in question, and in consultation with the project supervisors. Paper copies of the participant documents and questionnaires may be provided to these venues to share with people who might struggle to access the study online due to difficulties with or lack of access to technology.

As participants are being recruited in their role as carers and not as patients, they are considered "healthy volunteers." Because of this, and in addition to the fact that the recruitment strategy is passive (copies of the advert will be displayed but healthcare professionals will not direct people towards or otherwise promote the study), this approach does not require HRA or NHS REC approval.

Where appropriate, I will attend relevant community groups in person to discuss the study and provide further information. Interested parties will have the option to complete the study at the time, or to take away details of the study or copies of the questionnaires to complete on their own. No pressure or expectation will be placed on group members to complete the study, and all group members will be informed that participation is voluntary. If people do decide to complete the questionnaires while I am present, a box will be provided for people to post their responses into so that it is not possible to see who has completed which questionnaires. Group members will be informed that, as the questionnaires are anonymous and no identifying data will be collected, it will not be possible to withdraw their responses after they have been submitted. Group members will be given the opportunity to ask questions as part of the group, and will also be provided with contact details (email and research phone number) so that if they have questions they would prefer not to raise in front of the other group members, they have the option to do so privately.

Revised adverts for the study have also been submitted in an effort to make these more engaging and interesting for potential participants. The document contains separate two adverts, Design A and Design B, so that the design can be alternated at venues to promote engagement.

Will your project require NHS REC approval? (If you are not sure please read the guidance in the information button)

○ Yes ● No

Do you need Health Research Authority (HRA) approval? (Please read the guidance in the information button)

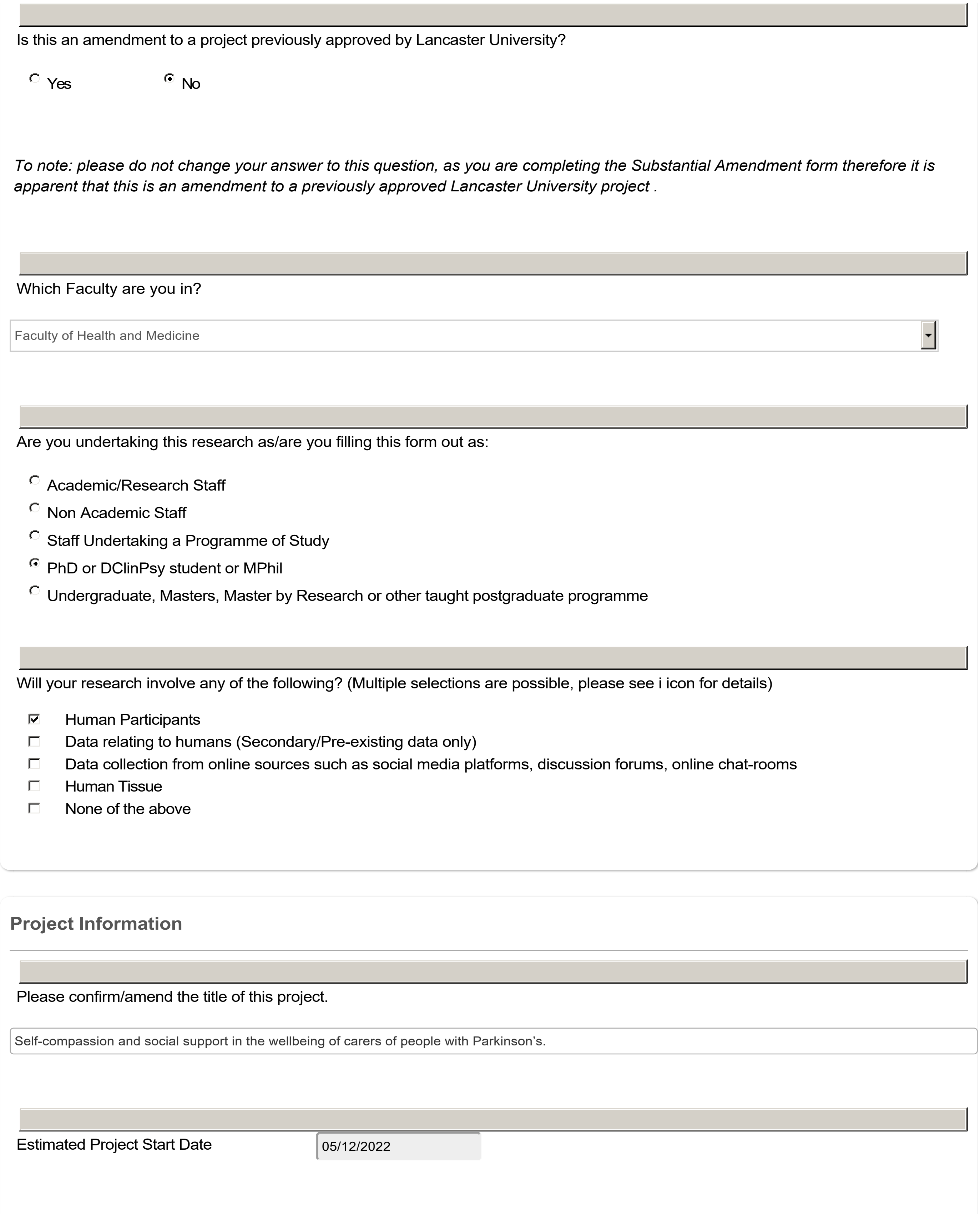
○ Yes ● No

Have you already obtained, or will you be applying for ethical approval, from another institution outside of Lancaster University? (For example, an external institution such as: another University's Research Ethics Committee, the NHS or an institution abroad (eg an IRB in the USA)? Please select one of the following:

● No, I do not need ethical approval from an external institution.

○ Yes, I have already received ethical approval from an external institution.

○ Yes, I will be applying for ethical approval from an external institution after I have received confirmation of ethical approval from my Faculty Research Ethics Committee (FREC) at Lancaster University, if the FREC grants approval.



Is this an amendment to a project previously approved by Lancaster University?

○ Yes ● No

*To note: please do not change your answer to this question, as you are completing the Substantial Amendment form therefore it is apparent that this is an amendment to a previously approved Lancaster University project .*

Which Faculty are you in?

Faculty of Health and Medicine

Are you undertaking this research as/are you filling this form out as:

- ○ Academic/Research Staff
- ○ Non Academic Staff
- ○ Staff Undertaking a Programme of Study
- ● PhD or DClinPsy student or MPhil
- ○ Undergraduate, Masters, Master by Research or other taught postgraduate programme

Will your research involve any of the following? (Multiple selections are possible, please see i icon for details)

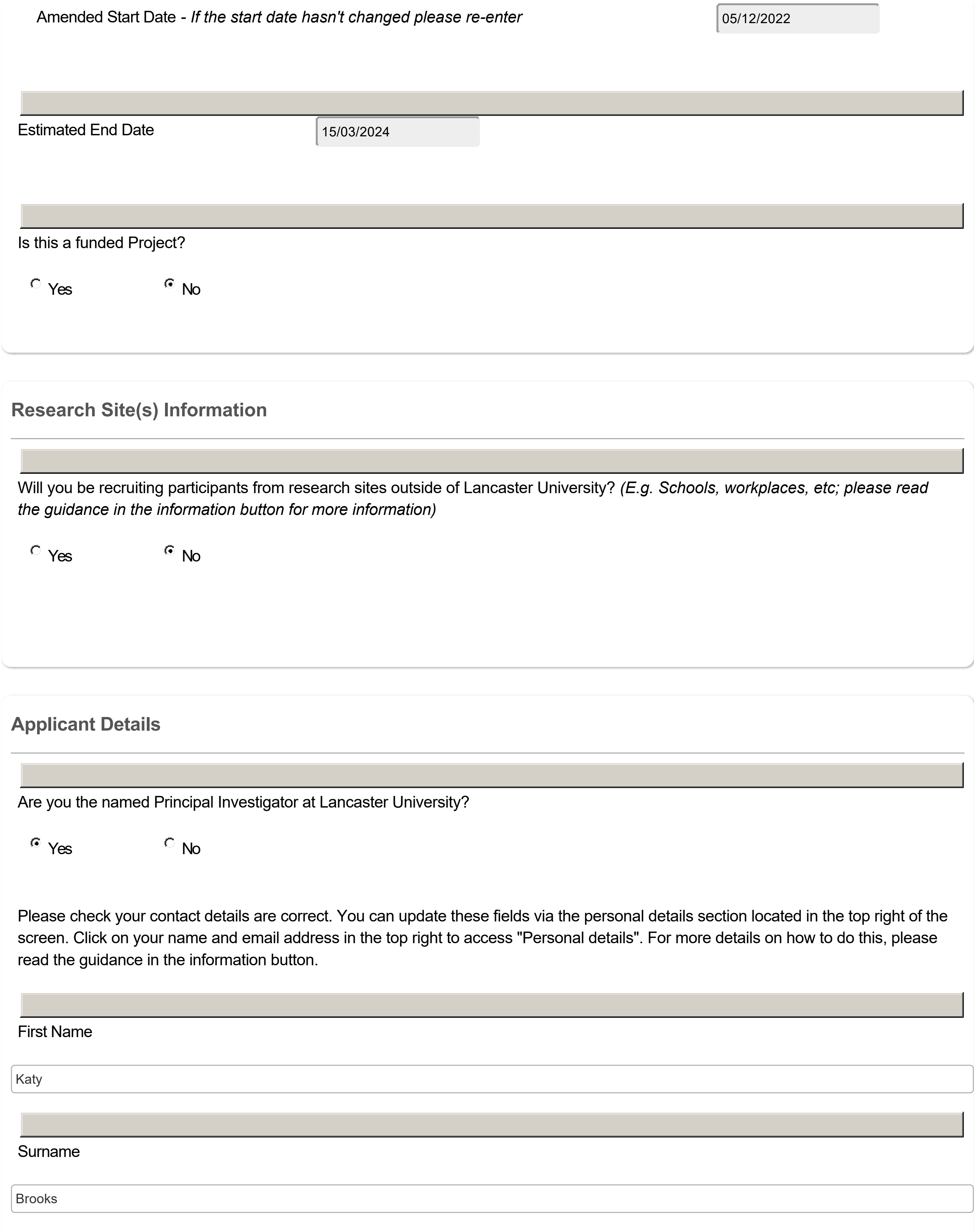
- ☑ Human Participants
- ☐ Data relating to humans (Secondary/Pre-existing data only)
- ☐ Data collection from online sources such as social media platforms, discussion forums, online chat-rooms
- ☐ Human Tissue
- ☐ None of the above

## Project Information

Please confirm/amend the title of this project.

Self-compassion and social support in the wellbeing of carers of people with Parkinson’s.

Estimated Project Start Date 05/12/2022



Amended Start Date - *If the start date hasn't changed please re-enter* 05/12/2022

Estimated End Date 15/03/2024

Is this a funded Project?

○ Yes ● No

**Research Site(s) Information**

Will you be recruiting participants from research sites outside of Lancaster University? *(E.g. Schools, workplaces, etc; please read the guidance in the information button for more information)*

○ Yes ● No

**Applicant Details**

Are you the named Principal Investigator at Lancaster University?

● Yes ○ No

Please check your contact details are correct. You can update these fields via the personal details section located in the top right of the screen. Click on your name and email address in the top right to access "Personal details". For more details on how to do this, please read the guidance in the information button.

First Name

Katy

Surname

Brooks

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

k.brooks2@lancaster.ac.uk

Please enter a phone number that can be used in order to reach you, should an emergency arise.

07539260878

## Supervisor Details

Search for your supervisor's name. *If you cannot find your supervisor in the system please contact rso-systems@lancaster.ac.uk to have them added.*

First Name

Fiona

Surname

Eccles

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

f.eccles@lancaster.ac.uk

Do you need to add a second supervisor to sign off on this project?

○ Yes ● No

## Additional Team Members

Other then those already added, please select which type of team members will be working on this project:

- ☑ I am not working with any other team members.
- ☐ Staff
- ☐ Student
- ☐ External

## Details about the participants

As you are conducting research with Human Participants/Tissue you will need to answer the following questions before your application can be reviewed.

If you have any queries about this please contact your Ethics Officer before proceeding.

What's the minimum number of participants needed for this project?

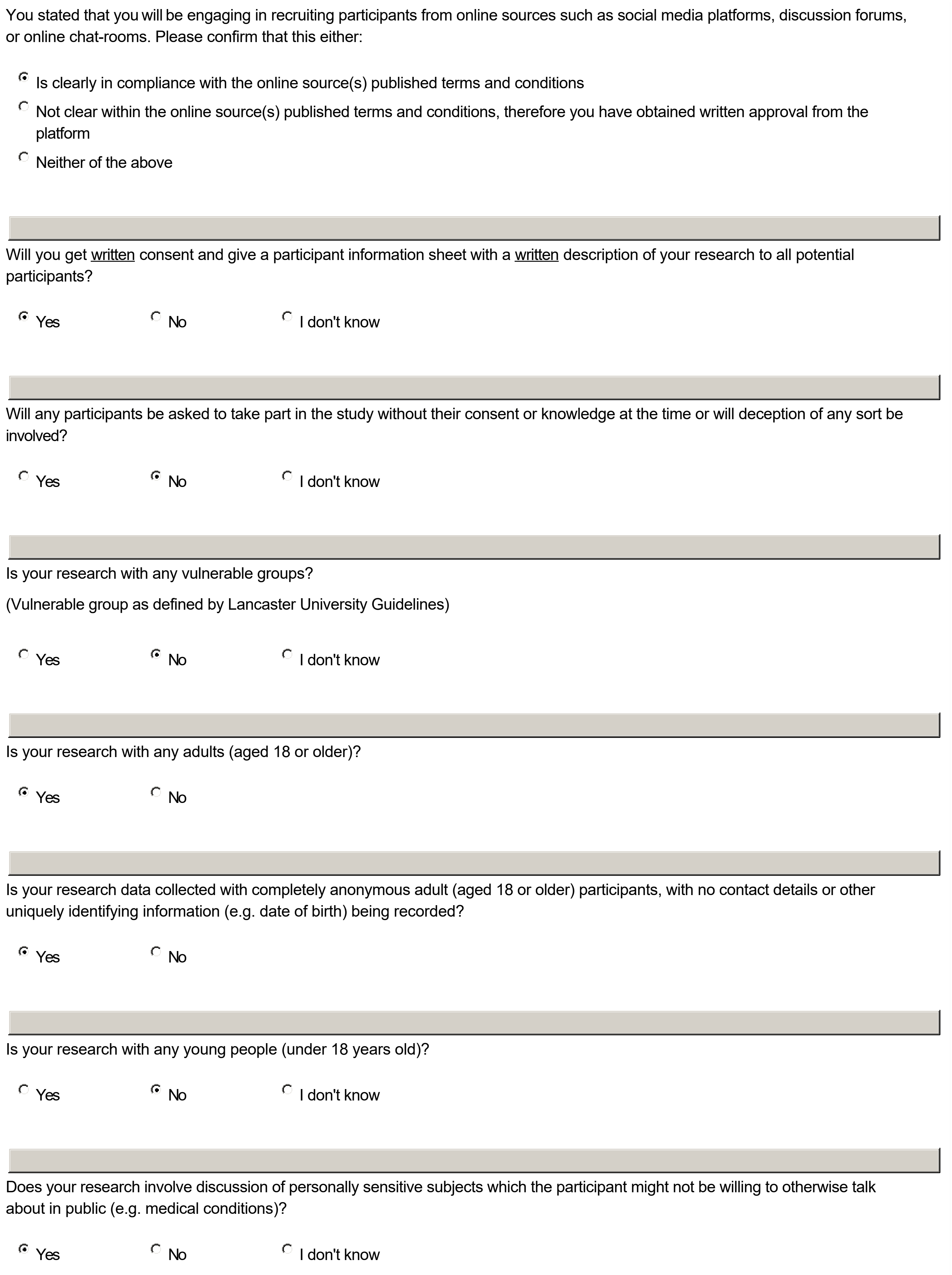
100

What's the maximum number of expected participants?

350

Do you intend to recruit participants from online sources such as social media platforms, discussion forums, or online chat rooms?

● Yes ○ No



You stated that you will be engaging in recruiting participants from online sources such as social media platforms, discussion forums, or online chat-rooms. Please confirm that this either:

● Is clearly in compliance with the online source(s) published terms and conditions
○ Not clear within the online source(s) published terms and conditions, therefore you have obtained written approval from the platform
○ Neither of the above

Will you get <u>written</u> consent and give a participant information sheet with a <u>written</u> description of your research to all potential participants?

● Yes ○ No ○ I don't know

Will any participants be asked to take part in the study without their consent or knowledge at the time or will deception of any sort be involved?

○ Yes ● No ○ I don't know

Is your research with any vulnerable groups?

(Vulnerable group as defined by Lancaster University Guidelines)

○ Yes ● No ○ I don't know

Is your research with any adults (aged 18 or older)?

● Yes ○ No

Is your research data collected with completely anonymous adult (aged 18 or older) participants, with no contact details or other uniquely identifying information (e.g. date of birth) being recorded?

● Yes ○ No

Is your research with any young people (under 18 years old)?

○ Yes ● No ○ I don't know

Does your research involve discussion of personally sensitive subjects which the participant might not be willing to otherwise talk about in public (e.g. medical conditions)?

● Yes ○ No ○ I don't know

Is there a risk that the nature of the research topic might lead to disclosures from the participant concerning either:

- Their own or others involvement in illegal activities
- Other activities that represent a threat to themselves or others (e.g. sexual activity, drug use, or professional misconduct)?

○ Yes ● No ○ I don't know

Does the study involve any of the following:

- Physically intrusive procedures including touching or attaching equipment to participants
- Administration of substances
- Ultrasound or sources of non-ionising radiation (e.g. lasers)
- Sources of ionising radiation, (e.g. X-rays)
- Collection or use of samples of Human Tissue (e.g. Saliva, skin cells, blood etc.)

○ Yes ● No ○ I don't know

## Details about the relationships with participants

Do you have a current or prior relationship with potential participants? For example, teaching or assessing students or managing or influencing staff (this list is not exhaustive).

○ Yes ● No ○ I don't know

If you need written permission from a senior manager in an organisation where research will take place (e.g. school, business) will you gain this in advance of undertaking your research?

○ Yes ○ No ○ I don't know ● N/A

Will you be using a gatekeeper to access participants?

● Yes ○ No ○ I don't know if I will be using a gatekeeper

The gatekeeper will be in a position of authority or have influence over potential participants (e.g., a teacher or manager). However, I will take the gatekeeper's assurance that they will stay completely impartial and  that I will ensure that there is no perceived pressure to participate, and I will explain to participants that their decision on whether to participate or not will have no effect on their treatment or rights (e.g., learning or assessment).

○ Yes ● No ○ I don't know

The gatekeeper will be able to tell who has participated (e.g., participants’ responses will be made directly to the gatekeeper or if the researcher will inform the gatekeeper of who has participated), but I have assurance that they will not use this knowledge to treat participants differently.

○ Yes ● No ○ I don't know

Will participants be subjected to any undue incentives to participate?

○ Yes ● No ○ I don't know

Will you ensure that there is no perceived pressure to participate?

● Yes ○ No ○ I don't know

## Details about participant data

Will you be using video recording or photography as part of your research or publication of results?

○ Yes ● No

Will you be using audio recording as part of your research?

○ Yes ● No

Will you be using portable devices to record participants (e.g. audio, video recorders, mobile phone, etc)?

- ● No
- ○ Yes, and all portable devices will be encrypted as per the Lancaster University ISS standards, in particular where they are used for recording identifiable data
- ○ Yes, but these cannot be encrypted because they do not have encryption functionality. Therefore I confirm that any identifiable data (including audio and video recordings of participants) will be deleted from the recording device(s) as quickly as possible (e.g. when it has been transferred to a secure medium, such as a password protected and encrypted laptop or stored in OneDrive) and that the device will be stored securely in the meantime

Will you be using other portable storage devices in particular for identifiable data (e.g. laptop, USB drive, etc)? (Please read the help text)

- ○ No
- ● Yes, and they will be encrypted as per the Lancaster University ISS standards in particular where they are used for recording identifiable data

Will anybody external to the research team be transcribing the research data?

○ Yes ● No

## General Queries

Does the funder or any organisations involved in the research have a vested interest in specific research outcomes that would affect the independence of the research?

○ Yes ● No ○ I don't know

Does any member of the research team, or their families and friends, have any links to the funder or organisations involved in the research?

○ Yes ● No ○ I don't know

Can the research results be freely disseminated?

● Yes ○ No ○ I don't know

Will you use data from potentially illicit, illegal, or unethical sources (e.g. pornography, related to terrorism, dark web, leaked information)?

○ Yes ● No ○ I don't know

Will you be gathering/working with any special category personal data?

● Yes ○ No ○ I don't know

Are there any other ethical considerations which haven’t been covered?

○ Yes ● No ○ I don't know

## REC Review Details

Based on the answers you have given so far you will need to answer some additional questions to allow reviewers to assess your application.

It is recommended that you do not proceed until you have completed **all of the previous questions**.

Please confirm that you have finished answering the previous questions and are happy to proceed.

☑ I confirm that I have answered all of the previous questions, and am happy to proceed with the application.

## Questions for REC Review

Summarise your research protocol in lay terms (indicative maximum length 150 words).

Note: The summary of the protocol should concisely but clearly tell the Ethics Committee (in simple terms and in a way which would be understandable to a general audience) what you are broadly planning to do in your study. Your study will be reviewed by colleagues from different disciplines who will not be familiar with your specific field of research and it may also be reviewed by the lay members of the Research Ethics Committee; therefore avoid jargon and use simple terms. A helpful format may include a sentence or two about the background/ “problem” the research is addressing, why it is important, followed by a description of the basic design and target population. Think of it as a snapshot of your study.

The study will explore the roles that self-compassion and social support play in the wellbeing of carers of people with Parkinson's. Parkinson's is a degenerative neurological condition which can have a significant impact on people's physical and emotional wellbeing. People living with Parkinson's typically require additional support as the condition progresses. This support is often provided by informal family carers such as spouses, siblings and adult children. The wellbeing of informal carers is often overlooked, by both carers themselves and by services. The study will recruit people who identify as carers of people with Parkinson's. Participants will complete a series of online questionnaires related to the care they provide, and their levels of social support, self-compassion, and wellbeing. Some demographic data will be collected. All data will be anonymous. Data will be analysed to explore the impact of self-compassion and social support on the relationship between carer stressors and wellbeing. Experts by experience (recruited through Parkinson's UK) have been involved in the design of the project. Conversations with the experts by experience around elements of their caring role which they felt it was important to capture in the research has shaped the direction of the project, and the feedback on the participant information documents and questionnaires has also been incorporated into the survey design.

State the Aims and Objectives of the project in Lay persons' language.

The study will aim to explore factors which may have an impact on the wellbeing of carers of people with Parkinson's. In particular, the study will explore whether carer stressors, social support, and self-compassion predict wellbeing. The study will also consider the extent to which either self-compassion or social support influence the relationship between stressors and wellbeing.

The study will aim answer the following research question: to what extent do self-compassion and social support effect the relationship between carer stressors and carer wellbeing?

## Participant Information

Please explain the number of participants you intend to include in your study and explain your rationale in detail (eg who will be recruited, how, where from; and expected availability of participants). If your study contains multiple parts eg interviews, focus groups, online questionnaires) please clearly explain the numbers and recruitment details for each of these cohorts (see help text).

Participants will be recruited through Parkinson's UK's Take Part Hub. Parkinson's UK have already been contacted and have agreed to promote the study. Depending on recruitment success, other organisations providing support to people who provide care to people with Parkinson's may also be approached, including, but not limited to, Carers UK, Parkinson’s New Zealand, Parkinson’s Australia, and Parkinson’s Association of Ireland. Lancaster University’s Psychology Department also holds a list of people interested in Parkinson’s research and this may be utilised for recruitment. The study will also be promoted on social media where it is anticipated it will be shared and retweeted by other users. Only professional accounts, set up specifically for the purpose of promoting this research, will be used to post about the study.

Paper copies of the advert will be shared with community venues or health venues where they might be seen by carers of people with Parkinson’s, such as community centres, GP surgeries (with the consent of the relevant trust) or libraries. Where appropriate, physical copies of the questionnaires and participant documents may also be shared with these venues to make the study more accessible for people who are not confident with, or do not have access to, technology. As participants are being recruited in their role as carers and not as patients, they are considered "healthy volunteers." Because of this, and in addition to the fact that the recruitment strategy is passive (copies of the advert will be displayed but healthcare professionals will not direct people towards the study), HRA or NHS REC approval is not required to display the study in GP surgeries, waiting rooms, or other health venues.

The researcher may also attend relevant groups or events for people with Parkinson’s and their carers to discuss the study and provide information on how to participate. Interested parties will have the option to complete the study at the time, or to take away details of the study or copies of the questionnaires to complete on their own. No pressure or expectation will be placed on group members to complete the study, and all group members will be informed that participation is voluntary. If people do decide to complete the questionnaires while I am present, a box will be provided for people to post their responses into so that it is not possible to see who has completed which questionnaires. Group members will be informed that, as the questionnaires are anonymous and no identifying data will be collected, it will not be possible to withdraw their responses after they have been submitted. Group members will be given the opportunity to ask questions as part of the group, and will also be provided with contact details (email and research phone number) so that if they have questions they would prefer not to raise in front of the other group members, they have the option to do so privately.

Participants will be adults (aged 18 or over) who identify as carers of people with Parkinson's. There will be no upper age limit to be eligible for the study. Participants can be any gender.

Interested participants will see an advert displaying the title of the study followed by a short description of the project. At the end of the description, interested participants will have the option to follow a link (https://lancasteruni.eu.qualtrics.com/jfe/form/SV_0TUiioW0WfoveEC) or QR code which will direct them to a Qualtrics landing page containing the participant information, consent form, and questionnaires.

Participants will also be informed that they can request a paper copy of the survey by contacting the researcher via email or phone (a university email address, and a specific research contact number will be included on the advert). A paper copy will then be posted to an address they provide, including a stamped envelope in which to return it. Paper copies shared with community venues will be provided in a free post envelope for participants to return them in. Participants accessing the study from outside the UK will not be able to request hard copies of the survey. Any addresses provided by participants will be stored for the minimum length of time possible to send out the pack of questionnaires, and will then be destroyed.

For multiple regression analysis using 3 to 6 predictors, a priori power analysis suggests a sample size of between 77 and 98 participants. A larger sample size of 316 participants is necessary for moderation analysis. This study will therefore aim to recruit between 100 and 350 participants.

You have selected that the research may involve personal sensitive topics that participants may not be willing to otherwise talk about. Please indicate what discomfort, inconvenience or harm could be caused to the participant and what steps you will take to mitigate or manage these situations.

Participants will answer questions which will ask them to reflect on the nature of care they provide to someone with Parkinson's. They will also be asked to answer questions about the social support they receive, their levels of self-compassion, and their wellbeing. It is unlikely that these topics will cause discomfort, inconvenience or harm to participants. However, there is a small possibility that reflecting on their experiences could cause some discomfort. Relevant support services will be highlighted at the beginning of the questionnaires in the participant information sheet, and at the end of the questionnaires in the participant debrief sheet. Participants will be able to end their participation, without giving a reason, at any time, by closing the online window. The full questionnaire and participant information documents has also been reviewed by experts by experience (recruited through Parkinson's UK) prior to launch, in the interests of addressing any elements with the potential to cause distress prior to the study's launch. No elements with the potential to cause distress were identified by the experts by experience.

You stated that the study could induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant’s usual, everyday life. Please describe the question(s) and situation(s) that could lead to these outcomes and explain how you will mitigate this.

Participants will be asked to answer questions related to their caring role, their social support, self-compassion and wellbeing. It is not anticipated that these questions should cause stress or anxiety, but there is a small possibility that reflecting on these topics could cause cause distress for some participants. Some examples of questions which have the potential to cause distress are: (Participants are asked to what extent the following statements apply to them) "I feel like I am missing out on life"; "I resent the person I care for"; "I feel emotionally drained due to caring". Relevant support services will be highlighted in the participant information sheet and debrief sheet, and participants will be invited to contact the researchers should they experience any distress as a result of taking part. Participants will be informed of their right to end their participation at any time without providing a reason, and they can do this by closing the questionnaire window. Questionnaires and participant information documents have been reviewed by experts by experience (recruited via Parkinson's UK) in an effort to identify and address any potentially distressing elements which may not have been considered by the researchers. No such distressing elements were identified either by the researchers or by the experts by experience.

## Participant Relationships

Your answers about gatekeepers has indicated that there is a power imbalance due to there being no precautions to prevent undue pressure. Please explain the situation and how you plan to mitigate and manage the effects of this.

Gatekeepers will not be in a position to apply undue pressure to participants. Parkinson's UK will act as gatekeepers in that they will promote the study through their Take Part hub, where interested parties can access information about range of research projects. Parkinson's UK will not be made aware of whether individuals take part or not, and prospective participants will access the study through a Qualtrics link rather than via application to Parkinson's UK. Where the study is advertised in community or health venues, there will be no incentive for the venue to promote the study to participants and they will be not be made aware whether or not interested parties choose to take part. There will be no incentives or penalties made to individuals regardless of whether or not they decide to take part.

## Additional Information

What are your dissemination plans? E.g publishing in PhD thesis, publishing in academic journal, presenting in a conference (talk or poster).

The research will be presented as part of my DClinPsy thesis and may be submitted for publication in an academic journal or presented at a conference. A summary of the findings will also be shared with any organisations which support with recruitment for further dissemination.

## Online Sources

You have indicated site users have a reasonable expectation of privacy and therefore you will need to obtain consent to use their data for this project. Please explain how you propose to obtain consent.

Prior to beginning the questionnaires, participants will be asked to read an information sheet detailing the project and to complete a consent form. Participants will be asked to indicate whether they understand the information provided, whether they consent to take part, and whether they consent to their data being used for the project. Participants who indicate they do not consent will not be able to proceed to the online questionnaires to take part in the study. Participants who receive hard copies of the questionnaires will be informed that if they answer 'no' to any of the consent questions, they should not complete the questionnaires.

## General Queries

You have indicated that you will be gathering/working with special category data. Please confirm here how you will comply with data protection law (GDPR) for use of special category personal data.

Participants will be asked to provide a small amount of demographic information which will include some special category data (eg. gender, ethnicity). This data will used for the purposes of descriptive statistics and may be discussed in the research paper if it is felt that this data is relevant to the findings. All participant data will be anonymous and participants will not be personally identifiable from the data they provide. The data will be stored securely in line with GDPR and university guidelines, and only the researcher and research supervisors will have access to the raw data.

## Additional Information for REC Review

How long will you retain the research data?

All electronic data will be securely stored in a password protected file, and only the researcher and research supervisors will have access to the raw data, in line with university policy on data storage. Once the project is complete and the project has been examined, the SPSS file containing the data will be sent securely to the research coordinator of the DClinPsy who will store it for 10 years. It will then be securely destroyed, under the supervision of the research supervisor, Fiona Eccles.

How long and where will you store any personal and/or sensitive data?

All data, including special category data, will be securely stored in a password protected University Onedrive for ten years, in line with University policy, after which it will be destroyed. All data will be stored anonymously.

Any names and addresses provided for the purposes of providing physical copies of the questionnaires will be saved in a password protected file only until the questionnaires have been posted, which will take place at the earliest opportunity. After the questionnaires have been posted, this information will be destroyed.

Please explain when and how you will anonymise data and delete any identifiable record?

Participants will not be asked for their name at any point during the data collection process, and no information which could make participants personally identifiable will be collected. If any participants provide their name and address in order to receive paper copies of the questionnaires, these will be saved in a password protected file only until the requested questionnaires have been posted, which will be at the earliest opportunity. After posting, the provided name and address will be destroyed and will not be retained for any other purpose.

## Document Upload

***Important Notice about uploaded documents:***

When your application has been reviewed if you are asked to make any changes to your uploaded documents please highlight the changes on the updated document(s) using the highlighter so that they are easy to see.

Please confirm that you have read and applied, where appropriate, the guidance on completing the Participant Information Sheet, Consent Form, and other related documents and that you followed the guidance in the help button for a quality check of these documents. For information and guidance, please use the relevant link below:

FST Ethics Webpage

FHM Ethics Webpage

FASS-LUMS Ethics Webpage

REAMS Webpage

☑ I confirm that I have followed the guidance.

As you are in FHM please upload your Research Protocol:

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Research Proposal | Research Protocol V3 | Research Protocol V3.pdf | 09/05/2023 | 3 | 210.2 KB |

In addition to completing this form you must submit all supporting materials.

Please indicate which of the following documents are appropriate for your project:

- ☐ I have no updated documents and confirm that all relevant documents were included in previous submissions.
- ☑ Advertising materials (posters, emails)
- ☑ Research Proposal (DClinPsy)
- ☐ Letters/emails of invitation to participate
- ☑ Consent forms
- ☑ Participant information sheet(s)
- ☐ Interview question guides
- ☐ Focus group scripts
- ☑ Questionnaires, surveys, demographic sheets
- ☐ Workshop guide(s)
- ☑ Debrief sheet(s)
- ☐ Transcription (confidentiality) agreement
- ☐ Other
- ☐ None of the above.

Please upload the documents in the correct sections below:

Please ensure these are the latest version of the documents to prevent the application being returned for corrections you have already made.

Please upload a copy of all of the consent forms that you will be using:

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Consent Form | Consent form - online version | Consent form - online version.docx | 29/11/2022 | V1 | 35.2 KB |
| Consent Form | Consent form - hard copy version | Consent form - hard copy version.docx | 29/11/2022 | V1 | 35.7 KB |

Please upload a copy of all of the Participant Information Sheets that you will be using in this study.

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Participant Information Sheet | Information Sheet V2 (online version) | Information Sheet V2 (online version).pdf | 29/11/2022 | V2 | 126.3 KB |
| Participant Information Sheet | Information Sheet V2 (hard copy version) | Information Sheet V2 (hard copy version).pdf | 29/11/2022 | V2 | 127.7 KB |

Please upload all of the advertising materials relevant for this project:

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Advertising materials | Advert V2 | Advert V2.pdf | 19/04/2023 | 2 | 162.0 KB |

Please upload all questionnaire, surveys, demographic sheet templates used in this project:

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Questionnaires, surveys, demographic sheets | Questionnaires (Hard Copy Version) | Questionnaires (Hard Copy Version).pdf | 29/11/2022 | V1 | 79.1 KB |

Please upload all debrief sheets used for this project.

Documents

| Type | Document Name | File Name | Version Date | Version | Size |
|---|---|---|---|---|---|
| Debrief sheet | Debrief Sheet (Hard Copy Version) | Debrief Sheet (Hard Copy Version).pdf | 29/11/2022 | V1 | 92.2 KB |
| Debrief sheet | Debrief Sheet (Online Version) | Debrief Sheet (Online Version).pdf | 29/11/2022 | V1 | 98.5 KB |

## Declarations and Sign off

***Please Note***

Research Services monitors projects entered into the online system, and may select projects for quality control.

All research at Lancaster university must comply with the LU data storage and governance guidance as well as the General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018. (Data Protection Guidance webpage)

☑ I confirm that I have read and will comply with the LU Data Storage and Governance guidance and that my data use and storage plans comply with the General data Protection Regulation (GDPR) and the UK Data Protection Act 2018.

Have you that you have undertaken a health and safety risk assessment for your project through your departmental process? (Health and Safety Guidance)

☑ I have undertaken a health and safety assesment for your project through my departmental process, and where required will follow the appropriate guidance for the control and management of any foreseeable risks.

When you are satisfied that this application has been completed please click "Request" below to send this application to your supervisor for approval.

**Signed:** This form was signed by Professor Jane Simpson (j.simpson2@lancaster.ac.uk) on 09/05/2023 10:55

Please read the terms and conditions below:

- You have read and will abide by Lancaster University's Code of Practice and will ensure that all staff and students involved in the project will also abide by it.
- If appropriate a confidentiality agreement will be used
- You will complete a data management plan with the Library if appropriate. Guidance from Library.
- You will provide your contact details, as well as those of either your supervisor (for students) or an appropriate person for complaints (such as HoD) to any participants with whom you interact, so they know whom to contact in case of questions or complaints?
- That University policy will be followed for secure storage of identifiable data on all portable devices and if necessary you will seek guidance from ISS
- That you have completed the ISS Information Security training and passed the assessment
- That you will abide by Lancaster University's lone working policy for field work if appropriate
- On behalf of the institution you accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).
- To the best of your knowledge the information you have provided is correct at the time of submission
- If anything changes in your research project you will submit an amendment

**To complete and submit this application please click "Sign" below:**

**Signed:** This form was signed by Katy Brooks (k.brooks2@lancaster.ac.uk) on 09/05/2023 10:53

## Appendix 4.3: Ethics Amendment Approval Letter

FHM-2023-0941-SA-2 Self-compassion and social support in the wellbeing of carers of people with Parkinson’s.

Dear Katy Brooks,

Thank you for submitting your ethics amendment application in REAMS, Lancaster University's online ethics review system for research. The amendments have been approved by the FHM REC.

Yours sincerely,

Faculty Research Ethics Officer on behalf of FHM

## Appendix 4.4: Study Advert A

### Are you a carer for someone with Parkinson's?

I am conducting a research study as part of a thesis project for the Lancaster University Clinical Psychology Doctorate programme. The project is looking at factors influencing the wellbeing of carers of people with Parkinson's. The study will explore the roles that self-compassion and social support play in the relationship between carer stressors and carer wellbeing.

If you are aged 18 or older, are currently caring for someone with Parkinson's and have been doing so for at least a year, I would be very grateful if you would consider taking part in this study. Care or support may include physical or emotional support, help with day-to-day tasks, such as shopping or managing medication, or financial support. Taking part will involve answering a series of questions using an online questionnaire. All responses will be anonymous, and none of the answers you provide will make you personally identifiable.

You can access the questionnaire using this link:
https://lancasteruni.eu.qualtrics.com/jfe/form/SV_0TUiioW0WfoveEC

Or by scanning this QR code:

If you would prefer to complete the questionnaire by hand, you can request a paper copy by contacting the researcher on 07852 516812 or by emailing k.brooks2@lancaster.ac.uk

## Appendix 4.5: Study Advert B

# Are you a carer for someone with Parkinson's?

# Have you been providing care or support for over one year?

# Are you aged 18 or over?

If you answered yes to these questions, please consider taking part in this research study, which is part of a thesis project for the Lancaster University Doctorate of Clinical Psychology.

**What do I have to do?**

You will be asked to answer a series of questions using an online questionnaire.

You will be asked for a little bit of information about yourself and your caring role. Then you will be asked to answer some multiple-choice questions.

All responses are anonymous.

**What is it about?**

The research is looking at the roles of social support and self-compassing in the wellbeing of people who care for someone with Parkinson's.

**How do I take part?**

You can take part using this link: https://lancasteruni.eu.qualtrics.com/jfe/form/SV_0TUiioW0WfoveEC

Or by scanning the QR code

You can also request a paper copy of the questionnaires by contacting the researcher on 07852 516812 or emailing k.brooks2@lancaster.ac.uk

**Scan here to take part:**

## Appendix 4.6: Participant Materials

# Participant Information Sheet

## *Self-compassion and social support in the wellbeing of carers of people with Parkinson's.*

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is Katy and I am conducting this research as a student in the Doctorate of Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

**What is the study about?**
The purpose of this study is to increase understanding of the roles that self-compassion and social support may have in the wellbeing of carers of people with Parkinson's.

**Why have I been approached?**
You have been approached because you are currently providing support or care to someone with Parkinson's. You may provide support or care to a friend, neighbour, or relative, but this should not be in a professional (paid or registered volunteer) capacity. This support may be in the form of physical or emotional support, help with day-to-day tasks, such as shopping or managing medication, or financial support. You must have been providing care or support for at least one year and be 18 or over to take part.

**Do I have to take part?**
No. It's completely up to you to decide whether or not you take part. You can leave the survey at any time by closing the browser window. However, please be aware that any answers you have already entered up to that point will still be retained.

**What will I be asked to do if I take part?**
If you decide you would like to take part, you will be asked to answer a series of questions. First you will be asked to provide us with some information about yourself (you will not be asked to provide your name and none of the questions will ask you anything which could make you personally identifiable) and the kind of care you provide. You will then be asked a series of multiple-choice questions related to your caring experiences, self-compassion, social support, and wellbeing.

**What will happen to my data?**
The data you provide will be stored securely by the Lancaster Doctorate of Clinical Psychology programme for 10 years, in line with university policy on data storage. Following this time period, all data will be securely destroyed.

**Will my data be Identifiable?**
The data collected for this study will be stored securely on a password protected file and only the researchers conducting this study will have access to this data.

- Hard copies of questionnaires will be uploaded as electronic copies at the earliest opportunity. Physical copies will be destroyed immediately after uploading.
- The files on the computer will be encrypted, and no-one other than the researchers will be able to access them.
- All reasonable steps will be taken to protect the anonymity of the participants involved in this project. If you provide your name and address to receive paper copies of the questionnaires, this information will be destroyed immediately after posting and will not be retained for any other purposes.
- Your responses are anonymous, and all data is confidential.

**What will happen to the results?**
The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal and presented at conferences. The results will also be given to the organisations that help with recruitment, so they can disseminate them to their members.

**Are there any risks?**
There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and you can access additional support by contacting the resources listed below.

**Are there any benefits to taking part?**
Although there are no direct benefits to individual participants, you may find participating interesting, and the results of this study may be used to make recommendations around future care and support provided to carers of people with Parkinson's.

**Who has reviewed the project?**
This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

**Where can I obtain further information about the study if I need it?**
If you have any questions about the study, please contact:

Katy Brooks – k.brooks2@lancaster.ac.uk
Fiona Eccles – f.eccles@lancaster.ac.uk

**Complaints**
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Ian Smith, DClinPsy Research Director
Tel: (01524) 592282
Email: i.smith@lancaster.ac.uk
Clinical Psychology
Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

### Resources in the event of distress

If you are experiencing distress as a result of caring, please speak to your General Medical Practitioner (GP) or another professional who is involved in the care of the person with Parkinson's. Should you feel any distress as a result of taking part in this survey, you may find the following helpful:

**Parkinson's UK**
www.parkinsons.org.uk
Tel: 0808 800 0303
Email: hello@parkinsons.org.uk
**Parkinson's Association of Ireland**
www.parkinsons.ie
Tel: 01-8722234
Email: nationaloffice@parkinsons.ie.

**Parkinson's New Zealand**
www.parkinsons.org.nz
**Tel:** 0800 473 4636
**Email:** info@parkinsons.org.nz

**Parkinson's Australia**
www.parkinsons.org.au
**Tel:** 1800 644 189

**The Michael J Fox Foundation (Canada)**
www.michaeljfox.org
Tel: 1-212-509-0995
Email: info@michaeljfox.org

**American Parkinson's Disease Association**
https://www.apdaparkinson.org
Tel: 800-223-2732
Email: apda@apdaparkinson.org

If you are accessing this study from outside the countries listed, you can still access information on any of the websites above. Alternatively, you can seek support from your local or national Parkinson's organisation.

Other support services:

**Carers UK:**
www.carersuk.org
Tel: 0808 808 7777
Email: advice@carersuk.org

**Samaritans:**
www.samaritans.org
Tel: 116 123
Email: Jo@samaritans.org

**Mind:**
www.mind.org.uk
Tel: 0300 123 3393
Email: info@mind.org.uk

Thank you for taking the time to read this information sheet. If you would like to download a copy of this information, you can do so here: Information sheet

You can now continue to the questionnaires by clicking the arrow at the bottom right of this page.

# Consent Form

**Project Title: Self-compassion and social support in the wellbeing of carers of people with Parkinson's**
Name of Researchers: Katy Brooks
Email: k.brooks2@lancaster.ac.uk

Please be aware that if you answer 'Yes' to the following questions and proceed to the questionnaires, it will not be possible to withdraw your data from the study. This is because all data are anonymous, and it will therefore not be possible to identify which data you have provided.

If at any point you decide you no longer wish to continue with the study, you can exit the study by closing the browser window at any time. However, please be aware that any answers you have provided up to that point will still be stored.

| | **Yes** | **No** |
|---|---|---|
| 1. Have you read and understood the participant information sheet? | ☐ | ☐ |
| 2. Are you aged 18 or over? | ☐ | ☐ |
| 3. Do you currently provide unpaid care or support to someone with a diagnosis of Parkinson's? | ☐ | ☐ |
| 4. Have you been providing unpaid care or support for at least one year? | ☐ | ☐ |
| 5. Do you consent to your responses to the survey contributing towards a research paper which may be published in an academic or professional journal or presented at conferences? | ☐ | ☐ |
| 6. Do you consent to the information you provide being stored in line with Lancaster University guidelines, as described in the participant information sheet? | ☐ | ☐ |
| 7. Do you agree to take part in the study? | ☐ | ☐ |

**Participant Survey**

The following questions ask for some information about you. You will not be personally identifiable from any of the responses you provide.

What is your age?

________________________________________________

Which of the following best represents your gender? (Please tick)

○ Female

○ Male

○ Non-binary

○ Transgender

○ Gender non-conforming

○ Prefer to self-identify ____________________________________

○ Prefer not to say

Which country do you currently live in? (Please tick)

○ England

○ Northern Ireland

○ Scotland

○ Wales

○ None of the above (please specify)

______________________________________

What term best defines your ethnicity?

________________________________________________

Which of the following best describes your partnership status? (Please tick)

○ Married or have a partner

○ Single

○ Widowed

○ Other (please describe)

________________________________________________

○ Prefer not to say

Which of the following best describes your paid employment status? (Please tick)

○ Full-time employment

○ Part-time employment

○ Unemployed

○ Unable to work due to caring responsibilities

○ Retired

○ Full-time education

○ Part-time education

○ Other (please describe)

________________________________________________

○ Prefer not to say

The following questions ask for some information about your role as a carer to someone with Parkinson's and the kinds of support you provide.

When did the person you provide care or support to receive a diagnosis of Parkinson's?

____________________________________________________________

Which best describes your relationship to the person you provide care or support to?

○ I am their child

○ I am their friend

○ I am their grandchild

○ I am their neighbour

○ I am their sibling

○ I am their spouse or partner

○ Other relationship (please describe)

______________________________________________

How long have you been providing care or support to someone with Parkinson's? (Please give your answer to the nearest year)

________________________________________________________

On average, how many hours of care or support do **<u>you</u>** provide to someone with Parkinson's in one week?

_____________________ hour(s)

Do you currently live with the person you provide care or support to? (Please tick)

○ Yes

○ No

How many hours per week does the person with Parkinson's receive **<u>paid</u>** care or support? (i.e. help from a paid professional with washing, dressing, providing food, etc.)

_____________________ hour(s)

Does the person with Parkinson’s currently live in a residential care or supported living setting? (Please tick)

○ Yes

○ No

What kinds of care or support do you provide to someone with Parkinson's? (Please tick all that apply)

☐ Support with household jobs or tasks (eg. cleaning, cooking)

☐ Support with jobs or tasks outside the home (eg. food shopping, attending GP or hospital appointments)

☐ Support with movement (eg. getting in or out of a chair, climbing stairs, crossing a road)

☐ Support with personal care (eg. washing, dressing, going to the toilet)

☐ Support with meals (eg. prompts to eat or drink, physical support with feeding)

☐ Support with psychological difficulties (eg. mood changes, hallucinations, disinhibited behaviour, memory difficulties)

☐ Support to access benefits or formal care services

☐ Support to source mobility aids or home adaptations (eg. grab rails, commodes, walking frames)

☐ Support to manage personal finances (eg. paying bills, managing bank accounts)

☐ Support to manage medication

☐ Support in medical appointments (eg. explaining medical information or advice, advocating for the needs of someone with Parkinson's to medical staff)

☐ Other support (please give details if you wish)

____________________________________________________________

The following statements ask you to think about some of the stressors people may experience as a carer.

For each statement, please tick the option which best represents your experiences.

| | Never | Rarely | Sometimes | Quite frequently | Nearly Always |
|---|---|---|---|---|---|
| The person I care for needs my help to perform many daily tasks | ○ | ○ | ○ | ○ | ○ |
| The person I care for is dependent on me | ○ | ○ | ○ | ○ | ○ |
| I have to watch the person I care for constantly | ○ | ○ | ○ | ○ | ○ |
| I have to help the person I care for with many basic functions | ○ | ○ | ○ | ○ | ○ |
| I don't have a minute's break from their chores | ○ | ○ | ○ | ○ | ○ |
| I feel that I am missing out on life | ○ | ○ | ○ | ○ | ○ |
| I wish I could escape from this situation | ○ | ○ | ○ | ○ | ○ |
| My social life has suffered | ○ | ○ | ○ | ○ | ○ |
| I feel emotionally drained due to caring | ○ | ○ | ○ | ○ | ○ |
| I expected that things would be different at this point in my life | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I am not getting enough sleep | ○ | ○ | ○ | ○ | ○ |
| My health has suffered | ○ | ○ | ○ | ○ | ○ |
| Caregiving has made me physically unwell | ○ | ○ | ○ | ○ | ○ |
| I am physically tired | ○ | ○ | ○ | ○ | ○ |
| I feel embarrassed over the behaviour of the person I care for | ○ | ○ | ○ | ○ | ○ |
| I feel ashamed of the person I care for | ○ | ○ | ○ | ○ | ○ |
| I resent the person I care for | ○ | ○ | ○ | ○ | ○ |
| I feel uncomfortable when I have friends over | ○ | ○ | ○ | ○ | ○ |
| I feel angry about my interactions with the person I care for | ○ | ○ | ○ | ○ | ○ |
| I don't get along with other family members as well as I used to | ○ | ○ | ○ | ○ | ○ |
| My caregiving efforts are not appreciated by others in my family | ○ | ○ | ○ | ○ | ○ |
| I've had problems with my significant relationships | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I don't get along with others as well as I used to | ○ | ○ | ○ | ○ | ○ |
| I feel resentful of other relatives who could help but do not | ○ | ○ | ○ | ○ | ○ |

The following statements describe how you might relate to yourself.

For each statement, please tick the box which best represents how true the following statements are of you.

| | Not true at all | Rarely true | Sometimes true | Often true | Always true |
|---|---|---|---|---|---|
| I'm good at recognising when I'm feeling distressed | ○ | ○ | ○ | ○ | ○ |
| I understand that everyone experiences suffering at some point in their lives | ○ | ○ | ○ | ○ | ○ |
| When I'm going through a difficult time, I feel kindly towards myself | ○ | ○ | ○ | ○ | ○ |
| When I'm upset, I try to stay open to my feelings rather than avoid them | ○ | ○ | ○ | ○ | ○ |
| I try to make myself feel better when I'm distressed, even if I can't do anything about the cause | ○ | ○ | ○ | ○ | ○ |
| I notice when I'm feeling distressed | ○ | ○ | ○ | ○ | ○ |
| I understand that feeling upset at times is part of human nature | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| When bad things happen to me, I feel caring towards myself | ○ | ○ | ○ | ○ | ○ |
| I connect with my own distress without letting it overwhelm me | ○ | ○ | ○ | ○ | ○ |
| When I'm going through a difficult time, I try to look after myself | ○ | ○ | ○ | ○ | ○ |
| I'm quick to notice early signs of distress in myself | ○ | ○ | ○ | ○ | ○ |
| Like me, I know that other people also experience struggles in life | ○ | ○ | ○ | ○ | ○ |
| When I'm upset, I try to tune in to how I'm feeling | ○ | ○ | ○ | ○ | ○ |
| I connect with my own suffering without judging myself | ○ | ○ | ○ | ○ | ○ |
| When I'm upset, I try to do what's best for myself | ○ | ○ | ○ | ○ | ○ |
| I recognise signs of suffering in myself | ○ | ○ | ○ | ○ | ○ |
| I know that we can all feel distressed when things don't go well in our lives | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| Even when I'm disappointed with myself, I can feel warmly towards myself when I'm in distress | ○ | ○ | ○ | ○ | ○ |
| When I'm upset, I can let the emotions be there without feeling overwhelmed | ○ | ○ | ○ | ○ | ○ |
| When I'm upset, I do my best to take care of myself | ○ | ○ | ○ | ○ | ○ |

The following statements ask you to think about your wellbeing. Below are some statements about feelings and thoughts.

For each statement, please tick the option that best describes your experience **<u>over the last two weeks.</u>**

| | None of the time | Rarely | Some of the time | Often | All of the time |
|---|---|---|---|---|---|
| I've been feeling optimistic about the future | ○ | ○ | ○ | ○ | ○ |
| I've been feeling useful | ○ | ○ | ○ | ○ | ○ |
| I've been feeling relaxed | ○ | ○ | ○ | ○ | ○ |
| I've been feeling interested in other people | ○ | ○ | ○ | ○ | ○ |
| I've had energy to spare | ○ | ○ | ○ | ○ | ○ |
| I've been dealing with problems well | ○ | ○ | ○ | ○ | ○ |
| I've been thinking clearly | ○ | ○ | ○ | ○ | ○ |
| I've been feeling good about myself | ○ | ○ | ○ | ○ | ○ |
| I've been feeling close to other people | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I've been feeling confident | ○ | ○ | ○ | ○ | ○ |
| I've been able to make up my own mind about things | ○ | ○ | ○ | ○ | ○ |
| I've been feeling loved | ○ | ○ | ○ | ○ | ○ |
| I've been interested in new things | ○ | ○ | ○ | ○ | ○ |
| I've been feeling cheerful | ○ | ○ | ○ | ○ | ○ |

The following statements ask you to think about the support you receive as a carer.

Please think about your experience as a carer **<u>in the last two weeks</u>** and tick the option which best applies to you for each statement.

| | Never | Some of the time | A lot of the time | Always |
|---|---|---|---|---|
| I have a good level of emotional support | ○ | ○ | ○ | ○ |
| My needs as a carer are considered by professionals | ○ | ○ | ○ | ○ |
| I'm happy with the professional support that is provided to me | ○ | ○ | ○ | ○ |
| I feel able to get the help and information I need | ○ | ○ | ○ | ○ |
| I have all the practical support I need | ○ | ○ | ○ | ○ |

**<u>End of Questions</u>**

## Participant Debrief Sheet

## *Self-compassion and social support in the wellbeing of carers of people with Parkinson's.*

Thank you for taking part in this research. The purpose of the research is to explore the impact that self-compassion and social support have on the relationship between carer stressors and carer wellbeing in people who support someone with Parkinson's. We predict that the relationship between carer stressors and wellbeing will be reduced in carers who report higher levels of self-compassion and greater social support. If this is the case, this has implications for recommendations about the kind of support which would be beneficial to carers of people with Parkinson's. If you have any questions about the study, you can contact the researchers using the following details, and we will be happy to provide further information:

Katy Brooks – k.brooks2@lancaster.ac.uk
Fiona Eccles – f.eccles@lancaster.ac.uk

If you would like to hear about the results of the study, the findings will be shared with Parkinson's UK, and other international organisations who are involved in sharing this survey, where you will be able to access them when the research is complete.

We hope that you found taking part in the study to be a positive experience. If you are experiencing distress as a result of caring, please speak to your General Medical Practitioner (GP) or another professional involved in the care of the person with Parkinson's. If you experienced any distress as a result of taking part in this research, or if you feel that you would benefit from additional support, you may find the following organisations helpful:

**Parkinson's UK:**
www.parkinsons.org.uk
Tel: 0808 800 0303
Email: hello@parkinsons.org.uk
**Parkinson's Association of Ireland:**
www.parkinsons.ie
Tel: 01-8722234
Email: nationaloffice@parkinsons.ie.

**Parkinson's New Zealand:**
www.parkinsons.org.nz
**Tel:** 0800 473 4636
**Email:** info@parkinsons.org.nz

**Parkinson's Australia:**
www.parkinsons.org.au
**Tel:** 1800 644 189

**The Michael J Fox Foundation (Canada)**
www.michaeljfox.org

Tel: 1-212-509-0995
Email: info@michaeljfox.org

**American Parkinson's Disease Association**
https://www.apdaparkinson.org
Tel: 800-223-2732
Email: apda@apdaparkinson.org

Other support services:
**Carers UK:**
www.carersuk.org
Tel: 0808 808 7777
Email: advice@carersuk.org

**Samaritans:**
www.samaritans.org
Tel: 116 123
Email: Jo@samaritans.org

**Mind:**
www.mind.org.uk
Tel: 0300 123 3393
Email: info@mind.org.uk

If you are accessing this study from outside the countries listed, you can still access information on any of the websites above. Alternatively, you can seek support from your local or national organisations.

Once again, thank you for taking part in this study. If you would like to download a copy of this information, you can do so here: Debrief Sheet

**Please click on the arrow to the bottom right of this page to submit your responses.**