# The Relationship between Self-Compassion, Caregiver Guilt and Depressive Symptoms in Family Caregivers of People with Dementia

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**THESIS PORTFOLIO: CANDIDATE DECLARATION**

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| **Declaration and signature of candidate** |
| I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.I confirm that the decision to submit this thesis is my own.I confirm that except where explicitly stated, the work has not been submitted for another academic award.I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.Signed:  Date: 28.04.22 |

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**Thesis Abstract**

Paper one is a literature review that explores the psychological wellbeing factors and social resources related to loneliness in informal dementia carers. Thirteen relevant studies were identified following a systematic search of the literature. The review highlighted that greater levels of loneliness are associated with greater levels of caregiver burden, depression, stress, suicidal ideation, and lower levels of wellbeing and life satisfaction. Relevant social resources were identified including the importance of the quality of the carer’s relationship with the person they care for and their relationship with their social network. Methodological limitations were highlighted, particularly issues around reflexivity and recruitment. Clinical and research implications are discussed. The second paper describes a cross-sectional quantitative study, which investigates the relationship between caregiver guilt, self-compassion, depressive symptoms and the number of hours per day providing care. Eighty-four family caregivers of an individual with dementia were recruited for the study. Multiple regression analyses and a mediation analysis were conducted. The results suggested that lower levels of self-compassion and greater levels of caregiver guilt predicted higher levels of depressive symptoms in this population. The number of hours per day spent providing care was not a significant predictor of depressive symptoms. The findings also indicated that caregiver guilt mediates the relationship between self-compassion and depressive symptoms. The findings suggest that increasing self-compassion may be a useful approach to help carers to manage experiences of caregiver guilt and depressive symptoms. Clinical implications and recommendations for future research are discussed. The third paper is an executive summary of the research study carried out in this thesis and is written for family dementia caregivers as well as anyone else who may be interested in this research. This paper received valuable consultation from two individuals who care for a relative living with dementia.

**Paper 1: Literature Review**

# The Psychological Wellbeing Factors and Social Resources involved in Loneliness for Informal Caregivers of People with Dementia: A Review of the Literature

**Word count:** 7995 (Excluding the title page, references and appendices)

This literature review is intended for publication in the journal ‘Dementia’. The referencing style of this paper is APA 7th edition, in line with the journal requirements. Author guidelines for the journal can be found in Appendix A. Further modifications will be made before submitting to the journal to meet these guidelines.

# Abstract

Loneliness is common in dementia caregivers, and is associated with poor psychological wellbeing, for example, higher levels of depression and stress. In older adults, loneliness has been linked to social resources, which encompass an individual’s relationships with their social network and spouse, as well as their emotional/social support and amount of social activity. This review aimed to critically evaluate research investigating psychological wellbeing factors and social resources linked with loneliness in informal dementia caregivers. A systematic search of peer-reviewed literature was conducted encompassing five electronic databases. Thirteen studies were included, nine quantitative, three qualitative and one mixed method. The findings indicate caregiver loneliness is associated with greater caregiver burden, stress, depression, suicidal ideation and lower levels of wellbeing and life satisfaction. Loneliness was also linked to the quality of the carer’s relationship with the care recipient and their social network. The reviewed studies varied in methodological quality; however, the findings did not differ significantly between studies of different quality. Professionals working with dementia caregivers need to be aware of caregiver vulnerability to loneliness and the negative outcomes associated with this.

# Introduction

## Dementia Caregivers

Dementia refers to a group of progressive brain diseases characterised by symptoms such as memory loss, confusion, disorientation and difficulty carrying out everyday tasks (Alzheimer’s Society, 2017). Most people with dementia in the UK are cared for at home by an ‘informal caregiver’, defined as someone who provides unpaid care and support for a relative or friend who needs help due to an illness or disability (Alzheimer’s Research UK, 2020). Over 850,000 people in the UK are living with dementia and this is predicted to increase to over one million by 2025, and over two million by 2050 (Prince et al., 2014). There are an estimated 700,000 informal caregivers in the UK and this will increase as the number of people with dementia increases (Lewis et al., 2014).

Due to the physical and psychological demands of caregiving, carers often experience a negative impact on their mental health (Carers UK, 2019; Schulz & Sherwood, 2008). Depression, anxiety and stress are common in carers and even more pronounced when caring for a relative with dementia in comparison to other health needs (Schulz & Sherwood, 2008). This is due to people with dementia generally requiring more supervision and carers having to deal with progressive cognitive decline and potential personality and behavioural changes, which may impact their relationship (Lloyd et al., 2018; Schulz & Sherwood, 2008). Due to these relationship changes, and the demands of caregiving reducing opportunities to socialise, caregivers often experience loneliness (Leszko et al., 2020).

## Loneliness

Loneliness has been defined as distress due to an individual’s perceived dissatisfaction and negative appraisal of the quantity or quality of their relationships (Perlman & Peplau, 1981). Weiss (1973) proposed two types of loneliness: emotional loneliness (a lack of intimate or close relationships) and social loneliness (a deficit in the amount or quality of relationships with social networks potentially due to poor integration or rejection).

Research with the general population has linked loneliness to an increased risk of depression and anxiety (Beutel et al., 2017). Furthermore, loneliness has been proposed as a risk factor for poor physical health (Valtorta et al., 2016), mortality (Holt-Lunstad et al., 2015), suicidal thoughts and self-harm (McClelland et al., 2020), and dementia (Lara et al., 2020).

## Caregiver Loneliness

Loneliness is common in caregivers, with Carers UK (2015) reporting that eight in 10 UK caregivers have felt lonely or isolated due to caregiving. While loneliness is an issue for many populations, the UK government’s loneliness strategy highlighted carers as a particularly vulnerable group (Department of Culture, Media and Sport [DCMS], 2018). This increased vulnerability can be attributed to reduced opportunities to socialise and carers often having to give up employment due to the demands of caregiving (DCMS, 2018), thus further reducing opportunities for the quantity and quality of social contacts (Leszko et al., 2020). These concerns may be amplified for dementia caregivers who may not only experience changes in relationships with their social network, but also changes in their relationship with the care recipient (Beeson et al., 2000).

## Loneliness and Psychological Wellbeing

Psychological wellbeing is a complex and multidimensional construct with no universal definition, however, two main approaches have emerged (Dodge et al., 2012). The hedonic approach comprises life satisfaction, and positive and negative affect (Bradburn, 1969). The eudaimonic approach encompasses effective functioning (Rogers, 1961; Ryff, 1989), which comprises purpose in life, personal growth, mastery, positive relationships, and self-acceptance (Ryff & Singer, 2008). The caregiver literature emphasises the importance of both approaches, however, most caregiver research focuses on negative indicators of wellbeing such as depression and burden, rather than positive aspects such as personal growth and mastery (Marino et al., 2017). Given the relevance within the caregiving literature (Marino et al., 2017), psychological wellbeing is defined in this review using both approaches.

Given the link between loneliness and psychological wellbeing in the general population, it is unsurprising that dementia caregiver research also demonstrates these associations. A study with 49 dementia caregivers identified loneliness as a significant predictor of depression (Beeson, 2003). Greater loneliness in dementia carers is also associated with poorer life satisfaction (Leszko, 2020) and wellbeing (Victor et al., 2020).

## Loneliness and Social Resources

A review on loneliness in older adults (Cohen-Mansfield et al., 2016) linked an individual’s ‘social resources’ to loneliness, including an individual’s relationship with their social network and spouse, their level of emotional/social support, social activity, social contacts and opportunities to meet new people (Cohen-Mansfield et al., 2016). For the current review, social resources are defined using these themes from the literature.

Social resources are impacted by caregiving as carers often have less opportunity to socialise due to the demands of caregiving and inability to leave their loved one unsupervised (Leszko et al., 2020). This reduced social engagement may contribute to an increased risk of loneliness (Ekwall et al., 2005). Carers may also experience loneliness within their relationship with the care recipient (Mayo et al., 2020), with poorer relationship quality with the care recipient associated with greater loneliness (Beeson, 2003; Victor et al., 2020). A change in relationship closeness is understood to be key in loneliness, for example, a longitudinal study of over 9,000 older adults indicated a change of closeness with a spouse, rather than the loss of a spouse, had a greater impact on loneliness scores (Yang, 2018).

## Previous Review

Bergman-Evans (1994) reviewed loneliness, depression and social support in caregivers of spouses with Alzheimer’s disease or other cognitive impairments. Some of the studies described as exploring loneliness in Bergman-Evans’ (1994) review actually investigated other constructs, such as social contacts (Chenoweth & Spencer, 1986) and restricted social activities (Miller & Montgomery, 1990). As loneliness is a subjective perception (Perlman & Peplau, 1981), it cannot be assumed from other constructs. The inclusion of these studies may represent the paucity of dementia caregiver loneliness research in 1994, however, since then various research studies exploring loneliness in this population have been conducted.

## Rationale for this Review

Dementia caregiver loneliness has been linked to negative wellbeing outcomes (Victor et al., 2020). Research has also linked loneliness to social resources (Cohen-Mansfield et al., 2016). Given these associations and the increased vulnerability to loneliness in caregivers, a review would be pertinent to better understand how psychological wellbeing and social resources are related to loneliness in dementia carers. This understanding may help to identify risk factors and protective factors for loneliness in dementia carers and inform psychosocial interventions for loneliness in this particularly vulnerable population.

## Aim

To critically evaluate the empirical literature investigating the psychological wellbeing and social resources associated with loneliness in informal caregivers of people with dementia living in the community.

# Method

## Search Strategy

A preliminary search was completed on Google Scholar and the Cochrane Database to establish if any reviews similar to the current one had already been completed. A systematic search was then carried out using CINAHL, MEDLINE, PsycARTICLES, PsychINFO and Scopus. Limiters of English language and, where possible, peer-reviewed articles were used. As a limiter of peer-review was not available on all databases, this was confirmed manually during screening.

No start date was specified but as the searchers were conducted on 9th February 2021, studies published after this date were not reviewed. Search terms were determined through reviewing relevant literature and discussions with an academic librarian and clinical supervisor. The following search terms were used: (("dementia\*" OR "Alzheimer\*") AND ("caregiver\*" OR "carer\*") AND ("loneliness" OR "lonely")). “Psychological wellbeing” and “social resources” were not included as search terms because their inclusion significantly reduced the number of search results and consequently may have missed relevant studies. It was confirmed manually during screening that the paper investigated psychological wellbeing and/or social resources in relation to caregiver loneliness.

## Selection Criteria

### Inclusion Criteria

* Published in a peer-reviewed journal
* Published in English due to lack of translation resources
* Participants were current informal caregivers of people with dementia who lived in the community
* Caregiver loneliness was investigated or explored as part of the study aims, measured as a variable or identified as a theme within the findings
* Caregiver psychological wellbeing and/or social resources were investigated with caregiver loneliness, either by the relationship being measured or discussed within a theme of loneliness
* If eligible studies investigated additional topics or populations, only findings relevant to the current review were reviewed and appraised

## *Exclusion Criteria*

* Review, intervention study, editorial, commentary, perspective/opinion piece
* The person with dementia was in a hospital, nursing home or had passed away
* Loneliness was investigated in relation to transitioning or decision-making regarding nursing home placement
* Loneliness was not considered in relation to psychological wellbeing and/or social resources, for example, the study solely measured caregiver loneliness over time
* The sample was mixed and it was not possible to separate data from current dementia caregivers and other populations, such as former dementia carers

## Selection Process

Figure 1 depicts the search process. Following the removal of duplicates and screening of titles and abstracts, the full texts of the remaining articles were reviewed against the above selection criteria. Twelve relevant articles were identified. A manual search was then conducted of the references cited in eligible articles and on Google Scholar. This resulted in one additional article being included.

**Figure 1**

*Flow chart of the search and selection process.*

**Articles identified through database searching (n=445)**

CINAHL (n=95)

MEDLINE (n=96)

PsychARTICLES (n=4)

PsychINFO (n=83)

Scopus (n=167)

**Articles excluded (n=62)**

Not written in English (n=1)

Review (n=4)

Commentary/perspective piece (n=11)

Participants were people with dementia (n=1)

Former dementia carers (n=3)

Carers of people with other conditions (n=2)

Mixed sample including carers of people with other conditions, former dementia carers and/or non-carers (n=21)

No focus on caregiver loneliness (n=13)

Focus on caregiver loneliness but not in relation to wellbeing and/or social resources (n=6)

**Articles screened by title and abstract**

**(n=217)**

**Duplicates removed**

**(n=228)**

**Articles excluded**

**(n=143)**

**Full-text articles assessed for eligibility**

**(n=74)**

**Articles eligible**

**(n=12)**

**Additional articles identified through hand searching**

**(n=1)**

**Articles included**

**(n=13)**

## Publication Bias

Google Scholar and the British Library EThOS database were used to search the grey literature to check for publication bias. One potentially relevant doctoral thesis abstract was found (Tzimoula, 2013); however, the full text was not available. Consequently, it was difficult to fully assess the relevance.

## Critical Appraisal

The studies were appraised by the author. The Critical Appraisal Skills Programme Qualitative Studies Checklist (CASP, 2018) was selected to appraise the qualitative studies given its focus on reflexivity and rigour. The Appraisal Tool for Cross-sectional Studies (AXIS; Downes et al., 2016) was used to appraise the cross-sectional studies due to its comprehensive consideration of the recruitment, design and reporting in cross-sectional studies. Leszko (2020) used mixed methods but only the quantitative element investigated loneliness, therefore, this study was appraised using the AXIS.

These tools have no numerical scoring systems; however, a three-point scale was created for the current review to help appraise and compare the quality of the studies. The papers were scored if they fully met the criteria (2 points), partially met the criteria (1 point), or did not meet or it was not possible to determine (0 points). If a question was not relevant to a study, the item was scored as ‘not applicable’ and excluded from the overall total. As the two tools had different total scores, it was difficult to compare studies of different designs, therefore, scores were converted to percentages to allow comparison. Appendix B presents the appraisal tool questions and scores for each reviewed paper.

# Results

A summary of the study characteristics is presented in Table 1.

**Table 1**

*Study characteristics.*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Author, Year and Location** | **Design, Methodology and Data Collection** | **Sample** | **Measures** | **Key Findings** |
|  |  |  | **Loneliness** | **Psychological Wellbeing and Social Resources** |  |
| **Beeson (2003)**US | Quantitative observational cross-sectional design Correlation and regression analysisQuestionnaires | 49 dementia caregivers | Loneliness Scale version-3 (UCLA; Russell, 1996) | **Depression:** Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1997)**Relational deprivation:** Relational deprivation scale (Pearlin et al., 1990)**Loss of self:** two questions | Greater loneliness was associated with greater relational deprivation, loss of self and depression. Loneliness accounted for 49% of the variance in depression.  |
| **Beeson et al. (2000)**US | Quantitative observational cross-sectional design Correlation and regression analysisSecondary analysis of data from a research centre | 242 dementia caregivers  | Loneliness item from the CES-D | **Depression:** CES-D**Relational deprivation:** Relational deprivation scale **Current and past relationship quality:** one question each**Distance felt due to caregiving:** one question | Greater loneliness was associated with greater relational deprivation, depression and poorer current relationship quality. Loneliness, past and current relationship quality, relational deprivation, and distance felt due to caregiving predicted 43% of the variance in depression. |
| **Fekete et al. (2019)**New Zealand | Quantitative observational cross-sectional design Latent profile analysisSecondary analysis of data from a previous study (Towers et al., 2016) | 336 dementia caregivers | De Jong Gierveld Loneliness Scale (De Jong Gierveld & Kamphuis, 1985) | **Mental health:** Short Form 12-item Survey (SF-12; Ware et al., 1998)**Depression:** CESD-10 (Kohout et al., 1993)**Quality of life:** Quality of Life Scale (CASP-12; Wiggins et al., 2008)**Life satisfaction:** one question  | Identified three ‘psychological functioning profiles’: poor, suboptimal and optimal. Loneliness was predictive of poor psychological functioning. |
| **Flaskerud and Lee (2001)**US | Quantitative observational cross-sectional design CorrelationQuestionnaires | 40 dementia caregivers | Loneliness item from the Symptom Checklist-90 (SCL-90; Derogatis et al., 1973) | **Depression:** CES-D | Greater loneliness was correlated with higher levels of depression.  |
| **Joling et al. (2018)**The Netherlands | Quantitative observational longitudinal designKruskal–Wallis testSecondary analysis of data from a previous study (Joling et al., 2008) | 192 dementia caregivers | De Jong Gierveld Loneliness Scale  | **Suicidal thoughts and depression:** International Neuropsychiatric Interview (MINI; Sheehan et al., 1998) | Carers experiencing depression and suicidal thoughts were significantly lonelier than carers with depression and no suicidal thoughts, and carers without depression.  |
| **Joling et al. (2016)**The Netherlands | Quantitative observational cross-sectional design Chi-squared analysisSecondary analysis of data from two studies (Dröes et al., 2004; MacNeil-Vroomen et al., 2015) | 528 dementia caregivers  | De Jong Gierveld Loneliness Scale  | **Resilience:** General Health Questionnaire (GHQ; Goldberg & Williams, 1988) | Feelings of loneliness were related to low resilience.  |
| **Leszko (2020)**Poland | Quantitative observational cross-sectional designCorrelationsQuestionnaires | 48 caregivers of people with Alzheimer’s disease  | Revised UCLA (R-UCLA; Russell et al., 1980) | **Depression:** Geriatric Depression Scale (GDS; Yesavage et al., 1983)**Life satisfaction:** Satisfaction with Life Scale (SWLS; Diener et al., 1985)**Time spent communicating online:** one question  | Greater loneliness was significantly associated with less time communicating online, lower life satisfaction and greater depression. |
| **Leszko et al. (2020)**Poland | Qualitative Thematic analysisSemi-structured interviews | 30 caregivers of people with Alzheimer’s disease | - | - | Themes of changes in social network and difficulty leaving the house due to caregiving. Caregiver loneliness resulted from reduced communication with the care recipient, leading to sadness and anger.  |
| **Luque-Carrillo et al. (2020)**Spain | Quantitative observational cross-sectional design Analysis of covariance and regression analysisQuestionnaires | 69 dementia caregivers | Social Loneliness Scale (ESTE-II; Pinel Zafra et al., 2009) | **Burden:** Zarit Burden Interview (ZBI; Zarit et al., 1980)**Depression:** Beck Depression Inventory (BDI; Beck et al., 1961) | Caregivers reporting depression had higher levels of loneliness. Caregivers experiencing burden were more likely to experience loneliness. |
| **Mayo et al. (2020)**US | QualitativePhenomenological analysisSemi-structured interviews | 11 dementia caregivers | - | - | “The sense of loneliness” theme described how carers felt lonely due to changes in their relationship with the care recipient and being excluded from social events. Loneliness was linked to sadness. |
| **Tomita et al. (2010b)**India, Taiwan and the US | Quantitative cross-sectional designCorrelation and regression analysisQuestionnaires | 167 dementia caregivers India (n=50)Taiwan (n=67)US (n= 50) | UCLA | **Depression:** CES-D**Burden:** ZBI 22 item (ZBI-22; Zarit et al., 1986)**Perceived caregiving rewards:** Picot Caregiver Rewards Scale (PCRS; Picot et al., 1997) | Greater loneliness was associated with greater depression. Perceived caregiving rewards were predictive of loneliness in the US and Taiwan, but not in carers from India. Greater caregiver burden was associated with greater loneliness but this finding was only significant in the US sample. |
| **Vasileiou et al. (2017)**England | QualitativeThematic analysisSemi-structured interviews | 7 dementia caregivers  | - | - | Dementia carers described how they felt lonely in their relationship with the care recipient due to their reduced ability to communicate. |
| **Victor et al. (2020)**UK | Quantitative observational cross-sectional designAnalysis of covariance and regression analysisSecondary analysis of data from the baseline wave of a cohort study (Clare et al., 2014) | 1,283 dementia caregivers | Revised De Jong Gierveld Loneliness Scale (De Jong Gierveld & Van Tilburg, 1999) | **Life satisfaction:** SWLS**Wellbeing:** World Health Organization-Five Wellbeing Index (WHO-5; Bech, 2004)**Relationship quality:** Positive Affect Index (PAI; Bengston & Schrader, 1982)**Social isolation:** The Lubben Social Network Scale (LSNS; Lubben et al., 2006)**Depression:** CESD-Revised (CESD-R; Eaton et al., 2004)**Stress:** Relatives’ Stress Scale (RSS; Greene et al., 1982) | Carers experiencing loneliness had smaller social networks, lower relationship quality, life satisfaction and wellbeing, greater depression and stress. Stress, social isolation, wellbeing, life satisfaction and relationship quality were significant predictors of loneliness, but depression was not. |

## Overview of the Studies

Three studies used a qualitative design. Leszko et al. (2020) explored experiences of loneliness using semi-structured interviews with 30 caregivers of people with Alzheimer’s disease recruited from a government list of carers eligible for financial aid. Vasileiou et al. (2017) explored experiences of caregiver loneliness using semi-structured interviews with informal caregivers recruited from a voluntary organisation, including seven dementia carers. Mayo et al. (2020) used semi-structured interviews to explore the lived experience of 11 dementia carers recruited from a faith-based carers’ support group.

Using mixed methods, Leszko (2020) explored the use of online communication in 48 caregivers of people with Alzheimer’s disease recruited from online advertisements and carer support services. Relevant to the current review, participants completed measures of loneliness, depression, and life satisfaction.

Four studies used a quantitative observational cross-sectional design using primary data. Beeson (2003) explored the relationship between loneliness, depression, relational deprivation and loss of self in 49 dementia carers enrolled at a dementia research centre. Flaskerud and Lee (2001) investigated caregiver risk factors for physical health problems, including loneliness. They recruited 40 dementia caregivers from a Veterans Affairs Medical Centre. Tomita et al. (2010b) compared psychological wellbeing in 167 dementia carers across India, Taiwan and the US. Fifty carers were recruited from day centres and a psychiatric clinic in India, 67 carers responded to an advert on an Alzheimer’s association website in Taiwan, and 50 carers were recruited from support groups in the US. Participants completed burden, depression, perceived caregiving rewards and loneliness measures. Luque-Carrillo et al. (2020) investigated the relationship between gender, education, loneliness, burden and depression in 69 dementia caregivers.

Four quantitative cross-sectional studies conducted a secondary analysis of data collected in previous studies. Beeson et al. (2000) investigated the relationship between loneliness, depression, relational deprivation, relationship quality and distance felt due to caregiving. Secondary data from 242 dementia caregivers from a research centre was used, however, the original purpose of the data collection was not reported. Joling et al. (2016) harmonized and integrated data from 528 dementia caregivers from two previous studies (Dröes et al., 2004; MacNeil-Vroomen et al., 2015) to investigate caregiver resilience, using psychological wellbeing, and loneliness. Fekete et al. (2019) used data from 336 dementia caregivers collected in a previous study (Towers et al., 2016) to investigate caregivers’ psychological functioning. Participants completed measures of loneliness, mental health, depression, quality of life and life satisfaction. Victor et al. (2020) investigated the prevalence and predictors of loneliness in 1,283 dementia caregivers using data from the baseline wave Improving the experience of Dementia and Enhancing Active Life (IDEAL) cohort study (Clare et al., 2014). Participants completed measures of loneliness, life satisfaction, wellbeing, relationship quality, social isolation, depression and stress.

Joling et al. (2018) conducted a secondary analysis of longitudinal data collected from 192 dementia caregivers in a previous study (Joling et al., 2008). Suicidal ideation and depression measures were completed every three months, for 24 months. Loneliness was only measured at baseline.

## Critical Appraisal

### Design and Methodology

Quality ratings ranged from 59% to 85%, with eight papers scoring 70% or above (Appendix B). A range of methodologies and designs were used, all of which were appropriate for the aims of the studies. This diverse range provides this review with a rich understanding of loneliness in dementia carers. Qualitative methodologies included phenomenological (Mayo et al., 2020) and thematic (Leszko et al., 2020; Vasileiou et al., 2017). Of the quantitative studies, five used a regression analysis (Beeson, 2003; Beeson et al., 2000; Luque-Carillo et al., 2020; Tomita et al., 2010b; Victor et al., 2020), Fekete et al. (2019) used latent profile analysis, Flaskerud and Lee (2001) and Leszko (2020) used correlations, Joling et al. (2016) used a chi-squared analysis, and Joling et al. (2018) used a Kruskal–Wallis test.

The qualitative studies provided information regarding their topic guide or example interview questions for their semi-structured interviews which were audio-recorded and transcribed. Six quantitative studies provided sufficient information regarding data collection procedures (Beeson, 2003; Fekete et al., 2019; Flaskerud & Lee, 2001; Leszko, 2020; Tomita et al., 2010b; Victor et al., 2020), for example, if measures were completed in person or via post. This detail allows for replication and increases the validity of findings. Such information was missing in three of the secondary analysis studies (Beeson et al., 2000; Joling et al., 2018; Joling et al., 2016), however, all but Beeson et al. (2000) referred to the original article where this information could be found. The data collection procedure was unclear in Luque-Carrillo et al. (2020). This paper was translated into English for publication and some of the wording was not easy to follow, therefore, it is important to be cautious when appraising this article.

Four studies reported that informed consent and ethical approval were obtained and were transparent about funding disclosures and conflicts of interest (Joling et al., 2018; Leszko, 2020; Mayo et al., 2020; Vasileiou et al., 2017). The remaining studies did not report at least one of these areas, which raises concerns about their ethical integrity. In further evaluation of the qualitative studies, Mayo et al. (2020) considered the impact of participating and attempted to minimise this by keeping interviews under one hour. Vasileiou et al. (2017) debriefed participants after participating. Leszko et al. (2020) did not discuss how they managed the potential impact of participating either during or after the study.

### Participants and Recruitment

Flaskerud and Lee (2001) and Leszko (2020) intentionally recruited solely female participants. Flaskerud and Lee (2001) focused on female caregivers as they identified them as a group particularly vulnerable to poor health outcomes. Leszko’s (2020) rationale for recruiting female caregivers appeared more relevant to their spousal role than their gender. The other studies recruited 51-91% female participants, with six studies recruiting 60-70% (Beeson et al., 2000; Fekete et al., 2019; Joling et al., 2018; Joling et al., 2016; Vasileiou et al., 2017; Victor et al., 2020). With a cultural expectation across the world that women will undertake caregiving roles (Erol et al., 2015; Godfry & Warshaw, 2009), most carers are female, with estimates suggesting 60-70% of UK dementia carers are female (Alzheimer’s Research UK, 2015). Therefore, except for Flaskerud and Lee (2001) and Leszko (2020) the samples are reasonably representative of the target population; however, caution should be used when generalising the results to male carers as males made up only a small percentage of some studies or were not represented at all.

Three studies intentionally recruited exclusively spousal carers (Beeson, 2003; Leszko, 2020; Leszko et al., 2020). Flaskerud and Lee (2019) did not report the caregiver relationship. In the remaining studies, spousal carers made up 19%-94% of the samples, with six studies recruiting over 50% spousal carers (Beeson et al., 2000; Joling et al., 2018; Joling et al., 2016; Mayo et al., 2020; Vasileiou et al., 2017; Victor et al., 2020). Findings may be less applicable for people who care for a parent, sibling or grandparent, as they may have a different caregiving experience due to generally not living with the care recipient and spending less time caregiving (Adelman et al., 2014).

As is common in dementia carer research, participants were mainly recruited from support groups and services, so may over-represent carers who are seeking help (Beeson et al., 2000). Consequently, findings may not be generalisable to carers who are not accessing support.

In the quantitative studies, response rates were reported by Flaskerud and Lee (2001) as 75% and Luque-Carrillo et al. (2020) as 96%. A response rate of 50%-60% or greater is considered appropriate for minimising non-response bias (Fincham, 2008), therefore, these levels were acceptable. The lack of information regarding non-responders in the other studies raises concerns about potential non-response bias.

Quantitative sample sizes ranged from 40 to 1,283. Flaskerud and Lee (2001), Luque-Carrillo et al. (2020) and Tomita et al. (2010b) reported using a power calculation to determine an appropriate sample size. Leszko (2020) and Tomita et al. (2010b) stated their studies were underpowered, restricting them from carrying out additional analysis or including all the measured variables in their analysis. It is concerning that the other studies did not report a power consideration, because if the sample size is too small then findings may be inaccurate. According to sample size rule of thumb guidance (VanVoorhis & Morgan, 2007), of the remaining studies, two recruited appropriate sample sizes for their methodology (Joling et al., 2016; Victor et al., 2020). Whereas Beeson (2003), Fekete et al. (2019) and Joling et al. (2018) may have been underpowered (VanVoorhis & Morgan, 2007; Spurk et al., 2020).

Flaskurd and Lee (2001), Leszko (2020) and Tomita et al. (2010b) used convenience sampling. While this method is commonly used in quantitative research, it can lead to a non-representative sample as the characteristics of individuals readily available to participate may differ from the target population, thus making it difficult to draw conclusions regarding the target population. Luque-Carrillo et al. (2020) reported recruiting a random sample, however, did not describe how this was done.

The qualitative studies used purposive (Vasileiou et al., 2017), purposive and snowballing (Mayo et al., 2020) and convenience sampling (Leszko et al., 2020). Qualitative research aims to gain an enriched understanding of the experience under investigation; therefore, purposive sampling is often used to select participants who can provide substantial contributions to the understanding of the topic (Polkinghorne, 2005). Convenience sampling may not achieve this, given it relies on participants who are readily available rather than purposely selected, and therefore is a limitation of Leszko et al. (2020).

All the qualitative researchers described how and where participants were recruited but did not discuss why the participants selected were deemed the most appropriate to provide the information sought by the researchers as opposed to other dementia caregivers. This makes it difficult to judge potential selection bias, consequently reducing the credibility and transparency of the findings.

### Measures

All of the studies used self-report measures and while common, they are vulnerable to subjectivity and social desirability which can reduce the validity of results (Rosenman, et al., 2011).

#### Loneliness Measures

Beeson et al. (2000) and Flaskerud and Lee (2001) used a single item to measure loneliness. While such measures have been criticised for low reliability due to participants potentially denying loneliness when asked directly because of the stigma attached to it (Shiovitz-Ezra & Ayalon, 2012), they have been found to correlate with the multi-item scales (Victor et al., 2005).

Four studies used the original or revised version of the De Jong Gierveld Loneliness Scale (De Jong Gierveld & Kamphuis, 1985), and three studies used revised versions of the UCLA (Russell, 1996; Russell et al., 1980). These measures are commonly used and well-validated with dementia carers, however, the UCLA has been criticised for only focusing on social loneliness, whereas the De Jong Gierveld Scale captures social and emotional loneliness (Penning et al., 2014). The different focuses of these measures make it difficult to directly compare the findings. It was not possible to assess the properties of the ESTE-II (Pinel Zafra et al., 2009) used by Luque-Carrillo et al. (2020), as the paper is not available in English.

#### Psychological Wellbeing Measures

Depression was measured in eight studies using validated measures; GSD (Yesavage et al., 1983), BDI (Beck et al., 1961), and CES-D (Eaton et al., 2004; Kohout et al., 1993; Radloff, 1977). The CES-D and GDS are commonly used with dementia caregivers (Watson et al., 2018). The CES-D covers depressive symptomology, depressed affect, positive affect, somatic difficulties, reduced activity and interpersonal problems, whereas the GDS only covers cognitive and affective symptoms (Watson et al., 2018). The difference in focus of these measures reduces the comparability across studies.

Several other measures validated with carers were used, including the ZBI and revised version (Zarit et al., 1980; Zarit et al., 1986), RSS (Greene et al., 1982), PCRS (Picot et al., 1997), SWLS (Diener et al., 1985) and WHO-5 (Bech, 2004). The use of validated measures is a strength as it improves the reliability and validity of the findings. Three measures were validated with the general population, but not specifically with carers; the MINI (Sheehan et al., 1998) which was used to measure suicidal ideation, GHQ (Goldberg & Williams, 1988), a measure of resilience, with resilience defined in the study as a positive outcome despite experiencing adversity (Joling et al., 2016; Masten, 2001), and CASP-12 (Wiggins et al., 2008) which was used to measure quality of life, comprising control, autonomy, self-realisation and pleasure.

Fekete et al. (2019) used a single-item rather than a validated scale to measure life satisfaction, and used the SF-12 (Ware et al., 1998) to measure ‘mental health’, however, this scale measures physical and mental health. Therefore, results from this study should be interpreted with caution due to the validity of these measures.

#### Measures of Social Resources

Validated measures were used to measure social isolation (LSNS; Lubben et al., 2006), quality of the current relationship (PAI; Bengston & Schrader, 1982) and relational deprivation, which is thought to develop from carers feeling deprived of a relationship with the care recipient (Pearlin et al., 1990). Single questions were developed by the authors (Beeson 2003; Beeson et al., 2000) to measure the loss of self-identity (exploring the carer’s identity and role within their spousal relationship), quality of the current and past relationship with the care recipient, and how distant the carer felt from the care recipient. The use of non-validated and single-item measures raises concerns about the validity and reliability of such measures and consequently the findings of these studies.

### Data Analysis

Qualitative researchers need to examine their role and impact on collecting and analysing data and be transparent about this for their findings to be credible. This can be achieved by demonstrating rigour and reflexivity. Mayo et al. (2020) demonstrated reflexivity by using triangulation to verify findings with participants and used bracketing to minimise the impact of the researchers’ beliefs and biases, which increases the trustworthiness of their findings. Vasileiou et al. (2017) and Leszko et al. (2020) did not discuss reflexivity which raises concerns about the credibility of their findings. Mayo et al. (2020) and Vasileiou et al. (2017) provided a sufficient description of their analysis to allow for replication, whereas Leszko et al. (2020) failed to report the analysis process making it difficult to fully assess the rigour in their study.

The quantitative studies all provided a clear description of their statistical analyses, thus allowing for replication. All of the studies reported the significance level used, however, only four reported confidence intervals (Fekete et al., 2019; Flaskerud & Lee, 2001; Luque-Carrillo et al., 2020; Victor et al., 2020). Confidence intervals are important as they provide a range in which the true value of the measured variable is in the population, with a certain level of confidence (usually 95%). Confidence intervals also provide the direction and strength of the effect, allowing conclusions to be made regarding the clinical relevance of the findings (du Prel et al., 2009).

## Synthesis of Findings

From a synthesis of the findings, five prominent areas were identified within the literature; 1) loneliness and depression, 2) loneliness, burden and stress, 3) loneliness, positive aspects of caregiving and wellbeing, 4) loneliness and the social network, and 5) loneliness in the relationship with the care recipient. These key areas are discussed below.

### Loneliness and Depression

Greater loneliness was associated with higher rates of depression in five studies, with correlations ranging from *r* = .50 to *r* = .68 (Beeson 2003; Beeson et al., 2000; Flaskurd & Lee, 2001; Leszko 2020; Tomita et al., 2010b). Furthermore, carers who experienced moderate or severe loneliness reported significantly more depressive symptoms (Victor et al., 2020), and carers with depression reported significantly more loneliness (Joling et al., 2018; Luque-Carrillo et al., 2020). Carers experiencing depression and suicidal thoughts were significantly lonelier than carers with depression and no suicidal thoughts (Joling et al., 2018).

While not explicitly referring to ‘depression’, qualitative research supports these findings, with carers associating loneliness with sadness. Carers linked feelings of sadness in loneliness to not having visitors and losing the ability to communicate with their loved one (Leszko et al., 2020; Mayo et al., 2020).

Beeson et al. (2000) identified loneliness as the strongest and only significant predictor of depression in a model that included relationship to the care recipient, current and past quality of the relationship, distance from relationship and relational deprivation. Beeson (2003) replicated these findings, reporting loneliness as the only significant predictor of depression in a model of relational deprivation, loss of self and loneliness. Victor et al. (2020) did not find depression to be a significant predictor of loneliness.

Fekete et al. (2019) identified psychological functioning “profiles”, categorised according to depression, mental health, quality of life and life satisfaction scores. Loneliness was identified as a significant predictor of psychological functioning, with higher levels of loneliness associated with poorer psychological functioning. The measures were not analysed individually with loneliness and therefore their individual impact could not be discerned.

### Loneliness, Burden and Stress

Greater caregiver burden was associated with greater loneliness in caregivers from Taiwan, India and the US, however, the finding only reached significance for the US sample (Tomita et al., 2010b). Caregiver burden (Luque-Carrillo et al., 2020) and stress (Victor et al., 2020) were identified as significant predictors of loneliness. A potential explanation for this relationship is that increased caregiving demands restrict carers from having social contact and consequently carers experience loneliness, which is supported by Leszko et al’s (2020) qualitative findings highlighting the impact of caregiver burden on loneliness and social isolation. Carers discussed how they spent more time at home due to caregiving demands, illustrated in a quote; “I’m busy all the time… I used to go out to play cards, but I don’t anymore because I don’t have time” (Leszko et al., 2020, p. 176). This demonstrates how demanding caregiving can be and suggests these demands restrict the carer from engaging in social contact.

### Loneliness, Positive Aspects of Caregiving and Wellbeing

Greater perceived caring rewards, defined as feelings of gain, satisfaction and personal growth due to providing care (Picot, 1995), were predictive of lower levels of loneliness in samples from Taiwan and the US, but not India (Tomita et al., 2010b). These findings suggest some potential cultural differences between Taiwan and the US, and India (Tomita et al., 2010b).

Personal growth is a positive aspect of caregiving which can include several aspects such as being more understanding, resilient and knowledgeable (Netto et al., 2009). Feelings of loneliness were related to low resilience in response to caregiving stressors such as more severe dementia, basic self-care limitations, behavioural problems and substantial time caring (Joling et al., 2016). Increased levels of wellbeing and life satisfaction were found to be associated with and predictive of a lower risk of loneliness (Victor et al., 2020). The association between loneliness and life satisfaction was supported by Leszko (2020), who reported that greater loneliness was associated with lower life satisfaction. The qualitative studies reviewed did not focus on this area.

### Loneliness and the Social Network

Carers who were more socially isolated were more likely to report loneliness, and social isolation was predictive of loneliness (Victor et al., 2020). In a study exploring internet-based communication, the less time carers spent communicating online, via social media, support groups, Skype and WhatsApp, the lonelier carers were (Leszko, 2020). As dementia progresses, carers become unable or fearful of leaving the house due to the care recipient’s needs, consequently reducing their social interaction and resulting in loneliness (Leszko et al., 2020). Some carers attributed their reduced social contact to not wanting to bother others or finding it difficult to attend to guests whilst meeting their loved one’s needs (Leszko et al., 2020). Another carer, however, blamed their social network, illustrated in the following quote “now when I call, they find excuses not to meet me” (Leszko et al., 2020, p. 177). Feeling excluded from social events precipitated feelings of loneliness, with one carer describing being a carer as “Lonely. My major thing is exclusion. Being excluded” (Mayo et al., 2020, p. 22), attributing their exclusion to others feeling uncomfortable around the person with dementia. Another carer spoke about how they would benefit from having someone else present to help deal with difficult caregiving situations, and felt lonely without this social support (Vasileiou et al., 2017).

*Loneliness in the Relationship with the Care Recipient*

The better the carers perceived their current relationship with the care recipient, the lower their risk of loneliness was (Beeson et al., 2000; Victor et al., 2020), leading Victor et al. (2020) to argue that relationship quality may be a protective factor against caregiver loneliness. Loss of carer self-identity within their spousal relationship was also significantly positively related to loneliness (Beeson, 2003). Past relationship quality and how distant the carer felt from the relationship had significant but weak correlations with loneliness (Beeson et al., 2000), suggesting these aspects may be somewhat less relevant to loneliness. Greater relational deprivation was associated with greater loneliness (Beeson, 2003; Beeson et al., 2000).

These results are bolstered by qualitative findings, for example, Vasileiou et al. (2017) reported that dementia carers linked loneliness to the loss of the relationship with the care recipient, “…the loneliness is there even when I’m with [wife’s name] because in reality, I am on my own because she’s not relating…” (Vasileiou et al., 2017, p. 5). Feelings of loneliness due to changes in the relationship with the person with dementia was a key theme in Leszko et al. (2020). While carers felt sadness but understanding about changes in their wider social network, they reported feeling sadness and anger about losing communication with the care recipient. Mayo et al. (2020) also reported that carers attributed loneliness to the loss of emotional connection and interaction with the person with dementia due to changes in their communication ability and awareness.

# Discussion

This review aimed to critically evaluate the literature on the psychological wellbeing factors and social resources associated with loneliness in caregivers of people with dementia living in the community. Thirteen relevant peer-reviewed articles were identified. A synthesis of the findings highlighted five prominent areas; 1) loneliness and depression, 2) loneliness, burden and stress, 3) loneliness, positive aspects of caregiving and wellbeing, 4) loneliness and the social network and 5) loneliness in the relationship with the care recipient. Greater loneliness was associated with greater depression, burden, stress and suicidal ideation, poorer wellbeing, life satisfaction and resilience, less social support, less time communicating with others online and poorer quality relationship with the care recipient.

While caution should be used when interpreting the results of low-quality studies, the findings did not vary between studies of differing quality. For example, Mayo et al. (2020) scored the highest (85%), while Leszko et al. (2020) only scored 60%; however, their respective study findings were similar. Furthermore, Joling et al. (2018) was the highest rated quantitative study (82%), and their results were similar to studies of lower quality (for example, Beeson et al., 2000), highlighting the significant relationship between loneliness and depression.

Greater loneliness was significantly correlated with greater depression; however, while Beeson (2003) and Beeson et al. (2000) reported loneliness as a significant predictor of depression, Victor et al. (2020) concluded that depression was not a significant predictor of loneliness. A longitudinal study with the general population supports these findings, reporting that loneliness was a significant predictor of depression, but depression was not a significant predictor of loneliness (Cacioppo et al., 2010).

The importance of researching positive aspects of caregiving has been highlighted in the literature (Carbonneau et al., 2010), and this review demonstrates such research is being undertaken, with lower levels of loneliness associated with greater positive aspects of caregiving and positive indicators of caregiver wellbeing, including caring rewards, resilience, life satisfaction and wellbeing. This, however, was not an area considered in the qualitative studies reviewed.

In keeping with previous research (Cohen-Mansfield et al., 2016; Ekwall et al., 2005), this review indicates that changes in the individual’s social network influence loneliness, with a smaller social network and less communication with their network associated with greater loneliness. Findings from the current review suggest some carers felt excluded by their social network (Leszko et al., 2020; Mayo et al., 2020), whereas other carers did not engage with their network due to not wanting to trouble them or not feeling able to interact with guests (Leszko et al., 2020). Previous research suggests withdrawal from social contact is self-imposed due to the stigma associated with dementia (Mukadam & Livingston, 2012). Vasileiou et al. (2017) attributed this to affiliate stigma which describes how carers may internalise the stigma associated with dementia (Mak & Cheung, 2008). This stigma may lead to social withdrawal and consequently less social support (Vasileiou et al., 2017).

## Clinical Implications

There are many psychosocial interventions for dementia carers (Wiegelmann et al., 2021). As the current review highlights the link between loneliness and psychosocial factors, for example, depression, burden, wellbeing and relationship quality, it could be argued that pre-existing interventions for these psychosocial factors may also reduce loneliness in this population. The addition of a loneliness outcome measure to these interventions would help discern if such interventions can reduce or buffer dementia caregiver loneliness (Victor et al., 2020).

This review indicates loneliness is an important issue for carers, consequently, interventions aimed specifically at reducing loneliness should be developed. Caregiver loneliness interventions might focus on building resilience, given that loneliness is linked to low resilience (Joling et al., 2016), and maintaining relationship quality and a sense of closeness (Leszko et al., 2020; Victor et al., 2020), particularly for spousal carers, as dementia progresses. Such an intervention could involve a dyadic approach to help foster and maintain the relationship quality, for example, a couples life story approach to reinforce the carer and care recipient’s sense of partnership (Ingersoll-Dayton et al., 2013).

While there are benefits to support groups for carers, including an opportunity to meet other people experiencing similar challenges (Fekete et al., 2019), carers often face challenges with access, such as lack of transport and leaving the care recipient alone (Flaskurd & Lee, 2001; Leszko et al., 2020). Leszko (2020) reported that online communication helped carers to maintain social contact with friends and family, with more time communicating online associated with lower levels of loneliness. Online communication, therefore, may reduce loneliness whilst mitigating the aforementioned challenges. Further research is warranted to understand which types of contact are helpful and for whom, as online contact may not be suited to all carers due to issues with access and confidence with technology, and preference, necessitating the need for face to face contact options, such as peer support groups.

Loneliness appeared to be linked to carers having less interaction with their social network, perhaps due to carers not being able to engage with others while meeting caregiving demands or being excluded by others. Respite opportunities to support carers to spend valuable time with others may help reduce loneliness. Recommendations from reviewed studies included mobilising caregivers’ social networks (Flaskurd & Lee, 2001; Fekete et al., 2019). An important part of this would be educational campaigns targeted at the wider social network explaining the valuable contribution that carers make alongside the challenges they face. This may reduce the stigma associated with dementia and caregiving, thus reducing exclusion (Flaskurd & Lee, 2001; Vasileiou et al., 2017).

## Review Limitations

While a systematic search strategy was used, relevant papers may have been missed, for example, papers that were not published in English and/or not peer-reviewed. One potentially relevant unpublished thesis was identified (Tzimoula, 2013). The thesis abstract indicated that social support and loss of companionship predicted loneliness, but social support did not buffer the impact of the loss of companionship on loneliness. This suggests that social support reduces some feelings of loneliness but not loneliness associated with the loss of a close relationship (Tzimoula, 2013). These findings are in keeping with the current review which highlights the impact of the relationship with both the care recipient and wider social network.

The literature search and appraisal were carried out by one person, therefore, were open to subjectivity and bias. To mitigate this, clear eligibility criteria were defined and published appraisal tools were used. Caution should be used when interpreting the appraisal results as the numerical scoring system was not part of the original tools, however, this scoring system and percentages helped to compare studies of different designs.

**Future Research**

All of the quantitative findings reviewed were cross-sectional, meaning that conclusions regarding causality cannot be made. Longitudinal studies would be beneficial for understanding whether loneliness simply correlates with poorer psychological wellbeing outcomes or whether it plays a role in the development of this distress.

Clear methodological limitations were identified in the quality appraisal of included studies. The qualitative studies demonstrated limited reflexivity and rigour and would have benefitted from further consideration of the researcher-participant relationship, selection bias and the potential impact of the study on participants. Key gaps in the quantitative studies were around recruitment and transparency in the reporting of sample size considerations and non-response bias. Future studies should strive to overcome these issues which would help reduce bias and improve the reliability and validity of findings.

While some of the studies considered positive aspects of caregiving, the studies mainly focused on caregiver depression and burden. Future research might focus on factors that buffer loneliness and thus identify ways to reduce or prevent loneliness in this population. While loneliness appears common amongst dementia caregivers, not all dementia carers experience loneliness (Victor et al., 2020); therefore, further research into protective factors would be useful.

## Conclusion

This review highlighted clear associations between caregiver loneliness and psychological wellbeing and social resources. While the quality of papers varied, the findings were generally consistent across studies. Professionals working with caregivers of people with dementia should be mindful of this population’s vulnerability to loneliness and the associated negative outcomes. Current psychosocial interventions for dementia caregivers should include a loneliness outcome measure, given the identified associations with psychosocial variables. Furthermore, interventions for loneliness should focus on psychological and social factors such as caregivers’ wellbeing and strengthening their relationships, including with the person with dementia.

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# Appendix A

# Journal Guidelines

Please refer to the Dementia Journal webpage for the author submission guidelines:

<https://journals.sagepub.com/author-instructions/DEM>

* Referencing style APA 7th edition is used in the current paper, as per the journal guidelines
* The word count for the current paper will be reduced prior to submission to the journal, as the journal word limit is 5,000 to 6,000

**Appendix B**

**Critical Appraisal Tables**

|  |  |  |  |
| --- | --- | --- | --- |
| **CASP Qualitative Studies Checklist (Critical Appraisal Skills Programme, 2018)** | **Leszko et al. (2020)** | **Mayo et al. (2020)** | **Vasileiou et al. (2017)** |
| 1. Clear aims? | 2 | 2 | 2 |
| 2. Qualitative methodology appropriate? | 2 | 2 | 2 |
| 3. Research design appropriate? | 1 | 1 | 2 |
| 4. Recruitment strategy appropriate? | 1 | 1 | 1 |
| 5. Data collection appropriate? | 1 | 1 | 2 |
| 6. Relationship between researcher and participants considered? | 0 | 2 | 0 |
| 7. Ethical issues considered? | 1 | 2 | 2 |
| 8. Data analysis rigorous? | 1 | 2 | 1 |
| 9. Clear statement of findings? | 1 | 2 | 1 |
| 10. Value of the research? | 2 | 2 | 2 |
| **CASP score** | **12/20** | **17/20** | **15/20** |
| **Overall percentage score** | **60%** | **85%** | **75%** |

*Note*. Studies were scored out of 20 as they were awarded 2 points if a criterion was fully met, 1 point if a criterion was partially met or 0 points if a criterion was not met or it was not possible to discern.

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **AXIS Questions (Downes et al., 2016)** | **Beeson (2003)** | **Beeson et al. (2000)** | **Fekete et al. (2019)** | **Flaskerud and Lee (2001)** | **Joling et al. (2016)** | **Joling et al. (2018)** | **Leszko (2020)** | **Luque-Carrillo et al. (2020)** | **Tomita et al. (2010b)** | **Victor et al. (2020)** |
| 1. Clear aims? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 2. Study design appropriate for aims? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 3. Sample size justified? | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 2 | 1 | 0 |
| 4. Target population clearly defined? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 5. Sample representative? | 2 | 0 | 0 | 0 | 0 | 2 | 1 | 2 | 1† | 1 |
| 6. Appropriate selection process? | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 1† | 0 |
| 7. Non-responders addressed? | 0 | N/A | N/A | 0 | N/A | N/A | 0 | 0 | 0 | N/A |
| 8. Variables appropriate to the aims? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 9. Variables measured correctly? | 1 | 1 | 2 | 1 | 2 | 2 | 1 | 2 | 1 | 2 |
| 10. Clear how statistical significance is determined? | 1 | 1 | 2 | 1 | 1 | 1 | 1 | 2 | 1 | 2 |
| 11. Clear methodology? | 2 | 1 | 2 | 2 | 1 | 1 | 2 | 1 | 2† | 2 |
| 12. Descriptive data presented? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2† | 2 |
| 13. Response rate concerning? \* | 0 | N/A | N/A | 2 | N/A | N/A | 0 | 2 | 0 | N/A |
| 14. Information on non-responders described? (If appropriate) | 0 | N/A | N/A | 0 | N/A | N/A | 0 | 0 | 0 | N/A |
| 15. Results internally consistent? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 16. All results presented? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 17. Conclusions justified by results? | 1 | 1 | 1 | 1 | 2 | 2 | 1 | 1 | 1 | 1 |
| 18. Limitations discussed? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 19. Conflicts of interest/ funding? \* | 0 | 0 | 2 | 1 | 2 | 2 | 2 | 0 | 0 | 1 |
| 20. Ethical approval/consent gained?  | 1 | 0 | 0 | 2 | 0 | 2 | 2 | 2 | 0 | 1 |
| **Reviewed Studies** | **Beeson (2003)** | **Beeson et al. (2000)** | **Fekete et al. (2019)** | **Flaskerud and Lee (2001)** | **Joling et al. (2016)** | **Joling et al. (2018)** | **Leszko (2020)** | **Luque-Carrillo et al. (2020)** | **Tomita et al. (2010b)** | **Victor et al. (2020)** |
| **Total score** | **25/40** | **20/34** | **25/34** | **28/40** | **24/34** | **28/34** | **27/40** | **31/40** | **24/40** | **26/34** |
| **Overall percentage score** | **63%** | **59%** | **74%** | **70%** | **71%** | **82%** | **68%** | **78%** | **60%** | **76%** |

*Note.* Studies were scored out of 40 as they were awarded 2 points if a criterion was fully met, 1 point if a criterion was partially met or 0 points if a criterion was not met or it was not possible to discern. If a question was not applicable for a study, N/A is indicated and the total possible score was reduced by two.

\* Items 13 and 19 are reversed scored

† Tomita et al. (2010b) published their demographic and methodology information in a separate paper (Tomita et al., 2010a) and signposted the reader to this information. Given that the information is reported, but is purposely done so in a separate paper, appraisal questions concerning these topics were awarded points if the information was in either paper.

# Paper 2: Empirical Paper

# The Relationship between Self-Compassion, Caregiver Guilt, Time Spent Caring, and Depressive Symptoms in Family Caregivers of People with Dementia

**Word count:** 7984 (Excluding the title page, references and appendices)

This literature review is intended for publication in the journal ‘Dementia’. The referencing style of this paper is APA 7th edition, in line with the journal requirements. Author guidelines for the journal can be found in Appendix A. Further modifications will be made before submitting to the journal to meet these guidelines.

# Abstract

Caring for a relative with dementia can have a significant impact on carers’ mental health, with many carers experiencing depression and caregiver guilt. Self-compassion has been suggested as a potential buffer to caregiver guilt and depressive symptoms, in the way that self-compassion encourages people to respond to self-critical thoughts with more compassion and kindness. The current study aimed to explore the relationship between caregiver guilt, self-compassion, gender, daily hours caregiving and depressive symptoms in informal dementia caregivers. A cross-sectional, multiple regression and mediation quantitative design was used. In total, 84 family dementia caregivers were recruited for the study. Participants completed a demographic questionnaire alongside three questionnaires measuring depressive symptoms, caregiver guilt, and self-compassion. The findings suggested that lower levels of self-compassion and greater caregiver guilt predict higher levels of depressive symptoms in family dementia caregivers, whereas the number of daily hours caregiving did not predict depressive symptoms. It was not possible to include gender in the analysis, due to the disproportionately low number of male carers recruited compared to female carers. Caregiver guilt was found to mediate the relationship between self-compassion and depressive symptoms. This suggests that caregiver guilt may be a mechanism behind the self-compassion and depressive symptoms relationship in dementia carers. Self-compassion-based interventions may be useful in supporting dementia caregivers to reduce depressive symptoms and caregiver guilt; however, further research is needed to fully understand the implications for clinical practice.

# Introduction

## Informal Dementia Caregivers

In the UK, around two thirds (61%) of people with dementia live at home (Prince et al., 2014). As the disease progresses, symptoms including problems with memory, communication, disorientation, and problem solving impact the individual’s ability to carry out day to day tasks (Alzheimer’s Society, 2021). Consequently, people with dementia often require support to remain living in the community, which is generally provided by their spouse or relative, often referred to as an ‘informal caregiver’ (Alzheimer’s Research UK, 2020). As the number of people with dementia increases, the number of family carers also increases, with estimates suggesting that one in three people will care for someone with dementia in their lifetime (Newbronner et al., 2013).

Caregiving can be a demanding role with reports suggesting 36% of informal dementia carers spend 100 or more hours per week providing care (Health & Social Care Information Centre, 2016). Along with the practical demands of caregiving, dementia carers must navigate the complex, unpredictable and progressive nature of the disease, accompanied by cognitive decline and often personality and behavioural changes in their loved one (Newbronner et al., 2013; Lloyd et al., 2019). Caregiving demands make it difficult for carers to tend to their own needs and carers often prioritise the needs of the care recipient over their own health and wellbeing (Carers UK, 2019; Schulz & Sherwood, 2008). As a consequence of these challenges, caregiving can be stressful and carers often experience depression, anxiety and isolation (Pinquart & Sörensen, 2003; Schulz & Sherwood, 2008).

## Depression in Dementia Caregivers

Depression is common amongst carers, with a recent meta-analysis of 43 studies including almost 17,000 participants, reporting the prevalence of depression in dementia carers as 31% (Collins & Kishita, 2020). This is much higher than the predicted prevalence of depression in the UK, estimated to be 4.5% (National Institute for Health and Care Excellence, 2022). Caregiver demographic characteristics have been associated with caregiver depression, for example, levels of depression are higher amongst female dementia caregivers than among male dementia caregivers (Pillemer, et al., 2018; Watson et al., 2019), with findings indicating that female dementia caregivers are 1.45 times more likely to experience depression (Collins & Kishita, 2020).

The number of hours spent providing care to an individual with dementia has also been suggested as a predictor of caregiver depressive symptoms, with more hours devoted to caring associated with higher levels of depressive symptoms (Covinsky et al., 2003; Jiménez-Gonzalo et al., 2020; Losada et al., 2018). Losada et al. (2018) speculated that carers providing more hours of care may experience greater depressive symptoms due to having less opportunity to engage in leisure activities as a result of the time spent caregiving.

Alongside the associations between caregiver depression and demographic characteristics, depression has also been linked to other psychological factors including caregiver guilt and burden (Losada et al., 2010; Schulz & Sherwood, 2008). While caregiver burden has been the focus of many dementia carer research studies (Watson et al., 2019), caregiver guilt has received less attention until recent years (Losada et al., 2010; 2018; Roach et al., 2013). Research with dementia caregivers suggests that greater caregiver guilt is associated with higher levels of depressive symptoms (Losada et al., 2010; 2018; Roach et al., 2013), however, limited research has considered variables that may reduce or buffer caregiver guilt.

## Caregiver Guilt

Prunty and Foli (2019) stated that caregiver guilt may be experienced when three critical aspects are met; the carer 1) feels a sense of moral responsibility to care for the person with dementia, 2) has a negative appraisal of their caregiving performance, and 3) feels they have acted against a moral or social standard of care due to their behaviour and/or thoughts, for example, leaving the care recipient in the care of someone else whilst they do another activity. Gallego-Alberto et al. (2020) explored caregiver guilt in a qualitative study with 13 dementia caregivers. This study identified situations in which carers experienced caregiver guilt, such as making or perceiving they had made a mistake while caregiving, with examples of losing patience with their loved one or feeling guilty for not knowing how to address difficult caring situations. Carers also experienced guilt for having negative feelings towards the care recipient, such as annoyance, and for neglecting other relationships (Gallego-Alberto et al., 2020). Caregiver guilt is considered a common experience amongst dementia carers, for example, Gonyea et al. (2008) reported that 65% of a sample of 66 adult daughter dementia carers experienced caregiver guilt.

Losada et al. (2010) developed the Caregiver Guilt Questionnaire (CGQ) to measure guilt in family dementia caregivers. They used this scale with 288 dementia caregivers living in Spain and reported that greater caregiver guilt was associated with more depressive symptoms, measured by the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). This finding was supported by Roach et al. (2013) who validated the CGQ with 221 British dementia caregivers. Martin et al. (2006), however, reported no association between caregiver guilt and depression in a sample of 70 dementia caregivers. Martin et al. (2006) used The Caring Shame and Guilt Scale, which has been criticised due to the lack of information regarding its development and validation and for using conditionally phrased statements, meaning that answers may reflect an imagined caring situation, rather than the carer’s actual situation (Losada et al., 2010).

It has been hypothesised that interventions targeting guilt, and specifically caregiver guilt, may reduce or prevent depression (Kim et al., 2011; Roach et al., 2013). This highlights a valuable area of research for supporting dementia caregivers who commonly experience caregiver guilt and depression (Collins & Kishita, 2020; Gonyea et al., 2008). Adopting a compassionate approach has been suggested as one way to buffer caregiver guilt (Gallego-Alberto et al., 2020; Losada et al., 2018; Owen & Dening, 2019). Guilt presents with issues of self-criticism with a negative self-appraisal for the carer (Prunty & Foli, 2019), whereas self-compassion encourages people to recognise difficult emotions, be sensitive to their distress and use more helpful strategies to manage this (Gilbert, 2005).

## Self-Compassion

Gilbert (2005) defines compassion from an evolutionary perspective, describing compassion as a trait that has evolved to promote caregiving qualities crucial for survival. Compassion can be described as “a sensitivity to suffering in self and others, with a commitment to prevent or alleviate it” (Gilbert, 2014, p.19). Gilbert (2009) proposes three types or ‘flows’ of compassion, as they are termed in this approach; compassion for others, compassion from other people, and self-compassion. This conceptualisation also describes three basic affect-regulation systems which are governed by an innate motivation for survival; 1) threat-self-protection system (helps one to identify and respond to threats), 2) drive-reward system (helps one to be motivated towards resources and achieving goals), and 3) soothing-affiliation system (helps one to have periods of rest and contentment when not in the threat or drive system).

The threat system can be activated by experiences of self-criticism and guilt, and this activation causes an imbalance in the three systems which has been linked to poor psychological wellbeing (Gilbert, 2013). Self-compassion is thought to facilitate emotional regulation by developing the soothing system, which balances out the three systems by preventing the over activation of the threat system (Gilbert 2013). Gilbert (2009) developed Compassion Focused Therapy (CFT), which helps individuals respond to self-critical thoughts with compassion, and consequently improve their wellbeing (Leaviss & Uttley, 2015). Therefore, self-compassion may prevent or reduce the activation of the threat system from self-criticism and guilt, consequently, the three systems remain balanced and this balance is linked to better wellbeing and a reduction in depression.

## Dementia Caregivers and Self-Compassion

In the general population, higher levels of self-compassion have been associated with lower levels of depression (MacBeth & Gumley, 2012). Self-compassion research with family caregivers is in its infancy (Murfield et al., 2020), however, Lloyd et al. (2019) studied self-compassion in dementia caregivers and reported that greater self-compassion was associated with more effective coping and less caregiver burden. In a sample of 55 carers of people with long-term conditions, including 11 dementia caregivers (20%), Hlabangana and Hearn (2020) reported that higher self-compassion was associated with better quality of life and lower levels of depression. Hlabangana and Hearn (2020) recruited a mixed sample of carers despite research suggesting carers have different experiences, depending on the diagnosis and needs of the care recipient (Pinquart & Sörensen, 2003; Schulz & Sherwood, 2008). Caring for an individual with dementia is thought to be particularly challenging, in comparison to caring for an individual who is physically frail, due to carers often having to provide more supervision and carers having to cope with the progressive cognitive decline and behavioural changes (Pinquart & Sörensen, 2003; Schulz & Sherwood, 2008). As such, further research is required to investigate if these findings are valid for dementia carers specifically.

## Self-Compassion and Caregiver Guilt

Self-compassion and caregiver guilt have not been investigated together in dementia caregivers. Research with parental caregivers of young children (Miller & Strachan, 2020; Sirois et al., 2019), however, suggests self-compassion may offer a positive way to cope with caregiver guilt, providing evidence for self-compassion as a buffer to caregiver guilt in a group of people who have caregiving responsibilities. In mothers of young children, Miller and Strachan (2020) reported that guilt mediated the relationship between self-compassion and engagement in personal health activities such as exercise and healthy eating. Specifically, as mothers’ levels of self-compassion increased, their guilt decreased, and in turn, lower levels of guilt were associated with increased engagement in health-related activities. Miller and Strachan (2020) linked this finding to self-compassionate individuals being less likely to over-identify with negative emotions and therefore able to overcome negative emotions, such as guilt. Additionally, Sirois et al. (2019) reported that parents who completed a self-compassionate exercise when recalling a challenging parenting event, reported higher self-compassion and less guilt compared to the control group who did not partake in the self-compassionate exercise.

Gallego-Alberto et al. (2019) delivered an intervention for caregiver guilt to four dementia carers based on self-compassion, Cognitive Behavioural Therapy, and Acceptance and Commitment Therapy. After the eight-week programme, three of the four participants reported reduced guilt. As this study only included one self-compassionate technique, self-compassion was not an outcome measure and only four carers participated, conclusions about the benefits of self-compassion should be interpreted with caution. Nevertheless, this preliminary evidence and the caregiver literature cited above suggests that higher levels of self-compassion may be associated with lower levels of caregiver guilt and self-compassion may help buffer guilt in caregiving populations.

## The Current Study

To summarise, higher levels of depressive symptoms have been associated with greater caregiver guilt in dementia carers (Losada et al., 2010; 2018; Roach et al., 2013), and lower levels of self-compassion in family caregivers (Hlabangana & Hearn, 2020). Being female and providing more daily hours of care have also been proposed as variables associated with higher levels of depressive symptoms (Collins & Kishita, 2020; Losada et al., 2018; Watson et al., 2019). Research has not previously investigated the variables of caregiver guilt, self-compassion, daily hours caregiving and gender together as predictors of depressive symptoms in dementia caregivers. Such research is vital given the levels of depression in dementia caregivers (Collins & Kishita, 2020).

Additionally, caregiver guilt and self-compassion have not been investigated together in dementia carers, however, parental caregiver research suggests self-compassion may buffer caregiver guilt (Miller & Strachan, 2020; Sirois et al., 2020). Furthermore, it is hypothesised that interventions targeting guilt may lead to a reduction in depression (Kim et al., 2011; Roach et al., 2013). Given this, and the theoretical understanding of self-compassion (Gilbert, 2013), it could be hypothesised that self-compassion may reduce depressive symptoms through a reduction in caregiver guilt. In other words, caregiver guilt may mediate the relationship between self-compassion and depressive symptoms. Such findings would support the use of self-compassion-based interventions for caregiver guilt and depression in dementia carers. Developing an understanding of the mechanisms behind caregiver depression is crucial to inform interventions given the growing number of dementia carers (Lewis et al., 2014), the levels of depression in this population, and the important role carers play in supporting people with dementia (Collins & Kishita, 2020).

## Aims and Hypotheses

This study aimed, firstly, to investigate whether self-compassion, caregiver guilt, hours spent caring per day and gender, predict depressive symptoms in family caregivers of people with dementia; and, secondly, to investigate whether caregiver guilt mediates the relationship between self-compassion and depressive symptoms in family dementia caregivers. The following hypotheses were tested:

1. Lower levels of self-compassion, higher levels of caregiver guilt, a higher number of hours per day spent providing care, and being female will predict higher levels of depressive symptoms.
2. Caregiver guilt will mediate the relationship between self-compassion and depressive symptoms.

# Method

## Design

Participants were recruited online and, when COVID-19 restrictions permitted, face to face, for a cross-sectional quantitative study exploring the relationship between self-compassion, caregiver guilt, hours per day spent providing care and depressive symptoms in informal dementia caregivers. Unfortunately, due to the disproportionately small number of male caregivers recruited for this study (5/84 participants), it was not possible to include gender in the analysis, as per the original hypothesis.

This study was reviewed and approved by Staffordshire University Ethics Committee (Appendix B). All participants provided informed consent before participating.

##

## Recruitment

To be eligible for the study, participants had to be aged 18 or over, currently provide care for a family member or partner with dementia, and the person with dementia must live at home (i.e., not in a nursing home). Individuals were asked to self-exclude if they were a paid or professional carer and/or were unable to understand written English, as there were no resources for translation. Caregivers who were friends or neighbours were not eligible to participate as one of the measures used (CGQ) was designed and validated for family caregivers, and many of the items refer to caring for ‘your relative’ (Losada et al., 2010). Additionally, more distant relations, such as friends or neighbours, may have a different caregiving experience (Covinsky et al., 2003).

Recruitment took place between March and November 2021. An online research advertisement (Appendix C) was posted on websites, e-bulletins and Facebook groups aimed at informal dementia carers, as well as on the researcher’s social media accounts (Facebook and Twitter). Sharing was enabled on the social media posts to allow people to share the advert, and hashtags, such as ‘#DementiaResearch’, were used to help the posts reach a wider audience. Participants were encouraged to share the research advert with people they knew who may also be interested in participating. The research advertisement and information sheet advised participants they could also request a paper participation pack from the researcher via email.

With permission from group facilitators, the study was also advertised in carer groups delivered by third sector and voluntary organisations, hosted online and in local face to face groups. Information about the study was shared with dementia caregivers by the group facilitators. Carers who expressed an interest in participating were given a paper participation pack, which included the study information, consent form, information on how to create a participant ID code (which was required if participants decided to withdraw their data after participating), questionnaires and a pre-stamped and addressed return envelope.

Online participants accessed the study using a URL link on the research advertisement. The study was hosted on Qualtrics (www.qualtrics.com). Participants were asked to read the information sheet (Appendix D) and, if they decided to proceed, complete the consent form. It was not possible to access the study without completing the consent form. Participants were informed that their data would be anonymised. Participants were provided with information on how to create a participant ID code. Participants then completed the demographic questions (Appendix E) and three questionnaires (Appendix F). After completing the study, participants were provided with debrief information (Appendix G).

## Participants

In total, 153 individuals accessed the participant information sheet via the study URL link. Of these, 33 (21.6%) did not progress past the information sheet and 41 (26.8%) began participating but withdrew before completion by closing their webpage and thus were not included in the analysis, as per the withdrawal information. The remaining 79 (51.6%) participants completed the study. A further five participants completed the study via the paper format. Thirty paper participation packs were sent to carers groups, but it is not possible to confirm if all 30 were handed out, and thus the response rate, as these were distributed by the group facilitators, rather than the researcher.

Eighty-four informal dementia caregivers aged 26-85 (*M* = 56.4, *SD* = 11.5) participated in this study. The majority of the sample were female (91.7%) and over half were living with the person they were caring for (61.9%). Most of the participants cared for a parent (60.7%) or spouse (27.4%), and the remainder (10.7%) selected the ‘other’ category and reported caring for a mother-in-law or grandparent. The majority of participants were caring for a relative with Vascular dementia (31%) or Alzheimer’s disease (26.2%). Participants had been providing care for an average of 46.4 months (*SD* = 33), which is approximately 3 years and 9 months. Caregivers provided on average 12.2 daily hours of care (*SD* = 8.1). Participant demographic data are presented in Table 1.

**Table 1**

*Sample Characteristics (n = 84).*

|  |  |  |
| --- | --- | --- |
| **Demographic Characteristic**  | **N (%)** | **M (SD) Range** |
| **Caregiver age (years)** |  | 56.6 (11.5) 26-85 |
| **Caregiver gender**FemaleMaleNon-binaryNot stated | 77 (91.7%)5 (6%)1 (1.2%)1 (1.2%) |  |
| **Relationship to the person with dementia**ChildSpouseOtherNot stated | 51 (60.7%)23 (27.4%)9 (10.7%)1 (1.2%) |  |
| **Daily hours caregiving** |  | 12.2 (8.1) 1-24 |
| **Length of time caring (in months)** |  | 46.4 (33) 4-206 |
| **Live with the person with dementia**YesNo | 52 (61.9%)32 (38.1%) |  |
| **Type of dementia**Vascular dementiaAlzheimer’s diseaseMixed dementiaLewy body dementiaType of dementia unknownFrontotemporal dementiaNot stated | 26 (31%)22 (26.2%)18 (21.4%)8 (9.5%)7 (8.3%)2 (2.4%)1 (1.2%) |  |

## Measures

### Demographic Information

Demographic information was collected using a questionnaire devised by the researcher (Appendix E). For the analysis, participants provided their gender and the average number of daily hours spent caregiving. In addition, demographic information was collected to describe the sample and facilitate comparison with other studies, including participants’ age, relationship to the care recipient, how long they had cared for them, if they live with the person they care for and the type of dementia the care recipient has.

### Depressive Symptoms

The Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) is a self-report 20-item questionnaire designed to measure depressive symptoms. This tool was selected as it is commonly used in dementia carer research (Collins & Kishita, 2020; Watson et al., 2019), and it does not contain an item explicitly using the term ‘guilt’. Measures containing the term ‘guilt’ may inflate the association between guilt and depressive symptoms (Kim et al., 2011). Respondents rate how frequently they have experienced particular feelings or behaviours over the past week. Example items include “I felt sad” and “My sleep was restless”. Each item is rated on a Likert scale, from 0 (rarely or none of the time [less than 1 day]) to 3 (most or all of the time [5-7 days]), with four items reverse scored. Scores range from 0 to 60, with a higher score representing higher levels of depressive symptoms.

The CES-D is validated for use with the general population where it has demonstrated good internal consistency (Cronbach’s α = .85; Radloff, 1977). This scale has also demonstrated good internal consistency (Cronbach’s α = .89) in a sample of 391 dementia caregivers (Adams, 2008). In the current study, internal consistency was excellent (Cronbach’s α = .94). The CES-D can be used free of charge without permission.

### ***Caregiver Guilt***

The Caregiver Guilt Questionnaire (CGQ; Losada et al., 2010) is a 22-item self-report questionnaire designed to measure caregiver guilt in family caregivers of an individual living in the community. Respondents rate how frequently they have experienced certain thoughts or feelings over the past two weeks. Example items include “I have thought that perhaps I’m not caring well for my relative” and “I have felt bad about having made some plan or done some activity without taking my relative into account”. Each item is rated on a Likert scale, from 0 (never) to 4 (always or almost always), with one item reverse scored. Scores range from 0 to 88, with a higher score representing higher levels of caregiver guilt. The CGQ was validated with a sample of 221 British dementia caregivers (Roach et al., 2013), demonstrating excellent internal consistency (Cronbach’s α = .93). In the current study, internal consistency was also excellent (Cronbach’s α = .93). This measure was used with permission from the author (Appendix H).

### Self-Compassion

The Compassionate Engagement and Action Scale (CEAS; Gilbert et al., 2017) comprises three self-report 13-item questionnaires designed to measure the three flows of compassion; self-compassion, compassion for others, and compassion from others. The scales can be used separately (Gilbert et al., 2017) and so the self-compassion scale was used alone, given this study is only investigating self-compassion. While other measures of self-compassion are available, including the Self-Compassion Scale (SCS; Neff, 2003) and the shortened version (SCS-SF; Raes et al., 2011), neither are validated with dementia carers or family caregiving populations. Furthermore, the SCS-SF demonstrated poor reliability when used with dementia caregivers (Lloyd et al., 2019). The CEAS has been validated with a sample of 171 family caregivers of older adults, including 62% dementia caregivers (Murfield et al., 2021), and demonstrated good internal consistency for the self-compassion scale (Cronbach’s α = .85). Internal consistency was also good in the current study (Cronbach’s α = .87). This measure was used with permission from the author (Appendix I).

Sample items from the CEAS self-compassion scale include “I think about and come up with helpful ways to cope with my distress” and “I am accepting, non-critical and non-judgemental of my feelings of distress”. The scale includes 10 positively phrased items and three negatively phrased items. The three negatively phased items are included in the scale to mitigate the impact of response bias but are excluded from scoring, as per Gilbert et al’s (2017) scoring instructions. Each item is rated on a Likert scale, from 1 (never) to 10 (always). Scores range from 10 to 100, with a higher score representing greater self-compassion.

## Power Analysis

A power calculation was used to determine the sample size for a multiple regression analysis using G\*power (Faul et al., 2009). Based on four predictor variables (self-compassion, caregiver guilt, gender, and hours spent caregiving), one criterion variable (depressive symptoms), a medium effect size (0.15), and power and alpha at the conventional 0.8 and 0.05 respectively, 84 participants were required. A medium effect size was chosen as it has been demonstrated in studies exploring the relationship between depressive symptoms and caregiver guilt (*r* = .46; Losada et al., 2010), and depressive symptoms and self-compassion (*r* = .52; MacBeth & Gumley, 2012).

## Data Analysis

The online responses were transferred from Qualtrics to SPSS and the paper responses were inputted manually. Statistical analysis was carried out using IBM SPSS Statistics (Version 28).

### Data Screening

Of the 84 participants, six (7.1%) had missing analysis data. In total, 0.4% of individual analysis data items were missing. One participant had excessive amounts of missing data (missing 26.8% of the analysis data, including 59.1% of the CGQ), and was therefore removed from the data set (Hair et al., 2010). Five other participants missed one or two questionnaire items, accounting for 1.8%-3.6% of their data, resulting in four questionnaire items having 1.2%-2.4% missing data. Little’s test (Little, 1988) indicated the data was Missing Completely at Random (MCAR), demonstrated by the non-significant result (Chi-Square = 367.93, DF = 365, *p* = .447). Given this, and the relatively small amount of missing data, participant mean substitution was used to manage the missing data (Bono et al., 2007). The analysis results in this report are from the imputed data set (*n* = 83). For comparison, the analysis was also performed on the original data set using a complete case approach (Hair et al., 2010) with the 78 participants who had complete analysis data (Appendix J). The analysis results were similar for both missing data strategies.

###  Statistical Assumptions

Data checks were conducted to check if the data significantly violated the assumptions for a multiple regression analysis, including absence of outliers, normality, linearity, homoscedasticity and absence of multicollinearity, and independence of residuals (Field, 2017). Hours per day caregiving was the only variable to violate these checks, showing a violation to normality, suggesting the distribution differed significantly from a normal distribution (Appendix K). Bootstrapping was used to address this violation and is reported in the regression model where daily hours caregiving is included (Field, 2017). Bootstrapping is a robust re-sampling method that can be used when the sample differs from normality as it does not assume normality, instead it estimates the properties of the sampling distribution using the study data (Field, 2017). When assessing the assumption of linearity, advice from a statistician was followed to use binning on the scatterplot for depressive symptoms and hours per day caregiving to help assess this relationship. A weak positive correlation was identified, meaning the assumption of linearity was not violated and thus this variable was included in the regression model.

### Method of Analysis

Correlations between the study variables were assessed as part of the regression and mediation analysis. A multiple regression analysis with bootstrapping was carried out to explore the relationship between the independent variables (self-compassion, caregiver guilt, and daily hours caregiving) and the criterion variable (depressive symptoms). PROCESS version 4.0 for SPSS (Hayes, 2018) was used to conduct a mediation analysis to investigate the direct effect of self-compassion on depressive symptoms and the indirect effect of self-compassion on depressive symptoms through caregiver guilt.

# Results

## Descriptive Statistics

The mean, standard deviation and range for the variables of depressive symptoms, caregiver guilt, self-compassion and daily hours caregiving are presented in Table 2.

**Table 2**

*Descriptive statistics for the analysis variables (n = 83).*

|  |  |  |  |
| --- | --- | --- | --- |
|  | **M** | **SD** | **Range** |
| **Depressive Symptoms (CES-D)** | 28.3 | 14.5 | 1-59 |
| **Caregiver Guilt (CGQ)** | 46.3 | 17.9 | 5-81 |
| **Self-Compassion (CEAS)** | 59.7 | 16.2 | 22-97 |
| **Daily hours caregiving** | 12.3 | 8.1 | 1-24 |

## Correlations

The correlations between the study variables are presented in Table 3. A significant strong positive correlation was found between depressive symptoms and caregiver guilt, with higher levels of depressive symptoms associated with higher levels of caregiver guilt (*r* = .7, *p* < .001). In addition, carers who reported higher levels of self-compassion reported lower levels of caregiver guilt (*r* = -.46, *p* < .001). A significant moderate negative correlation was found between depressive symptoms and self-compassion, with greater levels of self-compassion associated with lower levels of depressive symptoms (*r* = -.56, *p* < .001). A weak but significant correlation was found between hours per day caring and depressive symptoms (*r* = .21, *p* = .03).

**Table 3**

*Pearson’s r correlations for the study variables (n = 83).*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Variable** | **1** | **2** | **3** | **4** |
| 1. **Depressive Symptoms (CES-D)**
 | - |  |  |  |
| 1. **Caregiver Guilt (CGQ)**
 | .7\*\*\* | - |  |  |
| 1. **Self-Compassion (CEAS)**
 | -.56\*\*\* | -.46\*\*\* | - |  |
| 1. **Daily hours caregiving**
 | .21\* | .14 | -.12 | - |

*Note.* \**p* < .05; \*\**p* < .01; \*\*\**p* < .001.

## Multiple Regression Analysis

A multiple regression analysis was conducted with self-compassion, caregiver guilt and daily hours caregiving as predictor variables, and depressive symptoms as the criterion variable (Table 4; Appendix L). All predictors were entered into the model at the same time.

The regression model was significant (*F* (3,79) = 34.43, *p* < .001), accounting for 56.7% of the total variance in depressive symptoms (55% when adjusted). The hypothesis was partially met, as caregiver guilt (β = 0.54, *p* < .001) and self-compassion (β = -0.3, *p* < .001) were significant predictors of depressive symptoms, however, daily hours caregiving was not a significant predictor (β = 0.1, *p* = .2). Due to the violation to normality in the daily hours caregiving predictor, the model was rerun using Bootstrapping (Table 4; Appendix L). The bootstrapped confidence intervals were similar to those in the original model, suggesting that the degree of violation was not too significant for the model. These findings also indicate that daily hours caregiving is not a significant predictor of depressive symptoms.

**Table 4**

*Multiple regression analysis of self-compassion, caregiver guilt and daily hours caregiving as predictors of depressive symptoms, with and without bootstrapping (n = 83).*

|  |  |  |
| --- | --- | --- |
|  | **Multiple Regression** | **Bootstrapping** |
|  | **B** | **SE B** | **β** | **Sig.** | **95% CI** | **Bias** | **SE B** | **Sig.** | **95% BCa CI** |
| **Lower** | **Upper** | **Lower** | **Upper** |
| **Constant**  | 21.8 | 6.77 |  | .002 | 8.34 | 35.28 | 0.14 | 7.66 | .009 | 6.04 | 37.81 |
| **Caregiver Guilt (CGQ)** | 0.44 | 0.07 | 0.54 | <.001 | 0.31 | 0.58 | -0.001 | 0.07 | <.001 | 0.31 | 0.56 |
| **Self-Compassion (CEAS)** | -0.27 | 0.07 | -0.3 | <.001 | -0.42 | -0.12 | -0.002 | 0.09 | .005 | -0.44 | -0.1 |
| **Daily hours caregiving** | 0.17 | 0.13 | 0.1 | 0.2 | -0.1 | 0.44 | 0.004 | 0.12 | .16 | -0.07 | 0.42 |

*Note.* *R2* = 56.7%; Adjusted *R2* = 55%. Unstandardised coefficient, standard error, standardised coefficient, significance values and confidence intervals are presented, along with the bootstrapped comparison including bias-corrected accelerated confidence intervals. Bootstrap results are based on 1000 bootstrapped samples.

To improve the precision of the model, the analysis was rerun with only the significant predictors (self-compassion and caregiver guilt). This model was significant (*F* (2,80) = 50.42, *p* < .001), explaining 55.8% of the variance in depressive symptoms (54.7% when adjusted). Both self-compassion (β = -0.31, *p* < .001) and caregiver guilt (β = 0.55, *p* < .001) remained significant predictors of depressive symptoms, with caregiver guilt the strongest predictor (Table 5; Appendix L).

**Table 5**

*Multiple regression model for self-compassion and caregiver guilt as predictors of depressive symptoms (n = 83).*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **B** | **SE B** | **β** | **Sig.** | **95% CI** |
| **Lower** | **Upper** |
| **Constant** | 23.91 | 6.59 |  | <.001 | 10.8 | 37.03 |
| **Caregiver Guilt (CGQ)** | 0.45 | 0.07 | 0.55 | <.001 | 0.31 | 0.58 |
| **Self-Compassion (CEAS)** | -0.28 | 0.07 | -0.31 | <.001 | -0.42 | -0.13 |

*Note.* *R2* = 55.8%; Adjusted *R2* = 54.7%. Unstandardised coefficient, standard error, standardised coefficient, significance values and confidence intervals are presented.

## Mediation Analysis

A mediation analysis was used to test the direct effect of self-compassion on depressive symptoms and the indirect effect of self-compassion on depressive symptoms through caregiver guilt. PROCESS (Hayes, 2018) was used to test the mediation model with 5000 bootstrap samples and 95% percentile bootstrap confidence intervals. A significant mediation effect is indicated when the confidence interval does not contain a zero (Hayes, 2018). As shown in Figure 1, carers with greater levels of self-compassion reported lower levels of caregiver guilt (*a* = -0.5), and caregivers who had lower levels of caregiver guilt reported lower levels of depressive symptoms (*b* = 0.45). The bootstrap 95% confidence interval for the indirect effect (*ab* = -0.23) did not contain zero [-0.33, -0.14], indicating there was evidence of an indirect effect of self-compassion on depressive symptoms through caregiver guilt (Table 6; Appendix M). This supports the hypothesis that caregiver guilt mediates the relationship between self-compassion and depressive symptoms in dementia caregivers.

**Figure 1**

*A mediation model showing the relationships between self-compassion, caregiver guilt and depressive symptoms (n = 83).*

*a* = -0.5

*b* = 0.45

*c’* = -0.27

Depressive Symptoms

Caregiver Guilt

Self-Compassion

*Note.* Values on the arrows represented the unstandardised coefficients.

**Table 6**

*The total, direct and indirect effects in the model, with the predictor (self-compassion), mediator (caregiver guilt) and outcome variable (depressive symptoms) (n = 83).*

|  |  |  |  |
| --- | --- | --- | --- |
|  | **B** | **SE** | **95% CI** |
|  |  |  | **Lower** | **Upper** |
| **Total Effect** | -0.5 | 0.08 | -0.66 | -0.34 |
| **Direct Effect** | -0.27 | 0.07 | -0.42 | -0.13 |
| **Indirect Effect** | -0.23 | 0.05 | -0.33 | -0.14 |

*Note*. This table presents the unstandardised coefficients, standard errors and 95% percentile bootstrapped confidence intervals.

# Discussion

This study aimed to investigate the relationship between self-compassion, caregiver guilt, daily hours caregiving, gender, and depressive symptoms in dementia caregivers. The results of the two hypotheses will be discussed in turn.

The first hypothesis, that lower levels of self-compassion, higher levels of caregiver guilt, a higher number of daily hours providing care and being female will predict higher levels of depressive symptoms, was partially supported. The results indicated that lower levels of self-compassion and greater levels of caregiver guilt significantly predicted higher levels of depressive symptoms in dementia caregivers. The number of daily hours spent caregiving was, however, not a significant predictor. Furthermore, as stated previously, it was not possible to include gender in this analysis.

Caregiver guilt was the strongest predictor of depressive symptoms. Previous studies have found significant positive correlations between caregiver guilt and depressive symptoms; however, this study takes this relationship a step further, investigating the predictive nature of the relationship. This study identified a much higher correlation between depressive symptoms and caregiver guilt (*r* = .7) than research with dementia caregivers in Spain (*r* = .46, Losada et al., 2010) despite using the same measures for both variables. Furthermore, the current sample also had higher mean scores on the CES-D and CGQ than previous research with dementia carers in the UK (Roach et al., 2013) and Spain (Losada et al., 2010; 2018).

The COVID-19 pandemic is likely to have influenced the current findings, given the recruitment timeframe. COVID-19 has been linked to an increase in depressive symptoms in dementia caregivers (Altieri & Santangelo, 2021), which may be due to challenges such as fear or guilt related to spreading COVID-19 to the care recipient (Cohen et al., 2020; Ercoli et al., 2021), distress associated with giving up caregiving due to having COVID-19 (Losada et al., 2022), disrupted routines and lack of structure (Greenberg et al., 2020). Furthermore, the COVID-19 public health restrictions caused temporary closures of respite and day centres and reduced caregivers’ contact with friends and family for social support and help caregiving (Greenberg et al., 2021), consequently increasing caregiver anxiety and depression (Giebel et al., 2021; Hanna et al., 2021). Given these serious implications, the context of COVID-19 needs to be considered and offers an explanation for the higher levels of depressive symptoms and caregiver guilt in this sample compared with previous studies.

Another potential explanation for the higher levels of depressive symptoms may be that most of the current sample were females, and previous reviews indicate that female dementia caregivers experience higher levels of depression (Collins & Kishita, 2020; Watson et al., 2019). Previous research suggests lower levels of depression in male carers may possibly be due to male carers being less willing to report experiences of depression and potentially receiving support caregiving from female family members (Mc Donnell & Ryan, 2011; Pillemer et al., 2018). While other studies have also tended to recruit a mostly female sample, this study recruited over 90% females, compared to 65-79% in similar studies (Losada et al., 2010; 2018; Roach et al., 2013).

Self-compassion was also identified as a significant predictor of depressive symptoms. This finding is in keeping with research findings from a mixed sample of caregivers (Hlabangana & Hearn, 2020), however, as the current study recruited only dementia caregivers, it allows for greater confidence in generalising the results to dementia carers specifically who face unique caregiving challenges (Schulz & Sherwood, 2008). This finding also supports a broader body of evidence, not specific to dementia caregivers, which indicates that greater self-compassion is associated with lower levels of depressive symptoms in the general population (Macbeth & Gumley, 2012).

The number of daily hours spent providing care was not a significant predictor of, and only had a weak correlation with, depressive symptoms. It is important to note that daily hours caregiving was not normally distributed which may have impacted the results. In the current study, 23% of participants reported providing care 24 hours per day. This is similar to Roach et al’s (2013) UK based study, where approximately 26% of the sample reported spending 24 hours per day caregiving.

Previous research with dementia carers has identified a predictive or correlated relationship between greater daily hours caregiving and higher levels of depressive symptoms (Covinsky et al., 2003; Jiménez-Gonzalo et al., 2020; Losada et al., 2018). In contrast, Bednarek et al. (2016) did not identify a correlation between these two variables in dementia carers. The current study and Bednarek et al’s (2016) study both recruited relatively small sample sizes compared to the studies that found a stronger relationship between these variables, suggesting perhaps the current sample was too small to identify the extent of the relationship.

The second hypothesis, that caregiver guilt will mediate the relationship between self-compassion and depressive symptoms, was supported by the results. The findings indicate that dementia carers with higher levels of self-compassion, have lower levels of caregiver guilt, and, in turn, this reduction in caregiver guilt is associated with lower levels of depressive symptoms. Caregiver guilt, therefore, may be a potential mechanism through which self-compassion influences depressive symptoms in dementia caregivers. Mediation analysis requires theoretical evidence to guide the order of the variables and it could be argued that Gilbert’s (2013) theoretical understanding of self-compassion can be applied to this relationship. Gilbert’s (2013) theoretical conceptualisation suggests that self-compassion may help to reduce the activation of the threat system, which may be caused by self-critical thoughts related to guilt, and consequently reduce depressive symptoms.

As part of the mediation analysis, the relationship between self-compassion and caregiver guilt was assessed, indicating lower levels of self-compassion are significantly correlated with higher levels of caregiver guilt. This is the first study to explore the relationship between self-compassion and caregiver guilt in dementia caregivers. This finding is in keeping with results from other caregiver populations, for example, parental caregivers (Miller & Stratchen, 2020; Sirois et al., 2019), and with the theoretical understanding that self-compassion may help to combat self-critical thoughts associated with guilt (Gilbert, 2013).

## Limitations

While the majority of dementia caregivers are female, with reports suggesting 60-70% of dementia caregivers are female (Alzheimer’s Research UK, 2015), this study had a particularly large response from female carers (91.7%). The findings and conclusions from this study may, therefore, be less relevant to caregivers who are not female. This is particularly important to consider in a study investigating depressive symptoms, as research suggests female carers are more likely to experience depression than male carers (Collins & Kishita, 2020; Watson et al., 2019) and thus this may have impacted the reported levels of depressive symptoms. A further limitation of not recruiting more male or non-binary carers is that it was not possible to compare differences between different gender groups. It is unknown whether only or mostly female carers attended the groups and social media sites where the current study was advertised, or if males and/or non-binary carers also attended but choose not to participate.

While efforts were made to recruit participants face to face as well as via the internet, most participants were recruited online (94%), due to restrictions and issues recruiting face to face during the pandemic. Given this, the sample may not be representative of caregivers without access to the internet. Furthermore, this research was predominantly advertised in carer support groups, both online and face to face. This is common in caregiver research but raises concerns about the generalisability of the findings to carers who are not part of a carer group (Beeson et al., 2000).

This study recruited the sample size required to detect a medium sized effect in a regression model with four predictors. The number of participants in the analysis was less than this due to one participant having an excessive amount of missing analysis data. As one less predictor (gender) was included in the regression, the study was still sufficiently powered. The missing data was minimal and addressed using two methods to allow for a comparison of the results and to overcome any potential issues with each method. The violation to normality for daily hours caregiving means the results for this variable should be interpreted with caution. This concern is alleviated somewhat as the bootstrapped comparison analysis produced similar results (Field, 2017).

## Clinical Implications

While there is little experimental research investigating compassionate-based interventions for caregivers (Murfield et al., 2021; 2022) and specifically caregiver guilt (Gallego-Alberto et al., 2019), several studies have suggested this may be a useful approach to explore (Gallego-Alberto et al., 2020; Losada et al., 2018; Owen & Dening, 2019). The current study provides further evidence in support of this notion. As caregiver guilt is understood to be linked to carers’ negative appraisal of their ability (Prunty & Foli, 2019), such interventions may focus on promoting self-compassionate judgement and reducing self-criticism. Furthermore, this study provides preliminary evidence to support the use of self-compassion interventions for low mood in dementia carers and the mediation analysis suggests a potential pathway through which self-compassion may reduce depressive symptoms, via a reduction in caregiver guilt.

Compassion Focused Therapy (Gilbert, 2009) could be considered a promising intervention to help individuals respond to threats, such as self-criticism experienced in caregiver guilt, with compassion and kindness by developing their soothing system (Leaviss & Uttley, 2015), consequently reducing depression. This could be achieved by first encouraging identification of threats, such as self-criticism and guilt (Gilbert et al., 2017), followed by developing compassionate mind skills to help alleviate suffering, for example, mindfulness, breathing techniques, imagery and compassionate memory (Irons & Heriot-Maitland, 2020).

The application of these findings should be tentative, and consideration should be given to potential barriers, for example, the acceptability of compassion-based interventions for caregivers. Self-compassion has been perceived as overindulgent or self-pity by some dementia carers in previous studies (Lacey et al., 2017; Murfield et al., 2022), therefore, it is important to ensure an understanding of the concept of self-compassion. As stated by Murfield et al. (2022), a self-compassion-based intervention for dementia caregivers should cover compassion more broadly and consider fears, blocks and resistances to self-compassion, such as in CFT (Gilbert, 2014).

As well as clinical intervention, these findings may contribute to the assessment of caregiver distress, for example, low levels of caregiver self-compassion may act as a useful indicator for greater levels of caregiver guilt and depressive symptoms. The findings also indicate that depressive symptoms and caregiver guilt are highly correlated, and so may present together; therefore, if one of these is highlighted as an area of concern, it would be useful to explore the other to guide intervention appropriately. In addition, other potentially related constructs should also be considered in assessment, for example, stress and mental health more broadly, as well as caregiver burden which has been linked to self-compassion (Lloyd et al., 2019).

## Future Research

While this study proposes potential relationships between self-compassion, depressive symptoms and caregiver guilt, future research should explore these relationships in longitudinal and/or experimental studies to better understand the relationships, particularly the mediating role of caregiver guilt. This is important as the current study is limited by the cross-sectional and correlational design and, therefore, the relationships identified in this study cannot be assumed to be causal. A longitudinal study, for example, may measure these variables over time, providing an understanding of the development of caregiver guilt and depressive symptoms and if one tends to be experienced before the other as well as any other variables associated with these.

The current study suggests that self-compassionate interventions may be useful for dementia carers and thus further research should be considered in this area. An important step in moving towards appropriate interventions would be to consider the suitability of such intervention for caregivers. Murfield et al. (2022) began this work using a co-design approach, meaning that family dementia carers were directly involved in the intervention design, to start developing a self-compassion intervention for family dementia carers. Murfield et al. (2022) indicated that self-compassion focused interventions can target feelings of guilt, shame and self-criticism. Further research in intervention development may involve a comparison study to compare levels of depression and guilt before and after a self-compassion intervention, with a qualitative element alongside this to explore the experience and acceptability of the intervention for caregivers.

It is important to acknowledge there may be confounders as well as other mediators that explain the relationship in the current study. Future research would benefit from exploring other potentially related variables. Recent studies have highlighted a relationship between caregiver guilt, depressive symptoms and ambivalent feelings (Losada et al., 2018). Ambivalent feelings in the caregiving context are described as simultaneously experiencing positive and negative feelings towards the care recipient (Losada et al., 2018). While self-compassion was not explored in that study, it was recommended that self-compassion interventions may be useful to reduce feelings of guilt and ambivalence. Furthermore, considering that greater self-compassion is associated with lower levels of depressive symptoms and caregiver guilt, and lower levels of caregiver burden in previous research (Lloyd et al., 2019), future research could investigate if greater self-compassion is linked to other variables in caregivers such as stress and anxiety. Future research may also consider investigating the relationship with the other flows of compassion; compassion for others and from others. It was not possible to include additional variables in this study due to an attempt to minimise the burden on participants.

Recruitment issues reduce the generalisability of the current study’s findings to male and non-binary caregivers, caregivers without access to the internet and carers not accessing support services or groups. Future research may benefit from targeting these groups and investigating if the current findings are similar for those populations, to help guide interventions more specifically. Recruiting in face to face settings allows participants without access to the internet to be more easily recruited. Consultation with male caregivers may guide how male carers could be recruited, aside from targeting caregiver groups for male carers. Advertisements in GP surgeries and through other forms of media such as radio adverts may help to target caregivers from settings other than support groups.

The measures used in this study have all been used previously with dementia caregivers or at least family caregivers (including some dementia carers) and all demonstrated good reliability in the current study and, therefore, could be used with confidence in future dementia caregiver studies.

## Conclusion

This study has added to the limited evidence base of self-compassion research with dementia caregivers. It has provided preliminary evidence for self-compassion and caregiver guilt as significant predictors of depressive symptoms, and for the association between greater levels of self-compassion and lower levels of caregiver guilt. Furthermore, caregiver guilt has been proposed as a potential mediator in the self-compassion and depressive symptoms relationship. This offers an explanation of one way in which self-compassion may reduce depressive symptoms, through caregiver guilt. These findings are important as they provide an understanding of the predictors and mechanisms behind depressive symptoms for dementia caregivers (Collins & Kishita, 2020). More research is needed to further understand the relationship between these variables and influence the development of interventions for this client group.

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# Appendix A

# Journal Guidelines

Please refer to the Dementia Journal webpage for the author submission guidelines:

<https://journals.sagepub.com/author-instructions/DEM>

* Referencing style APA 7th edition is used in the current paper, as per the journal guidelines
* The word count for the current paper will be reduced prior to submission to the journal, as the journal word limit is 5,000 to 6,000

# Appendix B

**Ethical Approval from Staffordshire University**

# Appendix C

**Research Advertisement**



# Appendix D

**Participant Information Sheet**

**Title of Project:** The Relationship between Self-Compassion, Caregiver Guilt and Depressive Symptoms in Family Caregivers of People with Dementia.

**Name of Researcher:**Rebecca Wallace

**Ethics Approval:** This project was granted ethical approval by the Ethics Committee at Staffordshire University on [DATE]

Dear Carer,

I am Rebecca Wallace, a Trainee Clinical Psychologist studying for a Doctorate in Clinical Psychology at Staffordshire University. I would like to invite you to participate in this study as part of my research project for this qualification. Before you decide whether you want to take part, it is important for you to understand why I am carrying out this research and what taking part would involve for you. Please take your time to read the following information carefully and discuss it with others if you wish. If there is anything that is unclear or if you would like more information, please do not hesitate to contact me on the contact details at the end of this information sheet.

**What is the background and purpose of the study?**
Caring for a family member or partner with dementia can be both a challenging and rewarding experience. Sometimes carers may experience difficult feelings such as guilt in relation to their caring role. An example of this may be feeling guilty for leaving the person they care for in the care of someone else while they do another task such as attending an appointment or going shopping. Carers may also feel guilty for not being able to devote more time to their other family members or friends. Feelings of guilt can sometimes be related to low mood. We would like to learn more about how carers manage these feelings. Previous research has shown that being self-compassionate, defined as being kind to yourself, can affect how people experience difficult feelings. We are interested in investigating whether being self-compassionate affects how dementia caregivers manage feelings of guilt and low mood. The information gathered in this research project will help us to better understand the experience of caregivers and will hopefully be used to develop ways that carers can be supported.

**Who can take part in this study?**
If you meet the following inclusion and exclusion criteria then you are eligible to take part. You must be aged 18 or over and currently provide care for a family member or partner with dementia who lives at home. You are not eligible to participate if you are unable to read English, as the questionnaires are written in English. If you are a paid or professional carer then you are also not eligible to participate.

**What will happen if I take part?**
If you decide to take part, you will be asked to complete three questionnaires; you can complete these either online or you can request to be sent paper copies of the questionnaires by post. If you would like to participate using the paper format, please contact me using the details at the end of this information sheet and I will post all the necessary materials to your address (including a pre-stamped addressed envelope to return your consent form and questionnaires).
If you would like to participate online, then you can click ‘continue’ at the end of this page which will take you to a consent form. You will need to complete this consent form to proceed with the study. You will then be asked to create a participant ID code which you will need to quote if you decide to withdraw your data after taking part. Following this, you will be asked to complete a few questions about yourself and the person you care for, such as your age, gender and how long you have cared for the person with dementia.
After completing this section, you will be asked to complete three questionnaires. In the first questionnaire, you will be asked to rate how frequently you have experienced thoughts and feelings of guilt in the last few weeks. For each statement, you will be asked to rate the frequency on a scale from “never” to “always or almost always”. The second questionnaire asks about how you feel about yourself when things are difficult. You will be asked to rate on a scale how much each statement relates to you in times when you feel distressed, from “never” to “always". The last questionnaire contains statements designed to measure feelings and behaviours related to depression. You will be asked to rate how frequently you have experienced these in the past week. It will take approximately 15 minutes in total to complete these three questionnaires.

**Do I have to take part?**
No. Participation is completely voluntary, and you should only take part if you want to. Once you have read this information sheet, please contact me if you have any questions that will help you make a decision about taking part.

**What are the possible disadvantages or risks of taking part?**
Some people may feel distressed when asked to think about a loved one who has dementia, particularly about possible feelings of guilt they may experience in relation to their caregiving role. If you do feel any discomfort or distress in any way whilst taking part in this study, you can end your participation at any point by closing the webpage. If you do feel distressed, there are support services listed at the end of this sheet that you can contact if you feel you need further support.

**What are the possible benefits of taking part?**
Whilst this study does not have any immediate benefit for you, the information gathered from this study may help to improve understanding of how carers manage feelings of guilt related to caregiving. These results will add to the research in this area and could be used to inform the ways we support carers of people with dementia.

**How will my data be handled, and will it be kept confidential?**
Your data will be processed in accordance with the data protection law and will comply with the General Data Protection Regulation 2016 (GDPR). All of the information collected from you during this research will be kept strictly confidential. Your responses to the questionnaires and your background information will be anonymised, so no one can link the data you have provided to you. Your data will be held electronically on a password-protected document to ensure security. The researcher and members of the research team will have access to the anonymised data gathered in this study. Research completed at Staffordshire University is auditable and therefore the University may require access to the data for audit purposes. After the study has been completed all raw data will be stored in a locked cabinet in archives at Staffordshire University for 10 years, after which time it will be destroyed.

**Data Protection Statement**
Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). The data controller for this project will be Staffordshire University. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a ‘task in the public interest’. You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the Staffordshire University Data Protection Officer. If you wish to lodge a complaint with the Information Commissioner’s Office, please visit [ww.ico.org.uk](http://www.ico.org.uk/)

**What if I change my mind about taking part?**
If you change your mind about taking part during the study, you can end your participation at any point by closing the webpage. After completing the study, you can withdraw your data within two weeks of taking part. You can withdraw your data by contacting the researcher on the email address provided at the end of this document. You will need to quote your participant ID code which you will create after completing the consent form (guidance will be given on how to do this). You do not need to give a reason for withdrawing your data. Withdrawing from the study will not affect you in any way. If you choose to withdraw from the study, we will not retain any information that you have provided to us as a part of this study.

**What will happen to the results of the study?**
The results of this study will be written up as part of a thesis for a Doctorate in Clinical Psychology. This research will also be written up into a report and submitted for publication to a relevant academic journal. You will not be identified in any report or publication.

If you would like to hear about the final results of this study, you can contact the researcher on the email address provided at the end of this document to request a copy of the Executive Summary. This will provide an overview of the research and you can request this in paper or electronic format. It is expected that the Executive Summary will be available by September 2022.

**Who should I contact for further information?**
If you have any questions or require more information about this study, please contact me, the researcher, and I will be happy to answer your questions. Alternatively, you could contact one of my supervisors, details below, who are overseeing this research project.

**Researcher:** Rebecca Wallace, Trainee Clinical Psychologist, [UNIVERSITY ADDRESS, EMAIL ADDRESS]
**Academic Research Supervisor**: [NAME, UNIVERSITY ADDRESS, EMAIL ADDRESS]
**Clinical Research Supervisor**: [NAME, ADDRESS, EMAIL ADDRESS]

**What if I have further questions, or if something goes wrong?**
If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study, you can contact one of my study supervisors (contact details listed above) or the Chair of the [UNIVERSITY] Ethics Committee for further advice and information: [NAME, TELEPHONE, EMAIL ADDRESS]

**Information and Support Services**
If you want to talk about any concerns or worries then you can contact one of the support services listed below. Alternatively, you may wish to seek support through your GP.

**The Samaritans**are a free telephone service which you can use if you want to speak to someone about any concerns or worries that you have. The telephone service is open 24 hours a day, 365 days a year. You can also contact them by email or take a look at their website.

* **Telephone:** 116 123
* **Email:** jo@samaritans.org
* **Website:** https://www.samaritans.org/

**The Alzheimer’s Society**offers a Dementia Connect support line where a dementia adviser will listen to you and provide advice and support. Calls are charged at standard local rate. They also have a website which has lots of helpful information and factsheets on different dementia related topics.

* **Telephone:** 0333 150 3456
* **Helpline opening hours:**Monday to Wednesday: 9am – 8pm, Thursday and Friday: 9am – 5pm, Saturday and Sunday: 10am – 4pm
* **Website:**  https://www.alzheimers.org.uk/

**Carers UK**provide a helpline for people who look after a friend or family member. They can provide information and guidance on a range of topics related to caring.

* **Telephone:** 0808 808 7777
* **Helpline opening hours:**Monday – Friday: 9am – 6pm
* **Email address:** advice@carersuk.org
* **Website:**https://www.carersuk.org/help-and-advice/talk-to-us

**Thank you for taking the time to read this information sheet and for considering taking part in this research.**

# Appendix E

**Demographic Questionnaire**

Please answer the following demographic questions by writing a response in the space allocated or tick one of the multiple-choice responses where applicable.

Information about you

**What is your gender?**

* + Female
	+ Male
	+ Non-binary

**What is your age? (in years)**

Information about the person you care for and your caring role

**What is your relationship to the person with dementia that you care for?**

* Spouse
* Child
* Other (please state) \_\_\_\_\_\_\_\_\_\_\_

**What type of dementia does the person you care for have?**

* Alzheimer’s disease
* Vascular dementia
* Mixed Dementia
* Lewy Body dementia
* Other type of dementia (please state) \_\_\_\_\_\_\_\_\_\_\_\_\_
* Dementia – type unknown

**How long have you cared for the person with dementia? (in months or years)**

Please state if your answer is in months and / or years

For example, “6 months” or “1 year and 2 months” or “2 years”

**Do you live with the person you care for?**

* + Yes
	+ No

**On average, how many hours do spend caring each day? (in hours)**

# Appendix F

**Measures**

**Center for Epidemiologic Studies Depression Scale (CES-D)**

 Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

1. I was bothered by things that usually don’t bother me.
2. I did not feel like eating; my appetite was poor.
3. I felt that I could not shake off the blues even with help from my family or friends.
4. I felt I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
14. I felt lonely.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people dislike me.
20. I could not get “going.

*Note.* Response options for each question were: Rarely or none of the time (less than 1 day), Some or a little of the time (1-2 days), Occasionally or a moderate amount of time (3-4 days), Most or all of the time (5-7 days).

**The Compassionate Engagement and Action Scales**

**Self-Compassion Questionnaire**

When things go wrong for us and we become distressed by setbacks, failures, disappointments or losses, we may cope with these in different ways. We are interested in the degree to which people can be compassionate with themselves. We define compassion as “a sensitivity to suffering in self and others with a commitment to try to alleviate and prevent it.” This means there are two aspects to compassion. The first is the ability to be motivated to engage with things/feelings that are difficult as opposed to trying to avoid or supress them. The second aspect of compassion is the ability to focus on what is helpful to us. Just like a doctor with his/her patient. The first is to be motivated and able to pay attention to the pain and (learn how to) make sense of it. The second is to be able to take the action that will be helpful. Below is a series of questions that ask you about these two aspects of compassion. Therefore read each statement carefully and think about how it applies to you if you become distressed. Please rate the items using the following rating scale:

Never Always

1 2 3 4 5 6 7 8 9 10

**Section 1 – These are questions that ask you about how motivated you are, and able to engage with distress when you experience it. So:**

When I’m distressed or upset by things…

1. I am motivated to engage and work with my distress when it arises.
2. I notice, and am sensitive to my distressed feelings when they arise in me.
3. I avoid thinking about my distress and try to distract myself and put it out of my mind.
4. I am emotionally moved by my distressed feelings or situations.
5. I tolerate the various feelings that are part of my distress.
6. I reflect on and make sense of my feelings of distress.
7. I do not tolerate being distressed.
8. I am accepting, non-critical and non-judgemental of my feelings of distress.

**Section 2 – These questions relate to how you actively cope in compassionate ways with emotions, thoughts and situations that distress you. So**:

When I’m distressed or upset by things…

1. I direct my attention to what is likely to be helpful to me.
2. I think about and come up with helpful ways to cope with my distress.
3. I don’t know how to help myself.
4. I take the actions and do the things that will be helpful to me.
5. I create inner feelings of support, helpfulness and encouragement.

*Note.* Responses options of 1 (Never) – 10 (Always) were presented for each individual item.

**Caregiver Guilt Questionnaire**

 Below is a list of some feelings and thoughts. Please tell us how often you have had these feelings and thoughts during the past few weeks using the following options:

0 = never; 1 = rarely; 2 = sometimes; 3 = several times; 4 = always or almost always

1. I have felt bad about having made some plan or done some activity without taking my relative into account
2. I have felt guilty about the way I’ve sometimes behaved with my relative
3. I have felt bad for not looking after my other relatives (husband, wife, children ...) as I should, due to my caregiving
4. I have felt bad about not being able to devote more time to my family (husband, wife, children...), due to my caregiving
5. I have thought that I’m not doing things right with the person I’m caring for
6. I have thought that, given the circumstances, I’m doing a good job as a caregiver
7. When I’ve gone out to do some pleasant activity (e.g. eating out in a restaurant), I’ve felt guilty and unable to stop thinking that I should be caring for my relative
8. I have felt bad about things I may have done wrong with the person I’m caring for
9. I have thought that perhaps I’m not caring well for my relative
10. I have felt bad about getting angry with the person I’m caring for
11. I have felt bad about telling off the person I’m caring for, for some reason
12. I’ve got angry with myself for having negative feelings toward the person I’m caring for
13. I’ve found myself thinking that I’m not up to the job
14. I have felt bad about not having more patience with the person I’m caring for
15. I have felt bad about leaving my relative in the care of someone else while I do my own things (e.g. work, shopping, going to the doctor)
16. I have felt bad for leaving my relative in the care of someone else while I had fun
17. I have felt guilty about having wished that others “could have this burden” or suffer as I do
18. I have felt like a bad person for hating and/or envying other relatives who could have taken responsibility for some caring and do not do so
19. I have felt bad for having negative feelings (e.g., hate, anger or resentment) toward some relatives
20. I have felt guilty about having so many negative emotions in relation to caring
21. I have thought that the way I care for my relative may not be appropriate and may make his/her problem get worse
22. I have felt guilty thinking that my lack of information and preparedness might mean that I’m not handling the care of my relative in the best way possible

# Appendix G

**Participant Debrief Sheet**

Thank you for taking part in this study.

 **Please take your time to read this debrief information sheet. Once you have finished, please click "continue" at the end of this page to end the study.**

**Your participant ID code is: [IDCODE]**

If you decide you would like to withdraw your data from this study, you can do so within two weeks of the date you completed the study. You can withdraw by contacting the researcher on the details provided below and quoting your participant ID code, so please write down this number. Withdrawing from the study will not affect you in any way. If you choose to withdraw from the study, we will not retain any information that you have provided to us as a part of this study.

This research aims to investigate the relationship between caregiver guilt, self-compassion and depressive symptoms in family carers of people with dementia. Research suggests that caring for a relative with dementia can be challenging at times and carers sometimes experience feelings of guilt and low mood. We are interested in whether the level of compassion carers show towards themselves impacts how they experience feelings of guilt and low mood. It is hoped that this research will improve the understanding we have of carers’ experience and may also inform support for carers of people with dementia.

**If you know any other carers of people with dementia who may be interested in taking part in this study, please share the research advertisement with them.**

If you have any questions about this research, please contact the researcher: Rebecca Wallace, UNIVERSITY ADDRESS Email: EMAIL ADDRESS

**Support and Information Services**

If you want to talk about any concerns or worries then you can contact one of the support services listed below. Alternatively, you may wish to seek support through your GP.
**The Samaritans**are a free telephone service which you can use if you want to speak to someone about any concerns or worries that you have. The telephone service is open 24 hours a day, 365 days a year. You can also contact them by email or take a look at their website.

* **Telephone:** 116 123
* **Email:** jo@samaritans.org
* **Website:** https://www.samaritans.org/

**The Alzheimer’s Society**offers a Dementia Connect support line where a dementia adviser will listen to you and provide advice and support. Calls are charged at standard local rate. They also have a website which has lots of helpful information and factsheets on different dementia related topics.

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* **Website:** https://www.alzheimers.org.uk/

**Carers UK**provide a helpline for people who look after a friend or family member. They can provide information and guidance on a range of topics related to caring.

* **Telephone:** 0808 808 7777
* **Helpline opening hours:**Monday – Friday: 9am – 6pm
* **Email address:** advice@carersuk.org
* **Website:**https://www.carersuk.org/help-and-advice/talk-to-us

**Thank you again for your participation.**

# Appendix H

**Permission to use the Caregiver Guilt Scale**

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# Appendix I

**Permission to use the Self-Compassion Questionnaire**

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# Appendix J

**SPSS Analysis Output – Original Dataset**

## Multiple regression for three predictors using a complete case approach (n = 78), including the bootstrapped output.

|  |
| --- |
| **Model Summaryb** |
| Model | R | R Square | Adjusted R Square | Std. Error of the Estimate | Durbin-Watson |
| 1 | .745a | .555 | .537 | 9.581 | 1.556 |
| a. Predictors: (Constant), Hours caregiving per day, Self-Compassion , Guilt |
| b. Dependent Variable: Depression |

|  |
| --- |
| **ANOVAa** |
| Model | Sum of Squares | df | Mean Square | F | Sig. |
| 1 | Regression | 8463.091 | 3 | 2821.030 | 30.729 | <.001b |
| Residual | 6793.524 | 74 | 91.804 |  |  |
| Total | 15256.615 | 77 |  |  |  |
| a. Dependent Variable: Depression |
| b. Predictors: (Constant), Hours caregiving per day, Self-Compassion , Guilt |

|  |
| --- |
| **Coefficientsa** |
| Model | Unstandardized Coefficients | Standardized Coefficients | t | Sig. | 95.0% Confidence Interval for B | Collinearity Statistics |
| B | Std. Error | Beta | Lower Bound | Upper Bound | Tolerance | VIF |
| 1 | (Constant) | 16.244 | 7.067 |  | 2.299 | .024 | 2.163 | 30.326 |  |  |
| Guilt | .491 | .072 | .609 | 6.793 | <.001 | .347 | .636 | .748 | 1.337 |
| Self-Compassion | -.194 | .080 | -.214 | -2.435 | .017 | -.352 | -.035 | .778 | 1.285 |
| Hours caregiving per day | .077 | .141 | .043 | .545 | .588 | -.204 | .357 | .954 | 1.048 |
| a. Dependent Variable: Depression |







|  |
| --- |
| **Bootstrap for Coefficients** |
| Model | B | Bootstrapa |
| Bias | Std. Error | Sig. (2-tailed) | BCa 95% Confidence Interval |
| Lower | Upper |
| 1 | (Constant) | 16.244 | .147 | 7.882 | .042 | .887 | 30.929 |
| Guilt | .491 | -.003 | .067 | <.001 | .350 | .616 |
| Self-Compassion | -.194 | -.001 | .093 | .041 | -.387 | -.010 |
| Hours caregiving per day | .077 | .001 | .131 | .575 | -.200 | .338 |
| a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples |

## Multiple regression for two predictors using a complete case approach (*n* = 78).

|  |
| --- |
| **Model Summaryb** |
| Model | R | R Square | Adjusted R Square | Std. Error of the Estimate | Durbin-Watson |
| 1 | .744a | .553 | .541 | 9.536 | 1.564 |
| a. Predictors: (Constant), Self-Compassion , Guilt |
| b. Dependent Variable: Depression |

|  |
| --- |
| **ANOVAa** |
| Model | Sum of Squares | df | Mean Square | F | Sig. |
| 1 | Regression | 8435.846 | 2 | 4217.923 | 46.380 | <.001b |
| Residual | 6820.769 | 75 | 90.944 |  |  |
| Total | 15256.615 | 77 |  |  |  |
| a. Dependent Variable: Depression |
| b. Predictors: (Constant), Self-Compassion , Guilt |

|  |
| --- |
| **Coefficientsa** |
| Model | Unstandardized Coefficients | Standardized Coefficients | t | Sig. | 95.0% Confidence Interval for B | Collinearity Statistics |
| B | Std. Error | Beta | Lower Bound | Upper Bound | Tolerance | VIF |
| 1 | (Constant) | 16.749 | 6.973 |  | 2.402 | .019 | 2.858 | 30.641 |  |  |
| Guilt | .499 | .071 | .619 | 7.074 | <.001 | .359 | .640 | .778 | 1.285 |
| Self-Compassion | -.193 | .079 | -.213 | -2.435 | .017 | -.350 | -.035 | .778 | 1.285 |
| a. Dependent Variable: Depression |





## Mediation output using a complete case approach (*n* = 78).

Model : 4

 Y : Depress

 X : SelfComp

 M : Guilt

Sample

Size: 78

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

OUTCOME VARIABLE:

 Guilt

Model Summary

 R R-sq MSE F df1 df2 p

 .4708 .2217 240.3041 21.6459 1.0000 76.0000 .0000

Model

 coeff se t p LLCI ULCI

constant 78.0737 6.9483 11.2363 .0000 64.2348 91.9125

SelfComp -.5280 .1135 -4.6525 .0000 -.7540 -.3020

Standardized coefficients

 coeff

SelfComp -.4708

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

OUTCOME VARIABLE:

 Depress

Model Summary

 R R-sq MSE F df1 df2 p

 .7436 .5529 90.9436 46.3796 2.0000 75.0000 .0000

Model

 coeff se t p LLCI ULCI

constant 16.7493 6.9731 2.4020 .0188 2.8580 30.6406

SelfComp -.1927 .0791 -2.4353 .0173 -.3503 -.0351

Guilt .4992 .0706 7.0741 .0000 .3586 .6398

Standardized coefficients

 coeff

SelfComp -.2131

Guilt .6191

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\* TOTAL EFFECT MODEL \*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

OUTCOME VARIABLE:

 Depress

Model Summary

 R R-sq MSE F df1 df2 p

 .5046 .2546 149.6299 25.9624 1.0000 76.0000 .0000

Model

 coeff se t p LLCI ULCI

constant 55.7233 5.4829 10.1631 .0000 44.8032 66.6435

SelfComp -.4563 .0895 -5.0953 .0000 -.6346 -.2779

Standardized coefficients

 coeff

SelfComp -.5046

\*\*\*\*\*\*\*\*\*\*\*\*\*\* TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y \*\*\*\*\*\*\*\*\*\*\*\*\*\*

Total effect of X on Y

 Effect se t p LLCI ULCI c\_cs

 -.4563 .0895 -5.0953 .0000 -.6346 -.2779 -.5046

Direct effect of X on Y

 Effect se t p LLCI ULCI c'\_cs

 -.1927 .0791 -2.4353 .0173 -.3503 -.0351 -.2131

Indirect effect(s) of X on Y:

 Effect BootSE BootLLCI BootULCI

Guilt -.2636 .0624 -.3963 -.1493

Completely standardized indirect effect(s) of X on Y:

 Effect BootSE BootLLCI BootULCI

Guilt -.2915 .0615 -.4214 -.1739

# Appendix K

**SPSS Output - Normality Checks**

**Normality checks showing violations to normality for hours per day caregiving.**

|  |
| --- |
| **Descriptive Statistics** |
|  | N | Skewness | Kurtosis |
| Statistic | Statistic | Std. Error | Statistic | Std. Error |
| Mean Sub Depression | 83 | -.079 | .264 | -.685 | .523 |
| Guilt | 83 | -.226 | .264 | -.641 | .523 |
| Mean Sub Self-Compassion | 83 | -.046 | .264 | -.240 | .523 |
| Hours caregiving per day | 83 | .303 | .264 | -1.423 | .523 |
| Valid N (listwise) | 83 |  |  |  |  |

|  |
| --- |
| **Tests of Normality** |
|  | Kolmogorov-Smirnova | Shapiro-Wilk |
| Statistic | df | Sig. | Statistic | df | Sig. |
| Mean Sub Depression | .065 | 83 | .200\* | .978 | 83 | .164 |
| Guilt | .075 | 83 | .200\* | .979 | 83 | .191 |
| Mean Sub Self-Compassion | .038 | 83 | .200\* | .992 | 83 | .871 |
| Hours caregiving per day | .159 | 83 | <.001 | .872 | 83 | <.001 |
| \*. This is a lower bound of the true significance. |
| a. Lilliefors Significance Correction |



# Appendix L

**SPSS Analysis Output – Imputed Dataset**

Multiple regression for three predictors using the imputed **data set (*n* = 83), including the bootstrapped output.**

|  |
| --- |
| **Model Summaryb** |
| Model | R | R Square | Adjusted R Square | Std. Error of the Estimate | Durbin-Watson |
| 1 | .753a | .567 | .550 | 9.715 | 1.697 |
| a. Predictors: (Constant), Hours caregiving per day, Mean Sub Self-Compassion, Guilt |
| b. Dependent Variable: Mean Sub Depression |

|  |
| --- |
| **ANOVAa** |
| Model | Sum of Squares | df | Mean Square | F | Sig. |
| 1 | Regression | 9748.595 | 3 | 3249.532 | 34.426 | <.001b |
| Residual | 7456.875 | 79 | 94.391 |  |  |
| Total | 17205.470 | 82 |  |  |  |
| a. Dependent Variable: Mean Sub Depression |
| b. Predictors: (Constant), Hours caregiving per day, Mean Sub Self-Compassion, Guilt |

|  |
| --- |
| **Coefficientsa** |
| Model | Unstandardized Coefficients | Standardized Coefficients | t | Sig. | 95.0% Confidence Interval for B | Collinearity Statistics |
| B | Std. Error | Beta | Lower Bound | Upper Bound | Tolerance | VIF |
| 1 | (Constant) | 21.810 | 6.768 |  | 3.223 | .002 | 8.339 | 35.281 |  |  |
| Guilt | .441 | .068 | .544 | 6.513 | <.001 | .306 | .575 | .786 | 1.273 |
| Mean Sub Self-Compassion | -.268 | .074 | -.301 | -3.611 | <.001 | -.417 | -.120 | .789 | 1.268 |
| Hours caregiving per day | .171 | .133 | .096 | 1.280 | .204 | -.095 | .436 | .977 | 1.023 |
| a. Dependent Variable: Mean Sub Depression |





|  |
| --- |
| **Bootstrap for Coefficients** |
| Model | B | Bootstrapa |
| Bias | Std. Error | Sig. (2-tailed) | BCa 95% Confidence Interval |
| Lower | Upper |
| 1 | (Constant) | 21.810 | .138 | 7.660 | .009 | 6.043 | 37.814 |
| Guilt | .441 | -.001 | .066 | <.001 | .310 | .558 |
| Mean Sub Self-Compassion | -.268 | -.002 | .089 | .005 | -.435 | -.101 |
| Hours caregiving per day | .171 | .004 | .122 | .164 | -.065 | .419 |
| a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples |

## Multiple regression for two predictors on the imputed dataset (*n* = 83).

|  |
| --- |
| **Model Summaryb** |
| Model | R | R Square | Adjusted R Square | Std. Error of the Estimate | Durbin-Watson |
| 1 | .747a | .558 | .547 | 9.754 | 1.719 |
| a. Predictors: (Constant), Guilt , Mean Sub Self-Compassion |
| b. Dependent Variable: Mean Sub Depression |

|  |
| --- |
| **ANOVAa** |
| Model | Sum of Squares | df | Mean Square | F | Sig. |
| 1 | Regression | 9594.061 | 2 | 4797.031 | 50.419 | <.001b |
| Residual | 7611.409 | 80 | 95.143 |  |  |
| Total | 17205.470 | 82 |  |  |  |
| a. Dependent Variable: Mean Sub Depression |
| b. Predictors: (Constant), Guilt , Mean Sub Self-Compassion |

|  |
| --- |
| **Coefficientsa** |
| Model | Unstandardized Coefficients | Standardized Coefficients | t | Sig. | 95.0% Confidence Interval for B | Collinearity Statistics |
| B | Std. Error | Beta | Lower Bound | Upper Bound | Tolerance | VIF |
| 1 | (Constant) | 23.914 | 6.591 |  | 3.628 | <.001 | 10.797 | 37.031 |  |  |
| Mean Sub Self-Compassion | -.275 | .074 | -.308 | -3.689 | <.001 | -.423 | -.127 | .792 | 1.262 |
| Guilt | .449 | .068 | .554 | 6.633 | <.001 | .314 | .583 | .792 | 1.262 |
| a. Dependent Variable: Mean Sub Depression |







# Appendix M

**SPSS Analysis Output - Mediation Analysis**

**Mediation analysis output using the imputed dataset (*n* = 83).**

Model : 4

 Y : MSDepT

 X : MSSCT

 M : GuiltT

Sample

Size: 83

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

OUTCOME VARIABLE:

 GuiltT

Model Summary

 R R-sq MSE F df1 df2 p

 .4557 .2076 256.7310 21.2259 1.0000 81.0000 .0000

Model

 coeff se t p LLCI ULCI

constant 76.2919 6.7354 11.3270 .0000 62.8905 89.6933

MSSCT -.5019 .1089 -4.6072 .0000 -.7186 -.2851

Standardized coefficients

 coeff

MSSCT -.4557

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

OUTCOME VARIABLE:

 MSDepT

Model Summary

 R R-sq MSE F df1 df2 p

 .7467 .5576 95.1426 50.4194 2.0000 80.0000 .0000

Model

 coeff se t p LLCI ULCI

constant 23.9139 6.5911 3.6282 .0005 10.7972 37.0306

MSSCT -.2748 .0745 -3.6888 .0004 -.4231 -.1265

GuiltT .4487 .0676 6.6329 .0000 .3140 .5833

Standardized coefficients

 coeff

MSSCT -.3082

GuiltT .5541

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\* TOTAL EFFECT MODEL \*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

OUTCOME VARIABLE:

 MSDepT

Model Summary

 R R-sq MSE F df1 df2 p

 .5607 .3143 145.6452 37.1327 1.0000 81.0000 .0000

Model

 coeff se t p LLCI ULCI

constant 58.1425 5.0731 11.4609 .0000 48.0486 68.2364

MSSCT -.5000 .0820 -6.0937 .0000 -.6632 -.3367

Standardized coefficients

 coeff

MSSCT -.5607

\*\*\*\*\*\*\*\*\*\*\*\*\*\* TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y \*\*\*\*\*\*\*\*\*\*\*\*\*\*

Total effect of X on Y

 Effect se t p LLCI ULCI c\_cs

 -.5000 .0820 -6.0937 .0000 -.6632 -.3367 -.5607

Direct effect of X on Y

 Effect se t p LLCI ULCI c'\_cs

 -.2748 .0745 -3.6888 .0004 -.4231 -.1265 -.3082

Indirect effect(s) of X on Y:

 Effect BootSE BootLLCI BootULCI

GuiltT -.2252 .0498 -.3306 -.1373

Completely standardized indirect effect(s) of X on Y:

 Effect BootSE BootLLCI BootULCI

GuiltT -.2525 .0513 -.3597 -.1583

# Paper 3: Executive Summary

# Self-Compassion, Caregiver Guilt, and Depression in Family Caregivers of People with Dementia: An Executive Summary

**Word count:** 2494 (Excluding title page and references)

**Self-Compassion, Caregiver Guilt, and Depression in Family Caregivers of People with Dementia**

This report is a summary of a research project investigating self-compassion, caregiver guilt and depression in family carers of people with dementia. This summary has been written for family carers, however, it may also be of interest to people with dementia and professionals who work with people with dementia and their families or carers. This report has been developed in consultation with two carers who kindly reviewed the report and provided feedback on the wording, structure and layout.

**Background to the Research**

**Dementia**

Dementia is an umbrella term that describes a number of conditions which affect the brain (Dementia UK, 2021). As dementia progresses, problems with memory, thinking, language and problem solving begin to impact an individual’s ability to carry out day-to-day tasks (Alzheimer’s Society, 2021). As a result, people with dementia are often cared for by a family member, such as a spouse, or relative, sometimes referred to as an ‘informal carer’ (Alzheimer’s Research UK, 2020). Estimates suggest over 850,000 people are living with dementia in the UK and this is anticipated to increase to over one million by 2025 (Prince et al., 2014). There are around 700,000 family carers of people with dementia in the UK (Lewis et al., 2014) and around 60-70% of dementia carers are women (Alzheimer’s Society, 2015).

**Depression**

While caregiving can be rewarding, it can also be challenging (Quinn et al., 2019). Caregiving can impact a carer’s health and wellbeing, with an estimated 31% of dementia carers thought to experience depression (Collins & Kishita, 2020). Depression can involve feeling continually sad, tearful and having no motivation or interest in things (National Health Service, 2019). Factors such as spending more hours per day caregiving and being female have been identified as risk factors for depression in dementia carers (Losada et al., 2018; Watson et al., 2019). Higher levels of depression are also associated with higher levels of caregiver guilt (Losada et al., 2010; Roach et al., 2013).

**Caregiver Guilt**

Caregiver guilt has been described as an experience that carers may have if they believe they have acted against a moral or social standard of care in their behaviour and/or thoughts (Prunty & Foli, 2019). Caregiver guilt is thought to be a common experience, with one study reporting that 65% of a sample of 66 dementia caregivers experienced caregiver guilt (Gonyea et al., 2008). In research by Gallego-Alberto et al. (2020), examples of situations in which carers may experience caregiver guilt were identified by people who care for a relative with dementia. The box below presents some of these examples:

* Making or perceiving they have made a mistake whilst caregiving
* Being unsure of what to do in caregiving situations, for example, the person with dementia is repetitive or agitated
* When doing something other than caregiving, for example, self-care or leisure activities
* Spending less time with other family/friends due to caregiving
* Experiencing negative feelings or thoughts towards the person with dementia, for example, frustration or annoyance

While research has explored caregiver guilt and depression, limited research has looked at ways to reduce caregiver guilt. Self-compassion has been suggested as a way to reduce caregiver guilt (Gallego-Alberto et al., 2020; Losada et al., 2018).

**Self-Compassion**

Compassion has been defined as “a sensitivity to suffering in self and others, with a commitment to prevent or alleviate it” (Gilbert, 2014, p.19). An individual can experience compassion for others, from others, and for themselves, known as self-compassion (Gilbert, 2009). Greater levels of self-compassion are related to lower levels of depression in the general population (MacBeth & Gumley, 2012).

Self-compassion can be thought of as an alternative to self-criticism and self-judgement which are part of caregiver guilt (Gilbert et al., 2017; Prunty & Foli, 2019). Guilt is thought to activate part of the brain that is associated with perceiving threats or dangers. Self-compassion may be able to reduce this activation by teaching individuals to soothe themselves (Gilbert, 2005), meaning to be kind and show empathy to themselves in times of stress such as difficult caregiving situations.

**Why carry out this study?**

Past research suggests depression is common in dementia caregivers, and potential factors related to this may be greater levels of caregiver guilt, lower levels of self-compassion, a higher number of hours per day caregiving, and being female. However, these factors have not been investigated together to see if they predict depression in dementia carers. Understanding which factors are more likely to lead to depression in dementia carers is important because of the high levels of distress in this population due to the challenges associated with caregiving (Collins & Kishita, 2020).

Past research indicates that being self-compassionate may reduce levels of caregiver guilt. Furthermore, it has been suggested that interventions that reduce guilt may lead to a reduction in depression (Kim et al., 2011). It is important to understand the relationship between these factors to help develop interventions to support the growing number of dementia carers (Lewis et al., 2014).

**Aims of the Study**

1. To investigate whether self-compassion, caregiver guilt, hours per day caregiving and gender, predict depression in family caregivers of people with dementia.
2. To investigate whether self-compassion reduces caregiver guilt, which in turn, reduces levels of depression.

**Predicted Outcomes**

1. Lower levels of self-compassion, higher levels of caregiver guilt, a higher number of hours per day caregiving, and being female will predict higher levels of depression.
2. Carers with greater self-compassion, will have lower levels of caregiver guilt. In turn, lower levels of guilt will be associated with lower levels of depression.

**Method**

This study was reviewed and approved by Staffordshire University Ethics Committee.

**How were participants recruited?**

Participants were recruited between March and November 2021. A research advertisement was posted on social media, online groups, websites and newsletters aimed at carers. The study was also advertised at face to face carers groups run by charity and third-sector organisations.

**Who could take part?**

Carers had to meet the following criteria to be eligible to take part:

|  |  |
| --- | --- |
| **To take part, carers must be:** | **Carers could not take part if:** |
| * Aged 18 or over
* A current carer for a family member or partner with dementia
* The person with dementia must live at home (i.e. not in a nursing home)
 | * They were a paid carer
* They could not understand written English (as there were no resources for translation)
 |

**What did taking part involve?**

This research used a cross-sectional design, meaning that data was collected at one point in time. Participants could complete the study online or they could request a paper participation pack from the researcher. Online participants clicked a link on the online advertisement to access the study. This took participants to a webpage that gave information about the study to enable them to make an informed decision about taking part. If participants decided to proceed, they were asked to complete a consent form.

Participants were asked to complete several questions about themselves and their caring role, this included their:

* Age
* Gender
* Number of hours caregiving per day (on average)
* Length of time caregiving
* Relationship to the person with dementia
* Whether they live with the person they care for
* The type of dementia their loved one has

Carers were then asked to complete three questionnaires:

1. **The Center for Epidemiological Studies Depression Scale (Radloff, 1977)** is a 20-item questionnaire measuring low mood by asking participants to rate how often they have felt or behaved in certain ways in the last week, for example, *“I felt sad”*.
2. **The Caregiver Guilt Questionnaire (Losada et al., 2010)** is a 22-item questionnaire that measures caregiver guilt in family carers. It asks participants to rate how often they have had thoughts or feelings of guilt in the last two weeks, for example, *“I have felt bad about having made some plan or done some activity without taking my relative into account”*.
3. **The Compassionate Engagement and Action Scale: Self-Compassion (Gilbert et al., 2017)** is a 13-item questionnaire that measures levels of self-compassion by asking participants how well certain statements about how compassionate they are to themselves apply to them, for example, *“I am accepting, non-critical and non-judgemental of my feelings of distress.”*

**Who took part?**

Eighty-four participants were recruited for this study. The majority of participants were female (92%) and most carers lived with the person they cared for (62%). The age of participants ranged from 26 to 85. The number of hours per day providing care ranged from 1 to 24 and the average was 12 hours per day. The average length of time caregiving was 3 years and 9 months. Details about the type of dementia that the care recipient was diagnosed with and the carer’s relationship with the person with dementia are presented in the diagrams below. One participant had lots of incomplete questions and so it was not possible to include their information in the analysis. This meant that 83 participants were included in the analysis.

**How was the data analysed?**

Two types of statistical analysis were used. The first was a **multiple regression analysis**. This analysis shows whether there is a relationship between two or more things such as caregiver guilt and depression. These things are referred to as **variables**. If the regression analysis shows that a variable has an impact on another variable, it is described as a **significant predictor** of the other variable.

Researchers are often interested in why or how one variable affects another, this can be investigated using a **mediation analysis**.A mediation analysis investigates if a relationship between two variables is **direct** (one variable influences another) or **indirect** (one variable influences a second variable, which in turn influences a third variable). The variable in the middle is known as the **mediator** and is thought to explain how or why the first variable influences the third variable.

**Key Findings**

**Prediction One:***Lower levels of self-compassion, higher levels of caregiver guilt, a higher number of hours per day caregiving, and being female will predict higher levels of depression.*

Using the multiple regression analysis, higher levels of caregiver guilt and lower levels of self-compassion were found to be significant predictors of depression. The diagram below explains this. Caregiver guilt was the strongest predictor of depression, meaning that caregiver guilt explained more of carers’ depression scores than the other variables. The number of hours caregiving per day was not a significant predictor of depression. Unfortunately, it was not possible to include gender in the analysis as there were too few male carers recruited to enable a comparison with female carers.

Higher levels of depression

Higher levels of caregiver guilt

Lower levels of self-compassion

=

These results suggest that **prediction one** was partly correct; lower levels of self-compassion and higher levels of caregiver guilt were related to higher levels of depression in carers, however, the number of daily hours caregiving was not. It was not possible to assess gender.

**Prediction Two:** *Carers with greater self-compassion, will have lower levels of caregiver guilt. In turn, lower levels of guilt will be associated with lower levels of depression.*

The mediation analysis identified an **indirect effect** between self-compassion and caregiver depression, meaning that one variable influences a second variable, which in turn influences a third variable. The results suggest that higher levels of self-compassion are associated with lower levels of caregiver guilt, and lower levels of caregiver guilt are associated with lower levels of depression. This suggests that self-compassion reduces depression, by reducing caregiver guilt. Therefore, **prediction two** was fully supported by the results.

**Conclusions and Recommendations**

The findings of this study suggest that lower levels of self-compassion and higher levels of caregiver guilt significantly predict higher levels of depression in dementia caregivers. The findings also suggest that carers with higher levels of self-compassion have lower levels of caregiver guilt, and, in turn, the lowers level of caregiver guilt are associated with lower levels of depression.

These findings have some important implications for carers and professionals working with carers. Firstly, being more self-compassionate may help carers to reduce levels of caregiver guilt and depression, and secondly, reducing caregiver guilt may also reduce depression. Some ideas to help put this information into practice include:

* Using an intervention to increase self-compassion, such as **Compassion Focused Therapy** (Gilbert, 2009). This type of intervention encourages people to recognise difficult emotions and use more helpful strategies to manage their distress to reduce guilt, self-criticism and depression (Gilbert, 2005).
* Professionals should ask about caregiver guilt in assessments as it seems to be common, particularly if depression is identified.

**The Impact of COVID-19**

This study took place during the COVID-19 pandemic and this is likely to have impacted the results. Research suggests that the pandemic has been linked to an increase in stress and depression in caregivers, potentially due to challenges such as disrupted routines, closures of respite and day centres, reduced contact with friends and family, and fear of spreading COVID-19 to their loved ones (Cohen et al., 2020; Greenberg et al., 2020).

**Limitations of this Research**

* It was not possible to compare differences between genders as not enough male carers or carers identifying as non-binary took part.
* The results may only be relevant to female carers, as other carers were not well represented in this study.
* Most participants were recruited online (94%), therefore, the findings may not represent people who do not have access to the internet.
* Most participants were recruited from caregiver support groups and so their experience may be different to carers who do not engage in such groups.
* Participants were not asked if they had received any previous support to reduce depression and/or caregiver guilt, or an intervention to increase their self-compassion. Therefore, it is not possible to know the impact that previous interventions may have had on participants’ scores.

**Recommendations for Researchers**

It is important to remember that this is only one study, so there should be caution when applying the results. Further research should be done to help verify these results. Examples of future research include:

* Investigating caregiver guilt, self-compassion and depression in dementia carers over time. This would enable researchers to see if carers, for example, who experience caregiver guilt go on to experience depression over time.
* Investigating the relationship between these variables in groups of carers who were not well represented in this study, for example, non-female carers, carers without internet access, and carers not engaging in carer groups.
* Investigating if other factors are relevant to the relationship between the variables, for example, do anxiety and stress influence levels of caregiver guilt?
* A comparison study could be used to compare participants’ depression and caregiver guilt scores before and after receiving a self-compassion intervention to see if the intervention reduces their levels of depression and caregiver guilt.

**Who will this Research be shared with?**

Participants were advised they could contact the researcher to request a copy of this report to be shared with them once the research was complete. This research will also be submitted to a scientific journal called “Dementia” for publication.

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