



Explaining caregiver burden in a large sample of UK dementia caregivers: The role of contextual factors, behavioural problems, psychological resilience, and anticipatory grief

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Explaining caregiver burden in a large sample of UK dementia caregivers: The role of contextual factors, behavioural problems, psychological resilience, and anticipatory grief

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ABSTRACT

Objectives: Dementia caregiver burden is a significant public health concern, affecting both the wellbeing of caregivers and their care-recipients. This study investigated a range of variables associated with caregiver burden in a large sample of UK dementia caregivers. Clinical characteristics and novel psychological constructs were used – including anticipatory grief and psychological resilience. Anticipatory grief refers to the process of experiencing loss prior to the death of a significant person.

Method: Caregivers of persons with dementia ($N=530$) completed a survey obtaining the Zarit-Burden Interview (ZBI-SF) and other psychological and demographic/caregiving-related factors.

Results: Findings illustrate that 71% of the sample experienced high levels of caregiver burden and around 95% met the criteria for clinically significant levels of burden. A regression model explained 49% of the variance in subjective caregiver burden; contextual factors (care-recipients living situation, frequency of caregiving), behavioural challenges in the care-recipient (memory-related problem behaviours), caregiver psychological resilience and caregiver anticipatory grief (heartfelt long & sadness, worry & felt isolation) were all significant variables. Caregiver anticipatory grief, followed by psychological resilience, had the strongest association with burden

Conclusion: Caregiver anticipatory grief and psychological resilience, have a significant interaction with the clinical presentation of the dementia sufferer in explaining subjective caregiver burden. More grief and resilience-focused interventions targeting both the practical and emotional challenges are imperative to reduce burden and thus to ensure caregiver wellbeing.

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pre-death grief; mental health; personal strength; family members

Family members and friends provide the majority of support for people with dementia. Approximately 700,000 friends and family are dementia carers in the UK (Alzheimer's Research UK). These carers are required to be highly skilled and are essential to the fabric of our society in an aging population. They are integral to the quality of life of the care recipients. However, caring for a loved one with dementia is often an emotionally and physically demanding experience which has a significant impact on the carer's quality of life and wellbeing. The effects of being a family caregiver can bring about a complexity of emotions, and though sometimes positive, undoubtedly provide major challenges (Doris et al., 2018; Peacock et al., 2010). Often the caregiving experience can be described as a time filled with anxiety, heartache, uncertainty and fear (Holley & Mast, 2009).

A substantial amount of literature has documented caregiver burden, as well as the corresponding psychological distress it produces (del-Pino-Casado et al., 2019; Kim et al., 2012). Dementia caregivers have been found to experience significantly more burden than non-dementia caregivers and to suffer greater depressive symptoms (Pinquart & Sorensen, 2003; Cheng, 2017). Subsequently, family caregivers are often called the "invisible second patients" (Brodaty & Donkin, 2009, p. 217). The wellbeing of caregivers is, in itself, now a considerable public health concern (Alzheimer's Association, 2015). If, or when caregivers become unable to cope through their own incapacity, grave financial implications for governments are likely (Alzheimer's Disease International's, 2015).

Understanding the theoretical frameworks which attempt to explain the course and determinants of caregiver psychological distress is important to prevent or minimise it. Lazarus and Folkman's transactional stress process model remains the most dominant and widely used model within dementia caregiving literature (Judge et al., 2010; Pearlin et al., 2010). This framework specifically predicts that demographic and contextual factors, primary and secondary stressors, and mediators, interact to produce outcomes that lead to caregiver distress (Pearlin et al., 1990). In the context of dementia caregiving, subjective caregiver burden is the most commonly explored outcome variable. Caregiving burden refers to a caregiving state, characterised by a negative reaction to the impact of providing care. Vulnerability to burden is due to characteristics inherent in the dementia aetiology and in the caregiving trajectory (Pearlin et al., 1990; Sherwood et al., 2005).

Relevant caregiver characteristics and contextual factors as a category of variables, include caregiver gender, age, relationship to the care recipient, living arrangements and caregiving frequency. Being a female, spouse caregiver with a greater time commitment to caring duties has been consistently associated with greater levels of burden (Pinquart & Sorensen, 2005; Chappell et al., 2014; Conde-Sala et al., 2014). Literature however exploring the relationship between the care-recipients living arrangements and caregiver burden is inconsistent. Several studies have reported caregivers who lived with their loved one to experience higher burden (e.g. Grafström et al., 1992; Zarit &

Whitlatch, 1992). However, additional research highlights the complexity of difficulties associated with the caregiving situation irrespective of living circumstance. This includes literature describing the devastating impact and challenges that endure for a family when the care-recipient is institutionalized (Boltz et al., 2015; Shankar et al., 2014). Caregiver age is also an important, yet understudied variable of interest given the increase in prevalence of young onset dementia in the UK (The Alzheimer's Society, 2014). Limited quantitative research has reported younger caregivers to receive less social support, have greater psychological upset, and heavier burden than those caring for individuals with late onset dementia (Freyne et al., 1999; Aria et al., 2007). Additionally, given the neuropsychiatric, functional and cognitive impairments that a dementia diagnosis can bring, behavioural problems exhibited by the care recipient have been shown to be a key primary stressor. Behavioural problems commonly reported include concerning, inappropriate or potentially embarrassing behaviours such as aggression, forgetfulness, restlessness, hostility and/or apathy (Branger et al., 2018; Chappell & Penning, 1996).

Whilst these behavioural problems, combined with additional contextual factors, have the potential to have disruptive and emotional consequences for everyone involved, research has started to recognise multiple factors which can alleviate caregiver distress. An abundance of caregivers continue to function well in this role over extremely protracted periods of time. Reports have emphasised the positive effects additional support has on caregiver outcomes - including less depressive symptomatology (Clay et al., 2008; Schulz & Williamson, 1991; Roth et al., 2005) and lower perceived burden (Ruisoto et al., 2020). Significant associations between caregiver resilience and burden has also been reported (O'Rourke et al., 2010; Scott, 2013). A study by Ong et al. (2018) found perceived social support to mediate the association between resilience and caregiver burden. No research however has explored resilience in the context of caregiver burden within large samples.

Given previous research around the Stress Process Model, it can be speculated that our understanding of caregiving experiences is considerable. However, it is possible that the absence of grief and psychological resilience from conceptualizations of caregiver burden has hindered the development of a more in-depth, comprehensive understanding of the unique emotional experience of the dementia caregiving journey. Anticipatory Grief (AG), also known as "Pre-death grief" (Lindauer & Harvath, 2014), "Caregiver Grief" (Large & Slinger, 2015) and "Dementia Grief" (Blandin & Pepin, 2017), remains a relatively novel and debated subject in dementia caregiving literature despite its undoubted relevance. While the end-of-life trajectory for different life limiting conditions is undoubtedly complex, the fluctuating course and dual loss of the individual with dementia, in personality and then physically, is a particularly cruel adjustment. Caregivers have no control over rates of change and therefore have no choice but to witness multiple, incremental and unexpected losses through cumulative changes in personality, cognitive and physical capabilities. Consequently, dementia is often described as 'dual dying' (Jones & Martinson, 1992), with a 'bereavement' experienced first as the disease progresses and 'takes away' the known person, and secondly, when physical death ultimately occurs.

Understanding the emotionally complex losses associated with the dementia sufferer's cognitive, physical and personal decline has been challenging for researchers, caregivers and society alike. Whilst there is no clear consensus on the definition of AG, it has been described as both "multifaceted" and "inescapable". It ultimately refers to a process of experiencing the phases of bereavement in advance of the death of a significant person (Rando, 1986; 2000). Limited measurable models which specifically address AG have been offered in the literature. However, strong significant associations between anticipatory grief and burden (Walker & Pomeroy, 1997; Marwit & Meuser, 2002; 2005; Holley & Mast, 2009) have fuelled suggestions that grief explanations are a central component in understanding caregiver burden. Arguably, AG should "fit into" an expanded stress-process model of dementia caregiving (Noyes et al., 2010). This supports Holley and Mast (2009) finding who controlled for known covariates of caregiver burden, including age, gender, behavioural problems in the care recipient and depressive symptoms; and still indicated a significant, independent association between caregiver burden and anticipatory grief.

The key aim of this study is to explore how which variables contribute to explaining variation in the overall subjective burden experienced by caregivers. Specifically, it examines the ability of caregiver characteristics/contextual factors (age, gender, caregiver living situation, caregiver relationship to loved one, caregiver duration, caregiver frequency), primary stressors (behavioural problems), additional support, psychological resilience, and AG to explain variation in subjective burden. It was hypothesised that all study variables would relate with burden to some extent. However, based on previous research discussed, it was predicted that scale variables, particularly behavioural problems and AG would have strong associations with burden.

Methods

Participants

A sample of 530 informal caregivers of persons with dementia was recruited. Participants were primarily recruited from a dementia research register in the UK – Join Dementia Research, as well as online support groups and through Young Dementia UK. The inclusion criteria required that the caregiver is over the age of eighteen and provides some level of care, including assisting in the person's activities of daily living at the time of study participation.

Procedure

The study used Qualtrics software to create an online survey. Potentially eligible participants were identified through inclusion criteria screening with Join Dementia Research (JDR). Participants who met the inclusion criteria received a match on JDR prior to receiving information via email from the researchers and JDR regarding potential participation. Participants recruited from Young Dementia UK and online dementia support groups contacted the researchers to discuss potential inclusion. The study was granted ethical approval by Ulster Universities Research Ethics Committee. Prior to study completion, participants were provided with an information sheet and informed consent was obtained for each participant.

Measures

Primary outcome variable

Caregiver Burden – Zarit Burden Interview Short Form (ZBI-SF). Caregiver burden was assessed using the Zarit Burden Interview Short Form (ZBI-SF; Bédard et al., 2001) which is an abbreviated 12-item version of the original 22-item Zarit Burden Interview (Zarit et al., 1980; Zarit et al., 1985). This measurement examines burden/strain associated with the caregiving role. The items are rated on a 5-point Frequency scale, ranging from 'Never (0)' to 'Nearly always (4)', which is summed to generate a total score ranging from 0 to 48 (Bédard et al., 2001). The short form has been previously shown to correlate strongly with the original 22-item version ($r = .92-.97$) (Bédard et al., 2001). The reliability of the scale in this sample was high (Cronbach's $\alpha = .856$).

Variables

Contextual factors/caregiver characteristics & primary stressors

Socio-Demographic Variables – Socio-demographic variables were obtained from a short questionnaire at the beginning of the survey. Variables included caregivers age, gender, ethnicity, duration of caregiving (5-point Likert scale ranging from 'less than a year' to '7+ years', and frequency of caregiving (5-point Likert scale ranging from "full time care" to "once a week". The care recipients living arrangements (*transitions from independent living, living with family & supported accommodation*) and the caregiver's relationship to the care recipient (*parent, spouse/partner, other*) were also measured.

Behavioural Problems – The Revised Memory and Behaviour Problems Checklist (RM-BCP) The RM-BPC (Teri et al., 1992) is a 24-item caregiver report measure examining observable behavioural problems in the care recipient. The scale provides a total score, and three subscale scores for the care recipient's frequency of dementia-related problems: *memory, depression* and *disruptive behaviours*, and parallel scores in each subscale for caregiver reaction. The caregiver reaction refers to how much the care-recipients behaviour has bothered the caregiver. For frequency scoring of each problem question, caregivers are instructed to specify whether the problem has occurred in the past week – with an option of either 'yes' or 'no'. For reaction, a 5-point Likert scale is used ranging from '0 = not at all' to '4 = extremely', which are summed to generate a total score ranging from 0 to 96. The RM-BPC demonstrated good reliability in the current sample, with alphas of .826 for patient behaviour and .914 for caregiver reaction.

Caregiver Psychological Resilience – Wagnild and Young Resilience Scale Short Version (RS-14) – The RS-14 measures capacity to withstand life stressors, and to thrive and make meaning from challenges (Wagnild & Young, 1993). It comprises 5 essential characteristics of meaningful life – purpose, perseverance, self-reliance, equanimity and existential aloneness (Wagnild, 2009). The items are rated on a 7-point Likert scale ranging from 'Strongly Disagree (1)' to 'Strongly Agree (7)' which is summed to generate a total score ranging from 0 to 98. The short version has indicated good validity and reliability from several studies (Wagnild & Young, 1993; Wagnild, 2009), and the scale has demonstrated good reliability in this sample (Cronbach's $\alpha = .925$).

Additional Support – Subjective quality of caregiver additional support was measured on a 5-point Likert scale from 'no support' to 'excellent support'.

Caregiver anticipatory grief

Caregiver Anticipatory Grief – Marwit Meuser Caregiver Grief Inventory Short Form (MM-CGI-SF): The MM-CGI-SF (18-item) was used to assess caregiver grief. The MM-CGI-SF is a shortened version of the original 50-item Marwit Meuser Caregiver Grief Inventory (Marwit & Meuser, 2005). The MM-CGI is the most commonly used pre-death grief scale in dementia caregiving research (Marwit & Meuser, 2002; Meuser et al., 2004; Gilsenan et al., 2020). The MM-CGI-SF comprises of three subscales; (a) *personal sacrifice and burden* (b) *heartfelt sadness and longing* (c) *worry and felt isolation*. Items use 5-point Likert scales, ranging from 1 (strongly disagree) to 5 (strongly agree) which produces a range of 18–90. All three subscales scores range from 6–30. The Cronbach's alpha score for the total scale was .91 and ranged from .80 to .85 for the three subscale scores, indicating high internal reliability for each factor and the total score within the current sample.

Analytic strategy

Statistical analyses were performed using SPSS Statistics 25 (SPSS Inc, 2015). Descriptive statistics were used to examine mean scores and to characterize caregivers and care recipients in terms of sociodemographic characteristics. Bivariate correlations were computed to examine the relationship between the outcome variable, caregiver subjective burden (ZBI-SF), and all other variables. To examine factors explaining variability in caregiver burden, a multiple regression analysis was performed consisting of multiple 'predictor' variables; age, gender, caregiver living situation, caregiver relationship to loved one, caregiver duration, caregiver frequency, additional support, psychological resilience, behavioural problems (RM-BC subscales) and anticipatory grief (MM-CGI-SF subscales).

Results

An overview of the sociodemographic profiles and variable score means of the study participants are shown in Table 1. The mean age of caregivers was 54 years with the majority of the sample being over the age of thirty (92%). Caregivers were predominantly female (86.6%), white/white British (96.4%), who cared for a parent (50.5%) or spouse/partner (23.7%) with dementia. On average, caregivers had been providing care for 1-3 years, and caregivers most commonly reported that the care recipients had moved from independent living to living with family and/or receiving home care (66.3%). Caregivers most commonly reported providing care a few times a week (28.5%) or full-time care (35.7%).

The mean score of perceived burden was 24.93 ($SD = 9.07$). 4% of the sample reported no to mild burden, 24% reported mild to moderate burden, and 71% experienced high burden. The sample endorsed a mean AG score of 58.56 ($SD = 14.41$), 82% of participants reported medium to high levels of anticipatory grief (64%;18% respectively). The mean frequency score for behavioural problems was 35.89 ($SD = 4.46$) and the reaction score was 31.52 ($SD = 21.11$). Finally, the sample endorsed a

mean psychological resilience score of 74.18 ($SD=12.54$), which indicates a moderate resilience level within the sample.

Results from the correlation analyses are shown in Table 2. For caregiver socio-demographic and contextual factors, there were small to moderate significant relationships between burden and caregiver gender ($r=.103, p<.05$), caregiver relationship to loved one ($r=.098, p<.05$), and caregiver frequency ($r=-.151, p<.01$). Caregivers who were female, a spouse, and who reported a higher frequency of caregiving experienced significantly higher burden than male, non-partner/spouse and

less frequent caregivers. No significant relationships were reported between caregiver age, living situation and caregiving duration. Psychological resilience was negatively correlated with caregiver burden ($r=-.308, p<.01$). Additional support also significantly negatively correlated with burden in that lower subjective quality of additional support resulted in higher levels of caregiver burden ($r=-.290, p<.01$).

For primary stressors, behavioural problems were significantly positively correlated with burden such that higher behavioural frequency ($r=.370, p<.01$) and reaction scores ($r=.450, p<.01$) were related to higher levels of burden. Subscale examination (see Table 3) indicated that disruptive problems ($r=.323, p<.01$; $r=.433, p<.01$), depression relation problems ($r=.260, p<.01$; $r=.210, p<.01$) and memory related-problems ($r=.189, p<.01$; $r=.353, p<.01$) significantly correlated with burden. Lastly, AG was highly correlated with burden such that higher levels of AG were related to higher levels of burden ($r=.715, p<.01$). Subscale examination (see Table 3) indicated that MM-CGI subscale A-Personal sacrifice and burden, had the strongest relationship with caregiver burden ($r=.706, p<.01$). Subscale B-Heartfelt Longing and sadness had the smallest, yet moderate correlation with caregiver burden ($r=.460, p<.01$), and subscale C-Worry and felt isolation, had moderate to large correlations with caregiver burden ($r=.621, p<.01$).

The results of the multiple regression using multiple study variables are shown in Table 4. Based on the strong correlation ($r=.706, p<.01$) and potential overlap of items on the ZBI-SF and Personal Sacrifice and Burden subscale (PBS), the PSB subscale was not included in the regression analysis. The overall model with the remaining thirteen variables was statistically significant and explained 49% of the variance in caregiver burden scores ($F(13, 272) = 19.667, p<.001; R^2=.49$). The significant regression coefficients indicated that high caregiver burden scores were associated with the care-recipients living situation ($\beta=.031$), frequency of caregiving ($\beta=-.14$), lower levels of psychological resilience ($\beta=-.204$), higher levels of memory impairment ($\beta=120$), and higher subscale scores for Worry and Felt Isolation ($\beta=.396$) and Heartfelt Sadness and Longing ($\beta=.165$).

Discussion

This present study explored how multiple variables contribute to the overall subjective burden experienced by caregivers. Descriptive statistics were also carried to understand the nature and reality of the caregiving role. Our findings revealed that over ninety percent of caregivers in our sample have been caring for their loved one for over a year, with almost fifty percent

Table 1. Scale scores and demographic information of the caregivers and care recipients.

Characteristic	Caregivers
Age Mean (SD)	54 years (12.9)
Age range	18-85 years
Gender, n (%)	
Female	459 (86.6%)
Male	70 (13.2%)
Prefer not to say	1 (.2%)
Ethnicity, n (%)	
White/White British	511 (96.4%)
Other ^a	19 (3.6%)
Relationship to care recipient, n (%)	
Parent	267 (50.5%)
Spouse/Partner	125 (23.7%)
Other ^b	137 (25.8%)
Duration of caregiving (years) n (%)	
<1 year	37 (7.0%)
1-3 years	224 (42.4%)
4-6 years	155 (29.4%)
7+ years	112 (21.2%)
Frequency of caregiving n (%)	
Full time	188 (35.7%)
5+ hours a day	66 (12.5%)
1-4 h a day	89 (16.9%)
A few times a week	150 (28.5%)
Once a week	33 (6.3%)
Additional Support n (%)	
None	86 (16.3%)
Very little support	135 (25.7%)
Limited support	131 (24.9%)
Good support	105 (20.0%)
Excellent support	69 (13.0%)
MM-CGI-SF score, mean (SD)	58.56 (14.41)
ZBI-SF score, mean (SD)	24.93 (9.07)
RS-14 score, mean (SD)	74.18 (13.92)
RM-BC_Frequency Score, mean (SD)	35.89 (4.46)
RM-BC_Reaction Score, mean (SD)	31.52 (21.11)
Care Recipient Information	
Care Recipients living situation, n (%)	
IL to supported accommodation	99 (22.1%)
Living with family to supported accommodation	44 (9.8%)
Supported accommodation to living with family	8 (1.8%)
IL to living with family and/or receiving home care	297 (66.3%)

Notes: IL=Independent living. ^a Participants categorized as "other" consisted of prefer not to say, other, black/black Asian, Asian/Asian British and mixed. ^b Participants categorized as "other" consisted of siblings, sons, daughters, friends/neighbour, other relatives, and other.

Table 2. Pearson's correlations for the impact of demographics, resilience, behavioural problems and pre-death grief on caregiver subjective burden.

	Caregiver Burden	1	2	3	4	5	6	7	8	9	10
1.Caregiver age	-.073	–									
2.Caregiver Gender (Female)	.103*	-.185**	–								
3.Living Situation	-.065	.041	-.075	–							
4.Caregiver Relationship	.098*	-.345**	.050	-.132**	–						
5.Caregiver Duration	.057	.191**	-.097*	-.152**	-.035	–					
6.Caregiver Frequency	-.151**	-.200**	.191**	-.381**	-.078	.010	–				
7.Additional Support	-.290**	-.210**	-.014	.020	.136**	-.050	.208**	–			
8.Resilience	-.306**	.112*	-.083	.064	-.025	-.051	-.021	.124*	–		
9.RMBC Frequency	.370**	-.118*	.083	-.042	-.006	-.066	-.095	-.181**	-.105*	–	
10.RMBC Reaction	.450**	-.075	.022	-.103	-.041	.004	.068	-.130	-.266**	.623**	–
11.MM-CGI-SF Total	.715**	-.021	.061	.068	-.195**	.116*	-.186**	-.332**	-.254**	.278**	.417**

Notes: RM-BC=Revised Memory & Behaviour Checklist; MM-CGI=Marwit-Meuser Caregiver Grief Inventory; ZBI-SF=Zarit Burden Interview Short Form. * $p<.05$. ** $p<.01$.

Table 3. Pearson's Correlations for the impact of behavioural problems subscales and MM-CGI-SF subscales on subjective caregiver burden.

MM-CGI-SF Subscales & RM-BC Subscales	ZBI-SF
MM-CGI-SF Subscale A, personal sacrifice and burden	.706**
MM-CGI-SF subscale B, heartfelt longing and sadness	.460**
MM-CGI-SF subscale C, worry and felt isolation	.621**
<i>RMBPC Subscales (Frequency)</i>	
Memory-related problem behaviours	.189**
Depression-related problem behaviours	.260**
Disruptive problem behaviours	.323**
<i>RMBPC Subscales (Reaction)</i>	
Memory-related problem behaviours	.353**
Depression-related problem behaviours	.210**
Disruptive problem behaviours	.433**

Notes: RM-BC = Revised Memory & Behaviour Checklist; MM-CGI = Marwit-Meuser Caregiver Grief Inventory; ZBI-SF = Zarit Burden Interview Short Form. ** $p < .05$. *** $p < .01$.

Table 4. Regression analysis indicating variables of caregiver burden.

Predictor Variables	B	t-Value	β
Age	.016	.402	.021
Gender	.954	.789	.037
Living Situation	-.170	-.635	-.031*
Relationship to loved one	-.337	-1.932	-.094
Caregiver duration	-.180	-.362	-.017
Caregiver frequency	-.985	-2.838	-.147**
Additional Support	-.286	-.787	-.039
Resilience	-.136	-4.263	-.204**
RMBC Memory Subscale	.652	2.459	.120**
RMBC Depression Subscale	.378	1.918	-.097
RMBC Disruption Subscale	-.222	-.957	-.048
HSL subscale (MM-CGI-SF)	.269	2.759	.165***
WFI subscale (MM-CGI-SF)	.673	6.024	.396**

Notes: RM-BC = Revised Memory & Behaviour Checklist; MM-CGI-SF = Marwit-Meuser Caregiver Grief Inventory Short Form; HSL = Heartfelt Sadness & Longing; WFI = Worry & Felt Isolation; PSB = Personal Sacrifice & Burden. * $p < .05$. ** $p < .01$.

of caregivers giving over five hours of each day to their caregiving role. Seventy percent of caregivers also subjectively experienced either none, very limited or little support. These findings illustrate the capacity and time caregivers dedicate to their loved ones. They provide a level of care, often with minimal support, which is fundamental to both their loved one and to society in an ageing population. However, this is not without cost. Our findings also illustrate that the level of burden and grief the sample experienced is substantial and is higher than in previously studied populations (Bédard et al., 2001; Liew et al., 2018; Chan et al., 2017). This emphasises the substantial risk of burnout and psychological distress caregivers may face.

The regression model explained 49% of the variance in subjective caregiver burden. Significant variables included care-recipients living situation, frequency of caregiving, psychological resilience, behavioural challenges in the care-recipient (memory-related problem behaviours) and caregiver anticipatory grief (heartfelt sadness & longing; worry & felt isolation). Two contextual factors were significant; caregiving living situation and frequency of caregiving, supports research illustrating that caregivers who live with their care-recipient and provide more frequent daily care, will experience higher burden (e.g. Lou et al., 2015). This finding was not unexpected as this subgroup of caregivers are more likely to feel greater responsibility for caregiving tasks and sacrifice more of their own needs as part of their familial duties (Carretero et al., 2009).

Age, gender, caregiver duration, relationship to loved one and additional support did not independently contribute to the regression model. The variables which did indicate significant

independent correlations within the bivariable analysis suggests that their relationship is mediated by other aspects of the caregiving dynamic. For example, previous research has found support networks to have significant mediating effects on burden and every aspect of the caregiving experience (Roth et al., 2005; Drentea et al., 2006). However, our results seem reasonable when viewed in conjunction with frequency of caregiving and living situation. "A primary caregiver, who lives with their loved one, and is devoted to all aspects of their care daily, is likely to feel heavily burdened irrespective of the level of their perceived support. Age and caregiving duration were not significantly correlated with caregiver burden in the bivariate correlations, and this indicated that burden may be pervasive across all ages and duration of caregiving."

The frequency of behavioural problems exhibited by the care recipient played a role in explaining caregiver burden. Correlations between burden and the RM-BC subscales initially indicated that disruptive problem behaviours had the strongest correlation with burden, followed by depression related problems and memory. However, in the regression model, the memory subscale remained the only significant independent behavioural variable. This finding suggests that the cognitive decline associated with the dementia journey and the caregiver's role of reminding and 'holding the memories' for both people plays a part in the burden they experience. It is also possible that changes in memory represents the most prominent loss of the essence of that person to the caregiver thus impacting burden. This may be a particular burden in a spousal relationship which has spanned many decades and included innumerable shared experiences (Bédard et al., 1997). Further, this highlights that particular focus should be made to behavioural interventions supporting the caregiver to understand and cope with the memory impairments that develop in dementia.

Psychological resilience was an important and significant variable associated with burden. Few authors have examined the link between resilience and caregiver burden; however, in line with our findings, research has reported higher resilience levels for caregivers who score lower on burden (Scott, 2013). More resilient caregivers have also reported positive coping strategies and caregiving decisions (Gaugler et al., 2007) – which is likely to have an impact on burden. This is the first study to date which explores resilience within a model of multiple psychological and contextual variables in a dementia sample. It is a noteworthy finding in suggesting that a caregiver's inner ability to cope, adapt and feel emotionally connected, has profound effects on their caregiver experience. Ultimately it suggests that more psychologically resilient caregivers, irrespective of other variables, are likely to experience less burden. Therefore, while it is imperative to not neglect the practical supports which should be afforded to dementia caregivers, there may be great benefit in providing psychological support which focuses on building resilience and strengthening the personal resources of the carer. Literature suggests mixed evidence around the benefits of resilience-enhancing interventions for dementia caregivers (Petriwskyj et al., 2016). Resilience as a construct is multifaceted and can be influenced by numerous interrelated factors. Adopting resilience-focused interventions within a wider suite of supports may be more beneficial than adopting it as single-approach alone.

AG had the strongest association with caregiver burden. The three MM-CGI subscales had strong positive significant associations with subjective caregiver burden. In the regression model, the two subscales included (HSL & WFI) were significant.

This implies that consequences such as loss of personal freedom, in addition to the more psychological concepts bounded within the grieving process – such as feelings of despair, isolation and powerlessness, are what contributes to overall burden. Similar to Holley and Mast (2009) findings, our analysis suggests that AG is an integral component in understanding caregiver burden in dementia and thus incorporating this concept into theoretical models, such as Pearlin et al. (1990) stress-process model, will lead to improvement in their utility. The variables already considered in the stress process model are critical and conceptualise the multifaceted nature of caregiving into one framework. However, it seems likely that AG would be a unique addition in conveying the more emotional and psychological losses associated with caring for a loved one, particularly with dementia. Although the primary dementia caregiver is perhaps the most vulnerable to experiencing symptoms associated with AG due to their role and being more directly affected by the incremental losses, it could also be argued that AG is not only unique to the primary caregiver but to the loved one's wider circle should they be close enough to witness the dementia journey. No research to date however has explored whether AG is an emotion experienced within the wider family circle and not just for the primary caregiver.

Our study illustrates several implications for practice. They provide insight into the extent of challenges associated with caregiver burden – a difficult emotional experience which will continue to grow in our ageing population. Firstly, our findings indicate that caregivers who live with their loved one and provide care frequently, are more vulnerable to experiencing psychological distress. This sheds light on a target subgroup population who may require further clinical intervention and support. Secondly, our findings illustrate the need for grief and resilience-focused psychological interventions. Healthcare professionals provide support to persons with dementia and their caregivers on a regular basis. These services aim to provide appropriate access to recommended psychosocial interventions; including respite, day care, caregiver skills training and psychoeducation programs (NICE guideline, 2018). It would be of benefit for these professionals to be knowledgeable of and where appropriate skilled in recognising the grief process so that they can refer to appropriate services.

While caregivers may have access to practical support (although arguably still limited) their emotional needs receive comparatively less attention within health care services. A considerable portion (18%) of caregivers experienced high AG in this sample, yet there are no interventions in the UK which specifically target the complexity of emotional processes associated with pre-death grief. This lack of understanding is likely to be exacerbated by the lack of norms we have on how to address grief. Pilot cognitive-behavioural grief intervention studies have been developed in some areas (Meichsner et al., 2016; MacCourt et al., 2017; Meichsner & Wilz, 2018) – which have found grief-specific strategies to greatly reduce burden. Implementing grief and resilience focused interventions in the UK may help caregivers cope with the multiple, incremental losses associated with the pre-death grieving process. They have the potential to not only improve the lives of the caregivers and the care receiver, but to possibly delay admissions of long-term care, thereby minimizing system burden.

This study has several limitations which require acknowledgment. Firstly, the sample composed of predominately white, UK-wide caregivers who have signed up to Join Dementia Research or online dementia groups, and thus wish to actively

participate in dementia-related studies. It is possible that individuals who volunteered to take part in this study differ from caregivers who chose not to participate thus causing potential bias in the results. A significantly lower number of younger and ethnic minority caregivers participated in the study thus limiting the ability to conduct relevant subgroup analyses with sufficient power. Secondly, and in comparison to previous studies, few characteristics on care recipients' functioning were recorded. Research has reported activities of daily living, in contrast to instrumental activities of daily living, apathy, falls risk and incontinence to be particularly stressful to caregivers (Miyamoto et al., 2010; Kim et al., 2012; Kawaharada et al., 2019; Davis & Tremont, 2007; Nagaratnam et al., 1998; Leggett et al., 2018). Thirdly, the care-recipients stage (i.e. mild, moderate, severe) or form of dementia was not recorded in this study. Research suggests that caregiver distress is sensitive to disease severity (Liew et al., 2018). This also means that the caregiver sample were at very different phases of their care trajectories. Earlier studies have reported a 'plateau-phase' where the balance is found after initial diagnosis (Berger et al., 2005). Subsequently, it is unclear whether the model holds for all phases. A final limitation to note is that this was a cross-sectional study - causality cannot be inferred from many of the findings thus restricting conclusions. While the methodology of this study shed light into aspects of the caregiving experience that contribute to caregiver burden, future research employing a longitudinal design would be informative as this would illustrate directionality of associations. It would tap into the temporal variations in grieving experiences, as well as exploring the multitude of practical issues associated with managing major transitions including living arrangements and accessing support.

To our knowledge, this is the first study to adopt a large UK sample and explore variables related to caregiver burden, including two relatively novel constructs – anticipatory grief and psychological resilience. Our findings highlight that both these constructs play a fundamental role in understanding caregiver burden. It is hoped these findings will inform psychological interventions and thus aid in ensuring caregivers have access to the best possible, practical, financial and emotional support they deserve.

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Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to containing information that could compromise the privacy of research participants.

References

- Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 11(3), 332.

- Alzheimer's Disease International. (2015). *The global impact of dementia: An analysis of prevalence, incidence, costs and trends*. Author.
- Alzheimer's Society. (2014). *Dementia UK: Update*. Author.
- Bédard, M., Molloy, D. W., Pedlar, D., Lever, J. A., & Stones, M. J. (1997). Associations between dysfunctional behaviors, gender, and burden in spousal caregivers of cognitively impaired older adults. *International Psychogeriatrics*, 9(3), 277–290.
- Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist*, 41(5), 652–657. <https://doi.org/10.1093/geront/41.5.652>
- Berger, G., Bernhardt, T., Weimer, E., Peters, J., Kratzsch, T., & Frolich, L. (2005). Longitudinal Study on the Relationship Between Symptomatology of Dementia and Levels of Subjective Burden and Depression Among Family Caregivers in Memory Clinic Patients. *Journal of Geriatric Psychiatry and Neurology*, 18(3), 119–128. <https://doi.org/10.1177/0891988704273375>
- Blandin, K., & Pepin, R. (2017). Dementia grief: A theoretical model of a unique grief experience. *Dementia (London, England)*, 16(1), 67–78. <https://doi.org/10.1177/1471301215581081>
- Boltz, M., Chippendale, T., Resnick, B., & Galvin, J. E. (2015). Anxiety in family caregivers of hospitalized persons with dementia: Contributing factors and responses. *Alzheimer Disease and Associated Disorders*, 29(3), 236–241. <https://doi.org/10.1097/WAD.0000000000000072>
- Branger, C., Enright, J., O'Connell, M. E., & Morgan, D. G. (2018). Variance in caregiver burden predicted by patient behaviors versus neuropsychological profile. *Applied Neuropsychology. Adult*, 25(5), 441–447. <https://doi.org/10.1080/23279095.2017.1323754>
- Brodsky, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, 11(2), 217–228. <https://doi.org/10.31887/DCNS.2009.11.2/hbrodsky>
- Carretero, S., Garcés, J., Ródenas, F., & Sanjosé, V. (2009). The informal caregiver's burden of dependent people: Theory and empirical review. *Archives of Gerontology and Geriatrics*, 49(1), 74–79.
- Chan, W. C. H., Wong, B., Kwok, T., & Ho, F. (2017). Assessing grief of family caregivers of people with dementia: Validation of the Chinese version of the Marwit–Meuser caregiver grief inventory. *Health & Social Work*, 42(3), 151–158.
- Chappell, N. L., & Penning, M. (1996). Behavioural problems and distress among caregivers of people with dementia. *Ageing and Society*, 16(1), 57–73. <https://doi.org/10.1017/S0144686X00003135>
- Chappell, N. L., Dujela, C., & Smith, A. (2014). Spouse and adult child differences in caregiving burden. *Canadian Journal on Aging / La Revue Canadienne du Vieillessement*, 33(4), 462–472. <https://doi.org/10.1017/S0714980814000336>
- Cheng, S. T. (2017). Dementia caregiver burden: A research update and critical analysis. *Current Psychiatry Reports*, 19(9), 64. <https://doi.org/10.1007/s11920-017-0818-2>
- Clay, O. J., Roth, D. L., Wadley, V. G., & Haley, W. E. (2008). Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and White dementia caregivers. *International Journal of Geriatric Psychiatry*, 23(8), 857–862. <https://doi.org/10.1002/gps.1996>
- Conde-Sala, J. L., Turró-Garriga, O., Calvo-Perxas, L., Vilalta-Franch, J., Lopez-Pousa, S., & Garre-Olmo, J. (2014). Three-year trajectories of caregiver burden in Alzheimer's disease. *Journal of Alzheimer's Disease: JAD*, 42(2), 623–633. <https://doi.org/10.3233/JAD-140360>
- Davis, J. D., & Tremont, G. (2007). Impact of frontal systems behavioral functioning in dementia on caregiver burden. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 19(1), 43–49. <https://doi.org/10.1176/jnp.2007.19.1.43>
- del-Pino-Casado, R., Rodríguez Cardosa, M., López-Martínez, C., & Orgeta, V. (2019). The association between subjective caregiver burden and depressive symptoms in carers of older relatives: A systematic review and meta-analysis. *PLoS One*, 14(5), e0217648. <https://doi.org/10.1371/journal.pone.0217648>
- Doris, S. F., Cheng, S. T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies*, 79, 1–26. <https://doi.org/10.1016/j.ijnurstu.2017.10.008>
- Drentea, P., Clay, O. J., Roth, D. L., & Mittelman, M. S. (2006). Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease. *Social Science & Medicine* (1982), 63(4), 957–967.
- Freyne, A., Kidd, N., Coen, R., & Lawlor, B. A. (1999). Burden in carers of dementia patients: Higher levels in carers of younger sufferers. *International Journal of Geriatric Psychiatry*, 14(9), 784–788. [https://doi.org/10.1002/\(SICI\)1099-1166\(199909\)14:9<784::AID-GPS16>3.0.CO;2-2](https://doi.org/10.1002/(SICI)1099-1166(199909)14:9<784::AID-GPS16>3.0.CO;2-2)
- Gaugler, J. E., Kane, R. L., & Newcomer, R. (2007). Resilience and transitions from dementia caregiving. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 62(1), P38–P44. <https://doi.org/10.1093/geronb/62.1.P38>
- Gilsenan, J., Gorman, C., & Shevlin, M. (2020). Exploratory factor analysis of the caregiver grief inventory in a large UK sample of dementia carers. *Ageing & Mental Health*, 26(2), 320–327. <https://doi.org/10.1080/13607863.2020.1839856>
- Grafström, M., Fratiglioni, L., Sandman, P. O., & Winblad, B. (1992). Health and social consequences for relatives of demented and non-demented elderly. A population-based study. *Journal of Clinical Epidemiology*, 45(8), 861–870.
- Holley, C. K., & Mast, B. T. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist*, 49(3), 388–396.
- Jones, P. S., & Martinson, I. M. (1992). The experience of bereavement in caregivers of family members with Alzheimer's disease. *Image: The Journal of Nursing Scholarship*, 24(3), 172–176. <https://doi.org/10.1111/j.1547-5069.1992.tb00714.x>
- Judge, K. S., Menne, H. L., & Whitlatch, C. J. (2010). Stress process model for individuals with dementia. *The Gerontologist*, 50(3), 294–302.
- Kawaharada, R., Sugimoto, T., Matsuda, N., Tsuboi, Y., Sakurai, T., & Ono, R. (2019). Impact of loss of independence in basic activities of daily living on caregiver burden in patients with Alzheimer's disease: A retrospective cohort study. *Geriatrics & Gerontology International*, 19(12), 1243–1247.
- Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, 68(4), 846–855. <https://doi.org/10.1111/j.1365-2648.2011.05787.x>
- Large, S., & Slinger, R. (2015). Grief in caregivers of persons with Alzheimer's disease and related dementia: A qualitative synthesis. *Dementia (London, England)*, 14(2), 164–183. <https://doi.org/10.1177/1471301213494511>
- Leggett, A. N., Polenick, C. A., Maust, D. T., & Kales, H. C. (2018). Falls and hospitalizations among persons with dementia and associated caregiver emotional difficulties. *The Gerontologist*, 58(2), e78–e86.
- Liew, T. M., Yeap, B. I., Koh, G. C. H., Gandhi, M., Tan, K. S., Luo, N., & Yap, P. (2018). Detecting Predeath grief in family caregivers of persons with dementia: Validity and utility of the Marwit–Meuser caregiver grief inventory in a multiethnic Asian population. *The Gerontologist*, 58(2), e150–e159. <https://doi.org/10.1093/geront/gnx097>
- Lindauer, A., & Harvath, T. A. (2014). Pre-death grief in the context of dementia caregiving: A concept analysis. *Journal of Advanced Nursing*, 70(10), 2196–2207. <https://doi.org/10.1111/jan.12411>
- Lou, Q., Liu, S., Huo, Y. R., Liu, M., Liu, S., & Ji, Y. (2015). Comprehensive analysis of patient and caregiver predictors for caregiver burden, anxiety and depression in Alzheimer's disease. *Journal of Clinical Nursing*, 24(17–18), 2668–2678. <https://doi.org/10.1111/jocn.12870>
- MacCourt, P., McLennan, M., Somers, S., & Krawczyk, M. (2017). Effectiveness of a grief intervention for caregivers of people with dementia. *OMEGA - Journal of Death and Dying*, 75(3), 230–247. <https://doi.org/10.1177/0030222816652802>
- Marwit, S. J., & Meuser, T. M. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist*, 42(6), 751–765. <https://doi.org/10.1093/geront/42.6.751>
- Marwit, S. J., & Meuser, T. M. (2005). Development of a short form inventory to assess grief in caregivers of dementia patients. *Death Studies*, 29(3), 191–205. <https://doi.org/10.1080/07481180590916335>
- Meichsner, F., & Wilz, G. (2018). Dementia caregivers' coping with pre-death grief: Effects of a CBT-based intervention. *Ageing & Mental Health*, 22(2), 218–225. <https://doi.org/10.1080/13607863.2016.1247428>
- Meichsner, F., Schinköthe, D., & Wilz, G. (2016). Managing loss and change: Grief interventions for dementia caregivers in a CBT-based trial. *American Journal of Alzheimer's Disease & Other Dementias*, 31(3), 231–240. <https://doi.org/10.1177/1533317515602085>
- Meuser, T. M., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, 41(5), 658–670. <https://doi.org/10.1093/geront/41.5.658>

- Meuser, T. M., Marwit, S., & Sanders, S. (2004). Assessing grief in family caregivers. In *Living with grief: Alzheimer's disease* (pp. 170–195). Washington, DC: Hospice Foundation of America.
- Miyamoto, Y., Tachimori, H., & Ito, H. (2010). Formal caregiver burden in dementia: Impact of behavioral and psychological symptoms of dementia and activities of daily living. *Geriatric Nursing, 31*(4), 246–253. doi: <https://doi.org/10.1016/j.gerinurse.2010.01.002>
- Nagaratnam, N., Lewis-Jones, M., Scott, D., & Palazzi, L. (1998). Behavioral and psychiatric manifestations in dementia patients in a community: Caregiver burden and outcome. *Alzheimer Disease and Associated Disorders, 12*(4), 330–334. <https://doi.org/10.1097/00002093-199812000-00013>
- NICE guideline. (2018). Dementia: Assessment, management and support for people living with dementia and their carers. <https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#supporting-carers>
- Noyes, B. B., Hill, R. D., Hicken, B. L., Luptak, M., Rupper, R., Dailey, N. K., & Bair, B. D. (2010). The role of grief in dementia caregiving. *American Journal of Alzheimer's Disease and Other Dementias, 25*(1), 9–17. doi: <https://doi.org/10.1177/1533317509333902>
- Ong, H. L., Vaingankar, J. A., Abdin, E., Sambasivam, R., Fauziana, R., Tan, M.-E., Chong, S. A., Goveas, R. R., Chiam, P. C., & Subramaniam, M. (2018). Resilience and burden in caregivers of older adults: Moderating and mediating effects of perceived social support. *BMC Psychiatry, 18*(1), 27. <https://doi.org/10.1186/s12888-018-1616-z>
- O'Rourke, N., Kupferschmidt, A. L., Claxton, A., Smith, J. Z., Chappell, N., & Beattie, B. L. (2010). Psychological resilience predicts depressive symptoms among spouses of persons with Alzheimer disease over time. *Aging & Mental Health, 14*(8), 984–993. <https://doi.org/10.1080/13607863.2010.501063>
- Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., Leipert, B. D., & Henderson, S. R. (2010). The positive aspects of the caregiving journey with dementia: Using a strengths-based perspective to reveal opportunities. *Journal of Applied Gerontology, 29*(5), 640–659. <https://doi.org/10.1177/0733464809341471>
- Pearlin, L. I. (2010). The life course and the stress process: some conceptual comparisons. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 65B*(2), 207–215. <https://doi.org/10.1093/geronb/gbp106>
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583–594. doi: <https://doi.org/10.1093/geront/30.5.583>
- Petriwskij, A., Parker, D., O'Dwyer, S., Moyle, W., & Nucifora, N. (2016). Interventions to build resilience in family caregivers of people living with dementia: A comprehensive systematic review. *JBI Database of Systematic Reviews and Implementation Reports, 14*(6), 238–273. <https://doi.org/10.11124/JBISRIIR-2016-002555>
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250–267. <https://doi.org/10.1037/0882-7974.18.2.250>
- Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist, 45*(1), 90–106. doi: <https://doi.org/10.1093/geront/45.1.90>
- Rando, T. A. (1986). A comprehensive analysis of anticipatory grief: Perspectives, processes, promises, and problems. In T. Rando (Ed.), *Loss and anticipatory grief* (pp. 1–36). Lexington Books.
- Rando, T. A. (2000). Anticipatory mourning: A review and critique of the literature. In T. Rando (Ed.), *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones, and their caregivers* (pp. 17–50). Research Press.
- Roth, D. L., Mittelman, M. S., Clay, O. J., Madan, A., & Haley, W. E. (2005). Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychology and Aging, 20*(4), 634–644. <https://doi.org/10.1037/0882-7974.20.4.634>
- Ruisoto, P., Contador, I., Fernández-Calvo, B., Serra, L., Jenaro, C., Flores, N., Ramos, F., & Rivera-Navarro, J. (2020). Mediating effect of social support on the relationship between resilience and burden in caregivers of people with dementia. *Archives of Gerontology and Geriatrics, 86*, 103952. <https://doi.org/10.1016/j.archger.2019.103952>
- Schulz, R., & Williamson, G. M. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging, 6*(4), 569–578. <https://doi.org/10.1037/0882-7974.6.4.569>
- Scott, C. B. (2013). Alzheimer's disease caregiver burden: Does resilience matter? *Journal of Human Behavior in the Social Environment, 23*(8), 879–892. doi: <https://doi.org/10.1080/10911359.2013.803451>
- Shankar, K. N., Hirschman, K. B., Hanlon, A. L., & Naylor, M. D. (2014). Burden in caregivers of cognitively impaired elderly adults at time of hospitalization: A cross-sectional analysis. *Journal of the American Geriatrics Society, 62*(2), 276–284. doi: <https://doi.org/10.1111/jgs.12657>
- Sherwood, P. R., Given, C. W., Given, B. A., & Von Eye, A. (2005). Caregiver burden and depressive symptoms: Analysis of common outcomes in caregivers of elderly patients. *Journal of Aging and Health, 17*(2), 125–147. <https://doi.org/10.1177/0898264304274179>
- Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioural problems in dementia: The revised memory and behaviour problems checklist. *Psychology and Aging, 7*(4), 622–631. <https://doi.org/10.1037/0882-7974.7.4.622>
- Wagnild, G. (2009). A review of the Resilience Scale. *Journal of Nursing Measurement, 17*(2), 105–113. <https://doi.org/10.1891/1061-3749.17.2.105>
- Wagnild, G. M., & Young, H. M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement, 1*(2), 165–178.
- Walker, R. J., & Pomeroy, E. C. (1997). The impact of anticipatory grief on caregivers of persons with Alzheimer's disease. *Home Health Care Services Quarterly, 16*(1–2), 55–76. https://doi.org/10.1300/J027v16n01_05
- Zarit, S. H., & Whitlatch, C. J. (1992). Institutional placement: Phases of the transition. *The Gerontologist, 32*(5), 665–672. <https://doi.org/10.1093/geront/32.5.665>
- Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). *The hidden victims of Alzheimer's disease: Families under stress*. New York University Press.
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20*(6), 649–655. <https://doi.org/10.1093/geront/20.6.649>