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**Caring for someone with dementia: An investigation of factors associated
with carer mood**

&

Clinical Research Portfolio

Volume I

(Volume II bound separately)

Helen Janet Pulford, BSc, MSc

Submitted in partial fulfilment of the requirement of the

Degree of Doctorate in Clinical Psychology.

Institute of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

August 2015



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Systematic Review

A systematic review of the role of self-esteem on dementia caregivers' experiences

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Prepared in accordance with the instructions to authors for the Journal of Aging & Mental Health (see Appendix 1.1)

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Abstract

Objectives. Understanding the role of carer self-esteem in dementia care may have clinical implications for enhanced carer support. Few reviews have focused on the potential associations between self-esteem and dementia caregiver experience. A systematic literature search and quality rating of the quantitative research evidence on the role of self-esteem in dementia caregiving was therefore undertaken.

Methods. A systematic electronic and manual literature search identified 222 articles overall. Of these, 8 met the review inclusion criteria. Crowe's Critical Appraisal Tool (CCAT) was used to evaluate each article and relevant data was extracted and synthesized.

Results. Five appraised studies had a quality rating of 75% or over, presenting a practical and appropriate design. Associations were found between high levels of self-esteem and the following: increased social support, less significant loss of relationships, increased quality of relationship with the care-recipient and lower income. Caregiver self-esteem was found to correlate negatively with depression, depressive cognitions, anxiety, loss of self and stress but not carer burden.

Conclusions. These findings suggest that interventions aimed at dementia caregivers should focus on the examination and amelioration of self-esteem. This may be significant associated with their well-being and, ultimately, the care of their relative with dementia.

Introduction

Dementia is a significant public health challenge worldwide (Scottish Government, 2013). The Alzheimer's Society (2014) estimate that the number of UK inhabitants diagnosed with dementia will exceed two million by 2050. The term dementia encompasses a number of different neurological disorders, for instance, Alzheimer's disease, vascular or multi-infarct dementia, Lewy-body and fronto-temporal dementia. It is used to describe a progressive deterioration in cognitive ability and can be associated with a change in emotional and behavioural functioning. Early manifestations of the syndrome may be characterised by declining memory, with reduced ability to learn or recall new information. As dementia progresses, the severity of these symptoms can reduce a person's ability to live independently (Alzheimer's Association, 2014). In these instances carers are often required to help with everyday tasks, such as washing, dressing and eating.

Two thirds of people diagnosed with dementia are cared for in the community (Alzheimer's Society, 2012). The task of caring for an elderly person in poor health is often undertaken by their immediate family (Kasuya, Polgar-Bailey & Takeuchi, 2000). Research has demonstrated that 26 – 32% of dementia carers had a depressive disorder, compared with 0 – 4 % of non-caregivers (Dura, Stukenberg & Kiecolt-Glaser, 1991; Kiecolt-Glaser, Dura, Specier, Trask & Glaser, 199). This pattern was also indicated for anxiety, with 10% of carers meeting criteria for clinical anxiety compared to 1% of non-caregivers (Dura et al., 1991).

Dementia caregivers are also reported to experience high levels of burden (Brodaty, 2002; McCann, Hebert, Bienias, Morris & Evans, 2004). Ineffectively supporting carers with burden may place individuals with dementia at risk of patient neglect and abuse (Messinger-Rapport, McCallum & Hujer, 2006). It is therefore crucial to understand the factors contributing to caregivers' psychological well-being (Zarit, Reever & Bach-Peterson, 1980; Carretero, Garcés, Ródenas, Sanjosé, 2009).

It is also important that the role of mediating factors - factors which explain the relationships between contributing factors and carer outcome - are recognized. Pearlin, Mullan, Semple & Skaff (1990) devised a theoretical framework to conceptualize the relationship between carer stress and negative outcome (see Appendix 1.12). This Stress Process Model highlights how background and contextual factors, such as caregiver

characteristics, relate to primary and secondary stress indicators. Pearlin et al. (1990) posit that these stress indicators result in intra-psychic strains which impact upon the relationship between stress and negative outcome in caregivers. They also outline that the relationship between background characteristics and other elements of the stress process may be mediated by caregiver resources.

According to the model, a caregiver's age, gender or education may be associated with how they experience stress derived from the care-recipient's cognitive status or range of caregiver activities. This may in turn result in further stress generated by financial or familial difficulties. These stressors then influence the caregiver's self-esteem or self-efficacy, which further impacts upon the caregiver's well-being or physical health. According to the model, social support and coping style could be resources which explain the association between the caregiver characteristics and self-esteem, self-efficacy, well-being and stressors.

A review examining the influence of personality in dementia caregiving emphasized that underlying personality dispositions may also account for these differences (Lautenschlager, Kurz, Loi & Cramer, 2013). Lautenschlager and colleagues concluded from a review of 16 studies that elevated neuroticism led to an increase in caregiver burden, depression and poorer coping. Another review (Orgeta & Leung, 2015) concluded personality factors are consistently associated with psychological distress in dementia caregivers and their care-recipients.

To date, few reviews have focused on the role of personality factors in dementia carer outcome and, to the author's knowledge, none have specifically examined the role of self-esteem. Several forms of self-esteem are of relevance to this research area: Personal, social and care-derived self-esteem. Personal self-esteem represents the conventional notion of self-esteem as a global evaluation of the self, whereas social self-esteem refers to the evaluation of oneself in relation to others (Gruenewald, Kemeny, Aziz & Fahey, 2004). Care-derived self-esteem consists of the evaluation of oneself in a carer role (Given et al., 1992). Understanding the role of carer self-esteem in dementia care may have clinical implications for enhanced carer support, resulting in better outcomes for dementia caregivers and their care-recipients.

Aim

To undertake a systematic review and quality rating of the quantitative research evidence on the role of self-esteem in dementia caregiving.

Research Questions

1. What conclusions can be drawn from the quantitative research investigating the association between self-esteem and dementia caregiver psychological well-being?
2. What knowledge is available on the association between self-esteem and other dementia caregiver or care-recipient outcomes?

Method

Search Strategy

A librarian was consulted to ensure the comprehensiveness of the adopted search terms and strategy. A systematic literature search was conducted on the following computerised databases to ensure the search targeted key areas for research pertinent to this review: Medline (1950 to 22/04/2015), PsychInfo (1906 to 23/04/2015), PsychArticles (1994 to 23/04/2015), CINAHL (1982 to 22/04/2015) Psychology and Behavioural Sciences Collection (1991 – 23/04/2015), EMBASE (via OVID) and ASSAI (via OVID).

Titles and abstracts were searched using the terms ‘Alzheimer’ OR ‘Alzheimer’s disease’ OR ‘Alzheim*’ OR ‘dementia’ OR ‘dement*’, ‘caregiver’ OR ‘care-giver’ OR ‘carer’ OR ‘care-giv*’ OR ‘caregiv*’ OR ‘carer*’, ‘self-esteem’ OR ‘esteem’ OR ‘self-worth’. These three searches were then combined with the AND operator to identify the research literature on the role of self-esteem in dementia caregivers experiences. A hand search of the reference lists for included studies was then carried out to identify any additional relevant articles. Relevant articles indicated by these two search methods were then entered into Web of Science to allow identification of articles citing these articles. This did not highlight any additional articles.

Inclusion criteria

The following dementia presentations were included in the review:

- Alzheimer’s disease

- Vascular dementia
- Dementia with Lewy Bodies
- Fronto-temporal dementia
- Any rarer types of dementia

All forms of care-recipient/care-giver relationship were accepted into the review, including spouse, sibling, child or grandchild, professional carer and friend. The review also included carers living at home or in full time care facilities.

Exclusion criteria

Self-esteem was defined as a person's belief or confidence in their own self worth, rather than in their abilities. Consequently, articles that focused on self-efficacy in caregivers were excluded. The use of measures in studies examining self-concept without specific reference to self-esteem varied greatly. Ensuring that these studies were assessing caregivers' levels of self-esteem or self-worth only was considered problematic. Therefore these studies were also excluded.

Book chapters, systematic reviews and meta-analyses were excluded from the review as were studies:

- relating to the examination of the role of self-esteem in people with dementia
- whose sample comprised people with learning disabilities and a diagnosis of dementia
- relating to interventions for people with dementia or their caregivers
- in which self-esteem was mentioned incidentally
- in which samples combined caregivers and non-caregivers
- involving solely qualitative analysis
- not available in English

Quality Assessment

The NHS guidance for systematic reviews emphasises the need for a structured approach to quality assessment for quantitative studies. This review utilized the Crowe Critical Appraisal Tool (CCAT, v1.4 – see Appendix 1.2) in conjunction with the CCAT

User Guide (v1.4) to ensure validity and reliability (Crowe & Sheppard, 2011). This version of the CCAT was developed by Crowe (2013) and comprises 22 items divided into the following seven categories: Introduction, Sampling, Design, Data Collection, Results, Ethical Matters and Discussion. This tool provided the option to appraise the article's category and total quality rating. This prevents studies that receive a high total score but poor category scores being concealed amongst articles which score highly throughout categories. Total score is represented by number of points out of 39 and converted into a percentage score. Articles were rated by the author and a fellow trainee clinical psychologist. It was agreed at the outset that total scores within 2 points of each other would be accepted as reliable ratings. Initially, the raters agreed on the quality scores for 50% of studies. For the remaining articles, disagreements represented different scores in the 'ethical considerations' category, with one rater scoring zero where all ethical prompts were not mentioned. A process was agreed whereby articles describing processes of informed consent, ethical approval procedures or other relevant considerations would receive scores. Following this, a consensus was reached.

Synthesizing Quantitative Research

Narrative analysis was used to synthesize the data. In this context, narrative analysis refers to an approach by which words and text are used to summarise, explain or synthesize research findings from a broad range of studies (Popay et al., 2006). This was considered preferable to statistical synthesis for several reasons. Firstly, the statistical methods used in the studies varied; the majority of studies used regression analyses, however, type of regression model varied widely. Additionally, self-esteem was not consistently included in the regression analysis or was combined with other variables. This made it challenging to report any statistics meaningfully. Furthermore, a proportion of studies used only correlational analysis to investigate the relationship between self-esteem and other factors. As the review set out to analyze the role of self-esteem specifically, statistical synthesis of the regression models relating more widely to caregiver experience was deemed beyond the scope of this review. Therefore, using narrative synthesis was considered an appropriate way to meet the objectives of this review.

Results

In total, 222 titles and abstracts were screened for inclusion. Figure 1 presents a flowchart of the review process. From the initial search, 32 full text articles were reduced to 8 articles which met inclusion criteria. Excluded articles were care-recipient intervention studies (n=7), referred exclusively to care-recipient self-esteem (n=4), dissertations (n=3), not in English (n=3), only mentioned self-esteem incidentally (n=3), book chapters (n=2), studies which combined caregivers and non-caregivers (n=1) or were qualitative in design (n=1). Screening the reference lists of the included articles did not identify any further studies that met inclusion criteria.

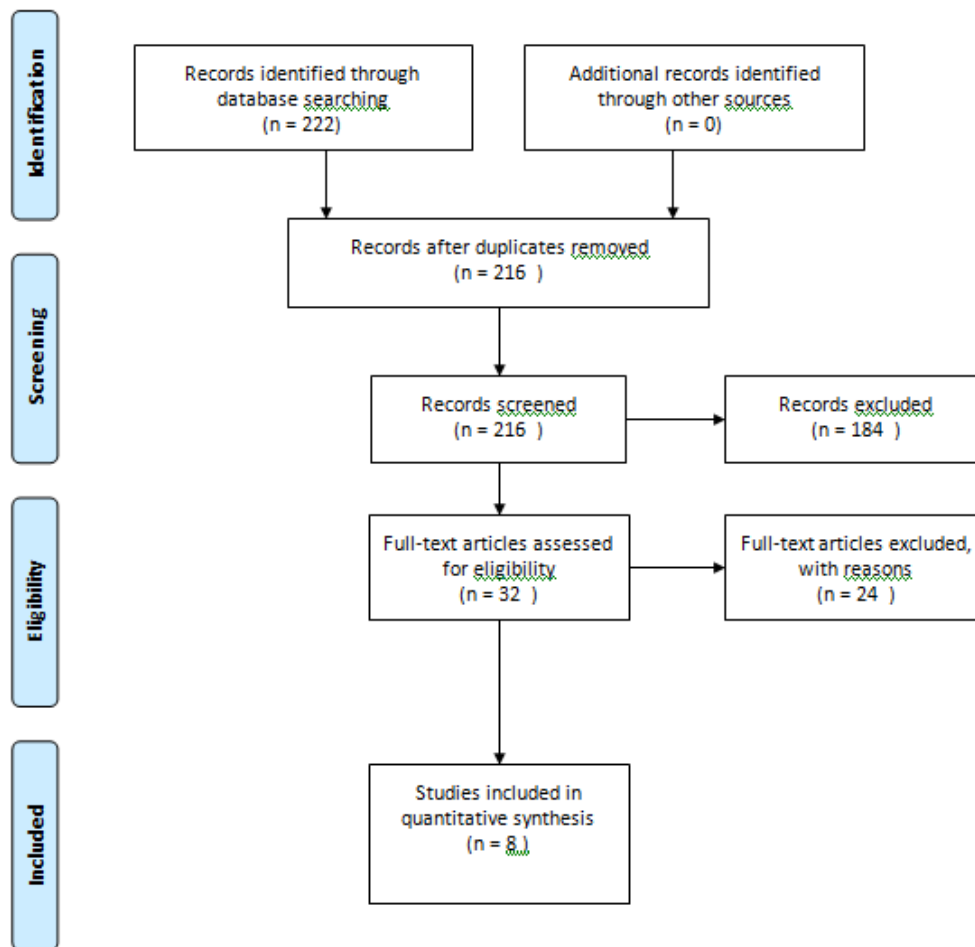


Figure 1. PRISMA (2009) Flow diagram of studies.

Methodological Quality

Using the CCAT quality assessment tool, five appraised studies had a quality rating of 75% or more. These studies presented a design that was practical and appropriate to the aims of the study. Occasionally the convenience of the samples meant that the generalizability of findings was compromised. For one particular article (Skaff & Pearlin, 1992), ratings were much lower (50%) and this reflected a lack of methodological detail that made appraisal of the quality less straightforward. Total quality ratings are presented in Table 1.

Studies Identified

The caregiver and patient characteristics of included articles are highlighted in Table 1. The studies examined associations between self-esteem and caregiver outcome, including burden (Robinson, 1990), depression and depressive cognitions (Pagel & Becker, 1987), positive and negative caregiving experiences (Meiland, Danse, Wendte, Klazinga & Gunning-Schepers, 2001; Talkington-Boyer & Snyder., 1994), loss of self (Skaff & Pearlin, 1992), chronic caregiver stress (Vedhara, Shanks, Anderson & Lightman, 2000), bereavement (Aneshensel, Botticello & Yamamoto-Mitani, 2004) and physical mistreatment (Vanderweerd, Paveza, Walsh & Corvin, 2013). The majority of studies were cross-sectional in nature (n=6), with two using a prospective design (Aneshensel, Botticello & Yamamoto-Mitani, 2004; Vedhara, Shanks, Anderson & Lightman, 2000).

In total, studies researched the experiences of 1,484 caregivers and 1,306 care-recipients. There was a higher proportion of female caregivers and female care-recipients (see Table 1). Caregivers ranged from the ages of 24 – 89 and were predominantly of Caucasian ethnicity. Care-recipients ranged from 44 – 96 years of age and had been displaying symptoms of dementia from 1 month to 16 years. The majority of care-recipients had a diagnosis of Alzheimer's disease, however, care-recipients with vascular dementia, multi-infarct dementia and Parkinson's disease with progressive dementia also made up the sample. Research took place in the U.K., Netherlands and various regions in the U.S.. Care-recipients predominantly resided in the community, with caregivers providing care between 1- 16 hours per day (Robinson, 1990; Vedhara, Shanks, Anderson & Lightman, 2000) and 1 – 81+ hours per week (Meiland, Danse, Wendte, Klazinga & Gunning-Schepers, 2001).

Table 1. Sample characteristics and quality ratings for included articles

Study (Author, Year, Country, Quality Ratings %)	Caregiver	Care-recipient
Aneshensel, Botticello & Yamamoto-Mitani (2004) California, USA 85%		
<i>N</i>	N = 291 Primary family caregivers for community-residing persons with dementia	N = 291 People with dementia
Age	Spousal carer: M = 72 years (SD = 8) Adult child carer: M = 50 years (SD = 9)	Mean age deceased: 80 years (SD=8)
Gender	27.49% Male 72.51 % Female	45% Male 54% Female
Ethnicity	88.66% Non-Hispanic white	-
Relationship to care-recipient	35.4% Wife 22.4% Husband 27.15% Daughter 15.2% Other	-
Education	M = 14 years	-
Duration of caregiving	M = 5 years	-
Daily hours caregiving	NA	-
Illness duration	-	M = 7 years
Residence	-	NA
Dementia type	-	NA
Meiland, Danse, Wendte, Klazinga & Gunning- Schepers (2001) Amsterdam, The Netherlands 90%		
<i>N</i>	N=93 Informal caregivers of dementia patients with new indications for psychogeriatric	N=93 People with dementia

Study (Author, Year, Country, Quality Ratings %)	Caregiver	Care-recipient
	nursing-home admission	
Age	24 – 89 years (M = 57, SD = 12)	51 – 96 years (M = 83, SD = 8)
Gender	57% Female 43% Male	70% Female 30% Male
Ethnicity	81% Native to the Netherlands	-
Relationship to care-recipient	16% Spouse 34% Daughter 20% Son 21% Other family 2% Friend	-
Education	NA	-
Duration of caregiving	M = 36 months (ranged from 1 - 180m)	-
Daily hours caregiving	Informal care hours/week: 1-2: 7 carers 3-8: 32 " 9-25: 19 " 26-80: 10 " <81: 22 " Missing: 3 "	-
Illness duration	-	NA
Residence	-	29% alone 15% with spouse 7% with other people 42% in institution
Dementia type	-	51% Alzheimer's disease 8% Vascular dementia 34% other
Pagel & Becker (1987) Washington, USA 85%		
<i>N</i>	N=68 spouse caregivers of patients	N=68 people with Alzheimer's disease
Age	37 – 85 years	NA

Study (Author, Year, Country, Quality Ratings %)	Caregiver	Care-recipient
	(M=65, SD= 9)	
Gender	43 Female 25 Male	NA
Ethnicity	NA	-
Relationship to care-recipient	NA	-
Education	NA	-
Duration of caregiving	NA	-
Daily hours caregiving	NA	-
Illness duration	-	Average time since diagnosis: 27 months
Residence	-	Residence: 47 at home 21 institutionalized
Dementia type	-	NA
Robinson (1990) Kentucky, USA 68%		
<i>N</i>	N=31 adult caregivers caring for an impaired elder with dementia	N=31 elders with dementia
Age	77% 50+ years	53 – 85 years
Gender	87% White female 13% Other	NA
Ethnicity		NA
Relationship to care-recipient	68% spouse or adult child of the care-recipient	-
Education	NA	-
Duration of caregiving	M= 2.6 years (range: 2 – 7 years).	-
Daily hours caregiving	M= 3.3 hours (range 1 – 16h)	-
Illness duration	-	NA
Residence	-	67% live with caregiver 24% live in nursing home
Dementia type	-	NA
Skaff & Pearlin		

Study (Author, Year, Country, Quality Ratings %)	Caregiver	Care-recipient
(1992) California, USA 50%		
<i>N</i>	N= 527, 310 spouses and 219 adult children caring for a relative with Alzheimer's disease.	N=527 people with Alzheimer's disease.
Age	62 years (SD = 13)	NA
Gender	NA	NA
Ethnicity	NA	-
Relationship to care-recipient	-	NA
Education	M=14 years	-
Duration of caregiving	NA	-
Daily hours caregiving	NA	-
Illness duration	-	NA
Residence	-	NA
Dementia type	-	NA
Talkington-Boyer & Snyder (1994) Texas, USA 70%		
<i>N</i>	N=110 caregivers to family members with Alzheimer's disease	N= 110 people with Alzheimer's disease
Age	28 – 81 years (M= 60, SD =12)	44 – 94 years (M=74, SD= 9)
Gender	24% Male 76% Female	47% Male 53% Female
Ethnicity	92.7% White 5.5% African American 1.8% Other	-
Relationship to care-recipient	NA	-
Education	7 – 10 years	-
Duration of caregiving	1 – 16 years	-
Daily hours caregiving	NA	-

Study (Author, Year, Country, Quality Ratings %)	Caregiver	Care-recipient
Illness duration	-	Years since caregiver noticed symptoms: 1 – 20.
Residence	-	67% live with caregiver 24% live in nursing home
Dementia type	-	NA
VanderWeerd, Paveza, Walsh & Corvin (2013) Florida, USA 93%		
<i>N</i>	N=254 family caregivers of people with Alzheimer's disease	N=76 elders with Alzheimer's disease
Age	63 years (+/- 13)	78 years (+/- 8)
Gender	74.8% Female 25.2% Male	59% Female 41% Male
Ethnicity	85.1% Caucasian 10.3% Hispanic 4.6% African American	84.8% Caucasian 9.4% Hispanic 4.5% African American 1.3% Other.
Relationship to care-recipient	34.2% Wife 18.5% Husband 33.2% Child 14% Other.	-
Education	NA	-
Duration of caregiving	NA	-
Daily hours caregiving	NA	-
Illness duration	-	Dementia symptoms noticed: 1-5: 1.3% 6-10: 24.1% 11-15: 49.1% 16-20: 25.4%
Residence	-	NA
Dementia type	-	NA
Vedhara, Shanks, Anderson & Lightman (2000) Bristol, United Kingdom		

Study (Author, Year, Country, Quality Ratings %)	Caregiver	Care-recipient
78%		
<i>N</i>	N=50 spousal caregivers of patients with dementia	N=50 patients with dementia
Age	72 years (+/- 8 years)	NA
Gender	24 Male 26 Female	NA
Ethnicity	100% White	NA
Relationship to care-recipient	NA	-
Education	NA	-
Duration of caregiving	NA	-
Daily hours caregiving	M= 13.8 hours	-
Illness duration	-	Mean time since diagnosis: 3.5 years
Residence	-	NA
Dementia type	-	78% Alzheimer's disease 17% Multi-infarct dementia 5% Parkinson's disease with progressive dementia

Nb. NA indicates information is not available

The design details for each study, as well as measures used and key findings, are presented in Table 2. Four studies assessed global self-esteem using Rosenberg's Self-Esteem scale (RSE; Rosenberg, 1965), the Tennessee Self-Concept Scale (TSCS; Fitts, 1972) and the Self-Esteem Self Report Inventory (SRI; Bown & Richek, 1967). The remaining studies examined social and personal self-esteem using the Culture Free Self-Esteem Inventory (CFSEI; Battle, 1981) and care-derived self-esteem using the Caregiver Reaction Assessment Scale (CRA; Given et al., 1992).

In correspondence with the research questions, articles were grouped under two different headings; one for those which examined the relationship between self-esteem and psychological well being (such as anxiety and depression) and the other covering those focusing on other carer or care-recipient outcome, for instance, carer burden or care-recipient physical mistreatment.

Studies examining the association between self-esteem and dementia caregiver psychological well-being

Regarding the first research question, one prospective study investigated the importance of stressors and psychosocial variables in the stress process (Vedhara et al., 2000). A one-way ANOVA revealed spousal dementia caregivers had a tendency to report lower personal self-esteem compared with non-caregivers at 0-, 3- and 6 - month follow up. The levels of social self-esteem did not differ between the groups. Results suggested that anxiety, depression and stress all correlated negatively with personal self-esteem, whereas only depression significantly correlated with social self-esteem (see Table 2). A factor analysis revealed that the combination of self-controlling-, confrontational- and escape avoidance-coping, poor self concept and low personal self-esteem significantly predicted stress, depression and anxiety at 3 and 6 months. However, it is impossible to ascertain from the analysis the contribution that self-esteem plays in these predictions.

The second prospective study examined depressive symptoms in caregivers following bereavement of the care-recipient, using a model depicting the care-related stress process and course of depressive symptoms after bereavement (Aneshensel et al., 2004). Caregivers completed six face to face interviews over a 6 year period. Comparisons were made between the carers' responses pre- and post-bereavement. The authors reported that self esteem was higher among caregivers who have few symptoms of depression after bereavement than those

with many symptoms after bereavement. High levels of self-esteem appeared to decrease the likelihood of being repeatedly symptomatic and temporarily distressed following bereavement.

In 1987, Pagel and Becker examined the mechanisms by which social supports and personality variables buffer against depression and depressive cognitions. In their predictive study, spouses of people with Alzheimer's disease participated in four interviews, each examining one of the following concepts: their attributions/expectations about their spouses Alzheimer's disease, social support, self-esteem and caregiver depression and depressive cognitions. Results indicated that higher levels of self-esteem were related to lower depression scores. Multiple hierarchical regression analysis indicated that higher levels of self-esteem were significantly associated with lower depressive cognitions. In conclusion, the authors highlighted the potential for high self-esteem to be indirectly related to reduced depression through its association with depressive cognitions. The authors emphasized that developing understanding of the contribution of self-esteem could potentially expand knowledge of why some caregivers experience depressive cognitions, where others do not.

Skaiff & Pearlin (1992) set out to investigate 'loss of self' in spouse and adult caregivers for relatives with Alzheimer's disease. Using structured interviews, they assessed caregivers loss of self (diminishment of their identity due to caregiver demands), self-esteem, competence, self-gain and depression. Correlational analysis indicated that self-esteem and loss of self were negatively and significantly correlated (see Table 2), with authors assuming that global self-esteem may buffer against caregivers experiencing a loss of self when in a caring role.

Table 2. Methodology and key findings for identified articles

Study (Authors, Year)	Research methodology/ Areas of focus	Standardized measure(s) used	Model used and key findings in the context of self-esteem
Aneshensel, Botticello & Yamamoto-Mitani (2004)	<p>Prospective design examining caregiver depressive symptoms after bereavement.</p> <p><i>Care-recipient</i> Cognitive difficulty, illness duration, residence</p> <p><i>Caregiver</i> Depressive symptoms, grief, self-esteem, mastery, network and support, various components of loss</p> <p><i>Caregiving</i> Caring duration, quality of pre-illness relationship</p>	<p><i>About caregiver:</i> 7 items of the Hopkins Symptom Checklist to measure depression</p> <p>Rosenberg Self-esteem Scale</p>	<p>Model used: The care-related stress process and the course of depressive symptoms after bereavement.</p> <p>A latent class mixture model revealed that self-esteem was greater among caregivers who had few, if any, symptoms of depression after bereavement, irrespective of whether subsequent well-being improved. Self-esteem decreased the odds of being repeatedly symptomatic, and decreased the odds of being temporarily highly distressed ($F=2.94$, $p<.001$).</p>
Meiland, Danse, Wendte, Klazinga & Gunning-Schepers (2001)	<p>Cross-sectional design examining caregiving of people awaiting admission to nursing homes.</p> <p><i>Care-recipient</i> Behavioural problems, performance of self-care, type and</p>	<p><i>About caregiver:</i> Three subscales of the Caregiver Reaction Assessment scale</p> <ul style="list-style-type: none"> - Loss of physical strength - Disrupted schedule - Care-derived self-esteem 	<p>Model used: Determinants of caregiver experiences.</p> <p>More self-esteem derived from informal care was related to lower income ($\beta=-.36$, $p<.01$), a better quality of the relationship ($\beta= 0.5$,</p>

Study (Authors, Year)	Research methodology/ Areas of focus	Standardized measure(s) used	Model used and key findings in the context of self-esteem
	severity of dementia		p<.01) and social support ($\beta = .22$, p<.05).
	<i>Caregiver</i> Burden, negative and positive reactions to caregiving, including care-derived self-esteem		
	<i>Caregiving</i> Co-residency, number of hours informal caregiving, use of support		
Pagel& Becker (1987)	Cross-sectional design examining associations between social/personality factors and depression.	<i>About the caregiver:</i> The Tennessee Self-Concept Scale, comprising 100 items that measure self-esteem The Hamilton Depression Rating Scale The Depression scale of Symptom Checklist – 90 The Global Satisfaction Scale	Model used: Drew upon Beck's cognitive theory (1967, 1976) and Abramsons et al.'s reformulated learned helplessness model (1978). Higher levels of self-esteem were related to lower depression scores ($r =$ -.55, $p < .001$). Depressive cognitions showed an inverse relationship with self-esteem ($r = -.35$, $p = < .005$). Suggested self-esteem may be indirectly associated with reduced depression through its relation with an individual's negative thought pattern. Social support was positively related to self-esteem ($r = .50$, $p < .005$).
	<i>Care-recipient</i> Functional status, course of illness, contact with healthcare system		
	<i>Caregiver</i> Attributions/expectations about spouse's disease, self-esteem, depressive symptoms, depressive cognitions, social support		

Study (Authors, Year)	Research methodology/ Areas of focus	Standardized measure(s) used	Model used and key findings in the context of self-esteem
Robinson (1990)	Cross-sectional design examining the relationship between social skills, social support, self-esteem and burden in adult caregivers. <i>Caregiver</i> Social skills, objective and subjective burden and self-esteem	<i>About the caregiver:</i> Subjective and objective burden instrument The Norbeck concept of Social Support Questionnaire The Sarason's Social Support Questionnaire Rosenberg's Self-Esteem Scale	Model used: Theoretical conceptualization of social support A significant positive relationship was found between functional social support and self-esteem ($r=.36$, $p<.05$). A significant negative relationship was found between loss and self-esteem ($r=-.53$, $p<.01$)
Skaff & Pearlin (1992)	Cross-sectional design to examine 'loss of self' in caregivers. <i>Care-recipient</i> Activities of daily living, cognitive decline, problem behaviours <i>Caregiver</i> Self-loss, competence and self-gain, self-esteem, depression, social contact, role incumbency, hours per week spent caregiving	<i>About the caregiver:</i> Rosenberg Self-Esteem Scale Measure of Mastery 7-item subscale of the Hopkins Checklist Devised own measure of 'loss of self' and 'caregiver competence'	No model reported. Loss of self was moderately but significantly related to self-esteem ($r=-.32$, $p<.0001$). When self-loss occurs in caregivers, it is related to diminished self-esteem.
Talkington-Boyer & Snyder (1994)	Cross-sectional design examining positive and negative impact of	<i>About the caregiver:</i> Caregiving Appraisal Scales	No model reported.

Study (Authors, Year)	Research methodology/ Areas of focus	Standardized measure(s) used	Model used and key findings in the context of self-esteem
	caregiving. <i>Care-recipient</i> Memory and behaviour problems <i>Caregiver</i> Subjective caregiver burden, caregiving satisfaction, caregiver mastery, positive and negative appraisals of caregiving, formal and informal support	Ego Strength Scale Coping strategies Inventory Self-Esteem Self-Report Inventory Depression measure	Caregiver self-esteem correlated significantly with caregiver mastery ($r=.38$, $p<.001$) and not with burden ($r=-.27$, $p=ns.$) or negative impact ($r=-.24$, $p=ns.$).
VanderWeerd, Paveza, Walsh &Corvin (2013)	Cross-section design examining physical mistreatment in people with Alzheimer's disease. <i>Care-recipient</i> Vulnerability, functional status, psychological health <i>Caregiver</i> Elder mistreatment, vulnerability, psychological status, burden, social support, self-esteem	<i>About the caregiver:</i> The Conflict Tactic Scale Norbeck Social Support Scale Center for Epidemiological Studies depression scale Rosenberg Self Esteem Scale Coping Styles Questionnaire	Model used: A Risk Vulnerability Model of Elder Mistreatment (Rose and Killian, 1983). Caregivers with high self-esteem were significantly less likely to engage In violent behaviour ($P=.046$; $CI=.591 - .748$)

Study (Authors, Year)	Research methodology/ Areas of focus	Standardized measure(s) used	Model used and key findings in the context of self-esteem
Vedhara, Shanks, Anderson & Lightman (2000)	<p>Prospective design examining the role of stressors and psychosocial variables in caregivers and non-caregivers.</p> <p><i>Caregiver</i> Stressful life events, daily hassles, burden, social support, self-esteem, coping style, self-concept, anxiety, depression, stress</p>	<p><i>About the caregiver:</i> Culture-Free Self-Esteem Inventory Savage Personality Screening Scale Global Measure of Perceived Stress</p>	<p>No model reported.</p> <p>There were significant differences in psychosocial mediators of stressors between caregivers and non caregivers, including self-esteem. Caregivers had a propensity towards lower personal self-esteem ($F= 7.91$, $p=.006$).</p> <p>The measure of depression was found to correlate with social self-esteem ($r=-.291$, $p<.05$). Personal self-esteem was found to correlate with anxiety ($r=-.765$, $p<.001$), depression ($r=-.495$, $p<0.001$) and stress ($r=-.502$, $p<0.001$).</p>

Studies investigating associations between self-esteem and other dementia caregiver outcomes

The four remaining studies investigated the associations between self-esteem and other carer or care-recipient outcomes. Two investigated correlations between self-esteem and caregiver burden. Robinson (1990) asked caregivers to complete questionnaires with an interviewer or in small groups with structured instructions. The author used a theoretical conceptualization of social support (Tolsdorf, 1976) to examine associations between social skills, social support, self-esteem and caregiver burden. A significant positive relationship between self-esteem and the amount of affection, affirmation and caregiver aid was found. Tolsdorf (1976) hypothesized that having increased social support enables caregivers to attain their goals or life demands, resulting in higher levels of self-esteem.

Caregivers who reported losing a higher number of relationships in the last year also reported lower levels of self esteem. Most frequent reason for loss of relationship was death of a significant other. Robinson (1990) suggested that losing relationships may diminish the caregiver's social network which, in turn reduces their self-esteem. The association between self-esteem and burden was not investigated; however, Robinson concluded that self-esteem may be a vital contributing factor to dementia caregivers' wellbeing.

By contrast, Talkington-Boyer and Snyder (1994) examined correlations between self-esteem and subjective carer burden, negative impact on caregiver's activities (e.g. negative family relations and lack of privacy), caregiver mastery and caregiver satisfaction using a postal survey. Results indicated that dementia caregiver self-esteem was significantly positively correlated with caregiver mastery, but not with caregiver burden, impact or satisfaction (see Table 2). The authors concluded that an important feature of caregiver interventions should focus on promoting positive self-statements that enhance caregiver's self-confidence.

One study examined the experiences of caregivers with relatives on the waiting list for admission to a nursing home (Meiland et al., 2001). Interviews were conducted to assess positive and negative reactions to caregiver experience. A research model on determinants of caregivers' experiences was utilized to examine how caregiver characteristics, care-recipient characteristics and caregiving context are related to caregiver experience. In contrast to previous articles outlined in the review, self-esteem was examined as a reaction to caregiving, alongside disrupted schedule and loss of physical strength. Multiple regression analyses

indicated that caregivers with lower income and a higher quality of relationship with the care-recipient were found to have higher levels of self-esteem.

Regarding care-recipient outcomes, VanderWeerd et al. (2013) investigated the risk factors for physical mistreatment in older people with Alzheimer's disease. Using a risk vulnerability model of elder mistreatment (Rose & Killian, 1983), they gathered information during in-home interviews with caregivers. Results demonstrated that caregivers reported having very high (44.7%) moderately high (30.2%) and high (18.1%) self-esteem. Only 6% and 0.9% of the sample indicated that they had low to moderately low self-esteem, respectively. Findings indicated that 17.2% of 254 caregivers engaged in physically violent behaviour. Logistic regression analyses revealed that caregivers with higher self-esteem were less likely to engage in violent behaviour ($P = .046$, $CI = .591 - .748$). Authors concluded that low self-esteem may increase the likelihood of physical mistreatment of elderly care-recipients.

Discussion

Main findings

The current review examined existing knowledge of the role of self-esteem in dementia caregivers' experiences. The only study that compared caregivers ($N=50$) with non-caregivers ($N=67$) found that carers reported lower self-esteem (Vedhara et al., 2000). However, VanderWeerd et al. (2013) found that out of 254 caregivers, 93.1% reported having high to very high levels of self-esteem.

Overall, evidence from the presented studies linking self-esteem and caregiver psychological well-being appears robust. Caregiver global, personal and social self-esteem was found to correlate negatively with depression, depressive cognitions, anxiety, loss of self and stress (Aneshensel et al., 2004; Pagel & Becker 1987; Skaff & Pearlin, 1992; Vedhara et al., 2000). Authors predominantly concluded that having high self-esteem may be associated with lower levels of depression, anxiety, loss of self and stress carers' experience in the dementia caregiving role.

Research examining the association between self-esteem and psychological outcome in other caregiver groups echoes this conclusion. Bakas & Burgener (2002) found that low

self-esteem in stroke caregivers was significantly related to higher levels of emotional distress. This has also been evidenced in parents caring for children with cerebral palsy, with research indicating that caregiver's with higher self-esteem experienced better psychological health (Raina et al., 2005). Kim, Loscalzo, Wellisch & Spillers (2006) also reported an association between husband caregivers' high levels of self-esteem and reduced stress in cancer caregivers.

Prospective studies revealed that self-esteem may predict caregivers' depression and anxiety levels over time (Vedhara et al., 2000) and that caregivers with high self-esteem (among other factors) decreased the likelihood that a caregiver would be repeatedly symptomatic of depression or temporarily distressed after the death of their loved one (Aneshensel et al., 2004). Similar predictions were reported in Roberts, Gotlib & Kassel's (1996) research into adult attachment security, which illustrated the increase in depressive symptoms in university students following reductions in their self-esteem.

Regarding the second research question, associations were found between high levels of self-esteem and the following: increased social support, less significant loss of relationships, increased quality of relationship with the care-recipient and lower income (Meiland et al., 2001; Robinson, 1990; Talkington-Boyer & Snyder, 1994). Associations were not found between self-esteem and carer burden (Talkington-Boyer et al., 1994). Three studies suggested that individuals with a strong support network have higher self-esteem (Meiland et al., 2001; Pagel & Becker, 1987; Robinson, 1990). This coincides with findings from broader caregiving research which suggested that self-esteem mediated perceived emotional support and negative reactions to caregiving in adult-child caregivers of elderly people (Malhotra, Malhotra, Østbye, Matchar & Chan, 2012). Understanding the causal relationship between these variables could have important implications for caregivers. These conclusions coincide with Lautenschlager et al.'s (2013) view that personality factors relate to caregiver outcome.

With regards to care-recipient outcome, one article examined the role of caregiver self-esteem in the context of the care-recipient's experience (VanderWeerd et al., 2013). This study demonstrated that caregivers' with higher self-esteem were least likely to engage in violent behaviour, which suggests that high caregiver self-esteem may also protect the care-recipient from physical mistreatment. These findings highlight the importance of a caregiver's level of self-esteem in mediating their experience of caregiving and,

subsequently, the level of care provided to the care-recipient. However, use of violence was assessed using a self-report measure. Given the sensitivity of disclosing use of violent behaviour when caring for someone with dementia, it is likely that self-report bias is evident in this data. Caregivers may have under-reported use of violent behaviour in order to be viewed more favourable, indicating the potential for social desirability bias within the study.

Strengths and Weaknesses

A strength of the review was the high quality level of articles included. This allowed for conclusions to be drawn from studies with relative confidence. Considering generalizability, one strength of the review was the wide range of caregiver age and length of time providing care. The majority of care-recipients were diagnosed with Alzheimer's disease and this is representative of the proportion of people with dementia in the UK who are diagnosed with Alzheimer's disease (Alzheimer's Society, 2014). Additionally, studies from several countries were included which allowed for some comparison internationally. On the other hand, all these countries adopt a western culture and this has implications for the applicability of these results worldwide.

There were also limitations in the available evidence. Ethnic minorities were under-represented in the samples and occasionally sample characteristics were missing altogether, rendering it difficult to draw conclusions about the generalizability of the study. Specifically, the Black or Minority Ethnic Group (BME) were under-represented in the U.S. and the UK. The sample comprised a small proportion of people with vascular or multi-infarct dementia and Parkinson's disease and dementia. People with mixed, Lewy body and fronto-temporal dementia were not included in any of the samples. This group collectively represents 16% of diagnoses of dementia which suggests that the sample is not entirely representative of the population of people diagnosed with dementia.

There were a number of convenience samples and notable self-report bias in the majority of studies included in the review. As the majority of studies included were cross-sectional in nature, it is also difficult to conclude the causality of the relationship found for correlations between variables. A longitudinal or prospective design would allow the assessment of self-esteem at different time points, allowing research to identify if being a carer impacts upon self-esteem by reporting changes in levels of self-esteem. This would

minimize the potential for bias, for example, by addressing the notion of whether individuals with low self-esteem are attracted to care roles, or whether being in a care role influences a person's self-esteem. Where multiple regression analyses were performed, self-esteem was often either grouped with other variables or left out completely, which reduced the conclusions that could be drawn about the role of self-esteem from the data.

Due to the aim and scope of this review, stringent search criteria were adopted as part of the review's search strategy. Only articles specifically using the words self-esteem were included. However, including the term 'self-concept' in the original search criteria may have identified a further 300-400 hundred articles. Selecting this approach may have reduced the breadth of the literature search, thus narrowing the results and reducing the extensiveness of conclusions drawn. The inclusion of qualitative studies could also have contributed to the comprehensiveness of conclusions drawn in this review. For instance, Lopez, Mazor, Mitchell and Given's (2013) identified self-esteem as a prominent theme in caregivers' appraisals of family centred care in their qualitative examination of dementia caregiving.

Conclusions

The current review has a number of clinical implications. The finding that self-esteem is associated with caregiver depression, anxiety and stress suggests that interventions aimed at dementia caregivers should focus on the examination and amelioration of self-esteem. This may have a significant impact on their well-being and, ultimately, the care of their relative with dementia. Studies suggest that caregiver interventions should consider the assessment of caregivers social support networks and recent losses (Robinson, 1990) as well as the use of positive self-statements (Talkington-Boyer et al., 1994).

Findings from the current review suggest that self-esteem plays an important role in the positive and negative experience of caring for a relative with dementia. Longitudinal research, with a more culturally diverse sample, is needed to ameliorate our understanding of the relationship between certain variables and self-esteem. Research that can assess this whilst reducing self-report bias could contribute significantly to the dementia caregiver knowledge base.

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Major Research Project

*Caring for someone with dementia: An investigation of factors
associated with carer mood*

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Plain English Summary

Individuals who care for people with dementia often experience stress and mental health problems. Various factors are associated with how an individual will cope when caring for someone with dementia, as well as the amount of distress they experience. Research suggests that a carer's level of self-esteem (how they measure their self-worth) and the level of burden they experience, may be related to how they feel (Schulz & Martire, 2004).

The number of men caring for someone with dementia is growing rapidly. The majority of previous research has investigated how women cope when caring for someone with dementia. More studies are needed to explore whether men and women experience caring differently, helping psychologists to support both when caring for people with dementia.

This research therefore aimed to examine the association between traits of masculinity and femininity, carer burden, daily caregiving hours, self-esteem and psychological distress. It explored whether having more masculine or feminine traits is related to the distress people experience when caregiving. It also investigated whether these traits are associated with the carer's self esteem, and whether their self-esteem is related to how they feel and cope as a carer.

The Scottish Dementia Clinical Research Network research register holds the names of dementia caregivers who have volunteered to take part in research. One hundred and eighty seven of these carers were posted questionnaires to complete and send back anonymously. These questionnaires asked about the person with dementia's current abilities, how the carer copes with their caring role, their levels of self esteem and current mood. Carers were also asked to indicate how much they associate themselves with different traits of masculinity and femininity.

Forty-four people caring for people with Alzheimer's disease, vascular dementia and rarer types of dementia returned questionnaires. Mild to severe anxiety symptoms were reported by 43% of carers, and 30% reported mild to moderate feelings of depression.

Findings from the study suggested that carers who reported high levels of burden and more daily caregiving hours experienced higher levels of depression and anxiety. Carers who reported that the person with dementia displayed frequent memory and behavioural problems also reported high anxiety levels. Caregivers with higher self-esteem reported significantly

lower anxiety and depression. Traits of masculinity or femininity in caregivers did not appear to be associated with their mood.

These findings emphasize the need for practical support and respite for carers experiencing high levels of burden to minimize their stress. These results also suggest that clinicians may be able to support carers to improve their mental well-being by enhancing their levels of self-esteem.

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Scientific Abstract

Objectives. Research indicates that dementia caregivers are at risk of experiencing mental health difficulties. This study examined factors associated with dementia carer anxiety and depression, drawing upon the Stress Process model of Caregiving to explore self-esteem in dementia caregiving.

Methods. Dementia caregivers were invited, via the Scottish Dementia Clinical Research Network, to complete a postal survey assessing their gender traits, self-esteem, burden, mental health and care-recipient functioning. Forty-four of 187 caregivers returned questionnaires (24% response rate).

Results. Carer burden and daily caregiving hours best predicted differing experiences of anxiety and depression among carers. High self-esteem was associated with lower anxiety and depression. Traits of masculinity and femininity were not significant predictors of psychological distress. A high percentage of the variance in dementia carer anxiety was explained by factors outlined in the Stress Process model.

Conclusions. This study provides further evidence that carer burden, self-esteem and daily caregiving hours are important predictors of anxiety and depression in dementia caregivers. This emphasizes that dementia caregivers could benefit from interventions reducing carer burden and enhancing self-esteem.

Key words: dementia care; caregivers; anxiety; depression; factors

Introduction

In 2014, the Alzheimer's Society reported that 835,000 people in the UK had a diagnosis of dementia, two thirds of whom were cared for in the community. Approximately 75% of people with dementia who receive community care obtain this support from family or friends (Schulz & Martire, 2004). Research suggests that carers of individuals with dementia are at a higher risk of depression (Baumgarten et al., 1992) and anxiety (Cooper, Balamurali & Livingston, 2007), with 30 to 40% of dementia caregivers experiencing depression and stress (Alzheimer's Association, 2004; Covinsky, Newcomer, Dane, Sands, Yaffe, 2003). This can have a negative impact on the care they provide which, in extreme cases, may result in incomplete treatment of patient symptoms, patient neglect and even abuse (Messinger-Rapport, McCallum & Hujer, 2006).

The number of people with dementia in Scotland is expected to double between 2011 and 2031 (Scottish Government, 2013). The predicted increase in people with dementia, coupled with Government's aim to improve their quality of life via greater emphasis on home care (Scottish Government, 2012), represents a major challenge. Greater numbers of carers will be involved, with the consequent risk of increased incidences of anxiety and depression in caregivers. It will be necessary for health professionals to provide high quality interventions in response to this. To ensure the effectiveness of these interventions, it is important to identify the key factors associated with a caregivers' ability to provide effective care.

Salient Factors Associated with Dementia Caregiving

Understanding the potential contributors to carer distress is crucial to supporting caregiver and care-recipients with dementia. Carer burden, daily caregiving hours, gender differences and self-esteem have all been hypothesized to relate to levels of anxiety and depression reported by dementia caregivers (Schulz, O'Brien, Bookwala & Fleissner, 1995).

Carer burden has been defined as the response to physical, psychological, social and financial stressors associated with caregiving (Kasuya, Polgar-Bailey, & Takeuchi, 2000). Research into dementia caregiving consistently reports a positive association between carer burden and depression (Schulz et al., 1995) and anxiety (Cooper et al., 2007). Carer burden may also place care-recipients at risk of poorer quality of life and early nursing home placements (Gaugler, Kane, Kane, & Newcomer, 2005; Yaffe et al., 2002). Another factor

associated with early nursing home placement is the number of hours spent providing care per day (Etters, Goodall, & Harrison, 2008). Longitudinal research and a British panel survey study indicated that providing care assistance for 20 hours or more per week resulted in increased psychological distress (Burton, Zdaniuk, Schulz, Jackson & Hirsch, 2003; Hirst, 2005).

Also of interest is the association between gender differences and a caregiver's experience. Longitudinal research (Schulz & Williamson, 1991) and cross sectional studies comparing dementia carers with non-caregivers (Baumgarten et al., 1992; Russo, Vitaliano, Brewer, Katon & Becker, 1995) suggest that female caregivers consistently report higher levels of distress than males. The social role hypothesis posits that men and women engage in continual construction of the social role that is expected of them (Eagly, 1997). Cultural positioning of females as natural nurturers may mean that women are expected to take on a wide range of caring tasks and responsibilities (O'Grady, 2005), leading to higher levels of distress. Alternatively, gender socialization hypothesis posits that women are more likely to possess traits related to communion, which indicate a concern for oneself in relation to others, than men (Bakan, 1966) and that these differences in sensitivity to relationships may cause women to be more vulnerable to experiencing distress than men (Kessler, 1979).

Self-esteem, often defined as an individual's overall sense of self-worth and personal value (Rosenberg, 1962), may also be associated with caregiver anxiety and depression. Both prospective and cross-sectional studies have highlighted that dementia caregivers with high self-esteem experience lower levels of depression and anxiety (Aneshensel, Boticello & Yamamoto-Mitani, 2004; Pagel & Becker, 1987; Vedhara, Shanks, Anderson & Lightman, 2000) and are less likely to engage in violent behaviour towards the care-recipient (VanderWeerd, Paveza, Walsh and Corvin, 2013). This is of particular interest within psychological research due to the potentially modifiable nature of self-esteem through intervention.

A conceptual framework of caregiving: The stress process model

Understanding not only the contributing factors, but also the process of dementia caregiving is necessary to develop effective carer interventions. To ensure an ordered examination of the process by which different factors relate to carer outcomes, it was necessary to adopt a suitable conceptual framework. The framework considered most appropriate for this study was the Pearlin, Mullan, Semple and Skaff (1990) stress-process

model of care-giving (see Appendix 1.12). This considers a number of components of caregiver stress and the relationship between them. Pearlin et al. posit that various background and contextual factors in the caregiving process (for instance, caregiver characteristics and duration of caregiving) relate to stressors resulting from providing care. Primary stressors (for instance, care-recipient cognitive functioning or problem behaviours) and secondary stressors (e.g. caregiver burden) result in intra-psychoic strains, such as self-esteem and self-mastery. Pearlin et al. propose that variance in coping and social support may account for the fact that caregivers experiencing similar stressors exhibit different responses to these stressors. These are accordingly detailed in the model as mediating factors.

The present study aims to identify the extent to which carer burden, daily caregiving hours, traits of masculinity/femininity and self-esteem predict carer anxiety and depression as part of the conceptual model proposed by Pearlin et al. (1990). In accordance with this model, this study also took into account other factors likely to be significantly associated with carer distress. Due to their identified relevance (Ducharme et al., 2007; Pearlin et al., 1990; Schulz et al., 1995), age, education, formal and informal support, care-recipient cognitive and behavioural functioning and duration of care-giving were also included (see Figure 1).

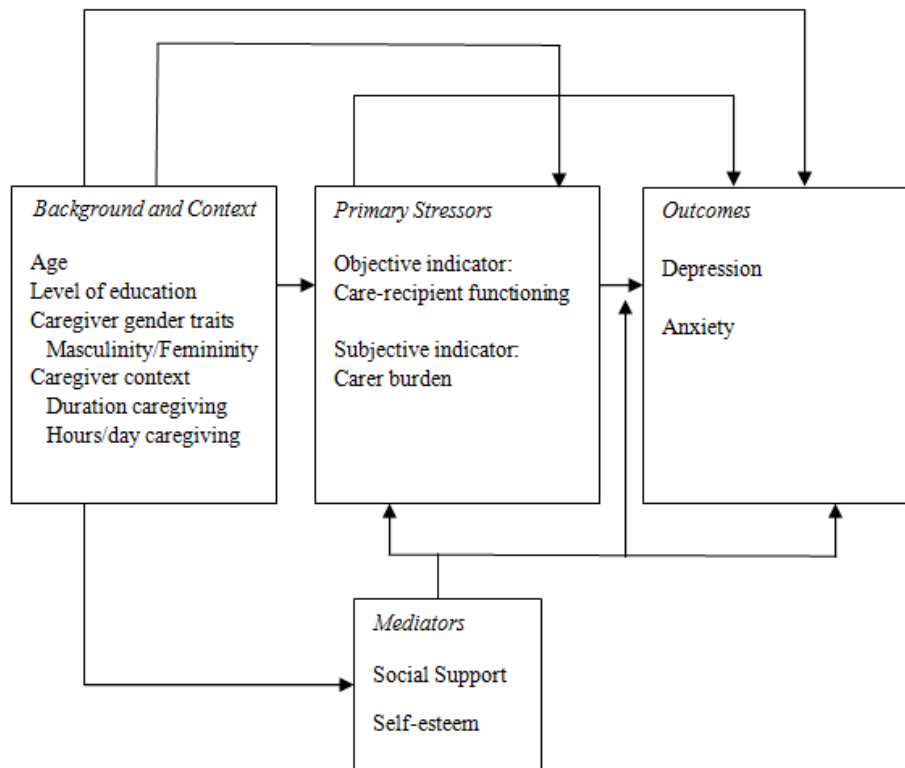


Figure 1. Stress Process Model of Caregiving as adapted for the present study

Self-esteem as a mediating factor

As research suggests that women of all ages report lower self-esteem than men (Orth, Trzesniewski & Robins, 2010), it appears important to consider the possible interaction between gender and self-esteem. Kim, Loscalzo, Wellisch and Spillers (2006) found that female carers reported lower caregiver esteem and, in turn, higher care-giving stress than males. This suggests self-esteem mediated the relationship between these two factors in cancer caregivers.

In summary, the present study aims to answer the following research questions:

1. Are carer burden, daily caregiving hours, self-esteem, traits of masculinity and femininity, duration of caregiving, care-recipient functioning, support, age and education associated with anxiety and depression?
2. To what extent do the identified factors predict depression and anxiety in carers?
3. Does self-esteem mediate the relationship between traits of masculinity/femininity and anxiety or depression?

Method

Participants

Dementia caregivers were recruited via the Scottish Dementia Clinical Research Network's (SDCRN) register, comprising 1,300 caregivers who have volunteered to be contacted about research. Inclusion criteria specified that potential participants should be aged 18 and over, male and female primary caregivers of people with dementia. The primary caregiver was defined as the principal person taking responsibility for the care of the individual with dementia. Care-recipients with a diagnosis of Alzheimer's disease, vascular dementia, dementia with Lewy Bodies, fronto-temporal dementia and any rarer types of dementia were

included. Caregivers of people with both Down syndrome and dementia were excluded as the needs and experiences of this group are likely to differ from other dementia caregivers.

Measures

The care-recipients' named diagnoses were available from the SDCRN database. To pilot the questionnaire pack, two dementia carers completed the measures, taking approximately 30 minutes. Participants were asked to complete a postal questionnaire pack, comprising the following seven measures and a page of demographic information (see Appendix 1.7):

Duration of care-giving. Previous research (Ducharme et al., 2007) has assessed this using the following questions: "How long have you been taking care of the person with dementia on account of their health problems?" and "How many hours per day do you spend providing care and attention to the person with dementia?".

Support. Two questions were devised by the researcher: 1. How much support do you receive from family and friends when caring for your relative with dementia? 2. How much support do you receive from other health professionals/NHS staff when caring for your relative with dementia? These were scored on a 5-point Likert scale ranging from *none* (1) to *a lot* (5). Participants were then asked to rate how helpful they found those supports on a 5-point Likert scale ranging from *unhelpful* (1) to *very helpful* (5).

Self Esteem. Global self-esteem was measured using the Rosenberg Self Esteem Scale (RSE, Rosenberg, 1962), comprising 10 items that consider beliefs in one's worth and competence. Five items are rated on a 5-point scale from *strongly disagree* (0) to *strongly agree* (3), while the remaining half are reversed scored. Higher scores indicate higher self-esteem. Previous reported reliabilities for the RSE range from .88 to .90 (Robins, Hendin & Trzesniewski., 2001).

Carer Distress. The 14-item Hospital Anxiety Depression Scale (HADS, Zigmond & Snaith, 1983) measured carer anxiety and depression. Total anxiety scores are derived from 7-items, with total depression scores calculated from the remaining 7-items. All items are scored on a 4-point scale from 0 to 3, with higher scores corresponding to higher levels of anxiety and depression. The scale has reported reliability scores averaging 0.83 for anxiety and 0.82 for depression (Bjelland, Dahl, Haug & Neckelmann, 2002). It has been evaluated as practical

for use with older adults, demonstrating robust psychometric properties and UK relevant content (British Psychological Society, 2004).

Masculinity/Femininity. Masculine and feminine traits were measured using the 30-item Bem Sex-Role Inventory Short Form (BSRI; Bem, 1974). Carers were requested to rate themselves against feminine, masculine and androgynous traits using a seven-point scale, ranging from 1 (*never or almost never true*) to 7 (*always or almost always true*). Masculinity scores were derived from a sum of the responses to 10 items measuring masculine traits (e.g. I am willing to take risks), with higher scores indicating increased masculinity. This was the same for femininity, with items such as 'I am sensitive to the needs of others' measuring feminine traits. Campbell, Gillaspay & Thomson (1997) found the BSRI short form to be more reliable than the BSRI original form ($\alpha_M = .82$, $\alpha_F = .89$).

Carer Burden. The 12-item Brief Zarit Burden Interview (B-ZBI, Bédard et al., 2001) was selected to measure caregiver role and personal strain. Responses are calculated using a five-point Likert scale from *never* (0) to *nearly always* (4). Higher scores indicate higher perceived burden. This scale has a reported internal consistency of $\alpha = 0.85$ (O'Rourke & Tuokko, 2003).

Memory and Behavioural Problems. The 48-item Revised Memory and Behaviour Problems Checklist (RMBPC, Teri et al., 1992) was used to measure the frequency of the care-recipient's observable behavioural problems and the caregiver's reaction to these. The frequency subscale comprises 24 items scored from *never occurred* (0) to *daily or more often* (4). The reaction subscale comprises 24 items ranging from *did not react at all* (0) to *reacted extremely* (4). Greater scores on the frequency and reaction scales indicate increased frequency of observed problems and a greater degree of reaction to these. Roth et al. (2003) reported that the frequency and reaction scales had an internal consistency of $\alpha=0.78$ and $\alpha=0.87$, respectively.

Ethics

Approval to carry out the research was granted by the West of Scotland Research Ethics Committee (see Appendix 1.3) and the NHS Highland Research and Development department (see Appendix 1.4). The study was adopted by the SDCRN following successful completion of the network's peer review. The SDCRN research register has been approved

by the relevant multi-centre research ethics committee. Information sheets outlining the research purpose and consent forms were sent to potential participants. They were provided with the option of contacting the researcher, or the SDCRN as an independent contact, to discuss research participation. Questionnaire packs containing an identifier were posted by the SDCRN, allowing the participants to remain anonymous to the researcher.

Participants who self-rated as 8 or higher on depression or anxiety subscales were unblinded by the SDCRN, allowing the researcher to contact them and their GP directly. Consent forms detailed that the researcher would notify the participant's GP of any clinical levels of distress reported. All information was stored in accordance with the Data Protection Act (2008) and NHS Highland local policies and procedures.

Procedure

In previous research, 112 of 500 surveys sent to people on the SDCRN register were returned within 10 weeks, representing a response rate of 23% (Law, Starr & Connelly, 2013). In the present study, the SDCRN identified 187 carers that fulfilled the criteria. Initially, 100 of the identified participants were posted a pack comprising an information sheet (Appendix 1.5), consent form (Appendix 1.6), questionnaires (Appendix 1.7) and sources of support for dementia caregivers (Appendix 1.8). Questionnaires and consent forms were then returned via freepost to the network, where all identifiable information was removed from packs and forwarded on to the researcher. As the initial response rate was not sufficient to meet the power calculated, a further 87 caregivers were invited to participate.

Data Analysis

Justification of sample size. Previous cross-sectional research examining carers for cognitively and functionally impaired individuals (Ducharme et al., 2007) used a similar model of analysis as that utilized in this research and had a sample size of 323 participants. A statistician from the Robertson Centre for Biostatistics calculated the adjusted R-squared based on the correlations found in the Ducharme et al. research. This demonstrated that to detect the same R-squared ($R^2 = 0.51$) with seven variables, 80% power and significance level of 5%, a sample size of 41 was required.

Analytic Strategy. The first analytic objective was to investigate the associations between the independent variables (age, education, care burden, daily caregiving hours, masculinity/femininity, self-esteem, duration providing care and support) and both dependent variables (anxiety and depression). Accordingly, correlation co-efficient analyses were performed. The second objective was to investigate the amount of variance in depression and anxiety explained by the predictor variables. Two steps were taken to achieve this. Firstly a multiple regression was performed on the data, with anxiety as a dependent variable. The level to which factors associated with Pearlin et al.'s (1990) framework predicted carer anxiety was analyzed. Secondly, a multiple regression was executed with depression as the dependent variable, to examine the extent to which the same factors predicted carer depression. This provided the opportunity to examine the degree to which factors described in Pearlin et al.'s model predict dementia caregiver depression and anxiety. In the event that the factors from this model did not predict carer distress significantly or explained a low amount of variance, the factors which significantly correlated with distress were analyzed using regression analyses. To meet the third objective, univariate regression analyses were performed to test the mediating effects of self-esteem.

Results

Sample Characteristics

Forty-four participants returned questionnaires, representing a response rate of 24%. One participant's data was excluded as they reported spending no time caring for their relative with dementia. Sample characteristics of caregiver and care-recipients are displayed in Table 1. A slightly higher percentage of carers were female (55.8%). The majority of the sample consisted of spousal or partner caregivers (81.4%) with the remaining participants comprising adult child caregivers and in one case a friend. The majority of care-recipients were diagnosed with Alzheimer's disease, followed by vascular dementia.

Table 1. Description of caregiver, care-recipient and caregiving situation (N=40)

Sample characteristics	Mean (SD) or Frequency (%)	Range
Caregiver		
Age (years)	71.58 (11.41)	42 – 91

Sample characteristics	Mean (SD) or Frequency (%)	Range
Gender		
Female	24 (55.8%)	
Male	19 (44.2%)	
Relationship with care-recipient		
Husband	18 (41.9%)	
Wife	16 (37.2%)	
Partner	1 (2.3%)	
Daughter	6 (14.1%)	
Son	1 (2.3%)	
Friend	1 (2.3%)	
Years in education	13.95 (3.8)	5 – 24
Duration of relationship with person (years)	51.67 (13.05)	14 – 75
<i>Care-recipient</i>		
Gender		
Male	22 (51.2%)	
Female	21 (48.8%)	
Diagnosis		
Alzheimer's disease	25 (58.1%)	
Vascular Dementia	7 (16.3%)	
Early onset Alzheimer's disease	6 (14.0%)	
Alzheimer's disease with cerebrovascular disease	5 (11.6%)	

The mean scores and standard deviations for the variables under study are presented in Table 2. Clinical levels of anxiety and depression consisted of scores between 8 and 21 indicate mild to severe anxiety or depression (Cameron, Crawford, Lawton & Reid, 2008).

Twenty-three percent of carers reported clinical levels of anxiety and depression. A further 20% reported clinical levels of anxiety only. Approximately 7% reported clinical levels of depression only. Levels of carer burden and frequency of care-recipient disruptive behaviours were in the low to middle range of possible scores. On average, participants reported spending approximately 14 hours per day caregiving.

Mean scores of female and male participants' masculinity traits were approximately 47 compared with mean femininity trait scores of 53 (males) and 59 (females), suggesting carers' identified with less masculine traits, regardless of their gender. However, these differences were not statistically significant, $t(39) = 2.37$, $p = .101$. The majority of caregivers reported scores between 15 and 25, indicating average to high levels of self-esteem. Eight carers reported scores of 25 or higher, compared with only four reporting scores below 15.

Table 2. Means, Standard Deviations and Range of variables

Variable	<i>M (SD)</i>	Range Actual	Range Possible
<i>Dependent Variables</i>			
Anxiety	7.37 (4.46)	0 – 19	0 – 21
Depression	5.95 (3.85)	0 – 19	0 – 21
<i>Background Variables</i>			
Duration of caregiving (years)	5.17 (2.88)	2 – 16	
Daily caregiving hours	14.45 (9.30)	1 – 24	1 – 24
Feminine traits			
Male	53.26 (9.63)	31 – 66	20 – 70
Female	59.68 (7.83)	37 – 70	20 – 70
Masculine traits			
Male	47.68 (8.96)	29 – 61	20 – 70
Female	47.36 (11.01)	26 – 62	20 – 70
<i>Primary Objective Stressors</i>			
Frequency of memory and behaviour problems	37.56 (14.61)	7 – 84	0 – 96
Reaction to memory and behaviour problems	25.21 (14.46)	0 – 75	0 – 96
<i>Primary Subjective Stressors</i>			
Caregiver burden	22.74 (7.86)	6 – 39	0 – 48
<i>Resources</i>			
Support			
From family/friends	3.26 (1.14)	1 – 5	1 – 5
From health professionals	2.72 (1.26)	1 – 5	1 – 5
Self-esteem	20.98 (5.04)	12 – 30	0 – 30

Factors correlating with anxiety and depression

The first research question sought to examine whether carer burden, daily caregiving hours, self-esteem, traits of masculinity and femininity, duration of caregiving, care recipient functioning, support, age and education are associated with anxiety and depression. Correlation co-efficients between carer distress (anxiety and depression) and these factors are displayed in Table 3. The assumption of bivariate normality was not clearly met for all pairs of variables. Therefore, Spearman's rho correlation was used throughout the analyses.

Anxiety

Anxiety significantly correlated with the following factors: carer burden ($r=.56$), daily caregiving hours ($r=.34$), self-esteem ($r=-.52$), family support ($r=-.34$), frequency of memory and behaviour problems ($r=.39$) and caregivers' reaction to these ($r=.42$). Caregivers reporting higher burden, lower self-esteem, increased hours per day caregiving, more frequent memory and behavioural problems and more extreme reactions to these

experienced higher levels of anxiety. Caregivers who receive less family support indicated increasing symptoms of anxiety.

Depression

Depression significantly correlated with the following: caregiver burden ($r=.40$), daily caregiving hours ($r=.45$), self-esteem ($r=-.42$) and support from health professionals ($r=.27$). Caregivers who reported higher levels of burden, professional support and hours per day caregiving, rated higher levels of depression. Caregivers with higher self-esteem reported lower depression.

Examining predictors of caregiver anxiety and depression

To answer the second research question, multiple regression analyses using the enter method were carried out. Including two highly correlated predictor variables in a regression analysis reduces the precision by which other variables predict the dependent variable (Baron & Kenny, 1986). The present analyses indicated a strong correlation between the frequency of memory and behavioural problems and reaction to these ($r=.69$). Therefore, it was decided that one of these variables should be excluded from both regression analyses. Given the stronger associations between the reaction to memory and behaviour problems and both dependent variables, it was decided that the frequency of problems variable should be excluded. Two multiple regression analyses, one with anxiety and the other with depression as dependent variables were executed.

Anxiety

On the basis of Pearlin et al.'s (1990) stress process framework, age, education, masculinity/femininity, carer burden, self-esteem, family and professional support, duration caregiving, daily hours caregiving, frequency of care-recipient memory and behaviour problems and caregivers reaction to these were considered for the regression analyses. Of these, carer burden, daily hours caregiving, self-esteem, family support and reaction to memory and behaviour problems correlated significantly with anxiety ($r>.30$) and were included in the regression.

Table 3. Inter-correlation of independent and dependent variables used in the regression analyses (N=43)

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Age	-	-.340*	.224	.471**	-.324*	-.341*	-.108	.139	-.349*	.204	-.114	-.371**	-.105	.094
2. Education		-	.006	-.283*	.168	.528**	.031	-.008	.121	-.096	.001	.295*	-.074	-.010
3. Duration caregiving			-	.372**	-.083	-.093	.025	.025	.050	.011	-.149	-.020	.142	.202
4. Hours/day caregiving				-	.060	-.440**	.211	.359*	.090	-.016	.054	-.285*	.337*	.449**
5. Femininity					-	.127	-.016	-.212	-.184	.114	-.015	.402**	.014	-.149
6. Masculinity						-	.030	-.072	-.003	.013	.009	.541**	-.220	-.169
7. Frequency MBPC							-	.678**	.452**	-.066	.272*	-.346*	.391**	.210
8. Reaction MPBC								-	.488**	-.063	.049	-.438**	.423**	.244
9. Burden									-	-.174	.237	-.398**	.558**	.396**
10. Family support										-	.153	.149	-.343*	-.160
11. Professional support											-	-.289*	.136	.275*
12. Self-esteem												-	-.516**	-.414**
13. Anxiety													-	.591**
14. Depression														-

Notes: MBPC = Memory and Behaviour Problems Checklist

* $p < 0.05$, ** $p < 0.01$

Masculinity and femininity both correlated with other predictor variables, and did not correlate with either dependent variable. This pattern was also indicated for age, education and duration of caregiving. These variables were thus removed to increase the precision with which other variables predicted anxiety. Using the enter method including hours per day caregiving, reaction to memory and behaviour problems, carer burden, social support and self-esteem resulted in a significant model, $F(5,33) = 8.46$, $p = 0.000$. This model explained 49.5% of the variance (Adjusted $R^2 = .495$). Table 4 presents information for the predictor variables included in the model. Increased carer burden and more hours per day caregiving were significant predictors of higher anxiety. Although caregiver reaction to memory and behaviour problems, self-esteem and social support increased the predictive value of the model, none of these individually predicted anxiety significantly.

Table 4. The unstandardised regression coefficients for variables entered into two regression analyses for Anxiety

Variable	Regression Model Coefficients		
	B	SE B	β
<i>Contextual variables</i>			
Hours/day caregiving	.133	.054	.300*
<i>Subjective/Objective Stressors</i>			
Reaction to MBPC	.004	.035	.015
Carer burden	.303	.073	.572**
<i>Resources</i>			
Self-esteem	-.031	.116	-.037
Social Support	-.619	.410	-.177

Nb. MBPC = Memory and Behavioural Problems Checklist

* $p < 0.05$ ** $p < .001$

Depression

Multiple regression analysis was repeated to determine the predictor variables' relationship with depression. Entering variables identified by Pearlin et al. (1990) resulted in a regression model that failed to achieve significance ($F(10,24) = 1.391$, $p = .276$), only explaining 8.6% of the variance (see Appendix 1.11, model (2a)). To produce a model which better explained the variance, daily caregiving hours, burden, self-esteem and professional

support were entered into the regression as they correlated significantly with depression. This resulted in a significant model: $F(4,34) = 4.354$, $p=.006$. However, this model only explained 26.1% of the variance. Unstandardized and standardized regression co-efficients are presented in Table 5. Of the three variables entered, only daily hours caregiving was a significant predictor of depression. The positive relationship between variables suggests that caregivers experience increasing depression, the more hours per day they dedicate to caregiving.

Table 5. Regression coefficients for the variables entered into the regression analysis for depression

Variable	B	SE B	β
<i>Contextual variables</i>			
Hours/day caregiving	.146	.061	.351*
<i>Subjective/Objective Stressors</i>			
Carer burden	.122	.078	.245
<i>Resources</i>			
Self-esteem	-.112	.132	-.144
Professional support	.457	.423	.157

Nb. * $p<.05$

The mediating effects of self-esteem

In response to the third research question, the current study investigated whether self-esteem mediated the relationship between traits of masculinity/femininity and carer distress. For a variable to mediate the relationship between two other variables, all variables must demonstrate a relationship with one another (Baron & Kenny, 1986). Masculinity and femininity did not correlate with anxiety or depression, therefore there could be no mediating effect from self-esteem.

Discussion

Research Question 1. Are carer burden, daily caregiving hours, self-esteem, traits of masculinity and femininity, duration of caregiving, care-recipient functioning, support, age and education associated with anxiety and depression?

Firstly, the study investigated the way in which factors of relevance to the caregiving process were associated with dementia carer anxiety and depression. Carer burden was significantly correlated with both depression and anxiety, which provides further evidence of the association between these factors found in cross-sectional (Anthony-Bergstone, Zarit & Gatz, 1988; Cairl & Kosberg, 1993; Draper, Poulos, Cole, Poulos & Ehrlich, 1992; Parks & Pilisuk, 1991) and longitudinal studies (Vitaliano, Russo, Young, Teri & Maiuro, 1991) examining dementia caregiving. Daily hours caregiving was also significantly correlated with depression and anxiety in carers. This corresponds with results from a British Household Panel survey demonstrating this trend in former and prospective caregivers of various care-recipient populations (Hirst, 2005). This also corroborates findings from a longitudinal study with dementia caregivers (Burton et al., 2003).

The finding that caregivers with higher self-esteem reported significantly lower anxiety and depression provides continued support for the notion that a caregiver's level of self-esteem and psychological response to caregiving are related (Skaff & Pearlin, 1992, Vedhara et al., 2000). This provides support for the vulnerability model which posits that individuals with low self-esteem are at greater risk of depression (Orth & Robins, 2013). Despite previous cross-sectional research into male caregivers indicating an association between masculinity and well-being (Bowers, 1999), current findings indicated no significant correlation between masculinity/femininity and anxiety or depression. This provides support for conclusions drawn from other gender trait studies in dementia and wider carer populations, which found that gender traits were not associated with psychological response to caregiving (Baker, Robertson & Connelly, 2010; Ducharme et al., 2007). Results indicated that carers' identified with fewer masculine traits, regardless of their gender. This may explain the lack of evidence that masculinity was correlated with psychological outcome.

Although frequency of memory and behavioural problems appeared to be associated with carers' anxiety, this was not found for depression. Results linking cognitive functioning and behavioural problems to psychological distress are divided, with little evidence of an association between carers' appraisals of memory problems or cognitive functioning and depression (Schulz et al., 1995). Evidence supporting associations between behavioural problems and depression is more robust (Schulz et al., 1995) and one explanation for the current findings may be the incorporation of both memory and behavioural problems in one assessment. Measuring these factors using separate scales may provide more conclusive evidence for the relationship between memory and behavioural problems and psychological response to caregiving.

Despite longitudinal research reporting a link between negative informal support and higher dementia carer depression (Schulz & Williamson, 1991), the current results reiterate other cross-sectional findings where this relationship was not indicated (Ducharme et al., 2007; Morrissey, Becker, & Rubert, 1990). Increased professional support was associated with increased depression, but not anxiety. No relationship between anxiety and formal support was indicated in Winslow's (1997) secondary analysis of longitudinal data from a sample of 452 spouse and adult child caregivers. Although causality cannot be inferred, this may reflect the potential for carers who are increasingly depressed (rather than anxious) to seek more professional support.

Surprisingly, duration of caregiving was not significantly related to either outcome variable, as has been demonstrated previously in dementia carers (Baumgarten et al., 1992). This may lend weight to findings from previous studies investigating the stress process, which indicated that duration of caregiving is not a significant predictor of dementia carer distress (Dura, Stukenberg, & Kiecolt-Glaser, 1991; Russo et al., 1995).

Research Question 2. To what extent do the identified factors predict depression and anxiety in carers?

Excluding masculinity and femininity, the variables from Pearlin et al.'s (1990) conceptual framework significantly predicted anxiety in dementia caregivers. The finding that carer burden and hours per day were the most significant predictors supports previous conclusions that caregivers providing high levels of assistance and experiencing caregiving as increasingly burdensome are more likely to experience anxiety symptoms (Brodaty, 2002; McCann, Hebert, Bienias, Morris & Evans, 2004; Russo et al., 1995; Vitaliano et al., 1991).

Entering variables identified by Pearlin et al. (1990) significantly predicted caregiver depression but did not explain a high degree of variance. Only daily caregiving hours significantly predicted carer depression. Previous research has identified robust statistical models predicting depression using factors highlighted in Pearlin et al.'s conceptual model (Ducharme et al., 2007). The present findings should be interpreted with caution as the percentage of clinical depression reported by caregivers (30%) was lower than reports of anxiety (43%). This may have contributed to the unexpected relationships between the predictor variables and depression.

Research Question 3. Does self-esteem mediate the relationship between traits of masculinity/femininity and anxiety or depression?

Unlike previous studies in cancer caregiving (Kim et al., 2006), results indicated that self-esteem had a direct, but no mediating, effect. Kim et al. specifically measured self-esteem derived from caregiving, concluding that this mediated the relationship between gender and carer stress. One explanation for this result is that although esteem derived from caregiving has demonstrated mediating effects, global self-esteem may not serve the same function. However, this should also be interpreted cautiously given that the current sample reported average to high levels of self-esteem in contrast to the low levels of self-esteem reported in dementia caregiver literature (Brodaty & Donkin, 2009; Vedhara et al., 2000). Of note is the importance Kernis, Cornell, Sun, Berry, & Harlow (1993) place on the relationship between self-esteem stability and depression. They highlight that measuring whether self-esteem fluctuates may be a better predictor for vulnerability to depression than the assessment of an individual's levels of self-esteem. The current study focused solely on caregivers levels of self-esteem and this may have reduced the utility of conclusions drawn.

Limitations

The current data is at risk of incorrectly rejecting the null hypothesis due to the implementation of multiple correlations without correction. This may have increased the likelihood of false positives in the current data. Given the small sample size and directional hypotheses, risk of failing to reject a false null hypothesis was minimized through the use of one-tailed correlations and conventional p-values. The study's cross-sectional design should also be taken into consideration. This design limits the researcher from drawing conclusions regarding causality between variables. It could be argued that people with lower self-esteem are more likely to be attracted to carer roles, rather than carer roles influencing self-esteem levels. A prospective study design would allow for the examination of the way in which self-esteem is influenced by the adoption of a caregiver role.

Participants were registered with the SDCRN and thus represent a self-selecting sample which may contain a voluntary response bias. In addition to this, the current sample, averaging 71 years of age, reported lower percentages of clinical depression than anxiety. According to Blanchard's (1992) 'understandability phenomenon', the elderly may assume that feeling depressed is a typical part of the aging process. It is plausible, therefore, that older people report less symptomology.

A further limitation is the possibility that the validity of the BSRI may be decreasing over time (Holt & Ellis, 1998). Holt and Ellis found that differences in the male and female preferences when using masculine or feminine adjectives were less pronounced than in the original sample examined by Bem (1974). They demonstrated that the gender role stereotyping in their sample of 130 individuals was less evident than previously found. They concluded that if this trend continued, the BSRI may no longer be a valid measure of gender role perceptions in future. However, considering the current sample largely consisted of participants over the age of 60, it is possible the sample hold more traditional views about gender identity which can still be measured with validity by the BSRI.

No mediating effects of self-esteem were indicated in the study and it may have been relevant to consider whether any variables moderated the relationship between other factors. Specifically, the study may have benefited from analysis of the moderating effect of social support between hours per day caregiving and psychological outcome.

Conclusions

Despite these limitations, the current research lends weight to the suggestion that gender traits are not likely to predict carer's responses to caregiving, thus replicating previous findings of this nature with husband carers (Baker et al., 2010; Ducharme et al., 2007) in a sample comprising both male and female, spouse and adult child caregivers. The study also provides evidence that Pearlin et al.'s (1990) conceptual framework significantly predicts variance in dementia caregivers' anxiety. Specifically, it demonstrates that carer burden, hours per day caregiving and self-esteem are significantly associated with psychological distress in dementia caregivers.

These findings have several implications. Firstly, they emphasize the need for practical support and assistance for carers spending a large number of hours per day caregiving and experiencing high levels of burden. This stresses the significance of multi-component interventions which allow practical assistance and respite to the carer (Etters et al., 2008). Psychosocial interventions which build upon this group's ability to manage the practical consequences of caregiving, provide relief from burden and increase their caregiver capacity are also important (Etters et al., 2008). Interventions that target carer burden through educational programmes, provision of information and enhancement of problem solving may

result in improved psychological well-being for the carer and delayed nursing home placement as well as enhanced quality of life for the individual with dementia (Gallagher-Thompson et al., 2003). Secondly, results suggest that caregivers with high self-esteem report lower levels of anxiety and depression. Although causality cannot be determined, it seems sensible to assume that enhancing, or stabilizing, a carer's sense of self-esteem could serve to prevent or reduce the psychological distress they experience in response to caregiving. This has clinical implications for the targeting of self-esteem in caregiver interventions as well as helping delineate which skills these interventions should seek to develop.

Future research comprising a longitudinal design is needed to further develop understanding of the direction of causality between the key predictors associated with caregiver distress. The implication that stability of self-esteem may be a more important vulnerability marker than levels of self-esteem should be considered in any future research examining this important contributor. A longitudinal design would allow the assessment of self-esteem at different time points, allowing the study to identify if being a carer impacts upon self-esteem by reporting changes in levels of self-esteem. This would, therefore, allow for the measurement of the stability of self-esteem. This research design would also identify if being a carer impacts upon self-esteem by reporting changes in self-esteem. Additionally, research clarifying the relationship between carer distress, masculinity/ femininity and type of self-esteem (global or care-derived) may further improve understanding of the potential interaction between these. This is necessary for the development of high quality interventions for individuals whose role as a dementia caregiver negatively impacts upon their emotional well-being.

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Advanced Clinical Practice I: Reflective Account

*A reflection on the ethical domain of competence in the context of
clinical practice*

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Abstract

This account presents a reflection on the development of my clinical practice with regards to upholding the British Psychological Society's (2009) ethical standard of competence as discussed in the Code of Ethics and Conduct. I aim to demonstrate, using Gibb's (1988) reflective cycle, how an encounter with one particular client inspired a reflection on my awareness and ability to know the limits of my practice. The current reflection illustrates the ways in which using supervision and re-acquainting myself with BPS and HCPC guidelines raised my awareness of and approach to working competently within the scope of my practice. Lastly, I outline how the development in my learning has ensured that if faced with a situation which challenges my professional expertise, I will seek supervision and/or consultation. Reflecting on this situation has allowed me to consider the importance of working within one's scope of practice and the implications of this for safeguarding service users' well-being.

Advanced Clinical Practice II: Reflective Account

A reflection on the management and provision of psychological systems and services in the context of clinical psychology practice

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Gartnavel Royal Hospital
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G12 0XH

Abstract

This account presents a reflection on the growth in my awareness of the wider role of the clinical psychologist in terms of service management and provision. Through this reflection I describe my outlook on the role of a clinical psychologist as an assistant psychologist and how my experiences both on placement and in academic training transformed this. I reflect upon a particular event which set my development in this area in motion. Using John's (1995) model of structured reflection, I present the ways in which expanding my knowledge and experience impacted upon my confidence with and commitment to the multidimensional role of a clinical psychologist. I discuss both the professional and personal implications this had for me as a person, particularly regarding how it strengthened my sense of what 'type' of clinical psychologist I hope to be. Lastly I outline how my learning in this area has contributed to any action I would take when faced with similar situations in the future to ensure my continued professional development.

Appendices

Appendix 1.1. *Journal of Aging & Mental Health* – Notes for Contributors

Instructions for authors

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- Manuscripts may be in the form of (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to 10,000 words), or (ii) short reports not exceeding **2,000 words**. These word limits **exclude** references and tables. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list). Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate Funding paragraph, as follows:
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- Each manuscript should have 3 to 5 keywords.
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- Section headings should be concise. The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content.
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Font: Times New Roman, 12 point. Use margins of at least 2.5 cm (1 inch). Further details of how to insert special characters, accents and diacritics are available [here](#).

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Appendix 1.2. Crow Critical Appraisal Tool (V.1.4)

Crowe Critical Appraisal Tool (CCAT) Form (v1.4)

Reference

Reviewer

This form must be used in conjunction with the CCAT User Guide (v1.4); otherwise validity and reliability may be severely compromised.

Citation	
	Year

Research design (add if not listed)	
<input type="checkbox"/> Not research	Article Editorial Report Opinion Guideline Pamphlet ...
<input type="checkbox"/> Historical	...
<input type="checkbox"/> Qualitative	Narrative Phenomenology Ethnography Grounded theory Narrative case study ...
<input type="checkbox"/> Descriptive, Exploratory, Observational	A. Cross-sectional Longitudinal Retrospective Prospective Correlational Predictive ... B. Cohort Case-control Survey Developmental Normative Case study ...
<input type="checkbox"/> Experimental	<input type="checkbox"/> True experiment Pre-test/post-test control group Solomon four-group Post-test only control group Randomised two-factor Placebo controlled trial ...
	<input type="checkbox"/> Quasi-experiment Post-test only Non-equivalent control group Counter balanced (cross-over) Multiple time series Separate sample pre-test post-test [no Control] [Control] ...
	<input type="checkbox"/> Single system One-shot experimental (case study) Simple time series One group pre-test/post-test Interactive Multiple baseline Within subjects (Equivalent time, repeated measures, multiple treatment) ...
<input type="checkbox"/> Mixed Methods	Action research Sequential Concurrent Transformative ...
<input type="checkbox"/> Synthesis	Systematic review Critical review Thematic synthesis Meta-ethnography Narrative synthesis ...
<input type="checkbox"/> Other	...

Variables and analysis		
Intervention(s), Treatment(s), Exposure(s)	Outcome(s), Output(s), Predictor(s), Measure(s)	Data analysis method(s)

Sampling					
Total size	Group 1	Group 2	Group 3	Group 4	Control
Population, sample, setting					

Data collection (add if not listed)	
Audit/Review	a) Primary Secondary ... b) Authoritative Partisan Antagonist ... c) Literature Systematic ...
Observation	a) Participant Non-participant ... b) Structured Semi-structured Unstructured ... c) Covert Candid ...
Interview	a) Formal Informal ... b) Structured Semi-structured Unstructured ... c) One-on-one Group Multiple Self-administered ...
Testing	a) Standardised Norm-ref Criterion-ref Ipsative ... b) Objective Subjective ... c) One-on-one Group Self-administered ...

Category Item	Item descriptors [<input checked="" type="checkbox"/> Present; <input type="checkbox"/> Absent; <input type="checkbox"/> Not applicable]
1. Preliminaries	
Title	1. Includes study aims <input type="checkbox"/> and design <input type="checkbox"/>
Abstract (assess last)	1. Key information <input type="checkbox"/> 2. Balanced <input type="checkbox"/> and informative <input type="checkbox"/>
Text (assess last)	1. Sufficient detail others could reproduce <input type="checkbox"/> 2. Clear/concise writing <input type="checkbox"/> , table(s) <input type="checkbox"/> , diagram(s) <input type="checkbox"/> , figure(s) <input type="checkbox"/>

2. Introduction	
Background	1. Summary of current knowledge <input type="checkbox"/> 2. Specific problem(s) addressed <input type="checkbox"/> and reason(s) for addressing <input type="checkbox"/>
Objective	1. Primary objective(s), hypothesis(es), or aim(s) <input type="checkbox"/> 2. Secondary question(s) <input type="checkbox"/>

Is it worth continuing?

3. Design	
Research design	1. Research design(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of research design(s) <input type="checkbox"/>
Intervention, Treatment, Exposure	1. Intervention(s)/treatment(s)/exposure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Precise details of the intervention(s)/treatment(s)/exposure(s) <input type="checkbox"/> for each group <input type="checkbox"/> 3. Intervention(s)/treatment(s)/exposure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/>
Outcome, Output, Predictor, Measure	1. Outcome(s)/output(s)/predictor(s)/measure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Clearly define outcome(s)/output(s)/predictor(s)/measure(s) <input type="checkbox"/> 3. Outcome(s)/output(s)/predictor(s)/measure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/>
Bias, etc	1. Potential bias <input type="checkbox"/> , confounding variables <input type="checkbox"/> , effect modifiers <input type="checkbox"/> , interactions <input type="checkbox"/> 2. Sequence generation <input type="checkbox"/> , group allocation <input type="checkbox"/> , group balance <input type="checkbox"/> , and by whom <input type="checkbox"/> 3. Equivalent treatment of participants/cases/groups <input type="checkbox"/>

Is it worth continuing?

4. Sampling	
Sampling method	1. Sampling method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of sampling method <input type="checkbox"/>
Sample size	1. Sample size <input type="checkbox"/> , how chosen <input type="checkbox"/> , and why <input type="checkbox"/> 2. Suitability of sample size <input type="checkbox"/>
Sampling protocol	1. Target/actual/sample population(s): description <input type="checkbox"/> and suitability <input type="checkbox"/> 2. Participants/cases/groups: inclusion <input type="checkbox"/> and exclusion <input type="checkbox"/> criteria 3. Recruitment of participants/cases/groups <input type="checkbox"/>

5. Data collection	
Collection method	1. Collection method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of collection method(s) <input type="checkbox"/>
Collection protocol	1. Include date(s) <input type="checkbox"/> , location(s) <input type="checkbox"/> , setting(s) <input type="checkbox"/> , personnel <input type="checkbox"/> , materials <input type="checkbox"/> , processes <input type="checkbox"/> 2. Method(s) to ensure/enhance quality of measurement/instrumentation <input type="checkbox"/> 3. Manage non-participation <input type="checkbox"/> , withdrawal <input type="checkbox"/> , incomplete/lost data <input type="checkbox"/>

Is it worth continuing?

6. Ethical matters	
Participant ethics	1. Informed consent <input type="checkbox"/> , equity <input type="checkbox"/> 2. Privacy <input type="checkbox"/> , confidentiality/anonymity <input type="checkbox"/>
Researcher ethics	1. Ethical approval <input type="checkbox"/> , funding <input type="checkbox"/> , conflict(s) of interest <input type="checkbox"/> 2. Subjectivities <input type="checkbox"/> , relationship(s) with participants/cases <input type="checkbox"/>

Is it worth continuing?

7. Results	
Analysis, Integration, Interpretation method	1. A.I.I. method(s) for primary outcome(s)/output(s)/predictor(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Additional A.I.I. methods (e.g. subgroup analysis) chosen <input type="checkbox"/> and why <input type="checkbox"/> 3. Suitability of analysis/integration/interpretation method(s) <input type="checkbox"/>
Essential analysis	1. Flow of participants/cases/groups through each stage of research <input type="checkbox"/> 2. Demographic and other characteristics of participants/cases/groups <input type="checkbox"/> 3. Analyse raw data <input type="checkbox"/> , response rate <input type="checkbox"/> , non-participation/withdrawal/incomplete/lost data <input type="checkbox"/>
Outcome, Output, Predictor analysis	1. Summary of results <input type="checkbox"/> and precision <input type="checkbox"/> for each outcome/output/predictor/measure 2. Consideration of benefits/harms <input type="checkbox"/> , unexpected results <input type="checkbox"/> , problems/failures <input type="checkbox"/> 3. Description of outlying data (e.g. diverse cases, adverse effects, minor themes) <input type="checkbox"/>

8. Discussion	
Interpretation	1. Interpretation of results in the context of current evidence <input type="checkbox"/> and objectives <input type="checkbox"/> 2. Draw inferences consistent with the strength of the data <input type="checkbox"/> 3. Consideration of alternative explanations for observed results <input type="checkbox"/> 4. Account for bias <input type="checkbox"/> , confounding/effect modifiers/interactions/imprecision <input type="checkbox"/>
Generalisation	1. Consideration of overall practical usefulness of the study <input type="checkbox"/> 2. Description of generalisability (external validity) of the study <input type="checkbox"/>
Concluding remarks	1. Highlight study's particular strengths <input type="checkbox"/> 2. Suggest steps that may improve future results (e.g. limitations) <input type="checkbox"/> 3. Suggest further studies <input type="checkbox"/>

9. Total	
Total score	1. Add all scores for categories 1–8

WoSRES

West of Scotland Research Ethics Service



Miss Helen Pulford
Drumossie Unit, New Craigs Hospital
6-16 Leachkin road
Inverness
IV3 8NP

West of Scotland REC 3
Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 20 March 2015

Direct line 0141 211 2482
Fax 0141 211 1847
E-mail WoSREC3@ggc.scot.nhs.uk

Dear Miss Pulford

Study title: Caring for someone with dementia: An investigation of factors associated with carer affect
REC reference: 15/WS/0040
IRAS project ID: 166134

Thank you for your letter of 18 March 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mrs Rose Gallacher, wosrec3@ggc.scot.nhs.uk. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper [Response to REC]	1	17 March 2015
GP/consultant information sheets or letters [Letter to GP]	2	24 November 2014
Other [Glasgow University Approval Proceed to Ethics Letter]	1	21 November 2014
Other [Letter to ppt re:informing GP]	2	24 November 2014
Other [Support Sources Sheet]	3	17 March 2015
Participant consent form [Consent form]	6	17 March 2015
Participant information sheet (PIS) [PIS]	6	14 March 2015
REC Application Form [REC_Form_16022015]		16 February 2015
Research protocol or project proposal [Research protocol]	11	14 March 2015
Summary CV for Chief Investigator (CI)	1	25 November 2014
Summary CV for supervisor (student research)	1	20 November 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Plain English Summary]	1	03 February 2015
Validated questionnaire [Questionnaire]	1	03 February 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

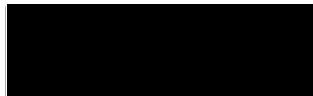
We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/WS/0040

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

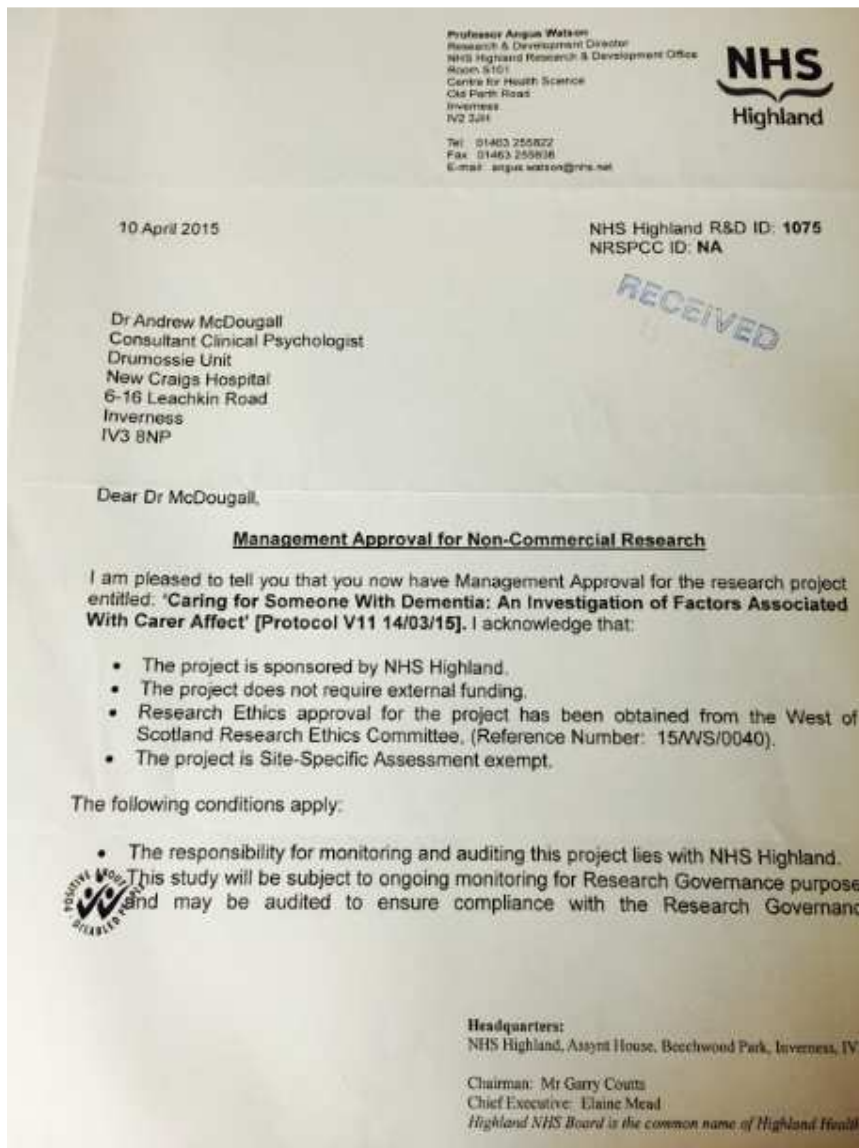


On behalf of
Dr Adam Burnes
Chair

Enclosures: *List of names and professions of members
who were present at the meeting and those who submitted written
comments
"After ethical review – guidance for
researchers"*

Copy to: *Ms Frances Hines, NHS Highland*

Appendix 1.4 Research and Development approval letter

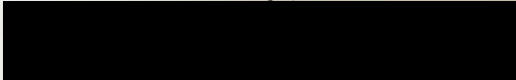


Framework for Health and Community Care in Scotland (2006, 2nd Edition), however prior written notice of audit will be given.

- All amendments (minor or substantial) to the protocol or to the REC application should be copied to the NHS Highland Research and Development Office together with a copy of the corresponding approval letter.
- The paperwork concerning all incidents, adverse events and serious adverse events, thought to be attributable to participant's involvement in this project should be copied to the NHS Highland R&D Office.
- Monthly recruitment rates should be notified to the NHS Highland Research and Development Office, detailing date of recruitment and the participant trial ID number. This should be done by e-mail on the first week of the following month.

Please report the information detailed above, or any other changes in resources used, or staff involved in the project, to the NHS Highland Research and Development Manager, Frances Hines (01463 255822, frances.hines@nhs.net).

Yours sincerely,



Frances Hines
Research, Development and Innovation Manager

cc Frances Hines, R&D Manager, NHS Highland Research & Development Office,
Room S101, The Centre for Health Science, Old Perth Road, Inverness, IV2 3JH

Helen Pulford
Drumossie Unit
New Craigs Hospital
6-16 Leachkin Road
Inverness
IV3 8NP



Caring for someone with dementia: An investigation of factors associated with carer affect

Information Sheet

Version 5 – 14/01/15

We would like to invite you to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is conducting the research?

The research is being carried out by **Helen Pulford, Dr Andrew MacDougall and Dr Jim Law** from the Department of **Clinical Psychology** at **New Craigs Hospital**, Inverness, and **Dr Alison Jackson** from the **University of Glasgow**.

What is the purpose of the research?

The purpose of this study is to investigate whether factors such as self esteem, masculinity and femininity, carer burden and social support are associated with the emotions and mood of people caring for someone with dementia. Please see the Plain English Summary for more detail.

Why have I been invited?

You have been invited to take part in this study as you currently care for someone with dementia and you have registered on the Scottish Dementia Clinical Research Network's (SDCRN) research register. This questionnaire pack has been sent to you by the SDCRN, on behalf of the researcher.

Do I have to take part?

No it is up to you to decide. This information sheet may help with this decision. You will be asked to sign a consent form to show you have agreed to take part. It may be advisable to take a minimum of 24 hours to decide whether to participate. You are free to withdraw at anytime, without giving a reason. This would not have any adverse consequences and would not impact on the health care provided for the individual you care for.

What does taking part involve?

You are being asked to complete the questionnaire pack posted to your home. This will ask you about the person you care for, what caring tasks you carry out, how you have been feeling lately and your personality traits. Altogether this should take no more than 30 minutes to complete and can be done whenever is convenient for you. The questionnaires do not need to all be completed at once if this is not convenient. You are then asked to return the questionnaire pack and signed consent form via a freepost envelope provided.

What happens to the information?

Your identity and personal information will be completely confidential and known only to the SDCRN. Part of this research will involve answering questions about your current mood. In the event that responses to this suggest that you are experiencing significantly high levels of anxiety or depression then your name and address will be provided to the researcher, who would send you a letter to encourage you to talk about this with your GP. Your GP would also be sent a letter informing them of this. If your responses to the mood questionnaire do not indicate significantly high levels of anxiety or depression then your GP will not be contacted for any other reason during the research study.

The information obtained will remain confidential and stored securely. The data are held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people, without your permission.

What are the possible benefits of taking part?

The information we get from this study may increase our understanding of how clinicians can support people caring for someone with dementia. If you wish to take part in the study and would like to receive a summary of the completed research, please tick the appropriate box on the consent form.

What are the possible disadvantages and risks of taking part?

As caring for someone with dementia is an emotive topic, it is possible that completing questionnaires on this topic may be distressing for some people. If you do feel distressed, we have included information on possible sources of support that you can contact.

Who has reviewed the study?

This study has been reviewed by the NRES Committee: West of Scotland REC 3.

If you have any further questions:

We have sent you this information sheet and a more detailed summary of the research. The research team's contact details are provided below. If you wish to speak to someone not closely linked to the study, please contact the Scottish Dementia Clinical Research Network (Tel. **01738 562322**).

Thank you for taking the time to read this.

Yours sincerely,

Helen Pulford – Main researcher

Trainee Clinical Psychologist

Department of Psychological Services,
Drumossie Unit,
New Craig's Hospital,
Leachkin Road,
Inverness, IV3 8NP

Tel. 01463 253 697**E-mail:** Helen.pulford@nhs.net

Other contacts:

Dr Andrew MacDougall – Clinical Supervisor

Consultant Clinical Psychologist
Clinical Psychology Services for Older People
Drumossie Unit,
New Craig's Hospital,
Leachkin Road,
Inverness, IV3 8NP
Tel. 01463 253 697

Dr Jim Law – Research Supervisor

Head of Clinical Psychology Services for Older People
Drumossie Unit,
New Craig's Hospital,
Leachkin Road,
Inverness, IV3 8NP
Tel. 01463 253 697

Dr Alison Jackson – Academic Supervisor

Academic Tutor
Mental Health and Wellbeing
University of Glasgow
First Floor Administration Building
Gartnavel Royal Hospital
1055 Great Western Road
G12 0XH

Tel: +44(0)141 211 3917

If you have a complaint about any aspect of the study:

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance. The normal NHS complaint procedure can also be followed.

Thank you for your time and co-operation.



Participant Consent Form:

I confirm that I have read and understand the information sheet dated 14/01/15 (version 5) for the above study and have had the opportunity to ask questions.

I understand my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason, without my medical care or legal rights, or that of the person I am caring for, being affected.

I understand that the information I provide will be made anonymous to ensure my participation is confidential.

I would like to receive a summary of the research when completed.

I understand that I will be sent a letter by the researcher if my questionnaire responses indicate that I am experiencing significantly high levels of anxiety and depression.

I give my permission for the researcher to contact my GP in this event, at the below address:

.....

.....

.....

I agree to take part in the above study.

.....
Name of Participant (printed): Date Signature

.....
Name of Researcher (printed): Date Signature



Caring for someone with dementia: An investigation of factors
associated with carer mood

Questionnaire Pack

Thank you for choosing to take part in this research study. Please answer all the questions below and **post this questionnaire pack** and your ***signed consent form*** back in the included freepost envelope.

Age: Gender:

How many years did you spend in education?

What is your relationship to the person with dementia (e.g. spouse/son/daughter/friend)?

.....

How long have you known the person with dementia?

How long have you been taking care of the person with dementia on account of their health problems?

How many hours per day do you spend providing care and attention to the person with dementia?

How much support do you receive from family and friends when caring for your relative with dementia?

None

Some

A lot

☐

☐

☐

☐

☐

How helpful do you find this support?

Very helpful

A bit helpful

Unhelpful

☐
☐
☐
☐
☐

How much support do you receive from other health professionals/NHS staff when caring for your relative with dementia?

None

Some

A lot

☐
☐
☐
☐
☐

How helpful do you find this support?

Very Helpful

A bit helpful

Unhelpful

☐
☐
☐
☐
☐

Rosenberg Self-Esteem Scale

Instructions: Below is a list of statements dealing with your general feelings about yourself. **Please tick the boxes according to how much you agree that the following statements:**

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. On the whole, I am satisfied with myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.* At times, I think I am no good at all.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I feel that I have a number of good qualities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I am able to do things as well as most other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.* I feel I do not have much to be proud of.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.* I certainly feel useless at times.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. I feel that I'm a person of worth, at least on an equal plane with others. ☐ ☐ ☐ ☐
- 8.* I wish I could have more respect for myself. ☐ ☐ ☐ ☐
- 9.* All in all, I am inclined to feel that I am a failure. ☐ ☐ ☐ ☐
10. I take a positive attitude toward myself. ☐ ☐ ☐ ☐

*Statements are reverse scored.

Bem Sex Role Inventory

Directions

On the next page, you will find listed a number of personality characteristics. We would like you to use those characteristics to describe yourself, that is, we would like you to indicate, on a scale from 1 to 7, how true of you each of these characteristics is. Please do not leave any characteristic unmarked.

Example: sly

Write a **1** if it is *never or almost never true* that you are sly.

Write a **2** if it is *usually not true* that you are sly.

Write a **3** if it is *sometimes but infrequently true* that you are sly.

Write a **4** if it is *occasionally true* that you are sly.

Write a **5** if it is *often true* that you are sly.

Write a **6** if it is *usually true* that you are sly.

Write a **7** if it is *always or almost always true* that you are sly.

Thus, if you feel it is **sometimes but infrequently true** that you are "sly," **never or almost never true** that you are "malicious," **always or almost always true** that you are "irresponsible," and **often true** that you are "carefree," then you would rate these characteristics as follows:

Sly	3
Malicious	1

Irresponsible	7
Carefree	5

Short Form

1	2	3	4	5	6	7
Never or almost never true	Usually not true	sometimes but infrequently true	Occasionally true	Often true	Usually true	Always or almost always true
1. Defend my own beliefs						
2. Affectionate						
3. Conscientious						
4. Independent						
5. Sympathetic						
6. Moody						
7. Assertive						
8. Sensitive to needs of others						
9. Reliable						
10. Strong personality						
11. Understanding						
12. Jealous						
13. Forceful						
14. Compassionate						
15. Truthful						
16. Have leadership abilities						
17. Eager to soothe hurt feelings						
18. Secretive						
19. Willing to take risks						
20. Warm						
21. Adaptable						
22. Dominant						
23. Tender						
24. Conceited						
25. Willing to take a stand						
26. Love children						
27. Tactful						
28. Aggressive						
29. Gentle						
30. Conventional						

Zarit Burden Interview –Short form

Please answer all questions using the following scale:

DO YOU FEEL . . .	Never	Rarely	Sometimes	Quite Nearly	Frequently	Always
1. That because of the time you spend with your relative that you don't have enough time for yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Stressed between caring for your relative and trying to meet other responsibilities (work/family)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Angry when you are around your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. That your relative currently affects your relationship with family members or friends in a negative way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Strained when you are around your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. That your health has suffered because of your involvement with your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. That you don't have as much privacy as you would like because of your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. That your social life has suffered because you are caring for your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. That you have lost control of your life since your relative's illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Uncertain about what to do about your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. You should be doing more for your relative? ☐ ☐ ☐ ☐ ☐

12. You could do a better job in caring for
your relative? ☐ ☐ ☐ ☐ ☐

Revised Memory and Behaviours Problem Checklist

The following is a list of problems people with dementia sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened? Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully.

FREQUENCY RATINGS:

- 0 = never occurred
- 1 = not in the past week
- 2 = 1 to 2 times in the past week
- 3 = 3 to 6 times in the past week
- 4 = daily or more often
- 9 = don't know/not applicable

REACTION RATINGS:

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = very much
- 4 = extremely
- 9 = don't know/not applicable

Please answer all the questions below. Please circle a number from 0 -9 for both *frequency* and *reaction*.

	Frequency	Reaction
1. Asking the same question over and over.	0 1 2 3 4 9	0 1 2 3 4 9
2. Trouble remembering recent events (e.g., items in the newspaper or on TV).	0 1 2 3 4 9	0 1 2 3 4 9
3. Trouble remembering significant past events.	0 1 2 3 4 9	0 1 2 3 4 9
4. Losing or misplacing things.	0 1 2 3 4 9	0 1 2 3 4 9
5. Forgetting what day it is.	0 1 2 3 4 9	0 1 2 3 4 9
6. Starting, but not finishing, things.	0 1 2 3 4 9	0 1 2 3 4 9
7. Difficulty concentrating on a task.	0 1 2 3 4 9	0 1 2 3 4 9
8. Destroying property.	0 1 2 3 4 9	0 1 2 3 4 9
9. Doing things that embarrass you.	0 1 2 3 4 9	0 1 2 3 4 9
10. Waking you or other family members up at night.	0 1 2 3 4 9	0 1 2 3 4 9
11. Talking loudly and rapidly.	0 1 2 3 4 9	0 1 2 3 4 9
12. Appears anxious or worried.	0 1 2 3 4 9	0 1 2 3 4 9
13. Engaging in behavior that is potentially dangerous to self or others.	0 1 2 3 4 9	0 1 2 3 4 9
14. Threats to hurt oneself.	0 1 2 3 4 9	0 1 2 3 4 9
15. Threats to hurt others.	0 1 2 3 4 9	0 1 2 3 4 9
16. Aggressive to others verbally.	0 1 2 3 4 9	0 1 2 3 4 9
17. Appears sad or depressed.	0 1 2 3 4 9	0 1 2 3 4 9
18. Expressing feelings of hopelessness or sadness about the future (e.g., "Nothing worthwhile ever happens," "I never do anything right").	0 1 2 3 4 9	0 1 2 3 4 9
19. Crying and tearfulness.	0 1 2 3 4 9	0 1 2 3 4 9

FREQUENCY RATINGS:

- 0 = never occurred
- 1 = not in the past week
- 2 = 1 to 2 times in the past week
- 3 = 3 to 6 times in the past week
- 4 = daily or more often
- 9 = don't know/not applicable

REACTION RATINGS:

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = very much
- 4 = extremely
- 9 = don't know/not applicable

Please answer all the questions below. Please circle a number from 0 -9 for both *frequency* and *reaction*.

20. Commenting about death of self or others (e.g., "Life isn't worth living," "I'd be better off dead").	0 1 2 3 4 9	0 1 2 3 4 9
21. Talking about feeling lonely.	0 1 2 3 4 9	0 1 2 3 4 9
22. Comments about feeling worthless or being a burden to others.	0 1 2 3 4 9	0 1 2 3 4 9
23. Comments about feeling like a failure or about not having any worthwhile accomplishments in life.	0 1 2 3 4 9	0 1 2 3 4 9
24. Arguing, irritability, and/or complaining.	0 1 2 3 4 9	0 1 2 3 4 9

Thank you for taking part in this research study. Please turn over to sign the consent form on the next page. Please sign and keep the second consent form for your own record.

Please **post this questionnaire pack** and your ***signed* consent form** back in the included freepost envelope to:

SDCRN Study 62
FREEPOST RSLC-RHRX-TASE
Murray Royal Hospital
Muirhall Road
PERTH
PH2 7BH



Caring for someone with dementia: An investigation of factors associated with carer affect

Sources of Support

1. **The Dementia Helpline:** Tel. 0808 808 3000

E-mail: helpline@alzscot.org

The 24 hour Dementia Helpline is a freephone Scottish service for people with dementia, carers, relatives, professionals, students and anyone concerned about dementia.

2. **Dementia Advisors and other local advice**

Alzheimer Scotland funds local Dementia Advisors, who support people with dementia, their partners, families and carers. They also work with local communities.

To find out more about support available locally, visit the Alzheimer Scotland website on http://www.alzscot.org/services_and_support/dementia_advisers_and_other_local_advice

Your local Dementia Advisor can:

- provide information and advice
- help you find the dementia support that you need
- connect you to local groups and services
- help your local community be more dementia-friendly
- help you influence the policies and services that affect you.

3. For information about **resources available to support carers**, visit: http://www.alzscot.org/information_and_resources/caring_for_someone_with_dementia/resources_for_carers

4. For information about **other sources of support**, such as dementia cafes & community activities, peer support, and dementia resource centers visit:
http://www.alzscot.org/services_and_support

Appendix 1.9 Additional information on measures

Table 1. Description of measures

Measure	N° of items	Score Type	Time Scale	Period Assessed
Bem Sex-Role Inventory Short Form (BSRI; Bem 1974)	30	Subscale score for masculinity Subscale score for femininity	5 – 10 mins	General
Duration of caregiving	2	Total score for duration of care (months) Total score for daily care (hours)	2 mins	General
Revised memory and behavioural problems checklist (MBPC, Teri et al., 1992)	24	Total score for frequency of care-recipients behaviours Three subscale scores for memory-related problems, affective distress and disruptive behaviours Total score for caregivers reaction to these behaviours	15 – 20 mins	Previous Week
Brief Zarit Burden Interview (B-ZBI, Bedard et al., 2001)	12	Total score for burden experienced Subscales for caregiver role strain and personal gain	15 mins	General
Social Support				
Rosenberg Self-esteem Scale (Rosenberg, 1962)	10	Total score of self-esteem	2 -5 mins	General
Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith , 1983)	14	Anxiety Score Depression Score	2 – 5mins	Previous week

Appendix 1.10. Major Research Project Proposal

Caring for someone with dementia: An investigation of factors associated with carer affect

Abstract

Background. Research indicates that caring for someone with dementia may lead to higher risk of experiencing mental health problems. Research into the factors associated with caregiver outcomes suggests that self-esteem is one potential mediator of caregiver outcome; and that gender differences may relate to distress experienced by carers.

Aims. This study aims to examine how traits of masculinity and femininity and levels of self-esteem are associated with distress experienced by carers of people with dementia. This will be investigated in relation to Pearlin et al.'s (1990) stress process model of caregiving.

Methods. Male and female caregivers of people with dementia will be recruited through the Scottish Dementia Clinical Research Network. Participants will be asked to complete a postal survey assessing gender identity, burden, self-esteem, care-recipient functioning and caregiver mental health.

Applications. Findings from this study could lead to further understanding of the variables that contribute to and mediate caregiver distress. This may highlight key areas of support to include in future interventions for caregivers of people with dementia.

Introduction

In 2012, the Alzheimer's Society released a report indicating that there were 800,000 people diagnosed with dementia in the UK. This report also indicated that two thirds of people are being cared for in the community. Approximately 75% of individuals receive community care from family or friends (Schulz & Martire, 2004). Research in the field of dementia indicates that caring for someone with dementia may lead to higher risk of experiencing depression (Baumgarten et al., 1992). If caregivers receive inadequate support, they can experience high levels of carer burden, which can negatively impact their physical, emotional and functional health (Zarit et al., 1980; Carretero et al., 2009). In extreme cases

this may result in incomplete treatment of patient symptoms, patient neglect and even abuse (Messinger-Rapport, McCallum & Hujer, 2006).

A number of factors have been researched in terms of their impact on caregiver distress and burden (i.e. moderators) as well as to what extent factors may explain the relationship between variables (i.e. mediators). Schulz et al. (1995) discuss several potential mediators of caregiver distress in their review of the care-giving literature, such as, level of disability, relationship to the caregiver, caregiver burden and caregiver self esteem.

Gender differences also appear to be associated with caregiver distress. Research to date suggests that female caregivers consistently report higher levels of distress than male carers (Harwood et al., 2000). The gender socialization hypothesis suggests that gender roles become internalised as personality traits following gender role socialization during childhood (Miller, 1990). This results in females possessing more communal traits, indicating a concern for oneself in relation to others, compared to men, who hold agentic personality traits, such as autonomy and self-assertion (Bakan, 1966). Gender differences in sensitivity to relationships may cause women to be more vulnerable to experiencing distress than men (Kessler, 1979).

Alternatively, the social role hypothesis posits that men and women engage in continual construction of the social role that is expected of them. According to this hypothesis, women will report higher levels of burden as they are more heavily involved in care-giving activities and access less informal support. Cultural positioning of females as natural nurturers (O'Grady, 2005) may mean that women are expected to take on a wide range of caring tasks and responsibilities. This may result in women setting high standards for themselves (Foucault, 1979) leading to internalisation of problems, self-sacrifice and absence of self-care (Jack et al., 2010) and thus higher levels of distress and burden. As incidences of dementia are increasing, changes in the demographic population mean that a higher number of men have found themselves in the care-giver role for people with dementia (Hirst, 2001). According to Baker and Roberston's (2008) review of 93 articles, the majority of past research makes little reference to individual gender differences and these demographic changes highlight the importance of understanding the role these play in caregiver distress.

Self-esteem, often defined as someone's overall sense of self-worth and personal value, is also a potential mediator of carer distress. This is of particular interest within psychological research due to the potentially modifiable nature of self-esteem through intervention. Research suggests that self-esteem reaches a peak at about age 60 years, and then declines in old age. Furthermore women of all ages report lower levels of self-esteem

than men (Orth et al., 2010). In line with the gender role perspective, Furr (2005) suggested that how well a person meets the expectations of the societal norms for their gender will dictate how high or low their self-esteem is. This suggests that men may experience an increased sense of self-esteem when meeting expectations of a carer role that is not expected of them. Kim et al. (2006) found that male carers of cancer survivors were more likely to report higher caregiver esteem and less carer burden than female carers, who reported lower caregiver esteem and, in turn, higher levels of care-giving stress.

The current research aims to investigate how gender differences such as traits of masculinity and femininity are associated with male and female caregiver's levels of self-esteem, burden and distress. Relevant situational variables include differences in care-recipient functioning, social support and time spent care-giving, thus these will also be included in the analysis. It is beyond the scope of this research to include all potential variables associated with distress.

Additionally, this study aims to investigate whether self-esteem mediates carer distress based on a stress-process model of care-giving derived by Pearlin et al. (1990). Pearlin et al. (1990) outline various background and contextual factors (e.g. caregiver characteristics) that relate to primary stress indicators (such as care-recipient behaviours) and secondary indicators (such as overload). These stress indicators result in intra-psychic strains (e.g. reduced sense of self-esteem). It is proposed that these strains mediate the relationship between caregiver stress and negative outcomes. Investigating these variables using this framework may further expand theoretical understanding of this topic.

In terms of clinical implications of the research, enhancing understanding of the role gender-related variables and self-esteem play in the mediation of appraisals of caregiver distress may provide useful information for the expansion of dementia caregiver interventions.

Aims and Hypothesis

Aims:

- To investigate whether masculinity/femininity, self-esteem, social support, care-recipient functioning, duration of care-giving, time per day care-giving and carer burden factors are associated with psychological distress in care-giving?
- To examine whether self-esteem has a mediating effect between subjective stressors (carer burden) and psychological distress?

Hypothesis: The researcher hypothesizes that masculinity/femininity, self-esteem, social support, care-recipient functioning, duration of care-giving, time per day care-giving and carer burden are associated with psychological distress and that self-esteem will have a mediating effect between carer burden and psychological distress.

Plan of Investigation

Participants: Participants will consist of male and female caregivers of people with dementia aged 18 and above who are currently registered on the Scottish Dementia Clinical Research Network (SDCRN)'s database as voluntary research participants. It is estimated that this register holds approximately 1,300 carers.

Inclusion and Exclusion Criteria: Inclusion criteria will specify that potential participants should be primary caregivers of people with dementia (Alzheimer's disease, vascular dementia, dementia with Lewy Bodies, Fronto-temporal dementia as well as any rarer types of dementia). The primary caregiver is a person that takes primary responsibility for another person who cannot care fully for themselves. Caregiver's of people with Down syndrome and dementia will be excluded.

Recruitment: Participants will be recruited from the Scottish Dementia Clinical Research Network (SDCRN). The researcher will contact the SDCRN and request for postal questionnaires to be sent to primary caregivers on their list of volunteers for recruitment to research. A previous study (Law et al., 2013) carried out with carers of people with dementia sent out 500 surveys to people on the SDCRN research register, of which 112 were returned over a 10 week period. This represents a response rate of 23%.

Design/ Research Procedures: Successful completion of the SDCRN peer review will allow the current research to be adopted by the SDCRN. This can be done parallel to NHS Ethics Committee approval being sought and can take up to 4 weeks. The research procedures will involve the researcher contacting the SDCRN, requesting that a proportion of caregivers meeting study criteria are invited to take part in the study. Participants will be provided with an information sheet, consent form and questionnaire pack. . Each pack will contain an identifier, allowing the participants to remain anonymous. Time taken to complete these measures is approximately 30 to 40 minutes. This is based on two dementia carers completing the questionnaires as a pilot run. Participants will also be provided with the option of being able to contact the researcher and the SDCRN as an independent contact to discuss research participation.

Measures: Respondents will be asked to provide demographic information, such as age, gender and years of education (See Appendix 1.7 for a draft questionnaire pack, this is for information only and layout will be edited when submitting to ethics). Named diagnosis (collected by the SDCRN) and an Addenbrooke's Cognitive Examination (ACE) will also be available for the care recipient from the SDCRN database. As these were completed when carers joined the SDCRN research database, they may not reflect the current cognitive status of the person with dementia, therefore participants will also be asked to complete a questionnaire regarding the care recipient's current condition. The following 7 factors will be examined (see Appendix 1.9 for further detail on each measure):

Masculinity/Femininity. Masculine and feminine traits will be measured using the 30 item Bem Sex-Role Inventory Short Form (BSRI; Bem 1974). Each participant will receive a mean masculinity score and a mean femininity score based on the responses provided.

Duration of care-giving. Carers will be asked to stipulate how long they have been taking care of the person with dementia and how many hours per day they provide care to the care recipient.

Memory and Behavioural Problems. The revised Memory and Behaviour Problems Checklist (MBPC, Teri et al., 1992) will be used to measure the frequency of the care-recipient's observable behavioural problems and the caregiver's reaction to these on 24 items.

Carer Burden. The 12-item Brief Zarit Burden Interview (B-ZBI, Bedard et al., 2001) has been selected to measure caregiver role strain (relating to the demands of the care-giving role) and personal strain (relating to the caregiver's sense of adequacy about being a carer).

Social Supports. Participants will be asked to answer several questions relating to support received from family and friends, as well as utility of these (see Appendix 1.7 for questions).

Self Esteem. Global self-esteem will be measured using Rosenberg Self Esteem Scale (Rosenberg, 1962) which comprises 10 items, rated on a five-point scale that consider beliefs in one's worth, competence and capacity for success.

Carer Distress. The 14-item Hospital Anxiety Depression Scale (HADS, Zigmond & Snaith, 1983) will be used to measure presence or absence of anxiety and depression symptoms in caregivers.

Data Analysis

Quantitative statistical analysis will be completed using SPSS. Based on advice from the Robertson Centre for Biostatistics, University of Glasgow, multiple linear regression analyses will be used to investigate whether the 7 above variables are associated with caregiver distress. Age will be analyzed as a covariate. In line with the first and second research aims, differences between distress, burden and self-esteem scores will be analyzed for male and female carers. Correlations between reported masculinity/femininity traits and distress, burden, social support and self-esteem will also be calculated. Regarding the third study aim, multi linear regression will be used to examine whether self-esteem mediates negative outcomes for carers using Pearlin et al.'s (1990) stress process model of caring.

Justification of sample size: Previous research in this area (Ducharme et al., 2007) used a similar model of analysis as the one proposed for this research and had a sample size of 323 participants. A statistician from the Robertson Centre for Biostatistics calculated the adjusted R-squared based on the correlations found in the Ducharme et al. (2007) research. This demonstrated that to detect the same R-squared ($R^2 = 0.51$) with 7 predictors, 80% power and

significance level of 5%, a sample size of 41 would be required. These numbers are based on a study in which carers were solely male, therefore analyses would be adjusted to allow for data being collected from both male and female carers.

Settings and Equipment: Computers and SPSS software will be used during this research. Research will be completed via postal survey therefore a clinical setting will not be utilised.

Health and Safety Issues

Researcher Safety Issues: As the research proposed does not involve face to face contact with participants, there will be few risk issues pertaining to the health and safety of the researcher. Further detail is provided in the Health and Safety Form (see Appendix 1.10).

Participant Safety Issues: It is possible that when completing the survey on the emotive topic of caring for someone with dementia, the participant may begin to feel distressed. See Ethical Issues section for details of the procedure in this instance.

Ethical Issues

The SDCRN register used for recruitment is approved by the relevant multi-centre research ethics committee and all participants give consent to join the register. In terms of consent, letters will be sent to the participant with an information sheet clearly outlining the purpose of the research and the participant's option to participate on a voluntary basis and opt out at anytime. Each postal pack will be coded by the SDCRN (who will hold all person identifiable information that belongs to each code) prior to distribution. Packs will be returned to the researcher at a freepost address. A system will be devised to ensure that if the occasion arises where a mood measure reveals that the participant caregiver is experiencing clinical levels of depression or anxiety (e.g. an anxiety or depression score of 8 or over as measured by the HADs), the SDCRN will unblind that participant, allowing the researcher to contact them and their GP directly. Consent forms will detail the procedure by which the researcher will notify the participant's GP of any clinical levels of distress reported. Participants will also be provided with contact details for the researcher to discuss their distress if they wish to, as well as an information sheet detailing independent sources of support.

All information will be stored in accordance with the Data Protection Act (2008) and NHS Highland local policies and procedures. Submissions of ethical applications will be made to NHS Highland Research and Development department and the Research Ethics Committee.

Financial Issues

Use of a University laptop and SPSS software will be needed to complete the analysis of this research. The methodology consists of questionnaires, therefore funding will be needed to cover the cost of purchasing the Bem Sex Role Inventory. Financial support will also be needed to cover the cost of producing the questionnaire packs and sending free post return envelopes. Cost estimates for this are detailed in the Research Equipment form (see 1.10).

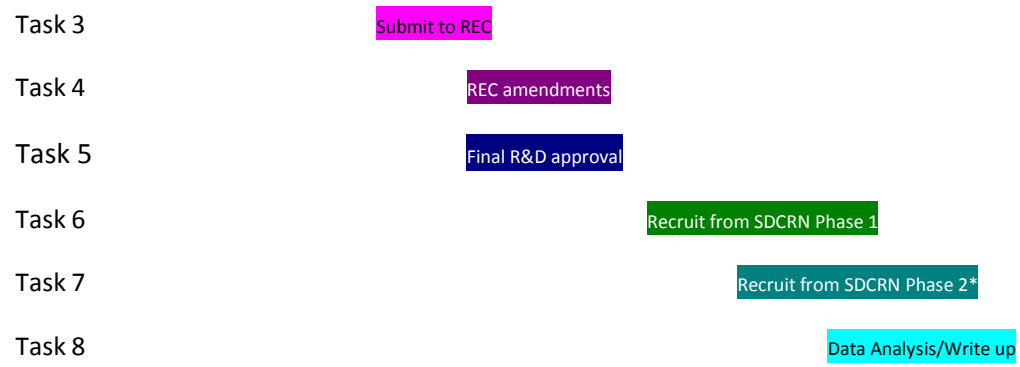
Practical Applications

The study aims to identify key predictors associated with the distress of caregivers of people with dementia. Findings from these investigations could lead to further understanding of what factors (such as self-esteem and types of support used) are important when considering possible interventions for carers of people with dementia, as well as what skills these interventions should seek to develop. This can be applied in clinical care to provide services that offer support and promote the mental health of those caring for people with dementia.

Timetable

Recruitment will take place from December 2014 until May 2015.

MRP	2014					2015											
	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	
Task 1																	Submit to SDCRN
Task 2																	Submit to R&D



*if required

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Appendix 1.11. *Regression models for anxiety (1) and depression (2a) & (2b)*

(1)

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.759 ^a	.575	.398	3.237

a. Predictors: (Constant), Level of social support from family/friends, BEM_Masculinity, Number of years cared for pwd, ZBI_Total, BEM_Femininity, Education, Number hrs caring per day, RMBPC_Reac_total, Age, Rosenberg self-esteem scale Total Score

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	340.773	10	34.077	3.252	.009 ^b
	Residual	251.513	24	10.480		
	Total	592.286	34			

a. Dependent Variable: HADS_Anxiety_Total

b. Predictors: (Constant), Level of social support from family/friends, BEM_Masculinity, Number of years cared for pwd, ZBI_Total, BEM_Femininity, Education, Number hrs caring per day, RMBPC_Reac_total, Age, Rosenberg self-esteem scale Total Score

Coefficients^a

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	4.353	11.706		.372	.713
	Age	-.034	.087	-.092	-.386	.703
	BEM_Masculinity	-.042	.076	-.094	-.547	.590
	BEM_Femininity	.004	.095	.008	.040	.969
	Education	-.041	.168	-.039	-.243	.810
	Number of years cared for pwd	.124	.254	.070	.489	.629
	Number hrs caring per day	.113	.087	.251	1.292	.209
	RMBPC_Reac_total	.008	.049	.031	.173	.864
	ZBI_Total	.307	.118	.590	2.607	.015
	Rosenberg self-esteem scale Total Score	.002	.209	.003	.011	.992
	Level of social support from family/friends	-.591	.525	-.167	-1.124	.272

a. Dependent Variable: HADS_Anxiety_Total

(2a)

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.596 ^a	.355	.086	3.562

a. Predictors: (Constant), BEM_Femininity, Number of years cared for pwd, Level of social support from family/friends, BEM_Masculinity, ZBI_Total, Education, Number hrs caring per day, RMBPC_Reac_total, Age, Rosenberg self-esteem scale Total Score

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	167.383	10	16.738	1.319	.276 ^b
	Residual	304.502	24	12.688		
	Total	471.886	34			

a. Dependent Variable: HADS_Dep_Total

b. Predictors: (Constant), BEM_Femininity, Number of years cared for pwd, Level of social support from family/friends, BEM_Masculinity, ZBI_Total, Education, Number hrs caring per day, RMBPC_Reac_total, Age, Rosenberg self-esteem scale Total Score

Coefficients^a

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	11.005	12.880		.854	.401
	Education	.036	.185	.038	.196	.847
	Number of years cared for pwd	.249	.280	.158	.890	.382
	Number hrs caring per day	.188	.096	.471	1.961	.062
	RMBPC_Reac_total	-.016	.054	-.068	-.305	.763
	ZBI_Total	.057	.129	.124	.444	.661
	Rosenberg self-esteem scale Total Score	-.195	.230	-.259	-.847	.405
	Level of social support from family/friends	.021	.578	.007	.036	.971
	Age	-.050	.096	-.153	-.520	.608
	BEM_Masculinity	.027	.084	.069	.325	.748
	BEM_Femininity	-.069	.105	-.154	-.659	.516

a. Dependent Variable: HADS_Dep_Total

(2b)

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.572 ^a	.327	.165	3.393

a. Predictors: (Constant), Level of social support from family/friends, Number of years cared for pwd, RMBPC_Reac_total, Education, Number hrs caring per day, ZBI_Total, Rosenberg self-esteem scale Total Score

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	162.407	7	23.201	2.015	.087 ^b
	Residual	333.864	29	11.513		
	Total	496.270	36			

a. Dependent Variable: HADS_Dep_Total

b. Predictors: (Constant), Level of social support from family/friends, Number of years cared for pwd, RMBPC_Reac_total, Education, Number hrs caring per day, ZBI_Total, Rosenberg self-esteem scale Total Score

Coefficients^a

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	3.793	5.062		.749	.460
	Education	.094	.162	.101	.578	.568
	Number of years cared for pwd	.071	.201	.057	.356	.725
	Number hrs caring per day	.153	.069	.386	2.208	.035
	RMBPC_Reac_total	-.010	.050	-.043	-.209	.836
	ZBI_Total	.099	.096	.209	1.038	.308
	Rosenberg self-esteem scale Total Score	-.152	.154	-.202	-.990	.330
	Level of social support from family/friends	-.141	.490	-.045	-.287	.776

a. Dependent Variable: HADS_Dep_Total

Appendix 1.12. *Pearlin, Mullan, Semple & Skaff's (1990) Stress Process Framework*

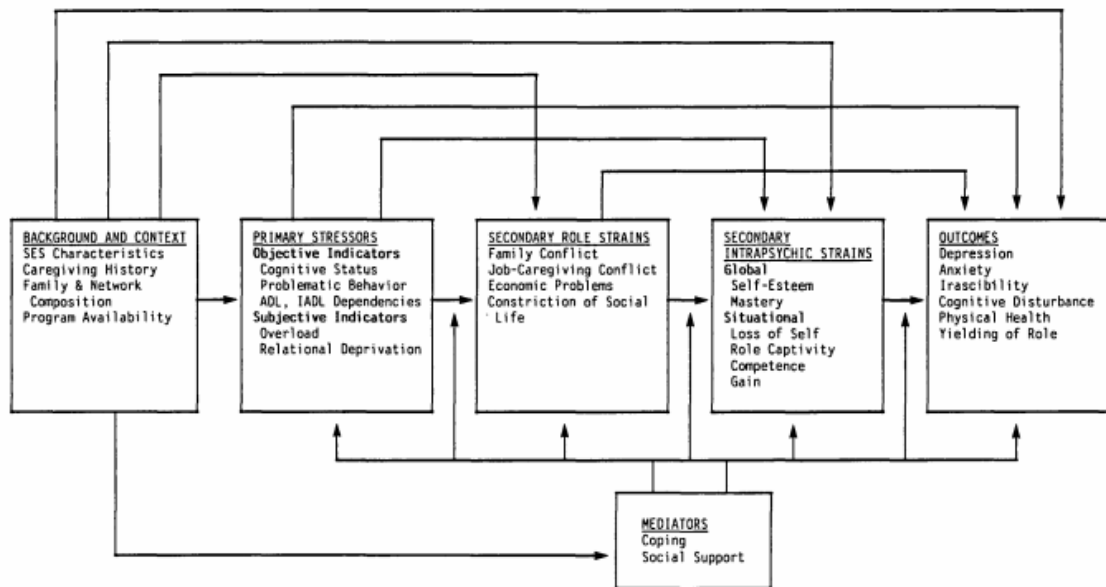


Figure 1. A conceptual model of Alzheimer's caregivers' stress. The stress process is made up of four domains: the background and context of stress; the stressors; the mediators of stress; and the outcomes or manifestations of stress.