Emotion Regulation and Positive Growth in Spousal Dementia Carers

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Declaration

I declare that this thesis and the research on which it is based are my own work. I confirm that this work has not been submitted for any other degree or professional qualification.

Roisin Ash

October 2013
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I am privileged to have been able to work with and learn from a range of clients and their families who live with dementia, all of whom inspire my continued questioning and learning and my motivation to share that learning compassionately.

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Content and Format

Chapter 1: Systematic Review is written in adherence of guidelines specified by International Psychogeriatrics. References cited within this article are listed at the end of this chapter. Appendix 1, pp. 174 – 182, displays the author guidelines for this journal.

Chapters 2: The Research Context is written in adherence of guidelines specified by the British Psychological Society (2004). A reference list containing the articles cited in this chapter combined with references in all other chapters is provided at the end of the thesis.

Chapter 3: Journal Article: Emotion Regulation and Positive Growth in Spousal Dementia Carers is written in adherence of guidelines specified by Clinical Psychology & Psychotherapy. References cited within this article are listed at the end of this chapter. Appendix 2, pp. 183 – 189, displays the author guidelines for this journal.
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<td>Adelaide Activities Profile</td>
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<td>ANOVA</td>
<td>Analysis of Variance</td>
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<td>BES</td>
<td>Basic Emotions Scale</td>
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<td>CDR</td>
<td>Clinical Dementia Rating, CDR</td>
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<td>CES-D</td>
<td>Centre for Epidemiologic Studies - Depression Scale</td>
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<td>Hamilton Depression Rating Scale</td>
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<td>IRAS</td>
<td>Integrated Research Application System</td>
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<td>Mini Mental Status Examination</td>
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<td>MSQ</td>
<td>Mental Status Questionnaire</td>
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<td>Principal Components Analysis</td>
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<td>PSS</td>
<td>Perceived Stress Scale</td>
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<td>Post traumatic growth inventory</td>
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<td>PTG</td>
<td>Post traumatic growth</td>
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<td>SDCRN</td>
<td>Scottish Dementia Clinical Research Network</td>
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<tr>
<td>SDS</td>
<td>Short Zung Interviewer Assisted Depression Rating Scale</td>
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<td>SIGN</td>
<td>Scottish Intercollegiate Guidelines Network</td>
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Abstract

**Background:** Despite evidence that caring for a spouse or partner with dementia may continue over a number of years, our understanding of how the carer’s experience unfolds over time is still in its infancy. In addition, the emotional experience of spousal dementia carers has been incompletely understood in research and clinical practice with a predominant focus upon negative emotional consequences. There is a need to contextualise the emotional experience of carers within a framework that enables understanding of positive aspects of the care experience.

**Objective:** This thesis is in two parts. Part one uses systematic review to critically evaluate evidence from published longitudinal studies that assess the impact of care transition (caring for spouse at home and placed spouse in care home) on the well-being of spousal dementia carers. Part two is an empirical study examining emotion regulation and positive growth in spouses who care for their partner with a diagnosis of dementia.

**Methods:** Systematic review of longitudinal studies that assess the impact of care transition on spousal carer well-being. The empirical study comprised a cross-sectional design comparing positive growth and emotion regulation in three carer groups (caring for spouse at home, placed spouse in care home or experienced death of spouse). 183 carers were recruited through a postal survey which comprised the following self-report measures: Post Traumatic Growth Inventory; Basic Emotions Scale; and Regulation of Emotions Questionnaire.

**Systematic Review Results:** Despite poorer psychological and physical well-being over time compared with non-carers, symptoms of depression, perceived burden and stress are stable over time for those who continue to care for their spouse at home. Mixed results are obtained for carer well-being when examining transition to permanent placement in care home and impede definitive conclusions.
**Empirical Study Results:** Spousal carers report more frequent feelings of fear and frustration compared to other basic emotions. Gender and care transition impact upon the experience and regulation of emotion and positive growth. Internalising emotion regulation strategies (for example, rumination) are associated with greater fear and frustration, sadness and guilt while strategies comprising social support seeking are associated with feelings of happiness in carers. Spouses report positive growth since taking on the role of carer and this is predicted in part by social support seeking emotion regulation strategies but not by experience of emotions.

**Conclusions:** Spousal carers are not a homogenous group. Further research on the experience of spousal dementia carers is required. This should include the development of tools and methods tailored to capture emotion regulation. The concept of positive growth following stressful events (for example, becoming a carer) may have potential for presenting an enriched understanding of the emotional consequences of the carer experience over time.
1 Systematic review: What happens to spousal dementia carer emotional well-being before and after care home placement?

1.1 Abstract

Background: Despite evidence that caring for a spouse or partner with dementia may continue over a number of years, our understanding of how this unfolds over time is still in its infancy. This systematic review aims to summarise and evaluate evidence from published longitudinal studies assessing the impact of care transition on emotional well-being of spousal carers.

Method: Embase, Medline, PsycINFO, CINAHL and ASSIA were searched between January 1980 and February 2013 for prospective cohort studies of emotional well-being of spousal dementia carers relating to care transitions. Case reports, intervention studies and qualitative studies were excluded from review.

Results: The literature search identified 166 articles of which ten met the criteria for inclusion. Carers have poorer psychological well-being over time compared with non-carers, although symptoms of depression, perceived burden and stress are stable over time for those who continue to care for their spouse at home. Findings were inconclusive within and between studies regarding transition to care home. Poorer emotional well-being and improvement in well-being were associated with permanent placement in five studies. Different outcome measures limit the comparability of studies while relatively short follow-up periods, with infrequent re-interview, restrict understanding of the care experience over time.

Conclusions: Longitudinal studies demonstrate that care placement impacts upon carer well-being, although inconsistent and contradictory results impede definitive conclusions. Spousal carers are not a homogenous group and merit further research using a wider range of study variables to examine carer well-being trajectories over longer periods of time.

Keywords: spouse; carer; depression; emotional well-being; transition; dementia; longitudinal; systematic review.
1.2 Introduction

1.2.1 Dementia

Dementia is a progressive degenerative condition, characterised by behavioural, psychological, physical and cognitive impairments, that affects the personality, mood and behaviour of the person with dementia and impacts upon those who care for and about them (Boss, 2011). The time from diagnosis of Alzheimer’s dementia to death may be several years (Sachs et al., 2004) with research highlighting a range from a median of 4 years (Wolfson et al., 2001), (4.2 years for males and 5.3 years for females (Larson et al., 2004)) up to 9 years (Walsh et al., 1990).

1.2.2 Estimates and National priorities

There are an estimated 821,884 people in the UK with dementia (1.3% of the UK population and 20% of those aged over 85 years, Knapp & Prince, 2007) costing £23 billion per year (Luengo-Fernandez et al., 2010). UK predictions suggest a rise in the number of people with dementia to 1.7 million by 2051 (Knapp & Prince, 2007). The number of people with dementia in Scotland is expected to double between 2011 and 2031. The scale and extent of dementia and the reliance upon family, health and social care systems place dementia as a significant public health concern (Scottish Government, 2013).

The Scottish Government have identified dementia as a national priority (Scotland’s National Dementia Strategy, 2010; 2013). In the drive to improve systems of dementia care, there is a focus across health boards in Scotland on early diagnosis and identification of dementia; post diagnostic support; and alternatives to hospitalisation. In addition, the need to support carers to maintain relationships and receive psychological support has been outlined in the standards of care (Standards of care for dementia in Scotland, 2011a) and in national guidance that evidences the use of psychological therapies (Scottish Government,
In the absence of a sound longitudinal dementia carer evidence base, the Scottish Government has given a commitment to providing one year post diagnostic support for dementia carers although it is not known whether the timing and duration of this provision is appropriate, effective or sufficient for the majority of carers.

1.2.3 Dementia care

Dementia care-giving is a dynamic process that may last several years during which time the carer may experience transitional stages such as care home placement (Gaugler et al., 2003a; 2003b) and loss of control associated with unpredictable deterioration in the care recipient (Ory et al., 2000). Dementia progression requires that dementia carers manage a challenging process of psychological adjustment (Pinquart & Sorenson, 2003a) including restructuring roles and systems of decision making (Qualls, 2008).

1.2.4 Psychological well-being in dementia care

The spouse is a key attachment figure (Hazan & Shaver, 1987) and spousal dementia care changes the relationship between spouses including the loss of the person the carer once knew (Shim et al., 2012). Social isolation (Drentea et al., 2006) and emotional loss (Rodriguez et al., 2003) are reactions associated with dementia care. Spousal dementia carers are more likely to experience depression (Adams, 2008; Joling et al., 2010; Pinquart & Sorenson, 2011), burden (Hong & Kim, 2008) and greater age-related health problems than other familial carers (Pinquart & Sorenson, 2007). This may impact negatively upon perceived stress levels (Pinquart & Sorenson, 2003a; 2011).

Higher anxiety and symptoms of depression in the month prior to interview in spousal dementia carers have been found to be associated with the perception that the dementia is impeding the carer’s social participation and relationships, with females reporting higher anxiety and males higher depression (Croog et al., 2006). Providing care for a partner with
dementia is associated with distress and challenges exceeding those of other types of spousal care (Schulz & Williamson, 1994). Cross-sectional dementia carer studies highlight negative impacts of caring on psychological health (Schultz et al., 1995), most notably amongst carers who report stress (Schulz et al., 1997; Schultz & Beach, 1999). Carers with high anxiety are likely to experience burden over time while those who report satisfaction with the quality and quantity of social support they receive are less likely to report burden (Vitaliano et al., 1991) and less likely to report symptoms of depression (Waite et al., 2004).

1.2.5 Psychological well-being and gender

A review of gender differences in psychological well-being amongst carers that included spouses with dementia found higher levels of depressive symptoms as measured by the CES-D (a self-report scale designed to measure symptoms of depression in the general population) in female carers in the majority of studies (Yee & Schulz, 2000). Systematic review of familiar carers, including dementia carers, found small yet significant effects of gender on depression and burden with higher depression and burden in female than male carers (Pinquart and Sorensen, 2006a). Cross sectional studies have found that female dementia carers report greater burden than male carers (Barush & Spaid, 1989; Gilhooley et al., 1984; Miller & Cafasso, 1992).

Although greater social and physical burden has been reported in female familial dementia carers compared to males, emotional burden was found to be similar in males and females (Akpinar et al., 2011). In contrast to Yee & Schulz (2000), Gallichio et al., (2002) found that symptoms of depression as measured by the CES-D were similar in male and female carers.
1.2.6 Physical health and dementia care

Ill health in carers has more generally been cited as a reason for permanent care placement (Chenoworth & Spencer, 1986) and associated with the level of disability of the care recipient and the length of time in the carer role (Sneyder & Keefe, 1985). Given the chronic stress involved in dementia caring, it may be expected that higher rates of physical illness will be found in carers (Dougal & Baum, 2012; Thoits, 2010). It is argued that spousal carers neglect their own health, indeed female spouses have been described as “hidden patients” (Fengler & Goodrich, 1979).

1.2.7 Permanent placement in care home

Care home placement is viewed as a major marker of dementia progression (Winblad et al., 2000 as cited in Gaugler et al., 2009a) and described as one of the core problematic decisions to be taken by carers (Livingston et al., 2010) yet understanding of psychological well-being when one’s spouse is in care is limited (Gaugler et al., 2007). Placement is associated with considerable distress amongst carers (Gaugler et al., 2008; 2009b) with increases in spousal carer depression, anxiety (Schulz et al., 2004), sadness and guilt (Rudd et al., 1999) following placement.

Family caregivers often retain an active role in care when residence has transferred to long-term residential care facilities (Brown-Wilson & Davies, 2009) and spouses in particular experience a different set of challenges compared with other familial carers (Zarit & Gaugler, 2006). These include reticence in placing their spouse in care (Montgomery & Koslovsi, 1994), providing higher levels of care after placement with greater frequency of visits (Gaugler et al, 2003a; Wright, 1998; Zarit & Gaugler, 2006). Nevertheless, assumptions continue to be made about the benefits of care home placement in reducing demands on the carer (Gaugler et al., 2011).
1.2.9 Variation in carer well-being

Variation in dementia carers’ psychological well-being has been noted with some carers improving and some deteriorating following care home placement (Gaugler et al., 2010) although the passing of time has been associated with an increase in well-being (Zarit & Whitlatch, 2002). Systematic review found that a large number of care recipient behaviours were associated with carer well-being although results were inconclusive regarding the link between care recipient behaviours and familial carer depression and burden (Ornstein & Gaugler, 2012).

The differential response to caring, whereby some carers experience marked decline in well-being whilst others do not (Gonzalez et al., 2011), may be best understood by studying care giving prospectively and over the course of transition to care home. The point at which carers may have the space to consider their own psychological needs may be at transition such as care home placement, making this worthy of study.

1.2.10 Understanding the impact of care transition over time

To understand the impact of care transitions such as permanent care home placement, it is important to examine the care experience over time, yet carers are not typically followed up over time (Schulz et al., 2001). A need for greater understanding of the longitudinal course of emotional distress in carers, and a lack of emotionally focussed interventions, was demonstrated in systematic review two decades ago (Knight et al., 1993) yet the evidence base to date consists mainly of cross-sectional studies which are limited in their ability to explain the development of carer experience (Gaugler et al., 2011).

Longitudinal research may inform more meaningfully on the impact of dementia carer emotional well-being over time although research has examined predictors of care home placement rather than the impact that care placement has upon carer psychological well-
being (Gaugler et al., 2011). Mixed results have been reported regarding the impact of familial carer intervention on delayed care home placement. Meta-analyses found that only multi-component intervention (a combination of different forms of intervention) delayed placement (Pinquart & Sorensen, 2006b). Systematic review demonstrated that combined individual and group counselling interventions but not multicomponent psychosocial intervention or individual training delayed placement (Goy & Kansagara, 2010). Longitudinal research found that support intervention, including counselling spousal dementia carers, delayed care home placement in spouses with dementia (Mittelman et al., 2006).

Meta-analysis of familial dementia carer interventions found beneficial effects of psychoeducational and respite intervention upon subjective well-being, burden and depression, while social support intervention improved subjective well-being (Pinquart & Sorensen, 2006b). Systematic review of interventions to support familial carers of people with dementia living in the community found a small, significant positive effect of multi-component and psycho-educational interventions on carer depression but no impact on burden (Parker et al., 2008). Gaugler et al., (2008) found that counselling and support group participation decreased depression and burden after care home placement in familial carers when compared with those who continue to provide care at home.

Systematic review of psychological interventions found that developing skills in managing emotional distress and developing dementia knowledge enabled carers to maintain levels of emotional well-being over time (Elvish et al., 2013). Individual CBT and group-based CBT with familial dementia carers have been found to be effective in treating depression and stress, respectively (Gallagher-Thompson & Coon, 2007).
While a great deal has been learned from dementia carer intervention studies the need for greater understanding of the course of emotional distress in carers who do not receive intervention, identified in the nineties (Knight et al., 1993), has largely been unmet. Some carers experience clinically significant emotional distress such as depression and burden (Gaugler et al., 2010) and may not possess the resources to engage with services and intervention treatment groups. Other carers manage their distress and experience positive aspects of caring for their spouse with dementia (Braun et al., 2009; Searson et al., 2008), most notably where the care role enabled continued spousal connection as part of the marital relationship (Lewis et al., 2005). These carers may be less likely to come to the attention of health services and there is a risk that we miss out on learning from those who adapt in their care role over time.

With an ageing population (Ferri et al., 2006; Knapp & Prince, 2007) there will be an increase in the number of older couples faced with managing dementia progression (Braun et al., 2009). There is a need for greater theoretical and empirical attention to be paid to spousal adaptation; in particular, lessons may be learned from spousal carers who exhibit stable patterns of well-being over time (Martin et al., 2009). There exists an outstanding need, therefore, to study the spousal care experience as it unfolds naturally and without intervention.

1.3 Aims of the study
A systematic review of research published from January 1980 to February 2013 was conducted to identify, quantify and distil what is known about spousal dementia carers’ emotional well-being over the course of the care journey and with particular reference to permanent care home placement. This involved a comprehensive search of the literature and critical appraisal of studies for the purpose of providing methodological quality ratings that were comparable between studies. This review will critically appraise and evaluate the
evidence-base examining the impact of care home placement and the emotional well-being of spousal dementia carers in an attempt to answer the following two questions:

1. Is the emotional well-being of dementia carer spouses different to non-carer spouses over time?

2. Is the emotional well-being of spousal dementia carers shaped by care transition?

1.4 Methods

1.4.1 Search strategy

The following databases were searched up to and including 4 February 2013: Embase, Medline, PsycINFO, CINAHL and ASSIA. The search terms used were (spouse* OR spousal OR husband* OR wife OR wives OR couple* OR significant others); (dementia OR Alzheimer’s disease); (transition OR trajectory OR stages OR grief OR longitudinal OR prospective OR follow-up). Relevant reviews and references of all included studies were hand searched and authors contacted about other studies and unpublished work.

1.4.2 Selection criteria

Inclusion criteria included all studies that were reported as primary longitudinal quantitative research studies, peer reviewed and published in English, that reported on the impact of transition to care home (an important change event that requires adjustment by carer and spouse with dementia) on spousal carer emotional well-being over time. Well-being was defined through the presence of positive components of the care experience, for example, care uplifts and positive spousal interaction, and absence of depression, burden and stress. Studies which included measures of positive components of care and/or perceived burden, stress or carer depression at baseline and follow-up were, therefore, included in the review. Studies which included baseline measures of carer well-being which were linked with subsequent care transition at follow-up were also included in the review. All dementia carers were residing long term with their spouse at baseline and either continued to reside with their
spouse or placed their spouse in permanent care during the follow-up period. There were no restrictions placed on the type of dementia included in studies selected for review although all care recipient spouses were required to have a formal diagnosis of dementia.

The interest in this review was in the adaptation of spousal dementia carers without intervention because this is less well understand compared to outcomes of carers following intervention which have been examined in a number of large scale programmes (for example, New York Caregiver Programme, Gaugler et al., 2011; Mittelman & Epstein, 2009; and Resources for Enhancing Alzheimer’s Caregiver Health (REACH) project, Hebert et al., 2006; Wisniewski et al., 2003). Intervention studies were, therefore, excluded from review.

The following criteria were used to exclude studies that were inappropriate for the purposes of this systematic review: cross-sectional, qualitative and case studies; spousal carer intervention studies; and longitudinal spousal carer studies that did not examine the impact of care transition on emotional well-being. Articles which amalgamated adult child carers with spousal carers were excluded from review.

1.4.3 Quality assessment

The quality assessment rating system was developed by the review author using principles derived from Cochrane Collaboration and Sign 50 guidelines and primary research non-intervention studies (Kmet et al., 2004) and based upon the quality assessment criteria for reviewing non-intervention studies used by the Eppi-centre (Harden et al., 2001). The methodological quality of included studies was rated on a three-point scale applied to ten criteria (equally weighted, see Table 1, below). The maximum score obtainable was 20 (ten criteria multiplied by score of two). An overall percentage was calculated by dividing the total score (ten criteria multiplied by the score (0, 1 or 2) by total of 20).
Studies were included in the review to inform on the impact of dementia care on emotional well-being over time. Points were awarded to studies that included an appropriate comparison group (important in determining whether it is the care experience or natural passage of time that is impacting on carers) and to studies that included a measure of dementia severity (important in contextualising the stage of dementia and challenges that may present for carers and care recipients). Table 1, below, displays the critical appraisal quality criteria.

| Table 1. Quality criteria: definitions for critical appraisal of review articles |
|----------------------------------|---------------------------------|
| 1. Study rationale: study rationale was clear and justified |
| WC: The aims of the study were clearly stated and the context of the study were well described with a clear explanation of, and justification for, the focus of the research and the methods used. |
| AA: Study aims and objectives were outlined |
| PA: Lack of clarity of study aims and objectives |
| 2. Theoretical framework: the study was based upon a theoretical framework |
| WA: The study provides an explicit account of the theoretical framework and/or includes a robust literature review which links the research to an existing body of knowledge. |
| AA: The study was based upon a theoretical framework and included an adequate literature review |
| PA: The literature review was inadequate and the study failed to make links between existing body of knowledge and research undertaken |
| 3. Sampling strategy: the study sampling strategy was clear and justified |
| WC: Clear rationale, justification and description of the circumstances under which the sample was recruited into the study |
| AA: Sampling strategy and recruitment adequately defined |
| PA: Lack of clarity in describing how the sample were targeted and recruited into the study |
| 4. Eligibility criteria: the study provides clear details of the sample of spouses used |
| WC: Inclusion/exclusion criteria for spouses included in the study clearly defined and limitations identified to enable contextualisation of results |
| AA: Inclusion/exclusion criteria for spouses defined to enable replication |
| PA: Inclusion/exclusion criteria for spouses poorly defined |
| 5. Comparison group: the study included an appropriate comparison group |
| WC: Rationale and justification for use of comparison group, inclusion criteria clearly defined, age matched, gender matched, spousal status matched, caregiving status monitored |
| AA: Age matched, gender matched, spousal status matched |
| PA: Use of comparison group unmatched on key features of age, gender and spousal status |
| NA: Study did not include comparison group |
| 6. Carer outcome measures: robust measures of well-being were used |
| WC: The measures used to examine well-being have robust validity and reliability for the spouses used in the studies |
| AA: The measures used to examine well-being have reasonable validity and reliability for the spouses used in the studies |
| PA: The measures used to examine well-being have questionable validity and reliability for the spouses used in the studies |
| NA: Well-being for the carer was not addressed using formal measures |
| 7. Care recipient outcome measures: robust measures of well-being were used |
| WC: The measures used to examine well-being have robust validity and reliability for the spouses with dementia in the studies |
AA: The measures used to examine well-being have reasonable validity and reliability for the spouses with dementia in the studies
PA: The measures used to examine well-being have questionable validity and reliability for the spouses with dementia in the studies
NA: Well-being of the spouse with dementia was not addressed using formal measures

8. Data analysis: methods of data analysis were appropriate to the study
WC: A clear and detailed description of methodology, including overall research framework, and use of data collection and data analysis methods that are valid and reliable for longitudinal/prospective data
AA: Adequate and suitable methods used to collect and analyse longitudinal/prospective data
PA: Inadequate methods used to collect and analyse longitudinal data, lacking detail to replicate
NA: Sample size too small for longitudinal analyses

9. Sample size: sample size was sufficient to enable longitudinal follow-up
WC: Attrition rates were reported at each follow-up stage, sample numbers included in analyses were clearly identified and the implications of sample size for analyses discussed
AA: Attrition rates were reported at follow-up
PA: Attrition rates were not reported in enough detail to ascertain sample size at follow-up
NA: Attrition was not addressed

10. Data Interpretation: the study included sufficient original data to mediate between data and interpretation
WC: The article presents sufficient data to enable the reader to see that the results and conclusions are grounded in the data. A clear path is identified between the data and the interpretation and conclusions. Consideration is given to the impact of the methods used on shaping the findings of the study to aid interpretation and judgement about the validity and generalisability of findings.
AA: Data reporting is adequate in enabling the reader to see results and conclusions are grounded in the data presented
PA: Data reporting is inadequate in enabling the reader to see that results and conclusions are grounded in the data
NA: Results and conclusions are not grounded in the data provided

<table>
<thead>
<tr>
<th>Well covered (WC): 2 points (++)</th>
<th>Poorly addressed (PA): 0 point (-)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequately addressed (AA): 1 point (+)</td>
<td>Not addressed (NA): 0 point (-)</td>
</tr>
</tbody>
</table>

1.5 Results

1.5.1 Literature Search

The search strategy uncovered 166 studies after removal of duplicates. These were screened by title and reduced further upon examination of the abstract of articles and in some instances by reviewing the full text (Figure 1, below, summarises the review process). Eight separate prospective cohort studies satisfied the main inclusion and exclusion criteria. Information on these eight studies was gathered from ten published articles with four articles providing information about two studies (Bond & Clark, 2002 and Bond et al., 2003: Study 1 and Wright 1994a; Wright 1994b: Study 7). There is a need to differentiate between each published article within study 1 or study 7 where they address a different aspect of a research question. Where each article is cited separately, however, it should be noted that each pair inform only one study.
The greatest number of articles were excluded on the grounds that they comprised carer or care recipient intervention studies (n=21), therefore negating the study of the care experience as it unfolds naturally without intervention, or because they amalgamated spousal with other familial or informal carers (n=21) which meant it was not possible to examine spousal responses. The remaining excluded studies were longitudinal studies that did not examine the care transition (n=10), studies whose population was non-dementia carers (n=6), studies whose design was qualitative (n=3), case study (n=2) or cross sectional (n=3) and a study in which the carer status of the spouse was not defined (n=1).
1.5.2 Assessment of study quality

Studies were scored using the criteria outlined in Table 1 and results are presented in summary in Table 2, below. Reviews have used a 60 per cent cut-off score to differentiate studies of higher quality (Luppino et al., 2010; Van der Kooy et al., 2007). Using this cut-off, two studies ranked as ‘higher quality’ (Bond et al., 2003; Clark et al., 2007), four studies scored 50 - 55 per cent and two studies scored 45 per cent.

Study methodology and quality ratings are summarised in Table 2, p.15, and Table 3, pp. 19 - 26. Tables 4 and 5, pp. 29 - 30, provide a summary of the scales used to assess well-being amongst spousal carers and Table 6, p. 30, to assess care recipients in each study. Table 7, pp. 36 - 42, summarises analyses, findings and conclusions of each study.

1.5.3 Setting and sampling of included studies

Eight prospective cohort studies were included, two were based in Australia and six in the US. Overall, the numbers of spousal carers ranged from 30 to 29 (Wright, 1994a) and 315 to 220 (Pruchno et al., 1990) between baseline and follow-up. Studies recruited through a combination of sources including Alzheimer’s association or Alzheimer’s disease research organisations, carer support groups and older adults’ services.

1.5.4 Coverage of the studies

1.5.4.1 The follow-up period

Follow-up duration varied between and within the eight studies subject to review (Table 3: Methods and Participants). Three studies (Kramer, 2000; Pruchno et al., 1990; Clark et al., 2007) reported follow-up data at one year after baseline interview or assessment and three studies at two years (informed by five articles: Bond & Clark, 2002; Bond et al., 2003; Wright, 1994a; 1994b; Zarit et al., 1986). Two studies followed up spouses more regularly at 6 monthly intervals (Grant et al., 2002; Mausbach et al., 2007).
**Table 2. Methodological quality indicators of longitudinal studies that examine caring for a spouse with dementia**

<table>
<thead>
<tr>
<th>FIRST AUTHOR</th>
<th>STUDY RATIONALE</th>
<th>THEORETICAL FRAMEWORK</th>
<th>SAMPLING STRATEGY</th>
<th>ELIGIBILITY CRITERIA</th>
<th>COMPARISON GROUP</th>
<th>CARER OUTCOME MEASURES</th>
<th>CARE RECIPIENT OUTCOME MEASURES</th>
<th>DATA ANALYSIS</th>
<th>SAMPLE SIZE</th>
<th>DATA INTERPRETATION</th>
<th>TOTAL SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bond (2002)</td>
<td>++</td>
<td>+</td>
<td>++</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>++</td>
<td>12 (60%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bond (2003)*</td>
<td>++</td>
<td>+</td>
<td>++</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>++</td>
<td>12 (60%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Clark (2007)</td>
<td>+</td>
<td>+</td>
<td>++</td>
<td>++</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>13 (65%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Grant (2002)</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>10 (50%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Kramer (2000)</td>
<td>+</td>
<td>++</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>-</td>
<td>10 (50%)</td>
<td>++</td>
<td></td>
</tr>
<tr>
<td>5. Mausbach (2007)</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>9 (45%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Pruchno (1990)</td>
<td>+</td>
<td>++</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>++</td>
<td>11 (55%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Wright (1994a)</td>
<td>++</td>
<td>++</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>11 (55%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wright (1994b)*</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>10 (50%)</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>8. Zarit (1986)</td>
<td>++</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>9 (45%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total score</strong></td>
<td><strong>12 (60%)</strong></td>
<td><strong>12 (60%)</strong></td>
<td><strong>13 (65%)</strong></td>
<td><strong>11 (55%)</strong></td>
<td><strong>4 (67%)</strong></td>
<td><strong>8 (50%)</strong></td>
<td><strong>10 (50%)</strong></td>
<td><strong>8 (50%)</strong></td>
<td><strong>12 (60%)</strong></td>
<td><strong>13 (65%)</strong></td>
<td><strong>12</strong></td>
</tr>
</tbody>
</table>

Well covered (WC): 2 points (++)

Adequately addressed (AA): 1 point (+)

Poorly addressed (PA): 0 point (-)

Not addressed (NA): 0 point (-)

* Please note that Study 1 and Study 7 are each informed by two published articles which are jointly assessed in this table. Where they address different aspects of review questions, published articles are cited separately for ease of reference. For example, Wright (1994a) includes a non-carer group to compare depression over time and is used to address review question 1 while Wright (1994b) does not include a comparison group although examines the association between spousal interaction and the association with subsequent care transition and is used to address review question 2. Bond & Clark (2002) examine baseline measures including decision to place in care and their association with care transition status at follow-up while Bond et al. (2003) include post-care transition measures which address different aspects of review question 2.
1.5.4.2 Attrition rates

Percentage attrition may be an inappropriately crude measure of study rigour and therefore it is important to contextualise follow-up figures by reference to the study population and assessment methodology (Amico, 2009). In the present review, Grant et al., (2002) purposively selected only those participants with a minimum of three data points (technically zero attrition) while Mausbach et al., (2007) did not report attrition rate. Six studies reported attrition rates with a range from 6 per cent (Clark et al., 2007) to 23 per cent (Kramer, 2000; Pruchno et al., 1990) at one year and from 3 per cent (Wright, 1994b) to 45 per cent (B. Mausbach, personal communication, 25 February 2013) at two years. Attrition rates are summarised in Table 3: Participants.

1.5.4.3 Time between transition and follow-up as a confounding factor

The average duration between care home placement and follow-up was from 5.6 months (SD = 3.4 months), Clark et al., (2007) to 15 months (SD = 7 months), Bond & Clark, (2002). Three studies (Pruchno et al., 1990; Wright, (1994a; 1994b); Zarit et al., 1986) did not report the length of time that had passed between care placement and follow-up. The confounding effect of time on transition outcomes in these studies cannot be examined and makes comparisons difficult.

1.5.4.4 Differences between participants who remain in the study versus drop-outs

Only two studies reported on differences between those who engaged in follow-up and those who were lost to follow-up, finding that those who continued in the study were younger (Bond et al., 2003; Pruchno et al., 1990). Six studies did not examine drop-outs and continued participants (Clark et al., 2007; Grant et al., 2002; Kramer, 2000; Mausbach et al., 2007; Wright (1994a; 1994b); Zarit et al., 1986) which limits interpretation of carer outcomes at follow-up.
1.5.4.5 Age, gender and physical health of spousal carers

The average age and gender of spousal carers (Table 3: Participants) ranged from 67 years (Wright, 1994b) to 74 years (Clark et al., 2007). Gender ratios were most commonly around 65 per cent female: 35 per cent male although ranged from 52 per cent female (Zarit et al., 1986) to 80 per cent female (Wright, 1994b) in seven studies subject to review. One study reported only on male spousal carers (Kramer, 2000) which impedes meaningful comparison with other studies in this review.

Six studies used six different physical health measures that differed in content, structure and administration (Table 5, p. 30). Three of these studies compared carers who continued to live with their spouse with carers who placed their spouse, one of which reported results at baseline only (frequency of illness: Pruchno et al., 1990) and two at baseline and follow-up (physical health status and perceived change in health: Bond et al., 2003; perceived change in health in the preceding year: Kramer, 2000). Two studies compared physical health of carers and non-carers at baseline (Wright, 1994a; Grant et al., 2002) and one study at baseline and follow-up (stress-related physiology measures: Clark et al., 2007). The diversity in measures limits the potential for comparison between studies although enables comparison between carer groups within studies (discussed further in sections 1.5.6.1, p. 31 (review question 1) and 1.5.8.1, p.34 (review question 2)).

1.5.4.6 Length of time in the carer role

There was variation in the reporting of duration of care (Table 3: Participants) with reports of average length of time in the carer role (range: 2.8 to 11.1 years, Bond & Clark, 2002; Grant et al., 2002; Pruchno et al., 1990), average time since diagnosis (around three years, Bond & Clark, 2002; Clark et al., 2007) and mean time since symptom onset (range: 5.2 to 6.5 years, Bond & Clark, 2002; Kramer, 2000; Wright, 1994a; Zarit et al., 1986). One article (Mausbach et al., 2007) did not report length of time in the carer role or symptom onset.
1.5.4.7 Dementia diagnosis

Five studies comprised carers of spouses with a diagnosis of Alzheimer’s disease (Bond & Clark, 2002; Clark et al., 2007; Grant et al., 2002; Mausbach et al., 2007; Wright, 1994a). Two studies comprised dementia (Kramer, 2000) and Alzheimer’s disease and related disorders (Pruchno et al., 1990). One study included two thirds Alzheimer’s disease and one third multi-infarct dementia (Zarit et al., 1986). Variation in population mix needs to be taken into account when comparing between studies. Table 3: Methods.

1.5.4.8 Dementia severity

Five measures of dementia severity (Functional Dementia Scale, FDS, Moore et al., 1983; Clinical Dementia Rating, CDR, Hughes et al., 1982; Geriatric Depression Scale (GDS), Brink et al., 1982; Global Deterioration Scale, Reisberg et al. 1982; Mental Status Questionnaire, MSQ, with Face Hand Test, Kahn et al., 1960) were used only at baseline in five studies (seven articles: (Bond & Clark, 2002; Bond et al., 2003); Grant et al., 2002; Mausbach et al., 2007; Wright (1994a; 1994b); Zarit et al., 1986) which limited comparability between studies (Table 6: Dementia severity scale, p. 30). Three studies (Clark et al., 2007; Kramer, 2000; Pruchno et al., 1990) included no formal measure of the severity or stage of the care recipient’s dementia which means that it is not possible to determine if there is an impact of spousal stage of dementia on carer emotional well-being in these studies.
### Table 3 Summary of methodology and quality rating for each included study

<table>
<thead>
<tr>
<th>STUDY</th>
<th>METHOD</th>
<th>PARTICIPANTS</th>
<th>CARER OUTCOMES</th>
<th>OUTCOME MEASURES</th>
<th>METHODOLOGICAL QUALITY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sample 1</strong>&lt;br&gt;Bond &amp; Clark (2002)&lt;br&gt;Predictors of care transition: placing spouse in care home</td>
<td>Recruited spousal carers registered with the Alzheimer’s Association of South Australia. Interview with registered carer at home. Follow-up 2 years later: written invitation to participate in follow up, telephone call 1 week later to establish caregiver status.</td>
<td>Country: Australia&lt;br&gt;Spousal carers, co-habiting with and actively providing care at baseline to spouse with geriatrician diagnosis of Alzheimer’s disease. Number: 163 &gt;=65 years&lt;br&gt;Mean age: 71 years (SD=7.6 years)&lt;br&gt;69 male: 94 female (58% female)&lt;br&gt;Mean years providing care: 3.2 (SD=3 years)&lt;br&gt;Follow up: 97% (n=158* carers) (N=60 (32%) continued care at home and N=98 (68%) placed spouse in care home)&lt;br&gt;Number in sample by years since diagnosis: N=46: &lt;= 1 year, N=60: 1- 4 years, N=57: &gt; 4 years&lt;br&gt;Comparison group: no&lt;br&gt;Mean duration between care home placement and follow-up: 15 months (SD=7 months)</td>
<td>Carer status: continued care at home or placement in care home</td>
<td>Carer self-report living arrangements of spouse with dementia&lt;br&gt;Carer depression</td>
<td>10/20 (50%)</td>
</tr>
<tr>
<td><strong>Bond et al. (2003)</strong>&lt;br&gt;Depression and care transition: placing spouse in care home</td>
<td>Same study as above.&lt;br&gt;Re-interview at home of caregivers 2 years after baseline.</td>
<td>Follow-up interview: 92% (n=150/163)&lt;br&gt;Attrition: 8%&lt;br&gt;63 male: 87 female (58% female)&lt;br&gt;Mean age carer: 71.3 years (SD=7.4)&lt;br&gt;Mean age care recipient: 74.3 years (SD=6.7)&lt;br&gt;Mean years providing care: 3.2 (3 years)&lt;br&gt;Years of care: continued caregivers: 2.9 years (SD=3.1 years); placed spouse: 3.3 years (SD=3.4 years); placed spouse then widowed: 3.5 years (SD=2 years)&lt;br&gt;Comparison group: no&lt;br&gt;Mean duration between transition and follow up (months): 13.8 months placement (SD=6.9 months)</td>
<td>Carer depression</td>
<td>Geriatric Depression Scale (GDS)&lt;br&gt;Carers who continued to live with spouse scored below cut-off indicating depression&lt;br&gt;Carers who placed their spouse in care scored above cut-off indicating depression&lt;br&gt;Carer activity</td>
<td>12/20 (60%)</td>
</tr>
</tbody>
</table>
Table 3 Summary of methodology and quality rating for each included study (Continued)

<table>
<thead>
<tr>
<th>STUDY</th>
<th>METHOD</th>
<th>PARTICIPANTS</th>
<th>CARER OUTCOMES</th>
<th>OUTCOME MEASURES</th>
<th>METHODOLOGICAL QUALITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample 2 Clark et al. (2007)</td>
<td>Recruited spousal carers associated with a memory clinic in Adelaide and non-caregiving spouses drawn from South Australian electoral database. Data reported are first 2 years of a 3 year study (baseline and follow up). Structured interview and questionnaires. Follow-up: 1 year later.</td>
<td>Country: Australia Participants were spousal carers, co-habiting with and primary caregiver of a spouse with geriatrician diagnosis of Alzheimer’s disease. Number: 200 carers comprising: 80 new carers (40%); mean time since diagnosis at baseline 0.5 years (SD=3 months) mean age: 73.9 years (52 - 87 years) 30 male:50 female (62.5% female), and 120 veteran carers (60%); mean time since diagnosis at baseline: 3.3 years (SD=1.5 years) mean age: 74.2 years (50 - 95 years) 41 male:79 female (66% female) Comparison group: yes</td>
<td>Carer status: continued care at home or placement in care home</td>
<td>Carer self-report living arrangements of spouse with dementia 13/20 (65%)</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>Psychological stress Perceived Stress Scale (PSS) in the last month Stress</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Environmental stress Geriatric Social Readjustment Scale Life events stress</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Care recipient No direct care recipient outcome measures reported</td>
</tr>
<tr>
<td>STUDY</td>
<td>METHOD</td>
<td>PARTICIPANTS</td>
<td>CARER OUTCOMES</td>
<td>OUTCOME MEASURES</td>
<td>METHODOLOGICAL QUALITY</td>
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<td>---------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Sample 3</td>
<td>Recruited as part of the University of California, San Diego (UCSD)</td>
<td>Country: US</td>
<td>Carer status: continued care at home or placement in care home</td>
<td>Carer self-report living arrangements of spouse with dementia</td>
<td>10/20 (50%)</td>
</tr>
<tr>
<td>Grant et al. (2002)</td>
<td>Alzheimer’s Caregiver Study Wave 1 (1996-2001) longitudinal study on</td>
<td>Participants were co-habiting and providing care for their spouse with a</td>
<td>Carer depression</td>
<td>Hamilton Depression Rating Scale (HDRS) No carers scored above clinical cut-off</td>
<td></td>
</tr>
<tr>
<td></td>
<td>health consequences of Alzheimer’s caregiving. Recruited through the</td>
<td>diagnosis of Alzheimer’s disease by neurologist or diagnosis of probable</td>
<td>Care recipient stage of dementia</td>
<td>The Clinical Dementia Rating (CDR) – nurse administered</td>
<td></td>
</tr>
<tr>
<td></td>
<td>University of California, San Diego (UCSD) Alzheimer Disease Research</td>
<td>Alzheimer’s disease by physician</td>
<td></td>
<td>The Memory and Behavior Problems Checklist</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Centre (ADRC) and community support groups or physician referrals.</td>
<td>Number: 119 carers</td>
<td></td>
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<tr>
<td></td>
<td>Participants were interviewed at home. Psychosocial information</td>
<td>Mean age: 70 years, 42 male: 77 female (60% female)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>were collected at home by research nurse and psychology research</td>
<td>Comparison group: yes</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>assistant, respectively.</td>
<td>Spousal non-carer: 48 age-matched (24 male: 24 female (50% female)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Periodic 6 month assessments</td>
<td>Follow up: 100%, n=119, sample selected for availability of data at minimum</td>
<td></td>
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<tr>
<td></td>
<td>thereafter for at least 18 months ranging to 48 months (regardless of</td>
<td>of three data points comprising:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>any change in caregiver status).</td>
<td>38 continued to care at home</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Diagnosis: Alzheimer’s Disease.</td>
<td>28 placement in home</td>
<td></td>
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<td></td>
<td></td>
<td>27 placement then death of spouse</td>
<td></td>
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<td></td>
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<td>26 death of spouse following care at home</td>
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<td>Mean duration between transition and follow-up:</td>
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<td></td>
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<td>6 months (except in cases of spousal death where average of 8 months (range</td>
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<td>6 - 12 months, no SDs provided)</td>
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<td></td>
<td></td>
<td>Mean time since diagnosis at baseline: 8.7 years (SD=1 year)</td>
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<tr>
<td>STUDY</td>
<td>METHOD</td>
<td>PARTICIPANTS</td>
<td>CARER OUTCOMES</td>
<td>OUTCOME MEASURES</td>
<td>METHODOLGICAL QUALITY</td>
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<tr>
<td><strong>Sample 4</strong> &lt;br&gt; Kramer (2000) Continuity and change through care transition (care home placement)</td>
<td>Multi-method recruitment through community agencies, geriatric services, media notices and word of mouth. Semi-structured interview and questionnaires were administered at location of choice of male primary caregivers who were co-habiting with their spouse with a diagnosis of dementia. Follow-up 1 year later to ascertain carer status and condition of spouse with dementia and re-interview carers with a living spouse. &lt;br&gt; Diagnosis: dementia.</td>
<td>Country: US &lt;br&gt; Participants were husbands caring for a spouse with dementia (as diagnosed by a neurologist) at time of baseline interview &lt;br&gt; Number: 74 male spousal carers (100% male) &lt;br&gt; Mean age: 72 years (SD=7) &lt;br&gt; Mean spousal illness: 6.5 years (no SD provided) &lt;br&gt; Comparison group: no &lt;br&gt; Follow-up interview : 77% (n=57/74), 43 caring at home and 14 for spouse in care home, Attrition:23% &lt;br&gt; Carers whose spouses were deceased were not re-interviewed. Mean duration between transition and re-interview not specified</td>
<td>Carer status: care at home or placement in care home &lt;br&gt; Carer depression</td>
<td>Carer self-report of living arrangements</td>
<td>10/20 (50%)</td>
</tr>
<tr>
<td><strong>Sample 5</strong> &lt;br&gt; Mausbach et al. (2007) Psychological well-being related to transition in care through placement of spouse in care home</td>
<td>Recruited as part of the University of California, San Diego (UCSD) Alzheimer’s Caregiver Study Wave 2 (2001-2006), longitudinal study of psychobiological responses to stress. Referrals were through the University of California, San Diego Alzheimer Disease Research Centre (ADRC), community support groups, health fairs, and media advertisements. Structured interview using questionnaires at home by research nurses. Longest follow-up: 30 months for placement in care home. &lt;br&gt; Diagnosis: Alzheimer’s Disease.</td>
<td>Country: US &lt;br&gt; Participants were spousal carers free of serious medical conditions, co-habiting with and providing care for a spouse with a documented diagnosis of Alzheimer’s disease. &lt;br&gt; Number: 126 carers (&gt;55 years) &lt;br&gt; Mean age:73 years (8.7 years) &lt;br&gt; Mean time married: 42 years (16.4 years) &lt;br&gt; 38 male: 88 female (70% female) &lt;br&gt; Comparison group: no &lt;br&gt; Follow-up:38% (n=48/126) of the original sample experienced transition &lt;br&gt; Estimated attrition 25% year 1 and 45% year 2 &lt;br&gt; 29 carers placed spouse in long-term care and 19 carers experienced death of spouse &lt;br&gt; Mean duration between transition and follow-up: 7 months after placement and 12 months otherwise (no SDs provided)</td>
<td>Carer status: care at home or placement in care home &lt;br&gt; Carer depression &lt;br&gt; Carer stress</td>
<td>Carer self-report of living arrangements &lt;br&gt; Pearlin Role Overload scale</td>
<td>9/20 (45%)</td>
</tr>
<tr>
<td>STUDY</td>
<td>METHOD</td>
<td>PARTICIPANTS</td>
<td>CARER OUTCOMES</td>
<td>OUTCOME MEASURES</td>
<td>METHODOLOGICAL QUALITY</td>
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<tr>
<td>Sample 6 Pruchno et al. (1990)</td>
<td>Predictors of care transition (placement in care home)</td>
<td>Recruited as part of a longitudinal study of 315 spouses in Philadelphia. Participants were sought through public announcement and community service and support groups, hospitals, synagogues and churches. Structured interview using questionnaires and rating scales at baseline were repeated a year later at follow-up interview with additional questions on carer status (continue to care at home and spouse institutionalised). Diagnosis: Alzheimer’s disease and related disorders.</td>
<td>Carer status: continued care at home or placement in care home</td>
<td>Carer self-report living arrangements of spouse with dementia</td>
<td>11/20 (55%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Country: US</td>
<td>Carer depression</td>
<td>Centre for Epidemiologic Studies – Depression Scale (CES-D, 20-item)</td>
<td>Carers who continue to live with spouse scored below clinical cut-off for depression at baseline</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Participants were spousal carers, co-habiting with and providing care for a spouse with a diagnosis of dementia. Number: 315 spousal carers (male: female 68% female). Mean age: 69 years (range 45 – 94 years, SD=?) Mean length of care: 2.8 years (range 1 month - 20.3 years SD=?) Follow-up: 220 spousal carers (70%) Comparison group: no N=152 continue to care at home, 48% N=68 spouse institutionalised, 22% N=72 lost to follow up, 23% attrition N=23 spouses died 7% -not included in follow-up Significant difference in age and education of follow up group compared with those interviewed at baseline and lost to follow-up Mean duration between care home transition and follow-up not specified</td>
<td>Carer perception of quality of relationship</td>
<td>Current quality of relationship: self-report</td>
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<td>Carer experience checklist (17-item)</td>
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<td>Carer experience rating (8-item)</td>
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<td>Carer perception of burden</td>
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<td></td>
<td>Caregiver perception of positive components of caring</td>
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<td></td>
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<td>Care recipient behaviour as rated by carer</td>
<td>Frequency of spouse behaviours associated with dementia (34 item) in the month prior to interview</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Carer plans to institutionalise</td>
<td>Carer actions relating to institutionalisation checklist (7-item)</td>
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</tr>
</tbody>
</table>
### Table 3 Summary of methodology and quality rating for each included study (Continued)

<table>
<thead>
<tr>
<th>STUDY</th>
<th>METHOD</th>
<th>PARTICIPANTS</th>
<th>CARER OUTCOMES</th>
<th>OUTCOME MEASURES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample 7</td>
<td>Purposive recruitment through agencies (Alzheimer’s Disease associations or private physician offices) and churches in two South Eastern states.</td>
<td>Country: US Participants spouse carers co-habiting with and primary carer of spouse in early-middle phase of Alzheimer’s disease and ‘relatively healthy’ non-carer spouse couples (those with common medical conditions were accepted into the study e.g. arthritis) where both spouses were without cognitive impairment</td>
<td>Carer status: continued care at home or placement in care home</td>
<td>Carer self-report living arrangements of spouse with dementia</td>
</tr>
<tr>
<td>Wright (1994a)</td>
<td></td>
<td>Number: 30 spousal carers Mean age: 67 years (SD=7, 51 - 81 years) 6 male: 24 female (80% female)</td>
<td>Carer depression</td>
<td>Short Zung Interviewer Assisted Depression Rating Scale (10-item)</td>
</tr>
<tr>
<td></td>
<td>Formal diagnosis of probable Alzheimer’s disease with spouse as primary caregiver. All couples were interviewed in their homes using semi-structured interview at baseline in 1987/1988.</td>
<td>Mean length of marriage: 38 years (SD=11.7 years, range 6 - 57 years) Mean length of dementia symptoms: 4.8 years (range 1-11 years) Follow up: carer status (living arrangements) information available for 100% of sample (n= 30 carers). Follow-up interview information obtained from Comparison group: 17 non-carer spouse couples, relatively healthy although common medical conditions were accepted into the study</td>
<td>No carers scored above clinical cut-off for depression</td>
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<td></td>
<td>Follow-up two years later by phone to ascertain living arrangements and gain approval for postal questionnaire with repeat of scales and questions used at initial interview.</td>
<td>Mean duration between transition and follow-up not specified</td>
<td>Carer self-report living arrangements of spouse with dementia</td>
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<td></td>
<td>Diagnosis: Alzheimer’s Disease.</td>
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<td>Carer self-report living arrangements of spouse with dementia</td>
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</table>

*significantly higher than mean length of marriage in carer group
<table>
<thead>
<tr>
<th>STUDY</th>
<th>METHOD</th>
<th>PARTICIPANTS</th>
<th>CARER OUTCOMES</th>
<th>OUTCOME MEASURES</th>
<th>METHODOLOGICAL QUALITY</th>
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</table>
| **Sample 7** | Same study as above. Purposive recruitment through agencies (Alzheimer’s Disease associations or private physician offices) and churches in two South Eastern states. Formal diagnosis of probable Alzheimer’s disease with spouse as primary carer. All couples were interviewed in their homes using semi-structured interview at baseline in 1987/1988. Follow-up two years later by phone to ascertain living arrangements and gain approval for postal questionnaire with repeat of scales and questions used at initial interview. Diagnosis: Alzheimer’s Disease. | Country: US  
Participants spouse carers co-habiting with and primary carer of spouse in early-middle phase of Alzheimer’s disease  
Number: 30 spousal carers  
Mean age: 67 years (SD=7.51 - 81 years)  
6 male: 24 female (80% female)  
Mean length of marriage: 38 years (SD=11.7 years, range 6 - 57 years)  
Mean length of dementia symptoms: 4.8 years (range 1-11 years)  
Mean GDS: 4.4 (range 2 - 6 years)  
Follow up: carer status (living arrangements) information available for 100% of sample (n= 30 carers). Follow-up interview information obtained from 29 carers, attrition: 3%  
Comparison group: data not used in this article  
Mean duration between transition and follow-up not specified | Carer status: continued care at home or placement in care home  
Carer depression  
Spousal interaction  
Care recipient functioning | Carer self-report living arrangements of spouse with dementia  
Short Zung Interviewer Assisted Depression Rating Scale (10-item)  
Dyadic Marital Adjustment Rating Scale (cohesion; tension; affection; overall marital happiness and commitment to future of the relationship, subscales)  
Mini Mental Status Examination (MMSE) and Global Deterioration Scale | 11/20 (55%) |
<table>
<thead>
<tr>
<th>STUDY</th>
<th>METHOD</th>
<th>PARTICIPANTS</th>
<th>CARER OUTCOMES</th>
<th>OUTCOME MEASURES</th>
<th>METHODOLGICAL QUALITY</th>
</tr>
</thead>
</table>
| Sample 8      | Recruitment of spousal carers through Alzheimer’s disease advocacy group membership and carer counselling and support clinic for burden study. Semi-structured interview and questionnaires were administered at home. Participants contacted at follow-up 2 years later to ascertain carer status and request repeat interview with carers whose spouse was still living. Additional questions were asked about the factors affecting the decision to place spouse in a care home at time 2. Diagnosis: two thirds Alzheimer’s disease and one third multi-infarct dementia. | Country: US  
Participants were spousal carers, co-habiting with and providing care for their spouse whose symptoms met DSM-III criteria for dementia (a third multi-infarct dementia, two thirds probable Alzheimer’s type)  
Number: 63 spousal carers, 31 male:33 female (52% female)  
Mean age: male: 72 years (SD=6.72), female: 63 years (SD=7.48)  
Mean length of marriage (at initial interview): male:43 years (SD=6.96), female: 36 years (SD=12.26)  
Follow up: carer status (living arrangements) information available for 91% of carers (n=58/64)  
Follow up interview information obtained from 82% of carers (n=53/64), attrition: 17%  
Living with N=32 (50%)  
Placed in care N=11 (23%)  
Bereaved N=15 (17%) not included in follow up measures  
Lost N=6 (9%)  
Comparison group: no  
Mean years of memory loss: males: 5.6 years (no SD given) and females: 5.9 years (no SD given) | Carer status: continued care at home or placement in care home  
Carer burden  
Carer perception of quality of relationship and social support  
Carer decisions to place in care home  
Care recipient | Carer self-report living arrangements of spouse with dementia  
Burden interview (20-item)  
Structured interview  
Open-ended questions regarding what led to decision to place  
Mental State Questionnaire and Face-Hand test Memory and Behavior Problem Checklist (28-item) | 9/20 (45%) |
1.5.5 Emotional well-being: measures

1.5.5.1 The focus on measurement of negative outcomes

As outlined in Table 4, pp. 29 - 30, the main carer well-being measures used in the eight studies were symptoms of depression, perceived burden and stress. The findings of the present review are, therefore, largely restricted to examining well-being of spousal dementia carers over time as defined by the absence of negative consequences than understanding positive aspects of the care experience. Pruchno et al., (1990) examined positive components of caring and Wright (1994b) assessed spousal interaction and general marital happiness (discussed further in section 1.5.8.4).

1.5.5.2 Depression measures

Measures of depression were included in six studies (Bond & Clark, 2002; Grant et al., 2002; Mausbach et al., 2007; Kramer, 2000; Pruchno et al., 1990; Wright, 1994a, Table 4: Depression) with four different scales; the Geriatric Depression Scale (GDS, Brink et al., 1982; Yesavage et al., 1983), Centre for Epidemiologic Studies - Depression Scale (CES-D, Radloff, 1977), Short Zung Interviewer Assisted Depression Rating Scale (SDS, 10-item, Zung, 1965) and the Hamilton Depression Rating Scale (HDRS), Hamilton, (1960), a clinician administered semi-structured interview (See Table 4: Depression).

The HDRS, CES-D, GDS and SDS use different response time frames: “the past week” (CES-D and HDRS), “past two weeks” (GDS), and “recently” (SDS), (Burns et al., 2002; Mui et al., 2002; Mulrow et al., 1995). Problems with mood vary depending upon the time frame examined (Teri et al., 1997) and the use of different scales which examine different time frames creates difficulties in comparing depression between studies. The different focus upon affective and somatic symptoms in each scale (Lyness et al., 1997, Sharp & Lipsky, 2002) and under-reporting of depressive symptoms by older adults may impact upon the relative accuracy and comparability of symptoms of depression (Arean et al., 1997).
1.5.5.3 Burden and stress measures

Two studies (Pruchno et al., 1990; Zarit et al., 1986) used self-report burden scales although one was not validated (Pruchno et al., 1990), thereby limiting comparability. In addition, the utility of carer burden as an indicator of carer well-being has been questioned in clinical practice with calls for the use of more clinically relevant measures such as depression when assessing well-being amongst dementia carers (Black & Almeida, 2004). Carer stress was examined in five studies using six different scales covering variable time frames of one week up to three years (See Table 4: Stress and Burden, p.29) and examining different aspects of carer experience (for example the perception of stress more generally in the last month, PSS as used by Clark et al., (2007) compared with general carer fatigue using the Pearlin Role Overload Scale, as used by Mausbach et al., (2007)). This restricts comparisons between studies.

1.5.5.4 Social support measures

Frequency of social support was measured by Zarit et al., (1986) and husband’s satisfaction with social participation was recorded by Kramer, (2000), using bespoke and non-comparable frequency and satisfaction ratings (Table 4: Social support). The Adelaide Activities Profile (AAP, Clark & Bond, 1995) was used in one study to measure frequency of lifestyle activities (including social activities) undertaken in the last three months (Bond & Clark, 2002; Bond et al., 2003). Although validated for use in older adults living in the community with adequate validity and reliability, the AAP has not been validated for use in dementia carers who may represent a unique group given the challenges of providing daily care. The retrospective time frame of three months would seem lengthy in the life of some dementia carers.
<table>
<thead>
<tr>
<th>Scale Used to Measure Carer Outcomes</th>
<th>Study First Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Depression</strong></td>
<td></td>
</tr>
<tr>
<td>Centre for Epidemiologic Studies – Depression Scale (CES-D, Radloff, 1977) 10-item</td>
<td>Kramer, 2000; Pruchno 1990</td>
</tr>
<tr>
<td>Geriatric Depression Scale (GDS, Brink et al., 1982; Yesavage et al., 1983)</td>
<td>Bond 2002; 2003</td>
</tr>
<tr>
<td>Hamilton Depression Rating Scale HDRS (clinician administered, Hamilton, 1960)</td>
<td>Grant 2002; Mausbach 2007</td>
</tr>
<tr>
<td>Short Zung Interviewer Assisted Depression Rating Scale (10-item, Zung, 1965)</td>
<td>Wright (1994; 1994b)</td>
</tr>
<tr>
<td><strong>Stress and Burden</strong></td>
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</tr>
<tr>
<td>Perceived Stress Scale (PSS, Cohen et al., 1983) -14 item in the last month</td>
<td>Clark 2007</td>
</tr>
<tr>
<td>Geriatric Social Readjustment Scale (Amster &amp; Kraus, 1974) - 35 life events in the last three years</td>
<td>Clark 2007</td>
</tr>
<tr>
<td>Katz Index of Activities of Daily Living 7-tasks (Katz et al., 1963) (with perceived stress rating: 0 - 3 (not at all stressful to extremely stressful))</td>
<td>Kramer 2000</td>
</tr>
<tr>
<td>Independent living 8 tasks (with perceived stress rating: 0 - 3 (not at all stressful to extremely stressful*) or perceived input (much/some/none help required*) and Activities of Daily Living 7 tasks with perceived input (much/some/none help required+)</td>
<td>*Kramer 2000; +Pruchno 1990</td>
</tr>
<tr>
<td>Memory and Behavior Problem Checklist (Zarit &amp; Zarit, 1987) 17-item with perceived stress rating 0 - 3 (not at all stressful to extremely stressful) in the past week</td>
<td>Kramer 2000</td>
</tr>
<tr>
<td>Memory and Behavior Problem Checklist (Zarit et al., 1980) 29-item with perceived tolerance rating (4-point scale: I can tolerate this behaviour when it occurs to I can no longer tolerate this behaviour and have to do something about it) in the past week</td>
<td>Zarit 1986</td>
</tr>
<tr>
<td>Bespoke 34-item problem behaviour checklist: 5-point frequency rating (never/1-2 times a month/3-4 times a month/2-5 times a week/almost daily) in the past month</td>
<td>Pruchno 1990</td>
</tr>
<tr>
<td>Pearlin Role Overload scale (4-item global) (Pearlin et al., 1990)</td>
<td>Mausbach 2007</td>
</tr>
<tr>
<td>Bespoke 17-item burden scale (based on Cantor, 1983; George &amp; Gwyther 1986, Zarit et al., 1986)</td>
<td>Pruchno 1990</td>
</tr>
<tr>
<td>Validated Burden Interview 20-item (Zarit et al., 1980)</td>
<td>Zarit 1986</td>
</tr>
<tr>
<td><strong>Lifestyle and Physical Activities</strong></td>
<td></td>
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<tr>
<td>Adelaide Activities Profile (AAP, Clark &amp; Bond, 1995)</td>
<td>Bond 2002; 2003</td>
</tr>
<tr>
<td><strong>Social Support</strong></td>
<td></td>
</tr>
<tr>
<td>Self-report frequency of informal and formal social support (weekly contacts) with 4-point quality rating (4: I get most of the help I need to 1: I feel overwhelmed and do not know where to turn)</td>
<td>Zarit 1986</td>
</tr>
<tr>
<td>Self-report satisfaction with social-recreational participation (bespoke frequency and quality ratings of: phone contact, visits with family and friends, personal hobbies, relaxing, club attendance and church attendance) no time frame indicated</td>
<td>Kramer 2000</td>
</tr>
</tbody>
</table>
### SCALE USED TO MEASURE CARER OUTCOMES

<table>
<thead>
<tr>
<th>Positive aspects of care</th>
<th>STUDY FIRST AUTHORS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of positive spousal interaction (Dyadic Marital Adjustment Rating Scale, Spanier &amp; Thompson, 1982) 6-point rating (more than once a day to never) and overall marital happiness rating current and prior to dementia (7-point rating: extremely unhappy - perfectly happy)</td>
<td>Wright 1994</td>
</tr>
<tr>
<td>Bespoke questions on carer uplifts: how often in the past month carer felt their input keeps spouse from getting worse and how often care recipient provided e.g. companionship/embraces/enjoyment (3-point scale ratings: most or some of the time or not at all)</td>
<td>Pruchno 1990</td>
</tr>
<tr>
<td>Quality of marital relationship: current marital quality rating 4-point (poor/fair/good/excellent)</td>
<td>Pruchno 1990</td>
</tr>
<tr>
<td>Quality of marital relationship: before dementia marital quality rating 10-point (poor-excellent)</td>
<td>Zarit 1986</td>
</tr>
</tbody>
</table>

### Table 5. Carer physical health measures

<table>
<thead>
<tr>
<th>Physical Health</th>
<th>STUDY FIRST AUTHORS</th>
</tr>
</thead>
<tbody>
<tr>
<td>SF-36 Health Survey and 5-point global health self-rating (excellent – poor) and 5-point perceived health decline in the preceding year (much better – much worse)</td>
<td>Bond 2002; Bond 2003</td>
</tr>
<tr>
<td>Multiple Assessment Instrument (MAI)</td>
<td>Wright 1994a; 1994b</td>
</tr>
<tr>
<td>Interval Medical History (IMED) and hospitalisation history</td>
<td>Grant 2002</td>
</tr>
<tr>
<td>Physiology measures (blood pressure, cholesterol and stress hormones)</td>
<td>Clark 2007</td>
</tr>
<tr>
<td>Self-report Illness checklist (12-item)</td>
<td>Pruchno 1990</td>
</tr>
<tr>
<td>Self-rating: 3-point scale better/about the same/worse than in the preceding year</td>
<td>Kramer 2000</td>
</tr>
</tbody>
</table>

### Table 6. Care recipient outcome measures

<table>
<thead>
<tr>
<th>Dementia severity/stage of dementia</th>
<th>STUDY FIRST AUTHORS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional dementia scale (FDS)</td>
<td>Bond 2002</td>
</tr>
<tr>
<td>The Clinical Dementia Rating (CDR) – nurse administered</td>
<td>Grant 2002; Mausbach 2007</td>
</tr>
<tr>
<td>Mental State Questionnaire (MSQ) and Face-Hand test</td>
<td>Zarit 1986</td>
</tr>
<tr>
<td>The Memory and Behavior Problems Checklist</td>
<td>Grant 2002; Mausbach 2007; Zarit 1986; Kramer, 2000</td>
</tr>
<tr>
<td>Frequency of spouse behaviours associated with dementia (bespoke 34 item rated by carer) in the month prior to interview</td>
<td>Pruchno 1990</td>
</tr>
<tr>
<td>Mini Mental Status Examination (MMSE) and Global Deterioration Scale</td>
<td>Wright (1994a; 1994b)</td>
</tr>
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<thead>
<tr>
<th>Lifestyle activities</th>
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</thead>
<tbody>
<tr>
<td>Adelaide Activities Profile (AAP)</td>
<td>Bond 2002</td>
</tr>
</tbody>
</table>
1.5.5 Positive dementia care outcome measures

Two studies (Pruchno et al., 1990; Wright, 1994b) examined positive aspects of care using different measures. Wright (1994b) examined daily ratings of positive spousal interaction and general marital happiness currently and prior to dementia (Dyadic Marital Adjustment Rating Scale, Spanier & Thompson, 1982). Pruchno et al., (1990) examined ratings of positive components of caring in the last month and of current relationship quality (using bespoke, non-validated rating scales). Zarit et al., (1986) also examined relationship quality prior to dementia (bespoke scale), see Table 4: Positive aspects of care, p.30.

1.5.6 Emotional well-being: outcomes relating to review question 1

1.5.6.1 Spousal carers compared with spousal non-carers

Non-carer spousal comparison groups used in three studies reported similar age, gender and marital status to spousal carers (Clark et al., 2007; Grant et al., 2002; Wright, 1994a). Two of these studies reported on socioeconomic status and education levels (no significant differences between carers and non-carers: Wright, 1994a; and “slightly higher” socioeconomic status in the non-carer group (Grant et al., 2002). Similar levels of physical health (Wright, 1994a) and physical symptoms were reported by carers and non-carers at baseline (Grant et al., 2002) although no comparisons were reported at follow-up. Physiological measures of stress were similar at baseline although higher levels were recorded in the carer group at follow-up (Clark et al., 2007). One study reported on length of marriage (significantly shorter in the carer than non-carer group due to second and third marriages, Wright, 1994a, Table 3: Participants).

1.5.6.2 Spousal carers compared with spousal non-carers: depression outcomes

Carers reported higher depression scores than non-carers at baseline and over time in two studies that compared depressive symptoms using two different measures (HDRS, Grant et al., 2002; SDS, Wright, 1994a, Table 7: Findings).
1.5.6.3 Spousal carers compared with spousal non-carers: burden and stress outcomes
Higher stress appraisal and frequency of stressful life events were found in carers at baseline and follow-up (Clark et al., 2007), see Table 7: Findings for a summary of results. No studies compared carers with non-carers using measures of burden or overload.

1.5.7 Emotional well-being: outcomes relating to review question 2

1.5.7.1 Carers who continue to live with their spouse: depression outcomes
Five studies reported stable depression ratings over time in carers who continued to care at home compared with those who experienced transition (Bond et al., 2003; Grant et al., 2002; Mausbach et al., 2007; Kramer, 2000; Wright, 1994a). Mausbach et al., (2007) found higher symptoms of depression in females than males over time.

1.5.7.2 Carers who continue to live with their spouse: burden and stress outcomes
In the absence of any change in frequency of behaviour problems, spouses who continued to care at home showed decreased burden and increased tolerance for memory and behavioural problems at follow-up (Zarit et al., 1986). Clark et al., (2007) found that perceived stress remained at the same level for carers who continued to live with their spouse (Table 7: Findings).

1.5.7.3 Carers who continue to live with their spouse: social support outcomes
Satisfaction with social activities (Kramer, 2000) and self-reported level of social activity (Bond et al., 2003) remained stable in those carers who continued to provide care at home, albeit at significantly lower levels than age normed older adults living in the community (Bond et al., 2003, Table 7, Findings).
1.5.7.4 Carers who experience permanent care home placement: depression outcomes

Three studies demonstrate that care home admission is associated with higher depression in carers who placed their spouse, with depression above clinical cut-off (Pruchno et al., 1990; Bond & Clark, 2002) and a significant rise in depression following placement where spouses subsequently died within 6 months (Grant et al., 2002). Mausbach et al., (2007) found a reduction in carer depression symptoms six to twelve months after placement of spouse in care. Two studies reported insufficient numbers to detect statistically significant change in depression scores following placement (Kramer, 2000; Wright, 1994a). Kramer (2000) reports that depression scores (CES-D) were above the cut-off for depression in a half of husbands who had placed their spouse and a third who continued to care at home.

1.5.7.5 Carers who experience permanent care home placement: burden and stress

Pruchno et al., (1990) and Zarit et al., (1986) found higher burden scores at baseline in carers who subsequently placed their spouse in care by follow-up at one and two years, respectively, which decreased significantly following transition (Zarit et al., 1986). Clark et al., (2007) report a significant increase in life events stress (in the last three years) yet a significant decrease in perceived stress in carers who placed their spouse in care. Kramer (2000) found a reduction in perceived stress (in the last week) relating to activities of daily living reported by husbands who had placed their spouse in care. Mausbach et al., (2007) report reductions in overload after placement. Table 7: Findings.

1.5.7.6 Carers who experience permanent care home placement: social support

Bond et al., (2003) found significantly lower social activity at baseline in carers who went on to place their spouses in care compared with carers who continued to live with their spouse (all carers were significantly lower than age normed levels) while Zarit et al., (1986) reported that availability of social support did not impact upon the decision to place one’s spouse in care. After transition, Kramer (2000) found an increase in satisfaction with social
and recreational activities for husbands who placed wives in care and Bond et al., (2003) found a significant increase in social activity in carers who placed their spouse in care (equivalent to age normed group).

1.5.8 Comparisons between carers who live with and carers who place spouses in care

1.5.8.1 Demographic, health and commitment comparisons

Five studies compared carer demographics recorded at baseline between carers who continue to live with their spouse and those who experience permanent care home placement by follow-up. Four studies reported no statistical differences between these two groups of carers in age, gender (Clark et al., 2007) and socioeconomic status (Grant et al., 2002; Kramer, 2000; Pruchno et al., 1990). As outlined in Table 7: Findings, p. 36 - 42, however, spouses who continued to care at home were younger than those who placed spouses in a care home (Bond et al., 2003; Pruchno et al., 1990) with greater commitment to the future of the relationships and more positive spousal interactions (Wright, 1994b).

Four studies found no difference in baseline physical health between carers who continue to live with their spouse and those who experience care home placement by follow-up, as measured by frequency of illness (Pruchno et al., 1990), physical health score (Bond et al., 2003), perceived change in health in the preceding year (Bond et al., 2003; Kramer, 2000) and stress-related physiology measures (Clark et al., 2007). Bond et al., (2003) and Kramer (2000) found that carers who placed their spouse perceived improvements in their health at follow-up whereas carers who continued to live with their spouse did not. Bond et al., (2003) found no differences between carer groups at follow-up in physical health scores.

1.5.8.2 Inconsistent findings: dementia severity and care home placement

Only three studies examined care transition and dementia severity. Bond et al., (2003) found that recipients who remained at home had lower dementia severity scores, in contrast to
Wright, (1994b) and Zarit et al., (1986) who found no association between dementia severity scores and care placement. Continued care at home was more accurately predicted in statistical models than care home placement (Pruchno et al., 1990; Wright 1994b).

1.5.8.3 Inconsistent findings: care home placement and clinical levels of depression

Spousal carers who had experienced care transition scored above the cut-off indicating depression in three studies (using the GDS: Bond & Clark, 2002; Bond et al., 2003, the CES-D: Kramer, 2000; CES-D, Pruchno et al., 1990). See Table 7: Findings. Two studies found that no carers scored above the clinical cut-off for depression (using the Hamilton Depression Rating Scale (HDRS): Grant et al., 2002, and the Short Zung Interviewer Assisted Depression Rating Scale (SDS): Wright, 1994a; 1994b).

1.5.8.4 Positive aspects of caring for one’s spouse with dementia

One study found that spouses who continued to care at home at two year follow-up reported greater positive spousal interactions, higher current marital happiness and commitment to the future of the relationship at baseline compared with those who placed their spouse in care by follow-up although no differences were found in ratings of past marital happiness or current affection and tension between carers at different stages of transition (Wright, 1994b). Pruchno et al., (1990) found that carers who continued to care at home at follow-up reported more uplifts in the month prior to baseline interview such as embraces with spouse, enjoyment, and companionship than those who placed their spouse in care.

Regarding quality of marital relationship ratings at baseline, no differences were found between carers who placed their spouse and carers who continued to care for their spouse within the following year (Pruchno et al., 1990 current marital quality ratings) or within the following two years (Zarit et al., 1986, marital quality ratings before dementia). See Table 7, Findings, pp. 39 - 42.
<table>
<thead>
<tr>
<th>STUDY (FIRST AUTHOR)</th>
<th>STATISTICS TESTS</th>
<th>FINDINGS</th>
<th>CONCLUSIONS</th>
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<tbody>
<tr>
<td>Bond (2002)</td>
<td>N = 163, 58% female</td>
<td><strong>Baseline</strong>: Baseline measures were conducted in 163 carers and differences were examined retrospectively by care transition as assessed at time 2 follow-up. <strong>Time 2 carer status comparisons</strong>: Carers who placed spouse in care home by time 2 report higher depression at time 1 (Geriatric Depression Scale, above clinical cut-off 11.2), greater use of respite services in three months prior to interview and less social activities (Adelaide Activities Profile) than carers who continued to care at home. Carers who placed their spouse in care were older than continued carers and were caring for spouses with greater dementia severity. Care placement was associated with greater dementia severity, lower levels of care recipient activity in the household. After controlling for dementia severity, only age and gender of caret/care recipient were significantly associated with care placement. Female carers more likely than males to place in care if perceived that spouse showed reduced activity in household.</td>
<td>Degree of transition occurring within the study marked two years as a long time in the spousal dementia career. Care recipient features: low household activity levels are associated with transition to care. Severity of dementia was identified as the key reason for transition to formal care. Carer features: older age, reduced social activity and depression are associated with transition to formal care. It is acknowledged that unmeasured age-related co-morbidities rather than age per se may account for age effects reported.</td>
</tr>
<tr>
<td>Bond (2003) Sample used in Bond (2002), above</td>
<td>N = 163 2 year follow up N = 150 58% female Living with spouse N=60 (40%) Placed in care N = 98 (62%) Living with spouse N=60(38%) Univariate tests of significance (t-tests and chi-squared tests) Logistic regression analyses and odds ratio calculations for carer and care recipient characteristics Logistic regression analyses to determine any predictors of care home placement independently of dementia severity</td>
<td>Baseline: Dementia severity was not included in analyses in this article given predictive for care transition (Bond, 2000). Social activities (Adelaide Activities Profile, AAP) in all carers were significantly lower than the norm in community dwelling older adults at time 1. <strong>Time 1 - Time 2: depression scores (GDS)</strong> Carers lost to follow-up at time 2: GDS scores were above clinical cut-off for depression at time 1 (11.3, SD=6) There is no statistical difference in depression scores of carers who continue to care at home or who place in care time 1 – time 2: Carers who continue to care for spouse at home remained below four in ten carers continued to care for their spouse at home two years later and over a third placed their spouse in care and a quarter were widowed, highlighting the transition that occurs within this time frame for spousal dementia carers. Authors note that the study was not designed to examine population incidence of care transition and transition proportions are particular to their sample (recruited through the Alzheimer’s Association). For those spouses continuing to care at home, depression below clinical cut-off and low levels of social activity remained stable over two years. Carers who placed in care home remained above clinical cut-off for depression and reported a significant increase in social activities to normal</td>
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Repeated measures multivariate ANOVA (time 1 vs time 2),
caregiver status as between subjects factor and gender as covariate
Post hoc tests: related-samples t tests (Bonferroni correction)
activity and psychological well-being
Hierarchical multiple regressions controlling for gender effect analysed trajectories of change in widowed carers and those whose spouses resided in care home

clinical cut off (8.8 (SD=6.2) - 9.8 (SD=5.8))
Carers who placed their spouse in care remained at clinical cut-off for depression (11.4 (SD=6.4) - 10.3 (SD=7.2))

Trajectories of change analyses revealed significant association between longer time since spouse placed in care and lower depression scores.

**Time 1 – Time 2: social activity scores (AAP) for carers**
Social activity levels of carers lost to follow up (19.2, SD=15.5) was below normed levels for elderly community dwelling adults (norm=50, SD=20).

Carers who placed their spouse by time 2 report a significant increase in social activity at Time 2 to normed levels: (26 (SD=17.6) - 52 (SD=22.7)).

Carers who continue to care for spouse at home remained below normed levels at time 2 (32 (SD=18.7) - 30 (SD=20.7))

**Baseline:** Carers report higher appraised stress (Perceived Stress Scale) and higher environmental stress (life events, Geriatric Social Readjustment Scale) than non-carers.

Carers who placed spouses in care report significant increase in life events score yet significantly lower psychological stress at time 2.

There was no significant change in psychological stress (PSS) for carers who continued to live with their spouse at home.

There was no correlation between environmental and psychological stress ratings and time since placement.

**Time 1 to Time 2 comparisons**
Carers who placed their spouse in care remained at clinical cut-off for depression (11.4 (SD=6.4) - 10.3 (SD=7.2))

There was no significant change in psychological stress (PSS) for carers who continued to live with their spouse at home.

Chronic stress is associated with caring for a spouse with dementia and the transitions that take place.

There was a significant increase in life events stress for carers who placed their spouse in care which authors argue reflects the demands surrounding care home admission. In contrast, a significant decrease in appraised or psychological stress was found at follow-up which authors argue may reflect the heightened stress levels in the lead up to relinquishing care.

Environmental and psychological stress should be distinguished analytically.
Grant (2002)  
N = 119 with three data points over 18 months were chosen from data set for follow up 60 % Female

Repeated measures ANOVA (care transition between subjects and follow-up point as within subjects) to examine depression. Analyses repeated with covariates: spouse’s CDR and length of caring at baseline

Baseline: carers have significantly higher depression scores (Hamilton Depression Rating Scale) than non-carers although below clinical cut-off for depression.

Time 1 – Time 2 Depression outcomes
Non carers and continued carers report stable depression symptoms Carers who placed spouse in care and then experience death of spouse (Home Placement Death) report a significant increase in depression symptoms following placement.

Baseline: Sample of husbands caring for their wives at home were compared on baseline measures by subsequent transition as well as within carer group comparisons.

Time 1 to Time 2 comparisons
Husbands who placed wives in care home by time 2 report greater spousal impairment at time 1 baseline interview (independent activities of daily living and memory and behavioural problems) than husbands who do not place wives by time 2.

Depression scores Time 1 – Time 2
No significant changes in depression scores as measured by the CES-D in all carers although scores were above clinical cut-off for depression at time 2 for carers who placed their spouse in care.

Carers who continue to care for spouse at home remained below clinical cut-off at time 2 (13.65 time 1 - 12.40, time 2, SD=?)

Carers who placed their spouse in care increased to above clinical cut-off at time 2 (15.86 time 1 - 17.36 time 2, SD=?).

Carer sub-groups: a third of husbands who continued to care at home and a half of husbands who placed spouses were above the

Care transition placement are associated with improvement in carer depression symptoms over time although not for spouses who place prior to death of spouse within 6 months of placement.

Authors note limitations of small sample size of carer sub-groups and lack of consideration given to other factors which may impact upon the carers experience (social support, financial situation, health of carer and coping methods, meaning given to transition).

Kramer (2000)  
N = 74 100% males
Follow up N = 57 (77%)
Living with spouse = 43 (58%)
Placed in care = 14 (19%)
Bereaved = 7 (9%)
Lost = 10 (14%)

Follow up Series of 2*2 repeated ANOVA and (time*placement status) for each stressor, stress appraisal, CES-D with univariate tests for further analyses

Baseline: Sample of husbands caring for their wives at home were compared on baseline measures by subsequent transition as well as within carer group comparisons.

Time 1 to Time 2 comparisons
Husbands who placed wives in care home by time 2 report no statistically significant increase in depression scores although time 2 above clinical cut-off (*small number of placement cases (n=14) meant insufficient power to detect an effect).

Author notes improvements in social resources following placement, anticipation of bereavement before and after transition to nursing home and loss through transition following crises.

Non-representative and small sample is noted as a limitation (likely failure to detect meaningful differences) and lack of pre-caregiving data, e.g. depression scores. Short follow-up time frame also limits examination of pattern of adaptation and over-reliance upon self-report data in the absence of objective measures limits understanding. Calls for further prospective, multi-wave longitudinal self-report and objectively measured data.
cut-off indicating risk of depression (two to four times the rate reported in the older adult population). Pre-care depression ratings were not available for carers. Satisfaction with social and recreational activities improved for husbands who placed wives and was stable for those who continued to care at home.

Perceived spousal dependency increased for both groups of carers (continued and placed spouse in care). Increase in personal care activities was greater for husbands who placed wives in care at time 2. Decrease in perceived stress related to memory and behavioural problems was greatest for husbands who placed wives in nursing home although decline also noted in husbands who continue to care at home at time 2.

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Mausbach (2007)  
N = 126 70% Female  
Follow up N=ns  
Placed in care N=29 (23%)  
Bereaved N=19 (15%)  
Random regression (mixed effects) models to evaluate change over time regarding placement and depressive symptoms (age at baseline and gender as covariates)  

Time1 to time2 – estimated trajectories  
No significant change in overload over time for carers who continue to care at home (Pearlin Role Overload Scale).  

Depression following transition – estimated trajectories  
Significant drop in depression (Hamilton Depression Rating Scale) in the 6 months (no SD) after placement although depression scores not reported in the study.  

Overload following transition - estimated  
Significant drop in overload in the 6 – 8 months (no SDs) after placement in care although stable over time thereafter. Females report greater overload and depression scores and lower mastery than males over time.

Carers experience significant improvement in psychological outcomes following placement in care which authors argue is sustained over the time-frame examined (24 months).  
Results suggest a temporal relationship between depression, overload and transition.  
Numbers of spouses experiencing the transition are small for statistical analyses conducted and authors highlight the need for replication with a larger sample over a longer time frame.  
It is unknown whether psychological distress continue to stabilise over time for those who experience transition in care.

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Pruchno (1990)  
N = 315 68% Female  
Follow up N=220 (70%)  
Living with spouse N=152 (48%)  
Placed in care N=68 (22%)  

Baseline: Carers considering placement at time1 were older than carers not considering placement and reported greater: spouse forgetfulness; assistance of spouse with daily living; use of services; use of medication to manage their own mood and sleep  

The best predictor is ‘desire’ to institutionalise. Relatively poor prediction of placement in care suggests the need to consider other variables to better explain this transition, for example, the meaning given to the carer role and to placement, the role of sudden change in functioning of either spouse and the role of social support. Placing a spouse in care is helpfully examined as
Bereaved N=23 (7%)
Lost N=72 (23%)

Bivariate correlations and regressions
Logistic regression tested model of predictors of institutionalisation

Time 1 to Time 2: lost to follow-up
Carers who were lost at follow-up were older than carers who participated at follow-up.

Time 1 to Time 2: depression scores (CES-D)
Carers who placed their spouse by time 2 reported significantly higher depression scores at baseline than carers who continue to care at home (as measured by the CES-D) and these scores were above cut-off (20.16, SD=?) for clinical depression at baseline. Carers who continued to care for their spouse report depression scores below clinical cut-off (14.93, SD=?) at baseline.

Time 1 to Time 2: burden and uplifts
Carers who placed their spouse by time 2 reported greater burden; use of services, use of medication to manage their mood or sleep; desire to place spouse; spouse forgetfulness; asocial behaviours and fewer uplifts (such as embraces with spouse, enjoyment, companionship, spouse gratitude) than those who continued to care at home. There were no differences in quality ratings of current relationship with spouse (4-point rating: poor/fair/good/excellent) between continued carers or those who placed.

Predictors of continue to care at home: higher carer satisfaction from caring and in caring relationship for a longer period of time. Predictors of placement: carer reports greater ‘desire’ to place in care at baseline; more forgetful spouses and fewer uplifts. Equation better predicts continued care at home compared with placement in care.

Wright (1994a) N = 30 80% Female
Two factor repeated measure ANOVA (time as repeated measure)
Pearson’s correlations analysed

Baseline: Carer depression scores are significantly higher than non-carers (no participant scored above the clinical cut-off for depression as measured by Short Zung Interviewer Assisted Depression Scale (SDS). Spouses were at ‘early to middle stages’ of dementia at baseline (as measured by Mini Mental State Examination (MMSE) and Global Deterioration Scale (GDS)).

a process spanning years rather than an event.

Carers who no longer derive positive value from caring are more likely to place spouse in care. Unsatisfying relationship combined with physical demands of care, dependent spouse and knowledge of alternatives may predispose carer to consider placement.

The authors acknowledge limitations of non-random purposive sampling (limits generalisation of findings and not representing the population of spousal carers more broadly).

Authors note that spousal carers in the poorest health are underrepresented in the present sample.

*Depression scores do not change over time for cares who continue to care at home and carers who place spouse in care home although small numbers mean that there is no statistical power to detect changes. MMSE and GDS scores of spouses with dementia in different transition groups are not significantly different at baseline. There is no measurement of change in MMSE and GDS over time to assess severity of dementia over time. Alzheimer’s disease may have progressed at different rates over the course
relationship between variables at time 1 and time 2

**Time 1 – Time 2: Depression symptoms**

There was no statistical change in depression scores over time for all participants (carers and non-carers therefore the significant difference between these two groups remained over time*).

Baseline: All carers scored below clinical cut-off for all carers as measured by Short Zung Interviewer Assisted Depression Scale (SDS).

**Time 1 to Time 2: Interaction and marital happiness**

Spouses who continue to care at home report greater marital happiness, positive spousal interactions, commitment to the future and fewer years as a carer characterised compared with those who place spouse in care.

There was no difference between carers at different stages of transition on past marital happiness, current affection and tension and no difference in care recipient MMSE and Global Deterioration Scale stages of transition.

Placement in care is predicted by low present marital happiness and low commitment to the future of the spousal relationship. Continued care at home is better predicted than placement.

Predictors of spouse remaining at home: continued commitment to the relationship, positive interaction between spouses and shorter time in carer role. Past marital happiness was not predictive of care status outcome. The author suggests that time since symptom onset may represent impairment or that energy is depleted amongst carers who have been in the role longer.

The author acknowledges the limitations of the small sample size (limits inferences drawn from statistical tests) and of the non-random purposive sampling (limits generalisation of findings). Longer follow-up periods with more frequent interview are appropriate to improve understanding of the dynamic nature of the spousal relationship and the marital interactions involved in maintenance, decline and mortality.

**Baseline**: carers who placed spouse in care had higher initial burden scores. Females report higher burden scores than males.

**Time 1 – Time 2: Memory and behavioural problems**

The total frequency of memory and behavioural problems remained the same time 1 compared to time 2. Memory and behaviour problems as scored by carers and as rated by clinician administered Mental Status Questionnaire did not differ between carers who placed in care and carers who continued to live at home with their spouse.

Carers’ perception of burden are associated with nursing home placement. Carer appraisal of care task requirements is important in determining the level of perceived burden. Carers vary in their problem solving ability and react differently to spouse behaviours.

Severity of care recipient symptoms did not predict care home placement although behaviours such as care recipient inability to undertake personal care were associated with placement.

Spouses report low levels of social support and a need for respite care.

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**Wright (1994b)**
Sample used in Wright (1994a), above

- N=30 80% Females
- Follow up N = 27 (90%)
- Living with spouse N=12 (40%)
- Placed in care N=7 (23%)
- Bereaved N=8 (27%)
- Lost N=3 (10%)

Discriminant analysis Wilks Lambda and univariate F-ratios tested for groups differences in demographic, marital relationship and social interaction variables

Non parametric Kruskal-Wallis also tested for group differences

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**Zarit (1986)**

- N = 64 52% Female
- Follow up N=58 (91%)
- Living with N=32 (50%)
- Placed in care N=11 (23%)
- Bereaved N=15 (17%)
- Lost N=6 (9%)

Baseline: t-tests compared baseline characteristics of carers who placed spouses and those of the two year follow-up and affected outcomes and a range of life events occurring over this time that were not assessed.

Authors recommend further longitudinal research with larger samples and more frequent testing over time.
who continued to care at home Zero-order correlations examined burden and carer variables at time 2.

Paired t-tests examined changes in carer scores time 1 to time 2

Care recipients who were less able to undertake personal care were more likely to be placed within the following two years. All carers reported more deficits in activities of daily living were reported at follow-up although some problematic behaviours were perceived to lessen by time 2.

**Time 1 – Time 2: Burden and social support**

Burden differences between males and females at baseline were not apparent at follow-up. Burden scores decreased significantly at time 2 for continued carers and those who placed their spouse in care. All carers reported relatively low levels of social support and greater tolerance for their spouses memory and behaviour problems at time 2. Availability of social support did not impact upon placement decision although authors note the limited statistical power due to small numbers in transition groups. There was no difference in baseline ratings of quality of marital relationship prior to onset of dementia (10-point rating: poor – excellent) between continued carers and those who placed their spouse in care homes, which they had been unable to obtain. A small number of carers report minimal social support after care placement which demonstrates a risk of isolation and lack of support following care placement. Authors note the limitations of small numbers in different care transitions groups on statistical analyses.

Authors argue that the study findings emphasise the adaptive nature of caring over time for a spouse with dementia and that carers’ ability to tolerate behaviour increased over time may be due to learning to manage problems and reappraising the care situation.

The challenges of caring for a spouse with dementia change with time although change does not necessarily represent an increase in difficulty.
1.6   Methodological limitations of studies included in the review

The studies included in this review are characterised by a wide range of carer and care recipient measures, of variable quality and of limited comparability, that are applied across different time scales and inconsistently reported. This diversity inhibits meaningful comparison within and between studies of the impact of caring for a spouse with dementia on psychological well-being over time. These are discussed in more detail below.

1.6.1 Sampling

Four studies noted issues of recruitment selection bias because the common method of sourcing through Alzheimer’s Associations and support groups excludes those not engaged and is not representative of carers more generally (Kramer, 2000; Pruchno et al., 1990; Wright, 1994a; Bond et al., 2003). There is disagreement as to whether this method of carer recruitment over-inflates rates of psychological distress because those in attendance may be in greater need of support (Schultz & Williamson, 1994) or underestimates problems because more impaired carers are unable to attend support groups (Dura et al., 1990). In this review, Pruchno et al., (1990) comment explicitly that their method of recruitment under-represents those carers who are in poorer health (Table 7: Conclusions, p. 40).

1.6.2 Outcome measures and follow-up

Studies were characterised by relatively short follow-up (one or two years) and it was not possible to examine, with certainty, the impact of care transition on carer well-being over comparable time frames because of variation in conducting and reporting of timing of follow-up studies and absence of reports of time elapsed since transition in three studies (Pruchno et al., 1990; Wright, 1994a; 1994b; Zarit et al., 1986). A number of authors called for longer prospective cohort studies with regular re-interview because one-off or short-term follow-up precluded thorough examination of the pattern of adaptation that may occur during the course of spousal caring (Bond & Clark, 2002; Grant et al., 2002; Wright, 1994b).
Limited assessment of positive aspects of spousal dementia care restricted the findings of carer emotional well-being to the absence of negative care outcomes such as depression, burden and stress which were assessed using different scales thereby restricting the potential for meaningful comparisons and definitive conclusions.

It was not possible to examine the impact of stage of dementia on carer well-being because only three studies reported on dementia severity scores taken at baseline rather than at follow-up (Bond et al., 2003; Wright, 1994b; Zarit et al., 1986). In addition, only two studies compared physical well-being between different carer groups using different measures at both baseline and follow-up (Bond et al., 2003; Kramer, 2000).

1.6.3 Relationship features

Seven studies included in this review gave no consideration to past or present quality of the spousal relationship despite the importance of current marital happiness and spousal interaction in predicting continued care at home (Wright, 1994b). Only two studies examined quality of marital relationship using different rating scales and time frames (current and past, Pruchno et al., 1990; Zarit et al., 1986, respectively). Authors of four studies acknowledged the need to examine the meaning and commitment associated with the care role (Bond et al., 2003; Pruchno et al., 1990; Grant et al., 2002; Wright, 1994a).

1.6.4 Small sample size following transition

Reduced power in statistical analysis due to small sample size is noted by authors in five studies in this review (Grant et al., 2002; Kramer, 2000; Mausbach et al., 2007; Wright, 1994b; Zarit et al., 1986, Table 7: Conclusions). This impeded comparison of basic demographics and examination of depression symptoms following care home transition (Kramer, 2000; Wright, 1994a).
1.6.5 Dementia severity and diagnosis

As outlined in section 1.5.4.8, p. 18, study samples varied in regard to dementia diagnosis mix although the majority of carers were looking after spouses with Alzheimer’s Disease. Although this is the most commonly diagnosed dementia, this limits the generalisability of findings. It is acknowledged that frontotemporal dementias may impact more severely upon carers (Nunnemann et al., 2012) with a greater proportion reporting depression than carers of individuals diagnosed with Alzheimer’s Disease (Mioshi et al., 2009; Kaiser & Panegyres, 2006).

1.7 Discussion

1.7.1 Summary of results

This review summarises and evaluates evidence from published longitudinal studies to assess whether there are differences in emotional well-being between carers and non-carers over time and examine the impact of care transition on the emotional well-being of spousal dementia carers. The review findings are summarised and discussed in more detail below and followed by a consideration of review limitations, clinical implications and research recommendations. Results uncovered by the review are described in Table 7.

1.7.2 Review Question 1: Is the emotional well-being of dementia carer spouses different to non-carer spouses over time?

This review demonstrates that spousal carers experience poorer emotional well-being than non-carers in regards to higher levels of perceived and environmental stress over time (Clark et al., 2007, section 1.5.6.3, p.32) and higher symptoms of depression at baseline (Grant et al., 2002; Wright, 1994a, section 1.5.6.2, p.31). The finding that spousal carers experience poorer emotional well-being over time compared with spousal non-carers (Clark et al., 2007; Grant et al., 2002; Wright, 1994a) is consistent with meta-analyses of dementia carers.
(Pinquart & Sorensen, 2011; Vitaliano et al., 2003; 2005), systematic review (Cuijpers, 2005) and cross-sectional research comparing spousal carers with non-carers (Adams, 2008; Mills et al., 2009).

However, there are a range of factors other than carer status that may account for differences in stress and depression levels between carers and non-carer spouses and consideration must be given to how well matched the comparisons groups were. Non-carer comparison spouses did not differ statistically in gender, age and marital status in the three studies although one study found that length of marriage was shorter in carer spouses compared to non-carer spouses due to second and third marriages. No statistical difference was found in measures of physical well-being between carers and non-carers at baseline in two studies although socioeconomic status and education levels were found to be “slightly higher” in non-carers in one study, similar in another study and not assessed in a third study (section 1.5.6.1, p.31). In addition, the absence of pre-care measures in studies included in the present review, means that causality cannot be attributed.

1.7.3 Review Question 2: is the emotional well-being of spousal dementia carers shaped by care transition?

1.7.3.1 Carers who continue to look after their spouse at home

This review discovered evidence of stability in well-being in carers who continue to live with their spouses at follow-up:

1. Stable levels of depression (Bond et al., 2003; Kramer, 2000; Grant et al., 2002; Wright 1994a, section 1.5.7.1, p.32), perceived stress (Clark et al., 2007) and reduced burden (Zarit et al., 1986) were found in carers who continued to care for their spouses at home, section 1.5.7.2, p.32.
2. Higher number of care uplifts (Pruchno et al., 1990) and greater marital happiness and positive spousal interactions (Wright, 1994b) reported at baseline were associated with continued care at home, section 1.5.8.4, p. 35.

Stable levels of depression and decreased perception of burden and stress in carers who continue to live with their spouse at home found in this review suggest a degree of carer adaptation over time. These findings are consistent with studies that highlight the benefits of training and support intervention in managing emotional distress in dementia carers (Elvish et al., 2013; Gallagher-Thompson & Coon, 2007) and in delaying care home placement in spousal dementia carers (Mittelman et al., 2006).

It is possible, however, that longitudinal study results underestimate negative impacts of care over time if carers with poorer outcomes, for example, higher depression and stress, are less likely to be recruited and more likely to disengage from longitudinal studies due to competing demands. Results from two studies in the present review that compared drop-outs with continued participants (Pruchno et al., 1990; Bond & Clark, 2002) suggest that healthier, younger carers remain engaged in longitudinal studies while older carers are more likely to drop out of longitudinal research.

The study with the highest attrition rate (Mausbach et al., 2007) reported the most positive psychological carer outcomes following transition relative to other studies in the review as evidenced by lower depression and overload. This may be because the most depressed and stressed carers disengage from the study or it may be because carers feel less depressed and overloaded following transition. It could be argued that this systematic review summarises and evaluates findings on spousal carers who are well enough to participate in long term research although it is not possible to address this point definitively because six studies failed to examine non-participation demographics.
It is noteworthy that only two studies in the present review (Section 1.7.3.1, finding 2) examined positive aspects of care, reflecting the tendency of research to focus on the negative aspects of dementia care at the cost of learning from positive, sustainable aspects of care. Both studies suggest that positive experiences in spousal care may be protective in enabling continued care at home and are worthy of further study.

Positive adaptation through adversity, posttraumatic growth (Tedeschi & Calhoun, 1996), has been examined empirically in familial carers of chronic health conditions such as cancer (Kim et al., 2008) and multiple sclerosis (Pakenham, 2005), although not in dementia carers. Assessing positive growth may contribute to understanding this population more fully and encourage the use of a positive conceptual framework to understand the experience of dementia carers. This may facilitate greater understanding of positive components of care and contribute to carer intervention programmes (Carbonneau et al., 2010).

1.7.3.2 Carers who experience the transition of their spouse to permanent placement in care home

This review found inconsistent evidence on the impact of care home placement on spousal carer well-being:

1. Emotional well-being of carers who placed spouses by follow-up was significantly lower at baseline than spouses who continued to care at home, as evidenced in three studies through lower social activities (Bond et al., 2003, section 1.5.7.6, p.33), greater burden (Pruchno et al., 1990; Zarit et al., 1986, section 1.5.7.5, p.33), and higher levels of depression (Bond & Clark, 2002; Pruchno et al., 1990, section 1.5.7.4, p.33).

2. Two studies found lower emotional well-being in carers who placed spouses at follow-up as evidenced by higher depression after placement and before the death of spouse within six months of placement (Grant et al., 2002, section 1.5.7.4, p.33.)
and significantly higher environmental stress levels (Clark, et al., 2007), section 1.5.7.5, p.33.

3. Improvements in emotional well-being were found following care home placement in five studies as evidenced by significant reductions in depression symptoms (Mausbach et al., 2007, section 1.5.7.4, p.33), burden (Zarit et al., 1986), perceived stress levels (Clark et al., 2007) and overload (Mausbach et al., 2007) (section 1.5.7.5, p. 33), and increases in social activities (Bond et al., 2003) and in husband’s satisfaction with social activities (Kramer, 2000), section 1.5.7.6, p. 33 - 34.

4. Carers who placed spouses in care reported symptoms of depression above clinical cut-off in four articles (Bond & Clark, 2002; Bond et al., 2003; Kramer, 2000; Pruchno et al., 1990) and below clinical cut-off in two articles (Grant et al., 2002; Wright, 1994a). Sub-groups of carers at risk of depression were identified in Kramer (2000) and Grant et al., (2002), section 1.5.7.4, p.33.

5. Dementia severity was associated with care home placement in one study (Bond et al., 2003) and not in two studies (Wright, 1994b; Zarit et al., 1986). It was not possible to comment definitively on the impact of care recipient impairment on carer well-being, section 1.5.8.2, pp. 34 - 35.

In the present review, emotional well-being of spousal dementia carers varied, with particular groups of spousal carers at heightened risk of, for example, depression compared to other groups of carers. This includes the period of time before (at baseline) and after placing spouse in a care home (Bond & Clark, 2002; Kramer, 2000; Pruchno et al., 1990). The results of the present review suggest that the period before care home placement may be particularly challenging emotionally for carers who place their spouse in care, as evidenced by heightened burden, depression and lower social activity at baseline compared to carers who continue to live with their spouse (Section 1.7.3.2, finding 1). In addition, the period after placement and before the death of spouse within six months of placement may be
emotionally challenging for carers with greater depression and stress (Section 1.7.3.2: finding 2). Furthermore, improvements in emotional well-being may follow care home placement as evidenced by significant reductions in depression, perceived stress levels, overload, burden and increases in social activities and in husband’s satisfaction with social activities (Section 1.7.3.2: finding 3).

Mixed results relating to care home placement may be understood alongside published literature. Care home placement is associated with depression, burden and emotional exhaustion in spousal dementia carers (Ablitt et al., 2009; Gaugler et al., 2010; Schulz et al., 2004) and with ambivalent emotional responses (Lundh et al., 2000), including relief, despair (Mullin et al., 2011) and guilt which may continue beyond the time of placement (Hennings et al., 2013). Emotional distress in spousal carers is also associated with lack of perceived support relating to the decision to place in care (Nolan & Dellasega, 2000) and carer concerns about the quality of care provided in care homes (Davies & Nolan, 2006; Train et al., 2005).

In the present review, examining emotional well-being at baseline whilst carers are living with their spouses showed that some carers experience poorer well-being in the year prior to care home placement. This suggests that there is a need to conceptualise care home placement as an integral part of the care process which merits attention while care is being provided at home. Examining well-being after care home placement in the present review showed that some carers experience an increase in well-being whilst others experience a decrease in well-being. These findings suggests that care professionals may need to be vigilant in monitoring emotional well-being before and after care home placement and supporting carers to maintain continuity of care for their spouse with dementia where this is desired.
1.7.4 Inconsistent results and methodological issues

Review findings were inconsistent and seem hard to reconcile because of a number of methodological issues pertaining to the studies in this review including the use of different age ranges and gender proportions, different scales to assess stress, depression and burden across different time frames and lack of assessment of stage or severity of dementia between baseline and follow-up. The relationship between care recipient well-being and spousal well-being is complex with both severity of behavioural problems and rate of change in care recipient functioning associated with carer well-being over time (Perren et al., 2006). It is important to consider that carers are looking after their spouse at different stages of dementia and it is possible that dementia severity is lower in those cases where carers continue to live with their spouse compared to cases where carers place their spouse in a care home.

Studies in the present review examined stage of dementia in a limited way. Only three studies reported on the association between dementia severity and care placement with mixed results (one study found a significant association between dementia severity and care home placement and two studies found no association between dementia severity and placement, Section 1.7.3.2: finding 5).

Not all dementia carers are equal in terms of distress tolerance and resources, for example, input received from other support services may impact upon carer outcomes (Knight et al., 1993) although studies included in the review did not assess such input. Differences in carer well-being outcomes have been understood more generally in the context of stress, appraisal, coping (Folkman & Lazarus, 1980; Folkman et al., 1986; Lazarus & Folkman, 1984) and adaptation (Pearlin et al., 1990). Coping refers to behavioural and psychological attempts to manage stressful situations (Folkman & Lazarus, 1988) which some carers manage better than others (Cooper et al., 2008; McLennon et al., 2011) although coping has been poorly
researched in dementia carers as demonstrated by systematic review and meta-analysis (Li et al., 2012).

Poor physical health in spousal dementia carers is associated with care home placement (Kiecolt-Glaser et al., 1991; Von Kanel et al., 2012) and may impact upon the emotional well-being of carers who place spouses in permanent care. Only two studies included in the review compared physical health of carers who placed their spouse and those who continued to live with their spouse at baseline and follow-up. Both studies found no difference at baseline between these two groups of carers and improvement in perceived change in health in carers who placed their spouse at follow-up although one study found no difference in physical health scores at follow-up between the carer groups, section 1.5.8.1, p. 34). We acknowledge that physical health is implicated in care transition although it was not possible in the present review to separate out the impact that physical health and dementia severity had upon carer well-being.

1.7.5 Review limitations
This systematic review is limited by the search strategy employed which covered articles published only in English and searched particular databases. Due to the elevated risk of retrieval bias, authors were contacted about additional published and unpublished research to ascertain whether there were further relevant publications in other languages or in other databases not uncovered by the literature search although no further papers were uncovered. The review relied upon studies which were dated, with research in three studies conducted almost twenty five years (Pruchno et al., 1990; Wright, 1994a; Zarit et al., 1986) and over a decade ago in three studies (Kramer, 2000; Grant et al., 2002; Bond & Clark, 2002). The findings of these studies may, therefore, demonstrate age-cohort effects including gender specific role focus (Zarit et al., 1986) and cohort related attitudes to marital commitment (Wright, 1994b) that may not exist in current or future spousal carers.
The lack of good quality up to date studies in this population is an important finding and the majority of studies were from the US and two from Australia. Both countries are culturally different from the UK with different systems of health and social care funding. Results from studies conducted in these countries may not generalise to the UK and have limited validity in informing the UK or European carer evidence base. No UK/European studies were uncovered in the literature search which limits the potential impact for research to shape practice at a clinical and policy level and demonstrates a need for high quality prospective spousal dementia carer cohort studies using comparable methods and times frames.

While the specific focus of this review is upon spousal carers because of the unique set of emotional and relationship challenges presented in caring for a spouse with dementia, we acknowledge that other carers such as adult child carers play a vital role in supporting individuals with dementia and are worthy of research attention. It is hoped that future longitudinal prospective cohort studies address some of the methodological weaknesses identified in this review and progress the carer evidence base by studying different sub-groups of carers over time with separate analyses for spousal, adult child and other familial carers.

### 1.7.6 Clinical Implications

Dementia carers have a vital role in looking after their spouse with dementia and in shaping person centred care for their spouse and require support to maintain their own psychological and physical health not least to be enabled to provide care over time and to be supported through care transitions. Despite limitations, this review has drawn together seemingly disparate and inconsistent findings to inform clinical practice.

- Poorer emotional well-being amongst carers compared with non-carers may highlight the need for basic primary health care health screening in this population over time that may usefully include symptoms of depression and stress examined
using standardised and validated measures for older adults to enable timely intervention, where appropriate.

- Examining emotional well-being, including perception of social support and positive aspects of the care role, for example, as part of psychosocial screening for carers, may identify carers who are at heightened risk of depression and stress and facilitate support and timely psychological intervention.

- Care professionals involved in care transition and working in care homes may have a role in identifying carers at risk of depression and stress.

- The transition to permanent care home placement is associated with heightened depression, particularly if spouses die within six months of placement. Blanket post-diagnostic support of one year is unlikely to meet the emotional needs of spousal carers which may span over years.

1.7.7 Research recommendations

The experience of dementia varies for each individual and carer, indeed spousal dementia carers are a diverse group who merit further research over longer periods of time. Multi-wave prospective cohort studies that employ qualitative and quantitative methods using standardised and validated carer and care recipient measures with regular tracking should be used to examine the care experience including meaning given to care, placement and loss alongside the factors associated with spousal dementia care such as depression and stress and positive aspects of care. Given the complex array of emotions experienced in caring for a partner with dementia and associated with care home placement, it will be worthwhile for future studies to examine the experience of emotions and how these are managed. It will be of use to identify sub-groups of carers who may be at risk of low emotional well-being and examine factors which support care at home for as long as is beneficial and appropriate for both spouses.
1.8 Conclusions

This review found that the available evidence base is restricted to a small number of low to medium quality longitudinal studies conducted over relatively short time frames in the US and Australia whose findings may not generalise to other countries. Due to methodological limitations, current longitudinal studies are unable to definitively conclude on the impact of care placement on emotional well-being of spousal carers over time and further analysis and exploration of the impact of care transition on carer emotional well-being is required.

There is a need to support the emotional well-being of spousal dementia carers at all stages in the care process and especially around transition to care home. It is challenging to identify and account for the range of variables that impact upon the care experience and we have much to learn from carers who continue to care for their spouse at home as well as from those who continue to care following permanent placement. There are sub-groups of carers who may experience poor emotional well-being during the course of care as well as positive adaption in their care role. More work is required on identifying and uncovering factors which may help predict and support these carers.

Conflict of interest

None

Description of author roles

Roisin Ash conceived the idea, designed the review, searched the literature, reviewed papers and wrote the paper. Professor Ken Laidlaw provided academic supervision and comments on drafts of the paper.

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1.9 References


Chapter 2 The Research Context

2.1 INTRODUCTION

2.1.1 Dementia

Even with the best support, a person with dementia will experience profound effects in their life as a result of their disease. The decline in mental capacity and ability to function independently, together with the effect dementia may have on mood and behaviour, is highly distressing to the person with dementia themselves, and creates difficulties for carers as they seek to respond appropriately. (p.xvii, Nuffield Council on Bioethics, 2009).

2.1.2 Family carers

Caring for a loved one with dementia is a dynamic process that may last several years during which time the carer may experience loss of control associated with unpredictable deterioration (Ory et al., 2000), cognitive loss and emotional and behavioural change (Pearlin, 1994) in the care recipient. Perhaps not surprisingly, knowledge about the experience of care-giving has been formed mainly from ‘burden’ (Ankri et al., 2005; Herbert et al., 2000; Zarit et al., 1980), stress (Pearlin et al., 1990) and coping (Pruchno & Resch, 1989) research that highlights the negative impact of care-giving on carer well-being (Hayley & Pardo, 1989).

2.1.3 Spousal carers

Research highlights that the experience of spousal dementia carers may differ from that of adult child carers, with greater depression and stress and lower social activities (Connell et al., 2001; George & Gwyther, 1986; Pinquart & Sorensen, 2011). Spousal dementia carers in particular experience high levels of distress (Burton & Sistler, 1996; Coppel et al., 1985) which may continue over time and beyond the death of the spouse (Tweedy & Guaraccia, 2007). However, spousal carers receive limited research attention in their own right with few studies examining their experience as dementia progresses (Robinson et al., 2005).
2.2 CARE TRANSITION

2.2.1 Placement in care

Spouses are less likely to place in care than adult children (Zarit & Whitlach, 1992) and report greater distress associated with care home placement (Eloniemi-Sulkava et al., 2002; Gaugler et al., 2010; Pinquart & Sorensen, 2011), and more frequent visits at care homes following placement (Wright, 1998) than other familial carers. While care home placement may be associated with opportunity for greater social activity for the carer (Matsuda et al., 1997), it may also generate new distress if carers, as they transition to their new role as care manager, perceive that their spouse experiences poor care quality (Zarit & Whitlach, 1982; Gaugler et al., 2000; Gaugler et al., 2011).

The decision to place one’s spouse in care is an emotive one which may be characterised by loneliness and sorrow (Eloniemi-Sulkava et al., 2002), and negative attitudes such as abandonment and letting down one’s spouse (Wright, 1998). Dementia carers are often required to make transition decisions without adequate support (Nolan & Dellasega, 2000). Spouses in particular may experience ambivalent emotional responses regarding the move to care home alongside difficulties in initiating and sustaining relationships with staff in care homes (Lundh et al., 2000). The decision to place in care has been found to be predicted by carer well-being, including depression and stress (Bond et al., 2003; Morycz, 1985; Riordan & Bennet, 1998; Townsend, 1990) although stress amongst spousal dementia carers may continue or increase following care home placement (Pagel et al., 1985).

2.3 THE EVIDENCE BASE

2.3.1 The imbalance in carer research

There have been calls for research on the positive experience of spouses or partners of those with dementia with a view to supporting togetherness in couples living with dementia
Research context

(McGovern, 2011). Although the focus of carer research has predominantly been upon carer burden and stress, positive features in dementia care-giving have been noted more generally within care giver research (Kinny & Stephens, 1989; Motenko, 1989, Pinquart & Sorenson, 2004). However, positive experiences of care giving are less likely to come to the attention of mental health services and positive aspects of the care process, especially amongst spousal carers, remain understudied. There is a risk that we may miss valuable learning about resilience and sustainability in spousal care if this imbalance is not addressed.

2.3.2 Post traumatic growth

Post-traumatic growth is defined as the experience of positive change that occurs as a result of the struggle with highly challenging life crises (Tedeschi & Calhoun, 1996). The conceptual model of post traumatic growth posits that a traumatic event which disrupts underlying assumptions about goals, beliefs and meaning leads to emotional distress which in turn sets off a process of thinking, problem solving and sense making which may bring about psychological change (Tedeschi & Calhoun, 1996; 2004; Joseph & Linley, 2006).

The concept of positive growth has been used to study the dynamic experience of psychological change following crises including bereavement (Currier et al., 2013; Edmonds & Hooker, 1992; Nerken, 1993) and chronic health conditions such as cancer (Cordova et al., 2001; Widows et al., 2005; Zwalen et al., 2010). Positive growth has been examined in familial carers of those with multiple sclerosis (Pakenham, 2005) and cancer (Kim et al., 2008) but has not yet been examined in spousal dementia carers.

Studying positive growth is important because of associations with improved well-being and adjustment for carers more generally which may be associated with reduction in the likelihood of care home placement (Gilley et al., 2005). The study of positive growth
represents a move in the literature towards redressing the balance between positive and negative aspects of care.

2.3.3 Emotion regulation

The experience of emotions and the ability to process emotional distress when dealing with crises are considered to be fundamental in facilitating personal growth (Tedeschi & Calhoun, 2004, Aldwin & Levenson, 2004) and in shaping adaptive functioning (Phillips & Power, 2007). Gross & Thomson (2007) outline the fundamental role of emotions, in aiding or harming our interpersonal interactions, behaviours and decision making and highlight the importance of being able to regulate emotion successfully.

The common theoretical conceptualisation underpinning emotion regulation research is that of a process of conscious or automatic emotion modulation in response to environmental demands which involves changes in the dynamic experience of emotions that may sustain, intensify or dampen positive or negative emotion (Bargh & Williams, 2007; Gross & Munoz, 1995).

Emotions arise when something is important to us and the way in which we appraise an emotional situation shapes our response to it (Lazarus, 1991). Different regulation strategies have different consequences for perceptual, physiological and behavioural components of emotion (Campbell-Sills & Barlow, 2007) and appropriate emotion regulation strategies are important for health and well-being (Davidson et al., 2000). Overuse of strategies such as suppression has been associated with anxiety (Campbell-Sills & Barlow, 2007) while cognitive reappraisal has been linked to successfully managing negative emotion (Gross, 1998).
It is not yet known how spousal dementia carers regulate their emotions, despite research that evidences the complex array of emotions experienced in caring for a partner with dementia (Malfullul & Morriss, 2000; Marwit & Meuser, 2002) and the adaptive function of emotion regulation strategies in managing emotions (Ochsner & Gross, 2004). Longitudinal research has demonstrated increased emotional stability and improved emotional regulation as people age (Carstensen et al., 2011) although it is not known whether such improvements are maintained in times of adversity. Studying emotion regulation in spousal dementia carers at different stages in their care journey and examining the association between emotion regulation and positive growth may shape understanding of the relative adaptive functioning of strategies that are used.

2.4 SUMMARY

The crucial role of familial dementia carers is emphasised across the care giving evidence base and the experience may present particular challenges for spouses who care for their partner with dementia. There is potential to learn valuable lessons from positive experiences of care-giving and of the emotional experience of spousal dementia carers, yet these areas are under researched. It is not yet known whether spousal dementia carers experience positive growth or if there are particular emotional experiences and care transitions which may impact upon psychological change. It is hoped that the work undertaken in this thesis contributes to our understanding of the experience of emotion and positive growth in the care process and redresses the imbalance in predominantly negative stress and burden literature.

2.5 THESIS FOCUS

2.5.1 Aims

Aim 1: This thesis began by examining what happens to spousal dementia carers over time using a systematic review to summarise and critically appraise evidence from published
longitudinal studies that assess the impact of care transition on spousal dementia carers over time. This research is reported in chapter one, Systematic review: what happens to spousal dementia carer emotional well-being before and after care home placement?

Aim 2: This thesis examines spousal carers’ experience and regulation of emotions and positive growth since taking on the role of carer and seeks to ascertain whether:

- experience and regulation of emotion in spousal dementia carers is moderated by carer gender or experience of care transition (care for spouse at home, placement of spouse in care home or death of spouse with dementia).
- adaptive emotion regulation strategies are associated with the experience of positive emotion.
- spousal dementia carers experience positive growth and if this is moderated by carer gender or experience of care transition (care for spouse at home, placement of spouse in care home or death of spouse with dementia).
- positive growth is moderated by the experience and regulation of emotions.

This research is reported in Journal article 2: Emotion regulation and positive growth in spousal dementia carers.

### 2.5.2 Hypotheses

Hypothesis 1: There will be a significant relationship between the experience of emotion and emotion regulation strategies employed since taking on the role of spousal carer, for example, a significant positive relationship between happiness and adaptive emotion regulation strategies.

Hypothesis 2: Spousal dementia carers will experience positive growth.
Hypothesis 3: There will be a significant positive relationship between adaptive emotion regulation strategies and positive growth.

2.5.3 Clinical Implications

It is intended that the exploratory research in this thesis contributes to a broader understanding of the spousal carer experience and furthers understanding of some of the factors which shape the experience of caring for a partner with dementia. Research outputs will shape the care-giving evidence base and provide families, professionals and policy makers involved in the care process with information about the emotions experienced by carers, how they manage these emotions and whether they experience positive growth in the care journey. It is hoped that the work in this thesis will challenge assumptions about the homogeneity of dementia carers and their support needs and raise the profile of spousal carers as partners of people with dementia.
Chapter 3

Journal Article

**Title:** Emotion regulation and positive growth in spousal dementia carers

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3.1 ABSTRACT

**Background:** The emotional experience of spousal dementia carers has, predominantly, been understood in research and clinical practice through a narrow lens of negative emotional consequences. There is a need to contextualise the emotional experience of carers within a framework that enables understanding of positive aspects of the care experience.

**Objective:** This study examined the experience and regulation of emotions and positive growth in spouses who care for their partner with a diagnosis of dementia.

**Methods:** Empirical study comprising a cross-sectional design comparing positive growth and emotion regulation in three carer groups (caring for spouse at home, placed spouse in care home or experienced death of spouse). Carers were recruited through a postal survey which comprised the following self-report measures: Post Traumatic Growth Inventory; Basic Emotions Scale; and Regulation of Emotions Questionnaire.

**Results:** Spousal carers report more frequent feelings of fear and frustration compared to other basic emotions. Gender and care transition impact upon the experience and regulation of emotion and positive growth. Internalising emotion regulation strategies (e.g. rumination) are associated with greater fear and frustration, sadness and guilt while strategies comprising social support seeking are associated with feelings of happiness in carers. Spouses report positive growth since taking on the role of carer and this is predicted in part by social support seeking emotion regulation strategies but not by experience of emotions.

**Conclusions:** Spousal carers are not a homogenous group. Further research on the experience of spousal dementia carers is required including the development of tools and methods tailored to capture emotion regulation. The concept of positive growth following stressful events (for example, becoming a carer) may have potential for presenting an enriched understanding of the emotional consequences of the carer experience over time.

**Keywords:** spouse; carer; dementia; emotion; emotion regulation; transition; positive growth.
Key Practitioner Message:

- Those involved in supporting dementia carers may wish to examine the experience and regulation of emotions, including negative and positive emotions, and the role that these may have in shaping the care experience.

- Particular attention to the absence of social support seeking skills and use of internalising strategies in the presence of fear, frustration, guilt or sadness may highlight potential support needs.

- Spousal dementia carers living with their spouse most frequently use refocusing strategies to regulate their emotions. This may inform clinical intervention.

- Spousal dementia carers experience positive growth since taking on the role of carer and clinicians may wish to consider how positive aspects of the care experience can be used to support carers.

- Positive growth is associated with emotion regulation strategies that utilise social support and refocusing (perspective and planning) to manage emotions experienced since taking on the role of carer.
3.2 INTRODUCTION

3.2.1 Spousal dementia carers

Research demonstrates that spousal carers provide more care and experience greater psychological distress than other familial carers (Pinquart & Sorensen, 2011). Spousal dementia carers experience poorer health outcomes (Pinquart & Sorensen, 2007; Gonzalez et al., 2011) and greater anxiety and depression around the transition of care home placement (Schulz et al., 2004) than other familial carers. Dementia spousal carers are at higher risk of depression than non-carer spouses (Adams, 2008; Joling et al., 2010) and are at risk of depression following the death of spouse with dementia (Tweedy & Guarnaccia, 2007).

Carers also report experiencing positive aspects of caring for their spouse with dementia including shared activities (Searson et al., 2008), finding meaning (Mclennon et al., 2011), and increased tenderness (Eloniemi-Sulkava et al., 2002) and closeness (DeVugt et al., 2003). Carers play a key role in supporting their spouse with dementia to live at home (Oyebode, 2003; Pinquart & Sorensen, 2011), providing continuity and support in maintaining their spouses personhood (Perry & O’Connor, 2002) and acting as mediators with social and health care networks (Jansson et al., 2001). A greater number of older couples will be faced with managing dementia as our population ages (Braun et al., 2009) and spousal dementia carers are, therefore, an important population to study (Martin et al., 2009).

3.2.2 Experience of emotions in dementia care

Dementia care may be characterised by a physical presence yet emotional absence of the spouse with dementia (Blieszner & Shifflett, 1990). Caring for a spouse with dementia presents many emotional challenges relating to uncertainty and loss (Boss, 2011) that may be heightened at care home placement (Lundh et al., 2000) and bereavement (Tweedy &

Spousal carers may experience loss of companionship (Quinn et al., 2009), sadness, worry and isolation (Meuser & Marwit, 2001; Ott et al., 2007) as dementia progresses. Dementia reduces the ability of the spouse with dementia to provide emotional and practical support (Baikie, 2002) which may have been present in the past. The spouse with dementia may experience emotional disinhibition, lability, and dulling (Bromley, 1990) and the spousal carer, therefore, faces challenges in managing their own emotional reaction to changes in their spouse’s emotional expression.

Depression has been found to correlate significantly with perceived lack of control over the carer’s own emotional response as well as over their spouse’s behaviour (Morris et al., 1989). Research has found that dementia carers who placed their spouse in care express greater guilt and grief than carers of spouses with physical illness (Tilse, 1998). Spaid & Baruch (1994) argue that, without emotional support, carers may experience difficulties which are enacted in the care situation including burn out, isolation and resistance to professional support.

3.2.3 Adaptation of carers
Caring for one’s spouse has been described as mentally demanding and stressful (Braun et al., 2009) yet some carers adapt to their situation (Perren et al., 2006). Emotions have been described as psycho-evolutionary social constructs that have an adaptive function in survival (Harre, 1986; Plutchik, 1980). Expressed through experience and actions, emotions shape perception, interpersonal interaction, decision making and behaviour (Gross & Thomson, 2007).
Research demonstrates that coping strategies have a role to play in maintaining well-being amongst carers (Cooper et al., 2008). Strategies used to manage spousal dementia carers’ emotional distress are more likely to be successful than attempts to manage situations that are outwith individual control (Pearlin & Schooler, 1978; Pruchno & Resch, 1989). Problem focused coping and affect regulation strategies have been associated with greater life satisfaction in dementia carers (Hayley et al., 1987).

Emotion regulation has been described as a subcategory of coping which focuses specifically on emotional goals (Gross, 1999). Ochsner & Gross (2004) argue that our capacity to adapt to a range of circumstances arises in part from our ability to regulate our emotions. Emotion-regulation strategies are used to modulate positive and negative emotions, either consciously or unconsciously, in response to environmental demands (Bargh & Williams, 2007; Gross & Munoz, 1995). It is argued that successful emotion regulation maintains arousal at a level where optimal social functioning is possible (Schore, 2003, as cited in Chambers et al., 2009). Whether emotion regulation strategies are adaptive or maladaptive depends upon the particular social context, the emotion goal and the flexible use of strategies to manage changing situational demands (Marroquin, 2011).

Charles (2010) argues that emotional well-being is related to how skilled people are in regulating their emotions. Research has found that emotion regulation is important in maintaining psychological well-being when managing distress (Mauss et al., 2007), depression (Aldao et al., 2010) and satisfaction with relationships (Lopes et al., 2005). Emotion regulation strategies such as reappraisal and self-disclosure are associated with healthy adjustment while strategies such as catastrophising, emotion suppression and rumination are associated with less healthy adjustment including symptoms of depression and lack of social support (Campbell-Sills & Barlow, 2007; Campbell-Sills et al., 2006).
Emotion regulation strategies such as reappraisal have been found to be helpful amongst students in managing anger and frustration (Szasz et al., 2011) while strategies such as suppression have been associated with lower closeness and less social support (Graham et al., 2008). Symptoms of depression amongst inpatients have been found to be associated with fewer emotion regulation skills (Fehlinger et al., 2013). Depression has been found to be associated with greater use of strategies such as rumination and self-blame and less use of positive reappraisal and positive refocusing than is the case in age and gender matched controls (Ehring et al., 2008).

Given the heightened risk of depression amongst spousal dementia carers (Adams, 2008; Pinquart & Sorensen, 2011) and the demonstrated benefit of social support upon carers’ subjective well-being (Elvish et al., 2013), the associations between emotion regulation strategies and depression and social support are noteworthy. Spousal dementia carers are faced with many challenging situations and interpersonal difficulties which elicit emotions and necessitate emotion regulation of the carer’s own emotions as well as of the emotions of their spouse with dementia.

3.2.4 Emotion regulation in older adults

According to socioemotional selectivity theory, goals relating to emotions and emotionally meaningful experiences take priority over knowledge acquisition goals in later life and older adults are, therefore, more motivated than younger adults to use emotion regulation strategies to maintain emotional well-being (Carstenssen, 2006). Magai et al. (2006) argue that life experience enables better prediction of one’s own emotions and those of others which leads to more skilful emotion regulation.
Research demonstrates that older adults are more motivated and better able to regulate emotional responses than younger adults (Orgeta, 2009; Scheibe & Carstensen, 2010). Life experience is thought to improve skills of emotion regulation and confidence in their use in specific situations in older age (Blanchard-Fields, 2007; Scheibe & Blanchard-Fields, 2009). Charles (2010) argues that age-related decline in ability to control one’s environment and decreased cognitive ability favour the use of emotion regulation strategies over trying to change the situation.

Age-related advantages in emotion regulation are believed to relate to greater use of antecedent strategies, which manage anticipated emotions and avoid emotionally challenging experiences, than response-focused strategies which manage emotions after they occur (Charles & Carstensen, 2007). Spousal dementia carers may face unavoidable and emotionally challenging situations on a day-to-day basis which they may attempt to manage with the use of cognitive restructuring and problem solving (Scheibe & Carstenssen, 2010).

However, Charles (2010) argues that exposure to chronic stressors such as spousal dementia care may impede age-related advantages in emotion regulation skills and cause a decrease in emotion regulation capacity. Longitudinal research has demonstrated increased emotional stability and improved emotional regulation with age, although it is not yet known if such improvements are maintained in times of adversity (Carstensen et al., 2011) such as living with the loss of a spouse with dementia over time.

Given that emotion regulation may be linked with broader life goals such as maximising positive emotional experience (Carstensen et al., 1999) and related to life experience about costs and benefits of using different emotion regulation strategies (Gross & John, 2002), it is of interest to consider if carers at different stages of their care journey experience different emotion profiles and whether they make different use of emotion regulation strategies.
3.2.5 Positive Growth

The concept of post traumatic growth (PTG), the experience of positive psychological change through adversity, provides a framework within which to examine positive psychological outcomes following situations of extreme stress (Schaeffer & Moos, 1992; Tedeschi & Calhoun, 1996; 2004). PTG refers to change or growth that is above and beyond the pre-crisis level of psychological functioning or adaptation (Tedeschi & Calhoun, 2004). It is argued that growth or psychological change comprises increased personal strength, new priorities or new possibilities in life, positive spiritual change, or increased appreciation of life (Tedeschi et al., 1998). Furthermore, that psychological change in some or all of these areas may occur as a result of the crisis or through learning that occurs when attempting to cope with the crisis (Tedeschi & Calhoun, 1996).

Experiencing and processing emotional distress when managing crises are believed to be fundamental in facilitating positive growth (Tedeschi & Calhoun, 2004, Aldwin & Levensen, 2004) and in shaping adaptive functioning (Phillips & Power, 2007). However, Zoeller & Maercker (2006) argue that the role of emotions, most notably positive emotions, has been underestimated in PTG research when compared to the treatment of the role of cognitive factors.

Zoeller & Maerker (2006) describe traumatic events as linked to life threat and loss and argue that those who experience trauma develop an awareness of the fragility of life more generally. This description parallels the experience of many spousal dementia carers and it is possible that carers may experience growth as a result of their care journey. Positive growth has been examined in familial carers of those with chronic health conditions such as Multiple Sclerosis (Pakenham, 2005), HIV/AIDS (McCausland & Pakenham, 2003), and cancer (Kim et al., 2008).
3.2.6 The focus upon negative aspects of dementia care

The predominant focus in carer research on symptoms of depression, anxiety and burden means that the emotional experience of carers is not fully understood. While post traumatic growth has been examined in carers of those with chronic illness, it has not yet been examined in spousal dementia carers. Despite the emotional nature of caring for one’s spouse with dementia and the importance of emotion regulation in adapting to stressful situations, a literature search uncovered no published work on emotion regulation amongst spousal dementia carers. There is a need to understand more fully the emotional experience of carers and the strategies used to regulate emotion and to examine the relationship between emotion regulation and positive growth. The current study focuses on deliberate strategies used to regulate emotions and perception of self-change as determined by self-report questionnaires.

3.2.7 Aims of the study

This study examines the relative frequency of emotions experienced by spousal dementia carers since taking on the role of carer and the strategies used to regulate these emotions, comparing spouses at different stages of care transition and explores the relationship between emotion regulation and positive growth.

The main aims of the current study were to examine the experience and regulation of emotions and positive growth amongst spousal dementia carers, and to ascertain whether:

1. experience and regulation of emotion in spousal dementia carers is moderated by carer gender or experience of care transition (care for spouse at home, placement of spouse in care home or death of their spouse with dementia).

2. adaptive emotion regulation strategies are associated with the experience of positive emotion.
3. Spousal dementia carers experience positive growth and if this is moderated by carer gender or experience of care transitions (care for spouse at home, placement of spouse in care home or death of their spouse with dementia).

4. Positive growth is moderated by the experience and regulation of emotions.

Hypothesis 1: There will be a significant relationship between the experience of emotion and emotion regulation strategies employed since taking on the role of spousal carer, for example, a significant positive relationship between happiness and adaptive emotion regulation strategies.

Hypothesis 2: Spousal dementia carers will experience positive growth.

Hypothesis 3: There will be a significant positive relationship between adaptive emotion regulation strategies and positive growth.

3.3 METHODS

3.3.1 Design

The current empirical study employed a cross-sectional design comparing positive growth and emotion regulation in spousal carer groups at three different stages of care transition: (1) caring for spouse at home; (2) placed spouse in care home; and (3) experienced death of spouse. All carers completed a set of self-report measures that assessed emotions experienced (Basic Emotions Scale), emotion regulation (Regulation of Emotions Questionnaire), and positive growth (Post Traumatic Growth Inventory).
3.3.2 Participants

Participants were spousal dementia carers who were registered as members of the Scottish Dementia Clinical Research Network (SDCRN), a Scottish Government funded research network holding details of dementia carers who have consented to be contacted about dementia-related research across NHS in Scotland Health Board regions. Ethical approval (IRAS) was obtained for the study. All participants were contacted by mail. A total of 400 questionnaire packs were sent to the homes of carers resulting in 183 spousal carers participating in the research (representing a 46 per cent postal survey response rate).

3.3.3 Measures of Emotion - The Basic Emotions Scale (BES)

The term ‘basic emotions’ refers to the small set of cross-cultural universal emotions (Carolan & Power, 2011) and is associated with theories that emphasise the functional nature of emotions to provide information about and shape adaptive responses to situations that arise in life (Finucane et al., 2012). The Basic Emotions Scale (BES; Power, 2006) is a 20 item questionnaire that asks respondents to rate the frequency of emotions experienced in a given time frame (the trait version asks about emotions in general while the state version asks about emotions over the past week). Frequency of emotions are rated on a seven-point Likert Scale from 1 (not at all) to 7 (all of the time). Each scale item corresponds to one of five basic emotions and, therefore, total scores are available for each emotion. Five emotions were confirmed using a student population with good internal consistency (happiness ($\alpha = .83$); anger ($\alpha = .81$); fear ($\alpha = .79$); sadness ($\alpha = .84$); and disgust ($\alpha = .84$)).

The BES has been used in clinical populations including those with psychosis (Livingstone et al., 2009), depression and anxiety (Power & Tarsia, 2007), bipolar disorder (Carolan & Power, 2011) and eating disorders (Fox & Froom, 2009) and has been used to explore the emotional experience of healthy and clinical groups, for example PTSD and chronic pain.
(Finucane et. al., 2012). In the present research, respondents were asked to report on the frequency of emotions experienced generally (trait version) since taking on the role of carer for spouse or partner.

3.3.4 Measures - The Regulation of Emotion Questionnaire (REQ)

Self-report emotion regulation measures differ in focus and coverage of strategies examined. The Difficulties with Emotion Regulation Scale (Grazt & Roemer, 2004), for example, focuses mainly on dysfunctional strategies (for example, non-acceptance of emotional responses such as ‘when I’m upset, I believe that there is nothing I can do to make myself feel better’) whereas the Emotion Regulation Questionnaire (ERQ, Gross & John, 2003) covers positive cognitive reappraisal (modifying thoughts about an anticipated emotional situation to affect the emotional impact) and suppression (inhibiting emotion expression of current emotions).

The Regulation of Emotion Questionnaire (REQ, Phillips & Power, 2007) examines the relative use of both functional (planning, perspective) and dysfunctional emotion regulation strategies (repression and rumination) in response to emotions experienced. The REQ examines use of internal and external strategies (for example, I keep the feeling locked up inside and I talk to someone about how I feel, respectively).

The frequency of use of each emotion regulation strategy is scored on a 5-point Likert Scale from 1 (never) up to 5 (always). Validated for use with adolescents, each REQ item corresponds to one of four emotion regulation strategies with reasonable internal consistency (internal functional ($\alpha = .76$), internal dysfunctional ($\alpha = .72$), external functional ($\alpha = .66$) and external dysfunctional ($\alpha = .76$)). The REQ has been used to examine the use of emotion
regulation strategies in females with anorexia nervosa (Fox et al., 2012) and in adults who have experienced psychosis (Livingstone et al., 2009).

We deemed the relatively broader coverage of internal and external functional and dysfunctional strategies in the REQ to be useful for examining emotion regulation in spousal dementia carers, for the first time. The REQ was, therefore, used in the present study to examine the general frequency of use of emotion regulation strategies.

3.3.5 Positive Growth Measures - The Post Traumatic Growth Inventory (PTGI)

The Post Traumatic Growth Inventory (PTGI) is a 21-item self-report questionnaire that measures positive growth following adversity with good internal consistency ($\alpha = .90$, subscales ranging from $.67 – .85$) and test-retest stability reported at two months ($r = .71$) (Tedeschi & Calhoun, 1996).

PTGI items have been mapped onto five growth sub-scales (relating to others ($\alpha = .85$), new possibilities ($\alpha = .84$), personal strength ($\alpha = .72$), spirituality ($\alpha = .85$), appreciation of life ($\alpha = .67$) (Tedeschi & Calhoun, 1996). Linley et al. (2007) and Taku et al. (2008) have replicated the five factor structure although from one to four factors have also been reported using the PTGI (Anderson & Lopez-Baez, 2008; Ho et al., 2004; Linley et al. 2007; Sheikh & Marotta, 2005).

To date, opinions differ as to the most appropriate factor structure, although Ho et al. (2004) argue that the factor structure of the PTGI requires appropriate modification depending on the population being examined.
PTGI respondents rate questionnaire items (statements of positive growth) on a six-point Likert Scale from 0 (I did not experience this change) up to 5 (I experienced this change to a very great degree). Responses are summed to represent a total score (0 - 105) for degree of positive growth experienced. In the present study, the questionnaire was reworded to examine the extent of change “as a result of caring for your spouse/partner” rather than from “as a result of your crises”.

Post Traumatic Growth (PTG) as measured by the PTGI has been observed in adolescent, student, community or mixed college and community populations (Vishnevski et al., 2010). PTG has also been found in carers of spouses with cardiovascular illness (Senol-Durak et al., 2010), bereaved spouses (Boyraz & Efstatnio, 2011), survivors of cancer (Morrill et al., 2008) and stroke (Ganstad et al., 2009) and was, therefore, used in the present study to examine post traumatic growth in spousal dementia carers.

3.3.6 Data Analysis
This study sought to examine emotion regulation and growth within and between three groups of spousal carers rather than to fit the data to previous models or compare with different clinical or adolescent populations. It is acknowledged that the questionnaires were being used for the first time in this population and, therefore, it was not known whether subscales found in previous research would apply to the participants in this study. Principal Components Analysis (PCA) was, therefore, conducted on responses to each scale (Costello & Osborne, 2005; Fabrigar et al., 1999; Phillips & Power, 2007) to assess how the data from each questionnaire reduced to a smaller set of composite variables whilst retaining information from the original variables (Fabrigar et al., 1999). Data reduction findings are reported in Section 1.
Section 2 addresses research aims 1 and 3 by examining the effects of care transition and gender on BES, REQ and PTGI scores using ANOVAs and independent t-tests. Section 3 addresses research aims 2 and 4 by examining the relationship between growth and experience and regulation of emotion with correlation and multiple regression analyses. Section 4 explores the relative frequency of emotions experienced, regulation strategies used to manage those emotions, and positive growth experienced within different care transition groups using paired carer transition group t-tests.

3.4 RESULTS

3.4.1 Descriptive Statistics

3.4.1.1 Care transition

Of the 183 carers, 131 (71 per cent) reported that they currently lived with their spouse at home, 29 (16 per cent) had placed their spouse in a care home and 23 (13 per cent) had experienced the death of their spouse with dementia. These three groups of spousal carers (living with spouse, placed spouse in care and experienced death of their spouse) did not differ significantly by ratio of males to females (Pearson’s $\chi^2(2) = 0.34, p = 0.843$), age group ratio (Pearson’s $\chi^2(8) = 6.51, p = 0.590$), and time together as a couple prior to taking on the role of carer caring ($F_{2,167} = 1.15, p = 0.238$). A one-way ANOVA revealed a significant effect of length of time caring on care transition ($F_{2,172} = 4.47, p = 0.013$) although post-hoc tests with Games-Howell procedure, appropriate for unequal sample sizes (Field, 2013), did not reach statistical significance (live with vs care home: $p = 0.086$, live with vs spouse deceased: $p = 0.221$, care home vs spouse deceased, $p = 0.960$). Descriptive statistics are displayed in Table 1.
3.4.1.2 Gender and age of spousal carers

The gender split was 46 per cent males and 54 per cent females with a significant association between gender and age (Pearson’s $\chi^2(4) = 21.93, \ p = 0.000$). There were a disproportionately high percentage of females in the 66 - 80 years age group and disproportionately high percentage of males in the age 81 - 95 years group relative to expected levels if age was assumed as being equal in each gender. There were no significant differences between males and females in care transition ($p = 0.843$), time together before taking on the role of carer ($p = 0.870$) and in length of time in care role ($p = 0.321$).

3.4.1.3 Length of time caring for spouse with dementia

The average time together as a couple before taking on the role of carer was 44 years (SD = 11 years, range 8 - 68 years). The average length of time caring was 4.4 years (SD = 2.7 years, range 0.5 - 18 years). The majority of spouses in the sample reported caring for between two and five years (67 per cent).

Table 1. Descriptive statistics for participants by care transition

<table>
<thead>
<tr>
<th>Age group</th>
<th>Living at home with spouse n (%)</th>
<th>Placed spouse in care n (%)</th>
<th>Spouse deceased n (%)</th>
<th>Total n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 50 years</td>
<td>1 (1%)</td>
<td>0</td>
<td>0</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>51 – 65 years</td>
<td>13 (10%)</td>
<td>6 (23%)</td>
<td>2 (10%)</td>
<td>21 (12%)</td>
</tr>
<tr>
<td>66 – 80 years</td>
<td>83 (66%)</td>
<td>17 (65%)</td>
<td>12 (57%)</td>
<td>112 (65%)</td>
</tr>
<tr>
<td>81 – 95 years</td>
<td>28 (22%)</td>
<td>3 (12%)</td>
<td>7 (33%)</td>
<td>38 (22%)</td>
</tr>
<tr>
<td>95+ years</td>
<td>1 (1%)</td>
<td>0</td>
<td>0</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>61 (47%)</td>
<td>12 (41%)</td>
<td>10 (43%)</td>
<td>83 (46%)</td>
</tr>
<tr>
<td>Female</td>
<td>69 (53%)</td>
<td>17 (59%)</td>
<td>13 (57%)</td>
<td>99 (54%)</td>
</tr>
<tr>
<td>Mean length of relationship prior to care role</td>
<td>44.53 (10.64)</td>
<td>40.48 (13.05)</td>
<td>43.00 (13.32)</td>
<td>43.71 (11.39)</td>
</tr>
<tr>
<td>Range (in years)</td>
<td>8 - 63 years</td>
<td>12 - 68 years</td>
<td>19 - 60 years</td>
<td>8 - 68 years</td>
</tr>
<tr>
<td>Mean time caring (years)</td>
<td>4.00 (SD=2.47)</td>
<td>5.45 (SD=3.29)</td>
<td>5.20 (SD=2.98)</td>
<td>4.37 (SD=2.72)</td>
</tr>
<tr>
<td>Range (in years)</td>
<td>0.50 - 15 years</td>
<td>1.0 - 18 years</td>
<td>2 - 12 years</td>
<td>0.5 - 18 years</td>
</tr>
<tr>
<td>Total</td>
<td>131 (72%)</td>
<td>29 (15.8%)</td>
<td>23 (12.6%)</td>
<td>183 (100%)</td>
</tr>
</tbody>
</table>

3.4.2 Using the BES, REQ and PTGI with Spousal Dementia Carers

Principal Components Analyses were conducted on data from each of the three questionnaires (BES, REQ and PTGI) using SPSS (Version 19.0). Although the sample size
of 183 was below Comrey and Lee’s (1992) criterion for a fair sample size for exploratory factor analysis (n = 200), the sample met adequate exploratory factor analysis sample size criterion (n = 100 to 200 with the majority of communalities above 0.5, MacCallum et al., 1999).

Sampling adequacy indicated a pattern of correlations within each scale suited to factor analysis (Kaiser-Meyer-Olkin Measure of Sampling Adequacy of .87 (BES); .71 (REQ); .90 (PTGI)). Variables within each scale were correlated with each other and therefore data were appropriate for factor analysis (Bartlett's test of sphericity, $p < 0.0001$). Multicollinearity, examined using Variation Inflation Factor (VIF) and tolerance statistics, was within acceptable limits (VIF < 4, tolerance > .20, Field, 2013).

Our expectation was that a number of sub-scales would be interrelated within each questionnaire and this, in combination with the finding that the majority of factor correlations were greater than .32, warranted use of oblique rather than orthogonal rotation (Tabachnick & Fidell, 2007).

### 3.4.3 Section 1: Data Reduction and Scale Trimming

PCA enabled comparisons with factor structures reported in the literature (BES: Power, 2006; Power & Tarsia, 2007; REQ: Phillips & Power, 2007; and PTGI: Tedeschi & Calhoun, 1996; Anderson & Baez, 2008). Results showed both similarity and overlap with factors described in the literature as well as evidence for different sub-scale groupings and scale trimming. The results for each scale are discussed, in turn, below.

#### 3.4.3.1 Experience of Emotions - The Basic Emotion Scale (BES)

PCA conducted on the BES yielded an initial five factor structure accounting for 68 per cent of common variance. Factor 5 was unstable, comprising two cross-loading items (anger and
loving) (Costello & Osborne, 1995). Following re-analysis, these items and a third low loading item (aggression loading < .45) were subsequently dropped from the analyses (Field, 2013; Stevens, 2009).

The resulting PCA conducted on 17 items yielded a four factor structure accounting for 70 per cent of common variance with the first factor accounting for most of the variance (42%). Table 2 displays the eigenvalues and variance explained by each factor before rotation. Promax rotation yielded item loadings ranging from .49 to .90. The four factors were stable and interpretable. We acknowledge that the Kaiser method may inflate the number of factors although Cattell’s (1966) scree plot test (Appendix 1) suggested a possible four factor solution.

Internal consistency on sub-scales was acceptable (Table 2). Disgust (renamed guilt in the present study), sadness and happiness (minus cross-loading item loving) were retained as factors in the current group of spousal dementia carers in line with factors reported by scale developers (Power 2006; Power & Tarsia, 2007) while frustration and irritation loaded with emotions previously reported as comprising fear to comprise the frustration and fear (tense) factor (Table 3).

Table 2. Mean, standard deviation (SD) and internal consistency of Basic Emotions Scale
Factors

<table>
<thead>
<tr>
<th>BES Factors</th>
<th>Eigenvalues</th>
<th>Variance Explained</th>
<th>Mean (SD)</th>
<th>Number</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.Tense</td>
<td>7.08</td>
<td>41.66%</td>
<td>3.90 (1.17)</td>
<td>170</td>
<td>α=0.89</td>
</tr>
<tr>
<td>2.Sad</td>
<td>2.32</td>
<td>13.63%</td>
<td>2.87 (1.30)</td>
<td>165</td>
<td>α=0.86</td>
</tr>
<tr>
<td>3.Guilty</td>
<td>1.47</td>
<td>8.65%</td>
<td>1.90 (1.14)</td>
<td>169</td>
<td>α=0.83</td>
</tr>
<tr>
<td>4.Happy</td>
<td>1.03</td>
<td>6.09%</td>
<td>3.45 (1.34)</td>
<td>172</td>
<td>α=0.84</td>
</tr>
</tbody>
</table>
Table 3. Data reduction of Basic Emotions Scale (BES) responses

<table>
<thead>
<tr>
<th>BES Factor</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
<th>Factor 4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BES Factor 1: Tension</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frustration</td>
<td>0.91</td>
<td>-0.13</td>
<td>-0.05</td>
<td>-0.09</td>
</tr>
<tr>
<td>Tense</td>
<td>0.86</td>
<td>0.09</td>
<td>-0.08</td>
<td>0.02</td>
</tr>
<tr>
<td>Irritation</td>
<td>0.85</td>
<td>-0.27</td>
<td>0.15</td>
<td>-0.02</td>
</tr>
<tr>
<td>Worried</td>
<td>0.54</td>
<td>-0.27</td>
<td>0.15</td>
<td>-0.02</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.52</td>
<td>0.34</td>
<td>0.00</td>
<td>0.02</td>
</tr>
<tr>
<td>Nervousness</td>
<td>0.49</td>
<td>0.22</td>
<td>0.14</td>
<td>0.08</td>
</tr>
<tr>
<td><strong>BES Factor 2: Sadness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Misery</td>
<td>0.01</td>
<td>0.95</td>
<td>-0.11</td>
<td>0.00</td>
</tr>
<tr>
<td>Gloominess</td>
<td>-0.02</td>
<td>0.87</td>
<td>0.01</td>
<td>0.00</td>
</tr>
<tr>
<td>Mournful</td>
<td>-0.18</td>
<td>0.85</td>
<td>0.11</td>
<td>-0.02</td>
</tr>
<tr>
<td>Despair</td>
<td>0.34</td>
<td>0.55</td>
<td>-0.04</td>
<td>-0.09</td>
</tr>
<tr>
<td><strong>BES Factor 3: Guilt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blameworthy</td>
<td>-0.06</td>
<td>-0.01</td>
<td>0.89</td>
<td>0.06</td>
</tr>
<tr>
<td>Humiliated</td>
<td>0.08</td>
<td>-0.11</td>
<td>0.86</td>
<td>-0.01</td>
</tr>
<tr>
<td>Shame</td>
<td>-0.02</td>
<td>0.08</td>
<td>0.75</td>
<td>-0.07</td>
</tr>
<tr>
<td>Guilt</td>
<td>0.14</td>
<td>0.16</td>
<td>0.63</td>
<td>0.00</td>
</tr>
<tr>
<td><strong>BES Factor 4: Happiness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joy</td>
<td>-0.21</td>
<td>0.13</td>
<td>0.13</td>
<td>0.91</td>
</tr>
<tr>
<td>Happiness</td>
<td>0.06</td>
<td>0.02</td>
<td>-0.15</td>
<td>0.90</td>
</tr>
<tr>
<td>Cheerful</td>
<td>0.15</td>
<td>-0.22</td>
<td>0.02</td>
<td>0.83</td>
</tr>
<tr>
<td><strong>BES: Excluded low loading (&lt; .45) item and unstable factor</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aggression</td>
<td>0.06</td>
<td>0.38</td>
<td>0.28</td>
<td>-0.04</td>
</tr>
<tr>
<td>Loving</td>
<td>0.11</td>
<td>0.18</td>
<td>-0.15</td>
<td>0.39</td>
</tr>
<tr>
<td>Anger</td>
<td>0.11</td>
<td>0.46</td>
<td>-0.07</td>
<td>0.14</td>
</tr>
</tbody>
</table>

3.4.3.2 Regulation of Emotions Questionnaire (REQ)

PCA conducted on the REQ with a fixed four factor structure to assess for internal and external dysfunctional and functional strategies (Phillips & Power, 2007; Livingstone et al., 2009) accounted for 47 per cent of common variance. Four items with low factor loadings were dropped from subsequent analysis (Field, 2013; Phillips & Power, 2007). The resulting PCA conducted on 17 items accounted for 54 per cent of common variance. Table 4 displays the eigenvalues and variance explained by each factor before rotation. Promax rotation yielded item loadings ranging from .48 to .82. Cattell’s scree plot test (Appendix 2)
suggested a possible four factor solution. Internal consistency was low on two sub-scales (Factors 3: externalise/hurt others and 4: refocus, Table 4).

Table 4. Mean, standard deviation (SD) and internal consistency of REQ Factors

<table>
<thead>
<tr>
<th>REQ Factors</th>
<th>Eigenvalues</th>
<th>Variance explained</th>
<th>Mean (SD)</th>
<th>Number</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Seek social support</td>
<td>3.33</td>
<td>19.59%</td>
<td>2.41 (0.69)</td>
<td>171</td>
<td>α=0.79</td>
</tr>
<tr>
<td>2. Internalise/ruminate</td>
<td>2.81</td>
<td>16.54%</td>
<td>2.31 (0.60)</td>
<td>170</td>
<td>α=0.65</td>
</tr>
<tr>
<td>3. Externalise/hurt others</td>
<td>1.54</td>
<td>9.08%</td>
<td>1.19 (0.29)</td>
<td>176</td>
<td>α=0.57</td>
</tr>
<tr>
<td>4. Refocus</td>
<td>1.50</td>
<td>8.83%</td>
<td>2.94 (0.60)</td>
<td>177</td>
<td>α=0.54</td>
</tr>
</tbody>
</table>

The resulting loadings of four factors obtained in this group of spousal dementia carers (Table 5) show overlap with factors reported in the literature (Phillips & Power, 2007). The external functional and dysfunctional factors retained the same items with the exception of two low loading items which were removed (exercise ‘I do something energetic (e.g. play sport, go for a walk’) and lashing out at objects ‘I take my feelings out on objects around me, e.g. deliberately causing damage to my house or outdoor things’).

Table 5. Data reduction of Regulation of Emotions Questionnaire (REQ) responses

<table>
<thead>
<tr>
<th>REQ Factor (REQ strategy description, Phillips &amp; Power, 2007)</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
<th>Factor 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor 1: Social support seeking (external functional)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. I talk to someone about how I feel (expression of feelings)</td>
<td>0.81</td>
<td>-0.01</td>
<td>0.11</td>
<td>-0.03</td>
</tr>
<tr>
<td>20. I telephone friends or family (new item 1)</td>
<td>0.77</td>
<td>-0.02</td>
<td>-0.03</td>
<td>-0.01</td>
</tr>
<tr>
<td>3. I seek physical contact from friends or family (e.g. hug, hold hands)</td>
<td>0.73</td>
<td>0.10</td>
<td>-0.18</td>
<td>-0.14</td>
</tr>
<tr>
<td>21. I go out and do something nice (new item 2)</td>
<td>0.65</td>
<td>-0.20</td>
<td>0.05</td>
<td>0.12</td>
</tr>
<tr>
<td>8. I ask others for advice (advice seeking)</td>
<td>0.64</td>
<td>0.15</td>
<td>0.02</td>
<td>0.13</td>
</tr>
<tr>
<td>Factor 2: Internalising</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I review (rethink) my thoughts or beliefs (re-appraisal)</td>
<td>0.19</td>
<td>0.71</td>
<td>-0.04</td>
<td>0.10</td>
</tr>
<tr>
<td>15. I keep the feeling locked up inside (repression)</td>
<td>-0.38</td>
<td>0.69</td>
<td>-0.07</td>
<td>0.13</td>
</tr>
<tr>
<td>7. I dwell on my thoughts and feelings (rumination)</td>
<td>0.16</td>
<td>0.65</td>
<td>0.00</td>
<td>-0.38</td>
</tr>
<tr>
<td>9. I review (rethink) my goals or plans (modification of goals)</td>
<td>0.19</td>
<td>0.49</td>
<td>0.11</td>
<td>0.24</td>
</tr>
<tr>
<td>14. I think about people better off and make myself feel worse (negative social comparison)</td>
<td>-0.11</td>
<td>0.48</td>
<td>0.18</td>
<td>-0.10</td>
</tr>
<tr>
<td>Factor 3: Externalising (external dysfunctional)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I take my feelings out on others physically (physical assault)</td>
<td>0.06</td>
<td>-0.09</td>
<td>0.80</td>
<td>0.00</td>
</tr>
<tr>
<td>17. I bully other people (bullying)</td>
<td>-0.04</td>
<td>-0.07</td>
<td>0.74</td>
<td>0.13</td>
</tr>
<tr>
<td>13. I try to make others feel bad (making others feel bad)</td>
<td>-0.14</td>
<td>0.16</td>
<td>0.62</td>
<td>0.01</td>
</tr>
<tr>
<td>2. I take my feelings out on others verbally (verbal assault)</td>
<td>0.12</td>
<td>0.27</td>
<td>0.59</td>
<td>-0.13</td>
</tr>
<tr>
<td>Factor 4: Refocusing (internal functional)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I put the situation into perspective (perspective)</td>
<td>-0.11</td>
<td>-0.05</td>
<td>0.13</td>
<td>0.82</td>
</tr>
<tr>
<td>16. I plan what I could do better next time (planning)</td>
<td>0.01</td>
<td>0.39</td>
<td>-0.15</td>
<td>0.66</td>
</tr>
<tr>
<td>12. I concentrate on a pleasant activity (concentration)</td>
<td>0.27</td>
<td>-0.14</td>
<td>-0.01</td>
<td>0.65</td>
</tr>
</tbody>
</table>
The internal functional factor retained three items (perspective, planning, concentration) while two items from this scale (re-appraisal and goal modification) loaded with items from the internal dysfunctional scale (repression, rumination, negative social comparison). Two low loading items were removed from the internal dysfunction scale (de-realisation: Things feel unreal (e.g. I feel strange, things around me feel strange, I daydream) and self-harm: I harm or punish myself in some way).

As outlined in the introduction, the adaptive or maladaptive nature of emotion regulation strategies is context specific. No assumptions were made about the dysfunction of emotion regulation strategies used by spousal carers, rather the four retained factors were renamed as social support seeking (external functional), internalising (mixed internal functional with dysfunctional), externalising (external dysfunctional) and refocusing (internal functional). These sub-categories were used to examine response patterns in dementia carers in this study.

3.4.3.3 Post Traumatic Growth Inventory (PTGI)

PCA conducted on the PTGI yielded an initial five-factor structure accounting for 70 per cent of common variance. Four low loading items (< .45) were subsequently dropped from the analyses (Field, 2013; Stevens 2006). The resulting PCA conducted on 17 items yielded a five-factor structure accounting for 73 per cent of common variance, with the first factor accounting for most of the variance (44%). Table 6 displays the eigenvalues and variance explained by each factor before rotation. Promax rotation yielded item loadings ranging from .46 to .96 (Table 7). Internal consistency on sub-scales was acceptable. The five factor

### REQ: Excluded low-loading items (< .45)

<table>
<thead>
<tr>
<th>Item</th>
<th>Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. I harm or punish myself in some way</td>
<td>-0.21</td>
</tr>
<tr>
<td>6. I do something energetic (e.g. play sport, go for a walk)</td>
<td>0.42</td>
</tr>
<tr>
<td>18. I take my feelings out on objects around me (e.g. deliberately causing damage to my house, or outdoor things)</td>
<td>0.03</td>
</tr>
<tr>
<td>19. Things feel unreal (e.g. I feel strange, things around me feel strange, I daydream)</td>
<td>0.03</td>
</tr>
</tbody>
</table>

Table 6: Eigenvalues and variance explained by each factor before rotation.
solution using the Kaiser method replicates previous research (Tedeschi & Calhoun, 1996; Taku et al., 2008) although the scree plot suggests a one or five factor solution (Appendix 3).

Table 6. Mean, standard deviation (SD) and internal consistency of Post Traumatic Growth Inventory (PTGI) Factors

<table>
<thead>
<tr>
<th>PTGI Factors</th>
<th>Variance explained</th>
<th>Eigenvalue</th>
<th>Mean (SD)</th>
<th>N</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Appreciation &amp; compassion</td>
<td>44.48%</td>
<td>7.56</td>
<td>2.43 (1.18)</td>
<td>175</td>
<td>α=0.85</td>
</tr>
<tr>
<td>2. Relying upon others</td>
<td>8.24%</td>
<td>1.40</td>
<td>2.38 (1.26)</td>
<td>176</td>
<td>α=0.88</td>
</tr>
<tr>
<td>3. New possibilities</td>
<td>7.50%</td>
<td>1.27</td>
<td>1.18 (1.08)</td>
<td>175</td>
<td>α=0.78</td>
</tr>
<tr>
<td>4. Priorities and values</td>
<td>6.95%</td>
<td>1.18</td>
<td>2.79 (1.29)</td>
<td>177</td>
<td>α=0.71</td>
</tr>
<tr>
<td>5. Spiritual change</td>
<td>6.10%</td>
<td>1.04</td>
<td>1.23 (1.54)</td>
<td>178</td>
<td>α=0.89</td>
</tr>
<tr>
<td>Total PTGI score 17 items</td>
<td>73.26%</td>
<td>2.00 (0.97)</td>
<td>165</td>
<td>α=0.92</td>
<td></td>
</tr>
</tbody>
</table>

Table 7. Data reduction of Post Traumatic Growth Inventory (PTGI) responses

<table>
<thead>
<tr>
<th>PTGI subscales (and PTGI original subscales)</th>
<th>Factor 1: Strength and compassion (relating to others/personal strength/new possibilities)</th>
<th>Factor 2: Relying upon others (relating to others)</th>
<th>Factor 3: New possibilities (new possibilities)</th>
<th>Factor 4: Priorities and values (appreciation of life)</th>
<th>Factor 5: Spiritual change (spiritual change)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Put more effort into my relationships</td>
<td>0.83</td>
<td>0.05</td>
<td>0.17</td>
<td>-0.14</td>
<td>-0.08</td>
</tr>
<tr>
<td>15. More compassion for others</td>
<td>0.77</td>
<td>0.15</td>
<td>-0.16</td>
<td>0.14</td>
<td>0.03</td>
</tr>
<tr>
<td>17. More likely to try to change things</td>
<td>0.67</td>
<td>-0.01</td>
<td>0.03</td>
<td>0.10</td>
<td>0.05</td>
</tr>
<tr>
<td>19. Discovered I am stronger than I thought</td>
<td>0.61</td>
<td>0.01</td>
<td>0.02</td>
<td>0.14</td>
<td>0.14</td>
</tr>
<tr>
<td>12. Better able to accept the way things work out</td>
<td>0.46</td>
<td>0.04</td>
<td>0.18</td>
<td>0.29</td>
<td>-0.01</td>
</tr>
<tr>
<td>6. I see I can count on people</td>
<td>-0.11</td>
<td>0.91</td>
<td>0.02</td>
<td>-0.01</td>
<td>0.07</td>
</tr>
<tr>
<td>21. Better accept needing others</td>
<td>0.28</td>
<td>0.82</td>
<td>-0.09</td>
<td>-0.06</td>
<td>-0.08</td>
</tr>
<tr>
<td>8. Greater sense of closeness with others</td>
<td>-0.03</td>
<td>0.68</td>
<td>0.14</td>
<td>0.17</td>
<td>0.05</td>
</tr>
<tr>
<td>20. Learned about how wonderful people are</td>
<td>0.42</td>
<td>0.65</td>
<td>-0.02</td>
<td>-0.12</td>
<td>0.00</td>
</tr>
<tr>
<td>3. Developed new interests</td>
<td>-0.30</td>
<td>0.26</td>
<td>0.82</td>
<td>0.06</td>
<td>0.03</td>
</tr>
<tr>
<td>14. New opportunities are available</td>
<td>0.16</td>
<td>0.08</td>
<td>0.82</td>
<td>-0.22</td>
<td>-0.01</td>
</tr>
<tr>
<td>11. Able to do better things with my life</td>
<td>0.30</td>
<td>-0.19</td>
<td>0.80</td>
<td>-0.03</td>
<td>-0.05</td>
</tr>
<tr>
<td>7. Established a new path for life</td>
<td>0.03</td>
<td>-0.18</td>
<td>0.52</td>
<td>0.36</td>
<td>0.06</td>
</tr>
<tr>
<td>1. Changed priorities about what is important in life</td>
<td>0.19</td>
<td>-0.18</td>
<td>-0.09</td>
<td>0.86</td>
<td>0.02</td>
</tr>
<tr>
<td>2. Appreciation for value of my own life</td>
<td>-0.05</td>
<td>0.32</td>
<td>0.00</td>
<td>0.78</td>
<td>-0.12</td>
</tr>
<tr>
<td>18. Have a stronger religious faith</td>
<td>0.15</td>
<td>-0.05</td>
<td>-0.04</td>
<td>-0.10</td>
<td>0.96</td>
</tr>
<tr>
<td>5. Better understanding of spiritual matters</td>
<td>-0.09</td>
<td>0.11</td>
<td>0.03</td>
<td>0.04</td>
<td>0.91</td>
</tr>
<tr>
<td>PTGI: Excluded low loading items (&lt; .45)</td>
<td>0.03</td>
<td>0.21</td>
<td>0.18</td>
<td>0.42</td>
<td>0.07</td>
</tr>
<tr>
<td>9. I am more willing to express my emotions</td>
<td>0.06</td>
<td>0.35</td>
<td>0.25</td>
<td>0.40</td>
<td>-0.09</td>
</tr>
<tr>
<td>10. I know better that I can handle difficulties</td>
<td>0.42</td>
<td>0.22</td>
<td>-0.10</td>
<td>0.38</td>
<td>0.05</td>
</tr>
<tr>
<td>13. I can better appreciate each day</td>
<td>0.44</td>
<td>-0.10</td>
<td>0.08</td>
<td>0.25</td>
<td>0.26</td>
</tr>
</tbody>
</table>

The five obtained factors were interpretable for spousal carers and show similarities and differences with the original five factor solution reported by Tedeschi & Calhoun (1996). (Table 7). ‘Spiritual change’ and ‘Appreciation of life’ (minus low-loading item ‘I can better
appreciate each day’) were retained as factors in the current group of spousal dementia carers. ‘Relating to others’ retained four of seven items. Two items (‘I put more effort into my relationships’ and ‘I have more compassion for others’) loaded with two items in personal strength ‘I am better able to accept the way things work out’ and ‘I discovered I am stronger than I thought I was’. One low loading item was removed ‘I am more willing to express my emotions’. ‘New possibilities’ retained four of five items while ‘I am more likely to try to change things’ loaded onto a different factor. Two low loading personal strength items were removed ‘I know better that I can handle difficulties’ and ‘I have a greater feeling of self-reliance’.

3.4.4 Section 2: Care Transition, Gender, Emotion Regulation (BES and REQ) and Positive Growth (PTGI)

3.4.4.1 Research Aims 1 and 3

Two-way ANOVAs were used to examine interactions between gender and transition in emotion regulation (research aim 1) and positive growth (research aim 3). The primary focus was to ascertain whether there were heightened levels of sadness and guilt in carers who had placed their spouse in care or differences in the use of social support and rumination (internalising) emotion regulation strategies and positive growth between carer groups given the importance of these processes in facilitating growth (Tedeschi & Calhoun, 1996).

There were significant main effects of care transition on REQ internalising strategies, for example, rumination and repression ($F^{2.163} = 4.36, p = 0.014$), BES guilt ($F^{2.163} = 6.68, p = 0.002$), sadness ($F^{2.158} = 8.04, p = 0.000$), and total PTGI scores ($F^{2.159} = 5.30, p = 0.006$). There were no significant gender and transition interactions (internalising: $p = 0.829$, guilt: $p = 0.379$, sadness: $p = 0.723$, PTGI: $p = 0.072$) and no significant main effects of gender on
these measures (internalising: $p = 0.358$, guilt: $p = 0.872$, sadness: $p = 0.161$, PTGI: $p = 0.057$). There was a significant main effect of transition ($F^{2.164} = 5.96, p = 0.003$) and gender ($F^{1.164} = 16.96, p = 0.000$) for social support seeking and no significant gender and transition interaction ($p = 0.192$).

Post hoc comparisons were conducted with Bonferroni tests to control for Type 1 error rate (Field, 2013), and Cohen’s $d$ (Cohen, 1992) for effect size. Carers who had placed their spouse in care reported significantly higher BES sadness ($p = 0.000, d = .81$) and guilt ($p = 0.001, d = .80$), greater use of REQ social support seeking ($p = 0.016, d = .56$) and internalising strategies such as rumination and repression ($p = 0.021, d = .59$) and greater positive growth (PTGI, $p = 0.043, d = .53$) than those who live with their spouse. Means by care transition are shown in Table 8.

Table 8. Mean Basic Emotions (BES) scores, Emotion Regulation (REQ) scores and Post Traumatic Growth (PTGI) scores by care transition

<table>
<thead>
<tr>
<th></th>
<th>Currently living with spouse</th>
<th>Placed spouse in care</th>
<th>Experienced death of spouse</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>N</td>
<td>Mean (SD)</td>
<td>N</td>
</tr>
<tr>
<td><strong>BES Factor</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tense</td>
<td>3.82 (1.11)</td>
<td>121</td>
<td>4.18 (1.33)</td>
<td>20</td>
</tr>
<tr>
<td>Happy</td>
<td>3.58 (1.32)</td>
<td>120</td>
<td>3.13 (1.34)</td>
<td>23</td>
</tr>
<tr>
<td>Sad**</td>
<td>2.65** (1.26)</td>
<td>116</td>
<td><strong>3.69</strong> (1.31)</td>
<td>22</td>
</tr>
<tr>
<td>Guilty</td>
<td>1.74* (0.96)</td>
<td>121</td>
<td><strong>2.62</strong> (1.56)</td>
<td>20</td>
</tr>
<tr>
<td><strong>REQ Factor</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>REQ Refocusing</td>
<td>2.94 (0.59)</td>
<td>127</td>
<td>2.95 (0.59)</td>
<td>29</td>
</tr>
<tr>
<td>REQ Social support</td>
<td>2.30** (0.65)</td>
<td>122</td>
<td><strong>2.66</strong> (0.69)</td>
<td>28</td>
</tr>
<tr>
<td>REQ Internalising</td>
<td>2.23** (0.60)</td>
<td>122</td>
<td><strong>2.58</strong> (0.52)</td>
<td>27</td>
</tr>
<tr>
<td>REQ Externalising</td>
<td>1.21 (0.31)</td>
<td>125</td>
<td>1.18 (0.24)</td>
<td>28</td>
</tr>
<tr>
<td><strong>PTGI factor</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Values</td>
<td>2.77 (1.26)</td>
<td>129</td>
<td>2.87 (1.04)</td>
<td>27</td>
</tr>
<tr>
<td>Strength</td>
<td>2.31 (1.18)</td>
<td>127</td>
<td>2.73 (1.01)</td>
<td>26</td>
</tr>
<tr>
<td>Relying</td>
<td>2.26 (1.27)</td>
<td>126</td>
<td>2.71 (1.09)</td>
<td>28</td>
</tr>
<tr>
<td>Spirituality</td>
<td>1.07* (1.40)</td>
<td>129</td>
<td><strong>2.04</strong> (1.86)</td>
<td>28</td>
</tr>
<tr>
<td>New possibilities</td>
<td>0.95** (0.90)</td>
<td>128</td>
<td><strong>1.73</strong> (1.18)</td>
<td>27</td>
</tr>
<tr>
<td><strong>PTGI Mean 17 item</strong></td>
<td>1.87* (0.93)</td>
<td>123</td>
<td><strong>2.39</strong> (0.83)</td>
<td>23</td>
</tr>
<tr>
<td><strong>PTGI Mean 21 item</strong></td>
<td>1.92* (0.97)</td>
<td>119</td>
<td><strong>2.42</strong> (0.79)</td>
<td>23</td>
</tr>
<tr>
<td><strong>PTGI Total Score</strong></td>
<td>40.40**(20.39)</td>
<td>119</td>
<td><strong>50.87</strong>**(16.69)</td>
<td>23</td>
</tr>
</tbody>
</table>

*p<0.05, **p<0.01 ~PTGI 21-item scores are shown to enable meaningful comparison with previous research
Further exploratory analyses on BES emotions revealed significant main effects of gender on happiness ($F^{2,165} = 7.66, p = 0.006$) and fear with frustration ($F^{2,163} = 7.54, p = 0.007$). There was no main effect of care transition (happiness: $p = 0.075$, fear with frustration: $p = 0.399$) and no significant gender and transition interaction (happiness: $p = 0.796$, fear with frustration: $p = 0.935$). Posthoc gender comparisons, Bonferroni corrected for multiple comparisons, revealed that females report significantly greater fear with frustration ($p = 0.007$, $d = 0.61$), happiness ($p = 0.006$, $d = 0.44$) and social support seeking ($p = 0.000$, $d = 0.79$) than males. Means by gender are displayed in Table 9.

<table>
<thead>
<tr>
<th>BES Factor</th>
<th>Female Mean</th>
<th>SD</th>
<th>Number</th>
<th>Male Mean</th>
<th>SD</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tense</td>
<td>4.22**</td>
<td>(1.03)</td>
<td>92</td>
<td>3.53**</td>
<td>(1.22)</td>
<td>77</td>
</tr>
<tr>
<td>Happy</td>
<td>3.72*</td>
<td>(1.24)</td>
<td>92</td>
<td>3.14*</td>
<td>(1.39)</td>
<td>79</td>
</tr>
<tr>
<td>Sad</td>
<td>3.10</td>
<td>(1.31)</td>
<td>88</td>
<td>2.61</td>
<td>(1.25)</td>
<td>76</td>
</tr>
<tr>
<td>Guilty</td>
<td>1.98</td>
<td>(1.18)</td>
<td>92</td>
<td>1.81</td>
<td>(1.09)</td>
<td>77</td>
</tr>
<tr>
<td>REQ Factor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>REQ Social support</td>
<td>2.64**</td>
<td>0.68</td>
<td>93</td>
<td>2.12**</td>
<td>(0.61)</td>
<td>77</td>
</tr>
<tr>
<td>REQ Internalise</td>
<td>2.38</td>
<td>0.58</td>
<td>93</td>
<td>2.23</td>
<td>(0.62)</td>
<td>76</td>
</tr>
<tr>
<td>REQ Externalise</td>
<td>1.21</td>
<td>0.31</td>
<td>95</td>
<td>1.17</td>
<td>(0.25)</td>
<td>80</td>
</tr>
<tr>
<td>REQ Refocus</td>
<td>3.04</td>
<td>0.61</td>
<td>96</td>
<td>2.83</td>
<td>(0.55)</td>
<td>80</td>
</tr>
</tbody>
</table>

*p < 0.005, **p < 0.001

These results suggest that males and females were not affected differently by care transition in regards to their feelings of guilt and sadness and in their use of internalising strategies. Placement in care was associated with increased guilt and sadness and use of internalising regulation strategies and with increased positive growth for males and females (Figure 1).

Females at all care transition stages reported greater use of social support seeking than males which paralleled total growth scores (Figure 2). It should be noted that numbers in the gender by transition groups were small and these results are only illustrative of trends in the data and should be interpreted cautiously.
3.4.4.3 Exploring Comparisons of Positive Growth with Published Findings

Although results from using the PTGI in the present sample of spousal carers provided evidence for scale trimming, total scores on the 21-item PTGI scale were reported to enable comparison with results reported in other populations in published literature. Total PTGI scores represent degree of reported change (ranging from no change (0), very small degree (21), small degree (42), moderate degree (63), great degree (84), and very great degree (105) of change).

Results in the present study with spousal dementia carers showed that a ‘small degree’ of positive growth was reported since taking on the role of spousal carer (mean total overall PTGI score 21-item = 42.86, SD = 20.72). The results were lower than reported by Tedeschi & Calhoun (1996) in their original study of female and male students (total PTGI scores of 75.18 (SD = 21.24) and 67.77 (SD = 22.07), respectively). Findings in the present study of spousal dementia carers are in line with results in an adult sample of husbands (mean = 46.00 SD = 22.83) whose wives had been diagnosed with cancer (Weiss, 2002).
3.4.5 Section 3. Exploring the Relationship between Positive Growth, Emotion and Emotion Regulation

3.4.5.1 Research Aims 2 and 4: Partial correlations

Partial correlations were undertaken to examine the relationship between emotion regulation and experienced emotion (research aim 2) and with positive growth (research aim 4). The interest was in examining whether adaptive emotion regulation strategies are associated with the experience of positive emotion and positive growth is moderated by the experience and regulation of emotions. Gender and care transition were controlled for because of statistically significant effects upon BES, REQ and PTGI scores (reported above in section 3.4.4). Total PTGI scores provide an indication of positive growth whereas scores from each sub-scale of the BES and REQ are interpretable. Total scores from the PTGI were, therefore, used with BES and REQ sub-scale scores in the correlation analyses. Correlations are shown in Table 10, below.

<table>
<thead>
<tr>
<th>REQ Social support</th>
<th>REQ Refocusing</th>
<th>REQ Internalising</th>
<th>REQ Externalising</th>
<th>PTGI Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>BES Tense .12</td>
<td>-.03</td>
<td>.58***</td>
<td>.19***</td>
<td>.20*</td>
</tr>
<tr>
<td>BES Sad .02</td>
<td>-.23</td>
<td>.56**</td>
<td>.32**</td>
<td>.02</td>
</tr>
<tr>
<td>BES Guilty .09</td>
<td>-.11</td>
<td>.50**</td>
<td>.28**</td>
<td>.19*</td>
</tr>
<tr>
<td>BES Happy .27**</td>
<td>.26**</td>
<td>-.18</td>
<td>-.08</td>
<td>.19*</td>
</tr>
<tr>
<td>PTGI Total .45**</td>
<td>.37**</td>
<td>.15</td>
<td>.01</td>
<td></td>
</tr>
</tbody>
</table>

*p < 0.05, **p < 0.001

The experience of positive emotion (happiness) correlate positively with emotion regulation strategies that involve seeking social support and constructive refocusing ($r = .27$ and $r = .26, p = 0.005$). The experience of negative emotions (sadness and guilt) correlate positively with REQ internalising ($r = .56, p = 0.001$: sadness and $r = .50, p = 0.001$: guilt) and REQ externalising strategies ($r = .32, p = 0.001$: sadness and $r = .28, p = 0.005$: guilt).
Positive growth and positive and negative BES emotions were positively and significantly correlated (fear with frustration ($r = .21, p = 0.013$), guilt ($r = .19, p = 0.024$), happiness ($r = .20, p = 0.020$). This suggests that experience of mixed and conflicting emotions relating to fear with frustration, guilt and happiness may play a role in the experience of positive growth. Positive growth and emotion regulation strategies seeking social support and refocusing correlated positively and significantly ($r = .45, p = 0.000$ and $r = .37, p = 0.000$, respectively). This suggests that use of social support seeking and refocusing efforts constructively may facilitate positive growth.

### 3.4.5.2 Relationship between positive growth, experience and regulation of emotion

A multiple hierarchical regression was carried out to examine the contributory effect of experience and regulation of emotion, taken together, upon positive growth (Research aim 4). The present correlation analyses and background literature which highlights the key role of social support in the experience of positive growth (Tedeschi & Calhoun, 1996) governed the order in which variables were entered into the regression analysis. Gender and transition were entered as control variables followed by step-wise addition of the REQ factor seeking social support, then constructive refocusing. BES factors, tension and guilt, were then entered, followed by the BES variable, happiness. Remaining REQ and BES factors were not included due to non-significant correlations with PTGI total scores as reported above.

Emotion regulation strategies that include seeking social support and constructively refocusing efforts explained a low level of the variation in positive growth scores (24 per cent). Including the experience of emotions relating to factors tense and guilty explained an additional 3 per cent of the variation in positive growth scores although including these variables and the variable happiness made no significant contribution to the model (all $p > 0.05$, as shown in Table 11 (p value)).
Table 11 Linear model of predictors of positive growth scores in dementia carers

<table>
<thead>
<tr>
<th>Variable (N=139)</th>
<th>B (SE B)</th>
<th>β (p value)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$R^2=0.12$, Adjusted $R^2=0.11$, p&lt;0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>1.52 (0.15)</td>
<td>p&lt;0.0001</td>
</tr>
<tr>
<td>Gender</td>
<td>0.52 (0.16)</td>
<td>0.27 (p=0.001)</td>
</tr>
<tr>
<td>Transition</td>
<td>0.13 (0.05)</td>
<td>0.21 (p=0.01)</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$R^2=0.28$ Adjusted $R^2=0.26$, $\Delta R^2=0.16$, p&lt;0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>0.35 (0.26)</td>
<td>p=0.17</td>
</tr>
<tr>
<td>Gender</td>
<td>0.22 (0.15)</td>
<td>0.11 (p=0.16)</td>
</tr>
<tr>
<td>Transition</td>
<td>0.07 (0.05)</td>
<td>0.11 (p=0.17)</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>0.60 (0.11)</td>
<td>0.44 (p&lt;0.0001)</td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$R^2=0.36$ Adjusted $R^2=0.34$, $\Delta R^2=0.08$, p&lt;0.0001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>0.86 (0.38)</td>
<td>p=0.03</td>
</tr>
<tr>
<td>Gender</td>
<td>0.19 (0.15)</td>
<td>0.10 (p=0.19)</td>
</tr>
<tr>
<td>Transition</td>
<td>0.09 (0.05)</td>
<td>0.14 (p=0.06)</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>0.48 (0.11)</td>
<td>0.35 (p&lt;0.0001)</td>
</tr>
<tr>
<td>Refocusing efforts</td>
<td>0.50 (0.12)</td>
<td>0.30 (p&lt;0.0001)</td>
</tr>
<tr>
<td><strong>Step 4</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$R^2=0.39$ Adjusted $R^2=0.36$, $\Delta R^2=0.03$, p&lt;0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-1.32 (0.42)</td>
<td>p=0.002</td>
</tr>
<tr>
<td>Gender</td>
<td>0.13 (0.15)</td>
<td>0.07 (p=0.39)</td>
</tr>
<tr>
<td>Transition</td>
<td>0.07 (0.05)</td>
<td>0.10 (p=0.15)</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>0.44 (0.11)</td>
<td>0.32 (p&lt;0.0001)</td>
</tr>
<tr>
<td>Refocusing efforts</td>
<td>0.53 (0.12)</td>
<td>0.32 (p&lt;0.0001)</td>
</tr>
<tr>
<td>BES tension</td>
<td>0.09 (0.08)</td>
<td>0.11 (p=0.23)</td>
</tr>
<tr>
<td>BES guilt</td>
<td>0.10 (0.07)</td>
<td>0.12 (p=0.17)</td>
</tr>
<tr>
<td><strong>Step 5</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$R^2=0.40$ Adjusted $R^2=0.37$, $\Delta R^2=0.01$, p=0.14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-1.53 (0.44)</td>
<td>p&lt;0.0001</td>
</tr>
<tr>
<td>Gender</td>
<td>0.08 (0.15)</td>
<td>0.04 (p=0.60)</td>
</tr>
<tr>
<td>Transition</td>
<td>0.07 (0.05)</td>
<td>0.11 (p=0.11)</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>0.40 (0.11)</td>
<td>0.29 (p&lt;0.0001)</td>
</tr>
<tr>
<td>Refocusing efforts</td>
<td>0.49 (0.12)</td>
<td>0.30 (p&lt;0.0001)</td>
</tr>
<tr>
<td>BES tension</td>
<td>0.12 (0.08)</td>
<td>0.14 (p=0.12)</td>
</tr>
<tr>
<td>BES guilt</td>
<td>0.10 (0.07)</td>
<td>0.12 (p=0.17)</td>
</tr>
<tr>
<td>BES happiness</td>
<td>0.09 (0.06)</td>
<td>0.12 (p=0.14)</td>
</tr>
</tbody>
</table>
3.4.6 Section 4: Exploring the Relative Frequency of Emotions Experienced and Emotion Regulation Strategies used by Spousal Dementia Carers Since Taking on the Role of Carer

3.4.6.1 Within Group Comparisons

Results from paired t-tests examining the relative frequency of emotions, emotion regulation and growth are shown in Table 12, below, with Bonferroni correction for multiple comparisons. Results show that there are similarities and differences in relative frequencies reported within different carer groups. Overall, externalising strategies (for example, bullying, making others feel bad) were used the least frequently and guilt reported least frequently by spousal carers.

3.4.6.2 Living with spouse

Carers who currently live with their spouse reported similar levels of positive (happiness) and negative emotion (fear with frustration) and experienced these emotions more frequently than sadness and guilt. Emotion regulation strategies comprising constructive refocusing (perspective, planning and concentration) were used more frequently than other strategies. There was significantly greater positive growth in ‘priorities and values’ than in other PTGI domains.

3.4.6.3 Placed Spouse in Care

Carers who had placed their spouse in care reported significantly more sadness than guilt, significantly more fear with frustration (tension) than happiness and guilt, and similar frequency of use of social support seeking, refocusing and internalising strategies (for example, rumination, repression). Carers reported significantly greater growth in ‘strength and compassion’ and ‘relying upon others’ compared with ‘new possibilities’
3.4.6.4 Experienced the Death of Spouse

Carers whose spouse was deceased reported significantly greater fear with frustration than other emotions and similar frequency of use of social support seeking, refocusing and internalising strategies. Significantly greater growth was reported in ‘priorities and values’ and ‘strength and compassion’ than ‘new possibilities’.

Table 12. Within group t-tests for BES, REQ and PTGI scores

<table>
<thead>
<tr>
<th>BES Within Group Comparisons*</th>
<th>Live with spouse N=125</th>
<th>Placed in care N=26</th>
<th>Spouse is deceased N=20</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tense versus Happy</td>
<td>1.26 0.210ns 3.30 0.003</td>
<td>3.02 0.007</td>
<td></td>
</tr>
<tr>
<td>Tense versus Sad</td>
<td>12.01 0.000 2.85 0.009ns</td>
<td>5.34 0.000</td>
<td></td>
</tr>
<tr>
<td>Tense versus Guilty</td>
<td>24.32 0.000 7.01 0.000</td>
<td>6.09 0.000</td>
<td></td>
</tr>
<tr>
<td>Happy versus Sad</td>
<td>4.73 0.000 1.70 0.102ns</td>
<td>0.06 0.950ns</td>
<td></td>
</tr>
<tr>
<td>Happy versus Guilty</td>
<td>11.15 0.000 1.34 0.192ns</td>
<td>3.31 0.004</td>
<td></td>
</tr>
<tr>
<td>Sad versus Guilty</td>
<td>9.04 0.000 4.96 0.000</td>
<td>4.08 0.001</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>REQ Within Group Comparisons*</th>
<th>*Bonferroni corrected p &lt; 0.008 level of significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refocus vs Social</td>
<td>10.69 0.000 1.50 0.480ns 0.93 0.363ns</td>
</tr>
<tr>
<td>Refocus vs Internalise</td>
<td>9.24 0.000 2.35 0.027ns 2.47 0.022ns</td>
</tr>
<tr>
<td>Refocus vs Externalise</td>
<td>26.55 0.000 13.66 0.000 12.11 0.000</td>
</tr>
<tr>
<td>Social vs Internalise</td>
<td>0.78 0.440ns 0.72 0.480ns 1.49 0.153ns</td>
</tr>
<tr>
<td>Social vs Externalise</td>
<td>16.64 0.000 10.05 0.000 8.67 0.000</td>
</tr>
<tr>
<td>Internalise vs Externalise</td>
<td>20.37 0.000 13.25 0.000 10.25 0.000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PTGI Within Group Comparisons*</th>
<th>*Bonferroni corrected p &lt; 0.005 level of significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Priorities/Values vs Strength and compassion</td>
<td>4.23 0.000 0.06 0.949ns 0.17 0.869ns</td>
</tr>
<tr>
<td>Priorities/Values vs Relying on others</td>
<td>4.21 0.000 0.50 0.623ns 0.47 0.647ns</td>
</tr>
<tr>
<td>Priorities/Values vs New possibilities</td>
<td>16.98 0.000 3.98 0.001 3.18 0.005</td>
</tr>
<tr>
<td>Priorities/Values vs Spirituality</td>
<td>12.82 0.000 2.02 0.054ns 4.30 0.000</td>
</tr>
<tr>
<td>Strength/compassion vs Relying on others</td>
<td>0.37 0.713ns 0.48 0.635ns 1.23 0.233ns</td>
</tr>
<tr>
<td>Strength/compassion vs New possibilities</td>
<td>15.22 0.000 4.37 0.000 5.12 0.000</td>
</tr>
<tr>
<td>Strength/compassion vs Spirituality</td>
<td>10.73 0.000 2.97 0.006ns 4.75 0.000</td>
</tr>
<tr>
<td>Relying on others vs New possibilities</td>
<td>13.26 0.000 3.66 0.001 2.47 0.023</td>
</tr>
<tr>
<td>Relying on others vs Spirituality</td>
<td>9.77 0.000 2.10 0.045ns 4.33 0.000</td>
</tr>
<tr>
<td>New possibilities vs Spirituality</td>
<td>0.90 0.368ns 0.95 0.352ns 2.10 0.049ns</td>
</tr>
</tbody>
</table>
3.5 DISCUSSION

3.5.1 Summary of key findings
The findings from examining basic emotions, emotion regulation and positive growth experienced since taking on the role of caring for one’s spouse with dementia suggests that carers experience a range of emotions that may be described as positive and negative, both simultaneously and separately, and that positive growth is experienced by spousal dementia carers. The results demonstrate that spousal carers are not a homogenous group and experience positive growth and use emotion regulation strategies differently to manage emotions experienced since taking on the role of carer. Key research findings are summarised and followed by discussion and consideration of study limitations, clinical implications and research recommendations.

3.5.2 Hypothesis 1: There will be a significant relationship between the experience of emotion and emotion regulation strategies used since taking on the role of carer.
Findings are summarised as follows:

- Carers who have placed their spouse in a care home report significantly more frequent feelings of fear and frustration compared to happiness while those living with their spouse report similar frequency of happiness and fear and frustration.
- Carers who live with their spouse report more frequent use of constructive refocusing (perspective, planning and concentration) than other emotion regulation strategies.
- Greater frequency of happiness is associated with greater use of constructive refocusing strategies.
- Greater frequency of sadness, guilt and fear and frustration is associated with greater use of internalising strategies.
- Carers who have placed their spouse report significantly greater frequency of guilt and sadness and greater use of internalising (for example, rumination, repression)
and social support seeking regulation strategies compared to carers who live with their spouse.

- Greater frequency of happiness is associated with greater use of social support seeking in carers.
- Females report significantly greater fear and frustration and happiness than males and significantly greater use of social support seeking emotion regulation strategies.
- All carers report infrequent use of externalising strategies (verbal assault, bullying others) to manage emotions and guilt is the least frequently reported emotion in all carers.

Fear and frustration were experienced frequently by spousal dementia carers in this study yet these are relatively under researched in this population. For example, systematic review of dementia carer anxiety demonstrated that research has focused upon psychological problems including psychological distress and symptoms of depression rather than examine the experience of worry and fear (Cooper et al., 2007). Qualitative research has found that fear in spousal dementia carers is associated with uncertainty of dementia progression and ability to cope with future unknown care needs, loss of control and loss of the cared for relative (Lindgren et al., 1999; O’Shaughnessy et al., 2010). Bramble et al. (2009) argue that fear about dementia progression may inhibit spousal dementia carers from seeking help.

Female carers experience higher levels of perceived threat and frustration than male carers in regard to physically aggressive behaviours associated with dementia (Bedard et al. 2005) and are more likely to report negative impact and lack of confidence in managing physical behaviours than male carers (Collins & Jones, 1997; Robinson et al. 2001). This may, in part, account for the greater frequency of fear and frustration reported by females in the present study. Females reported feeling happy more frequently than males with significantly
greater use of social support seeking. This concurs with previous studies which report significantly greater use of social support seeking coping (Tamres et al., 2002) and of emotion support seeking emotion regulation in females than males (Nolen-Hoeksema & Aldao, 2011). The findings of the present study suggest that social support seeking strategies in carers may help to manage difficult emotions such as fear and frustration and enhance positive emotions such as happiness.

Happiness is an emotion which is not widely associated with spousal dementia care in the research literature although, in this study, spousal carers who live with their spouse reported significantly greater positive affect (happiness) than sadness and guilt and greater use of constructive refocusing (for example ‘I put the situation into perspective’, ‘I plan what I could do better next time’) than other emotion regulation strategies. In contrast, carers who have placed their spouse in care or experienced the death of their spouse reported similar frequency of happiness, sadness and guilt and similar frequency of use of internalising, refocusing and social support strategies.

These findings may be understood by considering that involvement in activities that have purpose and personal meaning are likely to be supportive in maintaining psychological well-being (Laidlaw & Thompson, 2008) and that positive affect is increasingly associated with meaning in life as age increases (Hicks et al., 2012). Co-habiting may enable spousal carers to focus upon positive emotion goals and to derive meaning in life through the opportunities presented in the care role which may not be available when living apart from one’s spouse either through placement or bereavement. The care role may require regular use of refocusing strategies such as planning and putting things into perspective to manage the emotions that arise to enable a selective focus on obtaining positive rather than negative goals (Carstensen et al., 2011).
Spouses whose role as carer has shifted either through care home placement or death experienced significantly greater fear and frustration than happiness and, in comparison to carers who live with their spouse, reported greater sadness, guilt and use of internalising strategies (rumination, repression). Emotion regulation strategies such as rumination have been associated with less healthy adjustment including symptoms of depression and lack of social support (Campbell-Sills & Barlow, 2007; Campbell-Sills et al., 2006; John & Gross, 2007). Self-blame and less use of positive refocusing have also been associated with depression (Ehring et al., 2008). Carers who experienced care home placement or death of their spouse used social support significantly more frequently than carers who live with their spouse which may be a more important and protective strategy in managing emotions that arise following care transition.

It was surprising that guilt was the emotion reported least frequently by all carers given that guilt has been associated with psychological distress commonly experienced by familial dementia carers (Croog et al., 2006; Gonyea et al., 2008; McConaghy & Caltabiano, 2005). Qualitative research has found that spousal dementia carers report guilt, most notably in relation to managing the tension in meeting their spouses needs and their own needs (O’Shaughnessy et al., 2010) and to uncertainty regarding whether spouses are consenting to sexual activity (Baikie, 2002).

The association between care home placement and greater frequency of guilt in the present study is, however, in line with qualitative research which demonstrates heightened guilt and sadness in response to placing one’s spouse in care (Rudd, 1999; Finch, 1995; Lundh et al., 2000; Tilse, 1998; Wright, 1998) which may continue over a number of years after care home placement (Hennings et al., 2013; Ryan & Scullion, 2000). Anticipation of care home placement may also be associated with feelings of guilt and sadness and, combined with the
view of care home placement as a last resort, may be associated with the high frequency of care home placements that occur at times of crisis (Nolan & Dellasega, 2000).

There are a lack of empirical studies that examine the experience of guilt amongst dementia carers (Gonyea, 2008) which has been attributed to a lack of appropriate empirical measures for this population (Roach et al., in submission, 2013). The Caregiver Guilt Questionnaire has recently been validated for use in clinical and research settings in the UK (Roach et al., 2013, in submission) which may, in future, encourage the assessment of guilt at different stages of the care journey.

Fear and frustration were commonly experienced by all carers in the present study which may suggest that this is a particular area that intervention and support packages may wish to target in future. The finding that happiness is experienced by all carers and may be enhanced by social support or constructive refocusing strategies (where there are meaningful, purposive activities to undertake) is important in light of findings that suggest that positive emotions support recovery from the impact of negative emotions (Tugade & Fredrickson, 2004) and may inform carer interventions.

3.5.3 **Hypothesis 2: Spousal dementia carers will experience positive growth.**

Findings:

- Spousal dementia carers experience positive growth after taking on their care role.
- Carers who have placed their spouse in care report significantly greater positive growth than carers who live with their spouse, most notably in domains of ‘spirituality’ and ‘new possibilities’.
- Carers who have experienced the death of their spouse report significantly greater ‘new possibilities’ than carers who live with their spouse.
The present study found that positive growth, as measured by the PTGI, was evident among dementia caregivers, including those who are currently active in the care role, and was shaped, in part, by care transition and emotion regulation. Total positive growth scores in the present study were lower than the original study of students who had experienced a negative life event in the past five years including bereavement, accident and parental divorce (Tedeschi & Calhoun, 1996) and in line with scores reported in older adults whose spouses had been diagnosed with cancer (Weiss, 2002).

Tedeschi & Calhoun’s (1996) sample comprised younger participants than the present study which may generate greater growth because of greater openness to learning and change in the context of trauma in younger participants (Tedeschi & Calhoun, 2004). Caring for one’s spouse with dementia in later life is likely to be qualitatively different to adjusting to trauma experienced at university. Living daily with ambiguous loss, complicated grief, chronic sorrow and lack of closure (Boss, 2011) may differentiate the degree of growth experienced in spousal carers from other study populations. Intense demands of the carer role (Scarff & Zultner, 2012) may prohibit growth with limited opportunities, for example, to develop new interests or establish new paths. It was notable that carers who no longer lived with their spouse either through care home placement or death experienced greater growth in ‘new possibilities’.

3.5.4 Hypothesis 3: There will be a significant positive relationship between adaptive emotion regulation strategies and positive growth.

Findings:

- Positive growth since taking on the role of carer is predicted in part by social support seeking and constructive refocusing emotion regulation strategies but not by the experience of emotions.
Tedeschi & Calhoun (1996) argue that schema change contributes to the experience of growth although schema change relies upon managing emotional distress to the extent that cognitive processing to can take place. Growth in the present study was predicted partly by emotion regulation, a subcategory of coping (Gross, 1999) which facilitates adaptation to a range of circumstances (Ochsner & Gross, 2004) and not by experience of emotions. This suggests that it is what carers do to manage the emotion that facilitates growth. The present findings suggest that carers who are enabled to manage their emotions pro-actively are more likely to experience positive growth. These findings have implications for carer interventions which may usefully include support to develop emotional awareness and ways to regulate and manage emotions.

Carers who placed their spouse in care reported the greatest use of social support strategies and experienced the greatest degree of growth compared to those who live with their spouse. Internalising strategies did not contribute to predicted growth. Tedeschi & Calhoun (2004) argue that social support is important in facilitating growth and that self-disclosure of emotions over time in supportive social environments may facilitate cognitive processing and potential schema change leading to growth. A number of empirical studies report associations between social support and growth, most notably in emotional social support (Linley & Joseph, 2004; Weiss, 2004) rather than general social support. The importance of understanding the function of different types of social support has been highlighted through meta-analysis (Prati & Pietrantoni, 2009). These findings have implications for shaping dementia carer support groups over time.

### 3.5.5 Using the PTGI, BES and REQ with Spousal Dementia Carers

A number of low and cross loading items found in the data reduction analyses in the present study suggest the need for further qualitative research in assessing the use of these
questionnaires in the spousal dementia carer population and demonstrate that sub-scales reported in other populations may not be applicable in the present sample of spousal carers. As outlined in section 3.2.4, socioemotional selectivity theory would suggest that emotion regulation strategies in older adults are used to maintain emotional well-being. Low loading items may be considered in this context (REQ: ‘I harm or punish myself in some way’, ‘I do something energetic (e.g. play sport, go for a walk)’, ‘I take my feelings out on objects around me (e.g. deliberately causing damage to my house, or outdoor things’), ‘Things feel unreal (e.g. I feel strange, things around me feel strange, I daydream’). Self-harm or harm to property are unlikely to meet emotional goals or be of benefit to carers with responsibility for a vulnerable spouse. Opportunities to undertake energetic outdoor activities or daydreaming may be less available for spousal dementia carers.

The nature of the spousal carer experience more generally may account for the low loading items on the PTGI (‘I have a greater feeling of self-reliance’, ‘I am more willing to express my emotion’, ‘I know better that I can handle difficulties’, ‘I can better appreciate each day’). Carers may experience fear and uncertainty about their ability to cope with dementia progression and are reliant upon care professionals for support as dementia progresses which may impede feelings of self-reliance. Carers may not be enabled the time and space to better appreciate each day compared to life before taking on the role of carer and may experience the loss of mutual support and responsivity of their spouse to emotional expression. This may reduce willingness and motivation to express emotion in the spousal relationship and impede growth if there are limited socially supportive environments in which to express emotions.
3.5.6 Limitations of the study

3.5.6.1 Sampling

The present study was based on a sample drawn from a research register and is not, therefore, representative of all spousal dementia carers in Scotland more generally. There are many reasons for expressing interest in research and those who do so and then go on to participate may differ from those not targeted by the survey and from non-responders to the survey. Postal questionnaire responders in particular may represent higher socioeconomic status than non-responders (Tickle et al., 2003). Less than a half of respondents who were offered the chance to participate in the current study took up the offer and, although a reasonable response to postal survey, it is unknown how this group may differ more generally from the broader spousal carer base in Scotland.

3.5.6.2 Small sample size and additional factors that may affect care transition analyses

The present study found that there are emotional consequences for spousal carers whose spouses had moved to care homes including higher levels of guilt, sadness, social support seeking, internalising and positive growth. Many factors have been implicated in the decision to place a spouse with dementia in care including severity of dementia (Bond & Clark, 2002), lack of social support (Bond et al., 2003), higher socioeconomic status, older age (Gaugler et al., 2003) and poorer physical health of the carer (De Frias et al., 2005; Kiecolt-glaser et al., 1991; Von Kanel et al., 2012). We acknowledge the importance of these factors in the experience of caring for one’s spouse with dementia and their possible role in care home placement although these factors were not recorded in the present study. It is not possible, therefore, to ascertain their association with care home placement, emotion regulation and positive growth.

The relatively smaller size of the groups of carers who had placed their spouse in care and who had experienced the death of their spouse, in comparison to participants living with their
spouse, may suggest caution in reading the results. In addition, due to small numbers, it was not possible to conduct more detailed statistical analysis, for example gender comparisons within two of the care transition groups (placed in care and experience death of spouse). Spouses who have placed their spouse in care and those who have experienced the death of their spouse with dementia may be an especially challenging group of carers to recruit into research. The results presented in this study, while based upon small samples, provide some interesting insights to be followed up.

3.5.6.3 Self-report and bias

The present results demonstrate a need for continued research to further develop tools for use in this population. There were no published studies in an older adult or carer population using either of the emotion questionnaires employed in the present study. All three questionnaires (REQ, BES and PTGI) relied upon self-report and therefore capture carers’ perceptions of their emotional experiences, regulatory strategies and self-perceived growth at the time of survey. No objective measures were used to examine emotions or growth in the present study although the PTGI has been found to have inter-subjective validity between spouses (Weiss, 2002).

Published studies using the REQ and BES have not reported on biases that may exist, for example, on the social desirability of responses in the REQ and BES although the PTGI has been found to be independent of social desirability (Tedeschi & Calhoun, 1996; Wild & Paivio, 2002). The present study responses may, in part, be shaped by beliefs about what constitutes appropriate behaviour when caring for a vulnerable spouse with dementia.

3.5.6.4 Cross sectional research

As this study is cross-sectional it is not possible to comment definitively on the causal relationship between emotion regulation and personal growth or between care transition and
emotion regulation and positive growth. In addition, the present study did not examine the content and adaptive or maladaptive nature of particular emotion regulation strategies. It is not possible, therefore, to report on what it was about these strategies which may have facilitated growth.

As this is a retrospective study, carers were reliant upon long term memory when reporting emotion regulation and growth since taking on the role of carer. This has implications regarding the reliability of the study findings, including limited or reconstructed understanding of what has occurred and when (Jobe, Tourangeau & Smith, 1993), especially when recalling material which may be emotive in nature (Metts, Sprecher & Cupach, 1991). Questionnaire responses may be shaped by the timing of questionnaire completion on a particular day and may not capture the complexity of factors which shape emotional fluctuation more generally in this population.

The findings of the present study relate to the relative frequency of emotions experienced and it is not known whether and at what levels emotions impede carer adaptation or demonstrate a need for intervention and support. We concur with Joseph et al. (2012) that there is a need for longitudinal prospective studies which examine in detail the pattern of emotional state factors, appraisals, coping and post traumatic growth.

Despite these limitations, the present study was an important first step in exploring the emotional experience of spousal carers within a positive conceptual framework and the findings have a number of clinical implications which are outlined below.

3.5.7 **Clinical Implications**

In caring for a spouse with dementia, carers benefit from support to maintain their own psychological health although consideration of carers’ needs may currently be taking place
in the absence of a positive conceptual framework. This study highlights the following issues for clinical practice:

- The use of a positive conceptual framework in clinical practice including screening for positive growth may promote understanding of positive aspects of spousal dementia care and positive care outcomes.
- Particular attention should be given to the simultaneous occurrence of positive and negative affect that can occur during spousal care.
- Persistent use of internalising strategies in the absence of constructive refocusing and social support seeking and in the presence of negative emotions such as guilt, sadness and fear and frustration may highlight support and intervention needs.
- Routine assessment of carers’ emotional well-being may usefully include emotion profiling, the use of social support, and examination of the strategies used to manage the emotions experienced.
- Interventions that support carers to manage emotions including fear and frustration and encourage use of proactive emotion regulation strategies such as social support and constructive refocusing may enhance carer growth and support carers through care transition.

### 3.5.8 Research recommendations

Research is vital to inform the content and timing of psychological support and intervention for carers and to inform process and outcome evaluation. The results of the present study suggest the need for larger scale evaluations of concepts such as emotion regulation and PTG that have been ignored in spousal dementia care to date. Research priorities should include the examination of the experience of emotions in dementia carers and how these are managed within a positive framework, including awareness of emotions experienced; factors
that enable carers to manage their emotions; and availability, uptake and use of social support.

Future research will usefully incorporate longitudinal methods to further understand the experience of spousal carers and comparison groups matched in age, gender and marital status, over time. Consideration should be given to developing compassionate methods to recruit carers who are hard to reach, including those who have experienced care home placement or death of their spouse. There may be a role for qualitative and quantitative methods to capture the range of emotions, regulation strategies and growth that are experienced over time and in different contexts and how these interact with other variables involved in dementia care over time.

3.6 CONCLUSIONS

The present study found evidence of positive growth in spousal dementia carers, as demonstrated using the Post Traumatic Growth Inventory (PTGI), and evidences that carers experience a range of positive and negative emotions as they care for their spouse. Findings highlight the need for further exploration into emotion regulation and PTG with this population. Redressing the research balance using a positive conceptual framework may afford researchers an opportunity to look at positive as well as negative emotional consequences of caring for someone with dementia and the way in which emotional consequences are managed.

Conflict of interest

None
Acknowledgements

We would like to thank each individual who give their time to participate in this study and enable this research to happen. Thanks also to Dr Nuno Ferreira for guidance on statistical analysis, Phil Brown at the Scottish Dementia Clinical Research Network for facilitating access to the research register, and Hasnain Sheikh, sub postmaster at Warriston Post Office, for processing postal questionnaires.

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suppression and acceptance on emotional responses of individuals with anxiety and mood

conceptualizations and treatments of anxiety and mood disorders. In J. J. Gross (Ed.)


Appendix 1. Figure 3. Scree plot of BES factors

Table 13. Correlations between BES Factors: Factor correlation matrix

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Appendix 2. Figure 4. Scree plot of REQ factors

Table 14. Correlations between REQ Factors: Factor correlation matrix

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Appendix 3. Figure 5. Scree plot of PTGI factors

Table 15. Correlations between PTGI Factors: Factor correlation matrix

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APPENDIX 3 Thesis Folio References


APPENDIX 1 Author guidelines for journal articles written for submission to: International Psychogeriatrics

International Psychogeriatrics

Please read these instructions carefully before submitting articles. Articles which are not prepared in accordance with these guidelines will be returned to authors unreviewed.

Scope and contributions

International Psychogeriatrics is written by and for those doing clinical, teaching, and research work with elderly people. It is the official journal of the International Psychogeriatric Association (IPA) and is published by Cambridge University Press, Cambridge, UK. Although it is concerned primarily with psychogeriatrics, the journal welcomes contributions from all concerned with the field of mental health and aging. Original research papers are particularly sought.

Contributions include original research articles, reviews of the literature, “for debate” articles, case reports, letters to the editor, book reviews and editorials. Apart from editorials, “for debate” articles and book reviews, which are commissioned, contributions to International Psychogeriatrics are spontaneously written and submitted by authors. Papers are reviewed by at least two expert reviewers selected by the Editor-in-Chief. At present about half of the papers submitted are accepted for publication in the journal which is published twelve times per annum. The journal’s Science Citation Index Impact Factor (2011) is 2.24. Submission of a paper implies that it is neither under consideration for publication elsewhere, nor previously published in English.

Manuscripts must be formatted double-spaced with ample margins on all sides and the pages should be numbered. Please leave a blank line between paragraphs to enable typesetters to identify paragraph breaks without ambiguity. International Psychogeriatrics uses the spelling of American English. Manuscripts written by those whose primary language is not English should be edited carefully for language prior to submission. International Psychogeriatrics has a Language Advisory Panel of English speakers willing to check manuscripts for style prior to submission. Details can be found at both the journal website (http://journals.cambridge.org/ipp) under the related links icon and the IPA website (http://www.ipa-online.org/).

Submission of manuscripts

Manuscripts should be submitted online via our manuscript submission and tracking site, http://mc.manuscriptcentral.com/ipg. Full instructions for electronic submission are available directly from this site. If you are unsure of the suitability of your manuscript, please e-mail the abstract to the Journal Office before submitting online: ipa-ed@unmelb.edu.au

To facilitate rapid reviewing, communications for peer review will be electronic and authors will need to supply a current e-mail address when registering to use the system.

When submitting your manuscript you will need to supply:

A cover letter, the manuscript with the text file in MS Word format, and all figures in TIFF or JPEG format. If the paper reports the results of a randomized controlled trial please ensure that it conforms to our requirements listed below under the heading ‘Submission of randomized clinical trials’ on page 2. If the research was paid for by a funding organization, the cover letter must contain the following three statements (this information does not have to be included in the manuscript itself but only in the cover letter). If the research was not paid for by a funding organization only the third statement is required:

1. That the authors have not entered into an agreement with the funding organization that has limited their ability to complete the research as planned and publish the results.

2. That the authors have had full control of all the primary data.
3. That the authors are willing to allow the journal to review their data if requested.

Submission of a manuscript will be taken to imply that all listed authors have seen the final version and approved it.

All papers will be assessed by two reviewers. If their opinions are too disparate to permit the Editor-in-Chief to make a decision on publication or the reviewers are unable to make clear recommendations, the paper will be assessed by a third reviewer. The Editor-in-Chief's decision to accept, reject or request revision of the paper for publication will be final. The abstract and author details will be seen by prospective reviewers of the manuscript. Authors can suggest the names and contact information of experts qualified to review the work, but the Editor-in-Chief is not obliged to follow these suggestions. Papers must bear the authors' names, titles (e.g., Dr, Professor, etc.), affiliation(s), and address(es). This information will be seen by reviewers. Reviewers' names will not be supplied to authors unless a reviewer asks to be so identified. Authors will be provided with a copyright transfer form to sign after acceptance of the manuscript, consenting to publication of the paper in International Psychogeriatrics.

The receipt of all submitted papers will be acknowledged. Authors who do not receive an acknowledgement of receipt of their paper within three weeks of submission should assume that their paper has not been received and should contact ipgi-ed@unimelb.edu.au. Professor Nicola Lautenschlager, Normanby House, St George’s Hospital, 283 Gotha Road, Kew, Victoria, 3101, Australia, Tel: +61 3 9816 0485, Fax: +61 3 9816 0477. Most authors can expect to receive an initial decision on the fate of their paper together with referees' reports within no more than 100 days of submission. Authors who have received no further communication 120 days after acknowledgment of receipt of their article should contact ipgi-ed@unimelb.edu.au.

Submission of papers reporting randomized controlled trials

In order to ensure the public availability of the results of randomized controlled trials, the International Committee of Medical Journal Editors has suggested that all such trials should be registered. In common with many leading medical journals International Psychogeriatrics has decided to follow this policy. Since 31 December 2006 we will not review any paper submitted to us reporting a randomized clinical trial unless the trial was registered in a public trial registry from the date it commenced recruitment or, if recruitment started before 30 November 2006, we require that the trial was registered no later than 30 November 2006. For further details on the reasons for this policy see the June 2006 editorial, Ames, D. (2006). Registration of Clinical Trials submitted for publication in International Psychogeriatrics. International Psychogeriatrics, 18, 191-193.

All manuscripts reporting randomized controlled trials should have the following sent with them or they will be returned to the authors.

a. A check list and flow chart in accordance with the CONSORT guidelines which can be found at http://www.consort-statement.org. Please send in the checklist as a supplementary file and include the flow chart as Figure 1 in the manuscript.

b. The trial protocol is to be submitted as a supplementary file. This will not be published but it is needed to appraise and peer review the paper.

c. The registration number of the trial and the name of the trial registry in which it was registered. Please add these to the last line of the paper's structured abstract. Trials that began enrolment of patients after 31 December 2006 must have been registered in a public trials registry at or before the onset of enrolment to be considered for publication in International Psychogeriatrics. Trials that began enrolment prior to 30 November 2006 must have been registered no later than that date. Our criteria for a suitable public trial registry are: free to access; searchable; identification of trials by unique number; free or minimal cost for registration; validation of registered information; inclusion of details to identify the trial and the investigator within the registered entry (including the status of the trial); research question; methodology; intervention; and funding and sponsorship disclosed.
Organization and style of research articles

Title page and corresponding author: Each article must have a title page with the title of the article, a list of all authors and their titles, affiliations and addresses. Author qualifications should not be listed as these are not published in the journal. The title page should explicitly identify the author to whom correspondence about the study should be addressed and that author’s email address, telephone number, fax number and postal address must be clearly stated.

Abstract: Abstracts should be brief, structured and should incorporate the 4 sub-headings: background, method(s), results and conclusion(s). Abstracts should communicate the primary findings and significance of the research. They should not exceed 250 words in length.

Key words: Under this heading and beneath the abstract, please list up to 8 words for the purpose of indexing.

Running title: This should contain no more than 50 characters including spaces.

Introduction: Briefly state the relevant background to the study to provide the necessary information and context to enable non-specialists to appreciate the objectives and significance of the paper. Most introductions to articles received for review are too long.

Methods: Material and procedures should be described in sufficient detail to enable replication. Any statistical procedures used should be outlined and their use should be justified here. Results should not be included in the Method(s) section. If statistical procedures are used, they should be described here in adequate detail. Choice of statistical technique should be justified including some indication of the appropriateness of the data for the technique chosen. Adequacy of the sample size for each statistical technique(s) used must be addressed. If appropriate, a description of the statistical power of the study should be provided. If multiple univariate significant tests are used, probability values (p-values) should be adjusted for multiple comparisons, or alternatively a multivariate test should be considered.

Further advice about statistics and International Psychogeriatrics can be found in the following article: Chibnall, J. (2000) Some basic issues for clinicians concerning things statistical. International Psychogeriatrics, 12, 3-7. The following article may also be of assistance to intending contributors: Chibnall J.T. (2004). Statistical audit of original research articles in International Psychogeriatrics for the year 2003. International Psychogeriatrics 16, 389-396. Both of these are available at the International Psychogeriatrics website by following the link to Statistical Advice for Intending Contributors. This is also located under the related links icon at the journal homepage (http://journals.cambridge.org/ipg).

Results: This section may contain subheadings. Authors should avoid mixing discussion with the results. Sample sizes should be delineated clearly for all analyses. Some indicator of variability or sampling error should be incorporated into the reporting of statistical results (e.g. standard deviation, standard error of the mean). Wherever possible an indicator of effect size (e.g. Cohens d, r², Cramers V, 95% confidence interval) should be reported in addition to p values. If multiple univariate statistical tests are used p values should be adjusted for multiple comparisons or alternatively a multivariate test should be used. Obtained statistical values for tests should be reported with degree of freedom (e.g. t, F, χ²).

Discussion: Interpretation of the results with respect to the hypothesis(es) and their significance to the field should be discussed here. Results should be interpreted in the light of the size of the effect found and the power of the study to detect differences. Any methodological weaknesses of the study should be outlined, including limitations imposed by sample size. Careful consideration of the conclusion(s) for accuracy and alternative interpretation, and possible conflicts or resolution of conflicts in the field is encouraged. Limited speculation and directions for future research can be included.

Conflict of interest declaration: This section must be completed. This should follow the discussion and precede the references. Where there is no conflict of interest perceived to be present the heading Conflict of Interest should be included with the single word “none” underneath it. For full details see below.
Appendices

Description of authors' roles: This section must be completed if the paper has 2 or more authors. It should contain a very brief description of the contribution of each author to the research. Their roles in formulating the research question(s), designing the study, carrying it out, analysing the data and writing the article should be made plain. For example: H. Crun designed the study, supervised the data collection and wrote the paper. M. Bannister collected the data and assisted with writing the article. N. Seagoo was responsible for the statistical design of the study and for carrying out the statistical analysis.

Acknowledgements: Any acknowledgements other than conflict of interest declarations in regard to sponsorship should be listed briefly here.

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Where an article or book chapter has more than six authors only the first author’s name should be given followed by the words "et al."

For further examples of reference style see papers in recent issues of International Psychogeriatrics.

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There will normally be one of the following reasons for you to be supplying supplementary material to accompany the online version of your article:

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4. The file type and file size in parentheses.

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• Supply a laser print of all figures. List the name and version of the artwork package used and the names and libraries of fonts used in the artwork or EPS files.

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Appendices

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- Laser proofs: Supply a good quality laser proof of all figures. List the name and version of the artwork package used and the names and libraries of fonts used in the artwork. If we are unable to use your electronic file, we can scan in the laser proof as an alternative until a revised file can be supplied.

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Colour halftone or line subjects

- Do not submit line subject drawings with coloured tints unless the figure is required as a colour plate; use only black/white/grayscale.

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Checklists

- Always supply a printed directory of file names, laser proofs of all the figures, and a list of fonts/typefaces used in labelling artwork.

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- You can supply artwork files in any of the following media:

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  - 100/250 Mb Floppy ZIP drive
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Appendices

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(Revised 5 Jun 2013)
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Author Guidelines

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- Include up to six keywords that describe your paper for indexing purposes.

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A. A typical citation of an entire work consists of the author's name and the year of publication.

Example: Charlotte and Emily Bronte were polar opposites, not only in their personalities but in their sources of inspiration for writing (Taylor, 1990). Use the last name only in both first and subsequent citations, except when there is more than one author with the same last name. In that case, use the last name and the first initial.

B. If the author is named in the text, only the year is cited.

Example: According to Irene Taylor (1990), the personalities of Charlotte. . .

C. If both the name of the author and the date are used in the text, parenthetical reference is not necessary.

Example: In a 1989 article, Gould explains Darwin's most successful. . .

D. Specific citations of pages or chapters follow the year.

Example: Emily Bronte "expressed increasing hostility for the world of human relationships, whether sexual or social" (Taylor, 1988, p. 11).

E. When the reference is to a work by two authors, cite both names each time the reference appears.

Example: Sexual-selection theory often has been used to explore patterns of various insect matings (Alcock & Thornhill, 1983) . . . Alcock and Thornhill (1983) also demonstrate. . .

F. When the reference is to a work by three to five authors, cite all the authors the first time the reference appears. In a subsequent reference, use the first author's last name followed by et al. (meaning "and others").

Example: Patterns of byzantine intrigue have long plagued the internal politics of community college administration in Texas (Douglas et al., 1997) When the
reference is to a work by six or more authors, use only the first author's name followed by et al. in the first and all subsequent references. The only exceptions to this rule are when some confusion might result because of similar names or the same author being cited. In that case, cite enough authors so that the distinction is clear.

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Example: Jesse Moore (telephone conversation, April 17, 1989) confirmed that the ideas.

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- List two or more works by the same author in order of the date of publication: (Gould, 1987, 1989)
- Differentiate works by the same author and with the same publication date by adding an identifying letter to each date: (Bloom, 1987a, 1987b)
- List works by different authors in alphabetical order by last name, and use semicolons to separate the references: (Gould, 1989; Smith, 1983; Tutwiler, 1989).

All references must be complete and accurate. Where possible the DOI for the reference should be included at the end of the reference. Online citations should include date of access. If necessary, cite unpublished or personal work in the text but do not include it in the reference list. References should be listed in the following style:

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**Book**

**Book with More than One Author**


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- Graphs, drawings, etc - 800 dpi preferred; 600 dpi minimum
- Combinations of photos and drawings (black and white and colour) - 500 dpi

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APPENDIX 3 Distribution of scores the BES, REQ and PTGI

Distribution of REQ Total Scores

Distribution of Mean REQ Social Scores

Distribution of Mean REQ Refocus Scores

Distribution of Mean REQ Externalise Scores

Distribution of Mean REQ Internal Scores
Appendices

## Appendix 4  Z Score frequencies for the BES, REQ and PTGI

### Zscore: Fear with Frustration (Tension)

<table>
<thead>
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<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
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</thead>
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<td>2.7</td>
<td>2.9</td>
<td>2.9</td>
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<tr>
<td>Potential outlier (z-score &gt; 1.96)</td>
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<td></td>
<td></td>
<td></td>
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<td>Normal range</td>
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<td>97.1</td>
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<td>Total</td>
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### Zscore: BES Sadness

<table>
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<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
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<td>Potential outlier (z-score &gt; 1.96)</td>
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<td>1.6</td>
<td>1.8</td>
<td>2.4</td>
</tr>
<tr>
<td>Normal range</td>
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APPENDIX 5  IRAS ETHICAL APPROVAL

NRES Committees - North of Scotland
Summerfield House
2 Edray Road
Aberdeen
AB15 6RE

Telephone: 01224 558474
Facsimile: 01224 558600
Email: nosres@nhs.net

21 June 2012

Ms Roisin Ash
Trainee Clinical Psychologist
NHS Grampian
Department of Clinical Psychology
Older Adults
Royal Cornhill Hospital
Cornhill Road
ABERDEEN
AB25ZZH

Dear Ms Ash

Study title: The personal experience of caring for a spouse or partner with dementia
REC reference: 12/NS/0071

The Proportionate Review Sub-committee of the NRES Committees - North of Scotland (1) reviewed the above application by correspondence.

Ethical opinion

On behalf of the Committee, the Proportionate Review Sub-Committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

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).

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.

**Additional Conditions to be Met**

- The Proportionate Review Sub-Committee felt that some of the dementia sufferers may have died and ask that you acknowledge this possibility in the Participant Information Sheet and Letter of Invitation. This could be done by inserting a sentence to the effect that '...we recognise your spouse or partner may have died but we would still want you to take part in the study'.

- The Proportionate Review Sub-Committee wondered whether participants were aware that when they agreed to be on the list, that they would be approached by Postgraduate Researchers. Please comment.

- The Proportionate Review Sub-Committee felt that the Letter of Invitation should come from the Scottish Dementia Clinical Research Network as they are the primary contact for potential participants.

**Participant Information Sheet**

- Under the heading 'Why have I been chosen?', the Proportionate Review Sub-Committee ask that you remove 'alongside other spousal/partner carers in Scotland, to participate in this research' and replace with 'as you have previously consented to being contacted for future research by the Scottish Dementia Clinical Network'.

- Under the heading ‘Do I have to take part?’, final sentence, please remove 'Should you wish to withdraw, please return the questionnaires for disposal' as the Proportionate Review Sub-Committee did not feel that the participants should be required to return the questionnaire.

- Under the heading 'What happens if I choose to take part?' final sentence, please remove 'gender' and replace with 'sex'. This will also need to be changed in Q20 of the Carer Questionnaire.

- Under the heading 'Who has reviewed the study', please insert 'The North of Scotland Research Ethics Committee has reviewed this study'.

**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).**

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.
Approved documents

The documents reviewed and approved were:

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<td></td>
<td>24 May 2012</td>
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<tr>
<td>Letter of invitation to participant</td>
<td>2 April 2012</td>
<td>30 April 2012</td>
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<tr>
<td>Supervisor’s CV: Ken Laidlaw</td>
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<td>13 May 2012</td>
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Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
Further information is available at National Research Ethics Service website > After Review.

12/NS/0071 Please quote this number on all correspondence

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

Yours sincerely

Cath Irvine

Professor Siladitya Bhattacharya
Chair

Enclosures: List of names and professions of members who took part in the review
"After ethical review – guidance for researchers” SL-AR2

Copy to: Ms Marianne Laird
Dr Susan Ridge, NHS Grampian
Dear carer,

Your name and contact details have been provided to us by the Scottish Dementia Clinical Research Network (SDCRN) as you have registered interest in research participation through the Scottish Dementia Research Interest Register.

As part of my Clinical Psychology training, I wish to learn about the experience of dementia care. I am keen to learn from people with experience, past and present, of caring for a spouse or partner with dementia. This includes carers whose spouses/partners: live in the family home, or live outwith the family home, e.g. reside in a care home, or who are deceased. I understand that I have a great deal to learn from varied experiences and I would value the opportunity to learn from your experience of caring past and present.

I recognise that your spouse or partner may now reside outwith your family home or that you may have experienced the death of your spouse or partner but would still like you to take part in the study, if you wish. I would like to invite you to consider participating in my research which uses questionnaires that examine the role of emotion and change through caring. Further information on the questionnaire part of my study is provided on the accompanying Information Sheet for Questionnaire Participants.

Thank you for taking the time to consider your involvement in my research.

Kindest regards,

Roisin Ash
Chief Investigator
Clinical Psychology Trainee
NES/University of Edinburgh and NHS Grampian
INFORMATION SHEET FOR QUESTIONNAIRE RESPONDENTS

1. Study title: The personal experience of caring for a spouse or partner with dementia.

2. Invitation to participate

You are being invited to take part in a research study. Before you decide whether you wish to participate it is important that you understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please contact me, Roisin Ash, on 07787962177 or by email: roisin.ash@nhs.net

3. What is the purpose of the study?

This study seeks to learn from your experience as a carer which may be in the past or more currently, in particular, to examine the role of emotion and change through caring for a spouse or partner with dementia. We recognise that you may have experienced the loss of your spouse or partner for many reasons including moving to care home and bereavement and would still want you to take part in the study. This research is being conducted by Roisin Ash as part of the doctorate of Clinical Psychology at the University of Edinburgh, under the supervision of Dr Ken Laidlaw. This questionnaire part of this study is completed anonymously using envelope return.

4. Why have I been chosen to participate?

You have been contacted as a carer as you have previously consented to being contacted about future research through the Scottish Dementia Clinical Research Network.

5. Do I have to take part?

No, participation in this study is completely voluntary and you are free to withdraw from this study at any time without explanation or consequence. If you decide to take part, you are free to withdraw from the study at any time and without giving a reason. Any questionnaires that you have completed up to that point will be destroyed and will not be included in the study.

6. What happens if I choose to take part?

If you decide that you wish to take part in my study, please complete the questionnaires when you have the time. This may take up to 30 minutes of your time. We understand that you have other commitments and value learning from your expertise and experience. Questionnaire completion will be taken as evidence that you are consenting to take part in this study. Three questionnaires have been printed on A4 sheets for you to read through and complete in pen at a time and place that is suitable to you:

- Post Traumatic Growth Inventory (Tedeschi & Calhoun, 1996; 2004)
- Basic Emotions Scale - short form (Power, 2006; Power & Tarsia, 2007)
- Regulation of Emotions Questionnaire (Phillips & Power, 2007)
The questionnaires require mainly tick-box responses. Additional questions will enable you, for example, to record your sex, time spent in your care role and to write any comments that you wish to do so.

7. Will my taking part in this study be kept confidential?

All data collected by questionnaire will be anonymous and stored confidentially. You are NOT required to provide your name, date of birth or other information that could potentially identify you as a participant. The chief investigator, Roisin Ash, will have access to the data for analysis. All information will be recorded and reported in such a way that responses will not be able to be linked to any individual. The data you provide will be used for the specific research purposes of this study outlined above.

8. How can I take part?

The questionnaire part of this study will run throughout Autumn 2012 – Winter 2013 and if you decide that you would like to participate in this questionnaire study, it would be helpful if you would read and complete the questionnaires when you have the time.

9. How do I return my completed questionnaires?

The return envelopes enable you to return these questionnaires for collection by Roisin Ash at your support group centre. Can I ask that, where possible, you return questionnaires within 3 weeks of receiving them.

10. What will happen to the results of the research study?

Roisin Ash will write up the results of the research in a doctoral thesis which will be held within the University of Edinburgh library.

11. I would like to learn about the findings of the research

It is anticipated that research findings will be available in Winter 2013. If you wish to be provided with a summary of the research findings, please complete the separate opt-in sheet (section A). The opt-in sheet asks for your name and address for sending research findings. This information will be stored securely and separately to your questionnaire responses so that your questionnaire responses remain anonymous. You can also choose whether to be contacted in regards to participating in future research on dementia caring (Section B of the opt-in sheet).

12. Who has reviewed the study?

The North of Scotland Research Ethics committee has reviewed this study.

If you would like to speak with my university supervisor, Dr Ken Laidlaw, please contact: k.laidlaw@ed.ac.uk

If you would like to discuss taking part in my study please contact me, Roisin Ash, either by email: roisin.ash@nhs.net and/or phone: 01224 557497 and/or text on: 07787962177

If you wish to make a complaint about this study, please contact NHS [INSERT RELEVANT COMPLAINTS CONTACT FOR THE NHS REGION IN HERE]

Thank you for taking the time to read through this information, it is greatly appreciated.
APPENDIX 8  Scottish Dementia Clinical Network (SDCRN) Approval

Roisin Ash  
Departmental of Clinical Psychology  
Older Adults Services  
Block D  
Royal Cornhill Hospital  
Aberdeen  
AB25 2ZH

Our Ref  
NAN 23

Enquiries to  
Philip Brown, Administrator  
01738 562322  
philipbrown1@nhs.net

Dear Ms Ash

We have considered your study ‘The personal experience of caring for a spouse or partner with dementia’ for adoption to the Scottish Dementia Clinical Research Network.

We have pleasure in informing you that the network has approved adoption of your study for the following support:

- Access to carer data

We wish you every success in your project.

We would like to include a brief summary of your study and contact details on our website. Please let me know if this is not acceptable.

Please do not hesitate to contact me for further clarification and assistance when the time arises at emma.law@nhs.net.

Kind regards.

Yours sincerely

EMMA LAW  
Manager  
Scottish Dementia Clinical Research Network

29th June, 2012
APPENDIX 9  The Basic Emotions Questionnaire

THE BASIC EMOTIONS SCALE SHORT VERSION

When confronted with some experiences, people may react emotionally. Sometimes some of these emotions prevail over others and linger.

This scale is designed to explore how you have felt since taking on the role of carer for your spouse/partner.

For each emotion please circle ONE number only between 1 and 7 to indicate how often you have felt that emotion since you took on the role of carer.

<table>
<thead>
<tr>
<th>Emotion</th>
<th>not at all</th>
<th>some of the time</th>
<th>all of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>ANGER</td>
<td>1</td>
<td>2</td>
<td>3 4 5 6 7</td>
</tr>
<tr>
<td>DESPAIR</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>SHAME</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>ANXIETY</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>HAPPINESS</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>FRUSTRATION</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>MISERY</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>GUILT</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>NERVOUSNESS</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>JOY</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>IRRITATION</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>GLOOMINNESS</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>HUMILIATED</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>TENSE</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>LOVING</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>AGGRESSION</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>MOURNFUL</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>BLAMEWORTHY</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>WORRIED</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>CHEERFUL</td>
<td>1 2</td>
<td>3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>
# APPENDIX 10 The Regulation of Emotions Questionnaire (REQ)

## Regulation of Emotion Questionnaire

We all experience lots of different feelings or emotions. For example, different things in our lives make us feel happy, sad, angry and so on.

The following questions ask you to think about how often you do certain things in response to your emotions. You do not have to think about specific emotions but just how often you generally do the things listed below.

Please tick the box corresponding to the answer that fits best. We all respond to our emotions in different ways so there are no right or wrong answers.

<table>
<thead>
<tr>
<th>In GENERAL how do you respond to your emotions?</th>
<th>Never</th>
<th>Seldom</th>
<th>Often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I talk to someone about how I feel</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>2. I take my feelings out on others verbally</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>(e.g. shouting, arguing)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I seek physical contact from friends or family (e.g. a hug, hold hands)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>4. I review (rethink) my thoughts or beliefs</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>5. I harm or punish myself in some way</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>6. I do something energetic (e.g. play sport, go for a walk)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>7. I dwell on my thoughts and feelings (e.g. it goes round and round in my head and I can’t stop it)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>8. I ask others for advice</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
Appendix 10 (continued) The Regulation of Emotions Questionnaire (REQ)

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Seldom</th>
<th>Often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. I review (rethink) my goals or plans</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>10. I take my feelings out on others physically (e.g. fighting, lashing out)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>11. I put the situation into perspective</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>12. I concentrate on a pleasant activity</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>13. I try to make others feel bad (e.g. being rude, ignoring them)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>14. I think about people better off and make myself feel worse</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>15. I keep the feeling locked up inside</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>16. I plan what I could do better next time</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>17. I bully other people (e.g. saying nasty things to them, hitting them)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>18. I take my feelings out on objects around me (e.g. deliberately causing damage to my house, or outdoor things)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>19. Things feel unreal (e.g. I feel strange, things around me feel strange, I daydream)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>20. I telephone friends or family</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>21. I go out and do something nice (e.g. cinema, shopping, go for a meal, meet people)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
For each of the following statements please circle the number that best describes any changes in your life as a result of your experience of caring for your spouse/partner.

<table>
<thead>
<tr>
<th>As a result of caring for my spouse/partner:</th>
<th>I did not experience this change</th>
<th>I experienced this change to a very small degree</th>
<th>I experienced this change to a small degree</th>
<th>I experienced this change to a moderate degree</th>
<th>I experienced this change to a great degree</th>
<th>I experienced this change to a very great degree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I changed my priorities about what is important in life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have a greater appreciation for the value of my own life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I developed new interests</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have a greater feeling of self-reliance</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have a better understanding of spiritual matters</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I more clearly see that I can count on people in times of trouble</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I established a new path for my life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have a greater sense of closeness with others</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am more willing to express my emotions</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I know better that I can handle difficulties</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
### Appendix 11 (continued) The Post Traumatic Growth Inventory (PTGI)

<table>
<thead>
<tr>
<th>As a result of caring for my spouse/partner:</th>
<th>I did not experience this change</th>
<th>I experienced this change to a very small degree</th>
<th>I experienced this change to a small degree</th>
<th>I experienced this change to a moderate degree</th>
<th>I experienced this change to a great degree</th>
<th>I experienced this change to a very great degree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am able to do better things with my life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am better able to accept the way things work out</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I can better appreciate each day</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>New opportunities are available which wouldn't have been otherwise</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have more compassion for others</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I put more effort into my relationships</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am more likely to try to change things which need changing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have a stronger religious faith</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I discovered that I'm stronger than I thought I was</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I learned a great deal about how wonderful people are</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I better accept needing others</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>