Sense of competence in family carers of people living with dementia: A positive psychology perspective

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Declaration

I, Jacki Lisa Stansfeld, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Date: ________________  Jacki Lisa Stansfeld: ________________
Carer Sense of Competence

Abstract

Background

Carer sense of competence is related to their wellbeing and may play a role in reducing the risk of institutionalisation of the person with dementia. Little is known about the predictors of family carer sense of competence, particularly positive psychology factors.

Aim

To better understand the nature of sense of competence in family carers of people living with dementia.

Methods

Two systematic reviews: (1) of positive psychology measures and (2) exploring factors related to sense of competence, were used to design a national survey of sense of competence in 583 family carers. A meta-analysis examined the impact of psychosocial interventions on sense of competence. Sense of competence was examined in relation to carer mood and person with dementia factors using data from 468 dyads in the Valuing Active Life in Dementia (VALID) study. A qualitative study of family carers further explored the nature of sense of competence.

Results

In the survey, higher sense of competence significantly predicted better health related quality of life of carers, with this relationship mediated by sense of coherence. In the VALID study, carer mood significantly predicted variance in sense of competence scores, but clinical features of the person with dementia did not. In the qualitative study, carers’ perception of
challenges in the caring role and their cognitive appraisal had a strong influence on how competent family carers perceived themselves to be.

**Conclusions**

Positive psychology factors such as resilience and gains, and carer mood contribute to carer sense of competence. These findings inform understanding of the impact of positive psychology and psychosocial factors on family carer sense of competence. As such, a revised conceptual model of sense of competence incorporating positive psychology aspects of caring was proposed. Greater knowledge of the factors influencing sense of competence can improve the design of psychosocial interventions for carers.
Statement of Impact

This thesis presents a detailed investigation into family carer sense of competence, using a mixed methods approach. The findings of three complementary systematic reviews and three empirical studies advance knowledge of how positive psychology factors relate to and impact carer sense of competence. A mixed methods approach to this thesis enabled a deeper insight into sense of competence from both a quantitative perspective and in family carers’ own words. From this work, an updated conceptual model of sense of competence is presented, which incorporates positive psychology factors, person with dementia clinical characteristics and carer mood.

This model presents new insights into both the positive and negative aspects of the carer experience and sense of competence. This thesis presents evidence that support provided to family carers of people living with dementia should not just be focused on alleviating the negative aspects of caring, but also increasing the positive aspects. At a time when the number of people living with dementia is on the rise, it is imperative that better support is provided for family carers to enable both carers and people with dementia to live well with dementia.

Findings from this research also enhance existing knowledge of the positive experiences of family carers of people living with dementia and more specifically, family carer sense of competence, and indicate that carers can thrive in their role, despite the challenges of caring. These findings can
impact on the development of support services and improve the design of appropriate and relevant interventions in order to support family carers to feel more equipped and empowered to care for their friend or relative at home, potentially delaying institutionalisation of the person with dementia. The long-term aim is to adapt these findings to produce a relevant psychosocial intervention, grounded in positive psychology theory.

The impact of this thesis will be delivered by dissemination of the findings at national and international conferences, and publishing in peer-reviewed journals. Findings from the two systematic reviews have already been published in peer-reviewed journals and presented at national and international conferences. Findings regarding the updated conceptual model were presented at an international conference and generated lively discussion with researchers, carers and people with dementia, as to the need to view the carer experience in a more balanced light, considering both the positive and the negative in tandem. Findings will also be disseminated to family carers who participated in the research and participating third sector organisations in lay format enabling them to see the impact and outcome of their contribution. This varied dissemination of output will enable the findings to reach a wider audience.
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<th>Description</th>
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<tbody>
<tr>
<td>ADLs</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
</tr>
<tr>
<td>AUC</td>
<td>Area under the curve</td>
</tr>
<tr>
<td>B</td>
<td>Un-standardised regression coefficient</td>
</tr>
<tr>
<td>β</td>
<td>Beta</td>
</tr>
<tr>
<td>BADLS</td>
<td>Bristol Activities of Daily Living Scale</td>
</tr>
<tr>
<td>BECCA</td>
<td>BEfriending and Cost of CAring</td>
</tr>
<tr>
<td>BME</td>
<td>Black and Minority Ethnic</td>
</tr>
<tr>
<td>BPSD</td>
<td>Behavioural and Psychological Symptoms of Dementia</td>
</tr>
<tr>
<td>CASP</td>
<td>Critical Appraisals Skills Programme</td>
</tr>
<tr>
<td>CDR</td>
<td>Clinical Dementia Rating Scale</td>
</tr>
<tr>
<td>CFI</td>
<td>Comparative Fit Index</td>
</tr>
<tr>
<td>CINAHL</td>
<td>Cumulative Index to Nursing and Allied Health Literature</td>
</tr>
<tr>
<td>COTiD</td>
<td>Community Occupational Therapy in Dementia</td>
</tr>
<tr>
<td>CRF</td>
<td>Case Report Form</td>
</tr>
<tr>
<td>CSDD</td>
<td>Cornell Scale for Depression in Dementia</td>
</tr>
<tr>
<td>CSRI</td>
<td>Client Service Receipt Inventory</td>
</tr>
<tr>
<td>DEM-DISC</td>
<td>DEmentia-specific Digital Interactive Social Chart</td>
</tr>
<tr>
<td>DEMQOL</td>
<td>Dementia Quality of Life Scale</td>
</tr>
<tr>
<td>DF</td>
<td>Degrees of freedom</td>
</tr>
<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
</tr>
<tr>
<td>EQ-5D-5L</td>
<td>European Quality of Life – Five Dimensions, Five Level</td>
</tr>
<tr>
<td>FMTCS</td>
<td>Finding Meaning Through Caregiving Scale</td>
</tr>
<tr>
<td>GAIN</td>
<td>Gain in Alzheimer Care Instrument</td>
</tr>
<tr>
<td>GCP</td>
<td>Good Clinical Practice</td>
</tr>
<tr>
<td>HADS</td>
<td>Hospital Anxiety and Depression Scale</td>
</tr>
<tr>
<td>HRQoL</td>
<td>Health Related Quality of Life</td>
</tr>
<tr>
<td>IDDDD</td>
<td>Interview of Deterioration in Daily activities in Dementia</td>
</tr>
<tr>
<td>ISRCTN</td>
<td>International Standard Randomised Controlled Trial Number</td>
</tr>
<tr>
<td>ISS</td>
<td>Intrinsic Spirituality Scale</td>
</tr>
<tr>
<td>JDR</td>
<td>Join Dementia Research</td>
</tr>
<tr>
<td>LOA</td>
<td>Limits of Agreement</td>
</tr>
</tbody>
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Carer Sense of Competence

LSNS-6 Lubben Social Network Scale- 6 item
M Mean
MCAR Missing Completely At Random
MCI Mild Cognitive Impairment
MCSP Meeting Centres Support Programme
MIC Minimal Important Change
MMSE Mini Mental State Examination
n Number of participants
NELFT North East London NHS Foundation Trust
NFI Normed Fit Index
NHS National Health Service
NICE National Institute for Health and Care Excellence
NIHR National Institute of Health Research
NRES National Research Ethics Service
p Level of significance
PAC Positive Aspects of Caregiving Scale
PERMA Positive emotion, Engagement, Relationships, Meaning and Accomplishments
PPI Patient and Public Involvement
PRISMA Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RAM Reticular Action Model
RCT Randomised Controlled Trial
REC Research Ethics Committee
REMcare Reminiscence groups for people with dementia and their family CAREgivers
RMSEA Root Mean Square of Approximation
RR Responsiveness ratio
RS-14 Resilience Scale -14 items
RS-25 Resilience scale - 25 items
RSSE Revised Scale for Caregiving Self-Efficacy
SCIE Social Care Institute for Excellence
SCQ Sense of Competence Questionnaire
Carer Sense of Competence

SD Standard Deviation
SDC Smallest Detectable Change
SEM Structural Equation Modelling
SEMD Self-Efficacy for Managing Dementia
SHIELD Support at Home: Interventions to Enhance Life in Dementia
SMD Standardised Mean Difference
SOCoh-13 Sense of Coherence Scale
SPSS Statistical Package for the Social Sciences
SRMR Standardised Root Mean Square Residual
SSCQ Short Sense of Competence Questionnaire
SSS Spiritual Support Scale
STROBE STrengthening the Reporting of OBservational studies in Epidemiology
SWPP Second Wave Positive Psychology
TAU Treatment as Usual
UK United Kingdom
USA United States of America
VALID Valuing Active Life in Dementia
VAS Visual Analogue Scale
VIA Values in Action
ZBI Zarit Burden Interview
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Chapter 1 An introduction to dementia, caring and sense of competence

This introduction Chapter provides an overview of the existing literature in terms of: the prevalence, definition and impact of dementia, models of carer stress and coping, positive psychology models, and current understanding of sense of competence in family carers of people living with dementia in the community.

1.1 Epidemiology and nature of dementia

It is estimated that there are 850,000 people living with dementia in the United Kingdom (UK; Alzheimer’s Society, 2015). As the population continues to age and life expectancy increases, this number is expected to rise to over one million by 2025 and to over two million by 2051 (Alzheimer’s Society, 2015; Prince et al., 2014). Dementia has a vast economic impact and is estimated to cost £26.3 billion a year in the UK (Alzheimer’s Society, 2015; Prince et al., 2014). This cost is expected to rise as the number of people living with dementia increases, making service provision for people living with dementia and support for carers a health and social care priority for the National Health Service (NHS) and UK government (Alzheimer’s Society, 2015).

Dementia is an umbrella term describing a range of cognitive and behavioural symptoms that manifest as “memory loss, problems with reasoning and communication and change in personality, and a reduction in a person’s ability to carry out daily activities, such as shopping, washing,
dressing and cooking” (National Institute for Health and Care Excellence [NICE]/Social Care Institute for Excellence [SCIE], 2018, p. 6). Some forms of dementia can cause personality and behavioural changes, including disinhibition, impulsivity and difficulty controlling emotion (Alzheimer’s Research UK, 2016). These symptoms are often termed ‘behavioural and psychological symptoms of dementia’ (BPSD). The presentation of symptoms varies between individuals, stages and types of dementia (Brooker & Surr, 2005). Common types of dementia include Alzheimer’s disease, vascular dementia, dementia with Lewy bodies and fronto-temporal dementia. About two thirds of people with dementia in the UK have Alzheimer’s disease, making it the most common type of dementia. Vascular dementia is the second most common type of dementia (Prince et al., 2014).

Dementia can impact on all aspects of life and symptoms typically worsen over time due to its progressive nature.

1.2 Caring for a person with dementia

The majority of people with dementia in the UK live at home or with relatives in the community, with care provided by an estimated 670,000 family and friends (Alzheimer’s Society, 2015). In this thesis, a family carer is defined as an individual who gives a substantial amount of unpaid and informal care and support to a relative, partner or friend who is no longer able to care for themselves independently. Caring for a person with dementia involves both emotional and practical support, such as assistance with personal care and activities of daily living (such as feeding, dressing, and support with hobbies). As described previously, there is significant variability in the
presentation of dementia between individuals and stages of dementia and therefore the caring role is extremely complex and often varies between individual carers.

Family carers save health and social services approximately £11.6 billion a year (Prince et al., 2014). However, despite the essential role provided by family carers, many feel that they are not sufficiently trained or provided with enough information to feel competent to care for the person with dementia (Carers Trust, 2013). Carers report feeling unsupported by professionals due to the complex nature and structure of health and social care services (Alzheimer’s Society, 2015), and have described accessing support akin to navigating a maze (Peel & Harding, 2014). Family caring is a significant public policy issue, and this topic was raised in the Prime Minister’s challenge on dementia 2020 (Department of Health, 2015). This challenge recognised the need to provide more support for carers, and to skill up general practitioners and local authorities to support the needs of carers and direct them to relevant services. As dementia progresses, the person living with dementia generally needs increasing assistance from family carers, who may need support from services to cope. Family carers report experiencing feelings of burden, depression and stress as a result of caring (Cooper, Balamurali & Livingston, 2007; Crespo, Lopez & Zarit, 2005; Svendsboe et al., 2018; Chiao, Wu & Hsiao, 2015; Van der lee, Bakker, Duivenroorden & Droes, 2014). These negative aspects of caring can increase the carer’s risk of physiological and mental health problems (Richardson, et al., 2013; Cupidi et al., 2012; Alzheimer’s Association, 2012).
1.3 Theoretical models of dementia and caring

A biomedical approach has historically driven the theory and discourse surrounding dementia, resulting in the dominance of a pathological, loss-orientated model in dementia research and care. In the biomedical model, dementia is described as an organic brain dysfunction, which should be treated as a medical disease (Lyman 1989). This approach to dementia incorporates the view that the clinical presentation of dementia is purely explained by cerebral changes and the extent of damage in the brain. This model does not take into account individual differences between people with dementia and overlooks the social factors that may impact their experience. The dominance of these models has contributed to the stigma and fear that surrounds dementia (Mitchell, Dupuis & Kontos, 2013), resulting in the misconception that people with dementia are unable to 'live well', and cannot experience pleasure (Vernooij-Dassen et al., 2005). This notion was challenged by Kitwood (1997) who presented a counter-narrative about the nature of dementia and, through his work on defining the concept of 'personhood', initiated a shift towards the person-centred care approach; challenging the discourse surrounding dementia. The work of Kitwood described how people can live well with dementia and is credited with shifting the perception of living with dementia (Baldwin & Capstick, 2007).

Consistent with the negative discourse surrounding dementia, the dominant theoretical approach to understanding the experience of carers of people with dementia was previously also largely focused on negative aspects of caring such as stress and burden. The early theoretical models of stress-
Coping processes (Lazarus & Folkman, 1984; Hayley, Levine, Brown & Bartolucci; 1987) in caring failed to incorporate positive psychology factors and examine the potential for carers to have positive outcomes. Consistent with the original stress-coping models, much of the existing literature has been weighted towards these negative aspects of caring. Therefore, the role of the positive psychology factors was largely overlooked in the literature when these early models were first developed.

Therefore, early stress-coping models may not fully describe the caring experience, as positive psychology factors in caring have only received attention in recent years (Roff et al., 2004; Tarlow et al., 2004). Subsequently, there was a shift to consider wellbeing and quality of life in dementia and caring research, alongside positive factors, such as sense of competence, gains and the ability to find meaning (Lau & Cheng, 2015; Quinn, Clare, McGuinness & Woods 2012; Quinn, Clare & Woods 2012). Research has shown that carers can achieve personal growth as they learn new skills and develop in the caring role (Netto, Jenny & Philip, 2009). By overcoming challenges, carers have reported a greater sense of competence in their role (Quinn, Clare & Woods 2015; Shim, Barroso, Gilliss & Davis, 2013). Although not all carers are able to identify positive aspects of caring, it is evident that some are able to adapt and thrive in their role (Peacock et al., 2010). It has been theorised that positive psychology factors can serve as a buffer against the negative impact of caring such as stress (Koerner, Kenyon & Shirai, 2009; Carbonneau, Carron & Desrosiers, 2010), though the pathways through which this occurs are unclear. The
acknowledgement of, and investigation into the positive psychology factors in caring led to the adaptation of stress-coping models to represent both the positive and negative aspects of caring. The early stress-coping models and subsequent adaptions are detailed below.

1.3.1 Stress-coping model (Lazarus & Folkman, 1984)

Lazarus and Folkman’s (1984) stress-coping model (Figure 1.1) detailed the process by which carers cope with stress. Lazarus and Folkman (1984) defined stress as the outcome when the carer’s personal resources do not enable them to meet the demands placed on them by caring. In this model, when a stressful event occurs, a cognitive appraisal takes place in order to determine whether the stressor is harmful or not. If the event is considered stressful or harmful, coping mechanisms will be put into place to manage the event. Lazarus and Folkman defined coping as “the cognitive and behavioural efforts made to master, tolerate or reduce external and internal demands and conflicts among them” (Folkman & Lazarus, 1980, p. 223) and described two different coping mechanisms in their model, problem-focused coping and emotion-focused coping. Problem-focused coping involves evaluating the problem and trying to manage it in order to deal with the stressor. Emotion-focused coping comprises trying to alleviate the emotional response to stress such as by seeking support or avoiding the stress. If the coping mechanism is successful, the stress attached to the event will reduce. Lazarus and Folkman’s stress-coping model is a robust model and its strengths include the consideration of individual differences in responses to stressors, dependent on the cognitive appraisal or interpretation of the
event. However, despite the dominance of this model in the caring literature, the impact of positive psychology factors, such as sense of competence, gains and satisfaction with caring, on appraisal and coping mechanisms were not considered by authors.

Figure 1.1 Lazarus & Folkman's (1984) stress-coping model
1.3.2 Model of stress and coping among carers (Haley, Levine, Brown & Bartolucci, 1987)

Hayley et al. (1987) adapted Lazarus and Folkman’s (1984) model to produce a revised model of stress and coping in carers (Figure 1.2). Hayley et al. (1987) theorised that the severity of dementia, BPSD and ADLs were stressors for family carers. In this model, the cognitive appraisal of the stressor, the carer’s subsequent coping mechanisms and the availability of social support can all influence carer outcomes. Outcomes within this model include a reduction of emotional stress, because of the ability of the carer to manage the stressor, and an increase in carer sense of competence.

![Figure 1.2 Model of stress and coping among carers (Haley et al. 1987)]
Haley et al. (1987) found evidence to support their model in a cross-sectional study with 53 family carers of people living with dementia. The carers' cognitive appraisal, coping resources and higher levels of social support were significant predictors of carer outcomes (lower depression, higher life satisfaction and better self-reported health). However, this study had a small sample size ($n = 53$) and, due to its cross-sectional nature, it was not possible to evaluate how these outcomes changed over time.

The two models described above and similar stress-coping paradigms have been criticised for the lack of inclusion of positive psychology factors, such as sense of competence, gains or satisfaction in caring as mediators of carer outcomes. Subsequently, the need to incorporate positive psychology factors into existing models to explore how they can mediate outcomes for carers was increasingly recognised and further models were developed (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Kramer, 1997).

1.4 The development of stress-coping models to include positive psychology factors

Lawton et al. (1989) noted that positive psychology factors had been largely overlooked in existing carer literature and examined the concept of ‘personal mastery’, which had previously been included in the stress model of Pearlin and Schooler (1978). Personal mastery was defined as the perception of the self as able to deal with stressors as they occur and was considered to be a stable construct. Lawton et al. (1989) considered personal mastery to be the result of an appraisal of the self and the subsequent response to overcome
stressors. Pearlin, Mullan, Semple and Skaff (1990) also investigated positive psychology factors such as self-esteem, mastery, gain and competence in relation to carer stress in a conceptual model of Alzheimer’s carer stress. In addition to their proposed stress process model (Figure 1.3), they developed two outcome measures: one of competence and one of gains in caring. Competence was defined as a carers rating of their performance as carers. The concept of gains was defined as enrichment and inner growth as a result of carers facing the challenges of caring. The stress process model has four domains that impact outcomes: carer characteristics (such as age, gender, caring history and family network), primary stressors (such as BPSD), secondary role strains (such as family or job conflict) and secondary intrapsychic strains (such as competence and self-esteem). The coping mechanisms employed by the carer and their social support are hypothesised to moderate these four domains. The stress process model was the first conceptual model that included carer competence alongside gains, self-esteem and mastery as moderators of outcomes. During the development of the model, the measures of sense of competence and gains were tested. The authors found that carer competence and gains were moderately correlated ($r = .32$, $p > .05$). Despite the inclusion of positive concepts as moderators of carer outcomes, all the carer outcomes included in the model were negative (depression, anxiety, and cognitive disturbance) and no positive outcomes were measured. This demonstrated the need for further investigation into positive outcomes in caring and the processes that lead to these.
Figure 1.3 Stress process model (Pearlin et al., 1990)
1.4.1 Kramer's modified stress-coping model (1997)

Kramer (1997) also addressed the neglect of positive psychology factors in the caring literature by conducting a literature review to identify factors related to gains in caring. Kramer (1997) applied the results of this review to develop a modified stress-coping model (Figure 1.4). In this model, characteristics of the carer and person with dementia, such as gender and age play an important role in the experience of caring. These characteristics influence the psychological and emotional resources that the carer can draw on when dealing with stress and therefore account for the variation in gains and strain experienced by family carers. Whether the carer experiences gains or strain directly or indirectly impacts on outcomes, including positive wellbeing or stress. Kramer theorised that the most relevant indicators of wellbeing were sense of competence, purpose in life, personal growth and self-acceptance. In recognising gains during the caring role, Kramer (1997) introduced positive psychology factors to stress-coping models. Kramer's model is one directional, however, which does not fully represent the complexity of the caring experience as carers may be dealing with more than one challenging experience at any one time. Rapp and Chao (2000) examined carer's appraisals of gains and strain and found that positive appraisals are important factors for buffering against stress and are independent of negative appraisals. These findings lent empirical support to Kramer's (1997) model.
Figure 1.4 The modified stress-coping model (Kramer, 1997)
1.4.2 Heuristic conceptual framework (Sorensen & Conwell, 2011)

More recent caring models have attempted to address the one-directional nature of previous stress-coping models such as Kramer’s (1997) model. Sorensen and Conwell (2011) proposed a heuristic conceptual framework (Figure 1.5) that combined and adapted the stress-coping and appraisal models described previously (Pearlin et al., 1990; Lawton, Moss, Kleban, Glicksman & Rovine, 1991). This more recent model illustrates the complex nature of caring and proposes that carer outcomes are influenced by their appraisal of the situation, primary and secondary stressors and positive factors such as self-efficacy, sense of competence, coping resources, gains in caring and social support. The authors postulated that these factors moderate the impact of stress on the carer and the cognitive appraisal that the carer makes of the event. If positive psychology factors are considered as protective elements against the stress or burden of caring suggests that these factors could be a pathway to improved carer outcomes. Factors included in Sorensen and Conwell’s (2011) model such as self-efficacy are explored in detail in existing research but sense of competence is a concept is less comprehensively defined or examined.
Background and contextual factors
- Socioeconomic status
- Ethnicity/culture
- Gender
- Age
- Geography (rural / urban)
- Health systems

Primary Stressors
Patient characteristics
- Cognitive impairments
- Functional disability
- Problem behaviour
Care situation
- Duration of caring
- Hours of caring
- Number of caring tasks
Carer
Unmet need of carer

Secondary stressors
- Work interference
- Financial strain
- Family conflict
- Social isolation
- Reduced relationship quality
- Decreased leisure
- Other opportunity costs

Appraisal
- Perceived situational control
- Perceived role conflict (vs role enhancement)
- Role captivity
- Perceived adequacy of resources
- Positive appraisal
- Finding meaning
- Short-term vs long-term

Exacerbating/ameliorating factors (moderators)
- Lack of knowledge/information about dementia
- Self-efficacy/sense of competence/mastery
- Personality
- Coping resources
- Social, emotional, and financial support resources
- Physical health
- Formal service use
- Availability of informal assistance
- Quality of relationships
- Uplifts of caring

Outcomes
- Psychosocial
- Physiological
- Health behaviours
- General health

Figure 1.5 Heuristic conceptual framework (Sorensen & Conwell, 2011)
1.5 Sense of competence

The concept of sense of competence was first outlined in the literature by Vernooij-Dassen (1993) and was defined as the family carer’s own perception that they are capable of managing the caring task. The conceptualisation of sense of competence was rooted in the theoretical approaches of Bengtson and Kuyper’s (1985) family-crisis model, which details the impact of dementia on the family network, including the family carer. As dementia progresses, the family-crisis model states that the family must adapt in order to overcome challenges, as otherwise these dementia or ageing related changes may lead to a crisis (Bengtson and Kuypers, 1985).

The family-crisis model incorporates systems theory and the symbolic interactionistic perspective, which emphasise the importance of the meaning that carers ascribe to a situation and their ability to cope with challenges. Based on this theory and research already conducted with family carers of people living with dementia plus an existing outcome measure, the Zarit Burden Interview (ZBI; Zarit, Reever, & Bach-Peterson, 1980), the authors devised the sense of competence questionnaire (SCQ). The SCQ is similar to the ZBI, but has additional subscales and items, based on the idea that a carers sense of competence enables them to cope and reduce the burden of caring.

A conceptual model of sense of competence was developed according to existing literature and tested by Vernooij-Dassen, Persoon and Felling (1996) using a path analysis approach. The model included variables most
commonly associated with competence in the existing literature, such as
characteristics of the person with dementia, the person with dementia’s
social network and characteristics of the carer. The authors also included
ADLs of the person with dementia and carer neuroticism in the model. This
conceptual model of sense of competence is illustrated in Figure 1.6.

Vernooij-Dassen et al. (1996) found empirical support for their model in the
path analysis. Severity of dementia indirectly predicted sense of
competence, with this relationship moderated by the person with dementia’s
ADL impairment and BPSD. Furthermore, carer neuroticism, which can lead
to a negative appraisal of the caring experience, negatively predicted sense
of competence. Neuroticism was also strongly and indirectly associated with
sense of competence through the carers’ reports of mood changes and
behaviour in the person with dementia. Therefore, if the carer reported high
neuroticism, they were more likely to report poor behaviour and mood for the
person with dementia and, as a result, had a lower sense of competence.
From this finding Vernooij-Dassen et al. (1996) suggested that specific
personality traits influence the carer’s perception of their ability to care for
their relative/friend with dementia, thus demonstrating that the innate way in
which people see life and interpret events can impact sense of competence.
This reflects the theory behind previous stress-coping models such as that of
Sorensen and Conwell’s (2011) heuristic conceptual framework, which
suggest that a person’s appraisal of the caring situation can lead to positive
or negative outcomes and is mediated by the family carers perceived level of
Carer Sense of Competence

competence. However, the study by Vernooij-Dassen et al. (1996) was cross-sectional and therefore could not demonstrate causality or direction of influence, or explore how sense of competence may change over time. Additionally, despite the empirical support for the model, the impact of positive appraisal of the caring situation and positive personality traits on sense of competence were not explored. The existing model of sense of competence therefore does not adequately reflect the caring experience as there is an over-emphasis of the negative aspects of caring.

Since the original model of sense of competence, other studies have found that carer sense of competence can mediate outcomes such as depression and burden (Lau & Cheng, 2015; Kurz, Scuvee-Moreau, Vernooij-Dassen & Dresser, 2003) and delay institutionalisation of the person living with dementia (Borsje et al., 2016). However, little work has been done since the original conceptual model was developed to explore the role of positive psychology factors in the variability of sense of competence. This illustrates the need for further research in order to inform the development of an updated model.
Figure 1.6 Theoretical model of predictors of sense of competence (Vernooij-Dassen et al., 1996)
1.6 Positive psychology

The emerging field of positive psychology offers new perspectives, conceptual models and empirical findings, which can be applied to further understand sense of competence in family carers of people living with dementia. The positive psychology approach aims to achieve a greater understanding of wellbeing, even in the face of difficult circumstances (Keyes and Lopez, 2005; Clarke & Wolverson, 2016) and is a branch of psychology concerned with the study of strengths, virtues and positive emotions that enable people to thrive (Seligman, Steen, Park & Peterson 2005). A key figure in the rapid growth of positive psychology as a field of research was Martin Seligman. Seligman’s aim was to “catalyse a change in the focus of psychology from preoccupation only with repairing the worst things in life but also building positive qualities” (Seligman & Csikszentmihalyi, 2000, p. 5), thereby building on what is already known about stress and mental health disorders. There are a number of general models of positive psychology and, when applied to dementia caring, these are not intended to replace stress-coping models, but to provide a positive discourse that can work in tandem with stress-coping models, offering a more balanced view.

A number of positive psychology models have been proposed to describe the role of positive factors in wellbeing. Most of the research in this field has focused on the general population, but there has been recent interest in mental health (Macaskill, 2016) and in positive psychology outcomes for people with dementia (Clarke & Wolverson, 2016). Key models are
discussed below and their potential application to understanding carer sense of competence is considered.

### 1.6.1 Values in Action framework

The Values in Action (VIA) framework was proposed by Peterson & Seligman (2004) in order to facilitate the study and measurement of personality strengths across the lifespan. The aim of the VIA framework is to focus as much on strength as on illness in the psychological literature. The VIA framework details 24 character strengths, which are further categorised into six sets of virtues, proposed to span across cultures (Park, Peterson & Seligman, 2005). The six sets of virtues are: (i) wisdom, (ii) courage, (iii) humanity, (iv) justice (v) temperance and (vi) transcendence. These virtues are outlined in Figure 1.7. Evidence suggests that such character strengths can emerge from stressful circumstances (Schueller, Jayawickreme, Blackie, Forgeard, & Roepke, 2015), which can include caring. The VIA framework has been applied to research for carers of people living with dementia, where it was theorised that positive personality traits or virtues may counteract or balance the negative aspects of caring such as burden or stress (Gottlieb & Rooney, 2004). Recent literature suggests that sense of competence is associated with positive virtues, such as gratitude and the ability to find meaning in the caring experience (Lau & Cheng, 2015; Quinn et al., 2012a; Quinn et al., 2012b). An in-depth investigation of how these character strengths impact sense of competence would further assist in understanding how positive characteristics could be incorporated into the conceptual model of sense of competence, given its current weighting.
towards the negative aspects on caring. Additionally, character strengths may directly or indirectly impact on carer outcomes. Although this framework is useful in demonstrating the virtues or strengths that could be measured in psychosocial interventions, this approach cannot exclusively represent the caring role, as it may lead to undue pressure and expectations for carers who are not able to demonstrate these character strengths in caring.

Figure 1.7 VIA framework character strengths (Peterson & Seligman, 2004).

Figure downloaded from positive education library, Department of Applied Social Sciences, City University of Hong Kong, (2015)
1.6.2 Positive emotion, Engagement, Relationships, Meaning and Accomplishments model (Seligman, 2011)

The Positive emotion, Engagement, Relationships, Meaning and Accomplishments (PERMA) model was proposed by Seligman (2011) to consider wellbeing as a multi-dimensional construct. In this model there are five measurable dimensions of wellbeing: (i) positive emotion, such as feelings of happiness or joyfulness, (ii) engagement with activity, such as feeling absorbed in life (iii) positive relationships, such as the feeling of having social connections (iv) meaning, such as the belief one's life has a purpose and (v) accomplishment, such as the feeling of progress towards certain goals. These five constructs are defined as positive outcomes and together define a state of wellbeing. From this positive psychology perspective, wellbeing is shown to be more complex than the simple absence of negative affect and, therefore, a multi-dimensional model is needed to understand the nature of wellbeing. This model has been criticised however, as it does not encompass every factor that could theoretically impact on wellbeing, and therefore it is not necessarily a comprehensive model. Despite this, the PERMA model gives a greater understanding of wellbeing and its components. Theoretically, sense of competence would fall into the accomplishment domain, as it is promoted by a feeling that one has the capabilities to accomplish a task and therefore, sense of competence could potentially act as a pathway to promote wellbeing in family carers of people living with dementia.
1.6.3 Second wave positive psychology

Second wave positive psychology (SWPP) is a more recent approach and has been considered relevant to caring (Wong, 2011; Aspinwall & Tedeschi, 2010). SWPP derived from criticism of a ‘pure’ positive psychology approach, which did not sufficiently recognise the complexity of human emotions, such as the interplay between positive and negative feelings, particularly when people are exposed to stressful circumstances (Ivtzan, Lomas, Hefferon, & Worth, 2015; Lomas & Ivtzan, 2016; Wong 2011). SWPP approaches recognise the balance of positive and negative affect previously detailed by Lawton et al. (1991), who termed the co-existence of positive and negative aspects of caring as the “mixed valence” of caring (p. 182). This term will be used throughout this thesis to describe the balance of positive and negative experiences in care. The phenomenon of mixed valence describes how individuals can thrive even in the context of adversity. Within this approach, positive and negative states are not opposite ends of one spectrum and may interact to influence carer outcomes. Empirical research has supported the existence of this phenomenon, for example, Raschick and Ingersoll-Dayton (2004) found that carers for older adults reported both rewards and costs as a result of their caring role.

The SWPP approach is consistent with previous research into affect balance, which seeks to ascertain whether positive and negative affect are separate ends of one spectrum, if they interact, or if they are independent of each other. This has been debated in various conceptual models and empirical studies (Russell & Carroll, 1999; Tellegen, Watson & Clark, 1999;
Watson & Tellegen, 1985). The prevailing model has been that of Fredrickson (2001), who proposed that positive and negative affect can occur simultaneously, and that positive affect can buffer negative affect to produce positive outcomes overall. Empirical research incorporating SWPP theory may aid the understanding of key carer constructs such as sense of competence and the role of positive psychology factors in wellbeing. There is no current model that explains the complexity and mixed valence of the carer experience. This thesis seeks to investigate whether both positive and negative constructs relate to sense of competence in order to gain a balanced understanding of this domain.

1.7 Positive psychology and caring

The rise in positive psychology led to the development of models of the carer experience which are aligned to the positive aspects of caring. Carbonneau et al. (2010) conducted a mixed-methods systematic review, which included all papers reporting positive psychology factors in caring. From the results of this review, Carbonneau et al. (2010) proposed a conceptual model of the positive aspects of caring that had three domains: (i) determining factors (carers self-efficacy and enrichment in daily life), (ii) domains of positive aspects of caring (such as sense of competence in caring, meaning of the carer’s role and quality of relationship) and (iii) positive outcome, which was defined as carer wellbeing. This review indicated that positive psychology factors such as sense of competence can lead to positive outcomes and increase the longevity of caring. The work by Carbonneau et al. (2010) is a step-forward to considering the positive aspects of caring, however, the
model was not specific to carers of people living with dementia and has not been empirically tested. Therefore, this model requires empirical investigation in a population of family carers of people living with dementia in order to ascertain its relevance for this population.

Lloyd, Patterson & Muers (2016) conducted a critical review of the qualitative literature to investigate positive psychology factors identified by carers of people living with dementia. This review was the first to systematically examine the status of positive psychology research in this population. Positive aspects of caring were identified in 14 qualitative studies and included role satisfaction, emotional rewards, personal growth, sense of competence, spiritual growth, relationship gains, sense of duty, and reciprocity. Many of the identified positive aspects of caring were derived from strategies employed by carers to deal with a challenging situation in a positive way, reflecting the previously described VIA framework of positive character strengths and virtues (Peterson & Seligman, 2004). Hence, a positive psychology perspective allows a diversification of focus to not only include negative aspects of caring but also positive states and experiences in care, which has further benefits for health and wellbeing. The current model of sense of competence can be considered imbalanced as it fails to consider the positive psychology factors. Therefore, investigating sense of competence from a positive psychology standpoint may further the understanding of this concept, the interplay between positive and negative aspects of caring and how this influences how competent carers feel.
1.8 Measuring positive psychology outcomes and sense of competence

Given the previous focus on the negative aspects of caring, there has been a scarcity of relevant positive psychology outcome measures developed for family carers of people living with dementia. More recently, measures of psychological concepts developed for the general population such as sense of coherence and self-efficacy have been applied in carer research to explore how family carers can have positive experiences despite the stress of caring. However, reflecting previous literature, these scales are frequently negatively worded with an overarching focus on deficits rather than the strengths or assets of the carer.

A consensus of outcome measures for people with dementia and their family carers was conducted in 2008 (Moniz-Cook et al., 2008), and aimed to provide guidance on key outcome measures for examining the effectiveness of psychosocial interventions with people with dementia and their family carers. This process included various workshops and consultations with experts from eight European countries. Aside from generic measures of wellbeing or quality of life, the only positive measure (i.e. not measuring a negative concept such as depression or anxiety) to be recommended for use in pan-European interventional research in family carers of people living with dementia was the previously described SCQ (Vernooij-Dassen et al., 1996). In an updated consensus of outcome measures in 2015, the SCQ and its shortened version, the short sense of competence questionnaire (SSCQ), were recommended, as they demonstrated sensitivity to change. However,
they were included under the conceptual domain of burden (JPND Research, 2015). A systematic review of outcome measures used in health economics research reported that the SCQ is commonly used as an outcome measure in research studies evaluating the effectiveness of interventions (Jones, Edwards & Hounsome, 2012). The authors included the SCQ within the concept of mastery, and this measure appeared in 12 studies between 2000 and 2012. However, despite the popularity of the SCQ and recommendations for its use in research and practice, there are issues with its operationalisation. Although sense of competence in theory is a positive psychology construct, it contains several negatively worded items in its measurement (e.g. ‘I feel that my…. doesn’t benefit from what I do for him / her’). Therefore, the extent to which sense of competence can be fully considered a positive psychology construct merits exploration, considering that it was first conceptualised and operationalised before the positive psychology field fully developed. The negative items included within the measure may reflect the discourse surrounding dementia at the time of its development. As such, the SCQ and the conceptualisation of sense of competence as a domain requires further development and exploration from a positive psychology perspective.

1.9 The conceptualisation of sense of competence

As with the operationalisation of the scale, there are existing issues with the conceptualisation of sense of competence, which is a term often used interchangeably with other constructs in the literature, in particular, burden and self-efficacy. With the concepts of sense of competence and burden,
this is perhaps due to the similarities in the measures; the SCQ (Vernooij-Dassen, 1993) followed on from, and has several items in common with, the Zarit Burden Interview (Zarit & Zarit 1983), which measures carer burden. When Vernooij-Dassen (1993) first conceptualised sense of competence, it was explicitly made a positive construct in order to positively reflect the carer’s feelings of capability rather than to reflect burden. The authors noted that sense of competence and burden were “opposite sides of the same coin” (Vernooij-Dassen et al., 1996, p. 41). Competence reflects the carer’s positive appraisal of their ability to deal with the burden of caring, and whilst conceptually, sense of competence and burden may initially seem synonymous (Meiland et al., 2001), it has been noted in previous research that they are clearly distinct concepts (Riedijk, Duivenvoorden, Van Swieten, Niermeijer & Tibben 2009). Carers may feel burdened for a variety of reasons, but sense of competence refers to the carer’s own perceived ability and resources to deal with this burden, or with the task of caring. It is important to ensure that these two concepts, both widely researched in family carer literature, are explicitly defined.

Consideration must also be given to the overlap between the concepts of self-efficacy and sense of competence. Sense of competence is considered a global domain, relating not only to the carer’s ability to perform each task but also to how important each task is perceived to be, and how well received the care is by the person with dementia. Self-efficacy, however, is regarded as domain-specific, referring to “beliefs in one’s capabilities to organise and execute the course of action required to produce given
attainments” (Bandura, 1997, p. 3), and therefore may vary from task to task. Further work to understand and conceptualise sense of competence considering the emerging field of positive psychology is clearly required and warrants further discussion and critical investigation.

1.10 Summary

There is no existing empirical research that has comprehensively investigated whether positive psychology factors influence a carer’s perception of how competent they are. It is clear that there is an urgent need for a theoretical model of sense of competence that applies positive psychology theory to existing literature. In order to understand sense of competence, it is necessary to consider the constructs, both positive and negative, that are associated with and impact this domain. Additionally, the conceptualisation and definition of sense of competence must be further examined. Clinically, learning more about how to improve a carer’s sense of competence can assist with the development of support services and improve the design of appropriate interventions that target this domain. This in turn, may result in family carers feeling able to care for their loved one at home for longer, delaying institutionalisation and leading to better outcomes overall.
Chapter 2  Positive psychology outcome measures for family carers of people living with dementia: A systematic review

This systematic review has been published in International Psychogeriatrics (Stansfeld, J., Stoner, C., Wenborn, J., Vernooij-Dassen, M., Moniz-Cook, E., & Orrell, M, 2017).

2.1 Introduction

Positive and negative states can coexist in caring (Dickinson et al., 2016; Lawton et al., 1991; Tremont, 2011) but as discussed in Chapter 1, whilst carers report positive aspects of caring, the role of these positive psychology factors in wellbeing has been largely overlooked (Roff et al., 2004; Tarlow et al 2004), and has only received attention more recently (Carbonneau et al., 2010; Orgeta & Leung, 2015). These positive factors may serve as a protective factor for the stress of caring (Koerner et al., 2009).

Studies exploring how families can have positive experiences caring for someone with dementia have most commonly noted the importance of self-efficacy, resilience, and sense of coherence. Aside from these popular constructs, there has historically been a scarcity of relevant positive psychology outcome measures used in interventional research with this population (Tarlow et al., 2004; Wilks, Little, Gough & Spurlock, 2011; Crellin, Orrell, McDermott & Charlesworth, 2014). Recently, existing measures of positive psychology validated for use with the general population have been applied to carer research. Validating an outcome measure involves an assessment of the psychometric properties of a
measure, usually when applied to a population different to that which it was
developed for, or in a different language. However, researchers sometimes
pay little attention to the psychometric implications of unilaterally adopting
measures developed for other populations. Furthermore, there is currently
no consensus as to which measures may be most appropriate to use for this
population.

2.2 Aim

To identify positive psychology measures with robust psychometric
properties for family carers of people living with dementia and to establish
the potential utility of identified outcome measures in research and practice.

2.3 Method

2.3.1 Design

A systematic search was conducted to identify positive psychology outcome
measures developed for or validated with family carers of people living with
dementia in the community. Systematic principles outlined by the Preferred
Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)
group were followed for searching and screening results (Moher, Liberati,
Tetzlaff, Altman & Prisma Group, 2009). A psychometric appraisal of the
identified measures was conducted using published quality criteria for
assessing the measurement characteristics of outcome measures (Terwee
et al., 2007).
2.3.2 Search Strategy

The following electronic databases were searched: PsychINFO, CINHAL, MEDLINE, EMBASE and PubMed. In addition to this, hand searching of references and prior citations were performed. Positive psychology search terms were derived from scoping existing literature using Seligman’s definition of positive psychology: the values, virtues, positive character strengths and emotions that enable people to flourish (Seligman et al., 2005) and the VIA framework as a guide (Peterson & Seligman, 2004). As discussed in Chapter 1, the VIA framework proposes character strengths that are grouped under six sets of ‘virtues’: transcendence, temperance, justice, humanity, courage and wisdom. An additional scope for other potential search terms was performed by comparing identified terms from the literature with a related review of positive psychology measures for chronic illness, traumatic brain injury and older adults (Stoner, Orrell & Spector, 2015).

Search terms were: “measure” AND “positive psychology” AND “family carer” AND “dementia”. The variants on terms used were as follows:

*Measure*: ‘measure’ OR ‘outcome’ OR ‘instrument’ OR ‘questionnaire’ OR ‘quiz’ OR ‘test’ OR ‘psychometric’ OR ‘analysis’ OR ‘validation’ OR ‘reliability’ OR ‘validity’ OR ‘scale’.

*Positive psychology*: ‘self-efficacy’ OR ‘hope’ OR ‘gain’ OR ‘resilience’, OR ‘wisdom’ OR ‘growth’ OR ‘sense of coherence’ OR ‘belief in a just world’ OR ‘control’ OR ‘autonomy’, OR ‘pleasure’ OR ‘self-realisation’ OR ‘positivity’ OR ‘optimism’ OR ‘agency’ OR ‘gratitude’ OR ‘satisfaction’ OR ‘outlook’ OR
‘uplift’ OR ‘meaning’ OR ‘happiness’ OR ‘transcendence’ OR ‘self-concept’ OR ‘humour’ OR ‘creativity’ OR ‘spirituality’ OR ‘love’ OR ‘compassion’ OR ‘mindfulness’ OR ‘affability’.

Family carer: ‘family carer’ OR ‘caregiver’ OR ‘care’ OR ‘relative’ OR ‘friend’ OR ‘spouse’

Dementia: ‘cognitive impairment’ OR ‘Alzheimer’ OR ‘senile’ OR ‘dementia’ OR ‘demented’.

Truncations of search terms were used where appropriate. All titles and abstracts were screened against the inclusion and exclusion criteria and specifically for the inclusion of a positive psychology measure developed for or validated with family carers of people living with dementia in the community. When an outcome measure was identified, a separate search for the relevant psychometric and / or development study was conducted. Sense of competence was not included as a search term in this systematic review due to doubt over whether the measure was truly aligned with positive psychology theory as there was negative wording in many of the items. As sense of competence measures were returned in the search, these measures were included in the results of this review as many of the positive psychology measures also had negative items.

2.3.3 Inclusion Criteria

- Publication language: Studies published in English only, unless a translation was available.
• Publication year: Studies published between 1980 (to include the point from which positive psychology ideas, such as ‘flow’ emerged in the literature) and October 2015 (date of the search).

• Outcome measures developed for or validated with a population of family carers of people living with dementia in the community (i.e. not those living in a care home).

• Outcome measures with psychometric properties published in a peer-reviewed journal.

• Outcome measures related to a positive psychology construct or positive psychology traits.

2.3.4 Exclusion Criteria

• Outcome measures only measuring external or situational contributors to wellbeing such as social support and external locus of control. These were excluded in order to restrict the breadth of the review to internal sources of wellbeing such as positive traits, strengths and virtues as detailed in the VIA framework (Peterson & Seligman, 2004).

2.3.5 Data Extraction

Titles and abstracts of the papers were exported to Mendeley Referencing Software (version 1.17.6), where the titles were screened against the inclusion and exclusion criteria. Abstracts were then screened and for those identified as relevant or in ambiguous cases, the full text was screened. The final eligibility decision was made by two reviewers (JS and Dr. Charlotte
Stoner (CS)) reading the full text and meeting to discuss. In three cases, a final agreement was reached with the involvement of a nominated supervisor (Professor Martin Orrell (MO)). After the full text had been exported, data relating to the sample, design, development, evaluation and feasibility of each outcome measure were extracted onto pre-prepared data extraction forms by the two reviewers. The process of this systematic review is outlined in Figure 2.1.

Figure 2.1 PRISMA diagram of systematic review process
2.3.6 Assessment of psychometric properties

Positive outcome measures were grouped by construct (with other measures that have a similar underlying theory). A quality assessment was conducted using guidance formulated by Terwee et al. (2007), which has been employed in reviews of a similar nature (Windle, Bennett & Noyes, 2011; Stoner et al., 2015). Two authors (JS and CS) undertook the quality assessment independently and a consensus meeting was held to discuss any disagreements in the scoring. The appraisal of the scale development papers was conducted to identify scales that had been rigorously developed and well reported and would be suitable for inclusion in interventional or cross-sectional research. The quality assessment tool scores the development of outcome measures based on the reporting of reliability and validity in the development paper a) content validity, b) internal consistency, c) construct validity d) reproducibility (agreement and reliability), e) responsiveness, f) floor and ceiling effects and g) interpretability, as outlined in Table 2.1. A score of two for each criterion was awarded for a study that was well designed and reported. A score of one was given if there were methodological flaws in the study design, methods, or if this information was not well reported. A score of zero was assigned if there was no information found for the given criteria. The individual scores were then summed to assess the overall quality of the development of the scale, with a possible score range of 0 - 18, with 18 being the best available score. For the purposes of this review, total scores were labelled increase interpretability. Scores 0 - 4 were assigned a label of ‘poor’, 5 - 9 were assigned a label of ‘moderate’, scores 10 - 14 were ‘good’, and scores 15 - 18 were ‘very good’. 
Table 2.1 Quality assessment criteria (adapted from Terwee et al., 2007)

<table>
<thead>
<tr>
<th>Property</th>
<th>Definition</th>
<th>Quality criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Content validity</td>
<td>The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire (the extent to which the measure represents all facets of the construct under question).</td>
<td>2 A clear description of measurement aim, target population, concept(s) that are being measured, and the item selection AND target population (investigators OR experts) were involved in item selection</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 A clear description of the above-mentioned aspects is lacking OR only target population involved OR doubtful design or method</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 No target population involvement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 No information found on target population involvement</td>
</tr>
<tr>
<td>Internal consistency</td>
<td>The extent to which items in a (sub)scale are intercorrelated, thus measuring the same construct.</td>
<td>2 Factor analyses performed on adequate sample size (7 times the number of items and &gt; = 100) AND Cronbach’s alpha(s) calculated per dimension AND Cronbach’s alpha(s) between 0.70 and 0.95</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 No factor analysis OR doubtful design or method</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 Cronbach’s alpha(s) &lt;0.70 or &gt;0.95, despite adequate design and method</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 No information found on internal consistency</td>
</tr>
<tr>
<td>Criterion validity</td>
<td>The extent to which scores on a particular questionnaire relate to a gold standard</td>
<td>2 Convincing arguments that gold standard is “gold” AND correlation with gold standard &gt; = .70</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 No convincing arguments that gold standard is “gold” OR doubtful design or method</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 Correlation with gold standard &lt; .70, despite adequate design and method</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 No information found on criterion validity</td>
</tr>
<tr>
<td>Construct validity (includes convergent validity)</td>
<td>The extent to which scores on a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured</td>
<td>2 Specific hypotheses were formulated AND at least 75% of the results are in accordance with these hypotheses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 Doubtful design or method (e.g.) no hypotheses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 Less than 75% of hypotheses were confirmed, despite adequate design and methods</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 No information found on construct validity</td>
</tr>
<tr>
<td>Property</td>
<td>Definition</td>
<td>Quality criteria</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Reproducibility -</td>
<td>The extent to which the scores on repeated measures are close to each other (absolute measurement error)</td>
<td>2 SDC &lt; MIC OR MIC outside the LOA OR convincing arguments that agreement is acceptable</td>
</tr>
<tr>
<td>Agreement</td>
<td></td>
<td>1 Doubtful design or method OR (MIC not defined AND no convincing arguments that agreement is acceptable)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 MIC ≤ SDC OR MIC equals or inside LOA despite adequate design and method</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 No information found on agreement</td>
</tr>
<tr>
<td>Reproducibility -</td>
<td>The extent to which patients can be distinguished from each other, despite measurement errors (relative measurement error)</td>
<td>2 ICC or weighted Kappa &gt; = .70</td>
</tr>
<tr>
<td>Reliability</td>
<td></td>
<td>1 Doubtful design or method</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 ICC or weighted Kappa &lt; .70, despite adequate design and method</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 No information found on reliability</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>The ability of a questionnaire to detect clinically important changes over time</td>
<td>2 SDC or SDC &lt; MIC OR MIC outside the LOA OR RR &gt; 1.96 OR AUC &gt; = 0.70</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 Doubtful design or method</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 SDC or SDC &gt; = MIC OR MIC equals or inside LOA OR RR &lt; = 1.96 or AUC &lt; .70, despite adequate design and methods</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 No information found on responsiveness</td>
</tr>
<tr>
<td>Floor and ceiling</td>
<td>The number of respondents who achieved the lowest or highest possible score</td>
<td>2 &lt; 15% of the respondents achieved the highest or lowest possible scores</td>
</tr>
<tr>
<td>effects</td>
<td></td>
<td>1 Doubtful design or method</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 &gt; 15% of the respondents achieved the highest or lowest possible scores, despite adequate design and methods</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 No information found on interpretation</td>
</tr>
<tr>
<td>Interpretability</td>
<td>The degree to which one can assign qualitative meaning to quantitative scores</td>
<td>2 Mean and SD scores presented of at least four relevant subgroups of patients and MIC defined</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 Doubtful design or method OR less than four subgroups OR no MIC defined</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 No information found on interpretation</td>
</tr>
</tbody>
</table>

SDC = smallest detectable difference (this is the smallest within-person change, above measurement error. A positive rating is given when the SDC or the limits of agreement are smaller than the MIC). MIC = minimal important change (this is the smallest difference in score in the domain of interest which patients perceive as beneficial and would agree to, in the absence of side effects and excessive costs). LOA = limits of agreement. AUC = area under the curve. RR = responsiveness ratio.
2.4 Results

The initial search identified 6677 papers, of which 48 potential scale development or validation papers were identified through screening abstracts. After screening the full text of these 48 papers, 18 papers met the inclusion criteria. These comprised 12 scale development and six validation papers. In this review, a scale development paper was defined as one that described the process of developing a measure, whereas a validation paper was defined as one that tested and described the psychometric properties of an existing measure in a specific population. The main reasons for exclusion of papers were that the scales did not measure a positive psychology construct \((n = 9)\), or the study population were not family carers of people with dementia living in the community \((n = 13)\).

For the quality appraisal, the outcome measures were then grouped by construct to facilitate comparison across the measures identified and appraised. Generally, measures scored moderately on the quality appraisal. However, criterion validity and responsiveness were quite poorly reported across papers. The Gain in Alzheimer Care Instrument (GAIN; Yap et al., 2010), was awarded the highest score \((10 \div 18)\), indicating that it has good psychometric properties. Scores for each individual aspect relating to psychometric properties are presented in Table 2.2.
Table 2.2 Quality criteria scores for the identified outcome measures

<table>
<thead>
<tr>
<th>Scale</th>
<th>Content validity</th>
<th>Internal Consistency</th>
<th>Criterion validity</th>
<th>Construct validity</th>
<th>Reproducibility Agreement</th>
<th>Reliability</th>
<th>Responsiveness</th>
<th>Floor/ceiling effects</th>
<th>Interpretability</th>
<th>Total score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Revised Scale for Caregiving Self-Efficacy (Steffen, McKibbin, Zeiss, Gallagher-Thompson &amp; Bandura, 2002)</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Self-Efficacy Questionnaire for Chinese Family Caregivers (Zhang, Edwards, Yates, Ruth &amp; Guo, 2012)</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Family Carer Self-Efficacy for Managing Dementia (Fortinsky, Kercher &amp; Burant, 2002)</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Sense of Competence Questionnaire (Vernooij-Dassen, 1993)</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Short Sense of Competence Questionnaire (Vernooij-Dassen et al. 1999)</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Intrinsic Spirituality Scale (Hodge, 2003)</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Scale</td>
<td>Content validity</td>
<td>Internal Consistency</td>
<td>Criterion validity</td>
<td>Construct validity</td>
<td>Reproducibility Agreement</td>
<td>Reproducibility Reliability</td>
<td>Responsiveness</td>
<td>Floor/ceiling effects</td>
<td>Interpretability</td>
<td>Total score</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>------------------</td>
<td>----------------------</td>
<td>--------------------</td>
<td>--------------------</td>
<td>----------------------------</td>
<td>----------------------------</td>
<td>----------------</td>
<td>------------------------</td>
<td>-----------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Spiritual Support Scale (Ai, Tice, Peterson, &amp; Huang, 2005)</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Perceived Caregiver Rewards (Picot, Youngblut &amp; Zeller, 1997)</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Positive Aspects of Caregiving Scale (Tarlow et al., 2004)</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>GAIN (Yap et al., 2010)</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Finding Meaning Through Caregiving Scale (Farran, Miller, Kaufman, Donner &amp; Fogg, 1999)</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Shortened Resilience Scale (Wilks, 2008)</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
</tbody>
</table>
The constructs identified and numbers of measures included for each construct were: self-efficacy and sense of competence ($n = 5$), spirituality ($n = 2$), rewards ($n = 3$), meaning ($n = 1$) and resilience ($n = 1$). A brief description of the outcome measures and reliability and validity statistics, where reported in the development papers are summarised in Table 2.3.

### 2.4.1 Self-Efficacy and Sense of Competence

Five outcome measures were identified for the construct of self-efficacy and sense of competence: The Revised Scale for Caregiving Self-Efficacy (RSSE; Steffen et al., 2002), the Self-Efficacy Questionnaire for Chinese Family Caregivers (Zhang et al., 2012), Family Caregivers’ Self-Efficacy for Managing Dementia scale (SEMD; Fortinsky et al., 2002), the SCQ (Vernooij-Dassen, 1993; Vernooij-Dassen et al., 1996), and its short version, the SSCQ (Vernooij-Dassen et al., 1999).

The RSSE (Steffen et al., 2002) scored moderately in the quality assessment (8 / 18). However, the development paper for this scale lacked information on responsiveness, floor and ceiling effects, and interpretability. Adequate internal consistency was found for the subscales, ranging from $\alpha = .70$ to $\alpha = .76$. Self-efficacy on the RSSE was found to have strong negative correlations with depression, measured with the Beck Depression Inventory (Beck, Steer & Brown, 1996; $r = .38$, $p < .01$) and with anger on the Spielberg’s Trait Anger Scale (Spielberger, Jacobs, Russell, & Crane 1983; $r = .45$, $p < .01$). Self-efficacy also had a strong positive correlation with perceived social support ($r = .47$, $p < .01$). This indicates that, in line with
expectations, higher self-efficacy was linked with lower depression and anger scores, and higher perceived social support scores, indicating good convergent validity.

The Chinese Self-Efficacy Scale (Zhang et al., 2012) scored poorly (3 / 18) on the quality assessment criteria, mainly due to lack of data on reproducibility, responsiveness and interpretability. No reliability and limited validity information was given. In a subsequent validation study (Zhang, Edwards, Yates, Ruth & Guo, 2013), internal consistency was high $\alpha = 0.94$ for the overall scale, which may indicate multicollinearity (overlapping of items). Nevertheless, there was adequate internal consistency for each subscale ($\alpha = 0.8$) and test-retest reliability was good ($\alpha = .74$).

The SEMD (Fortinsky et al., 2002) scored moderately on the quality assessment criteria (5 / 18), also due to lack of data in the development paper. This measure demonstrated good internal consistency at a subscale level ($\alpha = .77$ to .78). The symptom management self-efficacy subscale strongly and positively correlated with sense of competence ($r = .49$, $p < .05$). Higher symptom management self-efficacy scores were associated with fewer dementia symptoms ($\beta = -.017$, $p < 0.05$), indicating good convergent validity.

The SCQ (Vernooij-Dassen, 1993) scored moderately on the quality assessment criteria (6 / 18). The SCQ had good internal consistency overall ($\alpha = .79$) but the subscales did not have adequate Cronbach’s alpha scores,
ranging from $\alpha = .5$ to $\alpha = .63$. The authors retained the factor structure in order to explore domain specific patterns of sense of competence. Sense of competence was negatively correlated with apathy of the person with dementia ($r = -.31, p < 0.01$), indicating good convergent validity and duration of dementia was positively associated with satisfaction with one's own performance as a carer ($\beta = -.18, p < .05$).

The short version of this outcome measure, the SSCQ (Vernooij-Dassen et al., 1999) scored highest for the construct of self-efficacy and sense of competence (9 / 18). The SSCQ was developed from the 27-item SCQ and was intended for use in clinical practice. There was a high correlation between scores on the SCQ and SSCQ, and the SSCQ was found to have good internal consistency ($\alpha = .76$).

### 2.4.2 Spirituality

Two outcome measures were identified for the construct of spirituality: The Intrinsic Spirituality Scale (ISS; Hodge, 2003) and the Spiritual Support Scale (SSS; Ai et al., 2005).

The ISS (Hodge, 2003) was developed using a convenience sample of university students from a Baptist affiliated University. It scored poorly on the quality assessment criteria (3 / 18). The internal consistency score was found to be too high ($\alpha = .96$), indicating potential multicollinearity. Concurrent validity was good, as in line with the authors hypotheses, spirituality was negatively correlated with alcohol use, ($r = -.489, p < .001$)
and frequency of binge drinking \((r = -.464, p < .001)\). Spirituality was also positively correlated with secure attachment \((r = .223, p = .003)\), indicating good convergent validity. A subsequent validation study with carers of people with dementia (Gough, Wilks & Prattini, 2010) found a high Cronbach’s alpha \((\alpha = .92)\) and positive correlations with frequency of prayer \((r = .50, p < .05)\) and resilience \((r = .44, p < .05)\).

The SSS (Ai et al., 2005) was developed in America with 453 students, three months after the September 2001 terrorist attacks and scored poorly \((4 / 18)\) on the quality assessment criteria. Cronbach’s alpha was too high \((\alpha = .97)\), which was also found in a subsequent psychometric evaluation of the SSS in a sample of Alzheimer’s carers (Wilks, Ketchum, Chen & Bowman, 2013). Spiritual support positively correlated with resilience, measured by the Resilience Scale- 14 (RS-14, Wagnild, 2009) \((r = .25, p < .01)\), indicating good convergent validity.

### 2.4.3 Rewards

GAIN (Yap et al., 2010), Positive Aspects of Caregiving Scale (PAC; Tarlow et al., 2004) and Perceived Carer Rewards Scale (Picot et al., 1997) were identified for the construct of rewards.

GAIN was developed for use with carers of people with dementia. It scored the highest on the quality assessment criteria of all the scales identified in this review \((10 / 18)\). The measure demonstrated good internal consistency \((\alpha = .89)\) and test-retest reliability \((\alpha = .79)\). In terms of validity, the authors
hypothesised that scores on this measure would negatively correlate with burden, as measured on the Zarit Burden Interview, which was reported in the development paper \( (r = -.15, \ p = .02) \). Scores on the GAIN measure strongly and positively correlated with scores on the PAC scale \( (r = .68, \ p < .001) \), which was also developed for carers of people with dementia.

The PAC (Tarlow et al., 2004) scored moderately on the quality assessment criteria \((8 / 18)\), demonstrating good internal consistency \( (\alpha = .89) \) and adequate validity. It was positively correlated with wellbeing \( (r = .24, \ p < .05) \), and negatively associated with burden \( (r = .23, \ p < .05) \), although the correlations were only small. A validation of this study for the Chinese version of the measure (Zhang et al., 2013) produced similar results in terms of reliability \( (e.g. \ \alpha = .89) \) and validity.

The Perceived Carer Rewards Scale (Picot et al., 1997) was developed with female carers of people with dementia. It scored moderately \((5 / 18)\) in the quality assessment criteria. It had good internal consistency \( (\alpha = .83) \) and convergent validity, as perceived rewards was negatively correlated with carer burden \( (r = -.35, \ p < .001) \), depression \( (r = -.30, \ p < .001) \) and carer demands \( (r = -.22, \ p = .04) \), as expected. The authors (Picot et al., 1997) recommended further psychometric testing of this measure in a longitudinal study in order to explore whether perceived rewards change over time.
2.4.4 Meaning

The Finding Meaning Through Caregiving Scale (FMTCS; Farran et al., 1999) was the only outcome measure to be identified for the construct of meaning. This measure had a moderate score (7 / 18) on the quality assessment criteria, mostly due to a lack of information on responsiveness, interpretability and floor and ceiling effects. Internal consistency was high ($\alpha = .91$) and test-retest reliability was good ($\alpha = .80$). The ‘provisional meaning’ subscale was positively correlated with marital satisfaction, carer satisfaction and personal gains ($r = .24$ to .64, $p = .01$). Convergent validity was supported by the finding of inverse relationships between the loss / powerless subscale and marital satisfaction, carer satisfaction and personal gains ($r = -.38$ to -.53, $p = .01$).

2.4.5 Resilience

Resilience is characterised as the ability of carers to adapt to the caring role and overcome challenges. The only measure identified for resilience that had been developed for or validated with the dementia carer population was the Shortened Resilience Scale (Wilks, 2008), which scored moderately (7 / 18) for scale development. It lacked evidence on reproducibility, responsiveness, and floor and ceiling effects. Internal consistency was too high ($\alpha = .96$) suggesting significant overlapping of items. Convergent validity was good, with resilience negatively correlating with stress ($r = -.6$, $p < .01$).
Table 2.3 Summary of included outcome measures

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Sample Population</th>
<th>Description</th>
<th>Reliability</th>
<th>Validity</th>
<th>Validation Studies</th>
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<tbody>
<tr>
<td>Revised Scale for Caregiving Self-Efficacy</td>
<td>145 female carers for someone with dementia (mean age = 77.3)</td>
<td>15 item measure, 3 domains. Likert scale from 0-100. Higher scores reflect greater self-efficacy</td>
<td>Internal consistency: $\alpha = .75 - .85$. Test-retest reliability was $\alpha = .70 - .76$ for the three subscales</td>
<td>Factor analysis: a three factor model fit, was found with a CFI of .93. Strong negative correlation with the Beck Depression Inventory ($r = .38$), Spielberger's Trait Anger Scale ($r = -.45$), and MAACL Anxiety Brief ($r = -.37$). Strong positive correlation with perceived social support ($r = .47$)</td>
<td>CFA in dementia carers, (Penacoba et al., 2008) found adequate fit matrices (CFI = .90). Reliability and validity study of a Spanish version. Good internal consistency ($\alpha = .79 - .86$) for the three subscales (Marquez-Gonzalez et al., 2009).</td>
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<tr>
<td>Self-Efficacy Questionnaire for Chinese Family Caregivers</td>
<td>10 family carers of people with dementia (age range 33 to 81)</td>
<td>35 item measure, 5 domains</td>
<td>No reliability information presented in development study</td>
<td>Good content validity</td>
<td>Reliability and validity tested (Zhang et al., 2013) and Cronbach’s $\alpha$ = 0.94 overall and $\alpha = 0.8$ for subscale. Test-retest reliability was good ($\alpha = .74$).</td>
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<tr>
<td>Family Carer Self-Efficacy for Managing Dementia</td>
<td>197 family carers of people with dementia (mean age= 56 years)</td>
<td>10 item measure, 2 domains</td>
<td>EFA found 9 items in distinct factors explained 52% overall variance. Internal consistency ranged from $\alpha = .77$ to $\alpha = .78$</td>
<td>Symptom management self-efficacy had a strong positive correlation with carer competence ($r = .49$). Higher symptom management self-efficacy scores were associated with fewer dementia symptoms ($\beta = -.017, p&lt;0.05$)</td>
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<tr>
<td>Instrument</td>
<td>Sample Population</td>
<td>Description</td>
<td>Reliability</td>
<td>Validity</td>
<td>Validation Studies</td>
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<tr>
<td>SCQ (Vernooij-Dassen, 1993)</td>
<td>141 carers of people living with dementia (mean age = 63)</td>
<td>27 item measure, 3 domains. Likert scale: disagree very strongly to agree very strongly.</td>
<td>Internal consistency: $\alpha = .79$.</td>
<td>Positive correlation of duration of dementia ($\beta = 0.19, p &lt; .05$) with domain 'satisfaction with self as carer'.</td>
<td>Validation Studies</td>
</tr>
<tr>
<td>SSCQ (Vernooij-Dassen et al., 1999)</td>
<td>Same population as SCQ development paper (Vernooij-Dassen, 1993)</td>
<td>7 item measure. Likert scale: disagree very strongly to agree very strongly.</td>
<td>Internal consistency: $\alpha = .76$.</td>
<td>High correlation between SSCQ and SCQ ($r = .88, p &lt; .01$), however, it was tested in the same population.</td>
<td>Validation Studies</td>
</tr>
<tr>
<td>Intrinsic Spirituality Scale (Hodge, 2003)</td>
<td>Convenience sample of 172 university students from a Baptist church affiliated university (mean age = 19.26).</td>
<td>6 item measure with a Likert scale from 0-10.</td>
<td>Internal Consistency: $\alpha = .96$.</td>
<td>Spirituality was negatively correlated with alcohol use ($r = -.489, p &lt; .001$), frequency of binge drinking ($r = -.464, p &lt; .001$) and positively correlated with secure attachment ($r = .223, p = .003$)</td>
<td>Validation with carers of people with Alzheimer's (Gough et al., 2010). Internal consistency: $\alpha = .92$. Validity: Positive correlation with prayer frequency ($r = .50, p &lt; .05$) and resilience on the Connor-Davis resilience scale ($r = .44, p &lt; .05$)</td>
</tr>
<tr>
<td>SSS (Ai et al., 2005)</td>
<td>453 undergraduate and postgraduate students. (mean age = 12 item measure. Scores between 1-4, 1 = Strongly Disagree and 4 = Strongly Agree. High scores</td>
<td>Internal consistency: $\alpha = .97$. EFA showed a unidimensional solution, with a single factor</td>
<td>SSS was positively correlated with frequency of prayer ($r = .79, p &lt; .001$)</td>
<td>Validation of SSS in Alzheimer's carers (Wilks et al., 2013). Internal consistency: Cronbach's $\alpha = .97$ Validity: SSS negatively correlated with emotion focused coping ($r = -$)</td>
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<td></td>
<td>29 years)</td>
<td>reflect greater spiritual support. explaining 76% of the variance.</td>
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<td>.12, p &lt; .01) and positively correlated with resilience measured on RS-14 (r = .25, p &lt; .01).</td>
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<tr>
<td>Perceived Caregiver Rewards (Picot et al., 1997)</td>
<td>83 female carers of people with dementia (mean age = 58.9)</td>
<td>27 item measure. 0 = not at all, 1 = a little, 2 = somewhat, 3 = quite a lot, 4 = a great deal. Internal consistency: Cronbach’s α = .83. Positively associated with carer demands (r = 22, p = .04), and with palliative coping (r = .26, p = .02).</td>
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<tr>
<td>Positive Aspects of Caregiving Scale (Tarlow et al., 2004)</td>
<td>1229 family carers of a person with Alzheimer’s disease (mean age = 63)</td>
<td>9 item measure with 2 subscales, self-affirmation and outlook on life. 5 point Likert scale from 1-5, 1 = disagree a lot and 5 = agree a lot. Internal consistency: Cronbach’s α = .89 EFA found two components with variable loadings &gt; .45. Positively associated with wellbeing (r = .24 p &lt; .05), self-reported health (r = .01, p &lt; .05), and satisfaction with received social support (r = .15, p &lt; .05). Negatively correlated with burden (r = -.23, p &lt; .05). Validation in Chinese dementia carers. Good internal consistency (α = .89). Good convergent validity, associated with fewer disruption related problem behaviours and better caring confidence.</td>
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<tr>
<td>GAIN (Yap et al., 2010)</td>
<td>321 family carers of people with dementia (mean age = 50.1)</td>
<td>10 items. 5 Responses ranging from disagree a lot to agree a lot. Higher scores = greater gains. Internal consistency: Cronbach’s α = .89. Two week test-retest reliability: α = .79. Strongly associated with scores on the positive aspects of caregiving scale (r = .68, p &lt; .001), There was a weak but negative correlation with burden measured on the ZBI (r = -.01, p = .02).</td>
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<tr>
<td>Instrument</td>
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<tr>
<td>FMTCS (Farran et al., 1999)</td>
<td>46 dementia carers (mean age = 65.5 years)</td>
<td>43 item measure, 5-point Likert scale. 1 = strongly disagree to 5 = strongly agree. A higher score indices greater meaning.</td>
<td>Internal consistency: α = .91. Test-retest reliability α = .80 CFA found support for three subscales with a goodness of fit index of .76, $\chi^2 = 1444$, df = 832.</td>
<td>Provisional meaning subscale was positively correlated with carer satisfaction, and personal gains ($r = .24$ to $64$, $p = .01$)</td>
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<tr>
<td>Shortened Resilience Scale (Wilks, 2008)</td>
<td>Alzheimer's carers. Sample 1 ($n = 115$, mean age = 44.9), sample 2 ($n = 114$, mean age = 44.6).</td>
<td>15 item measure, Likert responses range on a 7 point scale from disagree to agree. Higher scores indicate a greater resilience.</td>
<td>Internal consistency: Cronbach’s α = .96. Factor analysis indicated a unidimensional solution, which explained 64% of the variance.</td>
<td>Resilience was negatively correlated with stress in the Perceived Stress Scale ($r = -.6$, $p &lt; .01$).</td>
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</table>
2.5 Discussion

This review is the first to systematically identify and evaluate positive psychology outcome measures for family carers of people with dementia, using clear and comprehensive criteria. Twelve outcome measures developed for, or validated with this population, were identified for the constructs of self-efficacy and sense of competence, resilience, rewards, meaning and spirituality. The majority of scales scored moderately on the quality criteria, notably with a lack of information on reproducibility, floor and ceiling effects and responsiveness. Despite this, the majority of outcome measures reported information for content validity, which could be considered the most important aspect of the development of a measure. Although quality scoring of outcome measures is helpful when choosing which measure to employ, authors may also wish to choose a measure based on its underlying theory and relevance to the study rather than total quality score and therefore these scores should be interpreted with caution.

Despite increasing recognition of the importance of positive psychology in measuring and understanding wellbeing (Keyes & Lopez, 2005), there are currently few high quality positive psychology scales for family carers of people with dementia, as evidenced in this review. This may be due to the prevalence of negative concepts underlying the development of current measures, which are often aligned to stress-coping models to explain and understand the negative impact of the caring experience (Tarlow et al., 2004; Lawton et al., 1991; Pearlin et al., 1990). There is a need for the
development of new measures that draw on models which are more closely aligned to the discipline of positive psychology (Clarke & Wolverson, 2016). This would provide the outcome measures through which researchers can develop a theoretical model applying positive psychology to dementia caring research in the context of other factors already incorporated in stress-coping models.

2.5.1 Methodological limitations

Seligman’s definition of positive psychology was chosen due to its inclusive and accessible nature; however, there are a number of alternative theories of positive psychology. These concepts may not have been captured in this review, such as Ryff’s (1989) scales of psychological wellbeing, which were considered too broad for the review. Therefore, there is the potential that some scales may have been missed, despite a thorough review process including hand searching of references and prior citations.

Although the scales included in this review relate to concepts that reflect positive psychology literature, an in-depth review of the items in each measure revealed that scales comprised mainly of negative wording. This was apparent in the self-efficacy scales in particular, for example, in the RSSE, “How confident are you that you can control thinking about unpleasant aspects of taking care of [person with dementia]?” This created ambiguity over whether these measures are truly aligned with positive psychology principles and if they really measure a positive construct. Although these scales were included due to the importance of self-efficacy
as a stress-adaptation mechanism, it is recommended that negative phrasing
should be used in combination with positive wording in order to give a
balanced perspective that reflects the co-existence of both positive and
negative emotions as indicators of wellbeing. This in turn would more
comprehensively represent the mixed valence and interplay of positive and
negative experiences in caring (Clarke & Wolverson, 2016).

The quality criteria to assess the development process of the identified
scales were used in a related review of positive psychology measures in
chronic illness, traumatic brain injury and older adults (Stoner et al., 2015). In
both reviews, and an additional previous review of resilience scales (Windle
et al., 2011), conclusions were limited due to the under reporting of many of
the criteria such as responsiveness and reproducibility. In order to conduct a
comprehensive assessment of the quality of a measure, development
authors are recommended to report this information in more detail.

There were positive psychology scales frequently in use with family carers of
people with dementia that did not meet the inclusion criteria here because
they were developed for the general population and had not been validated
for use with family carers of people with dementia. Using measures that
were developed for a different population and assuming the content validity
remains the same is potentially problematic and may limit the conclusions
that can be drawn from the studies. Therefore, future authors may wish to
conduct in depth psychometric analyses of scales frequently used with family
carers of people with dementia that have not yet been validated with this
Carer Sense of Competence

population. Such scales include, but are not limited to: the Sense of Coherence scale (Antonovsky, 1993), the Connor-Davidson Resilience Scale (Connor & Davidson, 2003) and the Resilience Scale-14 items (RS-14; Wagnild, 2009).

2.5.2 Future Research

This review did not extend to extrinsic factors that may influence wellbeing and only searched for intrinsic positive psychology factors, in order to contain the breadth of the review. Therefore, another systematic review could be conducted which explores the development of positive psychology outcome measures related to extrinsic factors such as social support and external locus of control, and investigates how far these aspects contribute to wellbeing.

Some of the measures discussed in the context of this review have already been used within interventional research in this population e.g. the SCQ, SSCQ, RSSE and PAC, with variable results. Whilst it was beyond the scope of this review to examine this, future researchers may wish to review the results of such studies from a psychometric viewpoint in order to further assess validity.

2.6 Conclusion

This review demonstrated that there are some robust measures in existence for family carers of people with dementia, which could be incorporated into interventional studies. The most psychometrically sound measure in this
review was the GAIN instrument (Yap et al., 2010). It is recommended that this scale be evaluated further, as the development authors were not able to provide evidence of responsiveness. Although 12 positive outcome measures for family carers of people with dementia were identified in this review, there is still work to be done to develop more high quality positive psychology scales for this population. The self-efficacy and sense of competence scales identified within this review contained predominantly negative wording and therefore the development of a more positive, psychology centered, scale measuring sense of competence is warranted. Development of these scales with a firm theoretical grounding would facilitate a better understanding of the positive aspects of caring and how these contribute to wellbeing. This would ultimately aid in the development of relevant positive psychology interventions.
Chapter 3  Factors related to sense of competence of family carers of people living with dementia in the community: A narrative synthesis

This systematic review has been published in International Psychogeriatrics (Stansfeld, J., Crellin, N., Orrell, M., Charlesworth, G., Wenborn J., & Vernooij-Dassen, M, 2018).

3.1 Introduction

The existing theoretical model (see Section 1.5) and subsequent research into sense of competence (Vernooij-Dassen et al., 1996) found associations between sense of competence and factors related to the personality of the carer, such as neuroticism, perceived social support and also person with dementia factors such as apathy and behavioural disturbances. However, the impact of positive appraisal of the caring situation and positive personality traits on sense of competence were not explored. Although sense of competence is increasingly being recognised as an important concept in international research for this population (Moniz-Cook et al., 2008; Lau & Cheng, 2015), little further work has been done since the original conceptual model and no systematic review has been undertaken to address this gap. Knowledge of how to improve carer’s feelings of competence and the factors that relate to this concept can inform the design of support services and interventions to enable them to care for the person with dementia in the community for longer.
3.2 Aim

To explore and develop further the conceptual model of factors related to sense of competence. Specifically, this review addressed the following research questions:

1. What carer factors are related to sense of competence?
2. Are positive psychology factors related to sense of competence?
3. What person with dementia factors are related to sense of competence?

3.3 Method

3.3.1 Design

A narrative synthesis design was employed for this review, using guidance from a published protocol (Popay et al., 2006). This approach allows the combination of qualitative, quantitative and mixed methods studies to reach a conclusion based on interpretation of the text.

3.3.2 Narrative Synthesis Methodology

There are four steps in narrative synthesis, as follows:

I. Development of a theory

Stage one involved scoping of the literature, before conducting the search, to guide the research question and the inclusion and exclusion criteria. Current theoretical models of the carer stress-coping process described in Chapter 1 (e.g., Sorensen & Conwell, 2011), and the existing theoretical model of sense of competence were used to guide the review (Vernooij-Dassen et al., 1996).
II. Development of a preliminary synthesis of the findings

Stage two involved grouping the papers according to design (qualitative, quantitative or mixed methods). Data were extracted from each of the studies and clustered by design, then tabulated to enable comparison.

III. Exploring the relationships in the data within and between studies

The tabulated summary was used to explore the relationships within the data. Similarities and differences between outcomes in the studies were considered. Factors that may have influenced heterogeneity in findings, such as differences in study design, methodological quality or characteristics were explored.

IV. Assessing the robustness of the synthesis

For stage four, the methodological quality of each included study was assessed using two standardised tools (STrengthening the Reporting of OBservational studies in Epidemiology (STROBE, Appendix 1.1) and Critical Appraisals Skills Programme (CASP, Appendix 1.2) quality assessment checklists in order to ensure that all included evidence was of good quality, as this would affect the robustness of the synthesis. At all stages of the review, the robustness of the methods and synthesis were evaluated with an informal critical reflection, looking back over the methodology and review process to identify any limitations or biases that may have impacted the review findings. These are reported in the discussion section where applicable.
The narrative synthesis approach may be adopted to generate a conceptual map of findings (Popay et al., 2006). The author used the results of this review to generate a conceptual map to reflect the findings. In order to generate a model, findings were grouped by concept where applicable, for example, BPSD and coping style. The relationship of these concepts with sense of competence was considered and a model was then developed from the findings. A consensus meeting was held between JS and supervisors (MO and Professor Vernooij-Dassen (MVD)) to agree and finalise the conceptual map according to the literature and to incorporate these with the existing model of sense of competence (Vernooij-Dassen et al., 1996).

The search terms for this review were developed through scoping of previous literature in order to guide the inclusion and exclusion of papers in the systematic review. Scoping of previous literature was conducted by searching for and reading relevant published papers related to sense of competence to ensure familiarity with the topic and to generate search terms.

### 3.3.3 Search Strategy

A systematic search was conducted in Medline, PsycINFO, CINAHL and EMBASE electronic databases. These databases were chosen due to their relevance to the aims and topic of this review. Search terms were divided into three categories: sense of competence, family carer and dementia. The search terms were combined ('sense of competence' AND 'family carer' AND 'dementia'), with truncations of terms used where appropriate.
Search terms for sense of competence included overlapping constructs such as self-efficacy and burden in order to ensure that all possible relevant papers were identified: ‘sense of competence’ OR ‘competence’ OR ‘perceived competence’ OR ‘mastery’ OR ‘self-efficacy’ OR ‘burden’ OR ‘SCQ’ OR ‘capability’.

Search terms for family carer were: ‘family carer’ OR ‘carer’ OR ‘caring’ OR ‘care’ OR ‘carer’ OR ‘relative’ OR ‘friend’ OR ‘spouse’ OR ‘supporter’ OR ‘support’.

Search terms for dementia were: ‘cognitive impairment’ OR ‘Alzheimer’ OR ‘senile’ OR ‘dementia’ OR ‘demented’ OR ‘MCI’. The terms ‘cognitive impairment’ and ‘MCI’ were included in order to ensure that studies with mixed populations were captured.

Hand searching of references and citations of all papers included at the full-text stage was conducted to ensure a thorough search, however; no additional papers were identified. The principles outlined by the PRISMA group were followed (Moher et al., 2009).

3.3.4 Inclusion Criteria

- Publication language: Studies published in English only, unless a translation was available
- Publication year: Studies published from the earliest date available on each database to November 2016 (date of the search).
- Studies examining the relationship between or factors affecting sense of competence. This did not have to be the primary aim of the study.
• Qualitative or quantitative studies. Quantitative studies were required to include a standardised measure of sense of competence

3.3.5 Exclusion Criteria

• Systematic review papers

• Studies conducted with family carers of people living in residential care

• Intervention studies, as these only investigate the impact of an intervention on sense of competence rather than factors relating to this construct.

• Qualitative or quantitative studies deemed to be of ‘poor quality’ as assessed by the STROBE and CASP checklists.

3.3.6 Data Extraction

Titles and abstracts of identified papers were exported to Mendeley Referencing Software (version 1.17.6) and checked for duplicates. Titles were screened and irrelevant titles that did not meet the inclusion criteria were excluded. Titles where it was not possible to determine if they should be included were retained in order to screen in further detail. Abstracts were then screened and for those identified as relevant the full text was downloaded. The final eligibility decision was made by reading the full text. In cases where more information was needed to determine eligibility, or when there was difficulty obtaining the full text, the study authors were contacted.
Once the full-texts had been obtained, two researchers (JS and Dr. Nadia Crellin (NC)) independently reviewed a randomly chosen sub-set of five papers against the inclusion and exclusion criteria. Data relating to the design, methodology, author, year, sample population, sample size, measures used, analysis and findings were extracted onto a data extraction database. A consensus meeting was held to cross-check data extraction and eligibility of the papers. In instances when there was disagreement regarding whether a paper should be included \((n = 1)\), discussions were held until a consensus was reached. As agreement was high, the remaining full-texts were randomly divided between the two researchers for screening against inclusion and exclusion criteria, and a further consensus meeting was held before the two data extraction databases were merged. JS completed a quality assessment checklist for all included full-text papers and a consensus meeting was held with NC to discuss any ambiguity over scores. A flow chart of the systematic review process is presented in Figure 3.1.
3.3.7 Quality Assessment

The methodological quality of the quantitative studies was evaluated using the 22-item STROBE checklist (von Elm et al., 2007), which was developed to assess the methodological quality of the reporting of observational research. The author scored each of the items according to whether it had been met: no (scored zero) and yes (scored one point). Item scores for each study were summed to create a total quality score out of 22 and this was
represented as a percentage of the total possible score. Cut-off scores were devised in order to allow ease of description of the quality of each of the studies and categorisation of the methodological quality. Studies that scored below 50% were considered to be of ‘poor quality’ and were excluded from the review, as the robustness of the synthesis is dependent on the quality of the included studies. Studies scoring 50 - 74% were rated to be of moderate quality and studies scoring 75% and above were graded as high quality. Both moderate and high quality studies were included in this review, as these were considered sufficiently robust for the synthesis.

3.3.8 Qualitative papers

Qualitative studies were assessed for quality using the 10-item CASP qualitative research appraisal criteria (Public Health Resource Unit, 2006). This tool scores methodological quality using 10 items, with response items scored as: meeting the criteria (score of one), unable to tell (score of zero) or not meeting the criteria (score of zero). The scores are summed to produce an overall quality score. Only studies rating more than five out of ten (50%) were included in the review in order to ensure the quality of the research did not bias the results.

3.3.9 Mixed methods papers

Mixed methods studies were subject to both the STROBE and CASP quality assessment and had to meet the predefined standards for both.
3.4 Results

The initial search returned 9370 papers after duplicates were removed. There were 49 potential full-text publications extracted. After reviewing the full text, 17 met the inclusion criteria; 13 quantitative studies, three mixed methods and one qualitative study. The most common reason for exclusion at this stage was that they were intervention studies ($n = 14$) or that the population was not family carers of people with dementia living in the community ($n = 7$). Following quality assessment, no further studies were excluded. Complete quality assessment scores and detail on included papers, such as design, analysis and sample size are reported in Tables 3.1 and 3.2.

Stage 2: Preliminary synthesis of the findings

The papers were largely from the Netherlands ($n = 8$), but also from the UK ($n = 3$), USA ($n = 2$), Taiwan ($n = 1$), Belgium ($n = 1$), Singapore ($n = 1$) and Canada ($n = 1$). The majority of studies were cross-sectional ($n = 9$) or longitudinal ($n = 5$) in design. Two of the mixed methods papers reported results from interview studies alongside quantitative findings. One reported results from interviews and focus groups. One paper reported mixed methods results from a case study. The total number of family carers in all studies was 2463 ($M = 144$, range = 1 - 447). For quantitative studies the total number of family carers was 2277 ($M = 190$, range = 56 - 447). For the mixed methods studies, the total number of family carers participating was 150 ($M = 50$, range = 1 - 99). In the one qualitative study (Peacock et al., 2010), there were 39 participants.
Table 3.1 Observational studies including a sense of competence measure (n=13)

<table>
<thead>
<tr>
<th>Author</th>
<th>Year/Country</th>
<th>Sample</th>
<th>Design/Analysis</th>
<th>Sense of competence measure</th>
<th>Keyfindings</th>
<th>Quality assessment</th>
</tr>
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<tbody>
<tr>
<td>Borsje et al.</td>
<td>2016 Netherlands</td>
<td>117 carers</td>
<td>Prospective observational cohort study / ANOVA (Analysis of Variance), chi-square and t-tests</td>
<td>SCQ (Vernooij-Dassen et al., 1993)</td>
<td>In a fixed effects model, carers of patients admitted to a long-term care facility during follow-up had statistically lower sense of competence scores ($b = -8.55$; 95% CI [-13.4 to -3.6] $p = 0.001$). Statistically significant lower sense of competence scores found in informal carers age group 50 - 70 years compared with &lt;70 years of age. Higher SCQ scores were found in adult child carers compared to spouses ($b = 8.29$; 95% CI [1.8 to 14.8] $p = 0.014$).</td>
<td>86% (19/22) High quality</td>
</tr>
<tr>
<td>Feast, Orrell, Russell, Charlesworth &amp; Moniz-Cook</td>
<td>2016a UK</td>
<td>157 carers</td>
<td>Cross-sectional / Path analysis</td>
<td>SSCQ (Vernooij-Dassen et al., 1999)</td>
<td>Sense of competence correlated with BPSD related distress ($r = -0.43$, $p &lt; .01$), frequency of BPSD ($r = -0.042$, $p &lt; .01$), relationship quality ($r = 0.71$, $p &lt; .01$), carer guilt ($r = -0.44$, $p &lt; .01$), carer burden ($r = -0.50$, $p &lt; .01$) and reactivity to BPSD ($r = -0.41$, $p &lt; .01$). Sense of competence mediated the relationship between BPSD frequency and BPSD-related distress. Increased guilt was indirectly related to higher BPSD-related distress through reduced sense of competence.</td>
<td>82% (18/22) High quality</td>
</tr>
<tr>
<td>Fortinsky et al.</td>
<td>2002 USA</td>
<td>197 carers</td>
<td>Cross-sectional validation/correlation analysis</td>
<td>4 item Caregiving Competence Scale (Pearlin et al., 1990)</td>
<td>Self-efficacy for managing dementia was positively correlated with global carer competence ($r = 0.49$, $p &lt; 0.05$).</td>
<td>82% (18/22) High quality</td>
</tr>
<tr>
<td>Author</td>
<td>Year/Country</td>
<td>Sample</td>
<td>Design/Analysis</td>
<td>Sense of competence measure</td>
<td>Key findings</td>
<td>Quality assessment</td>
</tr>
<tr>
<td>------------------------</td>
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<tr>
<td>Kurz et al.</td>
<td>2003 Belgium</td>
<td>193 carers Mean age = 70</td>
<td>Cross-sectional study/descriptive statistics</td>
<td>SCQ</td>
<td>Carers of people with severe dementia had a total sense of competence score (M = 19.3), which was comparable to that of patients with mild (M = 21.8) to moderate (M = 20.7) dementia. But sense of competence decreased as severity of dementia increased.</td>
<td>64% (14/22) Moderate quality</td>
</tr>
<tr>
<td>Lau &amp; Cheng</td>
<td>2015 Taiwan</td>
<td>109 carers Mean age = 57.6</td>
<td>Cross-sectional/Structural equation modelling</td>
<td>4 item Caregiving Competence Scale</td>
<td>Gratitude was related to sense of competence ($r = .31, p &lt; .01$). Competence was also negatively associated with depression symptoms ($r = .29, p &lt; .01$) and positively correlated with emotion-focused coping ($r = .24, p &lt; .05$).</td>
<td>64% (14/22) Moderate quality</td>
</tr>
<tr>
<td>Millenaar et al.</td>
<td>2015 Netherlands</td>
<td>220 young onset dementia and 108 late onset carer dyads</td>
<td>Longitudinal modelling</td>
<td>SSCQ</td>
<td>Sense of competence scores were not significantly different between young onset and late onset dementia carers. Changes in sense of competence scores over the two year course of the study did not differ between young onset and late onset dementia carers ($b = -0.11, t = -0.527, p = 0.6$).</td>
<td>77% (17/22) High quality</td>
</tr>
<tr>
<td>Quinn</td>
<td>2012a &amp; 2012b (reporting on same data) UK</td>
<td>447 carers Mean ages 67.8 (2012a) and 68 (2012b)</td>
<td>Cross-sectional/correlational analysis</td>
<td>3 item caregiving scale (Robertson, Zarit, Duncan, Rovine &amp; Fernia 2007)</td>
<td>Finding meaning in caring was moderately and positively correlated with competence ($r = .46, p &lt; .01$). Pre-caring relationship quality had a small positive correlation with sense of competence ($r = .16, p &lt; .01$), as did current relationship quality ($r = .2, p &lt; .01$). Providing greater hours of care was associated with higher competence (adjusted $r^2 = 0.02, F(4,371), p &lt; .05$).</td>
<td>Both papers received a quality score of 82% (18/22) High quality</td>
</tr>
<tr>
<td>Author</td>
<td>Year/Country</td>
<td>Sample</td>
<td>Design/Analysis</td>
<td>Sense of competence measure</td>
<td>Key findings</td>
<td>Quality assessment</td>
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<tr>
<td>Tan, Yap, Ng, &amp; Luo</td>
<td>2013 Singapore</td>
<td>246 carers Mean age = 50.3</td>
<td>Cross-sectional / validation</td>
<td>SSCQ</td>
<td>The negative subscale of dementia-specific strategies scale was correlated significantly with sense of competence ($r = -.52, p &lt; .001$). Sense of competence did not correlate with positive subscale of the dementia-specific strategies scale ($r = .04$). Carers that employ negative caring strategies may report a lower sense of competence.</td>
<td>68% (15/22) Moderate quality</td>
</tr>
<tr>
<td>Van der lee, Bakker, Duivenvoorden &amp; Droes.</td>
<td>2015 Netherlands</td>
<td>148 carers Age = in intervention group (M = 57.9), control group (M = 58.8)</td>
<td>Cross-sectional analysis of 6 month data / Longitudinal Regression</td>
<td>SCQ modified by Teunisse, &amp; de Haan (1994) to 28 items</td>
<td>Sense of competence was a significant predictor of burden. In a regression model, sense of competence, severity of neuropsychiatric symptoms in the person with dementia and high carer dominance scores were significant predictors of emotional stress ($b = 0.9, CI = -0.66, p &lt; .01$)</td>
<td>86% (19/22) High quality</td>
</tr>
<tr>
<td>Vernooij-Dassen et al.</td>
<td>1996 Netherlands</td>
<td>141 carers Mean age = 63</td>
<td>Cross-sectional / Path analysis</td>
<td>SCQ</td>
<td>Severity of dementia had no impact on sense of competence but had an indirect affect. The more severe the dementia, the more the apathetic behaviour of person with dementia. Higher levels of apathetic behaviour negatively impacted sense of competence. Neuroticism had a moderate negative correlation with sense of competence but a strong indirect effect through the carers reports of apathy of the person with dementia ($r^2 = 0.51, p &lt; .05$) $F(3,131) = 48.30; p &lt; .001$)</td>
<td>64% (14/22) Moderate quality</td>
</tr>
<tr>
<td>Vernooij-Dassen, Felling &amp;</td>
<td>1997 Netherlands</td>
<td>138 carers Mean age = 63 years</td>
<td>Prospective longitudinal study</td>
<td>SCQ</td>
<td>A longer duration of dementia predicted a decrease in carer sense of competence ($b = -0.21, p = 0.04$). Compared with male carers, being a female carer</td>
<td>73% (16/22) Moderate</td>
</tr>
<tr>
<td>Author</td>
<td>Year/Country</td>
<td>Sample</td>
<td>Design/Analysis</td>
<td>Sense of competence measure</td>
<td>Key findings</td>
<td>Quality assessment</td>
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<td>Persoon</td>
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<td>living with a person with dementia predicted a lower sense of competence ((b = -0.40, p = .02)). Compared with no religious involvement, being either a catholic ((b = 0.34, p = .01)) or protestant ((b = 0.22, p = .01)) positively influenced the change in sense of competence.</td>
<td>quality</td>
</tr>
<tr>
<td>Vernooij-Dassen et al.</td>
<td>2003</td>
<td>56 carers Mean age = 61</td>
<td>Cross-sectional / Correlational analysis</td>
<td>SCQ</td>
<td>Sense of competence scores ranged from 5.2 to 27. (M = 18.7, SD = 5.9). Specific information about patient’s behaviour and professional care was more often given when carers had a lower sense of competence (median 15.6 compared to 22.8) and when patients had more cognitive, behavioural or activities of daily living problems.</td>
<td>73% (16/33) Moderate quality</td>
</tr>
<tr>
<td>Author</td>
<td>Year/Country</td>
<td>Sample</td>
<td>Design/Analysis</td>
<td>Sense of competence measure</td>
<td>Themes in qualitative research</td>
<td>Key findings</td>
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<tr>
<td>De Vugt et al.</td>
<td>2004, Netherlands</td>
<td>99 carers</td>
<td>Semi-structured interviews/ Grounded theory</td>
<td>SSCQ</td>
<td>Carer management strategies were typified as nurturing, supporting or non-adapting.</td>
<td>Carers who used a non-adapting coping strategy had a significantly lower sense of competence ($F = 6.1, p &lt; .01$). There was a significant difference between carers who used a supporting strategy and the carers who used a non-adaptive strategy ($t = 3.4, p &lt; .001$).</td>
</tr>
<tr>
<td>Graff et al.</td>
<td>2006a, Netherlands</td>
<td>1</td>
<td>Case study/ content analysis of an OT patient record plus quantitative assessments</td>
<td>SCQ</td>
<td>Primary carer theme - feelings of helplessness and decrease of sense of competence</td>
<td>No quantitative findings related to determinants of sense of competence. Qualitative theme of hopelessness was associated with a feeling that sense of competence had decreased.</td>
</tr>
<tr>
<td>Narayan, Lewis, Tornatore, Hepburn &amp;</td>
<td>2001, USA</td>
<td>50</td>
<td>Cross-sectional/ correlational analysis</td>
<td>4 item Caregiving competence scale</td>
<td>Confidence Positive aspects of caring in competence Negative aspects of</td>
<td>Positive aspects of caring and sense of competence were correlated ($r = .46, p &lt; .01$) Qualitative themes demonstrated that sense of competence was a</td>
</tr>
<tr>
<td>Author</td>
<td>Year/Country</td>
<td>Sample</td>
<td>Design/Analysis</td>
<td>Sense of competence measure</td>
<td>Themes in qualitative research</td>
<td>Key findings</td>
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</tr>
<tr>
<td>Corcoran-Perry</td>
<td></td>
<td></td>
<td>Semi-structured interviews/thematic analysis</td>
<td>caring</td>
<td></td>
<td>positive aspect of caring. Caring was experienced as self-affirming despite the challenges of the role.</td>
</tr>
<tr>
<td>Peacock et al.</td>
<td>2010 Canada</td>
<td>36</td>
<td>Interviews (n = 3) and focus groups (n = 6)</td>
<td>N/A</td>
<td>Sense of competence as a positive aspect of caring</td>
<td>A higher sense of competence was felt when carers were able to cope with challenging situations. They were able to take these experiences, build on them and feel more competent and proud of their accomplishments in caring over time.</td>
</tr>
</tbody>
</table>
Stage 3: Exploring relationships within and between studies: Factors related to sense of competence

Factors related to sense of competence identified in the systematic review were related to both the person with dementia and carer. All included studies were of moderate to high quality. The quantitative papers were mostly of high quality (54%) and the remainder of the papers were of moderate quality (46%). The mixed methods papers all scored moderately on the STROBE checklist for the quantitative methodology and high on the CASP checklist for the qualitative methodology. The one solely qualitative study scored high on the CASP checklist. The evidence presented in all the included papers was considered robust enough to be included in the synthesis. The mean age of carers across the included studies was 61.6 with a standard deviation of 5.07. All of the included studies were conducted in the community and carers were caring for a person with dementia who was a family member or friend. The preliminary updated model of sense of competence presented below was informed by the results of this review (Figure 3.2).

3.5 Carer factors related to sense of competence

3.5.1 Socio-demographics

Compared with male carers, being a female carer living with a person with dementia predicted a lower sense of competence in a prospective longitudinal study (Vernooij-Dassen et al., 1997). In addition, the age of the carer was associated with sense of competence, with younger carers (50 to 70 years of age) reporting a lower sense of competence than older carers (>70 years of age) in a fixed effects model (Borsje et al., 2016). Borsje et al.
(2016) also found that adult child carers had a higher sense of competence than spouses and that a lower sense of competence was associated with the likelihood that the person with dementia would be admitted to a long-term care facility. Millenaar et al. (2015) found that there was no difference between carers of young onset and late onset dementia over the course of a two year study.

3.5.2 Negative aspects of caring

There was a small but significant negative correlation between sense of competence and symptoms of depression in the carer (Lau & Cheng, 2015). This indicates that the higher the depressive symptoms, the lower the sense of competence the carers felt. Similarly, in the qualitative literature, a theme of hopelessness emerged, which was associated with a decrease in sense of competence. This theme included a fear of not knowing what to do and how this might impact the future: “I don’t know how I can help him. I’m tired and I have back problems because of all the things I have to do myself at the moment. I am afraid for the future” (Graff et al., 2006b, p. 513).

3.5.3 Positive psychology factors

Despite this, a higher sense of competence was also related to positive psychology factors. Carer competence was found to moderately correlate with self-efficacy for managing dementia in a validation study (Fortinsky et al., 2002). Other positive aspects of caring such as gratitude were also moderately related to increased caring competence (Lau & Cheng, 2015). This was reflected in the qualitative literature, as carers were able to find
Carer Sense of Competence

confidence in themselves and learn about their strengths from the caring experience: “I have learned a lot about my own strengths - having more confidence in myself to make major decisions alone” (Narayan et al., 2001, p. 24).

In addition, the ability to find meaning in caring (Quinn et al., 2012a; Quinn et al., 2012b) was moderately related to sense of competence. In terms of coping strategies, the use of emotion-focused (Lau & Cheng, 2015) coping was moderately related to sense of competence, whereas the use of negative caring strategies was moderately related to a lower sense of competence (Tan et al., 2013). In a regression analysis, religious involvement positively predicted sense of competence (Vernooij-Dassen et al., 1997). In a longitudinal study, there was a significant difference between carers who used a supporting coping strategy and those who used a non-adaptive strategy, with carers using a supportive coping strategy demonstrating a higher sense of competence (De Vugt et al. 2004). Taking the findings of these studies together, it appears that the ability to identify positive aspects of caring, such as finding meaning and gratitude in the caring role may act as a protective factor for sense of competence against the negative outcomes in caring, such as depression.

3.6 Person with dementia factors related to sense of competence

Sense of competence was negatively associated with symptoms of BPSD of the person with dementia in three studies, with these associations being moderate to strong (Borsje et al., 2016; Feast et al., 2016a; Van der lee et
al., 2015). Sense of competence also mediated the relationship between BPSD frequency and BPSD related distress in a structural equation model (Feast et al., 2016a). Sense of competence was significantly and negatively associated with reactivity to BPSD and carer guilt, which were both moderate associations (Feast et al., 2016a). The qualitative literature reflected this finding, as it emerged that carers found their sense of competence was challenged by BPSD, however, finding a way to deal with these behaviours gave them a sense of accomplishment and pride which in turn improved their sense of competence, “It’s amazing the difference knowing what to do, and how to do it” (Peacock et al., 2010, p. 650). In a longitudinal study, sense of competence, severity of BPSD in the person with dementia and high carer dominance scores were significant predictors of emotional distress (Van der lee et al., 2015).

Severity of dementia was indirectly and moderately related to sense of competence through the carer’s reports of apathetic behaviour of the person with dementia in a path analysis model (Vernooij-Dassen et al., 1996). Therefore, the more severe the dementia, the more likely the carer was to report apathetic behaviour in the person with dementia and consequently, have a lower sense of competence. A longer duration of dementia was negatively associated with sense of competence (Vernooij-Dassen et al., 2003). However, in another study (Kurz et al., 2003), sense of competence scores for carers of people with severe dementia was found to be comparable to carers of patients with mild to moderate dementia, although these statistics were only descriptive.
Figure 3.2 Model of sense of competence based on existing literature
3.7 Discussion

This review is the first to systematically explore the factors related to sense of competence from a theoretical perspective. There were 17 studies included in this mixed methods review. The majority of the studies found that situational, demographic and personality characteristics of the carer related to carer sense of competence. In addition, person with dementia factors such as BPSD and duration of dementia were associated with sense of competence. Sense of competence mediated the relationship between BPSD frequency and distress, indicating that whilst sense of competence is influenced by factors such as BPSD, it may also serve as a protective factor against the negative outcomes of caring such as depression and distress if the carer can identify positive aspects of caring such as finding meaning in their role.

The findings identified in this review presented an opportunity to update the existing model of sense of competence in order to address conceptual gaps. The use of narrative synthesis enabled the combination of both qualitative and quantitative research to contribute to this model. The previously hypothesised theoretical model (Vernooij-Dassen et al., 1996) did not incorporate positive psychology factors, such as gratitude, meaning and caring self-efficacy alongside the association with the negative outcomes of caring. The preliminary updated model derived from existing literature contributes to a more comprehensive understanding of the positive and negative aspects of the caring experience and how they relate to sense of competence.
3.7.1 Critical reflection (narrative synthesis stage 4)

Critical reflection was undertaken throughout the review in order to identify any biases or limitations that could impact the review, according to published guidance (Popay et al., 2006). A formal approach to testing the robustness of the synthesis was not undertaken as the critical reflection is not a linear process. Therefore, the author recognises that potential limitations of this review may therefore be missed.

This review had well defined and broad inclusion criteria, which were identified from existing literature and sense of competence theory. However, as with all systematic reviews, the findings here rely on the quality of the included studies and the author notes that the findings were not weighted based on the methodological quality, which could weaken the quality of the review. This decision was made because narrative synthesis research takes a textual approach to presenting and combining evidence from different methodologies, making it difficult to fairly weight the evidence, as no single indicator of methodological quality was considered important for this review. Rather, the total score informed inclusion of studies. All of the included studies were of good methodological quality and therefore the results were considered equally.

Consideration must be given to the potential for measurement error to influence the findings of the review. Narrative synthesis combines results from included papers without re-analysis and therefore if measurement error is present in the included quantitative studies, it will carry forward to the
findings of this review. In addition, in qualitative or mixed methods studies, if there is any bias present in the qualitative analysis, this could affect the findings of the review. Despite this, the included qualitative and mixed methods papers were all of high methodological quality, so it is anticipated that the impact of bias is limited.

This review combined the results of several sense of competence outcome measures, which may present a methodological limitation due to differences in operationalisation between the scales. The conceptualisation of sense of competence is an existing methodological issue, as discussed in Chapter 1. To minimise the impact of this on the review, the author only included studies where sense of competence had been measured with a valid and standardised outcome measure. In addition, all included studies employed definitions of sense of competence reflecting that conceptualised by Vernooij-Dassen et al. (1996). Despite this, the author acknowledges that further work is required to fully conceptualise sense of competence and ensure that it is measured consistently between studies.

The majority of the studies included within the review were cross-sectional and reported correlations, therefore this study could only infer a relationship between sense of competence and the factors identified, rather than infer causality or identify change. Additionally, a number of studies were excluded as they contained mixed populations of carers of people living with dementia both in the community and residential care. However, these studies may have contained potentially relevant results. It is recommended that authors
endeavour to report the results from different populations (e.g. community and residential care) separately in research studies rather than pooling populations together, which could impact the results.

3.7.2 Future Research

Limited qualitative research investigating sense of competence was identified in this review. Qualitative exploration of what sense of competence means to family carers of people living with dementia, and their perceptions of how it can be improved would give a deeper understanding of what carers themselves feel determines their sense of competence. The theoretical model developed in this Chapter was based on the conceptual mapping of findings from 17 studies and has not been tested. Therefore, it is recommended that the model be statistically examined in both cross-sectional and longitudinal research. Despite this, the proposed theoretical model can contribute to the development of interventions aimed at increasing carer sense of competence.

3.8 Conclusion

This is the first review to investigate the factors related to sense of competence using a narrative synthesis approach. The proposed model indicates that both positive and negative aspects of caring can impact a carer’s sense of competence. It is likely that the positive and negative aspects of caring act in tandem to influence carer perception of their competence, reflecting the “mixed valence” of caring proposed in previous literature (Lawton et al. 1991, p. 182). This review has clinical relevance as it
gives an insight into the factors that relate to sense of competence, which may aid the design of interventions seeking to support family carers of people with dementia.
Chapter 4  The effect of psychosocial interventions on sense of competence in family carers of people living with dementia in the community: A systematic review and meta-analysis.

4.1 Introduction

The systematic review reported in Chapter 3 provided evidence that carer demographics such as gender and age (Vernooij-Dassen et al., 1997; Borsje et al., 2016), positive psychology factors such as meaning and gratitude (Lau and Cheng, 2015; Quinn et al., 2012a; Quinn et al., 2012b) and negative outcomes for carers such as depression and emotional distress (Van der lee et al., 2015; Lau and Cheng, 2015) are associated with sense of competence. Sense of competence can theoretically be increased by relevant psychosocial interventions and it is vital that interventions targeted at supporting carers to feel more competent are developed and robustly evaluated. Therefore, it is necessary to find out which interventions are successful at improving sense of competence in family carers of people living with dementia.

A previous systematic review of dyadic interventions found that there were few studies \( (n = 7) \) that investigated the impact of interventions on carer sense of competence (Smits et al., 2007). Within these seven studies, sense of competence improved in only two of the seven interventions. However, in this review, the included outcome measures were not standardised in all included studies and the domains of mastery, self-efficacy and knowledge on
dementia were included as measures of carer competence, rather than the review focusing specifically on sense of competence itself.

A subsequent systematic review also investigated the impact of interventions (van Mierlo, Meiland, Van der Roest & Droes, 2012) on several carer domains, including carer sense of competence. The authors categorised sense of competence and self-efficacy together and found that these domains commonly improved as a result of psychosocial interventions. However, the authors only included interventions that had been effective in the review. Additionally, this review did not distinguish between interventions that measured self-efficacy and those that measured sense of competence. Despite the significant overlap between these two concepts (discussed in Chapter 1), they represent separate domains. Therefore, a systematic review and meta-analysis was conducted in order to evaluate the effect of psychosocial interventions on family carer sense of competence.

4.2 Aim

To systematically review the literature and conduct a meta-analysis in order to investigate the impact of psychosocial interventions on sense of competence in family carers of people living with dementia.

4.3 Method

4.3.1 Design

A systematic search was conducted in Medline, PsycINFO, CINAHL and EMBASE electronic databases, as these were most relevant to the search
terms. Search terms were deliberately kept broad in order to identify all possible papers. PRISMA guidance was used (Moher et al., 2009) and the references of each included paper were searched for relevant papers.

4.3.2 Search strategy

Search terms were:

**Sense of competence:** ‘sense of competence’ OR ‘competence’ OR ‘perceived competence’ OR ‘mastery’ OR ‘self-efficacy’ OR ‘burden’ OR ‘capability’. Search terms for sense of competence included similar terms commonly used to describe overlapping features of sense of competence in order to capture all relevant papers.

**Family carer:** ‘family carer’ OR ‘carer’ OR ‘caring’ OR ‘care’ OR ‘carer’ OR ‘relative’ OR ‘friend’ OR ‘spouse’ OR ‘support’

**Dementia:** ‘cognitive impairment’ OR ‘Alzheimer’ OR ‘senile’ OR ‘dementia’ OR ‘demented’ OR ‘demented’.

The search terms were combined as follows: ‘sense of competence’ AND ‘family carer’ AND ‘dementia’. Truncations of terms were used where appropriate.

4.3.3 Inclusion criteria

- Publication language: Studies published in English only, unless a translation was available.
- Publication year: Studies published between inception to February 2018 (date of the search) were included in the review.
Carer Sense of Competence

- Population: Papers with family carers of people currently living with dementia in the community were included.
- Intervention studies were included (both randomised and non-randomised) if the trials contained a control group. The intervention studies did not have to be targeted at improving sense of competence however papers were required to report results from a standardised measure of sense of competence.
- Only published peer-reviewed papers were included in the review.

4.3.4 Exclusion criteria

- Systematic reviews or meta-analysis papers
- Studies conducted with a sole population of family carers of people with dementia living in residential care.
- Studies deemed to be of ‘poor quality’ as assessed by the Downs and Black quality assessment checklist.

All identified papers were exported to Mendeley Referencing Software (version 1.17.6). Only those titles or abstracts that met the inclusion criteria were downloaded as full-text papers. Two researchers (JS and Dr. Nadia Crellin) screened and checked the papers in order to make a final decision regarding whether they were included in the systematic review. If the full-text was not available ($n = 2$), the study authors were contacted in order to obtain the paper. The systematic review process is illustrated in Figure 4.1.
4.3.5 Quality Assessment

In order to assess methodological quality, both researchers (JS and NC) independently reviewed a randomly selected subset of five papers and a meeting was held to compare scores and calculate the inter-rater reliability between the two researchers, which was 95%. Due to the high inter-rater reliability, the remaining full-texts were divided equally between the two authors and a quality assessment of each paper was conducted. Regular consensus meetings were held in order to ensure that the assessment of quality was consistent.

The 27 item Downs and Black Quality Checklist (Downs & Black, 1998; Appendix 1.3) was used to assess the quality of all included studies. This checklist examines the methodological quality of randomised control trials (RCTs) and non-randomised trials. For RCTs, the tool comprises 27 items, with possible scores ranging from 0 - 28. For non-randomised trials, two items (items 23 and 24) are removed, giving a possible score of 0 - 26 for 25 items. In this tool, 26 of the items have three scoring options: unable to determine (scored zero), no (scored zero) and yes (scored one point), however, item 5 (‘are the distributions of principal confounders in each group of subjects to be compared clearly described’) is scored between 0 - 2 (not met, partially met and fully met). All the item scores were summed to generate a total quality score and a percentage was calculated from the total possible score. The author devised quality cut-off scores in order to allow for comparison between studies based on previous reviews that employed this checklist (Crellin et al., 2014; Feast, Moniz-Cook, Stoner, Charlesworth &
Orrell, 2016b): Papers below 50% quality were excluded. Studies scoring between 50 - 74% were considered to be of moderate quality and studies scoring above 75% were rated as high quality. Only moderate and high quality papers were included in this review.

![PRISMA diagram of systematic review process](image)

_Figure 4.1 PRISMA diagram of systematic review process_
4.3.6 Meta-analysis methodology

Review Manager 5.3, a computer programme developed by the Cochrane Collaboration (2014) was used to calculate the effect of each psychosocial intervention on sense of competence and the pooled effect of all interventions on sense of competence. Review Manager calculates standardised mean difference (SMD) scores, which is also known as Cohen’s d. These scores were used with a 95% confidence interval to explore the effect of each psychosocial intervention on sense of competence across studies at post-test, in comparison to the control group. Post-test sense of competence scores at the end of the intervention were used where stated or available, but if not available, then the follow-up closest to the end of the intervention was used. Cohen’s (1988) guidance was used to interpret the effect size, with values < .2 defined as a small effect, values between .2 and .5 as a moderate effect and values > .5 as a large effect.

As an indicator of heterogeneity (between-studies variance), the $Q$ and $I^2$ statistics were used. The $Q$ statistic represents a measure of weighted standard deviations and indicates whether heterogeneity exists amongst studies. $I^2$ is the ratio of true heterogeneity between studies to observed variation and represents the extent of heterogeneity as a percentage. $I^2$ is calculated by dividing the $Q$ value and degrees of freedom ($k - 1$), and multiplying by 100 (Huedo-Medina, Sanchez-Meca, Marin-Martinez & Botella, 2006). $I^2$ statistics < 25% were classed as low, 26 - 50% were classed as moderate and 51 - 75% were high (Higgins, Thompson, Deeks & Altman, 2003). In this study, heterogeneity was high between studies due to;
varied study and intervention designs (dyadic vs. non-dyadic), participant characteristics, and different sense of competence outcome measures being used. Therefore, a random effects model was employed for the analysis (Higgins et al., 2003; Borenstein, Hedges, Higgins, & Rothstein, 2010) to allow for variance between the studies. Random effects models incorporate true heterogeneity with random error within the analysis.

4.4 Results

The initial search returned 16,749 papers, of which 44 potential full-text publications were extracted. After screening the full-texts, 14 papers met the inclusion criteria. The most common reasons for excluding papers were that they were not intervention studies ($n = 17$) or that they were solely conducted in a population of family carers of people with dementia living in residential care ($n = 4$).

4.4.1 Study characteristics

Following quality assessment, no further papers were excluded. Quality assessment scores, assessment time points and outcome measures are reported in Table 4.1. Of the included studies, nine were of moderate quality and five were of high quality. Of the 14 papers, 11 reported results from RCTs and three reported results from non-randomised trials with control groups. The majority of follow-up assessments were conducted at six months post baseline assessment, however this ranged from two weeks to 12 months. All the papers included a standardised measure of sense of competence. The SCQ was the most common outcome measure (Vernooij-
Dassen et al., 1993) \((n = 6)\). Other sense of competence outcome measures were the SSCQ (Vernooij-Dassen et al., 1999) \((n = 3)\), the modified version of the Feeling of Competence Scale (Teunisse & De Haan, 1994) \((n = 2)\), the carer competence score (Pearlin et al., 1990) \((n = 2)\) and the 17 item carers competence scale (Huang, Shyu, Chen, Chen & Lin, 2003) \((n = 1)\). Sense of competence was the primary outcome measure for carers in three of the included papers (Graff et al., 2006a; Van der Roest, Meiland, Jonker & Droes, 2010; Xaio et al., 2016).

### 4.4.2 Participant characteristics

Half of the studies were conducted in the Netherlands \((n = 7)\), with two studies in the United States of America (USA), and one study each from France, Taiwan, Finland, Germany, and Australia. The mean age of all participants was 58 years \((\text{range} = 55 \text{ to } 75 \text{ years})\). The mean number of participants per study was \(n = 126\) \((\text{range} = 28 \text{ to } 215)\). Participant characteristics are reported in Table 4.2.
Table 4.1 Intervention studies including a sense of competence measure

<table>
<thead>
<tr>
<th>Author</th>
<th>Year/Country</th>
<th>Sample (n)</th>
<th>Design</th>
<th>Sense of competence measure</th>
<th>Intervention and comparison</th>
<th>Data collection</th>
<th>Key findings</th>
<th>Quality score</th>
</tr>
</thead>
<tbody>
<tr>
<td>De Rotrou et al.</td>
<td>2011 France</td>
<td>157</td>
<td>RCT</td>
<td>SCQ</td>
<td>A psycho-educational programme for family carers. 12 structured sessions with training coordinated by a psychologist Comparison = Treatment as Usual (TAU)</td>
<td>Baseline, 3 months (end of intervention) and 6 months.</td>
<td>No significant differences in sense of competence between groups at 3 and 6 months.</td>
<td>71% (20/28) Moderate quality</td>
</tr>
<tr>
<td>Dopp et al.</td>
<td>2015 Netherlands</td>
<td>71</td>
<td>Cluster RCT (clustered by service)</td>
<td>SCQ</td>
<td>A training package to implement a community occupational therapy programme for people with dementia and their carers Comparison = Less comprehensive training package for OTs.</td>
<td>Baseline, 6 months, 12 months.</td>
<td>No significant differences were found on carer sense of competence.</td>
<td>79% (22/28) Moderate quality</td>
</tr>
<tr>
<td>Dröes, Breebaart, Meiland, Van Tilburg &amp; Mellenbergh.</td>
<td>2004 Netherlands</td>
<td>55</td>
<td>Pre-/post-test control group design</td>
<td>Modified version of the Feeling of Competence Scale (Teunisse &amp; De Haan, 1994)</td>
<td>Testing the Meeting Centres Support Programme (MCSP), an integrated support program with people with dementia and their family carers. Comparison = A usual day care centre.</td>
<td>Baseline and 3 months.</td>
<td>No difference in carer competence between intervention and control group at 3 months ($F(184) = 1.22 (p = .14)$.</td>
<td>65% (17/26) Moderate quality</td>
</tr>
<tr>
<td>Author</td>
<td>Year/Country</td>
<td>Sample ((n))</td>
<td>Design</td>
<td>Sense of competence measure</td>
<td>Intervention and comparison</td>
<td>Data collection</td>
<td>Key findings</td>
<td>Quality score</td>
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<tr>
<td>Dröes, Meiland, Schmitz &amp; Van Tilburg</td>
<td>2006 Netherlands</td>
<td>84</td>
<td>Pre-/post-test control group design with two matched groups</td>
<td>Modified version of the Feeling of Competence Scale</td>
<td>Re-evaluating the MCSP programme (previously evaluated in 2004) in new regions. Comparison = A usual day care centre.</td>
<td>Baseline and 7 months.</td>
<td>At 7 month follow-up, there was a moderate positive effect on carers feeling of competence in the intervention group (F (1,36) = 3.4, \ p = 0.04) compared to the control group.</td>
<td>62% (16/26) Moderate quality</td>
</tr>
<tr>
<td>Graff et al.</td>
<td>2006a Netherlands</td>
<td>135</td>
<td>Single blind RCT</td>
<td>SCQ</td>
<td>To determine the effectiveness of 10 one hour sessions of community based occupational therapy (COTID) on daily functioning of people living with dementia and their carers. Comparison = TAU</td>
<td>Baseline, 6 weeks, and 3 months.</td>
<td>At 12 weeks, sense of competence was significantly higher in the intervention group (mean = 107.3) than control group (mean = 89.4).</td>
<td>79% (22/28) High quality</td>
</tr>
<tr>
<td>Hepburn, et al.</td>
<td>2006 USA</td>
<td>215</td>
<td>RCT</td>
<td>Caregiver competence score (Pearlin et al., 1990).</td>
<td>Savvy carers program, a psycho-educational programme for carers of people with dementia. Comparison = TAU, wait-list control.</td>
<td>Baseline, 6 and 12 months.</td>
<td>In the intervention group, sense of competence increased from 3.05 to 3.42 (p &lt; .001) at 6 month follow-up. Sense of competence did not change in the control group.</td>
<td>61% (17/28) Moderate quality</td>
</tr>
<tr>
<td>Author</td>
<td>Year/Country</td>
<td>Sample (n)</td>
<td>Design</td>
<td>Sense of competence measure</td>
<td>Intervention and comparison</td>
<td>Data collection</td>
<td>Key findings</td>
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<tr>
<td>Hepburn, Lewis, Tornatore, Sherman &amp; Bremer et al.</td>
<td>2007 USA</td>
<td>52</td>
<td>RCT</td>
<td>Carer competence score</td>
<td>Second trial of the savvy carers program, a psycho-educational programme for carers of people with dementia. Comparison = TAU, wait-list control.</td>
<td>Baseline and 5-6 months.</td>
<td>Sense of competence improved both groups. However, the increase in the intervention group was statistically greater than that in the control group ($d = .30$). This effect persisted at one year follow-up.</td>
<td>64% (18/28) Moderate quality</td>
</tr>
<tr>
<td>Huang et al.</td>
<td>2012 Taiwan</td>
<td>129</td>
<td>RCT</td>
<td>17 item caregivers competence scale (Huang et al., 2003)</td>
<td>Evaluating an individualised community based carer training programme with telephone consultations. Comparison = Carers received only written instructions and one phone call as opposed to the training programme.</td>
<td>Baseline, 2 weeks, 3 months, and 6 months (after the training program ended).</td>
<td>Family carers who received the intervention had a higher sense of competence ($t = 4.8$, df = 126, $p &lt; .001$) at 3 month follow-up. There was no difference in the control group.</td>
<td>71% (20/28) Moderate quality</td>
</tr>
<tr>
<td>Laakkonen et al.</td>
<td>2016 Finland</td>
<td>136</td>
<td>RCT</td>
<td>SCQ</td>
<td>Self-management group rehabilitation for people with dementia and their spouses. Comparison = TAU</td>
<td>Baseline, 3 months and 9 months.</td>
<td>No significant effects of the intervention or control group were observed on spouses’ sense of competence scores at 3 month follow-up.</td>
<td>82% (23/28) High quality</td>
</tr>
<tr>
<td>Author</td>
<td>Year/Country</td>
<td>Sample (n)</td>
<td>Design</td>
<td>Sense of competence measure</td>
<td>Intervention and comparison</td>
<td>Data collection</td>
<td>Key findings</td>
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<tr>
<td>Spijker et al.</td>
<td>2011</td>
<td>295</td>
<td>RCT</td>
<td>SCQ</td>
<td>Testing the systematic care for carers of people with dementia intervention, which trains professionals to help carers with sense of competence and symptoms of depression. Comparison = TAU</td>
<td>Baseline and 12 months.</td>
<td>No effects of the intervention were found at 12 month follow-up. In the control groups, a lower sense of competence was a significant predictor of the time to institutionalisation (CI: 0.97 - 1.00, Wald $x^2 = 3.15$, df = 1, $p = .08$).</td>
<td>75% (21/28) High quality</td>
</tr>
<tr>
<td>Van der Roest</td>
<td>2010</td>
<td>28</td>
<td>Pre-test and post-test control group design</td>
<td>SSCQ (Vernooij-Dassen et al., 1999)</td>
<td>Evaluating an internet intervention (DEM-DISC; DEMentia-specific Digital Interactive Social Chart), which gives advice to carers based on their needs. Comparison = TAU</td>
<td>Baseline and 2 months.</td>
<td>Carers in the intervention group reported significantly higher levels of competence than controls at 2 month follow-up ($F = 4.11$, df = 1, $p = .03$, $d = .93$).</td>
<td>69% (18/26) Moderate quality</td>
</tr>
<tr>
<td>Van Mierlo, Meiland, Van de Ven, Van Hout &amp; Droes</td>
<td>2015</td>
<td>73</td>
<td>Cluster RCT</td>
<td>SSCQ</td>
<td>Evaluating DEM-DISC further. Comparison = TAU</td>
<td>Baseline, 6 months and 12 months.</td>
<td>No change in sense of competence at 6 months. At 12 month follow-up there was a significant increase in sense of competence in the intervention group $p = .03$.</td>
<td>82% (23/28) High quality</td>
</tr>
<tr>
<td>Author</td>
<td>Year/Country</td>
<td>Sample (n)</td>
<td>Design</td>
<td>Sense of competence measure</td>
<td>Intervention and comparison</td>
<td>Data collection</td>
<td>Key findings</td>
<td>Quality score</td>
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<tr>
<td>Voigt-Radloff et al.</td>
<td>2011 Germany</td>
<td>141</td>
<td>RCT</td>
<td>SCQ</td>
<td>German trial based on Graff et al. (2006a). Translated COTiD and delivered 10 sessions of occupational therapy. Comparison = One home visit and otherwise, TAU.</td>
<td>Baseline, 6 weeks, 16 weeks and 26 weeks, with a postal questionnaire at 52 weeks.</td>
<td>No significant differences were found in carer’s sense of competence at 26 week follow-up. The intervention did not have an effect on carer sense of competence.</td>
<td>79% (22/28)</td>
</tr>
<tr>
<td>Xiao, De Bellis, Kyriazopoulos, Draper &amp; Ullah</td>
<td>2016 Australia</td>
<td>61</td>
<td>RCT</td>
<td>SSCQ</td>
<td>Testing a personalised carer support programme provided by a care coordinator in minority groups. Comparison = Usual carer support group.</td>
<td>Baseline, 6 months and 12 months.</td>
<td>There was an increase in carer sense of competence scores at 12 months compared to controls ($F = 15.76, p &lt; .001$).</td>
<td>64% (18/28)</td>
</tr>
<tr>
<td>Study</td>
<td>n</td>
<td>Age</td>
<td>Gender</td>
<td>Relationship</td>
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<tr>
<td>De Rotrou et al. 2011</td>
<td>157</td>
<td>65</td>
<td>50</td>
<td>107</td>
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<td>Dopp et al. 2015</td>
<td>71</td>
<td>68.9</td>
<td>27</td>
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<td>Dröes et al. 2004</td>
<td>55</td>
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<td>39</td>
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<tr>
<td>Dröes et al. 2006</td>
<td>84</td>
<td>-</td>
<td>15</td>
<td>69</td>
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<tr>
<td>Graff et al. 2006a</td>
<td>135</td>
<td>63.7</td>
<td>40</td>
<td>95</td>
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<tr>
<td>Hepburn et al. 2006</td>
<td>215</td>
<td>-</td>
<td>52</td>
<td>163</td>
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<td></td>
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<tr>
<td>Hepburn et al. 2007</td>
<td>52*</td>
<td>60.5</td>
<td>11</td>
<td>41</td>
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<tr>
<td>Huang et al. 2012</td>
<td>129</td>
<td>55</td>
<td>32</td>
<td>97</td>
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<tr>
<td>Laakkonen et al. 2016</td>
<td>136</td>
<td>75</td>
<td>51</td>
<td>85</td>
<td></td>
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<tr>
<td>Spijker et al. 2011</td>
<td>155</td>
<td>58.8</td>
<td>41</td>
<td>114</td>
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<tr>
<td>Van Der Roest et al. 2010</td>
<td>28</td>
<td>65.1</td>
<td>6</td>
<td>22</td>
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<td>Van Mierlo et al. 2015</td>
<td>73</td>
<td>61.7</td>
<td>32</td>
<td>41</td>
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<tr>
<td>Voigt-Radloff et al. 2011</td>
<td>141</td>
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<tr>
<td>Xiao et al. 2016</td>
<td>61</td>
<td>56</td>
<td>10</td>
<td>51</td>
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</table>

Note: Where no value is reported, it was not available in the paper.

*102 participants recruited into the study but only 52 completed follow-ups. This was the sample upon which the meta-analysis and demographics are based.
4.4.3 Risk of bias

A risk of bias summary was generated in order to explore and illustrate bias in the reported papers (Figure 4.2). Of the included studies, 11 out of the 14 clearly stated the use of random assignment in allocation of intervention or control. The remaining studies \((n = 3)\) employed a pre-test, post-test control design. For the studies that used random assignment, most demonstrated adequate allocation sequence or concealment \((n = 8)\) but in the remainder, it was unclear as the randomisation design was not reported in the paper. Only one of the 14 studies clearly stated that participants were blinded, but this is to be expected in these types of psychosocial interventions, where it would be difficult to conceal allocation from participants. Five of the included studies did not report clear details about whether treatment allocation was concealed from the outcome assessors who administered the follow-up measures. Incomplete outcome data did not appear to be a source of bias in most of the studies \((12 \text{ out of } 14)\), with missing outcome data balanced in numbers across intervention groups and not more than 20% attrition in short-term follow-ups and 30% in long-term follow-ups, which are cut-off scores recommended by the Cochrane handbook (Higgins & Green, 2011).
Figure 4.2 Risk of Bias Summary

Carer Sense of Competence
4.5 Intervention characteristics

A total of 1459 participants were included in the meta-analysis. The pooled effect of psychosocial interventions on sense of competence was compared at post-test to comparator conditions in 14 studies, however the control groups varied. Eight of the studies had a treatment as usual (TAU) control group, with two of these constituting wait-list controls and the rest of the comparator groups \((n = 6)\) contained a comparison rather than TAU. In one of the papers (van Mierlo et al., 2015) the authors were contacted to provide more information as mean and standard deviation scores for 12 months post-test were not reported in the paper. The authors provided this information for baseline and 12 month follow-up.

The combined effect of all psychosocial interventions on sense of competence was moderate \((d = 0.5; 95\% \text{ CI } [0.17, 0.83])\), however, heterogeneity was high \((I^2 = 88\%)\). This was likely due to varying study designs (RCT versus pre-test post-test control), differences in the included interventions (dyadic versus individualised interventions), and control groups (TAU versus active comparison), alongside variability in carer socio-demographics. In order to reduce heterogeneity and explore the data further, subgroup analyses were conducted to explore the efficacy of the different interventions on sense of competence. Subgroups can reduce the amount of heterogeneity by grouping similar studies together. Therefore, similar interventions were grouped and a consensus meeting was held with all supervisors (MO, Dr. Jennifer Wenborn (JW) and MVD) to agree final
subgroups. These subgroups included established methods such as psycho-educational training and occupational therapy interventions whereas others included approaches that were less easy to define, such as mixed interventions of support and training and online interventions. There was similarity between the interventions and therefore there is likely to be some overlap between the subgroups. Effect sizes for all the included studies and subgroups are illustrated in a forest plot in Figure 4.3. Although the pooled SMD is reported for each of the subgroups, this is not necessarily intended for use in ranking the effectiveness of interventions, due to significant heterogeneity between studies and various confounding variables. Key features of each of the interventions are summarised below.
Figure 4.3 Forest plot of intervention subgroups
4.5.1 *Psycho-educational interventions*

Three studies investigated the impact of psycho-educational interventions on sense of competence (de Rotrou et al., 2011; Hepburn et al., 2006; Hepburn et al., 2007). There were 334 participants included in this subgroup. When combining these interventions, there was no distinct heterogeneity ($I^2 = 0\%$).

The psycho-educational interventions in this subgroup focused on education, problem-solving techniques, coping strategies and management of the person with dementia’s behaviour. These interventions were all compared to TAU, though the two Hepburn et al. papers (2006; 2007) were wait-list controls. The pooled effect of the psycho-educational interventions was small ($d = 0.12; 95\% \text{ CI } [-0.10, 0.35]$).

The first study (de Rotrou et al., 2011) was a multi-site RCT and recruited people with dementia and their carers to take part. To be included in the study, carers were required to be providing care for a person with Alzheimer’s disease for a minimum of four hours per week. The psycho-educational training programme was delivered in a group setting to carers over three months with 12 group sessions of approximately two hours once a week. There were between 6 - 10 carers taking part in the groups, which were run by psychologists trained in the intervention. For this study, sense of competence was a secondary outcome measure. In terms of effectiveness, there was a very small SMD ($d = 0.14; 95\% \text{ CI } [-0.23, 0.51]$) and the authors reported no statistically significant increase in sense of competence. The authors hypothesised that sense of competence did not increase due high
levels of behavioural problems of the person with dementia, which were difficult for the carer to manage.

The second study (Hepburn et al., 2006) tested a similar psycho-educational programme and was also a multi-site RCT. The intervention was developed with a theoretical underpinning of the stress-coping models previously described (see Chapter 1; Lazarus & Folkman, 1984; Pearlin et al., 1990). The authors postulated that by enhancing the confidence, skills and education of the carers, the distress associated with caring could be reduced. Participants were included in the study if they were caring for a person with dementia in the community (the number of hours was not specified). This psycho-educational programme focused on developing mastery and a confident attitude towards challenges. The carers attended group sessions for two hours per week over six weeks. Sense of competence was a secondary outcome. There was a small to moderate SMD ($d = 0.15; 95\% \text{ CI } [-0.19, 0.49]$) between the intervention and TAU. The effect on sense of competence persisted at six months and the authors reported a statistically significant within-group difference in sense of competence scores at 12 months post-test.

The third study (Hepburn et al., 2007) also evaluated the previously described intervention (Hepburn et al., 2006). A multi-site RCT was employed across four sites to test how the programme could be used effectively at different sites, employing manuals and a compact disk to train those delivering the sessions. Again, six sessions were used to train carers
in a group setting, for two hours per session. The programme was led by a professional with a clinical or educational background with experience of working with people with dementia. There was a significant difference reported between the intervention and TAU, wait-list control group but the effect size was very small ($d = 0.03; 95\% \text{ CI} [-0.51, 0.57])$.

4.5.2 Professional support

Six studies investigated the impact of professional support on carer sense of competence (Dopp et al., 2015; Voigt-Radloff et al., 2011; Graff et al., 2006a; Huang et al. 2012; Spijker et al., 2011; Xiao et al., 2016). There were 755 participants included in this subgroup. When combining these interventions, the heterogeneity was high ($I^2 = 89\%$) but a random effects model was used to account for this in the analysis. The pooled effect of the psycho-educational interventions was moderate ($d = 0.49; 95\% \text{ CI} [-0.01, 0.96]$). It is probable that the heterogeneity of these interventions was high due to the wide range of study designs and types of support included in the interventions.

Three of these studies with 276 participants in total investigated the Community Occupational Therapy in Dementia programme (COTiD), as a dyadic intervention (Dopp et al., 2015; Voigt-Radloff et al., 2011; Graff et al., 2006a). This intervention was a community occupational therapy intervention and consisted of approximately 10 sessions over 10 weeks. The intervention involved the person with dementia and their family carer working with occupational therapists on meaningful goal setting to improve performance.
in activities of daily living. Graff et al. (2006a) originally developed the dyad intervention. Carers were included in this RCT if they were providing support to person living with dementia in the community at least once a week. Sense of competence was the primary outcome for carers and there was a large effect on sense of competence for carers in the intervention compared to TAU ($d = 1.27$; 95% CI [0.90, 1.65]).

Voigt-Radloff et al. (2011) translated and implemented the COTiD intervention in Germany and thus a different healthcare setting. The control group received one consultation with an occupational therapist. The authors reported a 26% attrition rate, with 37 dyads withdrawing from the study for reasons of over-burden and the involvement of too many professionals in their care. Sense of competence was a secondary outcome measure. In comparison with the Graff et al. (2006a) study, the Voigt-Radloff study did not show an effect of the COTiD intervention on sense of competence, demonstrating a negative SMD ($d = -0.18$; 95% CI [-0.58, 0.21]). Baseline sense of competence scores were lower in the intervention group than the control group and remained so at post-test. The authors suggested that this difference could be because their study included people with more severe dementia than in the Graff et al. (2006a) study, and also that the intervention was translated but not then adapted for specific use in Germany.

The Dopp et al. (2015) study was a cluster RCT, which randomised participants based on the service that they were in. This study evaluated the effectiveness of the usual COTiD intervention training package compared
with providing occupational therapists with a more complex and comprehensive training package. The main outcome for this study was the adherence of the occupational therapists to the programme. Sense of competence was a secondary outcome but inclusion criteria were the same as the original Graff et al. (2006a) study. There was only a small SMD in sense of competence between the intervention and control group ($d = 0.13; 95\% \text{ CI} [-0.47, 0.72]$).

Other professional support interventions incorporated support from care-coordinators or mental health professionals. An intervention of community based training for carers provided by registered nurses, according to a manual developed by the research team was studied by Huang et al. (2012). To be included in the research, carers were required to be spending most of their time caring for the person living with dementia but despite this, the majority of the carers were adult child carers (71%). The nurse was trained to support the carer to identify relevant services and in dealing with BPSD. Carers completed two sessions and then received telephone consultations with the nurse at one week and one month following the sessions. The control group received printed sheets with general information. There was a large SMD in sense of competence scores between the intervention and control groups ($d = 0.99; 95\% \text{ CI} [0.62, 1.35]$).

A similar intervention by Spijker et al. (2011) trained mental health professionals from community mental health services to support carers. This intervention was adapted from existing interventions (Vernooij-Dassen,
1993; Graff et al., 2006a) with the aim for it to be embedded in usual care. In order to participate in this RCT, carers were required to be providing support to the person living with dementia at least twice a week. This was a dyadic intervention but the support was adjusted dependent on the carers needs, following an initial assessment. The mental health professionals were trained to assess sense of competence and levels of depression in the carer and subsequently implement strategies to improve carer sense of competence. The effectiveness of the training programme was compared to TAU and sense of competence was a secondary outcome. No significant effect of the intervention was found on sense of competence but the authors suggested that the intervention might prevent deterioration of sense of competence, depending on the intensity of the programme. The SMD between sense of competence scores for the intervention and control was small (\(d = 0.11; 95\%\ CI [-0.13, 0.34]\)).

Xiao et al. (2016) aimed to test the hypothesis that personalised carer support by a care-coordinator would improve sense of competence for carers in minority groups. To take part in the research study, carers were required to be the primary carer and to be caring twice per week for the person with dementia for over a year. This study was a single site RCT running across seven community service providers. The intervention was compared to a usual carer support group. The care-coordinators were trained to support the carers and encouraged them to use a diary to record challenges in daily caring. The care-coordinators used the diary to identify challenges that the carer was having and provided tailored support to
address these challenges. Sense of competence was the primary outcome in this study. The intervention had a moderate effect on sense of competence ($d = 0.59; 95\% \text{ CI} [0.08, 1.11])$.

**4.5.3 Group support and training**

Three interventions consisted of group support and training (Dröes et al., 2004; Dröes et al., 2006; Laakkonen et al., 2016). There were 389 participants in this subgroup. The pooled effect of these interventions was small ($d = 0.25; 95\% \text{ CI} [-0.05, 0.54]$). Heterogeneity was not large ($I^2 = 10\%$), however, due to observed variation between the interventions and the outcome measures used, a random effects model was employed.

Two of these studies evaluated the Meeting Centres Support Program (MCSP), which aimed to provide information alongside practical, emotional and social support (Dröes et al., 2004; Dröes et al., 2006). This intervention was an integrated and dyadic support programme where carers and the person with dementia were both supported, compared to a regular day care group. It consisted of ten meetings and a discussion group every other week. Sense of competence was included as a secondary outcome in both studies. The first study (Dröes et al., 2004) used a quasi-experimental, pre-post control group design with matched groups. The experimental arm had a slightly lower sense of competence than the control group at post-test ($d = -0.08; 95\% \text{ CI} [-0.74, 0.59]$), however, the sense of competence scores were also lower at baseline. The authors reported a statistically significant increase in sense of competence scores between baseline and follow-up for
Carer Sense of Competence

carers in the intervention group, whereas in the control group sense of competence scores reduced. The second study (Dröes et al., 2006) re-evaluated the MCSP in other regions. To be included in this study, carers were required to be providing support at least once a week. There was a very small difference between groups ($d = 0.07$; 95% CI [-0.53, 0.66]).

Laakkonen et al. (2016) reported results from a single site RCT evaluating a group intervention, which trained carers in self-management techniques and supported them after their relative or friend received a diagnosis of dementia. This study compared the effects of self-management group rehabilitation with TAU. The aim of the intervention was to empower carers and promote self-efficacy. This was a dyadic intervention for the person with dementia and carers however they took part in separate groups. The intervention ran over eight sessions and was facilitated by two professionals who had been trained to deliver the intervention. This intervention was targeted towards dyads that had recently received a diagnosis of dementia. Sense of competence was the secondary outcome. There was not a statistically significant difference in sense of competence reported in the paper. The authors suggested that this could be because the participants in this intervention had just been diagnosed and were in the early stages of dementia and therefore the carers in this study had not needed to make many adaptions to manage their caring role. In this analysis however, a moderate SMD in sense of competence scores at post-test ($d = 0.42$; 95% CI [0.08, 0.76]) was found.
4.5.4 Web-based information provision

Two studies with a total of 110 participants evaluated the DEMentia-specific Digital Interactive Social Chart (DEM-DISC), which is a personalised search engine for family carers, providing answers about care and support services in their local area (van der Roest et al., 2010; Van Mierlo et al., 2015). The pooled effect of these interventions was large ($d = 1.06; 95\% \text{ CI} [0.26, 1.86]$). However, the heterogeneity was high considering that the interventions were the same ($I^2 = 88\%$). This could have been because the first study was a pre-post test control group study and was not randomised, whereas the second study was a cluster RCT. Additionally, the second study had a larger sample size ($n = 73$ compared to $n = 28$). The intervention was designed to be accessible at any time and tailored to the individual. The control group in both studies had no access to this information and received TAU. The carers were required to be supporting the person with dementia for at least four hours per week. Sense of competence was included in the first study (van der Roest et al., 2010) as the primary outcome for carers, and was a secondary outcome in the Van Mierlo et al. (2015) study. The results of the van der Roest et al., (2010) study indicated a large effect on sense of competence ($d = 1.06; 95\% \text{ CI} [0.26, 1.86]$). The authors theorised that the intervention was effective because carers were coping better as they felt they could use the DEM-DISC to better organise care for the person living with dementia. The study by Van Mierlo et al. (2015) also demonstrated a large effect of DEM-DISC ($d = 2.51; 95\% \text{ CI} [1.93, 3.10]$). In the Van Mierlo et al. (2015) study, the carers were given case managers who supported them in their use of the DEM-DISC, which was not the case
in the original study by van der Roest et al., (2010). The authors report that carers found the regular support from the case manager useful and hypothesised that this support drove the increase in sense of competence.

4.6 Discussion

This review is the first to systematically examine the effect of psychosocial interventions on family carer sense of competence. There was evidence that most of the identified psychosocial interventions contain elements that are effective in improving sense of competence, consistent with previous literature (van Mierlo et al., 2012). There were 14 interventional studies included in the review and the overall pooled effect of interventions on sense of competence was moderate ($d = 0.5$). However, the effect sizes between the different interventions varied and there was high heterogeneity between the studies. The interventions included varying participant characteristics, individual and group support and the follow-up times ranged from two weeks to one year. Several of the studies had small sample sizes and there was a mix of RCTs and non-randomised trials. A random effects model accounted for this to a degree, but results should be interpreted with caution.

There did not appear to be any difference between interventions that were low or high intensity or between those that had a short or long period of support, although this was not statistically examined due to heterogeneity between study designs. Additionally, although the description of the interventions within the included papers was generally good across studies, it was often unclear how treatments were standardised across participants.
and research sites. This made it difficult to describe the results and may therefore present difficulties when interpreting the results from this meta-analysis.

This review evaluated a wide range of interventions and strategies. Psycho-educational interventions generally demonstrated a small effect size. Previous literature (Thompson et al., 2007) has reported that interventions aimed at supporting or providing information to carers of people with dementia are not consistently effective. The results from this review echoed this to a certain extent, as small effects were found in each of the included interventions in the psycho-educational subgroup. Additionally, the group support and training interventions did not appear to have a large effect on sense of competence. The study by Laakkonen et al. (2016) had the largest effect on sense of competence within this group, possibly because the intervention provided self-management techniques that were specifically aimed at empowering carers and promoting self-efficacy.

More encouraging results were seen for interventions that provided professionals with training to support carers of people living with dementia. Within these, the occupational therapy interventions were moderately effective, though this was driven by the large effect size of the Graff et al. (2006a) study. The studies by Huang et al. (2012) and Xiao et al. (2016) also demonstrated a positive effect on sense of competence, training registered nurses and care-coordinators to provide structured care over a long period of time. The only research study in this subgroup that had no effect on sense of
competence was Spijker et al. (2011). This may have been because the support was less structured and the intensity of the programme was decided on an individual basis by the mental health professional, rather than the carer themselves driving the intervention intensity.

The subgroup with the largest effect size was two interventions testing the personalised and computerised education intervention, DEM-DISC \((d = 1.81)\). This intervention was accessible to the carers at any time and was personalised to their local area and caring context. It may be that enabling the carers to access just the information they needed increased their sense of competence as they felt they were making their own choices, rather than being provided information that may not be relevant. It is theoretically likely that this would improve sense of competence in carers of people living with dementia as it empowers carers to seek support when required. However, the two studies evaluating the DEM-DISC had small sample sizes and therefore may be underpowered. It would be beneficial to test this intervention in a larger sample size, using an RCT design.

It is clear that sense of competence is sensitive to change and can be increased by interventions, indicating that it is a modifiable domain. From these results it appears that different aspects of interventions may be useful to carers. The interventions that provided the carers with the power and autonomy to access help and support (both practical and emotional), when they needed it had the greatest effect on sense of competence. It may be that this made them feel empowered, and able to ‘learn themselves’,
knowing that assistance or support is there when they need it. This reflects findings from a recent report on dementia, which recommended that interventions should be tailored and designed for the family carer and have multiple components, allowing the carer to make ‘active choices’ (Livingston et al., 2017).

4.6.1 Limitations

The author included broad search criteria and identified search terms from existing literature, ensuring a thorough search. However, there were several limitations in this review. Overall, the evidence is relatively robust considering that the quality of included studies was moderate to high; however, there was a lack of clarity in the risk of bias assessment, with some studies failing to report whether outcome assessors were blinded (n = 4). Although it is not always feasible with psychosocial interventions to blind participants who are actively taking part in the interventions, only one of the studies was a double blind RCT, which is considered the ‘gold standard’ in empirical research. In addition, six of the included studies did not measure the intervention against a TAU control group, which presented difficulties when pooling the data to compare the efficacy of the intervention. All of the subgroup analyses were performed between interventions, and it was not possible to conduct within-interventions subgroup analyses due to the limited amount of data available in the papers. In addition, this meta-analysis only included results of published studies, as grey literature was not searched and therefore although a thorough search was conducted, relevant studies may have been missed and this review may be subject to publication bias.
The included papers did not make it clear which subgroups benefitted the most from the intervention. For example, outcomes were not often split or explored by gender, age or ethnicity. In addition, it was not clear whether there was a difference between carers who were experiencing mental health problems themselves and whether this could be a mediating factor in the effectiveness of the interventions on sense of competence. Additionally, several of the included studies had low sample sizes and were underpowered, which may have subsequently reduced the power of the meta-analysis. This review combined the results of several sense of competence outcome measures in the pooled analysis, which may present a methodological limitation due to differences in operationalisation between the scales. In order to minimise the impact of this on the review, the author only included studies where sense of competence had been measured with a validated and standardised outcome measure.

4.6.2 Implications and future research

The results from this meta-analysis indicate that psychosocial interventions are generally effective at improving sense of competence. There were a wide variety of interventions that were effective, but there were specific components of the interventions that appeared to be most helpful to carers. Interventions that allowed carers to access the support that they needed at a time relevant for them were the most effective at improving sense of competence, such as the DEM-DISC intervention and therefore should be developed and robustly evaluated.
Most interventions are time-limited, whereas caring for a person with dementia can last for many years, with points of crisis occurring at various points and the person with dementia potentially deteriorating over time. Different types of support or interventions are needed at different stages. If psychosocial interventions are to be successful, they must be developed and tested for long-term results and studies should therefore include a long-term follow-up. The longest follow-up found in this review was one year but the majority terminated after a few months, which did not provide sufficient information about whether they would be suitable for carers at all stages of dementia. Therefore, it is recommended that interventions are designed with longer follow-ups in mind, with the potential to apply for more funding to conduct further testing of successful interventions on a longer-term basis.

The majority of included studies were of moderate quality. More rigorous RCTs with larger sample sizes are required, with more clarity in the reporting of trial design. Therefore, it is recommended that interventions are rigorously tested in order for researchers to draw conclusions on the most effective support for carers. Additionally, the selection of outcome measures is important when evaluating the success of psychosocial interventions. Therefore, standardisation and agreement on the measurement of sense of competence would aid in a more robust comparison of interventions.
4.7 Conclusion

This review has clinical relevance as it demonstrates that psychosocial interventions can have positive effects and improve carer sense of competence. Importantly, a range of interventions were shown to be successful in this review but those that enabled the carers to guide the intensity or type of support were the most successful at improving sense of competence. These results indicate that it is not beneficial for interventions to be focused on one strategy or component, rather, researchers should consider the issue of personalisation and timing in the design of interventions. It is recommended that future interventions should provide the carer with the opportunity to access aspects of support that are tailored to their needs and the resources they require at that time. This would ensure that the right intervention is available to carers, at the right time.
Chapter 5  Investigating the relationship between positive psychology factors and carer sense of competence: A national survey of family carers of people living with dementia

5.1 Introduction

As described in Chapter 3, previous literature has reported positive correlations between sense of competence and self-efficacy (Fortinsky et al., 2002), the ability to find meaning in caring (Quinn et al., 2012a, 2012b), and the use of positive coping strategies (Lau & Cheng, 2015). However, no positive concepts are incorporated in the existing conceptual model of sense of competence (Section 1.5). Thus, there is a need to address this gap in the literature and update the existing theory of sense of competence. Therefore, a national survey was conducted to explore the relationship between sense of competence and positive psychology factors.

SECTION A: The association between sense of competence and positive psychology factors.

5.2 Aim

To explore the association between carer sense of competence and positive psychology factors.

5.3 Objectives

I. To investigate whether sense of competence is associated with and predicted by positive psychology factors: resilience, self-efficacy, gains in caring and sense of coherence.
II. To explore if sense of competence is associated with and predicted by health related quality of life (HRQoL) and social engagement.

5.4 Hypotheses

I. Increased sense of competence will be associated with higher resilience, self-efficacy, gains in caring, sense of coherence (positive psychology factors), HRQoL and social engagement.

II. Positive psychology factors will significantly predict carer sense of competence.

5.5 Method

5.5.1 Pilot phase participants

A pilot phase of the survey was conducted in order to ensure that it could be completed in the 15 minutes stated in the information sheet and that there were no difficulties with understanding the items. Out of 10 family carers who were invited to participate, eight completed the pilot survey. Participants were identified through the Join Dementia Research (JDR) register, a National Institute of Health Research (NIHR) initiative. The JDR is a register to which people with dementia and their family carers sign up to express their interest in taking part in relevant research. A comments box was included the end of the pilot survey.

5.5.2 Main survey participants

Participants for the main survey were 583 family carers of people living with dementia in the community. Family carers were identified through the JDR
register and matched with the inclusion criteria for the survey. Participants were also identified through adverts placed in newsletters or mail-outs of participant information leaflets containing a response slip and freepost envelope, through the contact lists of relevant charitable organisations for older people, people with dementia and their family carers. The charitable organisations that assisted with recruitment for this survey were: Havering Tapestry, Age UK Oxfordshire and Carers Oxfordshire. Carers who expressed an interest in completing the survey were emailed or contacted by phone with a link to the online version of the survey on SurveyMonkey but were also offered a paper copy of the survey with a freepost envelope for them to return the completed survey.

5.5.3 Inclusion criteria

To be eligible to take part in the survey, family carers had to meet the following inclusion criteria:

- Aged 18 or over
- Currently providing support with domestic and/or personal activities to the person with dementia
- Able to complete a survey in English
- Caring for a person with dementia who is currently living in the community

5.5.4 Data collection

In both the pilot and main survey, participants were first asked to read the information sheet and then give informed consent (Appendix 2.1) before
continuing with the survey. Respondents were unable to continue with the survey unless they had read the information and consented to take part. In order to consent, participants had to click to agree with every point on the consent form. There were two sections to the survey. Section one consisted of demographic questions about the family carer and the person with dementia that they supported. Section two consisted of positive psychology outcome measures, a social engagement measure and a HRQoL measure.

The pilot phase was conducted in July 2016. Recruitment for the main survey commenced in August 2016 and continued until January 2017. Carers completing the main survey were offered the opportunity to enter their details to win £50 Marks and Spencer vouchers in a prize draw.

5.5.5 Data collected (Appendix 2.2)

A demographic section collected information about the family carer and their friend or relative with dementia such as: age, gender, education, relationship status, plus the relationship between the family carer and the person they support, and the type of dementia that the person with dementia was diagnosed with.

SSCQ (Vernooij-Dassen et al., 1999): A 7-item measure derived from the longer, 27-item Sense of Competence measure. Scores can range from 7 to 35 and items are scored on a 5-point Likert scale from 1 (agree very strongly) to 5 (disagree very strongly). The reliability of the scale has been reported as good (α = .76; Vernooij-Dassen et al., 1999).
Carer Sense of Competence

Sense of Coherence Scale- 13 item (SOCoh-13; Antonovsky, 1987): A 13-item scale adapted from the longer 29-item scale (Antonovsky, 1987) with three subscales: meaningfulness (four items), comprehensibility (five items) and manageability (four items). Each item contains seven response options on a Likert scale for each question, with options changing between each item (for example, ‘very seldom’ or ‘never’ to ‘very often’). Five of the items were negatively worded and were reverse coded when summing the items to reach an item total, which can range from 13 – 91. A higher score represents a higher sense of coherence. Reliability estimates are good and range from $\alpha = 0.70 - 0.92$ (Eriksson & Lindstrom, 2005). The sense of coherence scale was included in this study as it was identified in Chapter 2 as a commonly used scale with family carers. The psychometric properties of the scale with this population were evaluated and the results are reported in a separate paper, currently published in the journal Health and Quality of Life Outcomes (Appendix 6).

Resilience Scale-14 (RS-14; Wagnild, 2009): A 14 item scale, derived from the original 25-item resilience scale (Wagnild & Young, 1993). Items are scored from one (strongly disagree) to six (strongly agree), with scores ranging from 14 to 84. The higher the score, the higher the level of resilience. The resilience scale identified in Chapter 2 was the shortened resilience scale (Wilks, 2008), which had been shortened from the resilience scale - 25 items (RS-25) without permission from the authors. Therefore, the RS-14 was utilised in this survey. Despite not being validated with this
population, it is commonly used in the existing literature, with good reliability estimates \((\alpha = .82\) and \(\alpha = .94;\) Wagnild, 2009).

SEMD (Fortinsky et al., 2002): Identified in Chapter 2, this is a 10 item scale that measures carers self-efficacy for managing the task of caring. Responses to each of the items are on a Likert scale from 1 (not at all certain) to 10 (very certain). Item scores are summed with total possible scores ranging from 10 to 100. Reliability scores for this scale are good \((\alpha = 0.77;\) Fortinsky et al., 2002).

GAIN (Yap et al., 2010): This is a 10 item scale with five response options from 0 (disagree a lot) to 4 (agree a lot). Item scores are summed to generate a total score, which can range from 0 – 40 and higher scores denote a higher feeling of gains in caring. This measure has good reliability \((\alpha = .89)\) and validity estimates (Yap et al., 2010) and was identified in Chapter 2 as a robustly developed measure.

The European Quality of Life – Five Dimensions, Five Level (EQ-5D-5L; EuroQol Group, 2009) measure provides a profile of self-reported HRQoL. The EQ-5D-5L is made up of two sections. First, there are questions pertaining to five dimensions (mobility, self-care, activity, pain/discomfort, anxiety/depression) of HRQoL with responses on a five point Likert scale. For the first three dimensions (mobility, self-care and usual activities), the response options are: no problems, slight problems, moderate problems, severe problems or extreme problems. For the pain/discomfort and
anxiety/depression dimensions, the response options are: None, slight, moderate, severe or extreme. Item scores for each dimension are converted into a single index value, with higher scores indicating a higher quality of life. The second section is a Visual Analogue Scale (VAS), where respondents are asked to rate their health today on a scale from 0-100, with a higher score indicating a better HRQoL (this is the EQ-VAS). The EQ-5D-5L has been used in a wide range of study populations due to its high reliability and good validity (Pickard, Wilke, Hsiang-Wen & Lloyd 2007; Dyer, Goldsmith, Sharples & Buxton, 2010; Noyes & Edwards, 2011).

The Lubben Social Network Scale- 6 item (LSNS-6; Lubben et al., 2006) is a self-report measure of social network size and engagement with family and friends. There are five possible response options for all the questions (0 = none, 1 = one, 2 = two, 3 = three, four, 4 = five – eight, 5 = nine or more), with each response option indicating the number of friends or family that respondents have for a variety of scenarios (for example, how many relatives of friends could be called on for help in a difficult time). Item scores are summed and the range of scores is 0 - 30, with a higher score indicating higher social engagement. This measure has good reliability estimates (α = .89; Lubben et al., 2006).

Qualitative data collection

Five qualitative questions were included to assess the content validity of the sense of coherence scale:
Did you find any of the 13 questions difficult to understand?
Is there anything you would add to the 13 questions above?
Is there anything you would change in the 13 questions above?
Is there anything you would remove in the 13 questions above?
Do you have any other comments about the 13 questions above?

An additional question at the end of survey stated: “If you have any comments about your experience completing this survey, please enter them below”.

5.5.6 Patient and Public Involvement (PPI)
Three former carers who were PPI representatives on the VALID research programme were consulted on the development of participant recruitment materials. Their feedback was incorporated, which included changing the images to incorporate more inclusive and active images on the front page and making the language more accessible.

5.5.7 Confidentiality
Confidentiality of participants was upheld at all times according to guidance in the Data Protection Act (1998). Every survey participant was assigned a unique participant identification code for when data was downloaded from SurveyMonkey and entered onto Statistical Package for the Social Sciences (SPSS). Completed hard copies of the survey were stored in locked filing cabinets.
5.5.8 Ethical approval

Ethical approval for this study was received as a substantial amendment to the VALID trial (Research Ethics Committee (REC) reference number: 14/LO/0736 / ISRCTN10748953) through the Camberwell St Giles NRES Committee.

5.5.9 Pilot survey data analysis

All data was downloaded from SurveyMonkey onto SPSS Version 25 and data from the hard copies were entered onto the SPSS database. The data was then visually inspected by generating scatterplots and frequency tables for outliers and missing data. Outliers were defined as cases that were significantly outside the pattern of distribution of the rest of the data (Moore and McCabe 1999). Percentages were calculated for each of the demographics.

5.5.10 Main survey data analysis

For the main survey phase, the data was analysed in accordance with a pre-defined statistical analysis plan which was developed by the author and agreed with the VALID statistician, Doctor Aidan O'Keefe. A significance level of $p = 0.05$ was employed for all analyses. Descriptive analyses were conducted to generate frequencies, means, standard deviations and percentages. T-tests and analysis of variance (ANOVAs) were conducted to compare sense of competence scores for different carer and person with dementia demographics.
The association between sense of competence, positive psychology factors, social engagement and HRQoL was explored with Pearson’s correlation coefficients. Linear regressions were also performed. Regression analysis is the next step from correlational analysis and explores how much variance in one concept can be explained by another, indicating how much one variable can predict the other. With large samples there is an increased chance of obtaining statistically significant findings, therefore Cohen’s (1988) guidelines were used to interpret effect sizes. Cohen (1988) advises that a relationship size (r) of 0.10 to 0.29 indicates a small effect, 0.30 to 0.49 is considered a moderate effect and 0.50 – 1.0 is considered a large effect.

There are several assumptions that need to be met in order for a regression analysis to be valid (Poole & O’Farrell 1971) and these were assessed as follows:

I. The sample size must be sufficient. Recommendations in the literature are for approximately ‘15 cases per predictor’ (Stevens, 1996, p. 72).

II. Variables in the model should be continuous.

III. The relationship between the dependent and independent variable is linear. This was assessed by visually scanning scatterplots to ascertain if this assumption had been met.

IV. There is no multicollinearity in the data. This was assessed by looking at collinearity statistics. If VIF scores were under 10 and tolerance scores were above 0.2, then this assumption was met.
V. The values of the residuals are independent. The Durbin-Watson statistic was used to ascertain if this assumption was met. If Durbin-Watson value was close to 2, this assumption was considered met.

VI. Data do not show homoscedasticity. To explore whether this assumption was met, the plot of standardised residuals vs standardised predicted values was scanned for signs of funneling. If no obvious signs of funneling or no extreme deviations were present this assumption was met.

VII. Observations should be independent. Cook’s distance values were calculated and, if under 1, it indicates that there are no influential cases biasing the model.

5.5.11 Missing data

Missing data (items and measures) were investigated and a missing value analysis was performed to determine the extent to which the clinical variables had missing values. A very small amount of missing data was found, between 3.9 - 6.7% on all variables. The missing data were explored to ascertain whether they were missing completely at random, using Little’s Missing Completely At Random (MCAR) test. If data was missing completely at random, the assumption was made that it would not affect the analysis to a significant degree, based on published guidance for dealing with missing data (Kang, 2013; Briggs, Clark, Wolstenholme & Clarke, 2003; Nakai & Ke, 2011). If the assumption of MCAR is met, list-wise deletion is considered an appropriate way to deal with small amounts of missing data in a large sample (Kang, 2013; Soley-Bori, 2013). In this dataset, the assumption of
MCAR was met, indicating that there was not systematic missing data and that data were missing completely at random. Therefore, the missing data was excluded list-wise from analysis in order to have a complete dataset, rather than using multiple imputation or other methods for handling missing data. Boxplots and scatterplots were generated to identify outliers. There were between 0 - 6.8% outliers present on all variables. Outliers were explored with regard to whether they impacted the analysis by running all analysis with and without the outliers present. None of the outliers significantly affected the results from the analysis; therefore, all were left in in order to retain a complete dataset.

5.6 Results

5.6.1 Pilot survey:

A question in the demographics section about the relationship between the family carer and the person with dementia, proved difficult for the participants to understand and consequently the wording was changed to make this clearer. There was no question that was repeatedly skipped or missed. The general comments about the survey were largely positive, e.g. “It was easy and nice, some make you feel worse and unhappy and depressed, but this was a great one to fill in”.

The mean age of carers completing the pilot survey ($n = 8$) was 52, with a range between 39 to 64. Family carers were all female, white British and were all adult child carers. Half of the carers were married, with 75% having completed further education. The majority were in current employment
(62.5%) and were not cohabiting with the person with dementia (62.5%). The people with dementia that they supported had a mean age of 80 years, with a range from 69 - 90. They were mostly female (75%) and were largely of white British ethnicity (87.5%). The most common diagnosis was Alzheimer's Disease (62.5%), but 12.5% had vascular dementia, 12.5% had fronto-temporal dementia and 12.5% did not know the diagnosis.

5.6.2 Main survey:

583 family carers of people living with dementia took part in the survey and demographics are summarised in Table 5.1. Most participants \( (n = 516, 89\%) \) opted to complete the online version of the survey. Carers who completed the online questionnaire were significantly younger (mean age = 58.3) than those who completed the paper version (mean age = 69; \( t = -6.7, p < .001 \)). Due to the varied strategies used for recruitment it was not possible to calculate the response rate. The mean age of carers was 59.5, with a range of 18 to 89. Family carers were mostly female (80.3%) and white British (93.2%). Over half of the participants were adult child carers (58.9%) and just under half were cohabiting with the person with dementia (42.7%). The highest education level of the majority of carers was secondary education (55.2%). The people with dementia that the carers supported had a mean age of 80, with a range of 39 to 99. The majority were female (63.4%) and half were married (50.3%). Almost all were white British (92.4%) and half of the people with dementia had a diagnosis of Alzheimer's Disease (50.5%).
<table>
<thead>
<tr>
<th>Demographics</th>
<th>Carer</th>
<th>Person with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong> n (%)</td>
<td>(n = 573)</td>
<td>(n = 571)</td>
</tr>
<tr>
<td>Female</td>
<td>460 (80.3)</td>
<td>362 (63.4)</td>
</tr>
<tr>
<td>Male</td>
<td>113 (19.7)</td>
<td>209 (36.6)</td>
</tr>
<tr>
<td><strong>Age M (SD) Range</strong></td>
<td>(n = 571)</td>
<td>(n = 556)</td>
</tr>
<tr>
<td></td>
<td>59.5 (12.3) 18-89</td>
<td>80 (9.5) 39-99</td>
</tr>
<tr>
<td><strong>Marital status</strong> n (%)</td>
<td>(n = 576)</td>
<td>(n = 571)</td>
</tr>
<tr>
<td>Single</td>
<td>81 (14.1)</td>
<td>17 (3)</td>
</tr>
<tr>
<td>Married</td>
<td>397 (68.9)</td>
<td>287 (50.3)</td>
</tr>
<tr>
<td>Divorced/ Separated</td>
<td>55 (9.6)</td>
<td>35 (6.2)</td>
</tr>
<tr>
<td>Widow/widower</td>
<td>13 (2.3)</td>
<td>227 (39.8)</td>
</tr>
<tr>
<td>Other</td>
<td>30 (5.2)</td>
<td>5 (0.9)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong> n (%)</td>
<td>(n = 573)</td>
<td>(n = 568)</td>
</tr>
<tr>
<td>White British</td>
<td>537 (93.2)</td>
<td>525 (92.4)</td>
</tr>
<tr>
<td>Mixed British</td>
<td>4 (0.7)</td>
<td>1 (0.2)</td>
</tr>
<tr>
<td>Other White</td>
<td>21 (3.6)</td>
<td>28 (4.9)</td>
</tr>
<tr>
<td>Asian</td>
<td>8 (1.4)</td>
<td>10 (1.8)</td>
</tr>
<tr>
<td>Black Caribbean/African</td>
<td>3 (0.5)</td>
<td>4 (0.7)</td>
</tr>
<tr>
<td><strong>Education completed</strong> n (%)</td>
<td>(n = 574)</td>
<td>(n = 567)</td>
</tr>
<tr>
<td>Primary or less</td>
<td>3 (0.5)</td>
<td>30 (5.3)</td>
</tr>
<tr>
<td>Secondary</td>
<td>136 (23.7)</td>
<td>313 (55.2)</td>
</tr>
<tr>
<td>Further</td>
<td>409 (71.3)</td>
<td>163 (28.7)</td>
</tr>
<tr>
<td>Other</td>
<td>26 (4.5)</td>
<td>61 (11.7)</td>
</tr>
<tr>
<td><strong>Relationship to person with</strong></td>
<td>(n = 574)</td>
<td></td>
</tr>
<tr>
<td>Dementia n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>173 (30.1)</td>
<td></td>
</tr>
<tr>
<td>Son/daughter</td>
<td>338 (58.9)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>63 (11)</td>
<td></td>
</tr>
<tr>
<td><strong>Cohabiting</strong> n (%)</td>
<td>(n = 574)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>245 (42.7)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>329 (57.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Receiving support</strong> n (%)</td>
<td>(n = 572)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>355 (62.1)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>161 (28.1)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>56 (9.8)</td>
<td></td>
</tr>
<tr>
<td><strong>Dementia diagnosis</strong> n (%)</td>
<td>(n = 570)</td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Disease</td>
<td>288 (50.5)</td>
<td></td>
</tr>
<tr>
<td>Vascular</td>
<td>108 (18.9)</td>
<td></td>
</tr>
<tr>
<td>Lewy Bodies Dementia</td>
<td>19 (3.3)</td>
<td></td>
</tr>
<tr>
<td>Fronto-temporal</td>
<td>22 (3.9)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>133 (23.3)</td>
<td></td>
</tr>
</tbody>
</table>
5.6.3 Family carer clinical variables

Carers generally had high levels of resilience (Table 5.2), with a mean of 76.1 (SD = 11.8). Self-efficacy (M = 55.9, SD = 18.5) and sense of competence scores (M = 23.3, SD = 5.5) were moderate to high across the whole sample. The ability to find gains in caring was generally high amongst the family carers in this sample (M = 24.9, SD = 7.6). There were good levels of social engagement (M = 20.9, SD = 5.6) and carers had high HRQoL (mean index value = .77, SD = .18, mean EQ-VAS = 76.5, SD = 43.18).

Table 5.2 Family carer clinical variables (n = 583)

<table>
<thead>
<tr>
<th>Measure</th>
<th>M</th>
<th>Mdn</th>
<th>SD</th>
<th>Range of scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>RS-14 Resilience</td>
<td>76.1</td>
<td>78</td>
<td>11.8</td>
<td>19 - 93</td>
</tr>
<tr>
<td>SSCQ Sense of competence</td>
<td>23.3</td>
<td>24</td>
<td>5.5</td>
<td>7 - 35</td>
</tr>
<tr>
<td>SEMD Self-efficacy</td>
<td>55.9</td>
<td>55</td>
<td>18.5</td>
<td>10 - 100</td>
</tr>
<tr>
<td>SOCoh-13 Sense of coherence</td>
<td>60.2</td>
<td>60</td>
<td>14</td>
<td>17 - 90</td>
</tr>
<tr>
<td>GAIN Gain in Alzheimer Caring</td>
<td>24.9</td>
<td>25</td>
<td>7.6</td>
<td>0 - 40</td>
</tr>
<tr>
<td>EQ-5D-5L Health-related quality of life</td>
<td>.77</td>
<td>.77</td>
<td>.18</td>
<td>-.05 - 1</td>
</tr>
<tr>
<td>EQ-5D-5L VAS</td>
<td>76.5</td>
<td>80</td>
<td>43.18</td>
<td>0 - 100</td>
</tr>
<tr>
<td>LSNS-6 Social network</td>
<td>20.9</td>
<td>21</td>
<td>5.6</td>
<td>0 - 30</td>
</tr>
</tbody>
</table>

*Note: All scales were positively scored.*
5.6.4 Distribution of the data

The data were inspected using histograms to assess normality (Field, 2009; Tabachnick & Fidell, 1996). Several of the scales demonstrated skew and/or kurtosis but these scores were not large enough to be of concern. Skewness indicates whether scores fall towards the higher (positive) or lower (negative) end of the scale and kurtosis denotes the steepness of the curve, with negative kurtosis values indicating a flat curve and positive values indicating a peaked curve. The majority of the variables were normally distributed, with slight positive skews shown on the SSCQ, sense of coherence scale and a larger positive skew found on the resilience scale (Appendix 5). For sample sizes greater than 300, an absolute skew value larger than two or kurtosis values larger than seven indicate substantial abnormality (Kim, 2013) and when scores are smaller than these cut-off points, parametric tests can be used without transformation of the data. The skewness and kurtosis scores in this data were all in the acceptable specified range and therefore parametric tests were used in all analyses.

5.6.5 Profile of sense of competence in family carers

The profile of sense of competence was calculated for the entire sample. Figure 5.1 illustrates the distribution of scores. The slight positive skew indicates that family carers were more likely to report higher levels of sense of competence.
5.6.6 Carer demographics and sense of competence

Scores on the SSCQ were evaluated using independent sample t-tests and one-way ANOVA with post-hoc Tukey test to evaluate whether they differed depending on carer and person with dementia demographics. Results are summarised in Table 5.3.

Carers who reported receiving additional help or support from friends or relatives with the person with dementia (M = 24.1) had a significantly higher sense of competence (t (502) = 3.4, p = .001) than those who did not (M = 158).
There were also differences in sense of competence scores \((F(2,556) = 4.7, p = .009)\) between type of relationship. Post-hoc comparisons using the Tukey test indicated that the mean sense of competence score for ‘other’ relationships (e.g. sibling, grandchild, niece/nephew \([M = 15.3]\)) were significantly lower than for spouse/partner \((M = 22.8)\), or adult child carers \((M = 23.2)\).

There were no significant differences in sense of competence between males \((M = 23.6)\) and females \((M = 23.2)\) \((t(556) = -.69, p = .48)\), between respondents who were cohabiting with the person with dementia \((M = 23)\) and those who were not \((M = 23.5)\), \((t(557) = -1.17, p = .24)\). There were no differences in sense of competence for different diagnoses of dementia \((Alzheimer’s disease \([M = 23.9, SD = 5.7]\), vascular dementia \([M = 22.7, SD = 5.8]\), dementia with Lewy bodies \([M = 24.7, SD = 3.7]\), fronto-temporal dementia \([M = 22.1, SD = 4.9]\), \((F(5,555) = 2, p = .08))\).
Table 5.3 *Family carer and person with dementia demographics and sense of competence*

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Family carer</th>
<th>n</th>
<th>Carer sense of competence M(SD)</th>
<th>Between groups comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>448</td>
<td></td>
<td>23.2 (5.5)</td>
<td><em>t</em> (556) = -.69, <em>p</em> = .49</td>
</tr>
<tr>
<td>Male</td>
<td>101</td>
<td></td>
<td>23.6 (5.4)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>79</td>
<td></td>
<td>22.5 (5.2)</td>
<td><em>F</em> (6,554) = 1.15, <em>p</em> = .332</td>
</tr>
<tr>
<td>Married</td>
<td>388</td>
<td></td>
<td>23.2 (5.5)</td>
<td></td>
</tr>
<tr>
<td>Separated</td>
<td>11</td>
<td></td>
<td>11 (5.1)</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>40</td>
<td></td>
<td>24.1 (5)</td>
<td></td>
</tr>
<tr>
<td>Widow(er)</td>
<td>13</td>
<td></td>
<td>24.2 (7.1)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>30</td>
<td></td>
<td>22.7 (7.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>523</td>
<td></td>
<td>23.5 (5.4)</td>
<td>Comparisons</td>
</tr>
<tr>
<td>White Irish</td>
<td>6</td>
<td></td>
<td>22.8 (3.8)</td>
<td>not performed</td>
</tr>
<tr>
<td>Mixed British</td>
<td>4</td>
<td></td>
<td>25.3 (4)</td>
<td>due to small sample sizes</td>
</tr>
<tr>
<td>Black</td>
<td>4</td>
<td></td>
<td>20 (6)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>5</td>
<td></td>
<td>20 (2.6)</td>
<td></td>
</tr>
<tr>
<td><strong>Relationship type</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Son/daughter</td>
<td>331</td>
<td></td>
<td>22.8 (5.7)</td>
<td><em>F</em> (2,556) = 4.7, <em>p</em> = .009</td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>172</td>
<td></td>
<td>23.2 (5.2)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>56</td>
<td></td>
<td>25.3 (5.5)</td>
<td></td>
</tr>
<tr>
<td><strong>Cohabiting</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>242</td>
<td></td>
<td>23 (5.4)</td>
<td><em>t</em> (557) = -1.17, <em>p</em> = .24</td>
</tr>
<tr>
<td>No</td>
<td>317</td>
<td></td>
<td>23.5 (5.5)</td>
<td></td>
</tr>
<tr>
<td><strong>Receiving additional support</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>346</td>
<td></td>
<td>24.1 (5.1)</td>
<td><em>t</em> (502) = 3.4, <em>p</em> = .001</td>
</tr>
<tr>
<td>No</td>
<td>158</td>
<td></td>
<td>22.3 (5.7)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Person with dementia</th>
<th>N</th>
<th>Carer sense of competence M(SD)</th>
<th>Between groups comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>208</td>
<td></td>
<td>22.9 (5.6)</td>
<td><em>t</em> = 1.4 (559) <em>p</em> = .16</td>
</tr>
<tr>
<td>Female</td>
<td>353</td>
<td></td>
<td>23.6 (5.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Dementia diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Disease</td>
<td>285</td>
<td></td>
<td>23.9 (5.2)</td>
<td><em>F</em> (5,555) = 2, <em>p</em> = .077</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>107</td>
<td></td>
<td>22.7 (5.8)</td>
<td></td>
</tr>
<tr>
<td>Lewy Bodies Dementia</td>
<td>19</td>
<td></td>
<td>24.7 (3.7)</td>
<td></td>
</tr>
<tr>
<td>Fronto-temporal</td>
<td>22</td>
<td></td>
<td>22.1 (4.9)</td>
<td></td>
</tr>
<tr>
<td>Do not know</td>
<td>33</td>
<td></td>
<td>22.0 (6.7)</td>
<td></td>
</tr>
</tbody>
</table>
5.6.7  Positive psychology factors, HRQoL, social engagement and sense of competence

The relationship between sense of competence, positive psychology factors (resilience, self-efficacy for managing dementia, gains, sense of coherence), social engagement and HRQoL was investigated using Pearson’s correlation coefficient (Table 5.4). Sense of competence was moderately correlated with sense of coherence \( (r = .42, p < .001) \), self-efficacy for managing dementia \( (r = .36, p < .001) \), gains in Alzheimer’s caring \( (r = .34, p < .001) \). There was also a strong positive correlation between sense of coherence and resilience \( (r = .56, p < .001) \).

Sense of competence had a small, positive association with carer HRQoL \( (r = .29, p < .001) \) and the EQ-VAS \( (r = .13, p < .001) \). There was a small positive relationship between sense of competence and social engagement \( (r = .24, p < .001) \).
Table 5.4 Pearson’s correlations between positive psychology measures and sense of competence

<table>
<thead>
<tr>
<th></th>
<th>Sense of competence</th>
<th>Sense of coherence</th>
<th>Self-efficacy</th>
<th>Gains</th>
<th>HRQoL Index</th>
<th>Resilience</th>
<th>Social engagement</th>
<th>HRQoL-VAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of competence</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sense of coherence</td>
<td>.42***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>.36***</td>
<td>.45***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gains</td>
<td>.33***</td>
<td>.26***</td>
<td>.31***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HRQoL Index</td>
<td>.29***</td>
<td>.39***</td>
<td>.22***</td>
<td>.15***</td>
<td></td>
<td>.31***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resilience</td>
<td>.25***</td>
<td>.56***</td>
<td>.45***</td>
<td>.35***</td>
<td>.31***</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social engagement</td>
<td>.24***</td>
<td>.4***</td>
<td>.18***</td>
<td>.26***</td>
<td>.26***</td>
<td>.25***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HRQoL-VAS</td>
<td>.13**</td>
<td>.25***</td>
<td>.12**</td>
<td>.1*</td>
<td>.3***</td>
<td>.19***</td>
<td>.01</td>
<td></td>
</tr>
</tbody>
</table>

Note: * p < .05, ** p < .01, *** p < .001
5.6.8 *Do positive psychology factors predict sense of competence?*

Since there were significant relationships between sense of competence and resilience, self-efficacy, gains and sense of coherence, linear regression analyses were conducted to explore this relationship further and establish whether sense of competence could be predicted by these factors. There were no violations of the assumptions of regression analysis (described in Section 5.5.10). Sense of coherence significantly predicted 17.6% of variance in sense of competence scores ($R^2 = .18$), $F (1, 544) = 115.97, p < .001$). Self-efficacy ($R^2 = .13$), $F (1, 554) = 83.17, p < .001$) and the ability to find gains in caring ($R^2 = .11$), $F (1, 550) = 69.6, p < .001$) also modestly predicted sense of competence (13.1% and 11.2% variance). The smallest predictor of sense of competence was resilience (6.5%), although this model was still statistically significant ($R^2 = .07$), $F (1, 558) = 38.516, p < .001$).

**SECTION B: Path analysis of the impact of positive psychology measures on sense of competence**

To further explore the pathways through which positive psychology factors impact on carer sense of competence, a path analysis was conducted. Path analysis is a form of Structural Equation Modelling (SEM) and models a series of multiple regression analyses simultaneously. Path analysis was chosen as the primary analysis as it enables modelling of relationships between latent (unobserved) variables and observed variables, which allows a theorised model to be tested. Path analysis measures relationships or pathways between variables but is not a causal modelling technique (Lomax...
& Schumacker, 2012). The goal of path analysis is to assess model fit and generate a novel model that is theoretically sound and sets the precedent for new theoretical models to be investigated (Kline, 2011). The model should be parsimonious and a good fit for the observed data (MacCallum & Austin, 2000).

5.7 Aim:

The aim of the path analysis was to construct and evaluate a model of sense of competence that specifically explored the predictive pathways between positive psychology factors, sense of competence and HRQoL.

5.8 Method

The sample for the analysis is reported previously in this Chapter. The current path analysis started with the specification of a model based on previous research. Data was screened and checked according to the assumptions of SEM:

I. Normality of data - The distribution of the data had been previously inspected for other analyses in this Chapter (Section 5.6.4). Skewness and kurtosis values were considered adequate to proceed with the analysis.

II. No presence of systematic missing data – There was no systematic missing data present (Section 5.5.11).

III. No multicollinearity - This had previously been inspected in the correlation analyses. Recommendations are that correlations should
not be higher than $r = .85$ (Kline, 1998), and therefore it was considered that no multicollinearity was present within the data.

IV. *There is a sufficient sample size* - There have been various recommendations for sample size in structural equation modelling. Kline (1998) recommended 10 - 20 cases per parameter whereas Bentler & Chou (1987) recommended 5 - 10 participants per parameter. The sample size for this model was considered adequate for the proposed model and number of parameters.

5.8.1 *Statistical software*

The statistical software programme MPlus 8 (Muthen & Muthen 1998 - 2011) was used to analyse the data. MPlus is a syntax based software and this software programme was chosen as it is specifically designed for the purposes of statistical modelling. After performing the path analysis, the model was evaluated for goodness of fit. MPlus enables diagrams of the model to be generated. In the resulting diagram, latent variables are represented by circles and observed variables are represented by squares. Straight arrows indicate the direction of the relationship and the estimated path coefficients are indicated on the line, with the standard error in brackets. Residuals are represented by a blue arrow, with the standard error in brackets.

5.8.2 *Assessing model fit*

Global model fit was assessed using the chi-squared statistic ($\chi^2$) with the $\alpha$ level set at 0.05. In path analysis, a non-significant value indicates that the
model is a good fit but as this statistic is sensitive to sample size and can be skewed by large samples (Tabachnick & Fidell, 1996), other model fit indices were used to establish a more accurate indicator of model fit. These were: Comparative Fit Index (CFI, Bentler 1990) and Normed Fit Index (NFI, Bentler & Bonett, 1980) which can fall between 0 - 1 and but values closer to 1 indicate the best fit (Bentler & Bonett, 1980), RMSEA and SRMR, for which values can vary between 0-1 but indices closer to 0 indicate a better fit (Hu & Bentler, 1999). Cut off scores for RMSEA are 0.06 and cut off scores for SRMR are .08 (Hu & Bentler, 1999).

### 5.9 Factors included in the analysis

The model was developed using previous literature and research findings in this thesis. Factors included in the model were: sense of competence, social engagement, resilience, self-efficacy, gains, sense of coherence, and HRQoL. All these factors had demonstrated a significant association with sense of competence.

#### 5.9.1 Positive psychology factors as predictors of sense of competence

Based on previous stress-coping models (Kramer, 1997; Sorensen & Conwell, 2011), it was hypothesised that sense of competence would exert a direct effect on positive psychology factors and HRQoL. Hypotheses related to each of the pathways included in the model are described below.
Pathway 1: Gains in caring as a predictor of sense of competence, self-efficacy and sense of coherence (Figure 5.2)

Previous research shows that gains in caring are associated with increased carer sense of competence (Liew et al., 2010), which was supported in this research study, as gains predicted 13.1% of variance in sense of competence. Carbonneau’s model (described in Section 1.7, p. 47) indicated that enrichment events, or gains were associated with self-efficacy and sense of coherence, which was supported in the Pearson’s correlation analysis in this Chapter. Therefore, a regression pathway was drawn between gains and sense of competence, sense of coherence and self-efficacy. It was hypothesised that gains would predict sense of competence, self-efficacy and sense of coherence.

![Diagram showing the pathway between gains, self-efficacy, sense of competence, and sense of coherence]

*Figure 5.2 Gains in caring as a predictor of sense of competence, self-efficacy and sense of coherence*
Pathway 2: Self efficacy as a predictor of sense of competence (Figure 5.3)

Carbonneau's model indicated that self-efficacy is likely to play a role in a carer's feeling of accomplishment, or sense of competence, which was supported by findings in this Chapter. Therefore, self-efficacy was added to the model as a predictor of sense of competence. It was hypothesised that self-efficacy would predict sense of competence scores.

![Diagram showing self-efficacy predicting sense of competence]

Figure 5.3 Self-efficacy as a predictor of sense of competence

Pathway 3: Resilience as a predictor of sense of competence, self-efficacy and sense of coherence (Figure 5.4)

A previous systematic review (Crellin et al., 2014) found that self-efficacy was correlated with positive psychology factors, including meaning, resilience and gains. Findings in this Chapter indicated that sense of competence, self-efficacy, sense of coherence and resilience were correlated. Resilience was added to the model as a predictor of self-efficacy, sense of competence and sense of coherence. It was hypothesised that resilience would predict sense of competence, sense of coherence and self-efficacy.
Pathway 4: Sense of coherence as a predictor of social engagement and HRQoL (Figure 5.5)

Sense of coherence was defined by Antonovsky (1979) and indicates how well a person can deal with identified stressors. Previous research has indicated that higher sense of coherence is associated with larger social networks and higher HRQoL (Ekwall, Sivberg & Hallberg, 2007). Therefore, a regression pathway was drawn between sense of coherence and social engagement. A regression pathway was also drawn between sense of coherence and HRQoL. It was hypothesised that sense of coherence would significantly predict carer HRQoL and social engagement.

Figure 5.5 Sense of coherence as a predictor of social engagement and HRQoL
Pathway 5: Sense of coherence as a mediator between sense of competence and HRQoL (Figure 5.6)

An indirect pathway was drawn between sense of competence and HRQoL, through the carer’s sense of coherence in order to explore whether sense of coherence mediates the relationship between sense of competence and HRQoL. It was hypothesised that sense of coherence would moderate the relationship between sense of competence and HRQoL.

![Diagram showing the relationship between sense of competence, sense of coherence, and HRQoL.](image)

*Figure 5.6 Sense of coherence as a mediator between sense of competence and HRQoL*
5.10 Hypothesised model

These five hypothesised pathways were combined and tested to produce a hypothesised model of sense of competence, positive psychology factors and carer HRQoL (Figure 5.7).

![Diagram of hypothesised model]

*Figure 5.7 Hypothesised model of sense of competence, positive psychology factors and HRQoL*
5.11 Results

The hypothesised model explained 27% of the variance in sense of competence scores ($R^2 = .27$). Sense of competence was directly associated with and predicted by positive psychology factors: self-efficacy, social engagement, gains and resilience. Sense of coherence proved to be an important mediator in the model, as there was an indirect relationship between sense of competence and HRQoL through sense of coherence. This indirect relationship was statistically significant ($p < .001$). However, inconsistent with hypotheses, sense of competence did not directly predict HRQoL. In terms of carer outcomes, the model also explained 28% of the variance in health-related quality of life, which was included as a dependent variable. Overall, the model demonstrated a good fit for the data (see Table 5.6), with CFI, RMSEA and SRMR scores all falling within the cut-off points described previously. The final model is illustrated in Figure 5.8.

| Table 5.5 Model fit statistics for path analysis |
|-----------------|-----------------|-----------------|-----------------|-----------------|
|                | $x^2$           | $df$           | CFI             | RMSEA           | SRMR            |
| **Model fit**  | 199.9           | 75             | 0.93            | 0.06            | 0.04            |

$x^2 = \text{Chi-Square goodness of fit}; \ df = \text{degrees of freedom}; \ RMSEA = \text{Root Mean Square Error of Approximation}; \ SRMR = \text{Standardised Square Root Mean Residual.}$
Figure 5.8 Model of sense of competence, positive psychology factors and carer HRQoL
5.12 Discussion

Consistent with the hypotheses (Section 5.4 and 5.9), sense of competence was significantly associated with positive psychology factors: resilience, self-efficacy for managing dementia, gains in caring and sense of coherence. This reflects previous literature described in Chapter 3, that higher levels of self-efficacy (Fortinsky et al., 2002), gratitude (Lau & Cheng, 2015) and finding meaning in caring (Quinn et al., 2012a, Quinn et al., 2012b) were associated with increased sense of competence.

In the path analysis, sense of competence was significantly predicted by positive psychology factors. In turn, sense of competence significantly predicted sense of coherence. Sense of competence did not have a direct association with HRQoL within this model but exerted an indirect effect on HRQoL, mediated by the carer’s sense of coherence. This relationship had not previously been tested and was a novel finding, indicating that sense of coherence, or the ability to finding meaning, to understand and cope with their role may be an important mechanism through which sense of competence can impact carer HRQoL. This is consistent with previous literature demonstrating that sense of coherence is strongly related with HRQoL. Sense of coherence has three components, meaningfulness, manageability and comprehensibility of the situation or stressor. These results indicate that an intervention aimed at improving a carer’s understanding and ability to find meaning in their caring role may in turn improve their perception of how competent they are to deal with the task of caring.
5.13 Methodological limitations

Despite recruitment of family carers of people living with dementia proving less challenging than originally anticipated, it proved difficult to engage family carers from BME groups. There were also some practical challenges, with the online survey proving more popular than the paper copies. This may have resulted in a more specific population being targeted, which could explain the higher number of adult-child carers than most studies of a similar population. One particular challenge that arose with the design of the survey was due to the inclusion of standardised questionnaires, as carers reported that the response options of the survey constrained reporting and limited exploration of the caring experience. Although this design is typical of standardised scales, it highlights the benefits of mixed methods research to explore the carer experience further.

5.14 Future research

A large number of participants left comments in the open-text boxes, indicating that family carers were eager to discuss their experiences in a setting that is not constrained by tick boxes or Likert scales. This data will be explored further in Chapter 7. Qualitative research exploring sense of competence with this population is particularly important given the paucity of qualitative research identified in Chapter 2.

This survey only included current carers of people living with dementia in the community in order to focus the findings, yet during the recruitment process many carers who had previously cared for a loved one who had passed
away or had moved into residential care expressed interest in taking part in the survey. It is important that the lived experiences of these carers are also explored, as many have a wealth of caring experience that they are eager to share. Therefore, the experiences of this group of carers should be further explored using mixed methods research, such as an additional survey to gather responses, coupled with qualitative interviews or focus groups. The ‘duties to care’ project (Peel & Harding 2014) is an example of this, using various methods to explore carer views, such as interviews, focus groups and a survey.

The proposed model only focused on positive psychology factors, which do not represent the entirety of the carer experience. Therefore, the model could be adapted and re-tested, incorporating more variables such as those measuring appraisal and coping within the predictive pathways to align it more closely to previous stress-coping models (Lazarus & Folkman, 1984; Haley et al., 1987). Furthermore, the model is based on cross-sectional data and as causality cannot be established, this limits the conclusions that can be drawn. Longitudinal research would enable greater understanding of how sense of competence changes over time, and consequently how the determinants would change as dementia progresses. Therefore, this proposed model should be tested further using longitudinal methodology.

5.15 Conclusion

The results from this study demonstrate that positive psychology factors are related to, and significantly impact, a carer’s feelings of being competent to
deal with the task of caring. This study found that the carers ability to find meaning and understanding in their role was a pathway through which carer sense of competence impacted HRQoL. The hypothesised model was a good fit for the data and explained 27% of the variance in sense of competence. These findings inform the development of sense of competence theory by modelling the pathways through which positive psychology factors impact carer sense of competence.
Chapter 6  Family carer sense of competence in relation to carer mood and person with dementia clinical characteristics

Data presented in this chapter is from the baseline data and the pre-determined outcome measures specified in the VALID research protocol however all analyses were conducted independently. My involvement in the VALID trial included: assisting with setting up research sites, which included conducting site initiation and outcome measures training for 12 of the 14 trial sites, recruiting dyads for the NELFT site, including screening potentially eligible participants, conducting a capacity assessment with eligible and interested participants and receiving consent for participants entering the trial in line with the research protocol, Good Clinical Practice (GCP) and standard operating procedures. I also collected follow-up data as a blinded researcher and provided support to researchers at external sites.

6.1 Introduction

The systematic review in Chapter 3 found that increased sense of competence was associated with decreased feelings of depression in the carer (Lau & Cheng, 2015). In addition, in the qualitative literature, carers reported feeling anxiety about the future, which in turn made them feel less competent (Graff et al., 2006b). Findings in Chapter 3 indicated that person with dementia BPSD predicted carer sense of competence scores and that sense of competence mediated the relationship between BPSD frequency and BPSD distress. However, there is almost no research on the association between sense of competence and other person with dementia clinical
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characteristics such as activities of daily living, dependency or mood. Where such research exists, there is no consensus on findings, for example, one study reported an indirect association between sense of competence and severity of dementia (Vernooij-Dassen et al., 1996), whereas another indicated that sense of competence of carers of people with severe dementia was comparable to carers of patients with mild to moderate dementia (Kurz et al., 2003). More research is needed to further explore these findings and investigate whether these clinical domains impact sense of competence, so that relevant interventions can be designed to target this domain.

Consistent with second wave positive psychology approaches, discussed in Chapter 1, it is important to investigate whether sense of competence is influenced by negative carer outcomes such as anxiety and depression, and challenges in the caring role, such as person with dementia dependency or difficulties completing ADLs. Therefore, this Chapter will explore the association between person with dementia clinical factors, carer mood and sense of competence.

6.2 Aim

To explore the association between sense of competence, carer mood and person with dementia clinical characteristics.

6.3 Objectives

I. To explore the association and predictive relationship between sense of competence, carer anxiety and depression, and person with
dementia clinical characteristics.

II. To investigate whether carer anxiety and depression predicts variance in sense of competence scores when person with dementia clinical characteristics are controlled for.

6.4 Hypotheses

I. Reduced ADL and lower mood in the person with dementia will be associated with a lower carer sense of competence.

II. Higher carer anxiety and depression will be associated with lower carer sense of competence.

III. Carer anxiety and depression will predict sense of competence scores, when controlling for person with dementia clinical factors.

6.5 Method

6.5.1 Design

Data were collected in the VALID RCT, which was led by Professor Martin Orrell as Chief Investigator and Dr. Jennifer Wenborn as Programme Manager. The VALID research programme received funding from the NIHR under its Programme Grants for Applied Research scheme (RP-PG0610-10108). This was a multi-site, pragmatic, single blind, RCT, which compared the effectiveness of a community occupational therapy intervention to TAU for people with mild to moderate dementia and their family carers. Participants randomised to the intervention group received up to ten hours of occupational therapy delivered at home or in the local community. The data analysed in this Chapter was collected as part of the baseline assessments
in the trial, before the participants were randomised. More information on the VALID trial is available in the published protocol (Wenborn et al., 2016).

6.5.2 Participants

470 dyads (family carer and person with dementia) consented to the trial but data was only collected for 468, as two dyads withdrew prior to data collection. All of the included participants resided in the community within one of the 14 sites across the UK in which VALID was open to recruitment.

6.5.3 Inclusion criteria for dyads

To be eligible to take part in the VALID research programme, dyads had to each meet the relevant inclusion criteria:

Inclusion criteria for family carers

- Aged 18 or over
- Currently providing practical support with domestic and/or personal activities to the person with dementia for a minimum of four hours per week
- Able to converse in English
- Has capacity to provide informed consent
- Not currently participating in another intervention research study

Inclusion criteria for people with dementia

- Living in the community in own home (includes sheltered accommodation)
Carer Sense of Competence

- Has a diagnosis of dementia, as defined by the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV; APA, 2013) and scoring between 0.5 and 2 on the Clinical Dementia Rating Scale (CDR; Hughes, Berg, Danziger, Coben & Martin, 1982)
- Able to converse in English

**Exclusion criteria for people with dementia**

- Participating in another intervention research study
- Currently in hospital or living in a care home

6.5.4 Recruitment

Recruitment began in September 2014 and continued until July 2017. Participants were recruited from community services, such as local charities and organisations, clinical services (including mental health services for older people and memory services), the JDR register and referred from local observational research studies. Information about the VALID research study was passed to potential participants by clinical or research staff when they received an expression of interest in the study. Participants who expressed interest in the study to clinicians were provided with oral information about the study and were asked if they consented for their details to be passed to the research team. In total, 1,570 expressions of interest were received from potential participants across all sites. Once participant details had been passed to the research team, they were contacted to discuss the study in more detail and the carer and person with dementia were each provided with a detailed participant information sheet. A minimum of 24 hours cooling off
period was given between participants receiving the information sheet and the informed consent process in line with GCP requirements.

6.5.5 Screening participants

Once participants had expressed their wish to participate in the research study, members of the research team assessed their eligibility against the inclusion and exclusion criteria over the telephone with the family carer, using a screening checklist (Appendix 3.1). Both the person with dementia and the family carer were required to meet all the eligibility criteria in order to participate in the research study. The screening process involved completing the CDR (Hughes et al., 1982) in order to assess the criteria for mild/moderate dementia. The CDR takes the format of a semi-structured interview and assesses the functioning of the person with dementia in six distinct domains (memory, orientation, judgement and problem solving, community affairs, home and hobbies, personal care). The CDR is rated on a 5-point scale from 0 - 3 (0 = normal, 0.5 = very mild dementia, 1 = mild dementia, 2 = moderate dementia, 3 = severe dementia). There were three possible outcomes to the screening process: 1) the dyad was eligible and a letter was sent confirming an appointment to go through the information and consent the dyad to the research study, 2) the dyad was not eligible at the time of screening but may be at a later point, so was placed on hold, 3) the dyad was not eligible and could not take part in the research.
6.5.6 The informed consent process

Informed consent was received from both the person with dementia and their family carer. Before receiving consent and assessing capacity, research staff discussed each point on the participant information sheet with the dyad and made sure that they understood the information. The family carers and person with dementia could only take part if they had capacity to consent to the research in line with the Mental Capacity Act 2005 (Johnson & Liddle, 2007). An informal capacity assessment was conducted and recorded to evidence that capacity to consent had been checked (Appendix 3.2). It determined whether participants were able to understand and retain the information, weigh-up their decision to participate, and communicate their decision clearly by asking relevant questions about the study. Once capacity had been confirmed, the research staff went through each point on the consent form with the person with dementia and their family carer separately (Appendix 3.3). All participants were made aware that they could withdraw from the study at any point without having to give a reason, and that their rights or healthcare would not be affected if they decided not to participate. Consent was considered to be an ongoing process and was verbally checked at each contact with the dyad to ensure their willingness to continue participating in the trial. GCP guidelines were followed at all times. Once the person with dementia and the family carer had both consented, their general practitioner was informed of their involvement and the baseline assessment took place.
6.5.7 Data collection

The VALID research programme contained five data collection time points, baseline, 3 months, 6 months, 12 months and 24 months. Only baseline data was analysed in this Chapter. A flow diagram of the VALID trial design is illustrated in Figure 6.1

6.5.8 Interview procedure

Research staff collected the data for the family carer and the person with dementia. The assessments were conducted at the home of the person with dementia, unless the dyad specified another preference. If possible, the assessments were conducted with the person with dementia and their carer in separate rooms to minimise distraction and to ensure confidentiality. If the dyads preference was to remain together, this was accommodated. Research staff were considerate of the comfort of participants, pausing the assessment if the participants appeared tired, and expressed compassion if participants became emotional during the course of the assessment. If a participant became distressed or too tired to continue, the assessment was terminated and if appropriate, was rearranged. All the research staff conducting the assessments had been trained by the central research team. This training covered the procedure if any risks, such as safeguarding alerts or suicidal intent were disclosed during the course of the assessment. The instruments in each of the assessments are outlined in Table 6.1.
Figure 6.1 Flow diagram of the VALID trial
Table 6.1 Outcome measures completed at baseline assessment

<table>
<thead>
<tr>
<th>Outcome measure</th>
<th>Family carer (approximately 2 hours)</th>
<th>Person with Dementia (approximately 1 1/2 hours)</th>
<th>Positive (+) or negative (-) scoring?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bristol Activities of Daily Living Scale (BADLS)</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia Quality of Life Scale (DEMQoL &amp; DEMQOL-Proxy)</td>
<td>X</td>
<td>X</td>
<td>+</td>
</tr>
<tr>
<td>European Quality of Life – Five Dimensions, Five Level (EQ-5D-5L)</td>
<td>X</td>
<td>X</td>
<td>+</td>
</tr>
<tr>
<td>Hospital Anxiety and Depression Scale (HADS)</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interview of Deterioration in Daily activities in Dementia (IDDD)</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCQ</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mini Mental State Examination (MMSE)</td>
<td></td>
<td>X</td>
<td>+</td>
</tr>
<tr>
<td>Cornell Scale for Depression in Dementia (CSDD)</td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

6.5.9 Socio-demographic information

Both the family carer and the person with dementia were asked about their demographic information including their age, identified gender, ethnicity, marital status, living situation, education status and work status. These questions were included in the Case Report Forms (CRFs) along with the other outcome measures (Appendix 3.4 and 3.5).
6.5.10 Outcome measures for people with dementia

Bristol Activities of Daily Living Scale (BADLS; Bucks, Ashworth, Wilcock & Siegfried, 1996) - Carer rated

The BADLS assesses the person with dementia’s basic and instrumental daily-living abilities such as dressing, bathing and preparing food. This scale contains 20 items, with each item score summed to generate a total score. There is a minimum possible score of 0 (totally independent) and a maximum score of 60 (totally dependent). The BADLS is carer rated and has good test-retest reliability ($r = -.07, p < .001$) and validity estimates (Bucks et al., 1996; Byrne, Wilson, Bucks, Hughes & Wilcock et al., 2000). It takes approximately 15 minutes to complete.

Mini Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975) – Person with dementia rated

The MMSE includes 30 questions and is commonly used to screen for cognitive impairment. This measure is scored across the following domains: orientation, registration, attention and calculation, recall, language and copying. Scores for each of the domains can be summed to produce an overall score, which can range from 0 - 30. The MMSE has demonstrated good reliability and validity (Tombaugh & McIntyre, 1992). There have been a variety of cut-off scores proposed to indicate cognitive impairment, with a general agreement that 23 is the cut off score for cognitive impairment (O’Bryant et al., 2008; Kochhann, Varela, Lisboa & Chaves 2010). It takes approximately 10 minutes to complete.
Interview of Deterioration in Daily activities in Dementia (IDDD; Teunisse, Derix & van Crevel, 1991) – Carer rated

The IDDD was used to evaluate whether ADLs had deteriorated and to investigate the level of assistance required by the person with dementia to complete ADLs. This measure was carer rated but concerned the person with dementia’s ADLs. Each item was scored on a three point scale and responses were added to generate a total score which could range from 33 (no deterioration) to 99 (severe deterioration), with higher scores indicating greater deterioration. This scale has been used in other, similar research (e.g. Graff et al., 2006a) and has demonstrated good reliability and validity (Teunisse & Derix, 1997). The development paper reports good internal consistency (Teunisse & Derix, 1991). This measure takes approximately 15 minutes to complete.

Dementia Quality of Life Scale (DEMQOL; Smith et al, 2005) – Person with dementia rated and DEMQOL-Proxy (Smith et al, 2005) – Carer rated

The DEMQOL is a 28-item questionnaire that measures five domains of quality of life of the person with dementia. The items are summed to generate a final quality of life rating (ranging from 29 - 128), with higher scores indicating a higher quality of life. The DEMQOL has good reliability ($\alpha = .84$) and psychometric properties for people with mild-moderate dementia (Smith et al., 2005). This measure takes approximately 10 minutes to complete. The DEMQOL-Proxy is administered with family carers about the person with dementia and is a 31-item questionnaire. Items 1, 3, 5, 6, 10 and 29 require reverse scoring before summation of scoring. The items are
summed to generate a final quality of life rating (ranging from 32 – 116), with higher scores indicating a higher quality of life. The DEMQOL-Proxy, like the DEMQOL, has good psychometric properties (Smith et al., 2005). It takes approximately 10 minutes to complete.

**EQ-5D-5L (Available [http://www.euroqol.org](http://www.euroqol.org)) – Person with dementia rated**

The EQ-5D-5L is described in Chapter 5, including validity and reliability information. This measure takes approximately 5 minutes to complete.

**Cornell Scale for Depression in Dementia (CSDD; Alexopolous, Abrams, Young & Shamoian, 1988) – Person with dementia rated**

The CSDD is designed to assess the presence of depression in people with dementia and is a self-report measure administered with the person with dementia. The CSDD takes the format of a semi-structured interview and is scored based on the participant interview and direct observation. There are 19 items in this scale and each of these items are rated on a scale from 0 - 2. These items are summed and can range from 0 – 38. A higher score indicates a higher level of depression. The CSDD has good reliability (α = .84) and validity (Alexopolous, Abrams, Young & Shamoian, 1988) This measure takes approximately 20 minutes to complete.

**6.5.11 Outcome measures for family carer (all carer rated)**

**SCQ (Vernooij-Dassen, Persoon & Felling, 1996)**

The SCQ is a 27-item scale to measure the carer’s perspective of their own competence to cope with the person with dementia. This questionnaire has
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three subscales (satisfaction with the person with dementia as a recipient of care, satisfaction with one’s own performance as a carer, consequences of involvement in care for the personal life of the carer). Each item is rated on a 5-point scale, from agree very strongly (1) to disagree very strongly (5). Scores can range from 27 – 135 and higher scores indicate a higher sense of competence. Reliability (α = .79) and validity estimates are good for this scale and it was designed for use in this population (Vernooij-Dassen et al., 1993).

*European Quality of Life – Five Dimensions (EQ-5D) 5 Level (Available [http://www.euroqol.org](http://www.euroqol.org)) -* This is a self-report measure and its scoring is described in Chapter 5.

*Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)*

The HADS is a frequently used measure of anxiety and depression and is included as a measure of carer mood. This scale was chosen as it was used in the original study conducted in the Netherlands (Graff et al., 2006a). In this 14 item scale, seven of the items measure anxiety and seven measure depression. Items are scored from 0 - 3, where a higher score is indicative of higher anxiety/depression or lower mood. The scores are added to generate a total score between 0 - 21 for either anxiety or depression, so 42 is the combined score to represent carer mood in this thesis. This scale has good reliability and validity in a range of populations (Mykletun, Storal & Dahl, 2001; Bjelland, Dahl, Haug & Neckelmann, 2002; Snaith, 2003) and takes approximately 5 minutes to complete.
6.5.12 Confidentiality

Confidentiality was maintained at all times in accordance with the UK Data Protection Act (1998). In order to ensure that confidentiality was upheld, participants were assigned a unique participant identification code, which was not connected with their personal details at any time. All identifiable information was stored separately from non-identifiable information. All data was stored in locked filing cabinets and was only accessible to research staff directly involved with the VALID research programme.

6.5.13 Monitoring serious adverse events

Serious adverse events were defined as events that were life threatening, resulted in hospitalisation or death. These events were monitored and reported by research staff throughout the trial.

6.5.14 Ethical Approval

The VALID RCT was approved by the National Research Ethics Service Committee London – Camberwell St Giles (ethical approval reference number: 14/LO/0736) in June 2014. The study was registered with North East London NHS Foundation Trust (NELFT) Research and Development Department and had R&D approval at each of the 14 recruiting sites. The trial was registered with the International Standard Randomised Controlled Trial Number (ISRCTN) register: ISRCTN10748953.
6.5.15 Data analysis

Cross-sectional analyses were conducted on the baseline data using the statistical software programme SPSS Version 25. Descriptive analyses were conducted to generate frequencies, means, standard deviations and percentages. T-tests and ANOVA were conducted to investigate if sense of competence scores differed between carer demographics such as gender, ethnicity, relationship with person with dementia as well as person with dementia diagnosis.

The relationship between sense of competence and carer mood, HRQoL and person with dementia clinical characteristics was investigated using Pearson’s correlation coefficient. Preliminary analyses and scatterplots were initially generated in order to ensure there was no violation of the assumptions of linearity and homoscedasticity. There were no extreme outliers so Pearson’s correlation tests were performed. In order to explore these relationships further, linear and hierarchical regressions were employed. There are several assumptions that need to be met in order for a regression analysis to be valid (Poole & O’Farrell 1971), described in Section 5.5.10. Cohen’s (1988) guidance was used to interpret effect sizes.

6.5.16 Data handling and storage

Data were collected onto hard copy CRFs and were then entered into the RedPill database, an online data management system managed by Sealed Envelope. RedPill maintains a record of any updates or edits to the data that had been input into the system, in order to keep an audit trail of all
information entered. The RedPill system mirrored the paper CRF, which enabled more efficient data entry. Data entry accuracy was monitored throughout the course of the trial at monitoring visits conducted at all sites on an annual basis. Once all baseline data had been entered, a final check for accuracy was completed. Following checking for accuracy and ensuring that any errors were corrected, the data was downloaded onto excel databases and then transferred to SPSS Version 25. During and following the transfer of data from excel to SPSS, checks were taken to ensure integrity of data. A random 10% proportion of data were screened manually for errors in data entry or transcription and any incorrect entries were rectified.

### 6.6 Results

#### 6.6.1 Missing data and outliers

The data were examined for the presence of outliers and missing values. Visually inspecting histograms and scatterplots and generating values for low and high extreme values for each of the variables enabled the identification of outliers. A very small number of outliers were found, with between 0 - 5.6% outliers present on all variables. In order to keep the case in the analysis, outliers were inspected to ensure that they were not erroneously entered. None of these data points were outliers due to erroneous data entry but were valid responses from the participants. The analysis was run twice, with the outliers removed and the outliers left in. If the outliers did not affect the results of the analysis they were left in, which was the case for all analyses reported in this Chapter. There was only a small proportion of missing data. Data was first explored to determine
whether the missing data was missing at random, using Little’s MCAR test. As the assumption of MCAR was met, list-wise deletion was conducted for each analysis.

6.6.2 Distribution of the data

Normality inspections of the data were conducted by producing histograms (Field, 2009; Tabachnick & Fidell, 1996) and visually scanning for skewness or kurtosis. There was no major deviation from normality on any of the scales. Due to the large sample size, the majority of the variables were normally distributed, with skewness or kurtosis scores close to 0 (Appendix 5), therefore the decision was made to not transform data and to use parametric statistical tests (Field, 2009).

6.6.3 Population

A total of 468 dyads completed the baseline assessments. Characteristics of the family carer and person with dementia are presented in Table 6.2. In this sample, the mean age of the carers was 69.3, with a range of 30 - 94. The mean age of the people with dementia in the study was 78.8, with a range of 56 - 98. The majority of carers were female (72.4%) and living with the person with dementia that they cared for (79.5%). Most were not in employment (76.7%). People with dementia were mostly male (57.1%) and had a diagnosis of Alzheimer’s disease (53.4%).
Table 6.2 Family carer and person with dementia descriptive demographics (n=468).

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Carer characteristics (n = 468)</th>
<th>Person with dementia characteristics (n = 468)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>339 (72.4)</td>
<td>201 (42.9)</td>
</tr>
<tr>
<td>Male</td>
<td>129 (27.6)</td>
<td>267 (57.1)</td>
</tr>
<tr>
<td><strong>Age M (SD) Range</strong></td>
<td>69.3 (11.9) 30-94</td>
<td>78.8 (7.2) 56-98*</td>
</tr>
<tr>
<td><strong>Marital status n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>34 (7.3)</td>
<td>11 (2.4)</td>
</tr>
<tr>
<td>Married</td>
<td>393 (84)</td>
<td>350 (74.8)</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>25 (5.3)</td>
<td>15 (3.2)</td>
</tr>
<tr>
<td>Widowed</td>
<td>11 (2.4)</td>
<td>92 (19.7)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (1.1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Highest completed level of education n (%)</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary education</td>
<td>280 (60)</td>
<td></td>
</tr>
<tr>
<td>Further education</td>
<td>174 (37.3)</td>
<td></td>
</tr>
<tr>
<td>Other general education</td>
<td>13 (2.8)</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>430 (91.9)</td>
<td>427 (91.2)</td>
</tr>
<tr>
<td>Asian</td>
<td>10 (2.1)</td>
<td>9 (1.9)</td>
</tr>
<tr>
<td>Black</td>
<td>9 (2.3)</td>
<td>10 (2.1)</td>
</tr>
<tr>
<td>Mixed</td>
<td>4 (0.9)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Other</td>
<td>13 (2.8)</td>
<td>22 (4.6)</td>
</tr>
<tr>
<td><strong>Relationship to person with Dementia n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>340 (72.6)</td>
<td></td>
</tr>
<tr>
<td>Son/Daughter</td>
<td>104 (22.2)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>24 (5.1)</td>
<td></td>
</tr>
<tr>
<td><strong>Cohabiting n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>372 (79.5)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>96 (20.5)</td>
<td></td>
</tr>
<tr>
<td><strong>Dementia diagnosis n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer's Disease</td>
<td>246 (53.4)</td>
<td></td>
</tr>
<tr>
<td>Vascular</td>
<td>91 (19.7)</td>
<td></td>
</tr>
<tr>
<td>Mixed</td>
<td>54 (11.7)</td>
<td></td>
</tr>
<tr>
<td>DLB/ Parkinson's</td>
<td>18 (3.9)</td>
<td></td>
</tr>
<tr>
<td>Fronto-temporal</td>
<td>11 (2.4)</td>
<td></td>
</tr>
<tr>
<td>Other/unknown</td>
<td>41 (8.9)</td>
<td></td>
</tr>
</tbody>
</table>

* n = 467, **n = 466, ***n =461
6.6.4 Gender mix of dyads

As described above, the majority of carers were female and the majority of people with dementia in the sample were male. Table 6.3 illustrates the gender mix of dyads. The most common dyad was a mix of female carer and male person with dementia, which made up 55.3% of the sample. The second most common mix was female carer with female person with dementia.

Table 6.3 Gender mix of dyads participating in the VALID trial

<table>
<thead>
<tr>
<th>Gender of carer</th>
<th>Gender of person with dementia</th>
<th>Total n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female n (%)</td>
<td>80 (17.1)</td>
<td>259 (55.3)</td>
</tr>
<tr>
<td>Male n (%)</td>
<td>121 (25.9)</td>
<td>8 (1.7)</td>
</tr>
<tr>
<td>Total n</td>
<td>201</td>
<td>267</td>
</tr>
</tbody>
</table>

6.6.5 Severity of dementia

Over half of the people with dementia had a CDR score of 1, indicating that they had mild dementia (53%). Thirty-three percent of people had very mild dementia, with a score of 0.5. The smallest group was those with moderate dementia, with a CDR score of 2, making up 12.8% of the sample. The severity of dementia for those participating in the VALID trial is illustrated in Figure 6.2.
6.6.6 Clinical variables

Scores for each of the clinical variables included in the analyses are reported in Table 6.4. Scores for each of the measures were explored using measures of central tendency. Generally, the scores were of a wide distribution and used most of the maximum possible range. Overall, people with dementia exhibited good quality of life on the DEMQOL (mean score = 91.5) and the DEMQOL-Proxy scores were similar (mean score = 93.3). With regard to HRQoL, carers and people with dementia were similar in their scores on both the EQ-VAS and quality of life index and exhibited good overall quality of life. When considering ADLs, it is important to note that the BADLS and IDDD are negatively scored, with higher scores indicating higher dependence or deterioration. ADL dependency measured by the BADLS was relatively low (mean score = 14.4), indicating that the people with
dementia did not have a high dependence on carers to complete activities of daily living. Similar results were found on the IDDD, which indicated mild deterioration in daily living activities (mean score = 46.4). Cognition in people with dementia measured by the MMSE was indicative of mild to moderate severity of dementia with a mean score of 22, however there was a wide range of scores (4 - 30). In terms of carer clinical characteristics, carers exhibited signs of anxiety or depression, with a mean score of 11. Sense of competence scores for carers were generally high (mean score = 94.3) but had a large spread, from 46 to 134.

Table 6.4 Family carer and person with dementia clinical variables (n=468)

<table>
<thead>
<tr>
<th>Measure</th>
<th>M</th>
<th>Median</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Person with dementia measures</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BADLS (n = 463)</td>
<td>14.1</td>
<td>13</td>
<td>9.4</td>
<td>0 - 45</td>
</tr>
<tr>
<td>CSDD (n = 462)</td>
<td>4.4</td>
<td>3</td>
<td>4</td>
<td>0 - 23</td>
</tr>
<tr>
<td>DEMQOL Proxy (n = 442)</td>
<td>93.3</td>
<td>93</td>
<td>13.2</td>
<td>53 - 121</td>
</tr>
<tr>
<td>DEMQOL (n = 446)</td>
<td>91.5</td>
<td>93</td>
<td>12.6</td>
<td>43 - 111</td>
</tr>
<tr>
<td>Eq-5d-5l Health today (n = 463)</td>
<td>72.7</td>
<td>75</td>
<td>19.2</td>
<td>0 - 100</td>
</tr>
<tr>
<td>Eq-5d-5l Index (n = 466)</td>
<td>0.8</td>
<td>0.8</td>
<td>0.2</td>
<td>-0.25 - 1</td>
</tr>
<tr>
<td>IDDD (n = 467)</td>
<td>46.4</td>
<td>44</td>
<td>11</td>
<td>28 - 88</td>
</tr>
<tr>
<td>MMSE (n = 468)</td>
<td>21</td>
<td>22</td>
<td>5.1</td>
<td>4 - 30</td>
</tr>
<tr>
<td><strong>Family carer measures</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eq-5d-5l Health today (n = 466)</td>
<td>74.4</td>
<td>80</td>
<td>17.6</td>
<td>10 - 100</td>
</tr>
<tr>
<td>Eq-5d-5l Index (n = 467)</td>
<td>0.8</td>
<td>0.8</td>
<td>0.2</td>
<td>-0.09 - 1</td>
</tr>
<tr>
<td>Anxiety on HADS (n = 467)</td>
<td>6.7</td>
<td>6</td>
<td>4.4</td>
<td>0 - 21</td>
</tr>
<tr>
<td>Depression on HADS (n = 467)</td>
<td>4.3</td>
<td>4.3</td>
<td>3.4</td>
<td>0 - 21</td>
</tr>
<tr>
<td>SCQ (n = 453)</td>
<td>94.3</td>
<td>95</td>
<td>16.7</td>
<td>46 - 134</td>
</tr>
</tbody>
</table>
6.6.7 Sense of competence

Of the three subscales of the SCQ, the highest scores were in the satisfaction with one’s own performance as a carer subscale (mean = 44.5). The subscales for ‘consequences of involvement in care for the personal life of the carer’ and ‘satisfaction with the person with dementia as a recipient of care’ had similar mean scores (mean scores = 23.17 and 26.47 respectively). For all the following figures, the curved line represents the normal curve. Figure 6.3 Illustrates the spread of scores on the SCQ, which are evenly distributed with a normal distribution.

![Figure 6.3 Distribution of scores for sense of competence](image-url)
The distribution of scores across the three subscales are illustrated in Figures 6.4 to 6.6. There was a minor negative skew for each of the subscales, with the largest skew seen in the satisfaction with the person with dementia as a recipient of care subscale, however the distribution of scores were similar.

Figure 6.4 Distribution of scores for subscale: Consequences of involvement in care for the personal life of the carer.
Figure 6.5 Distribution of scores for subscale: Satisfaction with one’s own performance as a carer

Figure 6.6 Distribution of scores for subscale: Satisfaction with the person with dementia as a recipient of care
6.6.8 Factors associated with sense of competence

T-tests and ANOVA were employed to examine whether sense of competence differed with family carer or person with dementia characteristics. Results are reported in Table 6.7 and key variables are discussed below.

Those who did not cohabit with the person with dementia had a significantly higher sense of competence (mean = 98.4) than those who lived together (mean = 92.7), \( t (451) = -3.3, p = .001 \). Carers who stated that they received extra support had a higher sense of competence (mean = 96.6) than those who did not (mean = 92.9), \( t (446) = 2.3, p = .02 \).

There was no significant difference in sense of competence between males and females \( t (451) = .75, p = .45 \) or between different relationship types, spouses, adult child carers or other relationships \( F (2,450) = 2.98, p = .052 \). Additionally, there was no difference in sense of competence scores for carers of different types of dementia \( (F (5,440) = .57, p = .73) \); Alzheimer’s disease \( [\text{mean} = 93.9] \), vascular dementia \( [\text{mean} = 93.4] \), mixed dementia \( [\text{mean} = 94.2] \), dementia with Lewy bodies / Parkinson’s \( [\text{mean} = 92.4] \), fronto-temporal dementia \( [\text{mean} = 95.3] \).
Table 6.5 Comparison of sense of competence with different carer demographics

<table>
<thead>
<tr>
<th>Carer demographics</th>
<th>n</th>
<th>Sense of competence scores M(SD)</th>
<th>Between groups comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>327</td>
<td>94.6 (16.6)</td>
<td>t (451) = .75, p = .45</td>
</tr>
<tr>
<td>Male</td>
<td>126</td>
<td>93.3 (17.2)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>430</td>
<td>94.4 (16.7)</td>
<td>Comparisons not performed</td>
</tr>
<tr>
<td>Asian</td>
<td>10</td>
<td>85.1 (22.4)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>9</td>
<td>90.4 (12.8)</td>
<td>due to small sample sizes</td>
</tr>
<tr>
<td>Mixed</td>
<td>4</td>
<td>96.5 (17.9)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
<td>100.8 (28.3)</td>
<td></td>
</tr>
<tr>
<td>Relationship type</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>327</td>
<td>94.4 (16)</td>
<td>F (2,450) = 2.98, p = .52</td>
</tr>
<tr>
<td>Son/daughter</td>
<td>102</td>
<td>93 (18.5)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>24</td>
<td>97.5 (18.2)</td>
<td></td>
</tr>
<tr>
<td>Cohabiting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>358</td>
<td>92.7 (16.8)</td>
<td>t (451) = -3.3, p = .001</td>
</tr>
<tr>
<td>No</td>
<td>95</td>
<td>98.4 (15.7)</td>
<td></td>
</tr>
<tr>
<td>Additional support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>174</td>
<td>96.6 (15.5)</td>
<td>t (446) = 2.3, p = .02</td>
</tr>
<tr>
<td>No</td>
<td>274</td>
<td>92.9 (17.2)</td>
<td></td>
</tr>
</tbody>
</table>

Person with dementia demographics

<table>
<thead>
<tr>
<th>Gender</th>
<th>N</th>
<th>Carer sense of competence scores M(SD)</th>
<th>Between groups comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>194</td>
<td>94.3 (16)</td>
<td>t (451) = 0.02, p = .98</td>
</tr>
<tr>
<td>No</td>
<td>259</td>
<td>94.3 (17.2)</td>
<td></td>
</tr>
<tr>
<td>Dementia type</td>
<td>N</td>
<td>Carer sense of competence scores M(SD)</td>
<td>Between groups comparison</td>
</tr>
<tr>
<td>Alzheimer’s</td>
<td>236</td>
<td>93.9 (15.7)</td>
<td>F (5,440) = 0.57, p = .73</td>
</tr>
<tr>
<td>Vascular</td>
<td>90</td>
<td>93.4 (19.5)</td>
<td></td>
</tr>
<tr>
<td>Mixed</td>
<td>53</td>
<td>94.2 (16.8)</td>
<td></td>
</tr>
<tr>
<td>DLB/Parkinson’s</td>
<td>18</td>
<td>92.4 (11.9)</td>
<td></td>
</tr>
<tr>
<td>Fronto-temporal</td>
<td>11</td>
<td>95.3 (16.9)</td>
<td></td>
</tr>
<tr>
<td>Other/unknown</td>
<td>38</td>
<td>98.3 (17.8)</td>
<td></td>
</tr>
</tbody>
</table>
6.7 The relationship between sense of competence and family carer clinical characteristics

The relationship between sense of competence, carer mood and clinical characteristics was calculated using Pearson’s correlation coefficient (Tables 6.6 and 6.7). Sense of competence was most strongly associated with family carer mood as measured on the HADS ($r = -.6, p = .000$). When the HADS score was broken down to its two components, anxiety ($r = -.54, p = .000$) and depression ($r = -.53, p = .000$) were both strongly and negatively associated with sense of competence. Sense of competence and carer HRQoL measured with the EQ-5D-5L index value were not significantly associated ($r = .08, p = .11$), however, the EQ-5D-5L VAS score was moderately and positively related to sense of competence ($r = .31, p < .000$), which indicates that the higher the carer’s sense of competence, the higher carers scored their own health.

6.8 The relationship between sense of competence and person with dementia clinical characteristics

In terms of person with dementia clinical characteristics, the strongest association with carer sense of competence was person with dementia quality of life on the DEMQoL Proxy ($r = .37, p = .000$). There was also a significant association between sense of competence and person with dementia quality of life on the DEMQoL rated by the person with dementia themselves ($r = .16, p = .000$). Sense of competence was significantly associated with dependency to complete ADLs (measured with BADLS) ($r = -.25, p = .000$) and deterioration in ADLs ($r = -.26, p = .000$), measured with
the IDDD. The higher the person with dementia’s dependency and deterioration for ADLs was, the lower the carers sense of competence. Symptoms of depression in the person with dementia scored on the CSDD were negatively associated with sense of competence, however, this was only a small relationship ($r = -.15, \ p = .000$). There was no relationship between cognition scored on the MMSE and sense of competence ($r = .06, \ p = .21$).
Table 6.6 Pearson’s correlations between carer factors and sense of competence

<table>
<thead>
<tr>
<th>Sense of competence</th>
<th>Carer anxiety</th>
<th>Carer depression</th>
<th>HRQOL carer index</th>
<th>HRQOL-VAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of competence</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Carer anxiety</td>
<td>-.54***</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Carer depression</td>
<td>-.53***</td>
<td>.62***</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>HRQOL carer index</td>
<td>.08</td>
<td>-.14**</td>
<td>-.1*</td>
<td>-</td>
</tr>
<tr>
<td>HRQOL-VAS</td>
<td>.31***</td>
<td>-.4***</td>
<td>-.52***</td>
<td>-.52***</td>
</tr>
</tbody>
</table>

Note: * p < .05, ** p < .01, *** p < .001
### Table 6.7. Pearson's correlations between person with dementia factors and sense of competence

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sense of competence</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. QoL (carer rated)</td>
<td>.37***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. HRQOL VAS</td>
<td>.16****</td>
<td>.28***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Deterioration in ADLS</td>
<td>-.26***</td>
<td>.14***</td>
<td>-.11*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Dependency for ADLs</td>
<td>-.25***</td>
<td>-.15***</td>
<td>-.17***</td>
<td>.75***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Depression in dementia</td>
<td>-.16***</td>
<td>-.28***</td>
<td>-.36***</td>
<td>.04</td>
<td>.05</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. QoL (person with dementia rated)</td>
<td>-.16***</td>
<td>.3***</td>
<td>-.43***</td>
<td>.02</td>
<td>-.00</td>
<td>-.7***</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. HRQOL Index</td>
<td>.06</td>
<td>.24*</td>
<td>.45***</td>
<td>-.13**</td>
<td>-.25***</td>
<td>-.45***</td>
<td>.43***</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>9. Cognition</td>
<td>.06</td>
<td>.02</td>
<td>.04</td>
<td>-.38***</td>
<td>-.37***</td>
<td>.04</td>
<td>-.03</td>
<td>-.06</td>
<td>-</td>
</tr>
</tbody>
</table>

*Note: * p < .05, **p < .01, ***p < .001*
6.8.1  *The role of person with dementia factors and carer mood in explaining the variance in carer sense of competence.*

Carer mood (anxiety and depression) demonstrated the strongest association with carer sense of competence. A linear regression was employed to explore this relationship further. Carer anxiety significantly predicted 29% of the variance in sense of competence scores ($F(1,451) = 171.5, p = .001$). Carer depression also predicted 27% of the variance in sense of competence ($F(1,451) = 188.3, p = .001$). There were no violations of the assumptions of regression analysis within this analysis (normality, linearity, homoscedasticity and multicollinearity).

6.8.2  *Does carer mood predict sense of competence when person with dementia clinical characteristics is controlled for?*

The relationship between carer mood and carer sense of competence was explored further to identify the extent to which it could explain the unique variance in sense of competence when person with dementia clinical characteristics were controlled for. In the first step of hierarchical regression, person with dementia clinical characterises were entered. They were: cognition, ADL dependency, depression, person with dementia quality of life (rated by the carer and person with dementia), HRQoL (index value and VAS score) and ADL deterioration. In the second step of the regression, carer anxiety and depression were entered as separate variables. Again, this model demonstrated no violations of the assumptions of regression analysis.
At step 1, this model was statistically significant ($F (8, 397) = 13.59, p = .000$), person with dementia clinical characteristics explained 21.5% of the variance in sense of competence scores. After entry of carer mood at step 2 of the model, the total variance explained by the model was 41.1% and the model was statistically significant ($F (10, 395) = 27.54, p = .000$). After controlling for person with dementia clinical characteristics, the addition of carer mood explained an additional 19.6% of variance in sense of competence scores. The results from the hierarchical regression are outlined in Table 6.8.
### Table 6.8 Hierarchical regression analysis results

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>β</th>
<th>t</th>
<th>R</th>
<th>R²</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1: Person with dementia characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognition (MMSE)</td>
<td>-.4</td>
<td>.17</td>
<td>-.11</td>
<td>-2.33</td>
<td></td>
<td></td>
<td>.46</td>
</tr>
<tr>
<td>ADL Dependency (BADLS)</td>
<td>-.32</td>
<td>.13</td>
<td>-.17</td>
<td>-2.44</td>
<td></td>
<td></td>
<td>.22***</td>
</tr>
<tr>
<td>Depression (CSDD)</td>
<td>-.4</td>
<td>.28</td>
<td>-.09</td>
<td>-1.44</td>
<td></td>
<td></td>
<td>.22***</td>
</tr>
<tr>
<td>Quality of life (person with dementia rated) (DEMQoL)</td>
<td>.05</td>
<td>.09</td>
<td>.04</td>
<td>-1.44</td>
<td></td>
<td></td>
<td>.54</td>
</tr>
<tr>
<td>Quality of life (carer rated) (DEMQoL)</td>
<td>.42</td>
<td>.06</td>
<td>.33</td>
<td>6.77</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health-related quality of life (index value) (EQ-5D-5L)</td>
<td>-13.15</td>
<td>4.3</td>
<td>-.17</td>
<td>-3.03</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health-related quality of life (EQ-5D-5L· VAS)</td>
<td>.05</td>
<td>.05</td>
<td>.06</td>
<td>1.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADL Deterioration (IDDD)</td>
<td>-.19</td>
<td>.11</td>
<td>-.12</td>
<td>-1.79</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 2: Carer mood</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.64</td>
</tr>
<tr>
<td>Carer anxiety (HADS)</td>
<td>-.17</td>
<td>.2</td>
<td>-.31</td>
<td>-5.96</td>
<td></td>
<td></td>
<td>.41***</td>
</tr>
<tr>
<td>Carer depression (HADS)</td>
<td>-1.08</td>
<td>.25</td>
<td>-.22</td>
<td>-4.32</td>
<td></td>
<td></td>
<td>.2***</td>
</tr>
</tbody>
</table>

*Note: * p <.05, **p<.01, ***p<.001*

### 6.9 Discussion

As hypothesised, clinical characteristics of the person with dementia were related to carer sense of competence and predicted 22% of the variance in scores. However, these associations were weaker than expected, with most effect sizes being small. This may have been due to the inclusion criteria for the research, as the people with dementia who took part in the trial had mild to moderate dementia and were therefore more likely to be less dependent...
on the family carer. There was not a high level of dependency or ADL deterioration present in the sample of people living with dementia and this may have limited the amount that person with dementia clinical characteristics impacted on sense of competence, as most people were still able to complete many ADLs without assistance from the carer.

In terms of carer factors, as expected, carer mood was strongly and significantly associated with sense of competence. This reflects the findings from the systematic review in Chapter 3, which reported a relationship between carer mood and sense of competence (Lau & Cheng, 2015). The Lau & Cheng (2015) study used structural equation modelling to explore the associations between gratitude, sense of competence, coping and depression in carers. They found that there was a small relationship between sense of competence and depression ($r = -0.29, p < 0.01$), however, a much larger relationship was found in this Chapter ($r = -0.53, p < 0.000$). This may have been due to the different measures employed to measure mood and sense of competence. Lau & Cheng (2015) measured sense of competence using a four item scale (Pearlin et al., 1990), whereas this study employed the SCQ (Vernooij-Dassen, 1993), which contains 27 items and measures sense of competence in three domains. To measure depression, Lau & Cheng (2015) used a scale that purely measured depression (The seven-item Center for Epidemiologic Studies Depression Scale; Herrero & Meneses, 2006), whereas this study measured depression as part of a mixed scale (HADS). This study extended the findings of Lau & Cheng
Carer Sense of Competence (2015) and is the first research to explore the role of carer anxiety and depression when explaining variance in sense of competence scores, whilst controlling for person with dementia clinical characteristics. Carer mood (anxiety and depression) was found to predict over a third (35%) of variance in sense of competence scores, though this reduced to 19.6% when person with dementia clinical characteristics were controlled for. These results indicate that the extent to which carers feel symptoms of anxiety or depression significantly impacts their sense of competence, much more than person with dementia clinical characteristics. Symptoms of anxiety and depression are commonly reported in carers of people living with dementia (Cooper et al, 2007; Mahoney, Regan, Katona & Livingston, 2005; Cuijpers, 2005) however, these are both modifiable factors and can be targeted by relevant interventions (Cooper, Balamurali, Selwood, & Livingston, 2007). Understanding the impact that modifiable states have on sense of competence can enable interventions and clinical services to better support carers to feel more competent in their role.

These results reflect previous literature discussed in Chapter 1, such as the model of Fredrickson (2001), who proposed that positive and negative affect can occur simultaneously, and that positive affect buffers negative affect to produce positive outcomes. The presence of carer sense of competence appears to buffer against the negative impact of caring such as anxiety and depression, even when person with dementia factors are accounted for. Stress-coping models such as that of Lazarus and Folkman (1984) theorise
that cognitive appraisal of stressors mediate both positive and negative emotions. It may be that when a carer feels more competent in their role, they are able to appraise situations in a more positive way, in turn impacting on carer outcomes, such as anxiety, depression or quality of life.

6.10 Limitations

The outcome measure used to measure ADL completion was the BADLS, which measures the person with dementia’s dependency on the family carer to complete personal ADLs. This measure may have not been as relevant for the participants in this research study, who all had mild to moderate dementia. A more appropriate measure would have been one that was activity based or goal centred, but such a measure could not be identified within the development work for the VALID trial. In previous research described in the review reported in Chapter 3, the motivation and apathy of the person with dementia was significantly related to sense of competence (Vernooij-Dassen et al., 1996). This study could not measure the motivation to complete or to initiate ADLs, rather just the ability to do so. Additionally, as with the sample in Chapter 5, it must be acknowledged that there was a lack of diversity in the sample and therefore the results may not represent all groups of carers and people with dementia. This will be discussed further in Chapter 8.
6.11 Implications

The results further the understanding of the nature of sense of competence in family carers of people living with dementia. The relationship between carer mood and sense of competence was consistent with previous findings. Carer mood is not just related to sense of competence but in fact predicted a third of the variance in this domain. This relationship remained even when the characteristics of the person with dementia were controlled for, although to a lesser extent (19.6%). If the carer is experiencing high levels of anxiety or depression, it appears to negatively impact their sense of competence to a far greater extent than the clinical characteristics of the person with dementia. These findings suggest that providing support for carer anxiety and depression is imperative, alongside increasing the presence of positive psychology factors.

6.12 Future research

This study used solely quantitative data to explore the relationship between carer mood, person with dementia clinical characteristics and sense of competence. This would benefit from further exploration using qualitative methodology in order to understand the findings further. Conducting interviews with a sample of the carers who reported high levels of anxiety and depression and those who exhibited low symptoms of anxiety and depression would further explore the impact this has on their sense of competence in their role, in their own words.
6.13 Conclusion

The primary aim of this study was to increase the understanding of the impact of person with dementia clinical characteristics and carer mood on carer sense of competence. Carer mood had a significant impact on sense of competence and was much more strongly related with sense of competence that any of the person with dementia factors. These findings have significant theoretical and clinical implications. Theoretically, findings increase the understanding of factors that are associated with and predict carer sense of competence and contribute to the theoretical understanding of sense of competence. In terms of clinical implications, findings suggested that carer anxiety and depression were significant predictors of sense of competence. Therefore, it is important that family carers receive more support with anxiety and depression to enable them to feel more competent to care.
Chapter 7  Sense of competence of family carers of people living with dementia in the community: A qualitative study

7.1 Introduction

In the existing qualitative literature outlined in Chapter 2, carers described having increased confidence to make decisions following perceived challenges and felt that they had learnt more about their strengths through caring (Narayan et al., 2001; Lloyd et al., 2016). Carers also reported a sense of accomplishment and pride in the caring role (Peacock et al., 2010). Absent from the development of sense of competence theory are the carers voices themselves. In the survey reported in Chapter 5, many respondents used the available open-text boxes to explore and document their experience of caring and put their feelings in writing, indicating that family carers are eager to have their voices heard. There has not been a qualitative study that has investigated the meaning of sense of competence to family carers and the factors (both positive and negative) that contribute to how competent carers perceive themselves to be. Conducting an exploratory qualitative study with family carers of people living with dementia may provide important insights to the understanding of this concept and how it is embedded within the carer experience.
7.2 Aim

To examine the meaning of sense of competence to family carers of people living with dementia and the factors that influence how competent they perceive themselves to be.

7.3 Method

7.3.1 Design

This study used a two-part data collection process. Data was collected from two studies, the open-text boxes of the survey (Chapter 5), and individual interviews. These methods were chosen because in the survey there was a large amount of qualitative data provided by the participants, which was carefully inspected and considered adequate for analysis in order to gain new insights and prevent data waste (Lewis & Nicholls, 2014). The purpose of the interviews was to further explore the experiences of carers, combining this with the survey data in order to get both a broad overview and an in-depth focus on sense of competence.

7.3.2 Inclusion/exclusion criteria

To be included in the study, participants were required to meet the following inclusion criteria: 1) currently caring for a person with a diagnosis of dementia in the community, 2) over the age of 18 and 3) able to speak sufficient English to have a telephone interview.
7.3.3 Procedure

Recruitment for participants in the survey has previously been described in Chapter 5. Participants for the qualitative aspect of this survey comprised a convenience sample of 305 family carers of people living with dementia who made an additional comment on the open-text fields describing their experience as a carer (all comments pertaining to the sense of coherence scale were disregarded for the purpose of this analysis). For the interview study, participants were purposively sampled from the pool of family carers who completed the open-text fields of the survey and had agreed to be contacted about future research.

Participants for the interview study were sampled using a sampling framework in order to obtain as diverse a sample as possible. Participants were contacted by phone or email to discuss the study and those that expressed interest in taking part in the interviews were posted an information sheet and consent form (Appendix 4), with a freepost envelope for the return of the completed consent form. All participants gave informed consent by initialling and signing the consent form and sending it through the post. After carers returned the consent form, a mutually convenient time was arranged either over the phone or by email for the telephone interview to take place. At the time of the interview, information about the study was given verbally to all participants and the participants gave verbal consent to continue with the interview before proceeding. Capacity was informally assessed over the phone to ensure that all participants had capacity to continue with the
Carer Sense of Competence

interview. Twelve participants consented to take part but of these, only 10 were interviewed, as one participant was not available upon the arranged interview appointment and later declined to participate, and another withdrew following consent due to ill health of the person with dementia. The 10 interviews took place over the telephone and all participants confirmed that they were happy to be audio-recorded. An interview topic guide was employed to guide the discussion (Table 7.1). The topic guide included questions about the meaning of sense of competence to carers and about how positive and negative experiences impacted their sense of competence. The topic guide was deliberately broad and allowed flexibility for the interviewer to ask questions or explore a topic in more depth in line with the semi-structured nature of the interviews.
#### Table 7.1 Interview topic guide

<table>
<thead>
<tr>
<th>Interview Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sense of competence</strong></td>
</tr>
<tr>
<td>– What does the phrase ‘sense of competence’ mean to you?</td>
</tr>
<tr>
<td>– What does having a sense of competence in caring mean to you?</td>
</tr>
<tr>
<td>– What positively affects your sense of competence?</td>
</tr>
<tr>
<td>– What makes it difficult for you to feel competent?</td>
</tr>
<tr>
<td><strong>Positive experiences in caring and impact on sense of competence</strong></td>
</tr>
<tr>
<td>– Can you please tell me about any positive experiences you have had supporting your friend/relative?</td>
</tr>
<tr>
<td>– Could you tell me a bit more about… [refer to example given above]</td>
</tr>
<tr>
<td>– Do you feel that there have been positive aspects to being a carer?</td>
</tr>
<tr>
<td>– Do you think it has changed your relationship with [person with dementia] in a positive or negative way?</td>
</tr>
<tr>
<td>– How do you think these positive experiences have impacted your sense of competence in your role?</td>
</tr>
<tr>
<td><strong>Negative experiences in caring and impact on sense of competence</strong></td>
</tr>
<tr>
<td>– Have you had any difficult times when supporting your friend/relative?</td>
</tr>
<tr>
<td>– Could you tell me a bit more about… [refer to example given above]</td>
</tr>
<tr>
<td>– How do you think these difficult experiences have impacted your sense of competence in your role?</td>
</tr>
<tr>
<td><strong>Closing Questions</strong></td>
</tr>
<tr>
<td>– Is there anything else you would like to share with me?</td>
</tr>
</tbody>
</table>

#### 7.3.4 Thematic analysis

Thematic analysis was employed to analyse the data. Thematic analysis is a qualitative method used to identify themes and patterns and understand shared experience (Braun & Clark, 2006; Braun, Clarke, Hayfield, & Terry, 2019). Data from the two studies was initially analysed separately but then
integrated due to the significant overlap of themes derived from the data. However, the qualitative data from the survey informed the topic guide and gathering of information in the interview study, as illustrated in Figure 7.1.

For the survey qualitative data, all comments left by carers in the open-text boxes were downloaded onto an excel dataset to allow for the comments to be viewed in one dataset. Two researchers (JS, psychology background and JW, occupational therapist) familiarised themselves with the data by reading the textual data from the open-text boxes and conducted the initial analysis. For the interview study, each interview was transcribed verbatim from the audio recording and any personal data was redacted in order to anonymise the transcript. Two researchers initially conducted the analysis (JS and Georgina Buswell, a MSc clinical mental health sciences student at UCL).
The analysis for both studies was conducted in line with guidance outlined by Braun and Clarke (2006). In both studies, the two coders examined the data and read through the text in order to gain familiarity with the data. Initial codes were then generated independently by both coders by annotating the printed data, based on the meaning and interpretation of the data. A consensus meeting was then held to discuss codes and to generate an initial coding framework. This framework was used and modified as further transcripts were coded. The survey data was hand coded and the interview transcripts were coded using NVivo 12 due to the large amount of data. NVivo was chosen as the software as it enables electronic coding of passages of text, management of data, and the ability to sort coded data into themes and topics. For the interview study, coding continued after each interview until no new themes or topics were identified and at that point it was deemed that saturation had been reached. Saturation was reached after the 10th interview had been completed. Once saturation was reached, recruitment for the interviews was halted and a final consensus meeting was held to discuss and finalise themes. Once themes were finalised, they were defined and named.

The data from the two qualitative studies was then examined due to the large overlap of themes and codes and the results were integrated. This integration was led by JS but all coders agreed to the final themes and codes and the description of each. These were then discussed with a nominated supervisor (MO) and an agreement was made on the content of
themes and a description of each. For both studies, the carers discussed a range of experiences and topics but as the study aimed to explore the positive and negative aspects of caring and sense of competence, the analysis focused only on the data that related to sense of competence and the positive psychology factors.

7.3.5 Ethical Approval

Ethical approval for the survey and interview study was granted by Camberwell St Giles REC (REC 14/LO/0736) as a substantial amendment to the VALID research programme. The confidentiality of participants was maintained at all times and data was protected in accordance with the Data Protection Act 1998. To maintain anonymity, participants were assigned a unique participant identification number for their textual data. The textual data did not contain any personal details.

7.4 Results

In the survey qualitative study, the majority of participants were female (82.6%) and the mean age of participants was 61.1 (range = 18 – 89). Most of the participants were white British (94.8%), with only 2% from Black and Minority Ethnic (BME) groups, and 3.2% of participants not stating their ethnicity. Just under half (48.8%) were cohabiting with the person with dementia and most (66.9%) were receiving additional help with the person with dementia.
Ten family carers participated in the interviews, which took between 25 and 72 minutes. The average age of participants was 61 years (SD = 11.7) and there was an even distribution of people identifying as male (n = 5) and female (n = 5). Half of the family carers were spousal carers (50%) and most of these were husbands caring for their wives. The majority of the participants (70%) had completed tertiary or further education and the remaining 30% had completed secondary education. Demographic information for each of the interview participants is outlined in Table 7.2.
<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
<th>Relationship</th>
<th>Ethnicity</th>
<th>Cohabiting?</th>
<th>Approx. length of time caring</th>
<th>Type of Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>75</td>
<td>Female</td>
<td>Sister</td>
<td>White British</td>
<td>No</td>
<td>2 years</td>
<td>Vascular dementia</td>
</tr>
<tr>
<td>P2</td>
<td>59</td>
<td>Female</td>
<td>Daughter</td>
<td>White British</td>
<td>No</td>
<td>6 years</td>
<td>Unknown</td>
</tr>
<tr>
<td>P3</td>
<td>51</td>
<td>Female</td>
<td>Daughter</td>
<td>White British</td>
<td>No</td>
<td>8 years</td>
<td>Fronto-temporal dementia</td>
</tr>
<tr>
<td>P4</td>
<td>54</td>
<td>Male</td>
<td>Spouse</td>
<td>White British</td>
<td>Yes</td>
<td>4 years</td>
<td>Alzheimer’s Disease</td>
</tr>
<tr>
<td>P5</td>
<td>77</td>
<td>Female</td>
<td>Spouse</td>
<td>White Irish</td>
<td>Yes</td>
<td>7 years</td>
<td>Vascular dementia</td>
</tr>
<tr>
<td>P6</td>
<td>53</td>
<td>Male</td>
<td>Spouse</td>
<td>White British</td>
<td>Yes</td>
<td>3 years</td>
<td>Prosterior Cortical Atrophy</td>
</tr>
<tr>
<td>P7</td>
<td>77</td>
<td>Male</td>
<td>Spouse</td>
<td>White British</td>
<td>Yes</td>
<td>18 years</td>
<td>Unknown</td>
</tr>
<tr>
<td>P8</td>
<td>44</td>
<td>Male</td>
<td>Son</td>
<td>Pakistani</td>
<td>Yes</td>
<td>2 years</td>
<td>Parkinson’s Dementia</td>
</tr>
<tr>
<td>P9</td>
<td>62</td>
<td>Male</td>
<td>Spouse</td>
<td>White British</td>
<td>Yes</td>
<td>3 years</td>
<td>Unknown</td>
</tr>
<tr>
<td>P10</td>
<td>57</td>
<td>Female</td>
<td>Daughter</td>
<td>White British</td>
<td>No</td>
<td>10 years</td>
<td>Unknown</td>
</tr>
</tbody>
</table>
7.5 Definitions of sense of competence

Carers defined sense of competence as the feeling that they were able to manage the caring role and ‘succeed’ at caring.

“I think a big part of it is knowing that I am doing, you know, a good job of caring, that I am competent in what I’m doing… that I’m capable of helping her.” (P9)

Sense of competence was also retrospective, as it was guided by accomplishment of each caring task and overcoming obstacles or difficult situations.

“So that’s the motivation that I get and the competency I get is…we’ve got through another day…so I feel quite competent knowing that” (P8).

7.6 Themes and subthemes

Three themes were identified: overcoming challenges, self-belief and identity and focusing on the positives (Table 7.3). These themes and descriptions are described in the following section along with illustrative quotes.
Table 7.3 Themes and subthemes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overcoming challenges</strong></td>
<td>Successes and failures</td>
</tr>
<tr>
<td><em>The ability of the carer to overcome challenges and adjust to successes and failures impacts sense of competence. Support enabled carers to overcome challenges.</em></td>
<td>Support and coping</td>
</tr>
<tr>
<td><strong>Self-belief and identity</strong></td>
<td>Identity</td>
</tr>
<tr>
<td><em>Carers found it important to maintain their individual identity. This helped them employ coping strategies.</em></td>
<td>Coping mechanisms</td>
</tr>
<tr>
<td><strong>Focusing on the positives</strong></td>
<td>Resilience</td>
</tr>
<tr>
<td><em>Carers can experience positive aspects of caring. Those that can find positive factors in caring felt more competent and resilient.</em></td>
<td>Opportunity for learning</td>
</tr>
<tr>
<td></td>
<td>Making a positive difference</td>
</tr>
<tr>
<td></td>
<td>Love as a driving force for caring</td>
</tr>
</tbody>
</table>

7.7 Theme 1: Overcoming challenges

7.7.1 Successes and failures

Feeling competent was considered very important to carers as many of them felt that if they did not have the belief that they could accomplish caring tasks, it would result in stress and anxiety. Perceived successes or failures in the caring role particularly impacted their judgement of how competent they are. When carers overcame challenges or had a perceived ‘success’, they felt more competent.

“And when you have your little successes you know it’s brilliant.” (P3)

These successes could be quite small, but were connected to achieving and getting through everyday tasks.
“The cooking is done, the cleaning is done, the house is tidy, Mum is smiling, you know she’s taken her medication. So I feel quite competent knowing that…she’s not giving up the fight” (P8)

Carers felt that any mistakes or challenges were their responsibility. Even one perceived failure had a negative impact on sense of competence and impacted their global view of how competent they were.

“That made me feel incompetent because I realised I hadn’t realised, of course that he wouldn’t remember that the oven was on… I realised I made a mistake.” (P5)

Most of the carers reported that they felt that they were competent and could reflect positively on how they had overcome challenges. Taking part in the research allowed them space to reflect on their sense of competence and how they were coping.

“Made me realise how competent and capable I am and how much I love my husband at this stage in his life… our lives”.
(Survey participant)

Feelings of uncertainty were particularly difficult for carers to deal with, as caring for someone with dementia is unpredictable and therefore carers need to believe that they can overcome challenges that come up. This uncertainty caused stress and anxiety for carers.

“So my life is lived on this sort of short-term edge of will this work, or will it not work? Am I going to have to abort this, or
will I be able to carry it through? And often, usually I’d say, I can carry it through. But the stress of not knowing whether or not it’s actually going to work, I find very difficult.” (P7)

7.7.2 Support and coping

Carers spoke of the need for support to enable them to overcome challenges and obtain respite where it was needed. This support was needed from both family and friends, alongside professional support. If carers felt that this support was in place, it was an extremely important factor in making them feel they had a higher sense of competence.

“We’ve got a really good support network of family and friends…I know when things do get a bit tough, I have got people around me that I can ask or can…fall back on.” (P9)

When this support was not available, both professionally and personally, carers felt “diminished” and this impacted on their sense of competence.

“So everything conspires to make you feel diminished. And if you feel diminished it’s very difficult to feel competent.” (P5)

The availability of support enabled carers to feel that they could cope, with what for some was an unfamiliar and daunting task.

“The help that we can get that… we need and we deserve, erm, should sure up that sense of self-worth and competence that a carer has” (P2)
Practical support was also indispensable to carers, with a particular emphasis on the importance of having friends or family who would give them respite care to go and take some time for themselves. This relieved the burden of care and enabled carers to have time out and feel refreshed, even if the responsibility was still ever present in their mind. The ability to take this time enabled carers to feel more positive about their role.

“The things that keep me going are support from carers, and family and friends, that sort of thing. They relieve me of some of the...burden of care. They don't relieve me of the responsibility of care because the buck always stops with me. But they take away, for an hour or so, the task of caring.” (P7)

Despite the need for support and respite being spoken about by the majority of the carers, many expressed that they did not receive this support from services, particularly with budget cuts and difficulties accessing services for support and respite, which many carers have to now pay for. Carers felt failed and let down by the system, and this led to feelings of anger, isolation and disappointment.

“You kind of think, okay, mechanisms are in place and... no they're not because in our eyes, the system failed us” (P9)
7.8 Theme 2: Self-belief and identity

7.8.1 Maintaining the self

As carers adjusted and accepted the identity of being a carer, some felt as if they had lost their own individual identity. This impacted negatively on their sense of self and ability to make a judgement on their sense of competence, as they expressed that they had lost sight of themselves and felt they did not have anything left to give.

“I've always thought, ‘oh well, one day he'll go into a care home and he shall die; and then I'll start living again.’” (P5)

Some carers were able to maintain their sense of self by finding a form of, what they termed, “escapism”. Whether this was to pursue hobbies or just have some time to themselves. This helped carers to feel like they maintained their identity even if the caring role was challenging. The carers who had the support or time to do this expressed greater feelings of competence in general.

“What makes me feel more competent? Having another life actually...keeping as busy as I can and I'm fortunate that I've got brilliant carers who I can rely on”. (P10)

Many of the interview participants focused on what they could do to maintain their identity. This topic was raised in the survey but in a slightly different way. In the survey, a large number of carers reported a divide in the way that they saw their ‘general life’ and their ‘caring life’. It appeared as if they saw themselves as having two identities, with their caring role separate from their
Carer Sense of Competence
everyday life. This ‘two-fold identity’ was present in the comments of both spousal and adult child carers but was more prevalent in adult child carers. It appeared to create difficulty in answering some of the questions as carers did not know whether to answer as their ‘general self’ or their ‘caring self’. Participants noted how much their lives had changed since becoming a carer. This appeared to affect the carers own appraisal of themselves and how competent they were to manage this role, as they struggled with their own identity.

“I found it hard to disentangle responses in relation to how I feel about coping with and supporting my mum with Alzheimer’s and the other part of my life.” (Survey participant)

In particular, adult child carers seemed to find the transition into a caring role challenging, with some describing how they had to reduce their hours at work or stop working all together to provide care for a parent living with dementia.

“I have found the transition from running a business day to day to becoming a day to day carer frustrating, difficult and eye-opening.” (survey participant)

For spousal carers, there was also a transition period from spouse to carer but this was articulated as a change in the relationship prior to and after the diagnosis. A sacrifice of goals was also apparent in spousal carers. Most of the spousal carers were of retirement age and noted that as a result of caring for a spouse or partner, they had to narrow or change their view of how their life would be.
“Prior to dementia I had a goal to live out our lives doing all sorts of fun things whereas, after dementia, I only have one goal which is to look after my wife and die after her.” (Survey participant)

7.8.2 Coping mechanisms

Carers described the coping mechanisms they employed to enable them to feel more competent and to cope with the caring role. Most of the carers were very practical about the way that they coped, not focusing on the negative or emotional side, but taking a very problem-focused and practical approach.

“Neither of us have ever sort of erm…held on to negatives for very long. You know it’s a sort of...just chalk it up as a problem and then try and think of a better way round it next time” (P6)

The way in which some carers coped was by either taking time out for themselves, or by reframing the situation and focusing their mind on the positives. They coped by making the day more positive and taking control of this for themselves.

“I learnt that I need to spend five minutes when I get up in the morning, that’s me time, that just to think, okay, what exciting things are we going to do today.” (P9)

Carers also reflected on how well they thought they should be coping based on their previous work roles and background. A small proportion of the
carers stated that they felt they were not coping as well as they had anticipated. Although they believed they should be able to cope, they found the caring role challenging and needed help, whether this was from services or from other friends and family.

“I felt that with my abilities and background I should be able to cope without help, but I know now that I can’t.” (Survey participant)

### 7.9 Theme 3: Focusing on the positives

#### 7.9.1 Resilience

Carers emphasised the importance of focusing on the positives and the good things in life. Carers described this being a conscious choice made day after day to focus on the positive factors.

“You know, you can either decide the glass is half full or half empty, but I do think it’s a privilege to be able to look after somebody who returns some of the affections.” (P10)

Participants expressed a desire to be positive but it was clear that it was difficult to always feel positive about caring, particularly as the severity of dementia increased and carers found it harder to cope. This clearly demonstrates the challenges that carers face and the importance of staying resilient by trying to focus on the good things.
Carer Sense of Competence

“On the whole I feel positive. I try to focus on the good things but get ground down as mum’s condition deteriorates.”

(Survey participant)

Carers noted that even when there were difficult situations, they were able to rely on themselves to get through it. This resilience, despite the challenges they faced was key to carers perceiving themselves as more competent.

“I am generally able to help myself through the situation or consequences.” (Survey participant)

7.9.2 Making a positive difference

In the interview study, when asked what made them feel competent, the first answer given by many carers was that they felt they were doing their best for their family, whether this was keeping their loved one out of residential care or simply keeping them safe. This was particularly evident when they received a positive response from the person with dementia after an activity or caring task.

“I suppose just knowing that you’re doing the best for your family and erm… I mean our main aim is to keep her out of residential care for as long as we possibly can so that she can stay in her own home.” (P2)

For carers it was important, no matter how many challenges occurred, that they could look back and know they had done their best to keep the person with dementia happy and safe.
“You do your best and everybody does their best… I felt more competent, knowing, that I'd done everything I could” (P10)

Making a positive difference for carers did not have to be as significant as keeping the person with dementia out of residential care, but could just be enjoying little moments, or little victories, where they are able to spend time with the person with dementia. Carers spoke about specific positive events with pride and these seemed to be moments that the carers dwelled on when things were difficult.

“If I can't look back on this one day, if I out live him, and say, 'those were perfect moments’ then I'm expecting more than life will ever deliver.” (P5)

7.9.3 Opportunity for learning and growth

One of the things that made carers feel positive was the opportunity for learning that their caring role had given them. For some carers, this was learning to overcome challenges but for others this was simply an increase in confidence to advocate for the person with dementia when arranging appointments or care. Carers reflected on these positive changes and felt competent when they thought about how much they had learnt and developed in their role.

“I must say the one positive thing that has come out of it all is that it’s given me a lot of confidence to do…things…phone people up and you know, make a fuss, which I probably wouldn't do on my own account but I will do for Mum.” (P2)
Many of the carers took it upon themselves to research how to deal with caring challenges and how to find things to keep the person with dementia engaged in activity and community. This increased carer’s sense of competence because they felt empowered by taking their situation into their own hands.

“We did a lot of research I think that made us feel more competent because we were working together, we were able to bounce ideas of each other.” (P3)

7.9.4 Love as a driving force for caring

There are many reasons why carers would choose to care, and these were often shared within the two qualitative studies. Carers sometimes felt obligated to care for a person in order to ensure they stayed in the community, and some found the role to be fulfilling.

“Carer response to their duties varies from those who find it rewarding and fulfilling and to those who deeply resent their misfortune but are bound by their situation” (Survey respondent)

It may be that even when carers decide to care based on feelings of obligation, their love for their relative drives this decision. Indeed, love was frequently cited as a driving force for overcoming the challenges of caring and as a reason why carers continued to care. Particularly in the adult child carers, many expressed that they wanted to care for the person with
dementia to repay help or support that the person with dementia had given them in the past.

“It’s the love you have for your Mother you just… want the best for her and to do the best you can. You know, she’s looked after me…so I just want to do the same for her.” (P2)

Carers who described caring out of love rather than a sense of obligation used this as a motivator to become more competent, in order to provide the best care they could for the person with dementia.

“It is just to see her smile every day…that’s probably the motivation and the inspiration I get to become more competent to do a lot more things.” (P8)

7.10 Discussion

This study explored the meaning of sense of competence to family carers, in their own words. The description of sense of competence given by family carers reflected its current definition in the literature (Vernooij-Dassen et al., 1996), where sense of competence is defined as the internal feeling that they were able to manage the caring role. When family carers reflected on their sense of competence they initially made a judgement about their sense of competence overall, rather than breaking it down between tasks or situations. Therefore, sense of competence does not appear to be domain-specific, but a global construct. However, it is likely each individual task or situation, alongside the carers outlook and perspective feeds into and impacts this global view. Sense of competence was guided by the
accomplishment of tasks and ability to overcome challenges. In a sense, this domain was deeply related to the carer’s personal ability to thrive in the caring role, deal with challenges as they arose and then reflect on these perceived successes or failures. These successes or failures, in turn, seemed to impact on the carer’s appraisal of how competent they were, reflecting previous stress-coping models, which describe the important role that cognitive appraisal has in moderating carer outcomes (Lazarus & Folkman, 1984; Kramer, 1997).

These findings also reflect earlier work described in Chapter 3, where a higher sense of competence was felt by carers when they coped with challenging situations (Peacock et al., 2010). Challenging experiences made carers feel more competent as they could take pride in their successes. Consistent with previous research (De Vugt et al., 2004; Lau & Cheng, 2015), the coping mechanisms of the carer did have an impact on carer sense of competence. In this study, when carers were able to focus on the positives and have an adaptive and problem focused coping strategy, they expressed that this increased their sense of competence. Carers spoke of positive experiences within caring and described experiencing gains in caring such as self-growth, confidence and learning more about themselves. When carers could see a positive impact of what they were doing, or find meaning in their role, such as the person with dementia feeling safe in their care, this increased their sense of competence. This reflects previous
findings outlined in Chapter 5; that positive psychology factors increase a carer’s sense of competence.

Despite the ability of carers to identify positive aspects of caring, there was also a significant negative psychological impact described by carers. Carers reported feelings of strain in dealing with what, for some, was an unfamiliar and daunting task. These findings reflect previous literature reporting that family carers can experience both positive and negative emotions in the caring role. The experience of caring in this study was not necessarily reflected as a spectrum of being either positive or negative (Wong, 2011; Clarke & Wolverson, 2016). Rather, both the positive and negative aspects of caring were present. This was summarised by one carer who stated:

“I would like to enlarge on the heightened emotions – both positive and negative - I am experiencing when supporting a mother who no longer seems to recognise me… but whose occasional random smiles are extraordinary” (Survey participant).

This brings to life the importance of investigating both the positive and negative impact of caring on sense of competence.

7.11 Methodological Limitations

The participants were recruited from across the UK and a sampling framework was employed to include as diverse a group as possible. Despite efforts, it proved difficult to engage or recruit many non-white British carers
to participate in the interviews, which limits the generalisability of the results. Additionally, the participant’s sense of competence was not measured with a standardised measure at the time of the interview, so it is not possible to identify whether this sample was a group of carers that felt more or less competent than the rest of the population, or whether there were differences in sense of competence within the group.

The carers in this interview study had previously participated in a national survey and had agreed to be contacted about further research involvement. Therefore, it is possible that this group may represent a particularly motivated group of carers, who were already seeking to improve their sense of competence by engaging with services and clinical research. In addition, the interviews were conducted over the phone and therefore it was not possible to account for body language that could have provided additional information or guided the interviewer to explore topics in further depth. As such, the limitations of collecting the data in this manner must be acknowledged.

7.12 Future research

Future research could follow the carers up over time and conduct longitudinal interviews to investigate whether the carers descriptions of their sense of competence and factors that facilitate or hinder this change over time, and why. Additionally, due to the retrospective nature of sense of competence, it would be beneficial to conduct an interview study with past
Carer Sense of Competence

family carers and compare if there were any differences in the description of sense of competence between past and current carers.

7.13 Conclusions

This study investigated the meaning of sense of competence, using two sources of qualitative data. This qualitative study supports findings in previous Chapters, that carers are able to identify positive aspects of caring and these positively impact their sense of competence. Carers were able to focus on the positives and implement practical solutions to caring challenges, which increased their sense of competence. Sense of competence was retrospective and closely linked to the carers own feeling of accomplishment in their role. Perceived successes or failures in the caring role appeared to be an important factor that influenced the carer’s appraisal of their global competence to care, reflecting previous stress-coping models.
Chapter 8  Discussion

8.1  Summary of main findings

This was the first research to examine in depth the predictors of family carer sense of competence. This research was innovative, employing varied methodology including three systematic literature reviews, structural equation modelling and interviews with carers. Positive psychology factors (such as sense of coherence, self-efficacy and resilience) and negative carer outcomes (such as anxiety and depression) were strongly related to sense of competence but the person with dementia clinical characteristics only had a small association with carer sense of competence. Through the different components of this research, an updated model of sense of competence was proposed, which integrates the findings from systematic reviews (Chapters 2 and 3, discussed in Section 8.2.1) and empirical research (Chapters 5, 6 and 7, discussed in Section 8.2.2) with the previous model of sense of competence. In the proposed model (Figure 8.1), carer factors are represented with squares and person with dementia factors are represented with ovals. Predictive pathways are illustrated with an arrow and associations are represented with a straight line between factors.
Carer Sense of Competence

Carer context and demographics
- Gender
- Age
- Marital status
- Cohabiting
- Relationship type with person with dementia
- Relationship quality between carer and person with dementia

Social support and engagement

Determining factors
- Person with dementia clinical characteristics
  - Severity of dementia
  - Cognition
  - ADL impairment and deterioration
  - Frequency of BPSD

Overcoming challenges

Positive psychology factors
- Meaning
- Gratitude
- Self-efficacy
- Resilience
- Gains in caring

Sense of coherence

Outcomes
- Negative outcomes
  - BPSD related distress
  - Anxiety/depression
  - Hopelessness
  - Guilt

HRQoL

Sense of Competence

Figure 8.1 Proposed model of sense of competence
8.2 Findings in the context of previous literature

8.2.1 Findings from systematic reviews

First, a systematic literature review (Chapter 2) identified positive psychology outcome measures developed for or validated with family carers of people living with dementia. The findings from this review suggested that, despite increasing interest in the recognition and investigation of positive psychology concepts in understanding the carer experience (Keyes & Lopez, 2005), there were few high quality positive psychology scales that had been developed or validated for use with this population. The scales identified in Chapter 2 were closely aligned to the character strengths identified within the VIA framework proposed by Peterson & Seligman (2004). However, more work needs to be done to develop scales to further measure these character strengths. Findings from this review informed decisions about which standardised measures to incorporate into the survey described in Chapter 5.

A second systematic review (Chapter 3) searched the literature for published work exploring factors related to sense of competence. The narrative synthesis methodology employed in this review was a particular strength as it enabled integration of findings from both quantitative and qualitative papers. Findings demonstrated that both positive and negative aspects of caring and person with dementia factors were associated with carer sense of competence. These results informed the preliminary model of sense of competence outlined in this Chapter. The preliminary model proposed in this
Chapter was consistent with the theory proposed by Fredrickson (2001) and lent support to the theory of “mixed valence” within the caring experience (Lawton et al. 1991, p. 182), as described in Chapter 1. Caring for someone with dementia is complex, and therefore the interplay of positive and negative aspects of caring must be incorporated into the design of interventions and also the way that researchers measure the impact of interventions.

In order to explore the impact of psychosocial interventions on sense of competence, a further systematic review was conducted (Chapter 4) and meta-analysis methodology was employed. The interventions identified and included in the analysis were very heterogeneous, and there was no one strategy or type of intervention that was particularly efficacious to improve carer sense of competence. These results reflected findings in a recent systematic review that investigated which types of interventions are successful with family carers of people living with dementia (Kishita, Hammond, Dietrich & Mioshi, 2018), which also found that a combination of interventions is most effective to support carers. The results in Chapter 4 indicated that multi-component interventions tailored to the family carers needs were most effective at improving sense of competence. With the rise in dementia cases, family carers are being relied on more often to support their relatives in care and it is imperative that they are given enough support to safely carry out the caring task.
8.2.2 Findings from the empirical studies

The national survey, reported in Chapter 5 was mixed methods in nature and this methodology allowed the carer experience to be examined in greater detail, in a way that did not over-rely on standardised measures to explain complex domains. In the quantitative survey data, carers demonstrated moderate to high scores on measures of sense of competence, resilience, sense of coherence, self-efficacy and gains. This reflects previous literature, suggesting that it is possible for character strengths to emerge from stressful circumstances (Schueller et al., 2015), including caring. The survey aimed to investigate the association between sense of competence, positive psychology and HRQoL (Chapter 5). Path analysis was employed to test a hypothesised model of positive aspects of caring and sense of competence, which was theorised based on previous literature and evidence gathered throughout the thesis. The hypothesised model was a good fit for the data and, in line with previously specified hypotheses, sense of competence was significantly and positively related to positive psychology factors (resilience, self-efficacy for managing dementia, gains in caring and sense of coherence). These findings were consistent with the previously described conceptual model of positive psychology factors in caring (Carbonneau et al., 2010, see Section 1.7, p. 47), which suggested that, if the carer has a higher sense of competence, there will be more positive outcomes for the carer and increased longevity of caring. Qualitative data from the survey was combined with interview data (Chapter 7) in order to gain a further understanding of the meaning of sense of competence.
Cross-sectional baseline data from the VALID multi-site trial was used to examine sense of competence in relation to carer mood and person with dementia factors (Chapter 6). Findings from the narrative synthesis (Chapter 3) were employed to guide hypotheses. Consistent with hypotheses, the person with dementia’s level of dependency and their ability to independently complete ADLs significantly impacted on sense of competence, but these associations were smaller than expected. In line with hypotheses, carer anxiety and depression had a significant impact on sense of competence, even when person with dementia factors were controlled for, consistent with previous literature (Lau & Cheng, 2015). This was the first study to explore the relationship between carer mood, sense of competence and person with dementia clinical characteristics in detail. This research suggested that, although these factors do indeed play a role in sense of competence, the way in which the carer feels, i.e. their current state, is far more important than person with dementia factors when considering how competent they feel to care for the person with dementia.

The meaning of sense of competence to family carers was explored in two qualitative studies (Chapter 7). There are issues relating to the conceptualisation and definition of sense of competence, which is often used interchangeably with other constructs in the literature, such as burden or self-efficacy, as discussed in Chapter 1. In the interview study, sense of competence was described by family carers in a way that reflected the
existing definition (Vernooij-Dassen et al., 1996) but appeared to be more complex than previously defined. Sense of competence was not just related to a general feeling of capability to manage a task or manage the burden of caring but was a retrospective concept guided by the accomplishment of tasks and ability to overcome challenges. In the qualitative data, carers descriptions of sense of competence was rooted in their ability to thrive in the caring role and deal with challenges as they arose. This conceptualisation can be considered in the context of positive psychology theory, which investigates the ability of a person to thrive in adverse circumstances. This perspective has not previously been incorporated into the conceptualisation of sense of competence. The qualitative findings (Chapter 7) were consistent with previous research in which carers discussed the importance of overcoming challenging experiences and constantly adapting in order to feel more competent (Peacock et al., 2010). Thus, it may be the carers who are able to adapt to challenges that exhibit the highest sense of competence. Additionally, findings in Chapter 7 support previous research reporting that positive character strengths can counteract or balance the negative aspects of caring such as burden or stress (Gottlieb & Rooney, 2004).

A frequent debate within the conceptualisation of sense of competence is whether sense of competence is a trait or state. This has not yet been addressed in the existing literature and is not necessarily clear cut to define based on these findings. Sense of competence appears to be a dynamic and
reflective process in which carers learn and become more competent following overcoming challenges and difficulties. As such, evidence in this thesis suggests that sense of competence is a state, rather than being akin to a trait. However, a carer’s traits, such as ability to identify positive aspects of caring, may influence their sense of competence in turn.

8.3 Methodological considerations

8.3.1 Recruitment techniques and participant demographics

Recruitment of family carers of people living with dementia was conducted in two streams: for the national survey and for the VALID RCT. Recruitment for the national survey was much less challenging than expected. However, due to the nature of the recruitment methods (through the JDR register, carer charities and third sector organisations), it is probable that this study reached carers who were already engaged with services or research.

For the VALID RCT, recruitment proved more challenging. During the design of the COTiD-UK intervention study, some carers, particularly spouses, advised that they did not identify as a ‘carer’ and therefore recruitment materials were designed in collaboration with PPI colleagues. The term ‘supporter’ rather than ‘carer’ was subsequently used in recruitment materials in order to capture those relatives or friends who did not feel that ‘carer’ represented them. Reasons for declining to take part in the research were often due to time commitment, as the VALID intervention constituted approximately 10 hours of occupational therapy if randomised to the
intervention arm. In addition, this intervention was dyadic in nature, which did hinder recruitment somewhat as even if the carer wanted to take part in the trial, some of the people with dementia did not, or lacked insight into their difficulties and felt that they did not require help. Recruitment for the VALID trial was mostly through referrals from memory services. In one of the sites (NELFT) a mail-out took place through a local charitable organisation (Havering Tapestry), in which approximately 5% of carers expressed interest in taking part in the research. However, this method had its own challenges, as many of the dyads did not meet the inclusion criteria as they had not been pre-screened by a clinician. Many of the memory services involved with recruitment were often involved with other research and therefore the research team had to be proactive in spending time in memory services. Researchers embedded themselves within services and attended team meetings to present about the study and generate referrals, whilst also trying to minimise the burden on clinical staff. In order to ensure that recruitment challenges were overcome, monthly teleconferences were held with all sites taking part in VALID, which facilitated better engagement with research staff and allowed the sharing of recruitment methods and advice for researchers.

8.3.2 Participant characteristics compared with other studies

The sample in this research was consistent with other research studies conducted with family carer and people with dementia in the UK, such as the BEfriending and Cost of CAring (BECCA) trial (Charlesworth et al., 2008), the REMiniscence groups for people with dementia and their family CAREgivers (REMCARE) trial (Woods et al., 2012) and the Support at
Home: Interventions to Enhance Life in Dementia (SHIELD) programme (Orrell et al., 2017). The carers were predominantly white, female, cohabiting with the person with dementia, who were most commonly diagnosed with Alzheimer's. All of the people with dementia participating in the VALID trial had mild to moderate dementia. Most of the carers taking part in these aforementioned trials were spousal carers, probably due to the fact that interventions require a large commitment in terms of time and cannot often be offered outside working hours. This may reflect the differences between these samples and the demographic characteristics of the survey cohort in Chapter 5, in which most of the participants were adult child carers, as the survey could be completed at any time and therefore fitted in around work commitments.

8.3.3 Screening of participants

The design of the national survey did not enable pre-screening of participants. In order to ascertain that inclusion criteria were met, carers were required to tick boxes to confirm they met the inclusion criteria before proceeding with the survey. However, it is not possible to guarantee that all carers met the criteria, as there was no way of evaluating this.

For the VALID trial, screening of participants represented a challenge. Despite clear eligibility criteria in the protocol, much of the screening relied on gathering information from family carers regarding diagnosis and duration of dementia. This was particularly challenging when using the CDR as a screening tool to estimate the severity of dementia as in certain cases it was
difficult to ascertain all the information required to provide a score on this tool, particularly with carers who did not reside with the person with dementia, or where paid carers provided a lot of assistance with care. In order to ensure consistent screening of participants, all researchers at each of the sites were trained and group discussions were held in teleconferences in order to identify any common issues with screening and ensure they were resolved consistently across the trial.

8.3.4 Measures and data

The instruments used in the national survey were chosen because they best reflected the concepts they measured, had undergone a robust development process or had good psychometric properties, as described in Chapter 2. There were two measures included in the survey that were not identified in the systematic review (RS-14 and sense of coherence scale). The online survey took carers between 9 - 21 minutes to complete. The time carers took to complete the paper surveys was not recorded. Most carers reported in the open-text boxes at the end of the survey that the survey was easy to use and only a very small percentage reported technical difficulties ($n = 3$). One carer commented that the survey had been difficult to complete on an iPad and two carers reported that the survey froze on their computer whilst completing it.

The measures included in the VALID trial (Chapter 6) had good reliability and validity to support their use with this trial population. The choice of measures was guided by a previous trial evaluating COTiD (Graff et al.,
and agreed upon by the programme management group for the trial. In general, the measures were concise and easy to use however, the interview format could constrain the flexibility of data collection, as the standardised measures were limited to tick boxes and Likert scales. In the assessments carers often wanted to be given much more additional information to support their answers and it was not possible to record all of this, meaning that some potentially rich data could have been missed. In the future, assessments could be audio-recorded, provided that the participants agreed, in order to analyse any additional information given during the interviews. The length of the baseline assessment for VALID was between one and three hours and most assessments were conducted in the person with dementia’s own home. If possible, the carer and the person with dementia were seen separately due to the nature of the questionnaires. If the dyad did not want to separate for the assessment, these wishes were respected. There were instances in which participants reported becoming tired or upset during the assessment and some expressed frustration at how repetitive the questionnaires in the assessments were. In cases where participants were too tired to continue or became distressed, the assessments were terminated. Researchers were trained to recognise signs of distress and to offer comfort and frequent breaks where necessary.

8.3.5 Proxy Reporting

For the VALID trial, most of the person with dementia measures (such as the ADL measures) were proxy reports given by the family carer. This may have methodological implications as previous research has indicated that carer’s
proxy ratings were often lower than the person with dementia ratings (O'Shea et al., 2018). Predictors of this were the carer’s feeling of anxiety and depression, education, functional ability of the person with dementia and relationship quality.

8.4 Theoretical Implications

The findings further the understanding of sense of competence in family carers of people living with dementia by exploring its nature, associations, predictors and its relationship with carer outcomes. The research in this thesis responds to calls to recognise the positive psychology factors that impact the caring experience (Kramer 1997). It is imperative that positive psychology factors are incorporated into existing models of the carer experience, such as stress-coping models. In applying positive psychology theory to understanding carer sense of competence, the associations between sense of competence and positive psychology factors was explored in depth. Positive psychology factors significantly predicted 27% of variance in sense of competence scores. The findings inform existing conceptual models of carer coping in several ways. Firstly, they identified key positive psychology factors (such as sense of coherence, gains and resilience) that facilitate carer sense of competence, and factors that decrease sense of competence, such as carer anxiety and depression. These novel findings highlight the importance of recognising how competent carers feel and the relationship this has with outcomes such as anxiety, depression and HRQoL. In addition, these findings do not support uni-directional views that the carer
experience is exclusively either positive or negative but support the ‘mixed valence’ view of the caring experience, whereupon carers can experience both positive and negative outcomes simultaneously. This has also been found for similar domains such as self-efficacy that have demonstrated a dual action on carer outcomes, impacting both the positive and negative outcomes of carers (Crellin et al., 2014) Taken together, the results from this thesis can contribute to existing stress-coping models and enable a more holistic view of the carer experience. Consequently, the current findings substantially improve the theoretical understanding of sense of competence and the positive psychology factors that predict this domain. The proposed conceptual model of sense of competence advances theory and can be further tested and developed.

8.5 Clinical implications

Positive psychology factors predicted sense of competence, which has significant implications for the design of interventions and support services for family carers. Primarily, these findings indicate that interventions should refrain from exclusively using a loss-deficit model to evaluate the success or failure of an intervention. Rather, interventions should be designed to not just alleviate the negative aspects of caring but also increase the positive aspects, as these play an important role in carer outcomes. The meta-analysis (Chapter 4) gave guidance as to the components of effective psychosocial interventions on sense of competence and indicated that sense of competence was a modifiable state. Sense of competence can therefore
provide a powerful avenue through which carer outcomes such as quality of life can be improved. This stands in agreement with existing literature (Hilgeman, Allen, DeCoster & Burgio, 2007), which suggests that positive psychology factors moderate intervention outcomes.

Sense of competence was significantly predicted by carer anxiety and depression, a relationship that remained even when the clinical characteristics of the person with dementia were controlled for. Family carers are at high risk of mood disorders (Livingston et al., 2017) and as such, it is important to address feelings of anxiety and depression and support carers to adapt to challenges in the caring role, as this may in turn, increase how competent they feel.

8.6 Limitations

There are several limitations which could be addressed in future research. First, this research was cross-sectional in nature, and although this design enabled complex path analysis modelling across domains of sense of competence and positive psychology factors, it did not allow causality to be tested. In addition, it was not possible to model whether the relationships between positive psychology factors or carer mood and sense of competence would persist over time. This is particularly relevant for carers of people living with dementia, as due to the progressive nature of dementia, carer roles and responsibilities are likely to change over time. Longitudinal
modelling of the nature of sense of competence would provide a greater understanding of this concept.

There are several factors that were not included in the data collection or analysis that may have influenced or confounded results. For example, the nature and quality of the relationship between the person with dementia and the carer was not measured or accounted for in either of the empirical Chapters. Additionally, this thesis focused solely on current family carers of people living with dementia in the community. This excluded past carers of people with dementia who had passed away or carers of people with dementia who had moved into residential care. This decision was made to reduce the presence of confounding variables. However, this may have excluded important findings.

Participants in this study may represent a population of dyads that are engaging with services and therefore, research. Additionally, the empirical research sample was mostly comprised of white, female carers. Due to the lack of diversity in the sample of this thesis, the results may not be representative of all groups of carers and people with dementia, which may impact the generalisability of results as it limits the range of experiences included in the research. Due to the lack of ethnic diversity, it was not possible to evaluate whether this impacted sense of competence scores, which also represents a gap in the findings. Previous research has also found that carer outcomes differ according to factors such as gender and
ethnicity (Roth, Ackerman, Okonkwo & Burgio, 2008; Raschick & Ingersoll-Dayton, 2004) and consequently, further research with more diverse groups is required.

In order to improve diversity in the survey sample, efforts were made to engage with BME charitable organisations, but this did not significantly increase the ethnic diversity of respondents as most of these organisations declined to advertise the survey. In the VALID study, despite efforts to widen recruitment and the number of research sites, it proved difficult to engage carers from BME groups, reflecting challenges found in the survey. This was partially due to lack of diversity at sites and inclusion criteria only including English speaking participants. Additionally, research has found that BME groups are less engaged with services (Woodall, Morgan, Sloan & Howard, 2010). A recent systematic review (Liljas et al., 2017) indicated that BME groups lack self-confidence to engage with services and research, and barriers to this engagement included cultural difference and language challenges. Liljas et al. (2017) suggested that collaborating with community groups and cultural leaders, and addressing potential language barriers may increase engagement of BME groups in research. Therefore, future studies would benefit from including funding for translators to conduct the research assessments within the grant application.

Bonferroni corrections were not employed to interpret the \( p \) value in statistical analyses within this thesis as all analyses were specified a priori.
and were hypothesis driven. This reflects recommendations by Perneger (1998) that Bonferroni corrections are not required when testing previously specified hypotheses. The application of Bonferroni corrections to statistical analysis has been criticised for being too conservative and for increasing the risk of type two errors (accepting the null hypothesis, when an effect really exists) (Nakagawa, 2004). However, findings in this thesis may be weakened by an increased risk of type one errors (incorrectly rejecting the null hypothesis) due to the number of tests performed.

8.7 Further research

The systematic review in Chapter 2 indicated that more work needs to be conducted to develop and validate high quality positive psychology outcome measures. There is a growing need to develop new measures that draw on models closely aligned to the discipline of positive psychology, such as wisdom and optimism (Clarke & Wolverson, 2016), reflecting the VIA framework previously discussed in Chapter 1 (Section 1.6.1, p. 43). Many of the identified scales in this review had not yet been used to evaluate high quality RCTs of interventions, so it is recommended that these are incorporated into intervention studies to evaluate psychosocial interventions.

For the concept of sense of competence, there are several different measurement scales in use, though only two that have been specifically developed for or validated with family carers of people living with dementia (SCQ and SSCQ). These scales are used frequently in intervention research
Carer Sense of Competence (Jones et al., 2012) but also contain many negatively worded items. Correspondingly, and based on the results of this thesis, further work could usefully revise the SCQ, incorporating positive items within the scale. Findings from Chapter 7 indicated that sense of competence was retrospective and guided by accomplishments of tasks and overcoming challenging situations. Therefore, the measure should ask carers to consider challenges in the caring role and their response to these challenges, with respect to their global sense of competence. Once items have been generated, a focus group design would enable carers to provide feedback on the revised measure, in order to ensure that carer views are incorporated in the development of the measure.

Future research should seek to longitudinally model the relationship between sense of competence, anxiety and depression, taking into account the person with dementia clinical characteristics. Findings in Chapter 6 indicated that carer anxiety and depression predicted sense of competence, however, as a result of the cross-sectional methodology, it is not possible to explore how this relationship would change over time, as dementia severity potentially increases. The VALID trial adopted a longitudinal design (baseline, 3 months, 6 months, 12 months and 24 months) and data from these extended follow-ups could be used to conduct longitudinal modelling. It is recommended that future research models the relationship between anxiety, depression and sense of competence over time, using a structural equation modelling approach.
8.8 Conclusion

The results from this thesis demonstrate that positive psychology factors are related to, and significantly impact, carer sense of competence. In doing so, this research provided a wealth of data to advance the understanding of sense of competence. Findings support the application of positive psychology theory to better understand carer sense of competence from a more balanced view. Results reflected the mixed valence view of the caring experience proposed in previous research (Lawton, et al., 1991) as positive and negative aspects of caring both impacted sense of competence. The findings have theoretical and clinical implications for research and practice as the proposed conceptual model of sense of competence drives forward existing theory. These findings support the development of interventions that not only seek to alleviate the negative aspects of caring but also seek to elevate the positive experiences, to ultimately improve carer sense of competence.
References


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Downs, S. H. & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and


(Available [http://www.euroqol.org](http://www.euroqol.org))


Carer Sense of Competence


Carer Sense of Competence

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Peel, E., & Harding, R. (2014). ‘It’s a huge maze, the system, it’s a terrible maze’: Dementia carers’ constructions of navigating health and social care services. *Dementia 13*, 642-661.


Carer Sense of Competence


Carer Sense of Competence


health and social support services for informal carers and case managers of people with dementia; a cluster randomized trial. *International Psychogeriatrics, 27,* 1365-1378.


Voigt-Radloff, S., Graff, M., Leonhart, R., Hull, M., Rikkert, M. O., & Vernooij-Dassen, M. (2011). Why did an effective Dutch complex psycho-social
intervention for people with dementia not work in German Healthcare context? Lessons learnt from a process evaluation alongside a multicentre RCT. *BMJ Open, 9*, doi: 10.1136/bmjopen-2011-000094


### Appendix 1. Quality appraisal tools

#### Appendix 1.1. STROBE Checklist (von Elm et al., 2007)

**STROBE Statement**—Checklist of items that should be included in reports of *cross-sectional studies*

<table>
<thead>
<tr>
<th>Item No</th>
<th>Title and abstract</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>(a) Indicate the study’s design with a commonly used term in the title or the abstract</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(b) Provide in the abstract an informative and balanced summary of what was done and what was found</td>
<td></td>
</tr>
</tbody>
</table>

**Introduction**

- **Background/rationale**
  - 2 Explain the scientific background and rationale for the investigation being reported

**Objectives**

- 3 State specific objectives, including any prespecified hypotheses

**Methods**

- **Study design**
  - 4 Present key elements of study design early in the paper

- **Setting**
  - 5 Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection

- **Participants**
  - 6 (a) Give the eligibility criteria, and the sources and methods of selection of participants

- **Variables**
  - 7 Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable

- **Data sources/measurement**
  - 8* For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group

- **Bias**
  - 9 Describe any efforts to address potential sources of bias

- **Study size**
  - 10 Explain how the study size was arrived at

- **Quantitative variables**
  - 11 Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why

- **Statistical methods**
  - 12 (a) Describe all statistical methods, including those used to control for confounding
  - (b) Describe any methods used to examine subgroups and interactions
  - (c) Explain how missing data were addressed
  - (d) If applicable, describe analytical methods taking account of sampling strategy
  - (e) Describe any sensitivity analyses

**Results**

- **Participants**
  - 13* (a) Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
  - (b) Give reasons for non-participation at each stage
  - (c) Consider use of a flow diagram

- **Descriptive data**
  - 14* (a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders
  - (b) Indicate number of participants with missing data for each variable of interest

- **Outcome data**
  - 15* Report numbers of outcome events or summary measures

- **Main results**
  - 16 (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g. 95% confidence interval). Make clear which confounders were adjusted for and why they were included
  - (b) Report category boundaries when continuous variables were categorized
  - (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period

- **Other analyses**
  - 17 Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses
Discussion

| Key results | 18 | Summarise key results with reference to study objectives |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results |
| Other information | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based |

*Give information separately for exposed and unexposed groups.

Appendix 1.2. CASP Checklist (Public Health Resource Unit, 2006)

Critical Appraisal Skills Programme (CASP) making sense of evidence

How to use this appraisal tool:
Three broad issues need to be considered when appraising the report of qualitative research:
- Are the results of the review valid?
- What are the results?
- Will the results help locally?

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

Questions:

1. Was there a clear statement of the aims of the research?
Consider:
- What was the goal of the research?
- Why it was thought important?
- Its relevance

2. Is a qualitative methodology appropriate?
Consider:
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

Is it worth continuing?

Detailed questions:

3. Was the research design appropriate to address the aims of the research?
Consider:
- If the researcher has justified the research design (e.g. have they
discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research?
Consider:
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Were the data collected in a way that addressed the research issue?
Consider:
- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they used a topic guide?)
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered?
Consider:
- If the researcher critically examined their own role, potential bias and influence during:
  a. Formulation of research questions
  b. Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?
Consider:
- If there are sufficient details of how the research was explained to
participants for the reader to assess whether ethical standards were maintained

- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?
Consider:
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings?
Consider:
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher’s arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research questions

10. How valuable is the research?
Consider:
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used
Appendix 1.3. The Downs & Black Checklist (Downs & Black, 1998)

<table>
<thead>
<tr>
<th>Item</th>
<th>Criteria</th>
<th>Possible Answers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>Reporting</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Is the hypothesis/aim/objective of the study clearly described?</em></td>
<td>Yes = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No = 0</td>
</tr>
<tr>
<td>2</td>
<td><em>Are the main outcomes to be measured clearly described in the Introduction or Methods section? If the main outcomes are first mentioned in the Results section, the question should be answered no.</em></td>
<td>Yes = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No = 0</td>
</tr>
<tr>
<td>3</td>
<td><em>Are the characteristics of the patients included in the study clearly described? In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given.</em></td>
<td>Yes = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No = 0</td>
</tr>
<tr>
<td>4</td>
<td><em>Are the interventions of interest clearly described? Treatments and placebo (where relevant) that are to be compared should be clearly described.</em></td>
<td>Yes = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No = 0</td>
</tr>
<tr>
<td>5</td>
<td><em>Are the distributions of principal confounders in each group of subjects to be compared clearly described? A list of principal confounders is provided.</em></td>
<td>Yes = 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Partially = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No = 0</td>
</tr>
<tr>
<td>6</td>
<td><em>Are the main findings of the study clearly described? Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests which are considered below).</em></td>
<td>Yes = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No = 0</td>
</tr>
<tr>
<td>7</td>
<td><em>Does the study provide estimates of the random variability in the data for the main outcomes? In non-normally distributed data the interquartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.</em></td>
<td>Yes = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No = 0</td>
</tr>
<tr>
<td>8</td>
<td><em>Have all important adverse events that may be a consequence of the intervention been reported? This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events. (A list of possible adverse events is provided).</em></td>
<td>Yes = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No = 0</td>
</tr>
<tr>
<td>9</td>
<td><em>Have the characteristics of patients lost to follow-up been described? This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up.</em></td>
<td>Yes = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No = 0</td>
</tr>
<tr>
<td>10</td>
<td><em>Have actual probability values been reported (e.g. 0.035 rather than &lt;0.05) for the main outcomes except where the probability value is less than 0.001?</em></td>
<td>Yes = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No = 0</td>
</tr>
<tr>
<td>11</td>
<td><strong>External validity</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Were the subjects asked to participate in the study representative of the entire population from which they were recruited? The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.</em></td>
<td>Yes = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No = 0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unable to determine = 0</td>
</tr>
<tr>
<td>Question</td>
<td>Yes = 1</td>
<td>No = 0</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------</td>
<td>--------</td>
</tr>
<tr>
<td>Were those subjects who were prepared to participate representative of the entire population from which they were recruited? The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive? For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal validity - bias</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was an attempt made to blind study subjects to the intervention they have received? For studies where the patients would have no way of knowing which intervention they received, this should be answered yes.</td>
<td>Yes = 1</td>
<td>No = 0</td>
</tr>
<tr>
<td>Was an attempt made to blind those measuring the main outcomes of the intervention?</td>
<td>Yes = 1</td>
<td>No = 0</td>
</tr>
<tr>
<td>If any of the results of the study were based on “data dredging”, was this made clear? Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.</td>
<td>Yes = 1</td>
<td>No = 0</td>
</tr>
<tr>
<td>In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls? Where follow-up was the same for all study patients the answer should be yes. If different lengths of follow-up were adjusted for, for example, survival analysis the answer should be yes. Studies where differences in follow-up are ignored should be answered no.</td>
<td>Yes = 1</td>
<td>No = 0</td>
</tr>
<tr>
<td>Were the statistical tests used to assess the main outcomes appropriate? The statistical techniques used must be appropriate to the data. For example nonparametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.</td>
<td>Yes = 1</td>
<td>No = 0</td>
</tr>
<tr>
<td>Was compliance with the intervention(s) reliable? Where there was non-compliance with the allocated treatment or where there was contamination of one group, the question should be answered no. For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes.</td>
<td>Yes = 1</td>
<td>No = 0</td>
</tr>
<tr>
<td>Were the main outcome measures used accurate (valid and reliable)? For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.</td>
<td>Yes = 1</td>
<td>No = 0</td>
</tr>
<tr>
<td>Internal validity - confounding (selection bias)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population? For example, patients for all comparison groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case-control studies where there is no information.</td>
<td>Yes = 1</td>
<td>No = 0</td>
</tr>
<tr>
<td>Power</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| 27* Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%? Sample sizes have been calculated to detect a difference of x% and y%.

| Yes = 1 |
| No = 0 |
| Unable to determine = 0 |

*Item has been modified.

Reference

Appendix 2. National survey for family carers

Appendix 2.1. Survey consent form

Many thanks for your time.

Paper Copy of Positive Psychology in Family Carers of People Living with Dementia

1. Please tick the boxes below if they apply to you.

If the statements do not apply to you, or you do not wish to participate in the research, please do not continue any further.

- I am over 18
- I provide support to a friend/relative with dementia living in the community (i.e. not in a care home/hospital)
- I am willing to take part in this survey
- I understand that the responses I provide will be used as part of Jacki Statsfield’s PhD funded by the VALID research programme and my information will be kept confidential.
Appendix 2.2 Survey data collection

This section of the survey will ask some questions about yourself. Please choose the correct answer from the options given.

2. What is your age?

3. What is your gender?
   - Female
   - Male
   - Prefer not to say

4. What is your marital status?
   - Single/Unmarried
   - Married
   - Separated
   - Divorced
   - Widow/Widower
   - Other
   - Prefer not to say

5. What is your ethnic group?
   - White British
   - Mixed British
   - White Irish
   - Other White
   - Mixed White & Black Caribbean
   - Mixed White & Black African
   - Mixed White & Asian
   - Other Mixed
   - Indian or British Indian
   - Pakistani or British Pakistani
   - Bengali or British Bangladeshi
   - Chinese
   - Other Asian
   - Black Caribbean
   - Black African
   - Other Black
   - Other
   - Prefer not to say
6. What is your highest completed level of education?
   - Primary education or less
   - Secondary Education
   - Tertiary/further education
   - Other general education
   - Not known
   - Prefer not to say

7. What is your relationship with the person with dementia?
   - I am their Spouse/Partner
   - I am their Son/Daughter
   - I am their Parent
   - Other (please specify)

8. Do you live with the person with dementia that you are supporting?
   - Yes
   - No
   - Prefer not to say

9. Other than yourself, do any other people (such as friends or relatives) regularly provide help/support for your friend/relative with dementia?
   - Yes
   - No
   - Other (please specify)
10. What is your regular employment status?

- Employed
- Voluntary work
- Social enterprise
- Unemployed
- Student
- Housewife/husband
- Retired
- Other
- Prefer not to say

---

**Paper Copy of Positive Psychology in Family Carers of People Living with Dementia**

This section of the survey will ask some questions about the person with dementia that you are supporting. Please choose the correct answer from the options given.

11. What is their age?

12. What is your friend/relative's gender?

- Female
- Male
- Prefer not to say

13. What is your friend/relative’s marital status?

- Single/unmarried
- Married
- Separated
- Divorced
- Widow/Widower
- Other
- Prefer not to say
14. What is your friend/relative’s ethnic group?
- White British
- Mixed British
- White Irish
- Other White
- Mixed White & Black Caribbean
- Mixed White & Black African
- Mixed White & Asian
- Other Mixed
- Indian or British Indian
- Pakistani or British Pakistani
- Bangladeshi or British Bangladeshi
- Chinese
- Other Asian
- Black Caribbean
- Black African
- Other Black
- Other
- Prefer not to say

15. What is your friend/relative’s highest completed level of education?
- Primary education or less
- Secondary Education
- Tertiary further education
- Other general education
- Not known
- Prefer not to say
16. What is the type of dementia diagnosis?

- Alzheimer's Disease
- Vascular Dementia
- Dementia with Lewy Bodies
- Front-temporal Dementia
- Do not know
- Other (please specify)

17. Please read the following statements. To the right of each statement you will find seven numbers, ranging from 1 (Strongly Disagree) on the left to 7 (Strongly Agree) on the right. Tick the number which best indicates your feelings about that statement. Please consider all 7 responses to the scale when you answer.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>Strongly Agree</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>I usually manage one way or another</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel proud that I have accomplished things in life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I usually take things in my stride</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am friends with myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that I can handle many things at a time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
18. Please read the following statements. To the right of each statement you will find seven numbers, ranging from 1 (Strongly Disagree) on the left to 7 (Strongly Agree) on the right. Tick the number which best indicates your feelings about that statement. Please consider all 7 responses to the scale when you answer.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>Strongly agree</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>My belief in myself gets me through hard times</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In an emergency, I'm someone people can generally rely on</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My life has meaning</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>When I'm in a difficult situation, I can usually find my way out of it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

19. Please read the following statements. To the right of each statement you will find seven numbers, ranging from 1 (Strongly Disagree) on the left to 7 (Strongly Agree) on the right. Tick the number which best indicates your feelings about that statement. Please consider all 7 responses to the scale when you answer.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>Strongly agree</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am determined</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can get through difficult times because I've experienced difficulty before</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have self-discipline</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I keep interested in things</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can usually find something to laugh about</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
20. Please read the following statements. To the right of each statement you will find 5 possible answers, ranging from disagree very strongly on the left to agree very strongly on the right. Tick the answer which best indicates your feelings about that statement. Please consider all 5 responses to the scale when you answer.

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel that my present situation with my relative/friend doesn't allow me as much privacy as I'd like</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel stressed between trying to give to my relative/friend as well as to other family responsibilities, job etc.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wish that my relative/friend and I had a better relationship</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

21. Please read the following statements. To the right of each statement you will find 5 possible answers, ranging from disagree very strongly on the left to agree very strongly on the right. Tick the answer which best indicates your feelings about that statement. Please consider all 5 responses to the scale when you answer.

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel strained in my interactions with my friend/relative</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that my friend/relative behaves the way s/he does to have his own way</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that my friend/relative behaves the way s/he does to annoy me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that my friend/relative tries to manipulate me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
22. Please read the following statements. To the right of each you will find ten numbers, ranging from 1 (not at all certain) to 10 (very certain). Tick the number that best indicates your feelings about that statement. Please consider all numbers 1-10 on the scale when choosing your level of certainty.

<table>
<thead>
<tr>
<th>How certain are you right now that you can...</th>
<th>Not at all certain</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>5</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>Very certain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Handle any problems like memory loss</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deal with frustrations of caring</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Handle problems that come up in future</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do something to keep your relative independent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care for your relative without help from organizations or agencies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

23. Please read the following statements. To the right of each you will find ten numbers, ranging from 1 (not at all certain) to 10 (very certain). Tick the number that best indicates your feelings about that statement. Please consider all numbers 1-10 on the scale when choosing your level of certainty.

<table>
<thead>
<tr>
<th>How certain are you right now that you can...</th>
<th>Not at all certain</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>5</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>Very certain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Find ways to pay for services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Get answers to all questions about services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Find organisations or agencies that provide services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arrange for services yourself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Get answers to all your questions about your relative’s care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
24. Please read the following statements. To the right of each you will find five possible responses, ranging from disagree a lot to agree a lot. Please tick the response that best indicates your feelings about the statement. Please consider all 5 responses before choosing your answer.

**Providing care to my friend/relative has:**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree a lot</th>
<th>Disagree a little</th>
<th>Neither agree nor disagree</th>
<th>Agree a little</th>
<th>Agree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helped to increase my patience and be a more understanding person</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Made me a stronger and more resilient person</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased my self-awareness, making me more aware of myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased my knowledge and skills in dementia care and more</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helped me grow closer to my relative/friend with dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
27. Self-Care
- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

28. Usual Activities (e.g. work, study, housework, family or leisure activities)
- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

29. Pain/Discomfort
- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

30. Anxiety/Depression
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed
Carer Sense of Competence

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
- 0 means the worst health you can imagine.

31. Please write a number in the box below between 0 and 100 which indicates what your health is TODAY

[Blank Box]

Paper Copy of Positive Psychology in Family Carers of People Living with Dementia

This part of the survey asks 13 different questions so we can find out how much people feel that their life is predictable and that things will work out well in the end. After the set of questions, there will be a section asking for your thoughts on how much the questions below can find out this information.

Please read the following statements. Below each statement you will find a rating scale between 1-7. Please tick the response that best indicates the feelings about the statement.

Please consider each point on the rating scale when choosing your answer.

32. Do you have the feeling that you don’t really care about what goes on around you?

<table>
<thead>
<tr>
<th>Very seldom or never</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>![Circle]</td>
<td>![Circle]</td>
</tr>
</tbody>
</table>
### Carer Sense of Competence

33. Has it happened in the past that you were surprised by the behaviour of people whom you thought you knew well?

<table>
<thead>
<tr>
<th>Never happened</th>
<th>Always happened</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>

34. Has it happened that people whom you counted on disappointed you?

<table>
<thead>
<tr>
<th>Never happened</th>
<th>Always happened</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>

35. Until now your life has had:

<table>
<thead>
<tr>
<th>No clear goals or purpose at all</th>
<th>Very clear goals or purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td>7</td>
</tr>
</tbody>
</table>

36. Do you have the feeling that you’re being treated unfairly?

<table>
<thead>
<tr>
<th>Very often</th>
<th>Very seldom or never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>

37. Do you have the feeling that you are in an unfamiliar situation and don’t know what to do?

<table>
<thead>
<tr>
<th>Very often</th>
<th>Very seldom or never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>

38. Doing the things you do every day is:

<table>
<thead>
<tr>
<th>A source of deep pressure and satisfaction</th>
<th>A source of pain or boredom</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td>7</td>
</tr>
</tbody>
</table>

39. Do you have very mixed-up feelings and ideas?

<table>
<thead>
<tr>
<th>Very often</th>
<th>Very seldom or never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>
40. Does it happen that you have feelings inside you would rather not feel?

<table>
<thead>
<tr>
<th>Very often</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

41. Many people - even those with a strong character - sometimes feel like losers in certain situations. How often have you felt this way in the past?

<table>
<thead>
<tr>
<th>Never</th>
<th>Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7</td>
<td></td>
</tr>
</tbody>
</table>

42. When something happened, have you generally found that

<table>
<thead>
<tr>
<th>You over estimate or under estimated its importance</th>
<th>You saw things in the right proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7</td>
<td></td>
</tr>
</tbody>
</table>

43. How often do you have the feeling that there's little meaning in the things you do in daily life?

<table>
<thead>
<tr>
<th>Very often</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

44. How often do you have feelings that you're not sure you can keep under control?

<table>
<thead>
<tr>
<th>Very often</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The set of 13 questions above aimed to ask about how predictable life is. We are trying to understand how good the questions are at obtaining this information. Thinking about this, please answer the following questions:

45. Did you find any of the 13 questions difficult to understand?
46. Is there anything you would change in the 13 questions above?

47. Is there anything you would add in the 13 questions above?

48. Is there anything you would remove in the 13 questions above?

49. Do you have any other comments about the 13 questions above?

---

Paper Copy of Positive Psychology in Family Carers of People Living with Dementia

This section of the survey asks about the social support you are currently receiving. Please tick the correct response from the options below each question.

FAMILY: Considering the people to whom you are related by birth, marriage, adoption etc...

50. How many relatives do you see or hear from at least once a month?

- None
- One
- Two
- Three or four
- Five to eight
- Nine or more
51. How many relatives do you feel at ease with that you can talk about private matters?
   - None
   - One
   - Two
   - Three or four
   - Five or eight
   - Nine or more

52. How many relatives do you feel close to such that you could call on them for help?
   - None
   - One
   - Two
   - Three or four
   - Five to eight
   - Nine or more

FRIENDSHIPS: Considering all of your friends including those who live in your neighbourhood

53. How many of your friends do you see or hear from at least once a month?
   - None
   - One
   - Two
   - Three or four
   - Five to eight
   - Nine or more

54. How many friends do you feel at ease with that you can talk about private matters?
   - None
   - One
   - Two
   - Three or four
   - Five to eight
   - Nine or more
55. How many friends do you feel close to such that you could call on them for help?

- None
- One
- Two
- Three or four
- Five to eight
- Nine or more

This section of the survey asks for your contact details, for a chance to be entered into a prize draw to win £50 M&S vouchers as an acknowledgement for taking part. We will not give your details to anyone else and your survey responses will still be anonymised.

If you would prefer not to complete the personal information you will not be included in the prize draw, however you will still be able to submit your responses to the survey anonymously. If you would prefer not to complete the information, please leave it blank.

Thank you for taking part in this survey.

56. Please enter your full name below: 

57. If you have one, please enter your email address below: 

58. Please enter your telephone number below: 

59. Would you be happy to be contacted about further research? We will not share your details with anyone outside of the research team.

- Yes
- No

60. If yes, please provide your postcode, so we can contact you about research that is available in your area.

_________________________
61. You have now reached the end of the survey, thank you very much for your time.

If you have any comments about your experience completing this survey, please enter them below:
## Appendix 3. VALID trial

### Appendix 3.1. VALID Screening Checklist

![VALID Logo]

**VALID Screening Checklist:**

<table>
<thead>
<tr>
<th>Status: Eligible</th>
<th>Exclude</th>
<th>Hold</th>
<th>Date:</th>
<th>Screening ID:</th>
</tr>
</thead>
</table>

### Inclusion Criteria for person with dementia

- Does the person with dementia live in the community in their own home? *Can include sheltered housing, a retirement village or persons in care homes / respite care can be considered after they return home.*
- Does the person with dementia have a family carer who provides at least four hours of support a week?
- Does the care recipient have a diagnosis? *(of dementia or illness resulting in primary progressive dementia). What diagnosis?*  
  - Does the person with dementia score between 0.5 and 2 on the Clinical Dementia Rating Scale? *(Hughes et al., 1982)*
- Can the person with dementia speak English?
- Is the person with dementia able and willing to participate in the COTTID-UK intervention in partnership with their family carer, i.e. ten one hour sessions of home based occupational therapy?
- Does the person with dementia have capacity to provide his/her consent? *(This is provisional pending the formal capacity assessment)*

### Inclusion Criteria for family carers

- Is the family carer 18 or over?
- Is the family carer currently providing practical support with domestic and/or personal activities to the person with dementia for a minimum of four hours per week?
- Can the family carer speak English?
- Is the family carer able and willing to participate in the COTTID-UK intervention in partnership with the person with dementia that they support, i.e. ten one hour sessions of home based occupational therapy?
- Does the family carer have capacity to provide his/her consent?

### Exclusion Criteria for people with dementia *(Exclude if YES to any of the following)*

- Is the person with dementia participating in another intervention research study?
- Is the person with dementia currently in hospital or living in a care home?

### Exclusion Criteria for family carers *(Exclude if one or more criteria met)*

- Is the family carer participating in another intervention research study?
Eligibility criteria met for dyad? Yes/ No
If no, then please provide a reason for this candidate's exclusion.

<table>
<thead>
<tr>
<th>Include</th>
<th>Please arrange baseline assessment.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exclude</td>
<td>If the dyad is excluded please provide a reason:</td>
</tr>
</tbody>
</table>

Additional Notes

- Completed by _______________________

VALID Screening Checklist v4 25.03.2015
### Appendix 3.2. VALID Capacity Assessment

#### Capacity Assessment

**Instructions to researchers**

This is not a formal capacity assessment. If you are in any doubt as to whether a person has capacity to consent to participate in the research, discuss this with the Principal Investigator for the site.

**Process**

1. Introduce yourself to the potential participant and use the accessible information sheet to explain the study and what participation will involve.
2. Ask the potential participant if they are able to recall the information and if they can repeat the information you have given them.
3. Record whether the potential participant appears to have understood the information provided.
4. Record whether the potential participant appears to be able to make a decision about whether they would like to participate.

<table>
<thead>
<tr>
<th>Participant ID:</th>
<th>Date of assessment:</th>
<th>Interviewer ID:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. **Study explained to participant in full using accessible information sheet**

- [ ] Yes
- [ ] No

Comments: ____________________________________________________________

2. **Has the participant repeated back the information provided?**

- [ ] Yes
- [ ] No

Comments: ____________________________________________________________

3. **Does the participant appear to have understood the information?**

- [ ] Yes
- [ ] No

Comments: ____________________________________________________________

4. **Does the participant appear to be able to make a decision about whether they would like to participate?**

- [ ] Yes
- [ ] No

Comments: ____________________________________________________________
**Appendix 3.3. VALID consent forms.**

Valuing Active Life in Dementia (VALID)
Participant Consent Form: Person with Dementia

1. I confirm that I have read and understood the ‘Valuing Active Life in Dementia: Information for people with dementia’ booklet (version 1.1, date 06.01.2015). I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that if I withdraw from the study, that the information provided by me, or about me, will still be used unless I request otherwise.

4. I agree to my GP being informed of my participation in the study.

5. I understand that all the information given by me or about me will be treated as confidential by the research team. I understand that any data collected during the study may be looked at by the research team/individuals from regulatory authorities and/or North East London NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.

6. I understand that there is a 50:50 chance of receiving the occupational therapy visits, and that this decision is randomly generated by a computer.

7. I understand that the information collected by the researcher may be seen by the occupational therapist, if I receive the occupational therapy home visits.

8. I give my permission to be audio-recorded if I receive the occupational therapy home visits.

9. I agree to be contacted about further involvement in the VALID research study.

10. I agree to take part in the above study.

<table>
<thead>
<tr>
<th>Name of participant</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
1.) I confirm that I have read and understood the 'Valuing Active Life in Dementia: Information for supporters' booklet (version 1.1, date 06.01.2015) for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.

2.) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3.) I understand that if I withdraw from the study, that the information provided by me, or about me, will still be used unless I request otherwise.

4.) I understand that all the information given by me or about me will be treated as confidential by the research team. I understand that any data collected during the study may be looked at by the research team/individuals from regulatory authorities and/or North East London NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.

5.) I understand that there is a 50:50 chance of receiving the occupational therapy visits, and that this decision is randomly generated by a computer.

6.) I understand that the information collected by the researcher may be seen by the occupational therapist, if I receive the occupational therapy home visits.

7.) I give my permission to be audio-recorded if I receive the occupational therapy home visits.

8.) I agree to be contacted about further involvement in the VALID research study.

9.) I agree to take part in the above study.

Name of participant   Date   Signature

Researcher   Date   Signature
Appendix 3.4. Person with dementia data collection

VALID
Valuing Active Life In Dementia

BASELINE ASSESSMENT

PERSON WITH DEMENTIA
VALID Person with Dementia Questionnaire Pack
BASELINE ASSESSMENT

This booklet of questionnaires should be completed by a researcher in an interview with the person with dementia.

To be completed at assessment:

Screening ID Number

Does the person with dementia have capacity to consent? Yes / No

Has consent been given? Yes / No

Date of interview: d d m m y y y y

Start time: h h m m

Finish time: h h m m

Researcher ID

Site:

To be completed for database entry:

Entered into Red Pill database: Yes / No

Date: d d m m y y y y

Researcher ID

Dyad Number
SOCIODEMOGRAPHIC INFORMATION OF THE PERSON WITH DEMENTIA

Please write your answer in the space provided and tick the appropriate box

Date of birth
- - / - - / - - - -
d/ m/ y/ y y y

Sex
Female ☐
Male ☐

Marital status (please tick one)
Single/unmarried ☐
Married ☐
Separated ☐
Divorced ☐
Widow/widower ☐
Not known ☐

What is your ethnic group? (please tick one)

A White (British, Irish, Other White Background)
White British ☐
White Irish ☐
Other White Background ☐

B Black or Black British or
Caribbean ☐
African ☐
Other Black Background ☐

C Mixed or
White and Black Caribbean ☐
White and Black African ☐
White and Asian ☐
Other Mixed Background ☐

D Asian or Asian British
Indian ☐
Pakistani ☐
Bangladeshi ☐
Other Asian Background ☐

E Chinese or Other Ethnic Group
Chinese ☐
Other Ethnic Group ☐

F Do not wish to specify ☐
Country of birth ________________________________

First language (please tick one)

- English □
- Other language (but having good knowledge of English) □
- Other language (and having poor or no knowledge of English) □

Number of years of schooling in general education __________

Highest completed level of Education (please tick one)

- Primary education or less □
- Secondary education □
- Tertiary / further education □
- Other general education □
- Not known □

What further education or vocational training have you completed or are doing now? (tick all boxes that apply)

- Specific vocational training (< 1 year) □
- Specific vocational training (> 1 year) □
- Tertiary level qualification /diploma □
- University degree (undergraduate) □
- University higher degree (postgraduate) □
- Other vocational training □
- No further education or training □

Note: If anything is unanswered, please cover missing information with the individual’s supporter.
**Carer Sense of Competence**

**Mini Mental State Examination (MMSE)**

**Time Scale: None**

Instructions: The MMSE is a series of questions, which measure a number of different cognitive abilities, including a person’s memory, attention and language. Please ensure that you have the following tools to complete the MMSE and score the responses in the boxes where required.

Tools needed for MMSE:

**NAMING**  Wristwatch and Pencil

<table>
<thead>
<tr>
<th>1. ORIENTATION</th>
<th>Correct</th>
<th>Incorrect</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. What year are we in?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. What month is it?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. What day is it?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. What is the date?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. What is the time?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. What country are we in?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. What county are we in?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. What town are we in?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Can you tell me the name of this place/room?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>j. What floor of the building are we on?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Score 0-10
2. REGISTRATION

Ask the participant if you may test the participant’s memory. Then say the names of 3 unrelated objects, clearly and slowly, about one second for each, “lemon, key, ball”. After you have said all 3, ask the participant to repeat them. The first repetition determines the participant’s score (0-3) but keep saying them until the participant can repeat all 3, up to 5 trials. If the participant does not learn all 3 in 5 trials, recall cannot be meaningfully tested.

Score 0-3

Now say, “Please try to remember the words, as I will ask for them in a little while.”

3. ATTENTION AND CALCULATION

Ask the participant to first try the serial sevens question. Only if the participant cannot or will not try this option proceed to ask them the world option. Ask the participant to begin with 100 and subtract 7 from 100 and keep subtracting 7. Stop after 5 subtractions (93, 86, 79, 72, 65). Score the total number of correct answers.

Score 0-5

Or, if the participant cannot or will not attempt the serial 7s task, ask the participant to spell the word “world” backwards.

The score is the number of letters in correct order (e.g. dlrow = 5, dlrow = 3). The highest score will be recorded.

Score 0-5

Which option did the participant answer? Please tick.

Serial sevens World

4. RECALL

Ask the participant if they can recall the 3 words you previously asked them to remember.

Score 0-3

5. LANGUAGE

a. Show the participant a wristwatch and ask him/her what it is
b. Repeat for a pencil

Score 0-2
Carer Sense of Competence

Score 0-1

d. Have the participant follow this command: “Place index finger of right hand on your nose and then on your left ear.”

Score 0-3

e. Ask the participant to read and obey a written command (see overleaf). Ask them to read and do what it says. Score one point only if they actually close their eyes.

Written command:

Score 0-1

f. Ask the participant to write a sentence for you (see page 9). Do not dictate a sentence; it is to be written spontaneously. It must contain a subject and verb and be sensible. Correct grammar and punctuation are not necessary.

Score 0-1

6. COPYING

Show a picture (see page 10) of the intersecting pentagons; ask them to copy it exactly as it is. All 10 angles must be present and 2 must intersect to score one point. Tremor and rotation are ignored.

Score 0-1

Total Score
CLOSE YOUR EYES
Carer Sense of Competence

Cornell Scale of Depression in Dementia (CSDD)

**Time Scale: The last week**
Assesses signs and symptoms of major depression in people with dementia. No score should be given if symptoms result from physical disability or illness (e.g. if person with dementia has recently experienced cold/flu symptoms and feels they had a lack of energy over the last week as a consequence).

**Scoring:** 0 = Absent; 1 = Mild or intermittent; 2 = Severe

A. Mood-Related Signs

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Anxiety, anxious expression, ruminations, worrying</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>Sadness, sad expression, sad voice, tearfulness</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>Lack of reactivity to pleasant events</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>Irritability easily annoyed, short-tempered</td>
<td>0</td>
</tr>
</tbody>
</table>

B. Behavioral Disturbance

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Agitation, restlessness, handwringing, hair-pulling</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>Restlessness, slow movements, slow speech, slow reactions</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>Multiple physical complaints (score 0 if gastrointestinal symptoms only)</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>Loss of interest, less involved in usual activities (score only if change occurred acutely i.e. in less than 1 month)</td>
<td>0</td>
</tr>
</tbody>
</table>

C. Physical Signs

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Appetite loss - eating less than usual</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>Weight loss - score 2 if greater than 5 lb. in one month</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>Lack of energy, fatigues easily, unable to sustain activities (score only if change occurred acutely, i.e., in less than 1 month)</td>
<td>0</td>
</tr>
</tbody>
</table>
Carer Sense of Competence

Screening ID: ______________ Date of assessment: ___/___/___ Interviewer ID: ______

Scoring: 0 - Absent; 1 - Mild or intermittent; 2 - Severe

D. Cyclic Functions

1. Diurnal variation of mood symptoms worse in the morning 0 1 2
2. Difficulty falling asleep later than usual for this individual 0 1 2
3. Multiple awakenings during sleep 0 1 2
4. Early-morning awakening earlier than usual for this individual 0 1 2

E. Ideational Disturbance

1. Suicide feels life is not worth living, has suicidal wishes or makes suicide attempt 0 1 2
2. Poor self-esteem self-blame, self-deprecation, feelings of failure 0 1 2
3. Pessimism anticipation of the worst 0 1 2
4. Mood-congruent delusions delusions of poverty, illness or loss 0 1 2
**Carer Sense of Competence**

**DEMQOL**

**Time Scale:** The last week

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about your life. There are no right or wrong answers. Just give the answer that best describes how you have felt in the last week. Don’t worry if some questions appear not to apply to you. We have to ask the same questions of everybody.

Before we start we’ll do a practice question; that’s one that doesn’t count. *(Show the response card and ask respondent to say or point to the answer)* In the last week, how much have you enjoyed watching television?

<table>
<thead>
<tr>
<th>A LOT</th>
<th>QUITE A BIT</th>
<th>A LITTLE</th>
<th>NOT AT ALL</th>
</tr>
</thead>
</table>

First I am going to ask you about your feelings. In the last week, have you felt:

1. **Cheerful?**

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

2. **Worried or Anxious?**

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

3. **That you are enjoying life?**

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

4. **Frustrated?**

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>
5. Confident?

A lot | Quite a bit | A little | Not at all

6. Full of energy?

A lot | Quite a bit | A little | Not at all

7. Sad?

A lot | Quite a bit | A little | Not at all

8. Lonely?

A lot | Quite a bit | A little | Not at all

9. Distressed?

A lot | Quite a bit | A little | Not at all

10. Lively?

A lot | Quite a bit | A little | Not at all

11. Irritable?

A lot | Quite a bit | A little | Not at all
12. Fed up?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

13. That there are things you wanted to do but couldn’t?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

Next, I am going to ask you about your memory. In the last week, how worried have you been about...

14. Forgetting things that happened recently?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

15. Forgetting who people are?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

16. Forgetting what day it is?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

17. Your thoughts being muddled?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

18. Difficulty making decisions?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>
### 19. Poor concentration?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

Now I am going to ask you about your everyday life. In the last week, how worried have you been about...

### 20. Not having enough company?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

### 21. How you get on with people close to you?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

### 22. Getting the affection that you want?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

### 23. People not listening to you?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

### 24. Making yourself understood?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>
25. Getting help when you need it?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

26. Getting to the toilet on time?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

27. How you feel in yourself?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

28. Your overall health?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

We have already talked about a lot of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate...

29. Your quality of life overall?

<table>
<thead>
<tr>
<th>Very Good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
</table>
EQ-5D-5L

Time Scale: Today
For each category, read out the item and responses e.g. “Thinking about your mobility, which one of these responses best describes how you are today?”

MOBILITY
- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

SELF-CARE
- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

USUAL ACTIVITIES
(e.g. work, study, housework, family or leisure activities)
- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

PAIN / DISCOMFORT
- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

ANXIETY/DEPRESSION
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed
We would like to know how good or bad your health is TODAY

- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below

YOUR HEALTH TODAY = [Blank Box]
Appendix 3.5. Family carer data collection

Screening ID: ____________ Date of assessment: __/__/____ Interviewer ID: ________
<table>
<thead>
<tr>
<th>Field</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening ID Number</td>
<td>Blank</td>
</tr>
<tr>
<td>Has consent been given? Yes / No</td>
<td>Blank</td>
</tr>
<tr>
<td>Date of Interview</td>
<td>Blank</td>
</tr>
<tr>
<td>Start time</td>
<td>Blank</td>
</tr>
<tr>
<td>Finish time</td>
<td>Blank</td>
</tr>
<tr>
<td>Researcher ID</td>
<td>Blank</td>
</tr>
<tr>
<td>Entered into database? Yes / No</td>
<td>Blank</td>
</tr>
<tr>
<td>Date</td>
<td>Blank</td>
</tr>
<tr>
<td>Researcher ID</td>
<td>Blank</td>
</tr>
<tr>
<td>Dyad ID Number</td>
<td>Blank</td>
</tr>
</tbody>
</table>
Sociodemographic Information of the Supporter

Please write your answer in the space provided and tick the appropriate box.

Date of birth

Gender

Female ☐
Male ☐

Marital status (please tick one)

Single/unmarried ☐
Married ☐
Separated ☐
Divorced ☐
Widow/widower ☐
Other ☐
Not known ☐

What is your ethnic group? (please tick one)

A White (British, Irish, Other White Background)

White British ☐
White Irish ☐
Other White Background ☐

B Black or Black British

Caribbean ☐
African ☐
Other Black Background ☐

C Mixed

White and Black Caribbean ☐
White and Black African ☐
White and Asian ☐
Other Mixed Background ☐

D Asian or Asian British

Indian ☐
Pakistani ☐
Bangladeshi ☐
Other Asian Background ☐
### Carer Sense of Competence

**Screening ID:** ____________  **Date of assessment:** __/__/____  **Interviewer ID:** ______

**E Chinese or Other Ethnic Group**

<table>
<thead>
<tr>
<th>Option</th>
<th>☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chinese</td>
<td></td>
</tr>
<tr>
<td>Other Ethnic Group (please specify)</td>
<td></td>
</tr>
</tbody>
</table>

**F Do not wish to specify**

| ☐ |

**Country of birth** __________________________

**First language (please tick one)**

<table>
<thead>
<tr>
<th>Option</th>
<th>☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td></td>
</tr>
<tr>
<td>Other language (but having good knowledge of English)</td>
<td></td>
</tr>
<tr>
<td>Other language (and having poor or no knowledge of English)</td>
<td></td>
</tr>
</tbody>
</table>

**Number of years of schooling in general education** __________

**Highest completed level of education (please tick one)**

<table>
<thead>
<tr>
<th>Option</th>
<th>☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary education or less</td>
<td></td>
</tr>
<tr>
<td>Secondary education</td>
<td></td>
</tr>
<tr>
<td>Tertiary / further education</td>
<td></td>
</tr>
<tr>
<td>Other general education</td>
<td></td>
</tr>
<tr>
<td>Not known</td>
<td></td>
</tr>
</tbody>
</table>

**What further education or vocational training have you completed or are doing now? (tick all boxes that apply)**

<table>
<thead>
<tr>
<th>Option</th>
<th>☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific vocational training (&lt; 1 year)</td>
<td></td>
</tr>
<tr>
<td>Specific vocational training (&gt; 1 year)</td>
<td></td>
</tr>
<tr>
<td>Tertiary level qualification / diploma</td>
<td></td>
</tr>
<tr>
<td>University degree (undergraduate)</td>
<td></td>
</tr>
<tr>
<td>University higher degree (postgraduate)</td>
<td></td>
</tr>
<tr>
<td>Other vocational training</td>
<td></td>
</tr>
<tr>
<td>No further education or training</td>
<td></td>
</tr>
</tbody>
</table>
### Bristol Activities of Daily Living Scale (BADLS)

**Time Scale:** The last 2 weeks

**Assessment of:** Person with Dementia

Instructions: Thinking of the last 2 weeks, tick the box that represents the (person with dementia’s) AVERAGE ability to complete their Activities of Daily Living. (Tick ‘Not applicable’ if person with dementia never did that activity when they were well). Tick only 1 box per activity.

|   | Food                                      |   |   |   |   |   | Eating                                    |   |   |   |   |   |   | Drink                                    |   |   |   |   |   |   | Drinking                                  |   |   |   |   |   |   |
|   | Selects and prepares food as required    |   |   |   |   |   | Eats appropriately using correct cutlery |   |   |   |   |   |   | Eats appropriately if food made manageable and / or uses spoon |   |   |   |   |   |   | Uses fingers to eat food                |   |   |   |   |   |   | Needs to be fed                        |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   |
|   | Able to prepare food if ingredients set out |   |   |   |   |   | Eats appropriately if food made manageable and / or uses spoon |   |   |   |   |   |   | Uses fingers to eat food                |   |   |   |   |   |   | Needs to be fed                        |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   |
|   | Can prepare food if prompted step by step |   |   |   |   |   | Eats appropriately if food made manageable and / or uses spoon |   |   |   |   |   |   | Uses fingers to eat food                |   |   |   |   |   |   | Needs to be fed                        |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   |
|   | Unable to prepare food even with prompting and supervision |   |   |   |   |   | Eats appropriately if food made manageable and / or uses spoon |   |   |   |   |   |   | Uses fingers to eat food                |   |   |   |   |   |   | Needs to be fed                        |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   |
|   | Not applicable                           |   |   |   |   |   | Eats appropriately if food made manageable and / or uses spoon |   |   |   |   |   |   | Uses fingers to eat food                |   |   |   |   |   |   | Needs to be fed                        |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   | Not applicable                          |   |   |   |   |   |   |

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Carer Sense of Competence

Screening ID: ________________ Date of assessment: __/__/____ Interviewer ID: ______

5 DRESSING
a Selects appropriate clothing and dresses self
b Puts clothes on in wrong order and/or back to front and/or dirty clothing
c Unable to dress self but moves limbs to assist
d Unable to assist and requires total dressing
e Not applicable

6 HYGIENE
a Washes regularly and independently
b Can wash self if given soap, flannel, towel etc.
c Can wash self if prompted and supervised
d Unable to wash self and needs full assistance
e Not applicable

7 TEETH
a Cleans own teeth / dentures regularly and independently
b Cleans teeth / dentures if given appropriate items
c Requires some assistance, toothpaste on brush, brush to mouth, etc.
d Full assistance given
e Not applicable

8 BATH / SHOWER
a Baths regularly and independently
b Needs bath to be drawn / shower turned on but washes independently
c Needs supervision and prompting to wash
d Totally dependent, needs full assistance
e Not applicable

9 TOILET / COMMODE
a Uses toilet appropriately when required
b Needs to be taken to the toilet and given assistance
c Incontinent of urine or faeces
d Incontinent of urine and faeces
e Not applicable

10 TRANSFERS
a Can get in / out of chair unaided
b Can get into a chair but needs help to get out
c Needs help getting in and out of a chair
d Totally dependent on being put into and lifted from chair
e Not applicable
Carer Sense of Competence

Screening ID:______________  Date of assessment: __/__/____  Interviewer ID: ______

11 MOBILITY
a Walks independently
b Walks with assistance, i.e. furniture, arm for support
c Uses aid to mobilise, i.e. frame, sticks etc.
d Unable to walk
e Not applicable

12 ORIENTATION - TIME
a Fully orientated to time / day / date etc.
b Unaware of time / day etc. but seems unconcerned
c Repeatedly asks the time / day / date
d Mixes up night and day
e Not applicable

13 ORIENTATION - SPACE
a Fully orientated to surroundings
b Orientated to familiar surroundings only
c Gets lost in home, needs reminding where bathroom is, etc.
d Does not recognize home as own and attempts to leave
e Not applicable

14 COMMUNICATION
a Able to hold appropriate conversation
b Shows understanding and attempts to respond verbally with gestures
c Can make self understood but difficulty understanding others
d Does not respond to or communicate with others
e Not applicable

15 TELEPHONE
a Uses telephone appropriately, including obtaining correct number
b Uses telephone if number given verbally / visually or pre-dialled
c Answers telephone but does not make calls
d Unable / unwilling to use telephone at all
ej Not applicable

16 HOUSEWORK / GARDENING
a Able to do housework / gardening to previous standard
b Able to do housework / gardening but not to previous standard
c Limited participation even with a lot of supervision
d Unwilling / unable to participate in previous activities
e Not applicable
### Carer Sense of Competence

**Screening ID:** 
**Date of assessment:**__/__/____  
**Interviewer ID:** ________

17 **SHOPPING**
- a. Shops to previous standard
- b. Only able to shop for 1 or 2 items with or without a list
- c. Unable to shop alone, but participates when accompanied
- d. Unable to participate in shopping even when accompanied
- e. Not applicable

18 **FINANCES**
- a. Responsible for own finances at previous level
- b. Unable to write cheque but can sign name and recognizes money values
- c. Can sign name but unable to recognize money values
- d. Unable to sign name or recognize money values
- e. Not applicable

19 **GAMES / HOBBIES**
- a. Participates in pastimes / activities to previous standard
- b. Participates but needs instruction / supervision
- c. Reluctant to join in, very slow, needs coaxing
- d. No longer able or willing to join in
- e. Not applicable

20 **TRANSPORT**
- a. Able to drive, cycle or use public transport independently
- b. Unable to drive but uses public transport or bike etc.
- c. Unable to use public transport alone
- d. Unable / unwilling to use transport even when accompanied
- e. Not applicable
Interview for Deterioration in Daily Living Activities in Dementia (iDDD)

Time Scale: The last month (compare behaviour with how it was before the onset of dementia)
Assessment of: Person with Dementia

Functioning of the person with dementia is examined in a structured verbal interview with the supporter. Read each of the following questions verbatim and show the respondent the response card. The scoring is rated on a three-point scale:

1 - help is almost never needed or there has been no change
2 - help is sometimes needed or help is needed more than often than previously
3 - help is almost always needed or help is needed much more than previously.

8 - no evaluation possible
9 - not applicable

After a negative response the interviewer is asked to check that the behaviour is unchanged compared with what it was like previously and after a positive response questions are asked:
"Is the help really necessary?"
"What happens if you don't help?"
"Do you have to help more often than before?"

1. Do you have to tell her/him that s/he should wash herself (takes the initiative to wash her/himself, not only washing of hands or face, but also washing of whole body)?

2. Do you have to assist her/him in washing (finding face cloth, soap, soaping and rinsing of the body)?

3. Do you have to tell her/him that s/he should dry her/himself (take the initiative to dry her/himself, for example looking or fetching for the towel)?

4. Do you have to assist her/him in drying (drying individual body-parts)?

5. Do you have to tell her/him that s/he should dress her/himself (take the initiative to dress her/himself, for example walking to the wardrobe)?

6. Do you have to assist her/him in dressing her/himself (putting on individual clothes in right order)?
7. Do you have to assist her/him in doing up her/his shoes, using zippers or buttons? □

8. Do you have to tell her/him that s/he should brush her/his teeth or comb her/his hair? □

9. Do you have to assist her/him in brushing her/his teeth? □

10. Do you have to assist her/him in combing her/his hair? □

11. Do you have to tell her/him that s/he should eat (take the initiative to eat; in case eating selected by others, it should be asked if s/he would take the initiative spontaneously)? □

12. Do you have to assist her/him in buttering a slice of bread? □

13. Do you have to assist her/him in carving meat, potatoes? □

14. Do you have to assist her/him in drinking or eating? □

15. Do you have to tell her/him that s/he should use the toilet (take the initiative to go to the toilet when necessary)? □

16. Do you have to assist her/him in using the toilet (undressing her/himself, using toilet, using closet paper)? □

17. Do you have to assist her/him in finding her way in the house (finding different rooms)? □

18. Do you have to assist her/him in finding her/his way in familiar neighbourhood outside the house? □

19. Does s/he - as often as before - take the initiative shopping (take the initiative to figure out what is needed)? □

20. Do you have to assist her/him in shopping (finding her/his way in the shops; getting goods in needed quantity)? □

21. Do you - or the shop assistant - have to tell her/him that s/he should pay? □

22. Do you - or the shop assistant - have to assist her/him in paying (knowing how much s/he should pay and how much should be reimbursed)? □

23. Is s/he - as often as before - interested in the newspaper, books or post? □
Carer Sense of Competence

Screening ID: ___________ Date of assessment: ___/___/____ Interviewer ID: ____

24. Do you have to assist her/him in reading (understanding written language)?

25. Do you have to assist her/him in writing a letter or card, or completing a form (writing of more than one sentence)?

26. Does s/he - as often as before - start a conversation with others?

27. Do you have to assist her/him in expressing herself verbally?

28. Does s/he - as often as before - pay attention to conversation by other people?

29. Do you have to assist her/him in understanding spoken language?

30. Does s/he - as often as before – take the initiative to use the phone (both answering the phone and calling someone)?

31. Do you have to assist her/him in using the phone (both answering the phone and calling someone)?

32. Do you have to assist her/him in finding things in the house?

33. Do you have to tell her/him to turn off the gas?
Carer Sense of Competence

Screening ID: ______________ Date of assessment: __/__/____ Interviewer ID: __________

CLIENT SERVICE RECEIPT INVENTORY (CSRI)

Time Scale: Last 12 weeks.

Assessment of: Person with Dementia

This section asks about the health and social care services that the person with dementia has used.

1. SOCIODEMOGRAPHIC INFORMATION OF THE PERSON WITH DEMENTIA

1.1 Date of birth: d d/ m m/ y y

1.2 Sex

Female ☐
Male ☐

1.3 Marital status (please tick one)

Single/unmarried ☐
Married ☐
Separated ☐
Divorced ☐
Widow/Widower ☐
Not known ☐

1.4 What is your relative/friend’s ethnic group? (please tick one)

A White (British, Irish, Other White Background)

White British ☐
White Irish ☐
Other White Background ☐

B Black or Black British or

Caribbean ☐
African ☐
Other Black Background ☐

C Mixed or

White and Black Caribbean ☐
White and Black African ☐
White and Asian ☐
Other Mixed Background ☐
Carer Sense of Competence

Screening ID: ______________ Date of assessment: __/__/____ Interviewer ID: __________

D Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Other Asian Background

E Chinese or Other Ethnic Group
- Chinese
- Other Ethnic Group

F Do not wish to specify

1.5 Country of birth ________________________________

1.6 First language (please tick one)
- English
- Other language (but having good knowledge of English)
- Other language (and having poor or no knowledge of English)

1.7 Number of years of schooling in general education __________

1.8 Highest completed level of education (please tick one)
- Primary education or less
- Secondary education
- Tertiary / further education
- Other general education
- Not known

1.9 What further education or vocational training has your relative/friend completed or is doing now? (Tick all boxes that apply)
- Specific vocational training (< 1 year)
- Specific vocational training (> 1 year)
- Tertiary level qualification / diploma
- University degree (undergraduate)
- University higher degree (postgraduate)
- Other vocational training
- No further education or training

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1.10 What is the type of dementia diagnosed? (please tick one)
   - Alzheimer's Disease  
   - Vascular Dementia  
   - Dementia with Lewy Bodies  
   - Fronto-temporal dementia  
   - Other (please specify) ________________________________

1.11 Does he/she have any other co-existing medical conditions?  Yes/no
   If yes, please specify ___________________________________________________________

2. SOCIAL CONTACTS/ACTIVITIES

2.1 Social contacts - How many times over the last 12 weeks has the person with dementia met up with friends or family? (e.g. family or friends visiting person with dementia/person with dementia visiting them, social club) ________________

2.2 Leisure activities - How many times over the last 12 weeks has the person with dementia participated in any leisure activities? (e.g. hobbies) ________________

3. USUAL LIVING SITUATION

3.1 What is your relative/friend's usual/normal living situation now? (please tick one)
   - Living alone (+/- children)  
   - Living with husband/wife (+/- children)  
   - Living together as a couple  
   - Living with parents  
   - Living with other relatives  
   - Living with others  
   - Not known  

3.2 What kind of accommodation is it? (please tick one)

Domestic / family

Owner occupied flat or house
Privately rented flat or house
Rented from local authority or housing association/co-operative

Community (non-hospital)

Residential or nursing home
Hostel
Sheltered housing
Staffed group home
Unstaffed group home
Foster care
Supported lodging
Independent living

Hospital
Acute psychiatric ward
Rehabilitation psychiatric ward
Long-stay psychiatric ward
General medical ward
Homeless / roofless
Other
(please specify) _______________________________________

3.3 If person with dementia lives in domestic accommodation:

How many rooms are in this accommodation? _______________________

How many of those rooms are bedrooms? _______________________

How many adults live there? (over the age of 18) _______________________

And how many children? (under the age of 18) _______________________
3.4 Has s/he lived anywhere else in the last 12 weeks? Yes / No

If yes: please complete table:

<table>
<thead>
<tr>
<th>Accommodation type (see question 3.2 for details)</th>
<th>Number of days in last 12 weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. EMPLOYMENT AND INCOME

4.1 What is your relative/friend’s regular employment status? (tick all boxes that apply)

- Employed
  - Paid or self-employment
  - Voluntary work
  - Social Enterprise
- Not in employment
  - Unemployed
  - Student
  - Housewife/husband
  - Retired
  - Exempt through disability
  - Full Time Carer
  - Other (Please specify)

4.2 If employed: state occupation

How many hours per week does your relative/friend work? _____ / week

How many days has your relative/friend been absent from work owing to illness within the last 3 months? _____

4.3 If unemployed:

Number of weeks unemployed within the last 12 weeks

Number of weeks

4.4. If retired:

Occupation at retirement

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4.5 **What is your relative/friend's total personal income per week from all sources?** (Note: if gross income not known, please give net income, i.e. after tax and other deductions)

(please tick one)
- Under £149 □
- £150 - £204 □
- £205 - £279 □
- £280 - £392 □
- More than £393 □

Is this net or gross income? (please tick one)
- Gross Income □
- Net Income □
Carer Sense of Competence

Screening ID: ____________  Date of assessment: ___/___/____  Interviewer ID: _______

5. SERVICE RECEIPT

5.1 What hospital services has s/he used over the last 12 weeks? (Note 1, please enter ‘0’ in number of contacts if service has not been used)

<table>
<thead>
<tr>
<th>Service</th>
<th>Name of ward, clinic, hospital, centre</th>
<th>Reason for using service</th>
<th>Number of contacts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accident &amp; Emergency</td>
<td></td>
<td></td>
<td>______ visits</td>
</tr>
<tr>
<td>Walk-in Centre</td>
<td></td>
<td></td>
<td>______ visits</td>
</tr>
<tr>
<td>Hospital inpatient ward - acute hospital</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital inpatient ward - psychiatric hospital</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If yes, how many times were they compulsorily admitted under section?</td>
<td></td>
<td></td>
<td>______ times</td>
</tr>
<tr>
<td>Community Hospital ward</td>
<td></td>
<td></td>
<td>______ inpatient days</td>
</tr>
<tr>
<td>Outpatient services (list all)</td>
<td></td>
<td></td>
<td>______ attendances</td>
</tr>
<tr>
<td>Memory clinic</td>
<td></td>
<td></td>
<td>______ attendances</td>
</tr>
<tr>
<td>Day hospital</td>
<td></td>
<td></td>
<td>______ appointments</td>
</tr>
<tr>
<td>Other (Please specify)</td>
<td></td>
<td></td>
<td>______ appointments</td>
</tr>
</tbody>
</table>

Note 1: _______
5.2 What day activity services has s/he used over the last 12 weeks?
(Note: Please enter '0' in number of contacts if service has not been used)

<table>
<thead>
<tr>
<th>Day Services</th>
<th>Name of centre/service</th>
<th>Number of contacts</th>
<th>Average duration of attendance (mins)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day care – local authority social services department</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day care – voluntary organisation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day care – NHS (community-based)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lunch club</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social club</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient education/Expert Patient group - Please describe:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercise class</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5.3 What **community care services** has s/he used over the last 12 weeks?
(Note 1: please enter ‘0’ in number of contacts if service has not been used)

<table>
<thead>
<tr>
<th>Social Care</th>
<th>Provider Sector</th>
<th>Total number of contacts</th>
<th>Average contact time (mins)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social worker or Care manager</td>
<td>1=NHS, 2=social services department, 3=voluntary organisation, 4=private</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home care/home help worker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Night sitter/carer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sitting scheme (e.g. Crossroads)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meals on wheels</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laundry service</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Carer Sense of Competence

**Screening ID:** ____________  **Date of assessment:** ____/____/____  **Interviewer ID:** ______

<table>
<thead>
<tr>
<th>Community Mental Health Services</th>
<th>Provider Sector</th>
<th>Total number of contacts</th>
<th>Average contact time (mins)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrist</td>
<td>1=NHS, 2=social services department, 3=voluntary organisation, 4=private</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community psychiatric nurse/ Community mental health nurse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admiral Nurse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Health Support Worker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia Advisor / Outreach Worker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other mental health professional, describe:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*(Note: please enter '0' in number of contacts if service has not been used)*
# Carer Sense of Competence

<table>
<thead>
<tr>
<th>Primary Care, Community Health and Emergency Services</th>
<th>Provider Sector</th>
<th>Total number of contacts</th>
<th>Average contact time (mins)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paramedic (ambulance service)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Matron</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community/District Nurse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practice Nurse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Night visit from nursing staff</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialist nurse e.g. Respiratory, diabetes, cardiac or other, describe.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General practitioner</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dentist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optician</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physiotherapist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5.4 Please list any alterations to the person with dementia’s home and their use of specialist equipment IN THE LAST 12 WEEKS.
## Adapts, equipment and products

<table>
<thead>
<tr>
<th>Description</th>
<th>Type of adaption or equipment (list all)</th>
<th>Who supplied this? (generic or specific)</th>
<th>Who/What organisation paid for this? (Private/public)</th>
<th>Total Cost (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alterations to service user's home (e.g. putting in shower, stairlift)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continence products (e.g. pads, pull up pants)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Replacement of furniture, clothing, bedding or household goods due to incontinence problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 6. MEDICATION PROFILE

6.1 Please list below use of any psychotropic drugs taken over the last 12 weeks.

<table>
<thead>
<tr>
<th>Name of drug</th>
<th>Dosage if known (mg)</th>
<th>Dosage frequency (e.g. daily)</th>
<th>What is the medication prescribed for?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
7. SOCIAL CONTACTS/ACTIVITIES

7.1 Social contacts - How many times over the last 12 weeks have you met up with your friends or family? (e.g. family or friends visiting you/you visiting them, social club)

7.2 Leisure activities - How many times over the last 12 weeks have you participated in any leisure activities? (e.g. hobbies)

8. SUPPORT PROVIDED BY SUPPORTERS

8.1 What is your relationship to the person with dementia? (please tick one)

- Spouse/Partner
- Son/Daughter
- Parent
- Other (please specify)

8.2 What is your regular employment status? (tick all boxes that apply)

- Employed
- Paid or self-employment
- Voluntary work
- Social Enterprise

- Not in employment
- Unemployed
- Student
- Housewife/husband
- Retired
Carer Sense of Competence

Screening ID: ______________ Date of assessment: __/__/____ Interviewer ID: ______

Exempt through disability □ Full Time Carer □ Other (Please specify) □

8.3 If employed or volunteer, please describe your current job or voluntary activity.

8.4 How many hours do you typically work each week in all employment or volunteering activities?

__________ hours

8.5 What is your total personal income per week from employed or self-employed work? (Note: if gross income not known, please give net income, i.e. after tax and other deductions)

Under £149 □ £280 - £392 □
£150 - £204 □ More than £393 □
£205 - £279 □

□ Family carer is retired

Is this net or gross income? (please tick one)

Gross income □
Net Income □

8.6 Have you taken days off work or volunteering in order to provide care for your relative/friend? (please circle one)

Yes / no

If yes, how many days over the past 12 weeks? ________ days

8.7 Do you live with your relative/friend? (please tick one)

Yes (If yes please go to Q 8.8 and then continue to Q 8.11) □
No (If no then please go to Q 8.9 and answer all following questions) □
8.8 For a co-resident supporter, on a typical 24 hour day, how much of the time can you leave your relative/friend at home alone? (please tick one)

Never ☐
1% to less than 25% of the time ☐
25% to less than 50% of the time ☐
50% to less than 75% of the time ☐
75% to 100% of the time ☐

8.9 For a principal supporter who does not live with the person with dementia, how many hours do you spend each week caring for your relative/friend (including activities such as: phone calls, paperwork, laundry and shopping)?

__________________ hours

8.10 If you are NOT living with your relative/friend and you need to travel to his/her home:

a. How many times a week do you travel to his/her home? (we consider a travel as being "one return trip" to his/her place, so do not double count. For example, "once a week" includes the trip to go and the trip to return back home. If the supporter is visiting twice a day for 5 days a week, it will be 10 times and it will include the time to go and return)

__________________/week

b. How do you mainly travel to your relative/friend's home? (tick only the usual mode of transport)

Walking ☐
Cycle ☐
Bus ☐
Train/tube ☐
Taxi ☐
Private car ☐
Motorbike ☐
Other ☐

(please specify)__________________
c. Thinking about an average or typical week, what is the distance in miles that you travel in a week to reach your relative/friend’s home? (include in your calculation the return distance)

__________________________ miles/week

d. Thinking about an average or typical week, how many minutes do you spend in total travelling to your relative/friend’s home in a week (including return time)?

__________________________ minutes/week

e. How much do you spend in a week for public transport to travel to your relative/friend’s home (including return time)?

£__________________________/week

8.11 Other than yourself as principal supporter, do any other people (such as friends or relatives) regularly provide help for your relative/friend? (please circle one)

Yes / no

If yes: Thinking about an average or typical week, and about all such other supporters, for how many hours do they substitute for or assist you as the principal supporter?

__________________________ hours
9. SERVICES USED BY THE PRINCIPAL SUPPORTER

9.1 Have you yourself used any services over the last 12 weeks as a result of your caring activities?

(Examples might be additional visits to the GP, back clinic, psychiatric services, counselling, self help groups, education groups, expert relative groups, alternative therapies (osteopath, reflex), advice lines, Alzheimer's Café, Admiral Nurses.)

<table>
<thead>
<tr>
<th>Service Used</th>
<th>Total number of contacts in the last 12 weeks</th>
<th>Typical duration of contact (mins)</th>
<th>Who/what organisation paid for this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

9.2 Please list below use of any psychotropic medications taken yourself over the previous 12 weeks

<table>
<thead>
<tr>
<th>Name of medication</th>
<th>Dosage if known (mg)</th>
<th>Dose frequency (e.g. daily)</th>
<th>For how long have you taken this drug?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The Sense of Competence Questionnaire SCQ

**Consequences of involvement in care for the personal life of the supporter**

1. I feel that my present situation with my relative/friend doesn't allow me as much privacy as I'd like

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

2. Because of my involvement with my relative/friend I don't have enough time for myself

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

3. I feel that my social life has suffered because of my involvement with my relative/friend

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

4. I feel that I cannot leave my relative/friend alone. He/she needs me continuously

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>
Carer Sense of Competence

Screening ID:______________ Date of assessment: ____/____/____ Interviewer ID: ______

5 I feel stressed between trying to give to my relative/friend as well as to other family responsibilities, job etc.

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

6 I feel that my health has suffered because of my involvement with my relative/friend

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

7 I worry all the time about my relative/friend

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

8 I feel that my relative/friend seems to expect me to take care of him/her as if I were the only one s/he could depend on

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

Satisfaction with one's own performance as a supporter

9 I feel pleased about my interactions with my relative/friend

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

10 I don’t feel capable to care for my relative/friend

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>
### Carer Sense of Competence

**Screening ID:** __________  **Date of assessment:** __/__/__  **Interviewer ID:** __________

<table>
<thead>
<tr>
<th>Question</th>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>11  I wish that my relative/friend and I had a better relationship</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12  I feel guilty about my interactions with my relative/friend</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13  I feel strained in my interaction with my relative/friend</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14  I feel that in the past, I haven't done as much for my relative/friend as I could have or should have</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15  It is not clear to me how much care I should give to my relative/friend</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16  I feel that my friend/relative doesn't benefit from what I do for him/her</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17  I feel nervous or depressed about my interactions with my friend/relative</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*VALID trial CRF Baseline Assessment Supporter V.3 10.07.2015*

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## Carer Sense of Competence

Screening ID: ___________  Date of assessment: __/__/____  Interviewer ID: _______

### 18 I feel angry about my interactions with my relative/friend

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

### 19 I feel that I don’t do as much for my relative/friend as I should do

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

### 20 I feel useful in my interactions with my relative/friend

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

### Satisfaction with the person with dementia as a recipient of care

#### 21 I feel that my relative/friend behaves the way s/he does to have her/his own way

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

#### 22 I feel that my relative/friend behaves the way s/he does to annoy me

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

#### 23 I feel that my relative/friend tries to manipulate me

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

#### 24 My relative/friend appreciates my constant care less than the care others give him/her

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>
Carer Sense of Competence

Screening ID: ______________ Date of assessment: ___/___/___ Interviewer ID: ______

25 I feel that my relative/friend makes requests which I perceive to be over and above what s/he needs

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

26 I feel resentful about my interactions with my relative/friend

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>

27 I feel embarrassed over my relative/friend's behaviour

<table>
<thead>
<tr>
<th>Disagree very strongly</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Agree very strongly</th>
</tr>
</thead>
</table>
Carer Sense of Competence

Screening ID: ______________ Date of assessment: __/__/__ Interviewer ID: ____________

DEMOL: PROXY

Time Scale: The last week

Assessment of: Person with Dementia

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about your relative/friend’s life, as you are the person who knows him/her best. There are no right or wrong answers. Just give the answer that best describes how s/he has felt in the last week. If possible try and give the answer that you think s/he would give. Don’t worry if some questions appear not to apply to your relative/friend. We have to ask the same questions of everybody.

Before we start we’ll do a practice question, that one that doesn’t count. (Show the response card and ask respondent to say or point to the answer). In the last week how much has your relative/friend enjoyed watching television?

A LOT  QUITE A BIT  A LITTLE  NOT AT ALL

First I am going to ask you about your relative/friend’s feelings. (Circle one only in each row).

In the last week, would you say that your relative/friend has felt:

1. Cheerful?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

2. Worried or Anxious?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>
3. Frustrated?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

4. Full of energy?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

5. Sad?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

6. Content?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

7. Distressed?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>
8. Lively?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

9. Irritable?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

10. Fed-up?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

11. That he/she has things to look forward to?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

Next, I’m going to ask you about your friend/relative’s memory. In the last week, how worried would you say your relative/friend has been about...

12. His/her memory in general?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>
10. Forgetting things that happened a long time ago?

<table>
<thead>
<tr>
<th></th>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

14. Forgetting things that happened recently?

<table>
<thead>
<tr>
<th></th>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

15. Forgetting people’s names?

<table>
<thead>
<tr>
<th></th>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

16. Forgetting where he/she is?

<table>
<thead>
<tr>
<th></th>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

17. Forgetting what day it is?

<table>
<thead>
<tr>
<th></th>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>
### Carer Sense of Competence

<table>
<thead>
<tr>
<th>Screening ID:</th>
<th>Date of assessment:</th>
<th>Interviewer ID:</th>
</tr>
</thead>
</table>

18. **His/her thoughts being muddled?**

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

19. **Difficulty making decisions?**

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

20. **Making him/herself understood?**

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

Now, I’m going to ask you about your relative/friend’s everyday life. In the last week, how **worried** would you say your relative/friend has been about...

21. **Keeping him/herself clean (e.g. washing and bathing)?**

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

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22. Keeping him/herself looking nice?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

23. Getting what he/she wants from the shops?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

24. Using money to pay for things?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

25. Looking after his/her finances?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

26. Things taking longer than they used to?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>

27. Getting in touch with people?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Quite a bit</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
</table>
28. Not having enough company?

| A lot | Quite a bit | A little | Not at all |

29. Not being able to help other people?

| A lot | Quite a bit | A little | Not at all |

30. Not playing a useful part in things?

| A lot | Quite a bit | A little | Not at all |

31. His/her physical health

| A lot | Quite a bit | A little | Not at all |

We’ve already talked about lots of things: your relative/friend’s feelings, memory and everyday life. Thinking about all of these things in the last week, how would you say your relative/friend would rate:

32. His/her quality of life overall?

| Very Good | Good | Fair | Poor |

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ISRCTN10748953
### Carer Sense of Competence

**Screening ID:** __________  **Date of assessment:** ____ / ____ / ____  **Interviewer ID:** ________

**EQ-5D-5L**

<table>
<thead>
<tr>
<th>Time Scale: Today</th>
<th>Assessment of: Supporter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please indicate by ticking one statement for each item which best describes your health state today.</td>
<td></td>
</tr>
</tbody>
</table>

#### MOBILITY
- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

#### SELF-CARE
- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

#### USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)
- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

#### PAIN /DISCOMFORT
- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

#### ANXIETY/ DEPRESSION
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed
Carer Sense of Competence

Screening ID: ________________ Date of assessment: __/__/___ Interviewer ID: __________

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
- 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = [ ]
### Carer Sense of Competence

**Screening ID:**

**Date of assessment:**

**Interviewer ID:**

**HADS**

**Time Scale:** In the last week

**Assessment of: Supporter**

Participants are asked to choose one response from the four given for each question. They should give an immediate response and be dissuaded from thinking too long about their answers.

Think about how you have felt over the past week, which reply comes closest to how you have been feeling. *(Circle one only in each row).*

1. I feel tense or "wound up"

<table>
<thead>
<tr>
<th>Most of the time</th>
<th>A lot of the time</th>
<th>From time to time, Occasionally</th>
<th>Not at all</th>
</tr>
</thead>
</table>

2. I still enjoy the things I used to enjoy.

<table>
<thead>
<tr>
<th>Definitely as much</th>
<th>Not quite as much</th>
<th>Only a little</th>
<th>Hardly at all</th>
</tr>
</thead>
</table>

3. I get a sort of frightened feeling as if something awful is about to happen.

<table>
<thead>
<tr>
<th>Very definitely and quite badly</th>
<th>Yes but not too badly</th>
<th>A little, but it doesn’t worry me</th>
<th>Not at all</th>
</tr>
</thead>
</table>

4. I laugh and see the funny side of things.

<table>
<thead>
<tr>
<th>As much as I always could</th>
<th>Not quite so much now</th>
<th>Definitely not so much now</th>
<th>Not at all</th>
</tr>
</thead>
</table>

5. Worrying thoughts go through my mind.

<table>
<thead>
<tr>
<th>A great deal of the time</th>
<th>A lot of the time</th>
<th>From time to time but not too often</th>
<th>Only occasionally</th>
</tr>
</thead>
</table>
6. I feel cheerful.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Not often</th>
<th>Sometimes</th>
<th>Most of the time</th>
</tr>
</thead>
</table>

7. I can sit at ease and feel relaxed.

<table>
<thead>
<tr>
<th></th>
<th>Definitely</th>
<th>Usually</th>
<th>Not often</th>
<th>Not at all</th>
</tr>
</thead>
</table>

8. I feel slowed down.

<table>
<thead>
<tr>
<th></th>
<th>Nearly all the time</th>
<th>Very often</th>
<th>Sometimes</th>
<th>Not at all</th>
</tr>
</thead>
</table>

9. I get a sort of frightened feeling like "butterflies" in my stomach.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Occasionally</th>
<th>Quite often</th>
<th>Very often</th>
</tr>
</thead>
</table>

10. I have lost interest in my appearance.

<table>
<thead>
<tr>
<th></th>
<th>Definitely</th>
<th>I don't take so much care as I should</th>
<th>I may not take quite as much care</th>
<th>I take just as much care as ever</th>
</tr>
</thead>
</table>

11. I feel restless as if I have to be on the move.

<table>
<thead>
<tr>
<th></th>
<th>Very much indeed</th>
<th>Quite a lot</th>
<th>Not very much</th>
<th>Not at all</th>
</tr>
</thead>
</table>
12. I look forward with enjoyment to things.

<table>
<thead>
<tr>
<th>As much as I ever did</th>
<th>Rather less than I used to</th>
<th>Definitely less than I used to</th>
<th>Hardly at all</th>
</tr>
</thead>
</table>

13. I get sudden feelings of panic.

<table>
<thead>
<tr>
<th>Very often indeed</th>
<th>Quite often</th>
<th>Not very often</th>
<th>Not at all</th>
</tr>
</thead>
</table>

14. I enjoy a good book or radio or TV programme.

<table>
<thead>
<tr>
<th>Often</th>
<th>Sometimes</th>
<th>Not often</th>
<th>Very seldom</th>
</tr>
</thead>
</table>

END OF ASSESSMENT: PLEASE RECORD FINISH TIME ON FRONT PAGE
Appendix 4. Interview Study Consent Form

Interview Participant Consent Form

If you are willing to have a telephone interview with me please complete the agreement below:

1.) I confirm that I have read and understood the Interview Participant Information Sheet (v1. 15.10.17) for the interview study and have had the opportunity to ask questions.

2.) I agree to take part in an interview. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reasons.

3.) I give my consent to be audio-recorded during the interview.

4.) I understand that all the information given by me or about me will be treated as confidential by the research team.

5.) I give permission for any views I express to be anonymised and used in future analysis.

Please also complete the details below:

Name _____________________________________________

Date______________________________

Signature_____________________________________

Thank you for your time to complete this form, please return it via the stamped addressed envelope provided.
## Appendix 5. Data distributions

1. **Data distributions - Chapter 5**

<table>
<thead>
<tr>
<th></th>
<th>Skewness</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Statistic</td>
<td>Std. Error</td>
</tr>
<tr>
<td>Gains</td>
<td>-.42</td>
<td>.104</td>
</tr>
<tr>
<td>Resilience</td>
<td>-.125</td>
<td>.103</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>-.02</td>
<td>.104</td>
</tr>
<tr>
<td>Sense of coherence</td>
<td>-.18</td>
<td>.104</td>
</tr>
<tr>
<td>Sense of competence</td>
<td>-.33</td>
<td>.103</td>
</tr>
<tr>
<td>Social engagement</td>
<td>.12</td>
<td>.105</td>
</tr>
</tbody>
</table>

2. **Data distributions - Chapter 6**

<table>
<thead>
<tr>
<th></th>
<th>Skewness</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Statistic</td>
<td>Std. Error</td>
</tr>
<tr>
<td>Person with dementia rated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADL Dependency</td>
<td>.83</td>
<td>.11</td>
</tr>
<tr>
<td>ADL deterioration</td>
<td>1</td>
<td>.11</td>
</tr>
<tr>
<td>Cognition</td>
<td>-.69</td>
<td>.11</td>
</tr>
<tr>
<td>Depression</td>
<td>1.29</td>
<td>.11</td>
</tr>
<tr>
<td>Quality of life – carer rated</td>
<td>-.95</td>
<td>.12</td>
</tr>
<tr>
<td>Quality of life – person with dementia rated</td>
<td>-.4</td>
<td>.12</td>
</tr>
<tr>
<td>Carer rated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety and depression</td>
<td>.81</td>
<td>.11</td>
</tr>
<tr>
<td>Sense of competence</td>
<td>-.05</td>
<td>.12</td>
</tr>
</tbody>
</table>
Appendix 6. Presentations and Publications

Presentations:

I have presented at several national and international conferences:

“Valuing Active Life in Dementia (VALID): Development of a Community Occupational Therapy Intervention for People with Dementia and their Family Carers.” Poster session presented at Alzheimer Europe Conference, 22nd October 2014, Glasgow, UK.


“Positive psychology outcome measures for family caregivers of people living with dementia: a systematic review.” Poster session presented at Alzheimer Europe conference, 1st November 2016, Copenhagen, Denmark.


“Investigating the impact of positive aspects of caregiving on caregiver sense of competence: A national survey of family caregivers of people living with dementia.” Oral presentation at Alzheimer Europe conference, Tuesday 3rd October 2017, Berlin, Germany.
“Caregiving strengths: Sense of competence in family caregivers of people with dementia living in the community.” Poster session presented at Alzheimer Europe conference, Tuesday 3rd October 2017, Berlin, Germany.

Publications:

