

**The role of self-efficacy in the health-related quality
of life of family carers of individuals with dementia**

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DECLARATION

I, Nadia Crellin, 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.

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ABSTRACT

Background

The Self-Efficacy Theory has been widely applied to research exploring chronic stress and in recent decades has proved promising in explaining the experiences of family carers of individuals with dementia.

Aim

To investigate the role of self-efficacy in the health-related quality of life of family carers of individuals with dementia, with particular consideration of the positive and negative impact related to caring, coping strategies and social support.

Methods

The sample comprised 289 family carers and individuals with dementia. The data collected were the baseline data for the SHIELD (Support at Home: Interventions to Enhance Life in Dementia) Carer Supporter Programme and included caring domain-specific self-efficacy beliefs, coping strategies, social support, positive and negative impact related to caring, and carer health-related quality of life. Analytic methods included correlations, t-tests, ANOVA, multiple regression and path analysis.

Results

Carers reported experiencing positive and negative emotions related to the caring experience and self-efficacy beliefs were found to have a “dual action” in both increasing positive impact related to caring, whilst buffering against negative impact. Carer characteristics and psychosocial resources were found to be determinants of self-efficacy beliefs, although caring stressors were not. In addition, it was found that self-efficacy, particularly for obtaining respite and controlling upsetting thoughts exerts a direct effect on carer quality of life, however only self-efficacy for responding to disruptive behaviours moderates the association between behavioural and psychological symptoms of dementia and carer quality of life. Finally, mediating effects of

psychosocial resources including self-efficacy, coping strategies and social support were found in the association between stressors and carer quality of life.

Conclusions

Theoretically, findings have implications for informing conceptual models of carer coping and support the application of Self-Efficacy Theory to the caring experience. Clinically, findings assist in the design of effective carer interventions, specifically those directed towards enhancing self-efficacy.

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GLOSSARY AND ABBREVIATIONS

ADCS-ADL	Alzheimer's Disease Cooperative Scale-Activities of Daily Living
ADL	Activities of Daily Living
AMOS	Analysis of moment structures
ANOVA	Analysis of Variance
β	Beta
B	Unstandardised regression coefficient
BECCA	Befriending and costs of caring
BME	Black and minority ethnicities
BPSD	Behavioural and psychological symptoms of dementia
Brief-COPE	Brief Coping Orientation for Problem Experience
CASP	Critical Appraisal Skills Programme
CDR	Clinical Dementia Rating Scale
CEM	Caregiver Empowerment Model
CFI	Comparative Fit Index
COPE-Index	Carers of Older People in Europe Index
CRD	Centre for Reviews & Dissemination
CSP	Carer Supporter Programme
DeNDRoN	Dementias and neurodegeneration
df	Degrees of freedom
DSM-IV	Diagnosis and Statistical Manual of Mental Disorders (4th edition)
EQ-5D	EuroQoL 5 dimensions
GP	General Practitioner
GFI	Goodness of Fit Index
HADS	Hospital Anxiety and Depression Scale
IADL	Instrumental activities of daily living
ISRCTN	International Standard Randomised Controlled Trial Number
KMO	Kaiser-Meyer-Olkin
M	Mean
MMSE	Mini Mental State Examination
n	Number of participants
NA	Negative affect
NELFT	North East London NHS Foundation Trust

NFI	Normal Fit Index
NHS	National Health Service
NI	Negative Impact
NICE-SCIE	The National Institute for Health and Clinical Excellence-Social Care Institute for Excellence
NIHR	National Institute for Health Research
NPI	Neuropsychiatric Inventory
NPS	Neuropsychiatric symptoms
NS	Narrative Synthesis
p	Level of significance
PA	Positive affect
PANAS	Positive and Negative Affective Subscales
PANT	Practitioner Assessment of Network Type
PCA	Principal Component Analysis
PI	Positive impact
PPI	Patient and Public Involvement
PwD	Person with dementia
QoL	Quality of life
r	Pearson's correlation coefficient
R	Effect size
R ²	R squared (coefficient of determination)
REC	Research Ethics Committee
REMCARE	REMiniscence groups for people with dementia and their family CAREgivers
RMSEA	Root mean square error of approximation
RSSE	Revised Scale for Caregiving Self-Efficacy
RYCT	Remembering Yesterday Caring Today
SD	Standard deviation
SE	Self-efficacy
Se	Standard error
SEDB	Self-efficacy for Responding to Disruptive Behaviours
SECT	Self-efficacy for Controlling Upsetting Thoughts
SEM	Structural equation modelling
SEOR	Self-efficacy for Obtaining Respite

SF12 / SF36	12 / 36 item Short Form Health Survey
SHIELD	Support at Home: Interventions to Enhance Life in Dementia
SPSS	Statistical Package for the Social Sciences
TAU	Treatment as usual
UK	United Kingdom
US	United States
VIF	Variance Inflation Factor
WHO	World Health Organisation
χ^2	Pearson's Chi-square test

ETHICAL APPROVAL AND TRIAL REGISTRATION

Ethical approval

The SHIELD (Support at Home: Interventions to Enhance Life in Dementia) Carer Supporter Programme (CSP) was approved by the Outer North East London Research Ethics Committee (ethical approval reference number: 09/H0701/54) in July 2009 (Appendix 1.1).

Trial registration

The study was registered with the North East London NHS Foundation Trust (NELFT) Research and Development Department (Appendix 1.2), Berkshire Healthcare NHS Foundation Trust (Appendix 1.3), Norfolk and Waveney Mental Health NHS Foundation Trust (Appendix 1.4) and Northamptonshire Healthcare NHS Foundation Trust (Appendix 1.5). The trial was registered with the International Standard Randomised Controlled Trial Number (ISRCTN) register and assigned the following unique trial identification number: 37956201.

CHAPTER 1: INTRODUCTION

1.1 Dementia

1.1.1 Aging and the epidemiology of dementia

People are living longer today than ever before and as a result the population is aging. This poses a challenge for society, as it is associated with an increased prevalence of dementia. Dementia is a major global health challenge and one of the greatest difficulties confronting health and social care today (Alzheimer's Europe, 2006). It is estimated that there are more than 35 million people worldwide currently living with dementia and this is expected to triple to 115 million by 2050 (World Alzheimer Report, 2013). Within the UK, there are more than 800,000 people living with dementia, which is 1.3% of the total population (Alzheimer's Society, 2014). It is estimated that by 2051 there will be 1.7 million individuals with dementia living in the UK (Knapp, Comas-Herrera, Somani, & Banerjee, 2007).

1.1.2 Dementia

Dementia is a "clinical syndrome characterised by global cognitive impairment, which represents a decline from previous level of functioning, and is associated with impairment in functional abilities, and in many cases, behavioural and psychiatric disturbances" (National Institute for Clinical Excellence [NICE] / Social Care Institute for Excellence [SCIE], 2006, p.43). Dementia results in symptoms such as impairment in memory, communication, orientation, judgment, reasoning skills, cognition and activities of daily living. These symptoms impact upon all aspects of life, with individuals facing difficulties with remembering, knowing where they are, keeping track of the date, knowing who others are, decision-making and acquiring new information (Knapp et al., 2007; Perrin, May, & Anderson, 2008). Symptoms worsen

over time and individuals become increasingly dependent, although its progression and presentation varies between individuals (Brooker & Surr, 2005). Types of dementia include Alzheimer's Disease, vascular dementia, frontotemporal dementia, and Lewy-body dementia, with each differing in cause and characteristic symptoms. Despite the development of pharmacological and non-pharmacological interventions to alleviate symptoms and increase wellbeing, dementia remains without cure (NICE/SCIE, 2006).

1.1.3 The economic costs of dementia

Dementia has a significant economic impact on society: it costs social and health care services, family and friends £23 billion a year, which roughly equates to twice the cost of cancer, three times the cost of heart disease and four times the cost of stroke (Alzheimer's Research Trust, 2010). Given its increasing prevalence, it is estimated the costs associated with dementia will rise to £34.8 billion in 2026 (King's Fund, 2008).

As a result, dementia is under the international spotlight, it is now considered a worldwide clinical and research priority. Several key government policies have recently been outlined to improve health and social care service provision for people with dementia and their carers. For example, the 'Prime Minister's Challenge' (Department of Health, 2009) aims to enhance quality of life (QoL) for people with dementia and their carers and in December 2013 world leaders gathered in London for the G8 summit on dementia. One of the aims of which was to improve QoL for people with dementia and their carers.

1.2 Family caring

1.2.1 The economic value of family caring

A family carer (caregiver) is an individual who gives a substantial amount of regular

unpaid care and support to a relative, partner or close friend with a chronic illness who is unable to care independently for themselves. Individuals are living longer than ever before and, as a result, family members are increasingly likely to find themselves with caring responsibilities. In the UK there are estimated to be six million carers, with 1.4 million providing more than 50 hours of unpaid care per week (NHS Information Centre Social Care Team, 2010).

In the UK alone there are estimated to be 670,000 family members and friends providing care to people with dementia, which is estimated to save the economy over £8 billion a year (Alzheimer's Society, 2012). These carers form a major part of the support system, providing the majority of health and social care to individuals with dementia. This is not surprising given that two thirds of people with dementia live in the community (Alzheimer's Society, 2012). The contribution of family carers therefore has major economic and clinical consequences. Family caring continues to progress as a public policy issue: recent government policy including the national strategy for carers (Department of Health, 2008) and NICE-SCIE guidelines (2006) promise better support for carers.

1.2.2 What does caring involve?

Dementia is a complex condition, and therefore caring for an individual with dementia is both challenging and demanding. The caring role evolves over time; carers are called upon to provide increasing support as people with dementia find it increasingly difficult to cope with everyday activities. People with dementia require considerable practical assistance with daily tasks due to increasing functional dependence. For example, as dementia progresses people require more assistance with personal care and tasks such as getting in/out of bed, dressing, toileting, bathing and feeding, more hours of care and

supervision (Aguero-Torres et al., 1998). Carers also provide considerable emotional support and reassurance as the person with dementia deals with their diagnosis and increasing dependency.

People with dementia not only require practical assistance, but carers are also often faced with challenges resulting from behavioural problems and cognitive impairment. Murray, Schneider, Banerjee, and Mann (1999) found that spouses of individuals with dementia reported a range of caring demands including diminished quality of communication, memory loss, personality changes, and deterioration in social behaviour. In particular, neuropsychiatric symptoms (NPS) or behavioural and psychological symptoms of dementia (BPSD) (e.g. agitation, aggression, disinhibition) are a major cause of distress for carers, and are often considered the most challenging part of the caring experience. For instance, the reviews of Torti and Cwyther (2004), and Black and Almeida (2004) found that BPSD/behavioural disturbances are more predictive of carer burden and psychological wellbeing than cognitive or functional impairments. However there is considerable variability in the symptoms presented by individuals with dementia, making the caring experience extremely heterogeneous.

1.2.3 Objective and subjective stressors of the caring experience

Stressors are the conditions, experiences, and activities that challenge carers and are inherent to caring (Robertson, Zarit, Duncan, Rovine, & Femia, 2007). The caring experience involves both objective and subjective stressors. Objective stressors include actual care demands posed by the person with dementia that change over the course of the disease. Conceptual models of carer coping (e.g. Kramer, 1997; Pearlin, Mullan, Semple, & Skaff, 1990; Schulz & Salthouse, 1999) describe caring as involving three primary objective stressors: functional impairments, cognitive impairments and

behavioural problems. Similarly, Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch (1995) claimed that objective stressors include cognitive impairments of the person with dementia, activities of daily living dependencies, and behavioural problems. Subjective stressors refer to carer responses/reactions to objective stressors, such as distress and burden associated with the caring role. For instance, Aneshensel et al. (1995) claimed that subjective stressors include internal responses resulting from caring, such as role overload and loss of intimate exchange.

1.2.4 The impact of caring

Caring is both physically and mentally challenging, and has a practical and economic impact. There is an extensive evidence base demonstrating the detrimental influence of caring on mental health including depression, anxiety and psychological distress (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Zarit, Reever, & Bach-Peterson, 1980) and physical health including fatigue, greater risk of hypertension and cardiovascular disease, mortality and reduced immune functioning (Mausbach et al., 2007; Schulz & Martire, 2004; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Shaw et al., 1999). The burden faced by carers of individuals with dementia is greater than for carers of older people; the reviews of Pinquart & Sorensen (2003) and Ory et al. (1999) demonstrated that family carers of individuals with dementia have poorer wellbeing, physical and mental health. Suggested reasons for the high stress of caring for an individual with dementia include high caring demands, the increased need for supervision, limited ability of people with dementia to express gratitude and the progressive nature of dementia (Ory et al., 1999).

Caring for a person with dementia requires significant time, which can often lead to isolation and loneliness, with many carers reporting reduced participation in leisure

activities and socializing. For example, according to the review by Pinguart & Sorenson (2003) caring restricts social life, leaving less time to spend with friends/family and for leisure activities. However, it is important to note that the review was not specific to dementia caring. In addition, caring for people with dementia has significant economic costs, with many carers finding it difficult to cope financially. For example, Carers UK (2014) found almost half of carers were worse off financially as a result of assuming the caring role.

1.2.5 Positive aspects related to the caring experience

Until recent years, research had a tendency to focus on the negative aspects of caring (e.g. stress and burden), which precipitated a skewed perception of the caring experience and limited theoretical understanding. This was highlighted in Kramer's (1997) review of informal carers of older adults, that called for a more holistic view of the caring experience and greater recognition of positive aspects. Subsequently, in recent years there has been both a theoretical and empirical shift towards identifying and investigating positive aspects of caring. For example, Rapp & Chao (2000) found dementia carers reported positive aspects of caring including satisfaction, growth, and skill development. In addition, Cohen, Colantonio, and Vernich (2002) found 73% of Canadian carers of older adults identified at least one positive aspect of caring such as companionship, sense of fulfilment and enjoyment. Tarlow et al. (2004) conducted a review of dementia caring literature and identified positive experiences related to caring such as satisfaction, pleasures, rewards, enjoyment, and strengthened relationships. Furthermore, the review by Carbonneau, Caron, and Desrosiers (2010) proposed a conceptual framework of positive aspects of caring comprising three domains, including quality of relationship, feelings of accomplishment and role meaning, however the review was not specific to dementia.

1.2.5.1 The adaptive value of positive aspects of caring

Positive aspects of caring have been shown to serve adaptive functions for carer physical and mental health, and on-going carer involvement. For example, Pruchno, Kleban, Michaels, and Dempsey (1990) found that positive aspects determine whether individuals will continue to care, predicting institutionalisation in carers of persons with dementia. Consistently, the literature review of Carbonneau et al. (2010) demonstrated the importance of positive aspects for carer mental and physical health, and proposed positive aspects might maintain carer involvement by buffering against stress. In addition, the review by Folkman and Moskowitz (2000) found that positive experiences in caring are important for coping and resilience during stressful times. However neither review was specific to dementia caring.

1.2.5.2 Determining factors of positive aspects of caring

To understand the complexity of the caring experience, it is important to identify factors that precipitate/inhibit the manifestation of positive aspects. The integrative review of Carbonneau et al. (2010) reported that both carer characteristics and resources influence positive aspects of caring. In addition, Peacock et al. (2010) conducted a mixed methods study of 36 family carers of individuals with dementia and found adult children experience positive situations differently and report more positive feelings than spousal carers. Similarly, Raschick and Ingersoll-Dayton (2004) examined the association between relationship type and caring rewards in 978 carers of older family members and found that adult children experienced more benefits than spousal carers. It was suggested that spousal carers might have a stronger sense of social responsibility for caring, while adult children view caring as exceeding social expectations.

Empirical research has consistently demonstrated that black carers tend to report more positive caring experiences than white carers. For example, Roff et al. (2004) examined positive aspects of caring among black and white carers of individuals with dementia in the US and found that black carers reported more positive aspects. Similarly, Rapp and Chao (2000) found that black carers of relatives with dementia reported higher gains than white carers, however the sample size was small. White, Townsend, and Stephens (2000) found black carers reported more rewards than white carers of a cognitively impaired parent, however there was a huge disparity in numbers between groups and the study exclusively involved females. It was suggested that black carers find caring more rewarding because it is a normative experience and feel greater pride in fulfilling caring responsibilities; it is highly culturally valued. In support of this view, Tang (2011) found cultural values predicted positive aspects of caring in family carers of elderly relatives. However, the review of Hargrave (2006) found that white carers are more likely to be spouses, whereas black carers are more likely to be adult children, which might explain the difference in positive aspects reported.

Empirical evidence typically demonstrates that positive aspects of caring are influenced by the clinical characteristics of the person with dementia. For example, Depp et al. (2005) and Semiatin and O'Connor (2012) found BPSD frequency was negatively correlated with positive aspects of caring in carers of individuals with dementia. However, the Semiatin and O'Connor (2012) sample was small and comprised predominantly white, female carers, and the Depp et al. (2005) sample was exclusively female. In addition, Raschick and Ingersoll-Dayton (2004) found that problem behaviours and functional dependency were significant predictors of caring rewards in carers of older family members. Conversely, Lopez, Lopez-Arrieta, and Crespo (2005) found caring stressors did not predict caring satisfaction in informal carers of elderly

relatives.

Reasons for the discrepancy in findings might be due to the fact that the Lopez et al. (2005) study was not specific to dementia carers or due to differences in the conceptualisation and/or measurement of positive aspects of caring. The reviews by Kramer (1997) and Tarlow et al. (2004) on positive aspects of caring identified issues such as varied conceptual definitions between studies, variation in measurement scales across studies, lack of recognition of confounding variables, and limited statistical methods. These limitations likely contribute to contradictory findings and difficulties in making generalisations.

1.2.6 The “mixed valence” of caring

The co-existence of positive and negative aspects/emotions in the caring experience has been shown in both dementia and non-dementia caring populations. Lawton, Moss, Kleban, Glicksman, and Rovine (1991, p.182) termed this phenomenon as the “mixed valence” of caring. Lawton et al. (1991) found carers of people with dementia reported both burden and satisfaction. Similarly, Folkman (1997) conducted a longitudinal study of carers of individuals with AIDS and found carers reported both negative and positive psychological states throughout. In addition, Raschick and Ingersoll-Dayton (2004) found that caring for an older person results in both costs and rewards in carers of older family members.

Empirical research has been directed towards understanding the association between positive and negative aspects of the caring experience: whether positive and negative aspects exist at the opposite ends of one continuous spectrum or whether positive and negative aspects reflect independent dimensions. Several researchers (e.g. Cheng, Lam,

Kwok, Ng, & Fung, 2012; Rapp & Chao, 2000) have proposed that positive and negative aspects are qualitatively and theoretically distinct dimensions of the caring experience that have distinct influences on carer outcomes. In support, some researchers (e.g. Balducci et al., 2008; Narayan, Lewis, & Tornatore, 2001; Roff et al., 2004; Tarlow et al., 2004) have found no correlations or only weak inverse correlations between positive and negative subjective responses in family carers. This is compatible with two factor models of carer wellbeing such as the general health model (Schulz & Salthouse, 1999), modified stress and coping model (Kramer, 1997), and appraisal model (Lawton et al., 1991). These models recognise the existence of two independent pathways; positive appraisals lead to positive outcomes and negative appraisals lead to negative outcomes.

Conversely, other researchers have proposed that positive aspects of caring buffer against negative experiences and reduce the impact of burden related to caring. For example, Cohen et al. (2002) found positive feelings about caring predict depression in carers of older adults and concluded that the ability to identify positive aspects might buffer against negative consequences. Semiatin and O'Connor (2012) found depression was a significant negative predictor of positive aspects in female carers of individuals with dementia. In addition, Hilgeman, Allen, DeCoster, and Burgio (2007) found carers of relatives with dementia reporting more positive aspects of caring across time reported less depression and burden. Reasons for the discrepancy in findings concerning the association between positive and negative dimensions is likely due to differing conceptualisations and measurements scales of positive and negative aspects related to the caring experience.

1.2.7 Determinants of positive and negative aspects of caring

Empirical research has largely indicated the existence of different predictors for positive and negative aspects of caring, which is consistent with the view of the independence of negative and positive dimensions. For example, Rapp and Chao (2000) found that memory and behaviour problems were much more strongly correlated with carer strain than gain in dementia carers. Kramer (1997) found differential predictors of positive and negative aspects among 74 husband dementia carers, in particular memory and behaviour problems predicted strain. Subsequently, Kramer et al. (1997) proposed that gains might be more related to carer than person with dementia characteristics. Similarly, Harwood, Barker, Ownby, Agüero, and Ranjan (2000) found different predictors of satisfaction and burden in 40 Cuban American dementia carers, with behavioural pathology a predictor of burden but not satisfaction. In addition, Lopez et al. (2005) found that positive aspects of caring were mainly related to carer characteristics, but not to stressors in carers of elderly relatives. It appears to be a consistent finding that positive aspects are more strongly related to carer characteristics and negative aspects to care recipient characteristics, however it is important to note the wide variation in predictors evaluated, the cross-sectional nature of data and the small samples.

1.2.8 The structure of affect

Considering theory of the structure of affect, particularly conceptual models of the relationship between affective states in relation to models of carer coping is useful to gain a better understanding of the caring experience. This is important given the evidence concerning the co-occurrence of positive and negative states in caring. For years it was debated as to whether positive affect is the bipolar opposite of negative affect, or whether they are independent constructs. The two competing structural models

were the two-factor model of independent dimensions of activation, in which positive and negative affect were separate but related dimensions (Watson & Tellegen, 1985) and the bipolar, one-dimensional framework of positive and negative states on a continuum (Russell & Carroll, 1999). It was the view of independence that prevailed for many years.

Other perspectives have since emerged that comprise elements of both independence and bipolarity. Tellegen, Watson, and Clark (1999) proposed a three-level hierarchical structure of affective experience, with a higher order bipolar dimension of happiness/unhappiness and lower order independent dimensions of positive and negative affect. Zautra, Hoffman, and Reich (1997) proposed the dynamic model of affect. This integrative model places importance on the context of the affective experiences, with the relationship between affects being context dependent. Even more recently, Fredrickson (2001) proposed the “broaden-and-build” theory of positive emotions. Within this model, positive affect and negative affect can occur simultaneously and positive emotion can improve health and psychological outcomes by counteracting the arousal elicited by negative affect.

These models help to understand the role of positive and negative states in the caring experience. However, there is no one conceptual model that offers an adequate explanation of the complexity of caring and the complex association between positive and negative emotions when faced with caring stressors. Further research is needed to augment understanding of the interaction between affective states, caring stressors and outcomes of the caring experience.

1.3 Conceptual models of carer coping

Over the years, a number of conceptual models have attempted to explain the variability in carer coping. These models are important in guiding research and in the design of carer interventions.

1.3.1 Stress-coping paradigm and adaptations

The stress-coping model (Figure 1.1) of Lazarus and Folkman (1984) has dominated caring literature over the years, with caring seen as equivalent to experiencing a long-term stressor. It proposed carer outcomes are mediated by cognitive appraisals of stressors and coping resources. If stress is perceived, emotion-focused or problem-focused coping processes are initiated and lead to favourable or unfavourable outcomes. This model proved popular and influential, however it is constrained by its lack of recognition of positive aspects and relationships.

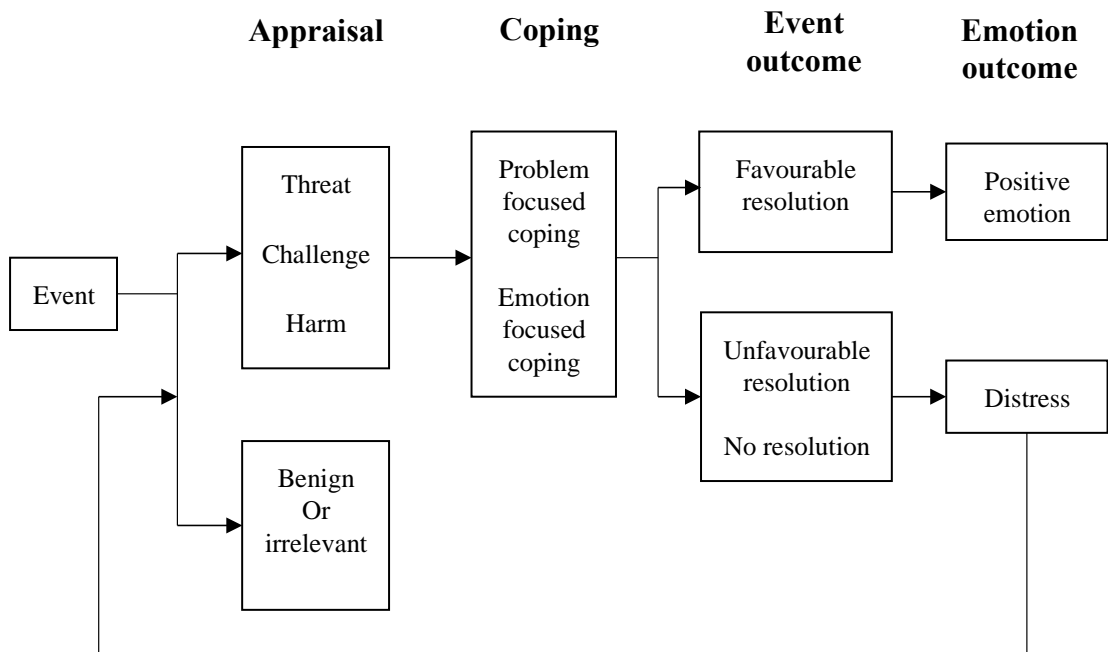


Figure 1.1 Lazarus and Folkman's (1984) Stress-coping model

There have been a number of adaptations of the stress-coping model in attempt to better represent the caring process. Haley, Levine, Brown, and Bartolucci (1987) empirically tested a modified stress-coping model with 54 family carers of individuals with dementia (Figure 1.2). The model included carer appraisals of caring stressors, self-efficacy (SE), coping and social support as mediators of the association between stressors and carer outcomes. Haley et al. (1987) found support for the model; improved carer wellbeing was associated with more benign/positive appraisals of stressors, higher SE, a higher level of perceived social support and the increased use of problem-focused coping responses. However, the study comprised a small sample and was cross-sectional, thus causality cannot be established.

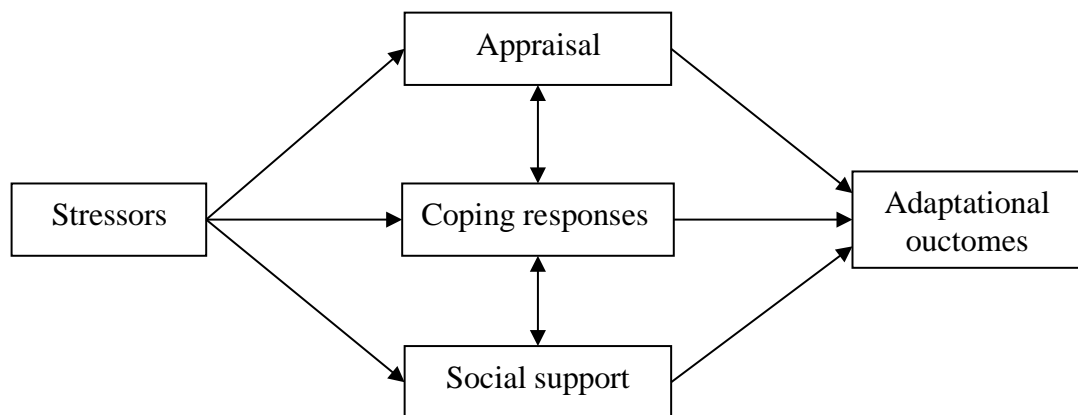


Figure 1.2 Original Haley et al. (1987) model of stress and coping among carers

Pearlin et al. (1990) conducted exploratory research with family carers of individuals with dementia and subsequently adapted the stress-coping paradigm for the stressors experienced in dementia caring. This model comprised four domains: stressor context and background (e.g. carer characteristics and personal/social resources), stressors (care recipient characteristics and demands), mediators of stressors (coping strategy and social support) and outcomes (e.g. wellbeing, burden). This model has been widely discussed in research, however it is constrained by its neglect of positive outcomes, lack

of consideration of the dyadic relationship and its uni-directional nature. Aneshensel et al. (1995) subsequently modified this model, instead proposing there to be three components: stressors (caring demands), outcomes (consequences on health and emotional wellbeing) and moderators, including social and personal resources (primarily social support and SE). However, Aneshensel et al. (1995) tested this model and found neither SE nor social support were moderators of the stress process in family carers.

The review of positive outcomes for carers of older adults conducted by Kramer (1993) used both empirical research and theoretical models to develop a modified stress and coping model. The model (Figure 1.3) claimed coping process are made up of three domains: background and context, intervening processes, and well-being outcomes. The model recognised resources and appraisal of gain and strain as intervening processes in negative and positive indicators of wellbeing. Importantly, the model acknowledges positive outcomes, however it has been criticised for its uni-directional nature.

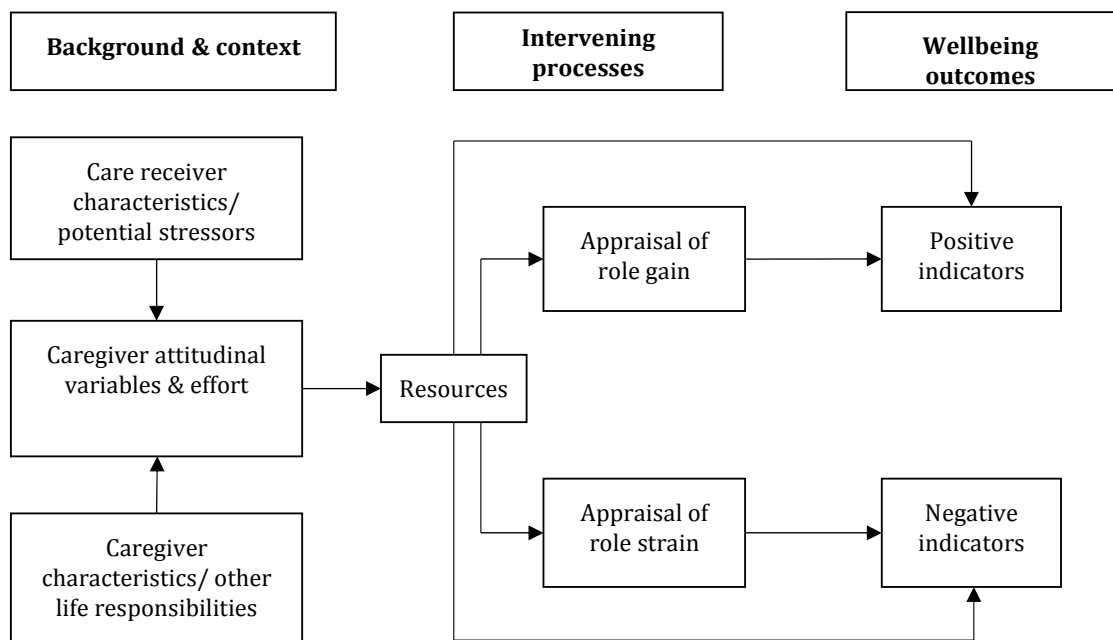


Figure 1.3 The modified stress and coping model of Kramer (1997)

Lawton et al. (1991) proposed an appraisal process model based on the stress process model and two-factor view of psychological wellbeing, and tested the model empirically in carers of individuals with dementia. The model recognised the mixed valence of caring and the relative independence of positive and negative outcomes; stressors can influence appraisals positively (e.g. satisfaction) or negatively (e.g. burden). However, the model has been criticised for the overlap between appraisals, resources and coping, and its cross-sectional nature. In addition, empirical testing of the model did not completely uphold the view of independence.

Folkman (1997) conducted a longitudinal study and found carers of a partner with AIDs can experience both positive and negative psychological states. This prompted Folkman to develop the revised stress-coping model to allow the role of positive psychological states in the coping process to be examined more systematically and rigorously.

1.3.2 Other models of carer coping

Other models include that of Schulz and Salthouse (1999), who applied a stress-health model to the caring process (Figure 1.4). This model involves stressors and carer appraisals of their ability to deal with stressors and the coping resources available, which lead to two pathways: i) if these are perceived as threatening or there are insufficient coping resources, appraisals promote negative affect, which influences behavioural or psychological responses and augment risk of psychiatric/physical illness; ii) benign stressor appraisals or perceived adequate resources elicit positive affect and positive physiological and behavioural responses. Beach, Schulz, and Yee (2000) tested the model empirically with 680 carers of a disabled spouse and findings were consistent with the model that caring can have both adverse and beneficial consequences. This

model recognises both the positive and negative health consequences of caring, however it is serial, uni-directional, simplistic and fails to recognise the role of moderators/mediators such as contextual factors and psychosocial resources.

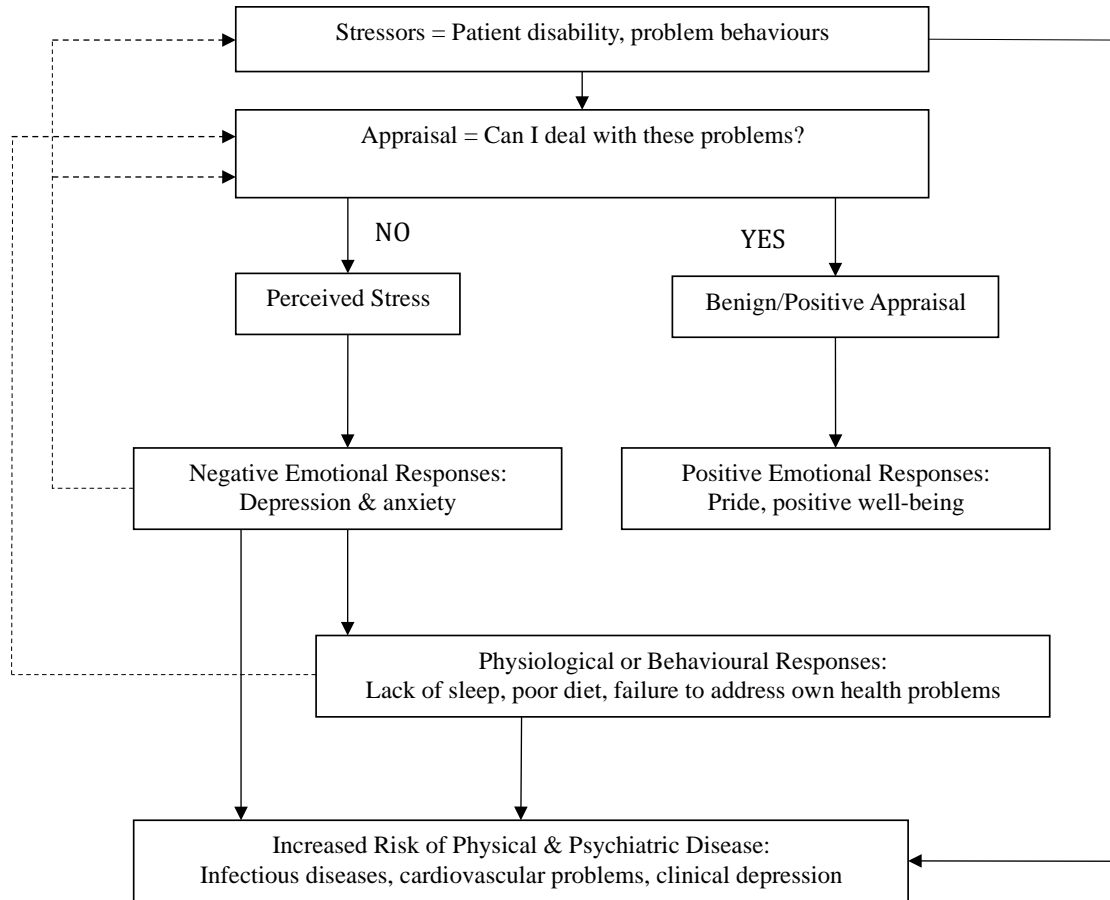


Figure 1.4 General model of the stress-health process applied to caring (Schulz & Salthouse, 1999) adapted from Cohen, Kessler, and Underwood (1995)

More recently, Sorensen and Conwell (2011) proposed a framework of dementia caring (Figure 1.5) by combining both the stress process (Pearlin et al., 1990) and appraisal models (Lawton et al., 1991). The framework proposed that carer appraisals of caring demands and secondary stressors influence the initiation of behaviours, which in turn determine carer emotional, psychological and health outcomes. This process is moderated by a host of internal and external factors such as carer self-efficacy (SE), coping resources and social support.

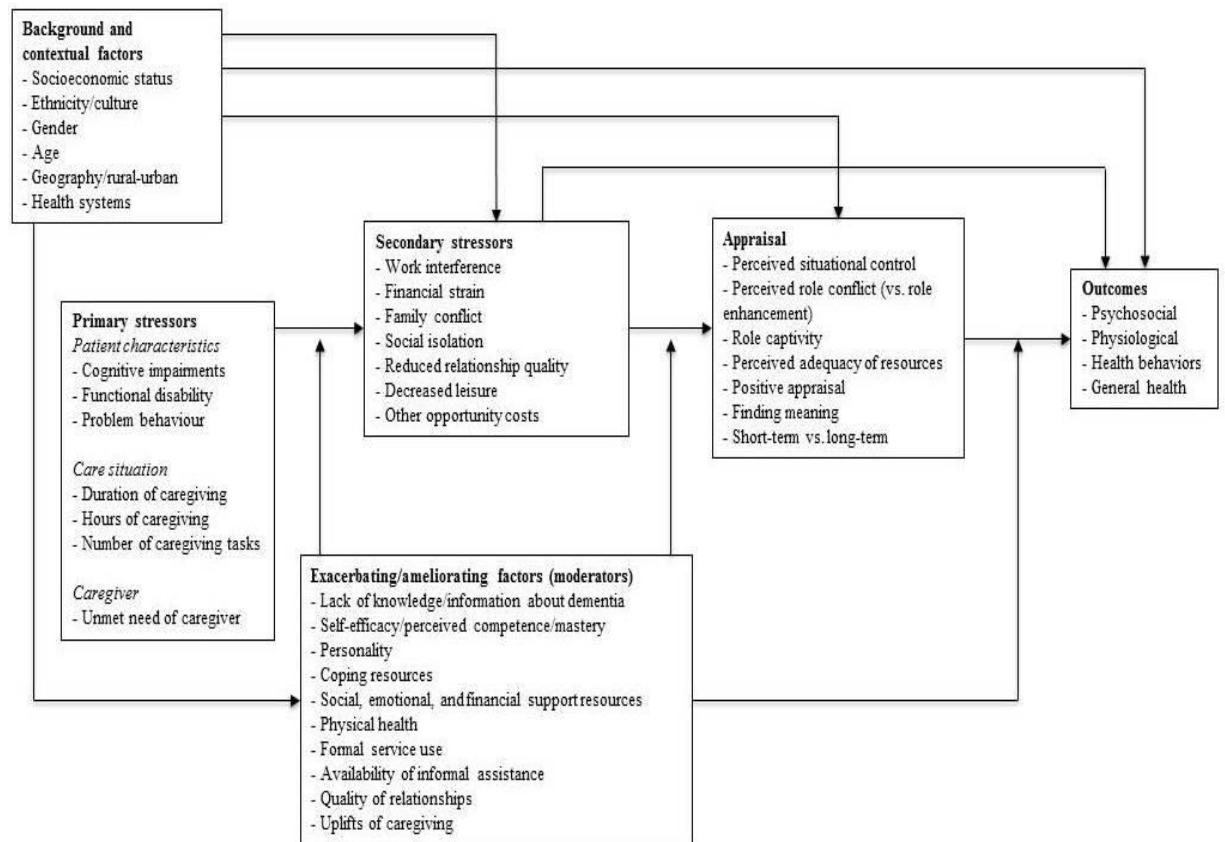


Figure 1.5 The combined stress process and appraisal model (Sorensen & Conwell, 2011)

In recent years, few conceptual models of carer coping have been developed and with the exception of the Sorensen and Conwell (2011) model, these have primarily been directed towards explaining positive experiences in caring. For example, Jones, Winslow, Lee, Burns, and Zhang (2011) developed a Caregiver Empowerment Model (CEM) based on empirical work in attempt to explain positive outcomes in caring. The model takes into account background variables (e.g. demographics), cultural beliefs about caring, caring demands (e.g. care recipient impairment), appraisals of demands, and specific resources that can facilitate positive outcomes (e.g. health and wellbeing). Resources (both interpersonal and external) are considered to promote positive appraisals and facilitate effective coping. In addition, Carbonneau et al. (2010) proposed

a conceptual framework of positive aspects of caring based on an integrative review. The model proposes three central domains of positive aspects of the caring role: the quality of carer and care-receiver relationship, feelings of accomplishment and the meaning of the caring role. The model suggests that positive aspects emerge through the occurrence of enrichment events, which are greatly conditioned by carer SE. The various components are interdependent and work together to reinforce well-being.

1.3.3 Summary

There are a number of conceptual models of carer coping that attempt to explain the variability in carer capacity to cope. However, at present, there is no one model that satisfactorily explains the caring experience. Further empirical evidence is needed to generate a model that is an adequate representation of the complexity of caring, and theoretical models of carer coping must advance with emerging empirical literature.

1.4 Coping efficacy versus self-efficacy

Previously, empirical research (e.g. Gottlieb & Rooney, 2004) has been focused towards exploring the influence of coping efficacy on carer outcomes. Coping efficacy is defined as subjective assessments of whether coping efforts were successful within a specific stressor context (Cummings et al., 1994). However in recent years, SE is a concept that has received increasing attention in caring literature. SE is broadly conceptualised as the belief that one can perform confidently and capably in a given situation (Bandura, 1977).

SE and coping efficacy (CE) can be distinguished from one another in two ways. Firstly, SE refers to belief in the ability to control important events (e.g. caring tasks), whereas coping efficacy refers to the efficacy of coping efforts within a particular

stressor context. Secondly, SE refers to confidence/expectations in dealing with future events, whereas coping efficacy refers to subjective evaluations of coping in past events. Today, caring literature tends to focus on the role of SE judgments for explaining variability in the caring experience and the capacity of carers to cope.

1.4.1 What is self-efficacy?

SE, as derived from social learning theory, was a concept introduced by Albert Bandura in the 1970's. SE refers to an individual's belief in their ability to perform a task and "mobilize the motivation, cognitive resources, and courses of action needed to meet situational demands" (Bandura & Wood, 1989, p. 408). According to Bandura (1982), SE perceptions vary in three dimensions: magnitude, strength and generality. Magnitude refers to task complexity; strength refers to level of confidence for performing the behaviour/task; and generality reflects the extent of transference of SE judgments from one situation to another. SE is distinct from more global terms such as self-esteem or locus of control, as SE judgements refer to specific expectations that differ across tasks, contexts and with experiences.

Bandura (1997) claimed that SE is predictive of emotional (affective), cognitive (appraisals) and behavioural responses to stressors. More specifically, SE beliefs determine: whether cognitions/appraisals are positive or negative; whether coping behaviours will be initiated and the type of coping behaviours (e.g. problem-focused or maladaptive coping responses); motivation and persistence; and emotional reactions (e.g. emotional robustness/vulnerability) when faced with stressful/challenging situations (Bandura, 1986).

SE is a psychological resource that can be learned and enhanced. According to SE Theory (Bandura, 1977) SE judgments are determined by four information sources:

- i. Performance accomplishments are based on personal mastery experiences: the successful performance of a behaviour is most influential in determining level of SE.
- ii. Vicarious experiences are based on social comparisons: SE is influenced by the observation of successful or unsuccessful performances of others.
- iii. Verbal persuasion: individuals believe that they can cope with a specific demand or perform a specific behaviour as a result of the encouragement of others.
- iv. Emotional arousal/perceived physiological state: individuals use physiological states to make judgments relating to their own capabilities. For example, those with low SE perceive arousal as an indication of lack of capabilities, but those with high SE perceive arousal as unrelated to ability.

1.4.2 The Self-Efficacy Theory applied to caring

The SE Theory has been widely applied to research exploring chronic stress, and in recent decades has proved promising in explaining the experiences of family carers of individuals with dementia and their ability to cope. According to SE Theory (Bandura, 1997) perceived SE could determine carer ability to regulate cognitive, motivational and affective processes, such as appraisals of the magnitude of challenges/demands, coping behaviours initiated and their persistence, and emotional responses when faced with challenges. For instance, it is hypothesised that individuals with high SE have more positive cognitions, provide care for longer with a higher level of motivation, tend to adopt more adaptive coping strategies, and experience lower levels of emotional distress and improved emotional wellbeing. In contrast, those with low SE have greater vulnerability to stressors, focus more on failure, have more negative cognitions, tend to

adopt maladaptive coping strategies, and experience high levels of emotional distress and much lower emotional wellbeing (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002).

The SE Theory (Bandura, 1997) claims that the SE belief system is not global, but is a differentiated set of beliefs related to independent domains i.e. it varies across domains and with experiences. The multi-dimensionality of SE has been demonstrated in a caring context by empirical research. In particular, distinct SE subscales have been found to express different patterns of association with other caring variables. For example, Steffen et al. (2002) found SE for obtaining respite was more closely related to social support than SE for controlling upsetting thoughts. In addition, empirical studies have demonstrated distinct SE domains to have moderator effects on carer intervention outcomes. For example, Rabinowitz et al. (2006) found SE for obtaining respite and SE for controlling upsetting thoughts moderated the association between a psychoeducational intervention and carer outcomes in a randomised controlled trial of carers of relatives with dementia, however SE for responding to disruptive behaviours did not.

Although many researchers (e.g. Davis, Martin-Cook, Hynan, & Weiner, 2006) have failed to consider SE relating to specific caring tasks, other studies have examined SE judgments relating to a number of specific caring tasks/domains. For example, Steffen et al. (2002) identified three distinct caring domains: SE for Obtaining Respite, Responding to Disruptive Behaviours, and Controlling Upsetting Thoughts. Fortinsky, Kercher, and Burant (2002) identified two distinct SE dimensions for managing dementia: SE for symptom management and for community support service use. Gottlieb and Rooney (2003) evaluated caring SE beliefs related to relational,

instrumental and self-soothing SE. The heterogeneity of SE domains studied in the caring literature has generated an inconsistent evidence base regarding its role in the caring experience, and subsequent difficulties with the interpretation of findings relating to the role of SE beliefs in the caring process.

1.4.3 The measurement of family carer self-efficacy beliefs

Three types of SE instruments have been used in caring literature, those which are: i) generic to the population (e.g. General SE Scale); ii) specific to caring (e.g. Caregiving SE Scale) and; iii) caring domain/task-specific (e.g. Revised Scale for Caregiving SE). Traditionally, SE instruments were generic, however more recently developed instruments are typically either specific to caring or partitioned into subscales corresponding to challenging caring tasks. Domain-specific instruments are more compatible with the domain-dependency specified by the SE Theory (Bandura, 1997) and provide greater capacity to account for variability in carer outcomes (Forsyth & Carey, 1998).

The most prevalent instrument of carer SE in recent years has been the Revised Scale for Caregiving Self-Efficacy (RSSE; Steffen et al., 2002). This instrument evaluates SE relating to Obtaining Respite, Responding to Disruptive Behaviours and Controlling Upsetting Thoughts. The scale has good validity and reliability, although it has not been validated specifically in a UK caring population. It is simple to administer and specific to dementia caring tasks. This is important given that caring for an individual with dementia is typically associated with higher levels of burden and poorer outcomes than caring for older adults. However the scale is designed for carers of individuals with moderate to severe dementia and subsequently might be subject to ceiling effects.

Other SE instruments applied in caring research include the RIS (Relational, Instrumental, Self-soothing) Eldercare SE scale (Gottlieb & Rooney, 2003), which evaluates SE beliefs specific to family caring, in particular relational, instrumental and self-soothing SE. Relational SE refers to beliefs about the ability to maintain a positive relationship with the care-recipient, the instrumental subscale evaluates beliefs about the ability to provide/assist with personal care, and self-soothing SE evaluates beliefs about ability to maintain one's own wellbeing. The subscales have demonstrated adequate psychometric properties (Gottlieb & Rooney, 2003).

Zeiss, Gallagher-Thompson, Lovett, Rose, and McKibbin (1999) developed an instrument to evaluate carer self-care SE and problem solving SE. The self-care SE domain relates to behaviours that carers could use to reduce distress, maintain pleasant events and social interaction (e.g. relaxation, social activities). The problem-solving SE domain refers to the use of problem-solving skills (e.g. specifying the problem, brainstorming, selecting a solution and putting it into action). The scales have demonstrated adequate reliability and validity in carers of frail and/or cognitively impaired older adults (Zeiss et al., 1999). However the scales are limited by potential ceiling effects, lack of sensitivity and the likelihood that problem-solving SE shows greater domain-specificity relating to particular tasks.

There remains a need to develop more adequate domain-specific measures of carer SE according to the most challenging caring tasks, such as the management of NPS or BPSD. It is important for scales to be tailored to the caring skills and demands that are most salient/challenging for carers. However, due to the complexity of caring and the variability in caring contexts, it is difficult to comprehensively evaluate an individual's 'SE for caring'.

1.5 Family carers and self-efficacy beliefs

Empirical research has consistently demonstrated that SE impacts upon carer outcomes; not only does SE function to augment positive outcomes in caring, it also acts to buffer against negative caring outcomes.

1.5.1 Self-efficacy beliefs and positive aspects of caring

Empirical research has demonstrated that SE judgments are related to positive aspects of caring. In particular SE is linked to a more positive view of the caring experience. For example, Cheng et al. (2012) found that SE for responding to disruptive behaviours had a direct effect on gains related to caring and SE for controlling upsetting thoughts moderated the relationship between problematic behaviours and caring gains in Chinese carers of relatives with dementia. However, SE for obtaining respite was not related to positive aspects. Similarly, Semiatin and O'Connor (2012) found global SE had a direct effect on positive aspects of caring in family carers of a relative with dementia. In addition, Haley et al. (1987) found that SE for responding to instrumental activities of daily living (e.g. shopping) was significantly correlated with life satisfaction in family carers of persons with dementia. However SE for managing memory and behaviour problems was not correlated with satisfaction. The integrative review by Carbonneau et al. (2010) proposed a framework of positive aspects of caring, in which positive aspects emerge through the occurrence of enrichment events, which are conditioned by SE beliefs. However the review was not specific to dementia caring.

However, it is important to note that all studies included small samples and were cross-sectional, therefore it is not possible to determine causality. It is also difficult to interpret findings due to the variability in instruments evaluating positive aspects and SE beliefs. For example Haley et al. (1987) examined generic satisfaction and used SE

items relating to specific caring domains that had not been previously validated, whereas Semiatin and O'Connor (2012) examined positive aspects specifically related to caring and evaluated global SE (computed from relational, instrumental and self-soothing SE).

1.5.2 Self-efficacy beliefs and negative aspects of caring

Empirical research has demonstrated the association between low carer SE and negative outcomes (e.g. distress and depression). For example, Steffen et al. (2002) found that SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts were correlated with depression and anxiety in family carers of individuals with dementia, however the correlations were modest. Steffen et al. proposed that carers with lower SE tend to focus on negative aspects of the caring experience. In addition, Gilliam and Steffen (2006) found a direct negative effect of SE for responding to disruptive behaviours on depression in carers of individuals with dementia, although the study involved a small sample of exclusively female carers. Similarly, Rabinowitz, Mausbach, and Gallagher-Thompson (2009) found SE for responding to disruptive behaviours and controlling upsetting thoughts had a direct effect on depression in female carers of relatives with dementia, although SE for obtaining respite did not predict depression. In addition, Gallagher et al. (2011) found that SE for managing dementia caring related tasks predicted both depression and burden in carers of relatives with dementia. It must be noted that studies examined a wide variety of SE judgements, assumptions cannot be made regarding causality due to the cross-sectional nature of studies and most studies involved predominantly white females, therefore the generalisability of findings is limited.

1.5.3 The “dual action” of family carer self-efficacy beliefs

Taken together, empirical evidence indicates a “dual action” of carer SE beliefs in the caring experience, in that SE judgments have the capacity to both protect against negative aspects of caring and also facilitate positive aspects. The proposal of a dual action of SE beliefs is compatible with the presuppositions of SE Theory (Bandura, 1997) that SE can determine carer outcomes by influencing how challenges are perceived (appraisals/cognition), coping behaviours (motivation) and emotional vulnerability (affective state). For example, carers with high SE focus on past accomplishments, perceive demands as challenges to be mastered, have more positive cognitions, persevere in the caring role for longer, adopt more adaptive coping behaviours and are more emotionally robust. Those with low SE tend to focus on past failures, make negative appraisals, have reduced motivation, lack persistence in coping behaviours, adopt maladaptive coping strategies, and are more emotionally vulnerable.

1.5.4 Caring outcomes and the role of self-efficacy beliefs

Carer SE judgments might help to explain why some carers cope better when faced with stressors than others. According to Aneshensel et al. (1995) there are three distinct roles that psychosocial resources such as SE might adopt in the association between stressors and carer outcomes: i) moderating effects ii) mediating effects or iii) independent/direct effects (Figures 1.6-1.8).

1.5.4.1 Moderation

SE might function as a moderator of the association between caring stressors and outcomes (Figure 1.6). In particular SE may alter the causal relation by changing the strength/magnitude of association between stressor and outcome. A moderating effect occurs when the resource (e.g. SE) combines with the stressor and the protective

function of resource increases as the stressor increases. For example, a carer with high SE and high stressors may report high QoL, while a carer with low SE and high stressors may report low QoL.

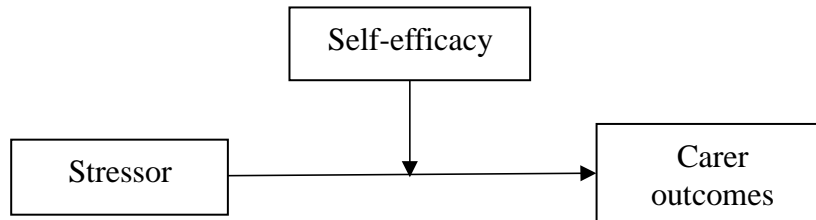


Figure 1.6 Moderation

1.5.4.2 Mediation

SE resources/beliefs might function as mediators between caring stressors and outcomes (presented in Figure 1.7), with stressors exerting an impact on carer outcomes through their effects on SE beliefs. Mediation occurs when an intervening variable forms part of the pathway, in that the intervening variable depends upon the independent variable and in turn influences the dependent variable. For example, a higher level of NPS of dementia might lead to reduced levels of carer SE (e.g. for managing these symptoms), which in turn is related to poorer carer outcomes.

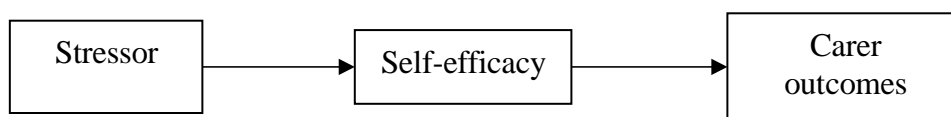


Figure 1.7 Mediation

1.5.4.3 Direct/independent effect

It might be that SE beliefs exert direct effects on carer outcomes that are independent of the stressor and are therefore beneficial to carers regardless of stressor intensity (Figure 1.8). For example, a higher level of SE might be directly associated with reduced carer distress, regardless of level of caring stressors (whether high/low).

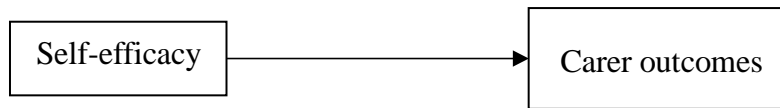


Figure 1.8 Direct effect

1.5.5 The role of self-efficacy in conceptual models of carer coping

The hypothesised role of SE in theoretical models of carer coping has varied over the years. For example, the modified stress process model (Pearlin et al., 1990) claimed the related concepts of global mastery and situational competence to be intrapsychic strains that mediate the association between stressors and outcomes. The modified stress model (Haley et al., 1987) claimed psychosocial resources mediate the effect of caring stressors on wellbeing and found that improved carer wellbeing was associated with more benign stressor appraisals (higher SE) when empirically tested. More recently, the framework of Carbonneau et al. (2010) specified that carer SE facilitates enrichment events, feelings of accomplishment and improved quality of relationships, which in turn determine positive aspects of caring. However, Aneshensel et al. (1995) proposed a stress process model in which mastery/SE is described as a moderator that alters the strength of associations between caring stressors and outcomes. Similarly, the combined stress process and appraisal model of Sorensen and Conwell (2011) proposed SE to moderate the relationship between primary stressors and both secondary stressors and appraisals.

Other theoretical caring frameworks fail to acknowledge SE judgments. In particular the stress-coping model (Lazarus & Folkman, 1984), revised stress-coping model (Folkman, 1997) and appraisal process model (Lawton et al., 1991) do not mention psychological resources such as SE. Other models do not explicitly mention SE and

instead describe generic terms or concepts that might be related to SE. For example, the modified stress and coping model of Kramer (1993) describes intervening processes, including internal resources (e.g. carer characteristics), as mediating the association between background and carer wellbeing. Therefore SE might be considered an internal resource. Similarly, the CEM model of Jones et al. (2011) specified that resources mediate the association between background and carer outcomes, therefore SE could be considered a carer resource. Given the abundant empirical research demonstrating the importance of SE judgments in the caring process, it is essential that theoretical models of carer coping recognise the role of caring SE beliefs.

1.5.5.1 Empirical research: Self-efficacy as a moderator or mediator?

Empirical research has primarily examined the moderating or direct effect of carer SE, usually between carer stressors (e.g. behavioural problems) and negative outcomes (e.g. distress, depression). For example, Rabinowitz et al. (2009) explored the moderating effect of SE on the relationship between memory and behavioural problems and depression in 256 carers of relatives with dementia. SE for responding to disruptive behaviours and SE for controlling upsetting thoughts were found to have direct effects on depression, and SE for responding to disruptive behaviours moderated the relationship between memory and behavioural problems and depression; SE was associated with lower depression when disruptive behaviours were high. However moderation effects were not found for SE for controlling upsetting thoughts or obtaining respite. Furthermore, Romero-Moreno et al. (2011) explored the moderating effect of SE for managing behavioural problems on the relationship between behavioural problems and burden, and the moderating effect of SE for controlling upsetting thoughts on the relationship between burden and distress in Spanish carers. SE for responding to

disruptive behaviours did not function as a moderator, however SE for controlling upsetting thoughts moderated the relationship between burden and distress; at high levels of burden high SE was associated with lower levels of carer distress.

In addition, Gilliam and Steffen (2006) found that SE for responding to disruptive behaviours did not moderate the relationship between cognitive and behaviour problems and depression in female dementia carers. However, SE was found to have a strong direct negative effect on depression. Cheng et al. (2012) examined the effects of SE beliefs in Chinese carers of individuals with dementia and found that carers with higher SE for controlling upsetting thoughts reported less burden and more gains when confronted with more behavioural problems. SE for obtaining respite had a direct negative effect on burden and depression, and SE for responding to disruptive behaviours had a direct positive effect on gains. Furthermore, Aneshensel et al. (1995) found psychosocial resources, including mastery did not mediate/moderate the impact of stressors on carer wellbeing.

Findings support assumptions of the SE Theory relating to the domain-dependency of SE beliefs and the proposition of Rabinowitz, Mausbach, Thompson, and Gallagher-Thompson (2007) that SE dimensions have distinct, independent effects on carer outcomes. It might be that different SE dimensions assume a function at different points in caring.

The inconsistency in findings regarding the role of SE in caring outcomes might stem from differences in methods of mediator/moderator analysis and/or variability in SE instruments, caring stressors (i.e. objective vs. subjective stressors) and outcome measures (e.g. burden, depression) across studies. In addition, studies were cross-

sectional, restricting inferences concerning causality, and there were cultural differences between samples. For example Romero-Moreno et al. (2011) involved Spanish carers, while Cheng et al. (2012) involved Hong-Kong Chinese carers. According to Aneshensel et al. (1995) it is important for studies to adopt a more conceptual orientation when exploring moderating/mediating effects in caring, with a more detailed/focused investigation of associations (e.g. specifying the stressor, resource, outcome, type of effect and time frame).

1.6 Predictors of family carer self-efficacy beliefs

Empirical research has demonstrated that carer SE beliefs are not determined by objective caring challenges, but instead vary with contextual variables such as carer characteristics and psychosocial factors.

1.6.1 Family carer characteristics and self-efficacy beliefs

Little empirical research has been directed towards investigating the effect of carer characteristics on SE beliefs. Semiatin and O'Connor (2012) explored the relationship between carer characteristics and SE in a US population of carers of individuals of dementia and found no correlation between carer SE and age or education. However, the sample was small, comprised predominantly highly educated, white females and a global SE score was used. Similarly, Aneshensel et al. (1995) found that background characteristics made only a small contribution to explaining the closely related concept of 'carer competence'. They also found that lack of competence was positively correlated with education, but not age, and that competence was negatively correlated with duration of caring.

Empirical evidence demonstrates that carer SE beliefs differ with ethnicity and carer care-recipient relationship type. For example, Depp et al. (2005) found ethnic differences in SE for responding to disruptive behaviours and controlling upsetting thoughts in Hispanic and white carers of individuals with dementia. However, the sample exclusively comprised only female carers and Hispanic carers were younger, less educated and had been caring for longer. Depp et al. suggested ethnic differences might be a result of sociocultural beliefs and traditions. In addition, Haley et al. (1996) found black carers of individuals with dementia reported higher SE for managing caring problems than white carers, although SE items had not been previously validated. In addition, Lawton, Rajagopal, Brody, and Kleban (1992) found black carers of individuals with dementia reported higher caring mastery than white carers, although caring mastery is more generic than SE. In addition, black carers were less likely to be spouses and were less educated, and there was a large disparity in the number of black and white carers. At present, there appears to be no existing research comparing SE in Asian, white and black carers.

Empirical research has demonstrated that son/daughter carers tend to report higher SE than spousal carers. For example, Depp et al. (2005) found that daughters reported higher SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts compared to spousal carers. However wives were older and less educated than daughters. Similarly, Skaff, Pearlin, and Mullan (1996) found that adult children reported higher mastery than spousal carers. However, whilst mastery is closely related to SE, it is a more generic concept. Conversely, Aneshensel et al. (1995) found no association between the related concept 'carer competence' and relationship type. Skaff et al. (1996) proposed that the multiple roles of adult-children (e.g.

employment, families) might enhance SE in other domains that transfer to the caring role.

1.6.2 Family carer self-efficacy and social support

Empirical research has demonstrated a positive association between carer SE judgments (particularly SE for obtaining respite) and social support. For instance, Steffen et al. (2002) found a strong positive correlation between social support and SE for obtaining respite in a US sample of family carers of individuals with dementia. However SE for controlling upsetting thoughts and SE for responding to disruptive behaviours were not associated with social support. Steffen et al. (2002) proposed that carers with lower SE for obtaining respite report less availability of help from family, as focus on negative aspects of the caring situation. Similarly, Depp et al. (2005) found that SE for obtaining respite from friends/family was directly related to a sense of others being available to assist with caring in female carers of persons with dementia. A positive correlation was also found between social support and SE for controlling upsetting thoughts in wives and white carers, but not daughters/Hispanic carers. In addition, Au et al. (2010) found significant positive correlations between social support and SE for obtaining respite and responding to disruptive behaviours but not SE for controlling upsetting thoughts in 134 informal carers of individuals with dementia.

Conversely, Wijngaart, Vernooij-Dassen, and Felling (2007) found SE was not correlated with instrumental support and only weakly related to informal instrumental and emotional support in 95 spousal carers of persons with dementia in the Netherlands. However, Wijngaart et al. evaluated general SE and included exclusively spousal carers. Similarly, Aneshensel et al. (1995) found mastery was not associated with instrumental social support (formal/informal), although was positively correlated with emotional

support. Discrepancies in findings between studies regarding the SE domains related to social support might be a result of the variability in support scales used, some examined perceived 'quality of support' while others examined 'quantity of support'. In addition, the social support instrument used by Steffen et al. and that used by Wijngaart et al. (2007) did not have established validity with older adults. Cultural differences such as diversity in cultural values, experiences and expectations might also explain the disparity in findings between studies, as Au et al. (2010) was conducted in Hong Kong, and Wijngaart et al. (2007) in the Netherlands.

1.6.3 Family carer self-efficacy and coping strategies

Coping refers to the "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands" (Lazarus & Folkman, 1984, p. 141). Coping skills are an important resource for carers, however few studies have examined the association between carer SE and coping strategies. Wijngaart et al. (2007) found that higher SE was correlated with greater use of problem solving coping strategies in a small sample of 95 spousal carers of individuals with dementia in the Netherlands, however a general SE scale was used. The association between carer SE and coping strategies is compatible with SE Theory (Bandura, 1997), which proposes that SE can influence cognitive and behavioural processes. More specifically it is suggested that carer SE can determine the initiation of coping strategies and persistence of coping behaviours. For example, low SE might be associated with more negative cognitions and maladaptive/dysfunctional coping behaviours. However, it is difficult to make any conclusions concerning the association between SE and coping strategies in caring due to the scarcity of empirical research. Further research is clearly needed.

1.6.4 Person with dementia characteristics and carer self-efficacy beliefs

Empirical research has demonstrated that person with dementia characteristics (e.g. behavioural problems, cognitive impairment, activities of daily living) are not related to carer SE judgments. For example, Semiatin and O'Connor (2012) found no association between SE and NPS of dementia frequency in a US sample of 57 predominantly white female carers of individuals with dementia, however the study used a global SE score. Similarly, Depp et al. (2005) found SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts in female carers were not correlated with behavioural problems of the person with dementia. Furthermore, Gilliam and Steffen (2006) found SE for responding to disruptive behaviours was not correlated with cognitive impairment, behaviour problems or activities of daily living in 74 female dementia carers. However it is important to note that Semiatin and O'Connor (2012) and Gilliam and Steffen (2006) used small samples and all studies involved predominantly white, female and well-educated carers.

1.6.5 Summary

Despite the heterogeneity in level of SE between carers, the identification of predictors of SE beliefs remains under-researched and the empirical research that does exist has notable limitations such as being cross-sectional, involving small samples and utilising a variety of SE instruments across studies. The identification of factors impacting on SE might facilitate improved responses to interventions aimed at improving SE and the identification of carers at greatest risk of having low SE.

1.7 Health-related quality of life (QoL)

Over the years, the assessment of caring outcomes has proved challenging. Conceptual models of carer coping typically describe outcomes in terms of broad, generic effects

(e.g. wellbeing) or more specific, uni-dimensional effects (e.g. depression, distress). It is important that outcome measures are capable of capturing the complexity and broad consequences of the caring experience. Health-related QoL is one multidimensional construct that is being increasingly used in caring literature as an outcome measure of the caring experience. Its widespread use stems from its ability to capture broad domains relating to health (Centers for Disease Control and Prevention [CDC], 2000).

1.7.1 What is health-related quality of life?

Health-related QoL is dynamic and subjective (Bakas et al., 2012). It refers to QoL in the context of one's health, and includes both positive and negative aspects. The most well-known conceptualisation of health-related QoL is that of the World Health Organisation (WHO, 1948), in which it is defined as "a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity." There are a number of different health-related QoL models used to guide research; the World Health Organisation (WHO, 1948) and Bowling (2005) report health-related QoL to be a multidimensional perspective of health comprising the domains of physical, mental and social functioning/wellbeing.

Health-related QoL is distinct from QoL, wellbeing and health status. Health-related QoL refers to QoL as influenced by health status, rather than social status. Nowadays, health-related QoL is typically favoured in research, as it comprises both health and non-health related domains, such as social wellbeing. Wellbeing typically refers to the positive evaluations of an individual's life (e.g. positive emotions), whereas health-related QoL encompasses both negative and positive aspects specifically affected by health (CDC, 2000). Health-related QoL measures are favoured over health status measures due to their broad evaluation of a number of domains (including emotional

and social wellbeing), instead of focusing on physical constraints/the impact of disease (Coen, O'Boyle, Swanwick, & Coakley, 1999).

1.7.2 Measuring health-related quality of life

Health-related QoL instruments can be classified as generic or disease-specific. Generic instruments allow comparisons across different populations, while disease-specific measures are designed for a particular disease. In caring literature, generic measures are most prevalent (e.g. SF-36, EQ5D), as allow comparisons across a wide range of caring populations.

One of the most popular generic measures is the 36-item Short-form Health Survey (SF-36). Initially developed in the US (Ware, Gandek, & IQOLA Project Group, 1994), a UK version of the scale has since been developed and validated (Jenkinson, Layte, Coulter, & Wright, 1996). The SF-36 comprises an eight-profile scale including physical functioning, role functioning, bodily pain, general health, vitality, social functioning, emotional and mental health. Its strengths include its validity, reliability and sensitivity (Jenkinson et al., 1996). However, the SF-36 is lengthy and places considerable burden on respondents. As a result, the 12-item Short-form Health Survey (SF-12) was developed, initially in the US (Ware, Kosinski, & Keller, 1996) and more recently in the UK (Jenkinson & Layte, 1997). The SF-12 evaluates the same eight domains as the SF-36 and also generates a physical and a mental component summary. It is brief, simple and demonstrates psychometric properties comparable to the SF-36 (Jenkinson & Layte, 1997; Jenkinson, Chandola, Coulter, & Bruster, 2001).

Other measures of health-related QoL include the EuroQol Group 5-Dimension questionnaire (EQ-5D; EuroQol group, 1990), which comprises a five-dimension health

state description, including mobility, self-care, usual activities, pain/discomfort and anxiety/depression. It is simple, valid and reliable. However, it is constrained by its dimensional structure, ceiling effects and lack of sensitivity.

1.7.3 Caring and health-related quality of life

Empirical literature has demonstrated an association between the caring experience and reduced carer health-related QoL. For example, Serrano-Aguilar, Lopez-Bastida, and Yanes-Lopez (2006) found Spanish carers of individuals with dementia reported lower scores than the general population for all dimensions of the EQ-5D, although differences between the personal care and mobility dimensions were modest. Similarly, Arango-Lasprilla et al. (2010) compared the QoL of carers of individuals with dementia and individuals from the general population in Colombia and found carers scored significantly lower on all SF-36 subscales.

Empirical research indicates that the caring role might exert a larger detrimental effect on carer mental health compared to physical health. For example, Markowitz, Gutterman, Sadik, and Papadopoulos (2003) found caring was associated with reduced SF-12 scores, particularly for mental functioning in carers of individuals with dementia compared to healthy controls. In addition, Gusi, Prieto, Madruga, Garcia, and Gonzalez-Guerrero (2009) found no significant differences in physical functioning, physical role limitations, bodily pain, or vitality between carers of individuals with dementia and age-matched non-carers in Spain, however carers had lower emotional, mental health, and social functioning. Argimon, Limon, Vila, and Cabezas (2005) assessed health-related QoL (using the SF36) in 181 Spanish family carers of individuals with dementia and 543 non-carers and found male carers had higher physical functioning but similar mental health and emotional scores compared to healthy controls, and female carers had

lower scores in all domains except physical function.

Reasons for discrepancies in findings between studies might include the impact of contextual variables (e.g. access to or use of resources) and differences in sample characteristics. For example, the Arango-Lasprilla et al. (2010) study primarily involved spousal carers, whereas Gusi et al. (2009) primarily studied adult child and exclusively female carers. It is possible that spousal carers are more vulnerable to health decline than son/daughter carers due to their age and loss of spousal support. Alternatively, the disparate findings could be explained by differences in dementia severity, with greater severity posing a greater burden. For example, Serrano-Aguilar et al. (2006) primarily involved carers of relatives with moderate to severe dementia. A final explanation for discrepancies in findings might be cultural differences such as diversity in cultural values, expectations and experiences between studies (e.g. Spanish vs. Colombian vs. American carers).

1.7.4 Predictors of family carer health related quality of life

The identification of factors that can influence carer health-related QoL is important to increase understanding of the caring process, improve the design of interventions and identify carers at risk of low health-related QoL.

1.7.4.1 Family carer characteristics and health-related quality of life

Empirical findings indicate gender differences in carer health-related QoL. For example, Markowitz et al. (2003) examined health-related QoL in 2477 carers of individuals with dementia and found male carers reported better mental health related QoL compared to females, although there were no differences in the physical health domain. Similarly, Gottlieb and Rooney (2004) found gender was a significant predictor of mental health in

Canadian carers of individuals with dementia, with males reporting better mental health. In addition, Argimon et al. (2005) found female Spanish carers of individuals with dementia had lower health-related QoL compared to healthy controls, however males reported similar health-related QoL compared to controls.

There are mixed findings concerning whether carer age is associated with health-related QoL. For example, Serrano-Aguilar et al. (2006) found health-related QoL was inversely correlated with age in Spanish carers of individuals with dementia. Similarly, Markowitz et al. (2003) found that older carers of individuals with dementia reported poorer SF-12 physical health. However, Valimaki, Vehvilainen-Julkunen, Pietila, and Pirttila (2009) found age was not significantly correlated with health-related QoL in spousal carers of individuals with mild dementia. Furthermore, Gottlieb and Rooney (2004) found age was not correlated with mental health related QoL in Canadian carers of individuals with dementia. Discrepancies in findings might be a result of differences in carer QoL outcome measures (SF-12/36 vs. EQ5D), sample characteristics, such as relationship-type and dementia severity, or cultural differences between studies (e.g. US vs. Spain).

Studies demonstrate educational differences in carer health-related QoL. In particular, Serrano-Aguilar et al. (2006) found health-related QoL was higher in more highly educated Spanish carers of individuals with dementia and proposed that carers with higher levels of educational achievement might have more realistic expectations, increased social and financial support and therefore cope better when faced with caring stressors. In addition, Markowitz et al. (2003) found that a higher level of education in carers of individuals with dementia was related to higher mental health but poorer physical health. The disparity in findings between studies might be due to cultural

differences or differences in outcome measures. For example, Serrano-Aguilar et al. (2006) used the EQ-5D to evaluate health-related QoL, whereas Markowitz et al. (2003) used the SF-12.

There is no empirical research that has investigated ethnic differences in carer health-related QoL, however ethnic differences have been demonstrated for other carer outcomes. For example, Connell and Gibson (1997) conducted a review of ethnic differences in dementia caring literature and found non-white carers reported lower stress, burden and depression. However, non-white carers were more likely to be adult children and it is not logical to group all non-white carers together, as the caring experience might be different for black and Asian carers.

1.7.4.2 Psychosocial resources and family carer health-related quality of life

Coping strategy and social support are two psychosocial resources that have been commonly posited by theoretical models to explain variability in carer outcomes. For example, the stress-coping paradigm (Lazarus & Folkman, 1984) and its adaptations (e.g. Haley et al., 1987) propose that the primary mediators between stressors and physical and mental health outcomes are coping strategy and social support. Haley et al. (1987) empirically tested the model in 54 carers of relatives with dementia and found coping responses and social support were significant predictors of outcomes. More specifically, better well-being was associated with more social support and higher use of problem-focused coping than avoidance or emotion-focused. Similarly, the longitudinal analysis conducted by Goode, Haley, Roth, and Ford (1998) in 122 carers of individuals with dementia found coping responses and social support were related to carer outcomes over time. In particular, use of approach coping (e.g. problem solving and support seeking strategies) and a higher level of social support were associated with

more positive health outcomes. In addition, Haley et al. (1996) found that the influence of caring stressors on carer well-being was mediated by social support and coping. In particular the use of avoidance (i.e. dysfunctional) coping strategies and lower social support were related to higher depression and lower satisfaction.

Little empirical research has explored the impact of coping strategies on carer health-related QoL as an outcome of the caring experience, despite the fact that literature has demonstrated the importance of coping strategies for other carer outcomes. For instance, Vedhara, Shanks, Wilcock, and Lightman (2001) found that dysfunctional, but not emotion or problem-focused coping strategies predicted higher anxiety and depression in a small sample of dementia carers. In addition, Cooper, Katona, Orrell, and Livingston (2006) found that the use of dysfunctional coping strategies predicted anxiety in carers of people with dementia. Similarly, Haley et al. (1996) found avoidance coping was positively associated with depression and negatively associated with satisfaction in family carers. The review by Kneebone and Martin (2003) in dementia carers found problem solving and acceptance coping to be beneficial for carers. Similarly, a review by Li, Cooper, and Livingston (2013) found higher use of dysfunctional and less use of acceptance-based coping styles were associated with carer depression and anxiety in dementia carers. However, it is difficult to interpret findings due to differences in the classification of coping strategies, variability in breadth of coping dimensions between studies, and lack of recognition of the social context (Gottlieb & Wolfe, 2002). Research is clearly needed to explore the association between carer coping behaviours and health-related QoL as an outcome.

Empirical research upholds the role of social support in carer health-related QoL. For example, Kuroda et al. (2007) found a significant positive correlation between

satisfaction with support and mental and physical health related QoL in carers of older adults. Similarly Markowitz et al. (2003) found a positive correlation between social support and carer mental health and physical well-being. Coen et al. (1999) found a positive correlation between informal social support and QoL in 50 carers of persons with dementia in Ireland. In addition, Balducci et al. (2008) found a moderate positive correlation between quality of support and health-related QoL (evaluated using the SF-36) in carers of older people across Europe. Marziali, McCleary, and Streiner (2010) found a significant correlation between perceived social support and mental health in carers of relatives with dementia, however social support was not found to be a significant predictor of mental and physical health. However, it is important to note that all studies were cross-sectional and primarily correlational.

1.7.4.3 Person with dementia characteristics and family carer health-related quality of life

Empirical evidence demonstrates the impact of person with dementia characteristics (e.g. behavioural problems, cognitive and functional impairments) on carer health-related QoL, however findings are constrained by the correlational nature of studies. For example, Machnicki et al. (2009) found significant negative correlations between health-related QoL and cognition and NPI scores in Argentinian carers of persons with dementia. In addition, Serrano-Aguilar et al. (2006) found health-related QoL was inversely correlated with person with dementia dependency. Gottlieb and Rooney (2004) found a significant negative correlation between mental health related QoL and memory and behavioural problems in carers of persons with dementia in Canada. Conversely, Kuroda et al. (2007) found that behaviour and functional problems were not significant predictors of physical or mental health related QoL in carers of impaired

older adults in Japan, however the study involved a small sample and failed to adjust for confounding variables.

1.7.5 Self-efficacy and health-related quality of life in caring

There is little extant empirical research that has investigated the relationship between carer SE judgments and health-related QoL, however the research that has been conducted indicates that higher levels of SE are typically associated with better health-related QoL. For example, Au et al. (2010) found that SE for responding to disruptive behaviours and SE for controlling upsetting thoughts were positively correlated with the physical health domain of QoL in 134 Hong Kong Chinese carers of individuals with dementia, however SE for obtaining respite was not. Marziali et al. (2010) found SE was a significant predictor of both the physical and mental domains of carer QoL in family carers of persons with dementia, however a generic SE scale was used rather than an instrument specific to caring tasks. In addition, Gottlieb and Rooney (2004) found relational and instrumental SE were significantly positively correlated with mental health related QoL in Canadian family carers of persons with dementia, although SE beliefs did not predict health-related QoL. However, the interpretation of findings is constrained by the wide variation in SE and health-related QoL instruments used across studies and the cross-sectional nature of data, therefore causality cannot be established. Further research is needed to better understand the role of SE beliefs relating to specific caring domains.

1.8 Conclusion

This background review provides an overview of the current evidence base concerning the application of SE Theory to the caring experience. Most notably, this review supports its application to the caring process and demonstrates the potential of SE

beliefs in explaining why some carers adapt better to the demands of caring than others. However, the review also highlights that further research is required to move beyond the simple, global evaluations of SE beliefs that have formerly been the focus of empirical research in the dementia caring field. Instead, it is important to evaluate the SE Theory applied to specific meaningful/salient caring domains and carer outcomes.

This review also assists with the identification of gaps in caring literature: it highlights the paucity of empirical research that has examined the relationship between SE beliefs and carer health-related QoL, particularly relating to moderation and mediation effects. The review also demonstrates a lack of empirical research that has investigated the determinants of carer SE beliefs, such as contextual factors and psychosocial resources (e.g. coping strategies and social support). It also highlights the scarcity of research that has examined the mediating effects of psychosocial resources on the caring process. Finally, it illustrates the need for future research to explore the association between carer SE beliefs relating to specific meaningful caring domains and the positive and negative dimensions of caring, to better understand the caring experience.

An improved understanding of the association between SE relating to specific caring domains, psychosocial resources, positive and negative impact related to the caring experience, and carer health-related QoL might have significant theoretical and clinical implications. Clinically, an augmented understanding could promote the provision of better support services, help to identify carers at risk of poorer outcomes and improve the design and assignment of effective interventions (e.g. serve as a useful pre-intervention screening tool), which in turn, might delay the institutionalisation of individuals with dementia. Theoretically, increased coherence of the caring process might inform conceptual models of carer coping and facilitate a better understanding of

the variability in carer ability to cope. This is valuable at a time when the projected number of families with dementia is expected to rise dramatically over the next few decades and given the profound cost of caring.

CHAPTER 2: A systematic review exploring the relationship between family carer self-efficacy and health-related quality of life

2.1 Background

This Chapter describes a systematic review conducted to explore the current evidence base concerning the influence of carer SE beliefs on positive and negative aspects of caring and carer health-related QoL. The findings of the review will be used to assist in shaping the thesis aims, objectives and hypotheses. The systematic review reported in this Chapter has been published (Crellin, Orrell, McDermott, & Charlesworth, 2014; see Appendix 7.3).

This review is important given the recent shift in caring literature away from the use of the term “coping efficacy” towards the use of the term “self-efficacy” (SE), as well as the shift from uni-dimensional outcome measures (e.g. depression) towards broader carer outcomes. For instance, in recent years, health-related QoL has gained increasing popularity as an outcome of the caring experience due to its broad, multidimensional nature (Coen et al., 1999). In addition, the SE Theory (Bandura, 1997) is being increasingly applied to help explain the variability in family carer ability to cope with stressors. This is not surprising given that SE has been demonstrated to vary with mood and experiences, and has been demonstrated to be modifiable through intervention, thus providing a powerful avenue to influence carer outcomes.

To date, reviews that have explored the caring experience have largely focused on burden, coping or physical health (Etters, Goodall, & Harrison, 2008; Gottlieb & Wolfe, 2002; Schulz et al., 1995; Torti & Cwyther, 2004; Vitaliano, Zhang, & Scanlan, 2003; Wolfs et al., 2011). There are no reviews that have investigated carer health-related

QoL as an outcome and there is limited literature concerning positive aspects of caring. This review explores the role of SE in family carer health-related QoL, adopting a Narrative Synthesis (NS) approach (Popay et al., 2006) to combine evidence from both qualitative and quantitative studies.

2.2 Aim

- To explore the association between SE and health-related QoL in family carers of people with dementia.

2.2.1 Objectives

- To explore the role of global and caring domain specific SE beliefs in relation to positive aspects of caring, as well as the mental and physical health domains of QoL.
- To develop a model of the role of SE beliefs in family carer health-related QoL in the context of existing theoretical models of caring.

2.3 Methods

An eligibility criteria was developed in order to inform the inclusion/exclusion of articles into the systematic review. Criteria were developed according to the review aims and by scoping existing literature to ensure the selection of articles was relevant to the review question. The eligibility criteria is outlined below:

- *Study design*: Epidemiological, cohort, longitudinal, cross-sectional, qualitative, case studies, and surveys.
- *Publication language*: Studies published in English only.
- *Publication year*: Studies published between 1980 and February 2012.

- *Types of participants:* Family carers supporting a relative with dementia.
- *The relationship:* Studies evaluating the relationship between SE and the physical and/or mental health domains of health related QoL, or positive aspects of caring related to QoL.
- In addition, quantitative studies required both a measure of SE, and a measure of health-related QoL or a measure of positive aspects of caring related to QoL.

2.3.1 Search methods

Once the eligibility criteria had been established, the search was performed in a number of electronic databases to identify all relevant published studies. The databases searched were Psyc Info, CINAHL EBSCO (Cumulative Index to Nursing and Allied Health), MEDLINE, EMBASE and Web of Science. These databases were chosen based on their compatibility with the review aims and eligibility criteria. Search terms (see Appendix 3.1 for the search strategy) included family caregiver, caregiver, carer, spouse, partner, care, caregiving, caregiv*, self-efficac*, mastery, competen*, dement*, Alzheimer's Disease, and memory problem*. Search terms were modified for each database to make sure all the relevant articles were captured. Grey literature including conference proceedings, research reports, unpublished manuscripts, and dissertations was searched using Google Scholar and Open Grey. A forward citation search was conducted using Web of Science. This involved searching for publications that had cited the articles that had met the review eligibility criteria. Reference searches were performed, which involved searching the reference lists of the included studies.

2.3.2 Data collection

The eligibility assessment was performed, in which one reviewer screened titles and abstracts of citations obtained from the search for eligibility, and irrelevant articles that did not meet the eligibility criteria were excluded. For those identified as relevant or ambiguous cases, in which it was not possible to determine eligibility by abstract alone, the full article was sought. The final eligibility evaluation was made utilising the full article, with those studies deemed eligible reviewed independently by a second reviewer. When disagreements arose between reviewers, discussions were held until a consensus reached. In cases in which it was necessary and feasible, additional information was obtained from the study authors to help resolve discrepancies.

Two reviewers independently extracted data from each included study using a data extraction form and the forms were crosschecked between reviewers. If any discrepancies were evident, the included article was revisited and discussions held until a consensus reached. For cases in which an agreement was not reached, a third author made the final decision. In instances of ambiguity in the data, the authors were contacted for further information. For each study included in the review, the information extracted is shown below:

- Participants' characteristics including sample size, type of dementia, stage/severity of dementia, relationship between carer and person with dementia, age, gender, ethnicity, duration of caring, and educational attainment.
- Study details, including country/setting and date of study.
- Study design.
- Method (including potential sources of bias/quality assessment).

- Outcome measures (including measures of SE, positive aspects of caring and health-related QoL).
- Results (the main findings).
- Key conclusions, including important comments and limitations.

2.3.3 Methodological quality assessment of studies

Quality assessment of the included studies was performed independently by two reviewers and subsequently discussed between the reviewers. If any disparities in scores were evident, a third author was consulted. Quality assessment forms an important part of the NS process in order to systematically appraise the methodological quality of studies and determine the robustness of the synthesis. It is important to rate the quality of evidence to enable the exclusion of any articles considered as poor quality.

The quality of the quantitative studies was evaluated by two reviewers using a modified version of the Downs and Black (1998) Quality Checklist (Appendix 3.3) recommended for systematic reviews in health care (Centre for Reviews & Dissemination [CRD], 2009). It was developed to evaluate methodological quality of both randomised controlled trials and non-randomised studies, and has been demonstrated to have adequate reliability (Downs & Black, 1998). This checklist evaluates the methodological strengths and weaknesses of studies, particularly the quality of reporting (i.e. whether the study makes an unbiased assessment of study findings), internal validity (i.e. confounding factors and bias) and external validity (i.e. the generalisability of findings).

Similar to Mani, Milosavljevic, and Sullivan (2010) and Munn, Sullivan, and Schneiders (2010) a modified version of the original checklist was used. The checklist originally comprised 27 items, however 11 items were removed, these being 4, 8, 13, 14, 15, 19, 21, 22, 23, 24, and 27, as these items were not considered applicable to the type of studies within this review. For example, items 14 and 15 related to intervention studies and these study designs were excluded from the review. In addition, three items were only completed for longitudinal designs, these being 9, 17 and 26 and were otherwise scored as 'not applicable'. Therefore the checklist was scored out of 17 for longitudinal studies and 14 for cross-sectional designs. Each item comprised three response options, these being 'yes' (1), 'no' (0) and 'unable to determine' (0), with items graded according to whether the article met the criteria. Item scores were summed to generate a total quality score. Studies achieving 75% or higher were considered high quality and those scoring 50-74% were rated as moderate. Studies scoring less than 50% were graded as low quality and excluded from the review.

The Critical Appraisal Skills Programme (CASP) qualitative research appraisal criteria (Public Health Resource Unit, 2006) were employed to assess the methodological quality of qualitative articles. This tool (Appendix 3.2) provided a structured method to evaluate rigor, research methods, credibility and relevance (CRD, 2009). It comprised 10 items, with the response options being 'yes' (1), 'no' (0) and 'unable to tell' (0). Item scores were summed to produce an overall quality score. Studies scoring less than six out of 10 were excluded from the review.

2.4 Narrative Synthesis (NS)

A narrative approach was used to synthesise the study findings, as guided by the protocol of Popay et al. (2006). This protocol outlines a range of tools and techniques to

for use in the NS process in order to analyse and interpret the study findings and ensure the synthesis is transparent. NS relies on the use of words or text and it was chosen for its ability to combine evidence from both qualitative and quantitative studies in attempt to generate novel insights. In contrast to meta-analysis, which involves a quantitative approach to evidence synthesis that simply pools numerical findings, NS is a textual approach where findings are integrated and interpreted, allowing the development of a more informed model of the caring experience. The NS comprised four stages performed non-sequentially (Figure 2.1), these being: 1) developing a theory; 2) developing a preliminary synthesis; 3) exploring relationships within and between studies; and 4) assessing the robustness of the synthesis.

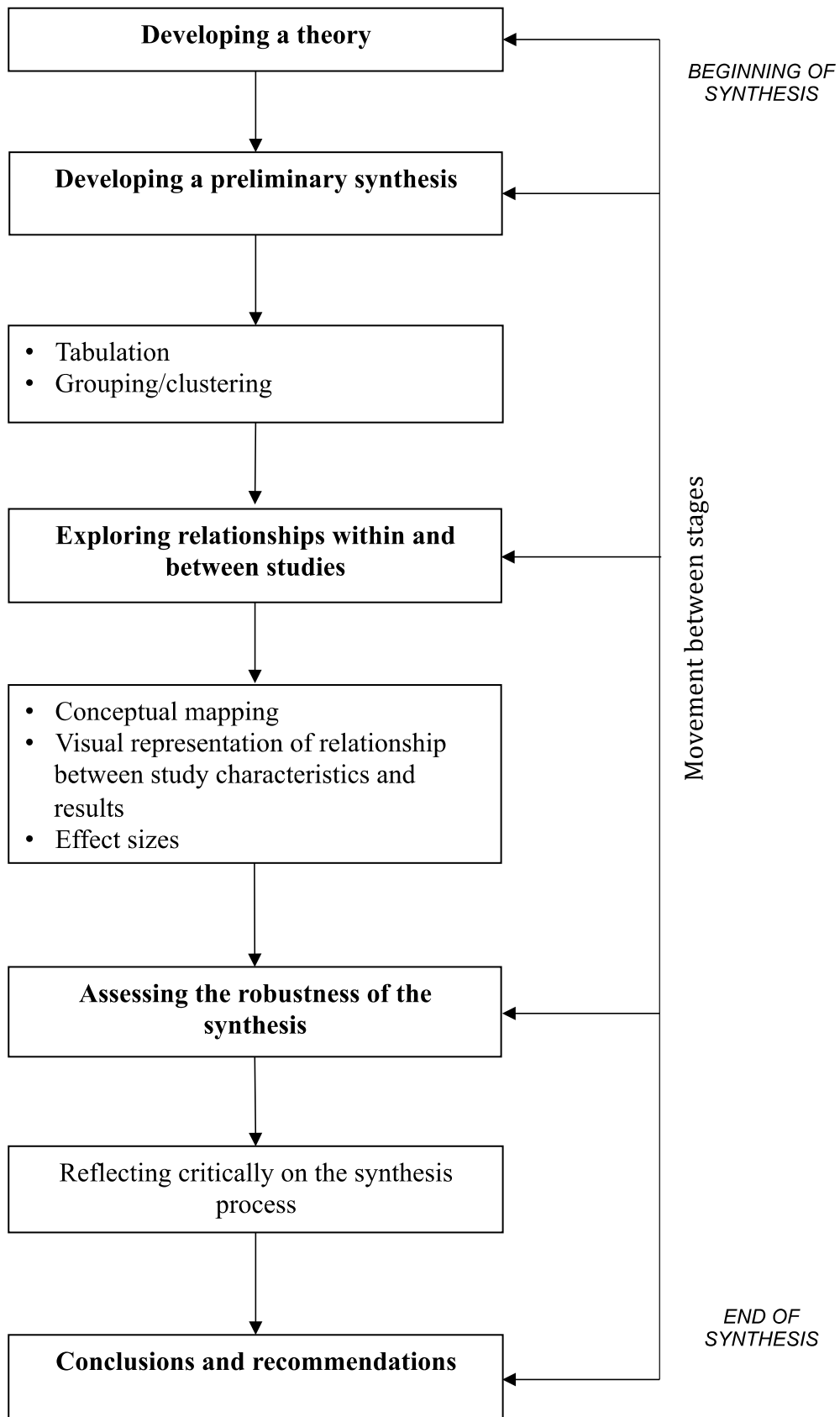


Figure 2.1 Flow diagram of Narrative Synthesis process

2.4.1 Stage 1: Development of the theory

This stage was performed early in the review process by scoping the literature to help inform the review question and inclusion criteria, and determine the existing state of theory.

2.4.2 Stage 2: Development of the preliminary synthesis

This stage involved the description and organisation of studies included in the review to assist in identifying patterns across studies. An initial description of the findings was generated for each article (Tables 2.1- 2.3). Tabulation was performed to assist with the comparison of data across the studies and to aid the identification of patterns relating to the size/direction of effects. Data extracted and presented in the tables included the author, year, methodological approach, sample, location, quality assessment, measures, statistical analysis and a summary of the main findings. Studies were clustered according to design (quantitative or qualitative) and outcome measure (evaluating health-related QoL or evaluating positive aspects of the caring experience).

2.4.3 Stage 3: Exploring the relationships within and between studies

This stage involved the exploration of relationships between study characteristics and findings and between the findings of different studies, as well as the identification of factors to explain heterogeneity in outcomes (e.g. variability in populations, study design, methodological differences and outcomes). To generate a visual representation of key findings in the form of diagrams and models, concept mapping of both qualitative and quantitative studies was performed. Concept mapping involved linking study findings, grouping empirically/conceptually similar findings and identifying relationships based on empirical evidence (Mulrow, Langhorne, & Grimshaw, 1997).

A summary model (presented in Figure 2.3) hypothesizing the role of SE beliefs relating to specific caring domains in family carer health-related QoL was developed by combining the conceptual maps describing the associations between SE, positive and negative dimensions of caring, and physical and mental health related QoL. To evaluate the direction and size of relationships in quantitative studies, standardised effect sizes were calculated when sufficient information was available to do so and an overall summary value was calculated (Field, 2005, p.192). To determine the magnitude of the effect size Cohen's (1988) guidance was used.

2.4.4 Stage 4: Evaluating the robustness of the synthesis

This stage involved examining the methodological quality of studies and the trustworthiness of the synthesis findings. To evaluate the review quality and determine the validity of the findings, a critical reflection of the review process was completed. This involved looking back retrospectively over the review process, including the methodology of the synthesis to identify any issues and/or limitations that might have constrained the validity of findings.

2.5 Results

2.5.1 Narrative synthesis element 1: Development of the theory

There were two different theoretical points to consider: 1) the role of SE beliefs in carer health related QoL and 2) the differential role of SE beliefs for positive and negative aspects of caring related to QoL.

SE Theory proposes that SE beliefs can determine cognitive, motivational, behavioural and affective processes (Bandura, 1997). When applied to caring, the SE Theory suggests that SE might determine carer outcomes by influencing how challenges are

perceived (i.e. appraisals), coping behaviours (i.e. motivation/behaviour) and emotional vulnerability (i.e. affective state). For example, family carers with higher SE might appraise stressors as challenges to be mastered, have more positive cognitions, reduced emotional distress and can maintain their own health and psychological wellbeing. While those with low SE might focus on failures, have negative cognitions, experience more negative emotions and have poorer physical and mental wellbeing (Steffen et al., 2002).

Conceptual models of caring such as that of Lawton et al. (1991), Kramer (1997), and Schulz and Salthouse (1999) recognise that there are both positive and negative emotional responses to caring (i.e. the mixed valence of caring). These models posit a two-factor view of psychological wellbeing, with independent negative and positive pathways, in which negative appraisals lead to negative outcomes, while positive appraisals lead to positive outcomes. These models are supported by empirical research, such as that of Narayan et al. (2001) and Roff et al. (2004), in which only weak correlations have been reported between measures of a positive and a negative subjective responses. It might be the case that SE impacts differently on positive and negative aspects of caring, with empirical research indicating that SE might attenuate negative aspects, but enhance positive aspects of caring. For example, Steffen et al. (2002) found that carers with lower SE are more focused on the negative aspects of caring, while Farran et al. (2004) found carers with higher SE are more likely to identify positive aspects in caring.

2.5.2 Narrative synthesis element 2: Preliminary synthesis

2.5.2.1 Study Characteristics

A flow diagram of the review search is reported in Figure 2.2. A total of 6194 references were identified, of which 5956 were excluded by screening the title and abstract. Of the remaining 227 references, full text was sought and assessed for eligibility, of which 34 articles met the inclusion criteria. Reasons for exclusion included that no health-related QoL instrument was used ($n = 57$), no SE instrument was used ($n = 25$), the article was a dissertation ($n = 8$), conference abstract/letter ($n = 5$), or review ($n=5$), the article was not specific to family carers of individuals with dementia ($n = 44$), there was no indication of the relationship between SE and health-related QoL ($n = 49$), or that it was not possible to obtain the article ($n = 11$). Of the 34 articles that met the inclusion criteria, 22 studies were retained (Tables 2.1-2.3).

The 22 studies included 17 quantitative, four qualitative, and one mixed method study. The articles were from the US ($n = 10$), Canada ($n = 4$), the Netherlands ($n = 3$), Hong Kong ($n = 2$), New Zealand ($n = 1$), Singapore ($n = 1$), and the UK ($n = 1$). Studies were primarily conducted within the last decade ($n = 18$). Quantitative studies were primarily cross-sectional ($n = 15$), with only two longitudinal designs. For the 17 quantitative studies and one mixed methods study, statistical methods included correlation analyses ($n = 11$), regression analyses ($n = 5$), and path modelling ($n = 2$). These studies were clustered according to the SE measure used; whether generic ($n = 6$), specific to caring ($n = 4$) or domain-specific ($n = 8$). For the qualitative studies and one mixed methods study, methodology included a case study ($n = 1$), semi-structured/open ended interviews ($n = 2$), a survey ($n = 1$) and a mixture of both interviews and focus groups ($n = 1$). Qualitative analytic methods included interpretive-descriptive, phenomenological approaches and grounded theory.

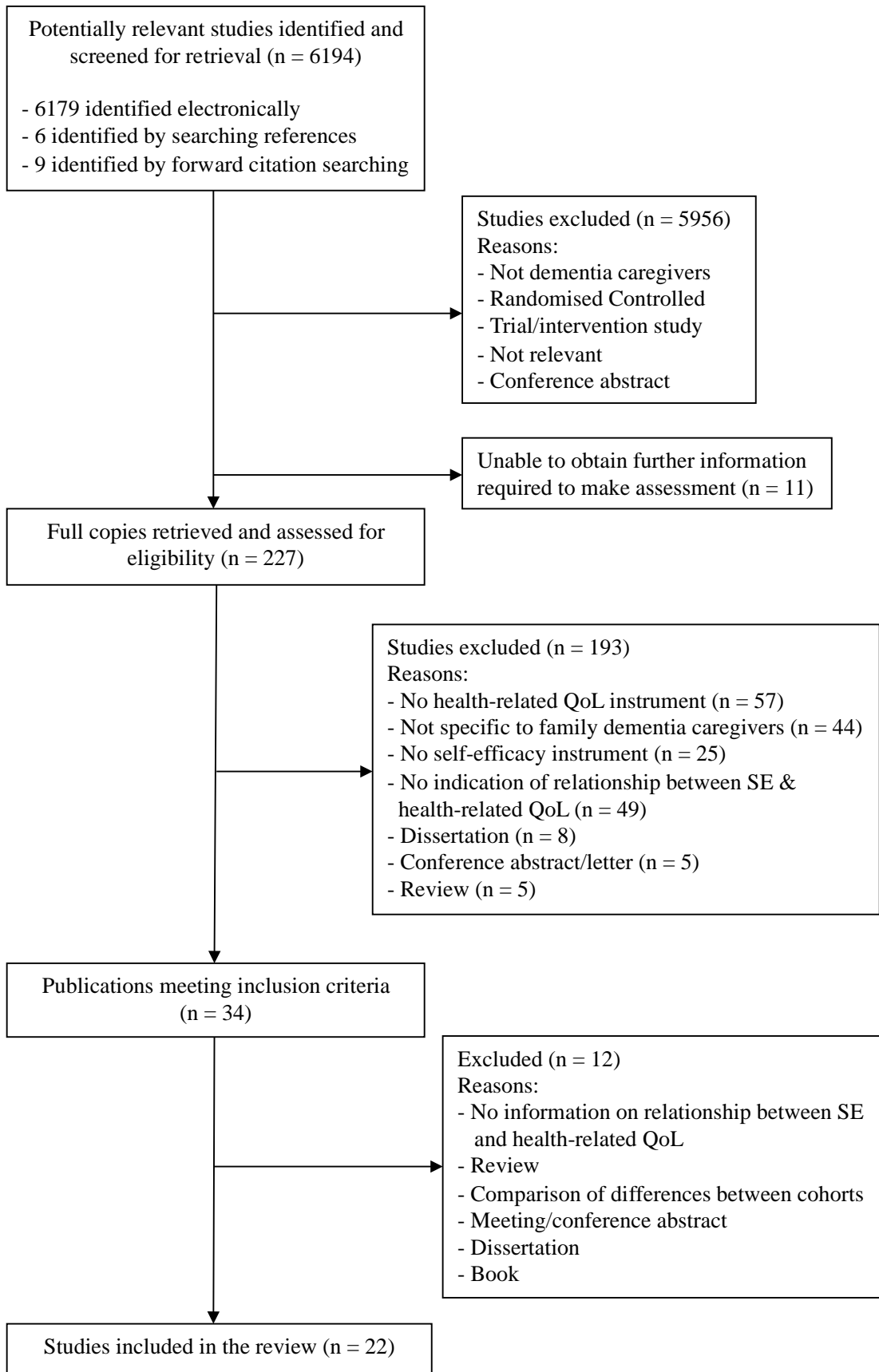


Figure 2.2 Flow diagram of review search

2.5.2.2 Participant characteristics

Participant characteristics are reported in Tables 2.1 to 2.3. Participants were recruited from a range of settings, including health professionals, social services, the media and primary healthcare. Of the included articles, sample sizes ranged from two to 447, with the total sample of family carers across the studies being 2929. Across the studies the mean carer age was 62 years. As expected, carers were primarily female (74%), and white (48%), Chinese (31%) or Latin American (8%). In terms of relationship type between carer and care-recipient across the included studies, there were fewer intergenerational (son/daughter) relationships (31%) than spousal/partner relationships (44%).

2.5.2.3 Quality Assessment

Quality assessment scores for each of the included studies are reported in Tables 2.1 to 2.3. Of the quantitative and mixed methods studies, 11 were graded as high quality and seven were graded as moderate quality, with an average quality rating of 77%. All four qualitative studies and the mixed methods study adequately met the CASP research appraisal criteria (Public Health Resource Unit, 2006), with scores ranging between six and eight out of a possible 10.

Table 2.1 Quantitative studies with health related QoL outcome measures

Author	Year/ Country	Sample	Design/ Analysis	SE measure		HrQoL measure	Quality Assessment	Effect Size (R)	Main findings
				Generic	Domain- specific				
Au et al.	2010 Hong Kong	134 carers 75% female Mean age = 54 yrs 25% spouse / partner 66% son/daughter	Cross- sectional Bivariate correlation Path analysis		RSSE	Chinese Version of the Medical Outcomes Study SF- 36 Health Survey	86% (12/14) High Quality	SE:DB & physical health (.25) SE:CT & physical health (.30)	PCS has a significant positive correlation with SE:DB ($r =$.25, $p < .01$), SE:CT ($r =$.30, $p < .01$) but not SE:OR. SE:DB & SE:CT are mediators of PCS.
Gottlieb & Rooney	2003 Canada	134 carers 73% female Mean age = 61 yrs 60% adult child 37% spouses	Longitudinal Correlation Hierarchical regression		RIS Eldercare SE Scale	SF-36 Affect Balance Scale.	78% (11/17) High Quality	Relational SE & generic HrQoL (.20) Self-soothing SE & generic HrQoL (.35)	Relational SE ($r = .20$, $p <$.05) & self-soothing SE ($r =$.35, $p < .001$) have significant positive associations with general health. Positive affect is positively correlated with relational SE ($r = .16$), instrumental SE ($r =$.16), & self-soothing SE ($r =$.28, $p < .05$)
Gottlieb & Rooney	2004 Canada	141 carers 74% female Mean age = 61 yrs 37% spouses 63% inter- generational	Cross- sectional Correlation Hierarchical regression		RIS Eldercare SE Scale	SF-36, Life Orientation Test, Affect Balance Scale.	71% (10/14) Moderate Quality	Instrumental SE & mental health (.31) Relational SE & mental health (.23)	Instrumental SE & relational SE have significant positive correlations with mental health ($r = .31$, $p < .001$; $r =$.23, $p < .01$), positive affect ($r =$.18, $p < .05$; $r = .17$, $p <$.05), & positive reframing ($r =$.22, $p < .01$; $r = .32$, $p < .001$)

Haley et al.	1987 US	54 carers 80% female Mean age = 56 yrs 55% adult child 28% spouse	Cross- sectional Pearson's correlation Multiple regression	Rating of SE for ADL, IADL & MPBC	Life satisfaction Index Form Z, Self-rated health (single item; poor- excellent)	86% (12/14) High Quality	SE MBPC & generic HrQoL (.11) SE ADL & generic HrQoL (.17) SE IADL & generic HrQoL (.17)	SE MBPC ($r = -.11, p = n.s.$), SE ADL ($r = -.17, p = n.s.$), SE IADL ($r = -.17, p = n.s.$) have negative associations with self-rated health problems, but do not achieve significance. SE MBPC ($r = -.19, p = n.s.$), SE ADL ($r = -.3, p = n.s.$), SE IADL ($r = -.31, p < .05$) have negative associations with satisfaction, but only SE IADL is significant.
Jansen et al.	2007 Netherl- ands	99 carers 71% female Mean age = 63 yrs 41% spouses 50% children	Cross- sectional Pearson's correlation	SCQ The Mastery Scale	SF-36 Self-rated health	86% (12/14) High Quality	SE & mental health domain (.28)	Moderate to strong positive association between carer competence subscales and mental QoL ($r = .24; r = .44; r = .16$). Satisfaction with person with dementia ($r = .16$) & with own performance ($r = .19$) has a small to moderate positive association with mastery.
Marziali et al.	2010 Canada	232 carers 75% female 56% spouses 36% children	Cross- sectional Pearson's correlation Regression	RSSE	HSQ12	57% (8/14) Moderate Quality	SE & physical health (.16) SE & mental health (.41)	SE has a significant correlation with physical health ($r = .16, p < .05$) and mental health ($r = .41, p < .001$). Carer physical health only predicted by SE ($t = 2.72, p < .01$).
Miller et al.	1995 US	215 carers 64% female Mean age =	Cross- sectional Correlation	Carer mastery (4-point	Self rated health – 4 items (poor	64% (9/14) Moderate Quality	Mastery & generic HrQoL (.15)	No association between mastery and carer health ($r = .15, p = n.s.$).

		75 yrs 100% spouse		likert scale)	– good)				
Montoro- Rodriguez & Gallagher- Thompson	2009 US	185 carers 100% female Mean age = 58 yrs	Cross- sectional Structural equation modelling		RSSE	Self-rated health (single item; poor- excellent)	86% (12/14) High Quality	Unable to calculate	Only SE:CT is positively associated with carer health (r = .18, $p < .05$).
Rabinowitz et al.	2009 US	256 carers 100% female Mean age = 57 yrs 61% spouse 39% non- spouse	Cross- sectional Bivariate correlation Multiple hierarchical regression		RSSE	Carer health (4 items of perceived physical health)	86% (12/14) High Quality	Unable to calculate	SE:DB & SE:CT are significant moderators of depression, which influences overall health. A significant interaction exists between memory and behaviour problems and SE:DB ($t = 1.98$, $p < 0.05$).
Riedijk et al.	2009 Nether- lands	46 carers 57% female Mean age = 61 yrs	Cross sectional Pearson's correlation Multiple regression Structural equation modelling		SCQ	SF-36	93% (13/14) High Quality	Unable to calculate	Sense of competence sacrifice subscale is associated with more psychological complaints ($r = .34$), reduced mental ($r = -.32$) & physical QoL ($r = .45$). Sense of competence sacrifice subscale is related with physical component of QoL (p = .001), mental component & psychological complaints ($p =$.03).

Wijngaart et al.	2007 Netherlands	95 carers 69% female, Mean age = 72 yrs	Cross-sectional Bivariate correlation Path analysis Regression	12-item Dutch Version of the General Self-Efficacy Scale	5 items of Dutch version of COOP / WONCA charts	86% (12/14) High Quality	SE & physical health domain (.13)	Positive association between SE & functional health status ($r = .13$, $p = n.s.$), but not significant.
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Note. Revised Scale for Caregiving Self-efficacy (RSSE); Sense of Competence Questionnaire (SCQ); 36 item Short-Form Health Survey (SF-36); Quality of Life (QoL); Self-efficacy for responding to disruptive behaviours (SE:DB); self-efficacy for controlling upsetting thoughts (SE:CT); self-efficacy for obtaining respite (SE:OR); activities of daily living (ADL); instrumental activities of daily living (IADL); memory and behaviour problems checklist (MBPC); Health Status Questionnaire (HSQ-12); Health related Quality of Life (HrQoL); Physical Component Summary (PCS); self-efficacy (SE); Relational, Instrumental and Self-care Eldercare self-efficacy scale (RIS Eldercare).

Table 2.2 Quantitative studies with positive outcome measures

Author	Year/ Country	Sample	Methodology/ Design	SE measure		Dependent variable	Quality Assessment	Main findings
				Generic	Domain specific			
Cheng et al.	2012 Hong Kong	99 carers 71% female Mean age = 59.9 yrs 35% spouse 64% son/daughter	Cross-sectional Multiple regression		RSSE	Positive Aspects of Caregiving Scale	86% (12/14) High Quality	SE:DB has a direct effect on positive gain ($\beta = 0.186, p < .05$). SE:CT moderates the relationship between BPSD and positive gain ($\beta = 0.192, p < .05$). The interaction effect of BPSD \times SE:CT contributes 3% of explained variance in positive gain. SE:OR is not associated with positive gain ($\beta = -0.021, p = n.s$).
Davis et al.	2006 US	49 carers 69% female Mean age not specified 92% spouses	Cross-sectional Pearson's correlation	GSE		FMTCS	64% (9/14) Moderate Quality	Finding meaning is positively associated with SE, but not significantly ($r = .23, p = .111; r = .06, p = n.s$). Higher SE is associated with lower depression ($r = -0.42, p = .003$).
Fitzpatrick & Vacha-Haase	2010 US	30 carers 70% female Mean age = 76.4 yrs 100% spouses	Cross-sectional Correlation	The SE scale		RS	57% (8/14) Moderate Quality	SE has a significant positive correlation with resilience ($r = .52, p < .05$)
Liew et al.	2010 Singapore	442 carers 71% female Mean age = 51.5 yrs 14% spouses 84% son/daughter	Cross-sectional Pearson's correlation Multiple regression	SSCQ		GAIN	86% (12/14) High Quality	Carer gain is positively correlated with sense of carer competence ($r = .24, p < .001$). Carer competence is not a significant predictor of gain ($p = n.s$).

Narayan et al.	2001 US	50 carers 74% female Mean age = 73 yrs 100% spouses	Cross-sectional Correlation	Caregiver Competence Scale	Positive Aspects of Caregiving Scale	71% (10/14) Moderate Quality	Positive aspects of caring exhibit a significant positive association with competence ($r = .46, p < .01$). No significant correlation exists between positive and negative subjective responses.
Quinn, Clare, & Woods	2012 UK	447 carers 67% female Mean age = 68 yrs 68.3% spouse/partner	Cross-sectional Pearson's correlation Multiple regression	Three-item Caregiving Competence Scale	12-item Meaning in Caregiving Scale	71% (10/14) Moderate Quality	Finding meaning significantly predicts competence ($\beta = 0.29, p < .001$). Competence has a significant positive association with finding meaning ($r = .46, p < .001$).
Roud et al.	2006 New Zealand	45 carers 60% females Mean age not specified 65% spouses 35% son/daughter	Longitudinal Pearson's correlation	Carer Competence	Positive scale of COPE- Index, Personal Gain	78% (11/17) High Quality	Carer competence has a positive association with positive aspects of caring, but it is not significant ($r = .16, p = n.s$).

Note. Revised Scale for Caregiving Self-efficacy (RSSE); General Self-efficacy scale (GSE); Short sense of competence questionnaire (SSCQ); Gains in Alzheimer's care Instrument (GAIN); Finding Meaning through Caregiving Scale (FMTCS); The Resiliency Scale (RS); self-efficacy for controlling upsetting thoughts (SE:CT); self-efficacy for responding to disruptive behaviours (SE:DB); behavioural and psychological symptoms of dementia (BPSD); self-efficacy for obtaining respite (SE:OR); Carers of Older People in Europe Index (COPE-Index).

Table 2.3 Qualitative studies

Author	Year/ Country	Sample	Methodology/ Design	Quality Assessment	Main findings
Narayan et al.	2001 US	50 carers 74% female Mean age = 73 yrs 100% spouses	Semi-structured interviews	CASP (2006) for qualitative research 7/10	Carers simultaneously experience caring as self-affirming, while also enduring losses and difficulties resulting from their caring role.
Peacock et al.	2010 Canada	39 carers 82% female Mean age not specified 56% spouse 33% adult-child	Interviews & focus groups Interpretive-descriptive	CASP (2006) for qualitative research 8/10	Five themes emerged, including feelings of competence in their role, which was derived from finding ways to cope with a challenging situation, such as disruptive behaviours and providing safe, competent care. This generated feelings of pride due to useful skill development, enhancing sense of meaning, and role satisfaction.
Sanders	2005 US	85 carers 69% female Mean age = 60 yrs 41% daughter/son 29% spouses	Open-ended questions (survey) Grounded theory	CASP (2006) for qualitative research 8/10	The majority (81%) of carers experienced feelings of gain, with spiritual growth, personal growth and feelings of mastery promoting these feelings. For most, the gains experienced related to mastery about themselves and their ability to perform a task they did not think they were capable of completing, while others came from the development of new skills that could be applied in other settings.
Simpson	2010 US	2 carers 100% female Mean age = 56 yrs 50% granddaughters 50% daughters	Case studies Interpretive phenomenological approach	CASP (2006) for qualitative research 8/10	The process of self-reconciliation between the different roles a carer may possess is important, with this being a form of mastery that aids finding meaning. A greater sense of mastery was evident in carers when they acknowledged themselves as a good carer and they gained satisfaction from this role identification.
Skaff & Pearlin	1992 US	Sample size not specified 100 % male Mean age = 62 yrs 100% spouse	Open-ended interviews	CASP (2006) for qualitative research 6/10	It was assumed that the personal resources, competence and mastery determine whether one will experience a loss of self due to the demands of a specific caring role and in time, this can lead to diminishment of global self-evaluations such as wellbeing.

Note. Critical Appraisal Skills Programme (CASP)

2.5.2.4 *Study measures*

SE and health-related QoL measures in the included articles are reported in Tables 2.1 to 2.3. There appear to be no existing reviews of measurement scales for SE or health-related QoL in caring literature. Of the studies included in this review, there were a number of different health-related QoL measures adopted. The most popular instrument was the 36-item Short Form Health Survey (n = 5). Other instrument included the Health Status Questionnaire (n = 1), the COOP/WONCA charts (n = 1) and single items evaluations of health-related QoL (n = 4). It is important to note the limitations of single item measures, in particular the validity and sensitivity of these items are questionable.

Global (general population), caring specific and caring domain/task specific measures of SE were identified in the review (reported in Table 2.4). Global (general population) measures included the General SE scale (n = 3) and the Sense of Competence Questionnaire (n = 3). Measures specific to caring (e.g. Carer Competence Scale) were used in three studies. The most popular measure of domain-specific SE was the RSSE (n = 5). However, it is important to note that a number of measures evaluated carer competence/mastery rather than SE. These articles were included in the review due to their conceptual overlap with global/generalised SE beliefs.

Table 2.4 Self-efficacy measurement scales

	Self-efficacy instruments	
	Global Measure	Domain-specific measure
Carer-specific	<ul style="list-style-type: none"> - Carer Competence Scale - 3-item Caregiving Competence Scale - 4-point scale of Carer Mastery 	<ul style="list-style-type: none"> - RSSE - RIS Eldercare - Rating for SE for ADL, IADL and MBPC
General population	<ul style="list-style-type: none"> - GSE - SCQ - SSCQ 	

Note. Revised Scale for Caregiving Self-efficacy (RSSE); Sense of Competence Questionnaire (SCQ); Short Sense of Competence Scale (SSCQ); General Self-efficacy scale (GSE); Relational, Instrumental and Self-care Eldercare self-efficacy scale (RIS Eldercare); self-efficacy for activities of daily living, instrumental activities of daily living, and memory and behaviour problems checklist (SE ADL, IADL & MBPC)

2.5.3 Narrative synthesis element 3: Exploring relationships within and between studies

2.5.3.1 Self-efficacy and health-related quality of life

The effect size (r) was calculated for eight out of the eleven quantitative studies comprising a measure of health-related QoL. Of these studies, four demonstrated a statistically significant association between SE and health-related QoL domains (Table 2.1), and four studies found a weak or no association. The mean overall effect size with generic health-related QoL was 0.21, which is indicative of a small association according to Cohen's (1988) guidance. The mean effect size for the mental health domain was 0.31 and the physical health domain was 0.21. However, effect sizes varied considerably, possibly due to the varied measurement scales and/or caring SE domains evaluated in the studies, or reflecting the complexity of caring and other factors involved. In addition, it was not possible to evaluate the effect size for SE judgments relating to specific caring tasks due to the small number of studies and heterogeneity in SE instruments used.

2.5.3.2 *Self-efficacy and positive aspects of caring*

Nine quantitative studies found that at a higher level of SE, there was a corresponding increase in positive aspects of caring, including finding meaning, satisfaction, resilience, positive gain, and positive affect, with a mean overall effect size of 0.26. However the strength of associations varied considerably, which might be a result of the variation in positive outcome measures or the absence of a clear conceptualisation of positive aspects. For example, while Cheng et al. (2012) used the Positive Aspects of Caregiving Scale to evaluate generic positive aspects of caring, Quinn et al. (2012) specifically examined finding meaning using the Finding Meaning in Caregiving Scale. In addition, there were cultural differences between studies, for instance Cheng et al. (2012) was conducted in Hong Kong, while Fitzpatrick and Vacha-Haase (2010) was conducted in the US. There were also differences in sample characteristics between studies; Narayan et al. (2001) involved spousal carers only, while Liew et al. (2010) primarily involved son/daughter carers.

Furthermore, three studies found a weak or no association between SE and positive aspects of caring (e.g. Davis et al., 2006; Haley et al., 1987; Roud et al., 2006). Reasons for the disparity in findings might be due to the small samples used or due to differences in measurement scales, for example, Roud et al. (2006) used a measure of competence rather than SE and Haley et al. (1987) used single items to evaluate SE and these had not been previously validated.

Several themes relating to the relationship between carer SE and positive aspects of caring emerged from the conceptual mapping:

- i. Peacock et al. (2010) and Sanders (2005) found SE was associated with carer ability to cope with challenging situations, such as disruptive behaviours, and

- provide safe care, as well as the ability to perform a task that they thought they were not capable of completing. In turn, Peacock et al. (2010) found that mastering the complexity of caring generated satisfaction, meaning and pride.
- ii. Narayan et al. (2001) and Sanders (2005) highlighted the relationship between higher carer SE and the development of new skills transferable to other contexts (e.g. personal growth). Peacock et al. (2010) found that these skills generate enrichment events such as pleasant activities/events that make a positive contribution to the caring experience and enhance sense of meaning, satisfaction, gain and wellbeing.
 - iii. A close association between carer role identity and SE beliefs was outlined. In particular, Simpson (2010) found that reconciliation of self-identity between different roles (e.g. parenting, employment) influenced carer SE. In addition, Skaff and Pearlin (1992) proposed that SE influences whether one will experience a loss of sense of self (identity) as a result of caring stressors, which in turn determines carer well-being. Consistent with this proposition, Quinn et al. (2012) suggested that sense of meaning and satisfaction determine self-evaluations such as wellbeing.

However, it is important to note that studies were primarily qualitative and conducted in the US/Canada, therefore findings might not be generalisable to other populations. In addition, the Simpson (2010) article involved a case study of only two carers and therefore findings might not be generalisable, as caring experiences are extremely heterogeneous. Furthermore, Skaff and Pearlin (1992) did not specify a sample size or methods of recruitment, therefore it is not possible to determine the validity of the findings.

The limited literature makes it difficult to determine the roles of SE beliefs relating to specific caring domains in positive outcomes. Cheng et al. (2012) found task-specific SE beliefs have distinct associations with positive aspects: SE for responding to disruptive behaviours had a direct effect on positive gain, whereas SE for controlling upsetting thoughts moderated the relationship between stressors and gain. However, the study comprised a small Hong Kong sample and thus findings might not be generalisable. In addition, Gottlieb and Rooney (2004) found instrumental, relational and self-soothing SE beliefs were related to positive affect, however the underlying mechanism was unclear and correlations were modest.

2.5.3.3 Self-efficacy and negative aspects of caring

Low SE was related to negative outcomes in caring, such as depression. SE for obtaining respite, responding to disruptive behaviours, controlling upsetting thoughts, self-soothing SE and instrumental SE were negatively associated with negative outcomes (e.g. Au et al., 2010; Gottlieb & Rooney, 2003, 2004). For example, Rabinowitz et al. (2009) found SE for responding to disruptive behaviours and for controlling upsetting thoughts exerted a direct effect on depression and SE for responding to disruptive behaviours moderated the relationship between stressors and negative outcomes. In addition, Gottlieb and Rooney (2004) found an inverse correlation between negative affect and instrumental SE. While Au et al. (2010) found that SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts were moderately negatively correlated with depression. However, it is important to note study limitations, such as studies being correlational and therefore causality cannot be established, and measurement scales of carer SE varying across studies. In addition, Gottlieb and Rooney (2004) examined the mental health component of carer QoL only.

The association between SE and negative outcomes might be driven by the protective role of SE, particularly for responding to disruptive behaviours and controlling upsetting thoughts (described in Figure 2.3). Specifically, Au et al. (2010), Haley et al. (1987) and Rabinowitz et al. (2009) propose that SE might promote emotional robustness, positive appraisals (and cognitive processes) and lead to reduced emotional vulnerability and negative states. These assumptions are consistent with SE Theory (Bandura, 1997) that SE can determine cognitive and affective processes. However, the role of instrumental SE and self-soothing SE in negative aspects is not clear, although self-soothing SE might improve emotional regulation.

2.5.3.4 Self-efficacy and physical health related quality of life

There is limited literature concerning the role of SE in carer physical health related QoL. However, Rabinowitz et al. (2009) proposed SE beliefs exert a protective influence on physical health related QoL, and Au et al. (2010) and Marziali et al. (2010) found that higher SE was associated with improved physical health related QoL. More specifically, Au et al. (2010) found SE for responding to disruptive behaviours and controlling upsetting thoughts demonstrated the strongest associations with better physical health. In addition, Au et al. (2010) found that SE for controlling upsetting thoughts functioned as a mediator in the relationship between depression and physical health, with greater ability to manage negative thoughts protecting against negative emotions, and in turn impacting on perceived physical health related QoL. However, it is important to note that Marziali et al. (2010) examined generic SE only and the Au et al. (2010) study was conducted in Hong Kong, therefore findings might not be applicable to other caring populations. Overall, there was limited evidence concerning the pathway, thus findings must be interpreted with caution.

2.6 Discussion

The use of the NS methodology to draw together findings from qualitative and quantitative research has led to the development of a model hypothesising the role of caring task/domain-specific SE beliefs in family carer health-related QoL (Figure 2.3). This model might contribute to a better understanding of the caring experience and the individual differences that allow some carers to demonstrate more adaptive coping responses. In addition, this hypothesised model provides an indication of the current state of evidence concerning the association between SE, positive and negative aspects of caring and carer health-related QoL, including identifying gaps in caring literature for future research to build on.

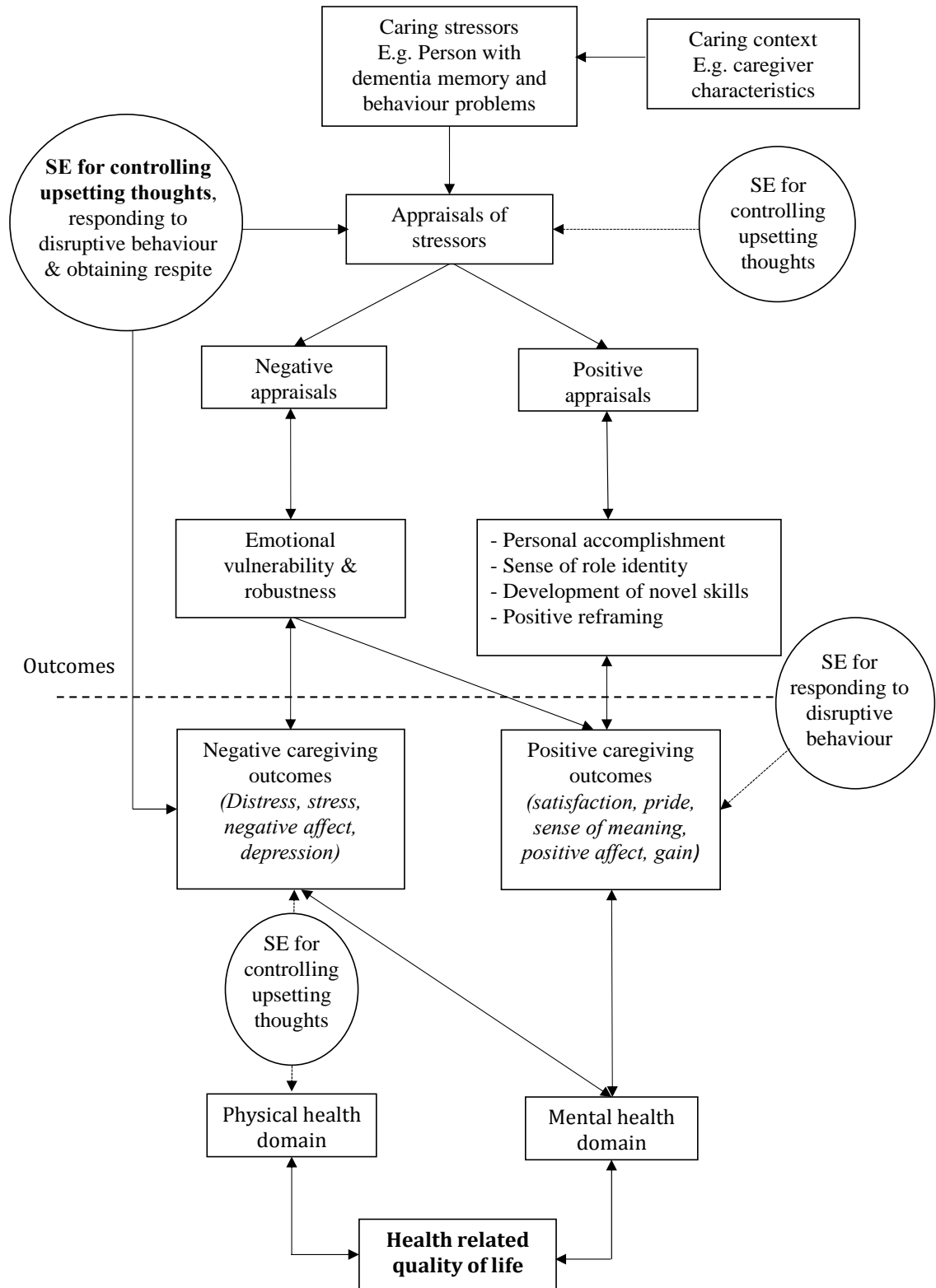


Figure 2.3 Hypothesised model of the relationship between carer SE beliefs and health-related QoL. Solid lines denote strong associations between variables and broken lines represent weaker associations.

2.6.1 The hypothesised model

The model (Figure 2.3) shows that carer appraisals of stressors are influenced by the stressor context such as carer characteristics. These appraisals lead to two distinct pathways: positive appraisals relate to emotional robustness, sense of accomplishment, development of skills, sense of identity and positive outcomes; and negative appraisals relate to emotional vulnerability and negative outcomes such as depression. The mental health domain of health-related QoL is associated with both the positive and negative pathways, however physical health is only influenced by negative aspects.

In the model, only SE for responding to disruptive behaviours is shown to directly influence positive outcomes, while SE for controlling upsetting thoughts is shown to mediate the association between negative outcomes and physical health, and also moderate the association between stressors and positive outcomes. SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts might moderate the association between stressors and negative outcomes, as well as directly influence negative outcomes. The model supports assumptions of the SE Theory concerning the multidimensionality of SE beliefs and propositions of Rabinowitz et al. (2007) that SE dimensions have distinct, independent effects on carer outcomes. It might be that distinct SE dimensions exert their influence at different points in the caring process. It is possible that SE for controlling upsetting thoughts and responding to disruptive behaviours might be the most valuable SE beliefs for family carers, which demonstrates some support for the proposals of Cheng et al. (2012). However, the apparent importance of these SE beliefs might be an artefact of the measurement scales in the included studies, as the RSSE is the most prevalent scale and therefore generates a larger evidence base concerning its SE subscales. The model supports the assumptions of a dual action of SE, that it can both attenuate negative aspects, and also enhance

positive aspects of caring. This is compatible with the empirical findings of Farran et al. (2004) and Steffen et al. (2002).

Although, a relationship was evident between SE and physical health related QoL, the mechanism was not transparent. However, research that did not meet the review eligibility criteria might assist in understanding the association. For example, Rabinowitz et al. (2007) examined the relationship between carer SE beliefs and cumulative health risk/health behaviours and found SE for obtaining respite and for controlling upsetting thoughts were related to reduced health risk. Rabinowitz et al. (2007) proposed that SE beliefs might mediate physical health by reducing the likelihood that carers engage in maladaptive coping or health risk behaviours (e.g. smoking, substance abuse) and result in more positive health decisions. Likewise, Harmell, Chattillion, Roepke, and Mausbach (2011) and Mausbach et al. (2007) proposed SE to have a positive influence on health beliefs, health behaviour and maintenance, with SE exerting a protective influence on health outcomes (e.g. immunity). However, this pathway has not been described in Figure 2.3, as further research is clearly needed.

In the hypothesised model, assumptions are made regarding the strength of associations between variables based on the quantity and quality of evidence. Solid lines denote strong associations between variables and broken lines represent weaker associations. Within the model, only SE judgments relating to specific caring tasks/domains are described. Global and caring SE beliefs were not reported due to their incompatibility with the assumptions of the SE Theory that SE beliefs are formulated from specific situations and vary with contextual factors (Bandura, 1997). It is important for caring

literature to continue the shift away from global SE beliefs towards SE beliefs related to specific caring domains.

2.6.2 Existing conceptual models of carer outcomes

The hypothesised model (Figure 2.3) can be discussed in the context of existing theory and conceptual models of caring. The model supports the application of SE Theory (Bandura, 1997) to caring: SE influences caring outcomes via cognitive and affective mechanisms leading to emotion regulation and behaviour modification. The hypothesised model offers support for the ‘mixed valence’ of caring (Lawton et al., 1991) and to an extent supports the two-factor view of carer appraisals, such as that proposed by the general health model (Schulz & Salthouse, 1999), the modified stress and coping model (Kramer, 1997), and the Appraisal model (Lawton et al., 1991). These models recognise the existence of two pathways; positive appraisals lead to positive outcomes and negative appraisals lead to negative outcomes. However, review findings do not support the independence of these pathways, instead indicating that the pathways may in fact be interrelated. These findings have theoretical implications in demonstrating that caring is more complex than current models (such as the two factor view) suggests and highlighting the need for models to recognise the complexity of interrelations between the positive and negative pathways. Further research is clearly needed to determine the strength and nature of association between positive and negative aspects of caring. For instance, it might be that carers are not on a fixed negative or positive pathway, but oscillate between the two pathways in a dynamic and fluctuating process that changes over time, as has been proposed in other dual process models such as Stroebe and Schut’s (2001) “dual process model of coping with bereavement”.

The role of SE has not been well defined in conceptual models of carer coping. Despite accumulating empirical evidence regarding the association between SE and carer outcomes, many conceptual models either do not outline the role of SE judgments (e.g. Lawton et al., 1991; Lazarus & Folkman, 1984) or describe only generic terms or concepts related to SE, such as mastery or competence. For example, the ‘modified stress process model’ of Pearlin et al. (1990) claimed global mastery and situational competence mediate the association between stressors and outcomes. Despite this, the explanatory model (Figure 2.3) does show some agreement with the modified stress-coping model proposed by Haley et al. (1987) that SE might influence the caring process through carer appraisals by mediating the association between caring stressors and outcomes. In addition, Haley et al. (1987) found that improved carer wellbeing was associated with more benign stressor appraisals and higher SE when empirically tested. Review findings not only stress the need for conceptual models to incorporate SE beliefs, but to consider it in its domain specific form, to better reflect SE Theory and recent empirical research. Thus, the hypothesised model might increase understanding of caring, health related outcomes, and guide the development of improved theoretical models.

2.6.3 Methodological challenges

The review highlights several methodological challenges in this area of research, in particular the conceptualisation and measurement of SE and health-related QoL. There have been several different conceptualisations of health-related QoL and models used to guide research. Despite similarities between these models, disagreement remains concerning the fundamental principles and terminology used, which has caused difficulties in developing a consistent evidence base to guide research (Bakas et al., 2012). This has also led to heterogeneity in measurement scales of health-related QoL

and the fundamental domains that these scales reflect. For instance, a number of scales evaluate only physical and mental health, neglecting all other health-related QoL domains. It is essential that caring literature reaches agreement on the conceptualisation of health-related QoL and its fundamental principles in order to generate consistency, allow comparisons to be made between research studies, and develop improved health-related QoL scales.

A further challenge stems from the shift in the conceptualisation of SE over time. Initially regarded as a global construct, SE is now considered to be domain/task-specific. This heterogeneity in the conceptualization and measurement of SE has generated inconsistencies in caring research and has led to difficulties with interpretation. In this review, this proved challenging when selecting studies with measurement scales that had proven validity and reliability for evaluating carer SE beliefs and in integrating findings from the included studies. The review highlights the need for research to further shift away from global SE or caring SE, and to consider SE related to specific caring challenges. To achieve this, is important to identify the caring domains/tasks that pose the greatest difficulty (e.g. problem behaviours) and to develop SE scales correspondingly. This is compatible with the propositions of Zeiss et al. (1999).

The review also highlights challenges with the conceptualisation and operationalisation of positive aspects of caring. Variability in measurement scales and definitions across studies facilitate inconsistencies in the evidence base, causing difficulties with the interpretation of findings and making it challenging to establish the precise role of SE beliefs in positive aspects of caring. These concerns are consistent with the critical reviews of Kramer (1997) and Tarlow et al. (2004) on positive aspects of caring that

identified issues such as varied conceptual definitions between studies and variation in measurement scales across studies, which in turn contribute to the contradictory findings and difficulties in making generalisations regarding positive aspects of caring. Future efforts must work towards addressing these limitations.

2.6.4 Narrative synthesis element 4: Assessing the robustness of the synthesis (critical reflection)

This review had fairly broad, but well-defined inclusion criteria. This was considered suitable due to the limited literature concerning SE in family carers to ensure included studies were sufficiently homogenous to be comparable, whilst ensuring the review was inclusive of all relevant studies. Quality assessment of included studies was conducted with well-established tools and all studies were found to have moderate methodological quality or above, which demonstrates the validity of the review findings. However, the Downs and Black (1998) Checklist was modified for the studies in this review and the validity and reliability of this modified version have not been established. In addition, the review might be constrained by the arbitrary levels assigned for the quality assessment tools as an indication of study quality.

NS was chosen for its ability to provide explanations and its flexibility to explore the role of SE combining a broad range of heterogeneous data (both qualitative and quantitative). This has the potential to generate novel insights, and enhance theory and understanding. However, NS is not without its limitations. The NS approach has been criticised for its lack of replicability, transparency and generalisability, as well as its subjectivity; it is extremely challenging to interpret results without being selective or placing greater emphasis on particular findings. In addition, the integration/synthesis of diverse quantitative and qualitative research can be challenging and time-consuming, as

data is not always complementary. Furthermore, the inclusion of qualitative research might reduce the review integrity, as qualitative studies are based on small samples and lack generalisability, and qualitative research is often criticised for its subjectivity, researcher bias and lack of replicability.

In addition, some authors criticise the NS approach for not being well developed, as it does not rely on rigorous techniques developed and tested over time. Furthermore, NS involves a wide range of tools and techniques to choose between that can create uncertainty, reduce validity and generate considerable heterogeneity. However the guidance of Popay et al. (2006) does create greater consensus on the elements used and the selection of tools (Figure 2.1) is typically determined by the nature of evidence being synthesised, which adds to the flexibility of the approach. It is also important to note the limitations of the NS tools, for example tabulation is often criticised for its loss of context/detail and over-simplistic reduction of data.

The review is constrained by the small number of studies and by the limitations inherent to cross-sectional designs. This makes it difficult to determine whether associations are reciprocal or an artefact of the cross-sectional research and makes it impossible to determine the temporal variability/stability of the role of SE over the caring process. The validity of the findings might be constrained by the inclusion of studies incorporating a non-validated single item measure of health-related QoL and due to the focus of this review on the physical and mental health domains, as these might act as a source of bias. The review may also be limited by the inclusion of studies focusing on mastery and competence. These were included due to the conceptual overlap of these constructs with global SE. The review might be constrained by the limited access to grey literature and the focus on English language papers; although the review search

was extensive, it is likely the review exhibits publication bias towards published studies, therefore there may be some important unpublished data that have not been considered.

The generalisability of the review findings might be constrained by the fact that studies were predominantly conducted in the US or Canada. The validity of the hypothesised model might be constrained by the lack of evidence concerning SE beliefs relating to specific caring domains. For instance, there was not enough evidence concerning self-soothing, instrumental or relational SE to describe these within the model, despite the fact that Gottlieb and Rooney (2004) found instrumental SE (i.e. ability to complete caring tasks) and relational SE (i.e. maintaining a cooperative relationship) were associated with positive caring outcomes, such as mental health in carers of persons with dementia.

The review is also constrained by the lack of evidence concerning coping, perceived social support, social networks and carer and person with dementia characteristics, which have in the past been found to influence carer outcomes. For example, Haley et al. (1987) tested a stress-process model in 54 dementia carers and found improved carer well-being was associated with more benign appraisals of primary stressors (higher SE), higher social support and coping responses characterised by more problem-focused coping than avoidance or emotion-focused coping. However, this research is dated and used a small sample of carers. Future empirical research should be directed towards exploring the relationship between psychosocial resources including SE, coping strategies, social support and carer health-related QoL.

2.6.5 Future Research

Methodological challenges contribute to the difficulty in drawing robust conclusions from the review. The explanatory model described is therefore tentative and there remains a need for a more comprehensive and empirically evidenced model of the role of domain-specific SE in carer health-related QoL. The hypothesised model can be implemented, however, to guide future research and identify gaps in caring literature.

The model highlights the need to explore the impact of contextual factors including carer characteristics and variables such as social support, social network and coping strategy on carer SE, and the association between SE and health-related QoL.

Consideration of these factors is important, as empirical evidence demonstrates that level of SE varies with contextual factors such as relationship-type and ethnicity (e.g. Depp et al., 2005; Gilliam & Steffen, 2006).

The model also highlights that attention must be directed towards SE measurement and the development of valid and reliable SE scales relevant to caring tasks that are the most challenging/prevalent (e.g. NPS of dementia). Review findings also highlight the need for longitudinal analyses and statistical methods to determine direction of causality. In addition, further research is needed to explore whether SE beliefs exert a mediating or moderating effect on the association between caring stressors and health-related QoL, particularly some form of mediation or moderation analysis (Baron & Kenny, 1986).

The review supports the domain specificity proposed by the SE Theory (Bandura, 1997), however it also highlights the need for further research towards generating a profile of SE beliefs specific to caring (e.g. whether some SE beliefs are more influential than others). In addition, further research is needed in attempt to determine

the pattern of association between positive and negative aspects in caring. Furthermore, although review findings support propositions of a dual action of carer SE beliefs in precipitating positive value, whilst buffering against negative value related to caring, future research should address the mechanism of dual action further.

2.6.6 Conclusion

This is the first review to explore family carer SE in relation to health-related QoL using an innovative NS approach. The explanatory model (Figure 2.3) is the first of its kind and provides a theoretical foundation to guide future research, including highlighting the need for the development of valid and reliable SE scales, indicating areas in which there is a paucity of empirical research and in the theoretical advancement of models of carer coping. The review highlights the current status of SE research applied to the caring context, including the methodological challenges concerning measurement and conceptualisation. Given that the SE Theory claims SE can be modified through intervention, SE likely offers a potential therapeutic avenue to influence carer outcomes. This review therefore might have significant clinical implications for designing effective carer interventions, particularly SE based interventions (e.g. SE training, coping effectiveness training and psychoeducational approaches) that might improve carer health-related QoL.

The findings of this systematic review will be used to assist in the formulation of the aims and hypotheses, and to inform the interpretation and discussion of findings within this thesis.

CHAPTER 3: The development and psychometric evaluation of the Carer Efficacy Scale for managing behavioural and psychological symptoms in dementia

This Chapter describes the development of a Carer Efficacy Scale for evaluating SE for managing NPS of dementia and has been published (Crellin, Charlesworth, & Orrell, 2014; see Appendix 7.2). This Chapter addresses one of the dominant methodological challenges highlighted by the systematic review (described in Chapter two) relating to the application of the SE Theory to the caring experience. In particular, the review emphasised the challenges with the interpretation of findings due to variability in the measurement and conceptualisation of carer SE beliefs over time. Review findings highlighted the need for the development of additional reliable and valid SE measurement scales relevant to caring tasks that prove most challenging/prevalent. These findings, taken together with empirical research that has demonstrated NPS of dementia to pose some of the greatest challenges facing family carers of individuals with dementia; the widely documented prevalence of NPS; and the poor outcomes associated with NPS for both carers and individuals with dementia provide a rationale for the development of the Carer Efficacy Scale.

3.1 Background

NPS are behavioural and affective symptoms such as apathy, depression, agitation, and aggression are common, presenting in 70%-90% of individuals with dementia (Lyketsos et al., 2000). NPS can present at any stage of dementia, although prevalence typically increases with disease progression. Early stages are characterised by symptoms such as depression, anxiety, apathy, and irritability, whilst later stages usually involve delusions, hallucinations, disinhibition, and wandering (Lopez et al., 2003).

Two-thirds of individuals with dementia reside in the community, therefore the majority of family carers are confronted with NPS of dementia (Ballard & Cream, 2005). NPS or BPSD are a primary cause of burden, distress, reduced mental health, and QoL for carers (Aneshensel, Pearlin, & Schuler, 1993; Ballard, Lowery, Powell, O'Brien, & James, 2000; Teri, Truax, Logsdon, & Pearson, 1989), as well as being predictive of institutionalization (Steele, Rovner, Chase, & Folstein, 1990). The difficulties posed by NPS are often considered the most challenging part of the caring experience, having a greater influence on psychological well-being than cognitive or functional impairments (Black & Almeida, 2004). Valid and reliable assessment of NPS of dementia is therefore crucial. Existing measures of NPS of dementia include the Revised Memory and Behaviour Problem Checklist (Teri et al., 1992) and the Behavioural Pathology in Alzheimer's Disease Rating Scale (Reisberg et al., 1987). However, the Neuropsychiatric Inventory (NPI; Cummings et al., 1994) is widely acknowledged as the gold-standard measure of NPS in dementia research.

Several authors (e.g. Steffen et al., 2002) have applied the SE Theory to explain the experiences of carers of individuals with dementia and the variability in their capacity to cope with difficulties such as NPS of dementia. SE is a potentially therapeutically modifiable construct that has implications for family carer QoL, mental and physical health (Gignac & Gottlieb, 1996). Bandura (1977) claimed interventions must both facilitate skill development and augment SE/confidence to use the newly acquired skills.

Carer SE varies with carer characteristics and psychosocial factors. For example, Depp et al. (2005) found that adult child carers report higher SE than spouses, which might be related to the multiple roles occupied by adult-children. Greater dementia severity is associated with increased dependency, functional impairment, NPS severity and

frequency, and thus higher levels of carer distress (Baumgarten, 1989). Therefore, more severe dementia and more frequent and severe NPS are likely to be associated with reduced carer SE for managing such behaviours. Negative psychological outcomes such as depression are associated with reduced SE; low SE is thought to be associated with emotional vulnerability and negative cognitions (Gignac & Gottlieb, 1996).

Today, measures of SE are typically partitioned into subscales corresponding to the most challenging caring tasks. The RSSE (Steffen et al., 2002) has proved to be a popular instrument of carer SE in recent years. Domain-specific measures of SE have greater predictive ability than generic measures and have greater capacity to facilitate more informed theoretical models of carer coping (Bandura, 2006).

The Carer Efficacy Scale is the first instrument to evaluate a specific set of self-beliefs relating to managing NPS of dementia; at present there is no measure of carer SE for the management of NPS. This scale might have valuable clinical implications in aiding the identification of carer strengths and vulnerabilities in perceived capabilities for responding to NPS, assisting clinicians in tailoring interventions accordingly, and in evaluating the effectiveness of such interventions.

3.2 Aim

To develop and evaluate the psychometric properties of a scale measuring carer SE for managing NPS of dementia.

3.2.1 Objectives

- To evaluate the internal consistency of the Carer Efficacy Scale by the

calculation of Cronbach's alpha coefficient.

- To determine the concurrent validity of the Carer Efficacy Scale by the evaluation of its correlations with the RSSE subscales (the existing gold standard measure).
- To determine the structural/construct validity of the Carer Efficacy Scale by the evaluation of its factor structure using an explanatory factor analysis, and evaluation of its correlations with dimensions of the NPI and negative carer outcomes.
- To determine the predictive/criterion validity of the Carer Efficacy Scale by evaluating how scores vary with carer characteristics and dementia severity.

3.3 Design and participants

A psychometric evaluation of a scale developed to measure carer SE for managing NPS of dementia was performed. The sample comprised 245 family carers and their relatives with dementia. This was only a sub-sample of the total 289 carers that took part in the SHIELD Carer Supporter Programme (data collection was not complete at the time that this analysis was performed). Details concerning the recruitment of participants, screening procedures and eligibility criteria are provided in the Methods section (see Chapter four).

3.4 Methods

3.4.1 Data collection/procedures

The data collection, interview and consent procedures, and the instruments used are as discussed in the methods section (see Chapter four).

3.4.2 Development of the Carer Efficacy Scale

The Carer Efficacy Scale was developed by the addition of a single 4-response item to each domain of the NPI (see Appendix 6.8 for the full scale). The Carer Efficacy Scale evaluates carer confidence in dealing with each behavioural disturbance and therefore draws on actual behaviours. For example, “How confident are you in dealing with the aggressive/agitated behaviour?” Responses range from 4 (not at all confident), 3 (fairly confident), 2 (confident), to 1 (very confident). If carers reported the presence of a symptom, the frequency, severity and carer distress were recorded as part of the NPI. Following this, carers were asked to report the level of SE in dealing with the particular NPS.

The 4-point scale and responses were chosen for their simplicity and compatibility with the likert-type responses of the NPI. The efficacy item is reverse scored, with a high score indicative of a greater lack of SE (low SE) and a low score indicative of a lower lack of SE (high SE) to respond to NPS. Reverse scoring was chosen to remain compatible with the NPI Carer Distress Scale, with a higher score indicative of greater distress. The Carer Efficacy Scale total is the sum of the efficacy scores for each NPS, with a range between 12 and 48.

The NPI was chosen due to its prevalence in dementia research, its proven reliability and validity, and its ability to capture information relating to behaviour frequency, severity, and associated carer distress. This made it possible to evaluate carer SE in relation to varying task demands. In developing a valid and reliable measure of SE there were important methodological issues to consider (Bandura, 2006). It was important that items related to ‘can do’, as opposed to ‘will do’, as SE involves perceived capability, and the term ‘confidence’ was used as opposed to ‘self-efficacy’ to ensure

that carers understood what was being asked. The Carer Efficacy Scale should be administered in conjunction with the NPI to allow SE to be considered in relation to NPS severity and frequency.

3.4.3 Psychometric evaluation of the Carer Efficacy Scale

The psychometric properties of the Carer Efficacy Scale were evaluated by examining its internal consistency, concurrent, construct and criterion validity, as well as conducting a Principal Component Analysis.

3.4.3.1 Internal consistency

The internal consistency of the Carer Efficacy Scale was evaluated by calculation of Cronbach's alpha coefficient (Cronbach, Gleser, Nanda, & Rajaratnam, 1972). Internal consistency is the extent to which items evaluate a common characteristic; coefficient values range between 0 and 1, with greater values indicative of greater reliability. Values of 0.80 are typically accepted as indicative of good internal consistency (Prince, 1998).

3.4.3.2 Factor Analysis

An exploratory Principal Component Analysis was performed to investigate the factor structure and construct validity of the Carer Efficacy Scale. SE is not a global trait, but a differentiated set of beliefs related to distinct domains of functioning (Bandura, 2006). Although SE Theory also suggests that if tasks involve similar skills, it is possible for SE to transfer across these domains. It was therefore expected that the Principal Component Analysis would reveal SE for managing NPS of dementia to be a multifactor construct, as some NPS require distinct skills, whilst those involving similar skills would demonstrate a similar level of SE. For example, reassurance might be an

important skill for carers to possess when dealing with behaviours such as anxiety or agitation, however it would be of little use for behaviours such as disinhibition or euphoria.

Suitability for the Principal Component Analysis was evaluated through inspection of Bartlett's test of sphericity, and the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy (Pallant, 2001), inter-item correlations and normality distributions. A Direct Oblimin Oblique rotation was performed to aid interpretation; this maximised the loading of items on dominating factors, whilst keeping the number of factors fixed (Kim & Mueller, 1978; Kline, 1994). Eigenvalues and variances for each of the factors were calculated and the number of factors extracted was determined by examining the scree plot for a change in curve direction (Catell's scree test; Catell, 1966) and Kaiser's criterion (eigenvalues that exceeded one were retained). An exploratory approach towards factor extraction was adopted according to the recommendation of Tabachnick and Fidell (1996); the number of factors to be extracted was restrained to three to investigate whether the data would support such dimensions.

3.4.3.3 Concurrent validity

Concurrent validity is the degree to which an instrument correlates with other 'gold standard' measures of the same construct. For this purpose, performance on the Carer Efficacy Scale was compared with the RSSE subscales (Steffen et al., 2002; as detailed in the methods section in Chapter four). It was expected that carer SE would be modestly associated with two subscales of the RSSE, these being those evaluating SE for Responding to Disruptive Behaviours and SE for Controlling Upsetting Thoughts, as it is anticipated that there is some overlap in carer skills within these caring domains. However, it is important to note that while the Carer Efficacy Scale is specifically

related to carer confidence in dealing with a range of NPS of dementia, the SE for Responding to Disruptive Behaviours subscale of the RSSE is focused more towards dealing with memory related problems.

3.4.3.4 Construct validity

Construct validity refers to whether an instrument measures the intended theorised construct. To evaluate convergent validity (whether a correlation exists where one would expect to find one), the relationship between the Carer Efficacy Scale and other standardised psychosocial factors, including negative carer outcomes such as depression, anxiety, negative affect, negative impact, distress, and dimensions of the NPI, such as NPS severity and frequency, were examined. The decision to investigate the relationship between SE beliefs and negative outcomes was driven by the large evidence base in support of the association. It was expected that a lack of carer SE would be associated with negative outcomes, higher distress and increased NPS severity and frequency. Measures included the Negative Affect Scale of the PANAS (Watson, Clark, & Tellegen, 1988), the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), and the Negative Impact Scale of the Carer of Older People in Europe Index (COPE-Index; McKee et al., 2003). Further details of the measures are reported in the methods section (Chapter four).

3.4.3.5 Criterion validity

The extent to which level of carer SE varied with level of carer depression and relationship-type between the carer and person with dementia were examined. Based on past empirical research and the SE Theory, it was expected that a lack of carer SE would be associated with greater dementia severity, the presence of carer depression and being a spousal carer.

In addition, the upper and lower quartiles of the Carer Efficacy Scale were calculated. Those carers in the highest quartile for SE scores were compared to those in the lowest quartile to determine if these groups differed in variables, such as dementia severity, depression, anxiety, negative affect and relationship-type. Based on existing theoretical and empirical evidence, it was expected that those with low SE would have lower psychological wellbeing, be caring for an individual with greater dementia severity and have a spousal relationship with the care-recipient.

3.4.4 Data Analysis

The Statistical Package for the Social Sciences (SPSS) Version 22 software (SPSS, 2013) was used to carry out the analyses. The data were screened manually for any inconsistencies or erroneous data entries.

3.4.1.1 Missing data

Missing data, including both missing items (by variable) and missing measures (by case) were explored and a missing value analysis performed to determine if data were missing at random or whether there were systematic differences. Overall, there were very little missing data by variables and cases. The missing value analysis found data were missing completely at random [$\chi^2(1350, N = 245) = 346.35, p = 1.00$].

Subsequently, expectation maximisation was used to impute missing values within participant measures at a 20% missing level. For example, for a five-item score, if one item was missing, it was imputed from the others items.

There was little variation in variable completion; the minimum number of responses on any given variable was 222 for the CDR and 228 for the RSSE subscale of SE for Responding to Disruptive Behaviours. However for all other variables the number of

complete responses varied between 240 and 245. Most variables had less than 5% of cases missing, with those above this being the RSSE subscale (7%) and the CDR (9%). The high number of cases missing for the RSSE subscale SE for Responding to Disruptive Behaviours was due to the large number of 'not applicable' responses. This might be a result of the sample being predominantly comprised of carers of individuals with mild dementia, as the RSSE is designed for carers of individuals with moderate to severe dementia. The higher number of missing cases for the CDR is likely due to researchers not completing the scale in instances when the person with dementia was not able to complete the research assessment.

3.4.1.2 Data distribution

Data distribution was evaluated by visual inspection of histograms (Field, 2009; Tabachnick & Fidell, 1996, p.73). The majority of variables were normally distributed, with the exception of the NPI total and distress score and also the Negative Affect subscale of the PANAS, which demonstrated positive skew. In addition, the RSSE subscales for Responding to Disruptive Behaviours and Controlling Upsetting Thoughts demonstrated a marginal negative skew, while SE for managing NPS of dementia demonstrated a slight positive skew, and the subscale of SE for Obtaining Respite demonstrated a slightly flat/kurtotic distribution. Further inspection of the skewness and kurtosis values revealed levels of skewness and kurtosis indicated no significant deviation from normality. In addition, with large sample sizes, the normality of the distribution is less of a concern and parametric tests are typically considered appropriate (Field, 2009). It was therefore decided not to transform data and to use parametric tests.

3.4.1.3 Psychometric evaluation

Pearson's correlation coefficient values were calculated to evaluate construct and concurrent validity. When interpreting effect size and determining the clinical significance of Pearson's correlation coefficient, Cohen's (1988) guidelines were used (described in the Methods section in Chapter four). One-way ANOVA and independent samples t-test were used to evaluate criterion validity. Independent samples t-tests and Pearson's Chi-square (χ^2) were used to compare the highest and lowest quartiles of the Carer Efficacy Scale (carers with low vs. high SE).

3.5 Results

3.5.1 Family carer characteristics and clinical variables

Table 3.1 reports family carer demographics. The sample comprised 245 family carers and their relative with dementia. As expected, the majority of family carers were female (71%), white British (92%) and married or living with a partner (84%). Almost two thirds were spousal carers (62%), while 27% of carers were sons/daughters caring for a parent. The mean age of carers was 66 years ($SD = 13.06$). Less than a third of family carers had completed further education beyond school level (28%).

Table 3.1 Family carer descriptive characteristics ($n = 245$)

	Total
Gender n (%)	
Female	173 (70.6)
Carer age M (SD) Range ($n = 244$)	66.4 (13.1) 18-91
Marital status n (%)	
Married/co-habiting/civil partner	206 (84.1)
Separated/divorced/widowed	15 (6.1)
Single/other	24 (9.8)
Relationship type n (%)	
Spouse/partner	152 (62.1)
Adult child	70 (28.6)
Other family/other relationship	23 (9.3)
Ethnicity n (%)	
White (British/Irish/Other)	226 (92.2)
Black (Caribbean/African/Other)	8 (3.2)
Asian (Indian/Pakistani/Other)	10 (4.1)
Level of education n (%)	
School educated only	177 (72.3)
Further education	68 (27.8)
Living situation ($n = 244$)	
Cohabiting with person with dementia n (%)	195 (79.9)

Note. The n for each measure was 245 unless stated in the table

Table 3.2 reports family carer clinical variables. Of the RSSE subscales, carers reported a similar level of SE for Responding to Disruptive Behaviours and Controlling Upsetting Thoughts, however much lower SE for Obtaining Respite. The NPI Distress Scale and Carer Efficacy Scale were used to evaluate carer distress associated with NPS and SE for managing NPS respectively, with the variability of these scores proving adequate. The subscales of the HADS, PANAS and COPE-Index used to evaluate negative outcomes demonstrated that carers reported experiencing the presence of some negative experiences/emotions. However, the extent of depression and anxiety reported by carers was low, with the mean value falling into the category of “non-caseness”. This

indicates that carers were typically not very anxious or depressed.

Table 3.2 Family carer clinical variables

Outcome measure		<i>M (Se)</i>	<i>Mdn</i>	<i>SD</i>	Range
NPI	Distress score (<i>n</i> = 242)	12.89 (0.62)	12.00	9.64	0-51
NPI	SE for managing NPS score (<i>n</i> = 242)	13.68 (0.56)	12.00	8.76	0-35
RSSE	Obtaining Respite score (<i>n</i> = 240)	54.90 (1.88)	56.33	29.15	0-100
	Responding to Disruptive Behaviours score (<i>n</i> = 228)	69.32 (1.37)	70.00	20.63	6-100
	Controlling Upsetting Thoughts score (<i>n</i> = 243)	70.48 (1.35)	76.00	20.98	4-100
HADS	Depression (<i>n</i> = 244)	5.74 (0.27)	5.00	4.28	0-21
	Anxiety (<i>n</i> = 244)	6.61 (0.28)	6.00	4.44	0-21
PANAS	Negative affect scale (<i>n</i> = 245)	19.24 (0.48)	18.00	7.50	10-45
COPE Index	Negative impact (<i>n</i> = 244)	11.82 (0.24)	11.00	3.76	6-24

3.5.2 Person with dementia characteristics

Table 3.3 reports the person with dementia demographics. Individuals with dementia had a mean age of 80 years and just over half were female (53%). The majority of individuals with dementia were married or living with a partner (68%) and almost all were white British (93%), while only 13% had achieved a level of education beyond school. Almost two-thirds had mild dementia (63%), 28% had moderate dementia and only 10% had severe dementia.

Table 3.3 Person with dementia characteristics

	Total
Gender (<i>n</i> = 243)	
Female <i>n</i> (%)	130 (53.5)
Age (Years) <i>M</i> (<i>SD</i>) Range (<i>n</i> = 239)	80.21 (8.0) 54-102
Marital status (<i>n</i> = 241) <i>n</i> (%)	
Married/co-habiting/civil partner	164 (68.1)
Separated/divorced/widowed	72 (29.9)
Single/other	5 (2.1)
Ethnicity (<i>n</i> = 242) <i>n</i> (%)	
White (British/Irish/Other)	224 (92.6)
Black (Caribbean/African/Other)	7 (2.9)
Asian (Indian/Pakistani/Other)	11 (4.6)
Level of education (<i>n</i> = 237) <i>n</i> (%)	
School educated only	207 (87.3)
Further education	30 (12.7)
CDR (<i>n</i> = 222) <i>n</i> (%)	
Mild	139 (62.6)
Moderate	61 (27.5)
Severe	22 (9.9)

3.5.3 Neuropsychiatric Inventory Profile

Table 3.4 reports person with dementia NPS as evaluated by the NPI. The majority of carers reported the presence of NPS, however there was variability in the extent of NPS reported, including the number, frequency and severity of behavioural symptoms.

Table 3.4 Person with dementia neuropsychiatric symptoms

Outcome measure		<i>M</i> (<i>SE</i>)	<i>Mdn</i>	<i>SD</i>	Range
NPI (<i>n</i> = 242)	Total score (frequency x severity)	25.28 (1.25)	22.00	19.51	0-109

Table 3.5 reports the dimensions of the NPI, including NPI total, carer distress and carer SE scores, allowing comparisons to be made between scales. The mean number of NPS of dementia reported by family carers was five. The most common symptoms were

apathy (72%), depression (59%) and agitation (56%), and the least common were euphoria (10%), hallucinations (24%), and delusions (34%). The pattern of scores differed between scales, which is indicative that each scale evaluates a different construct. The NPS with the highest total scores (frequency x severity) were found to be appetite and eating abnormalities, night-time behaviour disturbances, and apathy, while those with the lowest total scores were depression, hallucinations, and disinhibition. The NPS associated with the most carer distress were delusions and agitation, while those that invoked the least distress were euphoria, aberrant motor behaviour, and appetite and eating abnormalities. The highest mean SE scores were for managing symptoms such as euphoria and hallucinations, while the lowest SE scores were for managing irritability and depression.

Table 3.5 NPI dimensions, including NPI total, carer distress and SE scores

NPI symptoms	Number of people with behaviours <i>n (%)</i>	Total NPI score <i>M (SD)</i>	Distress <i>M (SD)</i>	Self- efficacy <i>M (SD)</i>
Delusions	83 (34)	4.85 (3.09)	3.12 (1.36)	2.60 (.84)
Hallucinations	60 (24)	3.29 (2.70)	2.27 (1.38)	2.37 (.74)
Agitation	137 (56)	3.50 (2.47)	2.99 (1.29)	2.63 (.86)
Depression	144 (59)	3.18 (2.65)	2.61 (1.21)	2.65 (.77)
Anxiety	131 (53)	3.59 (2.87)	2.43 (1.42)	2.53 (.81)
Euphoria	24 (10)	3.71 (2.76)	0.92 (1.32)	1.83 (.96)
Apathy	177 (72)	6.13 (3.32)	2.50 (1.33)	2.61 (.79)
Disinhibition	98 (40)	3.48 (2.86)	2.15 (1.46)	2.61 (.87)
Irritability	113 (46)	4.35 (2.96)	2.49 (1.41)	2.66 (.80)
Aberrant motor behaviour	112 (46)	5.78 (3.33)	1.96 (1.49)	2.38 (.84)
Night-time behaviour disturbance	107 (44)	6.48 (3.42)	2.14 (1.60)	2.51 (.94)
Appetite & eating abnormalities	125 (51)	6.80 (3.33)	1.97 (1.58)	2.52 (.97)

3.5.4 Carer Efficacy Scale Profile

Figure 3.1 presents the distribution of Carer Efficacy Scale scores, including the lower and upper quartile cut-off values. Quartiles were calculated to act as an indication of levels of high and low SE for managing NPS of dementia. The lower quartile cut-off was 7, with scores below this indicative of high SE for managing NPS, and the upper quartile cut-off value was 19, with scores above this indicative of low SE. However, the majority of scores were clustered between these values, with most carers reporting moderate levels of SE.

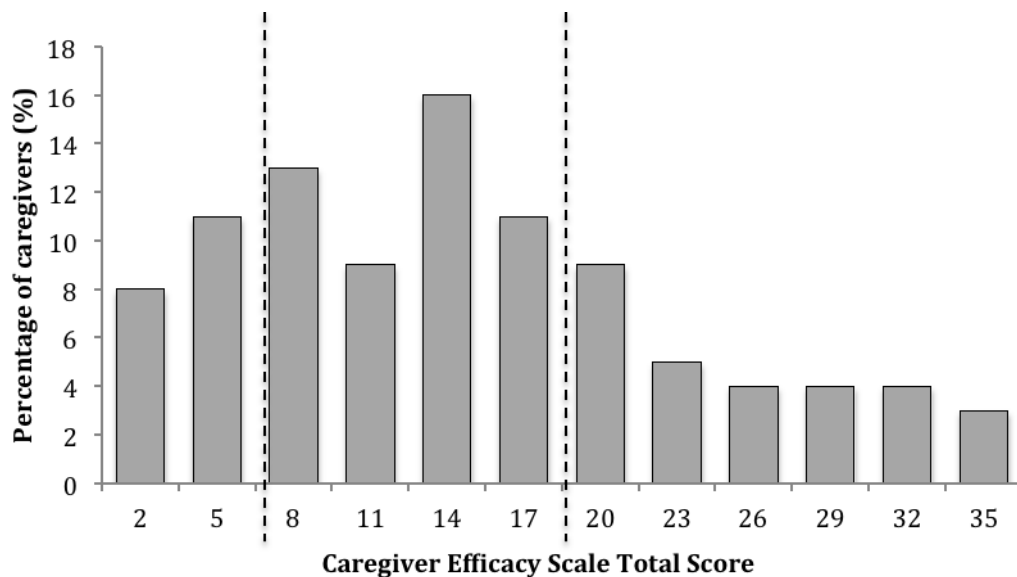


Figure 3.1 The distribution of Carer Efficacy Scale scores

3.5.5 Psychometric properties of the Carer Efficacy Scale

3.5.5.1 Internal Consistency

Cronbach's alpha coefficient was 0.79 for the 12-item Carer Efficacy Scale, indicating adequate internal consistency and homogeneity of the individual test items. The importance of each item to the Carer Efficacy Scale was demonstrated by the finding that all but one corrected item-total correlations (reported in Table 3.6) were higher than

0.3, this being euphoria. However, removal of this item had little effect on Cronbach's alpha coefficient, indicating it should be retained in the scale.

Table 3.6 Corrected item-total correlations for the Carer Efficacy Scale

NPI symptoms	Corrected item-total correlations
Delusions	.35
Hallucinations	.37
Agitation	.53
Depression	.44
Anxiety	.46
Euphoria	.24
Apathy	.49
Disinhibition	.55
Irritability	.51
Aberrant motor behaviour	.47
Night-time behaviour disturbance	.35
Appetite & eating abnormalities	.39

3.5.5.2 Concurrent validity

Table 3.7 reports the Pearson's correlation coefficient values between the Carer Efficacy Scale and subscales of the RSSE. A lack of carer efficacy as measured by the Carer Efficacy Scale significantly correlated with lower SE for obtaining respite ($r = -.27, p < .001$), responding to disruptive behaviours ($r = -.36, p < .001$) and controlling upsetting thoughts ($r = -.35, p < .001$). However, although significant the correlations of the RSSE subscales with the NPI Carer Efficacy Scale were only moderate according to Cohen (1988).

Table 3.7 Concurrent and construct validity of the Carer Efficacy Scale

Variable	Scale	Carer Efficacy score <i>r</i> (<i>p</i> -value)
NPI	Total score (<i>n</i> = 242)	.79***
	NPS frequency (<i>n</i> = 242)	.86***
	NPS severity (<i>n</i> = 242)	.87***
	Carer distress (<i>n</i> = 242)	.84***
HADS	Depression (<i>n</i> = 241)	.34***
	Anxiety (<i>n</i> = 241)	.38***
PANAS	Negative affect (<i>n</i> = 242)	.38***
COPE Index	Negative impact (<i>n</i> = 242)	.39***
RSSE	SE OR (<i>n</i> = 237)	-.29***
	SE DB (<i>n</i> = 225)	-.36***
	SE CT (<i>n</i> = 240)	-.35***

Note. SEOR = self-efficacy for Obtaining Respite; SEDB = self-efficacy for Responding to Disruptive Behaviours; SECT = self-efficacy for Controlling Upsetting Thoughts.

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

3.5.5.3 Construct validity

Table 3.7 reports the Pearson's correlation coefficient values between the Carer Efficacy Scale, dimensions of the NPI and negative carer outcomes. Strong positive correlations were found between the Carer Efficacy Scale and all of the dimensions of the NPI; correlations with the total NPI score ($p < .001$), NPS frequency ($p < .001$), severity ($p < .001$), and carer distress ($p < .001$) were highly statistically significant. Significant positive correlations were also found between lack of carer SE for managing NPS as measured by the Carer Efficacy Scale and poor psychological wellbeing, including depression ($p < .001$), anxiety ($p < .001$), negative affect ($p < .001$) and the

negative impact of caring ($p < .001$). Pearson's correlation coefficient values between the Carer Efficacy Scale and negative outcomes were moderate according to the guidelines of Cohen (1988).

3.5.5.4 Criterion validity

Table 3.8 reports the criterion validity of the Carer Efficacy Scale. This was evaluated by examining how the level of SE for managing NPS of dementia was associated with variables such as dementia severity, depression and relationship type. The one-way ANOVA demonstrated level of carer SE for managing NPS varied with dementia severity ($p = .037$). Post-hoc Tukey tests demonstrated moderate dementia was related to lower SE ($M = 15.79$) compared to mild dementia ($M = 12.54$), however there was no difference in level of SE between moderate and severe dementia ($M = 15.27$).

Independent samples t-test found level of carer SE for managing NPS varied with level of depression ($p < .001$); those who were not depressed (scored seven or less on the HADS-D) had higher SE ($M = 11.98$), while those who were depressed (11 or greater on the HADS-D) reported lower SE ($M = 17.99$). The independent samples t-test found level of carer efficacy for managing NPS did not vary with relationship type ($p = n.s$), there was no significant difference in SE scores between spousal/partner carers ($M = 13.65$) and son/daughter carers ($M = 13.82$).

Table 3.8 Criterion validity of the Carer Efficacy Scale

Variable	Level	SE for managing NPS of dementia		
		<i>M (SD)</i>	95% CI	Significance level (<i>p</i> -value)
Dementia severity (CDR)	Mild	12.54 (8.62)	11.08 – 14.00	$F(2, 218) = 3.36$
	Moderate	15.79 (8.38)	13.63 – 17.96	$p = .037^*$
	Severe	15.27 (9.35)	11.13 – 19.42	
Depression (HADS-D)	Depressed	17.99 (9.00)		$t(201) = 3.80$
	Not depressed	11.98 (8.17)		$p < .001^{***}$
Relationship type	Spouse/partner	13.65 (9.11)		$t(217) = 0.14$
	Son/daughter	13.82 (8.16)		$p = .89$

Note. Independent samples t-tests were conducted when the categorical variable comprised only two groups; one-way ANOVA were conducted when the categorical variable comprised more than two groups.

* $p < .05$, ** $p < .01$, *** $p < .001$

The Carer Efficacy Scale was divided into quartiles to identify carers reporting high and low levels of SE for managing NPS of dementia. Table 3.9 reports the comparison between carers with low SE for managing NPS to those with high SE for the demographic variable of relationship-type and negative outcome variables such as depression, anxiety, negative affect and the negative impact of caring. Comparison of upper and lower quartiles of SE scores demonstrated that groups differed with respect to several variables. Independent samples t-tests found the upper quartile (low SE) reported higher depression ($p < .001$), anxiety ($p < .001$), negative affect ($p < .001$) and negative impact ($p < .001$) when compared to the lower quartile (high SE). Pearson's Chi-square demonstrated no difference in carer care-recipient relationship type [$\chi^2(1) = .064, p = n.s$] between those with higher SE for managing NPS and those with low SE.

Table 3.9 Comparison of upper and lower Carer Efficacy Scale quartiles

Variable	Low SE for managing NPS	High SE for managing NPS	Statistic (p-value)
Depression <i>M (SD)</i>	7.52 (4.14)	3.83 (3.15)	$t(111) = 5.27$ $p < .001$ ***
Anxiety <i>M (SD)</i>	8.90 (4.40)	4.60 (3.37)	$t(111) = 5.87$ $p < .001$ ***
Negative affect <i>M (SD)</i>	22.70 (7.57)	15.38 (4.62)	$t(111) = 6.28$ $p < .001$ ***
Negative impact <i>M (SD)</i>	13.80 (4.19)	10.04 (2.99)	$t(111) = 5.54$ $p < .001$ ***
Relationship type <i>n (%)</i>			
Spouse/partner	40 (40.0)	36 (36.0)	$\chi^2(1) = .064$
Son/daughter	14 (14.0)	10 (10.0)	$p = .80$

Note. Independent samples t-tests were conducted for analyses involving one continuous and one categorical variable (with two groups); Pearson's Chi-square was used for analyses involving two categorical variables.

* $p < .05$, ** $p < .01$, *** $p < .001$

3.5.5.5 Factor Analysis

The Kaiser-Meyer-Olkin measure of sampling adequacy was found to be appropriate, at 0.846 and Bartlett's test of sphericity was significant, [$\chi^2(66, N = 245) = 540.67, p < .001$]. A three-factor solution of the 12 items was selected, accounting for 49.9% of the variance (see Table 3.10 for factors and eigenvalues). The first factor related to mood and hyperactivity (30.9% of the total variance) and included items such as appetite and eating abnormalities, apathy, aberrant motor behaviour, agitation, depression, disinhibition, irritability, and anxiety. The second factor related to psychosis and night-time disturbance (10.2% of the variance) and included items relating to hallucinations, delusions, and night-time behaviour disturbances and the final factor comprised euphoria (8.7% of the variance).

Comparable loadings on different factors were found for night-time behaviours in factors two (.34) and three (.31), depression in factor one (.54), two (.32) and three (-.40), and disinhibition in factors one (.53) and three (.41). Removal of these domains from the respective factors did not significantly improve the solution fit, therefore these items were retained. However, these findings of comparable loadings do not support the partitioning of the scale into subscales.

Table 3.10 Factors and eigenvalues for the Carer Efficacy Scale.

	Component		
	1	2	3
Appetite & eating abnormalities	.75		
Apathy	.73		
Aberrant motor behaviour	.62		
Agitation	.61		
Depression	.54	.32	-.40
Disinhibition	.53		.41
Irritability	.51		
Anxiety	.44		
Hallucinations		.81	
Delusions		.79	
Night-time behaviour disturbances		.34	.31
Euphoria			.82
Eigenvalues	3.71	1.22	1.05
Variance (%)	30.94	10.18	8.74

3.6 Discussion

The results demonstrate the Carer Efficacy Scale for measuring SE for managing NPS of dementia has adequate psychometric properties. The scale comprises cut-off points to indicate high and low carer SE and the semi-structured format of the scale allows ease of administration.

3.6.1 Internal consistency

Internal consistency of the Carer Efficacy Scale was adequate. Euphoria was the only item that had a corrected item-total correlation below 0.3, which may be a result of its extremely low prevalence. However, it is widely recognised that SE is task performance specific, therefore it was not necessary for the items to form a homogenous scale.

Rather carer SE is built on experiences of specific situations and varies with contextual factors (Bandura, 1997).

3.6.2 Neuropsychiatric Inventory profile

The most common NPS of dementia were apathy, depression, and agitation, which is consistent with the findings of Aalten et al. (2003) and Cummings (1997). This pattern might be a result of this study sample being predominantly categorised as having mild to moderate dementia because NPS typically vary with dementia stage. The pattern in carer efficacy towards the different NPS might be a result of the lower prevalence of euphoria and hallucinations, and the greater prevalence of depression and agitation. The pattern of carer efficacy does not appear to be related to the pattern in total NPI scores, nor the pattern of carer distress, which suggests that the scales measure different constructs.

3.6.3 The validity of the Carer Efficacy Scale

The Carer Efficacy Scale demonstrated adequate concurrent validity. As expected, it demonstrated a moderate correlation with the RSSE subscales of SE for Controlling Upsetting Thoughts and Responding to Disruptive Behaviours, however its correlation with Obtaining Respite was smaller. As anticipated, associations were not large enough to suggest the scales are evaluating the same efficacy beliefs; the Carer Efficacy Scale

evaluates efficacy for managing NPS of dementia, while the RSSE subscales evaluate efficacy relating to other caring tasks/domains, with the SE for Responding to Disruptive Behaviours subscale evaluating primarily memory related problems. Furthermore, it was found that the RSSE subscale of SE for Responding to Disruptive Behaviours had much lower correlations with the NPI dimensions compared to the Carer Efficacy Scale. This demonstrates that SE beliefs in one domain are not equivalent to another domain (Bandura, 1997) and also stresses the importance of developing the Carer Efficacy Scale to evaluate SE relating specifically to NPS.

Factor analysis of the Carer Efficacy Scale demonstrated the construct validity of the scale as a multifactor construct. The 12 items were grouped into three factors, labelled 'mood and hyperactivity', 'psychosis and night disturbance', and 'euphoria'. Although all items demonstrated high factor loadings (above 0.3), some of the items loaded similarly on several of the factors and such data did not support its partitioning into subscales. Furthermore, the factor structure varied widely with dementia severity. The potential partitioning of the Carer Efficacy Scale into subscales is a subject for future research. In addition, the factor 'euphoria' requires further exploration given the low corrected item-total correlation and its appearance as a single item factor, which might be an artefact of the extremely low incidence of euphoria reported by carers.

The Carer Efficacy Scale demonstrated adequate construct validity; there was a strong relationship between the Carer Efficacy Scale and dimensions of the NPI, indicating that the greater number of times a carer is faced with a particular NPS of dementia and the greater challenge it poses, the lower SE a carer has for managing that symptom. The strong association between lack of carer efficacy and greater distress upholds the validity of the scale, as the greater distress associated with a particular behaviour, one

would expect lower confidence. The finding that lack of carer efficacy was associated with reduced psychological wellbeing, including negative affect, depression, and anxiety, is consistent with the research of Gilliam and Steffen (2006) and Steffen et al. (2002). The conceptual model of Bandura (1997) recognises SE influences carer outcomes by altering affective, motivational and cognitive mechanisms, leading to behavioural and emotional regulation. Hence, at a low level of carer SE for managing NPS, there might be more negative appraisals, reduced motivation and a lack of persistence in coping behaviours, leading to greater distress and emotional vulnerability.

The Carer Efficacy Scale demonstrated adequate criterion validity. The finding that depressed carers had lower SE is in parallel with existing research concerning low SE and reduced psychological wellbeing (Gignac & Gottlieb, 1996). The association between greater dementia severity and lack of carer efficacy for managing NPS of dementia was expected because severity is typically associated with higher NPS frequency, severity and carer distress. Baumgarten (1989) found that with greater dementia severity, there is correspondingly higher carer distress, therefore one would expect reduced SE for managing NPS. However, the relationship between dementia severity and SE appeared to plateau at the moderate stage, which might be due to the small number of individuals with severe dementia in the sample or the fact that NPS are most challenging while the care-recipient remains physically active (Chiriboga, Weiler, & Nielsen, 1990). As expected, comparison between the upper and lower quartiles of SE scores demonstrated these carers differ in levels of anxiety, depression, negative affect, negative impact and dementia severity. Those with low SE have reduced psychological wellbeing and care for an individual with greater dementia severity. Although there was no difference in level of SE according to relationship type, this might be a result of the large number of spousal carers in the sample.

3.6.4 Methodological considerations

There were several methodological limitations. For example, with such a large sample, a cautious approach must be taken with interpretation, as clinical significance is not equivalent to statistical significance. Large samples increase the chance of finding significant correlations, therefore to assist with the interpretation of findings, Cohen's (1988) guidance of effect size was used. Study participants were primarily white British; subsequently the findings may not prove generalisable to other populations. In addition, there are challenges with the definition and quantification of NPS and BPSD (Moniz-Cook, Woods, Gardiner, Silver, & Agar, 2001) and these difficulties must be acknowledged in designing a measurement scale for SE for managing NPS. In particular, the Carer Efficacy Scale might be constrained by ceiling effects or by the use of a four-point response scale, since narrow response scales may lack sensitivity and reliability (Bandura, 2006). Furthermore, evaluation of the Carer Efficacy Scale construct validity was limited by the fact that discriminant validity was not assessed.

3.6.5 Implications

3.6.5.1 Implications for practice and clinical use

This study provides a psychometric underpinning for the use of the Carer Efficacy Scale in clinical practice. It is hoped the scale might aid the identification of areas of low SE for managing NPS of dementia and therefore allow interventions to be directed towards areas of difficulty. It is also hoped that the scale might assist with the identification of carers at greater risk of poorer outcomes, who will benefit from SE related interventions (e.g. psychoeducational approaches or SE training). The Carer Efficacy Scale might also be of use in evaluating interventions intended to improve carer efficacy for managing NPS of dementia. This is important given that SE is a potentially modifiable psychological construct (Bandura, 1997) and may provide a powerful avenue by which

interventions can influence wellbeing. It is also crucial given the prevalence of NPS of dementia and the associated poor outcomes for both carers and individuals with dementia. In turn, this scale might have economic implications in delaying care-recipient institutionalisation.

3.6.5.2 Implications for carer theory

The development of the Carer Efficacy Scale might prove of value for carer theory, to augment understanding of how SE beliefs influence variability in carer outcomes and facilitate informed conceptual models of carer adaptation. Conceptual models typically incorporate generic SE, despite the widely acknowledged domain-dependent nature of SE beliefs (Bandura, 1997). Carer theory therefore appears to be constrained by existing measures of SE and the lack of valid domain-dependent measures. The development of the Carer Efficacy Scale for managing NPS of dementia might allow these specific SE beliefs to be incorporated within conceptual models of the caring experience, to advance theory. This is important given that research has demonstrated the different roles of distinct domain-dependent SE beliefs in caring outcomes (Cheng et al., 2012).

3.6.5.3 Implications for research

The Carer Efficacy Scale offers promise for use in research settings. This scale might make it possible to explore how the degree of carer efficacy varies with time since onset of NPS of dementia, as one could expect SE to vary depending on how long carers have been dealing with a particular symptom. A further potential avenue for research for which the Carer Efficacy Scale might prove of value is in the exploration of positive and negative carer appraisals of NPS of dementia, appraisals of the changeability of NPS and SE for managing NPS. In particular, carer efficacy beliefs for dealing with NPS might be closely related to carer appraisals of whether NPS are part of the

dementia, whether symptoms can be altered, and whether carers make positive or negative appraisals of symptoms. With higher SE, carers might perceive NPS as challenges to overcome, but with lower efficacy beliefs they make more negative appraisals (Bandura, 1997).

Finally, the Carer Efficacy Scale might allow exploration of the relationship between the awareness of the individual with dementia and carer efficacy for managing NPS of dementia. Clare (2002) claimed that the perception of the extent to which the person with dementia is aware partly determines the way one responds to that individual. Awareness of NPS within dementia might influence the level of carer efficacy in dealing with these symptoms, as awareness may be closely related to whether the carer perceives the behaviour as modifiable or not.

3.6.6 Future Research

The Carer Efficacy Scale might aid the identification of predictors of SE for responding to NPS of dementia and also allow the exploration of the relationship between carer SE for managing NPS and carer outcomes. More specifically, a cohort study, preferably longitudinal, should be conducted to explore potential predictors of scores on the Carer Efficacy Scale, as well as the predictive ability of the Carer Efficacy Scale for carer outcomes. To develop the scale further and to determine its generalisability, the psychometric properties should be evaluated in different caring populations, particularly using confirmatory techniques (e.g. Confirmatory Factor Analysis).

3.7 Conclusion

The addition of an efficacy question to each domain on the NPI produces a measure of carer efficacy for managing NPS of dementia that has adequate reliability and validity,

supporting the use of this scale in a British population. This appears to be the first psychometrically validated scale specifically designed to evaluate carer efficacy for managing NPS. This might have important implications for understanding adaptation to the caring experience and have practical value in designing improved interventions tailored towards areas of difficulty. This is of particular importance due to the prevalence and burdensome nature of NPS and given the widely recognised need to develop measures of SE beliefs relating to the tasks that carers find most challenging.

The Carer Efficacy Scale was developed in response to the methodological challenges described in the systematic review in Chapter two. The findings of this Chapter have demonstrated the Carer Efficacy Scale to be psychometrically sound and as a result, the scale will be used as a measurement of SE for managing NPS of dementia in the subsequent data analysis (see the methods section in Chapter four).

CHAPTER 4: METHODOLOGY

4.1 Participants

Participants were 291 family carers supporting a relative with dementia residing at home within the community in North East London, Berkshire, Norfolk or Northamptonshire.

4.1.1 Inclusion criteria

To be eligible, participants had to meet the specified inclusion criteria:

- Caring for an individual with dementia living at home or in sheltered accommodation.
- English-speaking and aged 18 or over.
- Identified by themselves as a carer for person with a primary progressive cognitive impairment/dementia as defined by DSM-IV criteria for dementia (American Psychiatric Association, 1994; see Appendix 5.2).

4.1.2 Exclusion criteria

- Carers of individuals living in residential or nursing accommodation.
- Carers of individuals with congenital cognitive impairments, acquired non-progressive brain injury or cognitive impairments in the context of longstanding psychiatric illness.
- Carers with significant congenital or acquired cognitive impairment, or where cognitive deficits are suspected.
- Seriously ill carers, such as those receiving hospice or hospital treatment for terminal illness.

- Non-family, paid carers.
- Either party already taking part in a psychosocial research study.

4.2 Design

The data were collected as part of the SHIELD Carer Supporter Programme (Charlesworth et al., 2011), which was led by Professor Martin Orrell and Dr Georgina Charlesworth and funded by the National Institute of Health Research (NIHR). The Carer Supporter Programme was a four-arm, multi-site randomised controlled trial evaluating the effectiveness of a carer supporter intervention and ‘Remembering Yesterday Caring Today’ reminiscence intervention, and comparing these interventions to a control group.

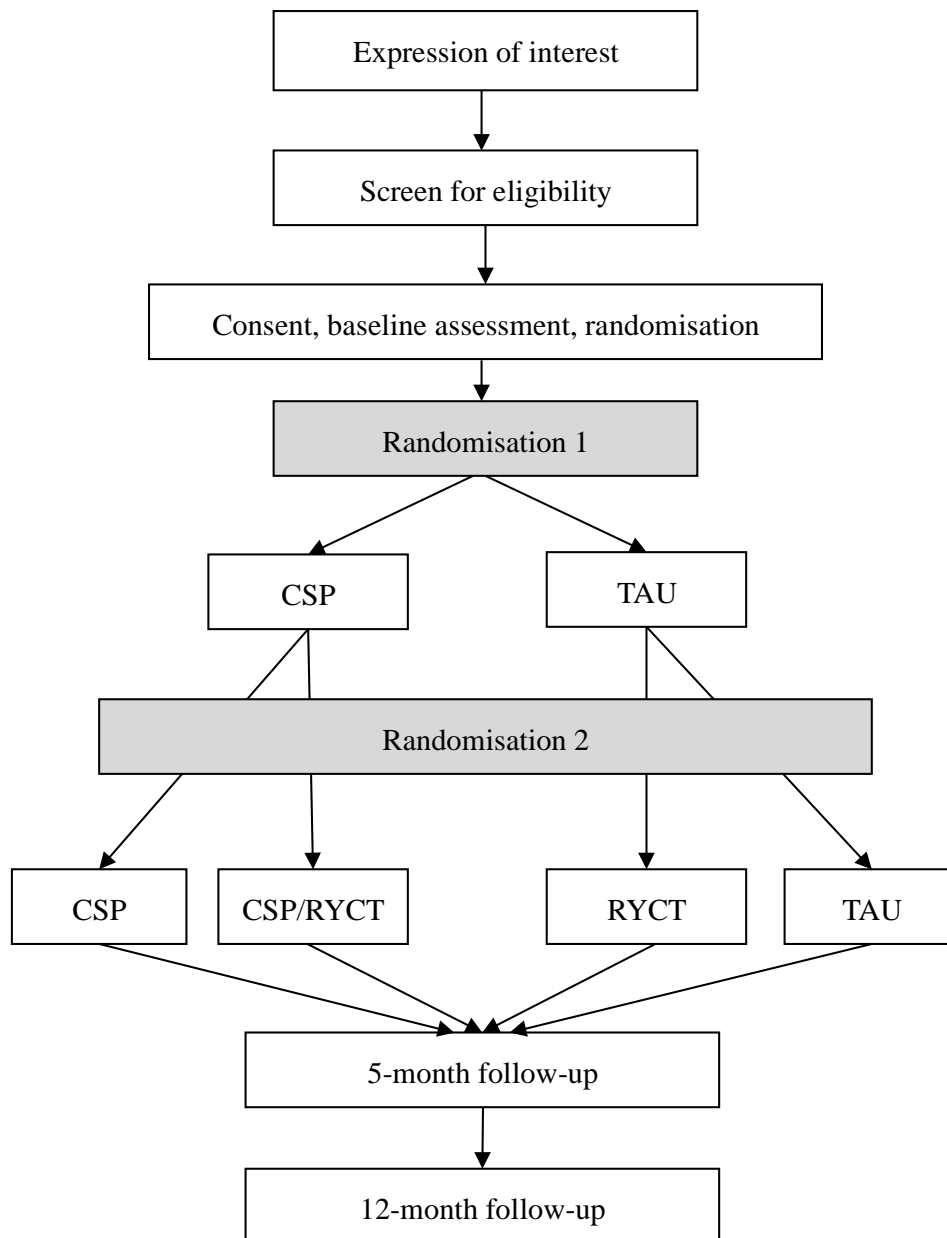


Figure 4.1 Flow diagram of SHIELD Carer Supporter Programme

4.3 Recruitment

Dyads were recruited within North East London, Berkshire, Norfolk and Northamptonshire between December 2009 and March 2012. Recruitment strategies were designed to target family carers of individuals with dementia. Recruitment took place through mental health services for older people, including memory clinics, outpatient clinics, older people's community mental health teams, old age psychiatrists,

admiral nurses, and community psychiatric nurses. As well as through relevant day services, older adult social services and voluntary organisations, such as the Alzheimer's Society, Age Concern, and Crossroads. General Practitioners (GPs) and local media were also used.

Written and/or oral information was distributed directly to potential participants (Appendix 4.2); members of the research team attended memory clinics, voluntary organization events, carer groups and social groups in the community. Information concerning the research was also distributed indirectly through members of staff/health professionals known as 'gatekeepers'. Information concerning the research aims, eligibility criteria and the importance of consent in passing on referrals to the research team was provided to gatekeepers via written materials (Appendix 4.1) and oral presentations. Gatekeepers assumed a position between the research team and potential participants and referred interested carers, published articles in newsletters and disseminated information to potential participants (e.g. via mail outs).

The contact details of the research team were available to carers interested in finding additional information about the research and thus it was the responsibility of the carer to contact the research team. In no instance did the research team gain the contact details of carers without permission. Once interested carers contacted the research team, they were given additional information via phone discussions with researchers and information booklets for both the family carer (Appendix 4.4) and person with dementia (Appendix 4.5). A cooling-off period was ensured by leaving a minimum of 24 hours between carers receiving the information booklets and obtaining informed consent.

4.4 Screening participants for eligibility

The eligibility of participants to take part in the research was assessed against the specified criteria using a screening checklist (Appendix 5.1) administered over the phone by a member of the research team. If there was any uncertainty regarding the eligibility status of a participant, further discussions were held with the research team and trial lead until a decision was made. Once screened, family carers were sent a letter confirming the date, time and venue of the interview/assessment (Appendix 4.3).

4.5 Consent and assent

Prior to the assessment, written consent was obtained from the family carer (Appendix 5.3) and individual with dementia (Appendix 5.4) by the research team. Before consent was ascertained, both the carer and person with dementia had the opportunity to read the information booklets, ask any questions, and discuss the procedures for withdrawal from the research and in what circumstances their details may have been passed on (e.g. to social services/community mental health teams). Participants were also made aware that there would be no disadvantage if they chose not to participate. It was assumed that carers were able to consent on their own behalf, however a multi-phase consent design was employed to reduce the cognitive load and simplify the process.

The majority of people with dementia were in the mild to moderate stages and were able to consent given that appropriate care and time was taken to explain the research. To ensure participants understood the information, the researcher observed their ability to ask relevant questions and requested that the participant repeat the information. In the instances when the person with dementia was not able to provide informed consent, assent was sought.

When seeking consent, guidance from the British Psychological Society on evaluation of capacity was followed. For each participant consent or assent was considered a continuing process and willingness to participate was continually checked throughout the assessments. For instance, if a participant became uncomfortable during the assessment it was paused or discontinued. The GP of the carer and person with dementia was informed about their participation within the research via letter (Appendix 5.5).

4.6 Data collection procedures

Data were collected as part of the longer interview schedule of the baseline assessments for the SHIELD Carer Supporter Programme. Details of the interview procedure and instruments are as follows:

4.6.1 Interview procedure

Trained members of the research team collected data from both family carers and individuals with dementia. Whenever possible, carers and individuals with dementia were assessed separately. The assessment time and venue was organised between the carer and researcher according to the caregiver's preference and thus most assessments were conducted in the caregiver's own home.

The pace of assessments varied according to the needs of the participant and if preferred, assessments were completed over two visits. The language used throughout the assessment was respectful, whether or not participants were judged to be able to understand. Assessments were conducted with understanding and sympathy, with appropriate responses to the disclosure of situations presenting risk to the wellbeing of participants (e.g. abuse, suicidal or homicidal intent). If the participant demonstrated

any agitation or distress, the assessment was paused or terminated as appropriate. The assessment length was approximately 2-3 hours for family carers and ½-1 hour for individuals with dementia. The assessment schedule and the participant that each instrument related to are reported in Table 4.1.

Table 4.1 List of instruments

Instrument	Family Carer	Person with Dementia
The Short Form-12 Health Survey (SF-12; Jenkinson & Layte, 1997)	X	
Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)	X	
Positive and Negative Affect Scale (PANAS; Watson et al., 1988)	X	
Carers of Older People in Europe Index (COPE-Index; McKee et al., 2003)	X	
The Practitioner Assessment of Network Type (PANT; Wenger, 1994)	X	
Revised Scale for Caregiving Self-Efficacy (RSSE; Steffen et al., 2002)	X	
Carer Efficacy Scale (Crellin, Charlesworth, & Orrell, 2014)	X	
Brief Coping Orientation for Problem Experience (Brief COPE; Carver, 1997)	X	
Alzheimer's Disease Co-operative Study – Activities of Daily Living Inventory (ADCS-ADL; Galasko et al., 1997)		X
Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975)		X
Clinical Dementia Rating (CDR; Hughes, Berg, Danziger, Coben, & Martin, 1982)		X
The Neuropsychiatric Inventory (NPI; Cummings et al., 1994)		X

4.6.2 Demographic data

Family carers (Appendix 6.1) and individuals with dementia (Appendix 6.2) were asked to provide details such as date of birth, gender, ethnicity, highest level of education achieved, marital status, carer-care recipient relationship type, living situation and duration of caring.

4.6.3 Family carer measures

The Short Form-12 Health Survey (SF-12; Jenkinson & Layte, 1997)

This scale (Appendix 6.3) evaluates generic health status from the perspective of the participant. It comprises eight concepts including physical functioning, role functioning physical, bodily pain, general health, vitality, social functioning, role functioning emotional and mental health. The scale generates two scores: the physical component summary and mental component summary, with a higher score indicative of better mental and physical health. To aid interpretation, scores are standardised to population norms, with the mean score set at 50 ($SD = 10$). The scale has demonstrated adequate validity and reliability (Ware et al., 1996; Ware, Kosinski, Turner-Bowker, & Gandek, 2009) and has been validated for use in the UK (Jenkinson, 1999; Jenkinson & Layte, 1997). The scale takes approximately five minutes to complete.

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

The scale (Appendix 6.4) comprises 14-items; seven items evaluate anxiety (e.g. “Worrying thoughts go through my mind”) and seven evaluate depression (e.g. “I have lost interest in my appearance”). Items are scored on a 4-point scale ranging from 0 to 3, with the higher score indicative of higher depression and/or anxiety. The scores for each subscale range from 0 to 21. Cut-offs can be used to indicate caseness: a score of 7 or below is indicative of a non-case, a score of 8–10 is indicative of a doubtful case, and a score of 11 or above is considered a definite case of anxiety/depression. The HADS has adequate reliability and validity in a range of contexts and populations (Bjelland, Dahl, Haug, & Neckelmann, 2002; Snaith, 2003). This scale was chosen as it has been used in previous studies with carers of individuals with dementia (e.g. Cooper et al., 2006). This scale takes approximately five minutes to complete.

Positive and Negative Affect Scale (PANAS; Watson et al., 1988)

This instrument (Appendix 6.5) comprises two 10-item mood scales that evaluate positive affect (i.e. the extent to which someone feels enthusiastic, active and alert) and negative affect (i.e. the extent to which someone feels distressed) respectively. Items are scored on a 5-point likert-type scale format, in which participants rate the extent they have felt each mood state ranging from 1 (*very slightly or not at all*) to 5 (*extremely*). Scores on each scale range between 10 and 50, with higher scores indicative of higher positive and negative mood on the respective subscales. The instrument has been used in a variety of research contexts and has good validity and reliability (e.g. Charlesworth et al., 2008). It takes approximately 10 minutes to complete.

The Carers of Older People in Europe Index (COPE-Index; McKee et al., 2003)

This measure (Appendix 6.6) comprises 17-items evaluating informal caregivers' subjective perceptions of positive and negative aspects of caring, as well as quality of support. The Negative Impact scale comprises eight items, while the Positive Impact and Quality of Support scales comprise four items each. Responses are scored on a 4-point likert type scale ranging through *never*, *sometimes*, *often*, and *always*. The negative subscale is reversed scored and ranges between 8 and 32, with a high score indicative of high negative impact. However, both the positive impact scale and quality of support scale range between 4 and 16, with higher scores indicative of higher positive impact and higher quality of support respectively. The index has good reliability and validity and takes approximately 15 minutes to complete.

Revised Scale for Caregiving Self-Efficacy (RSSE; Steffen et al., 2002)

This scale (Appendix 6.7) evaluates caring SE over three domains: SE for Obtaining Respite, Responding to Disruptive Behaviours and Controlling Upsetting Thoughts. The

scale consists of 15 items (five items in each domain), each evaluating perceived confidence to complete a task on a scale of 0-100 percent. Each item also comprises a *not applicable* response option. Subscale scores are calculated by summation of the five item scores, with each subscale ranging between 0 and 500. For all subscales, higher scores are indicative of higher SE. The scale was designed for carers of people with dementia and has good reliability and validity (Steffen et al., 2002).

Carer Efficacy Scale (Crellin, Charlesworth, & Orrell, 2014)

The Carer Efficacy Scale (Appendix 6.8) was developed by the addition of a single, four-response item to each domain of the NPI. For example, “How confident are you in dealing with the aggressive/agitated behaviour?” Responses range from 4 (*not at all confident*), 3 (*fairly confident*), 2 (*confident*), to 1 (*very confident*). The scale is reverse scored, with a high score indicative of a greater lack of SE (low SE) and a low score indicative of a lower lack of SE (high SE) to manage NPS. The total is the sum of the SE scores for each symptom, with the score ranging between 0 and 48. The development of the NPI Carer Efficacy Scale was described in detail in Chapter three.

Brief Coping Orientation for Problem Experience (Brief-COPE; Carver, 1997)

The Brief COPE (Appendix 6.9) is a shortened version of the original COPE scale (Carver, Scheier & Weintraub, 1989). The Brief COPE comprises 14 subscales describing different coping strategies, with two items per scale. For each item, responses are scored on a 4-point likert type scale ranging from 1 (*I haven't been doing this at all*) to 4 (*I've been doing this a lot*). The scale has good reliability and validity and has been used in a range of research contexts (e.g. Carver, 1997).

Items were divided into three subscales according to Coolidge, Segal, Hook, and Stewart (2000) and Cooper et al. (2006), these being Emotion-focused, Problem-focused and Dysfunctional coping strategies. Emotion focused strategies include acceptance, emotional support, humour, positive reframing and religion: problem focused strategies include active coping, instrumental support and planning: dysfunctional strategies include behavioural disengagement, denial, self-distraction, self-blame, substance use and venting. Scores were summed: the score range for dysfunctional coping was 12 to 48; emotion-focused coping 10 to 40; and problem-focused coping 6 to 24. For each subscale a higher score indicates a higher use of the coping behaviour.

The Practitioner Assessment of Network Type (PANT; Wenger, 1994)

The PANT (Appendix 6.10) identifies social support network type available to the participant. The eight items (e.g. “If you have any children where does your nearest child live?” and “How often do you see any of your neighbours to have a chat or do something with?”) evaluate three main features: i) frequency of contact with family, friends and neighbours, ii) geographical proximity to family and iii) information on local social ties (i.e. participation in social clubs, groups, religious meetings). Responses are used to categorise the individual into one of the five types of social networks: family dependent, locally integrated, local self-contained, wider community focused, and private restricted. The PANT takes approximately 10 minutes to complete and is relatively easy to administer. This instrument was chosen, as Wenger’s network typology has been previously used in a sample of carers and individuals with dementia (Wenger, 1994).

The Neuropsychiatric Inventory (NPI; Cummings et al., 1994)

The NPI (Appendix 6.11) evaluates 12 behavioural disturbances in dementia, these being delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviour, sleep disturbance and appetite and eating disorders in a semi-structured approach. All items are dementia specific, behaviour based and observable. Items are grouped into domains, each comprising a screening question to evaluate the presence or absence of a symptom. Each domain captures frequency, severity of each behaviour and carer distress associated with the behavioural symptom. Frequency is rated on a scale from 1 (*occasionally*) to 4 (*very frequently*), severity is rated from 1 (*mild*) to 3 (*severe*) and carer distress is rated from 0 (*no distress*) to 5 (*extreme or very severe distress*). The total score is calculated by multiplication of frequency and severity for each symptom (ranging between 0 and 12) and the addition of all item scores, ranging between 0 and 144. The distress total is calculated by the sum of the individual domain scores, with a range between 0 and 60. The validity and reliability have been demonstrated (Cummings, 1997). This scale takes between 10 and 20 minutes to complete depending upon the behavioural symptoms reported. It was chosen for its ability to assess a broad range of behavioural and psychological symptoms commonly reported in people with dementia.

4.6.4 Person with Dementia measures*Mini-Mental State Examination (MMSE; Folstein et al., 1995)*

The MMSE (Appendix 6.12) evaluates cognitive function including orientation to time and place, registration, attention and calculation, recall, language and visual construction. Items are summed to generate the total score, ranging between 0 and 30. A higher score is indicative of better cognitive function, with a score of 24 typically

regarded as being the level indicating the presence of cognitive impairment (depending on level of education). More specifically, scores of 21-24 usually indicate mild dementia, 11-20 denotes moderate dementia and 0-10 indicates severe dementia. This scale was selected as it has widely been used in clinical and research practice to determine severity of cognitive impairment and has been shown to have adequate reliability and validity. This scale takes approximately 10 minutes to complete.

Clinical Dementia Rating (CDR; Hughes et al., 1982)

The CDR (Appendix 6.13) is a global scale developed to clinically evaluate the presence of dementia and stage its severity. The scale involves semi-structured interviews with the person with dementia and carer to obtain information to rate cognitive performance in six domains: memory, orientation, judgment and problem solving, community affairs, home and hobbies and personal care. An overall rating is then given indicating no dementia (0), very mild (0.5), mild (1), moderate (2) or severe (3) dementia based on the scores in the six domains. A higher score indicates greater severity. Criterion validity for the CDR has been demonstrated and it has also been validated neuropathologically, particularly for the presence or absence of dementia. The researcher completed this scale retrospectively.

Alzheimer's Disease Co-operative Study – Activities of Daily Living Inventory (ADCS-ADL; Galasko et al., 1997)

The ADCS-ADL (Appendix 6.14) is a structured questionnaire originally developed to assess functional capacity for a number of daily tasks over a broad range of dementia severity. This inventory comprises 23 items covering physical and mental functioning, and independence in self-care. It is completed by the family carer and evaluates activities performed within the last four weeks. Each item consists of a series of

hierarchical questions designed to determine ability to perform an activity of daily living, ranging from total independence to total inability. The total score is calculated by summation of item scores, ranging between 0 and 78. Lower values are indicative of greater disability. The inventory has adequate psychometric properties (Galasko et al., 1997) and takes approximately 15 minutes to complete.

4.7 Patient and Public Involvement (PPI)

PPI occurred regularly throughout the SHIELD Carer Supporter Programme, with procedures for involvement determined by the “user involvement” strategy. Family carers and individuals with dementia were recruited through organisations with an interest in dementia and family carers, such as Uniting Carers for Dementia, DeNDRoN User/Carer groups, and the Alzheimer’s Society. PPI (typically in the form of consultation and consensus procedures) contributed to the development of research procedures, the creation of study documents such as participant information sheets and consent forms, and assisted with the development of the interventions (as part of the randomised controlled trial).

4.8 Data management

The data collected were managed through MACRO. This is an electronic data system that meets regulatory compliance for designing electronic case report forms, data entry, data monitoring, data export, and good practice guidelines. MACRO has built in systems for keeping an audit trail, quality assurance, and has the capacity to capture all trial information, including recruitment, demographic and clinical data. It is able to maintain and recover information, to store and archive data, and allows online and offline data collection. The format of MACRO followed the paper questionnaire format, however it allowed contradictory and incomplete responses to be flagged for resolution.

After entry into MACRO, data were screened, cleaned, coded and transferred to the statistical software package for analysis; either SPSS Version 22 (SPSS, 2013) or Analysis of Moment Structures (AMOS) Version 21 (Arbuckle, 2012). When the data were transferred between packages, checks were taken to ensure on-going data integrity.

4.9 Ethical approval

The SHIELD Carer Supporter Programme was reviewed and approved by the Outer North East London Research Ethical Committee (REC Reference number: 09/H0701/54, ISRCTN: 37956201). This ethical approval (Appendix 1.1) included scope for secondary analyses of the SHIELD Carer Supporter Programme data collected. The trial was part of the NIHR-funded SHIELD programme (RP-PG-0606-1083).

The Data Protection Act (1998) guidance was followed to uphold confidentiality. Data were only accessible to research staff and the personal details of participants' were stored separately from the data, to ensure that the data were unidentifiable. All information was kept in locked filing cabinets, and participant identification codes were used to store files, to ensure files were unidentifiable.

4.10 Data analysis

4.10.1 Data screening

Data were screened manually. Any uncertainties/erroneous data were checked between the MACRO system and the paper, hard-copy questionnaires and incorrect/invalid entries were corrected.

4.10.2 Detecting outliers

Data were examined to determine if any cases met the definition of an outlier. Outliers are cases with scores considerably different to the majority of scores, which can bias the mean and inflate the standard deviation (Field, 2009). Boxplots were inspected for extreme values and z-scores were examined according to Field (2009). Low numbers of outliers were found; the percentage of scores considered as outliers for variables (greater than 2 standard deviations) ranged between 0 and 5.9%. Outliers were replaced with the next highest/lowest score within the distribution that was not considered to be an outlier, plus/minus one. This enabled the case to remain in the analysis with lesser risk of distortion (Field, 2009; Tabachnick & Fidell, 1996).

4.10.3 Missing data and multiple imputation

Missing data, including both missing items (i.e. by variable) and missing measures (i.e. by case) were explored and a missing value analysis was performed to determine if data were missing at random or whether there were systematic differences. Once missing data were identified, for items missing within measures, the rules for completing missing data for the relevant measure were applied (see Appendix 2 for data analysis plan). Following this, a multiple imputation method was applied. Imputation was undertaken at a 20% level for the COPE-Index and MMSE, but at a 40% level for the RSSE subscales due to the high number of 'not applicable' responses. For example, at a 20% missing item level for a five-item score, if one item was missing, this was completed with the mean of the other four items.

Pre-imputation, within cases, there was considerable variation in variable completion; only 156 cases of the total 289 cases had complete data. The extent of missing data was a result of the large amount of data being collected, the burdensome nature of

assessments, researcher administration errors and routing errors. In addition, data collection with the person with dementia was often challenging or not possible due to the severity of cognitive impairment, visual or language difficulties.

However, there were little missing data by variable; most variables had less than 5% of cases missing. Those above 5% were the Carer Efficacy Scale (10%), ADCS-ADL (7%), RSSE subscales for Obtaining Respite (9%), Responding to Disruptive Behaviours (23%), Controlling Upsetting Thoughts (7%), and the MMSE (11%). The higher proportion of missing data for the MMSE was due to person with dementia physical ill health and inability and/or unwillingness to complete the research assessments. The higher number of missing cases for the Carer Efficacy Scale was a result of an administration error at one of the research sites. Routing problems and formatting issues in the paper assessments caused the high proportion of missing cases for the ADCS-ADL. In addition, the high number of cases missing for the RSSE subscales was a result of the large number of 'not applicable' responses recorded by carers, which is likely a result of the sample predominantly comprising carers of individuals with mild dementia.

Post imputation, variable completion by cases significantly improved; within cases, 277 dyads had complete data. All but two variables had complete cases, the two exceptions were the PANT and CDR, with these missing 1% and 3% of cases respectively. This was due to the categorical nature of these variables.

4.10.4 Data distribution

The distribution of the data was assessed for normality. Normally distributed data are characterised by a symmetrical, bell shaped curve, with the greatest frequency of scores

in the middle and smaller frequencies towards extremes. Distributions can deviate from normality by a lack of symmetry or 'peakedness'. Skewness is indicative of distribution symmetry, with skewed distributions indicative of non-symmetry. Kurtosis is indicative of the 'peakedness' of the distribution, with positive values indicating a peaked distribution and negative values indicating a flat distribution.

With large samples (more than 200), visual inspection of the shape of the distribution and examination of skewness and kurtosis values are recommended (Field, 2009; Tabachnick & Fidell, 1996, p.73). Therefore, the data distribution was evaluated by visual inspection of histograms. The majority of variables were found to be normally distributed, with the exception of the NPI total score, HADS subscales, PANAS Negative Affect subscale, which demonstrated a positive skew. In addition, the RSSE subscales of SE for Responding to Disruptive Behaviours and Controlling Upsetting Thoughts demonstrated a marginal negative skew, while the Carer Efficacy Scale demonstrated a marginal positive skew. In addition, the RSSE subscale of SE for Obtaining Respite demonstrated a slightly flat/kurtotic distribution. Further inspection of the skewness and kurtosis values revealed levels of skewness and kurtosis indicated no significant deviation from normality.

It has also been posited that with reasonably large samples, skewness and kurtosis do "not make a substantive difference in the analysis" and that the risk of underestimating the variance is small (Tabachnick & Fidell, 1996, p.73). In agreement, Field (2009) recommended that with large samples normality is less of a concern and parametric tests are considered appropriate. In addition, Tabachnick and Fidell (1996) proposed that the transforming of data can lead to difficulties with its interpretation and it is therefore not universally recommended. As a result, parametric analyses were conducted rather than

the less powerful alternatives and transformations of the data were not performed.

4.10.5 SECTION A: Participant demographics and clinical characteristics

Chapter three reported participant characteristics and properties of the SE scales in a subsample of participants (n = 245) taking part in the SHIELD Carer Supporter Programme. However this section will examine participant demographics and clinical characteristics in the total sample (n = 289) and comparisons will be made with the findings reported in Chapter three.

4.10.5.1 Aim

- To describe participant demographic and clinical characteristics.

4.10.5.2 Objectives

- To determine if sample characteristics are typical of UK caring populations.
- To examine the pattern of distribution of scores for the Carer Efficacy Scale and RSSE subscales.
- To evaluate the internal consistency of the Carer Efficacy Scale and RSSE subscales.
- To examine Pearson's correlation coefficient values between the Carer Efficacy Scale and RSSE subscales.

4.10.5.3 Hypotheses

- It is hypothesised that the SE subscales will demonstrate similar distributions.
- It is expected that there will be modest associations between SE subscales.

4.10.5.4 Data analysis

The number of expressions of interest and reasons for ineligibility were reported. Mean and median values, standard deviations, minimum and maximum values, frequencies and percentages were reported for carer and person with dementia characteristics and clinical variables.

Frequency distributions were inspected for the SE subscales relating to Obtaining Respite, Responding to Disruptive Behaviours, Controlling Upsetting Behaviours and managing NPS to determine the pattern of distribution of scores. In addition, Pearson's correlation coefficient values between the SE subscales were examined. With larger samples, there is an increased chance of obtaining statistically significant findings, therefore Cohen's (1988) guidelines were used to interpret effect sizes. Cohen (1988) recommended that a correlation (r) of 0.1 indicates a small effect, 0.3 reflects a medium effect and 0.5 is indicative of a large effect. Therefore values greater than 0.5 were considered large, 0.3 - 0.5 moderate and 0.1 - 0.3 were considered small.

The internal consistency of the RSSE subscales and Carer Efficacy Scale was evaluated by calculating Cronbach's alpha coefficient (Cronbach et al., 1972). Internal consistency is the extent to which items evaluate a common characteristic. Coefficient values range between 0 and 1, with greater values indicative of greater reliability. Values of 0.80 are typically accepted as indicative of good internal consistency (Prince, 1998). The corrected item-total correlations were also examined to evaluate the contribution of each item to the scale (above 0.3).

4.10.6 SECTION B: Factors associated with self-efficacy relating to specific caring domains

The reviews described in Chapters one and two highlighted the paucity of empirical research that has investigated predictors/determinants of carer SE beliefs (e.g. carer characteristics, coping strategies, social support). This is important given the propositions of the SE Theory (Bandura, 1997) that SE is built on experiences of specific situations and varies with contextual factors.

4.10.6.1 Aim

- To determine the influence of carer and person with dementia characteristics, and psychosocial resources on SE beliefs relating to specific caring tasks.

4.10.6.2 Objectives

- To evaluate the influence of carer characteristics, including gender, ethnicity, level of educational achievement, relationship-type and length of caring on SE relating to specific caring domains.
- To evaluate the influence of person with dementia clinical characteristics (objective caring stressors) including neuropsychiatric symptoms, cognitive function, activities of daily living and dementia severity on SE beliefs relating to specific caring domains.
- To evaluate the influence of psychosocial variables including coping strategies, social support and social network type on SE judgments relating to specific caring domains.

4.10.6.3 Hypotheses

- It is expected that level of SE will not be influenced by carer gender, level of education, duration of caring or person with dementia neuropsychiatric symptoms, cognitive impairment, activities of daily living or dementia severity.
- It is hypothesised that there will be differences in level of carer SE with ethnicity and relationship type.
- It is expected that carer SE will be associated with psychosocial resources including coping strategy, perceived quality of support and social network type.

4.10.6.4 Data analysis

A series of one-way ANOVA, post-hoc Tukey tests and independent-samples t-tests were conducted and Pearson's correlation coefficient values were calculated to determine if SE beliefs for obtaining respite, responding to disruptive behaviours, controlling upsetting thoughts and managing NPS were influenced by carer characteristics including gender, ethnicity, level of education, length of caring, or relationship-type with the person with dementia. It was also evaluated whether carer SE beliefs were influenced by psychosocial variables including coping strategies, quality of support and social network type, as well as person with dementia clinical characteristics such as dementia severity, activities of daily living, NPS and cognition. The family carer and person with dementia characteristics investigated were selected according to existing empirical evidence and theory.

4.10.7 SECTION C: The relationship between family carer self-efficacy beliefs and positive and negative impact related to the caring experience

The reviews in Chapters one and two demonstrated that, taken together, empirical research supports a dual action of carer SE beliefs, in that it both protects against

negative consequences of caring, while precipitating positive consequences. However, as yet, studies have only either investigated the predictive ability of carer SE beliefs in negative or positive aspects of caring. This is the first research to investigate the dual action of carer SE beliefs in a single study.

4.10.7.1 Aim

- To better understand the role of carer SE beliefs on the positive and negative impact of caring.

4.10.7.2 Objectives

- To determine the amount of variance in positive impact and negative impact accounted for by SE beliefs after controlling for carer characteristics and stressors known to influence positive and negative aspects of caring.
- To determine the relative contribution of SE judgments relating to specific caring domains (i.e. obtaining respite, responding to disruptive behaviours, controlling upsetting thoughts, managing NPS) in both the positive and negative impact of caring.

4.10.7.3 Hypotheses

- It is hypothesised that carer SE beliefs will account for a significant proportion of variance in both the positive and negative impact of caring.
- It is hypothesised that carer SE beliefs will demonstrate a dual action; SE beliefs will attenuate negative aspects and enhance positive aspects related to the caring experience.

- It is expected that there will be a different pattern of predictors for negative aspects compared to positive aspects of the caring experience.

4.10.7.4 Data analysis

Pearson's correlation coefficient values were calculated and multiple hierarchical regression analyses conducted to explore the relationship between person with dementia clinical characteristics, SE beliefs relating to specific to caring domains, and positive and negative impact related to the caring experience.

Two hierarchical regression analyses were performed; the dependent variables were positive and negative impact related to caring (as measured by the COPE-Index subscales). In the hierarchical regression, independent variables were entered in an order based on theoretical grounds and existing empirical evidence. Independent variables were entered manually in a series of blocks, in which each variable was assessed in terms of what it added to the prediction of the dependent variable after variables were controlled for. In block one, carer characteristics including gender, ethnicity and level of education were entered to control for the effect of these variables. In the second block, caring stressors were entered, including person with dementia cognition, activities of daily living and NPS. In the final block, SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts were entered. Once all variables were entered, the overall model was assessed in terms of its ability to predict the dependent variable and the relative contribution of each block of variables.

There are a number of assumptions that must be met when performing regression:

- The sample size should be sufficient. Stevens (1996, p.72) recommended roughly 15 cases per predictor for the analysis to be reliable, while Tabachnick

and Fidell (1996, p.132) proposed the following equation that takes into account the number of independent variables: $n > 50 + 8m$ (m is the number of independent variables). The sample of 289 in this study was considered adequate.

- ii. Dependent variables should be normally distributed. This was examined by inspection of the residuals scatterplot and Normal Probability Plot of the regression standardised residuals for both positive and negative impact. These were found to be acceptable.
- iii. Independent variables were inspected for multicollinearity by calculation of Pearson's correlation coefficient, inspection of the variance inflation factor and tolerance statistics (Field, 2005). Multicollinearity exists when independent variables are highly correlated. Tabachnick and Fidell (1996, p. 86) recommend that variables with a correlation of greater than 0.7 should not both be included in the regression analysis. Both the variance inflation factor and tolerance statistic demonstrated no collinearity within the model; VIF values were close to 1 and tolerance statistics were much higher than 0.2. However, Pearson's correlation coefficient demonstrated multicollinearity between NPI scores and SE for managing NPS ($r = .77$), therefore it was decided to omit SE for managing NPS from the analyses.

4.10.8 SECTION D: The impact of caring, psychosocial resources and family carer health-related quality of life

This section builds on the empirical research of Robertson et al. (2007) that examined the pattern of co-occurrence of positive and negative affect in carers of individuals with dementia. However, this is the first study to examine patterns of co-occurrence of negative and positive impact directly related to the caring experience.

4.10.8.1 Aim

- To better understand the impact of caring (positive and negative) and its association with psychosocial resources such as SE and social support, as well as carer health-related QoL.

4.10.8.2 Objectives

- To determine the proportion of carers reporting high versus low negative and positive impact related to the caring experience in attempt to form discrete “impact of caring” categories.
- To determine whether the impact of caring category membership is associated with carer characteristics (e.g. gender, ethnicity, age, level of education and relationship type), SE beliefs relating to specific caring domains, perceived quality of support, and carer health-related QoL.

4.10.8.3 Hypotheses

- It is expected that carers will report the co-occurrence of negative and positive impact associated with the caring experience.
- It is hypothesised that carer SE beliefs, the perceived quality of support, and health-related QoL will be related to impact of caring category membership.

4.10.8.4 Data analysis

The proportion of carers reporting high and low levels of positive and negative impact related to caring was examined using frequency distributions. Median split was used to partition carers into four categories according to their scores on the Positive Impact and Negative Impact of caring subscales, as evaluated by the COPE-Index. These categories

were positive impact (high positive, low negative), negative impact (high negative, low positive), high impact (high positive and high negative) and low impact (low positive and negative) associated with the caring experience. The proportion of carers categorised into each of these four categories was examined.

A series of one-way ANOVA, post-hoc Tukey tests and χ^2 tests were used to compare carer demographics including gender, age, relationship type, level of education and ethnicity across the four impact of caring categories. Similarly, a series of one-way ANOVA and post-hoc Tukey tests were used to examine the level of carer SE for obtaining respite, responding to disruptive behaviours, controlling upsetting thoughts and managing NPS, carer mental and physical health-related QoL and perceived quality of support across the four impact of caring categories.

4.10.9 SECTION E: The relationship between caring domain-specific self-efficacy beliefs and family carer health-related quality of life

The reviews in Chapters one and two highlighted the lack of empirical research that has explored the relationship between domain-specific caring SE beliefs and carer health-related QoL. In particular, there is no existing empirical research that has explored the moderating effect of carer SE beliefs relating to specific domains with carer health-related QoL as an outcome, as research has primarily examined negative outcomes (e.g. depression). This is the first research to examine the moderating effects of SE beliefs relating to specific caring tasks on the association between NPI scores and carer health-related QoL.

4.10.9.1 Aim

- To better understand the association between SE beliefs relating to obtaining respite, responding to disruptive behaviours, controlling upsetting thoughts and managing NPS and carer health-related QoL.

4.10.9.2 Objectives

- To evaluate the relative contribution of SE beliefs relating to specific caring domains in the mental and physical health components of carer QoL, after controlling for carer and person with dementia characteristics.
- To determine whether SE beliefs relating to specific caring domains have moderating effects on the association between NPI scores and the mental and physical health components of carer QoL.

4.10.9.3 Hypotheses

- It is expected that carer SE beliefs will account for a significant amount of variance in both the mental and physical health components of carer QoL.
- It is expected that carer SE beliefs will exert a moderating effect on the association between NPI scores and the mental and physical health components of carer QoL.

4.10.9.4 Data analysis

Pearson's correlation coefficient values were calculated to explore the relationship between person with dementia clinical characteristics, carer SE judgments relating to specific caring tasks and the mental and physical health components of carer QoL.

Two hierarchical multiple regression analyses were performed to determine the amount of variance in the mental and physical health components of carer QoL accounted for by carer SE beliefs, when carer and person with dementia characteristics were controlled for. Multiple regression assumptions (described in section 4.10.7.4 of this Chapter) were checked prior to conducting the analyses and found to be adequate. The variables selected and their order of entry into the regression was based on both theory and empirical evidence.

In the first step of the regression, carer characteristics, including age, gender, level of education and relationship type were entered. In the second step, person with dementia characteristics (objective stressors) were entered, including NPI scores, activities of daily living, and cognition. In the third step, carer SE beliefs relating to obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts were entered. Carer SE for managing NPS was not entered into the regression due to its multicollinearity with NPI scores.

Moderator analysis

A moderator analysis was conducted to evaluate whether SE beliefs relating to specific caring domains moderate the association between NPI scores and carer physical and mental health related QoL. This involved a series of hierarchical multiple regression analyses, with the SF-12 mental and physical health components as dependent variables. A moderator is a variable that impacts upon the direction and/or strength of relationship between an independent and dependent variable. Figure 4.2 presents the hypothesised moderator model of the association between NPI scores, carer SE beliefs and carer health-related QoL.

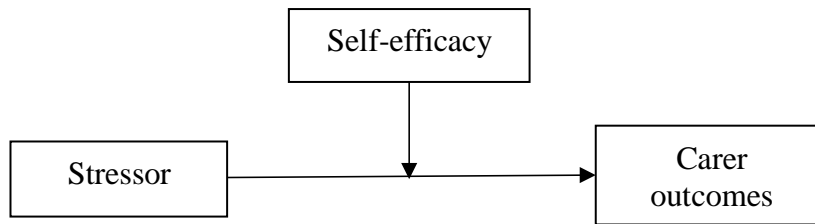


Figure 4.2 The hypothesised moderating effect of carer SE on the association between NPI scores and carer health-related QoL

The multiple linear regression approach used for the moderator analysis was based on Baron and Kenny's (1986) criteria. It involved the evaluation of the relationship between the independent and dependent variable at different levels of the moderator:

- i. The independent variable (NPI scores) was presumed to determine the dependent variable (carer mental and physical health related QoL).
- ii. The independent variable (NPI scores) and the moderator variables (SE beliefs related to specific caring tasks) were centred around the mean (i.e. the mean was subtracted from all values to generate a mean of zero), to reduce problems resulting from multicollinearity.
- iii. The centred independent variable (NPI scores) and moderator variables (carer SE relating to specific caring tasks) were multiplied together to create the interaction terms.
- iv. It was then examined whether the moderator variables (SE beliefs relating to specific caring tasks) changed the strength of the causal relationship between the independent variable (NPI scores) and dependent variables (carer mental and physical health related QoL). The moderator hypothesis is supported if the interaction is significant. There may also be significant main effects for the independent variable (NPI scores) and moderators (carer SE beliefs).

- v. Complete moderation is evident when the causal effect of the independent variable (NPI scores) on the dependent variable (mental and physical health related QoL) returns to zero when the moderator (carer SE belief) is added.

To complete steps four and five, a series of hierarchical regression analyses were performed in which NPI scores, carer SE variables and the interaction terms were regressed onto the mental and physical health components of carer QoL. Once again, regression assumptions were checked and found to be adequate. In the first block, NPI scores and SE beliefs relating to obtaining respite, responding to disruptive behaviours, and controlling upsetting thoughts were entered. In block two, the interactions between carer SE beliefs and NPI scores were entered. Significant interaction terms provided evidence of a moderating effect. It was not possible to evaluate SE for managing NPS as a moderator due to its multicollinearity with NPI scores.

4.10.10 SECTION F: The mediating effects of psychosocial resources on the association between behavioural and psychological symptoms in dementia and family carer health-related quality of life

This section is based on the stress coping model of Haley et al. (1987) described in Chapter one (Figure 1.2), in which coping responses and social support were proposed to mediate the effect of stressors on wellbeing. Although empirical research has demonstrated the importance of coping behaviours (e.g. Kneebone & Martin, 2003) and social support as resources in the caring experience, as yet, only Aneshensel et al. (1995), Haley et al. (1987, 1996) and Goode et al. (1998) have empirically examined psychosocial resources as mediators between caring stressors and outcomes. However these studies are dated and no research has evaluated carer health-related QoL as the outcome of the caring experience. This is the first study to examine the mediating effect

of psychosocial resources specifically on the association between NPI scores and the mental health component of carer QoL.

4.10.10.1 Aim

To construct and evaluate a modified version of the stress coping model of Haley et al. (1987), in which psychosocial resources including coping strategies, SE beliefs and social support mediate the association between NPI scores and the mental health component of carer QoL.

4.10.10.2 Hypotheses

The hypothesised model of the mediating effects of psychosocial resources on the association between NPI scores and the mental health component of carer QoL is shown in Figure 4.3.

- It is expected that higher NPI scores will be directly associated with reduced mental health related QoL.
- It is also hypothesised that psychosocial resources will mediate the association between NPI scores and the mental health component of carer QoL. More specifically, higher NPI scores will be related to lower SE for controlling upsetting thoughts, lower perceived quality of support and higher use of dysfunctional coping strategies, which in turn will be associated with reduced carer mental health related QoL.
- It is expected that SE for controlling upsetting thoughts will exert an indirect effect on the mental health component through dysfunctional coping strategies and quality of support. More specifically, higher SE will be related to reduced use of dysfunctional behaviours and higher perceived quality of support, which

in turn will be related to improved mental health related QoL.

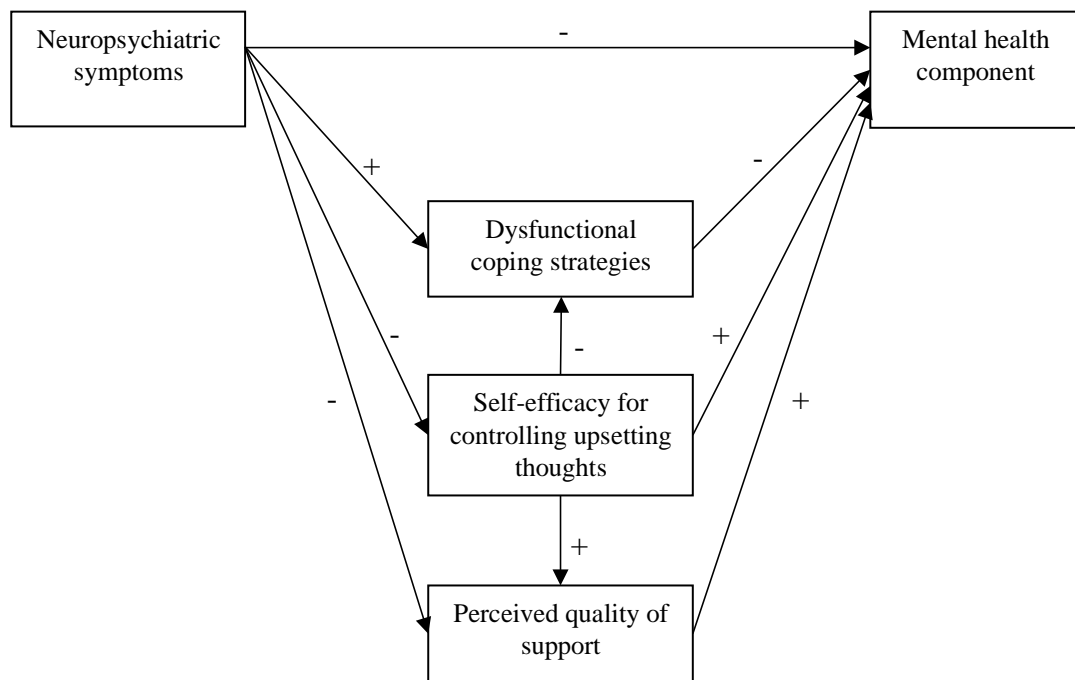


Figure 4.3 Hypothesised model of the mediating effects of psychosocial resources

4.10.10.3 Data analysis

Pearson's correlation coefficient values were calculated to determine the strength of associations between NPS of dementia, SE beliefs relating to specific caring domains, quality of support, coping strategies and the mental health component of carer QoL. Path analysis was then conducted using the software package AMOS (Arbuckle, 2012) to evaluate the hypothesised model.

Path analysis is a type of structural equation modelling (SEM) that can be used to establish causal relationships between variables. It is an extension of the regression model and is used "to test the fit of causal models against correlation matrices for the variables in the model" (Todman & Dugard, 2007, p.145). This technique provides a means of evaluating the importance of different paths between variables, including

indirect and direct effects. The output provides an indication of how well the hypothesised model fits the data (Byrne, 2001; Todman & Dugard, 2007). Its benefits include its flexibility in building causal models, its capacity to examine complex relationships and its ability to represent complex theory in a single, integrated model.

There are several steps outlined in path analysis/SEM. These include model specification, model identification, data preparation and screening, estimation and evaluation of fit (Kaplan, 2000; Kline, 2005):

Model specification

This stage involved the specification of variables and parameters in the path diagram. Model specification was guided by a combination of theory and empirical evidence to ensure the model was theory driven. Measured variables were specified, with these having associated error terms. The types of relations between variables were also specified, either as non-directional (covariance or correlation coefficient) or directional (regression coefficient). Parameters were specified to indicate the nature of relation between variables (fixed or free). Any unspecified associations were assumed to be zero.

Model identification

Identification checks were performed as part of the model fitting process. This involved examination of whether there were an adequate number of known parameters in the model to generate meaningful results. For the model to be identified, the number of parameters to be estimated should be equal to or less than the number of observations.

Data preparation and screening

A number of assumptions must be met before SEM can be performed:

- i. It is important that the sample size is adequate, as parameter estimates and fit indices are sensitive to sample size. The recommended sample size is typically determined by model complexity. For example, Kline (1998) recommended 10 to 20 cases per estimated parameter, while Weston and Gore (2006) recommend a sample size of approximately 200 for small to medium sized models. The sample size in this study was considered adequate to evaluate the proposed model.
- ii. SEM estimation techniques assume normality, as model fit is sensitive to the distribution of variables (Byrne, 2001). The distribution of data was evaluated by the visual inspection of histograms and the inspection of skewness and kurtosis values. Despite the fact that visual inspection demonstrated some variables were non-normally distributed, skewness and kurtosis values did not indicate a significant deviation from normality. In addition, due to the universally recognised difficulties with the interpretation of transformed data, it was decided to proceed with the analysis without transformation. The inspection of data distribution was described earlier in this Chapter (section 4.10.4).
- iii. Data were examined for multicollinearity by inspection of Pearson's correlation coefficient values. For SEM, Kline (2005) recommended correlations higher than $r = .85$ as indicative of multicollinearity. No multicollinearity was found.

Estimation

Maximum likelihood estimation was conducted to determine the values of the unknown parameters and the associated error terms. Both unstandardised and standardised parameter estimates and their significance was calculated.

Model Fit

The model was evaluated in terms of significance of estimated parameters (direction and magnitude), theoretical meaning of the model and the fit of the model to the observed data. A parsimonious fit was desired, in which the model provides the simplest explanation of the data. For absolute fit, the null hypothesis states that there will be no significant difference between the hypothesised model and the observed data (the model fit the data well).

Global model fit was assessed using χ^2 , with a non-significant value indicative that the model fit the data well. However, χ^2 is sensitive to sample size. Therefore, as recommended by Tabachnick and Fidell (1996), the ratio of χ^2 to degrees of freedom was examined. A value of less than two indicates that the model fit the observed data well. Other descriptive fit statistics used to evaluate model fit included the goodness of fit index (GFI; Joreskog & Sorbom, 1981), comparative fit index (CFI; Bentler, 1990), normal fit index (NFI) and the root mean square error of approximation (RMSEA; Steiger, 1990). The fit indices NFI, GFI, and CFI compare the hypothesised model with the null model, which specifies no relationships among variables. These fit indices vary between 0 and 1, and have a critical value of 0.90, with values higher than 0.90 indicative of good model fit (Bentler, 1990). The RMSEA index of fit can range between 0 and 1, with 0 indicating that the model fits the data exactly. Hu and Bentler (1999) recommended values below 0.06 as indicative of a good fit.

CHAPTER 5: RESULTS

5.1 SECTION A: Participant demographics and clinical characteristics

A total of 640 expressions of interest for the SHIELD Carer Supporter Programme were received from family carers and 639 were screened for eligibility. Of these, 292 family carers consented into the trial, while the remaining 347 were not eligible. Of the family carers that were ineligible, 170 declined involvement without giving any reason and the remaining 177 carers were not suitable for a number of reasons (reported in Table 5.1).

Table 5.1 Reasons for participant ineligibility into the research trial

Reason for ineligibility	<i>n</i>
Person with dementia deceased or in care	23
No longer caring for the person with dementia	2
Paid carer or not a family member/close friend	3
DSM-IV criteria not met (i.e. no diagnosis of dementia)	4
Time constraints	33
Out of area	6
Carer physical ill-health, cognitive impairment or stress	13
Person with dementia ill-health	5
Involved in other research	7
Dementia not primary diagnosis (e.g. Parkinson's disease)	4
Carer did not want person with dementia to be involved	10
Unable to contact	67
Carer declined involvement	170

Chapter three reported the demographics and clinical variables related to only a subsample of participants, however the demographic and clinical variables presented in this section relate to the total sample of participants who took part in the SHIELD Carer Supporter Programme. Of the 292 family carers consented into the trial, one withdrew before randomisation and two were removed before analysis due to there being no data

recorded for them at any time point in the trial. Overall, 289 participants were included in the analysis.

5.1.1 Family carer demographics

Family carer demographic data are summarised in Table 5.2. The mean age was 67 years, with a range between 21 and 91 years. Family carers were predominantly female, white, and were married or living with a partner. Over two-thirds of carers were school educated only, with less than one-third having completed further education (e.g. diplomas and university education). The mean length of time caring was 4.4 years (53 months), with caring duration ranging between 0 and 25 years. Roughly two-thirds of carers were spouses or partners to the person with dementia, while one-third were sons/daughters caring for a parent. Other relationships between participants included close friends and neighbours. In eight out of 10 cases family carers were co-residing with the person that they were caring for.

Table 5.2 Family carer demographics ($n = 289$)

	Total
Gender n (%)	
Female	197 (68.2)
Age M (SD) Range	66.7 (12.3) 21-91
Marital status n (%)	
Married/co-habiting/civil partner	248 (85.8)
Separated/divorced/widowed	16 (5.5)
Single/other	25 (8.7)
Relationship type n (%)	
Spouse/partner	183 (63.3)
Adult child/other family	101 (34.9)
Other relationship	5 (1.7)
Cohabiting with relative with dementia n (%)	230 (79.6)
Ethnicity n (%)	
White (British/Irish/Other)	269 (93.1)
Black (Caribbean/African/Other)	8 (2.8)
Asian (Indian/Pakistani/Other)	10 (3.5)
Mixed/other ethnic group	2 (0.6)
Level of education n (%)	
School educated only	201 (69.6)
Further education	88 (30.4)
Time caring in months ($n = 285$) M (SD) Range	52.5 (38.0) 0 - 300

5.1.2 Family carer clinical variables

Table 5.3 reports family carer clinical variables. The COPE-Index was used to evaluate the positive and negative impact of caring and perceived quality of social support. The SF-12 evaluated carer QoL and included both a mental and physical health component. Scores for the mental health component were marginally higher than for the physical health component. The Brief-COPE was used to assess emotion focused, problem-focused and dysfunctional coping strategies, with carers typically reporting the use of all three strategies. The PANT assessment of social network type (presented in Table

5.4) found that most family carers reported a locally integrated, family dependent or local self-contained network type.

Table 5.3 Family carer clinical variables

Outcome measure		<i>M (Se)</i>	Mdn	<i>SD</i>	Range	Maximum possible range	
SF12 UK version (<i>n</i> = 286)	Mental component	39.4 (0.41)	40.4	7.0	17 – 51		
	Physical component	36.5 (0.43)	37.5	7.3	16 – 51		
	COPE Index	Negative impact	13.1 (0.24)	13.0	4.1	7 – 26	8-32
		Positive impact	12.6 (0.13)	13.0	2.3	6 – 16	4-16
	Quality of support	10.6 (0.18)	10.0	3.1	4 – 16	4-16	
NPI	SE for managing NPS	12.9 (0.41)	12.0	7.0	0 – 37	0-48	
RSSE	SE OR	274.0 (8.50)	290.0	144.0	0 – 500	0-500	
	SE DB	351.0 (5.91)	363.0	100.0	0 – 500	0-500	
	SE CT	360.0 (6.25)	390.0	106.0	20 – 500	0-500	
BRIEF-Cope	Emotion focused coping	22.2 (0.27)	22.0	4.6	10 – 40	10-40	
	Problem focused coping	14.4 (0.23)	15.0	4.0	6 – 24	6-24	
	Dysfunctional coping	18.8 (0.26)	19.0	4.5	12 – 37	12-48	

Note. The *n* for each measure was 289 unless stated. NPS = neuropsychiatric symptoms; SEOR = self-efficacy for Obtaining Respite; SEDB = self-efficacy for Responding to Disruptive Behaviours; SECT = self-efficacy for controlling upsetting thoughts.

Table 5.4 Family carer social network type (n = 286)

		<i>n</i>	%
PANT	Family dependent	83	29.0
	Locally integrated	90	31.5
	Local self-contained	63	22.0
	Wider community focused	24	8.4
	Private	26	9.1

5.1.3 Profile of family carer self-efficacy beliefs

SE beliefs relating to four specific caring domains were evaluated by two distinct measurement scales: SE for Obtaining Respite, Responding to Disruptive Behaviours (i.e. memory related problems) and Controlling Upsetting Thoughts were evaluated by the RSSE, and SE for managing NPS of dementia was evaluated by the Carer Efficacy Scale (developed in Chapter three). It is important to note that the RSSE subscales were positively scored, with a higher score indicative of higher SE, however the Carer Efficacy Scale was negatively scored with a higher score indicative of lower SE. Of the RSSE subscales, the highest SE was reported for Controlling Upsetting Thoughts and Responding to Disruptive Behaviours, whilst SE for Obtaining Respite was considerably lower. This is consistent with the findings reported in Chapter three.

Figures 5.1 to 5.4 show the pattern of distribution of scores for caring domain-specific SE beliefs. The distribution of scores for SE for Obtaining Respite was slightly kurtotic (Figure 5.1), with a fairly even distribution across the subscale and larger variance than the other SE subscales. This indicates greater heterogeneity in levels of SE for obtaining respite between carers. The pattern of distribution of scores for SE for Responding to Disruptive Behaviours, Controlling Upsetting Thoughts and managing NPS were similar (Figures 6.2-6.4). The distribution of scores for SE for Responding to Disruptive Behaviours and SE for Controlling Upsetting Thoughts demonstrated marginal negative skew, whereas SE for managing NPS demonstrated a slight positive skew. This indicates that family carers tend to report higher levels of SE beliefs for these domains, which is likely a result of the sample being predominantly comprised of carers of individuals with mild to moderate dementia. These individuals typically present with lower levels of disruptive behaviours, NPS and functional impairment, as well as more

stability in the community. Further details relating to the inspection of data distribution is reported in Chapter four.

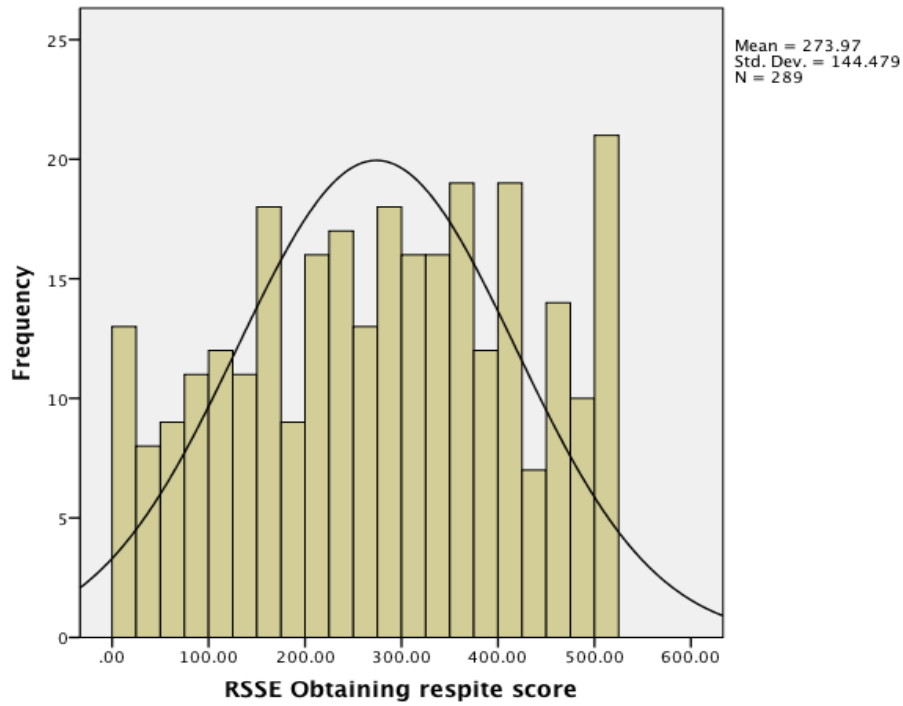


Figure 5.1 Frequency distribution for SE for Obtaining Respite

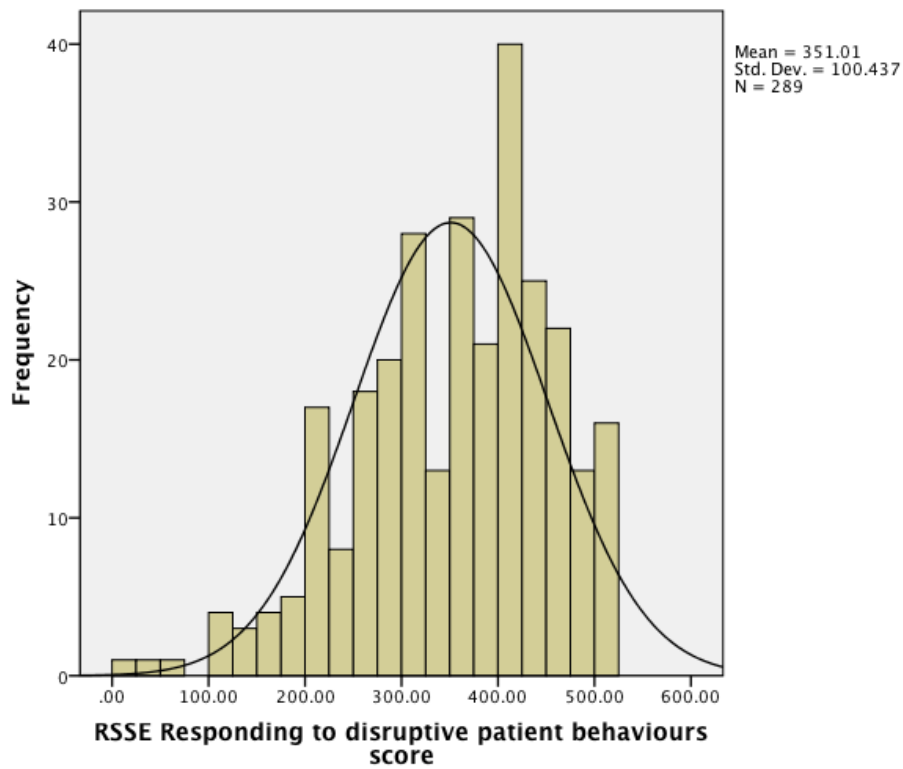


Figure 5.2 Frequency distribution for SE for Responding to Disruptive Behaviours

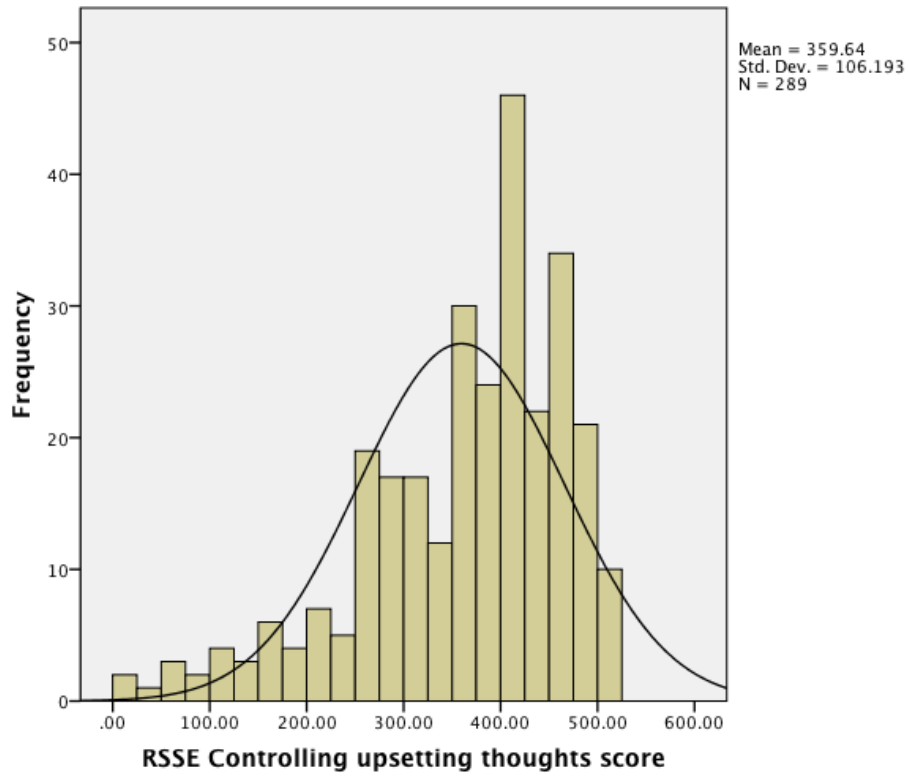


Figure 5.3 Frequency distribution for SE for Controlling Upsetting Thoughts

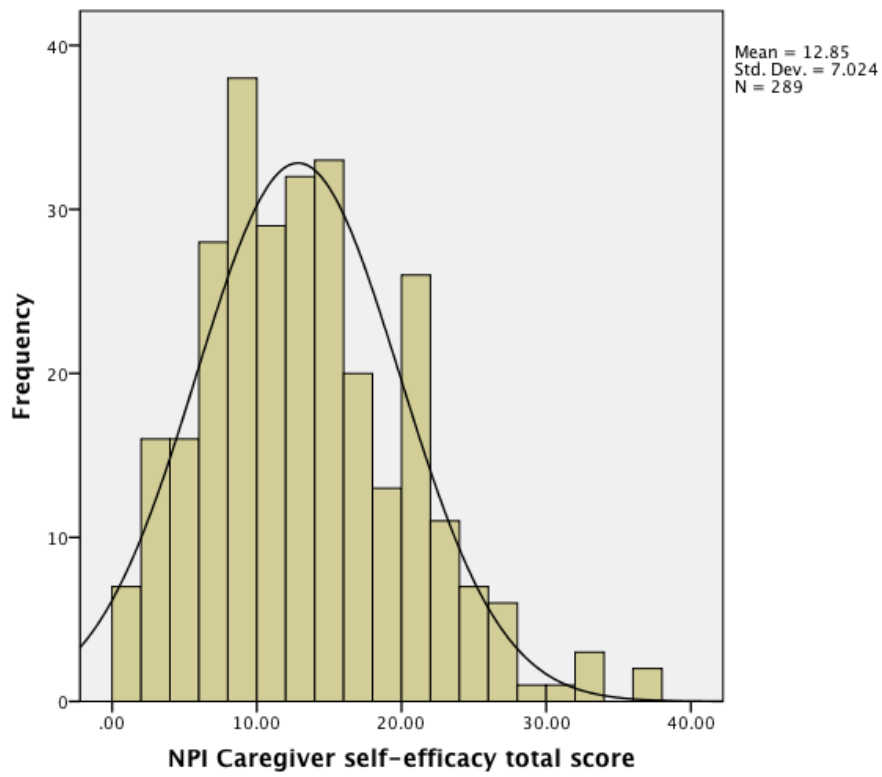


Figure 5.4 Frequency distribution for SE for managing NPS of dementia

5.1.4 Internal consistency of the self-efficacy scales

The Carer Efficacy Scale and RSSE subscales demonstrated adequate internal consistency, which indicates good inter-item reliability. The Cronbach's alpha coefficient for the RSSE Obtaining Respite subscale (five items) was 0.90, Responding to Disruptive Behaviours (five items) was 0.91 and Controlling Upsetting Thoughts (five items) was 0.91. The Cronbach's alpha coefficient for the 12-item Carer Efficacy Scale was slightly lower at .79, which might be a result of the lower corrected item-total correlation of the euphoria item (0.29). However, removal of this item had little effect on Cronbach's alpha coefficient, indicating it should be retained in the scale. Despite this, all other item-total correlations were greater than 0.3 for both the Carer Efficacy Scale and the RSSE subscales, demonstrating the importance of each item. The internal consistency of the Carer Efficacy Scale was almost identical to that reported in the subsample of family carers in the psychometric evaluation described in Chapter three.

5.1.5 Pearson's correlations between the self-efficacy subscales

Table 5.7 reports that Pearson's correlation coefficient values between all carer SE scales were significant, although most were modest. The strongest association was between SE for responding to disruptive behaviours (e.g. memory related problems) and controlling upsetting thoughts ($r = .57, p < .001$), indicating that these domains are closely related. As expected, there were small correlations between SE for obtaining respite and SE for responding to disruptive behaviours ($r = .25, p < .001$) and SE for managing NPS ($r = -.29, p < .001$). However, there was a moderate positive correlation between SE for obtaining respite and SE for controlling upsetting thoughts ($r = .37, p < .001$), between SE for responding to disruptive behaviours and SE for managing NPS ($r = -.32, p < .001$), and SE for controlling upsetting thoughts and SE for managing NPS ($r = .38, p < .001$). Generally, higher SE in one caring domain was

related to higher SE in the other caring domains. Pearson's correlation coefficient values between the Carer Efficacy Scale and RSSE subscales were similar in size and direction to those reported in the subsample of carers in Chapter three.

5.1.6 Person with dementia demographics

Person with dementia demographics are summarised in Table 5.5. There were slightly fewer participants with dementia included in the analysis ($n = 285$) compared to family carers, as some chose not to take part in the research assessments, while others were unable to complete the assessment due to cognitive impairment or physical ill health. Of the persons with dementia, the mean age was 80 years, with a range between 53 and 101 years. The sample comprised marginally more females than males. Persons with dementia were predominantly married, cohabiting or had a partner, and most were white and were school educated only. Most individuals were diagnosed with Alzheimer's Disease (51%), 18% were diagnosed with vascular dementia, while in 15% of cases the dementia type was unknown. The mean length of time since diagnosis was 2.5 years, with a range between 1 month and 13.6 years.

Table 5.5 Person with dementia demographics

	Total
Gender ($n = 285$) n (%)	
Female	153 (53.7)
Age ($n = 283$) M (SD) Range	79.6 (7.9) 53-101
Marital status ($n = 284$) n (%)	
Married/co-habiting/civil partner	196 (69.0)
Separated/divorced/widowed	83 (29.2)
Single/other	5 (1.8)
Living situation ($n = 284$) n (%)	
Living alone	44 (15.5)
Cohabiting with partner	194 (68.3)
Living in the community with relatives, friends/other people	46 (16.3)
Ethnicity ($n = 285$) n (%)	
White (British/Irish/Other)	266 (93.3)
Black (Caribbean/African/Other)	8 (2.8)
Asian (Indian/Pakistani/Other)	11 (3.9)
Level of education ($n = 277$) n (%)	
School educated only	230 (83.0)
Further education	47 (17.0)
Type of dementia ($n = 263$) n (%)	
Alzheimer's Disease	134 (51.0)
Vascular dementia	49 (18.6)
Other/not known	80 (30.4)
Time since diagnosis in months ($n = 257$) M (SD) Range	31.3 (26.3) 1 - 164

5.1.7 Person with dementia clinical variables

Table 5.6 reports person with dementia clinical variables. The CDR scale evaluated dementia severity and indicated most individuals had mild (63%) or moderate dementia (27%), while only 10% had severe dementia. The MMSE assessed the cognition of the person with dementia; the mean score was indicative of moderate dementia severity. The ADCS-ADL evaluated activities of daily living and demonstrated a large variance in the daily activities of individuals with dementia. The NPI illustrated that almost all carers reported the presence of NPS of dementia, however, the mean NPI value was

indicative of a moderate level of NPS, possibly due to the fact that most of the sample had mild dementia. The large variance indicated considerable variability in the level of NPS reported.

Table 5.6 Person with dementia clinical variables

Outcome measure		<i>M (Se)</i>	<i>SD</i>	Maximum possible range	Range	<i>n (%)</i>
ADCS-ADL	ADL	42.1 (1.1)	17.8	0-78	0 – 78	
MMSE	Cognition	17.3 (0.4)	6.5	0-30	0 – 30	
NPI	NPS	24.2 (1.1)	19.2	0-109	0 – 109	
CDR (<i>n</i> = 279)	0.5 - 1 (Mild)					176 (63)
	2 (Moderate)					75 (27)
	3 (Severe)					28 (10)

Note. The *n* for each measure was 289 unless stated

Table 5.7 Pearson correlation coefficient values between carer and person with dementia clinical variables (n = 289)

	Carer QoL			Carer self-efficacy				Support	Coping strategies			PwD characteristics		
	PI	MCS	PCS	SEOR	SEDB	SECT	SENPS	QS	EFC	PFC	DC	NPS	COG	ADL
NI	-.46***	-.51***	-.40***	-.38***	-.35***	-.49***	.40***	-.39***	-.098	.054	.46***	.44***	-.080	-.34***
PI	-	.37***	.23***	.33***	.61***	.50***	-.26***	.33***	.14*	-.031	-.37***	-.18**	.006	.13*
MCS	-	-	.84***	.34***	.35***	.41***	-.34***	.31***	.052	-.12*	-.43***	-.33***	.013	.20***
PCS	-	-	-	.29***	.27***	.33***	-.24***	.26***	.018	-.12*	-.32***	-.22***	.035	.15*
SEOR	-	-	-	-	.25***	.37***	-.29***	.46***	.15*	-.066	-.24***	-.25***	.064	.15**
SEDB	-	-	-	-	-	.57***	-.32***	.21***	.18**	.049	-.41***	-.25***	-.011	.042
SECT	-	-	-	-	-	-	-.38***	.33***	.10	-.13*	-.39***	-.32***	-.008	.081
SENPS	-	-	-	-	-	-	-	-.21***	.038	.14*	.28***	.77***	-.15*	-.21***
QS	-	-	-	-	-	-	-	-	.12*	-.076	-.17**	-.20**	.064	.14*
EFC	-	-	-	-	-	-	-	-	-	.45**	.087	.050	-.073	.014
PFC	-	-	-	-	-	-	-	-	-	-	.29***	.14***	-.004	.031
DC	-	-	-	-	-	-	-	-	-	-	-	.22***	.030	-.075
NPS	-	-	-	-	-	-	-	-	-	-	-	-	-.29***	-.35***
COG	-	-	-	-	-	-	-	-	-	-	-	-	-	.50***
ADL	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Note. NI = negative impact; PI = positive impact; MCS = mental component score; PCS = physical component score; SEOR = self-efficacy for obtaining respite; SEDB = self-efficacy for responding to disruptive behaviours; SECT = self-efficacy for controlling upsetting thoughts; SENPS = self-efficacy for managing neuropsychiatric symptoms; QS = quality of support; EFC = emotion-focused coping; PFC = problem focused coping; DC = dysfunctional coping; NPS = neuropsychiatric symptoms. This table is important and will be referred at several points throughout the results Chapter.

* $p < .05$, ** $p < .01$, *** $p < .001$

5.2 SECTION B: Factors associated with self-efficacy beliefs relating to specific caring domains

The associations between carer characteristics, psychosocial variables, person with dementia clinical characteristics and carer SE judgments were evaluated using Pearson's correlation coefficient, independent sample t-tests, one-way ANOVA and post-hoc Tukey tests (presented in Tables 5.7 – 5.9). Aims and hypotheses are detailed in Chapter four.

Table 5.8 The relationship between carer SE beliefs and social network type

PANT network type <i>n</i> = 286	Self-efficacy			
	Obtaining Respite <i>M</i> (<i>SD</i>)	Responding to Disruptive Behaviours <i>M</i> (<i>SD</i>)	Controlling Upsetting Thoughts <i>M</i> (<i>SD</i>)	Managing NPS (Carer Efficacy Scale) <i>M</i> (<i>SD</i>)
Family dependent <i>n</i> = 83	314 (134)	362 (104)	368 (113)	14 (7)
Locally integrated <i>n</i> = 90	289 (140)	358 (95)	370 (95)	12 (7)
Local self-contained <i>n</i> = 63	234 (148)	351 (104)	335 (114)	14 (7)
Wider community focused <i>n</i> = 24	246 (127)	293 (83)	349 (95)	13 (5)
Private <i>n</i> = 26	206 (162)	345 (107)	363 (115)	11 (8)
Statistic	^a <i>F</i> (4, 281) = 4.92 <i>p</i> = .001**	^b <i>F</i> (4, 281) = 2.42 <i>p</i> = .049*	<i>F</i> (4, 281) = 1.27 <i>p</i> = .28	<i>F</i> (4, 281) = 1.25 <i>p</i> = .29

^aPost-hoc comparisons demonstrated self-efficacy for obtaining respite was significantly higher in the family dependent network compared to the self-contained or private network type. ^bPost-hoc comparisons demonstrated self-efficacy for responding to disruptive behaviours was significantly lower in the wider community focused network type compared to family dependent or locally integrated network type.
p* < .05, *p* < .01, ****p* < .001

Table 5.9 Family carer and person with dementia characteristics, and carer self-efficacy beliefs

		Self-efficacy			
		Obtaining Respite	Responding to Disruptive Behaviours	Controlling Upsetting Thoughts	Managing NPS (Carer Efficacy Scale)
Length of caring (<i>n</i> = 285)		<i>r</i> (285) = .030 <i>p</i> = .62	<i>r</i> (285) = .059 <i>p</i> = .32	<i>r</i> (285) = .089 <i>p</i> = .14	<i>r</i> (285) = .081 <i>p</i> = .17
Gender	Female <i>M</i> (<i>SD</i>) <i>n</i> = 197	277 (139)	345 (102)	355 (104)	13 (7)
	Male <i>M</i> (<i>SD</i>) <i>n</i> = 92	267 (156)	363 (97)	369 (110)	13 (7)
		<i>t</i> (287) = 0.55 <i>p</i> = .58	<i>t</i> (287) = 1.41 <i>p</i> = .16	<i>t</i> (287) = 1.07 <i>p</i> = .29	<i>t</i> (287) = 0.32 <i>p</i> = .75
Education level	School educated <i>M</i> (<i>SD</i>) <i>n</i> = 201	275 (145)	350 (103)	369 (102)	13 (7)
	Further educated <i>M</i> (<i>SD</i>) <i>n</i> = 88	272 (144)	354 (96)	337 (112)	13 (7)
		<i>t</i> (287) = 0.14 <i>p</i> = .89	<i>t</i> (287) = 0.28 <i>p</i> = .78	<i>t</i> (287) = 2.37 <i>p</i> = .018*	<i>t</i> (287) = 0.014 <i>p</i> = .99
Ethnicity	White <i>M</i> (<i>SD</i>) <i>n</i> = 269	275 (143)	349 (101)	359 (104)	359 (104)
	Black <i>M</i> (<i>SD</i>) <i>n</i> = 8	291 (125)	367 (91)	444 (74)	444 (74)
	Asian <i>M</i> (<i>SD</i>) <i>n</i> = 10	237 (183)	383 (102)	312 (131)	306 (144)
		<i>F</i> (2, 284) = 0.39 <i>p</i> = .68	<i>F</i> (2, 284) = 0.67 <i>p</i> = .51	^a <i>F</i> (2, 284) = 3.92 <i>p</i> = .021*	<i>F</i> (2, 284) = 0.81 <i>p</i> = .45
Relationship type	Spousal/partner <i>M</i> (<i>SD</i>) <i>n</i> = 183	264 (143)	343 (100)	360 (102)	12 (7)
	Adult child <i>M</i> (<i>SD</i>) <i>n</i> = 101	293 (145)	369 (98)	361 (110)	14 (7)
	Other relationship <i>M</i> (<i>SD</i>) <i>n</i> = 5	238 (179)	275 (100)	332 (179)	11 (6)
		<i>F</i> (2, 286) = 1.47 <i>p</i> = .23	^b <i>F</i> (2, 286) = 3.79 <i>p</i> = .024*	<i>F</i> (2, 286) = 0.17 <i>p</i> = .84	^c <i>F</i> (2, 286) = 3.67 <i>p</i> = .027*

Dementia severity (CDR) <i>M (SD)</i> <i>n = 279</i>	Mild <i>n = 176</i>	286 (141)	352 (101)	364 (104)	11 (8.63)
	Moderate <i>n = 75</i>	250 (143)	344 (100)	349 (111)	15 (8.89)
	Severe <i>n = 28</i>	260 (170)	346 (104)	359 (124)	15 (10.09)
		$F(2, 276) = 1.76$ $p = .18$	$F(2, 276) = 0.49$ $p = .83$	$F(2, 276) = 0.51$ $p = .60$	${}^dF(2, 276) = 4.00$ $p = .019^*$

Note. ^aPost-hoc comparisons demonstrated self-efficacy for controlling upsetting thoughts was significantly higher for black carers compared to white and Asian carers; ^bself-efficacy for responding to disruptive behaviours was significantly higher in adult children caring for a parent compared to spouses or other relationship types; ^cself-efficacy for managing NPS was significantly lower for adult children compared to spouse/partner carers; ^dself-efficacy for managing NPS was significantly lower in carers of individuals with moderate dementia compared to mild dementia.

* $p < .05$, ** $p < .01$, *** $p < .001$

5.2.1 Self-efficacy for obtaining respite

5.2.1.1 Family carer characteristics

The associations between carer SE beliefs and carer characteristics are reported in Table 5.9. SE for obtaining respite did not differ with carer demographics including level of education, ethnicity, relationship type, gender or caring duration.

5.2.1.2 Family carer psychosocial resources

Pearson's correlation coefficient values between carer SE beliefs, coping strategies and social support are reported in Table 5.7. SE for obtaining respite was modestly correlated with lower use of dysfunctional coping behaviours ($r = -.24, p < .001$) and was not correlated with emotion focused ($r = .15, p = \text{n.s.}$) or problem focused coping strategies ($r = -.066, p = \text{n.s.}$). There was a moderate positive correlation ($r = .46, p < .001$) between SE for obtaining respite and perceived quality of support, with higher SE related to higher perceived quality. Table 5.8 shows that there were differences in SE for obtaining respite according to social network type ($p = .001$); SE was higher in the family dependent network ($M = 314$) compared to the self-contained ($M = 234$) or private ($M = 206$) network type.

5.2.1.3 Person with dementia clinical variables

Pearson's correlation coefficient values between carer SE beliefs and person with dementia clinical variables are reported in Table 5.7. Higher SE was modestly correlated with better performance of activities of daily living ($r = .15, p = .009$) and lower NPI scores ($r = -.25, p < .001$). However, Table 5.9 shows that SE for obtaining respite did not vary with dementia severity [$F(2, 276) = 1.76, p = .18$] or cognition ($r = .064, p = \text{n.s.}$).

5.2.2 Self-efficacy for responding to disruptive behaviours

5.2.2.1 Family carer characteristics

Table 5.9 shows that SE for responding to disruptive behaviours did not differ with carer educational level, ethnicity, gender or caring duration. However, SE was higher in sons/daughters caring for a parent ($M = 369$) compared to spouses ($M = 343$) or other relationship types ($M = 275$).

5.2.2.2 Family carer psychosocial variables

Table 5.7 demonstrates that higher SE for responding to disruptive behaviours was moderately correlated with lower use of dysfunctional coping strategies ($r = -.41, p < .001$). However, higher SE for responding to disruptive behaviours had a small correlation with higher emotion focused coping ($r = .18, p = .002$), and was not related to problem focused coping strategies ($r = .049, p = \text{n.s.}$). There was only a small positive correlation between SE for responding to disruptive behaviours was and perceived quality of support ($r = .21, p < .001$). In addition, Table 5.8 shows that SE for responding to disruptive behaviours varied according to social network type ($p = .049$); SE was lower in the wider community focused network type ($M = 293$) compared to the family dependent ($M = 362$) or locally integrated networks ($M = 358$).

5.2.2.3 Person with dementia clinical variables

Level of carer SE for responding to disruptive behaviours was not associated with person with dementia clinical characteristics, including activities of daily living, dementia severity or cognition (reported in Table 5.7 and 5.9). However, there was a small correlation between higher SE for responding to disruptive behaviours and lower NPI scores ($r = -.25, p < .001$).

5.2.3 Self-efficacy for controlling upsetting thoughts

5.2.3.1 Family carer demographics

Table 5.9 shows that there were no differences in level of SE for controlling upsetting thoughts with relationship type, gender or caring duration. However, carers who were school educated only had higher SE for controlling upsetting thoughts than those with further education ($p = .018$). In addition, SE for controlling upsetting thoughts was higher for black carers compared to white and Asian carers ($p = .021$).

5.2.3.2 Family carer psychosocial resources

Table 5.7 illustrates that SE for controlling upsetting thoughts was not correlated with emotion focused coping strategies ($r = .10, p = .084$) and only weakly correlated with problem-focused coping ($r = -.13, p = .023$). However, higher SE for controlling upsetting thoughts was moderately correlated with a lower use of dysfunctional coping strategies ($r = -.39, p < .001$), as well as with higher perceived quality of support ($r = .33, p < .001$). Table 5.8 demonstrates that there were no differences in SE for controlling upsetting thoughts across social network types ($p = n.s$).

5.2.3.3 Person with dementia clinical characteristics

A lower level of SE for controlling upsetting thoughts was moderately correlated with higher NPI scores ($r = -.32, p < .001$), however SE did not differ with activities of daily living, cognition or dementia severity (reported in Table 5.7 and 5.9).

5.2.4 Self-efficacy for managing neuropsychiatric symptoms of dementia

5.2.4.1 Family carer characteristics

Table 5.9 shows that SE for managing NPS did not differ with level of education, ethnicity, gender or caring duration. However, SE for managing NPS differed with relationship type ($p = .027$); SE was significantly lower for son/daughter carers compared to spouses or partners.

5.2.4.2 Family carer psychosocial resources

Tables 5.7 and 5.8 demonstrate that SE for managing NPS was not associated with the use of emotion focused coping ($p = n.s$), however SE for managing NPS demonstrated a small correlation with the use of problem focused coping ($r = .14, p = .017$) and dysfunctional coping strategies ($r = .28, p < .001$). There was a small correlation between SE for managing NPS and perceived quality of support ($r = .21, p < .001$), however level of SE was not related to social network type ($p = n.s$).

5.2.4.3 Person with dementia clinical variables

Table 5.7 illustrates that higher SE for dealing with NPS was weakly correlated with better performance of activities of daily living ($r = -.21, p < .001$), a higher level of cognitive function ($r = -.15, p = .012$) and strongly correlated with lower NPI scores ($r = .77, p < .001$). However, Table 6.9 shows that SE for managing NPS was associated with dementia severity; lower SE was found in carers of individuals with moderate dementia compared to mild dementia [$F(2, 276) = 4.00, p = .019$].

5.2.5 Summary

The distinct pattern of associations between SE beliefs relating to specific caring domains and other variables are compatible with the presupposition of SE Theory

concerning the domain-dependency of SE beliefs. Carer SE beliefs are most strongly related to psychosocial resources such as dysfunctional coping strategies, quality of support and social network type, and also demonstrate some variability with carer characteristics such as relationship type, level of education and ethnicity. With the exception of NPS, carer SE beliefs have little or no association with person with dementia clinical characteristics.

5.3 SECTION C: The relationship between family carer self-efficacy beliefs and positive and negative impact related to the caring experience

The amount of variance in the positive and negative impact of caring accounted for by carer SE beliefs was evaluated using Pearson's correlation coefficient and multiple hierarchical regression analyses.

5.3.1 Predicting the positive impact of caring

Table 5.7 reports Pearson's correlation coefficient values between carer SE judgments, person with dementia clinical characteristics and positive impact related to caring.

Higher positive impact was strongly correlated with higher SE for responding to disruptive behaviours ($r = .61, p < .001$) and with SE for controlling upsetting thoughts ($r = .50, p < .001$), was moderately correlated with higher SE for obtaining respite ($r = .33, p < .001$), and modestly correlated with higher SE for managing NPS ($r = -.26, p < .001$). The positive impact of caring was not associated with person with dementia clinical characteristics; positive impact demonstrated very small correlations with activities of daily living ($r = .13, p < .05$), with NPI scores ($r = -.18, p < .01$), and there was no correlation with cognition ($r = .006, p > .05$).

Table 5.10 reports the hierarchical multiple regression analysis with the positive impact of caring as the dependent variable (as evaluated by the COPE-Index subscale). The full model explained 44% of the variance in positive impact [$F(9, 265) = 23.26, p < .001; R^2 = .44$]. The largest R^2 change occurred in the third step of the regression [R^2 change = .38; $F(3, 265) = 59.91, p < .001$], with SE beliefs accounting for 38% of the incremental variance in positive impact related to caring, beyond carer characteristics and person with dementia clinical features (objective caring stressors). Person with dementia

clinical features (entered in the second step) accounted for only 4% of the incremental variance [R^2 change = .044, $F(3, 265) = 4.21$, $p = .006$].

In the final model, higher SE for obtaining respite ($\beta = .15$, $p = .003$), responding to disruptive behaviours ($\beta = .48$, $p < .001$), and for controlling upsetting thoughts ($\beta = .17$, $p = .004$) demonstrated significant main effects with a higher positive impact of the caring experience. SE for responding to disruptive behaviours accounted for the largest amount of variance, followed by SE for controlling upsetting thoughts and obtaining respite. In addition, better performance of activities of daily living ($\beta = .12$, $p = .039$) was directly associated with higher positive impact related to the caring experience.

Table 5.10 Hierarchical regression with positive impact as the dependent variable

Variable	B	Positive Impact	
		β	R^2 Change
Step 1: Carer characteristics			.018
Gender	-.33	-.068	
Ethnicity	.24	.020	
Relationship type	-.41	-.085	
Step 2: PwD clinical characteristics			.044**
NPI scores	.008	.068	
Activities of daily living	.015	.12*	
Cognition	-.009	-.027	
Step 3: Self-efficacy beliefs			.38***
SE for Obtaining Respite	.002	.15**	
SE for Responding to Disruptive Behaviours	.011	.48***	
SE for Controlling Upsetting Thoughts	.004	.17**	
			.44***

* $p < .05$, ** $p < .01$, *** $p < .001$

5.3.2 Predicting the negative impact of caring

Pearson's correlation coefficient values between carer SE beliefs, person with dementia clinical characteristics and the negative impact of caring are reported in Table 5.7. High

negative impact related to the caring experience was moderately correlated with low SE for controlling upsetting thoughts ($r = -.49, p < .001$), for managing NPS ($r = .40, p < .001$), for obtaining respite ($r = -.38, p < .001$) and for responding to disruptive behaviours ($r = -.35, p < .001$). Higher NPI scores ($r = .44, p < .001$) were moderately correlated with higher negative impact, while poorer performance of person with dementia activities of daily living ($r = -.34, p < .001$) was moderately associated with higher negative impact. However, there was no correlation between the cognition of the person with dementia and negative impact related to the caring experience ($r = -.080, p = \text{n.s.}$).

Table 5.11 reports the hierarchical multiple regression with negative impact related to the caring experience as the dependent variable (as evaluated by the COPE-Index subscale). The model explained 45% of the variance in negative impact [$R^2 = .45; F(9, 265) = 23.88, p < .001$]. The largest R^2 change occurred in the second step of the regression [R^2 change = .24; $F(3, 265) = 29.53, p < .001$], in which person with dementia clinical characteristics (objective caring stressors) accounted for 24% of the variance in negative impact beyond carer characteristics. The addition of SE beliefs in the final step accounted for 16% of variance beyond carer characteristics and stressors [R^2 change = .16, $F(3, 265) = 25.95, p < .001$].

In the final model, higher SE for obtaining respite ($\beta = -.18, p < .001$), responding to disruptive behaviours ($\beta = -.12, p = .05$) and controlling upsetting thoughts ($\beta = -.26, p < .001$) were significantly directly associated with a lower negative impact of caring. SE for controlling upsetting thoughts accounted for the largest amount of variance.

Furthermore, reduced activities of daily living ($\beta = -.27, p < .001$), higher NPI scores (β

= .21, $p < .001$) and a lower level of cognition ($\beta = .13$, $p = .022$) were directly associated with higher negative impact related to caring.

Table 5.11 Hierarchical regression with negative impact as the dependent variable

Variable	B	Negative Impact	
		β	R ² Change
Step 1: Carer characteristics			.050**
Gender	.23	.026	
Ethnicity	1.91	.087	
Relationship type	1.39	.16***	
Step 2: PwD clinical characteristics			.24***
NPI scores	.046	.21***	
Activities of daily living	-.061	-.27***	
Cognition	.079	.13*	
Step 3: Self-efficacy			.16***
SE for Obtaining Respite	-.005	-.18***	
SE for Responding to Disruptive Behaviours	-.005	-.12*	
SE for Controlling Upsetting Thoughts	-.010	-.26***	
			.45***

* $p < .05$, ** $p < .01$, *** $p < .001$

5.3.3 Summary

In summary, person with dementia clinical characteristics (objective stressors) explain greater variance in negative impact related to the caring experience compared to positive impact, however carer SE beliefs explain more variance in positive impact related to caring. This illustrates a disconnect between the negative and positive impact of the caring experience, in that carer SE beliefs predominantly operate through the positive arm, while objective caring stressors (person with dementia characteristics) assume a much larger role in regulating the negative impact of the caring experience.

5.4 SECTION D: The impact of caring, psychosocial resources and family carer health-related quality of life

The pattern of co-occurrence of positive and negative impact related to the caring experience and the association with psychosocial resources (i.e. carer SE beliefs and perceived quality of support) and carer health-related QoL was examined. Aims and hypotheses are detailed in Chapter four.

5.4.1 Positive and negative impact of the caring experience

Table 5.7 reports the Pearson's correlation coefficient between the positive and negative impact of caring, as measured by the COPE-Index. Higher positive impact was moderately correlated with lower negative impact related to the caring experience ($r = -.46, p < .001$).

Median split was used to partition carer scores for the Positive Impact and Negative Impact subscales of the COPE-Index into four categories. The proportion of family carers reporting high and low levels of positive and negative impact associated with caring are presented in Table 5.12. Four impact of caring categories were identified:

- i. Positive impact (PI) category (high positive impact and low negative impact)
- ii. Negative impact (NI) category (high negative impact and low positive impact)
- iii. High impact category (high positive and negative impact)
- iv. Low impact category (low positive and negative impact)

The majority of carers (36%) reported high positive impact and low negative impact (positive impact group), while 30% reported high negative impact and low positive impact (negative impact group). Only 13% of carers reported both a low negative and

positive impact (low impact group), however 22% reported both a high positive and negative impact of caring (high impact group).

Table 5.12 Carers reporting high vs. low positive and negative impact related to caring (n = 289)

		Positive impact of caring	
		Low n (%)	High n (%)
Negative impact of caring	Low	37 (13) ^a Low	104 (36) ^b Positive
	High	86 (30) ^c Negative	62 (22) ^d High

Note. ^alow impact of caring category; ^bpositive impact of caring category; ^cnegative impact of caring category; ^dhigh impact of caring category.

5.4.2 Participant characteristics and impact of caring categories

Table 5.13 reports the relationship between participant characteristics and impact of caring categories. There were no significant differences for carer gender, age, relationship type, level of education or ethnicity between the four impact of caring categories. Despite this, values indicated that the low impact category comprised a marginally higher proportion of white British carers and spousal carers compared to the other categories. In addition, there were marginally higher proportions of female carers in the negative impact and low impact of caring categories compared to the positive and high impact categories. Furthermore, those carers in the high impact and negative impact categories were marginally better educated.

Table 5.13 Participant characteristics by impact of caring categories (n = 289)

	Impact of caring categories				χ^2 /one-way ANOVA statistic (p value)
	High impact (High PI, high NI) n = 62	Positive impact (High PI, low NI) n = 104	Negative impact (High NI, low PI) n = 86	Low impact (Low PI, low NI) n = 37	
Gender					.12
Female n (%)	40 (64.5)	64 (61.5)	64 (74.4)	29 (78.4)	
Age					.73
Years M (SD)	65.9 (11.3)	67.5 (13.9)	65.9 (12.0)	67.6 (10.1)	
Relationship type n (%)					.61
Spouse	36 (58.1)	69 (66.3)	51 (59.3)	27 (73.0)	
Adult child/other family	24 (38.7)	34 (32.7)	33 (38.4)	10 (27.0)	
Level of education n (%)					.28
School educated only	38 (61.3)	77 (74.0)	58 (67.4)	28 (75.7)	
Further educated	24 (38.7)	27 (26.0)	28 (32.6)	9 (24.3)	
Ethnicity					.41
White British n (%)	51 (82.3)	93 (89.4)	78 (90.7)	36 (97.3)	

5.4.3 Psychosocial resources, family carer health-related quality of life and the impact of caring

The level of SE beliefs, perceived quality of social support and health-related QoL for carers reporting a high versus low positive and negative impact of caring is reported in Table 5.14.

Table 5.14 Psychosocial resources and impact of caring categories ($n = 289$)

	High impact (High PI, high NI) $n = 62$	Positive impact (High PI, low NI) $n = 104$	Negative impact (High NI, low PI) $n = 86$	Low impact (Low PI, low NI) $n = 37$	Statistics (ANOVA) p-value
SE for Obtaining Respite $M (SD)$	262.7 ^{a1} (145.5)	335.0 ^{a2} (130.1)	213.7 ^{a3} (135.0)	261.3 ^{a4} (140.7)	$F(3, 288) = 12.79$ $p < .001^{***}$
SE for Responding to Disruptive Behaviours $M (SD)$	380.6 ^{b1} (77.1)	402.8 ^{b2} (72.4)	278.4 ^{b3} (100.2)	324.7 ^{b4} (96.7)	$F(3, 288) = 36.84$ $p < .001^{***}$
SE for Controlling Upsetting Thoughts $M (SD)$	358.1 ^{c1} (112.7)	416.8 ^{c2} (70.3)	291.4 ^{c3} (104.0)	360.5 ^{c4} (91.9)	$F(3, 288) = 28.06$ $p < .001^{***}$
SE for managing NPS $M (SD)$	14.2 ^{d1} (7.3)	11.9 (7.2)	14.1 ^{d2} (6.9)	10.4 ^{d3} (5.5)	$F(3, 288) = 3.75$ $p = .011^*$
SF-12 Mental health component $M (SD)$	39.0 ^{e1} (6.3)	42.5 ^{e2} (5.8)	35.2 ^{e3} (7.04)	41.3 ^{e4} (6.02)	$F(3, 285) = 21.55$ $p < .001^{***}$
SF-12 Physical health component $M (SD)$	35.0 ^{f1} (7.04)	39.4 ^{f2} (6.6)	33.8 ^{f3} (7.5)	37.7 ^{f4} (6.3)	$F(3, 285) = 11.32$ $p < .001^{***}$
COPE-Index Perceived quality of support $M (SD)$	9.9 ^{g1} (3.2)	11.9 ^{g2} (3.04)	9.5 ^{g3} (2.7)	10.4 ^{g4} (2.5)	$F(3, 288) = 13.01$ $p < .001^{***}$

Note. Post-hoc comparisons demonstrated significant differences between the impact of caregiving categories: (a2 > a3; a2 > a1; a2 > a4); (b2 > b3; b2 > b4; b3 > b4; b4 < b1); (c2 > c3; c2 > c1; c2 > c4; c3 < c1; c3 < c4); (d2 > d3; d1 > d3); (e2 > e3; e2 > e1; e3 < e1; e3 < e4); (f2 > f3; f2 > f1; f3 < f4); (g2 > g3; g2 > g1; g2 > g4).

* $p < .05$, ** $p < .01$, *** $p < .001$

5.4.3.1 Family carer self-efficacy beliefs and the impact of caring

Post-hoc comparisons using the Tukey test (Table 5.14) demonstrated significant differences in the level of SE related to all caring domains across the impact of caring categories; SE was lowest in the negative impact group and highest in the positive

impact group. However, SE for managing NPS was similarly low in the negative and high impact groups and was highest in the low impact of caring group.

Post-hoc comparisons also demonstrated that the positive impact group had significantly higher SE for obtaining respite than all other impact of caring groups. In addition, the level of SE for obtaining respite reported in the high impact and low impact groups was almost identical.

Table 5.14 also demonstrates that the mean for SE for responding to disruptive behaviours reported in the positive impact group was significantly higher than the means of the negative and low impact of caring groups. In addition, the negative impact group reported significantly lower SE for responding to disruptive behaviours than both the high and low impact of caring groups. Level of SE for responding to disruptive behaviours was higher for the positive and high impact groups compared to the negative and low impact of caring groups. This suggests that SE for responding to disruptive behaviours might be more strongly related to the positive impact of caring.

In addition, there was a higher level of SE for controlling upsetting thoughts reported in the positive impact group than in all other impact of caring groups, and much lower SE for controlling upsetting thoughts in the negative impact group compared to all other groups.

Finally, post-hoc comparisons demonstrated that carers in the negative impact and high impact groups reported similar levels of SE for managing NPS of dementia, which was significantly lower than the low and positive impact of caring groups. This suggests that SE for managing NPS might be more strongly related to the negative impact of caring.

5.4.3.2 Perceived quality of support and the impact of caring

Post-hoc comparisons (Table 5.14) demonstrated that there were significant differences in level of perceived quality of support across the four impact of caring categories. In particular, the mean perceived quality of support was significantly higher in the positive impact of caring category compared to all other impact of caring categories.

5.4.3.3 Family carer health-related quality of life and the impact of caring

The post-hoc comparisons reported in Table 5.14 demonstrated there were significant differences in carer health-related QoL across the four impact of caring categories. The mean value for the physical health component of carer QoL was significantly higher in the positive impact of caring group compared to the negative and high impact groups, and was significantly lower in the negative impact group compared to the low impact of caring group. The mental health component of carer QoL was significantly higher in the positive impact of caring group compared to the negative impact and high impact of caring groups. In addition, mental health was lower in the negative impact group compared to the high and low impact of caring groups.

5.4.4 Summary

Four impact of caring categories were identified: i) positive impact (high positive impact, low negative impact); ii) negative impact (high negative impact, low positive impact); iii) high impact (high positive and negative impact) and; iv) low impact (low negative and positive impact) related to the caring experience. Psychosocial resources such as carer SE beliefs and quality of support, and mental and physical health components of QoL demonstrated differences across the four categories. This indicates that psychosocial resources and carer health-related QoL are associated with the pattern of co-occurrence of positive and negative impact related to caring and thus impact of

caring category membership. In particular, higher levels of SE were related to positive impact category membership and lower SE related to negative impact category membership. Higher carer health-related QoL was related to positive impact category membership and lower QoL related to negative impact category membership. Similarly, higher perceived quality of support was related to positive impact category membership.

5.5 SECTION E: The relationship between caring domain-specific self-efficacy beliefs and family carer health-related quality of life

Pearson's correlation coefficient values were calculated and hierarchical multiple regression analyses were conducted (Tables 5.15 - 5.18) to examine the amount of variance in carer health-related QoL accounted for by SE beliefs and also to determine whether SE beliefs have a moderating effect on the association between NPI scores and carer health-related QoL. Aims and hypotheses are described in Chapter four.

5.5.1 Family carer health-related quality of life and self-efficacy beliefs

Pearson's correlation coefficient values between carer SE beliefs and the mental and physical health components of carer QoL are reported in Table 5.7. Higher SE for obtaining respite ($r = .34, p < .001$), responding to disruptive behaviours ($r = .35, p < .001$), controlling upsetting thoughts ($r = .41, p < .001$) and for managing NPS of dementia ($r = -.34, p < .001$) were moderately positively correlated with the mental health component. There were small to moderate correlations between higher SE for obtaining respite ($r = .29, p < .001$), for responding to disruptive behaviours ($r = .27, p < .001$), for controlling upsetting thoughts ($r = .33, p < .001$), for managing NPS ($r = -.24, p < .001$) and higher scores for the physical health component. Overall, findings indicate a small to moderate association between SE beliefs relating to specific caring domains and carer health-related QoL.

5.5.2 Family carer health-related quality of life and person with dementia clinical variables

Pearson's correlation coefficient values between person with dementia clinical variables and carer health-related QoL are reported in Table 5.7. Person with dementia cognition ($r = .013, p = \text{n.s}$) was not associated with the mental health component of carer QoL,

however there was a small positive correlation between better performance of activities of daily living and improved carer mental health ($r = .20, p = .001$) and a moderate association between higher NPI scores and reduced carer mental health ($r = -.33, p < .001$). Similarly, there were small correlations between lower NPI scores ($r = -.22, p < .001$), better performance of activities of daily living ($r = .15, p = .012$) and higher physical health related QoL, however, cognition was not related to carer physical health ($r = .035, p = \text{n.s.}$).

5.5.3 Family carer self-efficacy beliefs and person with dementia clinical variables

Pearson's correlation coefficient values between carer SE beliefs and person with dementia clinical variables are reported in Table 5.7 and Section 5.2. Higher NPI scores were modestly associated with lower SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts and strongly associated with SE for managing NPS of dementia. A lower level of cognition for the person with dementia was weakly associated with lower SE for managing NPS, but was not associated with SE beliefs relating to any other caring domains. Activities of daily living were not associated with SE for responding to disruptive behaviours or controlling upsetting thoughts, however better performance of activities of daily living were weakly related to higher SE for obtaining respite and managing NPS.

5.5.4 Predicting family carer health-related quality of life

Table 5.15 reports the hierarchical multiple regression analyses with carer SE beliefs relating to specific caring domains regressed onto the mental and physical health components of QoL (as measured by the SF-12). With the mental health component as the dependent variable, the model accounted for 29% of variance [$F(10, 270) = 11.17, p$

< .001; $R^2 = .29$]. The addition of SE beliefs in the third step accounted for 13% of variance beyond carer characteristics and stressors [R^2 change = .13; $F(3, 270) = 16.70$, $p < .001$]. In the final model, better performance of activities of daily living ($\beta = .13$, $p = .040$), lower NPI scores ($\beta = -.18$, $p = .004$), higher SE for obtaining respite ($\beta = .18$, $p = .002$) and SE for controlling upsetting thoughts ($\beta = .22$, $p = .001$) accounted for a significant proportion of variance in carer mental health. This indicates a main/direct effect of SE for obtaining respite and controlling upsetting thoughts, with the latter proving to be the largest predictor.

The regression model with carer physical health related QoL as the dependent variable accounted for 19% of variance [$F(10, 270) = 6.51$, $p < .001$; $R^2 = .19$]. SE beliefs accounted for 10% of variance in the physical health component beyond carer characteristics and caring stressors [R^2 change = .10; $F(3, 270) = 11.15$, $p < .001$]. In the final model, higher SE for obtaining respite ($\beta = .16$, $p = .009$) and for controlling upsetting thoughts ($\beta = .20$, $p = .005$) were associated with better carer physical health related QoL. This indicates a main/direct effect of SE for obtaining respite and for controlling upsetting thoughts. Similar to the mental health component, the largest predictor was SE for controlling upsetting thoughts.

Table 5.15 Hierarchical regression analyses with the mental and physical health components of carer QoL as the dependent variables

Variable	Mental health				Physical health			
	<i>B</i>	β	<i>R</i> ² Change	Total <i>R</i> ²	<i>B</i>	β	<i>R</i> ² Change	Total <i>R</i> ²
Step 1: Carer characteristics			.029				.033	
Age	.001	.002			-.060	-.10		
Gender	-1.42	-.095			-1.40	-.089		
Education level	1.45	.095			1.23	.078		
Relationship type	.80	.055			.44	.029		
Step 2: PwD clinical characteristics			.13***				.061***	
NPI scores	-.064	-.18**			-.034	-.090		
Activities of daily living	.051	.13*			.030	.074		
Cognitive function	-.11	-.10			-.025	-.022		
Step 3: Self-efficacy beliefs			.13***	.29***			.10***	.19***
Obtaining Respite	.008	.18**			.008	.16**		
Responding to Disruptive Behaviours	.008	.11			.005	.072		
Controlling Upsetting Thoughts	.014	.22***			.014	.20**		

* $p < .05$, ** $p < .01$, *** $p < .001$

5.5.5 The moderating effects of family carer self-efficacy beliefs

Table 5.18 reports the series of hierarchical regression analyses conducted in which NPI scores (NPS of dementia), carer SE beliefs and interaction terms were regressed on the mental and physical components of carer QoL (as evaluated by the SF12).

5.5.5.1 *Self-efficacy for obtaining respite*

The regression model with SE for obtaining respite as the moderating variable accounted for 18% of variance in mental health related QoL [$R^2 = .18$, $F(3, 282) = 20.76$, $p < .001$] and 11% of variance in physical health related QoL [$R^2 = .11$, $F(3, 282) = 11.73$, $p < .001$]. The addition of the interaction term did not explain any additional variance in mental health [R^2 change $< .001$, $F(1, 282) = .092$, $p = .76$] and only 0.3% of variance in physical health [R^2 change = $.003$, $F(1, 282) = .92$, $p = .34$]. The interaction term was not significant, indicating that SE for obtaining respite does not function as a moderator between NPI scores and the physical or mental health components of carer QoL. However, there was a direct effect for SE for obtaining respite for both the mental ($\beta = .28$, $p < .001$) and physical health components ($\beta = .26$, $p < .001$).

5.5.5.2 *Self-efficacy for responding to disruptive behaviours*

The model with SE for responding to disruptive behaviours as the moderating variable accounted for 19% of variance in mental health related QoL [$R^2 = .19$, $F(3, 282) = 21.28$, $p < .001$] and only 12% of variance in physical health related QoL [$R^2 = .12$, $F(3, 282) = 12.18$, $p < .001$]. The addition of the interaction term did not lead to a significant change in R^2 , accounting for only 0.1% of variance in mental health [R^2 change = $.001$, $F(1, 282) = .44$, $p = .51$] and 2% of variance in physical health related carer QoL [R^2 change = $.015$, $F(1, 282) = 4.93$, $p = .027$]. For the mental health component of carer QoL, the interaction term was not significant, indicating SE for responding to disruptive

behaviours does not function as a moderator between NPI scores and mental health.

However, a direct effect for SE for responding to disruptive behaviours on the mental health component was found ($\beta = .28, p < .001$). For physical health component of carer QoL, there was a significant interaction between SE for responding to disruptive behaviours and NPI scores ($\beta = .13, p = .027$), indicating SE for responding to disruptive behaviours does function as a moderator between NPI scores and the physical health component of carer QoL. Furthermore, a direct effect for SE for responding to disruptive behaviours ($\beta = .23, p < .001$) was found.

Post-hoc analyses were conducted to explore the nature of the interaction. Two hierarchical regression analyses (Table 5.16 and 5.17) examined the association between NPI scores (NPS of dementia) and carer physical health related QoL at high and low levels of SE for responding to disruptive behaviours.

Table 5.16 Multiple regression with high SE for responding to disruptive behaviours as the moderator

Variable	Physical health			
	<i>B</i>	β	<i>t</i>	<i>p</i> value
Constant	38.41			
High SE DB	.017	.23	3.92	< .001
NPI scores	.000	.001	.006	.99
High SE DB X NPI scores	.000	.21	2.21	.028

Note. SE DB = self-efficacy for responding to disruptive behaviours

Table 5.17 Multiple regression with low SE for responding to disruptive behaviours as the moderator

Variable	Physical health			
	<i>B</i>	β	<i>t</i>	<i>p</i> value
Constant	35.10			
Low SE DB	.017	.23	3.92	< .001
NPI scores	-.095	-.25	-3.55	< .001
Low SE DB X NPI scores	.000	.15	2.23	.026

Note. SE DB = self-efficacy for responding to disruptive behaviours

At high levels of SE for responding to disruptive behaviours, the relationship between NPI scores and carer physical health related QoL was not significant ($\beta = .001, p = 0.99$). In contrast, at low levels of SE, the relationship between NPI scores and carer physical health related QoL was significant ($\beta = -.25, p < .001$). The moderating effect is presented in Figure 5.5. The slope for NPS of dementia was significant when SE for responding to disruptive behaviours was low, but not high. Therefore, for carers with high SE for responding to disruptive behaviours, there was little difference in carer physical health at different levels of NPS (high versus low NPI scores). However, at a low level of SE there was a large difference in carer physical health related QoL with NPS of dementia; physical health was much higher at a low level of NPS.

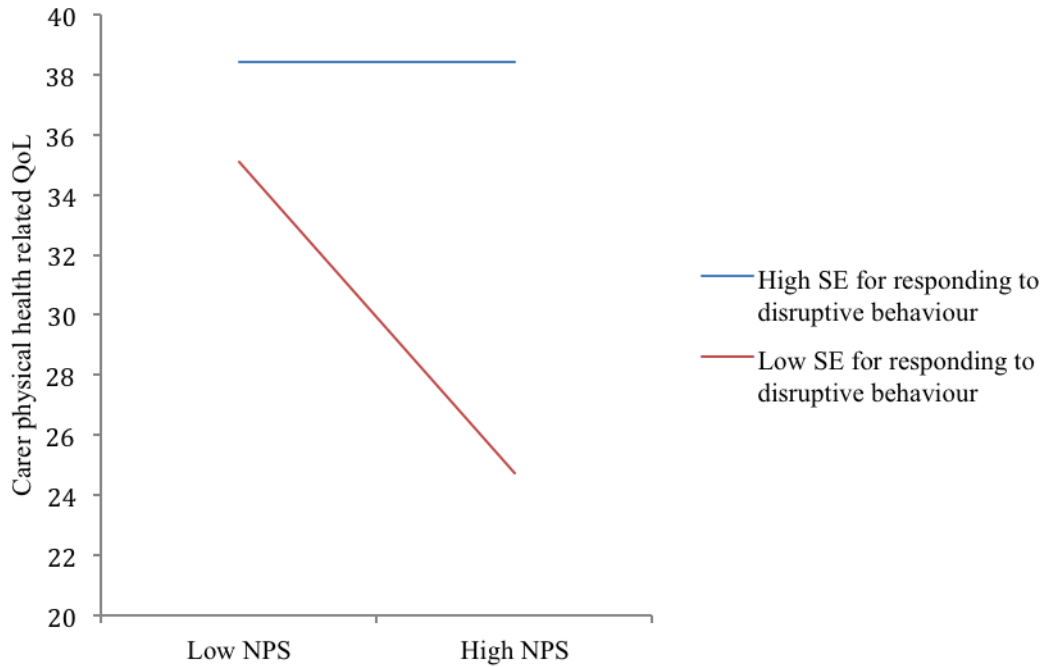


Figure 5.5 The relationship between NPI scores and carer physical health related QoL at high and low levels of SE for responding to disruptive behaviours

5.5.5.3 Self-efficacy for controlling upsetting thoughts

The model (reported in Table 5.18) with SE for responding to controlling upsetting thoughts as the moderating variable accounted for 21% of variance in mental health related QoL [$R^2 = .21$, $F(3, 282) = 25.32$, $p < .001$] and 12% of variance in physical health related QoL [$R^2 = .12$, $F(3, 282) = 13.28$, $p < .001$]. The addition of the interaction term accounted for only 0.3% of variance in mental health [R^2 change = .003, $F(1, 282) = .91$, $p = .34$] and did not account for any additional variance in physical health related QoL [R^2 change < .001, $F(1, 282) = .034$, $p = .85$]. The interaction term was not significant, indicating SE for controlling upsetting thoughts does not function as a moderator between NPI scores and the mental or physical health components of carer QoL. However, a direct effect for SE for controlling upsetting thoughts was found for both the mental ($\beta = .35$, $p < .001$) and physical health components ($\beta = .29$, $p < .001$).

5.5.6 Summary

SE beliefs accounted for a significant proportion of variance in the physical and mental health components of carer QoL. In particular, a direct effect of SE for obtaining respite and controlling upsetting thoughts was found on both the mental and physical domains, with the latter proving the largest predictor. Only SE for responding to disruptive behaviours was found to moderate the association between NPI scores (NPS of dementia) and the physical health component. More specifically, the physical health related QoL of carers with low SE for responding to disruptive behaviours varied considerably with level of NPS (high versus low NPI scores).

Table 5.18 Hierarchical regression analyses of the moderating effects of carer SE beliefs on carer health-related QoL

SE for Obtaining Respite	Mental health related QoL				Physical health related QoL			
	β	t	R^2 Change	Total R^2	β	t	R^2 Change	Total R^2
Step 1: Carer stressor & self-efficacy beliefs			.18***				.11***	
SE OR (Centred)	.28***	4.97			.26***	4.43		
NPI scores (Centred)	-.26***	-4.67			-.16**	-2.77		
Step 2: Interaction			.00	.18***			.003	.11***
SE OR x NPI scores (Centred)	-.017	-.30			-.055	-.96		
SE for Responding to Disruptive Behaviours	β	t	R^2 Change	Total R^2	β	t	R^2 Change	Total R^2
Step 1: Carer stressor & self-efficacy beliefs			.18***				.099***	
SE DB (Centred)	.28***	5.02			.23***	3.92		
NPI scores (Centred)	-.25***	-4.33			-.12*	-2.06		
Step 2: Interaction			.001	.19***			.015*	.12***
SE DB x NPI scores (Centred)	.037	.66			.13*	2.22		
SE for Controlling Upsetting Thoughts	β	t	R^2 Change	Total R^2	β	t	R^2 Change	Total R^2
Step 1: Carer stressor & self-efficacy beliefs			.21***				.12***	
SE CT (Centred)	.35***	6.07			.29***	4.79		
NPI scores (Centred)	-.23***	-4.13			-.13*	-2.10		
Step 2: Interaction			.003	.21***			.00	.12***
SE CT x NPI scores (Centred)	-.053	-.95			.011	.19		

* $p < .05$, ** $p < .01$, *** $p < .001$

5.6 SECTION F: The mediating effects of psychosocial resources on the association between behavioural and psychological symptoms in dementia and family carer health-related quality of life

Path analysis (a form of structural equation modelling) was employed to examine the association between NPI scores (NPS of dementia), carer SE for controlling upsetting thoughts, dysfunctional coping strategies, perceived quality of support and the mental health component of carer QoL. The aims and hypotheses are outlined in Chapter four. The hypothesised model (see Figure 4.1) was developed in line with existing empirical and theoretical evidence, and was informed by the Pearson's correlation coefficient values presented earlier (Table 6.7). The assumptions of linearity, multicollinearity and normality were satisfactory and post-imputation there were no missing data for any of the variables.

5.6.1 Model fit

The model is presented in Figure 6.6. The overall goodness of fit of the model as denoted by Chi-square ($\chi^2 = .19$, $df = 1$, $p = .67$) was non-significant, indicating that the model was a good fit. However, the χ^2 statistic is sensitive to sample size and some suggest it provides little guidance for determining model fit (Byrne 2010). As a result, the χ^2 to degrees of freedom ratio was calculated and found to be less than two ($\chi^2/df = .19$), which is also indicative of a good model fit (Schreiber et al., 2006). Alternative goodness of fit indices were also examined ($NFI = .99$, $CFI = 1.00$, $GFI = 1.00$, $RMSEA < .001$) and similarly these indexes indicated the model to be a good representation of the data. Values were > 0.95 for the CFI, GFI and NFI, and $< .05$ for the RMSEA, therefore the model was considered a good fit (Schreiber et al., 2006)

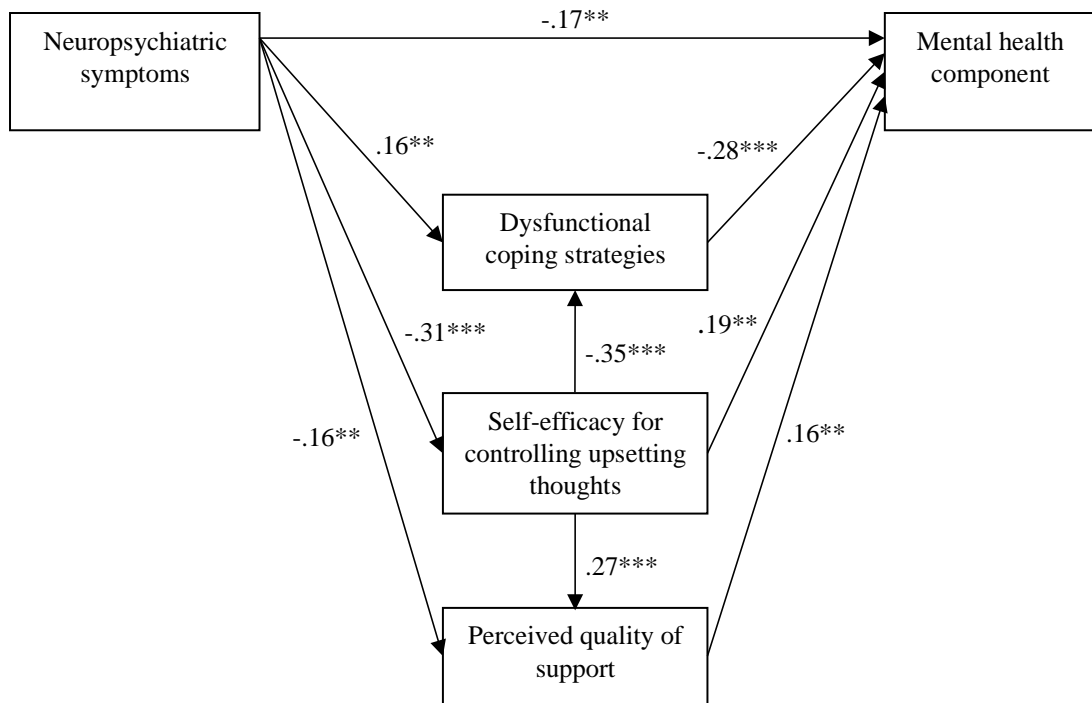


Figure 5.6 Standardised regression coefficients in the hypothesised model

* $p < .05$, ** $p < .01$, *** $p < .001$

5.6.2 Significance of parameters (direct and indirect effects)

The overall model (Figure 5.6) explained 31% of the variance in the mental health component of carer QoL ($R^2 = .31$). The variance in the mental health component was accounted for by the direct effects of NPI scores, SE for controlling upsetting thoughts, perceived quality of support and dysfunctional coping strategies. All parameter estimates reported in the model were significant.

Standardised regression coefficients for parameters are reported in Figure 5.6. There was a direct effect of NPI scores on carer mental health related QoL. There was also an indirect effect of NPI scores on mental health mediated by SE for controlling upsetting thoughts, perceived quality of support and dysfunctional coping strategies. In particular, higher NPI scores were associated with lower SE for controlling upsetting thoughts and

perceived quality of support, and with higher use of dysfunctional coping strategies, which in turn were associated with lower carer mental health related QoL.

In addition, there was an indirect effect of SE for controlling upsetting thoughts on mental health related QoL, mediated by perceived quality of support and dysfunctional coping strategies. In particular, higher SE was associated with higher perceived quality of support and reduced use of dysfunctional coping behaviours, which was related to better mental health related QoL.

5.6.3 Summary

To summarise, SE for controlling upsetting thoughts, perceived quality of social support and dysfunctional coping strategies mediate the association between NPI scores (NPS of dementia) and carer mental health related QoL. In addition, SE for controlling upsetting thoughts exerts an indirect effect on mental health related QoL, mediated through perceived quality of support and dysfunctional coping strategies.

CHAPTER 6: DISCUSSION

6.1 Overview

This is the first research to explore the association between carer psychosocial resources such as SE beliefs, social support and coping strategies, positive and negative aspects of caring, and carer health-related QoL. It is innovative in its investigation of carer characteristics, psychosocial resources and person with dementia clinical features that impact on carer SE beliefs, its investigation of the dual action of carer SE beliefs, its exploration of the co-occurrence of positive and negative dimensions in the caring experience and its evaluation of the mediating effect of psychosocial resources for carer health-related QoL. Importantly, study findings build on the review described in Chapter two to inform both theory and clinical practice, address gaps in caring literature and identify methodological and conceptual challenges.

Study findings support assumptions of the SE Theory (Bandura, 1997) and its application to the caring experience, including the domain-dependency of SE judgments and the influence of SE on affective, cognitive and behavioural processes.

Unexpectedly, only dysfunctional coping strategies were associated with carer SE judgments, with higher use of dysfunctional coping associated with lower SE for controlling upsetting thoughts and responding to disruptive behaviours. Perceived quality of support was strongly related to SE for obtaining respite. As expected, person with dementia clinical variables had little impact on carer SE beliefs. However, there were differences in carer SE beliefs according to carer characteristics; SE for controlling upsetting thoughts was higher for black carers compared to white and Asian carers and for carers who were school educated only, while SE for responding to disruptive behaviours was higher in son/daughter compared to spousal carers.

Results were consistent with the view of caring as triggering both positive and negative emotions (i.e. mixed valence), with carers reporting both positive and negative impact derived from the caring experience. Results were also consistent with the dual action of SE, in that SE can both facilitate positive experiences whilst buffering against negative experiences. SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts were important determinants of both the positive and negative impact of caring, although SE judgments exhibited much stronger associations with positive impact. Findings support the existence of conceptually distinct positive and negative dimensions of caring, however demonstrate the need to move beyond the overly simplistic two-factor view of caring. It was found that the pattern of co-occurrence of positive and negative impact related to caring can be divided into four categories: i) positive impact ii) negative impact iii) high impact and iv) low impact of caring groups, and that category membership is associated with psychosocial resources (e.g. quality of support, SE) and carer health-related QoL, but not carer characteristics.

Carer SE beliefs were found to be associated with the mental and physical health components of carer QoL. Specifically, SE for controlling upsetting thoughts and for obtaining respite demonstrated direct effects with both mental and physical health components. However, only SE for responding to disruptive behaviours was found to moderate the association between NPI scores (NPS of dementia) and carer physical health related QoL. Specifically, at low levels of SE, high NPI scores were associated with significantly lower carer physical health related QoL. In addition, path analysis found the effect of NPS of dementia on carer mental health related QoL was mediated by SE for controlling upsetting thoughts, perceived quality of support and dysfunctional coping strategies. SE also had an indirect effect on mental health, mediated by

dysfunctional coping and quality of support. This indicates the importance of considering psychosocial resources in the caring experience.

6.2 Methodological considerations

6.2.1 Recruitment

The recruitment of family carers of people with dementia proved challenging, particularly engaging with those less ingrained with services and non-white carers. Reasons for reluctance to engage in the research included that participants did not perceive themselves to be a 'carer', others voiced concern about research, while others were unwilling to take part due to the time commitment. There were also practical challenges, with some recruitment avenues proving more fruitful than others. For example, GPs were not an effective avenue of recruitment and within some services there were difficulties engaging with staff due to the saturation of research in the area and stress related to the structural reorganisations taking place in the NHS.

In response to these issues, effort was made to improve coordination and communication between researchers, which facilitated better engagement with staff. More time and effort was focused towards the successful recruitment avenues, including mail-outs and attendance at memory clinics and voluntary organisation events. To engage with the black and minority ethnic (BME) population, effort was made to attend BME groups in the community, as this population is less likely to engage with services. In addition, feedback from carers was used to make alterations to the recruitment literature, with particular attention focused towards terminology. For example, the term 'newer family carer' was changed to 'family carer'.

6.2.2 Screening participants

Participants who expressed an interest in taking part in the research were screened for eligibility. Despite the clearly defined inclusion/exclusion criteria, the screening of participants was, at times, challenging. It was dependent upon the reliability of the information provided by the participant, which in certain cases was inaccurate. For example, carers were not always aware as to whether their relative had a diagnosis of dementia and in some cases it was not clear who was the primary carer. To ensure that the screening of participants was consistent, researchers were trained to ask appropriate questions, group discussions were held with the trial lead and in some instances, the carer was advised to contact their GP for advice.

Another issue related to the inclusion of BME participants in the trial. Initially the inclusion criteria specified only English-speaking participants were eligible, however concerns were raised during recruitment that this would exclude a significant proportion of BME carers in the community. To increase the inclusivity of the trial, the eligibility criteria were modified to allow participants who could not speak fluent English to take part and for the use of translators. However, this created an additional challenge when conducting assessments; in some cases it was not possible to determine if participants understood what was being asked. In future studies it would be worthwhile having translators trained to conduct research assessments.

6.2.3 Instruments

All instruments were assessed as having adequate reliability and validity to support their use for this population and setting. This research was a cross-sectional analysis of baseline data collected as part of the SHIELD Carer Supporter Programme and instruments were selected from the assessment packs administered in the trial. The

RSSE was chosen, as it is a well-established instrument that evaluates SE relating to several salient caring domains and is compatible with the domain-dependency of SE Theory. The SF-12 was selected as it is short, relatively easy to complete and provides both a mental and physical health component score. The COPE-Index was chosen for its capacity to evaluate positive and negative impact directly related to caring and perceived quality of social support in a brief, simple scale.

6.2.4 Data collection

The length of the assessment was a common concern for carers, as the average assessment length was between two and three hours. There were instances of carers reporting fatigue, while others reported assessments to be repetitive and occasionally assessments were suspended/terminated. Despite this, the percentage of missing responses remained very low. To lessen the burden of the assessments, carers were given the option to complete the assessment over two separate visits, frequent breaks were offered and researchers were trained to recognise any signs of fatigue/distress. In addition, conducting assessments in their own homes rather than a clinical setting allowed participants to feel more comfortable. Future studies might consider how to minimise the assessment time by using shorter versions or omitting instruments.

6.2.5 Statistical analysis

The method of moderator analysis chosen in this study was developed by Baron and Kenny (1986). However, it is important to recognise that there are other methods of moderator analysis that have been developed more recently, such as the Hayes process method (Hayes, 2013). This uses PROCESS software in an ordinary least squares or logistic regression-based analytical framework to estimate models. The Baron and

Kenny (1986) method was selected, as it is a more prevalent and well-established method in research.

6.3 Comparison with findings from other studies

6.3.1 Participant demographics and clinical characteristics

The sample in this research study (reported in section 5.1) is comparable to other recent UK based studies involving family carers and individuals with dementia, namely the Befriending and Costs of Caring (BECCA) trial (Charlesworth et al., 2008) and the REMCare (REMiniscence groups for people with dementia and their family CAREgivers) trial (Woods et al., 2012). Therefore, findings are generalisable to the general carer population in the UK. Carers were predominantly white, female, spousal or son/daughter carers, and had a mean age of 67 years. Individuals with dementia were predominantly white, married, cohabiting and diagnosed with Alzheimer's Disease. Although, the ethnic makeup of the sample was similar to the REMCare trial, the sample was more ethnically diverse than that reported in the BECCA trial, which is likely a result of geographical differences. In addition, the proportion of BME carers was lower than that expected given the diverse population at several recruitment sites. The recruitment of BME participants into dementia research trials seems to be a pervasive challenge and it is crucial that future research is directed towards identifying the barriers and facilitators towards the engagement of BME carers. Furthermore, the proportion of adult child versus spousal carers that participated in the research might not be representative of the general caring population, as interventions require considerable time commitment and often take place during work hours. Therefore, adult child carers, who are typically more likely to be in full-time employment might be discouraged from taking part.

6.3.1.1 Family carer clinical characteristics

The US version of the SF-12 has proved a popular instrument in caring literature, however few studies have used the UK version in a UK population of carers of persons with dementia. Aguirre, Hoare, Spector, Woods, and Orrell (2014) used the SF-12 UK version in carers of individuals with dementia and reported marginally higher values for the mental and physical component scores than those reported in this study. However, Aguirre et al. (2014) used a small sample of primarily adult child carers and therefore the higher mental and physical health reported might be due to the lower age of the sample, though carer age was not reported. In addition, the physical and mental component scores reported in this study were as expected when compared with the UK version of the SF-12 in non-caring populations; scores were lower than those reported in a 'normal' population (Jenkinson et al., 2001) and similar to individuals diagnosed with congestive heart failure (Jenkinson et al., 1997). However, it might be suggested that individuals with congestive heart failure would report lower SF-12 scores compared to carers due to the associated physical health problems.

In this study, the level of negative impact related to caring reported by carers was similar to the McKee et al. (2003) study, which involved UK family carers of older people. However, the positive impact reported by family carers in this study was marginally lower than McKee et al. (2003). This could be due to the greater challenge posed by caring for an individual with dementia (Pinquart & Sorensen, 2005), or could be a result of the heterogeneity in participant characteristics and/or cultural differences across the McKee et al. (2003) sample, as data were collected across five countries (i.e. UK, Sweden, Greece, Italy and Poland). For example, the mean positive value in the UK was lower than that reported in the other countries, which might be a result of cultural expectations/values regarding caring. In addition, there was considerable

heterogeneity in sample characteristics such as gender, relationship type, and perceived health.

Comparison of the social network types reported in this study with the BECCA trial (Charlesworth et al., 2008) demonstrates a much higher proportion of carers were categorised as private restricted (i.e. no local relatives and little informal support) and fewer carers were family dependent (i.e. close family relationships) or locally integrated (i.e. close relationships with family/friends) in the BECCA trial. These differences might be explained by geographical differences (e.g. the availability of support services) or might be a result of contrasting recruitment strategies. For instance, participants in the BECCA trial were primarily recruited through primary care services, while this study recruited through a variety of services (both primary and secondary).

6.3.1.2 Family carer self-efficacy judgments

This appears to be the first study to use the RSSE in a UK caring population. However the level of SE reported was similar to that in studies of caring populations in other countries (e.g. Au et al., 2010; Rabinowitz, Saenz, Thompson, & Gallagher-Thompson, 2011; Steffen et al., 2002). In addition, the internal consistency of the RSSE subscales (see Section 5.1.4) was similar to that demonstrated by Steffen et al. (2002).

This is the first study to examine the distributions of SE scores across a number of caring domains. The distributions for SE for responding to disruptive behaviours, controlling upsetting thoughts and managing NPS (presented in Section 5.1.3) were similar, which according to the SE Theory (Bandura, 1997) is likely a result of the transference of SE between these domains. Alternatively, these findings could be considered as evidence contradicting the domain-specificity of caring SE beliefs. The

marginal negative skew demonstrated high levels of SE for these caring domains, which are likely a result of the sample being predominantly comprised of carers of individuals with mild dementia or could be an indication of potential ceiling effects. The distributions of the RSSE subscales are consistent with those reported by Rabinowitz et al. (2009). In addition, the finding that SE for controlling upsetting thoughts and responding to disruptive behaviours were considerably higher than SE for obtaining respite is consistent with Steffen et al. (2002). This might be indicative that carers find asking for support or gaining relief from the demands of caring particularly challenging or that the subscale items evaluating SE for obtaining respite were particularly demanding compared to the other SE domains. Moreover, findings indicate that SE judgments for responding to disruptive behaviours and controlling upsetting thoughts tend to show greater stability between carers than SE for obtaining respite, as the latter is likely dependent on the caring context (i.e. availability of support services).

Consistent with the findings of Steffen et al. (2002), SE for obtaining respite demonstrated a weak correlation with SE for responding to disruptive behaviours, and SE for controlling upsetting thoughts and SE for responding to disruptive behaviours demonstrated the strongest correlation (reported in Table 6.7). This strong association was expected as both scales evaluate carer ability to regulate emotional responses; responding to disruptive behaviours requires anger regulation, while controlling upsetting thoughts/negative cognitions involves anxiety regulation (Steffen et al., 2002). However, findings of a moderate association between SE for obtaining respite and SE for controlling upsetting thoughts contrast Steffen et al. (2002), who found no association between these SE domains. Despite this, the typically modest associations between SE beliefs relating to specific caring domains reported in this study support the domain-dependency posited by SE Theory (Bandura, 1997).

6.3.2 Factors associated with self-efficacy relating to specific caring domains

The reviews described in Chapters one and two highlighted the need for future research to explore the impact of contextual factors on carer SE judgments. Results (see section 5.2) demonstrate that carer SE beliefs are not dependent on objective caring stressors, but instead vary with carer characteristics, contextual and psychosocial variables.

6.3.2.1 Family carer demographics

In agreement with hypotheses, there were no differences in SE beliefs with carer gender or caring duration (reported in Table 6.9). To date, no research has examined gender differences in domain-dependent SE beliefs, however findings parallel those of Semiatin and O'Connor (2012) in a US sample of 57 carers of individuals of dementia, in which a global SE scale was used. Educational differences in level of SE for controlling upsetting thoughts were reported in this study (see Table 6.9). In particular, higher SE was associated with being school educated only. It might be that carers with higher education have more stressful employment and therefore less time for the caring role or have greater knowledge of dementia and concern about the challenges ahead. These educational differences contradict Semiatin and O'Connor (2012), who found no correlation between SE and level of education. However the discrepancy in findings might be due to the small sample size in the Semiatin and O'Connor (2012) study or due to the global SE score used (computed from relational, instrumental and self-soothing SE).

Contrasting expectations, ethnic differences were only observed for SE for controlling upsetting thoughts (reported in Table 5.9). Interpretation of these findings is difficult due to the extremely low number of black and Asian carers within this study and the validity of these findings is questionable. Comparison of the results with past research is

challenging, as no studies have investigated ethnic differences in SE beliefs relating to specific caring tasks. However, results are consistent with past, albeit dated research examining generic caring SE and mastery. For example, Haley et al. (1996) found black family carers of individuals with dementia reported higher SE for managing caring problems compared to white carers, however SE items had not been previously validated. Similarly, Lawton et al. (1992) found that black carers of individuals with dementia reported higher caring mastery than white carers. However, caring mastery is not identical to SE, black carers were less likely to be spouses and were less educated than white carers, and there was a large disparity in the numbers of black and white carers. Haley et al. (1996) and Lawton et al. (1992) suggested ethnic differences might be due to differences in cultural values (i.e. value placed on the caring role), family structure, or life experiences/expectations. There appears to be no existing research comparing SE in Asian, white and black carers, indicating that this is an area for future research.

Although differences in carer SE with carer/care-recipient relationship type were evident (see Table 6.9), findings were not as expected, as adult child carers reported higher SE for responding to disruptive behaviours only, compared to spousal carers. In addition, findings conflict with those of Depp et al. (2005) who found that adult children reported higher SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts compared to spousal carers. The disparity in findings might be due to the exclusively female sample or because wives were generally older and less educated than daughter carers in Depp et al. (2005). A potential explanation for the difference in level of SE for responding to disruptive behaviours with relationship type might be the 'loss' of spousal support for spousal carers, while son/daughter carers usually have their own network of friends/family or spousal support. Alternatively Skaff

et al. (1996) suggested that the multiple roles of adult-children (e.g. employment, families) might enhance SE in domains that transfer to the caring role.

6.3.2.2 Family carer coping behaviour

Contrasting with expectations, carer SE beliefs for responding to disruptive behaviours and controlling upsetting thoughts were only associated with dysfunctional coping behaviours (reported in Table 6.7). Specifically, higher levels of SE were associated with less frequent use of dysfunctional coping behaviours such as behavioural disengagement, denial, self-distraction, self-blame, substance use and venting. This is consistent with assumptions of the SE Theory (Bandura, 1997) that SE beliefs can determine cognitive and behavioural processes, as coping strategies are defined as behavioural and cognitive efforts. In particular, the SE Theory recognises that SE has the capacity to influence the initiation and persistence of coping behaviours when faced with challenges (e.g. low SE can precipitate maladaptive coping behaviours).

There is a paucity of empirical research that has examined the relationship between coping strategies and SE beliefs in carers, which makes it difficult to interpret the findings in the context of extant research. The finding that carer SE was not associated to problem or emotion focused coping strategies contradicts expectations and the findings of Wijngaart et al. (2007) that higher SE was associated with higher reported use of problem-solving strategies in spousal carers of individuals with dementia in the Netherlands. However, the disparate findings might be a result of the General Self-efficacy Scale used by Wijngaart et al. (2007) or differences in the measurement or classification of coping strategies. Coping research in older adults is constrained by the varied conceptualisation and operationalization of coping and lack of recognition of stressor specificity and the social context (Gottlieb & Wolfe, 2002). This research is one

of the first studies to examine the association between SE and coping strategies in carers, therefore further research is clearly needed.

6.3.2.3 Family carer perceived social support

As hypothesised, carer perceived quality of support was associated with higher SE for obtaining respite (presented in Table 6.7). In other words, SE to gain relief from caring stressors by social means was associated with perceived quality of support. In addition, higher SE for controlling upsetting thoughts was moderately correlated with higher quality of support. These findings parallel those of Depp et al. (2005) who found that social support and satisfaction with support were strongly correlated with SE for obtaining respite and moderately correlated with SE for controlling upsetting thoughts in female carers of individuals with dementia. However this association was only evident in wives and white carers.

Conversely, findings conflict with Steffen et al. (2002) who found social support was strongly correlated with SE for obtaining respite, but not for controlling upsetting thoughts or responding to disruptive behaviours in female carers of individuals with dementia. In addition, findings contrast those of Au et al. (2010), who found correlations between higher social support and SE for obtaining respite and responding to disruptive behaviours, but not SE for controlling upsetting thoughts in carers of individuals with dementia in Hong Kong. The discrepancies in findings relating to SE for specific caring domains might be because the Steffen et al. (2002) sample were younger, had been caring for less time, were less likely to be spouses or due to differences in social support instruments used across studies. For example, some studies examined 'quality of support' but others examined 'amount of support'.

Findings support assumptions of the SE Theory (Bandura, 1977), as well as presuppositions of Aneshensel et al. (1995) regarding the importance of considering carer SE in the context of the environment and external factors. Steffen et al. (2002) proposed that when confronted with caring demands, carers with low SE focus on negative aspects and report less availability of help from family/friends, though this does not explain why no relationship was found between SE for responding to disruptive behaviours and quality of support, in this study. In addition, it is important to consider the limitations of the quality of support subscale; McKee et al. (2003) reported that the subscale demonstrated considerable heterogeneity across countries and failed to demonstrate an acceptable level of internal consistency.

6.3.2.4 Family carer social network type

Consistent with hypotheses, differences in SE for obtaining respite according to social network type were found (see Table 6.8). In particular, SE for obtaining respite was higher in the family dependent network type (i.e. close family relationships) compared to network types characterised by more distant relationships (i.e. no local family/friends). More specifically, carers reported higher confidence for obtaining support from friends/family when they reported close family/friend relationships. Unexpectedly, carer SE for responding to disruptive behaviours also differed with social network. In particular, SE was higher in family dependent and locally integrated networks (i.e. close relationships with family/friends/neighbours) compared to distant family relationships (i.e. wider community focused network). A potential explanation might be related to the burdensome nature of behaviour problems, in that carers feel reassured when they have close family/friends to ask for support, which enhances their confidence in dealing with problem behaviours.

There appears to be no extant research of the association between carer SE and social network type, however, it is useful to consider findings in the context of carer network research. Wenger (1991) proposed individuals categorised in family dependent, local self-contained or private restricted networks tend to be more vulnerable. This contradicts the findings of this study that family dependent networks were related to improved SE for obtaining respite and responding to disruptive behaviours. This is clearly an area for future research, particularly given that interventions in the UK are increasingly directed towards developing ‘caring networks’.

6.3.2.5 Person with dementia clinical characteristics (objective stressors)

Consistent with expectations, SE beliefs were only weakly associated with person with dementia clinical characteristics, including behavioural problems, cognitive impairment and activities of daily living (reported in Table 6.7). The exception to this was the strong association between NPS of dementia and SE for managing NPS, which was expected as both variables were assessed by derivatives of the NPI. In addition, SE for managing NPS differed with dementia severity, with more severe dementia associated with lower SE. This association might be expected, as greater dementia severity is typically associated with correspondingly greater NPS frequency, severity, and carer distress (Baumgarten, 1989).

These findings uphold past research that has demonstrated that person with dementia characteristics are not related to carer SE judgements. For example, Semiatin and O’Connor (2012) found no association between NPS frequency and general SE in carers of individuals with dementia, however a global SE score was used. Similarly, Gilliam and Steffen (2006) found SE for responding to disruptive behaviours was not correlated with activities of daily living, cognitive impairment or behavioural problems in female

dementia carers. In addition, Depp et al. (2005) found SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts were not correlated with memory and behaviour problems of dementia in female carers of individuals with dementia. However, past research has noteworthy limitations such as small samples of predominantly white, female, well-educated carers and cross-sectional/correlational designs. In addition, while this study examined NPS frequency and severity, the majority of existing research has examined NPS frequency only.

6.3.3 Positive and negative impact related to the caring experience

6.3.3.1 The “mixed valence” of caring

The finding (reported in Table 6.3) that carers reported both positive and negative impact associated with the caring experience supports assumptions of the mixed valence of caring, that both positive and negative emotions can co-exist in caring (Lawton et al., 1991, p.182). Interpreting these findings in the context of existing research is challenging, as there is a paucity of quantitative research. However findings correspond with the qualitative research of Farran, Keane-Hagerty, Salloway, Kupferer, and Wilken (1991), who found that carers of people with dementia reported positive aspects of caring (e.g. maintaining positive relationships), but also loss and powerlessness. Similarly, Sanders (2005) found 81% of carers of individuals with dementia reported both strain and gain. Furthermore, Narayan et al. (2001) found that carers simultaneously experienced caring as self-affirming, while also reporting losses and difficulties related to the caring role. However, all of these studies were qualitative and therefore, this study appears to be innovative in its quantitative examination of the mixed valence of caring.

6.3.3.2 *The “two factor view” of caring*

Both similarities and differences in determinants of positive and negative impact related to caring were found (presented in section 5.3). The interpretation of findings in the context of past research is difficult, as this is the first study to examine positive and negative impact directly related to the caring experience. However, findings support past empirical research that has examined other positive and negative outcomes. For example, Kramer (1997) found differential predictors of positive and negative aspects among 74 dementia carers. Similarly, Harwood et al. (2000) found different factors were related to satisfaction and burden in Cuban American dementia carers. More specifically, study findings demonstrate that stressors primarily regulate negative impact, while SE beliefs predominantly regulate positive impact derived from the caring experience. Although this is the first study to specifically examine the role of SE relating to specific caring domains, findings are compatible with past research, such as Lopez et al. (2005), who found positive aspects of caring were primarily related to carer characteristics, but not to stressors in carers of older adults. Similarly, Kramer (1997) suggested that gains might be more related to carer than care recipient variables. In addition, Rapp and Chao (2000) found memory and behaviour problems were much more strongly correlated with strain than gain in carers of persons with dementia. However, it is important to note that past research has examined a variety of predictor and outcome variables and therefore might not be directly comparable to study findings. In addition, findings contradict empirical research that positive aspects of caring are influenced by clinical characteristics of the person with dementia such as functional dependency and behavioural problems (e.g. Depp et al., 2005; Raschick & Ingersoll-Dayton, 2004).

Results are compatible with assumptions that positive and negative aspects reflect qualitatively and theoretically distinct dimensions of the caring experience. These findings negate conceptual models of carer coping that fail to consider a negative versus positive dichotomy within the caring experience, such as the stress-coping model and its adaptations (e.g. Pearlin et al. 1990; Haley et al. 1987). Findings are, however, partly compatible with the two factor view of caring proposed by the general health model (Schulz & Salthouse, 1999) and stress and coping model (Kramer, 1997). These models recognise the existence of two distinct pathways of positive and negative dimensions. However, the review described in Chapter two illustrated the need to move beyond the overly simplistic two-factor view of caring. It proposed that the positive and negative dimensions in caring are not as independent as the two-factor view suggests and instead proposed that it is likely that the interrelations between positive and negative dimensions demonstrate much greater complexity. For example, it might be that carers are not on a fixed negative or positive pathway, but instead shift between the two pathways in a dynamic process that changes over time in an interactive manner with the environment and stressors, as proposed by Stroebe and Schut's (2001) dual process model of coping with bereavement. Alternatively, carers might be predisposed to use only the negative or positive pathway, those with a tendency to make negative appraisals remain on the negative pathway and vice versa or it might be that the interaction between the positive and negative pathway is much more dynamic and carers constantly and continuously oscillate between the two pathways.

Assumptions that the positive and negative dimensions in caring are interrelated in some way are supported by study findings of an inverse correlation between the positive and negative impact of caring. Although few research studies have examined the association between positive and negative impact directly related to the caring

experience, these findings are consistent with empirical research that has examined related outcomes. For example Cohen et al. (2002) found positive feelings about caring predicted depression in carers of older adults and concluded that the ability to identify positive aspects might buffer against negative consequences. Similarly, Hilgeman et al. (2007) found carers of individuals with dementia who reported higher positive aspects, also reported less depression across time. Similarly, Semiatin and O'Connor (2012) found depression was a significant predictor of positive aspects. However, not all empirical research upholds the notion that the positive and negative dimensions of caring are interrelated; several researchers (e.g. Narayan et al., 2001; Roff et al., 2004; Tarlow et al., 2004) have found only very weak correlations between positive and negative subjective responses. These inconsistencies in findings are likely due to differing conceptualisations of positive and negative aspects and the variation in measurement scales used.

6.3.3.3 The “dual action” of carer SE beliefs

Findings (see section 5.3) uphold the dual action of carer SE beliefs in not only buffering against negative experiences, but also precipitating positive experiences in caring. More specifically, it was found that SE beliefs accounted for a much larger proportion of positive impact compared to negative impact in caring. As expected, SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts exerted direct effects on the positive impact of caring. Interpreting these findings in the context of past research is challenging, as this is the first study to examine the role of domain-specific SE on positive impact related to caring. However, findings were consistent with Semiatin and O'Connor (2012), who found SE accounted for a significant proportion of variance in positive aspects of caring, although a global SE scale was used. Conversely, findings were not compatible with Cheng et al. (2012),

who found SE for responding to disruptive behaviours, but not for obtaining respite or controlling upsetting thoughts had a significant direct effect on gain in carers of relatives with dementia. However, Cheng et al. (2012) evaluated gain rather than positive impact related to caring and involved a small sample of Chinese carers, therefore differences in the conceptualisation and/or measurement of positive aspects of caring and/or cultural differences might explain the disparity in findings.

Consistent with expectations, a direct effect of SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts on the negative impact of caring was evident. This appears to be the first study to examine negative impact directly related to caring as an outcome, as past research has tended to focus on generic negative outcomes such as depression, therefore comparison with existing research is difficult. However, findings are compatible with Steffen et al. (2002), who found SE for obtaining respite, responding to disruptive behaviours and controlling upsetting thoughts were negatively correlated with depression in carers of individuals with dementia. Similarly, Gilliam and Steffen (2006) found a direct negative effect between SE for responding to disruptive behaviours and depression in female carers of individuals with dementia, however findings might not be generalisable to male carers and only SE for responding to disruptive behaviours was examined. Conversely, findings disagree with those of Rabinowitz et al. (2009), that SE for responding to disruptive behaviours and controlling upsetting thoughts, but not SE for obtaining respite had direct effects on depression. The discrepancy in findings might be a result of differences in outcome measures used. For instance, Rabinowitz et al. (2009) evaluated depression, whereas this study examined negative impact directly related to the caring experience.

The review in Chapter two outlined the pathways by which SE might exert its influence on the positive and negative dimensions of caring. It was proposed that sense of accomplishment, mastering the complexity of caring tasks, development of novel skills transferable to other contexts, and sense of role identity are related to carer sense of meaning, pride, enrichment events, which in turn determine positive outcomes.

This pathway demonstrates some similarities with the framework of Carbonneau et al. (2010), in which positive aspects of caring are precipitated by the occurrence of carer enrichment events (i.e. pleasant activities/events that make a positive contribution to the caring experience) that are mediated by carer SE beliefs, however the review by Carbonneau et al. (2010) was not specific to dementia caring. Chapter two also drew upon the SE Theory and empirical studies and proposed that SE might assume a protective role against the negative consequences of caring. More specifically, carer SE beliefs might predispose carers to focus on past accomplishments, increase positive appraisals and cognitions, and at the same time reduce the likelihood that carers will make negative appraisals. This in turn reduces emotional distress and vulnerability.

In addition, Chapter two outlined how the dual action of carer SE beliefs can be explained in the context of SE Theory. Specifically, SE can determine carer outcomes by influencing how challenges are perceived (appraisals), coping behaviours (motivation) and emotional vulnerability (affective state). For example, Steffen et al. (2002) proposed that carers with low SE have more negative appraisals/cognitions, reduced persistence in coping behaviours and reduced participation in pleasant (enrichment) events, and demonstrate greater emotional vulnerability. However, carers with high SE have more positive cognitions, demonstrate greater perseverance in coping, increased engagement in enrichment events, and increased emotional

robustness. Notably, this appears to be the first research to examine the dual action of carer SE beliefs in a single study and therefore further research is essential.

6.3.4 The pattern of co-occurrence of positive and negative impact related to caring

Four impact of caring categories were found (reported in section 5.4). These included positive impact (high positive, low negative), negative impact (high negative, low positive), high impact (high positive and negative) and low impact (low positive and negative) of the caring experience. A median split approach was used to generate these categories in attempt to provide an alternative perspective to examine the pattern of co-occurrence of positive and negative impact related to the caring experience. However, this approach is often criticised for being overly simplistic, its loss of information and reduced power. Carers predominantly reported caring as a largely positive experience (i.e. positive impact category) or a negative experience (i.e. negative impact category), however, caring was less commonly reported as a high or low impact experience. These findings are compatible with assumptions of a mixed valence of caring (Lawton et al., 1991) and empirical evidence concerning the co-existence of negative and positive emotions in the caring experience (e.g. Farran et al., 1991; Sanders, 2005). Perhaps most notably, findings demonstrate that not all carers are on a positive/negative continuum, rather the relationship between positive and negative dimensions of caring is much more complex. Results therefore provide an improved opportunity for the recognition of different types of carer.

This is the first study to explore the co-occurrence of positive and negative impact related to the caring experience using discrete categories and therefore it is difficult to

discuss findings in relation to existing empirical research. However, findings can be compared to those of Robertson et al. (2007), who used similar analytic methods to examine patterns of affect in 234 dementia carers and identified four groups: well adjusted (high positive affect [PA], low negative affect [NA]), ambiguous (low PA, low NA), intense (high PA, high NA) and distressed (high NA, low PA). The distinction between the positive and negative impact of caring categories is consistent with that between the well-adjusted and distressed groups, while the low and high impact of caring categories are comparable to the ambiguous and intense groups. Robertson et al. (2007) proposed the intense group might be better at balancing caring experiences and stressors, while the ambiguous group might represent carers who have become resigned or given up. However, it is important to note that Robertson et al. (2007) examined affective state, while this study examined patterns of co-occurrence of negative and positive impact directly related to the caring experience. Conversely, study findings differ with the qualitative research of Shim, Barroso, and Davis (2012) conducted in carers of people with dementia. Shim et al. (2012) identified three groups of carers based on how they described the caring experience; these included a negative group (i.e. expressed no positives about caring), an ambivalent group (i.e. mixed emotions about caring) and a positive group (i.e. focused towards positive appraisals and satisfaction). Contrasting the results of this study, Shim et al. (2012) identified caring to be a largely positive or negative experience and interpreted findings primarily using a negative versus positive dichotomy.

Carer characteristics (i.e. age, gender, relationship type, level of education and ethnicity) did not differ with impact of caring category membership (see Table 6.13). Despite this, there were small patterns that suggested that the low impact category comprised a higher proportion of white, spousal carers. In addition, there were

marginally higher proportions of female carers in the negative and low impact categories, and those carers in the high and negative impact of caring categories were marginally better educated. The fact that differences did not achieve statistical significance might be related to the disparity in numbers of carers between groups. To date, no research has investigated carer characteristics and mixed impact of caring category membership, however the weak patterns found are consistent with empirical research, such as that of Haley et al. (1996) and Kramer (1997) concerning ethnic and educational differences in dementia carers. This is an area for further investigation, to determine if these patterns generalise across sub-samples of carers.

As expected, caring category membership was associated to SE relating to specific caring domains (reported in Table 6.14); there were differences in SE for obtaining respite, responding to disruptive behaviours, controlling upsetting thoughts and managing NPS across the impact of caring categories. In particular, SE was typically highest in the positive impact group and lowest in the negative impact group. Findings also indicate that SE for responding to disruptive behaviours is strongly related to the positive impact of caring, as SE was higher for the positive and high impact groups compared to the negative and low impact groups, while SE for managing NPS had a stronger association with the negative impact of caring; SE was lower for the negative and high impact groups compared to the positive and low impact groups. This is the first study to examine impact of caring category membership and caring domain-specific SE and therefore cannot be directly compared to past research. Despite this, results are compatible with the dual action of SE beliefs described earlier and correspond with empirical research demonstrating that carer SE beliefs have predictive ability in both negative (e.g. Rabinowitz et al., 2009) and positive aspects (e.g. Semiatin & O'Connor, 2012) related to the caring experience. However, Rabinowitz et al. (2009)

evaluated depression, whereas this study examined negative impact directly related to the caring experience.

As hypothesised, impact of caring category membership was associated with carer physical and mental health related QoL (presented in Table 6.14). More specifically, better QoL was related to positive impact category membership, while poorer QoL related to negative impact category membership. No prior empirical research has examined the association between impact of caring category membership and health-related QoL, however findings correspond with empirical research concerning the adaptive significance of positive and negative aspects of caring for carer outcomes such as QoL and wellbeing. For example, the review by Carbonneau et al. (2010) demonstrated the importance of positive experiences for carer mental and physical health, but the review was not specific to dementia. Similarly, Marziali et al. (2010) found depression adversely influenced carer physical and mental related QoL in carers of persons with dementia.

As expected, impact of caring category membership was related to perceived quality of support (presented in Table 6.14). In particular, higher levels of support were associated with positive impact category membership and low levels were related to the negative impact category. It might be that feeling more support from friends/family increases the likelihood that carers will engage in positive activities and/or make more positive appraisals of caring experiences, which in turn influences the impact of caring. However, it is not possible to make assumptions about causality, therefore it might be that carers belonging to the positive impact of caring category tend to make more positive appraisals of support. Comparison with previous findings is challenging due to the dearth of empirical research that has explored the relationship between social

support and negative/positive aspects of caring, however findings are consistent with those of Kramer (1997) that social support was important for understanding variation in gain and strain in carers of individuals with dementia. But Kramer (1997) examined satisfaction with frequency and quality of social participation rather than perceived quality of support and involved a small sample of exclusively husband carers. It is also important to acknowledge the limited internal consistency of the quality of support subscale used in this study (McKee et al. 2003).

It is important to note that this is the first study to identify discrete impact of caring categories in attempt to illustrate the pattern of co-occurrence of positive and negative impact specifically related to caring. Past empirical research has typically focused towards investigating continuous variables or a positive vs. negative dichotomy (as driven by the two-factor view of caring). As a result, findings might not be directly comparable to past research, but provide an alternative perspective to examine the pattern of co-occurrence of positive and negative impact related to the caring experience.

6.3.5 Family carer health-related quality of life

As hypothesised, carer SE judgments explained a significant proportion of variance in the mental and physical health aspects of QoL, after controlling for carer and person with dementia characteristics (reported in section 5.5.4). Specifically, SE for controlling upsetting thoughts and for obtaining respite, but not SE for responding to disruptive behaviours had direct effects on both the mental and physical health domains, with the former exerting the largest impact. The interpretation of findings in the context of past research is challenging due to the dearth of empirical research that has examined the relationship between caring domain-specific SE and health-related QoL, and the

variability in SE domains examined. Findings, however, parallel those of Marziali et al. (2010) that SE had a direct effect on physical and mental health related QoL in Canadian carers of individuals with dementia, but Marziali et al. used a generic SE scale. On the other hand, results contradict the correlational findings of Au et al. (2010), who found that only SE for responding to disruptive behaviours and controlling upsetting thoughts were positively correlated with the physical health domain of carer QoL, however only the physical health domain was examined. Reasons for the discrepancy in findings might be due to cultural or sample differences, as the Au et al. (2010) study was conducted in Chinese carers, the sample was younger and dementia severity was greater. The findings support the domain-dependency proposed by the SE Theory (Bandura, 1977) and show some support for the proposals of Cheng et al. (2012) that SE for controlling upsetting thoughts might be the most important SE belief.

The association between carer SE judgments and health-related QoL can be explained by SE Theory (Bandura, 1997). In particular, SE can promote healthy behaviours, positive health beliefs, emotional robustness and in turn, improved physical and mental health related QoL. For example, Rabinowitz et al. (2007) found that female carers of individuals with dementia with higher confidence had reduced health risk behaviours (e.g. smoking, poor diet).

6.3.5.1 The moderating effects of family carer self-efficacy beliefs

Findings (see section 5.5.5) illustrate that SE beliefs do not typically moderate the association between NPS of dementia and carer mental or physical health related QoL. Only SE for responding to disruptive behaviours was found to function as a moderator on the relationship between NPS of dementia and the physical health domain. Specifically, the physical health related QoL of family carers who have higher

confidence/SE in their ability to handle problem behaviours is not influenced by level of NPS. However the physical health related QoL of those carers with lower confidence/SE in managing problem behaviours is determined by level of NPS (whether high or low). This moderating effect can be explained according to assumptions of the SE Theory (Bandura, 1977). When presented with high NPS, individuals with high SE tend to see difficulties as challenges to be mastered, are less likely to perceive NPS as burdensome or threatening, and tend to make more positive appraisals of demands and their own resources. In turn, this promotes the use of adaptive coping behaviours and protects the physical health related QoL of the carer.

Comparison of these findings with empirical research is challenging, as this appears to be the first study to examine whether SE beliefs relating to specific caring domains exert a moderating effect on the association between NPS of dementia and carer health-related QoL. Instead, past research has primarily focused on uni-dimensional negative outcomes. For example, Rabinowitz et al. (2009) found at a high level of memory and behavioural problems, SE for responding to disruptive behaviours was associated with lower depression, but found no moderation effects for SE for controlling upsetting thoughts or SE for obtaining respite in carers of persons with dementia. In addition, Cheng et al. (2012) found higher SE for controlling upsetting thoughts moderated the association between behavioural problems and gain and burden in Chinese carers of individuals with dementia, however SE for obtaining respite and for responding to disruptive behaviours had no moderating effects. It is also difficult to interpret findings in the context of conceptual models of carer coping, as most fail to specify the function of SE in the caring process and those that do, contradict propositions of the SE Theory by considering SE as a global entity rather than domain specific. It is important for conceptual models of carer coping to progress with empirical research, particularly

concerning the role of SE beliefs relating to specific meaningful caring domains.

6.3.6 The mediating effects of psychosocial resources

The systematic review conducted in Chapter two emphasised the need for research to investigate the role of psychosocial resources in the caring experience. In particular, little empirical research has explored the influence of SE beliefs, coping strategies and social support in caring. The model presented in Figure 6.6 was designed to evaluate the mediating effect of psychosocial resources between NPS of dementia and carer mental health related QoL. This was based on the modified stress process model (Haley et al., 1987) that proposed that psychosocial resources including coping responses, social support and appraisals mediate the effect of caring stressors on wellbeing.

As expected, in this study (Figure 6.6) SE for controlling upsetting thoughts, perceived quality of support and dysfunctional coping strategies were found to have a mediating effect on the association between NPS and carer mental health related QoL.

Specifically, higher NPI scores were related to lower SE and quality of support, and higher use of dysfunctional coping strategies, which in turn was associated with lower mental health. Although findings do not exactly replicate those of the original Haley et al. (1987) model, findings uphold its assumptions regarding the mediating effects of coping behaviours, social support and SE. In addition, findings are compatible with the stress-coping paradigm (Lazarus & Folkman, 1984) and its proposals that coping strategy and social support mediate the relationship between stressors and health outcomes. However, findings conflict with the propositions of Lazarus and Folkman (1984) that problem and emotion-focused coping are mediators rather than dysfunctional coping behaviours.

Interpretation of these findings in the context of existing empirical research is challenging due to the heterogeneity of variables examined by conceptual models. For example, results are only partly compatible with the empirical research of Haley et al. (1987), who tested the stress-process model in 54 dementia carers and found better carer well-being was associated with more benign appraisals of stressors (higher SE), higher social support, and problem-focused rather than avoidance coping. However, this study did not investigate problem focused coping behaviours. Similarly, Haley et al. (1996) found that the effects of caring stressors on carer well-being were mediated by appraisals, social support and coping behaviours. In particular, avoidance coping and lower social support were related to a higher depression and lower satisfaction. In addition, Goode et al. (1998) found psychosocial resources were related to carer outcomes over time in dementia carers. In particular, benign appraisals of stressors, the use of problem focused coping and social support were associated with more positive health outcomes. However, in contrast to study findings, Goode et al. (1998) found avoidance coping was not a mediator. Also opposing study findings, Aneshensel et al. (1995) found psychosocial resources, including mastery and social support did not mediate the impact of stressors on carer emotional wellbeing. It is important to note the difficulties with the interpretation of findings, such as that psychosocial resources are influenced by a host of factors (e.g. external resources), the heterogeneity in mediator and outcome variables examined and varied conceptualisations of coping behaviours.

Conjectures can be made concerning the mechanisms by which psychosocial resources exert their mediating effects on carer outcomes. For example, carers who belong to a supportive social network might perceive caring stressors as less challenging due to the emotional, informational or practical support provided by friends/family and as a result report better mental health related QoL. Carers with higher SE for controlling upsetting

thoughts might be more likely to make positive appraisals and less likely to make negative appraisals of the demands of caring (i.e. SE alters cognitive processes), in turn leading to improved mental health related QoL outcomes. Finally, carers who are less likely to use dysfunctional coping strategies might be less likely to engage in health risk behaviours (e.g. smoking, substance abuse), tend to make more positive health decisions (e.g. eating a balanced diet, exercising), adopt more adaptive coping styles (e.g. seeking support, problem solving), which leads to improved mental health related outcomes.

Consistent with expectations, an indirect effect of SE for controlling upsetting thoughts on carer mental health related QoL was found, this was mediated by perceived quality of support and dysfunctional coping strategies. In particular, higher SE was associated with higher perceived quality of support, reduced use of dysfunctional coping behaviours and improved mental health. It might be that confidence in controlling negative cognitions about caring influence whether carers engage in maladaptive coping strategies and positive social relationships and activities, as well as how they appraise support and coping resources, which determines carer QoL. This is the first study to use path analysis to examine the indirect effect of SE for controlling upsetting thoughts on mental health-related QoL via social support and coping behaviours. However, findings correspond with the correlational research, such as Depp et al. (2005) and Steffen et al. (2002) that SE for controlling upsetting thoughts was associated with perceived social support in carers of individuals with dementia. It is important to note the differences in support scales used, as Steffen et al. (2002) examined perceptions of availability of social support from family and Depp et al. (2005) examined instrumental, emotional and informational support. Findings also correspond with the assumptions of the SE Theory (Bandura, 1997) that SE influences cognitive and behavioural processes, such as the initiation and persistence of coping behaviours. Specifically, low SE might be

associated with more negative cognitions and facilitate maladaptive coping behaviours. For example, Steffen et al. (2002) suggested low SE was associated with lower use of behavioural (e.g. engaging in pleasant events) and cognitive coping strategies (e.g. challenging distorted thoughts).

6.4 Theoretical implications

The findings have theoretical implications for increasing understanding of the application of the SE Theory to the caring experience and its potential in explaining why some carers cope better with caring demands than others. More specifically, findings uphold the conjectures of the SE Theory relating to the ability of SE beliefs to influence cognitive, behavioural and affective processes, and that the SE belief system is not global, but is a differentiated set of beliefs in independent domains of functioning, that vary with the context and experiences (Bandura, 2006). Consistent with the proposals of Cheng et al. (2012), the findings also illustrate that SE for controlling upsetting thoughts might be most central to the caring process. Although the apparent importance of these SE expectations might also be an artefact of the SE measurement scales used.

Findings inform conceptual models of carer coping in several ways. Firstly, findings highlight the importance of recognising the role of SE within models of carer coping, specifically in its domain-dependent form, to better reflect SE Theory and empirical research. Secondly, results illustrate that there are several mechanisms by which SE beliefs are likely to exert their influence throughout the caring process (e.g. cognitive, affective and behavioural processes). Thirdly, findings support the conceptual shift towards perspectives that recognise the co-occurrence of positive and negative experiences, however indicate the need to move beyond the simplistic two-factor view

of carer wellbeing. In particular, findings suggest a more sophisticated model is needed, as caring is likely to involve more complex interrelations of positive and negative emotions than the two-factor view suggests. Lastly, study results uphold the role of carer psychosocial resources such as coping strategies, social support and SE beliefs as mediators of the caring process, particularly between stressors and carer mental health related outcomes.

This research is theoretically significant, as it appears to be innovative in a number of aspects. Firstly, it is original in its examination of the moderating effect of SE judgments relating to specific caring domains on carer health-related QoL. This is important given the current shift towards adopting more global, multidimensional indicators of carer outcomes that better reflect the caring experience. In addition, this is the first study to explore the dual action of SE judgments in the caring experience and to evaluate the mixed valence of caring using quantitative analytic methods rather than qualitative, in a single sample. Finally, it is innovative in its exploration of the co-occurrence of positive and negative impact in the caring experience in attempt to identify discrete carer categories, and in its exploration of how carer psychosocial resources might be related to impact of caring category membership. Consequently, this research offers a firm starting point for future research to build upon and has huge potential to increase understanding of the caring experience beyond the current scope.

Other theoretical implications of study findings include that the study responds to the demands of researchers to take a more holistic view of the caring experience. For example, Louderback (2000, p. 97) claimed that ‘lack of information regarding the positive dimensions of caring alter perceptions of the caring experience and limits the ability to enhance theory related to carer adaptation’. More specifically, findings aid the

identification of factors that facilitate/limit manifestations of positive aspects of caring. In addition, findings increase understanding of factors, such as carer characteristics and psychosocial resources directly related to carer SE beliefs, which is currently an extremely under-researched area. Finally, findings serve to identify methodological and conceptual issues/challenges in the field, in particular relating to positive dimensions of caring, SE beliefs and health-related QoL, and also highlight the caveats that must be considered when drawing interpretations and comparisons with other research.

6.5 Implications for practice

This research has clinical implications for designing effective interventions and support services. Study findings illustrate that SE is a valuable psychological resource to both protect against negative caring outcomes and also precipitate positive outcomes, and improved carer health-related QoL. This has significant practical implications when considered in context of the SE Theory. Bandura (1977) specified four major sources by which SE can be modified: i) guided performance via mastery experiences; ii) social comparison with others; iii) persuasive communication (encouragement) that one possesses certain capabilities and; iv) altering/reinterpreting physiological states/emotional arousal. Thus, findings suggest SE beliefs might provide a powerful therapeutic avenue by which carer outcomes can be influenced and reinforce the use of SE based interventions (e.g. psychoeducational strategies and skill mastery/development). These presuppositions are upheld by carer intervention research. For example, Au et al. (2010) found that a psychoeducational program for dementia carers significantly increased SE for controlling upsetting thoughts and handling disruptive behaviours and reduced depression. In addition, Melunsky et al. (2013) found that carers of people with dementia taking part in a reminiscence intervention reported

improved confidence in their own coping abilities related to skill development and learning coping strategies.

Findings have clinical implications in facilitating effective pre-intervention screening and assignment of interventions according to individual carer needs, which might allow more efficient use of resources. In particular, baseline levels of SE might serve as a useful screening tool to assign carer interventions appropriately (e.g. who can benefit most from SE related interventions). For example, psychoeducational interventions have been found to be more effective for carers reporting low SE, such that Rabinowitz et al. (2006) found that low baseline SE was more predictive of positive outcomes in a psychoeducational skill building intervention than in a support group in carers of relatives with dementia.

The moderating effect of SE for responding to disruptive behaviours on the association between NPS of dementia and carer physical health related QoL has significant practical implications. Specifically, SE for responding to disruptive behaviours is shown to be a valuable carer resource that might exert a protective effect on the physical health domain. In particular, it can aid the identification of carers at risk of poor physical health related QoL when faced with NPS and therefore identify carers who will benefit most from skill-based interventions (e.g. teaching/developing effective coping strategies for managing NPS). In addition, the direct effects of SE for obtaining respite and controlling upsetting thoughts on carer health-related QoL provide valuable insight for designing/assigning interventions. More specifically, it demonstrates the importance of designing psychological interventions to help carers manage negative/dysfunctional thoughts about caring, as well as interventions involving social support, social activity and obtaining respite. For example, Kwok et al. (2014) found cognitive behavioural

therapy increased SE for controlling upsetting thoughts in family carers of relatives with dementia, and a review by Gallagher-Thompson and Coon (2007) found cognitive-behavioural therapies were beneficial for carers in reducing distress.

Findings support the adoption of a more holistic approach towards designing carer interventions; interventions should be directed towards not only alleviating burden, but also enhancing positive experiences. In addition, this research increases understanding of factors that precipitate the occurrence of positive experiences in caring, which might assist in the development of effective interventions. This is important given that positive aspects have been shown to influence carer responsiveness to interventions. For example, Hilgeman et al. (2007) found positive aspects of caring demonstrated a moderating effect on intervention outcomes; carers who reported lower positive aspects benefitted most. In addition, increased understanding of positive aspects related to the caring experience might serve as an indicator of risk, as those carers who find it difficult to identify any positive aspects are likely at an increased risk for negative outcomes.

The identification of the impact of caring categories and associated patterns of psychosocial resources with category membership has noteworthy clinical implications. These categories might prove useful as a pre-intervention screening tool to identify carers at greatest risk of poor health-related QoL or to help direct interventions towards specific psychosocial resource needs. Carers may benefit from different interventions depending on whether they experience predominantly negative impact related to caring, predominantly a lack of positive impact, or both. For example, those carers in the negative impact of caring category might benefit from cognitive behavioural interventions designed to facilitate effective emotional regulation to inhibit dysfunctional thoughts, promote carer acceptance of the changes in the person with

dementia or facilitate ‘uncoupling’ the relationship between positive and negative experiences/emotions (Reich, Zautra, & Davis, 2003). However, those carers in the low impact category might benefit from interventions that facilitate the identification of positive feelings and experiences related to caring (e.g. rewards).

Finally, the path analysis (presented in Figure 6.6) has significant implications in demonstrating psychosocial resources buffer against stressors (such as NPS of dementia) in the caring process. Findings suggest that carer interventions should be directed towards providing social support and maintaining social networks and contact with supportive friends/family, towards enhancing the ability of carers to regulate their own dysfunctional/negative cognitions and towards modifying carer coping style by promoting the use of adaptive coping strategies and discouraging the use of maladaptive/dysfunctional behaviours. Overall, these findings might have considerable implications in the design and allocation of carer interventions. For example, Gallagher-Thompson et al. (2003) and Judge, Yarry, Looman, and Bass (2013) found psychoeducational interventions reduced the use of negative coping strategies and increased the use of positive coping strategies such as reframing and problem solving in carers of people with dementia.

6.6 Limitations

The sample was predominantly comprised of white carers of individuals with mild to moderate dementia; therefore findings might not be generalisable to other ethnic groups or carers of individuals with more severe dementia. This is important given that caring experiences vary with factors such as gender, ethnicity and relationship type. For example, Roth, Haley, Owen, Clay, and Goode (2001) found higher levels of depression in white compared to black dementia carers, and Raschick and Ingersoll-Dayton (2004)

found female carers experience more negative aspects of caring than males. Further research is important to determine if findings are generalisable to other contexts and caring groups. In particular, research should be directed towards examining homogenous sub-samples of carers; structural modelling could be adopted to compare models for distinct subgroups of carers (e.g. adult child vs. spousal).

The cross-sectional design makes it impossible to infer causality or assess temporal changes. Longitudinal modelling should be directed towards examining the temporal variability of SE over the caring process and how it is revised according to experiences and contextual factors. For example, Zeiss et al. (1999) proposed that long-term carers report higher confidence in their ability to respond to the demands of caring than short-term carers. This is important given that the SE Theory (Bandura, 1997) claims that SE beliefs show temporal variability. Future research should be directed towards longitudinal modelling to determine how the associations between variables change over time.

An additional limitation of the study relates to its neglect of the dyadic relationship between the family carer and person with dementia, including the quality of the relationship and changes in the relationship. This is important given the increasing attention directed towards investigating the dyadic relationship and the recognition that the carer does not exist in isolation, but is influenced by the environment/context. Similarly, results are constrained by the failure of the study to examine person with dementia characteristics such as self-efficacy, outlook, attitude, autonomy, health-related QoL, etc. This is clearly an area for future research.

The interpretation of results is constrained by the SE instruments used. In particular, the RSSE and Carer Efficacy Scale were adopted to evaluate SE relating to distinct sub-domains of caring, however it is possible that SE relating to other caring tasks might be stronger determinants of carer outcomes. Future research should be directed towards the examination of SE relating to other challenging caring domains. For example, Gottlieb and Rooney (2004) found instrumental SE (i.e. ability to complete caring tasks) and relational SE (i.e. maintaining a cooperative relationship) were associated with positive caring outcomes, such as mental health in carers of persons with dementia.

The systematic review conducted in Chapter two highlighted the challenges related to the conceptualisation and measurement of carer SE and health-related QoL that impede the interpretation of findings and inferences concerning generalisability. In particular, the shift in the conceptualisation of SE from a global belief system to a distinct set of beliefs relating to specific caring domains, inconsistencies in definitions of health-related QoL (i.e. fundamental principles and terminology), and the variability in measurement scales make it difficult to interpret study findings in the context of past research and must be recognised as a potential explanation for any disparities in findings. Future research should be directed towards improving the link between the theory and measurement of SE beliefs relating to specific caring domains and carer health-related QoL, in order to develop theory driven measurement scales and facilitate conceptual clarity.

Similarly, issues with conceptualisation and measurement hinder the interpretation of results relating to positive aspects of caring. Future research should aim to determine if results are generalisable to other positive outcome scales. There are also limitations associated with the adoption of broad classifications of coping behaviours (e.g.

emotional, dysfunctional and problem focused coping) that group together specific coping behaviours (e.g. venting and substance abuse), as these demonstrate considerable variation in breadth and content across studies. Gottlieb and Wolfe (2002) labelled these classifications as crude dichotomies that offer little theoretical insight, as they group together a large number of coping behaviours. In addition, stressor and temporal specificity were not taken into account when evaluating coping strategies. Future research should be directed towards evaluating specific coping behaviours in more clearly defined caring contexts.

The use of median split to identify impact of caring categories when examining the co-occurrence of positive and negative impact related to caring might not capture the full complexity of the caring experience. For example, it is possible that carers were only one/two points away from being classified into another category. In addition, given the cross-sectional design of the study, it was not possible to evaluate individual variability in category membership over time or causality of the association with psychosocial resources or QoL. Longitudinal research is needed to determine how group membership might change over the caring process and for assumptions to be made concerning causality of the relationship between category membership and psychosocial resources and carer health-related QoL.

It is important to acknowledge the limitations of path analysis. These constraints made it impossible to evaluate the original Haley et al. (1987) model (see Figure 1.2). In particular, it was not possible to examine the non-directional pathways between social support and coping responses, and appraisals and coping responses that were specified by the original model. This is because path analysis specifies that a correlational pathway can only exist between exogenous variables (variables that do not receive any

directional influence from another variable), however the mediator variables were endogenous (variables that receive a directional influence from another variable). In addition, it was not possible to include feedback loops between the mediator variables due to difficulties with model specification and identification relating to the number of known parameters required to generate meaningful findings. Identification checks are performed as part of the model fitting process and for the model to be identified there must be an equal or greater number of known parameters than unknown parameters. It is also important to note that it was not possible to replicate the original Haley et al. (1987) model due to the difference in measurement scales used and variables examined. For example, Haley et al. (1987) examined depression, life satisfaction and health as the caring outcome, but this study focused specifically on mental health related QoL.

Finally, it is important to acknowledge that Bonferroni corrections were not used when performing and interpreting the analyses. As a result, the findings might lack validity due to the number of tests conducted and the associated risk of the occurrence of type one errors (finding an effect, when one does not exist). Bonferroni correction uses a more stringent criterion (than the typical 0.05 alpha level) to evaluate statistical significance in order to account for the number of tests performed and therefore reduce the risk of type one errors. However, there is considerable debate and controversy concerning the use of Bonferroni corrections, as they often generate more difficulties than they resolve. It is criticised for being a conservative approach that increases the risk of type two errors (no effect is found, when there is an effect) and many researchers (e.g. Perneger, 1998) claim the inference that the interpretation of findings are dependent upon the number of tests performed defies logic. In addition, Perneger (1998) proposed that Bonferroni adjustments should not be used when testing specific hypotheses, instead it is more beneficial to clearly describe the tests that have been

conducted. Subsequently, it was decided not to apply Bonferroni corrections within this study, as the analyses within this study were underpinned by a clear set of a priori hypotheses and Cohen's (1988) guidance was used to interpret the correlations. Bonferroni corrections were not considered necessary.

6.7 Future research

This research highlights that there is a paucity of longitudinal studies in caring literature and therefore it is necessary for future research to be directed towards longitudinal analyses. The SHIELD Carer Supporter Programme adopted a longitudinal design, with data collected at three time-points (i.e. baseline, 5 months, and 12 months) and thus can be used for this purpose. For example, longitudinal path analysis could be conducted to investigate the relationship between positive and negative aspects of caring, and determine how variables and relationships change over time. Similarly, longitudinal modelling of the Carer Supporter Programme data could be conducted to further examine the dual action of carer SE beliefs in the caring experience. Finally, Carer Supporter Programme data could be used to explore the impact of contextual factors, such as carer characteristics and psychosocial resources on carer SE beliefs, as well as examine the temporal variability of SE beliefs over the caring process. Longitudinal analyses will allow assumptions to be made about causality and to identify any 'at risk' groups of carers who would benefit most from SE related interventions.

In addition, the longitudinal data collected as part of SHIELD Carer Supporter Programme could be used to further explore patterns of co-occurrence of negative and positive impact related to caring. Data collected over several time points concerning the impact of caring, potential predictors such as SE relating to specific caring domains and social support, and carer outcomes such QoL will allow a number of questions to be

addressed: i) whether carer membership within these categories changes over time; ii) whether these categories improve understanding of caring more so than the positive and negative dichotomy; iii) whether category membership is predicted by psychosocial resources (e.g. social support and SE) and; iv) whether category membership can predict outcomes such as carer QoL or institutionalization of the person with dementia.

The SHIELD Carer Supporter Programme was a randomised controlled trial evaluating the effectiveness of a peer support intervention and a reminiscence intervention, and comparing these to a control group. Data collected could be used to explore the process/mechanism of action of these interventions by examination of the moderating/mediating effects of carer SE judgments. This is particularly poignant given that the design of the peer support intervention was based on the Social Cognitive Model, which claims that new information and/or behaviours are directly learned by observing the behaviours of others in social interactions and modelling behaviours accordingly. For example, research could evaluate whether baseline levels of carer SE beliefs predict carer responses to interventions or whether interventions enhance feelings of SE, which in turn influence carer outcomes such as improved health-related QoL or positive/negative impact related to the caring experience.

Finally, future research must look towards designing interventions and support services that increase the capacity of carers to cope and results illustrate that SE related interventions represent a promising avenue that should be investigated. Specifically, interventions should be devised and evaluated to strengthen carer confidence relating to several caring domains, such as obtaining help from friends/family, controlling negative thoughts about caring and managing disruptive behaviours. A randomised controlled trial could be designed to compare the effectiveness of such interventions to other

interventions and/or a control group over time. Longitudinal analyses should explore whether carer SE beliefs moderate/mediate the effect of these interventions to understand the underlying mechanism and determine if baseline levels of SE predict outcomes.

6.8 Conclusion

The primary aim of this study was to increase understanding of the relationship between SE relating to specific caring domains, psychosocial resources, positive and negative dimensions of caring, and health-related QoL. This research appears to be innovative in several respects. It is the first study to systematically review caring literature relating to carer SE judgments and health-related QoL and to investigate the dual action of SE in the caring experience relating to the amount of variance in both positive and negative dimensions accounted for by carer SE, in a single study. It is original in its exploration of patterns of co-occurrence of positive and negative impact related to caring, the identification of discrete categories and exploration of determinants of category membership. Finally, the research is innovative in its focus towards global, multidimensional caring outcomes such as health-related QoL. In particular it appears to be the first study to examine the moderating effect of SE relating to specific caring domains on carer health-related QoL and in its evaluation of the mediating effects of psychosocial resources on the relationship between NPS and health-related QoL.

Notably, results support the assumptions of the SE Theory relating to the domain-dependency of SE beliefs and the influence of SE on affective, cognitive and behavioural processes, and also support its application to the caring experience. In addition, findings uphold the mixed valence view of caring, that positive and negative emotions co-exist in the caring process, however, demonstrate the need to move beyond

the simplistic two-factor view of carer wellbeing. Instead, findings suggest the need for a more sophisticated model that is able to account for the complex interrelations between positive and negative emotions. Furthermore, findings demonstrate the dual action of carer SE beliefs in both protecting against negative aspects and promoting positive aspects of the caring experience. Results increase understanding of the pattern of co-occurrence of negative and positive impact in the caring experience and demonstrate the relationship between category membership, psychosocial resources and carer health-related QoL.

Findings increase understanding of determinants of SE relating to specific caring domains; carer characteristics (e.g. ethnicity, relationship type) and psychosocial resources, including social support and networks, and coping strategies influence level of carer SE, however objective caring stressors do not. SE relating to obtaining respite and controlling upsetting thoughts were shown to exert a direct effect on carer health-related QoL, however only SE for responding to disruptive behaviours moderated the association between NPI scores (NPS of dementia) and the physical health domain of carer QoL. Finally, SE beliefs relating to controlling upsetting thoughts, dysfunctional coping strategies and quality of support were shown to mediate the association between NPS of dementia and carer mental health related QoL.

However, there are several noteworthy limitations. Firstly, the cross-sectional design makes it impossible to determine causality or temporal variability over the caring process. In addition, the interpretation of findings and drawing comparisons with past research is challenging due to the conceptual and measurement issues in this research field. Furthermore, the generalisability of findings might be constrained by the fact the sample was predominantly white and caring for relatives with mild to moderate

dementia. Despite these caveats, the research has important theoretical and practical implications. Theoretically, findings increase understanding of the caring process, inform theoretical models of carer coping, and identify the methodological and conceptual challenges in this field. Clinically, results demonstrate the potential of SE based interventions as a therapeutic avenue to improve carer outcomes (such as health-related QoL), the value of carer SE as a pre-intervention screening tool to identify carers who might benefit most from SE based interventions and to assist in the design of effective carer interventions and support services.

CHAPTER 7: REFERENCES

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APPENDICES

Appendices removed due to copyright issues.