

Self-efficacy and health-related quality of life in family carers of people with dementia: a systematic review

Nadia E. Crellin^{a,b*}, Martin Orrell^{a,b}, Orla McDermott^{a,c} and Georgina Charlesworth^{b,d}

^a*Division of Psychiatry, Faculty of Brain Sciences, University College London, London, UK;* ^b*Research and Development Department, North East London NHS Foundation Trust, London, UK;* ^c*Doctoral Programme in Music Therapy, Aalborg University, Aalborg, Denmark;* ^d*Research Department of Clinical, Educational & Health Psychology, University College London, London, UK*

(Received 18 November 2013; accepted 14 April 2014)

Objectives: This review aims to explore the role of self-efficacy (SE) in the health-related quality of life (QoL) of family carers of people with dementia.

Methods: A systematic review of literature identified a range of qualitative and quantitative studies. Search terms related to caring, SE, and dementia. Narrative synthesis was adopted to synthesise the findings.

Results: Twenty-two studies met the full inclusion criteria, these included 17 quantitative, four qualitative, and one mixed-method study. A model describing the role of task/domain-specific SE beliefs in family carer health-related QoL was constructed. This model was informed by review findings and discussed in the context of existing conceptual models of carer adaptation and empirical research. Review findings offer support for the application of the SE theory to caring and for the two-factor view of carer appraisals and well-being. Findings do not support the independence of the negative and positive pathways. The review was valuable in highlighting methodological challenges confronting this area of research, particularly the conceptualisation and measurement issues surrounding both SE and health-related QoL.

Conclusions: The model might have theoretical implications in guiding future research and advancing theoretical models of caring. It might also have clinical implications in facilitating the development of carer support services aimed at improving SE. The review highlights the need for future research, particularly longitudinal research, and further exploration of domain/task-specific SE beliefs, the influence of carer characteristics, and other mediating/moderating variables.

Keywords: caregivers; self-efficacy; quality of life; systematic review; narrative synthesis

Introduction

Most people with dementia live in the community and depend on a family member for assistance (Kneebone & Martin, 2003). Family carers provide a low-cost way to support individuals with dementia and save the UK roughly £12 billion a year (Alzheimer's Research Trust, 2010). Caring often comes at a great cost to the mental and physical health of family carers (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Zarit, Reever, & Bach-Peterson, 1980). Caring for an individual with dementia is associated with depression (Schulz, O'Brien, Bookwala, & Fleissner, 1995), anxiety (Cooper, Balamurali, & Livingston, 2007), greater risk of hypertension and heart disease, decreased immunity, and higher mortality (Mausbach et al., 2007; Schulz & Martire, 2004; Shaw et al., 1999).

In caring, positive and negative emotions can coexist (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991, p. 182). This 'mixed valence' of caring has been widely recognised in recent years. Positive experiences can benefit carer mental and physical health, and reinforce well-being (McIntyre, 2003; Pinguart & Sorensen, 2004). These include role enjoyment, positive affect, satisfaction, role gain, uplifts, rewards, accomplishment, growth, and meaning (Cohen, Gold, Shulman, & Zuccherro, 1994; Farran, 1997; Farran, Miller, Kaufman, Donner, & Fogg, 1999; Kramer, 1997; Lawton et al., 1991; Mowat &

Laschinger, 1994; Tarlow et al., 2004). Researchers have suggested that these positive aspects might be independent from negative aspects of caring (Rapp & Chao, 2000). Factors relating to positive aspects of caring, and the association between positive aspects and well-being is extremely under researched.

A number of conceptual frameworks have attempted to explain the heterogeneity in adaptation to the caring experience. The traditional stress–coping model of Lazarus and Folkman (1984) applied to caring dominated over the years, alongside a number of adaptations (Aneshensel, Pearlin, Mullen, Zarit, & Whitlatch, 1995; Pearlin, Mullan, Semple, & Skaff, 1990). However, these paradigms were criticised for their lack of recognition of positive aspects. Several authors (e.g. Folkman, 1997) refined the original stress–coping framework to accommodate positive states. In addition, the appraisal model of Lawton et al. (1991), modified stress and coping model of Kramer (1997), stress–health framework of Schulz and Salthouse (1999) recognised the mixed valence of caring and reported the existence of an independent negative and positive pathway.

Self-efficacy (SE) is conceptualised as the belief that one can perform confidently and capably in a given situation (Bandura, 1977). It is an important determinant of emotional and behavioural response to stressors (Bandura, 1997). SE

*Corresponding author. Email: n.crellin@ucl.ac.uk

theory might help to explain the variability in family carer ability to cope with stressors. Research has found SE to have positive implications for family carer quality of life (QoL), mental and physical health (Gilliam & Steffen, 2006). SE is not a fixed trait, but varies with mood and experience and can be modified through intervention. Therefore, SE might well provide a powerful avenue to influence health-related QoL in family carers (Bandura, 1997). In caring literature, SE has been conceptualised as global, specific to caring, or specific to particular caring domains/tasks. Today, the latter conceptualisation is preferred as SE beliefs formulate from specific situations and vary with contextual factors (Bandura, 1997).

Health-related QoL has gained increasing popularity as an outcome measure of the caring experience over recent years. It is a dynamic, subjective, multidimensional concept (Bakas et al., 2012) that refers to QoL in the context of one's health, including positive and negative aspects. There are a number of conceptualisations of health-related QoL, with perhaps the most prevalent being 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.' Several different health-related QoL models have been used to guide research. WHO (1948) reports health-related QoL to encompass the domains of physical, mental, social well-being, and autonomy, with this model recommended by the Bakas et al. (2012) review of health-related QoL models for use in research.

Measures of health-related QoL are typically favoured due to its multidimensional nature and its evaluation of a broad spectrum (Coen, O'boyle, Swanwick, & Coakley, 1999). However, 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 little literature concerning positive aspects of caring. This review explores the role of SE in family carer health-related QoL, adopting narrative synthesis (NS) (NS; Popay et al., 2006) to combine evidence from both qualitative and quantitative studies. 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.

Aims

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

Methods

Eligibility criteria

- *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 January 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 generic health-related QoL or a measure of positive aspects related to QoL.

Search methods

Electronic databases searched included: Psyc Info, CINAHL EBSCO (Cumulative Index to Nursing and Allied Health), MEDLINE (Medical Literature Analysis and Retrieval System Online), EMBASE (Excerpta Medica dataBASE), and Web of Science. Search terms included family carer, carer, caregiver, spouse, partner, care, caring, caregiv*, self-efficac*, mastery, competen*, dement*, Alzheimer's Disease, and memory problem*. Search terms were modified for each database. Grey literature was searched using Google Scholar and Open Grey. A forward citation search using Web of Science, and reference searches were performed.

Data collection

Titles and abstracts of citations obtained from the search were screened for eligibility by one reviewer and irrelevant articles were excluded. For those identified as relevant or ambiguous cases in which it was not possible to determine eligibility by abstract alone, the full text was sought. The final eligibility evaluation was made by utilising the full text, with those studies deemed eligible reviewed independently by a second reviewer and in cases with disagreements, discussions were held until a consensus reached.

Methodological quality assessment of studies

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. The quantitative studies were evaluated independently by two reviewers using a modified version of the Downs and Black Quality Checklist (1998) recommended for systematic reviews in health care (Centre for Reviews and Dissemination [CRD], 2009). This checklist evaluates the methodological strengths and weaknesses of studies, particularly the quality of reporting, internal and external validity. The checklist originally comprised 27 items; however, 11 items were removed as they were not applicable to the type of studies within the review. Three items were only

completed for longitudinal designs, therefore, the checklist was scored out of 17 for longitudinal 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 greater were considered high quality, 50%–74% as moderate. Studies scoring less than 50% were graded as low quality and excluded.

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 provided a structured method to evaluate rigor, research methods, credibility, and relevance (CRD, 2009). This tool 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 rating less than 6 out of 10 were excluded.

Narrative synthesis

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 be selected for use in the NS process. The NS comprised four stages (Figure 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.

NS 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, as well as determine the existing state of theory concerning the review question. There were two different theoretical points to consider: (1) the role of SE beliefs in health-related QoL and (2) the differential role of SE beliefs for positive and negative aspects of caring related to QoL.

The SE theory suggests 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 (appraisals), coping behaviours (motivation/behaviour) and emotional vulnerability (affective state). Family carers with higher SE might appraise stressors as challenges to be mastered, have more positive cognitions, reduced distress and can maintain their own health. While those with low SE might focus on failures, have negative cognitions, reduced motivation, and higher negative affect (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002).

Conceptual models of caring such as that of Kramer (1997), Lawton et al. (1991), and Schulz & Salthouse (1999) recognise that there are both positive and negative (i.e. mixed valence) emotional responses to caring. They posit a two-factor view of psychological well-being, suggesting independent negative and positive pathways, in

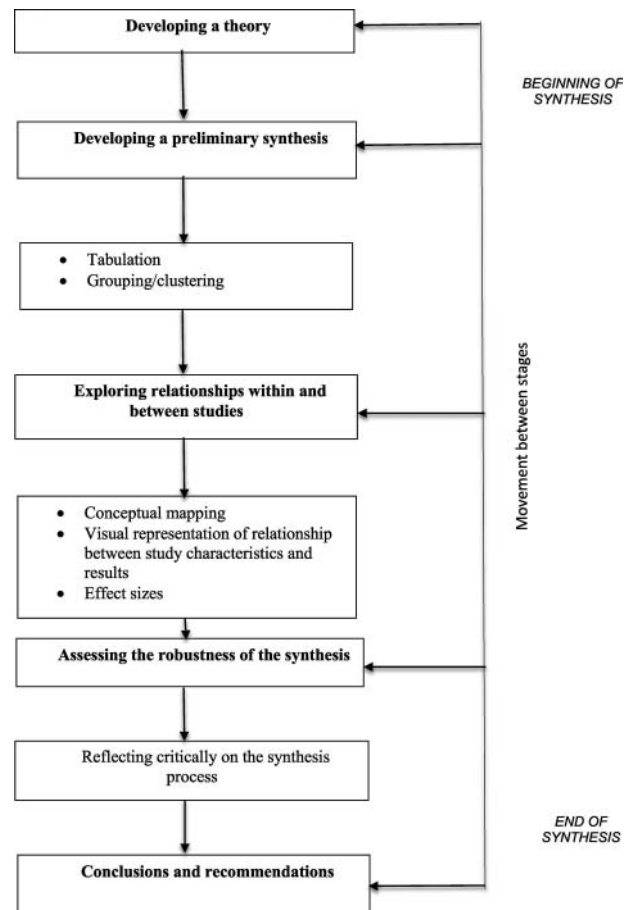


Figure 1. Flow diagram of narrative synthesis process.

which negative appraisals lead to negative outcomes, while positive appraisals lead to positive outcomes.

These models are supported by research, such as that of Rapp and Chao (2000). It might be the case that SE differentially influences positive and negative aspects of caring; empirical research indicates that SE might attenuate negative aspects, while enhancing positive aspects of caring (Farran et al., 2004; Steffen et al., 2002).

Stage 2: development of the preliminary synthesis

This stage involves the description and organisation of included studies to assist in identifying patterns across studies. An initial description of the findings was generated for each included article (Tables 1 and 2). Data extracted included the author, year, methodological approach, sample, location, quality assessment, measures, statistical analysis, and summary of main findings. Studies were clustered according to design.

Stage 3: exploring the relationships within and between studies

This stage involves 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 such as variability in study design and methodological

Table 1. Quantitative studies with health-related quality of life outcome measures.

Author	Year/ country	Sample	Design/analysis	Generic	SE measure			Main findings
					Domain-specific	HrQoL measure	Quality assessment	
Jansen et al.	2007/ Netherlands	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 and mental health domain (.28)	Moderate to strong positive association between carer competence subscales and mental QoL ($r = .24$, $r = .44$, $r = .16$). Satisfaction with the care recipient ($r = .16$) and with own performance ($r = .19$) has a moderate to strong positive association with mastery. Sense of competence sacrifice subscale is associated with more psychological complaints ($r = .34$), reduced mental ($r = -.32$) and physical QoL ($r = .45$). Sense of competence sacrifice subscale is related with physical component of QoL ($p = .001$), mental component and psychological complaints ($p = .03$).
Riedijk et al.	2009/ Netherlands	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	
Van Den Wijngaert 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 (ALCOS-12)	Five items of Dutch version of COOP/ WONCA charts	86% (12/14) High quality	SE and physical health domain (.13)	Positive association between SE and functional health status ($r = .13$), but not significant.
Au et al.	2010/ Hong Kong	134 carers 75% female Mean age = 54 yrs 2.5% horizontal kinship 66% vertical kinship	Cross-sectional/ bivariate correlation, path analysis	RSSE	Chinese (Hong Kong) Version of the Medical Outcomes Study SF-36 Health Survey	86% (12/14) High quality	SE:DB and physical health (.25) SE:CT and 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 and SE:CT are mediators of PCS.

(continued)

Table 1. (Continued)

Author	Year/ country	Sample	Design/analysis	SE measure			Quality assessment	Effect size (R)	Main findings
				Generic	Domain- specific	HrQoL measure			
Gottlieb & Rooney	2003/Canada	134 carers 73% female Mean age = 61 yrs 60% adult child 37% spouses	Longitudinal/ correlation, hierarchical regression	Generic	RIS Eldercare SE Scale	SF-36 Affect Balance Scale	78% (11/17) High quality	Relational SE and generic HrQoL (.20) Self-soothing SE and generic HrQoL (.35)	Relational SE ($r = .20, p < .05$) and 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 ($r = .16$), and 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	Generic	RIS Eldercare SE Scale	SF-36, Life Orientation Test, Affect Balance Scale	71% (10/14) Moderate quality	Instrumental SE and mental health (.31) Relational SE and mental health (.23)	Instrumental SE and relational SE have significant positive correlations with mental health ($r = .31, p < .001$) and $r = .23, p < .01$, positive affect ($r = .18, p < .05$ and $r = .17, p < .05$), and positive reframing ($r = .22, p < .01$ and $r = .32, p < .001$)
Haley et al.	1987/USA	54 carers 80% female Mean age = 56 yrs 55% adult child 28% spouse	Cross-sectional/ Pearson's correlation, multiple regression	Generic	Rating of SE for ADL, IADL and MPBC.	Life Satisfaction Index Form Z (LSIZ), Self-rated health (single item; poor – excellent)	86% (12/14) High quality	SE MBPC and generic HrQoL (.11) SE ADL and generic HrQoL (.17) SE IADL and generic HrQoL (.17)	SE MBPC ($r = -.11$), SE ADL ($r = -.17$), SE IADL ($r = -.17$) have negative associations with self-rated health problems, but they are not significant. SE MBPC ($r = -.19$), SE ADL ($r = -.3$), SE IADL ($r = -.31, p < .05$) have negative associations with satisfaction, but only SE IADL is significant.
Marziali et al.	2010/Canada	232 carers 75% female 56% spouses 36% children	Cross-sectional/ Pearson's correlation, regression	Generic	RSSE	HSQ12	57% (8/14) Moderate quality	SE and physical health (.16) SE and 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 is only predicted by SE ($t = 2.72, p < .01$).
Miller et al.	1995/USA	215 carers 64% female Mean age = 74.7 yrs 100% spouse	Cross-sectional/ correlation	Generic	Carer mastery (four-point Likert scale)	Self-rated health – four items (poor – good)	64% (9/14) Moderate quality	Mastery and generic HrQoL (.15)	No association between mastery and carer health ($r = .15$).

(continued)

Table 1. (Continued)

Author	Year/ country	Sample	Design/analysis	SE measure			Quality assessment	Effect size (<i>R</i>)	Main findings
				Generic	Domain- specific	HrQoL measure			
Montoro-Rodriguez & Gallagher-Thompson,	2009/ San Francisco, USA	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/USA	256 carers 100% female Mean age = 57 yrs 61% spouse 39% non-spouse	Cross-sectional/ bivariate correlation, multiple hierarchical regression		RSSE	Carer health (four items of perceived physical health)	86% (12/14) High quality	Unable to calculate	SE:DB and SE:CT are significant moderators of depression, which influences overall health. A significant interaction exists between memory and behaviour problems and SE: DB ($t = 1.98, p < 0.05$).

Notes: RSSE – Revised Scale for Caregiving Self-efficacy; SCO – Sense of Competence Questionnaire; SF-36 – 36-item Short-Form Health Survey; QoL – quality of life; SE:DB – self-efficacy for responding to disruptive behaviour; SE:CT – self-efficacy for controlling upsetting thoughts; SE:OR – self-efficacy for obtaining respite; ADL – activities of daily living; IADL – instrumental activities of daily living; MBPC – memory and behaviour problems; HSQ-12 – Health Status Questionnaire; HrQoL – health-related quality of life; PCS – physical component summary; SE – self-efficacy; RIS Eldercare – Relational, Instrumental and Self-care Eldercare Self-efficacy Scale.

differences. 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 hypothesising the role of domain-specific SE beliefs in family carer health-related QoL was developed by combining the conceptual maps describing the associations between SE, positive and negative outcomes, and physical and mental health. To evaluate the direction and size of any relationships in quantitative studies, standardised effect sizes were calculated when sufficient information was available to do so and an overall summary figure calculated (Field, 2005, p. 192). To determine the magnitude of the effect size Cohen's (1992) guidance was used.

Stage 4: evaluating the robustness of the synthesis

This stage involves examining the methodological quality of studies and the trustworthiness of the synthesis findings. To evaluate the review quality, a critical reflection of the review process was completed. This involved looking back retrospectively over the review process to acknowledge any limitations that might constrain the validity of findings.

Results

NS element 2: preliminary synthesis

Study characteristics

A total of 6194 references were identified (Figure 2), of which 5956 were excluded by screening the title and abstract. Of the remaining 227 references, full text was sought and 22 were retained (Tables 1–3). Reasons for exclusion included no health-related QoL measure ($n = 57$), no SE measure ($n = 26$), dissertation ($n = 8$), conference abstract or letter ($n = 5$), review ($n = 5$), not family carers of individuals with dementia ($n = 44$), no indication of the relationship between SE and health-related QoL ($n = 49$), and unable to obtain ($n = 11$).

The 22 studies included 17 quantitative, 4 qualitative, and 1 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 1 mixed-method study, data analysis included correlation ($n = 11$), regression ($n = 5$), and path modelling ($n = 2$), with these studies 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 case studies ($n = 1$), semi-structured/open-ended interviews ($n = 2$), surveys ($n = 1$), and a mixture of both interviews and focus groups ($n = 1$). Qualitative analysis included interpretive-descriptive, phenomenological approaches, and grounded theory.

Table 2. Quantitative studies with positive outcome measures.

Author	Year/ country	Sample	SE measure			Quality assessment	Main findings
			Methodology/ design	Generic	Domain- specific		
Cheng et al.	2012/ Hong Kong	99 carers 71% female Mean age = 59.88 yrs 35% spouse 64% intergenerational	Cross-sectional/ multiple regression		RSSE	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 to the final model for positive gain. SE:OR is not associated with positive gain ($\beta = -0.021$).
Davis et al.	2006/USA	49 carers 69.4% female Mean age not specified 92% spouses	Cross-sectional/ Pearson's correlation	GSE		64% (9/14) Moderate quality	Finding meaning (loss/powerlessness & provisional meaning) is positively associated with SE, but not significantly ($r = .23, p = .111$ and $r = .06, p = .671$). Higher SE is associated with lower depression ($r = -0.42, p = 0.003$). SE has a significant positive correlation with resilience ($r = .52, p < .05$)
Fitzpatrick & Vacha-Haase	2010/USA	30 carers 70% female Mean age = 76.4 yrs 100% spouses	Cross-sectional/ correlation	The SE scale		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% inter- generational	Cross-sectional/ Pearson's correlation, multiple regression	SSCQ		86% (12/14) High quality	Carer gain is positively correlated with sense of carer competence ($r = .24, p < .0001$). Well-being is an important predictor of gain ($p = .0014$). Carer competence is not a significant predictor of gain ($p = .295$).
Narayan et al.	2001/USA	50 carers 74% female Mean age = 73.3 yrs 100% spouses	Cross-sectional/ correlation	Caregiver competence scale		71% (10/14) Moderate quality	Positive aspects of caring express a significant positive association with competence ($r = .46, p < .01$). No significant correlation exists between positive and negative subjective responses.
Quinn	2010/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		71% (10/14) Moderate quality	High competence significantly predicts finding meaning ($p = .29$). Competence has a significant positive association with finding meaning ($r = .46, p < 0.001$).

(continued)

Table 2. (Continued)

Author	Year/ country	Sample	Methodology/ design	SE measure			Quality assessment	Main findings
				Generic	Domain- specific	Dependent variable		
Roud et al.	2006/ New Zealand	45 carers 60% females Mean age not specified 65% spouses 35% intergenerational	Longitudinal/ Pearson's correlation	Caregiver competence		Positive scale of COPE-Index, personal gain	78% (11/17) High quality	Carer competence has a positive association with the positive aspects of caring, but it is not significant ($r = .16$).

Notes: RSSE – Revised Scale for Caregiving Self-efficacy; GSE – General Self-efficacy Scale; SSCQ – Short Sense of Competence Questionnaire; GAIN – Gains in Alzheimer's care Instrument; FMTC – Finding Meaning through Caregiving Scale; RS – The Resiliency Scale; SE:CT – self-efficacy for controlling upsetting thoughts; SE:DB – self-efficacy for responding to disruptive behaviour; BPSD – behavioural and psychological symptoms of dementia; SE:OR – self-efficacy for obtaining respite; COPE-Index – Carers of Older People in Europe Index.

Participant characteristics

Participants were recruited from a range of settings, including health professionals, social services, the media, and primary health care. Of the included articles, sample sizes ranged from 2 to 447, with the total sample of family carers in the studies being 2929. The mean carer age was 62 years. As expected, there were more females (74%) than males, carers were mostly white (48%), Chinese (31%) or Latina (8%). There were fewer intergenerational kinships (31%) than spousal/partner kinships (44%).

Quality assessment

Of the quantitative and mixed-method studies, 11 were graded as high quality and 7 as moderate quality, with an average quality rating of 77%. All four qualitative studies and the mixed-method study adequately met the CASP research appraisal criteria (Public Health Resource Unit, 2006).

Study measures

There are no existing reviews of SE or health-related QoL measures in caring literature. Of the studies included in this review, there were a number of different health-related QoL measures adopted. These included the 36-item Short Form Health Survey ($n = 5$), Health Status Questionnaire ($n = 1$), the COOP/WONCA charts ($n = 1$) and single item measures of health-related QoL ($n = 4$). Global, caring specific and caring domain/task-specific measures of SE were identified in the review. Global measures included the General SE scale ($n = 3$) and the Sense of Competence Questionnaire ($n = 3$). Measures specific to caring were used in three studies. The most popular measure of domain/task-specific SE was the Revised Scale for Caregiving Self-efficacy scale ($n = 5$).

NS element 3: exploring relationships within and between studies

Self-efficacy and health-related quality of life

The effect size (r) was calculated for 8 out of the 11 quantitative studies incorporating a measure of health-related QoL. Of these studies, four demonstrated a statistically significant association between SE and health-related QoL domains (Table 2), and four studies found a weak or no association. The mean overall effect size with generic health-related QoL was 0.21, which is an indicative of a small to medium association. The mean effect size for mental health was 0.31 and physical health was 0.21. However, effect sizes varied considerably, possibly due to the varied measurement scales and/or task-specific SE evaluated in the studies, or reflecting the complexity of caring.

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

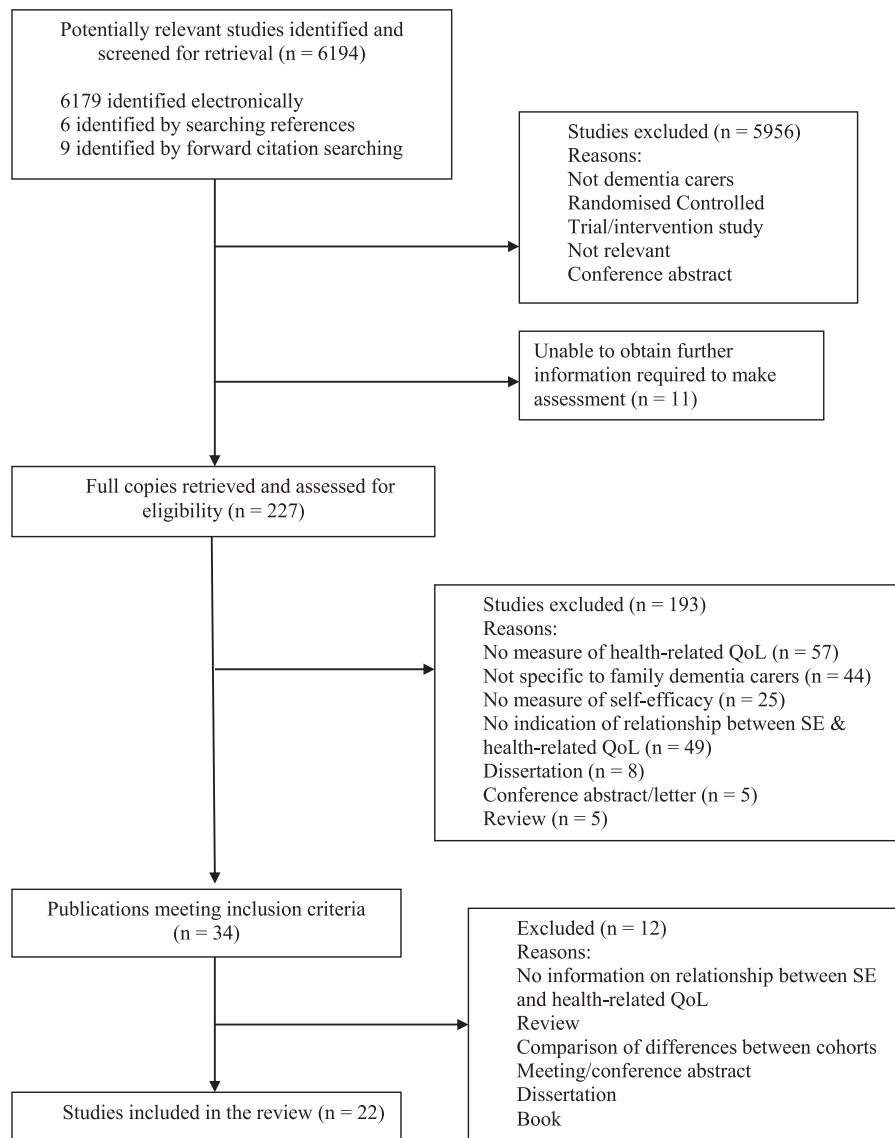


Figure 2. Flow diagram of review search.

effect size of 0.26. However, the strength of associations varied considerably, which might be a result of the wide variation in positive outcome measures or the absence of a clear conceptualisation of positive aspects related to QoL. Three studies found a weak or no association.

Conceptual mapping described the mechanism between SE and positive aspects in caring. Both Peacock et al. (2010) and Sanders (2005) found that SE was associated with an ability to cope with challenging situations, such as disruptive behaviours, and provide safe, competent care. In turn, Peacock et al. (2010) found that mastering the complexity of caring generated role satisfaction, meaning, and pride. Sanders (2005) and Narayan, Lewis, and Tornatore (2001) highlighted the relationship between SE and the development of new skills transferable to other contexts. 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 well-being (Peacock et al., 2010). A close association between role identity and SE beliefs was found. Simpson (2010) demonstrated reconciliation

of self-identity between different roles relates to SE. Skaff and Pearlin (1992) suggested that SE influences whether one will experience a loss of sense of self (identity) as a result of caring demands. Quinn, Clare, and Woods (2010) claimed that this determines self-evaluations (such as well-being) by promoting sense of meaning and satisfaction.

The limited literature makes it difficult to determine the roles of task/domain-specific SE beliefs in positive outcomes. Cheng, Lam, Kwok, Ng, and Fung (2012) found that task-specific SE beliefs have distinct associations with positive aspects: SE for responding to disruptive behaviour had a direct effect on positive gain; however, SE for controlling upsetting thoughts moderated the relationship between stressors and gain. Cheng et al. (2012) also found that task-specific SE beliefs differently influence positive and negative aspects. In addition, instrumental, relational, and self-soothing SE beliefs were also related to positive affect (Gottlieb & Rooney, 2003; Gottlieb & Rooney 2004); however, the role of these beliefs was unclear.

Table 3. Qualitative studies.

Author	Year/country	Sample	Methodology/design	Quality assessment	Main findings
Narayan et al.	2001/USA	50 carers 74% female Mean age = 73.3 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 and 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/USA	85 carers 69% female Mean age = 60 yrs 33% daughters, 29% spouses, 8% sons.	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/USA	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/USA	Sample size not specified 100% male Mean age = 61.90 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 well-being.

Note: CASP – Critical Appraisal Skills Programme.

Self-efficacy and negative aspects of caring

Low SE was related to negative outcomes in caring, such as depression. Low SE for obtaining respite, responding to disruptive behaviour, controlling upsetting thoughts, self-soothing SE, and instrumental SE were negatively associated with negative affect (Au et al., 2010; Gottlieb & Rooney, 2003; Gottlieb & Rooney, 2004). Both SE for responding to disruptive behaviour and for controlling upsetting thoughts exerted a direct effect on depression and moderated the relation between stressors and negative outcomes (Rabinowitz, Mausbach, & Gallagher-Thompson, 2009).

The association between SE and negative affect might be driven by the protective role of SE, particularly for responding to disruptive behaviour and controlling upsetting thoughts against negative affect (Figure 3).

Specifically, SE might promote emotional robustness, positive appraisals (and cognitive processes), reduced emotional vulnerability, and negative states (Au et al., 2010; Haley, Levine, Brown, & Bartolucci, 1987; Rabinowitz et al., 2009). The role of instrumental and self-soothing SE in negative affect is not clear, although self-soothing SE might improve emotional regulation.

Self-efficacy and physical health

There is little literature concerning the role of SE in physical health. However, Au et al. (2010) and Marziali, McCleary, and Streiner (2010) found that higher SE was associated with improved physical health. SE for responding to disruptive behaviour and for controlling upsetting thoughts might be the primary SE beliefs associated with

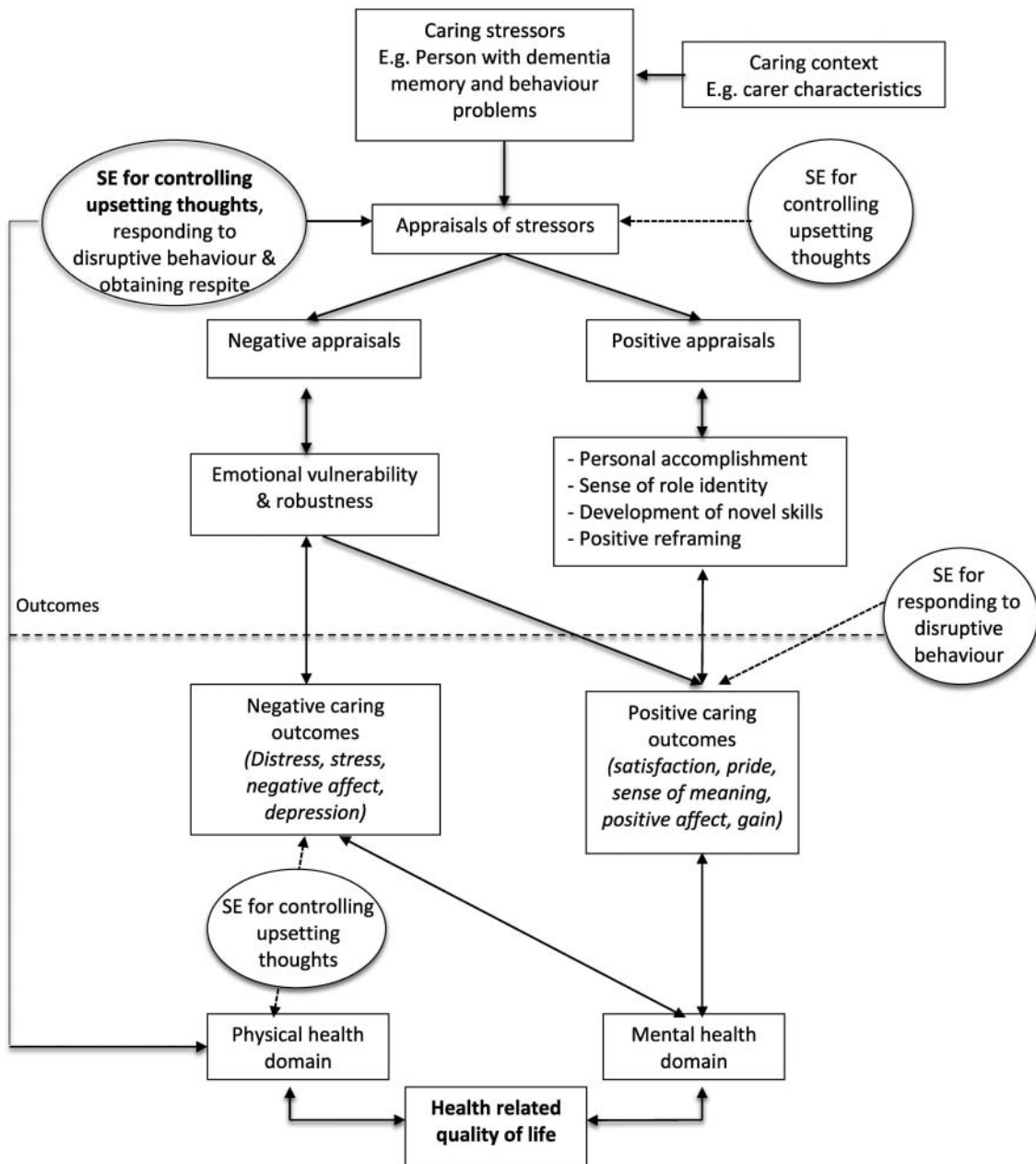


Figure 3. Hypothesised model of the role of carer self-efficacy in health-related QoL.

better physical health (Au et al., 2010), having a protective influence (Rabinowitz et al., 2009). Au et al. (2010) found that SE for controlling upsetting thoughts functions as a mediator in the relation between depression and physical health; greater ability to manage negative thoughts protects against negative affect and influences perceived physical health. There was limited evidence concerning the pathway.

Discussion

The use of the narrative synthesis methodology to draw together findings from qualitative and quantitative research has led to the development of a model hypothesising the role of task/domain-specific SE beliefs in family carer health-related QoL (Figure 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 responses.

The hypothesised model

The model 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 while 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 solely influenced by negative aspects.

In the model, only SE for responding to disruptive behaviour 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 behaviour and controlling upsetting thoughts might moderate the association between stressors and negative outcomes, as well as directly influence negative outcomes. The model supports the domain specificity of the SE theory and past research that distinct SE domains have different relations with variables (Rabinowitz, Mausbach, Thompson, & Gallagher-Thompson, 2007). It appears that SE for controlling upsetting thoughts and responding to disruptive behaviour might be the most valuable SE beliefs for family carers. However, the apparent importance of these SE beliefs might be a result of the measurement scales in the included studies, with the Revised Scale for Caregiving Self-efficacy (RSSE) being the most prevalent scale and, therefore, generating a larger evidence base concerning these domain-specific SE beliefs. The model supports assumptions that SE might attenuate negative aspects, but also enhance positive aspects of caring (Farran et al., 2004; Steffen et al., 2002).

Although a relationship was evident between SE and physical health, the mechanism was not transparent. However, research that did not meet the review eligibility criteria such as that of Rabinowitz et al. (2007) suggests that SE for responding to disruptive behaviour and controlling upsetting thoughts might mediate physical health by reducing the likelihood carers engage in maladaptive coping or health risk behaviours and result in more positive health decisions. Likewise, Harmell, Chattillion, Roepke, and Mausbach (2011) and Mausbach et al. (2007) found 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). This pathway has not been described in Figure 3.

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 domain/task-specific SE beliefs are described. Global and caring specific SE beliefs were not reported due to their incompatibility with SE theory, with SE beliefs formulated from specific situations and varying with contextual factors (Bandura, 1997).

Existing conceptual models of carer outcomes

The explanatory model (Figure 3) can be discussed in the context of existing theory and conceptual models of caring. The model supports the application of the 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 is most compatible with a two-factor view of carer appraisals, such as the Schulz & Salthouse (1999) general health model, the modified stress and coping model of Kramer (1997), and the appraisal model of 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. 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 suggest and highlighting the need for models to recognise the non-independence of the positive and negative pathway. However, further research is 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, despite accumulating empirical evidence regarding the association between SE and carer outcomes. However, the explanatory model (Figure 3) does show some

agreement with models proposed by Kramer (1997) and Haley et al. (1987) that SE might influence the caring process through carer appraisals. Kramer (1997) described SE beliefs as a carer characteristic that can influence role appraisal and well-being. Review findings not only stress the need for conceptual models to incorporate SE beliefs, but to consider it in its domain/task-specific form, to better reflect SE theory and recent empirical research. The hypothesised model might increase understanding of caring, health-related outcomes, and guide the development of improved theoretical models.

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 they 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 to generate consistency, allow comparisons to be made between research studies, and develop improved health-related QoL scales.

The second challenge highlighted 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 conceptualisation and measurement of SE has generated inconsistencies in carer SE research and has led to difficulties with interpretation. In this review, this proved a challenge when selecting studies with measurement scales that had proven validity and reliability in evaluating 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 specific to caring challenges. To achieve this, it is important to identify the caring domains/tasks that pose the greatest difficulty (e.g. problem behaviours) and to develop SE scales correspondingly.

NS element 4: assessing the robustness of the synthesis (critical reflection)

This review had well-defined inclusion criteria, and quality assessment of included studies was conducted with well-established tools. NS was chosen for its ability to provide explanations, its transparency, and flexibility to explore the role of SE combining a broad range of data. The selection of tools within the NS (Figure 1) was determined by the nature of evidence being synthesised. However, NS is not without limitations; it does not rely on

rigorous techniques developed and tested over time, and the integration of quantitative and qualitative research can be challenging. Furthermore, NS involves a wide range of tools and techniques to choose between that can create uncertainty and reduce validity. However, the guidance of Popay et al. (2006) does create greater consensus on the elements used.

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. 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. The review may also be limited by the inclusion of studies focusing on mastery and competence. These were included due to the overlap of these constructs with SE. The review might be constrained by the limited access to grey literature and the focus on English language papers.

The validity of the explanatory model might well be constrained by the lack of evidence concerning domain/task-specific SE beliefs. For instance, there was not enough evidence concerning self-soothing, instrumental or relational SE to describe these within the model. 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 been found to influence carer outcomes in the past.

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/task-specific SE in carer health-related QoL. The hypothesised model can be implemented, however, to guide future research. It highlights the need to explore the impact of contextual factors including carer characteristics, relationship-type, and variables such as social support, social network, and coping strategy on the association between SE and health-related QoL. Consideration of these factors is important, as empirical evidence demonstrates that the level of SE varies with contextual factors such as kinship and ethnicity (Depp et al., 2005; Gilliam & Steffen, 2006). The model also highlights that attention must be directed towards SE measurement, and the development of valid task-specific SE scales. Review findings also highlight the need for longitudinal analyses, statistical methods to determine direction of causality, as well as the need to explore whether SE beliefs act as mediators or moderators (Baron & Kenny, 1986). Research must also address the relationship between SE and social well-being.

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 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 for which empirical research is lacking, and in the theoretical advancement of models of carer adaptation. The review highlights the current status of SE research in caring and the methodological challenges concerning measurement and conceptualisation confronting this area. Given that SE is a potentially modifiable construct and might offer a potential therapeutic avenue to influence carer outcomes, this review might have clinical implications for carer interventions. SE-based interventions, such as SE training, coping effectiveness training, and psychoeducational approaches might have a role in improving carer health-related QoL.

Acknowledgements

The authors would like to thank grant holders: Professors Orrell (UCL), Woods (Bangor), Challis (Manchester), Moniz-Cook (Hull), Russell (Swansea), Knapp (LSE), and Dr Charlesworth (UCL). They would also like to thank the North East London NHS Foundation Trust for sponsoring this research programme.

Funding

This article presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme [grant number RP-PG 0606-1083]. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

References

References marked with an asterisk indicate studies included in the review.

- Alzheimer's Research Trust. (2010). *Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom* (Final report). Health Economics Research Centre, University of Oxford: Alzheimer's Research Trust. Retrieved from <http://www.herc.ox.ac.uk/pubs/downloads/dementiafullreport>.
- Aneshensel, C.S., Pearlin, L.I., Mullen, J.T., Zarit, S.H., & Whitlatch, C.J. (1995). *Profiles in caregiving: The unexpected career*. New York, NY: Academic Press.
- *Au, A., Lau, K.-M., Sit, E., Cheung, G., Lai, M.-K., Wong, S.K. A., & Fok, D. (2010). The role of self-efficacy in the Alzheimer's family caregiver stress process: A partial mediator between physical health and depressive symptoms. *Clinical Gerontologist*, 33(4), 298–315.
- Bakas, T., McLennon, S.M., Carpenter, J.S., Buelow, J.M., Otte, J.L., Hanna, K.M., ... Welch, J.L. (2012). Systematic review of health-related quality of life models. *Health and Quality of Life Outcomes*, 10, 134. doi:10.1186/1477-7525-10-134
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioural change. *Psychological Review*, 84, 191–215.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York, NY: W.H. Freeman and Company.
- Baron, R.M., & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51(6), 1173–1182.

Centre for Reviews and Dissemination. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care* (Research report). York, University of York: CRD. Retrieved from https://www.york.ac.uk/inst/crd/pdf/Systematic_Reviews.pdf.

- *Cheng, S.-T., Lam, L.C.W., Kwok, T., Ng, N.S.S., & Fung, A. W.T. (2012). Self-efficacy is associated with less burden and more gains from behavioral problems of Alzheimer's disease in Hong Kong Chinese caregivers. *The Gerontologist*, 53(1), 71–80.
- Coen, R.F., O'boyle, C.A., Swanwick, G.R.J., & Coakley, D. (1999). Measuring the impact on relatives of caring for people with Alzheimer's disease: Quality of life, burden and well-being. *Psychology & Health*, 14(2), 253–261.
- Cohen, C.A., Gold, P.D., Shulman, K.I., & Zuccherro, C.A. (1994). Positive aspects in caregiving: An overlooked variable in research. *Canadian Journal on Aging*, 13(3), 378–391. Retrieved from <http://dx.doi.org/10.1017/S071498080000619X>
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112, 155–159. Retrieved from <http://dx.doi.org/10.1037/0033-2909.112.1.155>
- Cooper, C., Balamurali, T., & Livingston, G. (2007). A systematic review of the prevalence and associates of anxiety in carers of people with dementia. *International Psychogeriatrics*, 28, 1–21.
- *Davis, B.A., Martin-Cook, K., Hynan, L.S., & Weiner, M.F. (2006). Caregivers perceptions of dementia patients functional ability. *American Journal of Alzheimer's Disease and Other Dementias*, 21(2), 85–91.
- Depp, C., Sorocco, K., Kasl-Godley, J., Thompson, L., Rabino-witz, Y., & Gallagher-Thompson, D. (2005). Caregiver self-efficacy, ethnicity, and kinship differences in dementia caregivers. *American Journal of Geriatric Psychiatry*, 13(9), 787–794.
- Downs, S., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health*, 52, 377–384.
- Etters, L., Goodall, D., & Harrison, B.E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20(8), 423–428.
- Farran, C.J. (1997). Theoretical perspectives concerning positive aspects of caring for elderly persons with dementia: Stress/adaptation and existentialism. *The Gerontologist*, 37(2), 250–256.
- Farran, C.J., Gilley, D.W., McCann, J.J., Bienias, J.L., Lindeman, D.A., & Evans, D.A. (2004). Psychosocial interventions to reduce depressive symptoms of dementia caregivers: A randomized clinical trial comparing two approaches. *Journal of Mental Health and Aging*, 10(4), 337–350.
- Farran, C.J., Miller, B.H., Kaufman, J.E., Donner, E., & Fogg, L. (1999). Finding meaning through caregiving: Development of an instrument for family caregivers of persons with Alzheimer's disease. *Journal of Clinical Psychology*, 9, 1107–1125. Retrieved from [http://dx.doi.org/10.1002/\(SICI\)1097-4679\(199909\)55:9<1107::AID-JCLP8>3.0.CO;2-V](http://dx.doi.org/10.1002/(SICI)1097-4679(199909)55:9<1107::AID-JCLP8>3.0.CO;2-V)
- Field, A. (2005). *Discovering statistics using SPSS* (2nd ed.). London: Sage.
- *Fitzpatrick, K., & Vacha-Haase, T. (2010). Marital satisfaction and resilience in caregivers of spouses with dementia. *Clinical Gerontologist*, 33(3), 165–180.
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science Medicine*, 45, 1207–1221.
- Gilliam, C.M., & Steffen, A.M. (2006). The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers. *Aging and Mental Health*, 10, 79–86.

- *Gottlieb, B. H., & Rooney, J. A. (2003). Validation of the RIS eldercare self-efficacy scale. *Canadian Journal on Aging, 22* (1), 95–107.
- *Gottlieb, B.H., & Rooney, J.A. (2004). Coping effectiveness: Determinants and relevance to the mental health and affect of family caregivers of persons with dementia. *Aging and Mental Health, 8*(4), 364–373.
- Gottlieb, B.H., & Wolfe, J. (2002). Coping with family caregiving to persons with dementia: A critical review. *Aging and Mental Health, 6*(4), 325–342.
- *Haley, W.E., Levine, E.G., Brown, S., & Bartolucci, A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging, 2*(4), 323–330.
- Harmell, A.L., Chattillion, E.A., Roepke, S.K., & Mausbach, B. T. (2011). A review of the psychobiology of dementia caregiving: A focus on resilience factors. *Current Psychiatry Reports, 13*(3), 219–224.
- *Jansen, A., van Hout, H., van Marwijk, H., Nijpels, G., Gundy, C., Vernooij-Dassen, M., . . . Stalman, W. (2007). Sense of competence questionnaire among informal caregivers of older adults with dementia symptoms: A psychometric evaluation. *Clinical Practice and Epidemiology in Mental Health, 3*(11). doi:10.1186/1745-0179-3-11.
- Kneebone, I. & Martin, P. (2003). Coping and caregivers of people with dementia. *British Journal of Health Psychology, 8*, 1–17.
- Kramer, B.J. (1997). Differential predictors of strain and gain among husbands caring for wives with dementia. *Gerontologist, 37*, 239–249.
- Lawton, M.P., Moss, M., Kleban, M.H., Glicksman, A., & Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. *Journal of Gerontology, 46*, 181–189.
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping*. New York, NY: Springer.
- *Liew, T.M., Luo, N., Ng, W.Y., Chionh, H.L., Goh, J., & Yap, P. (2010). Predicting gains in dementia caregiving. *Dementia and Geriatric Cognitive Disorders, 29*(2), 115–122.
- *Marziali, E., McCleary, L., & Streiner, D.L. (2010). Evaluation of an assessment battery for estimating dementia caregiver needs for health and social care services. *American Journal of Alzheimer's Disease and Other Dementias, 25*(5), 446–454.
- Mausbach, B.T., Patterson, T.L., von Kanel, R., Mills, P.J., Dimsdale, J.E., Ancoli-Israel, S., Grant, I. (2007). The attenuating effect of personal mastery on the relations between stress and Alzheimer caregiver health: A five-year longitudinal analysis. *Aging and Mental Health, 11*(6), 637–644.
- McIntyre, M. (2003). Dignity in dementia: Person-centered care in community. *Journal of Aging Studies, 17*(4), 473–484.
- *Miller, B., Campbell, R.T., Farran, C.J., Kaufman, J.E., & Davis, L. (1995). Race, control, mastery, and caregiver distress. *Journal of Gerontology: Social Sciences, 50B*(6), 374–382.
- *Montoro-Rodriguez, J., & Gallagher-Thompson, D. (2009). The role of resources and appraisals in predicting burden among Latina and non-Hispanic white female caregivers: A test of an expanded socio-cultural model of stress and coping. *Aging & Mental Health, 13*(5), 648–658.
- Mowat, J. & Laschinger, H.K. (1994). Self-efficacy in caregivers of cognitively impaired elderly people: A concept analysis. *Journal of Advanced Nursing, 19*, 1105–1113.
- Mulrow, C., Langhorne, P., & Grimshaw, J. (1997). Integrating heterogeneous pieces of evidence in systematic reviews. *Annals of Internal Medicine, 127*(11), 989–995.
- *Narayan, S., Lewis, M., & Tornatore, J. (2001). Subjective responses to caregiving for a spouse with dementia. *Journal of Gerontological Nursing, 27*(3), 19–28.
- Ory, M., Hoffman, R., Yee, J., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and non-dementia carers. *The Gerontologist, 3*, 177–185.
- *Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., . . . Hebderson, S.R. (2010). The positive aspects of the caregiving journey with dementia: Using a strengths-based perspective to reveal opportunities. *Journal of Applied Gerontology, 29*(5), 640–659.
- Pearlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*, 583–591.
- Pinquart, M., & Sorensen, S. (2004). Associations of caregivers' stressors and uplifts with subjective well-being and depressive mood: A meta-analytic comparison. *Aging & Mental Health, 8*(5), 438–449.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, . . . Duffy, S. (2006). *Guidance on the conduct of narrative synthesis in systematic reviews: A product from the ESRC methods programme* (Final report). Lancaster: Lancaster University.
- Public Health Resource Unit. (2006). *Critical Appraisal Skills Programme (CASP): Making sense of evidence. 10 questions to help you make sense of qualitative research*. England Public Health Resource Unit. Available from: <http://www.casp-uk.net/#!/casp-tools-checklists/>
- *Quinn, C., Clare, L., & Woods, R.T. (2010). The impact of motivations and meanings on the well-being of caregivers of people with dementia: A systematic review. *International Psychogeriatrics, 22*, 43–55.
- *Rabinowitz, Y.G., Mausbach, B.T., & Gallagher-Thompson, D. (2009). Self-efficacy as a moderator of the relationship between care recipient memory and behavioral problems and caregiver depression in female dementia caregivers. *Alzheimer Disease & Associated Disorders, 23*(4), 389–394.
- Rabinowitz, Y.G., Mausbach, B.T., Thompson, L.W., & Gallagher-Thompson, D. (2007). The relationship between self-efficacy and cumulative health risk associated with health behavior patterns in female caregivers of elderly relatives with Alzheimer's dementia. *Journal of Aging and Health, 19*, 946–964.
- Rapp, S.R., & Chao, D. (2000). Appraisal of strain and of gain: Effects of psychological well-being of caregivers of dementia patients. *Aging & Mental Health, 4*(2), 142–147.
- *Riedijk, S., Duijvenvoorden, H., Van Swieten, J., Niermeijer, M., & Tibben, A. (2009). Sense of competence in a Dutch sample of informal caregivers of frontotemporal dementia patients. *Dementia and Geriatric Cognitive Disorders, 27* (4), 337–343.
- Roud, H., Keeling, S., & Sainsbury, R. (2009). Using the COPE assessment tool with informal carers of people with dementia in New Zealand. *Journal of the New Zealand Medical Association, 119*(1237). Retrieved from <http://journal.nzma.org.nz/journal/119-1237/2053/>
- *Sanders, S. (2005). Is the glass half empty or half full? *Social Work in Health Care, 40*(3), 57–73.
- Schulz, R., & Martire, L.M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry, 12*(3), 240–249.
- Schulz, R., O'Brien, A.T., Bookwala, M.S., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist, 35*, 771–791.
- Schulz, R., Salthouse, T. (1999). *Adult development and aging: Myths and emerging realities*. Upper Saddle River, NJ: Prentice Hall.
- Shaw, W.S., Patterson, T.L., Ziegler, M.G., Dimsdale, J.E., Semple, S.J., & Grant, I. (1999). Accelerated risk of hypertensive blood pressure recordings among Alzheimer caregivers. *Journal of Psychosomatic Research, 46*, 215–227.

- *Simpson, C. (2010). Case studies of hispanic caregivers of persons with dementia: Reconciliation of Self. *Journal of Transcultural Nursing, 21*(2), 167–174.
- *Skaff, M., & Pearlin, L. (1992). Caregiving: Role engulfment and the loss of self. *The Gerontologist, 32*(5), 656–664.
- Steffen, A.M., McKibbin, C., Zeiss, A.M., Gallagher-Thompson, D., & Bandura, A. (2002). The revised scale for caregiving self-efficacy: Reliability and validity studies. *Journal of Gerontology: Psychological Sciences, 57B*, 74–86.
- Stroebe, M.S., & Schut, H. (2001). Meaning making in the dual process model. In R. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 55–73). Washington, DC: American Psychological Association.
- Tarlow, B.J., Wisniewski, S.R., Belle, S.H., Rubert, M., Ory, M.G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: Contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Journal of Family Nursing, 26*(4), 429–453.
- Torti, F.M., & Cwyther, L.P. (2004). A multinational review of recent trends and reports in dementia caregiver burden. *Alzheimer Disease and Associated Disorders, 18*, 99–109.
- Vitaliano, P.P., Zhang, J., & Scanlan, J.M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129*, 946–972.
- *Wijngaart, M.A.G.V.D., Vernooij-Dassen, M.J.F.J., & Felling, A. J.A. (2007). The influence of stressors, appraisal and personal conditions on the burden of spousal caregivers of persons with dementia. *Aging & Mental Health, 11*(6), 626–636.
- Wolfs, C.A.G., Kessels, A., Severens, J.L., Brouwer, W., de Vugt, M.E., Verhey, F.R.J., & Dirksen, C.D. (2011). Predictive factors for the objective burden of informal care in people with dementia: A systematic review. *Alzheimer Disease and Associated Disorders, 26*(3), 197–204.
- World Health Organization. (1948). *Preamble to the Constitution of the World Health Organization*. International Health Conference, New York, 19–22 June 1946.
- Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20*, 649–655.