

**Do knowledge and acceptance predict anxiety and depression in carers of individuals with Alzheimer's disease?**

**Beatrice Instone**

**Thesis submitted in partial fulfilment of the requirements of Staffordshire and Keele Universities for the jointly awarded degree of Doctorate in Clinical Psychology**

**July 2015**

## **Acknowledgements**

I would like to thank my academic supervisor, Dr Helen Scott, for her support and guidance throughout. I would also like to thank all of the carers who kindly agreed to take part in the research.

## Contents

Thesis abstract .....	6
Chapter 1: Literature review.....	7
Is the psychological wellbeing of dementia carers related to ‘Sense of Coherence’?.....	7
Abstract .....	8
Introduction.....	9
<i>Background</i> .....	9
<i>Sense of Coherence</i> .....	12
<i>Rationale for review</i> .....	16
Method .....	17
<i>Search strategy</i> .....	17
<i>Inclusion criteria</i> .....	18
<i>Exclusion criteria</i> .....	18
<i>Results</i> .....	18
<i>Critical appraisal</i> .....	18
Critique/synthesis .....	21
<i>Overview of selected studies</i> .....	21
<i>Theoretical perspectives of Sense of Coherence</i> .....	27
<i>Methodology: recruitment</i> .....	28
<i>Methodology: measures of SOC &amp; psychological wellbeing</i> .....	30
<i>Findings</i> .....	32
<i>Clinical implications</i> .....	34
Discussion of findings.....	37
Conclusion.....	40
References .....	41
Appendices.....	53
<i>Appendix 1: Figure 1. Flowchart showing Study Selection process</i> .....	53
<i>Appendix 2: Checklist of critical appraisal questions</i> .....	54
<i>Appendix 3: Hierarchy of evidence (Sackett et al., 1996)</i> .....	55
Chapter 2: Research report .....	56
Do knowledge and acceptance predict anxiety and depression in carers of individuals with Alzheimer’s disease? .....	56
Abstract .....	57
Introduction.....	58

<i>Aims and research questions/hypotheses</i> .....	64
Method .....	65
<i>Design</i> .....	65
<i>Participants</i> .....	65
<i>Procedure</i> .....	66
<i>Measures</i> .....	66
<i>Statistical analysis</i> .....	69
Results .....	69
<i>Regression analysis</i> .....	71
Discussion .....	73
<i>Clinical implications</i> .....	77
<i>Limitations</i> .....	78
Conclusion.....	80
References .....	82
Appendices.....	89
<i>Appendix 1: Demographic Information sheet</i> .....	89
<i>Appendix 2: Alzheimer’s Disease Knowledge Scale (ADKS)</i> .....	90
<i>Appendix 3: Acceptance &amp; Action questionnaire-II (AAQ-II)</i> .....	92
<i>Appendix 4: The Hospital Anxiety &amp; Depression Scale (HADS)</i> .....	93
<i>Appendix 5: Letters of permission to recruit participants (anonymised)</i> .....	95
<i>Appendix 6: Ethical approval confirmation (anonymised where appropriate)</i> .....	97
<i>Appendix 7: Participant information sheet</i> .....	99
<i>Appendix 8: Consent form</i> .....	102
<i>Appendix 9: Support information</i> .....	103
<i>Appendix 10: Author guidelines for submission to Dementia: The International Journal of Social Research and Practice.</i> .....	104
Chapter 3: Commentary & reflective review.....	107
Commentary and reflexive account of the research process .....	107
Abstract .....	108
Introduction.....	109
Reflective commentary .....	110
<i>Literature review</i> .....	110
<i>Research report</i> .....	111
Reflexive account .....	113
<i>Effect of research on researcher</i> .....	113

<i>Ethical Issues</i> .....	114
Conclusion & key learning points .....	115
References .....	117

## **Thesis abstract**

Carers of individuals diagnosed with dementia can often experience high levels of stress, anxiety and depression, which can have a negative impact on psychological wellbeing. Research has begun to explore the factors which influence the level of distress that carers experience. In particular, research has shown that coping strategies play a large role in mediating the relationship between caregiving and its associated stress. Given this finding, the aim of the thesis was to explore additional factors related to coping that may be associated with the wellbeing of carers. A review of the literature was undertaken, specifically focusing on the concept known as 'Sense of Coherence' (SOC), which is concerned with the extent to which a person perceives stressful life events as comprehensive, manageable and meaningful. The findings revealed that dementia carers with a high SOC were less likely to feel burdened by their situation or experience anxiety and depression, in comparison to carers with a low SOC. However, several limitations were identified regarding the extent to which SOC has a protective effect on symptoms such as depression.

The second part of this thesis involved carrying out a research study which attempted to explore psychological acceptance and knowledge of dementia (specifically pertaining to knowledge of Alzheimer's-type dementia) as possible predictors of anxiety and depression in carers of individuals with Alzheimer's disease, in order to address inconsistencies in the research and to strengthen the existing evidence base. The findings revealed that psychological acceptance was a significant predictor of anxiety and depression. This has implications for interventions that can enhance acceptance in order to reduce distress, such as Acceptance and Commitment therapy. A reflective account on the process of carrying out the research is offered, which also addresses some of the primary strengths and weaknesses of both the literature review and research study.

## **Chapter 1: Literature review**

**Is the psychological wellbeing of dementia carers related to  
'Sense of Coherence'?**

**Abstract**

Caring for somebody with dementia can have a profoundly negative impact on carers' psychological wellbeing. Research has shown that one factor that affects how well an individual copes with stressful situations is Sense of Coherence (SOC). SOC relates to a person's capacity to make use of the resources available to them and their ability to perceive a stressful situation as manageable. A high SOC has been positively associated with improved mental health. This paper reviews the evidence relating to the relationship between SOC and psychological wellbeing in dementia caregivers. A literature search identified nine relevant papers, looking at a range of different factors that affect emotional wellbeing such as anxiety, depression and burden. All of the papers found evidence to support the relationship between SOC and improved outcomes for carers' psychological wellbeing. However the research was not without its limitations and further studies are needed to increase the evidence base.



## **Introduction**

### *Background*

Dementia is defined as a syndrome, usually of a chronic or progressive nature, in which there is deterioration in cognitive function such as memory, thinking, comprehension, problem-solving and judgement (World Health Organisation [WHO], 2012). Dementia primarily affects adults above the age of 65 and is a major cause of disability and dependency among older adults worldwide. Currently there is no treatment available to cure dementia. The WHO (2012) recognises dementia as a public health priority and aims to improve the care and support for people with dementia and their caregivers. It is estimated that 35.6 million people suffer from dementia worldwide and the total number of people with dementia is predicted to almost double every 20 years (WHO, 2012). The predicted future increase of dementia cases means the costs are set to increase even more quickly than the prevalence, posing a significant challenge for health and social care systems (WHO, 2012). In the UK it is predicted that there will be approximately 850,000 people with dementia in 2015 (Alzheimer's Society, 2014) and the cost to the NHS is estimated to grow to £27 billion by 2018.

There are several forms of dementia. The most common form is Alzheimer's disease, which affects 62% of those diagnosed (Alzheimer's Society, 2014). Symptoms are caused due to damage to the brain caused by Alzheimer's disease, which leads to loss of brain tissue. Short-term memory and word-finding difficulties are the most common features in the early stages of Alzheimer's (Taylor & Thomas, 2013) which gradually worsen as the disease progresses. In the early stages symptoms are generally mild, and thus easier to cope with from a carer perspective. In the later stages the person will require more day-to-day support from those who care for them, and many people also display behaviours that appear out of character such as reacting aggressively (Alzheimer's Society, 2014). These behaviours can be distressing and challenging for the person and their carer to cope with.

The second most common type of dementia is Vascular dementia, which is caused when the brain is damaged because of problems in blood supply. A

number of risk factors can contribute to the development of Vascular dementia including smoking, obesity and hypertension. In addition to features of language and memory difficulties, as seen in Alzheimer's disease, anxiety, depression and slowing of cognitive processes are common (O'Brien et al., 2003), however symptoms vary depending on the underlying cause. For example, symptoms may develop suddenly following a stroke, or more gradually such as with small vessel disease. Similarly the speed and pattern of decline is often unpredictable and will vary depending on the underlying cause, which often makes the experience of caring for somebody with Vascular dementia increasingly difficult to cope with (Alzheimer's Society, 2014).

The third most common type of dementia which accounts for approximately 10% of cases is Dementia with Lewy bodies (Matsui et al., 2009), which is caused when there are changes to various areas of the brain. Symptoms of this type of dementia are similar to those seen in Alzheimer's. However features characteristic of Dementia with Lewy bodies include visual hallucinations, recurrent falls and mobility difficulties similar to those observed in individuals with Parkinson's disease (McKeith et al., 2005). Carers often find visual hallucinations very upsetting. In the later stages of Dementia with Lewy bodies, as with most types of dementia, individuals can present with challenging behaviours such as agitation and shouting out, which can be difficult for the carer to manage and often requires extensive nursing care.

Other less common types of dementia include frontotemporal dementia and mixed dementia. Both types can present with a variety of features depending on what part of the brain is affected. In of all types of dementia, research has shown that the severity of symptoms is a strong predictor of carer psychological distress (Cooper et al., 2008) including anxiety, depression (Garcia-Alberca, Lara, & Berthier, 2011) and burden (Chiu, Chen, Yip, Hua & Tang, 2006). More specifically, caring for somebody with a greater degree of physical and cognitive impairment and behavioural problems has been associated with increased distress for the carer (Mahoney et al. 2005; Schulz, O'Brien, Bookwala & Fleissner, 1995).

As dementia progresses there is an increasing likelihood that the individual can no longer be cared for in their own home. One third of individuals with dementia live in a care home whilst the majority (two thirds) live in the community (Alzheimer's Society, 2014), commonly cared for by their spouse. There are approximately 670,000 people in the UK acting as primary carers for people with dementia (Alzheimer's Society, 2012). Family carers of people with dementia save the UK economy approximately £11 billion per year (Alzheimer's Society, 2014).

Caring for somebody with dementia can understandably be stressful because of the complex, unpredictable nature of the illness and carers are at an increased risk of stress related illness such as anxiety and depression (Cooper, Balamurali & Livingston, 2007; Parks & Pilisuk, 1991; Pinquart & Sorensen, 2003; Royal College of Nursing, 2014; Vitaliano, Young & Zhang, 2004). Family carers of relatives with dementia are also more likely to experience high levels of burden compared to carers of other chronic illnesses (Draper, Poulos, Cole, Poulos & Ehrlich, 1992). This has been associated with decreased quality of life and depression, as well as early nursing home placement for the person with dementia (Gaugler, Kane, Kane & Newcomer, 2005; Yaffe et al., 2002). Studies have also confirmed the high level of mental distress experienced by family caregivers of people with dementia, and feelings of sadness, guilt, loss and anger are all common (Murray, Schneider, Banerjee & Mann, 1999).

Caregiving, therefore, has a large impact on an individual's psychological wellbeing and there are many factors that have been implicated in mediating the relationship between dementia caregiving and the wellbeing of carers. A literature review by Savage and Bailey (2004) identified a number of different factors associated with the impact of caring, including the relationship between caregiver and care recipient, the care recipient's level of disability, stage in the caregiving process, socioeconomic factors, social support, and coping strategies. In relation to coping, Cooper, Katona, Orrell and Livingston (2008) found that coping strategies are a strong predictor of psychological distress in carers of individuals with Alzheimer's disease. More specifically, carers using emotion-focused coping strategies, such as humour and seeking emotional support, in response to

caregiver burden were less likely to develop anxiety one year later. Furthermore using fewer emotion-focused strategies and more problem-focused strategies (which involves taking action and trying to come up with strategies for what to do, by seeking advice for example) mediated the relationship between caregiver burden and anxiety after controlling for potentially confounding factors such as demographic characteristics relating to the carer and care recipient. The study also showed that using fewer emotion-focused coping strategies predicted higher psychological morbidity in carers.

As previously discussed, a large majority of research in this area has focused on categorised coping strategies (Li, Cooper, Bradley, Shulman & Livingston, 2012) consisting of three styles of coping, including emotion-focused, problem-focused and dysfunctional coping (Carver, 1997; Lazarus & Folkman, 1984). Emotion-focused coping strategies involve attempts to regulate the emotional consequences of stressful events (such as re-framing situations in a positive light), whereas problem-focused strategies involve efforts to do something active to alleviate stressful circumstances and make the situation better. The third coping style, known as dysfunctional coping, involves attempts to avoid the stressful situation and engage in unhelpful behaviours such as self-blame. The style of coping utilised depends on several factors, including individual personal style and also the nature of the stressful event. Another aspect of coping which has received less attention is concerned with an individual's perceived ability to cope with stress associated with the caregiving situation. One way of defining this concept is known as Sense of Coherence (Antonovsky, 1979; 1987). According to Antonovsky (1979) the way a person interprets events is crucial in determining whether they are able to cope with the situation successfully or become stressed by it.

### *Sense of Coherence*

Sense of Coherence (SOC) is defined as:

“a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) stimuli deriving from one's internal or external environment in the course of living

are structured, predictable and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges worthy of investment and engagement” (Antonovsky, 1987, p.19).

Thus SOC is an individual’s perspective on the extent to which life events are seen as comprehensible, manageable, and meaningful.

The concept of SOC is derived from Antonovsky’s (1979) theory of Salutogenesis, which is defined as an approach which focuses on factors that keep people healthy and support wellbeing, in contrast to traditional perspectives of health which focus on illness and the causes of disease (pathogenesis). Other related concepts which focus on the promotion of health include concepts such as self-efficacy, resilience, hardiness, and locus of control. Consistent with SOC, these theories focus on factors that help an individual successfully cope with stressful life events and thus protect them from the negative effects of stress on psychological wellbeing. For example, self-efficacy refers to an individual’s belief in his or her ability to succeed in a particular situation, which determines how people think, behave and motivate themselves (Bandura, 1977; 1986). On the other hand resilience is defined as a protective mechanism which influences a person’s ability to recover and adapt well in the face of adverse experiences such as trauma, tragedy and other sources of significant stress (Rutter, 1987; Werner & Smith, 1982). Similarly, hardiness is described as a group of personality characteristics (consisting of commitment, control and challenge) designed to strengthen resilience to stressful events, whereas locus of control refers to the extent to which people believe they have power over events in their lives, specifically whether the individual perceives reinforcement to be controlled either internally or externally, based on their beliefs about the world (Rotter, 1966).

As previously noted, these personality characteristics overlap somewhat with the SOC construct, despite their different theoretical approaches (SOC being derived from sociological approaches whereas concepts such as locus of control and self-efficacy are based on psychological theories of learning, cognition and social factors). For example, core components within hardiness and resilience which relate to deriving meaning from stressful situations, investing and committing to

action and feeling in control of one's situation are also inherent characteristics of SOC. Furthermore a theoretical analysis by Lundman et al. (2010) found that the concepts of SOC, resilience and hardiness all have a common theme of 'inner strength' to explain positive health states.

There are however notable differences between these related models of health and SOC. For example Schnyder et al. (2000) stated that locus of control and hardiness were narrower in scope as independent concepts in comparison to the SOC construct which is broader, and King (2004) suggested that whilst elements of hardiness and SOC overlap, such as the desire for meaning in life, overall the other sub components of hardiness are more constricted in focus than SOC which is much more holistic. Moreover Antonovsky (1979) described that the elements of control found within the hardiness and locus of control constructs differ from the element of control in SOC, because SOC recognises that control does not always have to rest with an individual for it to be a positive factor, and can exist in outside forces such as the government or religious figures.

An additional contrast between SOC and related concepts is the strong focus on meaningfulness, which is seen as the most important component of SOC and motivates individuals to cope successfully (Antonovsky, 1979). Furthermore Antonovsky (1979) developed the SOC concept taking into consideration at least two other pre-existing constructs; hardiness and self-efficacy. This is supported by research showing that the theory of salutogenesis, operationalised by the SOC construct, is inclusive of related concepts such as resilience and hardiness (Almedom, 2005). In addition it has been suggested that locus of control and hardiness form part of an individual's SOC (Rosenbaum & Palmon, 1984; Rotter, 1996) and contribute to the overall strength of SOC (Antonovsky, 1987; Lightsey, 1996). Therefore SOC and salutogenesis theory offer a framework for understanding factors that mitigate stress related health problems which brings together and encompasses characteristics from a number of well-established models of health. This is advantageous since SOC provides a comprehensive framework for understanding wellbeing which considers other important constructs within the literature. There is also evidence showing that SOC correlates more strongly with health in comparison to related concepts

(Cederblad & Hansson, 1996; Johnson, 2004; Pallant & Lae, 2002; Smith & Meyers, 1997).

Antonovsky (1979) developed the salutogenesis theory from research studies exploring how people manage stress. He observed that whilst stress is universal, not all individuals suffer from the negative effects of stress. The fundamental concepts of Salutogenesis he identified are the General Resistance Resources (GRRs) and SOC. GRRs are biological and psychosocial factors that make it easier for people to perceive their lives as structured and consistent, such as self-esteem, money and intelligence, and SOC is a person's ability to make use of their GRRs. SOC provides an explanation for why some individuals exposed to a stressor experience negative effects, whilst others cope well and even flourish. Antonovsky (1987) believed that SOC can help prevent breakdown in stressful situations, with a weak SOC corresponding to reduced ability to cope (increased distress), whilst a strong SOC is related to increased ability to cope and therefore reduced distress, as measured by the validated Sense of Coherence Scale (Antonovsky, 1987).

According to Antonovsky (1979) SOC is a dispositional orientation which develops in childhood and early adulthood. Antonovsky (1979) felt that following this time, typically when a person reaches their fourth decade of life, they have attained sufficient life experience (such as a job or education) to be independent and form their own view of life, and only very major life changes could alter SOC after this time. However subsequent research in this area has resulted in some debate concerning the stability of SOC, as more recent studies have suggested that SOC is a continuous process (Hakanen, Feldt & Leskinen, 2007; Volanen, Suominen, Lahelma, Koskenvuo & Silventoinen, 2007), which increases throughout the whole lifespan, reaching its peak at old age (Eriksson & Lindstrom, 2005).

A systematic review by Eriksson and Lindstrom (2007) found that SOC is strongly related to perceived health, in particular mental health, which was determined by the number of subjective complaints and symptoms of illness reported by participants. The authors reviewed 471 research studies conducted primarily on

the general population and individuals with physical health complaints such as chronic pain. Overall they found a relationship between strong SOC, better perceived health and higher quality of life, and concluded that SOC appears to be a health promoting resource, based on evidence showing that a weak SOC is strongly associated with anxiety, anger, burnout, depression, hopelessness and post-traumatic stress disorder. There is also evidence from longitudinal studies that SOC has good predictive value in terms of promoting positive health outcomes in the short and long-term (Bengtsson-Tops & Hansson, 2001; Eriksson & Lundin, 1996; Ristner, Andersson, Johansson, Johansson & Ponzer, 2000). In relation to the caregiving population, a recent study by Tang, Cheng, Lee, Chen and Liu (2013) with carers of terminally ill cancer patients found that SOC was significantly associated with depression, caregiving burden and confidence in caregiving, highlighting the protective factors of SOC in this population.

#### *Rationale for review*

There is a growing body of evidence in the literature highlighting the positive role of SOC in coping with stressful situations; however, the evidence relating to the caregiving population is limited. Given that informal caregivers of individuals with dementia experience high levels of stress, burden and psychological distress, it would be highly valuable to investigate the impact of SOC on the psychological wellbeing of dementia carers, in order to gain a more thorough understanding of those individuals who may be particularly vulnerable to suffering the negative effects of caregiving.

The aim of this review, therefore, is to critically appraise the evidence pertaining to the relationship between SOC and psychological wellbeing in the dementia caregiver population by examining factors that impact upon wellbeing. This is important because vulnerable carers could be identified before they begin to show symptoms or experience distress, particularly at the beginning of the caregiving process when their role may be less demanding. In this context SOC has a potential role in the prevention of psychological distress by identifying high risk carers. Findings also have implications related to offering interventions



designed to strengthen SOC and therefore promote psychological wellbeing, which include approaches such as talking therapy based on salutogenic treatment principles (Langeland et al., 2006).

## **Method**

### *Search strategy*

In order to identify literature which addressed the question of whether the psychological wellbeing of dementia carers is related to Sense of Coherence, the following host databases and corresponding databases were searched for content available to the end of August 2014: EBSCO (AMED, MEDLINE, PsycINFO, SPORTDiscus, AgeLine, CINAHL and Academic Search Complete), Web of Science (Web of Science Core Collection) and The Cochrane Library (Cochrane Database of Systematic Reviews).

The search combined the terms 'dementia\*' OR 'Alzheimer\*' with 'carer\*' OR 'caregiver\*' OR "care giver\*" and 'Sense of Coherence'. The term 'psychological wellbeing' was not included as a search term as this narrowed down the results too much, thus excluding potentially relevant articles. Psychological wellbeing is a complex, multi-dimensional construct and no one universal definition exists (Dodge, Daly, Huyton & Sanders, 2012). However the key approaches to wellbeing in the literature usually conceptualise psychological wellbeing to encompass constructs such as happiness, positive and negative affect, satisfaction with life, and effective functioning (e.g., Bradburn, 1969; Diener, 1984; Lyubomirsky & Lepper, 1999; Rogers, 1961; Ryff, 1989). In the current review psychological wellbeing is defined in terms of these dominant themes from the literature.

In order to identify relevant studies, the abstracts of articles were reviewed with reference to inclusion and exclusion criteria, and in cases where this was not clear from the abstract the full text was reviewed. The reference lists of relevant articles were also hand searched to ensure no important studies had been overlooked.

### *Inclusion criteria*

The search included studies up until 31<sup>st</sup> August 2014. No start date was specified. The following studies were included:

- Peer reviewed studies
- Published in English, or translated in English
- Studies that directly measured the relationship between SOC and factors affecting psychological wellbeing (using the definition described above) in non-professional/informal caregivers of any form of dementia (as the primary focus of the study).

### *Exclusion criteria*

- Unpublished articles (as often these articles have not been through the same level of quality control as peer-reviewed studies).
- Book chapters
- Qualitative studies (because SOC is primarily measured numerically using a questionnaire and the current review is concerned with quantifiable relationships).

### *Results*

A total of 95 potentially relevant papers were identified. Forty-six of those papers were duplicates and immediately excluded from review. When the remaining papers were reviewed with the inclusion and exclusion criteria applied, 40 papers were excluded, including two unpublished studies reporting a positive relationship between SOC and improved coping in dementia carers (Bias, 1998; Blume, 1999). This left a total of nine studies to be reviewed. A flow chart illustrating this process is shown in figure 1 (appendix 1).



### *Critical appraisal*

As no one critical appraisal tool suited all included studies, a number of relevant sources were used which ensured a variety of different appraisal issues were considered. Thus questions were taken from the Critical Appraisal Skills Programme (CASP, 2013) checklists, Young and Solomon (2009) and the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement (von Elm et al., 2007) and compiled into a final checklist

used to critically appraise the papers (see appendix 2 for the final list of appraisal questions). A summary of whether the studies met the criteria in the checklist questions can be found in table 1 below. In studies which also addressed topic areas unrelated to the review question only the findings relevant to this review are critiqued.

**Table 1.** Responses to the questions from the critical appraisal checklist

Study	Checklist Questions																				
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21
Coe et al. (1992)	Yes	Yes	No	Yes	No	No	Yes	No	No	Yes	No	No	No	Yes	Yes	Yes	Yes	No	No	Yes	No
Gallagher et al. (1994)	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	No
Mockler et al. (1998)	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	Yes	No	Yes	No	Yes	Yes	No
Andren & Elmstahl (2005)	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Andren & Elmstahl (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Valimaki et al. (2009)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Orgeta & Sterzo (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Valimaki et al. (2014)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Matsushita et al. (2014)	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes

Key:  = Yes       = No

## **Critique/synthesis**

### *Overview of selected studies*

A summary of the studies can be found in table 2 below. In relation to the checklist that was used to assess the quality of the studies (described above), two of the studies (Andren & Elmstahl, 2008; Orgeta & Sterzo, 2013) met all of the criteria in the checklist and therefore could be considered to provide high quality evidence. Similarly Andren and Elmstahl (2005) and Valimaki et al. (2009) have met all but one criterion, and Matshushita et al. (2014) and Valimaki et al. (2014) have met all but two of the desired criteria, suggesting that the quality of evidence provided by these papers is relatively good. In comparison, the study by Coe et al. (1992) only met ten out of 21 criteria in the appraisal checklist, and the study by Mockler et al. (1998) only met 13 of the standards applied in the checklist criteria, which suggests that the quality of these papers is fairly poor. Finally the study by Gallagher et al. (1994) met 17 of the desired criteria, indicating that the standard of the study is fairly good quality.

**Table 2.** An overview of the nine studies exploring the relationship between Sense of Coherence (SOC) and psychological wellbeing in dementia caregivers.

<b>Author/s &amp; date</b>	<b>Study title</b>	<b>Setting</b>	<b>Design</b>	<b>Sample</b>	<b>Outcomes measured</b>	<b>Main findings</b>
Coe, Miller & Flaherty (1992)	“SOC and Perception of Caregiving Burden”	USA	Cross-Sectional	148 caregivers to chronically ill elderly persons. Number of carers in AD category unknown.	SOC: Antonovsky (1987) scale, short version Burden: Unclear	Carers of individuals with AD with a strong SOC more often reported that the role posed no burden.
Gallagher, Wagenfeld, Baro & Haepers (1994)	“SOC, coping and caregiver role overload”	Belgium	Cross-Sectional	126 primary caregivers to dementing (n=55) and non-dementing chronically-ill family members.	SOC: Dutch version of Antonovsky’s scale (Pottie, 1990). Coping & role overload: Pearlin (1990) ‘caregiving and the stress process’ scale.	SOC has a significant protective factor against ‘role overload’ and has a greater protective effect for carers to dementing patients in terms of selecting healthier coping strategies.
Mockler, Riordan &	“Psychosocial factors	UK	Cross-Sectional	50 primary carers cohabiting with an	SOC: Antonovsky (1987) scale, long version.	Carers in the non-service user group had significantly

Murphy (1998)	associated with the use/non-use of mental health services by primary carers of individuals with dementia”			individual with dementia (n=16 non-service users, n=34 service users).	Distress: General Health Questionnaire (Goldberg & Hiller, 1979) & Greene’s Behavioural Disturbance and Stress measure (Greene et al., 1982).	higher SOC scores and reported decreased mental health problems in comparison to carers accessing services.
Andren & Elmstahl (2005)	“Family caregivers’ subjective experiences of satisfaction in dementia care: aspects of burden, subjective health and SOC”	Sweden	Cross-Sectional	153 family caregivers to 153 elderly individuals with dementia.	SOC: Antonovsky (1987) scale, long version. Satisfaction: The carer’s assessment of satisfaction index (Nolan, Grant & Keady, 1996). Burden: Caregiver burden scale (Elmstahl, Malmberg & Annerstedt, 1996). Perceived health: The Nottingham Health Profile Scale (Hunt & McEven,	A significant association was found between SOC and burden, and SOC and subjective health, with carers scoring low on burden measures reporting significantly better perceived health and higher mean SOC scores compared to carers with higher burden.

					1980).	
Andren & Elmstahl (2008)	“The relationship between burden, caregivers’ perceived health and their SOC in caring for elders with dementia”	Sweden	Cross-Sectional	130 family caregivers to 130 relatives with dementia.	SOC: Antonovsky (1987) scale, long version. Burden: Caregiver burden scale (Elmstahl, Malmberg & Annerstedt, 1996). Perceived health: The Nottingham Health Profile Scale (Hunt & McEwen, 1980). Health related quality of life: The Euroqol instrument (Rabin & de Charro, 2001).	Caregivers with lower burden reported significantly better perceived health and higher mean scores of SOC than caregivers with higher burden.
Valimaki, Vehvilainen-Julkunen, Pietila & Pirttila	“Caregiver depression is associated with a low SOC and health-related quality of life”	Finland	Cross-Sectional	170 spouse carers and 170 elderly patients with recently diagnosed (mild) Alzheimer’s disease.	SOC: Antonovsky (1987) scale, long version. Depression: Beck Depression Inventory (Beck et al., 1961). Health related quality of life:	SOC was significantly negatively correlated to depressive symptoms and distress. Furthermore good health related quality of life positively correlated with



(2009)					15D instrument (Sintonen, 2001). Distress: General health questionnaire (Goldberg & Hillier, 1979).	strong SOC.
Orgeta & Sterzo (2013)	“SOC, burden and affective symptoms in family carers of people with dementia”	UK	Cross-Sectional	170 family carers of people with dementia.	SOC: Antonovsky (1987) scale, long version. Affective symptoms: Hospital anxiety and depression scale (Zigmond & Snaith, 1983). Burden: Relative Stress Scale (Greene et al., 1982). Physical health: Euro-Qol-Visual Analogue Scale (EuroQol, 1990).	Carers experiencing high levels of stress are less likely to score highly on measures of SOC, and are more likely to experience high levels of anxiety and depression.
Matsushita et al. (2014)	“Is SOC helpful in coping with caregiver burden	Japan	Cross-Sectional	78 carers of individuals with dementia.	SOC: Japanese version of the short item SOC scale (Sakano & Yakima, 2005).	Burden was significantly associated with low SOC.

	for dementia?"				Burden: Zarit Caregiver Burden Interview (Arai, Tamiya & Yano, 2003)	
Valimaki et al. (2014)	"Decreasing SOC and its determinants in spousal caregivers of persons with mild Alzheimer's disease in three year follow-up: ALSOVA study"	Finland	Longitudinal	170 spouse carers and 170 elderly patients with recently diagnosed Alzheimer's disease. Over the three year period data was obtained for 132 carers (at 1-year follow-up), 107 carers (at 2-year follow-up) and 87 carers (at 3-year follow-up).	SOC: Antonovsky (1987) scale, long version. Depression: Beck Depression Inventory (Beck et al., 1961). Health related quality of life: 15D instrument (Sintonen, 2001). Distress: General health questionnaire (Goldberg & Hillier, 1979).	The mean SOC of carers decreased over the 3-year period, this decline in SOC was significant in carers who had depressive symptoms at baseline, when compared with carers with non-depressive symptoms.

### *Theoretical perspectives of Sense of Coherence*

All of the research studies being reviewed define Sense of Coherence (SOC) in terms of Antonovsky's (1979; 1987) model of health, that is, SOC is the ability to cope with stress through the effective use of resources available to the individual. Furthermore all studies have clearly stated the focus of their research question, with varying levels of detail in relation to the predicted outcomes. For example, five studies pre-specified a hypothesis; that high SOC will be related to better perceived health/health-related quality of life and reduced burden (Andren & Elmstahl, 2008; Valimaki et al., 2009), as well as reducing the likelihood of an individual to experience role overload (burnout and exhaustion) and adopt maladaptive coping behaviours (Gallagher et al., 1994). Similarly Orgeta and Sterzo (2013) stated that increased levels of anxiety and depression will be associated with low levels of SOC, and Valimaki et al. (2009) predicted that strong SOC will be related to reduced depression, which is maintained at a three year follow-up (Valimaki et al., 2014). In the remaining studies the predicted outcomes are not clearly defined, despite the background literature highlighting the protective factors of SOC in coping with stressful situations. This is important since the hypothesis should be based on existing theory and used to inform the study design; it also gives the reader an indication of what the findings might be (Young & Solomon, 2009).

Furthermore some of the studies differ in their view as to whether SOC is a relatively stable or dynamic trait. Mockler et al. (1998) propose that SOC is a stable and enduring orientation to the world. This is consistent with Antonovsky's (1987) view that SOC develops throughout childhood and young adulthood and becomes relatively stable by the age of around 40. Conversely, Valimaki et al. (2009; 2014) and Orgeta and Sterzo (2013) have highlighted in their background literature that there is contradictory evidence regarding the stability of SOC and that research has suggested it continues to develop across the whole life span (Hakanen et al., 2007; Volanen et al., 2007).

This is important to highlight as it has implications for findings. For example, since the majority of studies are cross-sectional, measuring SOC at a single time

point may not be appropriate for predicting how a person may cope in the future and subsequently using this information to determine the level of support they may need, given that SOC may not be as stable as originally thought. Therefore by acknowledging this, findings from these studies can be reviewed in light of this important evidence. In the remaining studies there is no reference made to the stability of SOC over time prior to the study being conducted. It could be argued that in the older studies (Coe et al., 1992; Gallagher et al. 1994) less was known about the progression of SOC at the time, however more recent studies (Andren & Elmstahl, 2005; 2008, Matsushita et al., 2014) do not state in the background literature their position in relation to the stability of SOC prior to the study being carried out.

*Methodology: recruitment*

Andren and Elmstahl (2005; 2008) recruited potential participants via postal information letters from a large sample (n=1500+) of older adults living in the community who were receiving any form of support from social services. Drawing from a diverse sample of the general population improves the likelihood of achieving a random sample, however, only recruiting individuals in receipt of support from social services is not entirely representative of the target population, since it excludes individuals who are not accessing services. In both studies the authors used follow-up letters or reminders to increase the response rate, which is advantageous as it avoids potential non-response bias. Similarly Matsushita et al. (2014) randomly selected 1000 residents living in the community in Japan aged 65-years and over from a nationwide dementia prevalence study, although it is not stated how the randomisation process took place, thus reducing confidence in the integrity of the methodology. The selected residents were then sent a study invitation letter via post. In all three studies (Andren & Elmstahl, 2005; 2008; Matsushita et al., 2014) individuals with suspected dementia underwent in-depth cognitive and medical testing by appropriate healthcare professionals. In cases where dementia was diagnosed, carers were identified and invited to take part in the study.

In the remaining studies participants were recruited from either their involvement in previous research/studies in dementia/Alzheimer's (using their existing details to make contact and send information about the study via post) (Gallagher et al., 1994; Valimaki et al., 2009; 2014) or services accessed by the carer and/or care recipient such as GPs (Mockler et al., 1998), day care centres (Coe et al., 1992) and voluntary sector organisations offering support to carers of individuals with dementia (Orgeta & Sterzo, 2013). Whilst recruiting participants from the same setting (such as voluntary sector support services) enhances validity, it can also undermine generalisability in terms of applying the findings to carers in other settings. Furthermore Mockler et al. (1998) recruited carers who were users of mental health services and compared them with carers who were not accessing services. In the service user group carers were accessing services such as 'meals on wheels', community aids and psychiatric nurse intervention. It is not very clear however whether carers were receiving all of these services or just a selection. If it was the case that carers were receiving only a selection of services, the extent to which services such as 'meals on wheels' would classify as mental health services is questionable, and could be misleading when drawing conclusions about the factors associated with the use/non-use of mental health services by carers, which was the aim of the study.

Finally the majority of studies have clearly described how their sample size was arrived at and have provided response rates, however Coe et al. (1992) recruited participants via the directors/managers of day centres by asking them to distribute the questionnaires amongst carers and as a result it is unknown how many questionnaires were distributed, therefore a response rate cannot be determined. This increases the risk of non response bias and potentially decreases the representativeness of the sample. The authors have acknowledged this as a potential drawback. Furthermore Coe et al. (1992) have not clearly described the sample, since the demographic information relating to the carers of individuals with Alzheimer's disease has been grouped with carers of other conditions, therefore findings relating to SOC and the demographic characteristics of carers should be interpreted with caution.

*Methodology: measures of SOC & psychological wellbeing*

The primary means of data collection was questionnaires, which are appropriate for the study design as SOC is measured quantitatively. All studies measured SOC using Antonovsky's sense of coherence scale (1987) (short or long version). A high score on the scale is indicative of a high/strong SOC and vice versa; however, Antonovsky (1979; 1987) did not define what constitutes a 'normal' SOC so it is difficult to determine where the cut-off point is for a high or low SOC, thus complicating interpretation (Eriksson & Lindstrom, 2005). A review by Eriksson and Lindstrom (2005) demonstrates that the scale is a reliable and valid instrument for measuring how people manage stressful situations and cope successfully, with Cronbach's  $\alpha$ -values ranging from 0.70-0.95 for both versions.

In relation to wellbeing outcomes, burden was the most commonly measured in five studies (Andren & Elmstahl, 2005; 2008; Coe et al., 1992; Matsushita et al., 2014; Orgeta & Sterzo, 2013). Most studies have clearly specified the measures they employed and have used reliable and validated measures (Andren & Elmstahl, 2005; 2008; Matsushita et al., 2014; Orgeta & Sterzo, 2013) with the exception of Coe et al. (1992) who have not specified the measures used to assess perceived burden. Most of the studies have used different scales to measure burden which makes the interpretation and comparability of findings more complex as the scales could potentially be measuring different constructs, particularly since they are made up of different indices. For example, whilst Matsushita et al. (2014) have measured burden in relation to two constructs of strain, Andren and Elmstahl (2005; 2008) utilise five sub scales measuring general strain amongst other factors linked to burden. This issue has been reflected in research which has shown that one of the problems with measuring caregiver burden is that the concept lacks consistent conceptualisation and operational definitions (Chou, 2000). This lack of clarity reduces confidence in the replication of findings using other burden scales/questionnaires, thus compromising validity.

Other outcomes measured relating to psychological wellbeing include measures of distress (such as anxiety and depression) and measures of perceived physical and mental health, all of which have satisfactory reliability and validity (Mockler et

al. 1998; Orgeta & Sterzo, 2013; Valimaki et al. 2009; 2014). It is worth noting that all of these measures are self-report, and a common problem with the use of self-report measures is bias. For example, participants may not respond truthfully either because their perception may be different to reality or because they wish to present themselves in a favourable light, thus potentially reducing validity.

As the majority of studies were cross-sectional, measures were taken at a single point in time. One of the problems with cross-sectional studies is that they do not answer questions about causality, meaning that findings could be the result of factors other than the variables of interest. Valimaki et al. (2014) utilised a longitudinal design. In relation to the hierarchy of evidence framework (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996) (appendix 3) this design is considered to potentially provide higher quality of evidence in comparison to a cross-sectional design, because information can be obtained relating to patterns of variables over time (since observations of the variables are repeated over a number of time periods). In this case measures were repeated annually over a three-year period. Given the progressive nature of dementia/Alzheimer's, one would imagine that this would be sufficient time for any changes in SOC to occur given that the carer's situation is unlikely to improve as the disease progresses. One limitation of the study design, which is acknowledged by the authors, is the fairly high drop-out rate (44.7%). The authors state that one of the reasons for this was carer distress. One explanation for this could be that the carers who completed all of the follow-up visits represent a healthier (less distressed) group of individuals, in comparison to the carers who dropped out. This can cause potential bias since the findings may not be representative of the whole original study sample.

In addition to the data collection measures described above, all studies collected some information on the socio-demographic profile of participants. However, whilst some studies used this data to describe the sample, other studies have controlled for these variables as possible confounding factors in their analysis, thus minimising bias. Andren and Elmstahl (2005; 2008), Matsushita et al. (2014), Orgeta and Sterzo (2013) and Valimaki et al. (2009; 2014) controlled for at least four other demographic variables, including information relating to the

care recipient such as their level of disability and dependency on the caregiver. Controlling for such factors is desirable since it enhances validity and increases confidence that any differences found in the sample relating to psychological wellbeing can potentially be accounted for by differences in SOC, rather than other factors such as the demographic profile of participants. Only one study, Coe et al. (1992), appeared to control for social support in their analysis. This is an important variable to include since research has shown that perceived social support can enable individuals to cope more effectively with stressors (McSherry & Holm, 1994), indicating that it may be a significant moderator variable. However, as previously mentioned, findings from Coe et al. (1992) in relation to possible confounding factors (such as demographic characteristics) of the Alzheimer's carers were grouped with carers of individuals with other conditions, therefore it is difficult to draw definitive conclusions regarding the Alzheimer's carers, since only SOC scores and measures of perceived burden were reported independently for each of the conditions.

### *Findings*

Overall the studies found evidence that a low SOC was associated with negative psychological outcomes. All of the studies have provided p-values and effect sizes to support their results, and most have utilised a regression analysis, with the exception of Mockler et al. (1998) who used a correlation analysis. One disadvantage of using a correlational method instead of a regression analysis is that the interpretability of findings is limited, because the model cannot make predictions about the relationships between variables. Furthermore, it is also restricted due to only considering one variable whereas regression is not limited by this.

In relation to burden, Matsushita et al. (2014) found a significant association between a weakened SOC and burden. However after controlling for confounding factors, such as the care recipients' cognitive function, only the burden sub scale measuring 'personal strain' was associated with SOC, suggesting that SOC may only be related to certain aspects of burden. In this case 'role strain' was not associated with SOC, which is stress due to role conflict or overload (Kumamoto



& Arai, 2004). Similarly, Andren and Elmstahl (2005; 2008) found that perceived distress and SOC correlated with total burden; more precisely, carers who scored low on the burden measure reported significantly better perceived health and higher mean SOC scores compared to carers with higher burden. Finally with regards to perceived burden, Coe et al. (1992) found that carers who had a strong SOC were more likely to report that their role posed no burden. This finding was significant ( $p < .034$ ), however if the authors used a more common cut-off point such as ( $p < .01$ ) their finding would have been classed as non-significant. They also found that those carers with a strong SOC had better support systems.

In relation to psychological distress, Orgeta and Sterzo (2013) found that anxiety and depression was associated with low levels of SOC. Furthermore SOC was negatively correlated with stress/burden. Similar findings were reported by Valimaki et al. (2009) who found that SOC was significantly negatively correlated with depressive symptoms and distress, and increased health related quality of life correlated with strong SOC. The authors of both studies have provided a comprehensive account of their analysis procedure as well as providing relevant data to support their findings such as confidence intervals. This standard of reporting is advantageous as it enhances confidence in the credibility of findings.

Valimaki et al. (2014) found that the mean SOC of carers decreased over the 3-year period, with a significant decline in SOC in carers who had depressive symptoms at baseline, when compared to carers with non-depressive symptoms. They showed that SOC decreases over the course of caregiving irrespective of mood at baseline, especially if a spouse already has depressive symptoms. Although the authors had a fairly high drop-out rate, they took into account all available data from the original (baseline) sample in their analysis. By taking into account the characteristics of participants who had dropped out this reduces bias since analysis procedures were able to use this data to make estimations of the trajectories of SOC.

In the remaining studies, Gallagher et al. (1994) found SOC to be a significant protective factor against 'role overload' (burnout and exhaustion). More

specifically they found that SOC appears to have a greater protective effect for carers of individuals with dementia, when compared to carers of non-dementing chronically ill individuals in terms of selecting more realistic coping strategies and avoidance of unhealthy ones. These findings were significant and are supported by detailed data analysis. However, the authors do not appear to have taken into account many potentially confounding variables in their analysis, such as gender or relation to care recipient, other than the care recipients' level of disability. These factors would be important to consider since they have been shown to influence the impact of caregiving on wellbeing (Rankin, Haur, & Keefover, 1992; Verma & Anand, 2012). Furthermore the findings relating to SOC and coping responses have not been adequately discussed in relation to the original research question.

Finally Mockler et al. (1998) found a significant difference in SOC scores among carers in the service user group who were accessing professional and/or voluntary support from health and social services or other agencies, and carers in the non-service user group, who had declined any involvement by such services. More specifically, carers in the non-service user group had significantly higher SOC scores, and significant negative correlations were found between SOC scores, distress and stress levels, which the authors suggest may be indicative of a more healthy carer group. One might hypothesise that this could be due to the fact that these carers do not feel the need to access services, and therefore one might expect them to have sufficient coping abilities.

#### *Clinical implications*

Coe et al.'s (1992) study appears to be the first of its kind to explore the role of SOC in carers of individuals with dementia (Alzheimer's type). In discussing the implications of these findings, however, there is little mention of existing evidence in the field of SOC and caregiving, nor are there any suggestions made for how the findings contribute to practice. Conversely, Gallagher et al. (1994) suggest that their findings that SOC was only protective in the dementia sample could indicate a threshold effect of the nature of patient disability, with dementia exerting more strain and demands on carers when compared to carers of non-dementing illnesses. This suggests that dementia carers are particularly

vulnerable to experiencing the negative effects of caregiving. These findings highlight the need for increased awareness of the impact of caring in practice so that carers can receive appropriate support, especially since a recent report by the Carers Trust (2013) found that only 51% of dementia carers were given the opportunity to talk separately about their own needs.

Mockler et al. (1998) have begun to make some general, although vague suggestions for how their research can be applied in practice. The authors have highlighted the implications for training, support programmes (including carer education and workshops) and planning of service provision based on findings that the ability of a carer to cope and manage their situation is, in one way, related to an individual difference (SOC). A review by Harrop, Addis, Elliot and Williams (2007) identified a number of different intervention approaches in the literature in relation to the salutogenic model and SOC. One of these interventions was concerned with increasing meaning and control, which are among the key concepts of SOC, by giving individuals more knowledge and control of what to expect in their lives for example, which has been shown to improve quality of life. These techniques could be applied to dementia caregivers in terms of offering education workshops aimed at increasing knowledge surrounding dementia and caregiving so that carers can potentially feel more in control of their situation. Other intervention approaches designed to enhance SOC are aimed at increasing self-management and problem-solving skills (Lamprecht & Sack, 2003).

More recently, Andren and Elmstahl (2005; 2008) have made recommendations in relation to using SOC to identify carers at risk of experiencing the negative consequences of caring so they can be targeted for interventions to decrease burden and stress. They have described interventions for professionals such as facilitating carers to identify their negative experiences about caregiving and helping them to reflect upon their coping strategies (SOC) to find balance in their situation. Similarly Orgeta and Sterzo (2013) and Valimaki et al. (2009) have suggested using SOC to identify carers at risk of stress and depression. Valimaki et al. (2009) sampled carers of individuals with recently diagnosed Alzheimer's disease. In terms of assessing SOC, carers in the early stages of the caregiving

process are more likely to be in contact with healthcare professionals as they will have recently gone through the diagnosis procedure, meaning that they are possibly more accessible in order to measure SOC. In contrast, carers who are in the later stages of caregiving may be harder to access as they may be less likely to be in contact with services, making it more difficult to assess SOC. However in relation to this point, the practicalities of accessing carers and resources to administer the SOC scale is heavily dependent on service design and provision, which will be somewhat dependent on the healthcare system of that country or area. Orgeta and Sterzo (2013) carried out their study in the UK, which increases confidence that the implications can be applied to local settings.

Given the finding that SOC is not stable over time (Valimaki et al., 2014) caution should be taken when interpreting SOC based on findings from a single measurement. In practice it may be more helpful to measure SOC on a number of different occasions during the caregiving process in order to track any changes in carers' coping abilities, allowing professionals to intervene accordingly. Furthermore, Valimaki et al. (2014) suggest that a strong SOC might shield individuals from the burden of caring, but only when they do not suffer from depressive symptoms at the outset of caring. This has implications for findings of the previous studies as it would suggest that SOC has less protective value for those individuals suffering with depression, therefore further individual factors need to be explored in relation to this, such as alternative methods of coping that might act as a buffer against depression.

Findings from Matsushita et al. (2014) strengthened results from earlier studies relating to an association between SOC and burden, but in general their findings have not revealed anything particularly new. They do, however, discuss the use of psychotherapeutic interventions that enhance SOC. The implications of this for practice could be the delivery of interventions aimed at enhancing SOC and thus ability to cope with the negative effects of caregiving. For example Langeland et al. (2006) carried out a randomised controlled trial investigating the effect of talking-therapy groups based on salutogenic treatment principles on coping with mental health problems. The results showed that coping significantly improved in the intervention group. Other interventions that have been shown to increase

SOC include mindfulness-based stress reduction (Weissbecker et al., 2002). In addition, significant changes in SOC scores have been reported following a number of interventions aimed at increasing coping skills in several population groups including adults with mental health difficulties (Blomberg, Lazar & Sandell, 2001; Sack, Kunsebech & Lamprecht, 1997), suggesting that SOC can be modified. However further studies are needed in order to generalise findings to the caregiving population. Furthermore it is worth noting that interventions which focus on individual factors related to SOC, such as those increasing control, have been criticised by researchers such as Wallerstein (1992), who argues that such strategies could lead to feelings of frustration and powerlessness if the external environment is not also modified/controlled.

### **Discussion of findings**

Overall the findings provide preliminary evidence that a relationship exists between Sense of Coherence and psychological wellbeing in the dementia caregiver population, which is consistent with findings in other populations such as adults with mental and physical health problems (Eriksson & Lindstrom, 2006). Specifically the evidence supports a relationship between strong/high SOC and increased ability to cope with the negative effects of the caregiving situation, which is consistent with Antonovsky's (1979) view that a weak/low SOC corresponds to reduced ability to cope in stressful situations. Antonovsky (1987) proposed that individuals with a strong SOC have a more positive solution focused outlook, meaning that they will employ more adaptive coping responses such as proactive and meaning-focused coping, in which the person attempts to prepare for and derive meaning from the stressful situation.

As the studies measured a wide range of outcomes including burden, anxiety, depression, perceived health and quality of life, all of which have a significant impact on psychological wellbeing, it is hard to draw firm conclusions regarding the relationship between SOC and psychological wellbeing. This is because wellbeing can be influenced by a number of different factors, not just those listed above. This relationship is further obscured by the fact that most studies employed a cross-sectional design, which does not provide definitive information

about cause and effect relationships. Further longitudinal studies are needed in this unique population to study the changes and associations between variables over time, thus strengthening the evidence base, since information can be determined as to whether SOC is simply a correlate of distress or whether it plays a role in the development of such distress. This is particularly important given the emergence of fairly recent evidence that SOC appears to be a continuous process (Hakanen, Feldt & Leskinen, 2007; Volanen et al., 2007), rather than a relatively stable trait as initially proposed by Antonovsky (1987). In addition, another limitation that could be considered in the current review is that relevant literature relating to SOC and wellbeing may have been excluded due to not considering alternative terms to 'sense of coherence' in the literature search. As previously discussed, there are several related concepts which overlap with SOC such as resilience and hardiness, which focus on factors that promote psychological wellbeing in the face of stress. Therefore by not including these terms in the search potentially relevant articles could have been overlooked which could have provided valuable information in relation to identifying protective factors for wellbeing against stress in dementia carers.

Furthermore, given the lack of consideration of potentially confounding factors included in the analyses of several of the studies, such as social support, it cannot be ruled out that the findings could be accounted for by factors other than SOC. Although most studies did not control for social support, several studies, in particular Orgeta and Sterzo (2013) explored a number of potentially confounding factors and their relationship with SOC, thus enhancing the validity of findings. Moreover Eriksson and Lindstrom (2006) suggest that the strong correlation between SOC and psychological wellbeing raises the question of whether SOC is a parallel expression of mental health, meaning that it could in fact be of measure of wellbeing rather than relating to coping ability, as it overlaps with other constructs. Evidence for this has come from studies which have shown that SOC loads onto the same factor as scales measuring anxiety and depression, for example (Amelang, 1997; Gruszczynska, 2006; Korotkov, 1993).

Although all of the studies had a clearly defined population (carers of individuals with dementia) there are many different populations which exist within this group

of individuals. For example, different types of dementia exist and certain studies only included the Alzheimer's type (Coe et al., 1992; Valimaki et al., 2009; 2014). This may limit generalisability to other types of dementia as different types have slightly different characteristics which could potentially make the experience more or less stressful for the caregiver. For example, the symptoms of Alzheimer's are often gradual whereas in vascular dementia they may progress more quickly and be less predictable.

Additionally the experience of caring for an individual with dementia is dramatically influenced by a number of different factors such as the relation to the care recipient and severity of symptoms. For example, spousal caregivers experience more depressive symptoms than non-spousal carers (Baumgarten, Battista, Infante-Rivard, Hanley, Becker & Gauthier, 1992) and more severe dementia symptoms have been shown to increase the risk of anxiety and depression in carers (Garcia-Alberca, Lara, & Berthier, 2011). Most studies controlled for these factors, which is a strength, and some set specific inclusion and exclusion criteria to enable the sample to be as homogeneous as possible. However, given the range of sub-groups which exist within this population, further research exploring some of the less common profiles of carers, such as carers of individuals with early onset dementia, rarer forms of dementia, and non-relative carers is needed in order to develop the evidence base and generalisability of findings in this population.

An important question to consider is the usefulness of this research in practice and its clinical applications. Many of the studies have implicated the use of the SOC scale in identifying carers at risk of experiencing the negative effects of caregiving such as feelings of burden, anxiety and low mood. Existing research exploring the means of identifying factors that may make carers particularly vulnerable to experiencing distress has focused on a number of different factors such the impact of coping styles (Li et al., 2012). Further research is needed in order to determine the usefulness and practicalities of utilising the SOC scale for this purpose over other well-established measures of coping such as the 'COPE' inventory (Carver, Scheier & Weintraub, 1989).

Finally an additional implication from the research is the use of interventions aimed at strengthening SOC, such as talking therapies based on salutogenic treatment principles. For example, an RCT carried out by Langeland et al. (2006) found that talking-therapy groups for adults accessing outpatient mental health services aimed at enhancing SOC was effective in significantly improving coping in participants. Additional research is needed in order to determine the usefulness of this type of intervention with the dementia caregiver population in promoting coping and wellbeing. Such research would benefit from an experimental design in order to test the effectiveness of interventions aimed at enhancing SOC.

### **Conclusion**

There is a need for further research into the relationship between SOC and the psychological wellbeing of dementia caregivers. Existing research has demonstrated evidence for a link between SOC and outcomes affecting psychological wellbeing such as burden, depression, anxiety, stress, and quality of life. In particular, more longitudinal studies controlling for a range of potentially confounding factors are needed in order to explore the role of SOC in the development of distress in carers. Findings from one longitudinal study (Valimaki et al., 2014) revealed that SOC has less protective value for individuals suffering with depression from the outset of caring. Therefore further research would benefit from exploring other aspects of coping which potentially have a more influential impact on psychological wellbeing, thus acting as a protective factor for individuals who may be depressed early on in the caregiving process.

Words: 9,578



## References

- Almedom, A. M. (2005). Resilience, hardiness, sense of coherence, and posttraumatic growth: all paths leading to "light at the end of the tunnel"? *Journal of Loss and Trauma, 10*, 253-265.
- Alzheimer's Society. (2013). *What is dementia? Factsheet*. England, UK: Alzheimer's Society.
- Alzheimer's Society. (2013). *What is dementia with lewy bodies? Factsheet*. England, UK: Alzheimer's Society.
- Alzheimer's Society (2014). *Statistics*. Retrieved from <http://www.alzheimers.org.uk/statistics>
- Alzheimer's Society. (2014). *What is Alzheimer's disease? Factsheet*. England, UK: Alzheimer's Society.
- Alzheimer's Society. (2014). *What is vascular dementia? Factsheet*. England, UK: Alzheimer's Society.
- Amelang, M. (1997). Using personality variables to predict cancer and heart disease. *European Journal of Personality, 11*, 319-342.
- Andren, S., & Elmstahl, S. (2005). Family caregivers' subjective experiences of satisfaction in dementia care: aspects of burden, subjective health and sense of coherence. *Scandinavian Journal of Caring Sciences, 19*, 157-68.
- Andren, S., & Elmstahl, S. (2008). The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing, 17*, 790-9.
- Antonovsky, A. (1979). *Health, stress and coping: new perspectives on mental and physical wellbeing*. San Francisco: Jossey-Bass Inc.
- Antonovsky, A. (1987). *Unravelling the mystery of health: how people manage stress and stay well*. San Francisco: Jossey-Bass Inc.

- Arai, Y., Tamiya, N., & Yano, E. (2003). The short version of the Japanese version of the Zarit caregiver burden interview: its reliability and validity. *Nihon Ronen Igakkai Zasshi*, *40*, 497-503.
- Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioural change. *Psychological Review*, *84*, 191-215.
- Bandura, A. (1986). The explanatory and predictive scope of self-efficacy theory. *Journal of Clinical and Social Psychology*, *4*, 359-373.
- Baumgarten, M., Battista, R. N., Infante-Rivard, C., Hanley, J. A., Becker, R., & Gauthier, S. (1992). The psychological and physical health of family members caring for an elderly person with dementia. *Journal of Clinical Epidemiology*, *45*, 61-70.
- Beck, A., Ward, C., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, *4*, 571.
- Bengtsson-Tops, A., & Hansson, L. (2001). The validity of Antonovsky's sense of coherence measure in a sample of schizophrenic patients living in the community. *Journal of Advanced Nursing*, *33*, 432-8.
- Bias, E. S. (1998). *Mediating the stress-outcome relationship in Alzheimer's caregiving: the reciprocal influences of sense of coherence, coping, and boundary ambiguity* (unpublished dissertation). California School of Professional Psychology, US.
- Blomberg, J., Lazar, A., & Sandell, R. (2001). Long-term outcome of long-term psychoanalytically orientated therapies: first findings of the Stockholm outcome of psychotherapy and psychoanalysis (STOPP) study. *Psychotherapy Research*, *11*, 361-82.
- Blume, N. (1999). *"For better or worse": exploration of positive appraisal in the Alzheimer's caregiving situation* (unpublished dissertation). University of Kansas, US.
- Bradburn, N. (1969). *The structure of psychological well-being*. Chicago: Aldine.

- Carers Trust. (2013). *A road less rocky- supporting carers of people with dementia*. London, UK: Carers Trust.
- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: a theoretically based approach. *Journal of Personality and Social Psychology, 56*, 267-283.
- Carver, C. S. (1997). "You want to measure coping but your protocol's too long: consider the Brief COPE." *International Journal of Behavioural Medicine, 4*, 92-100.
- Cederblad, M., & Hansson, K. (1996). Sense of coherence: a concept influencing health and quality of life in a swedish psychiatric at-risk group. *Israel Journal of Medical Science, 32*, 194-9.
- Chiu, M., Chen, T., Yip, P., Hua, M., & Tang, L. (2006). Behavioural and psychologic symptoms in different types of dementia. *Journal of the Formosan Medical Association, 105*, 556-562.
- Chou, K. R. (2000). Caregiver burden: a concept analysis. *Journal of Paediatric Nursing, 15*, 398-407.
- Coe, R. M., Miller, D. K., & Flaherty, J. (1992). Sense of coherence and perception of caregiving burden. *Behaviour, Health & Aging, 2*, 93-99.
- Cooper, C., Balamurali, T. B. S., & Livingston, G. (2007). A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. *International Psychogeriatrics, 19*, 175-95.
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry, 23*, 929-936.
- Critical Appraisal Skills Programme (2013). *Critical appraisal skills programme: making sense of evidence about clinical effectiveness*. Retrieved from <http://www.casp-uk.net/>
- Diener, E. (1984). Subjective well-being. *Psychological Bulletin, 95*, 542-575.

- Dodge, R., Daly, A., Huyton, J., & Sanders, L. (2012). The challenge of defining wellbeing. *International Journal of Wellbeing*, 2, 222-235.
- Draper, B. M., Poulos, C. J., Cole, A. M., Poulos, R. G., & Ehrlich, F. (1992). A comparison of caregivers for elderly stroke and dementia victims. *Journal of the American Geriatrics Society*, 40, 896-901.
- Elmstahl, S., Malmberg, B., & Annerstedt, L. (1996). Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Archives of Physical and Medical Rehabilitation*, 77, 177-182.
- Emmons, R. A. (1999). *The psychology of ultimate concerns: motivation and spirituality in personality*. New York: Guilford Press.
- Eriksson, N. G., & Lundin, T. (1996). Early traumatic stress reactions among swedish survivors of the m/s estonia disaster. *British Journal of Psychiatry*, 169, 713-16.
- Eriksson, M., & Lindstrom, B. (2005). Validity of antonovsky's sense of coherence scale: a systematic review. *Journal of Epidemiology and Community Health*, 59, 460-466.
- Eriksson, M., & Lindstrom, B. (2006). Antonovsky's sense of coherence scale and the relation with health: a systematic review. *Journal of Epidemiology and Community Health*, 60, 376-381.
- Eriksson, M., & Lindstrom, B. (2007). Antonovsky's sense of coherence scale and its relation with quality of life: a systematic review. *Journal of Epidemiology and Community Health*, 61, 938-944.
- EuroQol. (1990). EuroQol- a new facility for the measurement of health-related quality of life. *Health Policy*, 16, 199-208.
- Gallagher, T. J., Wagenfeld, M. O., Baro, F., & Haepers, K. (1994). Sense of coherence, coping and caregiver role overload. *Social Science and Medicine*, 39, 1615-22.
- Garcia-Alberca, J. M., Lara, J. P., & Berthier, M. L. (2011). Anxiety and depression in caregivers are associated with patient and caregiver

- characteristics in Alzheimer's disease. *International Journal of Psychiatry in Medicine*, 41, 57-69.
- Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005). The longitudinal effects of early behaviour problems in the dementia caregiving career. *Psychology and Aging*, 20, 100-116.
- Goldberg, D. P., & Hillier, V. F. (1979). A scaled version of the general health questionnaire. *Psychological Medicine*, 9, 139-145.
- Greene, J. G., Smith, R., Gardiner, M., & Timbury, G. C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effect on relatives: a factor analytic study. *Age & Ageing*, 11, 121-126.
- Gruszczynska, E. (2006). What is measured by the orientation to life questionnaire? Construct validity of the instrument for the sense of coherence measurement. *Polish Psychological Bulletin*, 37, 74-83.
- Hakanen, J., Feldt, T., & Leskinen, E. (2007). Change and stability of sense of coherence in adulthood: longitudinal evidence from the health child study. *Journal of Research in Personality*, 41, 602-617.
- Harrop, E., Addis, S., Elliot, E., & Williams, G. (2007). *Resilience, coping and salutogenic approaches to maintain and generating health: a review*. Cardiff, UK: Cardiff Institute of Society Health and Ethics, Cardiff University.
- Hunt, S., & McEven, J. (1980). The development of a subjective health indicator. *Sociology of Health & Illness*, 2, 231-45.
- Johnson, M. (2004). Approaching the salutogenesis of sense of coherence: the role of 'active' self-esteem and coping. *British Journal of Health Psychology*, 9, 419-432.
- King, G. A. (2004). The meaning of life experiences: application of a meta-model to rehabilitation sciences and services. *The American Journal of Orthopsychiatry*, 74, 72-78.

- Korotov, D. L. (1993). An assessment of the (short form) sense of coherence personality measure: Issues of validity and wellbeing. *Personality and Individual Differences, 14*, 575-583.
- Kumamoto, K., & Arai, Y. (2004). Validation of 'personal strain' and 'role strain': subscales of the short version of the Japanese version of the Zarit Burden Interview. *Psychiatry and Clinical Neurosciences, 58*, 606-610.
- Lamprecht, F., & Sack, M. (2003). Vulnerability and salutogenesis in health and disease. *Public Health Reviews, 31*, 7-21.
- Langeland, E., Riise, T., Hanestad, B. R., Nortvedt, M. W., Kristoffersen, K., & Wahl, A. (2006). The effect of salutogenic treatment principles on coping with mental health problems: a randomised controlled trial. *Patient Education and Counselling, 62*, 212-219.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Li, R., Cooper, C., Bradley, J., Shulman, A., & Livingston, G. (2012). Coping strategies and psychological morbidity in family carers of people with dementia: a systematic review and meta-analysis. *Journal of Affective Disorders, 139*, 1-11.
- Lightsey, O. R. (1996). What leads to wellness? The role of psychological resources in well-being. *The Counselling Psychologist, 24*, 589-735.
- Lundman, B., Alex, L., Jonsén, E., Norberg, A., Nygren, B., Santamäki Fischer, R., & Strandberg, G. (2010). Inner strength- a theoretical analysis of salutogenic concepts. *International Journal of Nursing Studies, 47*, 251-260.
- Lyubomirsky, S., & Lepper, H. S. (1999). A measure of subjective happiness: preliminary reliability and construct validation. *Social Indicators Research, 46*, 137-155.
- Mahoney, R., Regan, C., Katona, C., & Livingston, G. (2005). Anxiety and depression in family caregivers of people with Alzheimer disease: the LASER-AD study. *American Journal of Geriatric Psychiatry, 13*, 795-801.

- Matsui, Y., Tanizaki, Y., Arima, H., Yonemoto, K., Doi, Y., Ninomiya, T., ...Sasaki, K. (2009) Incidence and survival of dementia in a general population of Japanese elderly; the hisayama study. *Journal of Neurology, Neurosurgery and Psychiatry, 80*, 366-370.
- Matsushita, M., Ishikawa, T., Koyama, A., Hasegawa, N., Ichimi, N., Yano, H., Hashimoto, M., Fujii, N., & Ikeda, M. (2014). Is sense of coherence helpful in coping with caregiver burden for dementia? *Psychogeriatrics, 14*, 87-92.
- McKeith, I. G., Dickson, D. W., Lowe, J., Emre, M., O'Brien, J. T., Feldman, H., ...Cummings, J. (2005) Diagnosis and management of dementia with Lewy bodies: third report of the dementia with Lewy bodies consortium. *Neurology, 65*, 1863-1872.
- McSherry, W. C., & Holm, J. E. (1994). Sense of coherence: its effects on psychological and physiological processes prior to, during, and after a stressful situation. *Journal of Clinical Psychology, 50*, 476- 487.
- Mockler, D., Riordan, J., & Murphy, M. (1998). Psychosocial factors associated with the use/non-use of mental health services by primary carers of individuals with dementia. *International Journal of Geriatric Psychiatry, 13*, 310-4.
- Murray, J., Schneider, J., Banerjee, S., & Mann, A. (1999). EURO CARE: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: factors associated with carer burden. *International Journal of Geriatric Psychiatry, 14*, 651-61.
- National Institute for Health and Care Excellence (NICE). (2010). *Dementia quality standard*. Manchester, UK: NICE.
- Nolan, M., Grant, G., & Keady, J. (1996). *Understanding family care*. Buckingham, UK: Open University press.
- O'Brien, J. T., Erkinjuntti, T., & Reisberg, B., Roman, G., Sawada, T., Pantoni, L., ...Bowler, J. V. (2003). Vascular cognitive impairment. *Lancet Neurology, 2*, 89-98.

- Orgeta, V., & Sterzo, E. L. (2013). Sense of coherence, burden, and affective symptoms in family carers of people with dementia. *International Psychogeriatrics*, 25, 973-80.
- Pallant, J. F., & Lae, L. (2002). Sense of coherence, well-being, coping and personality factors: further evaluation of the sense of coherence scale. *Personality and Individual Differences*, 33, 39-48.
- Parks, S. H., & Pilisuk, M. (1991). Caregiver burden: gender and the psychological costs of caregiving. *American Journal of Orthopsychiatry*, 61, 501-509.
- 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, 583-594.
- Pinquart, M., & Sorensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depression mood: a meta-analysis. *Journal of Gerontology: Psychological Sciences & Social Sciences*, 58, 112-128.
- Pottie, C. H. (1990). *Antonovsky's 'sense of coherence' and the operationalization of this concept in a flemish version questionnaire*. Belgium: Unpublished M. A. thesis.
- Rabin, A., & de Charro, F. (2001). EQ-5D: a measure of health status from the EuroQol group. *Annals of Medicine*, 33, 337-343.
- Rankin, E. D., Haul, M. W., & Keefover, R. W. (1992). Clinical assessment of family caregivers in dementia. *The Gerontologist*, 32, 813-821.
- Ristner, G., Andersson, R., Johansson, L. M., Johansson, S. E., & Ponzer, S. (2000). Sense of coherence and lack of control in relation to outcome after orthopaedic injuries. *Injury*, 31, 751-6.
- Rogers, C. (1961). *On becoming a person*. Boston: Houghton Mifflin.



- Rosenbaum, M., & Palmon, N. (1984). Helplessness and resourcefulness in coping with epilepsy. *Journal of Consulting and Clinical Psychology, 52*, 244-253.
- Rotter, J. B. (1966). Generalised expectancies for internal versus external control of reinforcement. *Psychological Monographs: General & Applied, 80*, 1-28.
- Royal College of Nursing. (2014). *Supporting people with dementia*. Retrieved from [http://www.rcn.org.uk/development/practice/dementia/supporting\\_people\\_with\\_dementia](http://www.rcn.org.uk/development/practice/dementia/supporting_people_with_dementia)
- Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry, 57*, 316-331.
- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological wellbeing. *Journal of Personality and Social Psychology, 57*, 1069-1081.
- Sack, M., Kunsebeck, H. W., & Lamprecht, F. (1997). Sense of coherence and psychosomatic treatment outcome. An empirical study of salutogenesis. *Psychotherapie Psychosomatik Medizinische Psychologie, 47*, 149-155.
- Sackett, D. L., Rosenberg, W. M. C., Gray, J. A., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine. What it is and what it isn't. *British Medical Journal, 312*, 71-2.
- Sakano, J., & Yajima, Y. (2005). Factor structure of the SOC scale 13-item version in Japanese university students. *Nihon Koshu Eisei Zasshi, 52*, 34-45.
- Savage, S., & Bailey, S. (2004). The impact of caring on caregivers' mental health: a review of the literature. *Australian Health Review, 27*, 111-7.
- Schnyder, U., Büchi, S., Sensky, T., & Klaghofer, R. (2000). Antonovsky's sense of coherence: trait or state? *Psychotherapy and Psychosomatics, 69*, 296-302.

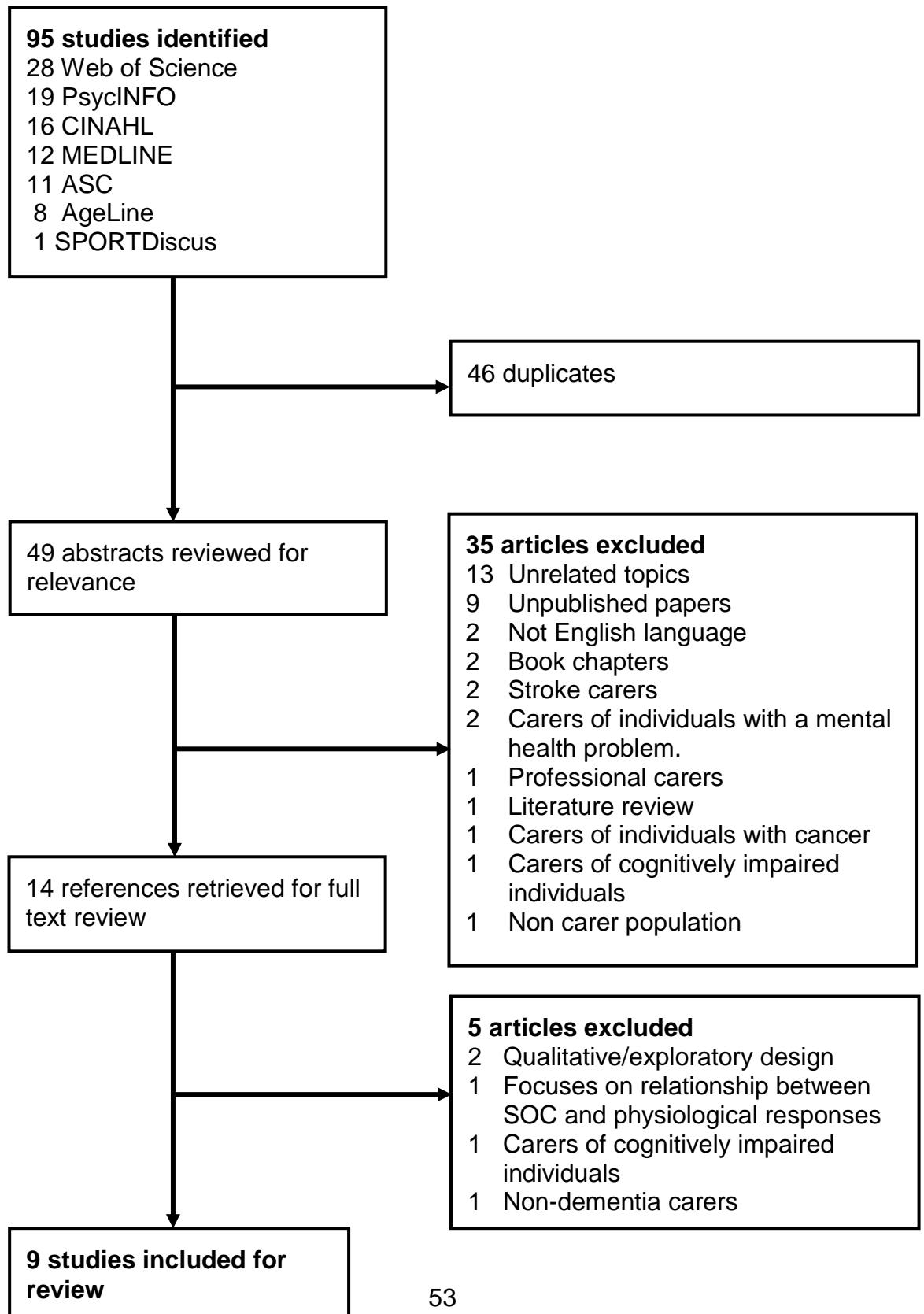
- Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist, 35*, 771-91.
- Sheldon, K. M., & Kasser, T. (1995). Coherence and congruence: two aspects of personality integration. *Journal of Personality and Social Psychology, 68*, 531-543.
- Sintonen, H. (2001). The 15D instrument of health-related quality of life: properties and applications. *Annals of Medicine, 33*, 328-336.
- Smith, T. L., & Meyers, L. S. (1997). The sense of coherence: its relationship to personality, stress and health measures. *Journal of Social Behaviour and Personality, 12*, 513-526.
- Tang, S. T., Cheng, C. C., Lee, K. C., Chen, C. H., & Liu, L. N. (2013). Mediating effects of sense of coherence on family caregivers' depressive distress while caring for terminally ill cancer patients. *Cancer Nursing, 36*, 25-33.
- Taylor, T. P., & Thomas, A. (2013) Alzheimer's disease. In T. Denning & A. Thomas (Eds) pp 431-455. *Oxford textbook of old age psychiatry: second edition*. Oxford: Oxford University Press.
- Valimaki, T. H., Vehvilainen-Julkunen, K. M., Pietila, A. M., & Pirttila, T. A. (2009). Caregiver depression is associated with a low sense of coherence and health-related quality of life. *Aging and Mental Health, 13*, 779-807.
- Valimaki, T., Martikainen, J., Hongisto, K., Fraunberg, M., Hallikainen, I., Sivenius, J., ...Vehvilainen-Julkunen, K. (2014). Decreasing sense of coherence and its determinants in spousal caregivers of persons with mild Alzheimer's disease in three year follow-up: ALSOVA study. *International Psychogeriatrics, 26*, 1211-1220.
- Verma, R., & Anand, K. (2012). Gender differences in anxiety and depression among the caregivers of patients with dementia. *Advances in Alzheimer's Disease, 1*, 17-21.

- Vitaliano, P. P., Young, H. M., & Zhang, J. (2004). Is caregiving a risk factor for illness? *Current Directions in Psychological Science*, 13, 13-16.
- Volanen, S. M., Suominen, S., Lahelma, E., Koskenvuo, M., & Silventoinen, K. (2007). Negative life events and stability of sense of coherence: A five-year follow-up study of Finnish women and men. *Scandinavian Journal of Psychology*, 48, 433-441.
- Von Elm, E., Altman, D. G., Egger, M., Pocock, S. J., Gøtzsche, P., & Vandenbroucke, J. P. (2007). The strengthening of reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *Bulletin of the World Health Organisation*, 85, 867-872.
- Wallerstein, N. (1992). Powerlessness, empowerment, and health: implications for health promotion programs. *American Journal of Health Promotion*, 6, 197-205.
- Weissbecker, I., Salmon, P., Studts, J. L., Floyd, A. R., Dedert, E. A., & Sephton, S. E. (2002). Mindfulness-based stress reduction and sense of coherence among women with fibromyalgia. *Journal of Clinical Psychology in Medical Settings*, 9, 297-307.
- Werner, E. E., & Smith, R.S. (1982). *Vulnerable but invincible: a longitudinal study of resilient children and youth*. New York: McGraw Hill.
- World Health Organisation (WHO). (2012). *The WHO report dementia: a public health priority*. Switzerland: WHO.
- Yaffe, K., Fox, P., Newcomer, R., Sands, L., Lindquist, K., Dane, K., & Covinsky, K. E. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *Journal of the American Medical Association*, 287, 2090-2097.
- Young, J. M., & Solomon, M. J. (2009). How to critically appraise an article. *Nature Clinical Practice Gastroenterology & Hepatology*, 6, 82-91.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavia*, 67, 361-370.

## Appendices

Appendix 1: **Figure 1.** Flowchart showing Study Selection process



## *Appendix 2: Checklist of critical appraisal questions*

Note: Questions derived from items in the Critical Appraisal Skills Programme (CASP, 2013), Young and Solomon (2009) and the Reporting of Observational Studies in Epidemiology (STROBE) statement (von Elm et al., 2007).

1. Did the study address a clearly focused issue?
2. Was the study design appropriate for the research question?
3. Does the study test a stated hypothesis?
4. Is the scientific background of the study clearly described?
5. Was the study sample clearly defined?
6. Is it clear how the sample size was arrived at?
7. Were participants recruited in an acceptable way?
8. Was a representative sample achieved (e.g. was the response rate sufficiently high)?
9. Was the follow-up of participants complete/long enough?
10. Were all participants accounted for in the analysis of results? (Including those that were lost to follow-up in the case of longitudinal studies).
11. Have the authors identified important confounding factors?
12. Do the measurements truly reflect what you want them to (have they been validated)?
13. Were efforts taken to address potential sources of bias?
14. Have the authors taken into account the confounding factors in the design and/or analysis?
15. What are the results of this study and are they precise?
16. Are the results believable?
17. Do the results of this study fit with other available evidence?
18. Are the results generalisable?
19. Can the results be applied to the local population?
20. Does the study add anything new?
21. Are the implications for practice clearly described?

Appendix 3: Hierarchy of evidence (Sackett et al., 1996)

1. Systematic reviews and meta-analyses
2. Randomised controlled trials
3. Cohort studies (longitudinal), case controlled studies
4. Surveys (cross-sectional)
5. Case reports
6. Qualitative studies
7. Expert opinion
8. Anecdotal opinion

Note: Greater weight is given to research higher up the hierarchy

## **Chapter 2: Research report**

**Do knowledge and acceptance predict anxiety and depression in carers of individuals with Alzheimer's disease?**



## **Abstract**

Caring for an individual diagnosed with dementia can be very stressful. Stress-related illnesses such as anxiety and depression are common. The extent to which an individual views a stressful situation as comprehensible, manageable, and meaningful (known as Sense of Coherence/ SOC) is thought to influence whether or not they can cope with the associated stress. One important aspect of SOC involves the ability to comprehend and make sense of a stressful event. This includes enhancing knowledge about the event/stressor in order to increase perceptions of control, which thus improves quality of life. However within the dementia carer population there have been mixed findings as to whether increased knowledge surrounding dementia is always beneficial, with studies exploring the impact of the possible avoidance of information. To explore this further, in the current study knowledge relating to dementia was explored in carers of Alzheimer's-type dementia, alongside psychological acceptance/avoidance, to determine whether they predict anxiety and depression.

Findings revealed that acceptance was a strong predictor of anxiety and depression, with increased acceptance corresponding to reduced distress. No relationship was found between knowledge and distress. The findings provide support for the possible utility of acceptance based psychological interventions for anxiety and depression. Further research is needed to determine the efficacy of these interventions with this population.

## **Introduction**

Dementia has been declared a public health priority by the World Health Organisation (WHO) (2012), and the number of reported cases is expected to almost double every 20 years due to better healthcare and an ageing population. The most common type of dementia is Alzheimer's disease, which is a degenerative type of dementia affecting 62% of those diagnosed (Alzheimer's Society, 2014), with ageing as a primary risk factor. The majority of individuals with dementia (two thirds) live at home, commonly cared for by their spouse (Alzheimer's Society, 2014).

Acting as a primary carer for a family member with dementia can have a major impact on psychological wellbeing, and is associated with feelings of burden (Draper, Poulos, Cole, Poulos & Ehrlich, 1992; Papastavrou et al., 2011), high levels of stress (Mahoney, Regan, Katona, & Livingston, 2005; WHO, 2012) and stress related illnesses such as anxiety and depression (Cooper, Balamurali & Livingston, 2007; Li, Cooper, Bradley, Shulman & Livingston, 2012; Pinquart & Sorensen, 2003; Royal College of Nursing, 2014; Vitaliano, Young & Zhang, 2004). Carers of individuals with dementia also experience greater distress and strain in general than carers of other elderly populations (Moise, Schwarzingler & Um, 2004). It is therefore vitally important that carers are supported in their role to cope with some of the negative effects on their emotional wellbeing, in order to improve both the carers' and care recipients' quality of life, as well as ensuring the continuation of home care (Gaugler, Kane, Kane & Newcomer, 2005; Yaffe et al., 2002).

There have been a number of factors implicated in mediating the relationship between the impact of caring on psychological wellbeing. As previously explored in chapter one, a review of the literature provided preliminary evidence for the construct of Sense of Coherence (SOC) (Antonovsky, 1979) as a protective factor against the development of anxiety, depression and other stress related health problems. More specifically, individuals with a strong SOC are more likely to consider their life as comprehensible, manageable and meaningful, and are therefore more likely to cope successfully in stressful situations and are less susceptible to feelings of

burden. In summary, the evidence supported a relationship between strong/high SOC and increased ability to cope with the distress associated with the caregiving situation. There is a need, however, for further research into additional aspects of coping which can act as a buffer against stress-related health problems associated with caregiving, given the significant impact upon psychological wellbeing and quality of life.

A literature review by Savage and Bailey (2004) has shed light on some of the demographic characteristics of carers associated with reduced ability to cope and vulnerability to poor mental health as a result of caregiving. For example, caring for a partner with dementia and caring for somebody with a greater degree of physical impairment, cognitive impairment and behavioural problems has been associated with increased depression (Schulz, O'Brien, Bookwala & Fleissner, 1995; Mahoney et al. 2005). Furthermore, carers residing with the care recipient also experienced increased feelings of burden (Baronet, 1999; Livingston, Mahoney, Regan & Katona, 2005) in comparison to carers not living with the care recipient.

In addition, the age of the carer has been shown to influence the impact of caring with evidence suggesting that impairments in physical ability associated with old age make caring more difficult/burdensome for elderly adults (Lawton, Rajgopal, Brody & Kleban, 1992). Women have also been found to experience more distress than men and report increased health problems, anxiety and depressive symptoms (Sorensen, Duberstein, Gill & Pinguart, 2006; Verma & Anand, 2012; Vitaliano, Yee & Schulz, 2000; Zhang & Scanlan, 2003). Draper (2004) suggested that female carers are more likely to be 'hands-on' and do everything themselves, whereas male carers tend to delegate tasks to others, allowing them to distance themselves somewhat from the stressful situation. Lastly, being a carer for a greater length of time has also been related to strain (Almberg, Jansson, Grafstrom & Winblad, 1998). In addition to the demographic characteristics of the carer and factors related to the care recipient, the way an individual manages/copos with stress, dependent on the type of coping strategy employed, has been found to be a strong predictor of psychological distress (Cooper, Katona, Orrell & Livingston, 2008).

Research has primarily focused on categorised coping styles using frameworks devised by Carver (1997) and Lazarus and Folkman (1984), consisting of three categories of coping. These include emotion-focused coping, problem-focused coping and dysfunctional coping. A meta-analysis by Li et al. (2012) showed that carers adopting dysfunctional coping strategies were at an increased risk of experiencing depression and anxiety, whereas carers utilising coping strategies based on acceptance and seeking emotional support (emotion-focused) reported reduced anxiety and depression. Individuals adopting a problem-focused approach seek out information about the problem in an attempt to change or eliminate the source of stress. In relation to information seeking and enhancing knowledge as a method of coping with stress, knowledge pertaining to dementia is generally thought to be useful and educational workshops aimed at increasing carers' knowledge are common interventions. However there have been several studies investigating the impact of knowledge about dementia on carers' wellbeing, which have revealed contradictory findings (Dieckmann, Zarit, Zarit & Gatz, 1988; Graham, Ballard & Sham, 1997a; Kahan, Kemp, Staples & Brummel-Smith, 1985).

The relationship between knowledge and distress has been explored by Graham, Ballard and Sham (1997b), who investigated the relationship between informal (unpaid) carers' knowledge of dementia, their coping strategies and levels of anxiety and depression. The authors found that carers who had greater knowledge about dementia (for example, information surrounding the causes, symptoms and epidemiology) adopted healthier coping strategies and experienced significantly lower rates of depression but higher rates of anxiety, compared to those carers who were less well informed. One explanation they have put forward for the findings is that carers who are more knowledgeable are aware of the full extent of the disease and the decline that will follow, thus increasing anxiety.

More recently, Proctor, Martin and Hewison (2002) explored the relationship between carers' knowledge about dementia, coping styles and reported levels

of anxiety, depression and strain. Specifically two coping strategies were investigated - monitoring and blunting (Miller, 1987). Individuals adopting the 'monitoring' strategy prefer to actively monitor for as much information as possible in relation to the stressful situation, whereas the 'blunting' style is associated with the avoidance of threat relevant information. The findings were consistent with the previous study in terms of increased knowledge correlating with elevated anxiety. In addition the monitoring coping style was the strongest predictor of anxiety and was positively associated with knowledge, suggesting that seeking out information in this case may be detrimental. However in contrast to the Graham et al. (1997b) study, there was no relationship found between depression, knowledge and coping. The potential reasons for the differences between studies could be due to a number of different factors such as the variation in measures used to assess distress, knowledge and coping strategies, and the relatively small sample (n=50) used by Proctor et al. (2002).

Finally the most recent study by Schindler, Engel and Rupprecht (2012) demonstrated that carers who scored highly on measures of perceived dementia knowledge were less burdened by their situation compared with carers who scored low on the measure. These studies clearly indicate the need for a greater understanding about the factors that are associated with knowledge about dementia, especially since there have been some inconsistencies in the research, with some studies showing that knowledge increases anxiety but reduces depression, and more importantly, the fact that most intervention and support for carers involves an educational element (NICE, 2013). As previously discussed, research has shown that coping strategies which encompass acceptance and emotional support are associated with better outcomes for the individual, such as reduced distress, in comparison to other coping methods. With regards to knowledge, coping strategies associated with the avoidance of information have been associated with reduced anxiety, in comparison to other coping styles (Proctor et al. 2002). Therefore in the current study psychological acceptance (the alternative to avoidance) is explored in order to address inconsistencies in the research and to determine whether acceptance is associated with knowledge, and

whether it has a role in reducing distress for knowledgeable individuals. This concept closely links to emotion-focused coping in that elements of the construct focus on the avoidance (suppression) and acceptance of distressing thoughts and feelings.

In the current study psychological acceptance is referred to in the context of the Acceptance and Commitment Therapy (ACT) model (Hayes et al. 2004). The ACT model offers a framework for intervention based on ACT principles which aim to treat the causes of psychological distress such as anxiety and depression. The ACT model of psychological health consists of two important concepts, experiential avoidance and acceptance, which are concerned with how people respond to distressing thoughts and feelings, or 'private' (cognitive or psychological) events. Experiential avoidance is the attempt to alter the form or frequency of difficult private events, whereas acceptance (the opposite of experiential avoidance) is the willingness to experience unwanted private events in order to gain some control over them (Bond et al., 2011).

Acceptance in the ACT model is an example of 'psychological flexibility', which can be defined as the ability to fully contact the present moment and thoughts and feelings, depending on how difficult the situation may be, in order to pursue one's goals. This is based on the notion that by accepting one's thoughts and feelings instead of struggling to change them or negatively judging them, which enhances distress, allows individuals to act more effectively as they are no longer disturbed by internal private events. The opposite of this is 'psychological inflexibility', which is concerned with attempts to avoid distressing situations and private events which in turn can enhance distress (Wenzlaff & Wegner, 2000) because, as previously discussed, individuals must be willing to contact and accept distressing thoughts and feelings in order to overcome them.

The underlying theory of ACT is Relational Frame Theory (RFT). RFT proposes that individuals negatively evaluate and avoid private (internal) events, since it is impossible to avoid negative states by only avoiding external situations (those occurring in the surrounding environment). For example, if

anxiety is perceived as 'bad' it is likely to be avoided, and whilst this can have immediate short-term gains, in the long-term avoidance has been associated with mental health problems such as anxiety and depression, and poor quality of life (Hayes et al., 2004). Hayes et al. (1999) developed ACT as an intervention to target emotional avoidance and improve quality of life by enhancing acceptance using a number of different techniques. Research has shown that ACT is effective in treating a wide range of problems such as anxiety (Zettle, 2003), depression (Zettle & Hayes, 1986) and psychotic disorders (Bach & Hayes, 2002). Most of this research has been carried out in the general adult mental health population, however, one study by Spira et al. (2007), explored psychological acceptance, experiential avoidance and depression in family carers of individuals with dementia. Their findings revealed a robust positive correlation between experiential avoidance and elevated scores on a depression inventory, suggesting that avoidance may be a risk factor for depression in dementia carers.

Since dementia carers are at an increased risk of developing stress related illnesses such as anxiety and depression, it is important to continue to research and understand the factors associated with increased distress so that carers at risk can be identified and offered appropriate support. Furthermore, given that most intervention packages and support for carers involves an educational/training element aimed at increasing dementia knowledge, it is important to understand the individual differences in how carers respond to this information. This would potentially enable professionals to put in place psychological support and teach carers strategies to manage the distress that increased knowledge and awareness may bring in order to improve quality of life.

To summarise, there is evidence to suggest that knowledge about dementia and psychological acceptance both play a role in mediating the relationship between anxiety and depression. However, this evidence is sparse and somewhat inconsistent. For example, in relation to knowledge, whilst earlier research is concerned with the overarching benefits of education surrounding dementia (Dieckmann et al., 1988; Graham et al., 1997a; Kahan et al., 1985),

more recent studies have suggested that well-informed carers are more anxious than less knowledgeable carers (Graham et al., 1997b; Proctor et al., 2002) but less likely to suffer from depressive symptoms (Graham et al., 1997b). Research has also explored the relationship between knowledge and coping styles in terms of predicting distress, although research in the dementia carer population has been fairly limited. A meta-analysis by Li et al. (2012) exploring generic coping strategies in dementia carers revealed that emotion-focused coping (based on acceptance and emotional support) was associated with reduced anxiety and depression.

#### *Aims and research questions/hypotheses*

Given the inconsistency in the literature, the aim of the current study is to investigate the relationship between dementia knowledge, psychological acceptance and anxiety and depression, in order to explore whether knowledge and acceptance predict anxiety and depression in dementia caregivers, and whether the two variables influence each other in any way. This is the only known study to explore the relationship between psychological acceptance in the context of ACT theory and anxiety in the dementia caregiver population, and one of few studies to explore depression. It is hoped that this information will enhance current understanding of how carers respond to information, in particular, whether acceptance can act as a protective factor against anxiety in knowledgeable carers. Furthermore, understanding more about the factors that mediate the relationship between caring and wellbeing is crucial in order to recognise and respond to those carers who experience distress.

It is hypothesised that: (1) carers who are most knowledgeable will be more anxious, (2) there will be a negative relationship between acceptance and depression/anxiety.

Specified research questions were: (1) Does knowledge predict depression? (2) What is the relationship between knowledge and acceptance, if any, in predicting anxiety and depression?



## **Method**

### *Design*

A cross-sectional design was used in order to explore whether knowledge and acceptance predict anxiety and depression. In addition to the predictor (independent) variables (knowledge and acceptance), potentially confounding variables were controlled for which included the age and gender of the carer and the duration of time spent caring, since these factors have been shown to influence the level of distress carers can experience (Almberg et al., 1998; Lawton et al., 1992; Sorensen et al., 2006).

### *Participants*

In order to determine the sample size for a regression analysis, a 'G' power calculation (Faul, Erdfelder, Buchner & Lang, 2009) was conducted with power set at 0.8 and significance at 0.05, for a medium effect size (.15); 78 participants were required. The minimum number of participants required was calculated to be 38, for a large effect size.

Participants were recruited from voluntary sector organisations in the local community offering peer support and social events for individuals with Alzheimer's disease (AD) and their carers. Inclusion criteria were that carers must identify themselves as the primary caregiver for a family member or non-relative with AD in an unpaid/informal capacity. Whilst the terms dementia and AD are often used interchangeably, and caring for a person with any type of dementia can be a stressful process, in the current study only individuals who identified themselves as caring for somebody with AD were included since the measure used to assess knowledge of dementia is specific to Alzheimer's-type dementia. Since some of the questionnaires were left with the organisers of the social groups where participants were recruited from to pass to carers, it is not accurately known how many questionnaires were distributed and what the actual response was.

### *Procedure*

Permission was given from the voluntary sector organisations recruited from (appendix 5), and ethical approval was granted by Staffordshire University's Faculty of Health Sciences Ethics and Peer Review Panel (appendix 6). Participants were recruited by the researcher attending venues which the organisations' used to host their social groups. Several visits were made to the venues and the researcher met individually with the carers to discuss the study with them using an information sheet about the study (appendix 7). Carers were asked to retain this information sheet and use the details provided to contact the research team if they had any questions about any aspect of the research. As the groups were attended on more than one occasion, carers were made aware that the researcher would be present to respond to any questions they may have in person as well.

If carers wished to take part they were asked to sign a consent form (appendix 8) with the researcher present, and then complete the questionnaires at home, independently, and return them by post using the provided stamped addressed envelope, so that it did not interfere with the activities planned in the group. Participants were also provided with a list of support services they could contact if they felt distressed because of participating in the study (appendix 9). Finally, participants were assured both in writing and verbally, that all information collected is strictly confidential and anonymised by assigning each participant with an ID number and separating the identifying information supplied in the consent form from the questionnaires.

### *Measures*

#### *Demographic information*

Demographic information was collected using an information sheet devised by the researcher (appendix 1). Carers were asked to provide information relating to themselves and the person they cared for. This included the carer's and care recipient's age and gender, duration of caring, relation to care recipient, duration of AD and whether or not they resided together.

A total of 56 carers agreed to take part in the study. Forty carers were female (71.4%) and 16 were male (28.6%). The mean age of carers was 69 ( $SD=11.24$ ; range 30-84) and the duration of caring ranged from 6 months to 17 years (mean= 4 years, 3 months), although one participant did not disclose this information. The majority of carers resided with the care recipient (69.6%) and were spouses (76.8%) or children of the care recipient (19.6%). Only 3.6% identified themselves as non-relatives. With regards to the care recipient, 31 were male (55.4%) and 24 were female (42.9%), and the mean age was 77 ( $SD=6.5$ ; range 60-89). This information was missing for one of the cases. Finally the duration of dementia ranged from 6 months to 17 years (mean= 4 years, 5 months). Three participants did not disclose this information.

*Alzheimer's disease knowledge scale (ADKS) (Carpenter, Balsis, Otilingam, Hanson & Gatz, 2009)*

In order to measure carers' knowledge of Alzheimer's-type dementia the ADKS was administered. The ADKS consists of 30 statements designed to assess knowledge of AD and covers risk factors, assessment, diagnosis, symptoms, course, life impact, caregiving and treatment and management. Participants are asked to rate whether the statement is true or false by circling the corresponding response. Correct answers are scored 1-point and are summed to provide a total score (out of a possible 30 points), therefore, the higher the score the greater the knowledge. The scale was chosen as it is the most recent and up-to-date knowledge scale (Spector, Orrell, Schepers & Shanahan, 2012) and therefore the most likely to reflect current scientific understanding of the disease. The ADKS has been shown to have adequate reliability (test-retest correlation= .81; internal consistency reliability= .71) and validity (Carpenter et al., 2009). This questionnaire is freely available for research use and a copy can be found in Appendix 2.

*Acceptance and action questionnaire (AAQ-II) (Bond et al., 2011)*

To measure acceptance the AAQ-II was employed. The questionnaire consists of 7-items which measure negative evaluations of feelings and avoidance of thoughts. Responses are self-rated and given using a 7-point Likert-style scale

ranging from 1 (never true) to 7 (always true). A total score is obtained by summing the scale scores from the seven items; scores can range from 7-49. Higher scores equal reduced acceptance and thus greater levels of psychological inflexibility and avoidance, and scores of >24-28 suggest probable clinical distress (Bond et al., 2011). The questionnaire has satisfactory reliability and validity (the mean alpha coefficient is .84 and the 3 and 12 month test-retest reliability is .81 and .79 respectively) (Bond et al., 2011). The measure is freely available to use for research purposes, and a copy of the full questionnaire can be found in Appendix 3.

There are several advantages that could be considered by operationalising coping using a measure of psychological acceptance and avoidance (the AAQ-II). Firstly, existing measures of coping relating to emotion suppression, avoidance and cognitive reappraisal for example, tend to focus on the form and frequency of behaviours (Kashdan, Barrios, Forsyth & Steger, 2005), whereas experiential avoidance and psychological acceptance as measured by the AAQ-II are understood within the context and function of valued goal-directed behaviours, which link to a well-established framework for psychological intervention. Furthermore research has shown that experiential avoidance and acceptance better accounted for psychological functioning over time, compared to another well-known coping strategy (cognitive reappraisal), and the relationship between coping and emotion regulation strategies used to manage symptoms of anxiety were minimized or eliminated when the effects of experiential avoidance/acceptance were controlled (Kashdan et al., 2005).

*Hospital anxiety and depression scale (HADS) (Zigmond & Snaith, 1993)*

The HADS was used to assess symptoms of anxiety and depression. It comprises 14 statements relating to how the individual has been feeling in the past week. Participants are presented with four multiple choice responses for each question and are asked to select one. Seven of the statements are relevant to generalised anxiety and the remaining seven to depression. Responses are assigned a score of 0-3 using the HADS standardised scoring template. A higher score equals a greater level of anxiety and depression. Two separate scores for anxiety and depression are yielded from the scale which

can range from 0-21. The scores can be categorised as normal (0-7), mild (8-10), moderate (11-14) and severe (15-21). A license agreement was completed and user fee provided in order to access the scale. A copy of the scale can be found in appendix 4.

### *Statistical analysis*

Statistical analysis of the data was carried out using IBM SPSS statistics software, version 22 (IBM Corporation, Armonk, NY, USA). Data were screened to check that none of the assumptions required for a multiple regression were significantly violated. In particular, tests were carried to check that the variables were normally distributed, which involved producing data plots, histograms and box plots to check that data was not highly skewed or kurtotic and to detect the presence of any outliers. Residual/scatter plots were also produced to check that there was a linear relationship between the independent and dependent variables, and plots of the standardised residuals (errors) were undertaken to ensure homoscedasticity of the data. All of the required assumptions were met for the data set. A multiple linear regression was then carried out in order to explore the relationship between the independent variables (knowledge, acceptance, age, gender and duration of caring [months]) and dependent variables (anxiety and depression). A separate regression analysis was carried out for each of the dependent variables. Multiple regression assumes that there is little or no multicollinearity in the data. This was tested using the correlation matrix, 'tolerance' unit (a measure of the influence of one independent variable on another independent variable) and Variance Inflation Factor (VIF). Multicollinearity was not found in the data.

### **Results**

The scores for anxiety ranged from 0-21, with the mean score being 8.54 ( $SD = 4.50$ ). Fifty-eight point nine percent of the sample scored within the clinical ranges for anxiety (mild to severe) with the most frequent scores falling within the mild (17.9%) and moderate (12.5%) ranges of anxiety. Depression scores ranged from 1-19, with a mean score of 7.04 ( $SD = 4.08$ ). The majority of the

sample (62.5%) scored within the normal ranges of depression, whilst 37.6% of the sample scored within the clinical ranges. More specifically, 19.6% scored in the mild range, 12.6% in the moderate range, and 3.9% in the severe range. With regards to the predictor variables, the mean score on the ADKS (AD knowledge) was 22.80 ( $SD = 3.20$ ) and ranged from 16-30, and the mean score on the AAQ-II questionnaire was 22.32 ( $SD = 10.72$ ), and ranged from 7-49. Correlations between the predictor variables and dependent variables can be found in tables 1 and 2.

**Table 1.** Pearson Correlations between anxiety and independent variables

	Anxiety	ADKS	AAQ-II	Age	Gender	Duration
Anxiety	1					
ADKS	0.08	1				
AAQ-II	0.66	0.10	1			
Age	-0.14	-0.05	-0.09	1		
Gender	0.04	-0.03	-0.09	-0.34	1	
Duration	0.04	-0.21	0.06	0.36	-0.29	1

*Note:* ADKS, Alzheimer’s Disease Knowledge Scale; AAQ-II, Acceptance and Action Questionnaire.

**Table 2.** Pearson Correlations between depression and independent variables

	Depression	ADKS	AAQ-II	Age	Gender	Duration
Depression	1					
ADKS	0.13	1				
AAQ-II	0.70	0.10	1			
Age	-0.17	-0.05	-0.09	1		
Gender	-0.18	-0.02	-0.09	-0.34	1	
Duration	-0.06	-0.21	-0.06	0.36	-0.29	1

Table 1 shows that anxiety was strongly positively correlated with avoidant coping ( $r = 0.66, p < 0.05$ ) which means that decreased anxiety is related to greater psychological acceptance. Similarly table 2 shows that depression was also strongly positively correlated with avoidant coping ( $r = 0.70, p < 0.05$ ) meaning that decreased depression is related to greater psychological acceptance.

### *Regression analysis*

A multiple linear regression was performed to investigate the relationship between anxiety, depression, AD knowledge and acceptance. A regression analysis was undertaken because the regression equation can be used to make predictions about the relationships between variables, whereas correlation analyses cannot make these predictions and therefore the interpretability of findings is limited. Furthermore a regression analysis is able to provide information relating to how much variance is accounted for by each predictor variable.

Potentially confounding variables were controlled for which included the age and gender of carers and the length of time they have been in the caring role. These specific variables were chosen because evidence has suggested that they correspond with carer distress (Almberg, Jansson, Grafstrom & Winblad, 1998; Lawton, Rajgopal, Brody & Kleban, 1992; Sorensen, Duberstein, Gill & Pinquart, 2006; Verma & Anand, 2012). Additional demographic data that was recorded but not controlled for in the analysis included the relationship between carer and care recipient and whether or not they resided together. However, given the relatively small sample size and because the majority of carers were spouses and resided together, this information was not included in the analysis. Similarly, the age and gender of the care recipient was not included because this information closely related to the age and gender of the carer (and thus captured somewhat by these variables). Also the duration of dementia closely corresponded with the duration of caring and so was not included in the analysis.

All of the predictor variables (AD knowledge, acceptance, age, gender and duration of caring) were entered at this stage. The findings showed that in relation to anxiety, the model was significant ( $F(5,49)= 8.00, p < 0.001$ ) and explained 44.9% of the variance, 39.3% adjusted  $R^2$ . For depression the model was also significant ( $F(5,49)= 11.69, p < 0.001$ ) and explained 54.4% of the variance, 49.7% adjusted  $R^2$ .

Tables 3 and 4 show a summary of the initial multiple regression analysis for anxiety and depression.

**Table 3.** Unstandardised and standardised coefficients of the independent variables as predictors of anxiety.

	B	SE B	$\beta$	p-value
Constant	2.91	5.23		0.58
AD Knowledge	0.03	0.15	0.02	0.86
Acceptance	0.28	0.05	0.65	0.00
Age	-0.03	0.05	-0.08	0.52
Gender	0.85	1.14	0.09	0.46
Duration of caring	0.01	0.01	0.06	0.62

**Table 4.** Unstandardised and standardised coefficients of the independent variables as predictors of depression.

	B	SE B	$\beta$	p-value
Constant	5.46	4.32		0.21
AD Knowledge	0.04	0.13	0.03	0.77
Acceptance	0.26	0.04	0.68	0.00
Age	-0.05	0.04	-0.13	0.23
Gender	-1.76	0.95	-0.19	0.07
Duration of caring	-0.01	0.01	-0.11	0.32

As shown in the tables above, acceptance was a significant predictor of both anxiety and depression, whereas AD knowledge, age, gender and duration of caring were not. Therefore in order to improve the precision of the model the regression was re-run with only the significant variable included. The findings



for anxiety showed that the model was significant ( $F(1,54)= 42.01, p < 0.001$ ) and explained 43.8% of the variance, 42.7% adjusted  $R^2$ . With regards to depression, the findings showed that the model was significant ( $F(1,54)= 51.87, p < 0.001$ ) and explained 49.0% of the variance, 48.0% adjusted  $R^2$ .

Tables 5 and 6 show a summary of the second regression analysis (with only the significant variables) for anxiety and depression.

**Table 5.** Unstandardised and standardised coefficients of acceptance as a predictor of anxiety

	B	SE B	$\beta$	p-value
Constant	2.34	1.06		0.32
Acceptance	0.28	0.04	0.66	0.00

**Table 6.** Unstandardised and standardised coefficients of acceptance as a predictor of depression

	B	SE B	$\beta$	p-value
Constant	1.09	0.92		0.24
Acceptance	0.27	0.04	0.70	0.00

As AD knowledge was not a significant predictor of anxiety or depression, the second research question exploring the relationship between knowledge and acceptance became redundant and was therefore not investigated.

## Discussion

The aim of the current study was to investigate the relationship between knowledge of Alzheimer's disease (AD), psychological acceptance, and anxiety and depression. The findings revealed that acceptance was a significant predictor of anxiety and depression in carers of individuals with AD, which supports the predicted hypothesis that there will be an association between increased acceptance and reduced anxiety and depression. These findings are consistent with studies carried out in the adult mental health population (Hayes et al., 2004) and dementia caregiver population in relation

to depression (Spira et al., 2007). Findings are also consistent with Li et al. (2012) who showed that coping strategies based on acceptance are associated with reduced anxiety and depression. The current study has built on these findings by exploring psychological acceptance within an ACT theoretical model, which has the advantage of offering a framework for targeted intervention methods to enhance acceptance. Psychological acceptance was also explored in conjunction with AD knowledge, which has not previously been explored.

Knowledge, however, was not a significant predictor of anxiety and depression, which does not support the predicted hypothesis that carers who are more knowledgeable will be more anxious. These findings are in contrast to previous studies which have found that carers who have greater knowledge of dementia experience significantly lower rates of depression but higher rates of anxiety (Graham et al., 1997b). Furthermore, Proctor et al. (2002) found that knowledge was positively associated with anxiety, however they found no relationship between knowledge and depression. Findings from the current study support this with regards to knowledge not being a significant predictor of depression.

The finding that knowledge was not related to anxiety and depression could be due to a number of factors. Firstly the current study utilised a different measure for knowledge in comparison to previous studies (Graham et al., 1997b; Proctor et al., 2002), therefore the cut-off point for high or low knowledge will vary depending on how many questions the measure consists of. The measure used in the current study consisted of 30 questions and the entire sample scored above 50% on the measure, which suggests that participants were relatively knowledgeable. This is not surprising since carers were recruited from organisations offering peer support and therefore carers are more likely to be knowledgeable about the disease since they are in contact with other carers, in particular the group organisers were experienced carers themselves. Therefore, findings from the current study are limited as they cannot draw conclusions about carers who have very little

knowledge about the disease, and therefore whether a lack of knowledge is related to anxiety and depression.

Secondly, in relation to anxiety and depression, whilst the sample on the whole could be considered to be suffering from symptoms of anxiety, as over half (58.9%) scored in the clinical ranges, with regards to depression the majority of the sample (62.5%) scored in the normal ranges. One reason for this may be because the sample were recruited from support groups and therefore are a non-clinical population, thus meaning they may be less likely to meet the criteria for mental health difficulties, in comparison to a clinical population. Furthermore it could be that as participants attended a support group, this might also be a protective factor against clinical levels of depression.

Consequently the findings in relation to knowledge and increased depression are limited since only a minority of the sample met the clinical criteria for depressive symptoms. Future studies would benefit from larger sample sizes in order to increase the range of carers' depressive symptoms, particularly since previous research in this area has been somewhat inconsistent; this is a drawback of the current study since the sample was only sufficient to achieve a large effect size.

In relation to potential confounding factors that were controlled for, the age and gender of the caregiver, as well as the duration of caring, were not significant predictors of anxiety and depression. Research into the influence of the characteristics of carers of individuals with dementia has found that female carers have higher rates of depression (Sorensen, et al., 2006; Vitaliano et al, 2003) and report more mental health symptoms, (Verma & Anand, 2012; Yee & Schulz, 2000), and older age has been linked to caregiver burden (Lawton et al., 1992). One reason for the finding that gender did not predict distress could be due to the unbalanced gender distribution of participants, since only 28.6% were male. With such a small proportion of males this makes it harder to detect any differences within the sample relating to gender. However, this gender balance is representative of the population with studies consistently

reporting that the majority of carers of individuals with dementia/ Alzheimer's are women (Alzheimer's Association, 2014). Similarly the mean age of participants was 69-years-old, thus most carers fell into the older adult age range making it difficult to detect differences relating to age as only 19.6% of the sample were under 60-years-old. This could account for why there were no significant findings in relation to age and distress. Again though, since dementia primarily affects older adults it would be expected that most carers would be of a similar age, given that spouses most often act as primary caregivers (Alzheimer's Society, 2014).

Finally, the duration of caring was not a significant factor in predicting anxiety and depression. Findings from the literature indicate that longer durations of the illness (dementia/AD), and therefore longer duration of caring, is associated with increased risk for anxiety and depression (Almberg et al., 1998; Eters, Goodall, & Harrison, 2008; Garcia-Alberca, Lara, & Berthier, 2011; Hubbell & Hubbell, 2002). This is likely to be due to the progressive nature of dementia/AD meaning that the person's condition worsens over time, and therefore caring becomes increasingly challenging. Although the range of time spent caring is widespread among the sample, this information does not necessarily correspond to the severity or stage of dementia, which may reflect why this variable was not significant in the study. Controlling for the duration of caring as well as severity of dementia would perhaps be a better indicator of this and thus more likely to correlate with distress.

In relation to acceptance, this is the only known study to explore the relationship between psychological acceptance, in the context of ACT theory, and anxiety in the dementia caregiver population. The current study supports findings by Spira et al. (2007) who found that psychological acceptance predicted depression in family carers of individuals with dementia. The findings from the present study suggest that carers who respond to difficult thoughts and feelings by attempting to avoid them or alter their form or frequency are at an increased risk for experiencing anxiety and depression, in comparison to individuals willing to experience (accept) them and not judge them negatively. This means that in distressing situations individuals who cope by accepting

their distressing thoughts and feelings, which may arise as a result of the challenges in caring for an individual with dementia, are less likely to become anxious or depressed. One explanation for this is that accepting thoughts and feelings for what they are (simply thoughts or feelings and not necessarily reality) is less likely to cause the individual distress. This is because they are no longer putting effort into trying to avoid or change them as they are no longer viewed as harmful or distressing, which increases the intensity of thoughts and feelings, particularly negative ones. As the findings revealed that knowledge was not a significant predictor of distress no conclusions can be drawn in terms of whether an interaction exists between knowledge and acceptance.

#### *Clinical implications*

The finding that acceptance is associated with anxiety and depression has important implications for practice. Firstly, it has contributed to the evidence base by expanding the breadth of understanding of individual factors that potentially mediate the relationship between distress and wellbeing in AD caregivers. Secondly, the findings have implications for interventions based on ACT theory which aim to enhance acceptance and thus reduce experiential avoidance, in order to promote psychological well-being and decrease distress. For example, the National Institute for Health and Care Excellence (NICE) (2013) recognises that dementia carers often experience high levels of anxiety, depression and stress, yet their needs often go unrecognised. NICE (2013) proposes that carers need increased access to emotional and psychological support, including access to psychological therapies to improve wellbeing. This would also benefit the person being cared for since carers who are supported in coping with the challenges of caring will be more able to continue providing home care, thus preventing hospital or residential home admissions (Gaugler et al., 2005).

The most commonly cited and researched intervention by NICE in relation to the treatment of anxiety and depression in adults is Cognitive-Behavioural Therapy (CBT). The theoretical framework of ACT shares many similarities

with CBT, such as the focus on developing an objective stance towards distressing thoughts and feelings. However unlike CBT there is less emphasis on problem solving and targeting thoughts for logical disconfirmation or change, rather the goal is self-observation of thoughts (Arch & Craske, 2008), in order to reduce distress. The theoretical concepts underpinning psychological acceptance/ACT offer an additional framework for understanding emotional distress, which is linked to the avoidance of distressing thoughts for example, rather than the actual content of these thoughts. Whilst there are preliminary findings supporting the efficacy of this approach in the caregiver population (Marquez-Gonzalez, Losada, & Romero-Moreno, 2014), further research is needed to explore the benefits of such an approach in comparison to well-established models such as CBT (Hayes et al., 1999).

Although, at present, research in this area is limited, there is a growing area of research supporting interventions for dementia caregivers based on ACT principles such as mindfulness and meditation-based interventions (Hurley, Patterson & Cooley, 2014; Oken et al., 2010; Whitebird et al., 2013). These interventions aim to increase acceptance by facilitating individuals to become aware of their thoughts and to respond to negative thoughts without judgement, so they are no longer viewed as harmful or avoided. In practice, ACT based psycho-educational approaches and techniques such as cognitive de-fusion and psychological acceptance strategies could be incorporated into support programs or training for carers to potentially alleviate distress. Another potential implication of findings from the current study is related to increased awareness for staff and healthcare professionals working with dementia/AD carers, in terms of understanding the impact of psychological acceptance/avoidance as a method of coping on carers' well-being.

### *Limitations*

It is worth highlighting that the findings from the current study are limited due to several drawbacks in the design. For example, participants were caregivers of individuals with Alzheimer's disease and were drawn from voluntary organisations offering peer support to carers. The findings, therefore, are not

representative of the whole population as the design excludes those caring for an individual with another type of dementia and carers who are not accessing peer support services, which limits the generalisability of findings. Similarly the measure of acceptance was originally designed for use in a clinical population, which carers in the current study were not, since they were recruited from peer support groups. This potentially impacts upon the validity of the measure/findings within this population.

Furthermore, the finding that knowledge was not a significant predictor of distress could be due to the small sample size. One explanation for this could be that the impact of knowledge may only be small and consequently a large sample is needed to detect this effect. Recruiting only Alzheimer's carers restricted the number of carers that could participate, therefore having a broader inclusion criteria which includes all types of dementia could have increased the sample size.

Moreover, the current study is limited by the correlational nature of the design, which means no definitive conclusions can be drawn regarding causation. In addition, because some of the questionnaires were left with the organisers of the social groups where participants were recruited from to pass to carers, it is not accurately known how many questionnaires were distributed and what the actual response was, therefore a response rate cannot be determined. This is a limitation of the current study since it introduces potential bias and undermines confidence that a representative sample was achieved.

There are also some limitations that are worth noting regarding the current scale that is used to measure acceptance (AAQ-II). In particular the AAQ-II has been criticised for not making a clear enough distinction between process and outcome (Chawla & Ostafin, 2007). For example Wolgast (2014) argued that it can be difficult to distinguish if a specific response to a question contained within the measure is grounded in levels of experiential avoidance/acceptance or levels of experienced unpleasant emotions or memories. More specifically, the question has been raised as to whether the scale measures an approach/ attitude towards internal events, or the outcome

of this approach in terms of emotional difficulties. Similarly, research has highlighted some problems with the discriminant validity of the AAQ-II scale in relation to an overlap between measures of psychological wellbeing and the AAQ-II, such as the Positive and Negative Affect Schedule (PANAS). This could potentially mean that any associations between the concepts measured in the AAQ-II and health related outcomes could be overestimated (Wolgast, 2014). This casts doubt as to whether strong associations between wellbeing and psychological acceptance/experiential avoidance as measured by the AAQ-II are due to the psychological processes assumed in the theoretical model, or whether it is a consequence of measurement and operationalisation, meaning that to some extent they may measure the same thing (Wolgast, 2014).

Finally, further research is needed in order to strengthen the finding that increased acceptance is associated with reduced anxiety and depression, because although the model accounted for nearly 50% of the variance, there are clearly other variables that were not accounted for that may also contribute to the variance. Although some potentially confounding variables were accounted for in the analysis, factors such as characteristics relating to the care recipient were not accounted for. For example, as previously discussed, the severity of dementia symptoms has been found to be a strong predictor for psychological distress (Cooper et al., 2008) as well as social support, carers level of education and coping styles, all of which have been shown to impact on carer distress (Garcia-Alberca et al., 2011; Li et al., 2012).

## **Conclusion**

Previous research has implicated knowledge of dementia and psychological acceptance as possible predictors of distress in caregivers. The aim of the present study was to investigate whether knowledge and acceptance predict anxiety and depression in AD carers, and whether acceptance can act as a protective factor for knowledgeable carers who are more likely to be anxious. The findings revealed that only psychological acceptance was a significant predictor of anxiety and depression, with individuals utilising more avoidance coping methods (as opposed to acceptance-based coping methods) scoring



higher on anxiety and depression measures. These findings support existing evidence in the non-caregiver population and reveal new findings in relation to anxiety in the dementia caregiver population. The hypothesis that knowledge would be a significant predictor of distress was not supported, therefore it can be concluded that in the current study there was no interaction between knowledge and acceptance. The study findings highlight the potential utility of acceptance based interventions using an ACT framework for reducing feelings of anxiety and depression in caregivers. However, further research is needed to determine the efficacy of such interventions. Further limitations and strengths of this study will be discussed in chapter 3.

Words: 7,651

## References

- Almberg, B., Jansson, W., Grafstrom, M., & Winbald, B. (1998). Differences between and within genders in caregiving strain: a comparison between caregivers of demented and non-caregivers of non-demented elderly people. *Journal of Advanced Nursing, 28*, 849-58.
- Alzheimer's Association. (2014). Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 10*.
- Alzheimer's Society (2014). *Statistics*. Retrieved from: <http://www.alzheimers.org.uk/statistics>.
- Antonovsky, A. (1979). *Health, stress and coping: new perspectives on mental and physical wellbeing*. San Francisco, US: Jossey-Bass Inc.
- Arch, J. J., & Craske, M. G. (2008). Acceptance and commitment therapy and cognitive behavioural therapy for anxiety disorders: different treatments, similar mechanisms? *American Psychological Association, 15*, 263-279.
- Bach, P., & Hayes, S. C. (2002). The use of acceptance and commitment therapy to prevent the rehospitalisation of psychotic patients: a randomised controlled trial. *Journal of Consulting and Clinical Psychology, 70*, 1129-39.
- Baronet, A. M. (1999). Factors associated with caregiver burden in mental illness: a critical review of the research literature. *Clinical Psychology Review, 19*, 819-841.
- Bond, F. W., Hayes, S. C., Baer, R. A., Carpenter, K. M., Guenole, N., Orcutt, H. K., ...Zettle, R. D. (2011). Preliminary psychometric properties of the acceptance and action questionnaire- II: a revised measure of psychological flexibility and experiential avoidance. *Behaviour Therapy, 42*, 676-688.
- Carpenter, B. D., Balsis, S., Otilingam, P. G., Hanson, P. K., & Gatz, M. (2009). The Alzheimer's disease knowledge scale: development and psychometric properties. *Gerontologist, 49*, 236-247.

- Carver, C. S. (1997). You want to measure coping but your protocol's too long: consider the brief cope. *International Journal of Behavioural Medicine*, 4, 92-100.
- Chawla, N., & Ostafin, B. (2007). Experiential avoidance as a functional dimensional approach to psychopathology: an empirical review. *Journal of Clinical Psychology*, 63, 871-890.
- Cooper, C., Balamurali, T. B. S., & Livingston, G. (2007). A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. *International Psychogeriatrics*, 19, 175-95.
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23, 929-936.
- Dieckmann, L., Zarit, S., Zarit, J., & Gatz, M. (1988). The Alzheimer's disease knowledge test. *The Gerontologist*, 28, 402-407.
- Draper, B. M., Poulos, C. J., Cole, A. M., Poulos, R. G., & Ehrlich, F. (1992). A comparison of caregivers for elderly stroke and dementia victims. *Journal of the American Geriatrics Society*, 40, 896-901.
- Draper, B. (2004). *Dealing with dementia: a guide to Alzheimer's disease and depression in caregivers of patients with dementia*. US: Department of Health and Human Services, Bureau of Health Professions.
- 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 Nursing Practitioners*, 20, 423-428.
- Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). Statistical power analyses using G\*Power 3.1: tests for correlation and regression analyses. *Behaviour Research Methods*, 41, 1149-1160.
- Garcia-Alberca, J. M., Lara, J. P., & Berthier, M. L. (2011). Anxiety and depression in caregivers are associated with patient and caregiver

- characteristics in Alzheimer's disease. *International Journal of Psychiatry in Medicine*, 41, 57-69.
- Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005). The longitudinal effects of early behaviour problems in the dementia caregiving career. *Psychology and Aging*, 20, 100-116.
- Graham, C., Ballard, C., & Sham, P. (1997a). Carers' knowledge of dementia and their expressed concerns. *International Journal of Geriatric Psychiatry*, 12, 470-473.
- Graham, C., Ballard, C., & Sham, P. (1997b). Carers' knowledge of dementia, their coping strategies and morbidity. *International Journal of Geriatric Psychiatry*, 12, 931-936.
- Harrop, E., Addis, S., Elliot, E., & Williams, G. (2007). *Resilience, coping and salutogenic approaches to maintain and generating health: a review*. Cardiff, UK: Cardiff Institute of Society Health and Ethics, Cardiff University.
- Hayes, S. C., Strosahl, K., & Wilson, K. G. (1999). *Acceptance and commitment therapy: an experiential approach to behaviour change*. New York, US: Guilford Press.
- Hayes, S. C., Strosahl, K. D., Wilson, K. G., Bissett, R. T., Pistorello, J., Toarmino, D., ...Polusny, M. A. (2004). Measuring experiential avoidance: a preliminary test of a working model. *The psychological Record*, 54, 553-578.
- Hubbell, L., & Hubbell, K. (2002). The burnout risk for male caregivers in providing care to spouses afflicted with Alzheimer's disease. *Journal of Health and Human Services Administration*, 25, 115-132.
- Hurley, R. V., Patterson, T. G., & Cooley, S. J. (2014). Meditation-based interventions for family caregivers of people with dementia: a review of the empirical literature. *Aging and Mental Health*, 18, 281-288.

- Kahan, J., Kemp, B., Staples, F. R., & Brummel-Smith, K. (1985). Decreasing the burden in families caring for a relative with a dementing illness: a controlled study. *Journal of the American Geriatrics Society*, *33*, 664-70.
- Kashdan, T. B., Barrios, V., Forsyth, J. P., & Steger, M. F. (2005). Experiential avoidance as a generalized psychological vulnerability: comparisons with coping and emotion regulation strategies. *Behaviour Research and Therapy*, *44*, 1301–1320.
- Lawton, M. P., Rajgopal, D., Brody, E., & Kleban, M. H. (1992). The dynamics of caregiving for a demented elder among black and white families. *Journal of Gerontology: Social Sciences*, *47*, 156-164.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Li, R., Cooper, C., Bradley, J., Shulman, A., & Livingston, G. (2012). Coping strategies and psychological morbidity in family carers of people with dementia: a systematic review and meta-analysis. *Journal of Affective Disorders*, *139*, 1-11.
- Livingston, G., Mahoney, R., Regan, C., & Katona, C. (2005). The caregivers for Alzheimer's disease problems scale (CAPS): development of a new scale within the LASER-AD study. *Age and Ageing*, *34*, 287-290.
- Mahoney, R., Regan, C., Katona, C., & Livingston, G. (2005). Anxiety and depression in family caregivers of people with Alzheimer disease: the LASER-AD study. *American Journal of Geriatric Psychiatry*, *13*, 795-801.
- Marquez-Gonzalez, M. O., Losada, A., & Romero-Moreno, R. (2014). Acceptance and Commitment Therapy with Dementia Care-givers. In N. A. Pachana & K. Laidlaw (Ed.), *The oxford handbook of clinical geropsychology*. Oxford, UK: Oxford University Press.
- Miller, S. M. (1987). Monitoring and blunting: validation of a questionnaire to assess styles of information seeking under threat. *Journal of Personality and Social Psychology*, *52*, 345-53.

- Moise, P., Schwarzingler, M., & Um, M. Y. (2004). *Dementia care in 9 OECD countries: a comparative analysis*. OECD Health Working Paper No 13. Paris: OECD
- National Institute for Health and Clinical Excellence (NICE). (2013). *Support for commissioning dementia care*. London, UK: NICE.
- Oken, B. S., Fonareva, I., Haas, M., Wahbeh, H., Lane, J. B., Zajdel, D., & Amen, A. (2010). Pilot controlled trial of mindfulness meditation and education for dementia caregivers. *Journal of Alternative and Complementary Medicine*, *16*, 1031-1038.
- Papastavrou, E., Tsangari, H., Karaviannis, G., Papacostas, S., Efstathiou, G., & Sourtzi, P. (2011). Caring and coping: the dementia caregivers. *Aging and Mental Health*, *15*, 702-11.
- Pinquart, M., & Sorensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depression mood: a meta-analysis. *Journal of Gerontology: Psychological Sciences & Social Sciences*, *58*, 112-128.
- Proctor, R., Martin, C., & Hewison, J. (2002). When a little knowledge is a dangerous thing...: a study of carers' knowledge about dementia, preferred coping style and psychological distress. *International Journal of Geriatric Psychiatry*, *17*, 1133-9.
- Royal College of Nursing. (2014). *Supporting people with dementia*. Retrieved from [http://www.rcn.org.uk/development/practice/dementia/supporting\\_people\\_with\\_dementia](http://www.rcn.org.uk/development/practice/dementia/supporting_people_with_dementia)
- Savage, S., & Bailey, S. (2004). The impact of caring on caregivers' mental health: a review of the literature. *Australian Health Review*, *27*, 111-7.
- Schindler, M., Engel, S., & Rupprecht, R. (2012). The impact of perceived knowledge of dementia on caregiver burden. *The Journal of Gerontopsychology and Geriatric Psychiatry*, *25*, 127-134.

- Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist, 35*, 771-91.
- Sorensen, S., Duberstein, P., Gill, D., & Pinquart, M. (2006). Dementia care: mental health effects, intervention strategies, and clinical implications. *The Lancet Neurology, 5*, 961-973.
- Spector, A., Orrell, M., Schepers, A., & Shanahan, N. (2012). A systematic review of 'knowledge of dementia' outcome measures. *Ageing Research Reviews, 11*, 67-77.
- Spira, A. P., Beaudreau, S. A., Jimenez, D., Kierod, K., Cusing, M. M., Gray, H. L., & Gallagher-Thompson, D. (2007). Experiential avoidance, acceptance, and depression in dementia family caregivers. *Clinical Gerontologist, 30*, 54-64.
- Verma, R., & Anand, K. (2012). Gender differences in anxiety and depression among the caregivers of patients with dementia. *Advances in Alzheimer's Disease, 1*, 17-21.
- Vitaliano, P. P., Young, H. M., & Zhang, J. (2004). Is caregiving a risk factor for illness? *Current Directions in Psychological Science, 13*, 13-16.
- Vitaliano, P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129*, 946-972.
- Wenzlaff, R. M., & Wegner, D. M. (2000). Thought suppression. *Annual Review of Psychology, 51*, 59-91.
- Whitebird, R. R., Kreitzer, M. J., Crain, L., Lewis, B. A., Hanson, L. R., & Enstad, C. J. (2013). Mindfulness-based stress reduction for family caregivers: a randomised controlled trial. *Gerontologist, 53*, 676-686.
- Wolgast, M. (2014). What does the acceptance and action questionnaire (AAQ-II) really measure? *Behaviour Therapy, 45*, 831-839.

- World Health Organisation. (2012). *The WHO report dementia: a public health priority*. Switzerland: WHO.
- Yaffe, K., Fox, P., Newcomer, R., Sands, L., Lindquist, K., Dane, K., & Covinsky, K. E. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *Journal of the American Medical Association*, *287*, 2090-2097.
- Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers. A review and analysis. *The Gerontologist*, *40*, 147-164.
- Zettle, R. D. (2003). Acceptance and commitment therapy vs systematic desensitisation in treatment of mathematics anxiety. *The Psychological Record*, *53*, 197-215.
- Zettle, R. D., & Hayes, S. C. (1986). Dysfunctional control by client verbal behaviour: the context of reason giving. *The Analysis of Verbal Behaviour*, *4*, 30-38.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, *67*, 361-70.



## Appendices

### *Appendix 1: Demographic Information sheet*

---

#### **PARTICIPANT BACKGROUND INFORMATION**

---

Title of Study: **Do knowledge and acceptance predict anxiety and depression in carers of individuals with Alzheimer's Disease?**

#### Carer Information

- Age:.....
- Gender:.....
- Duration of caring (approximately):.....
- Relation to 'cared for' (e.g. partner, child, friend):.....
- Living arrangements (e.g. living together with cared for, living apart)  
.....

#### 'Cared for' Information

- Age:.....
- Gender:.....
- Duration of disease (approximately):.....

*Appendix 2: Alzheimer's Disease Knowledge Scale (ADKS)*

**Alzheimer's Disease Knowledge Scale**

Below are some statements about Alzheimer's disease. Please read each statement carefully and circle whether you think the statement is True or False. If you aren't sure of the right answer, make your best guess. It's important to circle an answer for every statement, even if you're not completely sure of the answer.

- |     |   |      |       |
|-----|---|------|-------|
| 1.  | People with Alzheimer's disease are particularly prone to depression.   | True | False |
| 2.  | It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease.   | True | False |
| 3.  | After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years.   | True | False |
| 4.  | When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation.                                      | True | False |
| 5.  | People with Alzheimer's disease do best with simple, instructions given one step at a time.   | True | False |
| 6.  | When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away.  | True | False |
| 7.  | If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day. | True | False |
| 8.  | In rare cases, people have recovered from Alzheimer's disease.  | True | False |
| 9.  | People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety.   | True | False |
| 10. | If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease.   | True | False |
| 11. | Most people with Alzheimer's disease live in nursing homes.   | True | False |
| 12. | Poor nutrition can make the symptoms of Alzheimer's disease worse.  | True | False |
| 13. | People in their 30s can have Alzheimer's disease.   | True | False |

14.	A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse.	True	False
15.	When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.	True	False
16.	Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care.	True	False
17.	Eventually, a person with Alzheimer's disease will need 24-hour supervision.	True	False
18.	Having high cholesterol may increase a person's risk of developing Alzheimer's disease.	True	False
19.	Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease.	True	False
20.	Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease.	True	False
21.	Alzheimer's disease is one type of dementia.	True	False
22.	Trouble handling money or paying bills is a common early symptom of Alzheimer's disease.	True	False
23.	One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things.	True	False
24.	When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline.	True	False
25.	Prescription drugs that prevent Alzheimer's disease are available.	True	False
26.	Having high blood pressure may increase a person's risk of developing Alzheimer's disease.	True	False
27.	Genes can only partially account for the development of Alzheimer's disease.	True	False
28.	It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the car at all times.	True	False
29.	Alzheimer's disease cannot be cured.	True	False
30.	Most people with Alzheimer's disease remember recent events better than things that happened in the past.	True	False

Appendix 3: Acceptance & Action questionnaire-II (AAQ-II)

**ACCEPTANCE & ACTION QUESTIONNAIRE-II (BOND ET AL., 2011)**

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice. Please answer every question even if you are not sure.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

1. My painful experiences and memories make it difficult for me to live a life that I would value.	1	2	3	4	5	6	7
2. I'm afraid of my feelings.	1	2	3	4	5	6	7
3. I worry about not being able to control my worries and feelings.	1	2	3	4	5	6	7
4. My painful memories prevent me from having a fulfilling life.	1	2	3	4	5	6	7
5. Emotions cause problems in my life.	1	2	3	4	5	6	7
6. It seems like most people are handling their lives better than I am.	1	2	3	4	5	6	7
7. Worries get in the way of my success.	1	2	3	4	5	6	7

*Appendix 4: The Hospital Anxiety & Depression Scale (HADS)*

Anxiety and Depression Scale (Zigmond & Snaith, 1983)

This questionnaire is designed to help measure how you have been feeling in the past week. Read each item and circle the letter corresponding to the response which best describes how you have been feeling in the past week. Please answer every question even if you are unsure.

**1. I feel tense or wound up:**

- A. Most of the time
- B. A lot of the time
- C. From time to time, occasionally
- D. Not at all

**2. I still enjoy things I used to enjoy:**

- A. Definitely as much
- B. Not quite so much
- C. Only a little
- D. Hardly at all

**3. I get a sort of frightened feeling as if something awful is about to happen:**

- A. Very definitely and quite badly
- B. Yes, but not too badly
- C. A little, but it doesn't worry me
- D. Not at all

**4. I can laugh and see the funny side of things:**

- A. As much as I always could
- B. Not quite so much now
- C. Definitely not so much now
- D. Not at all

**5. Worrying thoughts go through my mind:**

- A. A great deal of the time
- B. A lot of the time
- C. Not too often
- D. Very little

**8. I feel as if I am slowed down:**

- A. Nearly all the time
- B. Very often
- C. Sometimes
- D. Not at all

**9. I get a sort of frightened feeling like 'butterflies' in the stomach:**

- A. Not at all
- B. Occasionally
- C. Quite often
- D. Very often

**10. I have lost interest in my appearance:**

- A. Definitely
- B. I don't take so much care as I should
- C. I may not take quite as much care
- D. I take just as much care as ever

**11. I feel restless as if I have to be on the move:**

- A. Very much indeed
- B. Quite a lot
- C. Not very much
- D. Not at all

**12. I look forward with enjoyment to things:**

- A. As much as I ever did
- B. Rather less than I used to
- C. Definitely less than I used to
- D. Hardly at all

**6. I feel cheerful:**

- A. Never
- B. Not often
- C. Sometimes
- D. Most of the time

**7. I can sit at ease and feel relaxed:**

- A. Definitely
- B. Usually
- C. Not often
- D. Not at all

**13. I get sudden feelings of panic:**

- A. Very often indeed
- B. Quite often
- C. Not very often
- D. Not at all

**14. I can enjoy a good book or radio or TV programme:**

- A. Often
- B. Sometimes
- C. Not often
- D. Very seldom

*Appendix 5: Letters of permission to recruit participants (anonymised)*

**XXXXXXXXXX**

X XXXXXXX XXXXX  
XXXXXXXXXX  
XXXXX  
XXXX XXX  
XXXXXX

To whom it may concern

**Re: Beatrice Instone**

Beatrice contacted me saying that she was interested in conducting a piece of research with Carers who are currently involved with dementia.

I subsequently contacted Beatrice and we met to discuss the possibility of her attending our Groups in order to meet the people attending and hopefully to recruit Carers who could help with her research.

Beatrice has also visited one of the XXXXXXXX and spent an evening chatting informally to the people attending.

I have read Beatrice's proposal and have given her permission to come along in the future to any of our XXXX Groups to speak to the Carers and cared for attending.

Over the years we have had at least two students carrying out similar types of research; both students found the groups helpful to their projects.

We would welcome the opportunity to have Beatrice attending the groups in the future.

Please do not hesitate to contact me on XXXXXXXXXXXX if you require any further information.

XXXXXX XXXXX  
**Project Co-ordinator/Trustee**

Dear Beatrice,

This letter is to confirm that I have met with you to speak about your research and give you permission to come along to the [REDACTED] to speak to the carers about your research study.

Yours sincerely,

[REDACTED]

S [REDACTED]





Faculty of Health Sciences

**ETHICAL APPROVAL FEEDBACK**

<b>Student name:</b>	Beatrice Instone
<b>Title of Study:</b>	Does Knowledge and Acceptance predict Anxiety and Depression in Family Caregivers of Dementia
<b>Award Pathway:</b>	DClinPsy
<b>Status of approval:</b>	Approved


**Action now needed:**

Your project proposal has now been approved by the Faculty's Ethics Panel and you may now commence the implementation phase of your study. You do not need to approach the Local Research Ethics Committee. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

You should arrange to meet with your supervisor for support during the process of completing your study and writing your dissertation.

**Comments for your consideration:**

Thank you for forwarding the amendments requested by the Panel

  
PP: **Signed:** Professor Vish Unnithan  
Chair of the Faculty of Health Sciences Ethics  
Panel

**Date:** 6<sup>th</sup> November 2013

Faculty of Health/Faculty of Sciences

**ETHICAL APPROVAL FEEDBACK**

<b>Student name:</b>	Beatrice Instone
<b>Title of Study:</b>	Does Knowledge and Acceptance predict Anxiety and Depression in Family Caregivers of Dementia
<b>Award Pathway:</b>	DClinPsy
<b>Status of approval:</b>	Approved

**Action now needed:**

Your project proposal amendment has now been noted and approved by the Faculty's Ethics Panel subject to our receiving the letter of permission from [REDACTED]

You should note that any further divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

Thank you for forwarding the amendments as requested by the Panel



PP **Signed:** Professor Vish Unnithan  
Chair of the Faculty of Health Sciences Ethics  
Panel

**Date:** 19<sup>th</sup> June 2014

---

**PARTICIPANT INFORMATION SHEET**

---

**Study Title: Do knowledge and acceptance predict anxiety and depression in carers of individuals with Alzheimer's Disease?**

Dear Carer,

I would like to invite you to take part in my research study. Before you decide I would like you to understand why I am carrying out this study and what it would involve for you. Once you have read this information sheet please feel free to ask further questions you may have and I will be happy to answer them.

What is the purpose of the study?

I am currently a student at Staffordshire University studying Clinical Psychology. I am very interested in exploring the types of distress that carers of Alzheimer's disease may experience, and more importantly, how to overcome this distress. I became interested in this topic a couple of years ago whilst working in a dementia service. Previous research has suggested that the more knowledgeable carers are about Alzheimer's, the more anxious they are likely to be. Previous research has also shown that individuals who score highly on measures of acceptance are less likely to be anxious or depressed. The aim of my study is to explore the role of Alzheimer's knowledge and acceptance in predicting anxiety and depression in caregivers of individuals with Alzheimer's disease, and whether there is any relationship between knowledge and acceptance.

Why have I been invited to take part?

You have been invited to take part because you care for somebody with Alzheimer's Disease. There will be approximately 78 carers taking part in this study and I have recruited participants by contacting organisations in the area who offer support for people with Alzheimer's and their carers.

Do I have to take part?

No. It is up to you to decide to take part in the study. If you wish to take part I will ask you to sign a consent form. If you change your mind part way through, you are free to withdraw from the study at any time, without giving a reason. Any questionnaires you have completed will be destroyed. If you choose to withdraw from the study you can do this by contacting myself or my academic research supervisor. In order to preserve your anonymity, when you request for your information to be withdrawn, please use the participant identification number that you have been assigned which you can find in the top left hand corner of this information sheet.

### What will I have to do?

If you decide to take part I will ask you to complete three short questionnaires, independently, at home, and return them using the enclosed stamped addressed envelope. This should take no longer than 15 minutes. In one questionnaire you will be asked to answer some true or false questions designed to measure your knowledge about Alzheimer's. In the second questionnaire you will be asked to rate some statements on a scale of 1-7 depending on how much they apply to you. These statements are designed to measure acceptance and avoidance as methods of general coping. The final questionnaire contains multiple choice questions designed to measure feelings of anxiety and depression you may have experienced in the past week. As well as completing the three questionnaires you will be asked to provide some background information about yourself and the person you care for such as age, gender and duration of caring.

### What are the possible disadvantages or risks of taking part?

Occasionally some people may feel distressed when they are asked to think about how they are feeling, in particular, if they have recently been feeling anxious or depressed. In this study you will be asked some multiple choice questions which are designed to measure if you have been feeling anxious or depressed in the past week. After completing the questionnaires I will provide you with another information sheet which contains a list of organisations who you can get in touch with if you are feeling distressed in any way who can offer support.

### What are the possible advantages or benefits of taking part?

Whilst this study will not have any immediate benefit for you, the information we get from this study may help to improve our understanding of how carers respond to information about Alzheimer's and depending on the findings, education packages aimed at increasing Alzheimer's knowledge may wish to incorporate a psychological aspect focused on helping carers to cope with feelings of anxiety.

### Will my participation in the study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential. Your responses to all three questionnaires will be kept anonymous as well as any background information collected. The questionnaire data will be kept separate from the consent form and background information so that nobody can link the data you have provided to the identifying information you supplied in the consent form. Any information you provide will be stored manually and securely in a locked cabinet. Data will also be held electronically in a password protected document to ensure security. Only the researcher and members of the research team at the University will have access to this data. Once the study has been completed all raw data will be stored in locked cabinets in archives

at the University for 10 years, after which it will be destroyed. All electronic data containing participant information will be destroyed.

What will happen after I take part?

The results from the study will be written up into a report and submitted for publication to a relevant journal. You will not be identified in any report/publication unless you request to be. If you wish to find out about the final results of this study please do not hesitate to contact a member of the research team on the contact details provided below.

Further information and contact details

If you wish to find out more information or you have any concerns about the study please speak to myself (the researcher) and I will be glad answer your questions. Alternatively you could speak to one of my supervisors who oversee the research project.

Beatrice Instone, Trainee Clinical Psychologist (researcher)  
Staffordshire University, College Road, Stoke-on-Trent, ST4 2DE  
Email: [DClinPsy@staffs.ac.uk](mailto:DClinPsy@staffs.ac.uk), Telephone: 01782 294007

Dr Helen Scott, Senior Lecturer in Clinical Psychology, (academic research supervisor)  
Staffordshire University, College Road, Stoke-on-Trent, ST4 2DE  
Email: [helen.scott@staffs.ac.uk](mailto:helen.scott@staffs.ac.uk), Telephone: 01782 294007

Dr Angela Young, Consultant Clinical Psychologist (clinical research supervisor)  
Older Adults Dementia team, Park House, Park Road, Cannock, WS11 1JN  
Email: [angela.young6@nhs.net](mailto:angela.young6@nhs.net), Telephone: 01543 431529

*Thank-you for taking the time to read this information and for your participation in this study if you decide to take part.*

---

**CONSENT FORM**

---

Title of Study: **Do knowledge and acceptance predict anxiety and depression in carers of individuals with Alzheimer's Disease?**

Name of Researcher: **Beatrice Instone**

Please initial boxes

1. I confirm that I have read and understand the information sheet. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
  
3. I understand that the data collected during the study may be looked at by researchers and other responsible individuals at Staffordshire University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.
  
4. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Name of Person                      Date                      Signature

taking consent.

---

## USEFUL ORGANISATIONS

---

If participating in this study has caused you distress, you may wish to contact one of the following organisations who can offer you information and support:

### **Age UK**

Tavis House, 1-6 Tavistock Square, London, WC1H 9NA

Telephone: 0800 169 6565

Website: [www.ageuk.org.uk](http://www.ageuk.org.uk)

### **Alzheimer's Society**

Devon House, 58 St Katherine's Way, London, E1W 1LB

Telephone: 020 7423 3500

Email: [enquiries@alzheimers.org.uk](mailto:enquiries@alzheimers.org.uk)

Website: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### **Mind**

15-19 Broadway, Stratford, London, E15 4BQ

Telephone: 020 8519 2122

Email: [contact@mind.org.uk](mailto:contact@mind.org.uk)

Website: [www.mind.org.uk](http://www.mind.org.uk)

### **Samaritans**

Freepost RSRB-KKBY-CYJK, Chris, PO Box 90 90, Stirling, FK8 2SA

Telephone: 08457 90 90 90

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

Website: [www.samaritans.org](http://www.samaritans.org)

### **Sane**

1<sup>st</sup> Floor, Cityside House, 40 Adler Street, London, E1 1EE

Telephone: 0845 767 8000

Website: [www.sane.org.uk](http://www.sane.org.uk)

*Appendix 10: Author guidelines for submission to Dementia: The International Journal of Social Research and Practice.*

Manuscript submission guidelines (for chapters 1 & 2), downloaded from:  
<http://www.sagepub.com/journals/Journal201266/manuscriptSubmission>

### **Article types**

*Dementia* welcomes original research or original contributions to the existing literature on social research and dementia. *Dementia* also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words. The journal also publishes book reviews.

### **How to submit your manuscript**

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

*Dementia* is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne<sup>®</sup> Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/dementia> to login and submit your article online.

### **Manuscript style**

#### **File types**

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, DOCX, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork [and supplemental files] below.



## **Journal Style**

*Dementia* conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style.

Lengthy quotations (over 40 words) should be displayed and indented in the text.

*Language and terminology.* Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. demented). Language that might be deemed sexist or racist should not be used.

*Abbreviations.* As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

## **Reference Style**

*Dementia* adheres to the APA reference style. [Click here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

## **Manuscript Preparation**

The text should be double-spaced throughout with generous left and right-hand margins. Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Innovative practice papers should be between 750-1500 words.

## **Keywords and Abstracts: Helping readers find your article online**

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract

and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#). The abstract should be 100-150 words, and up to five keywords should be supplied in alphabetical order.

### **Corresponding Author Contact details**

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

### **Guidelines for submitting artwork, figures and other graphics**

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

## **Chapter 3: Commentary & reflective review**

**Commentary and reflexive account of the research process**

**Abstract**

Research has demonstrated that coping strategies are a strong predictor of distress in dementia carers. In chapter 1, Sense of Coherence (SOC) was explored in relation to the psychological wellbeing of carers. Studies showed that a high SOC was associated with an increased ability to cope and improved psychological wellbeing. In chapter 2, psychological acceptance and knowledge were explored to determine whether they predict anxiety and depression in carers of individuals with Alzheimer's-type dementia. Only acceptance was a predictor of distress, highlighting the role of interventions such as Acceptance and Commitment Therapy (ACT) for anxiety and depression. The current paper will offer a reflection on the process of carrying out the previous two papers. In addition, a reflexive account is offered focusing on the impact of the research on the researcher as well as ethical issues that arose during the course of the study.

## **Introduction**

Caring for a family member or close friend with dementia can be stressful. Individual differences in the way a person copes with this stress (by employing coping strategies) has been shown to be strong predictor of psychological distress (Cooper, Katona, Orrell & Livingston, 2008). One method of coping, which is concerned with the extent to which an individual perceives their situation as comprehensible, manageable and meaningful (known as Sense of Coherence/SOC), has been linked to burden, anxiety, depression and reduced quality of life (see chapter 1). In chapter 2, the relationship between knowledge, psychological acceptance and distress was explored. The findings showed that acceptance was a strong predictor of anxiety and depression in caregivers of individuals with Alzheimer's disease (AD). The hypothesis that knowledge of AD would be linked to distress was not supported.

The aim of the current paper is firstly to provide a reflective commentary on the process of carrying out the research and, secondly, to offer a reflexive account considering some of the personal issues highlighted for the researcher during this process.

## **Reflective commentary**

### *Literature review*

Initially it was difficult to decide on a topic for the literature review relating to how carers cope with the distress and challenges that caring for somebody with dementia can bring. This was because of the vast amount of research that already existed in relation to coping which made it difficult to narrow down the focus of the topic. However, in deciding on a topic it felt important to choose an area of coping that acknowledged the protective factors as well as the possibly negative effects of a certain method of coping for the individual. It also felt important to focus on a topic which offers scope for recommendations and interventions based around enhancing an individual's coping ability so that they are less susceptible to some of the negative effects of caring on their psychological wellbeing. The Sense of Coherence (SOC) construct appeared to offer a valuable solution to narrow the focus of the topic whilst also focusing on some of the positive/protective factors associated with this construct related to coping with stressful life events.

SOC appeared to have been fairly well-researched among non-carer populations, whereas the evidence surrounding the dementia caregiver population was far less prevalent. One limitation of choosing a focused topic was that it excluded potentially insightful articles that utilised a qualitative design. Although the review question was better suited to be answered by papers using a quantitative approach, since the aim was to establish whether there was a relationship between SOC and wellbeing, the qualitative papers contained rich information concerned with how SOC is constructed and how carer's personal experiences impact on their SOC. Future reviews in this area may wish to focus on the experiences of SOC from the carer's perspective in order to provide a rich qualitative account of SOC and its impact on wellbeing.

Conversely, whilst the review topic was fairly focused, a strength was that the inclusion criteria allowed for a broad range of issues relating to psychological wellbeing to be explored. This included areas such as mental health problems, general stress and strain, burden and quality of life. As the evidence base is

expanded, there will be more scope for future reviews to focus on a single aspect of distress impacting upon wellbeing, and its relationship with SOC. Overall the review revealed some encouraging findings in relation to the impact of SOC upon carers' psychological wellbeing. More importantly, recent studies have highlighted interventions that can target/modify SOC which have implications for clinical practice.

### *Research report*

Findings from the literature review highlighted the scope for further research into constructs related to coping which potentially influence the development of mental health problems such as depression, since SOC was only found to be protective over time in individuals without depression from the outset of caring (Valimaki et al. 2014). Interestingly some of the interventions relating to enhancing SOC were concerned with increasing knowledge in order to increase the perception of control the person felt they had over their situation. However, research into the impact of knowledge, particularly knowledge of dementia, has been conflicting in terms of the impact that it has on carers' mental health.

One of the aims of the research report was to address these inconsistencies in the research. The cross-sectional design of the research was influenced by the epistemological position of the researcher, which was that of critical realism. This approach emphasises that there is an objective reality that can be measured and studied to some extent, however it also recognises that relationships are complex. Therefore findings from research should be interpreted tentatively, since the way we perceive the world is influenced by our context and individual beliefs, meaning that complete certainty can be hard to achieve (Bunge, 1993). When carrying out the research with participants it became apparent that carers were just as interested in the research as they were with sharing their experiences. In this sense a qualitative approach, or even a mixed methods approach utilising both quantitative and qualitative elements felt as if it would have been able to capture the carers' personal stories and experience. Having to balance this because of the constrictions

placed around the role of the researcher in terms of the study design raised some ethical issues, which will be discussed later in the reflexive account.

One of the limitations of the research, as previously discussed in chapter 2, is the inclusion of only Alzheimer's carers, which excludes carers of other types of dementia. Initially it was decided that all types of dementia would be included and to accommodate this using a questionnaire designed to assess knowledge surrounding dementia in general, rather than a specific type. However, when discussing the dementia questionnaire with professionals working in dementia services it was felt that many of the questions were outdated. Therefore it was decided that the knowledge scale should be up-to-date in order to reflect current understanding of the disease, and the most recent validated scale was only specific to Alzheimer's knowledge. Not only did this limit the number of participants that could be accessed, it also raised ethical issues in terms of having to turn away carers who wished to participate but did not meet the inclusion criteria.

Another potential drawback of the study design was the data collection procedure, which relied on carers returning completed questionnaires by post which inevitably did not result in an optimal response rate, since many questionnaires were not returned, despite carers agreeing to take part. Because of the demands placed on carers it is understandable that they may not have returned the questionnaires after providing consent. However given that recruitment took place at social groups for carers and individuals with AD it would not have been appropriate to complete questionnaires at the groups, especially since the person that they cared for was also present and would often require their full attention. Future studies would possibly benefit from recruiting carers from other venues such as training workshops, for example. These venues may be better suited to enable carers to complete questionnaires at the event since they would not be social groups/evenings where carers come to relax and socialise with others, this would also have the added benefit of the researcher being present in order to answer any queries participants may have.



## **Reflexive account**

### *Effect of research on researcher*

My interest in this topic area stemmed from previous work experience in a memory clinic which involved conducting cognitive assessments with individuals suspected of having dementia. In this role I regularly came into contact with individuals going through the dementia screening process and their relatives. Often relatives were understandably very distressed at having to come to terms with the prospect that their loved one may have dementia, which was one of the reasons I chose to explore the factors that impact upon carer distress. I feel that carrying out this structured role in the memory clinic involving administering assessments to yield a profile of scores of cognitive ability influenced my choice of study design in terms of using structured questionnaires and quantifiable data. Carrying out the research was rewarding but also emotionally demanding at times as it sometimes felt disappointing that there were no immediate benefits for carers taking part.

Another emotionally demanding aspect of carrying out the research was related to working with people experiencing terminal illness and loss. In particular the research evoked feelings of sadness at times when listening to carers' experiences, which ultimately made me confront past losses and think about future losses, in terms of how I would cope if my partner, for example, received a diagnosis of dementia. Sharing these feelings with colleagues, particularly other trainee clinical psychologists on placements in dementia services was invaluable in helping me to normalise and overcome some of these feelings.

Furthermore whilst conducting the research I was often confronted with feelings of helplessness, which in turn led to frustration and dissatisfaction with the work. In particular when thinking about the value of the research and whether the implications of the research, such as interventions based on Acceptance and Commitment Therapy, would actually benefit carers. Although I was aware that such interventions would most likely be helpful in reducing carers' mental health symptoms, I was often reminded that dementia is a

progressive disease with often only one painful outcome, which could not be changed through the use of a psychological intervention. This led me to think about some of the personal challenges I may face in my future career as a practitioner possibly working in dementia services.

### *Ethical Issues*

As previously mentioned, one ethical issue that was raised for me during the research process was having to decline involvement from carers of people with other types of dementia who were willing to take part in the research, especially carers who felt that they would be able to answer the questions relating to Alzheimer's disease (and the fact that a large majority of the questions in the scale apply to all types of dementia). In order to overcome this I had to make it very explicit from the beginning that only carers of individuals with Alzheimer's disease could participate. However, this led to feelings of disappointment when other carers could not take part. If an opportunity arose where I could conduct similar research in the future, I would use a dementia knowledge questionnaire to ensure all carers could participate. Although this would mean that the questions may not be as up to date, one option could be to modify questions to ensure they were currently relevant.

As discussed in the commentary, carers would often want to share their experiences of caring for a close family member with dementia. I was very eager to listen to their experiences but at the same time was aware that the rich information they were sharing would not form part of the actual data analysis. In particular some of the main points that were raised by carers were the day-to-day differences in their mood and perceived ability to cope. Several carers commented that you can have 'good and bad days' depending on the mood and behaviour of the person they are caring for. This is important to be mindful of when interpreting findings from cross-sectional studies given that in this study a measure of anxiety and low mood was only taken once and will be partially influenced by the carer's mood on the day, which will be dependent upon a number of different factors, as several carers implied.

Another ethical issue that I faced involved the completion of questionnaires, specifically the questionnaire relating to psychological acceptance. As I attended the social groups on more than one occasion, I would often come into contact with carers who had already completed the questionnaires. On occasions carers would wish to talk with me about the research separately and give me feedback about how they found the process, which I was more than happy to receive. Some of the feedback I received was related to how completing the acceptance questionnaire made carers feel somewhat distressed; this was also evident in the discussions I had as some carers become quite tearful when sharing this. In my role as a scientist-practitioner I had to be aware of my duty as a researcher and it was difficult not to offer further support in my role as a practitioner. Supervision proved vital in order to manage this and to have a space to discuss some of the concerns I had. Furthermore I always ensured that carers who were feeling distressed were aware of the organisations and support services that could be accessed.

### **Conclusion & key learning points**

Overall the findings from the thesis have contributed to the understanding and evidence base surrounding the factors that may mediate the relationship between caregiving and distress. Specifically, constructs related to coping such as Sense of Coherence and psychological acceptance have been shown to act as a protective factor against psychological distress. Interventions such as psychological therapy aimed at strengthening SOC and Acceptance and Commitment therapy have been shown to be effective at enhancing coping abilities and reducing distress, although further research is needed in order to strengthen these findings amongst the caregiver population. In practice it is hoped that the findings will contribute to the awareness of the psychological needs of dementia carers as well as revealing psychological techniques and interventions that could enhance coping, which could possibly further promote a positive attitude among professionals who may believe that the situation is unchangeable.

On a personal note, carrying out the thesis has enabled me to appreciate and recognise the value of research and draw theory-practice links in my day-to-day work. It has also increased my self-awareness in relation to some of the ethical issues and personal feelings that were raised for me during the course of the research.

Words: 2,469

Word count for whole thesis: 20,000

## References

- Antonovsky, A. (1979). *Health, stress and coping: new perspectives on mental and physical wellbeing*. San Francisco: Jossey-Bass Inc.
- Bunge, M. (1993). Realism and antirealism in social science. *Theory and Decision*, 35, 207-235.
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23, 929-936.
- Hayes, S. C., Strosahl, K. D., Wilson, K. G., Bissett, R. T., Pistorello, J., Toarmino, D., ...Polusny, M. A. (2004). Measuring experiential avoidance: a preliminary test of a working model. *The psychological Record*, 54, 553-578.
- Langeland, E., Riise, T., Hanestad, B. R., Nortvedt, M. W., Kristoffersen, K., & Wahl, A. (2006). The effect of salutogenic treatment principles on coping with mental health problems: a randomised controlled trial. *Patient Education and Counselling*, 62, 212-219.
- Valimaki, T., Martikainen, J., Hongisto, K., Fraunberg, M., Hallikainen, I., Sivenius, J., ...Vehvilainen-Julkunen, K. (2014). Decreasing sense of coherence and its determinants in spousal caregivers of persons with mild Alzheimer's disease in three year follow-up: ALSOVA study. *International Psychogeriatrics*, 26, 1211-1220.