Expressed Emotion in caregivers of persons with dementia and the relationship with psychological outcomes in caregivers and persons with dementia.

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health

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**List of abbreviations**

(ADL) Activities of daily living scale
(ASBS) Alzheimer’s spouse burden scale
(AES) Anger expression scale
(AQ) Attribution questionnaire
(BDI) Beck depression inventory
(BHS) Beck hopelessness scale
(BDS) Beck self-report depression scale
(BPSD) Behavioural and psychological symptoms of dementia
(BMD-Stress) Behavior and mood disturbance -stress scale
(BRS) Behaviour rating scale
(BS) Bimodal scale
(BP) Blood pressure
(BIPQ) Brief Illness Perception Questionnaire
(BSI) Brief symptom inventory
(BIN) Burden interview
(BI) Burden inventory
(CAGE) Alcohol screening questionnaire
(CAS) Cognitive Assessment Scale
(CASPB) Relative’s attributional scale for problem behaviour
(CFI) Camberwell Family Interview
(CES-D) Center for epidemiological studies depression scale
(CAPE) Clifton assessment procedures for the elderly
(CDR) Clinical dementia rating
(CORE) Clinical Outcomes in Routine Evaluation
(CS) Clinical Sensorium
(CBT) Cognitive Behavioural Therapy

(CTS) Conflicts tactics scales

(CRBRS) Modified Crichton royal behavioural rating scale

(CSDD) Cornell scale for depression in dementia

(CRS) Relative resentment scale

(DEMQOL) Dementia Quality of life measure

(DAD) Disability assessment for dementia

(EPHPP) Effective Public Health Practice Project

(EES) Emotional expressivity scale

(EOI) Emotional over-involvement

(EE) Expressed Emotion

(FAS) Family Attitude Scale

(FEICS) Family Emotional Involvement and Criticism Scale

(FIQ) Family interaction questionnaire

(FMSS) Five Minute Speech Sample

(GAI) Geriatric Anxiety Inventory

(GDS) Geriatric Depression Scale (Shortened Version)

(GHQ) General health questionnaire

(GHQ-30) General health questionnaire-30

(GSS), Gilleard strain scale

(GDS) Global deterioration scale

(HADS) Hospital anxiety and depression scale

(HDRS) Hamilton depression rating scale

(HRQL) Health-related QOL

(HEE) High Expressed Emotion

(HSC) Hopkins symptoms checklist

(HPA) Hypothalamic pituitary adrenal axis
(IRAS) Integrated Research Application System

(IQ) Intimacy questionnaire

(IADL) Instrumental activities of daily living

(JDR) Join Dementia Research

(LASER-AD) London and the South East Region Alzheimer's Disease

(LEES) Level of Expressed Emotion Scale

(LEE) Low Expressed Emotion

(MOUSEPAD) Manchester and Oxford University for psychopathological assessment in dementia

(MCSDS) Marlowe-Crowne social desirability scale

(M) Mean

(MAS) Mechlin activity scale

(MOS SF-36) Medical Outcomes Study Short Form 36

(MMSE) Mini mental state examination

(M) Moderate

(MoCA) Montreal Cognitive Assessment

(NHS) National Health Service

(NCRB) Negative care recipient behaviours

(NPI) Neuropsychiatric inventory

(NR) Not reported

(N) Number

(OMFAQ) Older Americans resources and services multi functional assessment questionnaire

(OPASQ) Older person’s attribution style questionnaire

(OPPES) Older person’s pleasant events schedule

(OPUES) Older person’s unpleasant events schedule

(PIS) Participant information sheet
(PTSD) Post-traumatic stress disorder
(PR) Patient rejection scale
(PCS) Perceived Criticism Scale
(PWD) Persons with dementia
(PSMS) Physical self-maintenance scales
(PICS) Preference for institutional care scale
(QCPR) Quality of Carer-Patient Relationships scale
(QOL) Quality of life
(RIL) Record of independent living
(RQ) Relationship quality
(RSS) Relative stress scale
(RDC) Research diagnostic criteria
(REC) Research Ethics Committee
(RMBPC) Revised memory and behaviour problem checklist
(SCI-90) Depression scale of the symptom checklist-90
(SLS) Satisfaction with life scale
(SADS) Schedule for affective disorders and schizophrenia interview
(SCB) Screen for Caregiver Burden
(SSI) Site Specific Assessment
(SIS) Social interaction scale
(SD) Standard deviation
(SCS) Steinmetz control scale
(S) Strong
(UK) United Kingdom
(WCCL) Ways of coping checklist
(W) Weak
(ZBI) Zarit Burden Inventory
Abstract

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health in July 2018.

Candidate: Roxanne Safavi


This thesis explored caregiver responses to persons with dementia (PWD) in association with psychological outcomes in both caregivers and PWD, using a variety of methods, including a systematic review, a naturalistic study using the Expressed Emotion (EE) methodology with cross-sectional and longitudinal elements, and a mediation analysis. The systematic review (Paper 1; Chapter 2) showed that caregiver factors, such as interpersonal relationships, responses and beliefs, are associated with wellbeing outcomes in caregivers of PWD. Methodological limitations of previous work and gaps in research were identified from the review and the subsequent empirical papers presented attempt to address these.

The first empirical study (Paper 2; Chapter 5) utilised the EE framework to explore the impact of key aspects of interpersonal relationships on caregiver outcomes. A cross-sectional relationship was found between caregiver EE, burden and psychological distress. Furthermore, when controlling for baseline measures, high-EE caregivers showed increased levels of burden and distress over time. Paper 3 (Chapter 6) explored the influence of caregiver EE on psychological wellbeing in PWD. Interestingly, low-EE appeared to have a protective effect, as PWD with low-EE caregivers experienced a reduction in depression and anxiety over 6 months, whereas those with high-EE caregivers maintained baseline levels of depression and anxiety. Decomposing EE into its constituent constructs, caregiver emotional over involvement predicted greater levels of PWD anxiety and critical comments predicted greater levels of PWD depression. Paper 4 (Chapter 7) examined the relationship between caregiver distress, caregiver criticism and psychological wellbeing in PWD. There were cross-sectional and longitudinal relationships between caregiver distress, critical comments, anxiety in PWD and depression in PWD. Furthermore, baseline caregiver distress was found to be predictive of poorer quality of life in PWD at 6 month follow-up, and this relationship was mediated by the number of caregiver critical comments. Taken together, the findings presented within this thesis provide evidence for the impact of caregiver factors on psychological outcomes in both caregivers and PWD. Finally, the results suggest that the development of caregiver-focused interventions may be beneficial for both PWD and caregiver outcomes.
Declaration

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Preface

I graduated in Neuroscience and Psychology from Keele University in 2008. I then went on to obtain a Postgraduate Certificate in Psychological Therapies from the University of Nottingham in 2009 and worked as a Psychological Wellbeing Practitioner. I completed a Masters in Clinical Research in 2012, entitled “Psychological therapies for older adults” and then went on to obtain a Postgraduate Diploma in Cognitive Behavioural Therapy from the University of Manchester and have since been working as a Cognitive Behavioural Psychotherapist. Within this role I work with persons with common mental health conditions and long term health conditions. Since 2012, I have been studying part-time for my PhD at the University of Manchester. The basis for this research stems from my passion for understanding and enhancing wellbeing in persons with long term neurological conditions, such as dementia, and their caregivers.
Journal thesis format

The current thesis has been prepared in journal format and consists of four papers including a systematic review and three empirical papers. Paper 1; the systematic review presented in Chapter 2 has been published in Aging and Mental Health. Paper 2 presented in Chapter 5 has been accepted for publication in the Journal of Family Psychology. Paper 3 presented in Chapter 6 is currently under review for publication in Aging and Mental Health. Paper 4 presented in Chapter 7 is currently under review for publication in Family, Systems and Health. The planning, design, execution, data acquisition, analysis and write up of the papers have been conducted by the first author. This work has been overseen by the project supervisors, Professor Alison Wearden and Doctor Katherine Berry. They are therefore listed as co-authors on each of the papers outlined above.

The first chapter contains an overview of dementia followed by a discussion on the influence dementia has on both caregivers and persons with dementia. Chapter 2 reports on the findings of the systematic review and meta-analysis (Paper 1). Chapter 3 contains information about the aims of the thesis. Chapter 4 provides additional information about the methodological considerations employed in each of the empirical papers. Chapter 5 reports on the association between EE and caregiver measures (Paper 2). Chapter 6 reports on the association between EE and psychological wellbeing in persons with a recent diagnosis of dementia (Paper 3). Chapter 7 reports on the relationship between caregiver distress and criticism, and psychological wellbeing of persons with dementia (Paper 4). Chapter 8 provides a discussion about the key findings and clinical implications.
Chapter 1: Background

1.1 Dementia

1.1.1 Overview of Dementia

Dementia is characterised as a progressive degenerative disease, which affects cognitive abilities, behavioural disturbances, psychiatric disturbances and it has a significant impact on a person’s ability to maintain the activities of daily living (World Health Organization, 2017). As the condition progresses, the level of dependency and morbidity increase, as illustrated in Table 1. However, it is important to note that the stages outlined in Table 1 are a generalisation, as the rate of degeneration will differ from person to person (World Health Organization, 2012).

Dementia takes various forms, including: 1) Alzheimer’s disease, the most common cause of dementia contributing to 60 to 70% of cases, is caused by a change in the chemistry and structure of the brain resulting in the death of brain cells, 2) vascular dementia is due to a loss of oxygen supply to the brain causing the death of brain cells, 3) dementia with Lewy bodies is as a result of the development of abnormal cells within the nerve cells causing the degeneration of brain tissue, 4) Parkinson’s disease dementia is caused by Lewy bodies spreading into different parts of the brain, 5) mixed dementia is where abnormalities in the brain are due to more than one form of dementia and 6) fronto-temporal dementia is caused by damage to the front part of the brain (World Health Organization, 2012). The boundaries between these various forms of dementia are indistinct and mixed forms of dementia often co-exist (Prince & Jackson, 2009). Figure 1 outlines the estimated proportion of the different dementia subtypes in the United Kingdom (UK).
Table 1: Common symptoms experienced by people with dementia (World Health Organization, 2012)

<table>
<thead>
<tr>
<th>Early stage of dementia (1-2 years after diagnosis)</th>
<th>Middle stage of dementia (2-5 years after diagnosis)</th>
<th>Late stage of dementia (5+ years after diagnosis)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The early stage of dementia can often be seen as a normal part of the ageing process and therefore can be disregarded by relatives and professionals. The common symptoms include: Forgetfulness Difficulty finding words Disorientation Losing track of the time Difficulty with decision making Difficulty with personal finances Difficulty with complex household tasks Reduction in activity level, motivation and interest Depression and/or anxiety Occasional anger and/or aggression</td>
<td>The symptoms become more apparent and restrictive as dementia progresses. The common symptoms include: Very forgetful, particularly of names and recent events Disorientated and lost at home and in familiar places Difficulty comprehending time, date and place Difficulty with communication, particularly with speech and comprehension Unable to successfully prepare food or clean Unable to live alone safely without considerable support Behavioural changes such as repeated questioning, disturbed sleep and hallucinations Inappropriate behaviour such as aggression or disinhibition</td>
<td>The last stage involves a noticeable increase in dependence, inactivity, memory difficulties and physical changes. The common symptoms include: Loss of awareness of time and place Difficulty comprehending what’s happening around them Unable to recognise relatives, friends and familiar objects Needing assistance when eating Difficulty swallowing Possible bladder and bowel incontinence Mobility changes Behaviour changes such as aggression and/or agitation Unable to find their way around the home</td>
</tr>
</tbody>
</table>
Figure 1: The distribution of dementia subtypes within the UK (Knapp et al., 2007; Prince et al., 2014)

1.1.2 Prevalence of dementia

The number of people living with dementia worldwide in 2013 was estimated to be 44 million and it is predicted that numbers will almost double every 20 years to reach 76 million in 2030 and 135 million in 2050, as outlined in Figure 2 (Alzheimer’s Disease International, 2013a). Age is the strongest known risk factor for the onset of dementia, although dementia is not an automatic consequence of ageing. Improved health care, along with social and economic developments, has increased life expectancy and reduced mortality rates in older adults, thus resulting in a rapid increase in the ageing population. Population ageing, along with changes in behaviour and lifestyle such as physical inactivity, high dietary consumption of salt, fat and sugar, smoking and alcohol use, are the main drivers for the predicted increase in the prevalence of dementia (World Health Organization, 2017). Persons with young onset dementia, which is defined as the onset of
symptoms before the age of 65 accounts for up to 9% of cases (Alzheimer’s Disease International, 2013b).

**Figure 2:** World population aged 60 years or over, 1950–2050 (Alzheimer’s Disease International, 2013a).

### 1.1.3 Long term care for dementia

Long term care is used to describe a range of services which aim to meet both medical and non-medical needs of people with chronic illness who struggle to care for themselves. This includes 1) diagnostic services, which involves the identification, assessment and diagnosis of dementia, 2) post-diagnostic services, which focus on planning for the patients’ future, offering information and advice, guidance on symptoms management and helping people to maintain independence, 3) community services, which offer help for persons with dementia (PWD) to remain at home and providing respite to caregivers, and 4) continuing care, which involves caring for people who are no longer able to stay at home and delivering support for the end stages of dementia (World Health Organization, 2012).

However, three key barriers which prevent many PWD from accessing and receiving appropriate care have been identified: 1) identification and planning, 2) inequality of access and 3) the quality of care experienced by PWD (Marie Curie Cancer Care &
Alzheimer’s Society, 2014). In England it is estimated that the average rate of dementia diagnosis is 48% with an estimated 416,000 people living with dementia but without a diagnosis (Marie Curie Cancer Care & Alzheimer’s Society, 2014). Dementia is often difficult to diagnose in its early stages and involves a number of investigations such as examining personal clinical history, physical examination (i.e. blood tests), cognitive testing and neuro-imaging. In the early stages of dementia, symptoms such as confusion and memory loss are often dismissed by PWD, families and professionals as normal signs of ageing. These factors often result in a delay in people receiving a formal diagnosis of dementia which generally prevents people from accessing services and therefore restricts early support to both PWD and their family (Marie Curie Cancer Care & Alzheimer’s Society, 2014).

1.1.4 Pharmacological treatment of dementia

The symptoms of dementia are believed to be related to impaired neurotransmission and degeneration of neuronal pathways in the brain (Ellis, 2005; Poirier, 2002). Drug treatments have been developed for persons with Alzheimer’s Disease (Ellis, 2005). These treatments are aimed at restoring or otherwise boosting neurotransmission, thereby stabilising and/or reducing atypical behavioural patterns and the decline in cognition and activities of daily living in PWD. Although these drug treatments have been found to be moderately effective at reducing the symptoms of cognitive impairment and slowing disease progression, there are no curative treatments as yet for the dementias. Nor are there any treatments that alter the progressive course of dementia, although numerous new therapies are currently being investigated in clinical trials (Ellis, 2005; World Health Organization, 2012). A cure for any type of dementia is unlikely in the near future (Shah et al., 2016), therefore, as the number of persons living with dementia rises, it is becoming increasingly important to explore and promote psychological wellbeing and quality of life.
for those affected by the condition now (Algar, Woods, & Windle, 2014; Overshott & Burns, 2005).

1.1.5 Non-pharmacological treatment of psychological symptoms of dementia

Research has shown that non-pharmacological treatments, as outlined in Table 2, can be beneficial in reducing behavioural and psychological symptoms of dementia (BPSD) (Oliveira et al., 2015). BPSD such as screaming, delusions, impatience, repeated questioning, wandering, agitation, aggression, depression and apathy, have been reported to affect up to 90% of PWD during the course of the disease (Hersch & Falzgraf, 2007). As dementia progresses the number and severity of BPSD worsen which leads to an increased need for support. The increase in BPSD have also been associated with illness progression, increased cognitive decline, greater impairment in activities of daily living and increased hospitalisation (Haupt, Kurz, & Jänner, 2000; Paulsen et al., 2000).
**Table 2:** Examples of non-pharmacological therapies for persons with dementia (Douglas, James, & Ballard, 2004)

<table>
<thead>
<tr>
<th>Non-pharmacological therapies</th>
<th>Aims of non-pharmacological therapies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioural therapy</td>
<td>Reducing or eliminating unhelpful/challenging behaviours by using the principles of the conditioning derived from learning theory.</td>
</tr>
<tr>
<td>Reality orientation</td>
<td>Helping people with memory loss and disorientation by reminding them of facts about themselves and their environment.</td>
</tr>
<tr>
<td>Validation therapy</td>
<td>Facilitating the person with memory loss and disorientation to be in the ‘here and now’ by building trust and a sense of security.</td>
</tr>
<tr>
<td>Reminiscence therapy</td>
<td>Assisting PWD to recall one’s life events by talking about things from their past.</td>
</tr>
<tr>
<td>Life story work</td>
<td>Stimulating PWD to recall events from their past by combining photos, notes and keepsakes from their childhood to the present day.</td>
</tr>
<tr>
<td>Art therapy</td>
<td>Improving attention and stimulating conversation, by encouraging PWD to express themselves through art.</td>
</tr>
<tr>
<td>Music therapy</td>
<td>Improving emotional wellbeing through the use of cognitive stimulation and social interaction.</td>
</tr>
<tr>
<td>Activity therapy</td>
<td>Improving physical and mental health by enhancing physical activity such as dance, sport and drama.</td>
</tr>
<tr>
<td>Aromatherapy</td>
<td>Enhancing wellbeing and interaction through the use of sensory experience.</td>
</tr>
<tr>
<td>Bright-light therapy</td>
<td>Reducing agitated behaviours and improving sleep in PWD by enhancing daily exposure to more light through the use of a light box.</td>
</tr>
<tr>
<td>Cognitive behavioural therapy</td>
<td>Reducing anxiety and depression through understanding and changing unhelpful patterns of thoughts and behaviours.</td>
</tr>
<tr>
<td>Interpersonal therapy</td>
<td>Reducing anxiety and depression by exploring and enhancing relationships with others.</td>
</tr>
</tbody>
</table>
1.2 Caregivers of persons with dementia

1.2.1 The role of caregivers

The delay in persons receiving a formal diagnosis of dementia along with the failings of a divided health and social care system within the UK mean that thousands of informal caregivers (i.e. persons who provide unpaid assistance with activities of daily living) are left with the responsibility of caring for their relative with dementia (Knapp, Prince, & Dementia, 2007). Furthermore, a systematic review of service interventions offered to PWD caregivers, found that caregivers did not experience significant reductions in levels of burden when utilising the limited dementia care services (Corbett et al., 2012). Research has also shown that caregivers of persons within the early stages of dementia are often reluctant to access educational or supportive interventions offered as they perceive them to primarily focus on problems likely to be experienced later on as the condition progresses (Whitlatch, Judge, Zarit, & Femia, 2006). Family and friends play a significant role in the support of PWD and can be defined in two categories; 1) primary caregivers, who spend most of the time with the person with dementia, and 2) secondary caregivers, who play a supplementary role to the care of a relative or friend (Gaugler, Kane, Kane, Clay, & Newcomer, 2003). Caregivers are confronted with numerous evolving tasks throughout the course of dementia including, but not limited to, general supervision, assistance with activities of daily living (e.g. walking, dressing, bathing, eating, getting out of bed and using the toilet) and instrumental activities of daily living (e.g. preparing meals, grocery shopping, making telephone calls, helping with medication, managing money, managing appointments) (Fisher et al., 2011).

Research has shown that early-stage caregivers can find it particularly difficult adjusting to their role and the restrictions it places on their lives which can result in increased distress soon after their relative is diagnosed with dementia (Egilstrom, Ravn, & Petersen, 2018). However, research suggests that formal support (i.e. support from professionals) for
caregivers is often inadequate (Aggarwal et al., 2003) and lacking during these early stages of dementia (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). During the course of dementia, the extent and type of support required depends on numerous factors including type and severity of dementia, symptomatology, physical difficulties, psychological problems, personality and relationship factors. However, the level of support required generally increases, beginning with support for daily living (e.g. household, financial and social activities), gradually increasing to personal care and almost constant supervision (World Health Organization, 2012).

As the condition progresses, particularly during the late stages, the involvement of professional support and care often increases. However, the reluctance and/or fear of PWD and their caregivers in identifying/acknowledging symptoms, the difficulty of health professionals in identifying and diagnosing dementia, particularly within the early stages, and the limited availability of support, treatment and appropriate care often means that family and friends become responsible for the majority of care and support of PWD (Marie Curie Cancer Care & Alzheimer’s Society, 2014; World Health Organization, 2012).

1.2.2 Consequences of caring

Many family and friends who provide informal care take pride in their role and they perceive it to be rewarding, fulfilling, enjoyable and meaningful (Prince & Jackson, 2009; Wolff, Dy, Frick, & Kasper, 2007; World Health Organization, 2012). However, the nature of dementia and its symptomatology place heavy demands on caregivers and can result in diverse negative consequences. Unsurprisingly, these demands have been associated with more emotional, interpersonal and health problems in caregivers of PWD in comparison to the general population. This includes a decline in psychological wellbeing (Bledin, MacCarthy, Kuipers, & Woods, 1990; Pinquart & Sorensen, 2003; Rabins, Mace, & Lucas, 1982; Shaw et al., 1997; Teri, 1994), increased levels of subjective burden (Wagner, Logsdon, & Pearson, 1997), poor self-care (Shaw et al., 1999), physical health problems
(Haley, 1997; McNaughton, Patterson, Smith, & Grant, 1995; Shaw et al., 1999; Vitaliano, Zhang, & Scanlan, 2003), sleep disturbances (McCurry, Logsdon, Teri, & Vitiello, 2007) and poor patient-relative relationships (Fearon, Donaldson, Burns, & Tarrier, 1998; Morris, Morris, & Britton, 1988). Furthermore, the conclusions drawn from two systematic reviews have shown that the prevalence of depression and anxiety is higher in caregivers of PWD than compared to matched control groups (Cooper, Balamurali, & Livingston, 2007; Cuijpers, 2005). All the above effects of caregiving highlight the importance of providing support to primary caregivers who are a crucial resource in the long term care arrangements for the person with dementia (World Health Organization, 2012).

Depression rates in caregivers of PWD range from 30 to 80%, thus demonstrating that the consequence of caring varies from person to person and that not all caregivers experience a change in their mental health (Schoenmakers, Buntinx, & Delepeleire, 2010). In a recent systematic review which aimed to explore which caregiver and PWD characteristics are associated with caregiver depression, the authors found that female caregivers and spouses experienced greater levels of depression than men and other caregiver groups. Caregivers who perceived themselves to have a high workload, reported higher levels of depression than those who reported lower workloads. Increased PWD needs and poor cognitive functioning was also associated with higher levels of depression (Schoenmakers et al., 2010).

Research has found an association between poor health in caregivers and sub-standard care, neglect and/or abuse of the PWD (Cooper, Blanchard, Selwood, Walker, & Livingston, 2010a; Cooper et al., 2010b; Shaffer, Dooley, & Williamson, 2007). Studies have also found an association between poor health in caregivers and an increased use of services outside the family/friend support network, and an increased likelihood of the PWD entering residential care, both of which present considerable health care and human costs (Armstrong, 2000).
Caregivers often make a number of personal sacrifices to keep caring for the person with dementia at home (Park, Butcher Howard, & Maas Meridean, 2004). Making a decision to place a loved one with dementia into a care home is one of the most difficult experiences that caregivers are faced with and often results in exhaustion, ruptured relationships, deep upset, sorrow and uneasiness (Park et al., 2004). The decision to place a relative with dementia into a care home often comes at a time of crisis, whereby there is deterioration in neuropsychiatric symptoms (i.e. behavioural disturbances, agitation), increased level of dependency, safety concerns and a deterioration in cognition (Afram et al., 2014).

Caregiver factors such as increased burden and stress, changes in physical and psychological health and lack of social support also contribute to home care becoming more problematic (Afram et al., 2014). However, interestingly, a study conducted in the US found caregivers, particularly spouses, did not experience an improvement in their own wellbeing after their care-recipient was placed into a care home, possibly because they continued to visit and support their loved one on a regular basis (Schulz et al., 2004). A study on 238 PWD living in residential care homes across the UK found that physical health and environmental needs were often met. However, sensory needs (i.e. eyesight and hearing), physical needs (i.e. incontinence), mental health needs and social needs (i.e. company and activities) were often unmet, all of which were associated with increased psychological distress (Hancock, Woods, Challis, & Orrell, 2006). This highlights the complexities for caregivers who are involved in making decisions about the long term care of their loved one with dementia.
1.3 Persons with dementia

1.3.1 Psychological disorders in persons with dementia

The occurrence of mental health conditions, predominantly mood disorders, in PWD has been well established (Ballard, Boyle, Bowler, & Lindesay, 1996; Reding, Haycox, & Blass, 1985; Wands et al., 1990; Zuidema, Koopmans, & Verhey, 2007). The most commonly reported mental health conditions in persons with a diagnosis of dementia are 1) depression, which has been found in approximately 20-30% of PWD, with higher rates in persons with vascular dementia and dementia with Lewy bodies (Enache, Winblad, & Aarsland, 2011) and 2) anxiety, which is estimated to affect 5 to 21% of PWD (Ferretti, McCurry, Logsdon, Gibbons, & Teri, 2001).

Depression is diagnosed on the basis of persistently depressed mood, loss of positive affect or pleasure, loss of appetite, sleep disturbances, fatigue, feelings of hopelessness and/or worthlessness, loss of concentration, suicidal ideation, withdrawing from others and irritability (American Psychiatric Association, 2013). In 2001, the National Institute of Mental Health assembled a panel to develop a provisional set of diagnostic criteria for depression in dementia (see Table 3) (Olin et al., 2003; Olin et al., 2002). Prevalence rates of depressive symptoms in PWD have been found to range from 10% to 62% (Enache et al., 2011). Studying anxiety in dementia can be difficult due to the overlap between the two conditions. Symptoms that have been found to independently predict anxiety in dementia include excessive worry, restlessness, irritability, muscle tension, fears and respiratory symptoms (Starkstein, Jorge, Petracca, & Robinson, 2007). The prevalence of these anxiety symptoms is estimated to affect up to 71% of PWD (Ballard et al., 2000).
### Table 3: Provisional Diagnostic Criteria for Depression in Alzheimer’s disease (Olin et al., 2003; Olin et al., 2002)

<table>
<thead>
<tr>
<th></th>
<th>Depression in Alzheimer’s Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Three (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning. At least one of the symptoms must either be depressed mood or decreased positive affect or pleasure.</td>
</tr>
<tr>
<td></td>
<td>1. Clinically significant depressed mood</td>
</tr>
<tr>
<td></td>
<td>2. Decreased positive affect or pleasure in response to social contacts and usual activities</td>
</tr>
<tr>
<td></td>
<td>3. Disruption in appetite</td>
</tr>
<tr>
<td></td>
<td>4. Disruption in sleep</td>
</tr>
<tr>
<td></td>
<td>5. Psychomotor changes</td>
</tr>
<tr>
<td></td>
<td>6. Fatigue or loss of energy</td>
</tr>
<tr>
<td></td>
<td>7. Feelings of worthlessness, hopelessness, or excessive or inappropriate guilt</td>
</tr>
<tr>
<td></td>
<td>8. Diminished ability to think or concentrate</td>
</tr>
<tr>
<td></td>
<td>9. Recurrent thoughts of death, suicidal ideation, plan or attempt</td>
</tr>
<tr>
<td></td>
<td>10. Social isolation or withdrawal</td>
</tr>
<tr>
<td></td>
<td>11. Irritability</td>
</tr>
<tr>
<td>B</td>
<td>All criteria are met for Dementia of the Alzheimer Type (DSM-IV)</td>
</tr>
<tr>
<td>C</td>
<td>The symptoms are not better accounted for by other conditions e.g. major depressive disorder, bipolar disorder, bereavement, schizophrenia, schizoaffective disorder, psychosis of Alzheimer’s disease, anxiety disorders, or substance-related disorders</td>
</tr>
<tr>
<td>D</td>
<td>The symptoms are not due to the direct physiological effects of a substance</td>
</tr>
<tr>
<td>E</td>
<td>The symptoms cause clinically significant distress or disruption in functioning</td>
</tr>
</tbody>
</table>

Despite the high prevalence of mental health conditions such as depression and anxiety within the dementia population, a recent Cochrane review found that PWD have limited opportunities for psychological treatments aimed at improving their wellbeing (Orgeta, Qazi, Spector, & Orrell, 2015). Psychological disorders result in increased distress to PWD, impaired cognitive functioning and reduced performance of activities of daily living (Ballard et al., 2000; Burns, 1991; Fitz & Teri, 1994; Seignourel, Kunik, Snow, Wilson, & Stanley, 2008). Increased morbidity, mortality, and health care costs have also been found.
to relate to psychological disorders (Dorenlot, Harboun, Bige, Henrard, & Ankri, 2005; Janzing, Bouwens, Teunisse, Van't Hof, & Zitman, 1999; Richard Schulz, Drayer, & Rollman, 2002).

There has been some evidence to suggest the rate of co-existing dementia and psychological symptoms reduce as the severity of the cognitive impairment increases (Giebel et al., 2015; Reifler, Larson, & Hanley, 1982), thus suggesting persons during the early stages of dementia are at greater risk of psychological symptoms. This may be explained by persons with later stage dementia lacking insight about their mental health due to a decline in cognitive functioning. Also as the disease progresses a person’s experience of complex emotions is likely to change (Forsell & Winblad, 1997). Gaining further understanding about factors which influence psychological symptoms, particularly in persons recently diagnosed with dementia, would provide important insight to improve the efficacy of interventions that facilitate psychological wellbeing (Sharpe & Curran, 2006).

### 1.3.2 Quality of life in persons with dementia

Quality of life (QOL) is a multi-dimensional concept which can be defined as an individual’s perception of their position in life in the context of their cultural and values system, and encompasses physical, social and psychological domains (Felce & Perry, 1995). Health-related QOL (HRQL) refers to aspects of QOL that are most likely to be affected by various diseases. Having insight into HRQL is of interest to clinicians, PWD and their families, as it helps to effectively plan care and support for PWD and their family members in order to enhance QOL (Guyatt, Feeny, & Patrick, 1993). PWD experience varying deficits of memory, attention, communication, judgement and insight, all of which may compromise the person’s ability to comprehend questions and/or to self-report on their own subjective states (Logsdon, Gibbons, McCurry, & Teri, 2002). For this reason,
measuring HRQL in PWD poses unique challenges and therefore HRQL has not been widely explored in this population (Logsdon et al., 2002). However, despite these challenges, there is a growing body of evidence that suggests that people with dementia have a meaningful experience of QOL that they are able to reliably and validly report on (Hoe, Katona, Roch, & Livingston, 2005; Logsdon et al., 2002; Smith et al., 2007). Various methods of assessing HQOL in PWD have been developed including 1) self-reports by the individual with dementia, 2) proxy reports by a family member or significant other and 3) direct observation of behaviours related to QOL (Logsdon et al., 2002).

Self-reports give PWD the opportunity to talk about their own personal experiences and therefore places value on individual perspectives. However, it is important to note that in order for self-reports to be effective they must be designed in a way to facilitate understanding despite having a cognitive impairment. The use of clear instructions, visual cues to remind of the responses and face-to-face administration can help enhance the comprehension of questions and selection of appropriate responses. Furthermore, follow-up questions can be used to assess comprehension when the respondent provides an unclear or inconsistent response (Logsdon et al., 2002). However, given the progressive nature of the disease, factors which influence a person with dementia’s perceptions of his or her HRQL are likely to change over time. Additionally, ability to report on QOL may also change, so the methods of assessing HRQL will need to differ in the early and late stages of dementia (Logsdon et al., 2002; Smith et al., 2007).

Proxy reports avoid the difficulties that cognitive limitations may cause and therefore can be used throughout the course of the disease. However, it is important to note that characteristics of the proxy such as their expectations, beliefs, nature of relationship, time spent with the person with dementia, and their own levels of depression and burden, may influence their reports (Logsdon, Gibbons, McCurry, & Teri, 1999). Investigations that
have compared responses from persons with and without cognitive impairments have
found that proxy responses consistently rate QOL lower than the individual themselves and
therefore do not replicate the person with dementia’s perception of QOL (Hoe, Katona,
Orrell, & Livingston, 2007; Logsdon et al., 1999; Sainfort, Becker, & Diamond, 1996).
Direct observation reports are based on pre-defined criteria, such as observed affect and
pleasant events, and therefore have the benefits of being deemed more objective. However,
there is uncertainty about whether the person with dementia considers the pre-defined
criteria to be important in their QOL. This method may also be associated with the
potential biases associated with proxy ratings (Logsdon et al., 1999).

1.3.3 Examples of tools used to measure psychological symptoms and quality of life
in persons with dementia

Due to the nature of dementia, PWD can often experience difficulties in decision making,
speech and memory, and this can become more apparent over time which can make it
difficult for PWD to report on their psychological symptoms and QOL (Sheehan, 2012).
Table 4 outlines examples of tools which have been used to measure psychological
symptoms and QOL in PWD.

Table 4: Example of measures used to assess Depression, Anxiety and Quality of life in
PWD (Gibbons, Teri, Logsdon, & McCurry, 2006; Perales, Cosco, Stephan, Haro, &
Brayne, 2013; Sheehan, 2012)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Completed by</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Measures of Depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geriatric Depression Scale (shortened version)</td>
<td>PWD (self-reported)</td>
<td>15 item scale which takes approximately 5 to 10 minutes to complete. Respondents are asked to give a ‘yes’ or ‘no’ response to each question. Validated for use with persons with mild dementia.</td>
</tr>
<tr>
<td>Cornell Scale for depression in dementia</td>
<td>PWD and caregiver</td>
<td>19 item scale which takes approximately 30 minutes to complete. The scale is rated on a 4-point Likert-scale (unable to evaluate, absent, mild or intermittent, severe). Validated for persons with dementia.</td>
</tr>
</tbody>
</table>
### Measures of Anxiety

<table>
<thead>
<tr>
<th>Measure</th>
<th>Assessment Method</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Montgomery Asberg Depression Rating Scale</td>
<td>Trained assessor</td>
<td>10 item scale which takes approximately 15-20 minutes to complete. Responses are collected on a 6-point Likert scale. Suitable for persons with mild dementia.</td>
</tr>
<tr>
<td>Hospital Anxiety and Depression Scale</td>
<td>PWD (self-reported)</td>
<td>14 item scale which takes approximately 3-5 minutes to complete. However, it has little practical use for adults with cognitive impairments.</td>
</tr>
<tr>
<td>Dementia mood assessment scale</td>
<td>Trained assessor</td>
<td>Relies on direct observation of individuals’ behaviour by trained assessors.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Measure</th>
<th>Method</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geriatric Anxiety Inventory</td>
<td>PWD (self-reported)</td>
<td>20 items and respondents are asked to state whether they agree or disagree with the statement. Good psychometric properties for populations of persons with cognitive impairments.</td>
</tr>
<tr>
<td>Rating Anxiety in Dementia (RAID) scale</td>
<td>Staff/caregiver report, PWD interview and clinical notes.</td>
<td>20 item scale, items are rated on a 4-point scale. Good reliability and validity in populations of persons with dementia.</td>
</tr>
</tbody>
</table>

### Dementia specific measures of Quality of life

<table>
<thead>
<tr>
<th>Measure</th>
<th>Assessment Method</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia Quality of Life Measure</td>
<td>PWD or caregiver</td>
<td>PWD (28 items) and proxy (31 items) versions are available. Takes approximately 10-20 minutes to administer. Uses a 4-point scale. Good psychometric properties for use with mild to moderate dementia.</td>
</tr>
<tr>
<td>Alzheimer’s Disease-related Quality of Life measure</td>
<td>PWD or caregiver</td>
<td>PWD and proxy versions are available. 13 item scale which takes approximately 10-15 minutes to administer. Uses a 4-point scale. Suitable for use with PWD.</td>
</tr>
</tbody>
</table>

It is recognised that symptoms of dementia may overlap with psychological symptoms such as anxiety, this combined with changes in memory and language in people with dementia can make it difficult to measure psychological wellbeing in PWD (Kwak, Yang,
& Koo, 2017). However, research has shown that PWD are able to reliably and meaningfully self-report on psychological symptoms and quality of life (Monahan et al, 2014). This provides useful information which enables the valid exploration of the subjective experiences of people with dementia (Trigg, Jones, & Skevington, 2007). The ability to self-report on psychological wellbeing is particularly important as research has shown that proxies consistently rated higher levels of disability than the person with cognitive impairments would rate themselves (Logsdon et al, 1999).

When selecting suitable self-report measures for PWD it is important to select tools which have good rates of reliability and validity, are practical and do not cause upset or exhaustion for the person with dementia (Sheehan, 2012). The Geriatric Depression Scale, Geriatric Anxiety Inventory and Dementia Quality of Life Measure are the only known suitable self-report measures for use with persons with cognitive impairments (Feher, Larrabee, & Crook, 1992; Smith et al., 2007; Rozzini et al., 2009). Furthermore these tools have good psychometric properties, use simple and straightforward language, have a limited number of response options and are fairly brief to administer, thus making them suitable for use in a population of PWD.

1.4 Expressed Emotion

1.4.1 The development of the Expressed Emotion construct

The concept of Expressed Emotion (EE), which is defined as a measure of the family environment, stems from Brown and colleagues’ work in the 1950s (Brown, 1985). Brown and colleagues conducted a series of investigations over a period of twelve years aimed at gaining a better understanding of explanations of relapse in schizophrenia (Vaughn, 1989). They were particularly interested in exploring the relationship between the quality of the patient-significant other (mainly family) relationship and clinical outcomes in psychiatric patients. Their initial study of 229 male patients with schizophrenia who had been
inpatients for two or more years showed an association between relapse and the type of living group they returned to following discharge. Patients were more likely to experience a relapse in their condition when they return to live with a parent or wife in comparison to patients who went to live with a sibling or in non-family residences (Brown, Carstairs, & Topping, 1958).

A follow-up study focusing more specifically on measures of family relationships was designed (Brown, Monck, Carstairs, & Wing, 1962). This study found relapse rates were higher in patients who returned to live with “high emotional involvement” relatives as opposed to other relatives. The relationship between high levels of family emotional involvement and relapse was not explained by differences in clinical condition at discharge. However, numerous questions remained unanswered including the concept of emotional involvement, the direction of effect, and the role of external factors such as pharmacology, frequency and type of relative-patient contact and the occurrence of significant life events (Vaughn, 1989). A further study focusing on the measurement of EE was designed, and this led to the development of the Camberwell Family Interview (CFI); an instrument aimed at eliciting ordinary feelings and emotions expressed within families (Brown & Rutter, 1966).

After a period of refinement, it was found that a small number of key constructs, that could be measured by the CFI, were predictive of relapse. These constructs included criticism, hostility and emotional over-involvement (EOI). Criticism refers to critical comments about the patient’s behaviour or characteristics that the caregiver resents; these are rated from both the content and the tone of the caregiver’s speech. Hostility refers to when the caregiver makes one or more generalised criticisms about the patient, or statements indicating rejection of the patient. EOI refers to behaviours indicative of exaggerated emotional response which are rated together with evidence from speech or behaviour of
over-identification with the patient and over-intrusive or self-sacrificing behaviour (Barrowclough & Hooley, 2003; Hooley & Parker, 2006).

A study conducted by Brown, Birley and Wing (1972a) found a relationship between post-discharge relapse rates in patients with schizophrenia and relatives’ critical comments, hostility and EOI as measured using the CFI. The combination of these key three scales was used to measure EE in caregivers. This study was replicated by Vaughn and Leff (1976) and Vaughn, Snyder, Jones, Freeman, and Falloon (1984). All three studies found patients returning to high-EE families were significantly more likely to relapse during a nine-month follow-up period in comparison to patients returning to low-EE families. The construct of EE has since served as a major focus of research into the influence of family relationships on medical and mental health status (Barrowclough, Tarrier, & Johnston, 1996; Barrowclough, Johnston, & Tarrier, 1994; Scanzufca & Kuipers, 1996; Tarrier et al., 2002; Wagner et al., 1997).

1.4.2 Measuring Expressed Emotion

EE is a construct used to measure some key aspects of interpersonal relationships, through evaluating the way in which a caregiver talks about the patient and their relationship with them. The CFI is regarded as the gold standard for measuring EE for the reasons outlined later in this section (Vaughn & Leff, 1976). This semi-structured interview is generally conducted with the patient’s key caregiver, and aims to gather information about the onset and development of the patient’s disorder, patient symptomatology, frequency of irritability, tension within the household and the quality of the relationship (Vaughn & Leff, 1976). The interview is recorded and then a trained rater will code the interview to produce quantitative measures on the five scales; 1) criticism, 2) hostility, 3) EOI, 4) warmth, and 5) positive remarks (Barrowclough & Hooley, 2003; Hooley & Parker, 2006; Vaughn & Leff, 1976). Criticism, hostility and EOI are the most important for predicting relapse, however, warmth and positive remarks are also measured because the relationship
between the five constructs and the course of illness may well vary across different cultures and for different diagnostic groups (Vaughn & Leff, 1976). Warmth refers to kindness, concern and empathy expressed by the respondent when talking about the patient and a positive comment refers to a statement which demonstrate praise, approval or appreciation of the patients behaviour or personality (Barrowclough & Hooley, 2003; Hooley & Parker, 2006). The scores assigned to critical and positive comments are based on a frequency count of comments made during the CFI, whereas hostility, EOI and warmth are all global scales in which the rater makes an overall judgement after taking into account emotion, comments and attitudes expressed during the entire interview (Hooley & Parker, 2006).

Caregivers are classified as high- or low-EE based on the presence of criticism, hostility or EOI. Positive attributes are rated and may have some predictive role, but are not conventionally involved in classifying EE measured using the CFI (Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000). If the caregiver is above the threshold for criticism, and/or makes hostile remarks, and/or shows evidence of marked EOI they are classified as high-EE (Van Humbeeck, Van Audenhove, De Hert, Pieters, & Storms, 2002). Traditionally, high-EE is defined by 6 or more critical comments; however, there is a lack of consensus about what the criticism threshold should be for high-EE, and this may differ from condition to condition. This is demonstrated by Hooley, Orley and Teasdale (1986) and Vaughn and Leff (1976) who used a threshold of two critical comments, as opposed to the conventional threshold of 6 comments, to identify a correlation between high-EE caregivers and relapse of persons with depression. This suggests that the threshold for the predictive power of critical comments to predict relapse may vary depending on the specific features and symptoms of the condition under consideration.

A number of measures have been developed to assess EE. The CFI is the only measure which provides data on all 5 variables of EE (i.e. criticism, hostility, EOI, warmth and
positive remarks), which is important in gaining a comprehensive understanding of family emotions and interactions. Furthermore, during the CFI the caregiver is given the opportunity to talk about his/her experience of supporting someone with mental and/or medical health difficulties, which is often viewed, by the caregiver to be a helpful and positive experience. This is particularly important in the development of a positive relationship between the caregiver and interviewer, which is crucial for longitudinal research where the researcher and caregiver remain in contact for the purpose of data collection. Furthermore, the information gained during the CFI is often over and above what is required for rating EE, including persons symptoms and behaviours as well as caregiver perceptions, and therefore can be used for other research purposes such as extracting attributions for person’s behaviours. The probes used within the CFI are also flexible enough to adapt to different populations (Hooley & Parker, 2006).

However, the CFI can only be administered by raters who have had formal specialised training, which is costly and difficult to acquire, and the process of administering and coding the CFI is labour intensive and time consuming, typically taking 1-2 hours to administer and 2-4 hours to code (Hooley & Parker, 2006). These factors have led to the development of alternative methods of measuring EE, such as the Five Minute Speech Sample (FMSS) (Magaña et al., 1986). During this interview the caregiver is asked to talk about the patient for five uninterrupted minutes. The rater then codes the interview on the following four dimensions, using a brief rating manual: 1) quality of the preliminary statement (positive, neutral or negative), 2) quality of the relationship (positive, neutral or negative), 3) critical comments (frequency count), and 4) EOI (statements of attitude, emotional display, self-sacrificing or overprotective behaviour, lack of objectivity, excessive detail, positive remarks), and the caregiver is then classified as high- or low-EE. Conventionally, hostility and warmth are not rated, however researchers have since adapted the scale to include warmth in ratings (Van Humbeeck et al., 2002). However, one
problem with the FMSS is that it under identifies high-EE relatives, thus reducing the reliability and predictive validity of the FMSS and therefore this is not an optimum substitute measure of EE (Hooley & Parker, 2006). Furthermore, there are significant discrepancies between the CFI and FMSS, particularly in relation to the EOI dimension (Band, Chadwick, Hickman, Barrowclough, & Wearden, 2016). For example, with the FMSS one way in which the caregiver may be rated as high-EE is if he/she makes five or more positive remarks whereas in the CFI positive remarks are not used in classification of high- or low-EE (Magaña et al., 1986).

Questionnaires, outlined in Table 5, have also been developed as an easier and less time consuming way of measuring EE. The Perceived Criticism Scale (PCS), (Hooley & Teasdale, 1989) is usually completed by patients as a measure of the extent to which they find their relatives critical. As it consists of one or two visual analogue scales, it is quick to obtain, however, it only measures the critical aspect of EE and therefore is not deemed a substitute for the CFI (Hooley & Parker, 2006). The Family Emotional Involvement and Criticism Scale (FEICS), which is another patient administered tool, focuses on the critical and EOI elements of EE. The items contributing to the EOI scale may measure something different from what is identified when the CFI is coded. Although the FEICS enables the concept of EE to be applied to family research in a less time intensive manner, the method is not deemed a substitute for measuring EE with the CFI (Shields, Franks, Harp, McDaniel, & Campbell, 1992). Both the Level of Expressed Emotion Scale (LEES), (Cole & Kazarian, 1988) and the Family Attitude Scale (FAS) (Kavanagh et al., 1997) which measure several aspects of the EE constructs, have been found to correlate well with the CFI, and have predictive validity for patients with psychotic disorders. However, neither measures have been validated for persons with other diagnoses’ such as dementia (Hooley & Parker, 2006). The LEES and FAS can be completed by either the patient (i.e. the patient’s perspective of how his/her caregiver responds) or the caregiver (i.e. the
caregiver’s perspective of his/her own attitudes and responses). These questionnaires differ immensely from the CFI whereby EE spontaneously emerges through natural conversation with a relative because within the questionnaires relatives are asked directly to reflect on their own responses to the patient.

Table 5: Overview of the more widely used questionnaires to measure EE (Hooley & Parker, 2006)

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCS</td>
<td>This represents the key element of EE (criticism) and consists of one question “How critical do you consider your relative to be of you?” Responses are collected on a 10 point Likert-type scale. It takes approximately 1 minute to administer and is rated by the patient.</td>
</tr>
<tr>
<td>FEICS</td>
<td>This consists of 14 items which assess EOI and perceived criticism. It is administered to the patient and takes approximately 10 minutes to complete.</td>
</tr>
<tr>
<td>LEES</td>
<td>A 60 item scale that measures the emotional environment in the patient’s significant relationships. Items cover attitude towards intrusiveness, emotional response, attitude towards illness and tolerance and expectations. It takes approximately 20 minutes to administer and is completed by either the patient or caregiver, thus provides two different responses.</td>
</tr>
<tr>
<td>FAS</td>
<td>This 30 item scale is based on the criticism and hostility elements of EE. It takes approximately 15 minutes to administer and can be completed by either the patient or caregiver, thus again providing two different responses.</td>
</tr>
</tbody>
</table>

1.4.3 Mental health, Physical health and Expressed Emotion

Studies have been consistent in highlighting a relationship between EE and relapse in people with schizophrenia, whereby being in contact with high-EE families correlates with greater relapse rates in patients with schizophrenia (Butzlaff & Hooley, 1998). A similar relationship has been found between EE and relapse in psychiatric disorders other than
schizophrenia. Among patients with bipolar disorder, those who have high-EE caregivers are more likely to relapse than those with low-EE caregivers (Miklowitz, Goldstein, Nuechterlein, Snyder, & Mintz, 1988; Priebe, Wildgrube, & Muller-Oerlinghausen, 1989). Patients with eating disorders (Le Grange, Eisler, Dare, & Hodes, 1992; Szmukler, Eisler, Russell, & Dare, 1985; Van Furth et al., 1996), post-traumatic stress disorder (Tarrier, Sommerfield, & Pilgrim, 1999) and alcohol abuse (Fichter, Glynn, Weyerer, Liberman, & Frick, 1997; O'Farrell, Hooley, Fals-Stewart, & Cutter, 1998) have also been found to have poor outcomes when being cared for by a high-EE caregiver.

The EE construct has also been used to explore the influence that family relationships and psychosocial factors may have on illness outcomes in patients with long term medical conditions. The effects of caregiver EE on the outcomes for patients with physical health conditions are not as marked or well established as in populations with psychiatric illnesses in terms of predicting relapse and the course of the illness outcome. However, patients with high-EE caregivers have been found to have poorer management of their health condition, less adaptive coping behaviours, poorer psychological adjustment, more frequent health attacks, poorer compliance to treatment and/or poorer physical health outcomes than those with low-EE caregivers (Wearden et al., 2000). It is important to note that these studies are much less consistent in showing an association between EE and patient outcomes than those within the mental health literature, which could be because of the natural course of the illness along with numerous other variables.

1.4.4 Persons with dementia and Expressed Emotion

Seven cross-sectional studies investigated associations between caregiver EE and the symptomatology of PWD. Three studies found an association between high-EE caregivers and increased severity of behavioural disturbances (Spruytte, Van Audenhove, Lammertyn, & Storms, 2002; Tarrier et al., 2002), more psychotic disturbances (Tarrier et al., 2002), and greater functional impairment (Vitaliano, Becker, Russo, Magana-Amato, & Maiuro,
In contrast, four studies did not find an association between caregiver EE and level of functioning or behavioural disturbances in persons with a diagnosis of dementia (Bledin, MacCarthy, Kuipers, & Woods, 1990; Gilhooly & Whittick, 1989; Nomura et al., 2005; Wagner et al., 1997). The inconsistent findings with respect to EE and psychotic, behavioural and functional impairments in PWD may be related to caregivers’ understanding of dementia symptoms, the heterogeneous nature of dementia symptoms, and the level of contact caregivers had with the person with dementia. It is important to note that the majority of these studies used caregivers’ reports of PWD symptomatology and behaviour. It might be expected that caregivers’ report of PWD symptoms and behaviour would be more closely aligned with caregiver EE although we do not know this, and in any case, using caregivers’ reports introduces the possibility of common method variance in the associations found.

One longitudinal study, with a sample of 79 dyads, investigated associations between caregiver EE, as measured by the FMSS, and functioning in PWD over a period of 15-18 months (Vitaliano, Young, Russo, Romano, & Magana-Amato, 1993). Vitaliano et al. (1993) found PWD with high-EE caregivers displayed increased negative behaviours over time (i.e. being uncooperative, threatening, physically abusive, angry, ungrateful, paranoid and prone to wander) than those with low-EE caregivers. Negative behaviours were rated by caregivers using the Screen for Caregiver Burden (SCB) (Vitaliano, Russo, Young, Becker, & Maiuro, 1991). Vitaliano et al. (1993) minimised the influence of common method variance by selecting questions free from caregiver affect thus enhancing the reliability of the findings. This was achieved by selecting questions whereby the caregiver merely states the presence or absence of negative behaviour thus removing questions relating to emotion. However, it must be noted that although the authors took steps to guard against common method variance, the measures which were positively related were nevertheless taken from caregivers. Caregiver EE was unrelated to decline in

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cognitive functioning, as measured by mini mental status examination (MMSE; Folstein, Folstein, & McHugh, 1975), and activities of daily living, as measured by the record of independent living (Vitaliano, Breen, Albert, Russo, & Prinz, 1984; Vitaliano et al., 1993). Vitaliano et al’s (1993) study provides evidence to suggest caregiver EE may influence negative behaviour in PWD over time. This is consistent with findings from EE studies in psychiatric populations, as several longitudinal studies have found an association between high-EE caregivers and poorer patient outcomes in comparison to those with low-EE caregivers (Wearden et al., 2000). The effects of caregiver EE on the outcomes for patients with physical health conditions are not as well established. Nonetheless, cross-sectional studies have found patients with physical health conditions with high-EE caregivers have poorer management of their health condition, less adaptive coping behaviours, poorer psychological adjustment, more frequent exacerbations of health conditions, poorer compliance with treatment and poorer physical health outcomes than patients with low-EE caregivers (Wearden et al., 2000).

Our ability to evaluate the predictive value of EE in outcomes of PWD is limited by the lack of longitudinal studies. Furthermore, the single longitudinal study that has explored the influence of caregivers EE on PWD, focused on behaviour and functioning rather than psychological wellbeing of the PWD. Having considered the effects of caregiver EE on PWD, the research suggests that the association between caregiver EE and outcomes in PWD is worth exploring, as there is some evidence to suggest caregiver EE may influence some outcomes. Within this context, the second chapter will explore what is known about the correlates of EE in caregivers of PWD and the potential reverse pathway of PWD influencing caregiver EE.
Chapter 2: Systematic review

2.1 Outlining the paper

The overall aim of this thesis is to examine the impact of caregiver factors on PWD and caregiver outcomes. A review of the literature examining caregiver EE in dementia and the association to caregiver outcomes was conducted. The findings of this systematic review are presented in the following paper, which has been published in Aging & Mental Health; Roxanne Safavi, Katherine Berry & Alison Wearden (2015): Expressed Emotion in relatives of PWD: a systematic review and meta-analysis, Aging & Mental Health. Poster presentations have also been given at the 2016 University of Manchester postgraduate (PGR) conference and the 2016 Aberdeen European health psychology society and British psychological society division of health psychology (EHPS/DHP) conference.

2.2 Paper One: Expressed Emotion in relatives of persons with dementia: a systematic review and meta-analysis
Expressed Emotion in relatives of persons with dementia. A systematic review and meta-analysis.

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2.2.1 Abstract

Objective:
Expressed Emotion (EE) refers to a number of key aspects of interpersonal relationships which have been shown to relate to outcomes in relatives of people with health conditions.

Design:
A systematic review and meta-analysis of EE and outcomes in relatives of persons with dementia is reported. Potential research studies were identified via a search of three electronic databases; PsychINFO, MEDLINE, and the Web of Science between 1960 and 2015.

Results:
We reviewed 12 studies investigating correlations between EE and wellbeing in relatives of patients with dementia. Factors hypothesised to influence EE including attributions, social support, coping strategies and relationship quality were also reviewed.

Conclusions:
High-EE relatives were found to have increased levels of burden ($Z = 6.967, P < 0.001$) and greater levels of depression ($Z = 5.842, P < 0.001$). Compared to low-EE relatives, High-EE relatives were more likely to attribute the patient’s problems to factors that were personal to and controllable by the patient. Relatives with less social support, inefficient coping strategies, and a poor relationship with the patients, were more likely to be classified as high-EE.

Key words:
Expressed Emotion; Dementia; Psychological Wellbeing; Burden.
2.2.2 Introduction

Dementia is characterised as a progressive degenerative disease, which manifests itself in 3 ways; 1) cognitive components of amnesia, aphasia, apraxia and agnosia, 2) non-cognitive components of behavioural disturbances and psychiatric symptoms, and 3) difficulties with activities of daily living (Burns, 2000). There are approximately 800,000 people with dementia living in the UK, and an estimated 670,000 family members and friends acting as primary caregivers (Lakey, Chandaria, Quince, Kane, & Saunders, 2012). Dementia predominantly affects those over the age of 65, however there are more than 17,000 people under the age of 65 suffering with the condition (Crutch & McCulloch, 2012).

The number of people living with dementia worldwide in 2013 is estimated at 44.35 million and is predicted to reach 75.62 million in 2030 and 135.46 million in 2050 (Alzheimer’s Disease International, 2013a, 2013b). There are no curative treatments as yet for the dementias, therefore it is becoming increasingly important to explore and promote wellbeing and quality of life to improve the lives of those affected by the condition now and their relatives (Algar et al., 2014; Alzheimer’s Disease International, 2013a, 2013b).

Dementia can take various forms; 1) Alzheimer’s disease, the most common cause of dementia, caused by a change in the chemistry and structure of the brain resulting in the death of brain cells, 2) vascular dementia caused by a loss of oxygen supply to the brain resulting in the death of brain cells, 3) dementia with Lewy bodies caused by the development of abnormal cells within the nerve cells leading to the degeneration of brain tissue, and 4) fronto-temporal dementia caused by the death of nerve cells in the frontal and/or temporal lobes of the brain. There are many other diseases, such as Parkinson’s disease, which can lead to the development of dementia as the disease itself progresses (Crutch & McCulloch, 2012).
The nature of dementia and its symptomatology place heavy demands on relatives. Unsurprisingly, these demands have been associated with the following emotional, interpersonal and health problems in relatives: lower psychological wellbeing, as measured by social and economic resources, mental and physical health, activities of daily living, burden, strain and distress (Bledin et al., 1990; Shaw et al., 1997; Wagner et al., 1997), poor self-care (Shaw et al., 1999), physical health problems (Haley, 1997; Shaw et al., 1999; Vitaliano, Zhang, & Scanlan, 2003), sleep disturbances (McCurry et al., 2007) and poor patient-relative relationships (Fearon et al., 1998; Morris et al., 1988), in comparison to the general population.

Research has found an association between poor health in relatives of people with dementia and sub-standard care, neglect and/or abuse of the patient (Cooper et al., 2010a; Cooper et al., 2010b). Studies have also found an association between poor health in relatives and increased use of services outside the family/friend support network and increased likelihood of the dementia sufferer entering residential care, both of which present considerable health care costs (Armstrong, 2000).

The construct of Expressed Emotion (EE) has been a major focus of research into the influence of family relationships in a variety of health conditions. EE is a construct representing aspects of interpersonal relationships measured by evaluating the way in which a relative talks about the patient and their relationship with them during the course of a semi-structured interview, the Camberwell Family Interview (CFI). The CFI is conducted with the patient’s key relative, and is regarded as a highly reliable and valid construct for measuring EE (Vaughn & Leff, 1976). It is audio recorded, and then a trained rater codes the interview in accordance with the following five scales; 1) criticism, which refers to comments about the patient’s behaviour or characteristics that the relative is annoyed by, resents or disapproves of, and these are rated from both the content and the tone of the relative’s speech, 2) hostility, which is rated when the relative makes
generalised criticism about the patient, or statements indicating rejection of the patient, 3) emotional over involvement (EOI), which is rated from evidence from speech or behaviour which indicates an exaggerated emotional response, over-identification with the patient, over-intrusive or self-sacrificing behaviour, 4) warmth, and 5) positive remarks (Barrowclough & Hooley, 2003; Hooley & Parker, 2006). Conventionally relatives are classified as high-EE if they make 6 or more critical comments, there is a presence of hostility or there is an EOI score of 3 or more. Relatives who do not meet these cut-off points are classified as low-EE. The CFI is time consuming to administer and rate, therefore shorter ways of assessing EE have been developed. These include the five minute speech sample (FMSS) (Magaña et al., 1986) which is widely used as a screening instrument but has been found to produce false negatives (Hooley & Parker, 2006; Hooley & Richters, 1991) and various questionnaires including the Perceived Criticism Scale (PCS) (Hooley & Teasdale, 1989), the Level of Expressed Emotion (LEES) scale (Cole & Kazarian, 1988) and the Patient Rejection Scale (PRS) (Kreisman, Simmons, & Joy, 1979).

EE has been shown to be a robust predictor of patient outcomes in mental health conditions and some physical health conditions (Butzlaff & Hooley, 1998; Wearden et al., 2000). The correlates, origins and moderators of EE have also been studied. For example, some studies have examined associations between EE and relative outcomes such as psychological wellbeing, burden and distress (Pinquart & Sörensen, 2011; Scazufca & Kuipers, 1996). The origins of EE in relatives’ attributions has been reviewed (Barrowclough & Hooley, 2003) and a third set of studies have investigated factors which may influence the relationship between EE and relatives wellbeing, such as social support, coping strategies and relationship factors (Wearden et al., 2000). Given the high levels of distress in relatives or persons with dementia it is important to identify the predictors of distress. EE may be one predictor however it is important to assess the literature to find out what specific aspects of wellbeing is linked to EE, the quality of the evidence that supports any
associations between EE and wellbeing, the strength of any effects, and to identify which factors are associated with or determine high-EE in the context of caring for someone with dementia.

2.2.2.1 Aims

The focus of the present review will be on the published work on EE in dementia and aims to answer the following questions; (i) What is the rate of High-EE in relatives of persons with dementia? (ii) What is the correlation between relative EE and relative psychological wellbeing? and (iii) What is the correlation between relative EE and relative attributions, social support, coping strategies and relationship quality? A series of meta-analyses will be conducted to explore the relationship between relative EE and wellbeing. The included research studies will also be evaluated and critically appraised in order to identify key questions for future EE research in dementia. The clinical implications from the available evidence will also be explored.

2.2.3 Methods

2.2.3.1 Search Procedure

Potential research studies were identified via a search of three electronic databases; PsycINFO, MEDLINE, and the Web of Science between 1960 and 2015. The terms ‘Dementia’ OR ‘Alzheimer$ Disease’ OR ‘Vascular Dementia’ OR ‘Lewy Body Dementia’ OR ‘Fronto Temporal Dementia’ OR ‘Cognitive Impairment’ AND ‘Expressed Emotion’ OR ‘EE’ OR ‘critical comments’ OR ‘over involvement’ OR ‘hostility’ AND ‘burden’ OR ‘distress’ OR ‘wellbeing’ OR ‘depress*’ OR ‘anxiety’ OR ‘adjustment’ OR ‘stress’ OR ‘quality of life’ OR ‘activities of daily life’ OR ‘behaviour’ OR ‘cognitive impairment’ OR ‘psychiatric symptoms’ OR ‘behavio* disturbances’ OR ‘accept*’ were entered for searching in study abstracts. Duplicates were discarded. The abstracts of articles identified as potentially relevant by title were reviewed. Articles that were
identified as potentially relevant by abstract were obtained and assessed for appropriateness in accordance with the inclusion criteria by the first author in consultation with the other two authors. Reference lists of articles were also searched.

2.2.3.2 Inclusion Criteria

Studies were reviewed to determine whether they met the following inclusion criteria; a sample of patients with dementia and/or relatives of patients with dementia; included a measure of Expressed Emotion; included a measure of at least one relative factor (psychological wellbeing, subjective burden, physical health, quality of life, coping mechanisms, attributions, relationship quality) and written in English. Dissertation abstracts, editorials, review papers and commentaries were excluded. Out of 65 full-text articles assessed for eligibility, a total of 12 met inclusion criteria (Figure 3).
Figure 3: PRISMA flow chart

Records identified through database searching
(N = 3342)

Titles screened
(N = 3342)

Abstracts screened
(N = 213)

Full-text articles assessed for eligibility
(N = 65)

Studies included in narrative synthesis
(N = 12)

Studies included in quantitative synthesis (meta-analysis)
(N = 6)

Records excluded
(N = 3129)

Records excluded, due to absent sample type and/or inadequate measures.
(N = 148)

Full-text articles excluded, due to duplication or inadequate measures.
(N = 53)

Additional records identified through other sources
(N = 1)
2.2.3.3 Quality Assessment

The Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies was selected and adapted to assess the methodological quality of each study (Thomas, Ciliska, Dobbins, & Micucci, 2004). This tool has good content and construct validity (Jackson & Waters, 2005; Thomas et al., 2004) and can be used with satisfactory inter-rater reliability (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012). The tool was adapted to include four domains; (A) selection bias, (B) confounders, (C) blinding and (D) data collection methods. Each domain was rated as either weak (3 points), moderate (2 points) or strong (1 point). The scores were averaged to provide a total score and studies were assigned an overall quality rating of strong (1.00 to 1.50), moderate (1.51 to 2.50) or weak (2.51 to 3.00) (Thomas et al., 2004).

2.2.3.4 Meta-analysis

Six studies were excluded from the meta-analysis as they did not report on the relationship between relative EE and wellbeing. The remaining six studies were included (Bledin et al., 1990; Li & Lewis, 2013; Tarrier et al., 2002; Vitaliano et al., 1988; Vitaliano et al., 1993; Wagner et al., 1997). Four separate meta-analyses were conducted, to determine the associations between; (1) EE and relative depression (4 studies), (2) EE and relative strain (2 studies), (3) EE and relative burden (4 studies), and (4) EE and relative distress (3 studies). All included papers were screened for relevant data which could be used for calculating the value of Cohen's $d$ and the effect size correlation. Effect sizes were calculated by subtracting the average score of low-EE relatives from the average score of high-EE relatives and dividing the result by the pooled standard deviations of the high- and low-EE groups (Field & Gillett, 2010). When the average score of low- and high-EE relatives was not reported then t-values and degrees of freedom were used to calculate the effect size. An effect size of .30 indicates a small effect, while an effect size of .50
indicates a medium effect and an effect size of .80 indicates a large effect (Cohen, 1992; Field & Gillett, 2010). In calculations of effect sizes only those instruments that explicitly measure depression, strain, burden or distress were included. A random effects model was used to account for heterogeneity.

As an indicator of homogeneity, Cochran’s heterogeneity statistic Q was calculated. This statistic is calculated as the weighted sum of squared differences between individual study effects and the pooled effect across studies. It tested whether effect sizes from each of the studies were similar enough that a common population effect size could be calculated (Cochran, 1954). The $I^2$ statistic was also calculated to describe the percentage of variation across studies that is due to heterogeneity rather than chance. A value of 0% indicates no observed heterogeneity, and larger values show increasing heterogeneity (Higgins, Thompson, Deeks, & Altman, 2003)

### 2.2.4 Results

#### 2.2.4.1 Overview of reviewed studies

Table 6 provides an overview of the characteristics of published articles in chronological order.
Table 6: A Summary of the characteristics of the published articles in date order

<table>
<thead>
<tr>
<th>Author and date</th>
<th>Country</th>
<th>Sample (inc p’pant, sample size, diagnoses,)</th>
<th>Relative-patient relationship</th>
<th>Living situation / involvement with the patient</th>
<th>Source of recruitment</th>
<th>Design</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orford, et al (1987).</td>
<td>UK</td>
<td>65 relatives of: 1) younger psychiatric patients, 2) elderly dementia group, 3) functional psychiatric elderly group, 4) physically ill elderly group.</td>
<td>Family relatives</td>
<td>Patients lived with the relative for at least 12 months and the patient and key relative were expected to continue living with each other</td>
<td>New admissions at a psychiatric day hospital and a geriatric day centre.</td>
<td>Cross sectional quantitative design.</td>
</tr>
<tr>
<td>Vitaliano, et al. (1988).</td>
<td>USA</td>
<td>79 dyads (relatives and patients with a DSM diagnosis of dementia).</td>
<td>Spouse</td>
<td>Relatives lived with the patient.</td>
<td>General community.</td>
<td>Cross sectional quantitative design. (First wave of a longitudinal study)</td>
</tr>
<tr>
<td>Gilhooly &amp; Whittick. (1989).</td>
<td>UK</td>
<td>48 relatives of patients with a diagnosis of dementia.</td>
<td>Unknown</td>
<td>24 relatives were co-resident and 24 relatives were non-resident</td>
<td>Two day hospitals.</td>
<td>Cross sectional quantitative design.</td>
</tr>
<tr>
<td>Bledin, et al. (1990).</td>
<td>UK</td>
<td>25 relatives of patients with dementia.</td>
<td>Daughters</td>
<td>Primary relatives</td>
<td>Local authority day centres, community psychiatric nurses, day centres, supporter groups.</td>
<td>Cross sectional quantitative design.</td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Sample Size</td>
<td>Participants</td>
<td>Relationship to Patient</td>
<td>Location Details</td>
<td>Research Design</td>
</tr>
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</tr>
<tr>
<td>Fearon, et al. (1998).</td>
<td>UK</td>
<td>99 relatives of patients with a DSM-III-R diagnosis of dementia.</td>
<td>Spouse, offspring or other relatives.</td>
<td>Relatives lived with the patient or visited them on four or more occasions per week</td>
<td>Old age psychiatry services.</td>
<td>Cross-sectional quantitative.</td>
</tr>
<tr>
<td>Tarrier, et al (2002).</td>
<td>UK</td>
<td>100 patients with a DSM-III-R diagnosis of Alzheimer’s disease and their primary relative.</td>
<td>53 relatives were spouses, 36 were offspring, 11 were another relative.</td>
<td>Lived with the patient or visited on 4 or more occasions per week.</td>
<td>Old age psychiatric services.</td>
<td>Cross-sectional quantitative design.</td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Sample Size</td>
<td>Participants</td>
<td>Setting</td>
<td>Design</td>
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<tr>
<td>Li &amp; Lewis (2013).</td>
<td>Taiwan</td>
<td>65 family caregivers of patients with a diagnosis of dementia.</td>
<td>Spouse, adult children and other family members.</td>
<td>Living with the patient at least three months prior to the time of the study and having direct daily contact with the patient.</td>
<td>Study centre and recruitment sites in Taiwan.</td>
<td>Cross sectional quantitative design.</td>
</tr>
</tbody>
</table>
2.2.4.2 **Quality of studies**

Table 7 provides an overview of the quality ratings of published articles. All 12 studies recruited participants from a clinical setting. However as there was no report of the selection procedure and/or the number of eligible dyads who agreed to participate, the studies were rated as ‘moderate’ in the selection bias domain. Two studies reported on confounding variables and they were given a rating of ‘strong’ on this domain (Vitaliano et al., 1988; Vitaliano et al., 1993). One study reported on confounding variables, however did not specify whether they had been controlled in the design or analysis and was therefore given a rating of ‘moderate’ (Li & Lewis, 2013). The remaining studies were rated as ‘weak’. Seven studies were rated as ‘strong’ on the blinding domain as the ratings of EE were carried out blind to the outcome measures of the care recipient and their spouse (Bledin et al., 1990; Fearon et al., 1998; Nomura et al., 2005; Tarrier et al., 2002; Vitaliano et al., 1988; Vitaliano et al., 1993; Wagner et al., 1993). The remaining five studies were rated as ‘moderate’ as they did not report on blinding (Cooney, Howard, & Lawlor, 2006; Gilhooly & Whittick, 1989; Li & Lewis, 2013; Orford, O'Reilly, & Goonatilleke, 1987; Spruytte, Van Audenhove, Lammertyn, & Storms, 2002).

Six studies used the CFI to measure relatives’ EE (Bledin et al., 1990; Fearon et al., 1998; Gilhooly & Whittick, 1989; Nomura et al., 2005; Orford et al, 1987; Tarrier et al., 2002) and as this is a valid and reliable measure they were rated as ‘strong’ on the data collection methods domain. Three studies using the FMSS were rated as ‘moderate’, as although the FMSS is an established EE measure it has been found to produce false negatives (Vitaliano et al., 1988; Vitaliano et al., 1993; Wagner et al., 1997). The remaining three studies used the PRS, LEES and PCS which are valid and established EE measures; however as these measures are not deemed as substitutes for the CFI, the studies were rated as ‘moderate’ (Cooney et al., 2006; Li & Lewis, 2013; Spruytte et al., 2002). All 12 studies used valid and reliable measures for relative outcome measures.
Table 7: Quality Ratings for the Four Domains of the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies and the Overall Quality Rating

<table>
<thead>
<tr>
<th>Study</th>
<th>(A) selection bias</th>
<th>(B) confounders</th>
<th>(C) blinding</th>
<th>(D) data collection methods for relatives</th>
<th>Overall rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vitaliano, et al. (1988).</td>
<td>M</td>
<td>S</td>
<td>S</td>
<td>M</td>
<td>(1.5) S</td>
</tr>
<tr>
<td>Bledin, et al. (1990).</td>
<td>S</td>
<td>W (NR)</td>
<td>S</td>
<td>S</td>
<td>(1.5) S</td>
</tr>
<tr>
<td>Vitaliano, et al. (1993).</td>
<td>M</td>
<td>S</td>
<td>S</td>
<td>M</td>
<td>(1.5) S</td>
</tr>
<tr>
<td>Tarrier, et al. (2002).</td>
<td>S</td>
<td>W (NR)</td>
<td>S</td>
<td>S</td>
<td>(1.5) S</td>
</tr>
<tr>
<td>Li &amp; Lewis. (2013)</td>
<td>S</td>
<td>M</td>
<td>M</td>
<td>M</td>
<td>(1.75) M</td>
</tr>
</tbody>
</table>

Each domain was rated as either weak (W) (3 points), moderate (M) (2 points) or strong (S) (1 point). Where the domain was not reported (NR) a rating of weak (W) was given. The scores were averaged to provide a total score and studies were assigned an overall quality rating of strong (S) (1.00 to 1.50), moderate (M) (1.51 to 2.50) or weak (W) (2.51 to 3.00).
2.2.4.3 Main findings

Table 8 provides an overview of the results of the published articles and summarises the key findings from the reviewed studies.

2.2.4.3.1 Rates of EE in relatives

The presence of high-EE ranged from 17% (Orford et al., 1987) to 44% (Bledin et al., 1990) across studies; these differences are possibly associated with the different threshold used for classifying relatives as high- or low-EE, different patient samples, the use of different measures and different primary relatives.

2.2.4.3.2 Relative EE and relative demographics

Three studies examined the relationship between gender and EE. One study found females were more critical than males (Gilhooly & Whittick, 1989), whereas the other two studies found no association between relatives’ gender and EE (Li & Lewis, 2013; Wagner et al., 1997). Wagner et al (1997) found no correlation between relative EE and age or years of education. Similarly Li and Lewis (2013) did not find a correlation between relative EE and age, however they did find a correlation between relative EE and relative education and household income. Taken together, these findings suggest that demographic factors may play a limited role in determining EE status.

2.2.4.3.3 Relative EE and relative wellbeing

Five studies found a relationship between high-EE and greater levels of depression (Gilhooly & Whittick, 1989; Li & Lewis, 2013; Vitaliano et al., 1988; Vitaliano et al., 1993; Wagner et al., 1997). The studies used a variety of measures including the Beck Depression Inventory (BDI) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961; Vitaliano et al., 1988; Vitaliano et al., 1993), the Center for Epidemiological Studies Depression Scale (CES-D) (Li & Lewis, 2013; Radloff, 1977; Wagner et al., 1997), and the Older Americans Resources and Services Multidimensional Functional Assessment
Questionnaire’s mental health scale (OMFAQ) (Duke University Older Americans Resources and Services, 1978; Gilhooly & Whittick, 1989). These measures have been found to be valid and reliable in assessing psychological wellbeing in older adults (Gallagher, Nies, & Thompson, 1982; Radloff & Teri, 1986). A variety of samples were used including those in earlier stages of dementia where there is likely to be uncertainty about the diagnosis, thus enhancing the generalizability of the findings. Vitaliano et al (1988; 1993) excluded patients with severe cognitive impairment as defined by a score of 9 or less on the MMSE (Folstein, Folstein, & McHugh, 1975); they felt that relative distress would be difficult to interpret because relatives would be responding to the different stages and severity of dementia. This is the only study that measures patients’ functioning with a view to try to obtain a homogenous relative-patient sample with respect to severity of cognitive difficulties.

Four studies found a relationship between high-EE and high levels of burden (Li & Lewis, 2013; Nomura et al., 2005; Vitaliano et al., 1988; Wagner et al., 1997). The subjective measures of burden used were the well-established Burden Inventory (BI) (Zarit, Reever, & Bach-Peterson, 1980) and the Alzheimer Spouse Burden Scale (ASBS) (Vitaliano, Maiuro, Ochs, & Russo, 1989). The known good psychometric properties of these measures enhance the reliability and validity of the findings. More recently, Nomura et al (2005) conducted a cross-cultural study to explore the relationship between EE and the burden of care, as identified by the BI, BDI and General Health Questionnaire (GHQ) (Goldberg, 1972), of two disorders; dementia and schizophrenia. They collected data from 80 patient-relative dyads that were suffering from either dementia or schizophrenia and were residing in either England or Japan. These findings differ from the other studies as EE status was only significantly correlated with relative burden in the Japanese-dementia sample; criticism was significantly associated with relative burden for the Japanese-dementia sample but not for the English-dementia sample, the English-schizophrenia
sample or the Japanese-schizophrenia sample. However, it is important to note that the English-dementia sample was drawn from a larger sample which may have led to anomalies happening by chance and the loss of some significance.

In a recent study, Li and Lewis (2013) interviewed 65 primary family relatives of persons with dementia living in Taiwan and found a significant correlation between relative EE, as measured by the LEES, and relative burden, as measured by the BI. Cultural variation have been found to affect the degree and type of relative EE (Bhugra & McKenzie, 2003), however these findings along with Nomura et al (2005) suggests cultural variation may have a limited role in relative EE and burden.

Two studies used the GHQ, the Relative Stress Scale (RSS) (Greene, Smith, Gardiner, & Timbury, 1982), the Behaviour and Mood Disturbance Stress Scale (BMD-Stress) (Bledin et al., 1990), the Gilleard Strain Scale (GSS) (Gilleard, 1985) and the Bimodal Scale (BS), to explore relatives strain and distress (Bledin et al., 1990; Tarrier et al., 2002). Both studies found high-EE relatives, as identified through the CFI, reported significantly higher levels of strain and distress than low-EE relatives (Bledin et al., 1990; Tarrier et al., 2002). It could be argued that different relative-patient relationships should not be combined in EE studies as pre-existing relationships will be different and therefore losses and frustrations experienced are likely to differ.

One study explored the potential consequences of burden and wellbeing by examining the prevalence of abuse of persons with dementia by their relative and how this correlated with relative factors, patient factors and the relative-patient relationship (Cooney et al., 2006). Based on a sample of 82 relatives, the authors found an association between EE status, as assessed by the PRS, and level of verbal, physical and neglectful abuse, whereby abusers as a group scored significantly higher on the PRS than non-abusers. Furthermore, relatives who disclosed abuse had significantly higher ratings of psychological distress, as rated
through the GHQ and BSI, thus providing some support for the correlation between EE status and psychological wellbeing. However this study focused on the relationship between EE and abuse, and did not examine the direct relationship between EE and relative wellbeing.

2.2.4.3.4 Findings from meta-analysis

A series of meta-analyses were conducted to determine the pooled effect size for relationships between EE and relatives’ wellbeing using variables which had been reported by multiple studies (Table 9). There were statistically significant relationships between relative EE and depression (0.404, 95% CI 0.277, 0.517, Z = 5.842, p < 0.001), burden (0.448, 95% CI 0.333, 0.549, Z = 6.967, p < 0.001), strain (0.422, 95% CI 0.264, 0.558, Z = 4.905, p < 0.001), and distress (0.316, 95% CI 0.167, 0.450, Z = 4.042, p < 0.001), with high-EE relatives reporting higher levels of each outcome than low-EE relatives.
<table>
<thead>
<tr>
<th>Authors &amp; date</th>
<th>Measures</th>
<th>Key results</th>
</tr>
</thead>
</table>
<em>Relative EE/Attributions:</em> CFI.  
Cut-off points: 2 or more critical comments, a presence of hostility and/or EOI score of 3 or more.  
<em>Relative measures:</em> FIQ.  | Only 17% of dementia relatives had high-EE. Relatives of dementia patients were described as more dominant, more protective, and less submissive towards the patient than relatives of psychiatric or physically ill patients. Relatives of persons with dementia were also found to give and receive more hostile-dominance, and giving and receiving less affection. They were also found to give more hostile-dominance than they received. Relative burden and distress was not explored. Family interactions, as identified in the FIQ, were not found to influence relative EE. (Family interactions refer to the following: ignore-rebel, dominance, submission, hostile-dominance, affection, and protection). |
<em>Relative EE/Attributions:</em> FMSS.  
<em>Relative measures:</em> BDI, ASBS, AES, WCCL.  | 22% spouses were classified as high-EE and 78% spouses were classified as low-EE. Spouses with high-EE reported more depression, burden, anger held in, and less anger control than spouses with low-EE. The high-EE group reported using more avoidance, blame of others and less counting ones blessings. |
<em>Relative EE/Attributions:</em> CFI.  
Cut-off points not reported.  
<em>Relative measures:</em> OMFAQ, PICS.  | Female relatives were more critical than male relatives. There was a significant correlation between amount of contact with friends and relative EE; relatives with more contact with friends made less critical comments. Also there was no association between amount of help from services and presence of relative EE. The presence of EE in relatives of persons with dementia was high. Psychological wellbeing was significantly correlated with EE; the greater the number of critical comments, the lower the relatives morale and the poorer the ratings of mental health. Quality of past relationship significantly correlated with critical comments; relatives with good relationships with the patient with dementia were less critical of the patient with dementia. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Authors</th>
<th>Relative EE/Attributions</th>
<th>Cut-off points</th>
<th>Relative measures</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Bledin, et al. (1990)</td>
<td>Relative EE/Attributions: CFI</td>
<td>4 or more critical comments, and/or a presence of hostility</td>
<td>RSS, GHQ, BMD-Stress</td>
<td>Relatives with more efficient coping strategies made fewer critical comments and more positive remarks. High-EE relatives had no living siblings, and were more likely to have had a respite break from caring. 44% of relatives of persons with dementia were rated as low-EE and 56% of relatives were rated as high-EE. High-EE relatives reported greater strain and distress.</td>
</tr>
<tr>
<td>5</td>
<td>Vitaliano, et al. (1993)</td>
<td>Relative EE/Attributions: FMSS</td>
<td></td>
<td>BDI, SLS</td>
<td>At baseline, 62 relatives were classified as low-EE and 15 relatives were classified as high-EE. 15 to 18 months later 63 relatives EE remained stable, however 10 low-EE relatives were re-classified as high-critical/over involvement, and 4 high-EE relatives were re-classified as low-EE. Both at baseline and follow up, high-EE relatives were significantly more depressed, had lower life satisfaction and reported more suppressed anger. However there was no correlation between EE and expressed anger.</td>
</tr>
<tr>
<td>6</td>
<td>Wagner, et al. (1997)</td>
<td>Relative EE/Attributions: FMSS</td>
<td></td>
<td>BI, CES-D, SADS</td>
<td>There was no relationship found between relative EE and relative demographics e.g. age, years of education, or gender. 40% of relatives were high in EE, 60% were low in EE. High-EE relatives were significantly more likely to be clinically depressed and have higher levels of burden than low-EE relatives. There was no relationship found between relative EE and their relationship to the patient.</td>
</tr>
<tr>
<td>7</td>
<td>Fearon, et al. (1998)</td>
<td>Relative EE/Attributions: CFI</td>
<td>6 or more critical comments, a presence of hostility and/or EOI score of 4+</td>
<td>IQ</td>
<td>65 relatives were classified as low-EE and 34 were classified as high-EE. Relative burden and distress was not explored. The level of intimacy (both past and current) between the relative and person with dementia is significantly related to relative EE; low intimacy was associated with high-EE.</td>
</tr>
</tbody>
</table>
Of the 100 relatives, 41 were rated as high-EE. High-EE relatives were significantly more likely to report higher levels of strain and distress in comparison to those with low-EE. High-EE relatives made significantly more attributions for patient problems that were personal to, and controllable by, the patient than relatives with low-EE.

Family relatives who made more ‘internal’ attributions, perceiving the problem behaviour as ‘under the control’ of the patient, and the patient has a higher functional level, the relative tends to be more critical of the patient. Relatives who were partners to persons with dementia expressed less warmth and more conflict and criticism than relatives who were children or children in law.

There was a difference between the frequency of criticism in the Japanese and English Samples; English samples had greater numbers of critical comments than Japanese samples. In the Japanese dementia sample, criticism was significantly associated with relative burden.

EE was found to be present in relatives of persons with dementia. Abusers, as a group, had significantly higher ratings of psychological distress. High-EE in relatives was highly correlated with all types of abuse. 52% relatives admitted to having carried out some form of abuse; 51% admitted to verbal abuse, 20% admitted to physical abuse and 4% admitted to neglect abuse.

High-EE relatives had significantly greater levels of depression and burden than low-EE relatives. High-EE relatives also had significantly lower levels of perceived health than low-EE relatives. EE was also negatively associated with relative education and income, whereby high-EE relatives had lower income and lower levels of education than low-EE relatives.

Note: Activities of daily living scale (ADL), Alcohol screening questionnaire (CAGE), Alzheimer’s spouse burden scale (ASBS), Anger expression scale (AES), Attribution questionnaire (AQ), Behavior and mood disturbance-stress scale (BMD-Stress), Beck depression inventory (BDI), Beck hopelessness scale (BHS), Beck self-report depression.
scale (BDS), Behaviour rating scale (BRS), Bimodal scale (BS), Blood pressure (BP), Brief symptom inventory (BSI), Burden inventory (BI), Burden interview (BIN), Clinical dementia rating (CDR), Cornell scale for depression in dementia (CSDD), Camberwell family interview (CFI), Center for epidemiological studies depression scale (CES-D), Clifton assessment procedures for the elderly (CAPE), Clinical sensorium (CS), Cognitive assessment scale (CAS), Conflicts tactics scales (CTS), Depression scale of the symptom checklist-90 (SCI-90), Disability assessment for dementia (DAD), Emotional expressivity scale (EES), Family interaction questionnaire (FIQ), Five minute speech sample (FMSS), General health questionnaire (GHQ), Global deterioration scale (GDS), General health questionnaire-30 (GHQ-30), Gilleard strain scale (GSS), Hamilton depression rating scale (HDRS), Hopkins symptoms checklist (HSC), Hypothalamic pituitary adrenal (HPA) axis, Intimacy questionnaire (IQ), Instrumental activities of daily living (IADL), Manchester and Oxford University for psychopathological assessment in dementia (MOUSEPAD), Marlowe-Crowne social desirability scale (MCSDS), Mechlin activity scale (MAS), Modified Crichton royal behavioural rating scale (CRBRS), Mini mental state exam (MMSE), Negative care recipient desirability scale (NCRB), Neuropsychiatric inventory (NPI), Older Americans resources and services multi functional assessment questionnaire (OMFAQ), Older person’s pleasant events schedule (OPPES), Older persons unpleasant events schedule (OPUES), Older person’s attribution style questionnaire (OPASQ), Patient rejection scale (PRS), Perceived criticism scale (PCS), Physical self-maintenance scales (PSMS), Preference for institutional care scale (PICS), Quality of relative-patient relationships (QCPR), Relative’s attributional scale for problem behaviour (CASPBR), Record of independent living (RIL), Revised memory and behaviour problem checklist (RMBPC), Record of independent living (RIL), Relationship quality (RQ), Relative resentment scale (CRS), Relative stress scale (RSS), Research diagnostic criteria (RDC), Satisfaction with life scale (SLS), Schedule for affective disorders and schizophrenia interview (SADS), Social interaction scale (SIS), Steinmetz control scale (SCS), Ways of coping checklist (WCCL), Level of Expressed Emotion (LEES), Medical Outcomes Study Short Form 36 (MOS SF-36).
### Table 9: Summary of findings from the studies included within the hedges-vevea random effects meta-analysis

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number of Studies</th>
<th>Total pooled sample size</th>
<th>Heterogeneity Q Statistic</th>
<th>Pooled effect size</th>
<th>Overall effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>EE and Depression</td>
<td>4</td>
<td>278</td>
<td>X²(3) = 3.11, P = 0.375</td>
<td>0.404 (95% CI 0.277, 0.517)</td>
<td>Z = 5.842, p &lt; 0.001</td>
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<tr>
<td></td>
<td>Vitaliano et al (1993)</td>
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<td></td>
<td>Wagner et al (1997)</td>
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<tr>
<td></td>
<td>Li &amp; Lewis (2013)</td>
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<tr>
<td>EE and Strain</td>
<td>2</td>
<td>125</td>
<td>X²(1) = 0.704, P = 0.401</td>
<td>0.422 (95% CI 0.264, 0.558)</td>
<td>Z = 4.905, p &lt; 0.001</td>
</tr>
<tr>
<td></td>
<td>Bledin et al (1990)</td>
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<td></td>
<td>Tarrier et al (2002)</td>
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<tr>
<td>EE and Burden</td>
<td>4</td>
<td>221</td>
<td>X²(3) = 2.286, P = 0.515</td>
<td>0.448 (95% CI 0.333, 0.549)</td>
<td>Z = 6.967, p &lt; 0.001</td>
</tr>
<tr>
<td></td>
<td>Wagner et al (1997)</td>
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<tr>
<td></td>
<td>Li &amp; Lewis (2013)</td>
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<td></td>
<td>Nomura et al (2005)</td>
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<tr>
<td></td>
<td>Japanese sample</td>
<td></td>
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<tr>
<td>EE and Distress</td>
<td>3</td>
<td>165</td>
<td>X²(3) = 1.375, P = 0.711</td>
<td>0.316 (95% CI 0.167, 0.450)</td>
<td>Z = 4.042, p &lt; 0.001</td>
</tr>
<tr>
<td></td>
<td>Bledin et al (1990)</td>
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<td>Japanese sample</td>
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<td>Nomura et al (2005)</td>
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<td>English sample</td>
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</table>
2.2.4.4 Relative EE and relative factors

2.2.4.4.1 Causal attributions

Relative EE has been found to reflect their underlying beliefs about a patient’s symptoms and behaviour, and therefore may play a role in patient outcomes (Barrowclough & Hooley, 2003). High-EE has been found to reflect relatives’ beliefs that patients, with a broad range of mental and physical health problems, have the potential to control aspects of their illness and behaviour (Hooley, 1985, 1987). Tarrier et al (2002) and Spruytte et al (2002) found high-EE relatives, as rated by the CFI and PCS respectively, made significantly more causal attributions for patient problems to factors that were personal to, and controllable by, the patient than low-EE relatives. These findings are based on two cross-sectional studies with relatively large samples of 100 (Tarrier et al., 2002) and 144 (Spruytte et al., 2002) which include a range of types of patient-relative relationships, including spouses and children. However, one study used the same source (the CFI) for eliciting relative EE and attribution and therefore the possibility of confounding must be acknowledged (Tarrier et al., 2002).

2.2.4.4.2 Coping mechanisms

One study explored the correlation between coping strategies and EE (Bledin et al., 1990). Relatives who used more problem solving, distraction and wishful thinking strategies, as measured by MacCarthy and Brown’s (1989) measure of coping strategies, were found to make more positive comments and fewer critical remarks, as measured by the CFI. These findings are based on a small sample of 25 (Bledin et al., 1990), comprising daughter-patient dyads, therefore caution must be taken when generalising to other patient-relative relationships.
2.2.4.4.3 Support

Two studies found a correlation between social support and relatives’ EE, whereby relatives who had less contact with friends or no living siblings were more likely to be classified as high-EE, as measured by the CFI (Bledin et al., 1990; Gilhooly & Whittick, 1989). Both studies were given an overall quality rating of moderate due to the use of blinding and the CFI, therefore giving some strength to the reliability of the findings. Relatives who have less available social support or are less likely to seek social support may have a reduced opportunity for emotional and practical support which may contribute to high-EE. Gilhooly and Whittick (1989) found no correlation between relative EE and professional support as measured by home help and community nurse involvement, whereas Bledin et al (1990) found relatives who had regular respite were more likely to be rated as low-EE. Intensive professional input whereby the patient and relative spent periods of time apart may be more helpful in reducing EE in comparison to professional visits alongside care provided by relatives.

2.2.4.4.4 Relationship quality

Five studies examined the association between relative EE and the quality of relative-patient relationships (Fearon et al., 1998; Gilhooly & Whittick, 1989; Orford et al., 1987; Spruytte et al., 2002; Wagner et al., 1997). Three studies, all given an overall quality rating of moderate, were consistent in finding that high-EE was more likely where the relationship was deemed less satisfactory, either currently or in the past (Fearon et al., 1998; Gilhooly & Whittick, 1989; Spruytte et al., 2002). Relatives who had poor relationships with the patient, as measured on a five-point scale, (Gilhooly & Whittick, 1989) and low levels of intimacy with the patient, as measured by an intimacy questionnaire (IQ) (Fearon et al., 1998; Morris et al., 1988) were more critical and significantly more likely to be high-EE. Furthermore, partners of the patient expressed less
warmth and more conflict and criticism than children and/or children-in-law (Spruytte et al., 2002). These findings are based on a variety of relative-patient relationships including children and other relatives.

In contrast, Wagner et al. (1997) and Orford et al. (1987), both of whom primarily explored spouse-patient relationships, found no significant association between relative EE and the patient-relative relationship or family interactions, as identified in the Family Interaction Questionnaire (FIQ). The studies included a variety of relative-patient relationships and therefore quality of relationship and levels of intimacy are likely to differ. There is some suggestion of a greater association between high-EE and less satisfactory relationships in non-spouse-patient relationships. This may be explained by the responsibilities other relatives (children, children in law and siblings) may have in addition to caring for the patient such as employment and family.

2.2.5 Discussion

The studies were consistent in identifying a presence of high-EE in relatives of persons with dementia. However in most studies the majority of relatives were classified as low-EE and the presence of high-EE was primarily based on the critical attitude rather than high-EOI. On the whole, rates of high-EE among relatives of persons with dementia were lower than relatives of patients with psychiatric disorders (Wearden et al., 2000). For example, a recent study on relatives of patients with schizophrenia rated 39% of relatives as high-EE (Carrà, Cazzullo, & Clerici, 2012) and in a study on relatives of post-traumatic stress disorder (PTSD) patients rated 51% as high-EE (Tarrier et al., 1999). A study of relatives of patients with type 1 diabetes rated 17% as high-EE based on the conventional classification criteria, this suggests that relatives of medical health conditions also exhibit lower rates of criticism and EOI than psychiatric disorders. The different rates of high-EE in medical and psychiatric disorders may be related to the diverse natural courses of these
disorders. It has also been suggested that relatives may be more likely to be critical in illnesses where there are periods of wellness, as opposed to illnesses where there is a continual deterioration in illness course (Wearden et al., 2000).

The studies are consistent in suggesting high-EE relatives experience higher levels of burden and poorer psychological wellbeing. These findings replicate EE research in psychiatric and medical health populations, whereby relative EE has been found to positively associate with relative burden and wellbeing (Wearden et al., 2000). However, the studies are all cross-sectional and therefore the associations found within these studies tell us little about whether high-EE leads to high levels of burden and poor psychological wellbeing, whether high levels of burden and poor psychological wellbeing lead to high-EE, or whether a common third factor accounts for the association. Most probably there is a bidirectional, dynamic relationship between high-EE and poorer psychological wellbeing. The majority of these findings are based in the USA or UK, and therefore may not generalise to different cultural groups. However two recent studies suggest high-EE relatives from non-Western countries also experience higher levels of burden and depression than low-EE relatives. It is also worth noting that the majority of the studies were conducted over 10 years ago and therefore are not necessarily generalisable to today’s population, as there are likely to be changes in peoples’ understanding of dementia and the provision of professional support.

The findings from two studies that found a relationship between high-EE and causal attributions for patient problems that were personal to, and controllable by, the patient, support research investigating the relationship between causal attributional beliefs and EE in relatives of other conditions such as psychosis (Spruytte et al., 2002; Tarrier et al 2002). These studies have shown that high-EE is related to certain attributional styles, namely attributing patient problems to factors internal to and potentially controllable by the patient (Barrowclough & Hooley, 2003).
Studies have also found relative coping mechanisms and social support are associated with EE, whereby more efficient coping strategies and increased social support correlates with low-EE. Similar patterns between EE and coping mechanisms have been found in relatives of persons with psychosis, whereby relatives’ critical comments were significantly correlated with avoidant coping strategies (Kavanagh, 1992; Kuipers et al., 2006). However, the direction of effect is unknown, high-EE relatives may have received less support resulting in them feeling more stressed or alternatively low-EE relatives may have coped better and sought regular respite, whereas high-EE relatives may have persevered. No correlation was found between EE and home help or community nurse involvement, however relatives who had regular respite were more likely to be rated as low-EE. This suggests patients and relatives having an opportunity for time apart may be more helpful in reducing EE than professional visits alongside care provided by relatives.

The findings from five studies exploring the correlation between relationship factors and EE are inconsistent. Three studies found high-EE is associated with a poor past and current relationship, and the remaining two studies did not find a significant association between relative EE and the relative-patient relationship. These discrepant findings may be explained by the inclusion of different patient-relative dyads (spouse, siblings, children) and/or measuring different aspects of the relationships (prior relationship, current relationship or level of intimacy). Spouse caregivers are likely to have a closer relationship with the patient than siblings or adult children. They are also more likely to live with the patient and therefore provide more hours of support with less respite, and are more likely to have health concerns due to age (Pinquart & Sörensen, 2011). In light of this we may expect more spouse caregivers to be high-EE than other relative caregivers.

The research suggests that the correlations between attributions, coping mechanisms, support, relationship factors, and relative EE, are worth exploring further as they are likely to highlight factors that influence or maintain relatives’ EE. Our ability to evaluate the
predictive value of EE in relative outcomes is limited by the lack of longitudinal studies as we are unable to draw conclusions about causality. Nevertheless the research suggests that the association between EE and relative outcomes is worth exploring, as there is some evidence to suggest relative EE may influence or be influenced by relative factors.

2.2.6 Limitations of the review

The findings of this review need to be interpreted in conjunction with the methodological limitations of the included studies. A fear of disclosure of critical comments, hostility or EOI may have influenced relatives’ responses and potentially bias the associations between EE and influencing factors. Database searches covered all countries, however the majority of the included studies were in the USA or UK and there is a lack of ethnic diversity therefore increasing the possibility of cultural bias. This may have implications on generalisability of the data to areas other than the USA and UK. Three electronic databases were utilised, along with follow up from reference lists, to ensure all relevant studies were identified and included within the review. However, unpublished data was not included and therefore there is a potential that studies were missed. Only the first author was involved in the identification of studies which introduces the possibility of bias into decisions on study inclusion. The first author was also responsible for extracting data, therefore there was no independent reliability check. However any queries that arose during the data extraction process were discussed with the second and third author. The quality appraisal tool, the EPHPP, was adapted for the purpose of the review however the adaptation had not undergone any validation.

2.2.7 Implications for future research and practice

Longitudinal studies investigating associations between attributions, coping mechanisms, relationship quality and EE would enable researchers to identify factors that have a positive influence on relative EE and psychological wellbeing. This information would aid
the development of interventions aimed at modifying causal attributions, improving coping strategies and improving the patient-relative relationship quality. In doing so this would enhance wellbeing and quality of life to improve the lives of those affected by the condition now. Longitudinal studies into the association between relative EE and relative psychological wellbeing would be necessary to explore whether high-EE causes poor psychological wellbeing or whether poor psychological wellbeing causes high-EE. This insight would be crucial for promoting wellbeing and quality of life of those affected by dementia, through the development of intervention aimed at improving interpersonal relationships or relatives’ psychological wellbeing. Research exploring adjustment in relatives of patients with dementia would give insight into factors that enhance adjustment, and therefore be crucial to supporting those who are new to the care giving role. Dementia is a progressive degenerative disease, research exploring EE and wellbeing of caregivers throughout the course of dementia, taking into account the form of dementia, illness severity and patient-relative relationships would enable the development of interventions which enhance factors found to be influential in promoting relative wellbeing throughout their care giving role.

2.2.8 Conclusions

The number of people affected by dementia is rapidly increasing and as there are no curative treatments as yet for the dementias, it is becoming increasingly important to understand and promote wellbeing and quality of life to improve the lives of those who are affected by the condition now (Alzheimer’s Disease International, 2013a, 2013b). This review has presented findings from the literature on EE and dementia, in order to answer the following questions: (i) What is the correlation between relative EE and relative psychological wellbeing? and (ii) What is the correlation between relative EE and relative attributions, social support, coping mechanisms and relationship quality? High-EE relatives report increased levels of burden, greater levels of depression and make more
causal attributions for patient problems that are personal to and controllable by the patient than low-EE relatives. Furthermore, relatives with less social support, inefficient coping strategies, and a poor relationship with the patient, are likely to be classified as high-EE.

As noted earlier, studies investigating the correlation between relative EE and relative factors have been cross-sectional and therefore show little about causality. In light of this, future longitudinal research to explore the influence relative EE has on relative outcomes would help in exploring and promoting factors to improve the lives of patients and relatives affected by dementia.
2.2.9 References


Chapter 3: Aims of the research and organisation of the thesis

3.1 The Research Questions

There is a growing emphasis on the early detection and diagnosis of dementia, in order to ensure PWD and caregivers access the necessary support and gain help in coming to terms with the diagnosis and prognosis (Robinson, Clare & Evans, 2005). However, failings of a divided health and social care system and the lack of appropriate dementia services within the UK (Corbett et al., 2012), mean early detection often does not happen. There is frequently a delay in persons receiving a formal diagnosis of dementia meaning that PWD and their relatives are not eligible to access dementia care services. Caregivers, who often feel under a great deal of strain, also find it particularly challenging, time-consuming, unpredictable and stressful trying to access appropriate services (Corbett et al., 2012). These factors mean informal caregivers are often left with the sole responsibility of caring for their relative with dementia (Knapp et al., 2007).

The systematic review (Paper 1), documented in Chapter 2, consistently found a relationship between caregiver EE and caregiver outcomes including burden and psychological wellbeing. However, the studies investigating caregiver EE and outcomes have been cross sectional and therefore shows little about causality. Furthermore, there is a scarcity of evidence examining the association between EE and wellbeing outcomes in dementia despite the associations between EE and patient outcomes in other mental and physical health conditions (Wearden et al., 2000).

The literature outlined in the previous chapters, along with the limited provision of appropriate dementia services, increased pressure on caregivers and findings of the systematic review, provides the rationale for examining caregiver factors in association with outcomes in both caregivers and PWD. The findings from the literature have highlighted that the relationship between EE, caregiver factors and PWD outcomes is worth exploring as there is evidence to suggest caregiver EE may influence or be influenced by caregivers and PWD factors.
Despite the importance of early detection, there has been little research into caregiver EE in families of persons with a recent diagnosis of dementia. Furthermore, several methodological limitations with the current literature have been highlighted, including predominance of cross sectional research within the field of EE and dementia, and therefore there is little insight into the direction or nature of causal effects. One longitudinal study has explored the influence caregiver EE has on outcomes in PWD, however, the study focused on behaviour and functioning rather than psychological wellbeing. Therefore, the longitudinal studies and mediation study which are reported in the following chapters of this thesis aim to investigate the association between caregiver EE and psychological outcomes in both caregivers and PWD.

Despite the development of less labour-intensive measures of EE, as outlined in Chapter 1, section 1.4.2, many commentators deem that there is no satisfactory substitute for the CFI, so the CFI continues to be the most well regarded measure. In this context, the CFI was selected as a measure of EE to address the research questions. Using the CFI aimed to enhance the reliability and validity of the findings, as well as reducing the methodological issues of the alternative briefer methods of measuring EE. The use of the CFI also enabled the tailoring of questions to ask about symptoms relevant to PWD, and gave the opportunity to gather data across all five variables of EE (i.e. criticism, hostility, EOI, warmth and positive remarks). Furthermore, the CFI offered caregivers the opportunity to talk about their experiences which has been found to be important in building a relationship between researcher and caregiver and in this work this was viewed as a critical factor to reduce attrition throughout the longitudinal study (Hooley & Parker, 2006).
3.2 The empirical studies

The distinct aim of each empirical study is outlined as follows:

- The first empirical study (Paper 2) will investigate burden and distress in caregivers of persons with a recent diagnosis of dementia. This will be examined both cross-sectionally and longitudinally to determine if EE can predict caregiver outcomes over time.

- The second empirical study (Paper 3) will examine psychological outcomes (anxiety, depression and quality of life) in persons diagnosed with dementia in the previous 24 months in association with caregiver EE. These associations will be examined both cross-sectionally and longitudinally over a period of 6 months to look at the predictive validity of EE.

- Finally, the third empirical study (Paper 4) will expand the current literature by exploring the association between caregiver psychological distress and psychological wellbeing in persons with a recent diagnosis of dementia, and examines the potential mediating role of EE, particularly critical comments. The cross-sectional and longitudinal design will help us to evaluate the predictive validity of caregiver distress.
Chapter 4: Methods

4.1 Overview

This chapter outlines the methodological considerations common across each of the three studies for which the data were collected. This will be followed by further discussion of specific aspects of the methodologies employed in each of the three empirical papers. A brief description of the methodology used for each study is presented within each of the empirical papers. Additional relevant material for each of the empirical papers, which was excluded from the papers due to the journal word limits, is presented within this chapter.

4.2 Inclusion and exclusion criteria

Participant inclusion and exclusion criteria were chosen to enhance the validity and generalisability of the conclusions arising from the data and to ensure that all the research questions posed within these studies could be addressed. Participants were recruited for all three studies at the same time i.e. the same participants were recruited for study 1, study 2 and study 3. Participants were recruited as dyads, and therefore the criteria outlined below include both PWD and caregiver criteria.

PWD were required to have received a clinician diagnosis of dementia (Alzheimer’s disease, vascular dementia, mixed dementia, frontotemporal dementia or Lewy body dementia) within the past 24 months to be eligible for inclusion within the studies. Potential participants were asked to confirm that they had received a clinical diagnosis of dementia within the past 24 months. It is noted that PWD may have experienced symptoms for differing periods of time before their diagnosis; information regarding recalled timing of onset of symptoms was collected from both the caregiver and person with dementia during the research meeting. However, due to the gradual and progressive nature of dementia it is highly likely that there would have been unnoticed symptoms long before the diagnosis and for this reason it is extremely difficult to pinpoint a precise start point as to when the person with dementia began to experience symptoms. In addition, PWD were
required to have an appropriate caregiver who was willing to participate in the studies. An appropriate caregiver was specified to be the individual with the most day-to-day involvement with the person with dementia and our criteria stipulated that the caregiver must live with, or have a minimum of 10 hours of weekly contact with the person with dementia. The requirement for a minimum of 10 hours contact per week is standard in EE research. Further inclusion criteria were set for all participants, and included:

- Sufficient levels of English i.e. an individual who is able to verbally comprehend spoken English and read/comprehend documents written in English.
- Aged 18 years or above.
- To be able to provide informed consent to the study.
- Caregivers provided consent to record the Camberwell Family Interview

Caregivers with a diagnosis of dementia, a complex psychiatric illness (i.e. schizophrenia, psychosis, bipolar disorder, personality disorder), and/or a major physical illness, which impacted on their ability to participate in study procedures were also not eligible for inclusion in the studies. The eligibility criteria were explained to potential participants during the initial briefing to ensure there was a suitable caregiver who was eligible for participation. The exclusion criteria were set to avoid recruiting dyads where the caregiver may also have been experiencing a chronic disorder, as it was expected that the role of caregiver factors would be qualitatively different within these dyads.

4.3 Recruitment

Prior to commencement, presentations were made to clinicians working within North West National Health Service (NHS) Services and Age UK Services, entailing the outline of the studies, requirements of participants and eligibility criteria. Recruitment into the studies was conducted by the author with the collaboration of the UK North West NHS services, Age UK and the Join Dementia Research (JDR) network. The same procedure was used to
recruit from North West NHS Services and Age UK. Potential participants included those newly referred into services, those currently on clinician case-loads and/or those accessing group support. R&D approvals were granted from all respective NHS trusts and Age UK. The study was advertised on the JDR network, which is accessible by persons with a diagnosis of dementia and/or their caregiver. Two procedures for recruitment were used; 1) persons were able to express an interest in the studies by contacting the first author directly, the first author would then contact them within 3 to 5 days of them expressing an interest to discuss the studies further, 2) persons who matched the eligibility criteria for the studies were contacted by the author to determine whether they would be interested in participating in the studies.

Potential participants who expressed an interest in the studies were given an invitation letter (see appendix 2) and a Participant Information Sheet (PIS) (see appendix 3 and 4); they either took the information away and contacted the author directly or provided verbal consent to their clinician for the author to contact them. Those who provided their contact details were contacted by the author by telephone after 3 to 5 days. During the telephone conversation a study screen was completed to ensure the persons met the eligibility criteria. Additionally, the caregiver eligibility criteria were explained to ensure an appropriate caregiver was willing to take part in the studies. Any questions about the studies were addressed during the initial telephone contact.

Subsequently, a meeting with the author was arranged with those PWD and their caregivers who were willing to participate to discuss the research. The meeting was arranged at a time and place most convenient to the participants. PWD and caregiver interviews were conducted during the same research meeting or individually, depending on the preferences of the participant. During the meeting caregivers completed the CFI and a series of questionnaires, as outlined in Chapter 4, section 4.5.1. PWD completed a series of questionnaires, as outlined in Chapter 4, section 4.5.2. The caregiver and PWD measures
were completed separately from each other i.e. on an individual basis, even if both sets of data collection took place during one research visit. During the research visit the author gained consent to contact the person with dementia and caregiver in 6 months’ time to arrange a follow-up visit. The author then contacted the participants 6 months following their initial research meeting (i.e. when baseline measures were collected) to arrange a follow-up. Again, a research meeting was arranged at a time and place convenient to the participants. All research visits were carried out by the author, who also collected all the data for these studies.

4.4 Ethical considerations

4.4.1 Approval

Prior to the commencement of the studies the author compiled a research proposal along with an Integrated Research Application System (IRAS) form and a series of Site Specific Assessment (SSI) forms. A range of documents were prepared that included an invitation letter, a PIS, a consent form (see appendix 5 and 6), interview schedule and a series of questionnaires. These documents were reviewed by the University of Manchester Ethics committee and an NHS Research Ethics Committee (REC). Following the author’s attendance at the NHS REC on 12th December 2013, the study was given a provisional favourable opinion based on further information/clarification of the letter of invitation, the PIS and the caregiver consent form. The further information was reviewed by the NHS REC North West – Greater Manchester South and given a favourable opinion on 11th February 2014 (reference 13/NW/0836; see appendix 1).

In addition, five NHS Research and Development (R&D) departments granted approval of the research studies. Approval and right of access was obtained for Greater Manchester West NHS Trust, Manchester Mental Health and Social Care NHS Trust, Cheshire and Wirral Partnership NHS Trust, Mersey Care NHS Trust and Pennine Care NHS
Foundation Trust, however, recruitment primarily took place in two of these trusts; Manchester Mental Health and Social Care NHS Trust and Pennine Care NHS Foundation Trust. A research passport was also granted.

On 19th August 2014, substantial amendment 1, proposing amendments to the inclusion criteria was submitted to the NHS REC. A favourable opinion was given by the NHS REC North West – Greater Manchester South on 3rd October 2014 (reference 13/NW/0836). This enabled the inclusion of persons with a diagnosis of dementia of all types, as opposed to solely persons with a diagnosis of Alzheimer’s disease, along with their caregiver, thus enabling the exploration of persons and caregivers across a broader range of dementia types. On 27th April 2015, substantial amendment 2, proposing amendments to the data collection at time 2 was submitted to the NHS REC. A favourable opinion was given by the NHS REC North West – Greater Manchester South on 11th May 2015 (reference 13/NW/0836). This enabled the assessment of caregiver psychological wellbeing at time 2 which had been inadvertently omitted in the original application.

4.4.2 Participant consent

Informed consent was sought after participants, both PWD and their caregiver, had read the PIS and asked questions about the study. Participants were also informed about the voluntary nature of participation and that they had the right to refuse participation and to withdraw from participation at any time. Informed consent was sought individually from the person with dementia and their caregiver. These individuals were assured that no disadvantage in their care would occur if they chose not to participate or if they withdrew. PWD recruited into the studies had a recent diagnosis of dementia therefore it was expected that they would be competent to give informed consent for participation, provided that appropriate care was taken in explaining the studies and sufficient time was allowed for them to reach a decision. It was also helpful for a caregiver or supporter to be involved when the author was explaining the study to the person with dementia and this
was done wherever possible. Given that participation in the studies lasted over a period of 6 months, in seeking consent we followed current guidance from the British Psychological Society on evaluation of capacity. In this context, consent was regarded as a continuing process rather than a one-off decision and willingness to continue participating was regularly checked through discussion with participants. It was anticipated that where the participant's level of impairment increased, so that they were no longer able to provide informed consent, the provisions of the Mental Capacity Act 2005 would be followed. Any data collected from the participant prior to the loss of capacity would be anonymised and used within the analysis, provided consent was obtained to do so at time 1. However, the participant would be withdrawn from any further involvement in the studies. Two patients were deemed to have lost capacity at time 2 and therefore questionnaires were not completed. Although on each occurrence their caregiver consented to continue with the studies and completed the time 2 questionnaires.

4.4.3 Participant confidentiality and anonymity

All participant interviews were conducted individually, although, it was necessary to audio tape all interviews to allow for later EE coding. To ensure participants could not be identified all audio-recordings were numbered and in accordance with University of Manchester and NHS policy all audio-recordings, transcripts and questionnaires were stored within password protected files on encrypted hard-drives or in securely locked filing cabinets. The data for this research was collected in connection with a part-time PhD study therefore ethical approval was granted to securely store the data in a locked cabinet or encrypted hard-drive for 5 years after collection (interviews commenced in February 2015). However, personal details were destroyed after they were no longer required. Participants were asked to sign consent forms which outlined the use and storage of data collected during the interviews. Ethical permission was granted to retain consent forms as essential documents. Furthermore, anonymity was maintained as any participant
identifiable material was removed. Participants were also assured that no information would be given by one member of the dyad to the other. They were made aware of the limitations to confidentiality, that is if a caregiver were to disclose mistreating a patient then the necessary services would be contacted.

4.4.4 Participant burden

The procedure for the studies was designed considering potential burden to participation. PWD were given time to complete the questionnaires at their own pace, they were supported by the author where required (i.e. reading each question and response options, re-reading questions and using response cards as mentioned in Chapter 4, section 4.5.2.3). The self-report measures completed at time 1 were limited so as to take approximately 30 to 45 minutes for PWD to complete and at time 2 the number of self-report measures was reduced and took approximately 30 minutes for PWD to complete. At time 1, caregivers completed an interview which took approximately 1 hour and responded to a series of self-report measures which took approximately 15-30 minutes. At time 2 caregivers completed self-report measures which took approximately 10-15 minutes. Both the person with dementia and their caregiver were given the opportunity to complete the measures over a number of visits if required.

4.4.5 Participant distress

The studies involved discussion about personal and potentially sensitive information; therefore, it was possible that participants may experience distress as a result of participation. All participants were informed about the nature of the questions, both in the interview and questionnaires and procedures were put in place to safeguard each participant. This included participants knowing that they could pass over any question if they felt unclear or uncomfortable or to have a break or to terminate the interview or questionnaires. Furthermore, participants were also made aware that the author could provide them with details of local support services if any participant wished. If the
participant disclosed having thoughts of suicidal intent then consent would be sought from the individual to speak to the relevant professional/s such as their GP or mental health professional. In the unlikely event of the participant indicating severe and imminent risk of harm to self or others, disclosure would be made without consent. However, no participant became distressed during any aspect of the studies and in fact participants reported to have appreciated having the opportunity to talk about their experiences. This has been reported to be an advantage of the CFI as it gives persons the opportunity to discuss their experiences which is deemed a positive experience (Hooley & Parker, 2006).

4.4.6 Lone working
The University lone working policy, which includes a comprehensive risk assessment, was followed to ensure the author’s safety whilst out on research visits. A designated individual was given details of each home visit and the author made contact with them before and after each research visit.

4.5 Data collection
4.5.1 Caregiver measures
Caregiver measures were completed at baseline and at follow-up (6 months after baseline).

4.5.1.1 Demographics.
This included caregiver characteristics and demographics e.g. age, sex, socio-economic status, marital status, employment, formal support (from health care professionals), informal support (from friends and family), relationship to the person with dementia, date of diagnosis and when symptoms of dementia were first noticed (see appendix 7). This data enabled the investigation of the possible confounders to the relationship between caregiver EE and outcomes in both caregivers and PWD in all three studies (reported in Paper 2; Chapter 5, Paper 3; Chapter 6 and Paper 4; Chapter 7).
4.5.1.2 Expressed Emotion.

A modified version of the CFI, lasting approximately 60 to 90 minutes was administered and used to rate caregiver EE (see appendix 8). The CFI was recorded and then transcribed. As outlined in Chapter 1, section 1.4.2, there is no suitable substitute for the CFI which continues to be the gold standard measure of EE and therefore was chosen for the purpose of these studies. The modifications of the CFI were minimal; they focused on the list of symptoms explored about dementia and are outlined in Chapter 4, section 4.8.1.1. Data collected from the CFI was used in all three studies (reported in Papers 2, 3 and 4).

4.5.1.3 Psychological wellbeing.

The Clinical Outcomes in Routine Evaluation; CORE (Barkham et al., 1998; Barkham et al., 2013) is a questionnaire which includes indicators of anxiety, depression, physical problems, trauma, general functioning, close relationships and social relationships (see appendix 9). The CORE 10, which is fairly brief and easy to administer, was deemed a suitable measure to evaluate caregivers’ psychological distress. The CORE 10 covers a wide range of areas including, depression, anxiety, panic and sleep disturbances. The measure also provides good psychometric properties and good sensitivity to change. The 10 items are rated on a five-point-Likert scale (0 = Not at all, 1 = Only Occasionally, 2 = Sometimes, 3 = Often, 4 = Most of the time). A higher overall score indicates greater levels of psychological distress. Data from the CORE was used within studies 1 (reported in Paper 2) and 3 (reported in Paper 4).

Example of questions from the CORE 10:

I have felt tense, anxious or nervous

I have felt able to cope when things go wrong

Talking to people has felt too much for me
4.5.1.4 Burden.

The Zarit Burden Inventory (ZBI) (Zarit et al., 1980), which is commonly used in
caregiver research, was selected as an appropriate measure to evaluate caregivers’ level of
subjective burden (see appendix 10). The questionnaire consists of 22 items and has good
internal consistency, with a Cronbach’s alpha coefficient of .92. Furthermore, the ZBI is
deemed suitable for a variety of populations as it has been found to be unrelated to
demographic factors such as age, gender, living situation, marital status or employment
(Hébert, Bravo, & Préville, 2010). Responses are collected on a five point-Likert scale (0 =
ever, 1 = rarely, 2 = sometimes, 3 = quite frequently, 4 = nearly always) and a higher
overall score represents a higher level of burden. Data from the ZBI was used in study 1
(reported in Paper 2).

Example of questions from the ZBI:

- Do you feel that your relative asks for more help than he/she needs?
- Do you feel embarrassed about your relative’s behaviour?
- Do you feel strained when you are around your relative?
- Do you wish you could just leave the care of your relative to someone else?

4.5.1.5 Relationship quality.

The Quality of Carer-Patient Relationships scale (QCPR) (Spruytte et al., 2002), was used
to measure the caregiver-PWD relationship (see appendix 12). The questionnaire was
chosen as it is easy to use and implement, has good internal consistency of .82 and is
appropriate for measuring different dyad relationships (i.e. parent-patient, partner-patient,
relative-patient and child-patient). This was important for this study as caregivers with
differing relationships with PWD were included in the study provided they had a minimum
of 10 hours of weekly contact with the person with dementia. The 14 items of the
questionnaire are designed to assess aspects of warmth, affection, conflict and criticism
within a relationship (Spruytte et al., 2002). Responses are collected on a five point-Likert
scale (1 = totally not agree, 2 = not agree, 3 = undecided, 4 = agree, 5 = totally agree) and a higher score implies the presence of warmth and affection and the absence of conflict and criticism in the relationship (Spruytte et al., 2002). Data from the QCPR was used in study 1 (reported in Paper 2).

Example of questions from the QCPR:

I get along well with my relative
I often get irritated by my relative
I blame my relative for being the cause of my problems

4.5.1.6 Illness perception.

The Brief Illness Perception Questionnaire (BIPQ) (Broadbent, Petrie, Main, & Weinman, 2006) was modified (to refer to “your relative’s dementia”) to use with caregivers of PWD (see appendix 11). The questionnaire assesses different domains of illness perceptions including consequences, timeline, personal control, treatment control, identity, coherence, emotional representation, illness concern and causal beliefs. Responses can be grouped into categories such as stress or lifestyle, or alternatively an overall score can be computed. A higher score reflects a more threatening view of the illness. The BIPQ was selected as it shows good test re-test reliability and validity with relevant measures (Broadbent et al., 2006). Illness perception in caregivers was not included in any of the analyses presented in this thesis.

Example of questions from the BIPQ:

How much does your relative’s dementia affect your life?
How much control do you feel your relative has over their dementia?
How concerned are you about your relative’s dementia?

4.5.2 Persons with dementia measures

The self-report PWD measures were chosen for use in the studies as they were deemed suitable for use with persons with mild to moderate dementia. The author took good care
when explaining the measures and sufficient time was allowed for persons to complete them. Further explanation was provided to persons when it was felt necessary. PWD measures were completed at baseline and at follow-up (6 months after baseline).

4.5.2.1 Demographics.
This included persons’ characteristics and demographics e.g. age, sex, socio-economic status, marital status, date of diagnosis and when symptoms of dementia were first noticed (see appendix 13). This data was collected to enable us to explore potential confounders to the relationship between caregiver EE and outcomes in both caregivers and PWD, in all three studies.

4.5.2.2 Cognitive functioning.
The Montreal Cognitive Assessment; MoCA (Nasreddine et al., 2005), was used to evaluate cognitive functioning (see appendix 14). Poorer cognitive functioning has been found to relate to EE and increased anxiety and poorer quality of life, (Beaudreau & O'Hara, 2008; Woods, Thorgrimsen, Spector, Royan, & Orrell, 2006). Hence, cognitive functioning was measured as a potential confounding variable. Sheehan (2012) reviewed and outlined a number of brief tools, all of which are under 30 minutes, which can be used to assess cognitive functioning in adults. These include the abbreviated mental test score, the clock drawing test, the mini cog test, the 6 item cognitive impairment test, the general practitioner assessment of cognition, the memory impairment screen, the mini-mental state examination and the Addenbrookes cognitive assessment. The MoCA was selected as it is freely available for research purposes, it takes approximately 10 minutes to administer and has good psycho-metric properties. Both test-retest reliability and internal consistency of the measure has been found to be high, .92, and .83 respectively (Nasreddine et al., 2005). The MoCA was used in study 2 (reported in Paper 3).
4.5.2.3 Psychological wellbeing.

The concept of psychological wellbeing refers to psychological functioning and experience (Ryan & Deci, 2001). Two key perspectives, based on two distinct philosophies, are considered to be important in the definition and measurement of wellbeing; (1) the hedonic view, whereby wellbeing is believed to consist of pleasure or happiness (Kahneman, Diener, & Schwarz, 1999) and (2) the eudaimonic view, which is classified as one’s ability to pursue activities which are meaningful to the individual and society (Dodge, Daly, Huyton, & Sanders, 2012; Ryan & Deci, 2001; Waterman, 1993). Evidence from a number of studies have suggested that wellbeing is best viewed as a multidimensional concept taking into consideration both the hedonic and eudaimonic perspectives of wellbeing (Huppert & So, 2013; King & Napa, 1998; McGregor & Little, 1998). This suggests that psychological wellbeing should be measured through different components to encompass both the hedonic view, for example by examining the presence of psychological symptoms and the eudaimonic view, for instance by measuring one’s quality of life.

The measures below were chosen for the present research as they measure different aspects of psychological wellbeing i.e. anxiety & depression, as well as quality of life, positive affect, life satisfaction and self-esteem in PWD, thus encompassing the two key perspectives of psychological wellbeing. It is well recognised that memory and language difficulties in PWD may impact on their ability to express their own feelings, especially as the condition progresses (Kwak, Yang, & Koo, 2017). It is also noted that symptoms of dementia may overlap with psychological symptoms such as anxiety and depression, as outlined in Chapter 1, section 1.3. These factors can make it difficult to measure psychological wellbeing in persons with dementia. Sheehan (2012) highlighted that when selecting suitable tools for measuring symptoms within this population it is important to ensure that the scales have good rates of reliability and validity within a population of
persons with cognitive impairments. Additionally, the tools should be practical (i.e. short so that participants are not overburdened) and acceptable so that they do not cause upset or exhaustion for the person with dementia. The importance of taking time to carefully explain the measure and its purpose to PWD was also discussed (Sheehan, 2012).

There are various tools which have been used to measure psychological symptoms and quality of life, as outlined in Chapter 1, section 1.3.3. Therefore when selecting measures for this research it was important to ensure the following; 1) that PWD could self-rate to reduce the possibility of caregiver-EE influencing the ratings of psychological wellbeing in PWD, 2) the tools were manageable to complete as a number of measures were being used and it was important to not overwhelm the person with dementia and 3) the tools were valid for use in dementia populations.

The Geriatric Depression Scale (Shortened Version) (GDS) (Yesavage et al., 1982) was used to measure symptoms of depression in PWD (see appendix 18). The GDS was selected as it is a suitable self-report measure for use with older adults with mild to moderate dementia (Feher, Larrabee, & Crook, 1992). Many measures of depression in PWD rely upon caregiver reports of wellbeing. The GDS uses simple and straightforward language and only has 2 responses (i.e. yes or no) which mean PWD are able to report on the presence of psychological symptoms themselves reducing the possibility of caregiver-EE influence. A total score of 5 out of 15 indicates probable depression, however, within empirical studies 2 (Paper 3) and 3 (Paper 4) the GDS was used to measure the levels of depressive symptoms.

**Example questions from the GDS**

Have you dropped many of your activities or interests?

Do you often get bored?

Do you feel happy most of the time?
The Geriatric Anxiety Inventory (GAI) (Pachana et al., 2007) was used to measure anxiety in PWD (see appendix 17). The GAI shows good reliability and validity within a population of persons with cognitive impairments (Rozzini et al., 2009). It has 20 items and respondents are asked to state whether they agree or disagree with the statements, its simple language and limited response options makes it a suitable self-report measure for use with older adults with cognitive impairments. Rozzini et al (2009) suggested a cut off of 10/11 out of 20 is indicative of generalised anxiety disorder and a cut off of 8/9 out of 20 is indicative of anxiety disorders (Pachana et al., 2007). Within studies 2 (Paper 3) and 3 (Paper 4) the GAI was used to measure the level of anxiety symptoms.

Example questions from the GAI

I worry a lot of the time
I often feel jumpy
I often feel nervous

The Dementia Quality of life measure (DEMQOL) (Smith et al., 2007) is a tool with good psychometric properties, which is effective at evaluating QOL in persons with mild to moderate dementia and therefore was used for the purpose of these studies (see appendix 15). The tool, which takes approximately 10 to 20 minutes to administer, uses simple language and respondents are given a card with response options to aid memory (i.e. a lot, quite a bit, a little, not at all) (see appendix 16). The advantage of this measure is that the interviewer can obtain information on positive and negative affect, feelings of belonging and self-esteem directly from the person with dementia, thus reducing the influence of caregiver EE on responses.

Example of questions from the DEMQOL

In the last week, have you felt cheerful?
In the last week, how worried have you been about forgetting who people are?
In the last week, how worried have you been about people not listening to you?
The psychological wellbeing measures (i.e. GDS, GAI, DEMQOL) were used in studies 2 (reported in Paper 3) and 3 (reported in Paper 4).

4.5.2.4 Relationship quality.

QCPR scale (Spruytte et al., 2002), was used to measure the relative-person relationship from the perspective of the person with dementia (see appendix 12). It was selected as it is an appropriate measure for assessing relationships among different dyads within the dementia population and has good psycho-metrics (Spruytte et al., 2002). Examples of questions from the QCRP are outlined in Chapter 4, section 4.5.1.5. Relationship quality, as reported on by PWD, was not included in any analyses presented in this thesis.

4.5.2.5 Perceived EE.

The Perceived Criticism Scale (PCS) (Hooley & Teasdale, 1989) was used to measure perceived criticism (see appendix 19). The scale asks one question ‘How critical do you consider your relative to be of you?’ It was administered as a 10-point Likert-type scale and anchored with the values ‘not at all critical’ and ‘very critical indeed’. This measure was selected as it can be obtained from PWD quickly and correlates reasonably well with EE as assessed by the CFI although it is not a suitable substitute to the CFI as highlighted in Chapter 1, section 1.4.2. Perceived EE, as reported on by PWD, was not included in any analyses presented in this thesis.

4.5.2.6 Illness perception.

The BIPQ (Broadbent et al., 2006) was modified to use with PWD to assess the perception of their illness (see appendix 20). The measure has good psychometric properties as outlined in Chapter 4, section 4.5.2.6. Illness perceptions of PWD were not included in any analyses presented in this thesis.

Examples of questions from the BIPQ

How much do you feel your dementia affects your life?

How much control do you feel you have over your dementia?
How concerned are you about your dementia?

### 4.6 Sample size calculations

Testing the hypotheses within the study involves comparing variables of interest (i.e. PWD and caregiver psychological and quality of life outcomes) based on caregiver EE ratings. Estimating the likely size of the difference in outcomes between high- and low-EE groups was hampered by the fact that there is little existing relevant data within the dementia population. When considering the potential difference in outcome between PWD and caregivers in the high- and low-caregiver EE groups, an effect size of .75 (i.e. a medium effect) was thought to be sufficiently large enough to be of interest to clinicians and researchers. The likely distribution of high- and low-EE in the population of caregivers of persons with recent-onset dementia was estimated, again, on the basis of little existing data. Based on previous work in the UK, (Fearon et al., 1998) it was estimated that a split of 40 low-EE caregivers and 20 high-EE caregivers. A power calculation was performed using nQuery Advisor 7.0, assuming normally distributed data and based on comparing two groups using a two-sample t-test, at the conventional two-sided 5% significance level (alpha 0.05). With 40 and 20 dyads in the two groups (60 dyads in total) it was calculated that the study would have 80% power to detect an effect size of at least .780 between two groups. A sample size of 60 dyads was therefore used to answer research questions posed within the three studies (reported in Papers 2, 3 and 4).

Mediation analysis is a popular statistical method however several reviews have highlighted that discussion about power analysis and sample size calculations for mediation models are fairly sparse (Schoemann, Boulton, Short, 2017). A Monte Carlo power analysis, using R, was performed to assess the sufficiency of the power for a mediation analysis. Using the variable correlation coefficients and standard deviations
found within this study it was calculated that with a sample size of 61 the mediation analysis would have 67% power to detect an indirect effect in the model.

4.7 Attrition from the studies

Figure 4 presents a flow chart outlining the recruitment and attrition from the three studies.

**Figure 4: Flow chart outlining recruitment and attrition**

Dyad expressed an interest in the studies / Identified from JDR.

Screened by inclusion criteria
- PWD had a clinician diagnosis of dementia within the past 24 months.
- PWD had a caregiver who lives with, or has a minimum for 10 hours weekly contact with the person with dementia.
- Sufficient levels of English
- Aged 18 years or above.
- Ability to consent to the study.
- Caregivers must provide consent to record the CFI.

Recruit (N = 21) dyads from NHS services in the North West England.
Recruit (N = 7) dyads from Age UK.
Recruit (N = 33) dyads from JDR.

Informed consent taken from PWD and their caregiver (N = 61).

Baseline data collection from PWD (N = 61).
Baseline data collection from caregiver (N = 61).

6 month follow-up data collection from PWD (N = 54) (89%).
6 month follow-up data collection from caregiver (N = 51) (83%).

Reason for drop outs
- Loss of capacity (N = 2).
- Unable to contact (N = 5).
- Circumstances (N = 3).
- Health difficulties (N = 2).
- Unable to contact (N = 5).
4.8 Specific methodological considerations

4.8.1 Paper 2 (Chapter 5): Expressed Emotion in significant others of people with a recent diagnosis of dementia predicts increased significant others burden and distress.

The aim of this study was to investigate burden and distress in caregivers of persons with a recent diagnosis of dementia by examining both cross-sectional and longitudinal (6 month) relationships between EE status, caregiver burden, distress and the quality of relationship between caregiver and PWD. Expressed Emotion was derived from the CFI as outlined below, Chapter 4, section 4.8.1.2. Caregiver burden and distress were derived from the ZBI and the CORE10. The quality of relationship between the caregiver and person with dementia was obtained from the QCPR as reported on by the caregiver.

4.8.1.1 CFI adaptations for dementia

The CFI Schedule (Vaughn & Leff, 1976) was used within the current studies to determine caregiver EE ratings. The CFI was originally developed for relatives of persons with schizophrenia (Brown & Rutter, 1966). However, the CFI has been used in mental and physical health conditions and can be modified for this purpose (Wearden et al., 2000). Several modifications were made to the conventional CFI schedule to ensure it was applicable to the dementia population.

The CFI has two sections. In its original form section A explores the onset of difficulties and then focuses on a current episode, irritability, quarrels and nagging/grumbling. For the purpose of these studies the section on a recent episode was removed as it was deemed less relevant for a dementia population, and therefore section A included information on the period since diagnosis, current functioning, irritability, quarrels and nagging/grumbling. Typically section B explores symptoms experienced by the patient. This section was modified to incorporate symptoms relevant to the dementia population such as ability to complete tasks, communication difficulties and confusion. An example of the modified
CFI schedule can be found in the appendices (see appendix 8). Each interview took approximately one hour to administer. The CFI is more like a conversation with the caregiver as opposed to a formal structured interview, during which the interviewer asks the caregiver open questions and encourages them to talk about the person with dementia and their behaviour. The EE statements emerge spontaneously from what the caregiver says.

4.8.1.2 CFI coding

4.8.1.2.1 Learning to code (CFI training)

The CFI interviews were administered and coded by the author, in line with the EE training manual (Vaughn & Leff, 1985). Each interview took approximately one hour to administer and typically two to three hours to code. The author was trained in EE by Christine Vaughn. The training course took place over a two week period in London and was conducted on a one-to-one basis. It involved learning how to effectively conduct and code a CFI. There was an in-depth discussion about the five components of EE (criticism, hostility, EOI, warmth and positive remarks) and how to identify their presence within an interview. In conjunction with the training the author coded approximately 15 CFI’s, which had previously been coded by Christine Vaughn and achieved inter-rater reliability (0.82) across the four ‘key’ scales of EE (i.e. critical comments, EOI, hostility and overall EE). This demonstrates the author achieved reliability in coding EE with Christine Vaughn, one of the originators of the EE construct. Furthermore, bias in CFI coding was minimised by not summing the scores on caregiver outcomes measures (i.e. burden and distress) and PWD outcome measures (i.e. PWD depression) until after the CFI coding had been completed.

4.8.1.2.2 Critical comments

Criticism is defined as a statement which constitutes an unfavourable remark upon the behaviour or personality of the person to whom it refers. Criticism may be evident in 1) the
content of the comment or 2) the vocal aspects of speech. Comments are deemed to be considered as critical when there is a clear unambiguous statement that the caregiver dislikes, disapproves of or resents a behaviour or characteristic or where there is a rejecting remark which usually involves a negative comment about the person as a whole or a statement of frank dislike. When coding based on vocal aspects of speech it is important to take into consideration the natural vocal style of the caregiver as this is likely to differ from person to person. Coding the vocal aspects of speech is based on pitch, speed and inflection. It is important to note that a new critical remark is only rated when there is a clear change of topic. The critical comment scale is based on a frequency count i.e. the number of critical comments at any point in the interview (Leff & Vaughn, 1985).

Example of critical comments

- “She hoovers for hours and hours, she nearly burns the motor out cos she keeps going over it and over it, I say “Stop *** hoovering!”
- “It’s just this year I mean it’s an absolute joke that he has his chair and sits in his chair and in the other house he’d worn the carpet.”
- “He’ll have the tele on a lot during the day. It will drive me barmy.”

4.8.1.2.3 Hostility

Hostility is classified as either 1) a generalised comment whereby the person is attacked for who they are as a person rather than for a particular behaviour or attribute or 2) a rejecting remark whereby the caregiver makes a direct statement which indicates generalised negative feeling about being in the presence of the person. Hostility is coded on a four-point global scale as follows; 0 = No hostility, 1 = Present as generalisation only, 2 = Present as rejection only, and 3 = Present as generalisation and rejection. One clear generalisation of criticism or rejecting remark is sufficient enough for a coding of hostility (Leff & Vaughn, 1985).

Example of hostility
• “She’s just a nasty person, really, quite horrible” (Generalisation of criticism)
• “I might go and do the cleaning just to get away from her – I don’t feel I can breathe being near someone like that” (Rejecting remark)

4.8.1.2.4 Emotional over-involvement

The presence of EOI can be identified from two aspects i.e. 1) the reported behaviour of the caregiver or 2) the behaviour of the caregiver during the interview. There are several reports of behaviours which may indicate over concern of a caregiver. These include i) an exaggerated emotional response in the past that is directly related to the person’s welfare and can be an indication of over-identification between caregiver and PWD, ii) unusually self-sacrificing and devoted behaviour such as sacrificing one’s own hobbies or social life and/or iii) extremely over-protective behaviours which indicate attempts by the caregiver to exert psychological or physical control over the person with dementia. The second aspect refers to over concern being displayed through statements of attitude such as the impact of the illness on the caregiver and/or the caregiver’s pre-occupation with the person with dementia, emotional displays during the interview and/or dramatization of relatively minor incidents or problems, as identified through tone, tempo and the level of detail given, which cannot be explained by merely style of speech. EOI is measured on a six-point global scale as follows; 0 = None (0 is rated when there are no characteristics of EOI), 1 = Very little, 2 = Some (1 and 2 are rated when there is some presence of EOI, but not to any significant extent), 3 = Moderately high, 4 = High (3 and 4 are rated when there is clear evidence of EOI), and 5 = Marked (5 is rated when there is an extreme manifestation of EOI) (Leff & Vaughn, 1985).

Example of EOI

• “There’s no way I could have a life of my own, no way at all, he needs me 24/7”
• “We won’t go out anywhere without him, if we’re going out we always have to take him”
4.8.1.2.5 Warmth

This scale refers to warmth expressed in an interview about the person with dementia. Warmth is identified through tone of voice (i.e. enthusiasm, positive changes in manner when talking about the person), spontaneous expressions of warmth, sympathy, concern and empathy when talking about the behaviour or problems of the person and enthusiasm and interest in the person and their achievements. This scale is rated on a six-point global scale (0 = No warmth, 1 = Very little warmth, 2 = Some warmth, 3 = Moderate warmth, 4 = Moderately high warmth, 5 = High warmth) (Leff & Vaughn, 1985).

Example of warmth

- “I feel so sorry for her. I do feel really sorry for her”
- “He’s always been caring”
- “It was just too much for her”

4.8.1.2.6 Positive Remarks

A positive remark refers to a comment which indicates praise, approval or appreciation of the personality or behaviour of the person to whom it refers. A frequency count is used to measure the occurrence of positive remarks during the CFI. A positive remark must only be counted if it is bound by a new question or a change in topic (Leff & Vaughn, 1985).

Example of positive remarks

- “He had a brilliant brain he’s a clever man”
- “She's always been spot on with all that so there's nothing that even needs to be done”
- “She’s very loving”

4.8.1.2.7 Classifying caregivers as High- or Low-EE

The typical threshold for high- and low-EE, as outlined in Chapter 1, section 1.4.2, was used. Caregivers were classified as high-EE when there was the presence of six or more critical comments, was the presence of hostility or rejection on the hostility scale, and/or
there was a rating of three or above on the EOI scale. Those that did not reach these thresholds were classified as low-EE. Warmth and positive remarks were not included in the categorisation of high- and low-EE and have not yet been included in any analyses.

**4.8.2 Paper 3 (Chapter 6): Expressed Emotion in caregivers and psychological wellbeing in persons with dementia.**

This paper focused on the cross-sectional and longitudinal examination of the relationship between caregiver EE and PWD psychological wellbeing (quality of life, depression and anxiety). The role of high levels of caregiver critical comments and EOI were examined separately. EE was derived from the CFI ratings as outlined above for Paper 2; Chapter 4, section 4.8.1.2. PWD wellbeing was derived from the GDS, the GAI, and the DEMQOL.

**4.8.3 Paper 4 (Chapter 7): Critical comments mediate the association between caregiver distress and psychological symptoms in persons recently diagnosed with dementia.**

This paper examined potential pathways for the effects established in Papers 2 and 3. In paper 3 it was deduced that caregiver high-EE was associated with poorer wellbeing in PWD over the six month period in comparison to PWD with low-EE caregivers. Paper 2 highlighted that high-EE was associated with distress in caregivers both cross-sectionally and longitudinally. It was hypothesised that caregiver distress might be one of the drivers of caregiver criticism. Exploring this relationship offers insight into how other caregiver factors may inadvertently affect PWD wellbeing. This insight could then be used to implement clinical intervention aimed at targeting these areas (i.e. caregiver distress and critical comments) to enhance both caregiver and PWD wellbeing. We therefore carried out a mediation analysis to determine whether, in a recently diagnosed dementia population, caregiver psychological distress is associated with PWD psychological wellbeing, and if so, whether criticism was a mediator of that association. This question was explored both cross-sectionally and longitudinally over a period of 6 months. The
number of critical comments was extracted from the CFI as outlined above for Paper 2; Chapter 4, section 4.8.1.2.2. Caregiver distress was derived from the CORE10 and psychological wellbeing in PWD was obtained from the DEMQOL, the GDS and the GAI.
Chapter 5: Expressed Emotion and caregiver outcomes

5.1 Outlining the paper

The following paper reports on the relationship between EE and caregiver measures of burden and psychological distress both cross-sectionally and longitudinally over a period of 6 months. The association between EE and the current caregiver-PWD relationship quality will also be explored. This paper has been accepted for publication in the Journal of Family Psychology. The findings arising from this study have also been disseminated as oral presentations at the American Psychosomatic Society Annual conference, Louisville, Kentucky, 7-10 March 2018. The findings from this study will be disseminated as an oral presentation at the Division of Health Psychology Annual Conference, Newcastle, Gateshead, 5-6 September 2018.

5.2 Paper 2: Expressed Emotion in significant others of people with a recent diagnosis of dementia predicts increased significant others burden and distress.
Expressed Emotion, burden and distress in significant others of people with dementia.

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The data from this study has been presented at the American Psychosomatic Society Annual conference, Louisville, Kentucky, 7-10 March 2018.

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5.2.1 Abstract

Significant others of people with dementia suffer high levels of burden and distress, creating the conditions for the negative attitudes and unhelpful responses described within the construct of Expressed Emotion (EE). It is not known however, whether EE then further enhances significant other burden and distress, and whether these processes operate early after symptoms of dementia have started. The current study used a longitudinal design to examine the potential influence of EE on burden and distress in significant others of people with a recent diagnosis of dementia. Sixty-one significant others of people with dementia were recruited. Significant other EE was coded from the Camberwell Family Interview. Significant other burden and distress, and relationship quality were collected through questionnaires at baseline and at 6-month follow-up. Significant other high-EE was associated with higher levels of burden and greater distress at both baseline and 6-month follow-up, when existing relationship quality was controlled for. High-EE significant others showed increases in burden and distress from baseline to follow-up not seen in low-EE significant others. Interventions aiming to modify significant other response styles and to reduce high-EE may potentially benefit significant others by reducing their levels of burden and distress.

Keywords

Dementia
Expressed Emotion
Burden
Distress
Caregivers
5.2.2 Introduction

Due to population ageing and lifestyle factors, it is estimated that the number of people living with dementia worldwide will increase from 44 million in 2013 to 75 million by 2030 (World Health Organization, 2012). Family and friends play a significant role in the support of persons with dementia (Brodaty & Donkin, 2009). Many of those who provide informal care perceive it to be fulfilling, enjoyable and meaningful, and take pride in their role (Prince & Jackson, 2009). However dementia is associated with complex needs, and as the condition progresses levels of dependency and morbidity increase (World Health Organization, 2012), placing heavy demands on significant others. These demands have been associated with greater levels of depression, increased levels of burden, strain and distress (Safavi, Berry, & Wearden, 2015), poor self-care (Shaw et al., 1999), health problems (Pinquart & Sörensen, 2011), sleep disturbances (McCurry et al., 2007) and poor patient-significant other relationships (Fearon et al., 1998).

Expressed Emotion (EE) is a well-established construct for exploring family environments (Vaughn & Leff, 1976). Ratings of EE are typically made from evidence obtained from the semi-structured Camberwell Family Interview (CFI; Vaughn & Leff, 1985), during which the relative talks about the patient and their relationship with them. A trained rater codes the interview along the following 5 scales; 1) critical comments, which refers to the presence of a strong tonal criticism or unambiguous evidence for irritation, resentment or dissatisfaction with the patient’s behaviours or characteristics, 2) hostility, which is indicated by a generalised critical comment about the patient, or statements indicating rejection of the patient, 3) emotional over involvement (EOI), which is identified by exaggerated emotional response, over identification with the patient, self-sacrificing or being over-intrusive, 4) warmth, and 5) positive remarks. Conventionally, significant others are conceptualised as high-EE if they make 6 or more critical comments, and/or if there is a presence of hostility and/or if there is a score of 3 or more on the 0-5 EOI scale.
(Barrowclough & Hooley, 2003). The CFI is the gold standard measure of EE, but is time consuming; alternative, briefer methods have therefore been developed (Hooley & Parker, 2006).

High-EE has consistently been associated with significant other distress and burden within dyads where the patient has mental (Scazufca & Kuipers, 1996) or physical (Pinquart & Sörensen, 2011) health conditions. In the dementia literature, significant other high-EE has been associated with increased depression (Li & Lewis, 2013; Vitaliano et al., 1993; Wagner et al., 1997), higher strain (Bledin, MacCarthy, Kuipers, & Woods, 1990; Tarrier et al., 2002), higher burden (Li & Lewis, 2013; Nomura et al., 2005; Vitaliano et al., 1993; Wagner et al., 1997), increased psychological distress (Bledin et al., 1990; Nomura et al., 2005; Tarrier et al., 2002) and poorer patient-significant other relationships (Bledin et al., 1990). Previous literature has also documented an association between poorer relationship quality and negative response styles, such as unhelpful communication with the patient, reduced intimacy, distancing from the patient, greater emotional reactivity and increased risk of nursing home placement (Quinn, Clare, & Woods, 2009).

Studies with the dementia populations have been consistent in suggesting that EE is associated with significant other burden and psychological wellbeing, but due to their cross-sectional nature it is difficult to draw conclusions about whether distress and burden lead to, or create the conditions for high-EE, or whether being a high-EE relative feeds into distress and burden. Greenley (1986) suggested that high-EE is more likely to be present in anxious and fearful families and that it represents their attempts at interpersonal social control in order to cope with difficulties experienced when caring for a loved one. In reality, it is likely that bidirectional processes are at work, with distress engendering high-EE and then high-EE and associated behaviours and consequences feeding back into greater distress (Hooley, 2007), but the ability of EE to predict significant other distress has not yet been explored. Additionally, pre-existing relationship quality may play a role in
these processes, as high-EE has been found to be associated with poorer past relationships (Safavi et al., 2015).

As the number of people living with dementia grows, it is becoming increasingly important to understand early predictors of significant other burden and psychological distress in order to improve the lives of those affected by dementia. The current study aimed to investigate burden and distress in significant others of patients with a recent diagnosis of dementia by examining both cross-sectional and longitudinal (6-month) relationships between EE, significant other burden, distress and relationship quality. This was the first study to explore the longitudinal relationship between EE in significant others of patients recently diagnosed with dementia, and significant other measures of burden and psychological distress, and therefore provides information about the potentially bidirectional relationship between EE and distress.

First, we predicted that, at baseline, cross-sectional associations between i) high-EE and greater burden and distress in significant others, and ii) high-EE and poorer quality of relationship with the patient would be replicated. Second, we predicted that high-EE would be associated with greater burden and distress in significant others at 6-month follow-up than low-EE when controlling for the effect of relationship quality. Third, we predicted that high-EE significant others would show more deterioration in burden and distress than low-EE significant others.

5.2.3 Methods

Participants

To be eligible for participation persons had to have a diagnosis of dementia made within the past 2 years, and a significant other who had a minimum of 10 hours per week contact with them. Participants were recruited in dyads; 21 from National Health Service (NHS) memory services, 7 from Age UK and 33 from Join Dementia Research, for a total of 61
dyads. Both participants had to be aged 18 years or above and have adequate fluency in English. No participants were excluded during recruitment for having a health condition that may influence their ability to complete the measures or for any other reason. Significant others were between the ages of 29 and 88 years (M = 66, SD = 12.05). The average age of persons with dementia was 72 years (SD = 10.08). Thirty four (56%) persons with dementia were male and the average number of months since diagnosis was 11.9 (SD = 6.13). Table 10 contains a summary of the descriptive characteristics of significant others at baseline.

Procedures

Ethical approval was given by a NHS research ethics committee (13/NW/0836). Significant others completed the CFI and questionnaire measures at baseline (time 1). Questionnaires were repeated at a 6-month follow-up (time 2). CFI interviews were audio-recorded and transcribed verbatim to facilitate ratings. Questionnaires measuring quality of life and wellbeing were also completed with the patient at baseline and at a 6-month follow-up and the findings have been reported elsewhere. No incentives were offered in return for participation, and written informed consent was obtained from all participants.
Table 10: Descriptive characteristics of significant others \((N = 61)\)

<table>
<thead>
<tr>
<th>Significant other</th>
<th>(N(%))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
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<tr>
<td>Male</td>
<td>21 (34.4)</td>
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<tr>
<td>Female</td>
<td>40 (65.6)</td>
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<tr>
<td>Ethnicity</td>
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<tr>
<td>White</td>
<td>53 (86.9)</td>
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<tr>
<td>Mixed / multiple ethnic groups</td>
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<tr>
<td>Asian / Asian British</td>
<td>3 (4.9)</td>
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<tr>
<td>Black/African/Caribbean</td>
<td>1 (1.6)</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>2 (3.3)</td>
</tr>
<tr>
<td>Relationship status</td>
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</tr>
<tr>
<td>Single</td>
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<td>Married/civil partnership</td>
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<tr>
<td>Widowed</td>
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<td>Divorced</td>
<td>1 (1.6)</td>
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<tr>
<td>Living status</td>
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<tr>
<td>Living with the patient</td>
<td>53 (87.0)</td>
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<tr>
<td>Education</td>
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<td>Higher education</td>
<td>20 (32.9)</td>
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<td>Employment status</td>
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<tr>
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<td>9 (14.8)</td>
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<tr>
<td>Unemployed</td>
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</tr>
<tr>
<td>Retired</td>
<td>42 (68.9)</td>
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<tr>
<td>Other</td>
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<tr>
<td>Relationship with patient</td>
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<tr>
<td>Spouse/Partner</td>
<td>48 (78.7)</td>
</tr>
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<td>Son/daughter</td>
<td>10 (16.4)</td>
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<tr>
<td>Daughter in law</td>
<td>1 (1.6)</td>
</tr>
<tr>
<td>Niece</td>
<td>1 (1.6)</td>
</tr>
<tr>
<td>Close friend</td>
<td>1 (1.6)</td>
</tr>
</tbody>
</table>

Measures

**Expressed Emotion.** Significant others completed the CFI at baseline. The interview, which took approximately 1 hour, was modified for this study by adapting the symptom list to include items such as communication and confusion, appropriate for dementia patients.

**Psychological distress.** The Clinical Outcomes in Routine Evaluation; CORE (Barkham et al., 2013) was used to evaluate significant others’ psychological distress over the past
week. The questionnaire, which has good psychometric properties, has 10 items measuring anxiety, depression, physical problems, general functioning and relationships (Barkham et al., 2013). Responses were made on a five point-Likert scale, and scores summed. A higher overall score indicates higher levels of distress.

**Burden.** The Zarit Burden Inventory; ZBI (Zarit, Reever & Bach-Peterson, 1980) was used to evaluate the level of subjective burden in significant others since they began caring for the patient. The questionnaire has 22 items and good internal consistency (Hébert et al., 2010). Responses were collected on a five point-Likert scale and summed. A higher overall score represents a higher level of burden.

**Relationship quality.** The Quality of Carer-Patient Relationships scale; QCPR (Spruytte et al., 2002), was used to measure the significant other-patient relationship. The questionnaire, which has good internal consistency, has 14 items which assess aspects of warmth, affection, conflict and criticism within a relationship (Spruytte et al., 2002). Responses were collected on a five point-Likert scale and summed. A higher score implies the presence of warmth and affection and the absence of conflict and criticism (Spruytte et al., 2002).

**Overview of Analyses**

**EE coding.** The first author, who was trained by Christine Vaughn and achieved inter-rater reliability with her, administered the CFIs and rated them for EE using the conventional criteria (Vaughn & Leff, 1985). An overall rating of High- or Low-EE (HEE and LEE) was given based on critical comments and/or EOI and/or hostility.

**Statistical analysis.** SPSS version 22 was used to conduct statistical analyses. Shapiro-Wilk tests showed all significant other measures (i.e. ZBI, CORE 10 and RQCRS) were normally distributed. No outliers were identified. Comparison analysis of significant other demographic variables, illness-related variables and outcome measures for those who completed follow-up and those who did not were conducted. Demographic variables (age,
gender, relationship status) were compared with significant other outcome variables (burden, distress and relationship quality) and predictor variables (EE) to identify any significant associations that may have influenced the relationship between predictor and outcome variables. These variables were referred to as confounding variables.

Comparisons of outcomes in HEE versus LEE significant others were performed using independent t-tests. These comparisons were conducted at baseline and repeated at follow-up. Subsequently regression analyses were conducted to assess HEE and LEE in predicting significant other outcomes of burden and distress at 6-month follow-up. Baseline measures were included in the models to control for previous level of burden, distress and relationship quality.

5.2.4 Results

Sample at six-month follow-up

Fifty-one (83%) significant others completed the follow-up measures. Comparison analysis indicated that there were no significant differences between significant others who completed follow up assessments and those that did not on demographic variables, illness-related variables, outcome measures, or EE variables.

Descriptive data summary for EE

At baseline, twenty eight percent ($N = 17$) of significant others received a rating of HEE. Sixty one percent ($N = 37$) made at least one critical comment. Fifteen percent ($N = 9$) of significant others made six or more critical comments. Ten percent ($N = 6$) of these critical significant others were rated positively for hostility. Hostility always occurred in combination with a high level of critical comments within the sample. On the EOI scale, 69% ($N = 42$) of significant others showed very little EOI (a score of one), and the median level was ‘some EOI’ (a score of two). Sixteen percent ($N = 10$) showed high levels of EOI, based on the conventional criteria of 3 or more, with 13% ($N = 8$) of significant
others being classified as HEE based on evidence for EOI solely. Three percent \((N = 2)\) of significant others reached the conventional threshold for both critical comments and EOI and were categorised as HEE.

**Descriptive summary of significant other outcome measures**

Mean \((SD)\) scores on significant other outcome measures at baseline and follow up, along with reliability estimates are provided in Table 11.

**Table 11: Significant other burden, distress and relationship quality scores at baseline and follow-up**

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th></th>
<th>Follow-up (6 month later)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>LEE</td>
<td>HEE</td>
<td>LEE</td>
</tr>
<tr>
<td></td>
<td>Mean ((SD))</td>
<td>Mean ((SD))</td>
<td>(\alpha)</td>
</tr>
<tr>
<td>ZBI</td>
<td>28.39 (13.79)</td>
<td>42.41 (14.60)</td>
<td>0.92</td>
</tr>
<tr>
<td>((N = 44))</td>
<td>((N = 17))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CORE 10</td>
<td>7.89 (5.17)</td>
<td>11.47 (4.78)</td>
<td>0.71</td>
</tr>
<tr>
<td>((N = 44))</td>
<td>((N = 17))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>QCRS</td>
<td>57.57 (8.26)</td>
<td>50.41 (9.79)</td>
<td>0.85</td>
</tr>
<tr>
<td>((N = 44))</td>
<td>((N = 17))</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: Zarit Burden Inventory (ZBI), Clinical outcomes in routine evaluation 10 (CORE-10), Quality of Carer-Patient Relationships scale (QCRS).*

**Preliminary Analyses**

There were no significant associations between the possible demographic confounding variables (age, gender, significant other-patient relationship) and significant other outcomes (burden, psychological distress) or EE.
Expressed Emotion and Cross-Sectional Significant Other Outcomes

In line with study predictions, independent-samples t-tests indicated that both baseline levels of burden and baseline psychological distress were significantly higher for high-EE significant others than for low-EE significant others \([t(59) = 3.50, p = .001\) and \(t(59) = 2.48, p = .016\) respectively]. In line with study predictions, the baseline quality of relationship with the person with dementia was significantly lower for high-EE significant others than for low-EE significant others \([t(59) = -2.88, p = .006\].

Expressed Emotion and Significant Other Outcomes at 6-months

Comparison analyses. In line with study predictions, levels of burden at 6-month follow-up were significantly higher for high-EE significant others than for low-EE significant others \([t(18.41) = 3.81, p = .001\). Furthermore, psychological distress at 6-month follow-up, was significantly greater for high-EE significant others than for low-EE significant others \([t(49) = 4.60, p = .000\].

Regression analyses. In line with study predictions, high-EE significantly predicted increased burden and greater psychological distress in significant others at 6-month follow-up while controlling for baseline levels of burden, distress and relationship quality (see Table 12).
Table 12: Summary of hierarchical regression analysis for variables predicting significant other outcome measures at 6 month follow-up ($N = 54$)

<table>
<thead>
<tr>
<th>Variable</th>
<th>$\Delta R^2$</th>
<th>$B$</th>
<th>$SE$</th>
<th>$\beta$</th>
<th>95% CI</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outcome: Significant other burden (ZBI) at 6 month follow-up</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td>.481</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline burden</td>
<td>.510</td>
<td>.141</td>
<td>.503</td>
<td>.226, .794</td>
<td>.030*</td>
<td></td>
</tr>
<tr>
<td>Baseline relationship quality</td>
<td>-.428</td>
<td>.228</td>
<td>-.262</td>
<td>-.886, .030</td>
<td>.066</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td>.543</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline burden</td>
<td>.424</td>
<td>.136</td>
<td>.418</td>
<td>.150, .698</td>
<td>.003*</td>
<td></td>
</tr>
<tr>
<td>Baseline relationship quality</td>
<td>-.331</td>
<td>.216</td>
<td>-.202</td>
<td>-.767, .104</td>
<td>.133</td>
<td></td>
</tr>
<tr>
<td>High/Low-EE</td>
<td>-9.986</td>
<td>3.630</td>
<td>-.295</td>
<td>-17.29, -2.68</td>
<td>.008*</td>
<td></td>
</tr>
<tr>
<td><strong>Outcome: Significant other psychological distress (CORE 10) at 6 month follow-up</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td>.399</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline psychological distress</td>
<td>.801</td>
<td>.206</td>
<td>.600</td>
<td>.387, 1.215</td>
<td>.000**</td>
<td></td>
</tr>
<tr>
<td>Baseline relationship quality</td>
<td>-.053</td>
<td>.116</td>
<td>-.070</td>
<td>-.285, .180</td>
<td>.651</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td>.516</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline psychological distress</td>
<td>.742</td>
<td>.186</td>
<td>.555</td>
<td>.368, 1.116</td>
<td>.000**</td>
<td></td>
</tr>
<tr>
<td>Baseline relationship quality</td>
<td>.038</td>
<td>.107</td>
<td>.050</td>
<td>-.177, .253</td>
<td>.725</td>
<td></td>
</tr>
<tr>
<td>High/Low-EE</td>
<td>-5.921</td>
<td>1.673</td>
<td>-.381</td>
<td>-9.29, -2.55</td>
<td>.001*</td>
<td></td>
</tr>
</tbody>
</table>

Note. *$p < .05$, **$p < .001$ |

5.2.5 Discussion

This study examines the relationship between significant other EE and psychological distress and burden, and found that high-EE is associated with greater significant other distress and burden both cross-sectionally and longitudinally, thus supporting hypotheses 1 and 2. Additionally, significant others in high-EE dyads report poorer relationship quality than those in low-EE dyads, thus supporting hypothesis 1. In support of hypothesis 3, with relationship quality controlled for, high-EE significant others show greater levels of psychological distress and increased burden at follow-up than low-EE significant others. This provides evidence to suggest that EE status can predict significant other burden and distress at 6-month follow-up, over and above the potential effects of relationship quality.
The cross-sectional association between high-EE and higher levels of burden and poorer psychological wellbeing is consistent with previous research on EE in psychiatric and medical conditions (i.e. diabetes, asthma, epilepsy), and dementia populations (Safavi et al., 2015; Wearden et al., 2000). This suggests that significant others’ attitudes and response styles towards the patient, (i.e. critical comments, emotional over involvement and hostility), are associated with their own psychological wellbeing. This may be because high-EE significant others are more likely to perceive the patient as experiencing more difficult symptoms and are less likely to perceive themselves to be coping well with these difficulties than low-EE significant others.

The longitudinal association between high-EE and higher levels of burden and distress is a new finding in the dementia population but is in line with findings of a recent study which found EE to be a significant longitudinal predictor of burden in caregivers of people with an eating disorder (Coomber & King, 2013). Longitudinal studies such as the present one provide an opportunity to evaluate the predictive validity of EE for health related outcomes. However, when interpreting the findings it is important to note that there is likely to be a bi-directional relationship between EE and significant other outcomes, potentially with poorer outcomes contributing to the maintenance of high-EE responses.

In the present study, the diagnosis of dementia had been made within the preceding two years, and patients had mild to moderate levels of symptoms. Previous studies using different theoretical approaches have found that caregivers who use more avoidant coping strategies, report more conflict, and express less tolerant response styles towards the patient, the latter of which may be related to high-EE critical responses, report more subjective burden and increased depression over time (Zarit, Todd, & Zarit, 1986; Goode, Haley, Roth, & Ford, 1998). The present study demonstrates that, even relatively early after the diagnosis of dementia, high-EE is predictive of future significant other distress.
The finding that high-EE significant others experienced a poorer current relationship with the patient than low-EE significant others supports some previous findings (Fearon et al., 1998; Gilhooly & Whittick, 1989; Spruytte et al., 2002). There are however, some inconsistencies in the literature between EE and relationship quality, as shown within a recent meta-analysis of dementia patients and caregivers, possibly due to studies including dyads with different significant other-patient relationships (Safavi et al., 2015). Spouse significant others are more likely to live with the patient and to provide more hours of support without respite. They may also have a closer relationship with the patient than siblings, adult children or other relatives, and therefore changes in relationship quality may be more noticeable (Safavi et al., 2015). As the present study sample consisted mainly of dyads with spouse significant others it was not possible to conduct further exploration of potential differences between relationship subgroups.

It has been proposed that high-EE, particularly criticism, may represent an attempt by distressed relatives to gain more control over patient behaviours that are perceived to be disruptive, upsetting, or unacceptable (Greenley, 1986; Weisman de Mamani, Weintraub, Maura, Martinez de Andino, & Brown, 2017). Significant others’ attempts at social control may be perceived by the patient as overly intrusive and unpleasant and may result in the patient feeling irritated and resentful. Patients’ expression of these feelings may in turn negatively affect the quality of the significant other-patient relationship, further reducing significant other wellbeing (Quinn et al., 2009). Additionally, the excessive demands that significant others who are high in EOI place on themselves may add to their feelings of being burdened and overwhelmed.

Cognitive behavioural interventions can help reduce high-EE by addressing factors which underlie high-EE responses, such as beliefs about the patient’s behaviour, appropriate coping strategies and the quality of the patient-significant other relationship (Tarrier et al., 1988). Offering such interventions to significant others shortly after the patient had been
Diagnosed with dementia might not only reduce EE but could also enhance significant other wellbeing. These interventions would also improve quality of life in those affected by the condition and could increase the length of time persons with dementia are supported within the community (Mohamed, Rosenheck, Lyketsos, & Schneider, 2010). The study has some limitations. The sample recruited to this study may not be representative of all significant others of people with dementia. Those who felt highly burdened or distressed may not have had time to complete the study or may have been too distressed by their situation to take part. It is likely that the relationship between EE, burden and distress would have been more pronounced in a more burdened or distressed population. Only the first author rated EE and therefore no inter-rater reliability could be obtained, although the first author had achieved reliability with the originator of the EE measure. There is also the possibility of interrater drift as the first author rated these interviews approximately 2 years after completing EE training. EE was collected at baseline only, so the reverse pathway between EE and significant other burden and distress could not be tested. It is possible that the relationship between EE, burden and distress reflects a third, unmeasured, confounding variable. The homogenous nature of the sample, primarily spouse-patient dyads, and predominantly female significant others, meant that it was not possible to reliably examine the impact of EE within different patient-significant other relationship types and limits the generalisability to other types of dyads. It is also important to note that the relationship quality scale used for the study replicates a number of key dimensions which overlap with EE (i.e. warmth, affection, conflict and criticism), although our regression analyses suggests that EE predicts distress and burden over and above relationship quality. Nevertheless there are other aspects of relationship quality such as commitment, trust, love and intimacy, not measured here, which may influence the relationship between EE and distress.
This study focused on the relationship between significant other EE and burden and psychological distress. Research examining other sources of or triggers to burden and psychological distress would be beneficial and could further inform psychosocial interventions. Research exploring the impact of illness beliefs, interpersonal social control strategies and relationship quality within the dementia population would inform clinical interventions, such as cognitive behavioural therapy, by elucidating appropriate illness beliefs and coping strategies to target. The potential differences in response styles between spouses, siblings, adult children and other relatives would be worth exploring in further research to help identify the unique contribution that relationship-type might bring to understanding predictors of relative burden and distress.
5.2.6 References


Chapter 6: Expressed Emotion and PWD outcomes

6.1 Outlining the paper

The following paper reports on caregiver EE in association with PWD psychological outcomes (depression, anxiety and quality of life) in cross-sectional and longitudinal analyses. This paper is currently under review for publication in Aging and Mental Health. The findings arising from this study have also been disseminated as oral presentations at the American Psychosomatic Society Annual conference, Louisville, Kentucky, 7-10 March 2018.

Expressed Emotion in caregivers and psychological wellbeing in persons with dementia.

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6.2.1 Abstract

Objectives: Persons with dementia (PWD) experience increased levels of anxiety and depression, which correlates with poorer quality of life, increased disability and hospitalisation. This study uses a longitudinal design to assess the influence of Expressed Emotion (EE) on wellbeing in PWD.

Method: Sixty-one PWD and their caregiver were recruited from UK memory services. Caregiver EE was coded from a modified Camberwell Family Interview conducted at time one. PWD outcome measures (quality of life, depression and anxiety) were collected at time one and at 6 months follow-up.

Results: Fifty-four PWD (89%) completed follow-up measures. Caregiver high-EE was associated with higher levels of PWD depression and greater anxiety at 6 month follow-up. Importantly the effects of EE on PWD outcomes were maintained when controlling for baseline scores of PWD anxiety and depression. Specifically, emotional over involvement predicted greater levels of anxiety and critical comments predicted greater levels of depression. Interestingly, low-EE appeared to have a protective effect on PWD wellbeing as PWD with low-EE caregivers experienced a small reduction in depression and anxiety over time, whereas those with high-EE caregivers maintained baseline levels of depression and anxiety.

Conclusion: Caregiver high-EE is associated with poorer PWD psychological outcomes over time. Clinical interventions focusing on caregivers emotional and behavioural responses to reduce the level of EE could be provided.

Keywords

Expressed Emotion, Dementia, Quality of life, Depression, Anxiety
6.2.2 Introduction

Dementia is a progressive disease of the brain in which there is a disturbance of multiple higher cortical functions, including memory, orientation, comprehension, calculation, learning capacity, language and judgement. These are commonly accompanied by deterioration in emotional control and social behaviour (World Health Organization, 2012). Alzheimer’s disease is the most common form of dementia and contributes to approximately 60 to 70% of cases. Other forms include vascular dementia, dementia with Lewy bodies and frontotemporal dementia (World Health Organization, 2012).

The population is ageing rapidly which means there are a growing number of people with dementia. It is estimated that in 2030, the number of people with dementia will be 66 million and this will further increase to 115 million in 2050 (Wortmann, 2012). The behavioural and psychological symptoms associated with dementia greatly affect the quality of life of people with dementia and their caregivers. No treatments are currently available to cure or alter the progressive course of dementia and therefore it is becoming increasingly important to explore ways to support and improve the lives of people with dementia and their caregivers (World Health Organization, 2012).

The experience of psychological symptoms such as anxiety and depression has been well established within the dementia population (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). It is estimated that 90% of persons with dementia (PWD) experience psychological symptoms over the course of their illness, which has been associated with poor outcomes, increased distress in patients and hospitalisation (Cerejeira et al., 2012). Increased psychological symptoms in PWD is associated with increased burden and poorer general health in caregivers (Black & Almeida, 2004). Caregivers play a key role in the day-to-day support of PWD, often without having gained prior training or knowledge about the condition (Burns, 2000). Without caregivers’ help, PWD would struggle to continue with their daily activities, however caregivers may also be a source of tension and strain.
(Vitaliano, Zhang, & Scanlan, 2003). It is therefore becoming increasingly important to explore the relationship between caregivers and PWD, particularly in persons shortly after diagnosis when people are coming to terms with the diagnosis and renegotiating relationships. The study of early dementia is also important to inform decisions about interventions which might be offered to PWD and their families early in the course of the illness to improve longer term outcomes in wellbeing.

A well-established framework for examining how caregiver factors impact on patient outcomes is the Expressed Emotion (EE) construct (Vaughn & Leff, 1976). EE comprises several key aspects of interpersonal relationships, measured through evaluating the way in which a caregiver talks about the patient and their relationship with them. Caregivers are conventionally classified as high- or low-EE on the basis of evidence for key components of the construct; criticism, hostility, and emotional over involvement (EOI) (Barrowclough & Hooley, 2003; Hooley & Parker, 2006). These components are identified from a semi-structured interview (the Camberwell Family Interview, CFI) where the caregiver talks about the patient. Critical comments are extracted when a caregiver displays strong tonal criticism or provides unambiguous evidence for annoyance, resentment or disapproval of the patient’s behaviours or characteristics. Hostility is indicated by a caregiver making generalised critical comments about the patient, or statements indicating rejection of the patient. EOI is characterised by exaggerated emotional response, over identification with the patient, over-intrusive or self-sacrificing behaviours. The semi-structured CFI is the gold standard method of eliciting evidence for these constructs (Vaughn & Leff, 1976).

Alternative shorter methods of measuring EE have been developed such as the five minute speech sample (FMSS) whereby the caregiver is asked to talk about the patient for 5 minutes and EE ratings similar to those for the CFI are made by a trained rater (Magaña et al., 1986). The perceived criticism scale (PCS) asks patients to rate how critical they think their relative is of them using a Likert scale (Hooley & Teasdale, 1989).
A strong association has been found between caregiver high-EE and poorer patient illness and treatment outcomes, across patients with a range of psychiatric conditions, but also with patients who have a physical health condition (Butzlaff & Hooley, 1998; Wearden et al., 2000). Much of the research has focused on the critical comments element of the construct, however, the importance of looking at the EOI element separately has been noted, as caregivers with high-EOI ratings are likely to display a different range of behaviours and attitudes than those with high critical comment ratings (Barrowclough & Hooley, 2003; Hooley, 1987; Wearden et al., 2000). For example critical caregivers are more likely to display frustration and coercion, whereas emotionally over involved caregivers are more likely to show high levels of concern for the patient, self-sacrificing and intrusive behaviours (Barrowclough & Hooley, 2003). Negative responses such as expression of irritation and frustration have been found to be predictors of increased patient depression, and unhelpful responses such as intrusive behaviours have been found to be associated with elevated levels of anxiety (Band, Wearden & Barrowclough, 2015). It was therefore hypothesised that these constructs and associated response styles are likely to have differing effects on persons’ outcomes.

The research on EE within the dementia field is limited (Safavi et al., 2015). Studies that have explored EE in dementia populations have focused on caregiver outcomes (e.g burden and wellbeing) and their correlates and on symptoms of dementia (cognitive functioning, behavioural disturbances and activity impairment) (Safavi et al., 2015).

The only known longitudinal study, based on a sample of 79 dyads, found relative EE, as measured by the FMSS, was predictive of negative behaviour in PWD, such as being uncooperative, threatening, physically abusive, angry, ungrateful, paranoid and prone to wander (Vitaliano et al., 1993). PWD outcome measures were collected at time one and 15-18 months later, and PWD with high-EE relatives were found to have increased negative behaviours over time, as reported by both the relative and an observer. However,
relatives’ EE was unrelated to PWD decline in cognitive functioning and activities of daily living (Vitaliano et al., 1993).

The studies reviewed above provide some evidence for relationships between EE and PWD behavioural and cognitive symptoms and functioning in the dementia population. However few studies have investigated EE in relation to other important outcomes, specifically PWD psychological wellbeing and adjustment (Safavi et al., 2015). Poorer psychological wellbeing, such as depression and anxiety, in PWD is particularly important as it has been found to be associated with decreased quality of life (Banerjee et al., 2006), higher disability rates, increased cognitive decline, early institutionalisation (Dorenlot et al., 2005) and is of course important in its own right.

The aim of the current study was to examine how caregiver EE is associated with PWD psychological wellbeing in a recently diagnosed dementia population, and to assess these associations both cross-sectionally and longitudinally over 6 months. The 6 month follow-up enables us to evaluate the predictive validity of EE. It was hypothesised that PWD whose caregiver is classified as high-EE would have poorer psychological wellbeing (quality of life, anxiety and depression) than PWD whose caregiver is classified as low-EE. Specifically it was predicted that (1) PWD within high-EE dyads will experience poorer psychological wellbeing at six month follow-up than PWD within low-EE dyads. Furthermore it was predicted that (2) the reduction in psychological wellbeing between baseline and follow-up (6 months later) will be greater in PWD within high-EE dyads than those within low-EE dyads. It was also hypothesised that (3) high level of caregiver EOI will be associated with poorer health related quality of life and higher levels of anxiety in PWD, and (4) that high levels of caregiver critical comments will be associated with higher levels of depression. Poorer cognitive functioning has been found to associate with EE and poorer psychological wellbeing, particularly anxiety and quality of life (Beaudreau &
O'Hara, 2008; Woods et al., 2006) and therefore was measured as a potential confounding variable.

6.2.3 Methods

Participants

Participants aged 18 and over were recruited for the study as dyads; the final sample included 61 PWD and their caregivers. Participants were recruited from specialist National Health Service (NHS) memory services (N = 21), Age UK (N = 7) and Join Dementia Research (JDR; a national service for people to register an interest in participating in dementia research) (N = 33). To be eligible for participation PWD were required to have received a clinician diagnosis of dementia within the past 24 months. In addition, PWD had to have a caregiver who was willing to partake in the study. The caregiver had to be the person with the most day-to-day involvement with the person with dementia and a minimum of 10 hours contact with the person with dementia per week. Both participants were required to have sufficient fluency in English to complete the assessments. Any ongoing conditions that may have impacted on the caregivers’ ability to complete the procedure such as a complex psychiatric illness and/or a major physical illness, was set as an exclusion criterion; however no participants were excluded during recruitment for this reason. No incentives were offered in return for participation and written informed consent was obtained from all participants.

Procedures

Ethical approval was granted from a NHS research ethics committee (13/NW/0836). Questionnaire measures were completed with PWD at an initial interview (time 1) and at a 6 month follow-up interview (time 2). All caregivers were interviewed individually in their
own or PWDs’ homes and were asked to complete questionnaires (time 1 and time 2). All interviews were conducted confidentially, and audio-recorded.

**PWD measures**

The self-report PWD measures were chosen for use in the study as they were deemed suitable for use with persons with mild to moderate dementia. The author carefully explained the measures and sufficient time was allowed for PWD to complete them. Further explanation about the measures was provided to PWD when it was felt necessary.

**Cognitive functioning.** The Montreal Cognitive Assessment (MoCA); a brief cognitive screening tool with high sensitivity for detecting mild cognitive impairment and early Alzheimer’s disease was used to evaluate cognitive functioning as a potential confounder (Nasreddine et al., 2005). The 11 items assess areas of language, visuospatial abilities, memory and recall and abstract thinking to give a representation of a person’s current cognitive ability. There is a total possible score of 30, with any score higher than 25 considered within the normal range (Nasreddine et al., 2005).

**Psychological wellbeing.** The Geriatric Depression Scale (15-item version) (GDS) (Yesavage et al., 1982) was used to measure depression in PWD. The GDS which contains 15 items and requires a “yes” or “no” response, has been validated as a suitable self-report measure for use with older adults with mild to moderate dementia (Sheehan, 2012).

The Geriatric Anxiety Inventory (GAI) (Pachana et al., 2007) was used to measure anxiety in PWD. It consists of 20 “Agree/Disagree” items designed to assess common anxiety symptoms and is a reliable and valid self-report measure for use with older adults with cognitive impairments (Rozzini et al., 2009).

The Dementia Quality of life measure (DEMQOL) (Smith et al., 2007) is an interview-administered measure which obtains self-reports of PWD quality of life. It has been validated as a suitable measure for persons with mild to moderate dementia (Brod, Stewart,
Sands, & Walton, 1999). The DEMQOL consists of 28 items about feelings, memory and everyday life of PWD within the past week. Responses are collected using a four point-Likert scale and a higher overall score represents a greater perceived quality of life (Chua et al., 2016).

Primary caregiver measures

Expressed Emotion (EE). All caregivers took part in a semi-structured interview, the CFI, which is used to assess levels of EE (Vaughn & Leff, 1976). The symptoms section of the CFI was adapted for this study to be relevant to dementia by including dementia specific symptoms such as memory problems and ability to carry out day-to-day tasks. The interviews lasted approximately 1 hour.

Overview of Analyses

EE coding. All CFI interviews were conducted by the first author, who was trained by Christine Vaughn and achieved inter-rater reliability with her, and rated using the conventional criteria (Vaughn & Leff, 1985). An overall rating of High- or Low-EE (HEE and LEE) is made on the basis of critical comments and/or EOI and/or hostility, conventionally caregivers are designated as high-EE when they score 6 or more critical comments, 1 or more hostile remark and/or a score of 3 or more on EOI (Vaughn & Leff, 1985). To enable the assessment of hypotheses for this study, caregivers were first classified on the basis of critical comments (HEE-C and LEE-C), and then reclassified according to EOI (HEE-EOI and LEE-EOI). Caregivers were classified as HEE-C if they made 6 or more critical comments, and classified as HEE-EOI if they demonstrated at least a moderately high level of EOI (a score of ≥ 3) (Vaughn & Leff, 1985).

Statistical data analysis. SPSS version 22 was used to conduct statistical analyses. Examination of skewness, standard error and kurtosis found all measures to be acceptable for normal distribution of the data. No outliers were identified. Comparison analyses of
PWD who completed follow-up and those who did not were conducted for demographic variables, illness related variables and EE measures using $X^2$ for categorical variables, and independent t-tests for continuous variables. In preliminary analyses, the relationships between demographic variables (age, gender, relationships status) and illness related variables (illness duration, cognitive functioning) on the one hand and both PWD outcome variables (quality of life, depression, anxiety) and predictor variables (EE) on the other hand were tested using correlations, chi-squared and independent t-tests to identify any significant associations that may influence the relationship between predictor and outcome variables. These variables are hereafter referred to as confounding variables. For the main hypothesis testing analyses, PWD measures (quality of life, depression and anxiety) at both baseline and follow up, for those with HEE versus LEE caregivers were compared using independent sample t-tests. Subsequently regression analyses were conducted to assess whether caregiver EE-C and EE-EOI predicted PWD outcomes at 6-month follow-up. Baseline measures of the outcome variables were included within the models to control for previous level of functioning.

6.2.4 Results

Sample characteristics

The mean age of PWD was 72 ($SD = 10.08$), ranging from 50 to 93. The mean age of caregivers was 66 ($SD = 12.05$), ranging from 29 to 88. The mean number of years PWD had been experiencing dementia symptoms was 3.26 ($SD = 1.92$), as reported on by caregivers. Four caregivers were unable to report on this. Table 13 contains a summary of the descriptive characteristics of PWD and their primary caregiver at baseline.
Sample at six-month follow-up

Fifty-four PWD (89% of baseline sample) completed the follow-up measures. Comparison analyses identified that there were no significant differences on demographic variables, illness related variables or PWD measures at baseline for those participants who completed follow-up compared with those who did not. Additionally, no significant differences were identified in caregiver EE variables (overall EE, critical comments, hostility or EOI).

Descriptive data summary for EE

At baseline, 17 (28%) caregivers received a rating of overall HEE. Twenty four (39%) caregivers made no critical comments. The median was one critical comment, ranging from 0 critical comments to 14 critical comments. Nine (15%) caregivers made six or more critical comments, meeting the conventional threshold for a HEE-C rating. In addition, six (10% of the total sample) of these critical caregivers demonstrated evidence for hostile behaviours or attitudes. As expected, hostility always occurred in conjunction with HEE-C within the sample. On the EOI scale, 19 (31%) caregivers demonstrated no EOI (i.e., a rating of zero), and the median level was rated as ‘some EOI’ (equivalent to a score of 2) within the sample, ranging from 0 (no EOI) to 5 (high EOI). Using the conventional criterion level of 3 or above, ten (16%) caregivers were classified as HEE-EOI, with eight (13%) caregivers achieving HEE status based on evidence for HEE-EOI only. Two (3.3%) caregivers were categorised as HEE based on reaching the conventional threshold for both critical comments and EOI.
Table 13: Descriptive characteristics of PWD and caregivers (N = 61)

<table>
<thead>
<tr>
<th></th>
<th>PWD</th>
<th>Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>34 (55.7)</td>
<td>21 (34.4)</td>
</tr>
<tr>
<td>Female</td>
<td>27 (44.3)</td>
<td>40 (65.6)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>57 (93.4)</td>
<td>53 (86.9)</td>
</tr>
<tr>
<td>Mixed / multiple ethnic groups</td>
<td>0 (0.0)</td>
<td>2 (3.3)</td>
</tr>
<tr>
<td>Asian / Asian British</td>
<td>1 (1.6)</td>
<td>3 (4.9)</td>
</tr>
<tr>
<td>Black/African/Caribbean</td>
<td>2 (3.2)</td>
<td>1 (1.6)</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>1 (1.6)</td>
<td>2 (3.3)</td>
</tr>
<tr>
<td>Relationship status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>2 (3.3)</td>
<td>2 (3.3)</td>
</tr>
<tr>
<td>Married/civil partnership</td>
<td>49 (80.3)</td>
<td>56 (91.8)</td>
</tr>
<tr>
<td>Widowed</td>
<td>8 (13.1)</td>
<td>2 (3.3)</td>
</tr>
<tr>
<td>Divorced</td>
<td>2 (3.3)</td>
<td>1 (1.6)</td>
</tr>
<tr>
<td>Living status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with the caregiver</td>
<td>49 (80.3)</td>
<td>-</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>23 (47.7)</td>
<td>19 (31.1)</td>
</tr>
<tr>
<td>Further education</td>
<td>14 (23.0)</td>
<td>21 (34.4)</td>
</tr>
<tr>
<td>Higher education</td>
<td>17 (27.9)</td>
<td>20 (32.8)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (11.5)</td>
<td>1 (1.6)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Disease</td>
<td>41 (67.2)</td>
<td>-</td>
</tr>
<tr>
<td>Young onset Alzheimer’s Disease</td>
<td>5 (8.2)</td>
<td>-</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>7 (11.5)</td>
<td>-</td>
</tr>
<tr>
<td>Frontal lobe dementia</td>
<td>4 (6.6)</td>
<td>-</td>
</tr>
<tr>
<td>Mixed dementia</td>
<td>2 (3.3)</td>
<td>-</td>
</tr>
<tr>
<td>Lewy body dementia</td>
<td>2 (3.3)</td>
<td>-</td>
</tr>
<tr>
<td>Relationship with PWD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>-</td>
<td>48 (78.7)</td>
</tr>
<tr>
<td>Son/daughter</td>
<td>-</td>
<td>10 (16.4)</td>
</tr>
<tr>
<td>Daughter in law</td>
<td>-</td>
<td>1 (1.6)</td>
</tr>
<tr>
<td>Niece</td>
<td>-</td>
<td>1 (1.6)</td>
</tr>
<tr>
<td>Close friend</td>
<td>-</td>
<td>1 (1.6)</td>
</tr>
</tbody>
</table>
Descriptive summary of PWD measures

Mean (SD) scores and reliability estimates on PWD measures at baseline and follow up are shown in Table 14.

Table 14: PWD measures at baseline and follow-up

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th></th>
<th></th>
<th>Follow-up (6 month later)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>A</td>
<td>Mean</td>
<td>SD</td>
<td>A</td>
</tr>
<tr>
<td>DEMQOL</td>
<td>89.72</td>
<td>15.25</td>
<td>0.92</td>
<td>94.37</td>
<td>12.25</td>
<td>0.91</td>
</tr>
<tr>
<td>GDS</td>
<td>4.33</td>
<td>3.4</td>
<td>0.82</td>
<td>3.8</td>
<td>3.55</td>
<td>0.87</td>
</tr>
<tr>
<td>GAI</td>
<td>3.31</td>
<td>4.9</td>
<td>0.93</td>
<td>2.43</td>
<td>3.81</td>
<td>0.90</td>
</tr>
</tbody>
</table>

Note. Dementia quality of life scale (DEMQOL); Geriatric depression scale (GDS); Geriatric anxiety inventory (GAI).

Preliminary Analyses

There were no significant associations between any of the potential demographic or illness related variables (age, gender, relationships status, illness duration, cognitive functioning) and PWD outcomes (quality of life, depression, anxiety) or EE.

Expressed Emotion and Cross-Sectional PWD Outcomes

There were no significant cross-sectional associations between caregiver EE status and PWD quality of life (DEMQOL), depression (GDS) and anxiety (GAI) measured at baseline.
Expressed Emotion and Longitudinal (6 month follow-up) PWD Outcomes

Main analyses. Comparisons of high- and low-EE groups (i.e. 6+ critical comments, 1+ hostility and/or 3+ EOI) were conducted for PWD psychological wellbeing outcomes at follow-up using independent sample t-tests. The results are shown in Table 15. In line with study predictions PWD with a HEE caregiver at baseline had significantly higher levels of depression at follow-up, but this result was due to PWD with low-EE caregivers experiencing a reduction in depression between baseline and follow up (see Table 15). Contrary to predictions, quality of life and anxiety in PWD at follow-up were not significantly associated with HEE. To test hypotheses 3 and 4, the specific impact of the components of EE, that is critical comments (HEE-C and LEE-C) and EOI (HEE-EOI and LEE-EOI) on depression, quality of life and anxiety was examined. In line with predictions, PWD with a HEE-C caregiver at baseline had significantly higher levels of depression at follow-up, with LEE-C once again associated with declining depression scores over the six month period. However, contrary to predictions, PWD with a HEE-EOI caregiver at baseline did not have significantly reduced quality of life or greater anxiety at follow up.

Regression analyses. A series of regression analyses were conducted to determine whether caregiver EE independently predicted PWD scores on the outcome measures at follow-up when baseline scores were controlled for. In line with study predictions caregiver HEE significantly predicted depression severity at follow-up and anxiety severity at follow-up (see Table 16).

Regression analyses were conducted to examine the individual impact of critical comments and EOI. Caregiver HEE-C significantly predicted greater depression severity at follow-up. Once baseline depression was added to the model, HEE-C remained a significant predictor. This was repeated for anxiety and quality of life in PWD. When entered alone, and also
with baseline measures, primary caregiver HEE-EOI significantly predicted greater anxiety reported at follow-up. However, HEE-EOI did not significantly predict quality of life in PWD (see Table 17).

Table 15: PWD mean outcome measures at baseline and 6-month follow-up and significant t-tests

<table>
<thead>
<tr>
<th>PWD mean at baseline</th>
<th>PWD mean at follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>LEE</td>
<td>HEE</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>DEM QOL</td>
<td></td>
</tr>
<tr>
<td>92.05 (13.26)</td>
<td>83.71 (18.63)</td>
</tr>
<tr>
<td>N = 44</td>
<td>N = 17</td>
</tr>
<tr>
<td></td>
<td>-1.69</td>
</tr>
<tr>
<td></td>
<td>22.55</td>
</tr>
<tr>
<td></td>
<td>.105</td>
</tr>
<tr>
<td></td>
<td>97.10 (8.41)</td>
</tr>
<tr>
<td></td>
<td>87.27 (17.36)</td>
</tr>
<tr>
<td></td>
<td>N = 39</td>
</tr>
<tr>
<td></td>
<td>N = 15</td>
</tr>
<tr>
<td>GDS</td>
<td></td>
</tr>
<tr>
<td>3.70 (2.83)</td>
<td>5.94 (4.24)</td>
</tr>
<tr>
<td>N = 44</td>
<td>N = 17</td>
</tr>
<tr>
<td></td>
<td>2.01</td>
</tr>
<tr>
<td></td>
<td>21.77</td>
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<tr>
<td></td>
<td>2.87</td>
</tr>
<tr>
<td></td>
<td>6.20</td>
</tr>
<tr>
<td></td>
<td>2.52</td>
</tr>
<tr>
<td></td>
<td>16.59</td>
</tr>
<tr>
<td></td>
<td>.022*</td>
</tr>
<tr>
<td>GAI</td>
<td></td>
</tr>
<tr>
<td>2.91 (4.18)</td>
<td>4.35 (6.36)</td>
</tr>
<tr>
<td>N = 44</td>
<td>N = 17</td>
</tr>
<tr>
<td></td>
<td>.866</td>
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<tr>
<td></td>
<td>21.54</td>
</tr>
<tr>
<td></td>
<td>.396</td>
</tr>
<tr>
<td></td>
<td>1.64</td>
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<tr>
<td></td>
<td>4.47</td>
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<tr>
<td></td>
<td>1.94</td>
</tr>
<tr>
<td></td>
<td>16.73</td>
</tr>
<tr>
<td></td>
<td>.070</td>
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<table>
<thead>
<tr>
<th>LEE-C</th>
<th>HEE-C</th>
</tr>
</thead>
<tbody>
<tr>
<td>GDS</td>
<td></td>
</tr>
<tr>
<td>3.83 (2.94)</td>
<td>7.22 (4.52)</td>
</tr>
<tr>
<td>N = 52</td>
<td>N = 9</td>
</tr>
<tr>
<td></td>
<td>2.17</td>
</tr>
<tr>
<td></td>
<td>9.21</td>
</tr>
<tr>
<td></td>
<td>.057</td>
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<tr>
<td></td>
<td>3.09</td>
</tr>
<tr>
<td></td>
<td>7.33</td>
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<tr>
<td></td>
<td>2.30</td>
</tr>
<tr>
<td></td>
<td>8.76</td>
</tr>
<tr>
<td></td>
<td>.048*</td>
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<table>
<thead>
<tr>
<th>LEE-EOI</th>
<th>HEE-EOI</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEM QOL</td>
<td></td>
</tr>
<tr>
<td>90.14 (15.47)</td>
<td>87.82 (14.78)</td>
</tr>
<tr>
<td>N = 50</td>
<td>N = 11</td>
</tr>
<tr>
<td></td>
<td>-.454</td>
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<tr>
<td></td>
<td>59</td>
</tr>
<tr>
<td></td>
<td>.651</td>
</tr>
<tr>
<td></td>
<td>94.56</td>
</tr>
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<td>93.44</td>
</tr>
<tr>
<td></td>
<td>-.246</td>
</tr>
<tr>
<td></td>
<td>52</td>
</tr>
<tr>
<td></td>
<td>.807</td>
</tr>
<tr>
<td>GAI</td>
<td></td>
</tr>
<tr>
<td>3.60 (5.12)</td>
<td>2.00 (3.41)</td>
</tr>
<tr>
<td>N = 50</td>
<td>N = 11</td>
</tr>
<tr>
<td></td>
<td>-.986</td>
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<td></td>
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<td>.860</td>
</tr>
<tr>
<td></td>
<td>9.29</td>
</tr>
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<td>.411</td>
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</table>

Note. *p < .05, **p < .001. Dementia quality of life scale (DEMQOL); Geriatric depression scale (GDS); Geriatric anxiety inventory (GAI).
Table 16: Summary of hierarchical regression analysis for EE predicting PWD scores on outcome measures at 6 month follow-up (N = 54)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Δ R²</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>95% CI</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outcome: PWD quality of life (DEMOLQ) at 6 month follow-up</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td></td>
<td>.366</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline quality of life</td>
<td></td>
<td>.516</td>
<td>.092</td>
<td>.615</td>
<td>.332, .700</td>
<td><strong>.000</strong></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td>.392</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline quality of life</td>
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<td>.094</td>
<td>.557</td>
<td>.278, .656</td>
<td><strong>.000</strong></td>
</tr>
<tr>
<td>High/Low-EE</td>
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<td>5.445</td>
<td>3.033</td>
<td>.201</td>
<td>-.645, 11.535</td>
<td>.079</td>
</tr>
<tr>
<td><strong>Outcome: PWD depression score (GDS) at 6 month follow-up</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td></td>
<td>.599</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline depression</td>
<td></td>
<td>.814</td>
<td>.091</td>
<td>.779</td>
<td>.632, .997</td>
<td><strong>.000</strong></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td>.623</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline depression</td>
<td></td>
<td>.750</td>
<td>.093</td>
<td>.717</td>
<td>.562, .938</td>
<td><strong>.000</strong></td>
</tr>
<tr>
<td>High/Low-EE</td>
<td></td>
<td>-1.455</td>
<td>.702</td>
<td>-.185</td>
<td>-2.865, -0.045</td>
<td><strong>.043</strong></td>
</tr>
<tr>
<td><strong>Outcome: PWD anxiety score (GAI) at 6 month follow-up</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td></td>
<td>.384</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline anxiety</td>
<td></td>
<td>.507</td>
<td>.087</td>
<td>.629</td>
<td>.332, .681</td>
<td><strong>.000</strong></td>
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<tr>
<td>Step 2</td>
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<td>.421</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline anxiety</td>
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<td>.472</td>
<td>.086</td>
<td>.586</td>
<td>.299, .644</td>
<td><strong>.000</strong></td>
</tr>
<tr>
<td>High/Low-EE</td>
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<td>-1.853</td>
<td>.898</td>
<td>-.220</td>
<td>-3.655, -.052</td>
<td><strong>.044</strong></td>
</tr>
</tbody>
</table>

Note: *p < .05, **p < .001
Table 17: Summary of hierarchical regression analysis for critical comments and expressed over involvement predicting PWD scores on outcome measures at 6 month follow-up (N=54)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Δ R²</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>95% CI</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outcome: PWD depression (GDS) at 6 month follow-up</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td>.599</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline depression</td>
<td>.814</td>
<td>.091</td>
<td>.779</td>
<td>.632, .997</td>
<td>.000**</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td>.626</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Baseline depression</td>
<td>.715</td>
<td>.099</td>
<td>.684</td>
<td>.551, .944</td>
<td>.000**</td>
<td></td>
</tr>
<tr>
<td>Critical comments</td>
<td>.199</td>
<td>.091</td>
<td>.206</td>
<td>-3.249, .307</td>
<td>.034*</td>
<td></td>
</tr>
</tbody>
</table>

| **Outcome: PWD quality of life (DEMQOL) at 6 month follow-up** |     |       |      |    |        |        |
| Step 1                 | .366|       |      |    |        |        |
| Baseline quality of life| .516| .092  | .615 | .332, .700 | .000** |
| Step 2                 | .354|       |      |    |        |        |
| Baseline quality of life| .516| .093  | .615 | .330, .703 | .000** |
| High/Low-EOI           | -.025| 3.602| -.001| -7.256, 7.207 | .995  |

| **Outcome: PWD anxiety (GAI) at 6 month follow-up** |     |       |      |    |        |        |
| Step 1                 | .384|       |      |    |        |        |
| Baseline anxiety       | .507| .087  | .629 | .332, .681 | .000** |
| Step 2                 | .430|       |      |    |        |        |
| Baseline anxiety       | .529| .084  | .657 | .360, .698 | .000** |
| High/Low-EOI           | -2.40| 1.06  | -.237| -4.519, -.277 | .027*  |

Note. *p < .05, **p < .001
6.2.5 Discussion

This study examined the impact of caregiver EE on depression, anxiety and quality of life in persons with a diagnosis of dementia within the past 2 years. In support of hypothesis 1, caregiver high-EE was associated with poorer outcomes in PWD at follow-up, particularly with respect to depression and anxiety. Regarding hypothesis 2, we had expected that PWD with high-EE caregivers would show increased depression severity and increased anxiety severity over time, i.e. between baseline and 6 month follow-up, than those with low-EE caregivers. What we in fact saw was that levels of depression and anxiety in PWD with high-EE caregivers were maintained, while levels of depression and anxiety in PWD with low-EE caregivers declined. In support of hypothesis 3, high levels of emotional overinvolvement were found to be predictive of greater anxiety at follow-up compared to PWD with low-EE-EOI caregivers, however contrary to predictions caregiver EOI was not found to be predictive of PWD quality of life. In support of hypothesis 4, high levels of critical comments were found to be predictive of greater levels of depression at follow-up compared to PWD with low-EE-criticism caregivers. There were no significant cross-sectional associations between caregiver and quality of life, anxiety and/or depression in PWD with a recent diagnosis of dementia, which suggests that EE was exerting influence over time.

The rates of high-EE fall within the prevalence rates found in other studies of caregivers of PWD (Li & Murray, 2015). The findings from this study are consistent with the idea that caregiver EE predicts PWD psychological outcomes over time. Inspection of Table 15 reveals that the effects may be explained by low-EE having a protective effect on wellbeing in PWD, who experienced a reduction in depression and anxiety symptoms over time, while those with high-EE caregivers maintain baseline levels of depression and anxiety. PWD with low-EE caregivers are likely to be encouraged to be more independent and experience more warmth and positive remarks than those with high-EE caregivers.
which may result in improvements in mood and reduced anxiety in PWD. Furthermore, after receiving a diagnosis of dementia persons are more likely to spend increasing amounts of time with their caregiver, and therefore more likely to be influenced by the protective effect of low-EE. The predictive validity of high-EE is consistent with previous literature which has shown patients within high-EE dyads display poorer illness and treatment outcomes (Band, Barrowclough, & Wearden, 2014; Barrowclough & Hooley, 2003; Dunkin & Anderson-Hanley, 1998; Wearden et al., 2000). Few studies have investigated the correlation between caregiver EE and persons’ outcomes in dementia and those that have looked at PWD outcomes have focused on functional impairment and behavioural disturbances as opposed to psychological wellbeing (Wagner et al, 1997; Vitaliano, Becker, Russo, Magana-Amato, & Maiuro, 1988, Vitaliano et al 1993; Teri, Hughes & Larson, 1990). One cross-sectional study of persons with Alzheimer’s disease measured PWD depression through the SADS interview conducted with primary relatives, along with the CED-S which was completed by relatives on behalf of the person with dementia (Wagner et al., 1997). Similar to our study, the authors did not find a cross-sectional relationship between relative EE, as measured through the FMSS, and the level of depression in persons with Alzheimer’s disease. The reason for the lack of cross-sectional relationship in Wagner et al’s (1997) study may be due to the inclusion of relatives of persons with a probable or possible diagnosis of dementia, and therefore the symptomology is likely to be different from persons with a firm diagnosis of dementia. Furthermore, the authors themselves acknowledged that there was insufficient variability in PWD depression to effectively explore the relationship between relatives’ EE status and PWD severity of depression.

In line with the study hypotheses, the critical comments and EOI elements of the EE construct were investigated separately. The positive association between EOI and PWD anxiety is consistent with research in other illness groups (Hooley, 2007; Wearden et al.,
High-EOI caregivers are likely to display emotional and behavioural responses such as exaggerated emotional response, over identification with the person, over-protectiveness, self-sacrifice, and excessive use of praise or blame (Barrowclough & Hooley, 2003). PWD in high-EOI dyads may feel particularly anxious as a result of the highly intrusive and controlling behaviours as well as the high levels of emotion displayed towards them. This may result in a reduction in their confidence and belief in their ability to cope and function with the diagnosis of dementia. Increased anxiety in PWD has also been found to relate to poorer quality of life, night-time behavioural disturbances, problem behaviours, limitations in activities of daily living, nursing home placement prospectively and accelerated cognitive decline (Seignourel, Kunik, Snow, Wilson, & Stanley, 2008; Teri, Hughes, & Larson, 1990). This highlights the negative impact of increased anxiety in person with a diagnosis of dementia. The lack of relationship between caregiver EE and the person with dementia’s quality of life may be explained by the inclusion of persons within the early stages of their diagnosis who are likely to still be engaging with activities of daily living and maintaining independence thus feeling a sense of achievement and purpose.

The significant relationship between high levels of critical comments and greater depression in PWD at follow-up is in line with previous literature which has found an association between critical comments and greater patient depression, and it supports the idea that caregiver critical comments may be related to negative response styles (Band et al., 2014; Kuipers et al., 2006). High-C caregivers are likely to express negative attitudes about patient behaviours, blame the patient for their behaviours, make generalised critical remarks and/or demonstrate rejection of the patient (Barrowclough & Hooley, 2003). PWD in high-C dyads may feel particularly depressed as a result of the highly critical and hostile remarks. This may result in an increase in their own negative self-critical thoughts and reduce their confidence, which can lead to more negative rumination, withdrawal and
isolation. Studies have consistently found depression in persons with Alzheimer’s Disease to be associated with additional disability, particularly in relation to greater functional impairment, behavioural disturbances (such as aggression) and wandering, despite comparable levels of cognitive impairment, thus indicating the detrimental effect depression can have on a person with dementia (Lyketsos et al., 1997; Teri et al., 1992).

The association between EE subtypes and affective symptoms are concerning because increased anxiety and depression have been linked to increases in functional impairment and behavioural disturbances (Teri & Wagner, 1992), as well as being an important outcome in their own right.

**Limitations and Strengths**

The sample was a convenience sample and it is possible that the process of recruitment could have introduced some level of bias. For example, highly critical caregivers may have been less likely to participate, which may have reduced the effects seen. The low prevalence of critical comments and EOI may be representative of the population of caregivers of PWD. Furthermore, the low prevalence of critical comments and EOI may lead to reduced power in detecting significant associations. Only the first author rated EE and therefore no inter-rater reliability could be obtained, although the first author had achieved reliability with the originator of the EE measure. There is also the possibility of interrater drift as the first author rated these interviews approximately 2 years after completing EE training. There has been suggestion that relationship type may influence EE (Band et al., 2014). The homogeneous nature of the current sample, predominantly spouse-PWD dyads, limited statistical power for examining the impact of EE within other relationship types and limits the generalisability to other types of dyads. It is possible that factors external to caregiver EE, such as other illnesses, bereavement and social isolation may be predicting PWD psychological wellbeing as these were not assessed.
Despite these limitations, this study has several strengths. First, unlike much of the previous research that has relied upon caregiver reports of PWD symptoms, we asked PWD to complete psychological wellbeing measures to eliminate the effect of caregiver EE bias on wellbeing ratings. Second, to our knowledge, this is the first study to explore caregiver EE and PWD psychological outcomes and wellbeing. This focus expands on previous literature which has explored caregiver EE and persons’ symptoms of dementia, and thus provides a more holistic picture of how caregiver EE is related to PWD outcomes. Third, the CFI, the gold standard measure of EE, was used to measure caregiver EE within the study. Lastly, the longitudinal design spanned approximately 6 months which enabled us to look at the predictive validity of caregiver EE, in comparison to other studies which have primarily used cross-sectional designs and therefore have not examined EE as a predictor.

Future directions

This study focused on the association between caregiver EE and PWD outcomes. However, research examining the relationship between caregiver beliefs, attributions and their emotional and behavioural responses would be beneficial in developing interventions to modify relative beliefs which drive unhelpful responding. Further work into the source of criticism, such as a content analysis of critical comments, may also be beneficial as this would highlight perceptions underlying critical attitudes which could then be modified via clinical interventions such as cognitive behavioural therapy. Research on the protective nature of low-EE is generally lacking and would also be beneficial in identifying caregiver responses which promote PWD psychological wellbeing. A better understanding of LEE could be used to inform clinical interventions which encourage and promote adaptive responding. This study involved primarily spouse-PWD relationships, therefore research to
clarify the relational processes in dyads by examining the association between EE and caregiver relationship type would be also beneficial (Safavi et al., 2015).

Conclusions
This study is the first to document the association between caregiver EE and persons’ psychological outcomes, such as depression and anxiety, within a dementia sample. The findings suggest that caregiver high-EE is associated with poorer PWD psychological outcomes over time, particularly depression and anxiety, and conversely, that having a LEE caregiver may be protective. The results provide the rationale for clinical interventions, such as cognitive behavioural therapy, to measure caregiver EE, deliver psycho-educational material on dementia symptomology, explore beliefs and provide coping strategies. Such interventions would aim to address caregiver emotional and behavioural responses that may inadvertently contribute to psychological wellbeing in PWD.
6.2.6 References


Chapter 7: Caregiver distress and psychological symptoms in PWD

7.1 Outlining the paper

This paper reports on the relationship between caregiver distress and criticism, and psychological wellbeing of PWD. The paper also examines whether criticism mediates the association between caregiver distress and PWD psychological wellbeing. This paper is currently under review for publication in Family, Systems and Health. The findings arising from this study are due to be disseminated as oral presentations at the European Health Psychology Society Conference, Galway, Ireland, 21-25 August 2018.

7.2 Paper 4: Critical comments mediate the association between caregiver distress and psychological symptoms in persons recently diagnosed with dementia.
Critical comments mediate the association between caregiver distress and psychological symptoms in persons recently diagnosed with dementia.

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7.2.1 Abstract

Objectives: Caregivers of persons with dementia (PWD) experience high levels of burden and distress and may employ criticism in an attempt to change the behaviour of PWD and thereby reduce their distress. We hypothesised that caregiver distress and criticism would each have an impact on the psychological wellbeing of the person with dementia, and examined whether criticism mediates the association between caregiver distress and PWD psychological wellbeing.

Methods: Sixty-one persons with a recent diagnosis of dementia and their caregiver were recruited via UK dementia services and assessed at two time points 6 months apart. Caregivers completed questionnaire measures of burden and distress. Critical comments were coded from a Camberwell Family Interview. PWD completed questionnaire measures of quality of life, depression and anxiety. Correlation, regression and mediation analyses were conducted to explore the relationship between caregiver variables and PWD psychological outcomes, and whether criticism mediated any relationship found.

Findings: Caregiver distress, caregiver critical comments and PWD anxiety and depression at baseline and 6 month follow-up, were all significantly correlated. Baseline caregiver distress predicted poorer quality of life in PWD at 6 month follow-up. The effect of caregiver distress on PWD quality of life was significantly \( (p < .01) \) mediated by the number of caregiver critical comments.

Discussion: Interventions addressing caregiver burden and distress and offering coping strategies to help them to reduce criticism of the person with dementia would improve the quality of life of those affected by dementia.

Keywords

Dementia is a term used to describe several diseases which progressively affect a person’s memory, cognitive functioning and ability to carry out activities of daily living. The most common form of dementia is Alzheimer’s disease, accounting for approximately 60-70% of all cases. Vascular dementia, dementia with Lewy bodies and frontotemporal dementia are other major forms of dementia. In 2015, dementia was reported to have affected approximately 47 million people worldwide, and this figure is predicted to rise to 75 million in 2030 and 132 million in 2050 (World Health Organisation, 2017).

Behavioural and psychological symptoms of dementia are common, affecting up to 90% of persons with dementia (PWD) (Feast et al., 2016; Mukherjee et al., 2017). Research has shown that increased anxiety in persons with a recent diagnosis of dementia, can be predictive of decline in learning and memory functioning (Bierman, Comijs, Jonker, Scheltens, & Beekman, 2009; Gallacher et al., 2009). It has also been well documented that caregivers of PWD experience increased level of burden and psychological distress (Safavi et al., 2015), which as well as being important in their own right, have been found to correlate with poorer quality of life, physical health decline, poorer life satisfaction and sleep disorders (Abreu, Rodrigues, Sequeira, Pires, & Sanhudo, 2017). However, many relatives do report positive aspects of caring such as satisfaction, emotional reward, personal growth, and relationship gains (Lloyd, Patterson, & Mueers, 2016).

People living with a person with poor psychological wellbeing are at greater risk of psychological symptoms themselves (Benazon & Coyne, 2000). Research within the cancer population has shown that there is a positive relationship between patient and caregiver psychological distress (Hodges, Humphris, & Macfarlane, 2005; Ko et al., 2005). This supports the idea that if one member of the dyad becomes distressed, it is likely that the other member will do so also (Manne, 1998). While there is no known research exploring this issue in dementia, it is likely that PWD who spend time with a highly
distressed caregiver may be at greater risk of experiencing psychological symptoms themselves. Exploring the relationship between caregiver distress and psychological outcomes in persons with a recent diagnosis of dementia would enable us to see whether caregiver distress predicts PWD wellbeing early on. This would provide a rationale for intervening early to improve wellbeing in PWD as well as reducing any acceleration of decline in learning and memory functioning. Furthermore, by understanding factors that mediate this relationship we can gain an insight in the implementation of interventions which target identified areas of difficulty.

Researchers have become interested in examining strategies that help caregivers manage their caregiving role, and these strategies may mediate the relationship between caregiver distress and PWD wellbeing. Hinrichsen and Niederehe (1994) identified three strategies which caregivers use to manage dementia-related problems; 1) criticism, (caregivers efforts to manage the patient by yelling, criticising, threatening and using negative emotional tone), 2) encouragement, (caregivers efforts to praise the patient, offer emotional support and use positive emotional tone), and 3) active management (caregivers efforts to modify difficult situations through offering assistance and avoiding conflict). More distressed caregivers tend to use strategies such as criticism for attempting to influence the patient’s behaviour (Di Mattei et al., 2008; Powers, Gallagher-Thompson, & Kraemer, 2002). Caregivers who use these non-adaptive management strategies encounter more behavioural and psychological symptoms (hyperactivity, mood/apathy and psychosis related symptoms) in PWD than caregivers who use supportive strategies such as adapting to needs, stimulating existing abilities and patience (de Vugt et al., 2004).

The Expressed Emotion (EE) construct is a well-established method of exploring key aspects of interpersonal relationships and how families cope with caring for a person with a psychological or physical health condition, and provides a well-validated measure of caregiver criticism (Brown, 1985; Vaughn & Leff, 1976). Ratings of EE are usually made
by evaluating the way in which a caregiver talks about the patient and their relationship with them during the Camberwell Family Interview (CFI). EE includes measurements of critical comments (conventionally regarded as the principal scale), hostility, emotional over involvement (EOI), warmth and positive comments. Criticism is operationalised as the total count of critical comments elicited from the CFI (Wearden et al., 2000); critical comments are statements about the behaviour or characteristic of the patient which the respondent resents or is annoyed by. Given the consistent association between high levels of caregiver distress and high-EE across conditions (Safavi et al., 2015; Safavi et al., in press; Wearden et al., 2000), caregiver EE-critical comments, will be explored as a potential mediator of the relationship between caregiver distress and PWD psychological outcomes in the present study.

The aim of the study is to expand the current literature by examining how caregiver psychological distress is associated with wellbeing in a recently diagnosed dementia population. This was explored both cross-sectionally and longitudinally over a period of 6 months to enable us to evaluate the predictive validity of caregiver distress. Firstly, we predicted that high levels of caregiver distress at baseline would be correlated with poor PWD psychological symptoms (quality of life, depression, anxiety) at baseline. Secondly, we predicted that higher levels of caregiver distress would be correlated with higher numbers of critical comments. Thirdly, we predicted that both higher levels of caregiver distress and higher number of critical comments would be correlated with higher levels of PWD psychological symptoms at 6 month follow-up. Fourthly, we predicted that the higher the level of distress in caregivers at baseline, the greater the deterioration in PWD psychological outcomes there would be. Lastly, we predicted that levels of critical comments would mediate any associations between caregiver distress at baseline and poorer PWD psychological outcomes at 6 month follow-up. Figure 5 outlines a
hypothesised model between caregiver distress, critical comments, and PWD psychological symptoms.

**Figure 5: Diagram showing the hypothesised relationship between caregiver distress, critical comments and PWD psychological wellbeing.**

![Diagram of the hypothesised relationship]

7.2.3 Methods

Participants

Participants were required to have a diagnosis of dementia within the past 24 months and a caregiver who was willing to take part in the study. The caregiver was required to have a minimum of 10 hours weekly contact with the person with dementia. Both participants had to be aged 18 or over and were required to be fluent in English. Any condition affecting the caregivers’ ability to complete the interview and measures was set as an exclusion criterion; however no participant was excluded from the study for this or any other reason.
Caregiver measures

**Expressed Emotion.** The CFI, which is the gold standard measure of EE (Vaughn & Leff, 1976), was revised for this study to incorporate dementia symptoms such as cognitive functioning and activities of daily living. The CFI was used to measure critical comments. Criticism may be evident in a) the content of the comment or b) the vocal aspects of speech i.e. the tone, speed and vocal variation (Vaughn & Leff, 1985).

**Psychological distress.** Caregiver psychological distress was measured using the Clinical Outcomes in Routine Evaluation; CORE (Barkham et al., 1998; Evans et al., 2002). The CORE has good internal consistency and consists of 10 items which assess depression, anxiety, functioning, trauma and relationships (Barkham et al., 2013). Responses are made on a five point-Likert scale and a higher score is indicative of higher levels of distress.

PWD measures

**Quality of life.** The Dementia Quality of life measure (DEMQOL) (Smith et al., 2007) has been validated as an appropriate interview-administered self-report measure for persons with mild to moderate dementia (Brod et al., 1999). The questionnaire is designed to assess PWD feelings, memory and day-to-day life over the past week. Responses to the 28 items are made on a four point-Likert scale and a higher score is indicative of greater quality of life (Chua et al., 2016).

**Depression.** Depression in PWD was measured using the Geriatric Depression Scale (GDS) (Yesavage et al., 1982). The scale, which has been validated as a suitable self-report measure for use with older adults with mild to moderate dementia (Sheehan, 2012), consists of 15 items requiring a “yes” or “no” response, with higher scores indicating greater levels of depression.

**Anxiety.** The Geriatric Anxiety Inventory (GAI) (Pachana et al., 2007), which consists of 20 “agree/disagree” items, was used to assess levels of anxiety in PWD. It is a valid self-
report measure for use with older persons who have cognitive impairments (Rozzini et al., 2009) and a higher score is indicative of higher levels of anxiety.

**Procedures**

A National Health Service (NHS) research ethics committee (13/NW/0836) granted ethical approval. PWD completed questionnaires on quality of life and psychological symptoms at baseline (time 1) and at 6 month follow-up (time 2). Caregivers completed the CFI, which took approximately 1 hour, at time 1. The interview, conducted by the first author, was audio recorded and later transcribed. Critical comments were extracted using the conventional criteria (Vaughn & Leff, 1985) and an overall critical comment count was calculated for each caregiver. Caregivers also completed a questionnaire on distress at time 1 and time 2. All interviews and questionnaires were completed independently within the participant’s own home. Informed written consent was gained from all participants and no incentives for participation were offered.

**Overview of Analyses**

**Statistical analysis.** All statistical analyses were conducted using SPSS version 22. Skewness, standard error and kurtosis indicated that all PWD and caregiver measures were within acceptable limits of normality. No outliers were identified. Demographic variables, illness-related variables and outcome measures for those who completed follow-up were compared to those that did not. Demographic variables (age, gender, relationships status) were compared with caregiver variables (distress, critical comments) and PWD outcome variables (quality of life, anxiety, depression) to identify any significant associations that may influence the relationship between caregiver and PWD variables. Correlation analyses between caregiver measures and PWD measures were performed using Pearson’s product-moment correlation. These analyses were conducted at baseline and repeated at follow-up.
Regression analyses were conducted to explore caregiver variables in predicting PWD outcomes of psychological symptoms at 6 month follow-up. PWD baseline measures were included in the regression analysis to control for previous levels of psychological symptoms.

**Mediation analysis.** The mediational role of critical comments between caregiver distress and PWD psychological symptoms, as outlined in Figure 1, was run using an SPSS macro introduced by Preacher and Hayes (2008). Mediation is said to exist if the following criteria are met: (1) the predictor (caregiver distress) has a significant direct effect on the criterion variable (PWD quality of life); (2) the predictor (caregiver distress) has a significant effect on the mediator (caregiver critical comments); (3) the mediator (caregiver critical comments) predicts individual variance in the criterion (PWD quality of life); and (4) the direct effect from predictor (caregiver distress) to the criterion (PWD quality of life) is significantly reduced after controlling for the indirect effect produced by the mediator (caregiver critical comments) (Baron & Kenny, 1986). Bootstrapping, namely resampling random subsets of data to yield more valid estimates of the indirect effects of interest, was used. The mediation analysis is based on 5000 resamples. The null hypothesis was rejected when the 95% confidence interval did not include zero (Preacher & Hayes, 2008).

### 7.2.4 Results

**Sample characteristics**

The sample consisted of 61 dyads, comprising 33 dyads from an online research network (Join Dementia Research), 21 dyads from NHS memory services and 7 dyads from Age UK. Table 18 contains a summary of the descriptive characteristics of PWD and their caregiver at baseline
<table>
<thead>
<tr>
<th></th>
<th>PWD</th>
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<th>Caregiver</th>
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<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>M, SD, (range)</td>
<td>N (%)</td>
<td>M, SD (range)</td>
</tr>
<tr>
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<td>-</td>
<td>3.26, 1.92, (1-12)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
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<tr>
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<td>34 (55.7)</td>
<td>-</td>
<td>21 (34.4)</td>
<td>-</td>
</tr>
<tr>
<td>Female</td>
<td>27 (44.3)</td>
<td>-</td>
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<td>-</td>
</tr>
<tr>
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<td>53 (86.9)</td>
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<td>-</td>
</tr>
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<td>-</td>
<td>1 (1.6)</td>
<td>-</td>
</tr>
<tr>
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<td>-</td>
<td>2 (3.3)</td>
<td>-</td>
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<td></td>
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<tr>
<td>Relationship status</td>
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<tr>
<td>Single</td>
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<td>2 (3.3)</td>
<td>-</td>
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<tr>
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<td>56 (91.8)</td>
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<td>2 (3.3)</td>
<td>-</td>
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<td>-</td>
<td>1 (1.6)</td>
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<tr>
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<td>-</td>
<td>-</td>
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<td>Education</td>
<td></td>
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</tr>
<tr>
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<td>19 (31.1)</td>
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<td>20 (32.9)</td>
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<td>Alzheimer’s Disease</td>
<td>41 (67.2)</td>
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<td>-</td>
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<td>-</td>
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<tr>
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<td></td>
</tr>
<tr>
<td>Disease</td>
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<td>-</td>
<td>-</td>
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<td>7 (11.5)</td>
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<td>-</td>
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<td>4 (6.6)</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Mixed dementia</td>
<td>2 (3.3)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Lewy body dementia</td>
<td>2 (3.3)</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Relationship with patient</td>
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<td></td>
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<td>-</td>
<td>48 (78.7)</td>
<td>-</td>
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<td>-</td>
<td>10 (16.4)</td>
<td>-</td>
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<td>Daughter in law</td>
<td>-</td>
<td>-</td>
<td>1 (1.6)</td>
<td>-</td>
</tr>
<tr>
<td>Niece</td>
<td>-</td>
<td>-</td>
<td>1 (1.6)</td>
<td>-</td>
</tr>
<tr>
<td>Close friend</td>
<td>-</td>
<td>-</td>
<td>1 (1.6)</td>
<td>-</td>
</tr>
</tbody>
</table>

*Note. N = number, M = mean, SD = standard deviation*
Sample at six-month follow-up
Fifty-four PWD (89% of baseline sample) and fifty-one caregivers (83% of baseline sample) took part in the follow-up measures. Comparison analysis of demographic variables, illness-related variables, baseline questionnaire measures and critical comments showed that there were no significant differences between participants that completed follow-up and those that did not.

Expressed Emotion
Twenty four caregivers made no critical comments (39%). The mean number of critical comments was 2.34 ($SD = 3.50$). The median was one critical comment, ranging from 0 critical comments to 14 critical comments. Nine (15%) caregivers made six or more critical comments.

Descriptive summary of caregiver and PWD measures
Mean ($SD$) scores and reliability estimates on caregiver and PWD measures at baseline and follow up are shown in Table 19.
Table 19: Caregiver distress and PWD anxiety, depression and quality of life at baseline and 6 month follow-up

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th></th>
<th>Six month follow-up</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>A</td>
<td>Mean</td>
</tr>
<tr>
<td>Caregiver distress</td>
<td>8.89</td>
<td>5.28</td>
<td>0.71</td>
<td>10.31</td>
</tr>
<tr>
<td>(CORE 10)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD Quality of life</td>
<td>89.72</td>
<td>15.25</td>
<td>0.92</td>
<td>94.37</td>
</tr>
<tr>
<td>(DEMQOL)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD depression</td>
<td>4.33</td>
<td>3.4</td>
<td>0.82</td>
<td>3.8</td>
</tr>
<tr>
<td>(GDS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD anxiety</td>
<td>3.31</td>
<td>4.9</td>
<td>0.93</td>
<td>2.43</td>
</tr>
<tr>
<td>(GAI)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Clinical outcomes in routine evaluation 10 (CORE-10), Dementia quality of life scale (DEMQOL); Geriatric depression scale (GDS); Geriatric anxiety inventory (GAI).

Preliminary Analyses

No significant associations were found between potential demographic variables (age, gender, relationships status) or illness-related variables (illness duration, cognitive functioning) and PWD measures (quality of life, depression, anxiety) or caregiver measures (psychological distress, critical comments).

Cross-Sectional analysis: Caregiver and PWD measures

Correlation analyses. Correlation analyses were conducted between caregiver distress at baseline, caregiver critical comments at baseline and PWD psychological wellbeing measures at baseline. In line with study predictions, there was a significant correlation between caregiver distress and caregiver critical comments ($r = .333, p = .009$), PWD...
depression \((r = .318, \ p = .013)\) and PWD anxiety \((r = .401, \ p = .001)\) at baseline. Contrary to predictions, the correlation between caregiver distress and PWD quality of life at baseline did not reach significance \((r = -.237, \ p = .066)\).

**Longitudinal analysis: Caregiver and PWD measures**

**Correlation analyses.** Correlation analyses were conducted between baseline caregiver measures and PWD psychological wellbeing measures at follow-up. In line with study predictions there were significant correlations between caregiver distress and PWD quality of life \((r = -.359, \ p = .008)\), PWD depression \((r = .290, \ p = .033)\) and PWD anxiety \((r = .432, \ p = .001)\) as well as between caregiver critical comments and PWD quality of life \((r = -.464, \ p = .000)\) and PWD depression \((r = .521, \ p = .000)\). Contrary to predictions, the correlation between caregiver critical comments and PWD anxiety did not reach significance \((r = .266, \ p = .052)\).

**Regression analyses.** A series of regression analyses were conducted to determine whether caregiver distress independently predicted PWD scores on the outcome measures at follow-up when baseline scores were controlled for. In line with study predictions caregiver distress at baseline significantly predicted poorer quality of life in PWD at follow-up. However, contrary to predictions, caregiver distress did not significantly predict PWD depression or anxiety at follow-up once baseline levels of these variables had been controlled for (see Table 20).
Table 20: Summary of regression analysis for caregiver distress predicting PWD scores on outcome measures at 6 month follow-up (N = 54)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Δ R²</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>95% CI</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outcome: PWD quality of life at 6 months follow up</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td>.366</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline quality of life</td>
<td></td>
<td>.516</td>
<td>.092</td>
<td>.615</td>
<td>.332, .700</td>
<td>.000**</td>
</tr>
<tr>
<td>Step 2</td>
<td>.418</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline quality of life</td>
<td></td>
<td>.476</td>
<td>.090</td>
<td>.568</td>
<td>.297, .656</td>
<td>.000**</td>
</tr>
<tr>
<td>Caregiver distress</td>
<td></td>
<td>-.573</td>
<td>.242</td>
<td>-.253</td>
<td>-1.059, -.087</td>
<td>.022*</td>
</tr>
<tr>
<td><strong>Outcome: PWD depression at 6 months follow up</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td>.599</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline depression</td>
<td></td>
<td>.814</td>
<td>.091</td>
<td>.779</td>
<td>.632, .997</td>
<td>.000**</td>
</tr>
<tr>
<td>Step 2</td>
<td>.594</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline depression</td>
<td></td>
<td>.797</td>
<td>.096</td>
<td>.762</td>
<td>.603, .990</td>
<td>.000**</td>
</tr>
<tr>
<td>Caregiver distress</td>
<td></td>
<td>.036</td>
<td>.061</td>
<td>.055</td>
<td>-.085, .158</td>
<td>.551</td>
</tr>
<tr>
<td><strong>Outcome: PWD anxiety at 6 months follow up</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td>.384</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline anxiety</td>
<td></td>
<td>.507</td>
<td>.087</td>
<td>.629</td>
<td>.332, .681</td>
<td>.000**</td>
</tr>
<tr>
<td>Step 2</td>
<td>.417</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline anxiety</td>
<td></td>
<td>.437</td>
<td>.091</td>
<td>.543</td>
<td>.254, .621</td>
<td>.000**</td>
</tr>
<tr>
<td>Caregiver distress</td>
<td></td>
<td>.159</td>
<td>.080</td>
<td>.226</td>
<td>-.002, .319</td>
<td>.052</td>
</tr>
</tbody>
</table>

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

**Mediation analyses.** Caregiver critical comments were correlated with both caregiver distress and PWD quality of life, and higher levels of caregiver distress were predictive of poorer quality of life in PWD even when baseline quality of life scores were controlled for.
Therefore conditions were met to allow for the potential mediation of the caregiver-distress-PWD quality of life relationship by critical comments to be formally tested. As can be seen in Figure 6, the first and second conditions of mediation analysis were supported as caregiver distress was found to be a significant predictor of PWD quality of life and caregiver critical comments. The third condition was also supported as caregiver critical comments significantly predicted reduced PWD quality of life after controlling for caregiver distress. Lastly, the direct effect of caregiver distress on PWD quality of life was reduced when caregiver critical comments were in the equation. Using 5000 resampling iterations, the confidence intervals associated with the indirect effect (via critical comments) of caregiver distress on PWD quality of life did not contain zero (95% CI = -.86, -.01). Thus, the effect of caregiver distress on PWD quality of life was significantly \( p < .01 \) mediated by the number of caregiver critical comments (see Figure 6).

**Figure 6: Mediation model of caregiver distress, critical comments and PWD quality of life.**

![Mediation Model Diagram](image)

- .814** (without CC)
  - .515 (with CC)
- .232*
- 1.288**

Note. *\( p < .05 \), **\( p < .001 \)
As the initial regression analyses did not show a significant relationship between caregiver
distress and PWD depression and anxiety mediation analyses were not performed for these
outcome variables.

7.2.5 Discussion

The study explored the relationship between caregiver distress and psychological
symptoms (quality of life, depression, anxiety) in persons with a recent diagnosis of
dementia. In support of hypothesis 1, there was a significant correlation between increased
distress in caregivers and greater baseline psychological symptoms in PWD, with respect
to depression and anxiety. However in contrast to predictions caregiver distress was not
found to correlate with PWD quality of life at baseline. In support of hypothesis 2, there
was a significant correlation between high levels of distress in caregivers and higher
numbers of critical comments. In support of hypothesis 3, there was a significant
correlation between both caregiver distress and higher numbers of critical comments and
PWD psychological symptoms at follow-up. In support of hypothesis 4, caregiver distress
was found to be predictive of PWD quality of life, however contrary to predictions
caregiver distress was not found to be predictive of PWD depression or anxiety. In support
of hypothesis 5, the effect of caregiver distress on PWD quality of life was significantly
mediated by the number of caregiver critical comments about the person with dementia’s
behaviour or characteristic.

The cross-sectional relationship between greater levels of psychological symptoms in
PWD, particularly with respect to depression and anxiety, and greater levels of distress
among caregivers is consistent with previous research (Black & Almeida, 2004; Ornstein
& Gaugler, 2012). Caregivers in high levels of distress are more likely to make negative
judgements about their situation, use avoidance, report more conflict and feel disconnected
and irritable (Stephens, Norris, Kinney, Ritchie, & Grotz, 1988) and previous research has
also shown a relationship between increased distress and increased critical comments (Safavi et al., 2015). The cognitive, emotional and behavioural responses from highly distressed caregivers may result in PWD feeling helpless and concerned about their relative and consequently experience higher levels of depression and anxiety. Within the present study the weaker and non-significant cross-sectional relationship between PWD quality of life and caregiver distress may be explained by the dementia quality of life scale measuring a broad range of symptoms including affect, memory and functioning. It is likely that in a population of persons with recently diagnosed dementia there may be relatively little deterioration in memory and functioning at baseline.

Much of the previous research exploring the relationship between caregiver distress and PWD psychological symptoms has used a cross-sectional design. Studies that have used a longitudinal design have focused on the impact PWD symptoms have on caregiver distress and/or burden. To our knowledge, this is the first study to examine the effect caregiver distress has on PWD psychological symptoms over a period of 6 months. Longitudinal research is particularly important as it gives us the potential to explore the predictive power of caregiver distress. The findings demonstrate that a greater level of distress in caregivers and a higher number of critical comments are associated with higher levels of depression and anxiety, and poorer quality of life in PWD 6 months later. This supports the idea that a greater level of distress experienced in family relationships and being subjected to more critical comments may result in persons becoming more self-critical and feeling less confident, and thus may play a causal role in reduced quality of life and poorer emotional wellbeing of people living in the distressed environment (Randall & Bodenmann, 2009). Furthermore, the findings provide evidence that caregiver distress predicts PWD quality of life over time when controlling for baseline measures, thus PWD whose caregiver is experiencing greater levels of distress showed more deterioration in quality of life than those whose caregiver was experiencing less distress.
The findings of this study are particularly important because they suggest by implementing interventions which are aimed at reducing caregiver distress, which is important in its own right, there is also the indirect potential to improve PWD psychological symptoms. Caregiver distress was not found to be predictive of depression and anxiety in PWD, which suggests factors external to caregiver distress such as illness appraisals, personal characteristics, illness factors and environmental factors, which were not measured within the present study, may have a greater direct impact on depression and anxiety in PWD (Cotrell & Schulz, 1993b).

The findings from the mediation analysis are consistent with the idea that caregivers who experience high levels of distress are more likely to make more critical comments about the person with dementia, which in turn affects psychological symptoms in PWD, particularly quality of life. Research suggests that critical comments made by relatives are reflective of their underlying beliefs that patients could do more to control their symptoms, and their use of criticism is a way of trying to exert control over the patient and/or situation (Barrowclough & Hooley, 2003). The attributional data suggests that implementing interventions which are aimed at changing attributional beliefs may decrease criticism. Combined with enhancing adaptive strategies (adapting to needs, stimulating abilities and patience), caregivers may feel better equipped and less distressed which may lead to improvements in PWD quality of life.

The sample was a convenience sample, and therefore it may not be representative of caregivers who may have felt too distressed to take part in the study. It is also possible that factors other than having a highly distressed caregiver may have contributed to psychological symptoms in PWD, such as social isolation and health concerns, which were not measured within this study. The sample primarily consisted of spouse-PWD dyads and therefore may not be representative of other relationships such as siblings and adult children, which limits the generalisability of the findings to other dyad types. It is also
important to acknowledge that the power calculation for the study was below the conventional power level of 80%. However a power level of 67% (as for this study) is close to the conventional cut off and the findings are consistent with previous literature thus suggesting there is little evidence to question to reliability of the findings. Despite these limitations, the study has numerous strengths. Firstly, the CFI, the gold standard measure of EE, was used to elicit caregiver critical comments. Secondly, we eliminated the effect of caregiver bias by asking PWD to self-report psychological symptoms. This differs to much of the previous research which has relied on caregiver reports of PWD symptoms. Thirdly, to our knowledge, this is the first study to look at the impact of caregiver distress on psychological symptoms in PWD. The longitudinal design enabled us to look at the predictive validity of caregiver distress, which gives us a clearer understanding of how caregiver factors relate to and influence outcomes in PWD.

This study focused on the association between caregiver distress and psychological outcomes in PWD. However, research examining the source of caregiver psychological distress and the source of critical comments (e.g. underlying beliefs about the illness or the person’s ability to control their behaviour) would be beneficial in highlighting potential triggers to distress which could be used to inform clinical interventions. Research exploring other caregiver factors, such as beliefs about dementia which may contribute to adaptive and non-adaptive strategies would be of benefit. This insight would guide the implementation of clinical interventions to target illness beliefs and enhance adaptive coping strategies. It would also be beneficial to explore other PWD factors such as illness beliefs, which may contribute to psychological symptoms. Identifying such factors would guide the implementation of interventions and support for PWD to provide understanding and target beliefs. Research examining the role of relationship history and quality in caregiver distress and PWD psychological outcomes, would guide the implementation of
couples interventions which would aim to target potential relationship factors that influence distress.
7.2.6 References


Ornstein, K., & Gaugler, J. E. (2012). The problem with “problem behaviors”: a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient–caregiver dyad. *International Psychogeriatrics*, 24(10), 1536-1552.


Safavi, R., Wearden, A., & Berry, K. (in press). Expressed Emotion in significant others of people with a recent diagnosis of dementia predicts increased significant others’ burden and distress. *Journal of Family Psychology*.


Chapter 8: General discussion

This chapter will provide a summary of the key findings presented within the previous chapters of the thesis. These key findings will then be discussed within the context of the wider literature. The strengths and weaknesses of the studies will also be discussed and the practical and clinical implications of the studies will be identified and key questions for future research will be proposed.

8.1 Key findings

8.1.1 Paper One: Expressed Emotion in relatives of persons with dementia: a systematic review and meta-analysis

A total of 12 published articles were identified which examined EE in caregivers of PWD and factors associated with caregiver EE. Six of these studies were included in a meta-analysis of caregiver EE and psychological wellbeing. The studies consistently found the presence of high-EE in caregivers of PWD, however, the rate of high-EE among this group was lower than caregivers of persons with psychiatric disorders. In relatives of persons with a psychiatric disorder the prevalence of high-EE is estimated to be between 45% to 75% (Hooley, Rosen, & Richters, 1995), whereas in relatives of PWD the prevalence of high-EE has ranged from 17% (Orford et al., 1987) to 44% (Bledin et al., 1990). There are several possible reasons for the differing prevalence rates across patient populations. It has been suggested that caregivers are likely to be more critical when patients experience periods of improvement as sometimes happens with psychiatric patients, whereas there is often continued deterioration in symptoms in PWD (Wearden et al., 2000).

One major area of interest has been on factors that may underlie relative responses, particularly the beliefs that high- and low-EE relatives hold about the patient and their illness. It has been suggested that these beliefs are likely to mediate different strategies to cope with patient symptoms and behaviour (Greenley, 1986; Hooley, 1987). For example, Greenley (1986) suggested that relatives who were more distressed, fearful and anxious
about the condition, which he predicted was more likely to be prevalent in high-EE relatives, would be more likely to try and control or change the patient’s behaviour. The systematic review also highlighted that critical and/or hostile relatives are more likely to make attributions to factors personal to and controllable by the patient, as opposed to low-EE relatives whose attributions about the illness are more likely to reflect factors universal to, and uncontrollable by the patient (Barrowclough & Hooley, 2003; Brewin, MacCarthy, Duda, & Vaughn, 1991). Hoe, Cooper and Livingston (2013) suggested that a caregiver’s attribution may be reflective of their understanding of dementia, or their attempts to diminish or deny the effects of the illness. This supports a study on partners of persons with early-stage dementia (i.e. a MMSE of 18/30 or above) whereby some partners had difficulty accepting and understanding the diagnosis, and were found to minimise the PWD’s problems or denying the diagnosis of dementia (Quinn, Clare, Pearce, & van Dijkhuizen, 2008). This may have implications for clinicians working with caregivers of PWD, particularly in relation to the delivery and content of information provided about the disease during the early-stages of dementia.

Dementia is a progressive illness which causes memory loss, disorientation and confusion, among many other symptoms (World Health Organization, 2017). Therefore relatives of PWD may be less likely to perceive the person with dementia to have control of their symptoms or difficulties. This may explain the lower rates of EE in the dementia population, as well as the diverse natural course of dementia itself. Furthermore, caregivers may become less critical as they realise the person with dementia is dependent on them, in contrast to other conditions whereby the level of dependency is more likely to fluctuate. In contrast, high-EOI relatives are less likely to blame the patient for their behaviour, and instead view the patient as an unfortunate victim of a severe condition (Barrowclough, Johnston, & Tarrier, 1994; Hooley, 1987). Moreover, high-EE-EOI has been associated to beliefs similar to those of low-EE relatives whereby the patient’s illness is perceived to be
caused by factors external to and uncontrollable by the patient (Barrowclough, Tarrier, & Johnston, 1996; Brewin et al., 1991). As a consequence, high-EOI relatives are more likely to attempt to improve the situation by using themselves as a buffer between the patient and the outside world, thus using self-sacrificing and intrusive behaviours in an attempt to control things themselves (Barrowclough & Hooley, 2003). For this reason, higher rates of EOI may be expected within the dementia population where there is likely to be a continual deterioration in symptoms and levels of functioning, as opposed to psychiatric populations where there is likely to be periods of wellness.

The review highlighted that high-EE caregivers were found to make more causal attributions for patient problems that are personal to and controllable by the patient, have less effective coping strategies, less social support and less opportunity for respite than low-EE caregivers. These findings are supportive of attributional research within psychiatric and mental health populations, whereby high-EE-critical relatives are more likely to attribute problems as personal to and controllable by the patient than low-EE relatives (Amaresha & Venkatasubramanian, 2012; Barrowclough et al., 1996; Barrowclough et al., 1994; Hooley & Licht, 1997; Weisman, Nuechterlein, Goldstein, & Snyder, 1998; Wendel, Miklowitz, Richards, & George, 2000).

Studies in the review consistently found a cross-sectional relationship between high-EE in caregivers and higher levels of burden and poorer psychological wellbeing, which replicated findings in psychiatric and medical populations (Wearden et al., 2000). More recently, the conclusions drawn from the review, outlined in Chapter 2, have been supported by research within psychiatric populations (Jansen, Gleeson, & Cotton, 2015), mental health populations (Bailey Rachel & Grenyer Brin, 2014), substance misuse populations (Kronenberg, Goossens, van Busschbach, van Achterberg, & van den Brink, 2016) and dementia populations (Li & Murray, 2015). A recent study, with a sample of 123 Chinese primary caregivers of relatives with dementia, found a positive correlation
between high-EE, as measured by the FAS, and greater levels of burden and poorer mental health in caregivers (Yu, Kwok, Choy, & Kavanagh, 2016). These findings provide more recent evidence, within the field of dementia, to support the systematic review outlined in Chapter 2.

The association between EE and dyads relationship quality was inconsistent. The discrepant findings may be due to the inclusion of different dyads (i.e. spouse, adult offspring, siblings and niece). Spouses and adult offspring are likely to have different experiences of caregiving. This is because the marital relationship differs to the parent-offspring relationship in terms of duration, intimacy, commitment and history (Quinn et al., 2009). Spouse caregivers are more likely to experience a gradual loss of a supportive companion with whom they are no longer able to share mutual activities or hobbies (DeLongis & O’Brien, 1990). Whereas adult offspring caregivers may have difficulties within the relationship due to a change from dominance to dependency on the part of the PWD (Lewis & Meredith, 1988). Furthermore, adult offspring caregivers are more likely to experience difficulties in balancing their caregiving role with their other responsibilities (i.e. work and family) as well as their relationships with others (i.e. partner, children and friends) (DeLongis & O’Brien, 1990).

Moreover, research has suggested that different relatives are likely to hold different beliefs about the patient and their illness as well as use different coping strategies (Wilcox, O’Sullivan, & King, 2001). Wilcox et al. (2001) explored the difference in coping strategies, using the Revised Ways of Coping Checklist, between 71 female caregivers of persons with dementia, 39 of whom were wives and the remaining 32 where daughters. They found daughters were more likely than wives to use problem-focused coping, and adaptive strategy. Daughters and wives were also found to use maladaptive strategies such as avoidance, self-blame and blame of others. However, it was suggested that the significantly higher levels of problem-focused coping in daughters may protect against the
potentially negative effects of the maladaptive strategies. This highlights that the inclusion of different types of dyads is likely to influence emotional and behavioural responses displayed by relatives.

There are numerous ways to measure the relationship quality between caregiver-PWD dyads, as outlined within a recent review by Quinn, Clare and Woods (2009) such as the pre-caregiving relationship, current relationship, intimacy, affection, marital relationship etc. The measurement of different aspects of the relationship quality, as outlined with the systematic review (Paper 1; Chapter 2) may also provide an explanation for the incongruent findings between EE and relationship quality.

8.1.2 Limitations in the current evidence base

A number of limitations were identified within the current evidence base which has been outlined in the preceding chapters of the thesis. (1) The numerous methods used for measuring EE makes it difficult to compare findings to the wider literature. The CFI is the conventional method used to assess EE. However, due to the labour intensive nature of the CFI, alternative measures have been identified. This includes the FMSS where the relative talks about the patient for 5 uninterrupted minutes, and questionnaires such as the PCS, LEES, FEICS and FAS, as outlined in Chapter 1, section 1.4.2. Nonetheless, two reviews have concluded that the CFI continues to be the measure of choice for the assessment of EE (Hooley & Parker, 2006; Van Humbeeck et al., 2002).

(2) The studies that have explored the relationship between EE and caregiver outcomes have relied upon a cross-sectional design which therefore limits the ability to explore the predictive value of EE in caregiver outcomes. (3) There has been little research on the relationship between caregiver EE and outcomes in PWD despite the considerable evidence demonstrating an association between EE and outcomes in persons with mental and physical health conditions (Wearden et al., 2000). (4) The few studies that have looked at the relationship between caregiver EE and outcomes in PWD have relied upon a cross-
sectional design, as seen with EE and caregiver outcomes, which limits the ability to make conclusions about causality.

(5) The studies which have explored caregiver EE and outcomes in PWD have primarily relied upon caregiver reports of symptomatology in PWD. This introduces the possibility of common method variance in associations found because the measures of EE are also derived from caregivers. Common method variance occurs when variation in responses is attributed to the measurement method and/or source rather than to the concepts the measures are expected to represent (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003). If common method variance causes a significant difference between true and observed relationships then method bias is said to be present (Ostroff, Kinicki, & Clark, 2002). In self-report questionnaire studies, if the same method/source (e.g. caregivers) is used to measure multiple constructs (e.g. EE, caregiver outcomes and PWD outcomes) this may result in bias occurring in the observed relationship between the measured constructs (Richardson, Simmering, & Sturman, 2009). The use of different methods and response formats for gathering data within this research (e.g. a semi-structured interview and questionnaires) also reduces common method variance (Podsakoff et al., 2003).

(6) Despite the high prevalence of psychological symptoms in PWD, as outlined in Chapter 1; section 1.3.1, there is no known research on the influence of caregiver EE on psychological outcomes in PWD. This area is of particular importance as the high prevalence of psychological outcomes in PWD is well reported and have been found to increase PWD distress, impair cognitive functioning, reduce daily functioning, increase health care costs and increase mortality rates (Ballard et al., 2000; Enache et al., 2011; Janzing et al., 1999; Seignourel et al., 2008). (7) The preceding chapters highlights that both caregivers and PWD experience psychological distress. It is known that persons cohabiting with someone with high psychological distress are likely to be at greater risk of poor psychological symptoms themselves (Benazon & Coyne, 2000). However, the
relationship between psychological distress in caregivers and PWD has not been explored within the dementia population.

The high prevalence of psychological symptoms in caregivers of PWD and the consequence of these symptoms, as outlined in Chapter 1, section 1.2, highlights the importance of exploring correlates of caregiver distress within the field of dementia. This would help in identifying factors for clinicians to target within clinical interventions in order to reduce the level of distress experienced by caregivers of PWD. Data collected from a large study; the London and the South East Region Alzheimer’s Disease (LASER-AD) study was used to examine the prevalence of psychological conditions in caregivers. Almost 25% of 153 caregivers in this study reported anxiety, and 10% reported symptoms of depression, both as measured by the hospital anxiety and depression scale (HADS) (Mahoney, Regan, Katona, & Livingston, 2005). Most caregivers in this sample were older therefore the levels of anxiety and depression in caregivers were compared to the general population of older adults. They found that the prevalence of caregiver anxiety to be higher than the general population, whereas depression was not found to be higher. Mahoney, Regan, Katona and Livingston (2005) suggested the lower rates may be due to clinicians effectively targeting caregiver depression, for example through medication and/or clinical interventions, as well as the use of psychological measures in previous studies which attributed psychological morbidity to depression as opposed to anxiety. The findings from the LASER-AD study show that caregivers of PWD experience higher levels of psychological distress than the general population.

In light of the limitations outlined above, the rationale for the first empirical study (Paper 2) was developed to explore the cross-sectional and longitudinal relationship between caregiver EE and caregiver outcomes, particularly burden and distress. In doing so it was important to use a well-validated measure of EE and therefore the CFI was selected for the reasons outlined in Chapter 1, section 1.4.2. Time was also taken when selecting caregiver
measures to assess burden and psychological distress. It was important to ensure both measure were fairly brief as caregivers were asked to complete these in addition to the CFI. Furthermore, it was crucial that the measure for burden was suitable for caregivers of PWD and that the distress measure covered a broad range of symptoms as distress can be experienced in different ways (i.e. anxiety, depression, functioning, relationships etc.).

The design of the second empirical study (Paper 3) was also in line with the identified limitations. This was to explore the relationship between caregiver EE, as measured by the CFI, and outcomes in PWD, particularly focusing on psychological wellbeing. A longitudinal design was chosen to enable questions about causality to be explored. Consideration was also given when choosing outcome measures for PWD as it was important to limit common method variance by selecting measures that were suitable for PWD to complete, as outlined in Chapter 4, section 4.5.2.

The third empirical study (Paper 4) was designed with the methodological limitations in mind and aimed to examine the relationship between caregiver distress and psychological symptoms in PWD. Both caregiver and PWD outcome measures were carefully selected for the reasons outlined for the first and second empirical studies. A longitudinal approach enabled us to evaluate the predictive validity of caregiver distress. The measure of critical comments, as elicited from the CFI, allowed for the exploration of factors that may mediate the relationship between caregiver distress and psychological symptoms in PWD.

8.1.3 Paper Two (Chapter 5): Expressed Emotion, burden and distress in significant others of people with dementia.

The aim of the first empirical paper was to examine burden and psychological distress in persons with a recent diagnosis of dementia. This was achieved by examining the cross-sectional and longitudinal relationship between EE, caregiver burden, caregiver distress and caregiver-PWD relationship quality.
Within this study, the prevalence of high-EE in caregivers of PWD identified was in line with EE research within the dementia field (Li & Murray, 2015), however the rates of EE was lower than EE observed within other samples including those with schizophrenia and depression (Li & Murray, 2015; Wearden et al., 2000). It has been suggested that that high-EE may be higher in populations where there are periods of wellness such as schizophrenia and depression, as opposed to medical populations where there is likely to be a continued deterioration in symptoms such as dementia (Brewin et al., 1991). As predicted, high-EE was found to be associated with greater burden and psychological distress in caregivers at both baseline and the follow-up after six months. High-EE caregivers reported a poorer relationship quality with the person with dementia than low-EE caregivers. When relationship quality was controlled for, further analyses demonstrated that high-EE caregivers experienced increased burden and greater levels of psychological distress at follow-up than low-EE caregivers.

The findings of the first empirical study build on previous literature by demonstrating that EE has predictive validity in caregiver burden and psychological distress. It also highlighted the importance of the relationship quality between caregivers and PWD. The importance of relationship quality is in support of Quinn et al’s (2009) review of the literature. They highlighted that caring for a person with dementia can influence the relationship quality between caregiver and PWD. Furthermore, they concluded that the quality of the caregiver-PWD relationship has an impact on caregiver wellbeing, mainly that poor relationship quality has a negative impact on caregiver wellbeing. Data collected from the LASER-AD study also showed that a poor-quality of relationship between the caregiver and care recipient predicted both caregiver depression and anxiety (Mahoney et al., 2005). Quinn et al (2009) also concluded that a poor quality of relationship affects the quality of care they provide towards the care recipient. The findings reported in Paper 2 provide support for the early implementation of caregiver interventions, utilising verbal
and non-verbal reattribution methods, which are aimed at reducing the level of EE and enhancing the quality of relationship between caregivers and PWD.


The aim of the second empirical study was to explore the relationship between caregiver EE and psychological wellbeing (depression, anxiety, quality of life) in persons with a recent diagnosis of dementia. These associations were examined both cross-sectionally and longitudinally over a period of six months. The follow-up enabled us to evaluate the predictive validity of EE in the psychological wellbeing of PWD.

Caregiver high-EE was found to be associated with poorer psychological wellbeing in PWD, particularly with respect to depression and anxiety. Within the study it was predicted that PWD with high-EE caregivers would show increased levels of depression and anxiety between baseline and six month follow-up than those with low-EE caregivers. However, it was established that low-EE had a protective effect on wellbeing in PWD, as PWD with low-EE caregivers experienced a reduction in depression and anxiety symptoms over time, while those with high-EE primary caregivers maintained baseline levels of depression and anxiety. Research has highlighted the importance of looking at the critical and EOI element of the EE construct separately as caregivers with high critical comment ratings are likely to display a different range of behaviours and responses to caregivers with high EOI ratings (Barrowclough & Hooley, 2003; Hooley, 1987; Wearden et al., 2000). In line with this, the study examined the critical comment and EOI ratings separately. High levels of EOI were found to be predictive of greater anxiety at follow-up compared to PWD with caregivers with low levels of EOI, however, contrary to predictions caregiver EOI was not found to be predictive of quality of life in PWD. High levels of critical comments were found to be predictive of greater levels of depression at follow-up compared to PWD with low-EE-criticism caregivers.
This is the first known study to report on the association between caregiver EE and psychological wellbeing in PWD. The findings outlined in Paper 3 demonstrate that caregiver high-EE is associated with poorer psychological outcomes in PWD over time, particularly with respect of depression and anxiety, and conversely, that having a low-EE caregiver may be protective. However, the research on the protective nature of low-EE is generally lacking and further research would be beneficial in identifying primary caregiver responses which promote PWD psychological wellbeing. These findings suggest that clinical interventions, such as cognitive behavioural therapy (CBT), that are aimed at addressing caregiver emotional and behavioural responses may inadvertently contribute to psychological wellbeing in PWD.

8.1.5 Paper Four (Chapter 7): Critical comments mediate the association between caregiver distress and psychological symptoms in persons recently diagnosed with dementia.

The aim of empirical study 3 was to build on the existing literature by examining the relationship between caregiver distress and psychological wellbeing in persons with a recent diagnosis of dementia. This relationship was explored both cross-sectionally and longitudinally. The longitudinal design enabled the exploration of the predictive validity of caregiver distress. Research has consistently demonstrated a relationship between high-EE and high levels of distress, therefore critical comments, which have been labelled the key element of the EE construct, was explored as a potential mediator between caregiver distress and wellbeing in PWD.

As predicted there was a significant correlation between high levels of distress in caregivers and greater levels of PWD psychological symptoms at baseline, with respect to depression and anxiety. The findings demonstrated that greater levels of distress in caregivers and higher numbers of critical comments were associated with higher levels of depression, anxiety and poorer quality of life in PWD at six month follow-up. When
controlling for baseline measures, high levels of distress in caregivers were found to be predictive of poorer quality of life in PWD, and this relationship was significantly mediated by the number of critical comments made by the caregiver.

Paper 4 builds on the previous literature as it is the first known study to report on the relationship between caregiver distress and psychological symptoms in PWD. The findings suggest that by implementing clinical interventions, such as CBT, which are aimed at improving caregiver distress, modifying emotional responses and developing coping strategies, all of which are important in their own right, there may also be an indirect potential to improve psychological symptoms in PWD.

8.2 General discussion

The empirical studies presented within this thesis extend the previous research examining the impact of caregiver responses on outcomes in caregivers and PWD. The findings outlined above demonstrate that caregiver emotional and behavioural responses are important for psychological outcomes in caregivers and PWD. The systematic review showed that interpersonal relationships have importance in caregiver and patient outcomes. However, the research within the field of dementia is limited. Much of the research on interpersonal relationships and outcomes in dementia has relied on a cross-sectional design. Furthermore, there have been no known studies exploring the relationship between interpersonal relationships and psychological wellbeing in PWD.

When considering the wider literature on caregiver and PWD outcomes, research has shown that both caregiver and PWD factors are associated with and predictive of poorer psychological outcomes in caregivers of PWD. On the whole, gender has been found to correlate with the development of depression and burden in caregivers, females have been reported to experience higher levels of depression and burden than males (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Etters, Goodall, & Harrison, 2008; Kim, Chang,
Rose, & Kim, 2012; Schoenmakers et al., 2010). Coping strategies have been found to influence burden and distress. Emotional-focused coping (i.e. advice from family/friends and praying), which is often seen in females, tends to be correlated with higher levels of burden and anxiety, than problem-focused coping strategies which are more likely to be seen in males (Cooper, Balamurali, Livingston, 2007; Cooper, Katona, Orrell, & Livingston, 2008; Etters et al., 2008; Kim et al., 2012). This may provide an explanation for the differing levels of distress in males and females.

Living arrangements and relationship type have also been found to be associated with distress. Caregivers who co-reside with the care recipient and have a closer relationship with the person with dementia, which is often seen in spouse-PWD dyads, tend to report higher levels of depression and burden than other caregiver-PWD dyad types (Adelman et al., 2014; Etters et al., 2008; Kim et al., 2012; Schoenmakers et al., 2010). In Asian cultures there is often a high sense of responsibility for older relatives and more reluctance to disclose family problems. This is likely to lead to less emotional and social support being sought within this cultural group. This may provide an explanation for why levels of depression and burden were reported to be higher in Asian caregivers than Caucasian caregivers (Etters et al., 2008).

PWD characteristics, particularly increased level of dependency in activities of daily living and functional decline, have also been found to relate to the progression of depressive symptoms in caregivers of PWD (Kim et al., 2012; Schoenmakers et al., 2010).

Unsurprisingly, caregivers who spend a greater number of hours per day caring for the person with dementia were found to experience higher levels of burden (Adelman et al., 2014; Kim et al., 2012). Social isolation, low educational accomplishment, financial pressure and having no choice about their caregiver role have also been found to increase the risk of caregiver burden and depression (Adelman et al., 2014; Schoenmakers et al., 2010). Caregivers who felt satisfied with their social network and engaged in more social
activities were found to have a significantly greater satisfaction with their life (Haley, Levine, Brown, & Bartolucci, 1987). Moreover, caregivers who were found to continually mourn the loss of the person with dementia were also found to have an elevated risk of developing depression (Schoenmakers et al., 2010). Caregivers’ appraisals were also found to significantly predict depression. Particularly the caregivers who made appraisals about the person with dementia’s behavioural problems and disabilities being stressful were significantly more depressed. Caregivers who did not perceive themselves to have confidence or self-efficacy in their ability to manage the behavioural problems and disabilities of the person with dementia were also found to have higher levels of depression (Haley et al., 1987). A fairly recent review of 56 studies, 32 with burden models and 24 with mental health models, found increased behavioural problems in PWD, poorer caregiver coping strategies, neurotic personality traits and not feeling competent within their caregiving role, to be the most significant determinates of increased caregiver burden and poorer mental health (van der Lee, Bakker, Duivenvoorden, & Dröes, 2014). The reviews are consistent in showing that caregiver factors have the greatest influence on caregiver psychological outcomes, however, as seen with the EE literature, there has been little focus on predictors of psychological outcomes in PWD.

8.2.1 Cross sectional findings

The findings reported in Paper 2 are consistent with previous research in psychiatric, mental health and physical health populations which have demonstrated a cross-sectional relationship between caregiver high-EE and greater levels of burden and distress (Safavi et al., 2015; Wearden et al., 2000). Furthermore, Paper 4 focused on the critical element of the EE construct and found a significant relationship between high levels of caregiver distress and a higher number of critical comments made about the person with dementia. These findings suggest caregivers’ attitudes and response styles (i.e. criticism, hostility and
EOI) directed at the person with dementia are associated with their own psychological wellbeing. Caregivers’ attributional beliefs have been found to underlie their emotional and behavioural responses towards patients. For example critical relatives who believe the patient to be responsible for their difficulties are more likely to exhibit controlling behaviour (Barrowclough & Hooley, 2003). Caregivers using more controlling strategies are likely to feel more responsible and overwhelmed, thus impacting on their level of burden and distress. We do not know whether caregiver distress is a driver of critical comments or a result of being critical, or whether there are bidirectional processes at play. Caregivers who are more distressed by the patient’s behaviours may be more inclined to express criticism of the patient as a way of attempting to control the behaviour. This in turn may impact negatively on patients’ behaviour and consequently create more problems and set up a vicious circle. Furthermore, caregivers who recognise that they are being critical may experience feelings of shame or guilt, thus adding to their distress. Moreover, the association found between high-EE dyads and poorer relationship quality than low-EE dyads, as reported in Paper 2, is consistent with a number of findings within the dementia field (Fearon et al., 1998; Gilhooly & Whittick, 1989; Spruytte et al., 2002). However, the literature on EE and relationship quality is inconsistent, as identified in the systematic review, Chapter 2. The inconsistencies in the literature may be explained to some extent by the inclusion of different caregiver-PWD dyads. Spouses are likely to spend more time and have more history with PWD than children, siblings and other relatives, therefore changes in the relationship are likely to be more noticeable. Furthermore, spouses of PWD are likely to have operated on an equal partnership, whereas after a diagnosis of dementia they may find themselves having to take on more responsibilities and make more decisions on behalf of the care recipient. In a study of 34 partners of persons with early-stage dementia (i.e. a MMSE score of at least 18/30) Quinn et al (2008) found partners were gradually having to take on additional roles and
responsibilities as they noticed increasing changes in the care recipient. Similarly, a recent review highlighted that spouses had to reconstruct their marital relationship, create a new identity and gain new independence to manage changes in former roles, routines and habits as their care recipient’s condition progressed (Egilstrød et al., 2018). This supports the idea that spouses are more likely to experience a change in the balance of their relationship with the care recipient as the care-recipient’s level of dependency increases. In contrast, caregivers of parents with dementia may be more likely to experience and be disconcerted by a reversal in the nurturing role. Adult offspring caregivers are more likely to experience a change from a dominant to a dependant relationship with their parent with dementia, as well as struggling to balance their caring role with other responsibilities and relationships (i.e. work, partner, children) (Quinn et al., 2009).

Moreover, relationship quality measures cover many aspects including love, trust and intimacy. Attachment has been another construct used to measure relationship quality within dyads. This stems from the work of Bowlby and Ainsworth which began in the 1930’s, who focused on the relationship between children and mothers which led to the identification of three key attachments styles (i.e. secure, avoidant and anxious/ambivalent) (Bretherton, 1992). Studies have shown that adult offspring with a secure attachment style to their parent with dementia report lower levels of burden than those with an insecure attachment style (Carpenter, 2001; Crispi, Schiaffino, & Berman, 1997), and those with an insecure attachment style experienced higher levels of psychological distress (Crispi et al., 1997). There is no known literature on EE and relationship quality as measured by attachment. However, data collected from the LASER-AD study has found caregivers who had a poorer relationship with the care recipient, as classified by an insecure or avoidant attachment style, reported higher levels of anxiety (Claudia Cooper, Owens, Katona, & Livingston, 2008). This highlights that the way in which relationship quality is measured,
whether it be love, trust, intimacy or attachment, varies across the literature which may also explain the inconsistent findings.

The findings of a review by Quinn et al (2009) confirmed that relationship quality can affect psychological wellbeing in caregivers of PWD. This conclusion has been supported more recently by Fauth et al (2012) who, using a sample of 235 dyads, found poor relationship quality between caregivers and PWD negatively impacts on caregiver psychological wellbeing. However, interestingly they did not find this relationship to persist over time. The authors suggested this may by indicative of caregivers withdrawing from emotional attachments within the relationship to protect their psychological wellbeing from deteriorating as the care-recipient’s condition declines. Whilst the impact of relationship quality on caregiver wellbeing has been explored, it is worth noting that there has been little exploration into the impact relationship quality has on psychological outcomes in PWD themselves (Quinn et al., 2009).

The findings reported in Paper 2, are in line with the findings of the current published literature, which suggest that exploring relationship quality within the field of dementia is important because it is associated with caregiver EE and psychological distress.

Furthermore, Paper 2 builds on the literature by showing that there is an association between EE and the quality of the caregiver-PWD relationship shortly after diagnosis as the caregiver is trying to adjust and adapt to their changes in role. This insight may be particularly important to clinicians as they support dyads that are coming to terms with a recent diagnosis of dementia by offering relationship support.

The findings in Paper 4 are consistent with previous dementia research from outside the EE field which has demonstrated a significant cross-sectional correlation between increased distress in caregivers and greater baseline psychological symptoms in PWD, with respect to depression and anxiety (Black & Almeida, 2004; Ornstein & Gaugler, 2012). Caregivers who are highly distressed are more likely to display unhelpful emotional and behavioural
responses (such as criticism, shouting, controlling behaviours, avoidance). This in turn may result in the person with dementia feeling helpless, concerned about their caregiver and they may begin to blame themselves, all of which can result in a deterioration in their own psychological wellbeing. The relationship between PWD quality of life and caregiver distress is weaker and non-significant. This finding may be explained by the dementia quality of life scale measuring a broad range of symptoms including distress, disorientation, memory and functioning. In a population of persons with a recent diagnosis of dementia, as within these studies, it is likely there may have been relatively little deterioration in disorientation, memory and functioning when measures were collected at baseline.

8.2.2 Longitudinal findings

The longitudinal analysis reported in Paper 2 demonstrated that high-EE was associated with greater burden and psychological distress in caregivers at six month follow-up. Furthermore, when controlling for baseline measures, high-EE caregivers showed greater levels of psychological distress and increased burden at follow-up than low-EE caregivers. This provides evidence that EE has predictive validity in relation to caregiver burden and distress. Within the dementia population there is no known literature on the longitudinal impact of EE on caregiver outcomes. Although, the findings reported in Paper 2 are in line with a study which found EE to be a significant longitudinal predictor of caregiver burden in relatives of people with an eating disorder (Coomber & King, 2013). Furthermore, research with caregivers of PWD has shown that caregivers who use more negative behavioural responses (e.g. behavioural disengagement, emotional venting, more conflict and are less tolerance) which may be indicative of high-EE responses, report greater levels of burden and depression overtime (Goode, Haley, Roth, & Ford, 1998; Lloyd, Muers, Patterson, & Marczak, 2018; Stephens et al., 1988; Zarit, Todd, & Zarit, 1986).
The longitudinal relationship between high-EE caregivers and higher levels of burden and distress at six month follow-up, builds on previous literature in suggesting that caregivers response styles have an influential effect on their levels of psychological distress and burden shortly after diagnosis. Understanding whether high-EE predicts outcomes shortly after diagnosis, which has not been previously examined, highlights the importance of intervening early to reduce burden and psychological distress in caregivers. However, it is important to note that there is likely to be a bi-directional relationship between EE and caregiver outcomes which has not been examined within this study. Two reviews have concluded that the CFI remains the measure of choice when examining EE (Hooley & Parker, 2006; Van Humbeeck et al., 2002). However, the CFI is labour intensive, both in terms of administering (i.e. 1-2 hours) and coding (i.e. 2-4 hours), as outlined in Chapter 1, section 1.4.2. This may be a contributing factor as to why it is difficult to conduct studies which allow for the examination of the temporal relationship between EE and caregiver outcomes. This is highlighted by the scant number of studies within the wider EE literature which have examined EE and/or administered the CFI several times over a time period in order to examine the bidirectional relationship between EE and outcomes (Hooley, 2007; Safavi et al., 2015).

The findings of Paper 3 and 4 expand the current knowledge base by exploring the relationship between caregiver factors and psychological symptoms in PWD. High-EE was associated with greater levels of anxiety and depression in PWD at six month follow-up. Interestingly, when baseline measures were controlled for, the findings outlined in Paper 3 showed that low-EE had a protective effect on psychological wellbeing in PWD. PWD in low-EE dyads experienced a reduction in anxiety and depression symptoms over time, whereas those within high-EE dyads maintained their baseline measures of depression and anxiety.
Low-EE caregivers are likely to exhibit more helpful responses including empathy, praise, appreciation, positive comments, warmth and encouragement to be independent, which may result in the person with dementia feeling more empowered and positive. This in turn may result in improvements in symptoms of depression and anxiety. It is likely that after receiving a diagnosis of dementia persons will be more likely to have more direct contact with the caregiver and therefore more likely to be influenced by the protective effect of low-EE. The predictive validity of high-EE on poorer patient outcomes is consistent with previous literature in mental and physical health conditions (Alway, McKay, Ponsford, & Schonberger, 2012; Band et al., 2014; Barrowclough & Hooley, 2003; Dunkin & Anderson-Hanley, 1998; Wearden et al., 2000). Furthermore, the protective nature of low-EE is in support of previous research within the psychiatric and mental health population which has demonstrated that the warmth aspect of the EE construct, as likely to be exhibited by low-EE caregivers, has a protective effect on patients and is a predictor of good outcomes (Bertrando et al., 1992; Le Grange, Hoste, Lock, & Bryson, 2011; López et al., 2004).

As reported in Paper 4, a significant correlation was found between baseline caregiver distress, baseline critical comments and psychological symptoms in PWD (quality of life, depression, anxiety) at six month follow-up. This supports the idea that living with someone in distress and being subjected to more critical comments may result in the care recipient being more self-critical, having less confidence and becoming more withdrawn. In turn this may result in the care recipient having a reduced quality of life and poorer psychological outcomes (Randall & Bodenmann, 2009). Furthermore, when controlling for baseline measures caregiver distress was found to be predictive of PWD quality of life at six month follow-up. Furthermore, this relationship was mediated by the number of critical comments made about the person with dementia’s behaviour and/or characteristics. The findings reported in Paper 4 are consistent with the idea that caregivers with high levels of
distress make more critical comments about PWD, which in turn reduces the person with dementia’s quality of life. Caregiver distress was not found to be predictive of PWD anxiety or depression. This suggests that caregiver emotional and behavioural responses, as outlined in Paper 3, and other factors not measured in the study (e.g. beliefs, health concerns, personal characteristics and environmental factors), may have a greater impact on psychological symptoms in PWD than caregiver distress (Cotrell & Schulz, 1993a). Research has shown that primary caregivers with high-EOI are likely to display different behavioural responses and attitudes than caregivers with high critical comment ratings (Barrowclough & Hooley, 2003; Hooley, 1987). Caregiver responses, as perceived by the patient, which are likely to be associated with high levels of critical comments (i.e. irritation, frustration and anger) have been found to predict increased depression in patients with unexplained chronic fatigue (Romano, Jensen, Schmaling, Hops, & Buchwald, 2009). More recently, Schmaling, Fales and McPherson (2017) have also found that caregiver negative responses, such as irritation, are associated with worsening mental health outcomes over time in persons with chronic fatigue. High-EOI caregivers may be more likely to show over-protective and intrusive behaviours than low-EOI caregivers. Studies have shown that perceived parental overprotection, as may be used by high-EOI caregivers, is associated with increased anxiety in adults with heart disease (Joekes, Van Elderen, & Schreurs, 2007; Ong, Nolan, Irvine, & Kovacs, 2011). This is consistent with the wider CBT literature which highlights the impact of overprotective and intrusive behaviours on maintaining and/or increasing levels of anxiety. This is because these behaviours reduce the patient’s ability to challenge their own beliefs about their abilities and prevents them from increasing their own confidence (Helbig-Lang & Petermann, 2010). These behaviours also reduce the individual’s skills and self-reliance, so that over time they become more dependent on the caregiver (Amaresha & Venkatasubramanian, 2012).
The findings reported in Paper 3 are consistent with findings reported by Romano et al (2009), Schmaling, Fales and McPherson (2017), Joekes, Van Elderen and Schreurs (2007) and Ong et al (2011). In the study reported in this paper, high levels of caregiver EOI were found to be predictive of greater anxiety in PWD at follow up, when compared with PWD with low-EE-EOI caregivers. Similarly, PWD whose caregivers had higher levels of critical comments had greater levels of depression at follow-up, when compared to PWD with low-EE-criticism caregivers. Although we have no direct measure of caregivers’ behavioural responses to PWD, these findings support the idea that the EE subtypes are associated with differing response styles. For example, caregivers who are high-EE-criticism are also more likely to express more generalised criticism about the person with dementia, are more likely to blame the person with dementia for their behaviours, hold negative attitudes about PWD and demonstrate rejection of the person with dementia (Barrowclough & Hooley, 2003). Consequently, the person with dementia who is on the receiving end of these responses are more likely to become self-critical, less confident and more withdrawn, all of which are associated with increased depressive symptoms. PWD may also become more resentful, angry and irritated which are also symptoms associated with depression. In contrast, PWD who observe more emotional displays from their caregiver and experience more intrusive controlling behaviours, are more likely to worry and lose confidence in their abilities, which in turn is likely to increase anxiety.

Understanding the relationship between EE subtypes and psychological symptoms is particularly important, as research has shown that increased anxiety and depression in PWD can result in an increase in functional problems and behavioural disturbances (Teri & Wagner, 1992).
8.3 Strengths and limitations

The strengths and limitations of the present research must be taken into account when evaluating the findings. Many of these strengths and limitations have been outlined in the empirical papers presented in Chapter 5, 6, and 7.

8.3.1 Strengths

The strengths of each empirical paper are summarised below. A key strength of this research, as outlined in the three empirical papers, was the use of the CFI which is identified as the gold standard measure of EE, as outlined in Chapter 1, section 1.4.2. The longitudinal design, as reported in Papers 2, 3 and 4, was another strength enabling us to look at predictive validity of EE. Paper 3 was the first known study to report on EE and psychological outcomes in PWD and Paper 4 was the first known study to report on the impact caregiver distress has on PWD psychological outcomes. Furthermore, as reported in Papers 3 and 4, PWD were asked to self-report on quality of life, depression and anxiety, using measures that have been identified as suitable within this population. This is particularly advantageous as it reduces common method variance which has frequently been identified to be a problem in research correlating two sets of self-reports, as outlined in Chapter 8, section 8.1.2 (Richardson et al., 2009). The previous literature on EE and caregivers, as outlined in the preceding sections, has shown that the majority of the studies to date have relied upon caregivers reports of symptoms of PWD, and therefore their responses are likely to be influenced by EE. Furthermore, the outcomes measures chosen for caregivers and PWD were carefully selected and deemed suitable within this population, as outlined in Chapter 4, section 4.5.

An important strength of this research as a whole is the use of a combination of methods including a systematic review, a cross-sectional design and a longitudinal design to explore the associations between caregiver factors and both caregiver and PWD outcomes. The systematic review highlighted the potential areas for future research along with the
methodological limitations of the existing literature. The conclusions drawn from the
review helped to inform the empirical studies outlined within this research.

Cross-sectional designs involve the examination of relationships between two variables
occurring at the same time point. The cross-sectional methods outlined within the three
empirical studies enabled the association between (1) caregiver EE, caregiver burden and
psychological distress (Paper 2), (2) caregiver EE and PWD measures, particularly quality
of life, depression and anxiety (Paper 3), and (3) caregiver distress and PWD quality of
life, depression and anxiety (Paper 4), to be explored. However, cross-sectional designs do
not enable the direction of association to be explored as the measures occur at the same
point. In 1965, Sir Austin Bradford Hill presented a framework which aimed to help
persons in weighing up the evidence for or against a cause-and-effect hypothesis, this is
known as the Bradford Hill Criteria (Hill, 1965; Höfler, 2005). The framework consists of
9 items, one of which is the temporal relationship of the association. Within cross-sectional
research a single snap shot of the current situation is taken therefore we are unable to
determine whether one variable occurred before another. Hill (1965) highlighted that in
order to make decisions about causality the effect has to occur after the cause. Therefore, a
longitudinal design element was also incorporated to each of the empirical studies.
A longitudinal design enables the assessment of the relationship between variables of
interest at two separate time points i.e. baseline and follow-up. The longitudinal design
outlined in the three empirical studies enabled the impact of caregiver factors to be
examined over time to determine whether (1) caregiver EE influences caregiver burden and
distress (Paper 2), (2) caregiver EE influences PWD quality of life, depression and anxiety
(Paper 3), and (3) caregiver distress influences PWD quality of life, depression and anxiety
(Paper 4). The advantage of the longitudinal design is that it enables the predictive validity
of variables, such as caregiver EE, to be explored in relation to caregiver and PWD
outcomes over time. This design also enabled baseline measures (i.e. caregiver burden,
caregiver distress, PWD depression, PWD anxiety, PWD quality of life) to be controlled for when conducting multivariate analyses on the follow-up data. This ensures the effect of the predictor variable can be determined.

The low level of attrition which was observed is another important strength of this research as it reduces attrition bias when analysing follow-up data. This may be part related to the use of the CFI, which is often viewed as a positive experience by caregivers. This may contribute to the development of a positive relationship between the researcher and caregiver which is extremely important in longitudinal research as the researcher and participant stay in contact for the purpose of data collection. Furthermore, the researcher conducted home visits both at baseline and follow-up and was flexible in terms of arranging a suitable day and time for both the caregiver and PWD. The researcher also gave the caregiver and PWD the opportunity to have separate home visits at baseline and follow-up; this was of particular benefit to those dyads that lived separately such as adult offspring. Additionally, the author took time when explaining the questionnaires and supported PWD to complete the questionnaires both at baseline and follow-up. Time and consideration was also taken when selecting appropriate measures for both caregivers and PWD, thus ensuring the measures were fairly easy and not overly time consuming for participants to complete. These factors are also likely to have enhanced the low level of attrition within this research.

There are a number of strengths of the EE methodology itself that are worth noting. The EE concept enables the interviewer to gain an insight into the interpersonal relationship between caregiver and care recipient through spontaneous expressions as opposed to didactic questioning. This means caregivers are not led into making comments but instead comments appear spontaneously during a natural flow of conversation. The EE concept also provides a way of identifying a number of cognitive, affective and behavioural characteristics of caregivers (Kuipers, 1979; Vaughn, 1989). It also provides insight into
the coping strategies that caregivers may use within their caring role and how these coping strategies may influence persons with differing disorders (Vaughn, 1989). Before using the concept of EE within research studies vigorous training must be sought, and trainees must reach reliability across the key EE domains before they are deemed to have successfully completed the training course. This requirement enhances the reliability of the data gained within the field of EE. Furthermore, the EE methodology has been shown to be a useful tool in predicting relapse, particularly in psychiatric populations although this is beginning to spread across other conditions (Kuipers, 1979).

8.3.2 Limitations

It is also important to consider the limitations when drawing conclusions from the current data set. The limitations of each empirical paper are summarised below and presented in Chapter 5, 6, and 7. The ability to generalise the findings to the wider dementia population must be considered. A convenience sample, which represents similar demographic characteristics to the wider population, primarily consisted of spouse-PWD dyads. This may not be representative of other relationships such as parents, siblings and adult offspring, which limits the generalisability of the findings to other dyads types, as outlined in the three empirical papers. No inter-rater reliability of EE could be obtained and also there is the possibility of interrater drift due to the time delay between the researchers EE training and rating of studies as reported in Papers 2 and 3. Furthermore, EE was collected at baseline only so the reverse pathway could not be explored (Paper 2). The low prevalence of high-EE may lead to reduced power in identifying significant correlations, as discussed in Paper 3. The longitudinal analyses presented in Papers 2, 3 and 4 are limited by the lack of detailed information about social and clinician involvement, caregiver factors and/or PWD symptomatology between baseline and follow-up. It was therefore not possible to control for potential confounding variables between caregiver EE and outcomes in caregivers and PWD. Reviews have found evidence to suggest professional support can
have a meaningful effect on psychological outcomes in caregivers of PWD, although there is inconsistency within the literature findings (Brodaty, Green, & Koschera, 2003; Pinquart & Sörensen, 2006), additionally there is little reported on PWD psychological outcomes. However, despite the potential confounding variables in the studies, the significant longitudinal associations between caregiver high-EE and poorer outcomes in both caregivers and PWD suggest that the effects associated with caregiver high-EE are genuine. Furthermore, as outlined in Paper 2, not all aspects of relationship quality were measured.

As explained above, EE was only collected at baseline therefore limiting the possibility of making any firm conclusions about whether EE drives outcomes in PWD and caregivers or reflects those outcomes i.e. whether EE influences psychological wellbeing, or whether psychological wellbeing influences EE. However, it is likely that there is a bi-directional relationship between caregiver EE and caregiver and PWD outcomes, potentially with poorer outcomes, in both caregivers and PWD, contributing to the maintenance of high-EE responses. Even more likely, is the fact that a complex vicious circle exists between caregiver EE, caregiver burden and distress, and PWD psychological wellbeing similar to the idea of the maintenance processes documented within the CBT literature (Beck, 2011). Furthermore, as with most naturalistic longitudinal studies an extended snapshot of variables was taken over a six month time period. Within the studies reported in Papers 2 and 3, high-EE preceded both caregiver burden and distress and PWD psychological symptoms, however, we did not have information on what happened before the studies i.e. it could have been that the caregiver was distressed before their significant other was diagnosed with dementia, or equally PWD may have been experiencing psychological symptoms prior to the caregiver expressed critical comments or EOI.

Recruitment of dyads within the field of dementia can be particularly difficult. Although, it is becoming increasingly important to understand the experience of living with dementia
which is difficult to obtain from proxy reports (Wilkinson, 2002). There are many challenges to the recruitment of dyads within dementia including ethical issues (e.g. decision making, capacity), emotional issues (e.g. anxiety, depression, grief, despair and feelings about the diagnosis itself) and practical issues (e.g. selection of appropriate measures, communication abilities, requirement of a study partner, awareness of research trials, delay in diagnosis itself) (Hubbard, Downs, & Tester, 2003). For the purpose of this research a convenience sample was used, as outlined above, and therefore it is important to acknowledge the possibility of self-selection bias at recruitment. Caregivers who felt particularly burdened may not have felt they had time to engage in the study, or equally may have felt too distressed by their current circumstances to participate. Additionally, highly critical caregivers may have been less likely to participate in the study due to the fear of judgement by the researcher which may have reduced the effects seen between variables.

Clinicians within the NHS and Age UK provided the author with the details of persons interested in participating in the studies therefore it is difficult to report on the number of persons approached for the studies. However, for empirical studies 1 and 3, 29 caregivers (recruited as dyads) expressed an interest in participating in the studies, as identified by clinicians in the NHS and Age UK, and of these 97% consented to taking part. Fifty one percent of caregivers approached from JDR consented to the studies. Eighty three percent of caregivers completed both baseline and follow-up measures. For empirical studies 2 and 3, 29 PWD (recruited as dyads) expressed an interest in participating in the studies, and of these 97% consented to taking part. Fifty one percent of PWD approached from JDR consented to the studies. Eighty nine percent of PWD completed both baseline and follow-up measures. It is therefore possible that the current sample reflects individuals who were highly motivated to participate in psychological research. However, there is no evidence to suggest this may be a biased sample. Furthermore the age and gender breakdown of the
caregiver and PWD sample reported within this research is similar to that in other studies of caregivers and persons with recent onset dementia (Johannessen & Moller, 2013; Quinn et al., 2008).

The limitations of the EE methodology must also be considered. The EE methodology enables researchers to reliably identify various aspects of inter-personal relationships including criticism, hostility, EOI, warmth and positive remarks, however, based on the ratings themselves it is impossible to say what behavioural responses the measures actually reflect. This is partly because the concept of EE relies on semantic and vocal data (Kuipers, 1979). However, researchers have become increasingly interested in what these responses suggest (Greenley, 1986). Furthermore, the use of a content analysis of the critical comments made by caregivers is a way of exploring factors underlying responses (Vaughn & Leff, 1981). The EE methodology enables us to find associations, however as documented earlier, it does not enable us to imply causations; that is it cannot be used to imply a simple unidirectional relationship between EE and outcomes (Vaughn & Leff, 1981). Furthermore, it is important to note that EE ratings are not necessarily fixed over time, in fact Brown et al (1972a) found that levels of relative criticism reduced following improvements in the patient’s condition.

Vaughn (1989) concluded that EE is best seen as an indicator of emotional nature and relative responses within a household at a given time point. Lastly, the EE concept has been criticised for placing blame on relatives as they are placed into two categories high-EE, which has been viewed as “bad” and low-EE, which has been viewed as “good” (Hatfield, Spaniol, & Zipple, 1987). However, Vaughn (1989) argued that there is significant level of variation within these two categories and therefore when assessing EE a comprehensive approach, such as that provided by the CFI, should be used in order to understand the individual function, characteristics and needs of relatives. Furthermore, the categories (i.e. high-EE and low-EE) are not intended to label an individual as “good” or...
“bad” but instead to help identify relatives and care recipients who may be at risk of poorer outcomes and are in need of additional support. That is not to say that low-EE relatives are not in need of support, just to say that the support required may be of a different nature.

8.4 Clinical implications

The findings from the empirical studies suggest that the development of caregiver focused interventions which are aimed at reducing high-EE and caregiver distress may be beneficial for psychological wellbeing in both caregivers and PWD. Interventions would be aimed at addressing factors which might underlie caregiver high-EE responses and distress, such as beliefs about the person with dementia’s behaviour, coping strategies and the quality of the caregiver-PWD relationship. The findings also suggested that interventions which are aimed at enhancing low-EE would be beneficial. This is because low-EE was found to have a protective effect on wellbeing in PWD i.e. low-EE reduces the likelihood of PWD experiencing poorer levels of depression and anxiety over time. Little is known about the features of low-EE that may contribute to wellbeing in PWD; however, a study on the effects of music on wellbeing in PWD demonstrated persons who felt empowered and stimulated, who had meaningful experiences and felt socially connected experienced improved wellbeing (Sixsmith & Gibson, 2007). Similarly, a study on the wellbeing of 76 PWD living in a formal care setting found PWD who experienced social interaction, who were encouraged to engage in meaningful activities, who had good relationships and who were in positive relaxed atmosphere experienced enhanced wellbeing (Innes & Surr, 2001). Therefore, interventions which are aimed at enhancing low-EE emotional and behavioural responses in caregivers such as encouraging the PWD to become more independent, empowering the PWD, encouraging the PWD to engage in stimulating and meaningful experiences, providing more warmth and making more positive remarks, would also be beneficial. Offering caregiver interventions shortly after
diagnosis, which are aimed at addressing primary caregiver emotional and behavioural responses would enhance the well-being and quality of life of those recently affected by dementia. In doing so it would fit with the national dementia strategy of helping PWD and their families to be supported to live well with dementia (Department of Health, 2009). It may also increase the length of time PWD are supported within the community.

Several interventions utilising the EE construct have been previously developed for families experiencing psychosis and eating disorders. Evidence has shown that family interventions are effective at reducing hospital admission as well as reducing caregiver EE, reducing levels of burden, improving social functioning in patients, improving psychological functioning and enhancing patients quality of life (Eisler et al., 2000; Pharoah, Mari, Rathbone, & Wong, 2010). A randomised control trial by Leff et al (2003) found evidence to suggest that a reduction in EE is a crucial mechanism for promoting change which accounted for the success of interventions that improved patient outcomes. This highlights the importance of targeting caregiver EE in interventions.

Research has consistently shown that education alone is ineffective at reducing caregiver distress. This may be because caregivers do not understand how the information provided applies to the person they are caring for and therefore attribute the problem behaviours to other causes (Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007). This is not to say psycho-education is not important, but rather that when providing caregivers with information it would be beneficial if the information is directly related to the person with dementia that the caregiver is looking after (Selwood et al., 2007). This supports the idea that interventions should be personalised to meet individual and family needs (Lobban et al., 2013). Furthermore, caregivers should be guided to understand the relationship between their own beliefs, behaviours and PWD symptoms through the use of guided discovery and Socratic questioning. This is recognised to be crucial in empowering people to make change as widely documented within the CBT literature (Beck, 2011).
Similarly, caregivers who have attended group support sessions report little change in burden or depression, which may be because the methods utilised are not informed by any methods of provoking change as well as the group nature of the sessions being unlikely to be individualised to personal needs (Selwood et al., 2007).

Evidence has suggested that family focused CBT which consists of education, stress management and coping skills training, can be beneficial in reducing levels of depression and burden in caregivers of PWD, as well as reducing behavioural disturbances and improving activities of daily living in PWD (Losada et al., 2015; Marriott, Donaldson, Tarrier, & Burns, 2000). However, information alone was found to have little impact on improving caregiver or PWD outcomes (Marriott et al., 2000). In 2009, a trial with 115 caregivers of persons with Alzheimer’s disease, found caregivers who accessed an 8 week course which consisted of psycho-education about dementia and CBT strategies (i.e. activation scheduling, cognitive restructuring, problem solving and increase of rewarding activities) experienced reduced levels of burden and improvements in quality of life (Martín-Carrasco et al., 2009). However, the research on the effectiveness of family focused CBT within the field of dementia has primarily targeted caregiver depression and burden. There is scarce evidence of interventions which are aimed at targeting other forms of distress in caregivers such as anxiety (Cooper, Balamurali, Selwood, & Livingston, 2006). Additionally, interventions which have looked at the effectiveness of caregiver interventions have focused on caregiver outcomes, as opposed to psychological outcomes in PWD.

The findings reported in Paper 2 suggested that caregiver high-EE is associated with higher burden and distress in caregivers at both baseline and six month-follow-up. Given these findings, education and interventions such as cognitive restructuring which address individual factors that underlie caregiver high-EE such as individual beliefs about the
person with dementia’s behaviour, would reduce caregiver burden and psychological
distress which is important in its own right.

Paper 3 highlights that high-EE was associated with poorer psychological outcomes in
PWD at baseline and follow-up. Additionally, levels of anxiety and depression were
maintained in high-EE dyads, whereby they reduced in PWD of low-EE caregivers.
Furthermore, high-EOI was predictive of greater anxiety in PWD whereas high critical
comments were predictive of depression. These findings suggest that by implementing
interventions, such as CBT, which are aimed at changing factors underlying caregiver
high-EE and enhancing low-EE responses it would also inadvertently improve
psychological wellbeing in PWD over time. The findings from Papers 2 and 3 also
suggested that interventions would need to be aimed at provoking change in caregivers (i.e.
reducing high-EE emotional and behavioural responses and enhancing low-EE responses)
in order to have an influential effect on both caregiver and PWD outcomes. More
specifically, interventions such as cognitive restructuring whereby the caregiver is
encouraged to question their thoughts, would challenge beliefs underlying caregiver EE,
reduce the number of critical comments and enhance elements of low-EE such as empathy
and understanding. Encouraging the caregiver to recognise positives would also enhance
the positive remarks element of low-EE. Interventions aimed as highlighting the
importance of self-care, such as behavioural activation, would reduce the EOI element
(self-sacrificing and devoted behaviour) of high-EE.

The findings outlined in Paper 4 showed that a high level of distress in caregivers is
associated with poor psychological wellbeing in PWD. Furthermore, caregiver distress has
predictive validity in PWD, and this relationship is mediated by the number of critical
comments made by caregivers. This provides evidence to suggest that clinical
interventions, which are aimed at addressing caregiver distress by changing attributional
beliefs such as cognitive restructuring and enhance adaptive strategies such as problem
solving, would reduce caregiver distress and empower them to feel more equipped to cope within their caring role, and in doing so would improve the quality of life of PWD.

8.5 Proposals for future research

The current findings have contributed to our understanding of the role of interpersonal processes in the outcomes of caregivers and PWD. However, a number of areas have been identified where further research and clarification would be beneficial. Firstly, there is a lack of research examining the protective nature of low-EE. A better understanding of low-EE would help in identifying caregiver responses which promote psychological wellbeing in PWD. This insight could then be used to inform clinical interventions which are aimed at promoting adaptive responses. Furthermore, much of the literature has focused on the negative aspects of EE (i.e. criticism, hostility, and EOI) whereas the positive aspects of EE (i.e. warmth and positive remarks) have been widely overlooked. However, the beneficial effect of warmth, in the absence of criticism and EOI, was recognised in schizophrenia during the development of the EE construct (Brown, Birley, & King, 1972b). More recent research on the positive aspects of EE within the schizophrenia population has shown that a high level of positive EE, particularly warmth, has a protective effect on patients (Bertrando et al., 1992; López et al., 2004). Family based interventions have also shown that the presence of warmth may be a predictor of good outcomes in persons with anorexia nervosa (Le Grange et al., 2011). It is therefore possible that the presence of positive aspects of EE such as warmth may play an important role in outcomes in PWD. Further research on this would be beneficial in guiding clinical interventions which are aimed at supporting caregivers to show more warmth and to make more positive remarks in reference to the person with dementia. Warmth can be measured by tone of speech, spontaneity of positive feeling, sympathy, concern, empathy, and/or interest shown towards the person. It would also be of interest to explore which aspect of warmth is
particularly important in protecting and predicting good outcomes which has not been discussed within the studies mentioned above.

The assumption that the principle EE subscales and caregiver emotional and behavioural responses are linked was not explored within this research. It would be useful to examine these relationships by exploring the effect that caregiver EE may have on interactions with the person with dementia in everyday life. It would be of particular interest to distinguish the responses associated with EOI and those that are associated with criticism. This would help to provide more understanding of how and why EOI and criticism impacts on PWD anxiety and depression respectively. There is very little research on the behavioural correlates of CFI measured EE. However, evidence suggests that high-EE-critical, high-EE-EOI and low-EE relatives display different behavioural patterns and these are associated with patient outcomes (Hahlweg et al., 1989). Behavioural correlates could also be examined using the experience sampling methodology, this is whereby individuals provide self-reports on behaviour, emotions and thoughts, at random occasions during the day to assess associations between variables (Csikszentmihalyi & Larson, 2014). This method can be used to explore interactions within dyads (Roche, Pincus, Rebar, Conroy, & Ram, 2014). This is demonstrated by a recent study which used the experience sampling methodology to examine the relationship between significant other responses and outcomes in patients with chronic fatigue syndrome (Band, Barrowclough, Emsley, Machin, & Wearden Alison, 2015).

Furthermore, examination of the beliefs underlying EOI and criticism may be beneficial. Previous research has suggested that EE, particularly the criticism element, is reflective of caregivers attributional beliefs about the patient’s ability to control their symptoms (Barrowclough & Hooley, 2003). Having more insight into this would help in developing interventions which are aimed at modifying caregivers’ beliefs which drive unhelpful emotional and/or behavioural responses.
Further understanding into the source of criticism, through a contents analysis, would be helpful in determining caregiver perceptions which underlie critical comments. These could then be altered through clinical interventions such as CBT. This approach has been used to understand the source of criticism in relatives of persons with schizophrenia. They found that the most common critical comments related to positive symptoms (e.g. hallucinations, delusions and bizarre behaviour), life problems (e.g. financial management) and negative symptoms (e.g. over sleeping, personal hygiene, appearance) (Shimodera, Inoue, Tanaka, & Mino, 1998). Moreover, research into other factors which underlie caregiver distress and burden such as perceived expectations/rules and uncertainty about how to manage difficult behaviours would be helpful. This insight could be used to tailor clinical interventions which are aimed at changing expectations/rules and building confidence in managing behaviours through behavioural and cognitive re-attribution strategies. It would also be beneficial to gain more understanding of caregiver factors such as their understanding of, and beliefs about dementia which may influence adaptive (assisting and modifying daily routines) and non-adaptive behaviours (irritation, controlling behaviours and criticism). Understanding these factors could be used to tailor clinical interventions such as CBT which would be aimed at making rules and expectations more flexible as well as modifying beliefs. Individualised psycho-education and interventions would also be useful in enhancing adaptive behaviours and gaining more understanding on how to manage difficult behaviours. It would also be beneficial to explore other PWD factors such as understanding of the condition, beliefs and adaptive strategies which may contribute to psychological symptoms. This information would help in implementing clinical interventions, such as CBT, which are aimed at providing psycho-education about the condition, modifying underlying beliefs and enhancing adaptive strategies, which would in turn reduce psychological symptoms in PWD.
Future research incorporating objective measures of caregiver factors and PWD outcomes may also be beneficial. This may include observational measures of caregiver-PWD interactions to explore if caregiver responses correspond with their EE, for example more negative behaviours (e.g. more coercion, less flexibility, more vigilance, more conflict) which are associated with high-EE (Hubschmid & Zemp, 1989). Lastly, the potential differences in response styles between spouses, siblings, adult offspring and other relatives would be worth exploring in further research. This would help in developing appropriate clinical interventions which are directly aimed at the primary caregiver as this may be different for spouse-patient dyads as opposed to other dyads.

8.6 Conclusions

The work presented within this thesis highlights a novel examination of the relationship between caregiver factors and outcomes in both caregivers and PWD. The findings suggest that caregiver factors are important in the psychological outcomes of caregivers and PWD. Furthermore, it suggests that the EE subscales and subsequent response styles have a differing impact on the person with dementia i.e. more critical comments is predictive of depression and higher EOI is predictive of anxiety, whereas low-EE seems to have a protective effect on psychological outcomes in PWD. It is important to understand that high-EE caregivers are not “bad” or “difficult” people. In actual fact the vast majority of high-EE relatives are highly motivated individuals aiming to help the patient. However, in contrast to low-EE relatives, high-EE family members appear to have distinct and definite ideas about how to improve the current situation. These desires to change the situation and beliefs that the patient should or could do something to positively change their circumstances are thought to be the basis for why relatives develop critical attitudes (Hooley, 2007). Furthermore, being classified as low-EE does not mean relatives experience fewer difficulties and are therefore not in need of additional support (Hooley,
2007). The findings presented within this thesis suggest that clinical interventions for both caregivers and PWD, which use verbal and non-verbal reattribution methods, would be useful in providing psycho-education on dementia, modifying unhelpful beliefs and providing idiosyncratic coping strategies. This would be of benefit in improving the lives of persons affected by dementia.
References


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Ornstein, K., & Gaugler, J. E. (2012). The problem with “problem behaviors”: a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient–caregiver dyad. International Psychogeriatrics, 24(10), 1536-1552.


patients and optimally healthy aged individuals. *Journal of Gerontology, 39*(1), 58-64.


Appendices

Appendix 1: NREC letter of favourable approval

11 February 2014

Miss Roxanne Safavi
PhD Student and Senior Psychological Wellbeing Practitioner
Pennine Care NHS Foundation Trust
Psychological Therapies Department
Stepping Hill Hospital
Poplar Grove
SK2 7JE

Dear Miss Safavi,

Study title: The influence of relatives' Expressed Emotion on the psychological adjustment of people recently diagnosed with dementia and their relatives' wellbeing.

REC reference: 13/NW/0836
Protocol number: N/A
IRAS project ID: 116825

Thank you for your letter, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and delegated member.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Miss Nicola Burgess, nrescommittee.northwest-gmsouth@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.
Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 8 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhrs.net), the HRA does not, however, expect exceptions to be made.

Guidance on where to register is provided within IRAS.
It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

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Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

Feedback

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

Further information is available at National Research Ethics Service website > After Review

13/NW/0836

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee’s best wishes for the success of this project.

Yours sincerely

[Signature]

PP:
Professor Sobhan Vinjamuri
Chair

Email: nrescommittee.northwest-gmsouth@nhs.net

Copy to: Ms Lynne Macrae
Ms Reagan Blyth, Research and Innovation Department
Appendix 2: Participant Invitation letter

Miss Roxanne Safavi  
Coupland 1 building  
School of Psychological Sciences  
University of Manchester  
Oxford Road  
Manchester  
M13 9PL  

Mob: 07500816481  
E-mail: alzresearch@yahoo.com

Letter of Invitation

Dear Sir/Madam

We are writing to inform you of a new project that is being carried out at the University of Manchester that you and your relative are invited to take part in. We are writing to persons with a recent diagnosis of dementia and their closest relative via the National Health Service (NHS) in the North west, and persons who have an association with the Alzheimer’s Society, to ask for your help with our research. We have passed this letter and the attached information sheet to the respective health care professionals or Alzheimer’s Society staff and they have sent them on to you on our behalf.

We are interested in learning more about your relationship with your relative following a diagnosis of dementia. We are also interested in looking at what factors may influence wellbeing and adjustment in persons with dementia and their relatives. A better understanding of the factors influencing wellbeing will help to inform the development of effective ways of supporting relatives and persons with dementia.

An information sheet about the study has been enclosed and you are advised to read this carefully before making a decision about whether or not to take part. Please contact us if you would like any further information about the study or would like to participate. You can contact us by sending a text message or calling 07500816481. You can also send us an email to alzresearch@yahoo.com. When contacting us, please provide your name and contact number and a time when you prefer to be contacted. Roxanne Safavi will then contact you at your specified time and answer any of your questions about the research.

Thank you for your time.

Yours faithfully,

Roxanne Safavi  
Chief Investigator of the study

Encl. 1 Participant Information Sheet

Invitation Letter date of issue: [19.08.2014]  
Invitation Letter version number: [VERSION 3]
Appendix 3: Participant Information Sheet for caregivers

Participant Information Sheet (Relative)

The influence of relatives’ Expressed Emotion on the psychological adjustment of people recently diagnosed with dementia and their relatives’ wellbeing.

We would like to invite you to take part in our research study, before you decide we would like you to understand why the research is being done and what it would involve for you. Please take time to read the information carefully and ask questions about anything that you are unsure of. Talk to others about the study if you wish.

What is the purpose of the study?

The purpose of the study is to explore the possible factors influencing the wellbeing of relatives and patients with dementia. We are interested in getting relatives perspective of what it is like to be in the home with someone who is suffering with dementia. There are no right or wrong answers. A better understanding of the factors influencing these difficulties will help to inform the development of effective ways of supporting relatives and persons with dementia.

Why have I been invited?

You have been invited to take part in this study because you are a relative for someone with dementia.

Do I have to take part?

No, it is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

A member of the research team will contact you to arrange a face-to-face interview, which will last approximately 60 minutes. The interview will be conducted at your home or a convenient location, and at a time convenient to you. The interview will aim to get insight into your experiences of living with or having regular contact with a person suffering from dementia. You will also be asked to fill in some questionnaires which will take approximately 30 minutes. The questionnaires will provide insight into your health, relationship, and illness beliefs. You will be contacted 6 months later and asked to fill in some more questionnaires lasting approximately 20 minutes. The researcher will meet with you on a one-to-one basis. The interview and questionnaires can be completed over a number of visits if you should wish.
What will I have to do?

We will contact you to ask whether you would like to participate in the study. If you do wish to participate then we will ensure that you have understood the purposes of the study and what is expected of you. Then you will be asked to sign a consent form, a copy of which will be given to you to keep along with this information sheet.

What are the possible disadvantages and risks of taking part?

The interviews will explore your experiences of caring for a person with dementia and it will also explore your wellbeing. For some people, this might bring up some unpleasant memories. If this happens, we have information on local counselling services where you can access support, we will discuss these options with you if you wish for us to do so. Please also feel free to discuss the study with any support systems that you might already have before you decide to participate.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we get from this study will help us gain insight into improving the support offered to persons with dementia and their relatives.

What if there is a problem?

We do not anticipate that taking part in the study will cause any problems. If, however, you are unhappy with any aspect of the study, you should inform Roxanne Safavi, Alison Wearden or Katherine Berry. If an issue arises and you wish to discuss this with someone other than the researcher or supervisor, please contact the University Research Office: 0161 275 8795 or Research.complaints@manchester.ac.uk. If you wish to discuss the research study with someone other than the researcher or supervisors then you can contact your local Patient Advice and Liaison Service (PALS).

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information collected about you during the course of the research will be kept strictly confidential, unless we felt you or someone else is at significant risk of harm and then we will have to speak to a third party about this. Interviews will be recorded and transcribed. No information you provide will be given to your relative. All data will be stored by the researcher in a locked cabinet or on an encrypted NHS USB drive or on a password protected computer, only the researcher and supervisors will have access to the data. Data will be destroyed once it is no longer required by the University. Information about you will be anonymised to ensure the information collected can not be traced back to you. The University of Manchester is registered under the Data Protection Act of 1998.

What will happen if I don’t want to carry on with the study?

You have the right to withdraw and no longer participate in the study at any time, but we would like to use the data collected up to your withdrawal provided you were happy for us to do so. In the event that you lose the capacity to consent to the study, you will be withdrawn from the study. With your permission, we would like to keep the data collected up to that point.

What will happen to the results of the research study?

The interview will be recorded using a digital recorder. This is to make sure that your views are represented correctly in the study. The information you give will be used along with the information from other participants to generate insight into improving the support available for persons with dementia and their relatives. We hope to publish the results in a medical or health journal, and would ensure there is no identifiable information. If you would like a copy of the results, we would be happy to send you a copy.
Who is organising and funding the research?

The study is being undertaken as part of a PhD in the faculty of medical and human sciences at The University of Manchester. The chief investigator is Roxanne Safavi. The academic supervisors are Prof Alison Wearden and Dr Katherine Berry.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion BY North West Research Ethics Committee [13/NW/0836].

Further information and contact details

If you have any further questions or queries please do not hesitate to contact us on the contact details provided.

Chief investigator: Roxanne Safavi

Address: University of Manchester, School of Psychological Sciences, Coupland 1 Building, Oxford Road, Manchester, M13 9PL.

Email address: roxanne.safavi@postgrad.manchester.ac.uk

Contact number: 07500816481

Supervisor: Prof Alison Wearden

Address: University of Manchester, School of Psychological Sciences, Coupland 1 Building, Oxford Road, Manchester, M13 9PL.

Email address: alison.wearden@manchester.ac.uk

Contact number: 0161 275 2684

Supervisor: Dr Katherine Berry

Address: University of Manchester, School of Psychological Sciences, Oxford Road, Manchester, M13 9PL.

Email address: Katherine.Berry@manchester.ac.uk

Contact number: 0161 306 0400

Thank you for taking the time to read this information sheet.

Participant Information sheet (relative) date of issue: [27.11.2014]
Participant Information sheet (relative) version number: [VERSION 3]
Appendix 4: Participant Information Sheet for PWD

Participant Information Sheet (Patient)

The influence of relatives’ Expressed Emotion on the psychological adjustment of people recently diagnosed with dementia and their relatives’ wellbeing.

We would like to invite you to take part in our research study, before you decide we would like you to understand why the research is being done and what it would involve for you. Please take time to read the information carefully and ask questions about anything that you are unsure of. Talk to others about the study if you wish.

What is the purpose of the study?

The purpose of the study is to explore the possible factors influencing the wellbeing of relatives and persons with dementia. We are interested in whether you have noticed any changes in your memory, mood, anxiety and behaviour. There are no right or wrong answers. A better understanding of the factors influencing these difficulties will help to inform the development of effective ways of supporting relatives and persons with dementia.

Why have I been invited?

You have been invited to take part in this study because you have a diagnosis of dementia.

Do I have to take part?

No, it is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

A member of the research team will contact you and ask you to fill in some questionnaires, which will take approximately 90 minutes. The questionnaires will give us an insight into your memory, psychological adjustment, relationship and quality of life. The questionnaires will be given to you for completion at your home or a convenient location, and at a time convenient to you. You will be contacted 6 months later and asked to fill in some more questionnaires. The researcher will meet with you on a one-to-one basis. The questionnaires can be completed over a number of visits if you should wish.

What will I have to do?

We will contact you to ask whether you would like to participate in the study. If you do wish to participate then we will ensure that you have understood the purpose of the study and what is expected of you. Then you will be asked to sign a consent form, a copy of which will be given to you to keep along with this information sheet.
What are the possible disadvantages and risks of taking part?

There are no major risks in taking part in this study. However, the questionnaires will explore your memory, mood, anxiety and behaviour. For some people, this might bring up some unpleasant memories or feelings. If this happens, we have information on local counselling services where you can access support, we will discuss these options with you if you wish for us to do so. Please also feel free to discuss the study with any support systems that you might already have before you decide to participate.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we get from this study will help us gain insight into improving the support offered to persons with dementia and their relatives.

What if there is a problem?

We do not anticipate that taking part in the study will cause any problems. If, however, you are unhappy with any aspect of the study, you should inform Roxanne Safavi, Alison Wearden or Katherine Berry. If an issue arises and you wish to discuss this with someone other than the researcher or supervisor, please contact the University Research Office: 0161 275 8795 or Research.complaints@manchester.ac.uk. If you wish to discuss the research study with someone other than the researcher or supervisors then you can contact your local Patient Advice and Liaison Service (PALS).

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information collected about you during the course of the research will be kept strictly confidential, unless we felt you or someone else is at significant risk of harm and then we will have to speak to a third party about this. No information you provide will be given to your relative. All data will be stored by the researcher in a locked cabinet or on an encrypted NHS USB drive or on a password protected computer, only the researcher and supervisors will have access to the data. Data will be destroyed once it is no longer required by the University. Information about you will be anonymised to ensure the information collected can not be traced back to you. The University of Manchester is registered under the Data Protection Act of 1998.

What will happen if I don’t want to carry on with the study?

You have the right to withdraw and no longer participate in the study at any time, but we would like to use the data collected up to your withdrawal provided you were happy for us to do so. In the event that you lose the capacity to consent to the study, you will be withdrawn from the study. With your permission, we would like to keep the data collected up to that point.

What will happen to the results of the research study?

The information you give will be used along with the information from other participants to generate insight into improving the support available for persons with dementia and their relatives. We hope to publish the results in a medical or health journal. If you would like a copy of the results, we would be happy to send you a copy.

Who is organising and funding the research?

The study is being undertaken as part of a PhD in the faculty of medical and human sciences at The University of Manchester. The chief investigator is Roxanne Safavi. The academic supervisors are Prof Alison Wearden and Dr Katherine Berry.
Who has reviewed the study?

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Further information and contact details

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Chief investigator: Roxanne Safavi

Address: University of Manchester, School of Psychological Sciences, Coupland 1 Building, Oxford Road, Manchester, M13 9PL.

Email address: roxanne.safavi@postgrad.manchester.ac.uk

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Contact number: 0161 275 2684

Supervisor: Dr Katherine Berry

Address: University of Manchester, School of Psychological Sciences, Oxford Road, Manchester, M13 9PL.

Email address: Katherine.Berry@manchester.ac.uk

Contact number: 0161 306 0400

Thank you for taking the time to read this information sheet.

Participant Information sheet (patient) date of issue: [06.01.2014]
Participant Information sheet (patient) version number: [VERSION 2]
Appendix 5: Consent form for caregivers

Title of Project: The influence of relatives’ Expressed Emotion on the psychological adjustment of people recently diagnosed with dementia and their relatives’ wellbeing.

Name of Researcher: Roxanne Safavi, (roxanne.safavi@postgrad.manchester.ac.uk)

Name of supervisors: Prof Alison Wearden, (alison.wearden@manchester.ac.uk) and Dr Katherine Berry, (Katherine.Berry@manchester.ac.uk)

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 06/01/2014 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

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

3. I understand that relevant sections of my data collected during the study, may be looked at by individuals from The University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I understand that the interview will be recorded and that the tapes will be transcribed. The recordings and transcriptions will be stored in a secure location and destroyed by the researcher when the study is completed.

5. I understand the questionnaires will be stored in a secure location and destroyed by the researcher when the study is completed.

6. I agree to the use of my direct quotes in any reports or publications of the research study. If my quotes are used, they will be used in such a way to prevent me from being identified

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

____________________________  ______________________________  ______________________________
Name of Participant                      Date                      Signature

____________________________  ______________________________  ______________________________
Name of Person taking consent                      Date                      Signature

Consent form (relative) date of issue: [06.01.2014]
Consent form (relative) version number: [VERSION 2]
### CONSENT FORM (Patient)

**Title of Project:** The influence of relatives’ Expressed Emotion on the psychological adjustment of people recently diagnosed with dementia and their relatives’ wellbeing.

**Name of Researcher:** Roxanne Safavi, (roxanne.safavi@postgrad.manchester.ac.uk)

**Name of supervisors:** Prof Alison Wearden, (alison.wearden@manchester.ac.uk) and Dr Katherine Berry, (Katherine.Berry@manchester.ac.uk)

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 06/01/2014 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

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

3. I understand that relevant sections of my data collected during the study, may be looked at by individuals from The University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I understand the questionnaires will be stored in a secure location and destroyed by the researcher when the study is completed.

5. I agree to the use of my responses in any reports or publications of the research study. If my responses are used, they will be used in such a way to prevent me from being identified.

6. In the event that I lose the capacity to consent during the course of the study I understand that I will be withdrawn. I agree that any data collected up to that point can be kept and used for the research.

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

__________________________________________________________________________

Name of Participant Date Signature

__________________________________________________________________________

Name of Person taking consent Date Signature

Consent form (patient) date of issue: [14.06.2013]
Consent form (patient) version number: [VERSION 1]
Appendix 7: Caregiver personal details form

**Relative Personal Details Form**

**This section is about you:**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Male □</th>
<th>Female □</th>
</tr>
</thead>
</table>

**Ethnicity**

<table>
<thead>
<tr>
<th>Relationship Status</th>
<th>Single □</th>
<th>Married/Civil Partnership □</th>
<th>Widowed □</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Partner □</td>
<td>Divorced/Separated □</td>
<td>Other □</td>
</tr>
</tbody>
</table>

**Living situation**

<table>
<thead>
<tr>
<th>Did not complete school □</th>
<th>Additional training (e.g. apprenticeship etc.) □</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secondary School □</td>
<td>Undergraduate university □</td>
</tr>
<tr>
<td>College □</td>
<td>Postgraduate university □</td>
</tr>
</tbody>
</table>

**Employment status**

<table>
<thead>
<tr>
<th>Student □</th>
<th>Unemployed □</th>
<th>Other □</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed □</td>
<td>Retired □</td>
<td></td>
</tr>
</tbody>
</table>

**What is your relationship to your relative with dementia?**

<table>
<thead>
<tr>
<th>Spouse/Partner □</th>
<th>Parent □</th>
<th>Son/Daughter □</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling □</td>
<td></td>
<td>Other □</td>
</tr>
</tbody>
</table>

**The following questions are about your relative with dementia and the support you may receive:**

- When was your relative diagnosed with dementia?

- To the best of your knowledge, when did your relative start experiencing symptoms of dementia?

- Do you receive any support from healthcare professionals to help you in supporting your relative with dementia? □ Yes □ No

- Do you receive any support from friends, family, neighbours etc. to help you in supporting your relative with dementia? □ Yes □ No

- Do carers come on a regular basis to help you in supporting your relative with dementia? □ Yes □ No

- Does your relative with dementia receive any respite care or a sitting service? □ Yes □ No

- Does your relative with dementia attend a day care service? □ Yes □ No

**Thank you for your time**

Relative Personal Details Form date of issue: 23.08.2022
Relative Personal Details Form version number: VERSION 1
Appendix 8: Adapted Camberwell Family Interview Schedule

Camberwell Family Interview Schedule

(Vaughn and Leff, 1976)

To be completed at time of first interview

Centre Number:
Study Number:
Participant Identification Number:

<table>
<thead>
<tr>
<th>Date</th>
<th>Respondent</th>
<th>Interviewer</th>
<th>Tape made</th>
<th>Tape No.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>1. Yes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2. No</td>
<td></td>
</tr>
</tbody>
</table>

Background Information

Composition of household (i.e. sharing same cooking facilities).

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship to patient</th>
<th>Age</th>
<th>Sex</th>
<th>In education or employment (i.e. to establish level of face to face contact with the patient)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
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<tr>
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<td>5</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total number of members in household: ______________
When questioning for specific symptoms (Sections A and B) use the following checklist of detailed questions

**Onset:**
When did this first begin?
How it occurred during the last 3 months?

**Severity:**
How did this show itself? (obtain example)
How marked was this behaviour/ideas?

**Frequency:**
How often did ______________?
Did it happen all the time? --- Everyday?, Once a week?, etc.

**Social context:**
Where did it happen? Who was there?
What time of day?

**Reactions:**
How did (all present) react?
What effect did this have on ____________?

**Tension:**
Does/did it make you feel on edge?
Is/was there an atmosphere in the home?

**Legitimacy:**
Do you think s/he could do/have done any more to control it?

**Coping:**
How did you deal with ______________?
How effective were you in dealing with it?
Did you find any way of preventing it?

**Illness history**

**Instructions**

Obtain a brief chronological account of whole history of illness including:

- Approximate dates of onset
- Any periods of normality of 3 months of longer

Question in detail about the ILLNESS including:

- Details for each symptom
- Arrangements of contacts with services
- The overall pattern of severity of the illness
SECTION A

Onset
I would like to begin by asking when _________ (patient’s) difficulties first began?

Useful probes:  
When did you first notice something different about him/her?  
When would you say s/he was his/her normal self?  
Sudden or gradual deterioration?

General probes:
Get events:  How was behaviour at this time?
Ask for concrete examples:  What happened then?
Ref. symptoms:  How long has this been going on?  
How do you feel when s/he is doing it?  
Make you feel on edge?
If denial:  Anything unusual about his behaviour?

Refer to checklist for each symptom

Current illness
How did (you or patient) come to contact the clinic?
When did it begin to get worst?
What did ______ do?
What happened?
Worse recently?
How did (patient) feel about coming to the clinic?
How did s/he behave?
Who was involved in making arrangements to come to the clinic?
Any difficulties?
Family time budget

I would like to get a picture of how (patient) usually spends/spent a day?

Note: Obtain details of how patient’s routines relate to contact with other members. Aim to assess “face to face” contact with other members (who is at home with patient)

A usual/typical weekday
What time would s/he_____ (see behaviours below)
How would s/he ______ (see behaviours below)
Who would be there?

And how about weekends?
What time would s/he_____ (see behaviours below)
How would s/he ______ (see behaviours below)
Who would be there?

Behaviours:
Get up
Have breakfast
How would (patient) spend the morning
Have lunch
How would (patient) spend the afternoon
Have dinner/tea
How would (patient) spend the evening
Go to bed

Irritability

One of the ways in which this kind of difficult can affect people is to make them more irritable. By this I mean snappy, or more likely to “fly off the handle” at things that would not normally worry them.

Obtain:
1. Presence of irritability (general question)
2. Present vs past irritability
3. Example of last time irritability shown
4. Change with illness

Probe for all forms of behaviour defined as irritability (e.g. severe snapping or shouting, flying of the handle, picking on, getting impatient with, quarrelling or bickering).

Refer to checklist for each symptom
How often has (patient) been irritable?

How often this sort of thing would occur?

How often has (patient) been like this with (each household member)?

Can you describe what happened?

When did this last occur?

What happened the last time?

What (other) sorts of things make him/her irritable with ____?

How often would s/he have been irritable with _____ in the last week ____etc?

Has there been any one week when it was worse?

Did this usually happen at any particular time of the day?

How about at (other times)?

Getting up

Breakfast time

Other mealtimes

Evenings

Bedtime

Weekends

Who else would be there?

How would _____ react? (name all present)

Informant only:

Can you control or cope with the irritability at all? _____ How? _____ To what extent? _____

Check irritability between all household members:

i.e. patient, spouse, children, etc

If more severe irritability mentioned first:

Apart from the arguments you have just mentioned, are there other times in which you got a bit snappy or cross – as people often do when they are worried – but which are not as such as an argument?

If denial (i.e. if the relative recalls no irritability)

- Not been cross at all?
- Can you remember a time when s/he lost temper in past year?
- Ever occur before difficulties started?
- (if yes) why do you think this has changed?
- Have you (relative) noticed any changes in your own irritability?
Quarrels

Patient and others in the household:

Most families have quarrels or arguments from time to time – apart from the sort of irritability we have been talking about – has (patient) had any rows or quarrels with you or with anyone else in the family (mother, father, spouse, children)?

How about with other members? Can you describe the last time?

When did it occur?

What sort of things did you say to each other?

Have you ever parted because of a quarrel – even overnight?

Tension probes: Whether lead to an atmosphere in the home?

How other people respond when they visit your house?

How did children react?

Probes to establish/define quarrelling:

1. Do you/they call each other names?
2. Do you/they shout at each other?
3. Have you/they ever hit each other during a quarrel?
4. How long does a disagreement last?
5. Do you/they ever have periods of not speaking following a disagreement?
6. Had (patient) ever left home as long as overnight because of a quarrel?
7. Or packed his/her things to go?

Refer to checklist for each symptom

Nagging and grumbling

Note: nagging involves one way going on and on, moaning, etc.

Apart from the irritability you have mentioned. Do you ever nag or grumble at (patient)?

Probes: What sort of things do you complain about?

What do you say?

How often has this occurred in the last week____month____3 months?

Has the amount of irritability (patient) has shown changed since the difficulties started?
Collect details if the frequency of irritability has changed

- How about with ______ (spouse, child etc)?
- Any change in irritability towards ______ (each member of the household)?
- Has the amount of irritability you have shown changed since (patient's) trouble started?
- How about with ______ (each family member as above)?
SECTION B

I would like to ask some questions about the way (patient) may have been affected by these difficulties and about some sorts of behaviour which people we see sometimes have. Of course, many won’t apply, but I should like to run through these quickly and perhaps you would tell me whether or not (patient) has been like this, particularly in the last 3 months?

(only ask about area if its significant. If the relative says it’s not a problem or is not critical/dissatisfied then move onto the next questions)

Bodily functions

Sleep: What has (patient) sleep been like?
Has (patient) has any difficulty in getting off?
Has (patient) has any nightmares?
Has (patient) been waking up very early?

Appetite: What has (patient) appetite been like?
Has (patient) not wanted to eat?

Bodily complaints: Has (patient) complained of headaches or dizziness?
Has (patient) complained of any other pains?

Probe: How often has s/he complained?

Refer to checklist for each symptom

Under activity

Has s/he been lacking in energy?
----or tended to sit or lie around not doing much?
Has s/he stopped doing anything?

Refer to checklist for each symptom

Slowness

Has s/he seemed particularly slow doing things (for example dressing, shaving, making beds, washing dishes, etc)?

Refer to checklist for each symptom
Over activity

Has s/he had times of being unusually cheerful?

---- or of being excited or agitated?

---- or of being noisy or shouting a lot?

---- or of being restless – such as pacing about, not sitting through meals, etc…?

---- has s/he had times of being more talkative? Or swearing? Or being rude?

Probe: what about during the night?

Refer to checklist for each symptom

Violence

Has s/he hit or hurt anyone?

Has s/he attempted or threatened to …..?

Probe: When did it happen? Can you describe what happened?

Refer to checklist for each symptom

Destructive behaviour

Has s/he been destructive?….or knocked things about in the house?

Refer to checklist for each symptom

Withdrawal

Has s/he kept to himself/herself a lot? …. Or refused to meet people?

Has s/he tended to avoid anyone in the household?

What about relatives?….or friends?….or people that come to the door?

Has s/he had times of being less talkative?

Probes: Does s/he answer (person) when s/he speaks to him/her?

Does this mean that s/he can’t go out?

Does it limit him/her in any other way?

Refer to checklist for each symptom
Dementia specific symptoms

Memory

Has s/he had any marked difficulties with memory such as not being able to find his/her way home, or forgetting his/her address, or anything like that?

Probes: Does s/he have any difficulty finding his/her way home?
Does s/he have any difficulty remembering his/her address?
Does s/he has difficulty in remembering names of people s/he knows well?
Does s/he have any difficulty with memory for recent events such as forgetting messages, remembering routes?
Does s/he ever seem confused in his/her mind?
Does this mean then s/he cannot go out along?
Does s/he ask questions repetitively?

Refer to checklist for each symptom

Tasks

Have you noticed any changes in ______ (patients) ability to carry out daily tasks?

Probes: Does s/he have any difficulty with tasks and activities that require organisation and planning?

Refer to checklist for each symptom

Confusion

Have you noticed ______ (patients) becoming confused in unfamiliar environments?

Refer to checklist for each symptom

Communication

Have you noticed ______ (patients) having difficulty finding the right words?

Refer to checklist for each symptom
Money

Have you noticed ______ (patients) having difficulty with numbers and/or handling money in shops?

Refer to checklist for each symptom

Personality and mood

Have you noticed any changes in ______ (patients) personality or mood?
Have you noticed any changes in ________ (patient) mood?
Has s/he been depressed?...miserable?...tearful?
….or said that life is not worth living?
Probes: what makes you think s/he was depressed/miserable?

Did s/he complain of being miserable?

How much?...to whom?
Has s/he blamed himself/herself for things that don’t seem important?
Has s/he tried to harm himself/herself – or take his/her life?
Have you been worried that s/he might do so?
Probes: When did it happen?

Can you describe what happened?

Refer to checklist for each symptom

Fears and anxiety

Has s/he had any unusual fears?
…or period of anxiety…or panic?
…or any special fears – such as of going out?
Probes: If focused did s/he try to stop (specified person) from doing things such as going out, work, play, shopping, etc?

Did the anxiety or panic occur at any special time? – such as: In the morning?, …or going out of the house?, … or going to work, somewhere in particular?. Or being left alone?

Did this mean that s/he could not go out along?
Does it limit him/her in any other way?

Did s/he talk about the fears at all?...how often?...to whom?

Refer to checklist for each symptom

Worry

Has s/he been worrying a lot about things?

…about you, (marital) or the children, … (parental) your husband/wife .. or anyone else?

…or about other things such as his/her health, work, or relationship with friends?

Probes: What makes you think s/he is worrying (about this)?

How much has s/he talked about this? How often? To whom?

Refer to checklist for each symptom

Obsessions

Has s/he been unusually fussy or finicky about anything?

Has s/he had routines of doing things only in a certain way even though it seems silly?

…or doing things over and over again? – like washing his/her hands, or keep checking that the door is locked?

Probes: Does s/he think it is silly to do this? Does it limit him/her in any way?

Refer to checklist for each symptom

Personal care and habits

Has s/he looked after himself/herself all right?

… and kept himself/herself clean and tidy?

Has the way s/he looks after himself/herself changed at all?

Des s/he look after him/herself as well as he/she used to?

Has s/he unusual habits or routines? – such as in dress, or shaving, or bating, or hoarding strange things?

Does/did s/he seem at all odd in appearance…(compared with siblings)?...or in manner, … or in movement, such as walking, shuffling, sitting rocking self, etc…?
Has his/her speech seemed odd or difficult to understand?... Such as being slurred or jumbled sentences, etc?

**Refer to checklist for each symptom**

**Delusions/hallucinations**

Has s/he become jealous of the way you treat the other people in the family?

Has s/he become jealous in any other way?

Has s/he had any strange ideas about you or others in the family?

Has s/he seemed strange…or expressed any odd ideas?

Has s/he seemed to think people were against him/her?...in what way?

…or were talking about him/her?

Has s/he accused anyone else of such things

Has s/he talked to himself/herself at all?...or laughed to himself/herself?

_Probes:_  
*How much did s/he talk about these things?...how often?*

*Did s/he do anything strange connected with these ideas?*

*Does it limit him/her in any way – such as being unable to get out?*

*What have you said to him/her concerning these odd ideas? ... or done?*

**Refer to checklist for each symptom**

**Drinking and gambling**

Has s/he been drinking a lot? …. or gambling a lot?

**Refer to checklist for each symptom**

**Bizarre behaviour**

Has s/he done anything else which seemed odd or unusual for him/her? …..such as wandering off from home?

…or has there been anything else about his/her behaviour which seemed different from his/her usual self?

**Refer to checklist for each symptom**
Very important questions:

What difference has (patients) difficulties made to you and the family?

From your own point of view, what has been the most disturbing aspect of (patients) difficulties?

Household tasks (this section may have been answered in the ‘time budget’ section)

About various jobs that have to be done in the family, what do you think (the patient) should do around the house? (E.g. food shopping, cleaning, washing clothes, cooking, washing dishes, care of garden, household repairs)

Has the amount (patient) has done in the way of helping to do things at home changed since the difficulties began?...in what way?

Are you satisfied with who does these things in the home?...i mean by that, are you satisfied with the way (give examples) are done?

….and the way you share things to be done?

If necessary: is there anything you would have done differently?

Do any of these things about the home lead to disagreement?

How do you feel about that now?

Has there been any change in how well (patient) has dealt with his/her money?

Probes : what sorts of things does (patient) do?

Who does what around the house?

If patient does things:

• on how many days is it done?
• How many days does the (patient) do it alone?
• How many days do you do it together?
• Any changes in who does this before the patient?

Has the way (patient) has done (activity) changed since the difficulties started?

How well has/had s/he done the task?

…any changes at all since the trouble began?...in what way?

Tell me more about that?

When did change occur?

What seems to have been the reason for the change?
Money/finances

Who mainly looks after money matters in the home?

(if the Patient does not handle money then establish this and do not question any further)

How do you feel about these arrangements?

Do they ever lead to disagreements?

Relationships

These questions are to be asked of a patient’s spouse or the mother/father of an adult patient, if appropriate.

In this section it is important for the interviewer to attempt to get the informant as involved as possible in the subject of his/her marriage.

The first 2 questions are intended as openers for the section in general. Neutral probes should be freely used to elicit feelings and attitudes.

How do you spend the evenings on which you do stay at home?

Are there any things which you and your (patient) do together in the evenings or at weekends?

Probe for: Watching TV, sitting and chatting, playing games, hobbies, etc

Are there any things which you enjoy doing together?

In general, how would you say you get on together?

Do you usually know when s/he is feeling moody or upset, …or when s/he is feeling pleased?

Do you think s/he usually knows when you are feeling upset or pleased?

Over the past year, have you been apart for any reason – such as visiting relatives or being away at work? – I mean as long as overnight?

How long was this for?...how did you feel about it?

In what ways do you tend to get on each other’s nerves?

If positive: do you nag your husband/wife about this – or grumble?

Does your husband/wife nag or grumble at you about this?
**Affection/warmth/interest**

Has the affection (patient) has shown you changed at all in the last year?

What about interest in you? Or in the things you do?

Does s/he show much interest?

In what (other) ways does s/he show affection to you?

Are you satisfied with the affection and interest s/he shows in you?

*If necessary: In what ways would you like to be different?*

*How do you feel about the change?*

*Does this bother you much?*

Has the way you feel about (patient) changed at all since the difficulties started?

In what way?

Has the affection (or interest) you have shown to (patient) changed at all?

In what way?

**Medication**

Has (patient) has any drugs or pills prescribed for his/her difficulties during the past 3 months?...when?...by whom?

Did s/he take them regularly?

Does s/he take them regularly now?

Does/did s/he take them herself/himself without any difficulties?

Do/did you remind him/her to take the medication – or help in any other way?

What did/do you say or do?

How often did/have you said/done in the last months?

How about in the rest of the last year – did you do or say anything then?

**Attitude to illness**

If the informant has already said enough about his/her attitudes for rating purposes, omit the following relevant probes; otherwise use only the following set of probes.

What do you think has made (patient) like this?
Do you think s/he could do any more to control his/her illness?

**Perception of illness**

Do you think (patient) is ill?

*If Yes: what kind of illness?*

**Ending**

Do you have any questions?

Is there anything you want me to pass over to health care professionals?

Camberwell Family Interview Schedule date of issue: [28.06.2013]
Camberwell Family Interview Schedule version number: [VERSION 1]
Appendix 9: Core 10

Core-10

Site ID: [Blank]

Client ID: [Blank]

Date form given: [Blank]

Male: [Blank]

Female: [Blank]

Stage Completed:
- S Screening
- A Assessment
- F First Therapy Session
- R Referral
- D During Therapy
- L Last Therapy Session
- X Follow up 1
- Y Follow up 2

Episode: [Blank]

IMPORTANT – PLEASE READ THIS FIRST

This form has 10 statements about how you have been OVER THE LAST WEEK. Please read each statement and think how often you felt that way last week. Then tick the box which is closest to this. Please use a dark pen (not pencil) and tick clearly within the boxes.

Over the last week

1. I have felt tense, anxious or nervous

2. I have felt I have someone to turn to for support when needed

3. I have felt able to cope when things go wrong

4. Talking to people has felt too much for me

5. I have felt panic or terror

6. I made plans to end my life

7. I have had difficulty getting to sleep or staying asleep

8. I have felt despairing or hopeless

9. I have felt unhappy

10. Unwanted images or memories have been distressing me

Total (Clinical Score*)

Procedure: Add together the item scores, then divide by the number of questions completed to get the mean score, then multiply by 10 to get the Clinical Score.

Quick method for the CORE-10 (if all items completed): Add together the item scores to get the Clinical Score.

THANK YOU FOR YOUR TIME IN COMPLETING THIS QUESTIONNAIRE

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Appendix 10: Zarit burden inventory

**ZBI**

**INSTRUCTIONS:** The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?
   - 0. Never
   - 1. Rarely
   - 2. Sometimes
   - 3. Quite Frequently
   - 4. Nearly Always

2. Do you feel that because of the time you spend with your relative you don’t have enough time for yourself?
   - 0. Never
   - 1. Rarely
   - 2. Sometimes
   - 3. Quite Frequently
   - 4. Nearly Always

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
   - 0. Never
   - 1. Rarely
   - 2. Sometimes
   - 3. Quite Frequently
   - 4. Nearly Always

4. Do you feel embarrassed about your relative’s behaviour?
   - 0. Never
   - 1. Rarely
   - 2. Sometimes
   - 3. Quite Frequently
   - 4. Nearly Always

5. Do you feel angry towards your relative when you are around him/her?
   - 0. Never
   - 1. Rarely
   - 2. Sometimes
   - 3. Quite Frequently
   - 4. Nearly Always

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?
   - 0. Never
   - 1. Rarely
   - 2. Sometimes
   - 3. Quite Frequently
   - 4. Nearly Always

7. Are you afraid of what the future holds for your relative?
   - 0. Never
   - 1. Rarely
   - 2. Sometimes
   - 3. Quite Frequently
   - 4. Nearly Always

8. Do you feel your relative is dependent upon you?
   - 0. Never
   - 1. Rarely
   - 2. Sometimes
   - 3. Quite Frequently
   - 4. Nearly Always

9. Do you feel strained when you are around your relative?
   - 0. Never
   - 1. Rarely
   - 2. Sometimes
   - 3. Quite Frequently
   - 4. Nearly Always

10. Do you feel your health has suffered because of your involvement with your relative?
    - 0. Never
    - 1. Rarely
    - 2. Sometimes
    - 3. Quite Frequently
    - 4. Nearly Always
11. Do you feel that you don’t have as much privacy as you would like because of your relative?

12. Do you feel that your social life has suffered because you are caring for your relative?

13. Do you feel uncomfortable about having friends over because of your relative?

14. Do you feel that your relative expects you to take care of him/her, as if you were the only one he/she could depend on?

15. Do you feel that you don’t have enough money to care for your relative, in addition to the rest of your expenses?

16. Do you feel that you will be unable to take care of your relative for much longer?

17. Do you feel you have lost control of your life since your relative’s illness?

18. Do you wish you could just leave the care of your relative to someone else?

19. Do you feel uncertain about what to do about your relative?

20. Do you feel you should be doing more for your relative?

21. Do you feel you could do a better job in caring for your relative?

22. Overall, how burdened do you feel in caring for your relative?
   0. Not at All  1. A Little  2. Moderately  3. Quite a Bit  4. Extremely

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### The Brief Illness Perception Questionnaire (amended)

For the following questions, please circle the number that best corresponds to your views:

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much does your relative’s dementia affect your life?</td>
<td>0 No affect at all 1 2 3 4 5 6 7 8 9 10 Severe affects my life</td>
</tr>
<tr>
<td>How much does your relative’s dementia affect their life?</td>
<td>0 No affect at all 1 2 3 4 5 6 7 8 9 10 Severe affects their life</td>
</tr>
<tr>
<td>How long do you think your relative’s dementia will continue?</td>
<td>0 A very short time 1 2 3 4 5 6 7 8 9 10 Forever</td>
</tr>
<tr>
<td>How much control do you feel you have over your relative’s dementia?</td>
<td>0 Absolutely no control 1 2 3 4 5 6 7 8 9 10 Extreme amount of control</td>
</tr>
<tr>
<td>How much control do you feel your relative has over their dementia?</td>
<td>0 Absolutely no control 1 2 3 4 5 6 7 8 9 10 Extreme amount of control</td>
</tr>
<tr>
<td>How much do you think your relative’s treatment can help your relative’s dementia?</td>
<td>0 Not at all 1 2 3 4 5 6 7 8 9 10 Extremely helpful</td>
</tr>
<tr>
<td>How much does your relative experience symptoms from the dementia?</td>
<td>0 No symptoms at all 1 2 3 4 5 6 7 8 9 10 Many severe symptoms</td>
</tr>
<tr>
<td>How concerned are you about your relative’s dementia?</td>
<td>0 Not at all concerned 1 2 3 4 5 6 7 8 9 10 Extremely concerned</td>
</tr>
<tr>
<td>How concerned is your relative about the dementia?</td>
<td>0 Not at all concerned 1 2 3 4 5 6 7 8 9 10 Extremely concerned</td>
</tr>
<tr>
<td>How well do you feel you understand your relative’s dementia?</td>
<td>0 Don’t understand at all 1 2 3 4 5 6 7 8 9 10 Understand very clearly</td>
</tr>
</tbody>
</table>
Appendix 12: The Scale for the Quality of the Current Relationship

The Scale for the Quality of the Current Relationship: 14-item version
(Spruijt, Von Audenhove & Lammertyn, 2000)

Answering categories:
1 = totally not agree
2 = not agree
3 = undecided
4 = agree
5 = totally agree

1. My relative and me, we often spend time together in a pleasant way
   
2. My relative and me, we often disagree
   
3. A great distance exists between my relative and me
   
4. My relative and me, we accept each other the way we are
   
5. When problems occur, my relative and me, we mostly can solve these problems easily
   
6. I get along well with my relative
   
7. My relative and me, we offer each other tenderness
   
8. I often get irritated by my relative
   
9. When I am with my relative, I feel very well
   
10. My relative and me, we often try to impose each other's opinion
    
11. I blame my relative for being the cause of my problems
    
12. My relative and me, we appreciate each other as a person
    
13. My relative does not appreciate enough everything I do for him/her
    
14. When I haven't seen my relative for a while, I am happy to see him/her again

QCRS date of issue: [14.06.2013]
QCRS version number: [VERSION 1]
Appendix 13: PWD personal details form

**Patient Personal Details Form**

Please complete the form below.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Male ☐</th>
<th>Female ☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship Status</td>
<td>Single ☐</td>
<td>Married/Civil Partnership ☐</td>
</tr>
<tr>
<td>Living situation</td>
<td>Alone ☐</td>
<td>Parents ☐</td>
</tr>
<tr>
<td>What is the highest level of education that you have completed? (please tick the highest level you have completed)</td>
<td>Did not complete school ☐</td>
<td>Additional training (e.g. apprenticeship etc.) ☐</td>
</tr>
<tr>
<td>Employment status</td>
<td>Student ☐</td>
<td>Unemployed ☐</td>
</tr>
<tr>
<td>When were you diagnosed with dementia?</td>
<td>M M Y Y Y Y</td>
<td></td>
</tr>
<tr>
<td>To the best of your knowledge, when did you start experiencing symptoms of dementia?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Thank you for your time
Appendix 14: Montreal cognitive assessment tool

Montreal Cognitive Assessment (MOCA)
Version 7.1 Original Version

VISUOSPATIAL / EXECUTIVE
- Copy cube
  - Draw clock (Ten past eleven) (3 points)

NAMING
- Rhinoceros
  - [ ]
- Camel
  - [ ]

MEMORY
- Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.
  - 1st trial
    - FACE VELVET CHURCH DAISY RED
  - 2nd trial
    - [ ]

ATTENTION
- Read list of digits (1 digit/sec.)
  - Subject has to repeat them in the forward order
    - [ ] 2 1 8 5 4
  - Subject has to repeat them in the backward order
    - [ ] 7 4 2

MEMORY
- Serial 7 subtraction starting at 100
  - [ ]

LANGUAGE
- Repeat: I only know that John is the one to help today.
  - The cat always hid under the couch when dogs were in the room.

FLOWER
- Name maximum number of words in one minute that begin with the letter F
  - [ ]

ABSTRACTION
- Similarity between e.g. banana - orange = fruit
  - [ ]

DELAYED RECALL
- Has to recall words with no cue
  - Category cue
  - Multiple choice cue

ORIENTATION
- Date
  - [ ]
- Month
  - [ ]
- Year
  - [ ]
- Day
  - [ ]
- Place
  - [ ]
- City
  - [ ]

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www.mocatest.org

Administered by: ____________________________

TOTAL ____________________________

Acid 1 point if < 12 yr edu

Made of 30
Appendix 15: Dementia quality of life tool

DEMQLQ (version 4)

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

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

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

a lot quite a bit a little not at all

Follow up with a prompt question: Why is that? or Tell me a bit more about that.

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For all of the questions I’m going to ask you, I want you to think about the last week.

First I’m going to ask about your feelings. In the last week, how have you felt........

<table>
<thead>
<tr>
<th>Question</th>
<th>a lot</th>
<th>quite a bit</th>
<th>a little</th>
<th>not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>cheerful? **</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>worried or anxious?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>that you are enjoying life? **</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>frustrated?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>confident? **</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>full of energy? **</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>sad?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>lonely?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>distressed?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>lively? **</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>irritable?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>fed-up?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>that there are things that you wanted to do but couldn’t?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Question</th>
<th>a lot</th>
<th>quite a bit</th>
<th>a little</th>
<th>not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>forgetting things that happened recently?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>forgetting who people are?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>forgetting what day it is?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

© Institute of Psychiatry, King’s College London
<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>17. your thoughts being muddled?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
<tr>
<td>18. difficulty making decisions?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
<tr>
<td>19. poor concentration?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
</tbody>
</table>

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

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>20. not having enough company?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
<tr>
<td>21. how you get on with people close to you?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
<tr>
<td>22. getting the affection that you want?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
<tr>
<td>23. people not listening to you?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
<tr>
<td>24. making yourself understood?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
<tr>
<td>25. getting help when you need it?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
<tr>
<td>26. getting to the toilet in time?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
<tr>
<td>27. how you feel in yourself?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
<tr>
<td>28. your health overall?</td>
<td>a lot</td>
<td>quite a bit</td>
<td>a little</td>
<td>not at all</td>
</tr>
</tbody>
</table>

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

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>29. your quality of life overall?</td>
<td>very good</td>
<td>good</td>
<td>fair</td>
<td>poor</td>
</tr>
</tbody>
</table>

**Items that need to be reversed before scoring**

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Appendix 16: Dementia quality of life response card

- A lot
- Quite a bit
- A little
- Not at all
Appendix 17: Geriatric anxiety inventory

Please answer the items according to how you’ve felt in the last week.

Tick the column under **Agree** if you mostly agree that the item describes you; tick the column under **Disagree** if you mostly disagree that the item describes you.

<table>
<thead>
<tr>
<th>Item</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I worry a lot of the time.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I find it difficult to make a decision.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I often feel jumpy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I find it hard to relax.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I often cannot enjoy things because of my worries.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Little things bother me a lot.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I often feel like I have butterflies in my stomach.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I think of myself as a worrier.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can’t help worrying about even trivial things.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I often feel nervous.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My own thoughts often make me anxious.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get an upset stomach due to my worrying.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I think of myself as a nervous person.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I always anticipate the worst will happen.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I often feel shaky inside.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I think that my worries interfere with my life.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My worries often overwhelm me.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I sometimes feel a great knot in my stomach.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I miss out on things because I worry too much.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I often feel upset.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Appendix 18: Geriatric depression scale

**GERIATRIC DEPRESSION SCALE (SHORT VERSION)**

<table>
<thead>
<tr>
<th>No.</th>
<th>Questions</th>
<th>Answer:</th>
<th>Test Answers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Are you basically satisfied with your life?</td>
<td>Yes / No</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>Have you dropped many of your activities or interests?</td>
<td>Yes / No</td>
<td>Yes</td>
</tr>
<tr>
<td>3</td>
<td>Do you feel that your life is empty?</td>
<td>Yes / No</td>
<td>Yes</td>
</tr>
<tr>
<td>4</td>
<td>Do you often get bored?</td>
<td>Yes / No</td>
<td>Yes</td>
</tr>
<tr>
<td>5</td>
<td>Are you in good spirits most of the time?</td>
<td>Yes / No</td>
<td>No</td>
</tr>
<tr>
<td>6</td>
<td>Are you afraid that something bad is going to happen to you?</td>
<td>Yes / No</td>
<td>Yes</td>
</tr>
<tr>
<td>7</td>
<td>Do you feel happy most of the time?</td>
<td>Yes / No</td>
<td>No</td>
</tr>
<tr>
<td>8</td>
<td>Do you feel helpless?</td>
<td>Yes / No</td>
<td>Yes</td>
</tr>
<tr>
<td>9</td>
<td>Do you prefer to stay at home, rather than go out and do things?</td>
<td>Yes / No</td>
<td>Yes</td>
</tr>
<tr>
<td>10</td>
<td>Do you feel that you have more problems with memory than most?</td>
<td>Yes / No</td>
<td>Yes</td>
</tr>
<tr>
<td>11</td>
<td>Do you think it is wonderful to be alive now?</td>
<td>Yes / No</td>
<td>No</td>
</tr>
<tr>
<td>12</td>
<td>Do you feel pretty worthless the way you are now?</td>
<td>Yes / No</td>
<td>Yes</td>
</tr>
<tr>
<td>13</td>
<td>Do you feel full of energy?</td>
<td>Yes / No</td>
<td>No</td>
</tr>
<tr>
<td>14</td>
<td>Do you feel that your situation is hopeless?</td>
<td>Yes / No</td>
<td>Yes</td>
</tr>
<tr>
<td>15</td>
<td>Do you think that most people are better off than you are?</td>
<td>Yes / No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Total Score**

*When a score of more than five is indicated, a more thorough clinical investigation should be undertaken.*

---

Appendix 19: Perceived criticism scale

<table>
<thead>
<tr>
<th>How critical do you consider your relative to be of you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>Not at all critical</td>
</tr>
</tbody>
</table>

Perceived Criticism Scale date of issue: [14.06.2013]
Perceived Criticism Scale version number: [VERSION 1]
Appendix 2: The brief illness perception questionnaire for PWD (modified)

The Brief Illness Perception Questionnaire (amended)

For the following questions, please circle the number that best corresponds to your views:

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you feel your dementia affects your life?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td></td>
<td>No affect at all</td>
</tr>
<tr>
<td></td>
<td>Severe affects my life</td>
</tr>
<tr>
<td>How long do you think your dementia will continue?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td></td>
<td>A very short time</td>
</tr>
<tr>
<td></td>
<td>Forever</td>
</tr>
<tr>
<td>How much control do you feel you have over your dementia?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td></td>
<td>Absolutely no control</td>
</tr>
<tr>
<td></td>
<td>Extreme amount of control</td>
</tr>
<tr>
<td>How much do you think your treatment can help your dementia?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td>Extremely helpful</td>
</tr>
<tr>
<td>How much do you experience symptoms from your dementia?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td></td>
<td>No symptoms</td>
</tr>
<tr>
<td></td>
<td>Many severe symptoms</td>
</tr>
<tr>
<td>How concerned are you about your dementia?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td></td>
<td>Not at all concerned</td>
</tr>
<tr>
<td></td>
<td>Extremely concerned</td>
</tr>
<tr>
<td>How well do you feel you understand your dementia?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td></td>
<td>Don't understand at all</td>
</tr>
<tr>
<td></td>
<td>Understand very clearly</td>
</tr>
<tr>
<td>How much does your dementia affect you emotionally?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td></td>
<td>Not at all affected</td>
</tr>
<tr>
<td></td>
<td>Extremely affected emotionally</td>
</tr>
</tbody>
</table>

Please rank order the three most important factors that you believe caused your dementia.

The most important causes are:

1. ........................................................................................................
2. ........................................................................................................
3. ........................................................................................................

Brief IPQ (adapted) date of issue: [26.08.2013]
Brief IPQ (adapted) version number: [VERSION 1]

Adapted version of the brief IPQ lslbroadband@clear.net.nz