

**An investigation of the efficacy of training care home staff in a formulation based  
functional analysis approach to understanding stress and distress behaviours with  
dementia**

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September 2016

Thesis submitted in part fulfilment of the degree of  
Doctoral Programme in Clinical Psychology  
University of East Anglia

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### Abstract

**Objectives:** The aim of this study was to evaluate the outcome of a package of evidence-based person-focused training for formal carers working with people with dementia living in care homes. Specifically evaluating the efficacy of a new Formulation based Functional Analysis (FFA) approach to understanding stress and distress behaviours (SAD-behaviours) with dementia.

**Design:** The study employed an open trial design, with three independent groups: two training interventions and a waiting list control.

**Method:** Forty eight care staff were recruited from care homes across Cambridgeshire. Participants in intervention group one attended 15 hours of training (CAMTED), participants in intervention group two attended 21 one hours of training including a FFA module in understanding SAD-behaviours (CAMTED-Plus). The waiting list control consisted of staff waiting to receive training. All participants completed outcome measures on knowledge and attitudes to dementia, burden, job satisfaction and perceived frequency of SAD-behaviours and confidence in managing SAD-behaviours at baseline and post-intervention.

**Results:** Due to the small sample size the waiting list group was excluded from data analyses. Results showed that there were no statistically significant differences between CAMTED and CAMTED-Plus on any of the outcomes at the end of the intervention. Within-group analyses of pre-post change found statistically significant differences for CAMTED in the degree of hopefulness about dementia and CAMTED-Plus in attitude to dementia, extent to which a person-centred approach is adopted and levels of depersonalisation. Positive feedback was provided on the use of the jigsaw training tool and verbal feedback indicated participants' positivity about the training.

**Conclusion:** The results provide preliminary support for the utility of the FFA approach as a training intervention. Although the results are limited due to the methodological shortcomings, they provide a range of evidence in support of the FFA approach, which may be built on in the future.

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### **Acknowledgements**

Thank you to all of the care homes and care home staff for taking part and supporting this study.

I would first like to thank the University of East Anglia Doctoral Programme in Clinical Psychology for supporting me over the past three years in pursuing a career I am passionate about. Special thanks go to my primary supervisor, Professor Ken Laidlaw (University of East Anglia), without whom this research would not have been possible. Your continued support, encouragement and expertise throughout this process have been immeasurable and invaluable. I would also like to thank Professor Dave Peck (University of East Anglia) for support and guidance with my data analyses.

An important thanks go to my external supervisor Alistair Gaskell and the local collaborating team Cambridgeshire Training, Education and Development for Older People (CAMTED-OP; Jim, Adrian, Rachael, Mary, Angela and Kathy), again without whom this research would not have been possible. I am grateful to all of you for your open, honest and continued support throughout this project, despite the various pressures on time.

On a more personal note, I would like to thank my incredible family for their continuous loving support and encouragement throughout the whole of my training journey and for always believing in me. I would like to show my heartfelt thanks to my partner Edward, for believing in me even before I did and who has supported me in all ways possible through this process.

Thanks also go to my course buddies and friends for supporting me especially through the final phase and taking my mind of things when needed.

I would like to dedicate this thesis to my beloved and cherished Grandad Mr Ronald 'Jock'  
Boyle who sadly passed away before it was completed.

Thank you for believing in me

"You're the greatest"

## Chapter One: Introduction

### 1.1 An Introduction to Dementia

Dementia is an umbrella term used to describe a broad group of progressive brain conditions, including Alzheimer's disease and Vascular Dementia (Alzheimer's Disease International, 2015). Over time, these conditions gradually lead to the death of brain cells by changing the structure and chemical composition of the brain, which leads to the progressive decline of multiple areas of functioning including memory, orientation, understanding, language and ability to perform activities of daily living (Department of Health, 2009). This is a significant decline from a previous level of functioning and causes substantial impairment in occupational and social functioning (Department of Health, 2009).

**1.1.1 Prevalence.** It is estimated that 46.8 million people are living with a dementia worldwide and this number is predicted to increase to 74.7 million in 2030 and 131.5 million by 2050 (Alzheimer's Disease International, 2015). Dementia has an enormous economic impact, the estimated worldwide cost of dementia is US \$818 billion, and it is predicted to reach US \$1trillion by 2018 (Alzheimer's Disease International, 2015).

Consistent with the profound demographic transition affecting all the nations in the world (United Nations Population Fund, 2012), the United Kingdom (UK) has an ageing population. In the UK there are currently estimated to be 850,000 people living with a dementia (Dementia UK, 2014). This figure is also predicted to increase significantly over the coming years to over one million by 2025 and over two million by 2051 (Dementia UK, 2014).

The total cost of dementia in the UK is £26.3 billion a year, which includes the costs of healthcare (£4.3 billion), social care (£10.3 billion) and unpaid informal care (£11.6 billion; Dementia UK, 2014). The financial cost of dementia is expected to grow to over £34 billion in 2025 and nearly £64 billion by 2050 (Dementia UK, 2014).

**1.1.2 Policy context.** Dementia is a global health priority and worldwide health challenge (World Health Organisation, 2012), which has been described as ‘exceptional’ (Wortmann, 2012) in relation to the number of people affected, its impact and the economic cost (Wortmann, 2012). Countries throughout the world are preparing for the future challenges of dementia and the ageing population (Alzheimer’s Disease International, 2009; World Health Organisation, 2012). In the UK, National Dementia Strategies have been published in the four nations, which all recognise the importance of improving the quality of dementia care services (Department of Health, 2009; Department of Health et al., 2012; NHS Education for Scotland, 2010; Welsh Assembly Government, 2011).

The National Dementia Strategy for Scotland (NES, 2010) proposed transforming dementia services to strengthen the integration of health and social care services. NES developed a framework to ensure that all care staff are skilled and knowledgeable about dementia (Scottish Social Services Council, 2011). The strategy advocated a biopsychosocial approach to dementia, which recognised this as being a significantly positive, person-centred and psychologically orientated (NES, 2010; Scottish Social Services Council, 2011).

In 2011 the Standards of Care for Dementia in Scotland and the Promoting Excellence Framework were published by Alzheimer’s Scotland Action on Dementia, 2011. More recently the Eight Pillars Model of Community Support (Alzheimer Scotland, 2012) and Advanced Dementia Practice Model (Alzheimer Scotland, 2015) policies were formulated to advocate an integrated and holistic approach to care. These recognised that dementia has many social implications that can be best met by drawing together the health and social care interventions required to meet individual needs (Alzheimer Scotland, 2012; Alzheimer Scotland, 2015). At a time of demographic change, this approach is said to be a coherent response to the increasing prevalence of dementia (Alzheimer Scotland, 2012).

**1.1.3 The demographic transition.** The demographic transition describes a change from a high-mortality and high-fertility society to a low-mortality and low-fertility society (Harper, 2014; Office for National Statistics, 2013). This results in an increase in the number of living generations, and a decrease in the number of living family members within these generations (Centre for Policy on Ageing, 2014; Harper & Levin, 2005; Office for National Statistics, 2013).

The Office for National Statistics (ONS) has estimated that in England in 2030, there will be 51 per cent more people aged 65 and over, and 101 per cent more people aged 85 and over compared to 2010 (House of Lords, 2013). This rapidly ageing society means that a proportion of older people will be living longer, often with multiple chronic health conditions (House of Lords, 2013; Alzheimer Disease International, 2013). These demographic projections suggest that there is going to be a significant increase in the demand for formal care services (House of Lords, 2013; Alzheimer Disease International, 2013).

It is predicted that there is going to be a substantial shift from informal family care to formal paid care services (Alzheimer Disease International, 2013). Changing societal models and trends in family structures, such as decreasing family size, increases in divorces and single-parent families are likely to lead to the reduction in the availability of family caregivers, leading to an increase in the need for formal paid care and placing pressure on the demand for long-term care services (Centre for Policy on Ageing, 2014; Organisation for Economic Co-operation and Development, 2011).

Demand for informal care is projected to rise by over 50 per cent between 2007 and 2032. However, the supply of this care is anticipated to rise by only 20 per cent (House of Lords, 2013). This imbalance has been described as the “*tipping point for care*” (Carers UK, 2015), which is the point in time, when the numbers of older people needing care will start to

surpass the numbers of family members available to provide care (Carers UK, 2015; House of Lords, 2013; Knapp, 2007).

In light of these statistics it is important that ageing is not presented here as an apocalyptic demography (Gutman, 2010; Martin, Williams, & O'Neill, 2009), whereby an ageing population is viewed as having negative implications for society and resources and older adults are viewed as primarily being frail and dependent (Gutman, 2010; Martin et al., 2009). Older adults are a heterogeneous group and the use of dependency ratios risks creating a false dichotomy that ignores the broader vision of ageing (Kwok & Ku, 2016; Martin et al., 2009). Many older adults remain in good health, continue to work and a proportion provide important care for spouses (Gutman, 2010). Alongside the challenges that an ageing population can present, this should also be celebrated as a social achievement (Gutman, 2010).

## **1.2 Behaviours with Dementia**

During the course of their life experience with dementia, people can experience the development of behavioural and psychological difficulties (Brechin, Murphy, James, & Codner, 2013). Symptoms of a dementia that will impact on an individual's experience and quality of life may include, hitting, kicking, shouting, pacing, non-compliance and disinhibition (James, 2011), as well as confusion, anxiety, depression, hallucination and agitation (Ballard, 2001; James, 2011).

Earlier studies exploring the occurrence of these difficulties were difficult to interpret due to problems defining the difficulties and the number of different assessment tools used (Zuidema, Derksen, Verhey, & Koopmans, 2007). More recently a number of studies have used similar assessment tools and research suggests that these difficulties occur in up to 90 per cent of people living with a dementia (PwD; Brechin et al., 2013; Lyketsos et al., 2002; Robert et al., 2005; Savva et al., 2009).

These difficulties have been found to be high around the world, irrespective of the measurement scale used (Brodaty et al., 2001; Zuidema, Derksen, Verhey, & Koopmanset, 2007). The frequency of these difficulties has been shown to vary depending on the setting and it is reported that difficulties are less frequent and severe in the community (56–98 per cent) compared to hospital or long-term care settings (91-96 per cent; Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; Frisoni et al., 1999). These difficulties have also been found to often occur in the later stages of the condition and an association has been found between severity of difficulty and severity of dementia (Brodaty et al., 2015; Thompson, Brodaty, Trollor, & Sachdey, 2010).

**1.2.1 Defining behaviours with dementia.** Defining the difficulties that can be displayed by PwD have evolved over the years and provoked much discussion in the dementia care literature (Bird, 1998; Bird & Moniz-Cook, 2008; Cohen-Mansfield, Marx, & Rosenthal, 1989; Finkel & Burns, 1999; James, 2011). A number of terms and definitions have been used to describe this phenomenology.

**1.2.1.1 Behavioural and Psychological Symptoms of Dementia.** The term Behavioural and Psychological Symptoms of Dementia (BPSD) has been widely used, particularly in neuropsychiatric research in North America (Finkel, 2000; Finkel & Burns, 1999). In 1996, the International Psychogeriatric Association (IPA) convened a consensus conference on what was known as the ‘behavioural disturbances in dementia’. The aim of the conference was to establish a term that all could use to describe the difficulties that can be displayed by PwD (Finkel, Costa, Cohen, Miller, & Sartorius, 1997).

The IPA conference decided on BPSD, which was defined as “*symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia*” (Finkel et al., 1997, p.1060). The IPA conference group suggested separating BPSD into specific symptom clusters, for example, behavioural symptoms, which included



physical aggression and restlessness, and psychological symptoms, which included anxiety, depression, hallucinations and delusions (Finkel et al., 1997).

The European Alzheimer's Disease Consortium (2005) recommended dividing BPSD it into several groups of symptoms, for example, apathy, mood/agitation and psychosis (Robert et al., 2005). The consortium suggested that sub-grouping BPSD provided a framework to compare treatment approaches across cultures (Robert et al., 2005).

The term BPSD was designed to promote clarity and precision in interventions and treatments for dementia and offer a shared language for professionals (Finkel et al., 1997). The term BPSD has been critiqued for the use of the word 'symptoms', which implies that the difficulties are a symptom or originate from the dementia and should be treated in this manner (French & Swain, 2012; Wood-Mitchell et al., 2008). Bird (2005) argued that the implications of this biomedical conceptualisation can mean other possible understandings or underlying factors, such as pain, could be identified as a symptom of dementia and subsequently go unnoticed. Bird (2005) also suggested that the term BPSD obscures the fact, that many idiosyncratic factors interact with the cognitive impairment associated with a dementia, such as, environmental and psychosocial factors, which determine not only if a difficulty presents itself but whether it is seen as a clinical problem (Bird & Moniz-Cook, 2008; Dewing, 2010; Epp, 2003; Stokes, 2000).

Consistent with this, Wood-Mitchell, James, Waterworth, Swann and Ballard (2008) conducted a qualitative study investigating the prescribing of medications by psychiatrists for BPSD. They reported that a number of participants thought BPSD was too broad a term and that 'unusual behaviours' could be labelled as BPSD, meaning that the real cause of the behaviour was missed (Wood-Mitchell et al., 2008).

**1.2.1.2 Challenging Behaviour or Behaviours that Challenge.** The term Challenging Behaviour (CB) originated in the intellectual disability literature and was

defined by Emerson (1995) as “*culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities*” (p. 4).

More recently the term CB has been used in dementia care literature to describe behaviours that are perceived to be challenging for caregivers (Moniz-Cook, Woods, Gardiner, Silver, & Agar, 2001a). Bird and Moniz-Cook (2008) proposed behaviours are “*a manifestation of distress in the person with dementia, or of distress in the carer*” (p. 573). The term CB realigned the focus from individual pathology to a problem occurring in interaction between caregivers and the environment (Blunden & Allen, 1987; Pimm, 1998).

Bird and Moniz-Cook (2008) argued that when attempting to understand a person’s behaviour, previous terms and definitions have encouraged the focus on external behaviours, rather than their underlying cause. In addition to this, it has been suggested that what is perceived as challenging varies between individuals and across settings (Bird & Moniz-Cook, 2008). What is acceptable for caregivers in one setting may not be for caregivers in another environment. Bird and Moniz-Cook (2008) and James (2011) have suggested that CB is socially constructed and is the product of an interaction between the individual and their environment. Behaviours only become a problem when they challenge the norms of the settings in which they take place and caregivers’ capacity to cope with them (Bird, 2005; Bird & Moniz-Cook, 2008; James, 2011).

There is evidence that caregivers differ widely in how they perceive CB. Moniz-Cook et al. (2001a) developed and reviewed the psychometric properties of the Challenging Behaviour Scale (CBS), a self-report measure of incidence and frequency of resident behaviour. The review indicated that adequate inter-rater reliability was only achieved when the scale was completed collaboratively by care home staff. Bird, Jones, Korten and

Smithers (2007) also found variability in levels of distress experienced by care home staff exposed to the same behaviour by the same person, indicating that there is a subjective idiosyncratic aspect to appraisal. Challenging behaviour is in the eye of the beholder and hence this presents some challenges when seeking to measure outcomes for interventions focused on CB's.

More recently James (2011) introduced the term Behaviours that Challenge (BTC) to describe the behaviours displayed by PwD. James (2011) defined behaviours as “*actions that detract from the well-being of individuals due to the physical or psychological distress they cause within the settings they are performed*” (p.12). The re-ordering of words by James (2011) signified a change in emphasis of the word ‘challenging’, which in comparison to earlier terms, highlighted to a greater extent the interaction between the individual and their environment.

**1.2.1.3 Stress and Distress Behaviours.** In the UK, until recently, CB (Bird & Moniz-Cook, 2008; Moniz-Cook, 2001a), or BTC in dementia (James, 2011) has been replaced with a term that is thought to be less stigmatising and more descriptive of the issue faced by PwD and their carers, Stress and Distress behaviours (SAD-behaviours; NES, 2013).

This term suggests that behaviour is usually driven by feelings of stress and distress in the person living with a dementia and as such behaviours are viewed as a coping response used by individuals to manage these difficult feelings (NES, 2013). SAD-behaviours are recognised as not being isolated to the person living with a dementia, but are also used by the general population at times of stress and distress, which represents a more normalising definition (NES, 2013; James, 2014).

SAD-behaviours capture the idiosyncratic perspective of the person living with a dementia, a move away from previous terms and definitions that have focused on the outward behaviour (NES, 2013; James, 2014). This is instrumental in encouraging those around an

individual to start to view and understand the world through the eyes of the person (NES, 2013; James, 2014).

This term also recognises the perspective of caregivers. It is equally valuable to understand the perception of those around an individual experiencing stress and distress (NES, 2013; James, 2014). It is recognised that SAD-behaviours can equally impact and influence the behaviour of others (Todd & Watts, 2005), which opens up the understanding that intervention should not just be focused at the level of the individual (NES, 2013). For the purposes of this thesis, the term SAD-behaviours has been adopted.

**1.2.2 Categorising types of SAD-behaviours.** Over the years researchers have attempted to conceptualise SAD-behaviours through the use of lists and categories. Ballard, O'Brien, James and Swann (2001) suggested that grouping behaviours was important for clinical and research purposes, and described four subcategories: agitation, psychosis, mood disorders and other. Bird and Moniz-Cook (2008) argued that categorising behaviours in this way is problematic, due to the overlap in categories. For example, symptoms of anxiety being included in both 'agitation' and 'mood disorder' categories.

Cohen-Mansfield (2001) categorised agitated behaviours into four types: verbally nonaggressive or physically nonaggressive behaviour and verbally aggressive or physically aggressive behaviour. James (2011) incorporated Cohen-Mansfield's categorisation system into his psychological intervention for BTC but augmented this by including people's beliefs about the nature of behavioural expressions of unmet need. James's (2011) categorisation system distinguished between non-active behaviours, which relate to apathy and depression and active behaviours, which are separated into four categories: those triggered by stress, disorientation, disinhibition, and environment. James (2011) suggested that by categorising behaviours in this way, it can help to understand the origins of behaviours and identify ways of reducing them.

Although the categorisation of behaviours has been described as a useful framework to compare interventions (Robert et al., 2005), the use of lists and categories has been described as problematic as it does not direct people to consider what might be causing or underlying the behaviour (Bird & Moniz-Cook, 2008; Cohen-Mansfield, 2003).

Bird et al. (1998) suggested that categorising behaviours portrays the person living with dementia as the '*patient*' and the behaviour the '*syndrome*' to be treated, with a standardised intervention. Bird et al. (1998) defined this as the "*one syndrome – one treatment paradigm*" and argued that this underlies the motivation to categorise behaviours.

A number of authors have presented the case for leaving categorisation conceptualisations in favour of aetiologies (Bird et al., 1998; Bird & Moniz-Cook, 2008; Cohen-Mansfield, 2003; Moniz-Cook, Stokes, & Agar, 2003). A number of case series studies have demonstrated that similar behaviours often have different aetiologies (Bird, Blair & Caldwell, 2006; Dwyer-Moore & Dixon, 2007). Moniz-Cook et al. (2003) found in their investigation of five nursing home residents presenting with uncooperative behaviour at mealtimes that similar behaviours had multiple aetiologies that included biological, psychological, social and environmental factors. The findings were consistent with an earlier study (Hope, Keane, Fairburn, McShane, & Jacoby, 1997). A limitation of this study is the use of single-case methodology and small sample size, which makes it difficult to generalise the findings. The use of a single-case design however, enables hypotheses about the function of the behaviour to be tested (Moniz-Cook et al., 2003; Nock, Michel, & Photos, 2007).

Research suggests a move away from the '*one syndrome-one treatment*' paradigm is needed (Bird et al., 1998), with interventions being targeted at case specific underlying factors rather than the behaviour, or being located as a characterological feature of the individual (Bird, Llewellyn-Jones, Smithers, & Korten, 2002; Bird & Moniz-Cook, 2008; Moniz-Cook, Woods, & Richards, 2001b; Moniz-Cook et al., 2003).

**1.2.3 Summary of defining behaviours with dementia.** During the course of their life experience with dementia, up to 90 per cent of PwD will experience the development of SAD-behaviours (Brechin et al., 2013). Defining these difficulties conceptually has been problematic given its socially constructed meaning, which has been shown to vary across settings and individuals (Bird & Moniz-Cook, 2008; James, 2011).

A number of terms and definitions have been introduced over the years that have been used and continue to be used inconsistently (Volicer, 2012). The lack of agreement on what these behaviours are extends to the instruments used to measure their occurrence (Cohen-Mansfield, 2000b; Gitlin et al., 2014). Given the difficulties in defining and measuring this construct, it understandably presents difficulties in developing interventions to improve the quality of life for PwD and caregivers.

### **1.3 The Care Home Sector, Dementia and SAD-behaviours**

In the UK, it is suggested that 80 per cent of people living in care homes have dementia or significant memory problems (Comas-Herrera, Somani, & Banerjee, 2007; Dementia, 2014; Knapp, Luengo-Fernandez et al., 2010). The demographic transition has changed the profile and characteristics of residents living in long-term care settings such as care homes (Cavendish, 2013). Recent reports suggest that care homes are no longer an alternative housing option, and are often a last resort for those with higher and more complex care needs (Alzheimer's Society, 2013). The decision to move into a care home is often made at a point of crisis, for example after a hospital admission or when support can no longer be provided at home (Alzheimer's Society, 2013). Compared to those living without a dementia, health and psychological well-being have been found to deteriorate significantly following transition to a care home, with a high risk of mortality (Alzheimer Disease International, 2013).

Several studies have investigated factors that predict transition into a care home. Cognitive impairment and caregiver distress have been found to be strong predictors of admission (Alzheimer's Disease International, 2011; Gaugler, Duval, Anderson, & Kane, 2007). These findings indicate that dementia care is now necessary in many settings, not just those services specialising in dementia (Banerjee, 2009; Centre for Policy on Ageing, 2012).

It has been estimated that nearly two thirds of people with a dementia living in a care home will experience SAD-behaviours at any one time (Dementia Action Alliance, 2011; Hardenacke, Bartholomeyczik, & Halek, 2011; Margallo-Lana, 2001; Schaufeli, Bakker, & Van Rhenen, 2009). People living with a dementia are often moved to a care home at the later stages of the condition, when SAD-behaviours are often more prominent and having a significant impact on caregivers (Luppa et al., 2008).

SAD-behaviours cause significant distress to the person living with a dementia and their caregivers and they have been found to be associated with more time spent caregiving (Cohen-Mansfield, 1995; Herrmann et al., 2006), increased likelihood of admission to long-term care or hospital and transfer between care settings (Colerick & George, 1986; de Vugt et al., 2005; Eters, Goodall & Harrison, 2008; Morris et al., 1990; O'Donnell et al., 1992; Ryu, Ha, Park, Yu, & Livingston, 2011).

### **1.3.1 Stress in the formal caregiver relationship with people with dementia.**

SAD-behaviours are one of the most common reasons care homes seek assistance from external professionals (Banerjee et al., 2003; Cohen-Mansfield, 2003; Moniz-Cook, Woods & Gardiner, 2000; Rodney, 2000). They are associated with care staff burnout, absenteeism and morbidity (Alzheimer's Society, 2011; Draper et al., 2000; Moniz-Cook et al., 2000; Rodney, 2000) and have been found to be distressing, frightening and difficult for formal care staff to manage (Cohen-Mansfield, 2003).

The term burnout in work-related settings is used to describe an individual's reaction to persistent stress at work (Maslach, Jackson, & Leiter, 1996). A model of occupational burnout was developed by Maslach et al. (1996), who identified three dimensions to be important in the development of burnout. These included increased feelings of emotional exhaustion, increased distance or detachment towards other people (depersonalisation) and reduced personal accomplishment. Maslach et al. (1996) found the potential consequences of burnout included, absenteeism, reduced staff well-being, low staff satisfaction and deterioration in the quality of care provided. Research has found increased levels of burnout in care home staff supporting PwD (Mackenzie & Peragine, 2003; Todd & Watts, 2005). For example, Duffy, Oyeboode and Allen (2009) found moderate levels of burnout in a sample of care home staff and more than two thirds were experiencing emotional exhaustion. This was consistent with earlier research that found high levels of burnout in dementia care staff (Mackenzie & Peragine, 2003; Todd & Watts, 2005).

The relationship between burnout and caregiver behaviour has been widely studied in care settings (Astrom, Nilsson, Norberg, Sandman, & Winblad, 1991; Jenkins & Allen, 1998; Todd & Watts, 2005). There is evidence to suggest that caregiver beliefs and perception of SAD-behaviours can influence emotional responses and behaviour, such as, whether or not an intervention is delivered effectively (Hastings & Remington, 1994). Todd and Watts (2005) investigated the impact of staff burnout in responses to challenging behaviour in real-life scenarios. They asked a group of nurses and psychologists to rate their responses to PwD experiencing SAD-behaviour. Burnout was found to be associated with less willingness to help, low optimism, and negative responses to behaviour (Todd & Watts, 2005).

Research has also explored the relationship between care staff burnout and various other factors, such as care staff attitudes, self-efficacy, job satisfaction and management of SAD-behaviours (Beck & Vogelpohl, 1999; Cohen-Mansfield & Werner, 1998; Duffy et al.,



2009; Evers, Tomic, & Brouwers, 2002). Zimmerman et al. (2005) explored attitudes towards dementia, stress and job satisfaction in 154 direct care providers using the Approaches to Dementia Questionnaire (ADQ: Lintern, Woods, & Phair, 2000). The personhood subscale, which indicates extent to which a person-centred approach is adopted, was found to be associated with staff satisfaction and perceived competence in providing dementia care, which was subsequently negatively correlated with stress. A limitation of these findings was a negative skew in the sample towards lower stress, meaning there may have been a bias in the sample. Staff with higher stress levels may have been less motivated to participate or be on sick leave from work (Pitfield, Shahriyarmolki, & Livingston, 2011).

Studies have also shown that stress is more often reported by younger care staff and staff working for less than two years (Zimmerman et al., 2005). Furthermore, younger care staff with less work experience were found to adopt more dementia friendly attitudes in comparison to older staff. These findings suggest the importance of focused attention at the early stages of employment, to support the development of knowledge and staff confidence, which may be important for long-term resilience and job stability (Elliot, Sterling, Martin, Robinson, & Scott, 2015).

Staff knowledge, feelings of control and feelings of support (Edvardsson, Fetherstonhaugh, McAuliffe, Nay, & Chenco, 2009; Fagin et al., 1996; Willemse, Jonge, Smit, Depla, & Pot, 2012) have also been found to be important in the development of burnout. It has been suggested that these factors may influence the dimensions of burnout (emotional exhaustion, depersonalisation and personal accomplishment), which may reduce levels of staff burnout and improve job satisfaction (Choi, Flynn, & Aiken, 2011; Zwijsen et al., 2014).

The interactions between these factors highlights the need to understand more about care staff knowledge and understanding of SAD-behaviours and how these understandings

influence the caregiver relationship. This understanding may inform interventions that reduce the chance of care placements breaking down, reduce staff turnover and improve job satisfaction (Hinshaw & Atwood, 1993, Kales et al., 2007).

#### **1.4 Psychological Models to Understand SAD-behaviour**

In adopting a psychological approach to understanding dementia, SAD-behaviours need to be seen as a result of more than organic changes to the brain (Laidlaw, 2013b). A number of psychological models currently exist for understanding SAD-behaviours with dementia.

**1.4.1 Progressively Lowered Stress Threshold Model.** The Progressively Lowered Stress Threshold model (PLST; Hall & Buckwalter, 1987) provides a conceptual understanding for the effects of stress in PwD. The model proposes that everyone possesses a stress threshold that is set in adulthood and that changes in biological mechanisms for coping can lower the stress threshold permanently (Hall & Buckwalter, 1987). The model suggests that with dementia, as a person's cognitive ability declines their threshold for experiencing stress also decreases. SAD-behaviours can be understood from the perspective of an individual having an increased vulnerability to overstimulation by their environment (Hall & Buckwalter, 1987).

The model predicts that by modifying environmental demands and regulating stressors, this can reduce stress and promote more adaptive behaviour (Hall & Buckwalter, 1987). The PLST model has provided an important framework for the education of formal and family caregivers, whereby principles of the model are applied to develop individualised plans of care that aim to promote functioning and reduce triggers that precipitate SAD-behaviours (Hall & Buckwalter 1987; Hall, & Buckwalter, 2004; Reisberg, 1984; Smith, Gerdner, Hall, & Buckwalter, 2004).

A substantial body of research has evaluated the use of the PLST model in a variety of clinical settings, such as care homes, dementia specific settings and hospital settings (Smith, Gerdner, Hall, & Buckwalter, 2004). Hall, Kirschling and Todd (1986) described one of the first applications of the PLST model. They evaluated the effect of nursing care interventions for 12 residents living in a special care unit. Changes after three months included improved socialisation, sleep, and nutrition. Agitation, wandering, repetitive questions, delusions and use of psychotropic medications decreased (Hall, Kirschling, & Todd, 1986).

A further study by Swanson, Maas and Buckwalter, (1993) evaluated the use of the PLST model in special care units compared to traditional integrated units within the same nursing home. Outcomes were explored over a 12 month period. Data were obtained for two data collection points before and two data collection points after the introduction of the special care unit. Significantly less adverse behaviour occurred during the post-test period in the PLST group compared to the control (Swanson, Maas, & Buckwalter, 1993; Swanson, Maas, & Buckwalter, 1994).

Some research has reported opposing findings for the PLST model (Voyer et al. (2005). Oh, Haur and Eom (2005) evaluated a training program based on the PLST model in a nursing home in Korea. Findings indicated a significant improvement in care staffs ability to manage aggressive behaviours at the end of the intervention, however, mean scores of aggressive behaviour did not significantly differ.

The PLST model has a number of recognised strengths including the emphasis on the interaction between the person and their environment, which moved understanding away from a biological perspective (Richard & Beck 2004). The six principles underlying the PLST model have been critiqued for lacking specificity and clarity regarding how the concepts are related to each other (Richard & Beck 2004). Furthermore, a number of studies

on the PLST model have been critiqued for not providing specific details about the relationships between the components of the model (Richard & Beck 2004).

The PLST model has been applied in a number of settings and findings support a positive influence on caregiver outcomes, such as depression and burden (Buckwater, 1998; Buckwalter, Gerdner, & Kohout, 1999). Less evidence is available about the direct effect on behaviours (Richard & Beck 2004).

Cohen-Mansfield (2003) has also voiced disagreement in the models ability to explain all types of behaviours. Research indicates SAD-behaviours can also result from an individual experiencing under-stimulation and behaviour may be an attempt by the individual to obtain stimulation from their environment (Calkins, 2002).

**1.4.2 Behavioural ‘Antecedent-Behaviour-Consequence’ Models.** Functional-Analytic Behavioural models that focus on ‘Antecedent-Behaviour-Consequence’ (A-B-C) understandings have also been used to try to understand the occurrence of SAD-behaviour in dementia (Bird, 2002; James, 2012). Antecedent-Behaviour-Consequence models are stimulus-response models based on learning theory and suggest behaviours can be reinforced either intentionally or unintentionally (Cohen-Mansfield, 2003; Waite, Harwood, Morton & Connelly, 2008).

A detailed assessment is used to identify antecedents of a specific behaviour, to define the behaviour itself and its consequences (Cohen-Mansfield, 2010). This information is then evaluated and an understanding is developed based on the relationship between these variables (Cohen-Mansfield, 2003). The model postulates that SAD-behaviours could be prevented by changing the relationship between the behaviour and its antecedents (Cohen-Mansfield, 2003; Waite et al., 2008).

Cohen-Mansfield (2003) reviewed the literature for behavioural interventions for SAD-behaviours. The methods used across studies included extinction, differential

reinforcement and stimulus control. Prosocial reinforcement included going outside, social activity and food. The majority of the studies included in Cohen-Mansfield's (2003) review reported a reduction in SAD-behaviours. However, a number of studies reported no effect or required a further procedure to produce an effect (Hanley, McGuire, & Boyd, 1981; Hussian, 1983; Mishara, 1978).

Landreville, Dicaire, Verreault and Lévesque (2005) described a training program for managing agitation in a long-term care setting. The program focused on the development of behavioural skills and included eight hours of classroom training followed by eight hours of weekly supervision by the trainers. During the supervision period, care staff developed and applied individualised intervention plans for two residents. Residents and staff were assessed pre-training and two months post-training. Findings indicated that both residents were less agitated after the interventions were implemented. Staff also reported to using behavioural techniques more and feeling more effective (Landreville et al., 2005).

Owing to their simplicity, Functional-Analytic (A-B-C) Behavioural models are considered to be useful in more straightforward cases (Spira & Edlestein, 2006) and a useful starting point for an intervention (James, 2014). The use of A-B-C charts to collect information on behaviours can facilitate caregivers recognition of possible understanding of behaviour, which can lead to changes in attitudes towards the person displaying a behaviour (James, 2014; Kitwood, 1997). Reviewing A-B-C charts as a group also enables information gathered to be discussed collectively and for everyone to contribute to the understanding, which can be a empowering intervention in itself (James, 2014; NES, 2012).

Functional-Analytic (ABC) Behavioural models of SAD-behaviours have been critiqued (Bird, 2005; Moniz-Cook et al., 2003) for not being person-focussed and incorporating a unique understanding of the person and their history (Bird, 2005; Bird & Moniz-Cook, 2008; Moniz-Cook et al., 2003). They are considered to be rarely applicable in

more complex cases in isolation. Moniz-Cook et al. (2003) suggested that behavioural models need to be more inclusive of factors that are invisible or unobservable in order to have more clinical utility.

**1.4.3 Unmet Needs Model.** The Unmet Needs model (Cohen-Mansfield, 2000b; Cohen-Mansfield, 2000c) stems from needs-based motivation theories that suggest human motivation comes from an individual's desire to fulfil or attain a need (Maslow, 1943).

Maslow (1943) suggested that all humans possess a hierarchy of needs, which can be divided into basic physiological needs (e.g. food and sleep) and higher level growth needs (e.g. love, belongingness and esteem). It is only once the lower level needs are met that progression is made to the higher level needs (Maslow, 1943).

The Unmet Needs model (Cohen-Mansfield, 2000b; Cohen-Mansfield, 2000c) suggest SAD-behaviours arise as a consequence of an individual's unmet needs, which manifest through the interaction between an individual's lifelong attributes, physical and mental health status and environmental factors. This model suggests that as the condition progresses, PwD are less able to manage their own needs and experience increasing difficulty in communicating their needs to others (Hancock, Woods, Challis, & Orrell, 2006).

In relation to needs, SAD-behaviours are suggested to reflect three functions: behaviours can be seen as a way of meeting a need, communicating a need or are the result of an unmet need (Cohen-Mansfield, 2000b; Cohen-Mansfield, 2000c). In all of these situations' behaviours are attempts by the individual to enhance and maintain a sense of well-being, or ease distress (Cohen-Mansfield, 2000b; Cohen-Mansfield, 2000c).

Cohen-Mansfield (2000b) suggested that by conceptualising the behaviour within the context of an individual's biography, caregivers can identify what the person's need is and consequently be able to find ways to meet the need, thus reducing the behaviour.

Several studies provide support for the Unmet Needs model. Opie, Doyle and O'Connor (2002) conducted a clinical trial of a psychiatric consultation intervention. Participants were nursing home residents with dementia who were displaying agitation. A consultation team consisting of a psychiatrist, psychologist and nurse, assessed residents before developing individual intervention plans, which included categories of the Unmet Needs model. The consultation programme resulted in significant decreases in aggression and verbal and physical agitation (Opi et al., 2002).

Kovach and colleagues (2006) reported similar conclusions in their double blind randomised controlled trial of the Serial Trial Protocol (STP), a protocol for assessment and management of unmet needs, in fourteen nursing homes with 114 residents with dementia. The purpose of the STP was to address resident unmet needs' by directing the nurse to respond to distressed behaviours identified. At post-intervention the STP intervention group had significantly less discomfort compared to the control group. In addition to this, more frequently behavioural symptoms returned to baseline in the intervention group (Kovach et al., 2006).

A limitation of the study is that it is difficult to determine the effectiveness of specific parts of the STP due the intervention being individualised (Kovach et al., 2006). The authors also noted that the lack of significant differences on the BEHAVE-AD scale (Reisberg et al., 1986) may have been influenced by a Hawthorne effect, whereby participants may have changed their perception of residents' behaviour through their participation in the study rather than a real behavioural change (Kovach et al., 2006).

Cohen Mansfield (2000a) extended the Unmet Needs model to the Treatment Routes for Exploring Agitation (TREA) framework. TREA emphasises an individualised approach to management based on the understanding that different SAD-behaviours have different aetiologies, which require different interventions (Cohen Mansfield, 2000a). TREA utilises a

decision tree to identify the most likely cause of the behaviour based on assessment of the behaviour, environment and information about past preferences and needs (Cohen Mansfield, 2000a). Once a cause has been hypothesised, a treatment approach is employed. If that treatment is unsuccessful, another is chosen, or a new hypothesis is formulated based on an improved understanding of the SAD-behaviour (Cohen Mansfield (2000a; James, 2011). TREA is designed to help care staff to identify causes of SAD-behaviours and corresponding treatment plans (Cohen Mansfield, 2000a; James, 2011).

A placebo-controlled study by Cohen-Mansfield, Libin and Marx (2007) aimed to evaluate the effectiveness of the TREA intervention in identifying treatments for agitation. The study was conducted in 12 nursing homes in Maryland. Participants were 167 nursing home residents with dementia. The TREA intervention involved identifying the type of agitation and unmet needs, before individual interventions were designed to meet the individual's needs. Results indicated that individuals in the intervention group displayed a significantly greater reduction in agitation and statistically significant increases in pleasure and interest (Cohen-Mansfield et al., 2007). A limitation of this study was that the researchers were unable to achieve full randomisation.

**1.4.4 Summary of psychological models to understand SAD-behaviours.** A number of psychological models have been proposed for understanding SAD-behaviours in dementia, including the PLST model (Hall & Buckwalter, 1987), Behavioural 'A-B-C' models (Bird, 2002; James, 2012) and the Unmet Needs model (Cohen-Mansfield, 2000b). These all attempt to move away from a neurologically defined perspective.

Cohen-Mansfield (2000b) suggested that these models are not mutually exclusive and should be considered complementary and interactive. For example, an environmental vulnerability may generate an unmet in someone that is experiencing overstimulation from the environment (Cohen-Mansfield, 2000b) and an environmental vulnerability may make



someone more vulnerable to antecedents and consequences in their environment (Cohen-Mansfield, 2000b).

These models have been described as useful explanatory models for understanding SAD-behaviours (Bird & Moniz-Cook, 2008). They have been critiqued for being generic and too simplistic, failing to integrate a unique person-focused approach (Bird & Moniz-Cook, 2008). It has been suggested that although these models have their place in more straightforward cases, they are rarely applicable in clinical settings in isolation (Bird & Moniz-Cook, 2008).

Many authors now accept that the causes of SAD-behaviours are multifactorial (Bird, 2005; Bird & Moniz-Cook, 2008; Cohen-Mansfield, 2000, James 2011; Stokes, 1996). Cohen-Mansfield and Libin (2005) explored verbal agitation and physical non-aggressive agitation in older people with cognitive impairment. They reported that verbal agitation was significantly related to cognitive impairment, low mood and diminishing activities of daily living (ADL). Although physically nonaggressive behaviours were also related to cognitive impairment, but were not related to affect or ADL functioning. This study provides support for the understanding that different SAD-behaviours may have different underlying causes (Cohen-Mansfield, & Libin 2005).

If SAD-behaviours are the result an interaction between many case-specific variables, it is likely in most cases standardised interventions will not be appropriate (Moniz-Cook & Bird, 2008). Instead, multidimensional assessment of the underlying causes is required, followed by case-specific targeting of interventions (Bird & Moniz-Cook, 2008).

## **1.5 Interventions for SAD-behaviours**

### **1.5.1 Pharmacological interventions.**

*1.5.1.1 Prevalence.* Historically, SAD-behaviours have been managed through the use of pharmacological interventions, such as, antipsychotic medications. There has been

longstanding concern for the excessive and inappropriate use of these medications for the management of SAD-behaviours with dementia (Ray, Federspiel, & Schaffner, 1980; Beers et al., 1988; Osborne, Hooper, Li, Swift, & Jackson, 2002; O'Brien, 2008). This concern was heightened by evidence that antipsychotic medication increased the risk of stroke, death and cognitive decline in PwD, with minimal benefits (Douglas & Smeeth, 2008; Schneider, Dagerman, & Insel, 2005; Schneider, Dagerman, & Insel, 2006; Sink, Holden, & Yaffe, 2005).

Studies have estimated the use of antipsychotic medication in care home settings and have found rates ranging from 20 to 50 per cent (Chen et al., 2010; Shah, Carey, Harris, Dewild, & Cook, 2011). One study set in Medway Primary Care Trust in England found that 26 per cent of the people on the dementia register who live within care homes are prescribed antipsychotic medications (Child, Clarke, Fox, & Maidment, 2012). People with dementia living in a care home have been found to be at increased risk of antipsychotic use compared to people in the community (Maguire, Hughes, Cardwell, & O'Riley, 2013). For example, studies have shown people with dementia living in a care home were nearly 3.5 times more likely to receive an antipsychotic than people living in their own homes (Child et al., 2012). Studies have also shown that 80 per cent of antipsychotic medications prescribed to care home residents are among those without a severe mental health difficulty (Chen et al., 2010; Gellad, et al., 2012; Shah et al., 2011). These findings indicate not only the variation in the use of antipsychotic medications across settings, but also the large variation across care homes. Many physicians have argued that more evidence-based guidelines for the use of antipsychotic medications are urgently needed, as many existing guidelines are not suitable in daily practice (McCleery & Fox, 2012).

In the UK the inappropriate prescription of antipsychotic medication with dementia was highlighted in the National Dementia Strategy England (NDSE; DOH, 2009). As part of

the NDSE the government commissioned the Banerjee Report, an independent review of the use of antipsychotic medication in PwD (Banerjee, 2009). The report was an honest account of the negative consequences of antipsychotic medications and concluded that antipsychotic use was too high and used too often inappropriately as a first-line response. Of the 180,000 people being treated with antipsychotic medication each year in the UK, only 20 per cent will derive some benefit (Banerjee, 2009). Furthermore, the use of these medications was reported to be associated with an extra 1,620 cerebrovascular adverse events and 1,800 deaths per year (Banerjee, 2009).

The report included a number of recommendations to reduce the use of these medications including research into the clinical and cost effectiveness of non-pharmacological interventions and proposing a national vocational qualification in dementia to improving the training and curriculum in care home settings (Banerjee, 2009). Following the report the government pledged to reduce the use of antipsychotic medication by two-thirds by 2011 (DOH, 2009).

**1.5.1.2 Efficacy of antipsychotic medications.** The use of antipsychotic medications with dementia has been extensively studied. A meta-analysis, conducted by Schneider, Dagerman and Insel (2006), included 15 published and unpublished trials. They assessed the efficacy of four different atypical antipsychotics for PwD. The findings indicated that overall efficacy from treating SAD-behaviours with risperidone and aripiprazole is modest. This was not found with olanzapine and there was insufficient evidence to analyse quetiapine (Schneider et al., 2006).

A more recent review found similar results to previous studies, with risperidone, olanzapine and aripiprazole showing slightly more effect than quetiapine (Maher et al., 2011). Overall, the findings of trials investigating the efficacy of antipsychotic medications have found minimal efficacy for the treatment of SAD-behaviours (Banerjee, 2009).

**1.5.1.3 Risks associated with antipsychotic medications.** Antipsychotic medications are associated with severe adverse events such as increased risk of stroke and death (Ballard et al., 2009; Ballard & Howard, 2006; Schneider et al., 2006) and multiple side effects, including, sedation, falls, weight gain, greater cognitive decline (De Deyn et al., 2004; Ballard et al., 2005) and extrapyramidal signs, such as muscular rigidity, tremors, slurred speech and dystonia (Schneider et al., 2006).

Early studies informed the development of a warning from the Committee on Safety of Medicine (CSM), which advised a two to threefold increase in the risk of stroke, for PwD, with the use of the atypical antipsychotics (CSM, 2004). Meta-analysis has shown a significant risk of cerebrovascular events, particularly with the use of risperidone (Ballard & Howard, 2006; Schneider et al., 2006). All atypical antipsychotics carry a black box warning from U.S Food and Drug Administration (FDA). The FDA (2008) compared the use of atypical antipsychotics with a placebo and found an increased risk of death between 1.5 to 1.7 times.

A meta-analysis by Schneider, Dagaman and Insel (2005) also observed a similar risk of death. Subsequently in 2008, based on the findings of two retrospective cohort studies (Gill et al., 2007; Schneeweiss, Setoguchi, Brookhart, Dormuth, & Wang, 2007), the FDA warning on increased risk of mortality was extended to include typical antipsychotics (FDA, 2008).

A recent retrospective case control study by Maust et al. (2015) examined the mortality risk associated with antipsychotics, valproic acid, and antidepressants in PwD and suggested a higher increased risk of mortality than previously reported (Schneider et al., 2005). For atypical antipsychotics, the numbers needed to harm (NNH) ranged from 27 to 50 compared to 100, which was originally reported by Schneider et al. (2005). The estimates

from earlier studies, such as Schneider et al. (2005) were from randomised controlled trials, which are less subject to confounding by indication (Maust et al. (2015).

**1.5.1.4 Current prescribing of antipsychotic medication.** Since Banerjee's (2009) report, there have been a number of initiatives to address antipsychotic use. In June 2011, the Dementia Action Alliance published a 'Call to Action', advocating that all people with dementia that are prescribed antipsychotic medication should have their medication reviewed and that alternatives to their prescription should be considered.

The National Dementia and Antipsychotic Prescribing Audit conducted in 2011 (Health and Social Care Information Centre, 2012) obtained data showing antipsychotic prescriptions for all individuals diagnosed with dementia from 46 per cent of general practitioner (GP) practices in England. The audit showed a decrease in antipsychotic prescription rates from approximately 17 per cent in 2006 to 7 per cent in 2011. The audit provided no information on duration of prescription or on care home settings (Health and Social Care Information Centre, 2012). Although reductions in prescribing rates were seen across England, there was still considerable variation in the percentage of people diagnosed with dementia prescribed an antipsychotic medication (Health and Social Care Information Centre, 2012).

In 2012, the Medicines and Healthcare products Regulatory Agency (MHRA) advised that no antipsychotic (with the exception of risperidone in some circumstances) is licensed in the UK for SAD-behaviours with dementia. However, in practice, antipsychotic medication is often still used as a first-line treatment rather than as a secondary alternative (Alexopoulos, Abrams, Young, & Shamoian, 2005; Alzheimer's Society, 2009).

## **1.5.2 Non-pharmacological interventions.**

**1.5.2.1 Staff training and education.** Non-Pharmacological Intervention (NPI) is recommended to be the first-line approach in the management of SAD-behaviours (Banerjee,

2009; DOH, 2009; NICE 2006). Training and education have been identified as a promising NPI that has been shown to improve the quality of care for PwD (Goyder, Orrell, Wenborn, & Spector, 2012; Spector, Orrell, & Goyder, 2013) and enhance the psychological well-being of staff (Moniz-Cook et al., 1998).

The DOH (2009) emphasised the importance of staff training, setting out a number of objectives in the NDSE for ensuring staff possess the necessary skills to care for PwD. The demographic transition has placed considerable demands on the care home workforce. The increase in the severity and complexity of care home residents has placed increasing pressure on care providers to ensure staff have the right knowledge and skills to meet the needs of these residents (Baker, Huxley, Dennis, Islam, & Russell, et al. 2015).

It is well recognised that the majority of dementia care is currently provided by care staff that have had very little training in dementia (Banerjee, 2009). Research suggests that the number of staff receiving training in dementia care is low, even within services specialising in dementia (Banerjee, 2009). For example, around one third of care homes with a specific dementia care workforce report having no specific dementia training for staff (Cavendish, 2013; Laing & Buisson, 2009; National Audit Office, 2007).

Hussein (2010) as part of the Social Care Workforce Periodical (SCWP) investigated the characteristics of the dementia workforce using data from employers who completed the National Minimum Data Set in Social Care (NMDS-SC). The aim of the study was to compare the profile and characteristics of staff working in settings providing care services to PwD with workers in other settings. Hussein (2010) examined the profile of workers using a database of 499,034 and reported that the dementia care workforce were significantly less likely to hold qualifications higher than NVQ level two and there were significantly higher levels of temporary and part time workers compared to other workers (Hussein, 2010). A

number of implications arise from these findings and may directly relate to the quality of care provided to PwD (The House of Commons' Committee on Public Accounts, 2010).

A number of factors have been found to impact on the well-being of care home staff and residents, including training and education (Hannan, Norman, & Redfern, 2001). A number of studies exploring knowledge of dementia (Hagen & Sayer, 1995) have found associations with job satisfaction and well-being (Elliot, Scott, Sterling, Martin, & Robinson, 2012). Relationships have also been found between care staff understanding of SAD-behaviour and job satisfaction (Hannan et al., 2001; Jeon et al., 2012).

In addition to this Zimmerman et al. (2005) found that more educated workers were more likely to report dementia-sensitive attitudes. Moniz-Cook et al. (1998) explored the frequency of SAD-behaviours before and after a training intervention. Results indicated that, although the frequency of behaviour remained unchanged, nurses' ratings of behaviour management difficulty were reduced, as behaviour was perceived to be less challenging.

McCabe et al. (2007) conducted a review of 19 studies published between 1990 and 2005, primarily looking at care home resident behaviours. Although they found no effect of training on resident behaviour, results indicated that training impacted on staff outcomes including job satisfaction and turnover rates.

These findings offer important insight into the impact of training on caregiver factors such as self-efficacy and competency in managing SAD-behaviours and their relationship with the perceived frequency of behaviours, shown to be more significant than a direct reduction in behaviour.

## **1.6 A Person-Focussed Approach to Behaviour in Dementia**

**1.6.1 Functional analysis.** Functional analysis is an extension of the Behavioural 'A-B-C' Model (Bird, 2002; James, 2011) previously discussed, but extends analysis to an understanding of the meaning or purpose of the behaviour (James, 1999; James, 2011).

Functional analysis provides a framework to plan and apply case specific interventions, which can be aimed at both the person living with dementia and caregivers, to relieve the distress caused by the behaviour (Stokes, 2000).

Functional analysis moves understanding and management away from a single explanation for a particular behaviour and standardised intervention to an idiosyncratic understanding and case-specific interventions (Bird et al., 1998). Functional analysis places greater emphasis on the wider context and caregiver response (Bird & Moniz-Cook, 2008; Moniz-Cook et al., 2001b).

The experimental literature on functional analysis with SAD-behaviours with PwD in care home settings is small but growing (Dwyer-Moore & Dixon, 2007). Moniz-Cook et al. (2001) used functional analysis to understand the role of superstition in the development, maintenance and management of SAD-behaviours in five residents living in care homes. By examining the meaning of the behaviour and systematically influencing trigger situations, the occurrence of SAD-behaviours reduced.

Functional analysis has been described by national guidelines as the first line alternative to pharmacological therapy for SAD-behaviours (National Institute for Health and Care Excellence, 2006).

**1.6.2 Formulation.** Case formulation is a conceptual and clinical tool used in psychotherapy (Division of Clinical Psychology, 2011; Sim, Gwee, & Bateman, 2005). It is used by clinicians to relate theory to practice and is considered a hypothesis about a person's presenting difficulties (Division of Clinical Psychology, 2011). There is no agreed definition of case formulation by practitioners, however, Wolpe and Turkat (1985) defined it as "*a hypothesis that relates all of the presenting complaints to one another, explains why these difficulties have developed and provides predictions about the patient's condition*" (p. 8).



Case formulation in psychotherapy originated from the scientist-practitioner model, which emerged from within the profession of clinical psychology (Division of Clinical Psychology, 2011). Psychologists as applied scientists, use the science of psychology to generate hypotheses about client difficulties, which are used to guide intervention (Division of Clinical Psychology, 2011; Kennedy & Llewelyn, 2001).

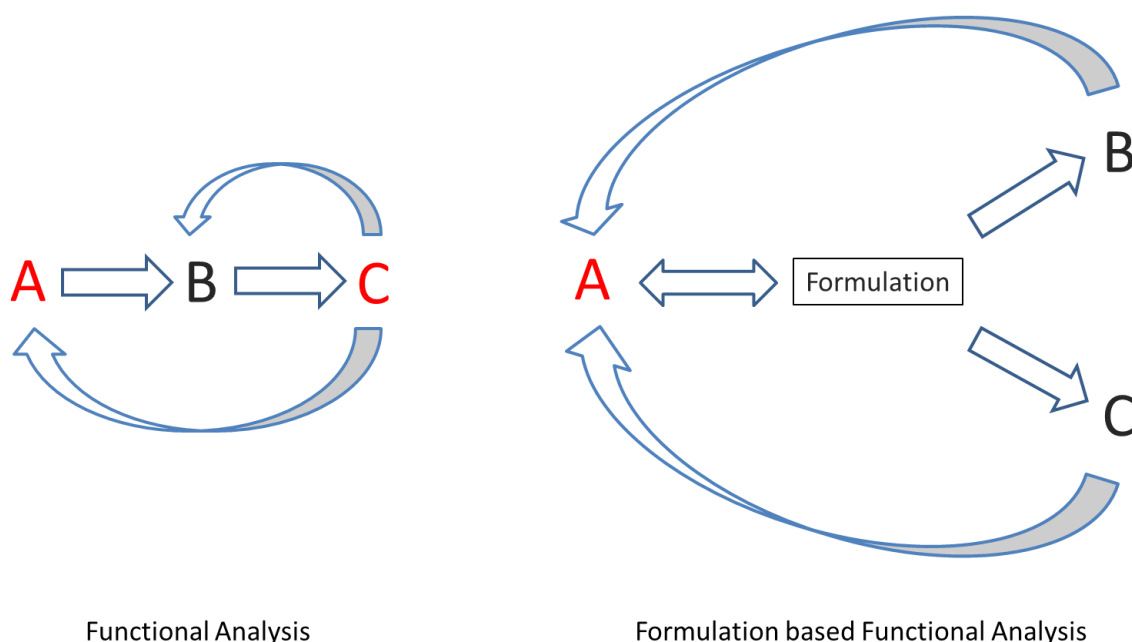
SAD-behaviours can also be understood through the building of a psychological case formulation (Bird & Moniz-Cook, 2008; James, 2011). This involves putting pieces of information together to form a narrative about the person with dementia and their distress (James, 2011; NES, 2013). Case formulation provides a framework to draw together the complex interaction of factors underlying the development of SAD-behaviours and helps to identify factors maintaining the difficulties (Berry, Barrowclough & Wearden, 2009). A case formulation guides the development and application of individualised intervention plans (Bird & Moniz-Cook, 2008).

**1.6.3 Formulation based Functional Analysis approaches.** A promising person-focussed approach to understanding SAD-behaviours is formulation based functional analysis (FFA; Bird, 2009; James, 2011). FFA approaches attempt to provide an understanding of people's experience of dementia. They are based on the understanding that PwD are affected internally and externally by their environments and are driven to moderate these (Cohen-Mansfield, 2000). Similarly, individuals differ in the underlying causes and maintaining factors influencing the distress they experience (Bird et al., 1998; Bird & Moniz-Cook et al., 2008). FFA approaches move away from a “*one syndrome - one treatment*” approach (Bird et al., 1998) by focusing on the wider context and meaning for the person with dementia and caregivers (Bird et al., 1998; Moniz-Cook et al., 2001).

Formulation based functional analysis approaches integrate theories of SAD-behaviours such as the Progressively Lowered Stress Threshold (PLST) and Unmet Needs

(Cohen Mansfield, 2000; Hall & Buckwalter, 1987) to develop a means for assessment and intervention. A functional analysis of the behaviour itself is also undertaken as part of the assessment contributing to the formulation (NES, 2013). Based on the formulation of the SAD-behaviour, hypothesis driven individualised interventions are derived (NES, 2013).

Formulation based functional analysis approaches are case-specific and emphasise the need for multidimensional assessment rather than applying a standard intervention (NES, 2013). An individual's care plan is based on an understanding of the person and the variety of factors influencing them (NES, 2013). A FFA approach is more than a person-focused approach. It is an individualised and formulation-led approach (James, 2014; NES, 2013). This means that each individual will have specific underlying factors that may be triggering and maintaining distress, which are beyond more overt antecedents (environmental factors) (NES, 2013). This approach to understanding SAD-behaviours focuses on internal as well as external stressors. Please see Figure 1.1 for a diagrammatic depiction of the differences between functional analysis and a FFA approach.



*Figure 1.1: A diagrammatic depiction of the differences between Functional Analysis and a Formulation based Functional Analysis approach.*

Formulation based functional analysis approaches are also useful in understanding the distress of caregivers (NES, 2013). It is important to consider caregiver feelings and experience of SAD-behaviour and how this impacts on the distress displayed by the person living with dementia (James, 2014). It has been suggested that understanding the dynamics associated with SAD-behaviour, caregivers can re-frame the behaviour (James, 2014). This understanding may encourage caregivers to focus on the person rather than on the behaviour by increasing compassion, empathy and understanding of the person's behaviour (James, 2014).

A number of FFA approaches for understanding and managing SAD-behaviours in PwD have been developed, most notably those by Bird (2009) and James (2011) who are considered pioneers in this area. These FFA approaches have been incorporated into staff training and education programmes that aim to improve the care and outcomes for PwD, their families and caregivers (Bird, 2009; James, 2011).

#### **1.6.4 Current Formulation based Functional Analysis Approaches**

**1.6.4.1 Newcastle Clinical Model.** James, (2011) developed The Newcastle Challenging Behaviour service (NCBS); based upon a FFA approach, it was developed in response to a need to offer formulation-led interventions for people with dementia living in a care home experiencing SAD-behaviours. The model for the NCBS draws on Cohen-Mansfield's (2000b) Unmet Needs Model and suggests SAD-behaviours are non-random and result from an unmet need. In order to understand a person's need, their current view of the world needs to be understood. The Newcastle approach involves collecting a range of information to assist in understanding the thoughts, emotions, and beliefs underlying the person's distress (Cohen-Mansfield, 2000b; James, 2011).

The Newcastle approach involves working with the individual's care team to create a shared formulation of the distress, which acknowledges the individual's life story, health factors and social and environment factors, which are drawn together to understand a

person's needs (James, 2011). This information is then used to create a care plan which targets these needs in order to reduce SAD-behaviours (James, 2011).

The Newcastle approach utilises a 5+9 week programme and consists of an intensive treatment phase (weeks 1-5), an onwards support phase (week 6) and ongoing support sessions (weeks 12-14; James, 2011). The most intensive work takes place in the first five weeks, with later stages focusing on monitoring the formulation and intervention and altering as a consequence of staff feedback (James, 2011). This approach to assessment and intervention ensures the intervention is: embedded within person-focused principles, encompasses a functional analysis, considers potential unmet needs, includes the interaction of others, environmental factors and is carer-focused (James, 2011; NHS Education for Scotland, 2012).

The Newcastle approach has been used in 82 care facilities (James & Stephenson, 2007). It has been evaluated via audits, which looked at the outcome data of two specialist nurses and an assistant psychologist conducting work in care homes (Wood-Mitchell, Mackenzie, Stephenson, & James, 2007). One audit looked at the frequency and severity of behaviour and caregiver distress using the Neuropsychiatric Inventory (NPI, Cummings, Mega, Gray et al. 1994; Wood-Mitchell et al., 2007) and the Neuropsychiatric Inventory Caregiver Distress Scale (NPI-D; Kaufer et al., 1998). For each resident, a member of staff was asked to complete an NPI-D pre and post-intervention. All participants were senior carers, or nurses. The results from the audit indicated a significant reduction in the frequency and severity of behaviour and caregiver distress pre and post-intervention. In addition to this, only five per cent of the team's referrals were admitted to hospital and only nine per cent were transferred to another care setting (Wood-Mitchell et al., 2007).

A limitation with evaluation studies of the NCBS is the use of outcome measures, such as the NPI to measure frequency and severity of behaviour. This measure is

underpinned by the medical model and was developed to help discriminate between different causes of dementia (Lai, 2014). The purpose of the NPI is to measure the occurrence of behaviour, which enables this measure to be easily administered (Gitlin et al., 2014; Lai, 2014). However, the meaning and context of the behaviour is left unconsidered (Gitlin et al., 2014; Lai, 2014).

The Newcastle approach is consistent with the objectives of the NDSE (DOH, 2009), National Service Framework for Older People (DOH, 2001) and Audit Commission (2002) “Forget me not”, regarding input of a specialist multidisciplinary outreach team into care home settings. It has also informed the development of other services in the UK (Northern Ireland, London, Aberdeen, Sheffield and Southampton). James (2011) suggested that the approaches success was related to the value it places on empowering caregivers to be involved in the management of SAD-behaviours.

The Newcastle approach is considered a ‘front loaded’ method of working, with most of the intensive work taking place in the first few weeks (Pachana, Laidlaw, & Knight, 2010). The approach advocates interventions guided by health and social care staff that are specifically trained and supervised, such as mental health nurses, occupational therapists and clinical psychologists (Brechin et al., 2013). The Newcastle approach has been incorporated into a ‘stepped’ model of care, whereby interventions for SAD-behaviours are identified based on the presenting level of need (Brechin et al., 2013). The Newcastle approach is recommended at step four, which represents the highest level of need and complexity (Brechin et al., 2013).

The Newcastle approach has been critiqued for its complexity and for being resource intensive. James (2011) has acknowledged these criticisms, and highlighted as a defence the approaches ability to work with complex and chronic presentations. Much of the evaluation work conducted by James and his team has focused on senior and qualified staff leading the

formulation-led interventions (Wood-Mitchell et al., 2007). Authors that have implemented the Newcastle approach into their services have described utilising elements of the approach into every day practice by direct care staff, rather than the application of the approach as a whole (Jackman & Beatty, 2015).

The complexity of this model, its use with more complex and chronic cases (James, 2011) and the requirement of assistance from specialist outreach teams (Brechin et al., 2013), brings into question its utility with direct care staff who are managing SAD-behaviours routinely as part of everyday practice. Consistent with James's (2011) ideas of empowering caregivers to be involved in the management of SAD-behaviours, this highlights the need for direct care staff to receive education on these advanced approaches and to have greater involvement in implementing such interventions, rather than isolating these to senior staff and external professionals that are not working with SAD-behaviours routinely (Moniz-Cook et al, 2012). Furthermore, in terms of empowering direct care staff, it is these individuals who hold key information about their residents, which is vital in informing formulation-led interventions.

**1.6.5 Research into Formulation based Functional Analysis approaches to understanding SAD-behaviours.** One previous review (Moniz-Cook et al., 2012) has examined the effectiveness of FFA approaches to understanding SAD-behaviours with dementia. Moniz-Cook et al. (2012) conducted a meta-analysis of FFA approaches in family settings, hospitals, care homes and assisted living settings. They reviewed 18 randomised controlled trials (RCTs), three of which were in a care home setting, and found positive effects for FFA approaches. Overall beneficial effects were found for the frequency of SAD-behaviour and for caregiver reaction (but not behaviour intensity, burden or depression). These effects were not seen at follow-up. The authors concluded that although FFA approaches showed promise, it was too early to draw conclusions about its efficacy,

especially in care home settings, due to the limited number of care home studies (Moniz-Cook et al., 2012).

Studies conducted in care home settings have historically been small scale and more clinically focused due to difficulties with attrition and organisational factors (McCabe et al., 2007). Consequently, studies evaluating FFA approaches are of variable methodology and quality and have often been excluded from systematic reviews (e.g. Moniz-Cook et al. 2012). It is therefore necessary to broaden the review of the FFA literature to capture those excluded studies. An evaluative narrative is presented, critically reviewing individual studies that form the body of evidence for FFA approaches in care home settings.

### **1.6.6 Formulation based Functional Analysis approaches in care home settings.**

**1.6.6.1 Randomised Controlled Trials.** A number of randomised controlled trials (RCTs) have explored FFA approaches in care home settings. Proctor et al. (1999) compared a staff training and education intervention with usual care in 12 UK care homes over a six month period. Staff in the intervention group attended seven, one hour seminars and a psychiatric nurse visited weekly to give advice and support in developing care plans. The main outcome measures were cognitive impairment and depression, behavioural disturbance, and functional ability, assessed by the geriatric mental state schedule (Copeland, Dewey, & Griffiths-Jones, 1986), Crichton Royal behaviour rating scale (Lefroy, Hobbs, & Hyndma, 1992) and Barthel index (Wade & Collin, 1988). The study did not find a statistically significant reduction in behaviour. However, residents in the intervention group had significant reductions in depression scores.

Fossey et al. (2006) compared a training and support intervention for nursing home staff with treatment as usual with 346 residents in 12 nursing homes in the UK. The training and support intervention was delivered over ten months by a psychologist, occupational therapist or nurse. Key elements of the programme involved skills training, behavioural

management techniques, which included training in the Cohen-Mansfield approach, and ongoing training and support. Main outcomes included neuroleptic prescription rates and levels of agitation as measured using the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, Marx, & Rosenthal, 1989) in each home at 12 months. Results indicated no statistically significant differences in the levels of agitated behaviour between intervention and control. At 12 months the number of residents in the intervention group prescribed neuroleptics was significantly lower than the control (Fossey et al., 2006).

A number of studies have been conducted in Australia. Davison et al. (2007) evaluated the impact of an eight session training programme with additional five session peer support compared to a waiting list control group with 113 residents and 90 care staff. Care staff in the training groups received eight sessions of 60–90 minute duration, which were delivered by mental health professionals (Davison et al., 2007). The research team facilitated five peer support sessions of 30–60 minute duration. Measures of staff attitudes and resident behaviours were collected pre and post-intervention, and at six month follow-up. The training programme did not significantly reduce agitated behaviour, although there was a positive trend. The training programs, with or without peer support, did not affect levels of care staff burnout. Care staff in both training groups reported improved attitudes regarding their knowledge and skills in managing SAD-behaviours at the end of the training intervention and six months later (Davison et al., 2007).

A study by the same research group, Visser et al. (2008) investigated the impact of staff education on the behaviour and quality of life of residents with dementia and on care staff attitudes and level of burnout. The study compared a training and peer support intervention with a control group with 76 residents and 52 staff in three care facilities. Staff allocated to the intervention groups received an eight-week behavioural based programme. Staff from one aged care facility also participated in a peer support group designed to



reinforce educational material. The education programme consisted of eight units that were run twice a week for 60-90 minutes. The first three units provided staff with information about dementia and behaviours. The following five units were facilitated workshops, where staff members developed individualised care plans for residents. These were based on the behavioural model (Visser et al., 2008).

Assessments were conducted pre and post-intervention and at three and six month follow-up. Similarly to Davison et al. (2007) they found no improvement in residents' levels of agitation across time or group of effects on staff burnout. A positive effect was found on the skills and knowledge subscale of the Staff Attitudes Questionnaire (Visser et al. 2008) for staff who attended the training programme.

In comparison, Chenoweth et al. (2009) compared caregiver training and support intervention in either Person Centred Care (PCC) or Dementia Care Mapping (DCM) with usual care. The study recruited 289 residents and 30 staff from urban residential sites. Caregivers received training and support in either PCC or DCM or continued with usual care. The primary outcome was agitation measured using the CMAI (Cohen-Mansfield et al., 1989). Outcomes were assessed before and after 4 months of intervention, and at 4 month follow-up. Residents whose caregivers were trained using PCC or DCM displayed a significant reduction in behaviours in comparison to the control group. This finding was consistent at follow-up.

More recently Rokstad et al. (2013) conducted a 10-month three armed cluster randomised controlled trial comparing DCM or the PCC practice model (VPM) with a control group in Norway with 624 residents. The primary outcome measure was the Brief Agitation Rating Scale (BARS; Finkel, Lyons, &, Anderson, 1993). Secondary outcome measures included the Neuropsychiatric Inventory Questionnaire (NPI-Q; Cummings et al., 1994), Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, &

Shamoian, 1988) and the Quality of Life in Late-Stage Dementia scale (QUALID; Weiner et al., 2000). This study found no significant differences in levels of agitation between either DCM or VPM and the control group after ten months. Positive differences were found for changes in NPI-Q, QUALID and CSDD.

In the Netherlands, Zwijsen et al. (2015) conducted a randomised controlled trial to evaluate the effects of the Grip on Challenging Behaviour care programme (GRIP) on staff burnout, job satisfaction and job demands of care staff working on dementia special care units. The care programme utilised a stepped wedge design in which 645 care staff from 17 dementia special care units were randomly divided into five groups with different application start times. The care programme consisted of an education package and various assessment tools that guide professionals through the analysis and evaluation of treatment of challenging behaviour. Burnout, job satisfaction and job demands were measured before, during and following application of the care programme. Burnout was measured with the Dutch version of the Maslach Burnout Inventory (MBI-DV; Schaufeli & Van Dierendonck, 1995). Job satisfaction and job demands were measured with subscales of the Leiden Quality of Work Questionnaire (LQWLQn; Van der Doef, & Maes, 1999). Significant outcomes were only found for job satisfaction.

**1.6.6.2 Critique of studies.** All studies utilised a Cluster Randomised Control Trial (CRCT), which were of varying quality. In CRCTs there is a lack of independence among individuals, which means a larger sample size is needed to ensure there is sufficient power and the analysis should be adjusted to take this into account (Kerry & Bland, 1998).

Davison et al. (2007) and Visser et al. (2008) did not account for the cluster design in the power calculation or failed to include a power analysis at all. These studies may have, therefore, had reduced statistical power to detect changes. Meanwhile, only three studies: Fossey et al. (2006), Chenoweth et al. (2009) and Rokstad et al. (2013) adjusted for clustering

effects in the analysis of their data, meaning the remaining studies are at increased risk of a type 1 error (Bland, 2004).

The quality of CRCT design varied considerably across studies. A number of studies (Fossey et al., 2006; Proctor et al., 1999; Visser et al., 2008) provided limited information on the methods of randomisation and blinding, which made it difficult to fully appraise the methods used. This lack of transparency needs to be taken into consideration when interpreting the results.

A common limitation cited amongst earlier studies (Proctor et al, 1999; Fossey et al, 2006) was a lack of a follow up, which makes it difficult to appraise the sustainability of the interventions. Four studies (Davison et al, 2007; Visser et al, 2008; Chenoweth et al, 2009; Rokstad et al, 2013) addressed this limitation, by including a follow up period, varying between three and ten months. Chenoweth et al. (2009), most notably, found significant reductions in behaviours in comparison to the control group after a four month follow-up.

The majority of studies reported levels of attrition (Proctor et al, 1999; Fossey et al, 2006; Chenoweth et al, 2009; Rokstad et al., 2013), although the reasons for dropout were often not clear (Davison et al, 2007; Visser et al, 2008). Although a number of studies appeared to be sufficiently powered (Proctor et al, 1999; Fossey et al, 2006; Chenoweth et al, 2009; Rokstad et al, 2013), some had small sample sizes and high attrition rates (Visser et al, 2008; Chenoweth et al, 2009; Rokstad et al, 2013) reducing the power of the study.

There was a lack of transparency across all studies regarding descriptions of procedures used to ensure treatment adherence and fidelity. It was not possible to evaluate and assess protocol adherence in a number of studies.

**1.6.6.3 Non-Randomised Trials.** A number of other studies utilising a non-randomised design have evaluated FFA approaches. Cohen-Mansfield et al. (2007) compared individualised interventions with a placebo controlled intervention with 167

residents in 12 nursing homes in the USA. For the intervention group, the TREA decision tree protocol was used to hypothesise possible reasons for each participant's agitated behaviour and corresponding treatment category was matched. Interventions were provided for ten days during the four hours of greatest agitation. Observations of agitation were recorded by trained research assistants via the Agitated Behaviour Mapping Instrument (ABMI; Cohen-Mansfield, Werner, & Marx, 1989). Evaluation of affect was also based on direct observation and assessed via Lawton's Modified Behavior Stream (Lawton, Van Haitsma, & Klapper, 1996). Results showed statistically significant reductions in agitation and increase in resident affect in the intervention group compared to the control.

Bird et al. (2007) conducted a naturalistic controlled trial comparing a case-specific intervention using psychosocial methods with a usual care control group. Participants were thirty-three residents who had been referred to a community psychogeriatric service (intervention group). Cases were managed primarily psychosocially with psychopharmacology as an addition. Case-specific interventions focused on understanding what was underlying resident behaviour and caregiver perception. A control group was made up of 22 referrals to a neighbouring service. Results indicated that both approaches produced equal reductions in the frequency and severity of behaviour. They also found a significant improvement in staff stress in both groups at two and five months follow-up. There was some improvement in staff attitude. However, this did not reach significance.

Bird, Llewellyn-Jones and Korten (2009) presented additional data on the causality focused approach, with the addition of eleven community participants who were excluded from their previous study (Bird et al, 2007) because of insufficient data. Forty-four consecutive referrals for SAD-behaviours (two-thirds in residential care) were assessed across multiple causal domains. Both assessment and development of interventions were undertaken in collaboration with family carers and care staff. Measures of behaviour and

caregiver distress were taken pre-intervention and at two and five month follow-ups. There were significant improvements in behaviour and caregiver distress.

Ballard et al. (2009) conducted a study to determine the feasibility of a Brief Psychosocial Therapy (BPST) intervention. Three hundred and eighteen residents with agitated behaviour were treated in an open design with BPST for four weeks, prior to randomisation to pharmacotherapy. The therapy involved social interaction, personalised music, or removal of environmental triggers. The therapists were either researchers with an undergraduate degree or research nurses and the intervention was designed to be undertaken by a care assistant. Overall, this study found significant reductions in behaviour post-intervention, as measured using the CMAI (Cohen-Mansfield et al., 1989).

Karlin, Visnic, Shealy-McGee and Teri (2012) conducted a pilot evaluation of the Staff Training in Assisted Living Residences (STAR; Teri, Huda, Gibbons, Young, & van Leynseele, 2005) approach. This was implemented in the Veteran Affairs (VA) healthcare system in 17 nursing homes in the United States, with 64 residents and 21 psychologists. The STAR-VA is an interdisciplinary behavioural intervention for managing SAD-behaviours based on the STAR intervention, originally developed for training direct care staff in assisted-living settings (Teri et al., 2005). Results showed that STAR-VA led to significant reductions in the frequency and severity of behaviours. Similarly to findings reported by Teri et al. (2005), the intervention also led to significant reductions in depression and anxiety in residents.

**1.6.6.4 Critique of studies.** The quality of non-randomised studies varies considerably. Cohen-Mansfield et al. (2007) and Bird et al. (2007) are of higher quality by their inclusion of a control group. Cohen-Mansfield et al. (2007) was one of the first placebo controlled trials in this area. However, a limitation of this study was that the researchers were unable to achieve full randomisation. Comparable to Davison et al. (2007) and Visser et al.

(2008), the authors attributed these difficulties to the organisational context. A number of other studies (Cohen-Mansfield et al, 2007; Bird et al, 2007; Bird et al, 2009) reported limitations with resources, which impacted on the quality of methodological quality implemented. These authors acknowledged their shortcomings, demonstrating transparency, and described ways in which they attempted to control these limitations.

Bird et al. (2009) provided further data to support their previous study (Bird et al, 2007). However, these findings need to be interpreted with caution as this study lacked a comparison group and used a small sample size, which prohibited controlling for baseline characteristics such as dementia subtype and accommodation. Ballard et al, (2009), again lacked methodological rigour, by not including a comparison group or follow-up, but demonstrated strength over other studies by including a detailed description of methods and assessment of treatment adherence and fidelity.

Similarly to Bird et al. (2009), Karlin et al. (2012) replicated the findings of a previous study (Teri et al., 2005). Unfortunately the evidence provided by this study needs to be interpreted cautiously, as this study again lacked a comparison group and behaviours were clustered for comparison, consisting of very small sample sizes and underpowered analyses.

A lack of follow-up was also present amongst these studies, with only two studies (Bird et al., 2007; Bird et al., 2009) providing follow-up data at two and five months, which showed promising results for behaviour.

**1.6.6.5 Summary of Formulation based Functional Analysis approaches in a care home setting.** The heterogeneity in methodology within this literature base complicates the interpretation of findings. Despite the number of RCTs, the proportion of high-quality studies is low, with similar limitations found across studies, such as small sample sizes and poorly defined interventions.

A diverse range of outcome measures were used across studies. Staff-reported measures were frequently used for assessing behaviour, such as the CMAI (Cohen-Mansfield et al., 1989). Few studies included an assessment of inter-rater reliability (Fossey et al, 2006; Cohen-Mansfield et al., 2007). Additionally, some studies used two or more measures for the same outcome, which may have increased the chances of finding a significant result.

A well-recognised methodological concern in research in this area is the appropriate measurement of SAD-behaviours (Gitlin et al., 2014). Gitlin et al. (2014) recently conducted a systematic review of outcome measures for assessing what they termed neuropsychiatric symptoms in people with dementia. They identified more than 45 outcome measures with reported psychometric properties. These measures varied widely in their characteristics and underlying conceptualisation, which reflected the lack of agreement on what neuropsychiatric symptoms (SAD-behaviours) are (Gitlin et al. 2014).

Gitlin et al. (2014) suggested that there was no current measure that identifies and assesses the context in which behaviours occur. They argued that existing measures decontextualize behaviours, focusing on the occurrence and severity, which does not fit with the current understanding that multiple idiosyncratic factors underlie SAD-behaviours (Bird et al., 1998; Bird & Moniz-Cook et al., 2008; Cohen-Mansfield, 2000; James, 2011). Gitlin et al. (2014) also concluded that few existing measures evaluate caregiver distress and none assess caregiver confidence or self-efficacy in managing SAD-behaviours, which they suggested could provide a more holistic understanding of the context of SAD-behaviours (Gitlin et al., 2014).

Interventions were primarily multicomponent programmes, where FFA was just one part of the intervention. There was considerable diversity on the theory underlying the intervention, for example: the PLST Model (Hall & Buckwalter, 1987), 'A-B-C' Model (Bird, 2002) and Unmet Needs Model (Cohen Mansfield, 2000b). Intervention length varied

from ten days (Cohen-Mansfield et al., 2007) to ten months (Rokstad et al., 2013). Similarly the professional background and amount of contact with professionals was wide ranging. This presents difficulty when comparing the interventions and limits conclusions that can be made. Additionally, although a number of studies provided details of the essential components of the intervention (Cohen-Mansfield et al., 2007; Karlin et al., 2012) and state a manual is available, few were accessible, limiting future replication.

It is important to provide a balanced perspective when reviewing the literature, as the challenges of conducting research in a care home setting are well known (McCabe et al., 2007). A number of authors were transparent with the challenges posed to their methodology and provided details of ways in which they attempted to control for limitations posed (Bird et al., 2007; Bird et al., 2009; Cohen-Mansfield et al., 2007).

Despite the methodological limitations in the literature there are promising findings for FFA approaches regarding the frequency of SAD-behaviours and caregiver factors, such as care staff attitudes, stress, self-efficacy and perception of behaviour. Research in this area appears to have lagged behind clinical developments and the literature suggests this is primarily because of difficulties designing research studies with sufficient power within local clinical contexts in which behaviour support services have been developed. There is also a problem with relevant measurement and adequate psychometric tools given the subjective nature of SAD behaviour.

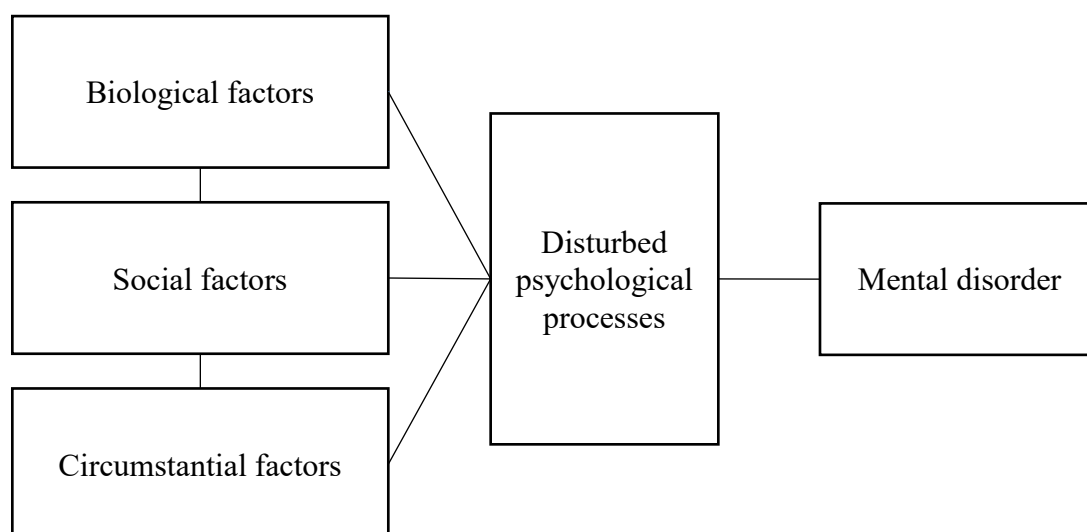
It is evident from the literature that few studies to date have been carried out in care home settings, with staff that care directly for residents displaying SAD-behaviours. In addition to this, studies have provided limited attention to the usual care practices of care home staff. Studies have often comprised of an experienced sample. Further research is required to assess the utility of FFA approaches with less experienced staff that may have less extensive education backgrounds.



## 1.7 Proposed new Formulation based Functional Analysis Approach

### 1.7.1 Theoretical background to the Mediating Psychological Processes Model.

Kinderman (2005) introduced the Mediating Psychological Processes Model of emotional and psychological difficulties following a critique and reformulation of the biopsychosocial model. The Mediating Psychological Processes Model suggests that biological and social factors, such as physical health, poverty and social deprivation, together with a person's life events (circumstantial factors), such as childhood trauma lead to the development of mental health difficulties through their combined adverse effects on psychological processes (Kinderman, 2005). Please see Figure 1.2 to see the Mediating Psychological Processes Model represented graphically.



*Figure 1.2: Kinderman and Tai (2001) Mediating Psychological Processes Model*

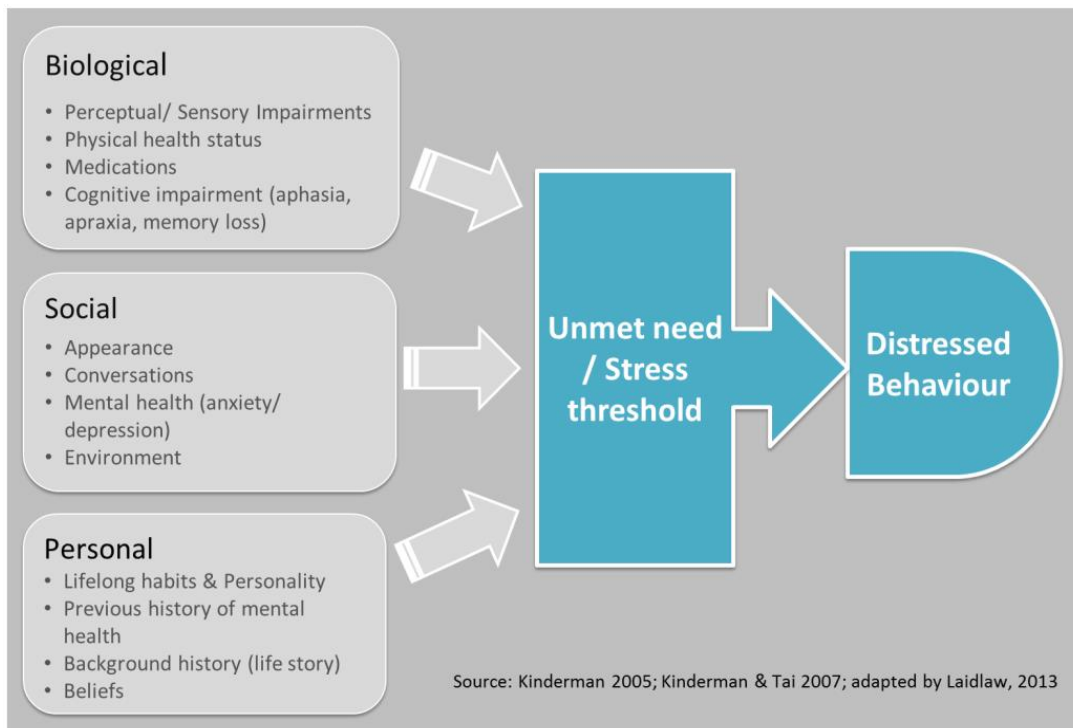
Kinderman and Tai (2006) proposed that psychological formulations rather than diagnoses should lead care planning, and such formulations should include the social, biological and circumstantial factors hypothesised to lead to the disruption of psychological processes. This approach is argued to be more normalising and person-focused than a diagnostic approach (British Psychological Society Division of Clinical Psychology, 2000; Tarrier & Calam 2002). In addition to this, Kinderman and Tai (2007) suggested that

interventions for mental health difficulties will have the most beneficial impact if targeted at these psychological processes.

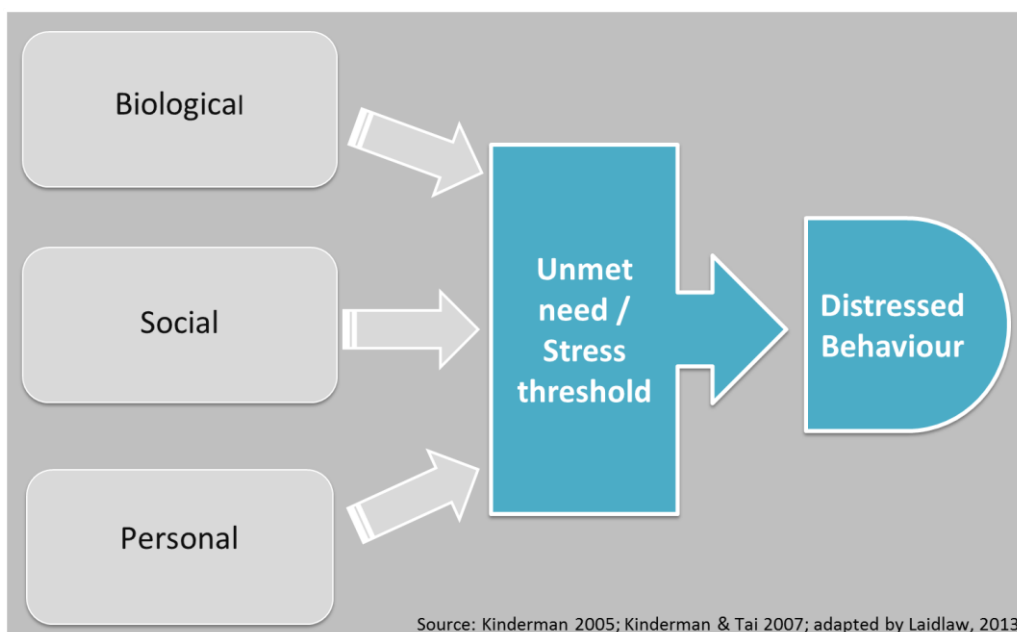
Kinderman (2005) outlined a range of research in support of the Mediating Psychological Processes Model. Supporters of this model argue that it offers a number of implications for clinical practice, including a broad and integrative approach to assessment, case formulation and intervention, drawing on a number of psychological approaches rather than invoking a single theoretical understanding (Kinderman, 2005). It offers a conceptual model that allows clinicians to separate and integrate multiple causal factors of mental health difficulty (Kinderman, 2005).

**1.7.2 A new Formulation based Functional Analysis Approach.** A new FFA approach for understanding SAD-behaviours is proposed (Figure 1.3) and has been simplified into a model to be used as a training tool (Figure 1.4). This model was adapted from Kinderman and Tai's (2007) Mediating Psychological Processes Model by Laidlaw (2013a) when a new multidisciplinary behaviour support service was developed in the NHS in Edinburgh. The treatment model suggests the interaction of biological, social and personal factors are of causal importance in understanding SAD-behaviour via mediating psychological processes related to unmet need or excess stress thresholds.

Features of two models previously described the PLST model and Unmet Needs model (Cohen Mansfield, 2000; Hall & Buckwalter, 1987), are incorporated within the formulation framework for this model and represent the mediating psychological processes.



*Figure 1.3: Laidlaw’s (2013) adaptation of Kinderman and Tai’s (2007) Mediating Psychological Processes Model*



*Figure 1.4: Simplified version of Laidlaw’s (2013) adaptation of Kinderman and Tai’s (2007) Mediating Psychological Processes Model to be used as a training tool*

This conceptualisation illustrates that the development of SAD-behaviours involves an interaction between the person and the care environment and by understanding the context of the individual and seeing the person, rather than focusing on the behaviour. Interventions can be targeted at these psychological processes, which can reduce the impact of SAD-behaviours. This approach is considered productive in identifying areas where it is possible to intervene, through an individualised formulation-led approach. This facilitates the potential for change and for a new perspective (James, 2014; Laidlaw, 2013c).

Through the use of this FFA approach it is hypothesised that care staff may increase their understanding of the underlying factors that may be causing and maintaining distress in an individual, promoting compassion and empathy towards the person and encouraging care home staff to focus on the person rather than on the behaviour (James, 2014; Laidlaw, 2013c). The primary aim is to facilitate carers 'seeing the person' beyond the behavioural expressions, and hence to apprehend distress levels. It facilitates a drive towards reducing stress and distress in the individual as a priority and moves away from behavioural control (Laidlaw, 2013b).

By re-framing behaviour in this context, this newfound knowledge and understanding of what may be underling SAD-behaviour, equips care home staff to intervene and enhance the well-being of the person (James, 2014; Laidlaw, 2013c). Subsequently care home staff may have greater confidence in their ability to cope with SAD-behaviours, which may reduce the occurrence or perceived occurrence of SAD-behaviours (Moniz-Cook et al., 1998).

This FFA framework was developed as a training package delivered to care home staff by the Edinburgh Behaviour Service (Laidlaw, 2013c) and has subsequently been developed into a tool to be used as part of a training package. It encourages care home staff to empathise with the person's situation and to try to understand the reasons behind

behaviour. This method encourages care home staff to look at the 'bigger picture' and see the person's behaviour with a new perspective.

### **1.8 Clinical Relevance of the Study**

This introduction chapter has presented the current status of Dementia as a global health priority and worldwide health challenge (World Health Organisation, 2012). The UK has an ageing population, resulting from changes in demographic, social and economic trends, meaning there is likely going to be increasing pressure on formal care services in the future (Alzheimer Disease International, 2013).

This chapter has discussed the changing profile of care homes and characteristics of residents. Dementia care is now necessary across care settings, not just those specialising in dementia (Banerjee, 2009; Centre for Policy on Ageing, 2012). Stress and Distress behaviours (SAD-behaviours) are estimated to be present in 90 per cent of PwD and two thirds of people with dementia living in a care home will experience these at any one time (Dementia Action Alliance, 2011; Hardenacke et al., 2011; Schaufeli et al., 2009).

Historically, antipsychotic medications were used routinely to manage SAD-behaviours. Increasing concerns over their limited use and significant side effects led to calls to reduce the use of these medications and for non-pharmacological interventions to be the first-line approach (Banerjee, 2009; DOH, 2009; NICE, 2006). Promising approaches for understanding SAD-behaviours are Formulation based Functional Analysis (FFA) approaches, which potentially provide an enhanced framework for psychological based assessments and interventions (James, 2011; Bird, 2009).

As demonstrated in the chapter, the evidence-base to date suggests FFA approaches are the most effective approach for understanding and reducing distress in PwD (Moniz-Cook et al., 2012). However, the literature has not reached a consensus about its efficacy in long-term care settings (Moniz-Cook et al., 2012). Current FFA approaches have been critiqued

for their complexity and for being resource intensive, requiring input from specialist teams and external professionals (James, 2011; Moniz-Cook et al., 2012). Their applicability with direct care home staff, with less extensive education and training backgrounds and who are managing SAD-behaviours routinely has been brought into question.

The study presented in this thesis addresses an important clinical gap in existing literature for FFA approaches, by proposing a new theoretical conceptualisation framework for understanding SAD-behaviours with dementia that has been simplified into a training package and tool. This study aims to address a current unmet need by investigating the utility of this simplified FFA approach with direct care staff, a group of staff who have been largely absent in the literature surrounding formulation-led interventions.

The study aimed to explore the efficacy of this FFA approach on important caregiver factors that have been identified as being important in dementia care literature. This includes knowledge and approach to dementia, feelings of burden and job satisfaction and perception of SAD-behaviours. Should differences be found in these caregiver factors, this may have important implications for the overall understanding of these constructs in relation to SAD-behaviours.

It is anticipated that by training care home staff in this FFA approach to assessment and intervention, care home staff may increase their understanding of the underlying factors that may be causing and maintaining distress in an individual. It is suggested that this increase in understanding will promote greater compassion and empathy, enabling care home staff to focus on the person rather than on the behaviour. By re-framing behaviour in this context, this newfound knowledge and understanding of what may be underlying SAD-behaviour, equips care home staff to intervene and enhance the well-being of the person (James, 2014, Laidlaw, 2013c). Subsequently care home staff may have greater confidence

in their ability to cope with SAD-behaviours, which may reduce their occurrence or perceived occurrence of behaviours (Moniz-Cook et al., 1998).

It is hoped that the evaluation of this new FFA approach will add important insight into the existing evidence base for FFA approaches in care home settings and provide preliminary evidence for a new theoretical conceptualisation of SAD-behaviours with dementia. It will offer a non-pharmacological approach to understanding and managing SAD-behaviours and provide care home staff with skills and knowledge, to work with behaviours, without reliance on antipsychotic medication as a first line intervention.

Finally it is hoped that this research may lead to the development of a new manualised package of training that embeds SAD-behaviours with dementia within an evidence-based psychological conceptualisation. This package would be consistent with current national guidelines (Banerjee, 2009; DOH, 2009; National Institute for Clinical Excellence, 2006) and offer a non-pharmacological approach to SAD-behaviours that has the potential to be utilised and generalised across care settings and caregivers, providing a means for future replication.

## **1.9 Research Questions**

**1.9.1 Primary Research Questions.** The research aimed to answer two main primary research questions, which consisted of two parts: Part (A) aimed to assess between group differences at the end of the intervention and Part (B) aimed to assess within-group pre-post changes.

*1. Do differences exist between CAMTED, CAMTED-plus and Waiting List in caregiver knowledge of dementia and compassionate awareness of need in dementia that presents as SAD-behaviour?*

*1(a): At the end of the intervention*

*1(b): Pre-post changes over time*

2. *Do differences exist between CAMTED, CAMTED-plus and Waiting List in caregiver approach to dementia care?*

2(a): *At the end of the intervention*

2(b): *Pre-post changes over time*

**1.9.2 Secondary Research Questions.** In addition to the primary research questions, this research also aimed to explore four supplementary research questions that were separated into two parts as detailed above.

3. *Do differences exist between CAMTED, CAMTED-plus and Waiting List in levels of caregiver burden?*

3(a): *At the end of the intervention*

3(b): *Pre-post changes over time*

4. *Do differences exist between CAMTED, CAMTED-plus and Waiting List in caregiver job satisfaction?*

4(a): *At the end of the intervention*

4(b): *Pre-post changes over time*

5. *Do differences exist between CAMTED, CAMTED-plus and Waiting List in caregiver perceived frequency and intensity of SAD-behaviours and confidence in managing SAD-behaviours?*

5(a): *At the end of the intervention*

5(b): *Pre-post changes over time*

6. *Do differences exist between CAMTED, CAMTED-plus and Waiting List in the number of care home referrals for SAD-behaviours and the number of people with dementia prescribed antipsychotic medication?*

6(a): *At the end of the intervention*

6(b): *Pre-post changes over time*



## **Chapter Two: Method**

### **2.1 Introduction to Study**

The aim of this study was to empirically evaluate the outcome of a package of evidence-based person-focused training for formal carers working with people with dementia living in care home environments. Specifically evaluating the efficacy of a Formulation based Functional Analysis (FFA) approach to understanding SAD-behaviours with dementia.

### **2.2 Collaboration**

The study was conducted in collaboration with Cambridgeshire Training, Education and Development for Older People (CAMTED-OP). CAMTED-OP is a Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) multi-disciplinary healthcare team, made up of registered health and social care professionals, with years of directly relevant knowledge and clinical experience, specialising in clinical psychology, mental health nursing, occupational therapy and speech and language therapy (CAMTED-OP, 2015).

CAMTED-OP provide training and practice development work in person-centred dementia care to a number of different care providers across Cambridgeshire, including care homes, homecare providers, hospitals and General Practitioners. CAMTED-OP is a 'hub' for training with the Older People's Mental Health Services (CAMTED-OP, 2015). A subsection of the dementia care training and development prospectus for CAMTED-OP can be found in Appendix A.

### **2.3 Design**

During the developmental phase of the study, alternative trial designs were considered in terms of their requirements and their strengths and weaknesses. The British National Institute for Health Research (NIHR) Evaluation, Trials and Studies Coordination Centre (NIHR, 2012) makes a distinction between feasibility and pilot studies. A feasibility study is typically conducted prior to a full trial in order to answer the question 'Can this study be

done?’ They are used to estimate important parameters that are required for a full trial (NIHR, 2012). Pilot studies are smaller versions of the full trial and support in determining whether the components of the full trial can work as a collective (NIHR, 2012). They focus on processes, for example to ensure recruitment, randomisation, intervention, and assessments are all carried out efficiently (NIHR, 2012).

Feasibility and pilot studies are often conceptualised along a continuum and these terms are frequently used interchangeably. This can create problems in a lack of clarity around the examination of outcomes (Orsmond & Cohn, 2015). Authors have argued that researchers should maintain awareness of the different requirements of feasibility and pilot studies to ensure appropriate reporting (Orsmond & Cohn, 2015). In practice this is more complicated, where it has been found that the definitions of feasibility and pilot studies are often not distinct and can vary between health research funding bodies (Orsmond & Cohn, 2015).

The value and importance of feasibility and pilot studies is recognised. These types of studies underpin important developmental learning processes and enable study procedures and interventions to be adapted as necessary, which helps to ensure that the methodology of the full trial is robust and feasible (Orsmond & Cohn, 2015).

In considering the requirements of feasibility and pilot trials in the present study, it was concluded that there would be little to be gained from conducting a study of this kind. The Medical Research Council (MRC) has published guidelines for conducting pilot and feasibility studies. This guidance suggests that thought should be given to the level of confidence in the intervention and whether reliable assumptions can be made about effect sizes and rates of recruitment (Craig, Dieppe, Macintyre, Michie, Nazareth, & Petticrew, 2011). The two interventions being delivered in the present study were both underpinned by preliminary knowledge on aspects of feasibility and there was a large existing literature base

for conducting research in a care home setting. It was with this knowledge that it was considered justified to conduct a full trial and that this would allow for optimal investigation.

Furthermore, when reflecting on the outcome of interest in the present study, which was to evaluate intervention efficacy. It was deemed that neither a feasibility nor pilot study would allow for the effective evaluation of this outcome. These studies are not designed (or powered) to address the efficacy of interventions (Lancaster, 2015) and in addition to this it was believed that a feasibility or pilot study would be less likely to lead directly to individual benefit and could possibly delay the answering of an important and clinically relevant research question (Lancaster, 2015).

Therefore, it was decided that this study would employ an open trial design, which is defined as a trial that compares two similar interventions to determine which is most effective. An open trial design permits participants and researchers to know which interventions are being used (Sedgwick, 2014). The limitations of this design are recognised, such as possible increase in bias as both researchers and participants would know which groups were receiving what intervention. However, this is often the case with psychosocial research. Considering the relative merits of an open trial design, it was considered to be the most optimal design for the circumstances.

The study utilised three independent conditions (two interventions and a control), which allowed for the exploration of between subject analyses of differences between groups. In intervention condition one, care home staff received CAMTED-OP's standard dementia care training package (CAMTED), consisting of five, three-hour training sessions, totalling 15 hours.

In intervention condition two, care home staff received CAMTED-Plus, which consisted of CAMTED-OP's standard training package with the addition of a formulation based functional analysis module in understanding SAD-behaviours, titled: "Person-centred

Approaches to Practice with dementia” (PCAP). CAMTED-Plus consisted of seven, three-hour training sessions, totalling 21 hours.

The control condition was a Waiting List (WL) group, consisting of care home staff waiting to receive training from CAMTED-OP.

Due to resources and practicalities of the trial, it was not possible to blind researchers to training allocation and consistent with a psychosocial trial it was not possible to blind participants from their condition.

## **2.4 Participants**

The sample was composed of formal caregivers (care-home staff), aged 18 years or over, working with adults living with dementia, in non-National Health Service community services. Participants were recruited from nine care homes across Cambridge, Huntingdon and Fenland in Cambridgeshire.

This study did not randomise participating care homes to a condition. Care home managers were invited to decide the condition in which they would like to be allocated. It was anticipated that this flexibility would promote continued engagement from care homes for the duration of the study.

### **2.4.1 Eligibility criteria.**

**2.4.1.1 Care home criteria.** Care homes were eligible to take part in the study if they were based in the Cambridgeshire locality and were entitled to receive training from CAMTED-OP. Care homes were also required to provide care to individuals living with dementia, either through residential, nursing or dementia specific care environments.

**2.4.1.2 Participant criteria.** The inclusion criteria required participants to be aged 18 years and over and to have worked at their current place of work for a minimum of one month. This was to ensure that participants had experience of working closely with people living with a dementia (PwD) and exposure to SAD-behaviours. It was hoped that this

minimum period would allow participants to bring knowledge and experience into the training sessions to facilitate their understanding and learning in situ.

Further inclusion criteria included participants who directly cared for PwD, who were available for the duration of the study and had received approval from their managers to attend the training. A final inclusion criterion was for participants to speak fluent English. It was anticipated due to the nature of the working environment that all care staff would have sufficient English language ability to participate. Participants were excluded if they had received CAMTED-OP training within the last year.

**2.4.2 Sample size.** A power calculation using G\*Power software version 3.1.9.2 (Faul, Erdfelder, Buchner, & Lang, 2009) was conducted in order to determine required sample size (see Appendix B). To achieve a sample size calculation which was appropriate for the data, a-priori one-way Analysis of Variance (ANOVA) was selected as the test statistic.

Effect size was calculated for this study, based on a relevant study by Bird et al. (2007), which found a large effect size of 1.2 between an active intervention and a non-active group, comparing scores at two time points (baseline and two months follow-up). As most outcome research obtain medium effects sizes it was decided that it would be appropriate to calculate sample size for this study using a medium effect size ( $f = .25$ ).

In order to achieve a power level of .8 with a .05 probability level, this required a minimum of 53 participants per group. The focus of this study was to evaluate a new intervention and as such the aim was to recruit as many participants as possible.

**2.4.3 Recruitment.** All participants were employed by non-National Health Service community services and were working in care home settings. The care homes were a mixture of residential, nursing and dementia specific, with some care homes operating across all three specialities. Care homes were identified across Cambridgeshire by CAMTED-OP, which

provides training across this locality free of charge due to centralised funding. In total 48 care home staff were recruited from eight care homes. A consort diagram, shown in figure 2.1, summarises the flow of participants through the research.

During the recruitment phase it was attempted to identify care homes based on their similarities across a number of variables, including, environment, and philosophy of care and profile of residents. This was to ensure standardisation of groups and control for confounding variables. Environmental details included where an individual staff member was located at their place of work, for example, residential, nursing or dementia specific care setting. Philosophy of care was measured by asking care home managers during initial meetings whether they had a 'philosophy of care' and whether they would be willing to share this with us.

**2.4.4 Attrition.** A limitation of research in this area is high attrition rates. To maximise participation, participants that missed training sessions were able to attend catch up sessions under the following conditions. In CAMTED, participants were able to attend catch up sessions regardless of the training session they missed. In CAMTED-Plus participants that attended the first day training session of the PCAP module were able to attend a catch up session of PCAP session two. Participants that did not attend the first training session of the PCAP module were not able to attend catch up sessions of PCAP session two, this being because of the in-between session task being set during PCAP session one. In these instances participants were not able to continue with the study.

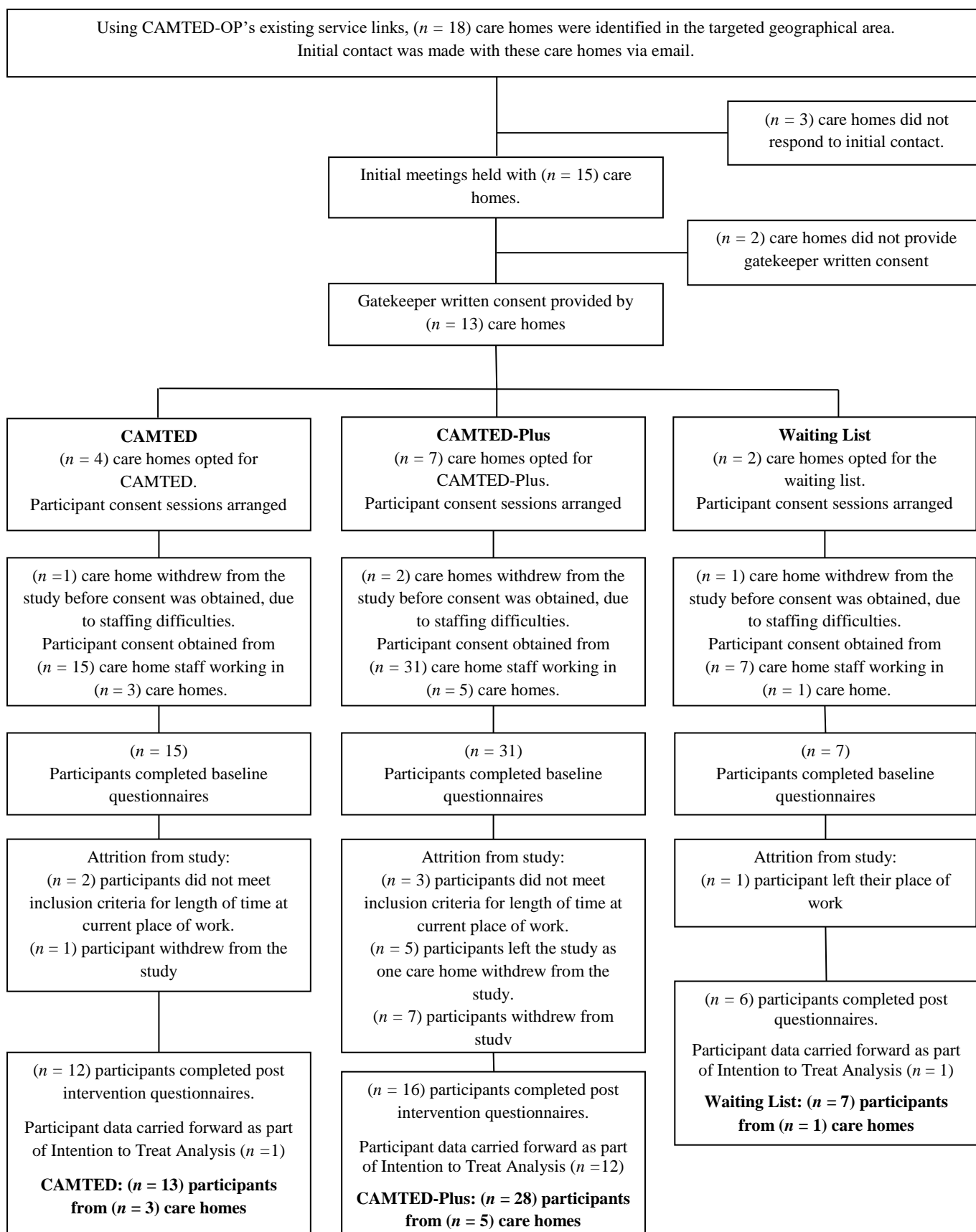


Figure 2.1: The flow of participants through the study.

## **2.5 Intervention Conditions**

### **2.5.1 CAMTED.**

*2.5.1.1 Development and aims of the training programme.* CAMTED consisted of CAMTED-OP's standard training package, which included five, three hour training sessions covering modules: what is dementia?, person-centred care, communication, purposeful activities and behaviours that challenge. CAMTED was delivered by means of PowerPoint presentations and individual and group exercises. This training was delivered by three registered health and social care professionals of CAMTED-OP. Please see Appendix C1 for an overview of the structure and learning objectives of CAMTED.

CAMTED was delivered at participants' place of work and aimed to support staff teams' development in line with standards three and seven of the common induction standards (CAMTED-OP, 2015; Skills for Care, 2010). CAMTED draws heavily on the person-centred dementia care approach and has been designed using the best available evidence and own clinical experience (CAMTED-OP, 2015).

CAMTED was delivered as either weekly, three-hour training sessions, across five weeks or five, three-hour training sessions divided across two and a half days, delivered across three weeks. It is acknowledged that this inconsistency in the delivery of the training affects method rigour. Due to a number of the participating care homes already having pre-existing relationships with CAMTED-OP and agreed training delivery plans, it was important to maintain some flexibility in the delivery of the training to be consistent and respectful of 'training as usual' and to support care home participation. The delivery options for CAMTED are displayed visually in Appendix D1.

### **2.5.2 CAMTED-Plus.**

*2.5.2.1 Development and aims of the training programme.* CAMTED-Plus consisted of CAMTED-OP's standard training package with the addition of a formulation



based functional analysis module for understanding SAD-behaviours, titled: 'Person-Centred Approaches to Practice' with dementia (PCAP).

PCAP (De Pfeiffer & Laidlaw, 2016b) was developed by the primary researcher and primary supervisor. The training package was reviewed prior to its delivery by Alistair Gaskell (CAMTED-OP lead; Clinical Psychologist) and Adrian Wilkinson (CAMTED-OP Mental Health Trainer; Registered Mental Health Nurse), the practitioners delivering PCAP as part of the study.

PCAP was guided by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) Promoting Excellence Framework (2011), which reports the knowledge and skills all health and social services staff should aim to attain regarding their job role. PCAP was developed in line with the 'Dementia Skilled Practice Level' objectives.

Laidlaw's (2013) adaptation of Kinderman and Tai's (2007) Mediating Psychological Processes Model was used as a contextualising framework, which provides a formulation based on functional analytic perspectives of behaviour and reinforcement contingencies integrating theories of SAD-behaviours with dementia such as the Progressively Lowered Stress Threshold (PLST; Hall & Buckwalter, 1987) and unmet needs (Cohen Mansfield, 2000) to develop a means for assessment and intervention. Please see Appendix C2 for an overview of the structure and learning objectives of the PCAP module.

PCAP consisted of two three-hour training sessions separated by one week. During the one week gap, an in-between session task was set. The purpose of this task was to ensure care home staff apply learning in situ. Care home staff were asked to identify an individual they were currently working with and to collect some details relating to the formulation model that they would be willing to share with their peer group at the next training session.

CAMTED-Plus was delivered as either weekly, three-hour training sessions, across seven weeks, or if CAMTED was delivered in the format of two and a half days, the two

PCAP sessions were delivered as two, three-hour training sessions, separated by one week following CAMTED. PCAP was delivered by two registered professionals of CAMTED-OP after they were briefed on the protocol by the primary researcher. The delivery options for CAMTED-Plus are displayed visually in Appendix D2.

**2.5.2.2 The Bigger Picture Jigsaw Activity.** A primary intervention within PCAP is the Jigsaw training tool (De Pfeiffer & Laidlaw, 2016b). This innovative learning resource facilitates a focus on the elements of an individual's characteristics and pattern of needs. The Jigsaw provides a metaphor of 'jigsaw pieces' that need to be placed in the right sequence so that the 'bigger picture' can emerge. The objective being that a person-centred compassionate focus emerges as participants learn to select a range of possible 'missing pieces' to inform their viewpoint of the individual with dementia and SAD-behaviours. The simple expedient of a jigsaw introduces attendees to the principles of formulation without overwhelming people with concepts that could prove to be intimidating to a population of caregivers with a diverse educational background. The approach is part of a formulation based approach to functional analysis of behaviour (FFA). The Jigsaw tool itself is a floor size jigsaw puzzle (420 x 594 mm). It is a highly interactive learning tool to facilitate carer's skill in integrating different pieces of knowledge held about a person living with dementia.

Each jigsaw piece represents an important domain of knowledge that would be important in understanding the background, culture and perspective of a person living with dementia. An important aspect of the learning experience of completing the jigsaw and 'seeing' the bigger picture of the person in their environment and with reference to their unmet needs, is that each jigsaw piece requires a choice decision on the part of the attendee completing the 'picture'. The Jigsaw tool is made up of nine individual pieces. Each of the nine individual pieces has three different pieces of information: correct informative information (the clear picture piece), somewhat correct and generic information (occluded,

blurred picture piece), and incorrect information (greyed out with no picture piece). By this means the attendees completing the jigsaw learn the consequences of incorrect or incomplete choices.

The jigsaw is printed on two sides and made up of nine individual pieces representing the main domains of knowledge necessary to formulate, or understand the individual in their current circumstances and environment. Side one has all the main knowledge domains (e.g. life story, cognitive status, personality, hobbies and interests, medical/physical factors, mental health etc.), and side two contains the face of an individual. If the carer(s) are able to piece the information together on side one of the jigsaw they will be able to turn over the jigsaw and clearly see the face of the person they are trying to understand. Two separate clinical case examples (one male and one female) are linked to the jigsaw pieces.

A photographic representation of the Jigsaw tool is included in Appendix E.

Jigsaws have a 'common currency' in that no instructions are necessary to understand the goal of completing a jigsaw. Jigsaws require little in the way of explanation as to how one approaches the task. Most people will try to fit the right pieces together based on the outline shapes and universally understand that a picture will gradually emerge when the correct pieces are connected. As such this is a simple way to introduce formulation based approaches to understanding SAD-behaviours in dementia. Often people whose behaviour is considered challenging are not being fully 'seen' by their caregivers and the 'bigger picture' (e.g. the person in their environment) is often not fully apprehended.

The Jigsaw tool allows people to quickly grasp the main concept of formulation e.g. seeing the 'bigger picture' that distressed behaviours are non-random and often can be prevented if we can more fully see how the person functions in their environment. Seeing the person will promote compassion and understanding about the vulnerability of the person.

In formulating all that is known about an individual, care staff are taught how to structure questions about the person and filter the use of different parts of information. The concept of piecing together a jigsaw, about an individual and their life, cues carers to gather all the 'pieces of the jigsaw' together and to think about how they all fit together. This is a gentler way to learn and will be less off-putting to people who may have many skills in working with people with dementia but would be less confident in classroom type situations.

The goal of the jigsaw is to take the different parts of knowledge and piece them together to 'see the bigger picture' in understanding the person in their environment. As each person with dementia will be different, a 'champion' who understands the person they are working with, and communicates this to others, will make a real difference to the quality of life of a person with dementia.

Once care staff learn the jigsaw, they can use this to teach/mentor others in understanding people with dementia in their environment and in understanding the impact of this on behaviour so that unmet needs can be addressed in a compassionate and respectful way. Facilitating understanding of the individual promotes a proactive approach to target interventions on the antecedents of behavioural episodes with the aim of reducing stress and distress in an individual in their environment.

**2.5.3 Waiting list.** The control condition was a waiting list group for training from CAMTED-OP. Participants in this group did not receive either training intervention for the duration of the study. At the end of the study care home managers were offered both training interventions and they could decide which one they wanted to receive.

**2.5.4 Intervention fidelity.** Intervention fidelity was examined to address internal and external validity of the study. The intervention fidelity plan involved two components: training and implementation. Training and ongoing consultation throughout the study was provided to the PCAP trainers by the primary researcher.

Implementation was assessed by means of audio recording all PCAP training sessions. The CAMTED-OP trainers were in agreement of this. This process took account of the need to ensure protocol compliance.

## **2.6 Outcome Measures**

All outcome measures were administered at baseline (Time 1) and at the end of the intervention (Time 2). Participants taking part in the WL condition completed outcome measures at Time 1 and Time 2, which was on average five weeks later. The research protocol had originally proposed a four week follow-up (Time 3). Resource and time limitations meant that this was not possible.

### **2.6.1 Primary measures.**

**2.6.1.1 Approaches to Dementia Questionnaire.** The Approaches to Dementia Questionnaire (ADQ; Lintern, Woods, & Phair, 2000a) was used to measure care home staff attitudes towards PwD. The ADQ is an easily administered, self-report measure, consisting of 19-items that are rated on a 5-point Likert scale from ‘*strongly agree*’ to ‘*strongly disagree*’ (see Appendix F1). The ADQ yields a total score and sub-scores for two attitude domains: ‘hope’ and ‘recognition of personhood’, which were derived from factor analyses (Lintern, 2001). Higher scores on both scales indicate greater degree of hopefulness about dementia and the degree to which a person-centered approach is adopted. The ADQ is reported to have good psychometric properties, with Cronbach’s Alpha of .83, Hope .76, Personhood .76 and test-retest reliability of .76 (Lintern & Woods, 2001; Lintern, Woods, & Phair, 2000b).

**2.6.1.2 Dementia Knowledge Questionnaire.** The Dementia Knowledge Questionnaire (DK-20; Shanahan, Orrell, Schepers, & Spector, 2013) was used to measure care home staff knowledge and approach to the care of PwD. The DK-20 consists of a 20-item scale covering different areas of knowledge about dementia (see Appendix F2).

The scale has two sub-scales, 'dementia core knowledge' (DCK), which is made up of eleven items (items 1-11), and 'dementia care knowledge' (DCaK), which is made up of nine items (items 12-20). Included under DCK are the sub-domains: general knowledge, behavioural and psychological symptoms of dementia. Included under DCaK, are the sub-domains: person-centeredness, communication, psychosocial interventions/activities, managing challenging behaviour, risk and abuse prevention and consent and decision making (Shanahan et al., 2013). Each item is awarded one mark for a correct answer with a total score of eleven awarded for the DCK domain and a total score of nine for the DCaK domain (Shanahan et al., 2013).

The authors reported marginal reliability .63 and acceptable test- retest reliability, ICC = .73 (Shanahan et al., 2013). The coefficient alpha was .58 for the DCK domain and .47 for the DCaK domain, suggesting there was not internal consistency between the domains (Shanahan et al., 2013).

## **2.6.2 Secondary measures.**

**2.6.2.1 Maslach Burnout Inventory.** The Maslach Burnout Inventory – Human Services Survey (MBI-HSS; Maslach, Jackson, & Leiter, 1996) was used to measure care home staff feelings of burden at their place of work (see Appendix F3). The MBI consists of 22 statements about job-related feelings that are rated on a 7-point Likert scale. Care staff are asked to read each statement and decide if they have ever felt that way about their job. If they have never had this feeling, care staff record the number 0 (*never*). If they have had this feeling they are asked to indicate 'how often' they have felt this way by recording a number ranging from 1 (*a few times a year or less*) to 6 (*every day*).

Responses to statements are divided into three subscales, Emotional Exhaustion (EE), Depersonalisation (DP) and Personal Accomplishment (PA). EE measures feelings of emotional exhaustion at work, DP measures feelings of detachment or impersonal response

towards residents and PA measures feelings of competence and achievement at work. Higher scores on the EE and DP subscales and lower scores on PA subscale indicate greater feelings of burden. The MBI is reported that have moderate internal consistency using Chronbach's alpha for each subscale: EE = .90, DP = .79 and PA = .71 (Maslach et al., 1996).

**2.6.2.2 Swedish Satisfaction in Nursing Care and Work Scale.** The English translation of the Swedish Satisfaction in Nursing Care and Work Scale (SNCW; Hallberg, Welandar, & Axelsson, 1994) was used to measure care home staff satisfaction and morale with their work (see Appendix F4). The SNCW scale consists of 35 items covering the domains: cooperation, development, quality of care, workload and knowledge of patients. Recipients respond to items on a 5-point Likert scale ranging from 1 (*complete agreement*) and 5 (*complete disagreement*).

Items are summed to obtain a total satisfaction score. Twenty Four of the items are positive and eight of the 32 items are negative (6, 12, 13, 21, 22, 23, 24), which are reverse coded. A lower total satisfaction score indicates greater satisfaction at work. The SNCW is reported to have good psychometric properties, including a Cronbach alpha value of  $\alpha = .86$  (Hallberg et al. 1994).

**2.6.2.3 Stress and Distress Behaviour Scale.** The Stress and Distress Behaviour Scale (SDBS) was developed by the primary researcher (LdP) and primary supervisor (KL) in response to a review of the existing measures in this area. It is well-recognised that there are challenges in appropriate measurement of SAD-behaviours (Gitlin et al., 2014). Time was spent during the developmental phase of the study searching for an appropriate measure and assessing how to evaluate this approach most optimally. Following the review of measures and consideration of their strengths and weaknesses, it was concluded that a measure did not currently exist that would capture this construct effectively and therefore it was decided to develop a measure for the purpose of the study.

The SDBS consists of eight rating scales that measure the incidence of a number of different SAD-behaviours in a care setting (see Appendix F5). This measure was piloted prior to its use in the study with ten trainee clinical psychologists to check it was understandable and easy to follow. This provided this measure with some preliminary face validity. It is recognised that developing a new outcome measure as part of this study meant there was a lack of psychometric properties. However, a number of existing measures in this area have consistently been found to have a number of shortfalls with their properties, such as weak inter-rater validity (Moniz-Cook et al, 2001a). Furthermore, without current consensus on the definition of SAD-behaviours, this brings challenges with its measurement and as such it was decided that developing a measure specifically for the present study, would enable this construct to be captured most optimally.

Care staff are asked to think about someone they currently care for or have recently cared for that they have found challenging or someone they consider to have been the most challenging in a professional context. Care staff rate on a 10 point Likert-scale ranging from 0 (*not at all*) to 9 (*all the time*), how challenging the behaviour has been.

Due to the subjective nature of SAD-behaviours and what is perceived to be challenging being in the '*eye of the beholder*' (Bird & Moniz-Cook et al., 2008), it is felt that this is the most appropriate and reliable way of measuring the incidence of SAD-behaviours.

**2.6.2.4 Frequency of SAD-behaviours Scale.** The frequency of SAD-behaviours was measured using a 7-point Likert scale that was developed by the primary researcher (LdP) and primary supervisor (KL; see Appendix F6). Participants rated how frequently they currently come into contact with SAD-behaviours at their place of work, from 0 (*no SAD-behaviours at their place of work*) and 6 (*SAD-behaviours occurring every hour*).

**2.6.2.5 Intensity of SAD-behaviours Scale.** The intensity of SAD-behaviours was measured using a 7-point Likert scale that was developed by the primary researcher (LdP)



and primary supervisor (KL; see Appendix F6). Participants rated the intensity of SAD-behaviours they currently experienced at their place work, from 0 (*not intense at all*) and 6 (*very intense*).

**2.6.2.6 Confidence in managing SAD-behaviours Scale.** Confidence in managing SAD-behaviours was measured using a 7- point Likert scale that was developed by the primary researcher (LdP) and primary supervisor (KL; see Appendix F6). Participants rated their current level of confidence in managing SAD-behaviours at their place work, from 0 (*not confident at all*) and 6 (*very confident*).

### **2.6.3 Additional measures.**

**2.6.3.1 Participant demographic questionnaire.** All participants completed a brief demographic questionnaire (see Appendix F7), which gathered information about age, gender, nationality, level of education, job title, training received in the past year, length of time in current employment, and length of time employed in services for people with dementia.

**2.6.3.2 Care home demographic questionnaire.** Care home managers also completed a brief questionnaire (see Appendix F8), which gathered information on the general age and gender profile of residents, philosophy of care, average length of stay and primary route to becoming resident. Philosophy of care was measured by asking care home managers whether they had a 'philosophy of care' and whether they would be willing to share this with us.

**2.6.3.3 Referrals made for SAD-behaviours.** The total number of referrals for SAD-behaviours was planned to be collected from care home managers for a period of four to six weeks prior to training to four to six weeks post training. It was not possible to collect this data due to time constraints.

**2.6.3.4 Antipsychotic prescription rates.** The total number of residents prescribed antipsychotic medication was planned to be collected from care home managers for a period of four to six weeks prior to training, to four weeks post training. It was not possible to collect this data due to time constraints.

**2.6.3.5 Jigsaw evaluation.** Participants receiving CAMTED-Plus were also asked to complete an evaluation questionnaire of the 'Bigger Picture Dementia Jigsaw' training activity (see Appendix F9). This questionnaire was designed by the primary researcher (LdP) and consisted of six, 9-point Likert scale questions looking at participant enjoyment, understanding and future use of the Jigsaw. Participants were also provided with a space to provide any verbal feedback. This questionnaire was developed following review of CAMTED-OP's standard training evaluation questionnaire and was designed to be consistent with this.

## **2.7 Ethical Considerations**

Ethical approval for this study was sought from and granted by the UEA Faculty of Medicine and Health Sciences Research Ethics Committee (see Appendix G). Guidance was sought from Bonnie Teague (Norfolk and Suffolk NHS Foundation Trust; NSFT Research Manager) who confirmed that an NHS ethics application was not necessary and that an application could be submitted to the University's internal ethics committee.

**2.7.1 Consent.** Approval was sought from care home organisations to recruit their staff and written consent was provided (see Appendix H). All participants were provided with a participant information sheet (see Appendix I) and had the opportunity to contact the primary researcher to ask any questions they had about the study. All participants were asked to sign a consent form (see Appendix J) to demonstrate that they agreed to take part in the research and understood the requirements.

**2.7.1.1 Prize draw.** On completion of a consent form, participants were given the opportunity to provide their details to enter a prize draw to win one of three £25 Amazon vouchers, as a way of thanking them for participating (see Appendix O). To ensure that information from the prize draw form could not be linked to individual participants, personal details were stored separately from the questionnaire data. Participants were informed at the point of entry to the study that if they withdrew from the study that they would no longer be eligible to enter the prize draw. On completion of the study, the primary researcher placed the names of all prize draw entrants into a hat and drew three names out at random. After informing the winners and delivering the prizes, all contact details were securely destroyed.

**2.7.2 Confidentiality.** This research adhered to the requirements of the Data Protection Act (1998). Data stored electronically were password protected and transferred using an encrypted memory stick. Any audio data were stored on an encrypted memory stick and physical data were stored securely in a locked filing cabinet.

Confidentiality was upheld by assigning each participant a code, which was recorded on their data instead of identifiable information. The data from this study will be kept for ten years in accordance with the UEA Research Data Management Policy. Participants were informed of these measures on the consent form.

All participants were made aware in the participant information sheet that their information would be treated confidentially, with the exception that should any potential concerns about malpractice or safeguarding arise, that confidentiality may have to be broken and specified procedures be followed in line with local trust policies.

**2.7.3 Impact of research.** It was possible participants may have wanted to disclose concerns they had about the care homes in which they work. If a concern was raised it would have been managed in line with Cambridgeshire and Peterborough NHS Foundation Trust

(CPFT) policies and procedures. A protocol was developed, which detailed how concerns would be managed by the research team under different conditions (see Appendix K).

There may have also been the possibility that participants could have become distressed by answering questions of an emotional nature, such as burden and job satisfaction. These materials were completed initially by participants in the presence of a member of the research team, and therefore any emotional distress would have been managed at the time. Participants were also provided with contact details for the primary researcher if they had any concerns they wished to discuss.

If a concern was raised, participants would have been able to discuss their concerns with the trainer(s) during the next available break. In addition, if participants found anything personally distressing at any point, they could leave the room without seeking permission or providing an explanation.

Participants may have also been identified as experiencing elevated levels of burden. This would have only been as a training group collective as all questionnaire data would be anonymous. If for example, it was identified that a training group were reporting elevated levels of burden. This would have been followed up at the next training session. This session would have been modified to provide a training session on self-care, as well as to provide some information for individuals to take away on an anonymous basis to seek further help and support as required.

## **2.8 Procedure**

Following receipt of a favourable ethical opinion (see Appendix G) CAMTED-OP's existing service links and knowledge were used to identify care homes in Cambridgeshire that met the criteria for the study. Initial meetings were arranged with interested care home managers to provide information about the study. Written consent was obtained from care home managers (see Appendix H) that approved for the study to take place and for their care

staff to be recruited. This was shared with the ethics committee. Care home managers were offered a choice of which intervention condition they wanted to be allocated to (CAMTED, CAMTED-Plus or WL).

Potential participants first heard about the study through their managers and/or senior care staff. They outlined the purpose of the study and what would be involved. Information sessions were initially planned to take place at care homes, where the primary researcher would meet with groups of staff to provide information about the study directly and answer any questions. When attempting to arrange information sessions, due to the nature of the care home environment, care home managers reported that it would be difficult to arrange for staff to attend these sessions.

In response to this an agreement was made to amend the protocol and an alternative proposed, which was approved by the ethics committee (see Appendix L). Information about the study was discussed with care home managers and/or senior members of staff who then shared this information with their care staff. Care home managers were provided with 'participant packs' to share with their staff, which contained a participant information sheet (see Appendix I) and expression of interest form (see Appendix M). If care staff were interested in taking part in the study they could complete the expression of interest form and return it to the primary researcher in the prepaid envelope provided. The participant information sheet also provided the primary researchers contact details should interested care staff have any questions about the study.

Following this, drop-in consent sessions were initially planned to take place, where care home staff that had previously expressed interest or wanted to express interest could attend to ask further questions about the study. During the drop-in sessions participants would be provided with a consent form (see Appendix J) which they could sign and return to the primary researcher or take away and return in the prepaid envelope provided.

Care home managers reported difficulty arranging drop-in sessions for care staff to attend to provide consent for the study due to shift patterns. In response to this an agreement was made to amend the protocol and an alternative proposed, which was approved (see Appendix L). If it was not possible to arrange a drop-in consent session on a day prior to the start of the training, a thirty minute session was planned to take place on the day of the first training session.

This procedure allowed care home managers to better manage their staff rotas and make arrangements for staff who wanted to take part in the study to be available on this day. During these sessions the primary researcher or CAMTED-OP trainer answered any questions about the study and provided consent forms to be completed by staff who wanted to take part in the study aspects of the training.

To clarify, the five training sessions that formed the CAMTED training package and the first five sessions of the CAMTED-Plus training package were ‘training as usual’. Written consent was not required from care staff to attend these sessions, as they were not considered a research component of the study.

The written consent provided by care home staff was only in relation to research components of the study. In CAMTED and WL conditions this consisted of completing outcome questionnaires at two time points and in CAMTED-Plus this consisted of completing outcome questionnaires at two time points and attending sessions six and seven of the training package, which were the two PCAP sessions. Care home staff could attend the five sessions of CAMTED training without signing a consent form.

The participant information sheet detailed the conditions in which participants could withdraw from the study. Participants were made aware that if they did not wish to attend the CAMTED training sessions, they would need to seek approval from their manager, as this may form part of their mandatory training. Participants could withdraw from completing

study questionnaires and in CAMTED-Plus attending the two PCAP sessions at any time without giving a reason.

Participants receiving CAMTED attended 15 hours of person-centred dementia care training. Participants receiving CAMTED-Plus attended 21 hours of person-centred dementia care training and completed an in-between session task. Participants on the WL for training did not receive any training for the duration of the study. At the end of the study care homes were offered both training interventions and they could decide which one they would like to receive.

Outcome measures were completed at the beginning of the first training session (Time 1) and at the end of the final training session (Time 2). Participants taking part in the WL condition completed outcome measures at Time 1 and Time 2, which was on average five weeks later.

It was not possible to collect four week follow-up data (Time 3) due to time constraints of the study. In addition to this, it was also not possible to collect data on referrals for SAD-behaviours and prescription rates due to time constraints. This data would have been requested from care home managers who would have been advised to send the data directly to the primary researcher in a prepaid envelope provided.

Once participants completed the study they received a debrief information sheet (see Appendix N), which provided contact details for the primary researcher and research supervisors should participants have any questions.

Following completion of the study the prize draw took place and three winners picked at random were notified. Once the study was completed in full a summary of the project was made available to care homes in the format of a newsletter.

## 2.9 Data analysis

The Statistical Package for Social Sciences (SPSS) version (3.1.9.2) was used to analyse data. Intention to treat analysis was applied using the last measurement carried forward method for data missing at post-intervention. The WL group was excluded from all statistical analyses due to the small sample size, comparisons were only made between the two intervention groups (CAMTED and CAMTED-Plus).

Prior to experimental testing the data were screened for outliers and examined to assess whether they met assumptions for parametric statistical analyses. Normal distribution was assessed through inspection of skewness and kurtosis values and the Shapiro–Wilk test (Shapiro & Wilk, 1965). Levene’s test (Levene, 1960) was used to assess homogeneity of variance between groups.

Independent samples t-tests were used to answer Part (A) of the research questions, which compared between group scores at the end of the intervention. Paired t-tests were used to answer Part (B) of the research questions, which assessed within-group pre-post changes from before the intervention to after the intervention. All analyses were two-tailed (unless otherwise specified).

Where variables deviated from a normal distribution parametric analyses were still utilised, however where there was a significant difference between the parametric and non-parametric results were the non-parametric outputs reported.

To correct for multiple comparisons and in order to control for Type 1 errors, a more conservative  $p$  value was adopted throughout ( $p < .01$ ). Bonferroni Correction (BC) to correct for multiple comparisons was considered in the present study. However, the  $p$  value was considered to be too conservative, which is a noted disadvantage in the literature on BC ((Perneger, 1998). The risk of detecting differences when they did not exist was perceived to be much less than the risk of potentially ignoring a true significant result. This risk would



have been magnified if a BC had been used. It was therefore decided to adjust the  $p$  value to 0.01 to be conservative.

## **Chapter Three: Results**

### **3.1 Chapter Introduction**

This chapter presents the results of the research in line with the research questions. This chapter begins with an initial examination of the data, describing the procedures used for screening and checking assumptions for parametric statistical analyses. A summary of the demographic characteristics of the study participants are presented with descriptive data described for all outcome measures. The statistical tests used to analyse the research questions are then presented with the results of each comparison. Quantitative and verbal feedback is provided regarding the use of the Jigsaw training tool. Finally, an overall summary is presented at the end of the chapter.

### **3.2 Data Screening**

Data were initially entered into SPSS and visually inspected for completeness and accuracy. Data were examined for outliers using box-plots. Identified outliers were double-checked against the raw data to ensure they were accurate. The accuracy of data entry was checked by randomly selecting participant data (approximately 10%) and comparing it to the raw data.

A number of outliers were found on all dependent variables excluding the Approaches to Dementia Questionnaire - Personhood subscale (ADQ-PH), Maslach Burnout Inventory - Emotional Exhaustion subscale (MBI-EE) and Maslach Burnout Inventory - Depersonalisation (MBI-DP) subscale. Box plots indicated that similar participants were found to be outliers across numerous variables (Participants: 2, 17, 20, 21, 25, 32 35 and 39).

In addition to this, participant seven's post outcome score on the Swedish Satisfaction in Nursing Care and Work Scale (SNCW) appeared to be an outlier. Upon review of this participant's questionnaire scores at Time 1 (53) and Time 2 (139), it was evident that this participant's level of job satisfaction had decreased considerably during the course of the intervention, where questionnaire items at Time 2 had been rated in complete opposition to

Time 1. It is believed that the Time 2 score may have mirrored how this participant felt in their current context and wider dynamics that had arisen during the course of the study.

There is conflicting guidance on managing outliers. Some authors suggest that where outliers are illegitimately included in the data that they should be removed (Barnett & Lewis, 1994). Others argue that removing outliers can produce detrimental outcomes and suggest that data considered to be legitimate are more likely to be representative of the population if not removed (Orr, Sackett, & DuBois, 1991).

Winorizing the data (Barnett & Lewis, 1994) was considered in the present study. This can reduce bias and improve accuracy by replacing outliers with adjacent values from the remaining data (Barnett & Lewis, 1994). It was anticipated that changing the outliers across variables would not change the distribution of the data. Furthermore, it was evident that in a number of cases, additional outliers would be produced.

A further option in the management of outliers is to repeat data analysis without the outlier(s) and compare the two outputs (Schoenbach & Arrighi, 1994). If results are the same, then the outlier(s) is deemed not to have a significant influence in the distribution of the variable and if results are not the same, both outcomes can be reported (Schoenbach & Arrighi, 1994). This approach was implemented in the present study, data analyses were repeated after removing outliers.

### **3.3 Descriptive Statistics**

A total of  $N = 48$  participants took part in the study: CAMTED  $n = 13$  (27%), CAMTED-Plus  $n = 28$  (58%) and Waiting List (WL)  $n = 7$  (14%). A description of the demographic profile of the sample can be found in Table 3.1. The overall sample consisted of 80% females and 20% males. In each of the three conditions the majority of participants were female: CAMTED (84%), CAMTED-Plus (74%) and WL (100%). The mean age of the overall sample was 34.5 (11.06). In CAMTED the majority of participants were aged 25-40

(54%), with a mean age of 34.4 (9.24). In CAMTED-Plus the majority of participants were also aged 25-40 (59%), with a mean age of 33.8 (11.25). In the WL condition the majority of participants were aged 40-55 (43%), with a mean age of 37.7 (14.28).

Table 3.1

*Baseline demographic characteristics of participants and comparisons*

Variable	Overall Sample	CAMTED	CAMTED-Plus	Waiting List <sup>a</sup>	Baseline test and significance statistics
Participants (%)	<i>N</i> = 48	<i>n</i> = 13 (27)	<i>n</i> = 28 (58)	<i>n</i> = 7(14)	-
Gender	<i>N</i> = 47	<i>n</i> = 13	<i>n</i> = 27	<i>n</i> = 7	<i>p</i> = .69
	Male (%): 9 (10)	2 (15)	7 (25)	0 (0)	
	Female (%): 38 (80)	11 (84)	20 (74)	7 (100)	
Age Range <sup>b</sup>	<i>N</i> = 47	<i>n</i> = 13	<i>n</i> = 27	<i>n</i> = 7	<i>t</i> = .169 <i>p</i> = .87
	<i>M</i> ( <i>SD</i> ): 34.5 (11.06)	<i>M</i> ( <i>SD</i> ): 34.4 (9.24)	<i>M</i> ( <i>SD</i> ): 33.8 (11.25)	<i>M</i> ( <i>SD</i> ): 37.7(14.28)	
	18-25 years (%): 9 (19)	2 (15)	5 (19)	2 (29)	
	25-40 years (%): 24 (51)	7 (54)	16 (59)	1 (14)	
	40-55 years (%): 11 (23)	4 (31)	4 (15)	3 (43)	
	55+ years (%): 3 (6)	0 (0)	2 (7)	1 (14)	

Nationality	<i>N</i> = 47	<i>n</i> = 13	<i>n</i> = 27	<i>n</i> = 7	<i>p</i> = .11
British (%): 25 (53)		4 (31)	14 (52)	7 (100)	
British Other (%): 3 (6)		4 (31)	0 (0)	0 (0)	
European (%): 10 (22)		3 (24)	7 (26)	0 (0)	
African (%): 3 (6)		0 (0)	3 (12)	0 (0)	
Filipino (%): 5 (11)		2 (15)	3 (11)	0 (0)	
Education Level	<i>N</i> = 38	<i>n</i> = 11	<i>n</i> = 20	<i>n</i> = 7	<i>p</i> = .18
GCSE (%): 5 (13)		0 (0)	3 (15)	2 (29)	
O Level (%): 1 (3)		0 (0)	1 (5)	0 (0)	
College Course/ A Levels (%): 6 (16)		3 (27)	3 (15)	0 (0)	
Diploma (%): 2 (5)		1 (10)	1 (5)	0 (0)	
Degree (%): 10 (33)		5 (45)	5 (25)	0 (0)	

	Other, NVQ, NVQ2, NVQ3 (%): 12 (32)	2 (20)	7 (35)	4 (57)	
	Not applicable/ None (%): 1 (3)	0 (0)	0 (0)	1 (14)	
Job Title	<i>N</i> = 46	<i>n</i> = 12	<i>n</i> = 27	<i>n</i> = 7	* <i>p</i> = .01
	Healthcare Assistant (%): 25 (54)	4 (33)	17 (63)	4 (57)	
	Senior Healthcare Assistant (%): 6 (13)	0 (0)	5 (19)	1 (14)	
	Nurse/ RGN (%): 5 (11)	3 (25)	2 (7)	0 (0)	
	Training Coordinator (%): 2 (4)	0 (0)	1 (4)	1 (14)	
	Activities Coordinator (%): 1 (2)	0 (0)	0 (0)	1 (14)	
	Team Leader/ unit manager (%): 5 (11)	3 (25)	2 (7)	0 (0)	
	Kitchen Assistant (%): 1 (2)	1 (8)	0 (0)	0 (0)	

	Administrator	1 (8)	0 (0)	0 (0)	
	(%): 1 (2)				
Length of	<i>N</i> = 46	<i>n</i> = 13	<i>n</i> = 27	<i>n</i> = 7	<i>p</i> = .03
time in					
current	Less than 3 months	1 (8)	1 (4)	0 (0)	
employment	(%): 2 (4)				
	Less than 1 year	8 (62)	7 (23)	1 (14)	
	(%): 16 (35)				
	1-2 years (%):	2 (15)	9 (33)	1 (14)	
	12 (26)				
	2-5 years (%):	0 (0)	8 (30)	3 (43)	
	11 (24)				
	5-8 years (%):	2 (15)	1 (4)	1 (14)	
	4 (9)				
	8-10 years (%):	0 (0)	0 (0)	1 (14)	
	1 (2)				
	More than 10 years	0 (0)	1 (4)	0 (0)	
	(%): 1 (2)				
Length of	<i>N</i> = 46	<i>n</i> = 12	<i>n</i> = 27	<i>n</i> = 7	<i>p</i> = .66
time working					
in services	Less than 1 year	5 (42)	7 (26)	0 (0)	
with PwD	(%): 12 (26)				
	1-2 years (%):	4 (33)	8 (30)	1 (14)	
	13 (28)				
	2-5 years (%):	1 (8)	6 (22)	3 (43)	



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	10 (22)				
	5-8 years (%): 6 (13)	2 (17)	3 (11)	1 (14)	
	8-10 (%): 2 (4)	0 (0)	0 (0)	2 (29)	
	10+ years: 3 (7)	0 (0)	3 (11)	0 (0)	

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Work	<i>N</i> = 42	<i>n</i> = 12	<i>n</i> = 23	<i>n</i> = 7	<i>p</i> = .32
Environment					
	Residential (%): 5 (12)	2 (17)	3 (13)	0 (0)	
	Nursing (%): 7 (17)	1 (8)	6 (26)	0 (0)	
	Dementia Specific (%): 6 (14)	0 (0)	4 (17)	2 (29)	
	Nursing and Dementia Specific (%): 2 (5)	0 (0)	1 (4)	1 (14)	
	Residential, Nursing and Dementia Specific (%): 9 (21)	3 (25)	5 (22)	1 (14)	
	Residential and Dementia Specific (%): 11 (26.2)	5 (42)	3 (13)	3 (43)	

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	Admin (%): 2 (4.8)	1 (8)	1 (4)	0 (0)	
Training in last year attended	<i>N</i> = 47	<i>n</i> = 13	<i>n</i> = 27	<i>n</i> = 7	<i>p</i> = .64
	Yes (%): 14 (30)	5 (39)	7 (26)	2 (29)	
	No (%): 33 (70)	8 (62)	20 (74)	5 (71)	
Type of training attended	<i>n</i> = 15	<i>n</i> = 5	<i>n</i> = 8	<i>n</i> = 2	<i>p</i> = .02
	Induction Training (%): 1 (7)	0 (0)	1 (12)	0 (0)	
	CAMTED <sup>c</sup> (%): 3 (20)	0 (0)	3 (38)	0 (0)	
	In-house Training (%): 1 (7)	1 (20)	0 (0)	0 (0)	
	E-learning (%): 4 (27)	4 (80)	0 (0)	0 (0)	
	1 day dementia course (%): 1 (7)	0 (0)	1 (12)	0 (0)	
	2 day dementia course (%): 3 (20)	0 (0)	1 (12)	2 (100)	
	1 week and 2 days (%): 1 (6.7)	0 (0)	1 (12)	0 (0)	
	PCC/understanding dementia/behaviours that challenge (%):	0 (0)	1 (12)	0 (0)	

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1 (7)

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*Note: \*p < .01, M = Mean, SD = Standard Deviation; NVQ = National Vocational Qualifications, RGN = Registered General Nurse, PCC = Person-Centred Care, PwD = People with Dementia.*

*<sup>a</sup>The waiting list group was excluded from baseline comparisons due to the small sample size.*

*<sup>b</sup>This variable significantly deviated from a normal distribution, but non-parametric analysis confirmed the reported parametric output.*

*<sup>c</sup>In CAMTED-Plus, three participants had started some training delivered by CAMTED-OP within the past year. However, this was cancelled due to insufficient numbers. It was decided to include these participants in the study, as at most, they had attended one or two sessions.*

**3.3.1 Baseline differences between the groups.** A series of Fisher's exact tests were performed to assess whether there were any significant differences between CAMTED and CAMTED-Plus participant characteristics. The WL group was excluded from comparisons due to the small sample size. Fisher's exact test was utilised in this study, as it is recommended to be used when expected frequencies are too low for a  $\chi^2$  and when sample size is smaller than 40 (Fields, 2013). See Table 3.1 for a summary of these comparisons.

There were no statistically significant differences between groups in terms of gender ( $p = .69$ ), nationality ( $p = .11$ ), education ( $p = .18$ ), length of time in current employment ( $p = .03$ ), length of time working with PwD ( $p = .66$ ), environment ( $p = .31$ ), training attended in the last year ( $p = .64$ ) and type of training attended in the past year ( $p = .02$ ). There was a statistically significant difference between groups in terms of job title ( $p = .01$ ).

Exploration of the data for job title and length of time in current employment indicated a possible link between these variables. Participants with more senior or experienced job titles, such as RGN, care home trainer or team leader, had worked at their current place of work for longer, in comparison to participants with less senior or experienced job titles, such as healthcare assistant or kitchen assistant. In CAMTED the average number of months in current employment was 36 for more senior/experienced job titles compared to 14 for less senior/experience job titles. In CAMTED-Plus the average number of months in current employment was 52 for more senior/experienced job titles compared to 18 for less senior/experienced job titles.

In terms of age, there was a significant positive skew for CAMTED-Plus meaning participants in this group were younger in age-range in comparison to participants in CAMTED. Additionally, the data were assessed statistically by using the Shapiro–Wilk test (S-W; Shapiro and Wilk, 1965), which tests the assumption that the distribution of the sample is not significantly different from a normal distribution. The S-W test was utilised rather than

Kolmogorov- Smirnov test as it is considered more robust for small sample sizes (Field, 2013). The S-W test indicated CAMTED-Plus to be significantly different, suggesting that the distribution of the sample was significantly different from a normal distribution. An independent samples t-test was used to compare age and confirmed that there were no statistically significant differences in age between groups,  $t(38) = .169, p = .87$ . A non-parametric analysis confirmed the reported parametric output.

**3.3.2 Intervention attendance.** A description of intervention attendance and intervention period can be found in Table 3.2. In CAMTED, 12 (92%) participants attended all five training sessions. In CAMTED-Plus, 13 (46%) participants attended all training sessions ( $M = 6.0, SD = 1.69$ ), 16 (57%) participants attended both sessions of the PCAP training module and 17 (43%) participants attended the first session of the PCAP training module, but not sessions two.

The intervention period details the length of time (number of weeks) between the intervention starting (baseline) and when the intervention ended (post-intervention). The average length of intervention for CAMTED was 3.1 weeks, CAMTED-Plus 9.5 weeks and WL 4.9 weeks.

Table 3.2

*Care staff attendance at training and intervention length*

Variable		<b>CAMTED</b>	<b>CAMTED-Plus</b>	<b>Waiting List</b>
Participants (%)		<i>n</i> = 13	<i>n</i> = 28	<i>n</i> = 7
	<i>N</i> = 48			
Session Attendance		<i>M</i> ( <i>SD</i> ) = 5 (0)	<i>M</i> ( <i>SD</i> )= 6 (1.69)	N/A
	Attendance of all sessions (%)	12 (92)	13 (46)	N/A
	4-6 sessions attended (%)	1 (8)	12 (43)	N/A
	1-3 sessions attended (%)	-	3 (11)	N/A
PCAP sessions attended	Attended both PCAP training sessions	N/A	16 (57)	N/A
	Attended PCAP training session 1	N/A	17 (43)	N/A
Number of hours of training attended		45	120	N/A
Intervention period in weeks	<i>N</i> = 48	<i>n</i> = 13	<i>n</i> = 28	<i>n</i> = 7
		<i>M</i> ( <i>SD</i> ) = 3.1 (1.01)	<i>M</i> ( <i>SD</i> ) = 9.5 (4.0)	<i>M</i> ( <i>SD</i> ) = 4.9 (1.07)
	3 weeks (%)	8 (62)	-	-

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4 weeks (%)	-	-	4 (57)
5 weeks (%)	5 (39)	-	-
6 weeks (%)	-	11 (39)	3 (43)
10 weeks (%)	-	6 (21)	-
13 weeks (%)	-	7 (25)	-
15 weeks (%)	-	4 (14)	-

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*Note:* M= Mean, SD= Standard Deviation, N/A= Not Applicable

**3.3.3 Care home demographics.** Care home managers were asked to provide some details on the demographics of their care home, these can be found in Table 3.3. Details of the general age and gender profile of residents were not consistently collected and are therefore not included in full. Three of the eight care homes taking part in the study did report a greater proportion of female residents. The care homes taking part in CAMTED and CAMTED-Plus catered for residents aged 18 and over and the care home taking part in the WL condition catered for residents aged 50 and over.

Details on the primary route to becoming a resident and average length of stay were again not provided consistently from all participating care homes. Two care homes that did provide details described a length of stay of between 2-2.5 years and one care home reported a length of stay of a few weeks to 10 years. Primary routes to becoming a resident included: health and social care referrals, continuing care referrals and enquires made by family members under stressful circumstances.

A number of care homes were recruited from the same care provider and provided similar philosophies of care and environmental details. The majority of care homes taking part in the study specialised in residential, nursing and dementia specific (63%).

All three of the care homes taking part in CAMTED provided details of their philosophy of care, these included: “*Care that is as individual as the people for whom we provide care*” and “*Feelings matter to us*”. All four of the care homes taking part in CAMTED-Plus provided details of their philosophy of care, these included: “*Feelings matter most*”, “*Care that is as individual as the people for whom we provide care*” and “*A respect and freedom for the individual to pursue personal goals and interests, constrained only by the needs of living with others*”. The care home taking part in the WL condition did not provide details of a philosophy of care.



Table 3.3

*Baseline characteristics of care homes*

Variable	Overall Sample	CAMTED	CAMTED-Plus	Waiting List
Care Home	<i>N</i> = 8	<i>n</i> = 3	<i>n</i> = 4	<i>n</i> = 1
Age of residents (care homes catered for)	18+	1 (33)	1 (25)	-
	50+	-	-	1 (100)
	60+	1 (33)	-	-
	65+	-	3 (75)	-
	85+	1 (33)	-	-
Care home size (number of residents)	<i>M</i> (SD)	<i>M</i> (SD):	<i>M</i> (SD):	N/A
	75 (30.19)	53 (30.99)	92 (23.78)	
	0-40 residents (%): 2 (25)	2 (67)	0 (0)	0 (0)
	40-80 residents (%): 2 (25)	0 (0)	1 (25)	1 (100)
	80+ residents (%): 4 (50)	1 (33)	3 (75)	0 (0)
Environment	Residential (%): 1(13)	0(0)	1(25)	0(0)
	Residential, Nursing, Dementia Specific (%): 5(63)	1(33)	3(75)	1(100)

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Residential, Dementia Specific (%): 2(25)	2(67)	0(0)	0(0)
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*Note: M = Mean, SD = Standard Deviation, N/A = Not Applicable*

### 3.4 Exploration of Data

The distributions of the data were assessed visually using histograms and statistically using the S-W test (Shapiro & Wilk, 1965) and by examining skew and kurtosis values (see Appendix P1). Assessment indicated that the Approaches to Dementia Questionnaire - Hope subscale (ADQ-H), Approaches to Dementia Questionnaire - Personhood subscale (ADQ-PH), Dementia Knowledge Questionnaire (DK-20), Dementia Knowledge Questionnaire - Dementia Core Knowledge subscale (DK-20-DCK), Dementia Knowledge Questionnaire - Dementia Care Knowledge subscale (DK-20-DCaK), and Frequency of SAD-behaviours Scale deviated significantly from a normal distribution (see Appendix P2).

Levene's test was used to assess homogeneity of variance between groups. This tests the hypothesis that the variances in the groups are unequal. No statistically significant results were found across variables.

Transformation of the data to correct the distribution was considered.

Transformations are recommended as a solution for outliers and to manage problems with normality and linearity. However, they are not universally recommended and should be used in an informed way (Howell, 2007; Osborne & Jason, 2002; Tabachnick & Fidell, 2014).

Transformations can improve normality by changing the relative distances between data points (Osborne & Jason, 2002). Some authors argue that this can impact on data interpretation and translation into clinical practice, which is considered a sufficient justification for not carrying out transformations (Howell, 2007; Osborne & Jason, 2002; Tabachnick & Fidell, 2014).

A primary aim of the present study was the clinical application of the findings. Considering the literature on transformation, the risk of a transformation hampering interpretation was considered to be high. Therefore, transformation was not considered to be appropriate for the study.

Although a number of variables deviated from a normal distribution, parametric tests were utilised as they are considered more robust and the statistical power of non-parametric tests are largely considered to be lower than that of their parametric counterpart. In the present study non-parametric tests were not considered to be an adequate test of this important clinical data (Hodges & Lehmann, 1956; Tanizaki, 1997). When variables deviated from a normal distribution, parametric analyses were run, but only where there was a significant difference between the parametric and non-parametric results are the non-parametric outputs reported.

**3.4.1 Baseline differences between the variables.** Descriptive statistics and data from the pre-training outcome measures are presented in Table 3.4. Descriptive statistics for the WL group can be found in Appendix P3. As can be seen from the table, participants in CAMTED and CAMTED-plus did not report statistically significant differences at baseline across all variables: ADQ,  $t(39) = .175$ ,  $p = .86$ , ADQ-H,  $t(39) = 1.670$ ,  $p = .10$ , ADQ-PH,  $t(39) = 1.289$ ,  $p = .21$ , DK-20,  $t(39) = .389$ ,  $p = .70$ , DK-20-DCK,  $t(39) = .630$ ,  $p = .53$ , DK-20-DCaK,  $t(39) = 1.909$ ,  $p = .06$ , Maslach Burnout Inventory – Emotional Exhaustion Subscale (MBI-EE),  $t(32) = 1.138$ ,  $p = .26$ , Maslach Burnout Inventory – Depersonalisation subscale (MBI-DP),  $t(32) = .387$ ,  $p = .70$ , Maslach Burnout Inventory – Personal Accomplishment subscale (MBI-PA),  $t(32) = .029$ ,  $p = .98$ , Stress and Distress Behaviour Scale (SDBS),  $t(33) = 1.238$ ,  $p = .22$ , Frequency of SAD-behaviours Scale,  $t(34) = 1.802$ ,  $p = .04$ , Intensity of SAD-behaviours Scale,  $t(34) = 1.606$ ,  $p = .13$ , Confidence in managing

SAD-behaviours Scale,  $t(34) = 1.167$ ,  $p = .25$ , Swedish Satisfaction in Nursing Care and Work Scale (SNCW),  $t(33) = .366$ ,  $p = .72$ .

Table 3.4

*Descriptive statistics for pre and post outcome measures and comparison data*

Primary Measure	CAMTED (n = 13 )		CAMTED-Plus (n = 28)		Statistics		Effect Size
	Mean	SD	Mean	SD	t	p	d
ADQ							
Pre-Intervention	72	7.92	72	6.06	.175	.86	
Post-Intervention	76	7.27	76 <sup>a</sup>	6.98	.115	.91	0
ADQ-H							
Pre-Intervention	24	5.15	26	3.86	1.670	.10	
Post-Intervention	26	3.78	27 <sup>a</sup>	5.03	.249	.81	0.1
ADQ-PH							
Pre-Intervention	48	5.07	46	4.47	1.289	.21	
Post-Intervention	48	4.23	48 <sup>a</sup>	4.91	.123	.90	0
DK-20							
Pre-Intervention	13 <sup>a</sup>	3.81	14	3.65	.389	.70	
Post-Intervention	15 <sup>a</sup>	2.77	15 <sup>a</sup>	3.36	.185	.85	0
DK-20-DCK							
Pre-Intervention	7	2.47	7	2.60	.630	.53	
Post-Intervention	8	1.27	7	2.25	.537	.59	0.2
DK-20-DCaK							
Pre-Intervention	6	1.91	7 <sup>a</sup>	1.44	1.909	.06	
Post-Intervention	7 <sup>a</sup>	2.28	7 <sup>a</sup>	1.66	.258	.80	0
Secondary Measure MBI-EE							

Pre-Intervention	23	13.47	17	12.0	1.138	.26	
Post-Intervention	21	11.68	16	11.95	1.130	.27	0.4
MBI-DP							
Pre-Intervention	6	4.93	5	3.85	.387	.70	
Post-Intervention	4	3.69	5	3.98	.424	.68	0.3
MBI-PA							
Pre-Intervention	34	10.43	34 <sup>a</sup>	9.97	.029	.98	
Post-Intervention	37	7.76	34	7.17	1.208	.24	0.4
SDBS							
Pre-Intervention	25	17.22	31	10.85	1.238	.22	
Post-Intervention	26	17.32	28	11.79	.317	.75	0.1
Frequency Scale							
Pre-Intervention	3	1.83	4 <sup>a</sup>	1.33	1.802	.04	
Post-Intervention	4 <sup>a</sup>	1.38	4 <sup>a</sup>	1.37	.548	.59	0
Intensity Scale							
Pre-Intervention	3	1.81	3	.84	1.606	.129	
Post-Intervention	3	1.66	3	1.08	.462	.65	0
Confidence Scale							
Pre-Intervention	5 <sup>a</sup>	.87	4 <sup>a</sup>	1.19	1.167	.251	
Post-Intervention	5	.80	5	.73	1.237	.23	0
SNCW							
Pre-Intervention	74	17.95	76	18.16	.366	.72	
Post-Intervention	71	19.15	79	19.76	1.180	.25	0.4

*Note:* ADQ = Attitudes to Dementia Questionnaire, ADQ-H = Attitudes to Dementia Questionnaire – Hope subscale (ADQ-H), ADQ-PH = Attitudes to Dementia Questionnaire – Personhood subscale, DK-20 = Dementia Knowledge Questionnaire, DK-20-DCK = Dementia Knowledge Questionnaire –

Dementia Core Knowledge subscale, DK-20-DCaK = Dementia Knowledge Questionnaire – Dementia Care Knowledge subscale, MBI-EE = Maslach Burnout Inventory – Emotional Exhaustion subscale, MBI-DP – Maslach Burnout Inventory – Depersonalisation subscale, MBI-PA = Maslach Burnout Inventory – Personal Accomplishment subscale, SDBS = Stress and Distress Behaviour Scale, Frequency Scale = Frequency of SAD-behaviours Scale, Intensity Scale = Intensity of SAD-behaviours Scale, Confidence Scale = Confidence in managing SAD-behaviours Scale SNCW = Swedish Satisfaction in Nursing Care and Work Scale;  $p < .01$ .

<sup>a</sup>*These variables significantly deviated from a normal distribution, but in each case non-parametric analyses confirmed the reported parametric output.*

### 3.5 Analysis of Outcome - Part A

It was originally proposed to use one-way Analysis of Variance (ANOVA) to answer the research questions. Due to the exclusion of the WL group from the data analyses because of the small sample size, the analysis plan subsequently deviated to a two arm trial and independent t-tests were used to compare the groups' scores at the end of the intervention.

Descriptive and group comparison statistics for primary and secondary outcome measures can be found in Table 3.4. The outputs from non-parametric analyses can be found in Appendix P4. The research questions have been adapted to reflect the exclusion of the WL group from comparisons.

#### 3.5.1 Primary Outcomes.

**3.5.1.1 Research question 1: Do differences exist between CAMTED and CAMTED-Plus in caregiver knowledge of dementia and compassionate awareness of need in dementia that presents as SAD-behaviour?** There was no statistically significant difference in knowledge of dementia at the end of the training intervention, as measured by the DK-20 (Shanahan et al., 2013), between CAMTED ( $M = 15, SD = 2.77$ ) and CAMTED-Plus ( $M = 15, SD = 3.36$ ),  $t(39) = .185, p = .85, d = 0, 95\% CI [-1.97, 2.37]$ .

In addition to this, no statistically significant difference was found between CAMTED ( $M = 8, SD = 1.27$ ) and CAMTED-Plus ( $M = 7, SD = 2.25$ ) in the DK-20-DCK subscale of this measure,  $t(39) = .537, p = .59, d = 0.2, 95\% CI [-1.00, 1.72]$ , or between CAMTED ( $M = 7, SD = 2.28$ ) and CAMTED-Plus ( $M = 7, SD = 1.66$ ) in the DK-20-DCaK subscale of this measure,  $t(39) = .258, p = .80, d = 0, 95\% CI [-1.43, 1.11]$ .

**3.5.1.2 Research Question 2: Do differences exist between CAMTED and CAMTED-Plus in caregiver approach to dementia care?** There was no statistically significant difference in attitude to dementia at the end of the training intervention, as



measured by the ADQ (Lintern et al., 2000), between CAMTED ( $M = 76, SD = 7.27$ ) and CAMTED-Plus ( $M = 76, SD = 6.98$ ),  $t(39) = .115, p = .91, d = 0, 95\% CI [-5.07, 4.53]$ .

In addition to this, no statistically significant difference was found between CAMTED ( $M = 26, SD = 3.78$ ) and CAMTED-Plus ( $M = 27, SD = 5.03$ ) in the ADQ-H subscale,  $t(39) = .249, p = .81, d = 0.1, 95\% CI [-2.79, 3.57]$ , which measures degree of hopefulness about dementia or between CAMTED ( $M = 48, SD = 4.23$ ) and CAMTED-Plus ( $M = 48, SD = 4.91$ ) in the ADQ-PH subscale,  $t(39) = .123, p = .90, d = 0, 95\% CI [-3.00, 3.39]$ , which measures the extent to which a person-centered approach is adopted.

### **3.5.2 Secondary Outcomes.**

**3.5.2.1 Research Question 3: Do differences exist between CAMTED and CAMTED-plus in levels of caregiver burden?** Comparisons were made between CAMTED and CAMTED-Plus on each of the three subscales of the MBI-HSS (Maslach et al., 1996) at the end of the training intervention.

There was no statistically significant difference in levels of caregiver emotional exhaustion, as measured by the MBI-EE subscale, between CAMTED ( $M = 21, SD = 11.68$ ) and CAMTED-Plus ( $M = 16, SD = 11.95$ ),  $t(32) = 1.130, p = .27, d = 0.4, 95\% CI [-3.86, 13.48]$ .

There was no statistically significant difference in levels of caregiver depersonalisation, as measured by the MBI-DP subscale, between CAMTED ( $M = 4, SD = 3.69$ ) and CAMTED-Plus ( $M = 5, SD = 3.98$ ),  $t(32) = .424, p = .68, d = 0.3, 95\% CI [3.43, 2.25]$ .

There was no statistically significant difference in levels of caregiver personal accomplishment, as measured by the MBI-PA subscale, between CAMTED ( $M = 37, SD = 7.76$ ) and CAMTED-Plus ( $M = 34, SD = 7.17$ ),  $t(32) = 1.208, p = .2, d = 0.4, 95\% CI [-2.20, 8.59]$ .

**3.5.2.2 Research Question 4: Do differences exist between CAMTED and CAMTED-Plus in caregiver job satisfaction?** There was no statistically significant difference in caregiver job satisfaction at the end of the training intervention, as measured by the SNCW (Hallberg et al., 1994), between CAMTED ( $M = 71, SD = 19.15$ ) and CAMTED-Plus ( $M = 79, SD = 19.76$ ),  $t(32) = 1.180, p = .25, d = 0.4, 95\% CI [-21.97, 5.84]$ .

**3.5.2.3 Research Question 5: Do differences exist between CAMTED and CAMTED-Plus in caregiver perceived frequency and intensity of SAD-behaviours and confidence in managing SAD-behaviours?** There was no statistically significant difference in perceived frequency of SAD-behaviours at the end of the training intervention, as measured by the SDBS, between CAMTED ( $M = 26, SD = 17.32$ ) and CAMTED-Plus ( $M = 28, SD = 11.79$ ),  $t(33) = .317, p = .75, d = 0.1, 95\% CI [-11.56, 8.44]$ , or measured by the Frequency of SAD-behaviours Scale, between CAMTED ( $M = 4, SD = 1.38$ ) and CAMTED-Plus ( $M = 4, SD = 1.37$ ),  $t(33) = .548, p = .59, d = 0, 95\% CI [-1.24, .71]$ .

In addition to this, there was no statistically significant difference in perceived intensity of SAD-behaviours, as measured by the Intensity of SAD-behaviours Scale, between CAMTED ( $M = 3, SD = 1.66$ ) and CAMTED-Plus ( $M = 3, SD = 1.08$ ),  $t(33) = .462, p = .65, d = 0, 95\% CI [-1.15, .73]$ , or confidence in managing SAD-behaviours as measured by the Confidence Scale, between CAMTED ( $M = 5, SD = .80$ ) and CAMTED-Plus ( $M = 5, SD = .73$ ),  $t(33) = 1.237, p = .23, d = 0, 95\% CI [-.21, .86]$ .

### **3.6 Analysis of Outcome - Part B**

In order to explore changes over time within the two groups, a series of paired t-tests were used to assess pre-post changes from before the intervention to after the intervention. Descriptive and group comparison statistics for primary and secondary outcome measures can be found in Table 3.5.

### 3.6.1 Primary Outcomes

#### 3.6.1.1 Research Question 1: *Compassionate awareness of need in dementia.*

Paired t-tests for each group separately revealed no statistically significant changes in knowledge of dementia (DK-20) for CAMTED, before ( $M = 13$ ,  $SD = 3.65$ ) and after ( $M = 15$ ,  $SD = 3.13$ ) the intervention,  $t(9) = 1.438$ ,  $p = .18$ ,  $d = 0.5$ , 95% CI [-5.917, 1.317], and CAMTED-Plus, before ( $M = 14$ ,  $SD = 3.13$ ) and after ( $M = 15$ ,  $SD = 4.97$ ) the intervention,  $t(27) = 2.174$ ,  $p = .04$ ,  $d = 0.4$ , 95% CI [-2.846, -.082].

Paired t-tests for each group also revealed no statistically significant changes in the DK-20-DCK subscale for CAMTED, before ( $M = 7$ ,  $SD = 2.81$ ) and after ( $M = 8$ ,  $SD = .94$ ) the intervention,  $t(9) = 1.029$ ,  $p = .33$ ,  $d = 0.3$ , 95% CI [-3.519, 1.519], and CAMTED-Plus, before ( $M = 7$ ,  $SD = 2.60$ ) and after ( $M = 7$ ,  $SD = 2.25$ ) the intervention,  $t(27) = 2.312$ ,  $p = .03$ ,  $d = 0.4$ , 95% CI [-1.213, -.072] and the DK-20 DCaK subscale for CAMTED, before ( $M = 6$ ,  $SD = 2.04$ ) and after ( $M = 7$ ,  $SD = 2.45$ ) the intervention,  $t(9) = 1.724$ ,  $p = .12$ ,  $d = 0.5$ , 95% CI [-2.775, .375], and CAMTED-Plus, before ( $M = 7$ ,  $SD = 1.44$ ) and after ( $M = 7$ ,  $SD = 1.66$ ) the intervention,  $t(27) = 1.063$ ,  $p = .30$ ,  $d = 0.2$ , 95% CI [-.628, .199].

**3.6.1.2 Research Question 2: *Caregiver approach to dementia.*** A paired t-test within the CAMTED group revealed that this group did not show any statistically significant difference in attitude to dementia (ADQ) before ( $M = 71$ ,  $SD = 7.93$ ) and after ( $M = 74$ ,  $SD = 7.44$ ) the intervention,  $t(9) = 2.132$ ,  $p = .06$ ,  $d = 0.7$ , 95% CI [-7.213, .213]. A paired t-test within the CAMTED-Plus group showed a statistically significant increase in attitude to dementia before ( $M = 71$ ,  $SD = 4.96$ ) and after ( $M = 74$ ,  $SD = 6.06$ ) the intervention,  $t(27) = 3.786$ ,  $p = .001$ ,  $d = 0.7$ , 95% CI [-5.507, -1.636].

A paired t-test within the CAMTED group revealed that this group showed a statistically significant difference in degree of hopefulness about dementia (ADQ-H) before ( $M = 23$ ,  $SD = 4.96$ ) and after ( $M = 27$ ,  $SD = 3.65$ ) the intervention,  $t(9) = 3.038$ ,  $p = .01$ ,  $d =$

0.9, 95% CI [-6.281, -.919]. A paired t-test within the CAMTED-Plus group revealed that this group did not show any statistically significant difference in degree of hopefulness about dementia (ADQ-H) before ( $M = 26, SD = 3.86$ ) and after ( $M = 27, SD = 5.03$ ) the intervention,  $t(27), t = .898, p = .38, d = 0.2, 95\% CI [-2.932, 1.146]$ .

A paired t-test within the CAMTED group revealed that this group did not show any statistically significant difference in the extent to which a person-centered approach is adopted (ADQ-PH), before ( $M = 48, SD = 5.58$ ) and after ( $M = 47, SD = 4.50$ ) the intervention,  $t(9) = .085, p = .93, d = .03, 95\% CI [-2.565, 2.765]$ . A paired t-test within the CAMTED-Plus group revealed that this group showed a statistically significant difference in the extent to which a person-centered approach is adopted, before ( $M = 46, SD = 4.47$ ) and after ( $M = 48, SD = 3.73$ ) the intervention,  $t(27) = .898, p = .07, d = 0.7, 95\% CI [-2.861, -.782]$ .

### **3.6.2 Secondary Outcomes.**

**3.6.2.1 Research Question 3: Caregiver burden.** Paired t-tests for each group separately revealed no statistically significant changes in levels of caregiver emotional exhaustion (MBI-EE) for CAMTED, before ( $M = 25, SD = 13.78$ ) and after ( $M = 22, SD = 11.20$ ) the intervention,  $t(8) = 1.322, p = .22, d = 0.4, 95\% CI [-2.397, 8.842]$ , and CAMTED-Plus, before ( $M = 17, SD = 12.09$ ) and after ( $M = 16, SD = 11.95$ ), the intervention,  $t(21) = .460, p = .65, d = 0.1, 95\% CI [-3.846, 6.028]$ .

A paired t-test within the CAMTED group revealed that this group did not show any statistically significant difference in levels of caregiver depersonalisation (MBI-DP) for CAMTED, before ( $M = 5, SD = 5.08$ ) and after ( $M = 2, SD = 2.35$ ) the intervention,  $t(8) = 2.199, p = .06, d = 0.7, 95\% CI [-.146, 6.146]$ . A paired t-test within the CAMTED-Plus group revealed that this group showed a statistically significant difference in levels of

caregiver depersonalisation (MBI-DP) before ( $M = 5$ ,  $SD = 3.85$ ) and after ( $M = 1$ ,  $SD = .87$ ), the intervention,  $t(21) = 5.509$ ,  $p = .00$ ,  $d = 1.2$ , 95% CI [2.454, 5.509].

Paired t-tests for each group separately revealed no statistically significant changes in levels of caregiver personal accomplishment (MBI-PA) for CAMTED, before ( $M = 33$ ,  $SD = 11.36$ ) and after ( $M = 36$ ,  $SD = 8.57$ ) the intervention,  $t(8) = 1.491$ ,  $p = .17$ ,  $d = 0.5$ , 95% CI [-8.490, 1.823], and CAMTED-Plus, before ( $M = 34$ ,  $SD = 9.97$ ) and after ( $M = 34$ ,  $SD = 7.17$ ), the intervention,  $t(21) = .285$ ,  $p = .78$ ,  $d = 0.1$ , 95% CI [-3.716, 4.898].

**3.6.2.2 Research Question 4: Caregiver job satisfaction.** Paired t-tests for each group separately revealed no statistically significant changes in job satisfaction for CAMTED, before ( $M = 76$ ,  $SD = .18.37$ ) and after ( $M = 68$ ,  $SD = 20.92$ ) the intervention,  $t(9) = 1.796$ ,  $p = .10$ ,  $d = 0.6$ , 95% CI [-2.049, 17.849], and CAMTED-Plus, before ( $M = 76$ ,  $SD = 18.16$ ) and after ( $M = 79$ ,  $SD = 19.76$ ), the intervention,  $t(21) = .398$ ,  $p = .69$ ,  $d = 0.1$ , 95% CI [-14.705, 9.978].

**3.6.2.3 Research Question 5: Frequency and intensity of SAD-behaviours and confidence in managing SAD-behaviours.** Paired t-tests for each group separately revealed no statistically significant changes in the frequency of SAD-behaviours (SDBS; Frequency Scale) for CAMTED, before ( $M = 28$ ,  $SD = 18.91$ ;  $M = 3$ ,  $SD = 1.99$ ) and after ( $M = 26$ ,  $SD = 19.67$ ;  $M = 4$ ,  $SD = 1.57$ ) the intervention,  $t(9) = .733$ ,  $p = .48$ ,  $d = 0.2$ , 95% CI [-3.546, 6.946],  $t(9) = 1.868$ ,  $p = .10$ ,  $d = 0.6$ , 95% CI [-1.990, .190]. Paired t-tests for each group separately revealed no statistically significant changes in the frequency of SAD-behaviours (SDBS; Frequency Scale) for CAMTED-Plus, before ( $M = 31$ ,  $SD = 10.85$ ;  $M = 4$ ,  $SD = 1.34$ ) and after ( $M = 28$ ,  $SD = 11.79$ ;  $M = 4$ ,  $SD = 1.362$ ) the intervention,  $t(21) = 1.810$ ,  $p = .09$ ,  $d = 0.4$ , 95% CI [-.547, 7.911],  $t(21) = .513$ ,  $p = .61$ ,  $d = 0.1$ , 95% CI [-.416, .689].

Paired t-tests for each group separately revealed no statistically significant changes in the intensity of SAD-behaviours for CAMTED, before ( $M = 3$ ,  $SD = 1.96$ ) and after ( $M = 3$ ,

$SD = 1.87$ ) the intervention,  $t(9) = .318$ ,  $p = .76$ ,  $d = 0.1$ , 95% CI [-1.623, 1.223], and CAMTED-Plus, before ( $M = 3$ ,  $SD = .85$ ) and after ( $M = 3$ ,  $SD = .23$ ), the intervention,  $t(21) = 1.000$ ,  $p = .33$ ,  $d = 0.2$ , 95% CI [-.245, .700].

Paired t-tests for each group separately revealed no statistically significant changes in the confidence in managing SAD-behaviours for CAMTED, before ( $M = 5$ ,  $SD = .97$ ) and after ( $M = 5$ ,  $SD = .88$ ) the intervention,  $t(9) = 1.96$ ,  $p = .08$ ,  $d = 0.6$ , 95% CI [-.646, .046], and CAMTED-Plus, before ( $M = 4$ ,  $SD = 1.19$ ) and after ( $M = 5$ ,  $SD = .15$ ), the intervention,  $t(22) = 1.500$ ,  $p = .15$ ,  $d = 0.3$ , 95% CI [-.829, .133].

**3.6.3 Summary of results.** An interim summary is provided and overall the analysis of the collected data found no statistically significant differences between CAMTED and CAMTED-Plus at the end of the intervention for any of the outcome variables. Within-group analyses of pre-post changes over time revealed that CAMTED had greater statistically significant change in degree of hopefulness about dementia. CAMTED-Plus was found to be a more powerful training intervention compared to CAMTED in overall attitude to dementia, the extent to which a person-centred approach is adopted and levels of depersonalisation. Overall the findings suggest that CAMTED-Plus, with the inclusion of the Person Centred Approaches to Practice (PCAP) module has some merit as an additional training component to the core CAMTED training package.

Table 3.5

*Descriptive statistics for pre-post change and comparison data*

Primary Measure	Change Score ( <i>M</i> )	SD	t	Statistics		Effect Size
				<i>p</i>	<i>d</i>	
ADQ						
CAMTED	- 4	5.19	2.132	.06		0.7
CAMTED-Plus	- 4	4.99	3.786	*.001		0.7
ADQ-H						
CAMTED	- 4	3.75	3.038	*.01 <sup>a</sup>		0.9
CAMTED-Plus	- 1	5.26	.898	.38		0.2
ADQ-PH						
CAMTED	.1	3.73	.085	.93 <sup>a</sup>		.03
CAMTED-Plus	- 2	2.68	3.595	*.001		0.7
DK-20						
CAMTED	- 2	5.06	1.438	.18 <sup>a</sup>		0.5
CAMTED-Plus	- 1	3.56	2.174	.04 <sup>a</sup>		0.4
DK-20-DCK						
CAMTED	- 1	3.38	1.029	.33 <sup>a</sup>		0.3
CAMTED-Plus	- 1	1.47	2.312	.03		0.3
DK-20-DCaK						
CAMTED	- 1	2.20	1.724	.12 <sup>a</sup>		0.5
CAMTED-Plus	-.2	1.07	1.063	.30 <sup>a</sup>		0.2
Secondary Measure						

MBI-EE					
CAMTED	3	7.31	1.322	.22	0.4
CAMTED-Plus	1	11.14	.460	.65	0.1
MBI-DP					
CAMTED	3	4.09	2.199	.06	0.7
CAMTED-Plus	4	3.45	5.421	*.000	1.2
MBI-PA					
CAMTED	- 3	6.71	1.491	.17	0.5
CAMTED-Plus	1	9.71	.285	.78 <sup>a</sup>	0.1
SDBS					
CAMTED	2	7.33	.733	.48	0.2
CAMTED-Plus	4	9.54	1.810	.09	0.4
Frequency Scale					
CAMTED	-.9	1.52	1.868	.10 <sup>a</sup>	0.6
CAMTED-Plus	.1	1.25	.513	.61 <sup>a</sup>	0.1
Intensity Scale					
CAMTED	-.2	1.99	.318	.76	0.1
CAMTED-Plus	.2	1.07	1.000	.33	0.2
Confidence Scale					
CAMTED	-.3	.48	1.964	.08 <sup>a</sup>	0.6
CAMTED-Plus	-.3	1.11	1.500	.15 <sup>a</sup>	0.3
SNCW					
CAMTED	8	13.91	1.796	.11	0.6
CAMTED-Plus	- 2	27.84	.398	.69	0.1

Note: \* $p < .01$ ,  $M$  = Mean,  $SD$  = Standard Deviation,  $ADQ$  = Attitudes to Dementia Questionnaire,

$ADQ-H$  = Attitudes to Dementia Questionnaire – Hope subscale ( $ADQ-H$ ),  $ADQ-PH$  = Attitudes to



Dementia Questionnaire – Personhood subscale, DK-20 = Dementia Knowledge Questionnaire, DK-20-DCK = Dementia Knowledge Questionnaire – Dementia Core Knowledge subscale, DK-20-DCaK = Dementia Knowledge Questionnaire – Dementia Care Knowledge subscale, MBI-EE = Maslach Burnout Inventory – Emotional Exhaustion subscale, MBI-DP = Maslach Burnout Inventory – Depersonalisation subscale, MBI-PA = Maslach Burnout Inventory – Personal Accomplishment subscale, SDBS = Stress and Distress Behaviour Scale, Frequency Scale = Frequency of SAD-behaviours Scale, Intensity Scale = Intensity of SAD-behaviours Scale, Confidence Scale = Confidence in managing SAD-behaviours Scale SNCW = Swedish Satisfaction in Nursing Care and Work Scale.

<sup>a</sup> *These variables significantly deviated from a normal distribution, but in each case non-parametric analyses confirmed the reported parametric output.*

### 3.7 Exploratory Analyses

**3.7.1 Controlling for baseline differences.** An Analysis of Covariance (ANCOVA) was considered to control for statistically significant baseline differences found between CAMTED and CAMTED-Plus regarding job title. As no statistically significant differences were subsequently found between dependent variables at baseline nor were statistically significant differences found between groups following experimental testing. It was concluded that the differences found between groups on this demographic variable would be unlikely to contaminate the results. It was therefore decided that ANCOVA analyses would not be pursued.

**3.7.2 Removal of outliers.** Following the main analyses of outcome, data analyses were repeated following the removal of outliers. There were no statistically significant differences found between groups at the end of the intervention for any of the dependent variables identified as having outliers ( $p > .01$ ; ADQ, ADQ-H, DK-20, DK-20-DCK, DK-20-DCaK, MBI-EE, Frequency of SAD-behaviours Scale, Intensity of SAD-behaviours Scale, Confidence in managing SAD-behaviours Scale and SNCW). The outputs of these analyses can be found in Appendix P5. In addition to this, within-group pre-post change analyses were found to be consistent with those reported for the main analyses of outcome.

### 3.8 Jigsaw Evaluation

The results of the Jigsaw evaluation can be found in Table 3.6. All participants that attended PCAP session two ( $N = 16$ ) completed the questionnaire. Twelve participants did not complete the study in the full and therefore did not complete the Jigsaw evaluation.

In terms of participant enjoyment of the Bigger Picture Jigsaw Activity, 63% of participants rated this at '9' on the scale, indicating the highest possible rating for enjoyment. Thirty one percent of participants rated enjoyment above average (5+) and one participant rated their enjoyment at '0', which is the lowest possible rating. This rating was considered

an anomaly when considering the rest of the feedback and it is believed that this rating may not have been a true reflection of the training, but may have reflected how this participant felt in their current context and wider dynamics that had arisen during the course of the study.

In terms of understanding the Bigger Picture Jigsaw Activity, 69% of participants rated this at '9', indicating the highest level of understanding. All remaining participants (31%) rated understanding above average (5+). For question three, which asked if participants found the Bigger Picture Jigsaw Activity helpful in demonstrating the ideas presented in the training, 63% of participants rated this at the highest level of helpfulness (9). Thirty two percent of remaining participants rated helpfulness above average (5+) and one participant rated '0', the lowest possible rating for helpfulness. This low rating was also considered to be an anomaly in comparison to other participants' feedback and it was believed that this rating was also a reflection of the above explanation that has been provided.

In terms of change in attitude and approach to PwD, 67% of participants rated this at the highest level (9), indicating the majority of participants felt their approach will change as a result of the training. All remaining participants (33%) rated above average (5+). It is acknowledged that a lower rating on this scale may reflect participants that believe their approach may not have changed as a result of the training and that their approach was already similar to that advocated in the training.

For question four, which asked participants if they feel their practice will change as a result of the training, 56% rated this at the highest level for practice changing (9). All remaining participants rated above average (5+). Similar to the previous question, a lower rating on this scale may reflect those who believe their practice is consistent with that encouraged in the training.

The final question asked how often participants believed they would use the ideas presented through the Bigger Picture Jigsaw Activity. Forty four percent of participants rated

this at the highest level for using the ideas in the future (9) and all remaining participants rated this above average (5+). It is acknowledge that this particular question did not have a qualitative space for feedback. It would have been interesting to gather information from participants that did not feel they would use the ideas in the future and why this would be.

Table 3.6

*Jigsaw evaluation data*

<i>N</i> = 16	Rating (0-9)	(%)
Question 1	9	10 (63)
Did you enjoy the use of the jigsaw activity in the training?	8	1 (6)
	7	3 (19)
	5	1 (6)
	0	1 (6)
Question 2	9	11 (69)
Did you understand the purpose of the jigsaw activity?	8	3 (19)
	7	1 (6)
	6	1 (6)
Question 3	9	10 (63)
Did you find the jigsaw activity helpful in showing the ideas presented in the training?	8	3 (19)
	7	2 (13)
	6	1 (6)
Question 4a	9	11 (67)
Do you think the jigsaw activity has changed your attitude/approach to people living with dementia?	8	1 (6)
	7	2 (13)
	6	1 (6)
Question 5a	9	9 (56)
Do you think that your practices will change as a result of the jigsaw activity?	8	3 (19)
	7	3 (19)
	5	1 (6)

Question 6	9	7 (44)
How often will you use the	8	4 (25)
ideas learnt through the	7	2 (13)
jigsaw activity?	6	1 (6)
	5	2 (13)

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### 3.8.1 Verbal feedback.

A number of the Jigsaw Evaluation questions, also provided space for qualitative feedback. Please see appendix P6 for a summary of all qualitative feedback provided from the questionnaires.

In terms of change in attitude and approach to PwD, all feedback provided was positive. Themes of feedback included having more understanding of dementia and the use of information to increase understanding of residents'. Example quotes include: *"Seeing the bigger picture...looking at persons' past to get a better perception of that person... why information is helpful/important"*, *"Understanding what are factual information and what are opinion ... information and to use ...on certain models"*, and *"It has made me understand that learning a person's background helps in understanding their unmet needs. It can also be wrong to judge person with dementia from just looking or taking statements from other people"*.

In terms of change in practice, all feedback was again positive. Themes included, taking time to find out more about someone, remaining calm and listening and applying knowledge learnt. Example quotes include: *"Taking the time to find out about a resident in greater detail for you to be able to deliver them better care"*, and *"Treat dementia persons' with more care and understanding"*. A number of participants also directly referenced knowledge learnt through the training in their feedback, for example: *"Looking at the bigger picture by knowing the facts... so unmet needs can be addressed or potentially de-escalate"*

*distressed behaviours”, and “I will take into account that unmet needs can lead to distress behaviour... try and identify the unmet needs to improve the quality of life”.*

A final space was provided at the end of the questionnaire where participants could provide any final comments about the Bigger Picture Jigsaw Activity and/or PCAP training. All comments were again positive and reflected knowledge gained through the training for example: *“I will use all what I learned in this course every day doing my daily work”, “Was very interesting training and is helpful for my work. Dementia training was very important for me”, and “Helped me understand a person with dementia from where they come from...by looking at their different stages in life. It is important to take into consideration their lives before dementia set in...help to identify their unmet needs and prevent their distress behaviour to make them happier and improve their quality of life and also to keep good care practices”.*

There was the exception of one more negative comment: *“Childish way of presenting an idea to ADULTS” [the upper case letters are the participant’s own]*. This again reflected an anomaly in the feedback in comparison to the feedback as a whole and was provided by the same participant that had provided earlier ratings of ‘0’. It is believed that this feedback may not have been a true reflection of the training, but may have reflected how this participant felt in their current context and wider dynamics that had arisen during the course of the study.

### **3.9 Results Summary**

To summarise, analysis of the collected data found no statistically significant differences between CAMTED and CAMTED-Plus at the end of the intervention in knowledge of dementia, attitudes to dementia, caregiver levels of burden, perceived frequency and intensity of SAD-behaviours, confidence in managing SAD-behaviours and caregiver job satisfaction.

Within-group analyses of pre-post change revealed a statistically significant difference over time for CAMTED in degree of hopefulness about dementia. Within-group analyses also revealed a statistically significant difference over time for CAMTED-Plus in overall attitude to dementia, extent to which a person-centered approach is adopted and levels of depersonalisation. All other within-group analyses found non-statistically significant differences for knowledge of dementia, caregiver feelings of emotional exhaustion and personal accomplishment, perceived frequency and intensity of SAD-behaviours, confidence in managing SAD-behaviours and job satisfaction. It was not possible to explore the research questions in full due the exclusion of the WL control group.

Descriptive statistics identified useful information about the possible association between factors such as job title and length of time in current employment. The Jigsaw Evaluation also provided valuable and positive feedback about the use of the Bigger Picture Jigsaw training tool. Qualitative feedback indicated participants' positivity about the training and also identified the possible influence of organisational and contextual factors on care home staffs' experience of training.



## Chapter Four: Discussion

### 4.1 Summary of Findings in Relation to the Research Questions

The aim of this study was to empirically evaluate the outcome of a package of evidence-based person-focused training for formal carers working with people with dementia living in care home environments. Specifically evaluating the efficacy of a new Formulation based Functional Analysis (FFA) approach to understanding SAD-behaviours with dementia. The study originally aimed to explore six research questions, which were separated into two parts to assess differences between groups at the end of the intervention (Part A) and within-group pre-post changes over time (Part B). These were reduced to five during the course of the study and were adapted to reflect the exclusion of the waiting list group from the study.

#### 4.1.1 Primary Research Questions.

*4.1.1.1 Research question one: Do differences exist between CAMTED and CAMTED-Plus in caregiver knowledge of dementia and compassionate awareness of need in dementia that presents as SAD-behaviour?* Knowledge of dementia was measured pre and post-intervention using the Dementia Knowledge Questionnaire (DK-20; Shanahan et al., 2013). Results showed that there was no statistically significant difference between CAMTED and CAMTED-Plus in caregiver knowledge of dementia at the end of the training intervention. Results also revealed that there were no statistically significant difference in caregiver knowledge of dementia over time for CAMTED and CAMTED-Plus.

This finding is consistent with the current evidence base. A review by McCabe et al. (2007) reported inconsistent findings across studies for the effectiveness of staff training programmes for SAD-behaviours in dementia. Although knowledge of dementia was found to increase following training, this was not the case for all training interventions (Feldt & Ryden, 1992). Furthermore, where an increase in knowledge was demonstrated, this was not maintained over time (Cohen-Mansfield et al., 1997).

McCabe et al. (2007) also concluded that only a few studies had been designed to evaluate knowledge of dementia directly. A number of other outcomes were used to evidence change, such as staff attitudes, resident behaviour and staff skills in managing behaviours. It is therefore not clear in the literature, how knowledge of dementia changes following a training intervention, as many outcomes have focused on behaviours rather than the understanding of care staff.

Outcome measures of knowledge of dementia have been described as useful in highlighting the gaps in care staff knowledge (Dieckmann, Zarit, Zarit, & Gatz, 1988; Spector et al., 2012). The present study utilised a direct measure of knowledge of dementia (DK-20; Shanahan et al., 2013). The DK-20 was designed to measure unqualified care staffs knowledge of dementia and is underpinned by a biopsychosocial perspective (Spector, Orrell, & Goyder, 2012). Measuring knowledge of dementia is considered an important outcome in evaluating the efficacy of non-pharmacological interventions (Cooke, McNally, Mulligan, Harrison, & Newman, 2001).

***4.1.1.2 Research question two: Do differences exist between CAMTED and CAMTED-Plus in caregiver approach to dementia care?*** Attitude towards dementia was measured pre and post-intervention using the Approaches to Dementia Questionnaire (ADQ; Lintern et al., 2000). Results show that there was no statistically significant difference between CAMTED and CAMTED-Plus in caregiver attitude to dementia at the end of the training intervention.

Results of the within-group analyses revealed a statistically significant difference over time for CAMTED-Plus in overall attitude to dementia and extent to which a person-centred approach is adopted. A statistically significant difference was also found over time for CAMTED in degree of hopefulness about dementia. All other within-group analyses of changes in attitude to dementia were found to be non-statistically significant.

The findings from the present study are consistent with existing literature in this area. A number of studies implementing an FFA approach have found positive findings for care staff attitudes following a training or education intervention. Visser et al. (2008) investigated the impact of staff education on the behaviour and quality of life of residents with dementia and on staff members' attitudes and level of burnout. Assessments were conducted pre and post-intervention and at three and six month follow-up. A positive effect was found on the skills and knowledge subscale of the Staff Attitudes Questionnaire for staff who attended the education programme (Visser et al. 2008). Similarly, Davison et al. (2007) evaluated the impact of an eight session training programme with additional five session peer support compared to a waiting list control. Care staff in both training groups reported improved attitudes regarding their knowledge and skills in managing SAD-behaviours, at the end of the training intervention and six months later.

Bird et al. (2007) in their controlled trial comparing a case-specific intervention with a care as usual control group also found some improvement in staff attitudes. However, this did not reach significance.

When reviewing the data in the present study, it is evident that the collected dataset is limited in fully understanding the efficacy of the training intervention on care staff attitudes to dementia. The mean score on the ADQ for both intervention groups indicated more positive attitudes towards dementia at baseline, which may account for the limited differences found at the end of the training intervention between groups.

#### **4.1.2 Secondary Research Questions.**

***4.1.2.1 Research question three: Do differences exist between CAMTED and CAMTED-Plus in levels of caregiver burden?*** Caregiver burden was measured pre and post-intervention using the Maslach Burnout Inventory – Human Services Survey (Maslach

et al., 1996). Results showed that there was no statistically significant difference between CAMTED and CAMTED-Plus at the end of the training intervention.

Results of the within-group analyses revealed a statistically significant difference over time for CAMTED-Plus in levels of depersonalisation. All other within-group analyses of changes in levels of caregiver burden were found to be non-statistically significant.

The evidence base for the efficacy of care staff training and education interventions on caregiver burden is inconsistent. Two systematic reviews (McCabe et al., 2007; Spector et al., 2013) reported a number of positive findings. Spector et al. (2013) identified two studies where a reduction in staff stress was obtained at the end of the training intervention (Magai et al., 2002; Finnema et al., 2005). McCabe et al. (2007) also concluded that training interventions can reduce care staff stress and staff turnover rates (Feldt & Ryden, 1992; Magai et al., 2002; McCallion, Toseland, Lacey, & Banks, 1999; Smith et al., 1994). Goyder (2011) also reviewed the effectiveness of staff training interventions for SAD-behaviours with dementia and concluded that the evidence indicated that care staff stress can be reduced, however burden is less responsive to change (Goyder (2011)).

Moniz-Cook et al. (2012) reported similar findings in their meta-analysis of the effectiveness of FFA approaches in different care settings. The review did not find beneficial effects for FFA approaches on caregiver burden. There are also inconsistent findings in other literature exploring FFA approaches. Davison et al. (2007) found that training programs, with or without peer support, did not impact on levels of care staff burnout. Equally Visser et al. (2008) did not find effects on care staff burnout in their study of a staff education intervention and Zwijsen et al. (2015) did not find significant changes in burnout following application of a care programme to evaluate the effects of the GRIP on challenging behaviour care programme.

In contrast, Bird et al. (2007) conducted a naturalistic controlled trial comparing a case-specific intervention with a control group. They found a significant reduction in staff stress in both the intervention and control group at two and five months follow-up.

Considering the current and inconclusive findings for the efficacy of FFA approaches on care staff feelings of burden, the current study would be consistent with the existing evidence base and may suggest that caregiver burden is influenced by a number of different factors, which may need to be taken into consideration (Zwijnsen et al., 2015).

**4.1.2.2 Research question four: Do differences exist between CAMTED and CAMTED-Plus in caregiver job satisfaction?** Caregiver job satisfaction was measured pre and post-intervention using the Swedish Satisfaction in Nursing Care and Work Scale (SNCW; Hallberg et al., 1994). The results show that there was no statistically significant difference between CAMTED and CAMTED-Plus at the end of the training intervention. Results also revealed that there were no statistically significant differences in caregiver job satisfaction over time for CAMTED and CAMTED-Plus.

The current evidence base for the efficacy of FFA approaches on staff satisfaction is inconsistent and limited due to an absence of literature evaluating these approaches on care staff outcomes such as job satisfaction (Zwijnsen et al., 2015). Zwijsen et al. (2015) found significant effects for job satisfaction in their evaluation of the effects of the GRIP on challenging behaviour care programme. Reviews by McCabe et al. (2007) and Spector et al. (2013) also reported that training and education interventions may lead to greater staff satisfaction and reduce staff turnover rates, although these reviews included training approaches with varying theoretical backgrounds. Goyder (2011) also concluded in her review of the effectiveness of staff training interventions that similarly to caregiver burden, job satisfaction may also be less responsive to change.

Considering the limited and inconclusive findings for the efficacy of FFA approaches on caregiver job satisfaction, the current study would be consistent with the current evidence base and may suggest that job satisfaction is influenced by a number of different factors, which may need to be taken into consideration (Zwijssen et al., 2015).

**4.1.2.3 Research question five: Do differences exist between CAMTED and CAMTED-Plus in caregiver perceived frequency and intensity of SAD-behaviours and confidence in managing SAD-behaviours?** Perceived frequency of SAD-behaviour was measured pre and post-intervention using the Stress and Distress Behaviour Scale (SDBS; LdP & KL) and Frequency Likert Scale. The results show that there was no statistically significant difference between CAMTED and CAMTED-Plus at the end of the training intervention. Intensity of SAD-behaviours was measured using the Intensity Likert Scale. The results show that there was no statistically significant difference between CAMTED and CAMTED-Plus at the end of the training intervention. Results also revealed that there were no statistically significant differences in the frequency and intensity of SAD-behaviours over time for CAMTED and CAMTED-Plus.

In the present study it is difficult to fully comprehend the efficacy of the FFA approach in relation to SAD-behaviours, as the reported frequency and intensity of SAD-behaviours at baseline was below average, which may account for the non-statistically significant differences found.

The current evidence base for the efficacy of FFA approaches with SAD-behaviours in dementia is inconclusive. A number of studies did not find significant changes in resident behaviour following a FFA intervention (Davison et al., 2007; Fossey et al., 2006; Protor et al., 1999; Rokstad et al., 2013; Visser et al., 2008). In comparison, a number of studies have reported significant outcomes for behaviour following an intervention (Ballard et al., 2009;

Bird et al., 2007; Chenoweth et al., 2009; Cohen-Mansfield et al., 2007; Karlin et al 2012).

However, these outcomes were often not seen at follow-up (Ballard et al., 2009).

Moniz-Cook et al. (2012) in their meta-analysis of 18 randomised controlled trials investigating the efficacy of FFA approaches with SAD-behaviours concluded that there were overall beneficial effects for the frequency of SAD-behaviours, but not behaviour severity and these effects were not seen at follow-up. The authors concluded that FFA approaches showed promise, but it was too early to draw conclusions about its efficacy, especially in care home settings, due to the limited number of care home studies.

Confidence in managing SAD-behaviours was measured using the Confidence Likert Scale. The results showed that there was no statistically significant difference between CAMTED and CAMTED-Plus at the end of the training intervention. Results also revealed that there were no statistically significant differences in confidence in managing SAD-behaviours over time for CAMTED and CAMTED-Plus.

It is an interesting observation that the mean score for confidence in managing SAD-behaviours in both groups remained average at baseline and at the end of the training intervention. This possibly indicates that care staff confidence in managing SAD-behaviours is influenced by a number of different factors, which may need to be taken into consideration.

A recent article by Gitlin et al. (2014) identified that a limitation of current behavioural outcome measures is that they do not cover caregiver confidence or self-efficacy in managing SAD-behaviours. The use of the Confidence Likert Scale in the present study was an attempt to gather information on caregiver perceived confidence in managing SAD-behaviours. Gitlin et al. (2014) suggested that assessing factors such as caregiver confidence could provide a more holistic understanding of the context of behaviour, which could guide intervention.

**4.1.3 Summary.** Data from this study reflect that this was a primary investigation of a training intervention, and as such the data are exploratory in nature. Consequently, the direction of research questions was not hypothesised prior to carrying out the study.

It is perhaps unsurprising that CAMTED and CAMTED-Plus report comparable outcomes in relation to the research questions. Both interventions represent evidence-based approaches to dementia.

Overall the findings indicate that CAMTED-Plus may be a more powerful intervention compared to CAMTED in improving overall attitude to dementia, the extent to which a person-centred approach is adopted and reducing feelings of depersonalisation. The results provide preliminary support for CAMTED-Plus as an intervention and that the PCAP module has some merit as an additional training component to the core CAMTED training package.

The unanswered questions from this study are how these two interventions compare to a control and whether true differences may exist if participant numbers were larger. The exclusion of the waiting list group, as a result of small sample size unfortunately limits conclusions that can be made about the efficacy of both interventions at this stage.

**4.1.4 Jigsaw evaluation.** Written feedback responses on the Jigsaw training tool provided by participants in the CAMTED-Plus group indicated this tool was well received. Responses on the Jigsaw Evaluation questionnaire showed that care staff enjoyed the use of the jigsaw and found it helpful in demonstrating the ideas presented in the training. Furthermore responses on the Jigsaw Evaluation also indicate that care staff thought that their approach to dementia and practice would change as a result of the training.

This feedback provides preliminary evidence for the use of the jigsaw training tool as an innovative learning resource and introduction to formulation based approaches to understanding SAD-behaviours in dementia. The qualitative feedback gathered from the



Jigsaw Evaluation also provides supporting evidence participants gain an enhanced awareness and understanding of the utility of formulation, when seeking to develop interventions that are person-centred to optimise beneficial outcomes addressing potential unmet needs of vulnerable individuals. For example: *'Seeing the bigger picture. Looking at person's past to get a better perception of that person'*; *'Looking at the bigger picture by knowing the facts so unmet needs can be addressed. Or potentially de-escalate distressed behaviours'*; *'It has made me understand that learning a person's background helps in understanding their unmet needs'*; *'I will try to find out more information about residents'*. These quotes indicate participants' gained an enhanced understanding of the ideas of formulation presented during the training, drawing together information about a person to see the 'bigger picture', in order to better understand a person and their distress in their environment.

When introducing a new approach to presenting the conceptual aspects of formulation in an accessible format to enable non-psychologists to use this approach to understanding others in context, it would be surprising if this met with universal and uncritical approval. One participant described the use of the Jigsaw training tool as a: *'Childish way of presenting an idea to ADULTS'*. [the upper case letters are the participant's own]. This response was an anomaly and inconsistent with the otherwise positive responses. The participant worked within a care home that had some organisational and systemic dynamics arise through the course of the training. This response highlights the importance of considering the influence of the wider context and system on participant's perception and engagement in training.

There is considerable literature on the influence and barriers of organisational factors such as management style and care home environment and culture in the application of training into practice (Beck, 2001; McCabe et al. 2007; Smyer, Brannon, & Cohn, 1992;

Spector et al., 2013). A number of studies evaluating FFA approaches have also reported their concerns that organisational factors may have limited the implementation of training programmes (Davison et al., 2007; Visser et al., 2008).

Baldwin and Ford (1988) proposed a model of 'transfer of learning', which can be applied to care home settings to understand the factors influencing the implementation of training into practice. They identified three areas that are important to consider in the transfer of learning: trainee characteristics (skill, motivation and personality), training design (clarity and chances to practice) and work environment (peer and supervisory support and opportunities to apply learning). A review by Blume, Ford, Baldwin and Huang (2009) found that trainee characteristics and the work environment contribute equally to outcomes following training.

Nolan et al. (2008) conducted a review on the role of education and training in supporting change in care homes. Motivation was found to be an important factor in training attendance. Furthermore, a lack of support and a culture that is not ready change were found to be important factors in reducing attendance at training (Grol & Grimshaw, 1999; Burgio, et al., 2000; Gates, et al., 2005).

## **4.2 Critique of the Study**

**4.2.1 Limitations of the research.** A limitation of the study was the small and uneven sample size across groups, which reduced the statistical power to detect changes between groups and resulted in the exclusion of the waiting list. The lack of a control group limits conclusions that can be made regarding the efficacy of the intervention. In defence of the study, it was a primary investigation aiming to recruit as many participants as possible. The intention was, therefore, not to sample the population of care home staff as a whole.

Due to time and resource constraints a number of protocol deviations were made. It was not possible to collect information on referrals for SAD-behaviours and antipsychotic

prescription rates. In addition to this, it had originally been proposed to repeat outcome measures four to six weeks post intervention. This was not possible due to time constraints of the trial and limits the findings of the study as longer-term differences have not been explored. The lack of follow-up may have limited the findings of variables, such as caregiver burden and job satisfaction, which authors have identified through reviews of the literature as being less responsive to change (Spector et al., 2013).

Caregiver burden and job satisfaction are multicomponent concepts influenced by many factors (Maslach et al., 1996), meaning that measurement of change is likely to require follow-up over a longer period of time. The MBI-HSS (Maslach et al., 1996) is currently the most widely used instrument for measuring enduring feelings of caregiver burden in research (Schaufeli & Enzmann, 1998). However, the stability of MBI-HSS at measuring feelings of burden overtime (over the course of up to one year), means it may not be sensitive to small variations and may be not adequate at measuring short term change (e.g. over a few weeks), which may be the case in the present study. Longitudinal research is needed to predict changes in burden over time. However, studies of this nature are still in the minority (Maslach, Schaufeli & Leiter, 2001; Schaufeli & Enzmann, 1998; Schaufeli & Greenglass, 2001).

In addition to this, research suggests that rates of SAD-behaviours are likely to increase following a training intervention due to staff becoming more aware and better able to identify types of SAD-behaviours (Boustani et al., 2005). To explore the efficacy of the intervention on occurrence of SAD-behaviours, a longer period of time may be required to accurately determine changes in this construct.

Care staff in the study also reported below average levels of SAD-behaviours in terms of frequency and intensity, which may explain why there was limited change post-intervention. Literature has suggested that care homes consenting to take part in research are

more likely to be stable and better resourced in terms of staffing levels (Burgio & Stevens, 1990), which may mean that care homes participating in research may have lower rates of reported SAD-behaviours in comparison to less stable care homes. The implication of this being that care homes recruited into the present study may have presented a bias towards care homes functioning at a more stable level.

This provokes some interesting observations when considering the data gathered in the study. Attitudes towards dementia were found to be more positive at baseline in both intervention groups, which may suggest that care homes and caregivers investing in training already have more positive attitudes towards dementia and are therefore more likely to be more tolerant and understanding of SAD-behaviours. This may explain why there were no significant differences between groups in perceived frequency and intensity of SAD-behaviours. The study sample may have been biased towards those who will more likely make a positive use of training to enhance an already positive and compassionate outlook.

This study is limited in fully understanding the efficacy of the FFA approach due to it being delivered as part of a training package. This is consistent with other research in this area, whereby FFA is often delivered as part of a broader intervention package (Fossey et al., 2006; Proctor et al., 1999; Visser et al., 2008). It would be important for future research to isolate the FFA approach and investigate it separately to gain greater understanding of its influence in the present study.

It should also be noted that there were inconsistencies in the length of the training period for CAMTED and CAMTED-Plus across care homes, which again limits the conclusion that can be drawn from the study. Although all care homes received the specified number of hours of training and the same content was delivered through the use of structured protocols. The overall period in which training was delivered varied across care homes. In CAMTED-Plus the intervention period depending on the delivery plan chosen (see Appendix

D) was between five and seven weeks. This period varied considerably across participating care homes from seven weeks to fifteen weeks. There were a number of factors that influenced the length of the intervention period including limited resources within the research team and care home organisational factors such as staff holiday, sickness and rota management that influenced the scheduling of the training. These challenges are well recognised within this setting due care staff predominantly working part time (Schonfeld et al., 1999).

Participating care homes often required an individualised training plan, which demonstrates the diverse nature of care homes and subsequent limitations with regards to maintaining standardisation when conducting research in this area (Smyer et al., 1992). Future research will need to maintain consistency in delivery plans, to fully comprehend the efficacy of the approach. It will also be important for future studies to maintain standardisation in the delivery of this intervention. CAMTED-Plus was delivered by two trainers. One trainer delivered the first five sessions of the standard CAMTED package and one trainer briefed in PCAP delivered the final two sessions. This added to the inconsistency in the delivery of training due to the handover period between sessions. It is anticipated that a more pragmatic approach to scheduling training dates and greater team resources to allow the same trainer to deliver the intervention in full, would alleviate some of this inconsistency.

The non-random assignment of care homes in this study also limits the conclusions that can be made. The participating care homes were identified through CAMTED-OP's existing service links and consenting care homes were likely to have better capacity to take part. This in itself could have influenced variables. Randomised controlled trials (RCT) are underutilised in care home settings due to the inherent difficulties with maintaining methodological rigor and controlling extraneous variables (Hall, Longhurst, & Higginson, 2009; Jackson, Mandel, & Blanchard et al., 2009; Menten & Tripp-Reimer, 2002).

Furthermore, care homes are unlikely to have engaged in a randomised capacity, thus it was important to offer a choice of condition, to promote engagement and participation. Although randomisation was not carried out, utmost care and attention was made to match groups on a number of variables. Reflection of the sample indicates this was somewhat successfully achieved as groups only differed statistically on one variable at baseline.

This is an interesting observation and indicates that the use of carefully matched controlled designs may be a useful alternative to RCT designs, which are often not practical or feasible in care home settings (Murfield, Cooke, Moyle, Shum, & Harrison, 2011). The present study has shown that it is possible to match care home participants on a number of demographic variables and this approach may be extended in the future to control for other variables more stringently, such as intervention period and environment. There is evidence in support of matched designs, which some suggest are useful in establishing preliminary evidence of an intervention's effectiveness, which may then be followed up through an RCT (Murfield et al., 2011; West et al., 2008).

It is recognised that a large number of outcome measures were used in the present study and it could be suggested that this increases the chance of finding a significant result. This was controlled for by adjusting for multiple comparisons during data analyses and use of a more conservative  $p$  value. The decision to use the number of outcome measures was due to the exploratory nature of the study, to gather a breadth of information that may inform the future direction of research.

There were challenges in the delivery of the outcome measures. Time was not factored adequately into the CAMTED training schedule for the completion of measures. CAMTED-OP trainers reported back difficulties in delivering these measures and the implication being that training material from the first training session had to be carried over

on occasion to the second training session. Pragmatically this limitation can be resolved in the future by specifying in the protocol, time allocated to outcome completion.

It is also possible that care staff may not have completed measures of job satisfaction and burden in full accuracy. It may have been difficult for care staff to report with full honesty with statements regarding their feelings about their place of work and residents. Research investigating burden may also be influenced by selective responding whereby care staff experiencing high levels of burden may be less likely to take part in research, which introduces bias into the findings (Schaufeli, 2003). The sample in the present study may have been subject to a 'healthy worker effect' where care staff experiencing burden may be less likely to attend training, have left their job or may be on sick leave (Schaufeli, 2003). The 'healthy worker' effect has been found in studies looking at job related stress (Karasek & Theorell, 1990). Reflection of the reasons for attrition from the study indicated that care homes often withdrew as a whole due to staff shortages and individual participants withdrew due to leaving their job role or long-term sick leave.

The nature of designs in innovative research and the difficult constraints of conducting a professional doctoral degree and recruiting sufficient numbers of participants to adequately develop an outcome design are recognised. A compromise therefore has to be made because of reasons to do with practicality, but notwithstanding that, innovative research designs should still feature in doctoral level research. The trade-off here for the researchers involved in the present study was to evaluate a new approach to dementia care training for care home staff managing SAD-behaviours and to adopt an appropriate research methodology. There are a number of alternative methods, none of these free from flaws or problems. The method adopted in this study was an open trial approach which was considered to be most optimal in the circumstances. Adopting any design opens additional

risk of bias, generalisability and threats to validity. These are acknowledged in the present study, but have been reduced where possible by adopting a conservative approach.

**4.2.2 Strengths of the research.** There were a number of important strengths in the present study. Firstly the research is clinically and currently relevant. There is a recognised deficit of research in this area (Goyder, 2011; Maas, Kelley, & Specht, 2002; McCabe et al., 2007). However, the need is exceptional when considering the consequences of the demographic transition and the “*tipping point*” of care we are approaching (Carers UK, 2015), and in light of Banerjee’s (2009) recommendations that non-pharmacological interventions should be the first-line approach for SAD-behaviours (Alexopoulos et al., 2005; Alzheimer’s Society, 2009).

The FFA approach in the present study builds on the pioneering work of Bird (2009) and James (2011) in FFA approaches to understanding SAD-behaviours with dementia. James developed The Newcastle Challenging Behaviour service (NCBS) in response to a need to offer formulation-led interventions for people with dementia living in a care home. Similarly to James (2011) the FFA approach in the present study is underpinned by psychological theory, such as Cohen-Mansfield’s (2000b) Unmet Needs model, which suggests SAD-behaviours are non-random and result from an unmet need.

The Newcastle approach has been used widely (James & Stephenson, 2007) and informed the development of other services in the UK. It has also been evaluated via audits that have found significant reductions in the frequency and severity of behaviours and caregiver distress (Wood-Mitchell et al., 2007). The Newcastle approach is consistent with the objectives of the NDSE (DOH, 2009) and National Service Framework for Older People (DOH, 2001) and has been incorporated into a ‘stepped’ model of care (Brechin et al., 2013).

James (2011) suggested that the success of the Newcastle approach was related to the value it places on empowering caregivers to be involved in the management of SAD-



behaviours. Comparable to James (2011) the FFA approach in the present study also places value on empowering direct care home staff. The Jigsaw training tool allows care staff to quickly grasp the main concept of formulation e.g. seeing the ‘bigger picture’ that distressed behaviours often can be prevented if we can more fully see how the person functions in their environment. This is a gentler way to learn and more accessible to people who may have many skills in working with PwD but would be less confident in traditional classroom based learning. The FFA approach recognises that direct care staff hold key information about the residents they work with, which is important in informing formulation-led interventions. Value is placed on collaborating with direct care staff, enabling the development of knowledge and skills in these approaches and empowering care staff to become ‘champions’ of their residents and communicate this knowledge to others.

This study operationalised a FFA approach to understanding SAD-behaviours in dementia into an interactive jigsaw training tool. Considering the challenges of conducting research in this area, the study has demonstrated potential applicability of this FFA approach in a care home setting and opened up possibilities for new areas of research to develop and upon which to expand.

Appropriate psychometrically robust quality measures were used to measure primary and secondary outcomes in the current study. As the concept underlying the FFA draws upon theoretical models (Bird, 2002; Cohen Mansfield, 2000; James, 2012; Kinderman & Tai, 2007; Hall & Buckwalter, 1987) to develop a means for assessment and intervention, careful consideration was made in assessing how to evaluate this approach most optimally. The use of the SDBS and Frequency and Intensity of SAD-behaviours Likert scales meant that care home staff rated their perception of SAD-behaviours with residents they were working with and knew well. Ratings were therefore based on own real experiences with real residents. There are well known difficulties with the measurement of the construct SAD-behaviours due

to its subjective nature (Bird & Moniz-Cook; 2008; Gitlin et al., 2014; James, 2011), this approach was considered to be a more reliable means of measuring the incidence of SAD-behaviours and change following training.

A number of newly developed measures and scales were used in the present study: (SDBS, Frequency and intensity of SAD-behaviours Likert scales, Confidence in managing SAD-behaviours Likert scale). The possible limitations of their use, such as a lack of psychometric properties are recognised, and a conservative approach to data derived from these measures is advocated. Supplementing the use of other well established, validated outcome measures alongside both qualitative and quantitative feedback was employed to help mitigate limitations.

The present study used an Intention to Treat Analysis (ITT: Fisher et al., 1990), where all participants that start a study are included in the final analysis (Gupta, 2011). Intention to Treat Analysis is considered a more robust test and strengthens the quality of the research, as it avoids biases in estimates of the efficacy of an intervention (Gupta, 2011). The ‘last measurement carried forward’ approach to input data missing at the end of the intervention was considered to be the best approach to adopt, as it enabled the sample size to be preserved, which may have been significantly reduced if dropouts were excluded, leading to a reduction in statistical power (Streiner & Geddes, 2001). It is recognised that the use of the ‘last measurement carried forward’ approach is widely debated in literature (White, Horton, Carpenter, & Pocock, 2011). The present study was believed to lend itself well to ITT as this approach provides a more realistic estimate of intervention effects in the real world, which was an important aim of this study (Gupta, 2011).

Monitoring of treatment fidelity was undertaken for PCAP sessions. This assessed the extent to which PCAP sessions were implemented as planned. This increases confidence that the PCAP sessions received by care staff were as intended. Monitoring of treatment fidelity

was, however, not carried out for CAMTED, due to resource limitations. It is not possible to conclude the degree of consistency in delivery of the CAMTED training sessions. CAMTED have a clear protocol for training and many years of experience in its delivery. It is expected that there would have therefore been high consistency in delivery.

The study was conducted in a naturalistic setting in collaboration with CAMTED-OP, a highly regarded service and team. Engagement from care homes was greatly increased through the pre-existing relationships care homes held with CAMTED-OP. This reduced attrition from the study and supported the recruitment process. Working alongside the reputation of CAMTED-OP supported the process of conducting the study and being able to bring care home staff on board.

### **4.3 Theoretical Implications**

Within the constraints of the methodological limitations that have been highlighted, a number of tentative theoretical implications can be made based on the findings. This study is the first time the Laidlaw (2013) contextualising framework has been evaluated in this context. Originally this model was developed as part of a new multidisciplinary behaviour that challenges service in the NHS in Scotland. Evaluation with 22 care home staff from Edinburgh city council funded care homes and third sector care homes. Of those participating in a 2 day training, 20/22 suggested good utility of this framework in helping them to access a new compassionate perspective on individuals with unmet need, commenting that “*training overall had influenced their views of dementia and challenging behaviour*” (Laidlaw, pers. Communication). This framework was useful in care home staff reporting a new perspective on individuals identifying as having behaviour that challenges in dementia. Some comments from care home staff after the end of training are reported here with permission from Laidlaw (pers. Communication)

*“The training has encouraged me to look at the aspects of the person and not just the person’s behaviour”*

*“Refreshed my views – that challenging behaviour could be a form of communication”*

*“Gave a deeper insight into how people with dementia perceive the world around them and how they may feel in stressful situations”*

*“The training has encouraged me to look at the aspects of the person and not just the person’s behaviour”*

*“Refreshed my views – that challenging behaviour could be a form of communication”*

*“Gave a deeper insight into how people with dementia perceive the world around them and how they may feel in stressful situations”*

This framework is explicitly grounded in psychological theory and was adapted from Kinderman & Tai’s (2007) Mediating Psychological Processes Model. It provides a formulation based on functional analytic perspectives of behaviour and reinforcement contingencies integrating theories of SAD-behaviours with dementia such as the Progressively Lowered Stress Threshold and Unmet Needs (Hall & Buckwalter, 1987; Cohen- Mansfield, 2000b) to develop a means for assessment and intervention.

This study has shown the utility and practical application of this new FFA approach in a care home setting. The training and Jigsaw tool were well received and preliminary feedback indicates care home staffs ability to grasp the psychological understandings of SAD-behaviours and the concept of formulation. This is a substantial advancement in the use of psychological assessment and formulation in dementia care and adds to the literature on FFA approaches offering a new integrated conceptualisation that can be applied with direct care home staff.

This study addresses a number of current limitations in the evidence base for FFA approaches. Few studies to date have applied approaches to staff that care directly for residents with SAD-behaviours. This study fulfilled its aim of recruiting a suitably

experienced sample that was neither too inexperienced nor experienced, although it is recognised the sample did not just comprise of direct care staff. The implications of this being that some participants with job roles, such as administrator, kitchen assistant and care home trainer may not involve working directly and routinely with residents displaying SAD-behaviours.

This study has shown the application of a theoretical model for understanding SAD-behaviours with direct care staff that may not have extensive educational backgrounds. A number of existing FFA approaches are primarily used with highly complex presentations and recommend the input of experienced external professionals.

This study has demonstrated that the principles of formulation can be developed into an accessible and convenient training tool to introduce the concept of formulation to caregivers with a diverse educational background. Jigsaws have a common currency and require little in the way of explanation as to how one approaches the task. As such this is a simpler way to introduce formulation based approaches to understanding SAD-behaviours in dementia. Developing the FFA approach into a training tool enables direct caregivers to receive important education on these advanced approaches, which will allow them to have greater involvement in implementing interventions, rather than these being isolated to senior staff and external professionals (Moniz-Cook et al., 2012). This approach fulfils a current gap in the literature where direct care home staff do not have access to this education that could be applied routinely to their work and have benefit to their well-being.

A limitation of previous FFA approaches is the diversity of the theoretical basis underlying the intervention. This FFA approach has a clearly defined basis and the essential components of the intervention are transparent and clear making them more accessible and amenable to replication and to the generation of more practice-based evidence.

#### 4.4 Implications for Clinical Practice

This study investigated the efficacy of training care home staff in a new FFA approach to understanding SAD-behaviours. The ability of staff to develop formulations and interventions for people with dementia has important implications for future clinical practice (Bird & Moniz-Cook, 2008; James, 2014; Moniz-Cook et al., 2012). The results indicate that training in this new FFA approach can lead to changes in attitudes towards PwD, reductions in caregiver feelings of depersonalisation and reductions in perceived frequency of SAD-behaviour, although the long-term effects of this approach are less understood.

Although it has not been possible to explore the efficacy of the FFA approach in isolation, strength of the approach is that it is not as timely and resource intensive as existing approaches. Delivered separately the FFA intervention consists of six hours, which lends itself well to clinical application in care home settings. High staff turnover rates are recognised in this setting (Burgio & Burgio, 1990), especially for younger, less senior staff, which highlights the need for brief training interventions at an earlier stage of employment (Elliot et al., 2015).

The study has highlighted the usefulness and applicability of the FFA approach, but has also highlighted potential barriers to the application of skills to practice, such as organisational and systemic factors. There is agreement in the literature that organisational support is important in ensuring staff have the opportunity to apply learning (Beck, 2001; Hoeffler, Rader, McKenzie, Lavelle, & Stewart, 1997; Smyer, Brannon, & Cohn, 1992; Strumpf, Evans, Wagner, & Patterson, 1992).

It is possible that the use of the Jigsaw training tool will overcome some of the barriers to the application of training into practice. The Jigsaw tool allows care staff to quickly grasp the main concept of formulation e.g. seeing the 'bigger picture' that distressed behaviours are non-random and often can be prevented if we can more fully see how the

person functions in their environment (James.2011). It is possible that this approach may provide care home staff with knowledge and an experience that will promote compassion and understanding about the vulnerability of the person experiencing SAD-behaviours, which may be a powerful intervention in itself and one that influences practice directly. Further research is needed to explore how to feasibly provide care staff with training and education and support implementation within the barriers and constraints of care homes.

#### **4.5 Suggestions for Future Research**

This is the first time that the FFA approach has been evaluated as part of a research study. As such a larger trial is needed to explore this approach further. This study may form the basis for future research as part of an iterative process to the development of programmatic approaches to research data generation, and may lend itself to future replication through the use of the standardised protocol and training manual. This study is promising in terms of the future of research in this area and for clinical practice.

Future research should attempt to address the methodological limitations of this study. A larger sample size should be utilised to ensure sufficient power to be able to perform statistical tests. The use of randomisation and a control group to enable the approach to be compared and better control for differences between groups. A sufficient follow-up period is also required to fully understand the long-term efficacy of the intervention, especially in relation to variables such as burden, job satisfaction and perceived frequency and intensity of SAD-behaviours.

This study has operationalized and developed the FFA approach into a Jigsaw training tool (see Appendix E) and this has been established into a jigsaw training package. Due to the nature of the trial, a preliminary prototype of the Jigsaw training tool was made for the purposes of the study. To fulfil its potential, the Jigsaw tool may be developed into

something more refined in the future, in order to fully appreciate the visual impact of the jigsaw concept of 'seeing the bigger picture' in full effect.

In addition to this, further research is required to isolate the FFA approach and explore it as an intervention in its own right, rather than as an adjunct to a broader training package. Greater consistency and standardisation in the delivery of the intervention is also required to strengthen the conclusion that can be drawn from the findings.

The qualitative feedback gathered from this study indicates the possibilities to gather important data via qualitative methods on the use and application of the FFA approach. Although the Jigsaw Evaluation gathered useful preliminary feedback on the experience of the Jigsaw tool, further research is required to gain more insight into care staff knowledge and perception of the application of training into practice. This would be a helpful way of identifying possible barriers to the future application of this approach into everyday practice following training. Similarly to other research in this area, it would also be important to consider factors that have been identified as influential in training programmes, such as motivation and organisational support (Elliott et al, 2012; Revolta, 2014)

#### **4.6 Concluding Comments**

The aim of this study was to investigate the efficacy of a new person-focused FFA approach to understanding SAD-behaviours in dementia. The study fulfilled the aim as it has provided some preliminary evidence on the potential efficacy of the FFA approach.

The present study has demonstrated some encouraging results, providing support for the utility of the FFA approach as a training intervention and tool for direct care home staff working with SAD-behaviours and this may have wide reaching implications for improving dementia care in the future. Although the results are limited due to the methodological shortcomings, they provide a range of evidence in support of the FFA approach, which may be built on in succeeding research.



The lack of significant differences does not indicate that the FFA approach does not have efficacy. Upon addressing the limitations of the study in future research, the training intervention could be shown to have efficacy in improving the skills of care home staff working with PwD experiencing SAD-behaviours.

The positive feedback regarding the Jigsaw training tool is an exciting advancement in the literature on FFA approaches and although the findings from this study are limited at present, it has highlighted the means in which this can be investigated further. If replicated on a larger scale, this study offers substantial development in psychological assessment and formulation in dementia care.

### References

- Alexopoulos, G. S., Abrams, R. C., Young, R. C., & Shamoian, C. A. (1988). Cornell scale for depression in dementia. *Biological Psychiatry*, 23(3), 271-284.
- Alexopoulos, G.S., Jeste, D.V., Chung, H., Carpenter, D., Ross, R., & Docherty, J.P. (2005). The expert consensus guideline series. Treatment of dementia and its behavioral disturbances. Introduction: methods, commentary, and summary. *Postgraduate Medicine*, 6-22, January.
- Alzheimer's Disease International. (2009). *World Alzheimer Report*. London: Alzheimer's Disease International.
- Alzheimer's Disease International. (2011). *World Alzheimer Report 2011: The benefits of early diagnosis and intervention*. London: Alzheimer's Disease International.
- Alzheimer's Disease International. (2013). *Journey of Caring: An analysis of long-term care for dementia*. London: Alzheimer's Disease International.
- Alzheimer's Disease International. (2015). *World Alzheimer Report*. London: Alzheimer's Disease International.
- Alzheimer's Society. (2011). *Support. Stay. Save. Care and support for people with dementia in their own homes*. London: Alzheimer's Society.
- Alzheimer's Society. (2009). *Counting the cost: Caring for people with dementia on hospital wards*. London: Alzheimer's Society.
- Alzheimer's Society. (2013). *Dementia 2013: The hidden voice of loneliness*. London: Alzheimer's Society.

Alzheimer Scotland. (2012). *Standards of Care for Dementia in Scotland: A guide for people with dementia and their carers*. Edinburgh: Alzheimer Scotland.

Alzheimer Scotland. (2015). *Advanced Dementia Practice Model: understanding and transforming advanced dementia and end of life care*. Edinburgh: Alzheimer Scotland.

Astrom, S., Nilsson, M., Norberg, A., Sandman, P., & Winblad, B. (1991). Staff burnout in dementia care-relations to empathy and attitudes. *International Journal of Nursing Studies*, 28(1), 65-75.

Audit Commission for Local Authorities and the National Health Service in England and Wales. (2002). *Forget me not 2002: Developing mental health services for older people in England*. Audit Commission for Local Authorities and the National Health Service in England and Wales.

Baker, C., Huxley, P., Dennis, M., Islam, S., & Russell, I. (2015). Alleviating staff stress in care homes for people with dementia: protocol for stepped-wedge cluster randomised trial to evaluate a web-based Mindfulness-Stress Reduction course. *BioMed Central Psychiatry*, 15(317), 1.

Baldwin, T. T., & Ford, J. K. (1988). Transfer of training: A review and directions for future research. *Personnel Psychology*, 41(1), 63-105.

Ballard, C., O'Brien, J., James, I., & Swann, A. (2001). Dementia: Management of Behavioural and Psychological Symptoms. *Nordic Journal of Psychiatry*, 57(2), 159-160.

- Ballard, C., Fossey, J., Chithramohan, R., Howard, R., Burns, A., Thompson, P., Tadros, G., & Fairbairn, A. (2001). Quality of care in private sector and NHS facilities for people with dementia: cross sectional survey. *British Medical Journal*, *323*(7310), 426-427.
- Ballard, C. G., Gauthier, S., Cummings, J. L., Brodaty, H., Grossberg, G. T., Robert, P., & Lyketsos, C. G. (2009). Management of agitation and aggression associated with Alzheimer disease. *Nature Reviews Neurology*, *5*(5), 245-255.
- Ballard, C., & Howard, R. (2006). Neuroleptic drugs in dementia: benefits and harm. *Nature Reviews Neuroscience*, *7*(6), 492-500.
- Ballard, C., Margallo-Lana, M., Juszczak, E., Douglas, S., Swann, A., Thomas, A., ... & Lee, L. (2005). Quetiapine and rivastigmine and cognitive decline in Alzheimer's disease: randomised double blind placebo controlled trial. *British Medical Journal*, *330*(7496), 874.
- Banerjee, S. (2009). *The use of antipsychotic medication for people with dementia: Time for action*. London: Department of Health.
- Banerjee, S., Murray, J., Foley, B., Atkins, L., Schneider, J. & Mann, A. (2003). Predictors of institutionalisation in people with dementia. *Journal of Neurology, Neurosurgery and Psychiatry*, *74*(9), 1315-1316.
- Barnett, V., & Lewis, T. (1994). *Outliers in statistical data* (3<sup>rd</sup> ed.). New York: Wiley.
- Barrett, J. J., Haley, W. E., Harrell, L. E., & Powers, R. E. (1997). Knowledge about Alzheimer disease among primary care physicians, psychologists, nurses, and social workers. *Alzheimer Disease and Associated Disorders*, *11*(2), 99-106.

- Beck, C. (2001). Identification and assessment of effective services and interventions: The nursing home perspective. *Aging and Mental Health*, 5(S1), 99-111.
- Beck, C. K., & Vogelpohl, T. S. (1999). Problematic vocalizations in institutionalized individuals with dementia. *Journal of Gerontological Nursing*, 25(9), 17-26.
- Beers, M., Avorn, J., Soumerai, S. B., Everitt, D. E., Sherman, D. S., & Salem, S. (1988). Psychoactive medication use in intermediate-care facility residents. *Journal of the American Medical Association*, 260(20), 3016-3020.
- Berry, K., Barrowclough, C., & Wearden, A. (2009). A pilot study investigating the use of psychological formulations to modify psychiatric staff perceptions of service users with psychosis. *Behavioural and Cognitive Psychotherapy*, 37(01), 39-48.
- Bird, M. (2005). A predominantly psychosocial approach to behaviour problems in dementia: treating causality. In A. Burns, D. Ames, & J. O'Brien (Eds.), *Dementia* (pp. 499-509). London: Arnold.
- Bird, M., Blair, A. L., & Caldwell, T. (2006). ACT Innovative Dementia Pilot. Adaptation of a Swedish clinical supervision and individually planned care model for dementia care in everyday Australian conditions: Evaluation of a controlled trial. *Unpublished Report to Australian Government Department of Health and Ageing*.
- Bird, M., Jones, R. H., Korten, A., & Smithers, H. (2007). A controlled trial of a predominantly psychosocial approach to BPSD: treating causality. *International Psychogeriatric*, 19(5), 874-891.
- Bird, M., Llewellyn-Jones, R., Smithers, H., Andrews, C., Cameron, I., Cottee, A., ... & Russell, B. (1998). Challenging Behaviours in Dementia: a Project at Hornsby/Ku-Ring-Gai Hospital. *Australasian Journal on Ageing*, 17(1), 10-15.

- Bird, M., Llewellyn-Jones, R., Smithers, H., & Korten, A. (2002). *Psychosocial Approaches to Challenging Behaviour in Dementia: A Controlled Trial*. Report to the Commonwealth Department of Health and Ageing, Canberra. Retrived from: <http://www.health.gov.au/internet/wems/publishing.nsf/Content/ageing-publicat-psychsoc.htm>
- Bird, M., Llewellyn-Jones, R. H., & Korten, A. (2009). An evaluation of the effectiveness of a case-specific approach to challenging behaviour associated with dementia. *Aging and Mental Health, 13*(1), 73-83.
- Bird, M., & Moniz-Cook, E. (2008). Challenging behaviour in dementia: A psychosocial approach to intervention. In R. Woods, & L. Clare (Eds.), *Handbook of the Clinical Psychology of Ageing* (pp. 571-594). Chichester, New York: Wiley.
- Bland, J. M. (2004). Cluster randomised trials in the medical literature: Two bibliometric surveys. *BioMed Central Medical Research Methodology, 4*(21).
- Blume, B. D., Ford, J. K., Baldwin, T. T., & Huang, J. L. (2010). Transfer of training: A meta-analytic review. *Journal of Management, 36*(4), 1065-1105.
- Blunden, R. & Allen, D. (1987). *Facing the Challenge: An Ordinary Life for People with Learning Difficulties and Challenging Behaviour*. London: Kings Fund.
- Boustani, M., Zimmerman, S., Williams, C. S., Gruber-Baldini, A. L., Watson, L., Reed, P. S., & Sloane, P. D. (2005). Characteristics associated with behavioral symptoms related to dementia in long-term care residents. *The Gerontologist, 45*, (Special Issue D), 56-61.
- Brechin, D., Murphy, G., James, I. A., & Codner, J. (2013). *Briefing Paper: Alternatives to antipsychotic medication: Psychological approaches in managing psychological and*

*behavioural distress in people with dementia*. Leicester: The British Psychological Society.

Brodaty, H., Draper, B., Saab, D., Low, L. F., Richards, V., Paton, H., & Lie, D. (2001).

Psychosis, depression and behavioural disturbances in Sydney nursing home residents: Prevalence and predictors. *International Journal of Geriatric Psychiatry, 16*(5), 504-512.

Brodaty, H., Connors, M. H., Xu, J., Woodward, M., Ames, D., & PRIME Study Group.

(2015). The course of neuropsychiatric symptoms in dementia: A 3-year longitudinal study. *Journal of the American Medical Directors Association, 16*(5), 380-387.

Buckwalter, K. C. (1998). *PLST Model: Effectiveness for rural ADRD caregivers, final report (R01-NR0234)*. Washington, DC: National Institute for Nursing Research.

Buckwalter, K. C., Gerdner, L., Kohout, F., Hall, G. R., Kelly, A., Richards, B., & Sime, M.

(1999). A nursing intervention to decrease depression in family caregivers of persons with dementia. *Archives of Psychiatric Nursing, 13*(2), 80-88.

Burgio, L. D., & Burgio, K. L. (1990). Institutional staff training and management: A review of the literature and a model for geriatric long-term care facilities. *International Journal of Aging and Human Development, 30*(4), 287-302.

Burgio, L. D., Allen-Burge, R., Roth, D. L., Bourgeois, M. S., Dijkstra, K., Gerstle, J., ... & Bankester, L. (2000). Come talk with me: Improving communication between enrolled nurses and nursing homes residents during care routines. *Gerontologist, 41*(4), 449-460.

Burgio, L. D., & Stevens, A. B. (1998). Behavioral interventions and motivational systems in the nursing home. *Annual Review of Gerontology and Geriatrics, 18*(1), 284-320.

Calkins, M. P. (2002). Environments that make a difference. *Alzheimer's Care Today*, 3(1), 5-7.

Cambridgeshire Training, Education and Development – Older People. (2015). *Dementia care training and development prospectus 2015-16*, Cambridgeshire and Peterborough NHS Foundation Trust.

Carers UK., & Age UK. (2015). *Caring into later life: The growing pressure on older carers*. Retrieved from: <https://www.carersuk.org/caring-into-later-life-report>

Cavendish, C. (2013). *The Cavendish review: An independent review into healthcare assistants and support workers in the NHS and social care settings*. London: Department of Health.

Centre for Policy on Ageing. (2012). *A profile of residents in Bupa care homes: Results from the 2012 Bupa census*. London: Centre for Policy on Ageing.

Centre for Policy on Ageing. (2014). *Centre for Policy on Ageing – Review: Changing family structures and their impact on the care of older people*. Retrieved from: [http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/CPA-Changing\\_family\\_structures.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/CPA-Changing_family_structures.pdf?dtrk=true)

Cerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E. B. (2012). Behavioral and psychological symptoms of dementia. *Frontiers in Neurology*, 73(3).

Chase, G. A., & Folstein, M. (1990). Psychiatric symptoms and nursing home placement of patients with Alzheimer's disease. *The American Journal of Psychiatry*, 147(8), 1049-1051.



Chen, Y., Briesacher, B. A., Field, T. S., Tjia, J., Lau, D. T., & Gurwitz, J. H. (2010).

Unexplained variation across US nursing homes in antipsychotic prescribing rates.

*Archives of Internal Medicine*, 170(1), 89-95.

Chenoweth, L., King, M. T., Jeon, Y. H., Brodaty, H., Stein-Parbury, J., ... & Luscombe, G.

(2009). Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: A cluster-randomised trial.

*Lancet Neurology*, 8(4), 317-325.

Child, A., Clarke, A., Fox, C., & Maidment, I. (2012). A pharmacy led program to review

anti-psychotic prescribing for people with dementia. *BioMed Central*

*Psychiatry*, 12(1), 1.

Choi, J., Flynn, L., & Aiken, L. H. (2011). Nursing practice environment and registered

nurses' job satisfaction in nursing homes. *The Gerontologist*, gnr101.

Choi, S., Cheong, K., & Feinberg, R. A. (2012). Moderating effects of supervisor support,

monetary rewards, and career paths on the relationship between job burnout and

turnover intentions in the context of call centers. *Managing Service Quality: An*

*International Journal*, 22(5), 492-516.

Cohen-Mansfield, J. (2000a). Nonpharmacological management of behavioural problems in

persons with dementia: the TREA model. *Alzheimer Care Quarterly*, 1(4), 22-34.

Cohen-Mansfield, J. (2000b). Theoretical frameworks for behavioral problems in dementia.

*Alzheimer's Care Today*, 1(4), 8-hyhen.

Cohen-Mansfield, J. (2000c). Use of patient characteristics to determine nonpharmacologic

interventions for behavioral and psychological symptoms of dementia. *International*

*Psychogeriatrics*, 12(1), 373-380.

- Cohen-Mansfield, J. (2001). Nonpharmacologic interventions for inappropriate behaviors in dementia: A review, summary, and critique. *The American Journal of Geriatric Psychiatry, 9*(4), 361-381.
- Cohen-Mansfield, J. (2003). Agitation in the elderly: Definitional and theoretical conceptualisations. In D. P. Hay, D. T. Klein, L. K. Hay, G. T. Grossberg, & J.S. Kennedy (Eds.), *Agitation in Patients with Dementia. A Practical Guide to Diagnosis and Management* (pp. 1-22). USA: American Psychiatric Publishing.
- Cohen-Mansfield, J., & Libin, A. (2005). Verbal and physical non-aggressive agitated behaviors in elderly persons with dementia: Robustness of syndromes. *Journal of Psychiatric Research, 39*(3), 325-332.
- Cohen-Mansfield, J., Libin, A., & Marx, M. S. (2007). Nonpharmacological treatment of agitation: A controlled trial of systematic individualized intervention. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences, 62*(8), 908-916.
- Cohen-Mansfield, J., Marx, M. S., & Rosenthal, A. S. (1989). A description of agitation in a nursing home. *Journal of Gerontology, 44*(3), M77-M84.
- Cohen-Mansfield, J., & Werner, P. (1998). The effects of an enhanced environment on nursing home residents who pace. *The Gerontologist, 38*(2), 199-208.
- Cohen-Mansfield, J., Werner, P., & Marx, M. S. (1989). An observational study of agitation in agitated nursing home residents. *International Psychogeriatrics, 1*(02), 153-165.
- Cohen-Mansfield, J., Werner, P., Watson, V., & Pasis, S. (1995). Agitation among elderly persons at adult day-care centers: The experiences of relatives and staff members. *International Psychogeriatrics, 7*(03), 447-458.

- Colerick, E. J., & George, L. K. (1986). Predictors of institutionalization among caregivers of patients with Alzheimer's disease. *Journal of the American Geriatrics Society*, *34*(7), 493-498.
- Committee on Safety of Medicines. (2004). *Atypical antipsychotic drugs and stroke*. Retrieved from: <http://www.gov.scot/Publications/2004/03/19074/34348>
- Cooke, D. D., McNally, L., Mulligan, K. T., Harrison, M. J. G., & Newman, S. P. (2001). Psychosocial interventions for caregivers of people with dementia: A systematic review. *Aging and Mental Health*, *5*(2), 120-135.
- Copeland, J. R. M., Dewey, M. E., & Griffiths-Jones, H. M. (1986). A computerized psychiatric diagnostic system and case nomenclature for elderly subjects: GMS and AGE-CAT. *Psychological Medicine*, *16*(01), 89-99.
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2011). Developing and evaluating complex interventions. Medical Research Council, UK. *British Medical Journal*, *337*, 979-983.
- Cummings, J. L., Mega, M., Gray, K., Rosenberg-Thomson, S., Carusi, D. A., Gornbein, J. (1994). The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology*, *44*(12), 2308-2314.
- Cummings, J. L. (1997). The Neuropsychiatric Inventory assessing psychopathology in dementia patients. *Neurology*, *48*(5/6), 10S-16S.
- Davison, T. E., McCabe, M. P., Visser, S., Hudgson, C., Buchanan, G., & George, K. (2007). Controlled trial of dementia training with a peer support group for aged care staff. *International Journal of Geriatric Psychiatry*, *22*(9), 868-873.

De Deyn, P. P., Carrasco, M. M., Deberdt, W., Jeandel, C., Hay, D. P., Feldman, P. D., ... &

Breier, A. (2004). Olanzapine versus placebo in the treatment of psychosis with or without associated behavioral disturbances in patients with Alzheimer's disease.

*International Journal of Geriatric Psychiatry*, 19(2), 115-126.

Dementia Action Alliance. (2011). *The right prescription: A call to action on the use of antipsychotic drugs for people with dementia*. [Online]. Dementia Action Alliance,

Retrieved from:

[http://www.dementiaaction.org.uk/news/article/6/the\\_right\\_prescription\\_a\\_call\\_to\\_action\\_on\\_the\\_use\\_of\\_antipsychotic\\_drugs\\_for\\_people\\_with\\_dementia](http://www.dementiaaction.org.uk/news/article/6/the_right_prescription_a_call_to_action_on_the_use_of_antipsychotic_drugs_for_people_with_dementia)

Department of Health. (2001). *National Service Framework for Older People*. London:

Department of Health.

Department of Health. (2009). *Living Well with Dementia: A National Dementia Strategy*.

London: Department of Health.

Department of Health. (2011). *Social Services and Public Safety - Improving Dementia Services in Northern Ireland: A Regional Strategy*. Belfast: Department of Health.

Retrieved from: <https://www.dhsspsni.gov.uk/publications/improving-dementia-services-northern-ireland-regional-strategy>.

Dewing, J. (2010). Responding to agitation in people with dementia: Although medication and physical restraint have traditionally been used to treat agitated behaviours, there is growing evidence that holistic approaches can be beneficial, says Jan

Dewing. *Nursing Older People*, 22(6), 18-25.

- De Pfeiffer, L. E. M., & Laidlaw, K. (2016a). PCAP – Person-Centred Approaches to Practice with dementia training module[Unpublished manuscript]. Clinical Psychology Department, University of East Anglia, Norwich.
- De Pfeiffer, L. E. M., & Laidlaw, K. (2016b). Jigsaw Training Tool [Unpublished manuscript]. Clinical Psychology Department, University of East Anglia, Norwich.
- De Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., & Verhey, F. R. (2005). A prospective study of the effects of behavioral symptoms on the institutionalization of patients with dementia. *International Psychogeriatrics*, *17*(04), 577-589.
- Dieckmann, L., Zarit, S. H., Zarit, J. M., & Gatz, M. (1988). The Alzheimer's disease knowledge test. *The Gerontologist*, *28*(3), 402-408.
- Division of Clinical Psychology. (2011). *Good Practice Guidelines on the use of psychological formulation*. Leicester: British Psychological Society.
- Douglas, I. J., & Smeeth, L. (2008). Exposure to antipsychotics and risk of stroke: Self-controlled case series study. *British Medical Journal*, *337*, a1227.
- Draper, B., Snowdon, J., Meares, S., Turner, J., Gonski, P., McMinn, B., ... & Luscombe, G. (2000). Case-controlled study of nursing home residents referred for treatment of vocally disruptive behavior. *International Psychogeriatrics*, *12*(03), 333-344.
- Duffy, B., Oyebode, J. R., & Allen, J. (2009). Burnout among care staff for older adults with dementia: The role of reciprocity, self-efficacy and organizational factors. *Dementia*, *8*(4), 515-541.

- Dwyer-Moore, K. J., & Dixon, M. R. (2007). Functional analysis and treatment of problem behavior of elderly adults in long-term care. *Journal of Applied Behavior Analysis*, *40*(4), 679-683.
- Elliott, K. E. J., Scott, J. L., Stirling, C., Martin, A. J., & Robinson, A. (2012). Building capacity and resilience in the dementia care workforce: A systematic review of interventions targeting worker and organizational outcomes. *International Psychogeriatrics*, *24*(06), 882-894.
- Elliott, K. E. J., Stirling, C. M., Martin, A. J., Robinson, A. L., & Scott, J. L. (2015). We are not all coping: A cross-sectional investigation of resilience in the dementia care workforce. *Health Expectations*.
- Emerson, E. (1995). *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge: Cambridge University Press.
- Epp, T. D. (2003). Person-centred dementia care: A vision to be refined. *The Canadian Alzheimer Disease Review*, *5*(3), 14-19.
- Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, *20*(8), 423-428.
- Edvardsson, D., Fetherstonhaugh, D., McAuliffe, L., Nay, R., & Chenco, C. (2011). Job satisfaction amongst aged care staff: exploring the influence of person-centered care provision. *International Psychogeriatrics*, *23*(08), 1205-1212.
- Evers, W., Tomic, W., & Brouwers, A. (2002). Aggressive behaviour and burnout among staff of homes for the elderly. *International Journal of Mental Health Nursing*, *11*(1), 2-9.

- Fagin, L., Carson, J., Leary, J., De Villiers, N., Bartlett, H., O'Malley, P., ... & Brown, D. (1996). Stress, coping and burnout in mental health nurses: Findings from three research studies. *International Journal of Social Psychiatry*, 42(2), 102-111.
- Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). Statistical power analyses using G\*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods*, 41(4), 1149-60.
- Feldt, K. S., & Ryden, M. B. (1992). Aggressive behavior: Educating nursing assistants. *Journal of Gerontological Nursing*, 18(5), 3-9.
- Finkel, S. I., Lyons, J. S., & Anderson, R. L. (1993). A brief agitation rating scale (BARS) for nursing home elderly. *Journal of the American Geriatrics Society*, 41(1), 50-52.
- Finkel, S., Costa E Silva, J., Cohen, G., Miller, S. & Sartorius, N. (1997). Behavioral and psychological signs and symptoms of dementia: a consensus statement on current knowledge and implications for research and treatment. *International Journal of Geriatric Psychiatry*, 12(11), 1060-1061.
- Finkel, S. (2000). Introduction to behavioural and psychological symptoms of dementia (BPSD). *International Journal of Geriatric Psychiatry*, 15 (Suppl 1), S2-S4.
- Finnema, E., Dröes, R.M., Ettema, T., Ooms, M., Adèr, H., Ribbe, M., van Tilburg, W., 2005. The effect of integrated emotion-oriented care versus usual care on elderly persons with dementia in the nursing home and on nursing assistants: a randomized clinical trial. *International Journal of Geriatric Psychiatry*, 20(4), 330–343.
- Fisher, L. D., Dixon, D. O., Herson, J., Frankowski, R. K., Hearn, M. S., Peace, K. E. (1990). Intention to treat in clinical trials. In K. E. Peace (Ed), *Statistical issues in drug research and development* (pp.331-350). New York: Marcel Dekker.

- Food and Drug Administration. (2005). *Deaths with antipsychotics in elderly patients with behavioural disturbances* [Online]. U.S. Food and Drug Administration Public Health Advisory (FDA). Available:  
<http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/DrugSafetyInformationforHealthcareProfessionals/PublicHealthAdvisories/ucm053171.htm>
- Food and Drug Administration. (2008). *Information for Healthcare Professionals: Conventional Antipsychotics* [Online]. U.S. Food and Drug Administration Public Health Advisory (FDA).
- Ford, J. K., & Weissbein, D. A. (1997). Transfer of training: An updated review and analysis. *Performance Improvement Quarterly*, 10(2), 22-41.
- Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R. & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: Cluster randomised trial. *British Medical Journal*, 332(7544), 756-761.
- French, S., & Swain, J. (2012). *Working with disabled people in policy and practice: A social model*. Basingstoke: Palgrave Macmillan.
- Frisoni, G., Rozzini, L., Gozzetti, A., Binetti, G., Zanetti, O., Bianchetti, A., ... & Cummings, J. (1999). Behavioral syndromes in Alzheimer's disease: Description and correlates. *Dementia and Geriatric Cognitive Disorders*, 10(2), 130-138.
- Gates, D., Fitzwater, E., Succop, P. (2005). Reducing assaults against nursing home caregivers. *Nursing Research*, 54(2), 119-127.



- Gaugler, J. E., Duval, S., Anderson, K. A., & Kane, R. L. (2007). Predicting nursing home admission in the US: A meta-analysis. *BioMed Central Geriatrics*, 7(1), 1.
- Gellad, W. F., Aspinall, S. L., Handler, S. M., Stone, R. A., Castle, N., Semla, T. P., ... & Hanlon, J. T. (2012). Use of antipsychotics among older residents in veterans administration nursing homes. *Medical Care*, 50(11), 954-960.
- Gerhard, T., Huybrechts, K., Olfson, M., Schneeweiss, S., Bobo, W. V., Doraiswamy, P. M., ... & Levin, R. (2013). Comparative mortality risks of antipsychotic medications in community-dwelling older adults. *The British Journal of Psychiatry*, 203, 1-8.
- Gill, S. S., Bronskill, S. E., Normand, S. L. T., Anderson, G. M., Sykora, K., Lam, K., ... & Gurwitz, J. H. (2007). Antipsychotic drug use and mortality in older adults with dementia. *Annals of Internal Medicine*, 146(11), 775-786.
- Goyder, J. (2011). *Staff Training Using STAR (Staff Training in Assisted Living Residences): A Pilot Study in UK Residential Care Homes* (Doctoral dissertation, University College London).
- Goyder, J., Orrell, M., Wenborn, J., & Spector, A. (2012). Staff training using STAR: A pilot study in UK care homes. *International Psychogeriatrics*, 24(06), 911-920.
- Grol, R., & Grimshaw, J. (1999). Evidence-based implementation of evidence-based medicine. *The Joint Commission Journal on Quality Improvement*, 25(10), 503-513.
- Gupta, S. K. (2011). Intention-to-treat concept: A review. *Perspectives in Clinical Research*, 2(3), 109.

- Gutman, G.M. (2010). Population ageing and apocalyptic demography: Separating fact from fiction. In L.B. Knudsen & A.L. Olsen (Eds.), *Our demographic future - a challenge: On the need for demographic analyses* (pp. 11-36). Aalborg Oest, Denmark: Aalborg University Press.
- Hagen, B. F., & Sayers, D. (1995). When caring leaves bruises: The effects of staff education on resident aggression. *Journal of Gerontological Nursing*, 21(11), 7-9.
- Hall, G., & Buckwalter, K. (1987). Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's disease. *Archives of Psychiatric Nursing*, 1(6), 399-406.
- Hall, G., Kirschling, M. V., & Todd, S. (1986). Sheltered freedom: An Alzheimer's unit in an ICF. *Geriatric Nursing*, 7(3), 132-137.
- Hall, S., Longhurst, S., & Higginson, I. (2009). Living and dying with dignity: A qualitative study of the views of older people in nursing homes. *Age and Ageing*, 38(4), 411-416.
- Hallberg I.R., Welander U. H., & Axelsson, K. (1994). Satisfaction with nursing care and work during a year of clinical supervision and individualized care. Comparison between two wards for the care of severely demented patients. *Journal of Nursing Management*, 1, 297-307.
- Hancock, G. A., Woods, B., Challis, D., & Orrell, M. (2006). The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry*, 21(1), 43-49.
- Hanley, I. G., McGuire, R. J., & Boyd, W. D. (1981). Reality orientation and dementia: A controlled trial of two approaches. *The British Journal of Psychiatry*, 138(1), 10-14.

- Hannan, S., Norman, I. J., & Redfern, S. J. (2001). Care work and quality of care for older people: A review of the research literature. *Reviews in Clinical Gerontology, 11*(02), 189-203.
- Hardenacke, D., Bartholomeyczik, S., & Halek, M. (2011). Implementation and evaluation of “Understanding Diagnostics” on the example of the light house project  
InDemA. *Pflege Gesellschaft, 16*(2), 101-115.
- Harper, S. (2014). Economic and social implications of aging societies. *Science, 346*(6209), 587-591.
- Harper, S., & Levin, S. (2005). Family care, independent living and ethnicity. *Social Policy and Society, 4*(02), 157-169.
- Hastings, R. P., & Remington, B. (1994). Rules of engagement: Toward an analysis of staff responses to challenging behavior. *Research in Developmental Disabilities, 15*(4), 279-298.
- Health and Social Care Information Centre. (2012). *National Dementia and Antipsychotic Prescribing Audit 2012*. Leeds: Health and Social Care Information Centre.
- Herrmann, N., Lanctôt, K. L., Sambrook, R., Lesnikova, N., Hébert, R., McCracken, P., ... & Nguyen, E. (2006). The contribution of neuropsychiatric symptoms to the cost of dementia care. *International Journal of Geriatric Psychiatry, 21*(10), 972-976.
- Hodges, J. L., & Lehmann, E. L. (1956). The efficiency of some nonparametric competitors of the t-test. *The Annals of Mathematical Statistics, 27*(2), 324-335.

- Hoeffler, B., Rader, J., McKenzie, D., Lavelle, M., & Stewart, B. (1997). Reducing aggressive behavior: During bathing cognitively nursing home residents. *Journal of Gerontological Nursing*, 23(5), 16-23.
- Hope, T., Keene, J., Fairburn, C., McShane, R., & Jacoby, R. (1997). Behaviour changes in dementia 2: are there behavioural syndromes? *International Journal of Geriatric Psychiatry*, 12(11), 1074-1078.
- House of Lords. (2013). Lords Select Committee: Ready for Aging? *House of Lords*. London: The Stationary Office.
- Howell, D. C. (2007). The treatment of missing data. In W. Outhwaite & S. Turner (Eds), *The Sage Handbook of Social Science Methodology* (pp. 208-224). London: SAGE.
- Hussian, R. A. (1983). A combination of operant and cognitive therapy with geriatric patients. *International Journal of Behavioral Geriatrics*, 1(4), 57-61.
- Hussein, S. (2010). The Dementia Social Care Workforce in England. London: Social Care Workforce Periodical. Retrieved from:  
[http://s3.amazonaws.com/academia.edu.documents/30404787/SCWP\\_Issue9.pdf?AWSAccessKeyId=AKIAJ56TQJRTWSMTNPEA&Expires=1470140236&Signature=rKtnFJtn8rwHcBdmc%2FyKsYhduTY%3D&response-content-disposition=inline%3B%20filename%3DThe\\_dementia\\_social\\_care\\_workforce\\_in\\_En.pdf](http://s3.amazonaws.com/academia.edu.documents/30404787/SCWP_Issue9.pdf?AWSAccessKeyId=AKIAJ56TQJRTWSMTNPEA&Expires=1470140236&Signature=rKtnFJtn8rwHcBdmc%2FyKsYhduTY%3D&response-content-disposition=inline%3B%20filename%3DThe_dementia_social_care_workforce_in_En.pdf)
- Huybrechts, K. F., Gerhard, T., Crystal, S., Olfson, M., Avorn, J., Levin, R., ... & Schneeweiss, S. (2012). Differential risk of death in older residents in nursing homes prescribed specific antipsychotic drugs: Population based cohort study. *British Medical Journal*, 344, e977.

- Jackman, L., & Beatty, A. (2015). Using the Newcastle model to understand people whose behaviour challenges in dementia care. *Nursing Older People*, 27(2), 32-39.
- Jackson, J., Mandel, D., Blanchard, J., Carlson, M., Cherry, B., Azen, S., ... & Granger, D. (2009). Confronting challenges in intervention research with ethnically diverse older adults: The USC Well Elderly II trial. *Clinical Trials*, 6(1), 90-101.
- James, I. A. (1999). Using a cognitive rationale to conceptualise anxiety in people with dementia. *Behavioural and Cognitive Psychotherapy*, 27(4), 345-351.
- James, I. A. (2011). *Understanding behaviour in dementia that challenges: A guide to assessment and treatment*. London: Jessica Kingsley Publishers.
- James, I. A. (2014). The Use of CBT for Behaviours that Challenge in Dementia. In N. A. Pachana & K. Laidlaw (Eds.), *Oxford Handbook of Clinical Geropsychology* (pp. 753-775). USA: Oxford University Press.
- James, I., & Stephenson, M. (2007). Behaviour that challenges us: The Newcastle support model. *Journal of Dementia Care*, 15(5), 19.
- Jeon, Y. H., Luscombe, G., Chenoweth, L., Stein-Parbury, J., Brodaty, H., King, M., & Haas, M. (2012). Staff outcomes from the caring for aged dementia care resident study (CADRES): A cluster randomised trial. *International Journal of Nursing Studies*, 49(5), 508-518.
- Jenkins, H., & Allen, C. (1998). The relationship between staff burnout/distress and interactions with residents in two residential homes for older people. *International Journal of Geriatric Psychiatry*, 13(7), 466-472.

- Kales, H. C., Kim, H. M., Zivin, K., Valenstein, M., Seyfried, L. S., Chiang, C., ... & Blow, F. C. (2012). Risk of mortality among individual antipsychotics in patients with dementia. *American Journal of Psychiatry*, *169*(1), 71-79.
- Kales, H. C., Valenstein, M., Kim, H. M., McCarthy, J. F., Ganoczy, D., Cunningham, F., & Blow, F. C. (2007). Mortality risk in patients with dementia treated with antipsychotics versus other psychiatric medications. *American Journal of Psychiatry*, *164*(10), 1568-1576.
- Karlin, B. E., Visnic, S., Shealy McGee, J., & Teri, L. (2014). Results from the multisite implementation of STAR-VA: A multicomponent psychosocial intervention for managing challenging dementia-related behaviors of veterans. *Psychological Services*, *11*(2), 200-208.
- Kaufers, D. I., Cummings, J. L., Christine, D., Bray, T., Castellon, S., Masterman, D., ... & DeKosky, S. T. (1998). Assessing the impact of neuropsychiatric symptoms in Alzheimer's disease: The Neuropsychiatric Inventory Caregiver Distress Scale. *Journal of the American Geriatrics Society*, *46*(2), 210-215.
- Kennedy P., Llewelyn S. (2001). Does the future belong to the scientist practitioner. *The Psychologist*, *14*(2), 74-78.
- Kerry, S. M., & Bland, J. M. (1998). Statistics Notes - Sample size in cluster randomisation. *British Medical Journal*, *316*, 549.
- Kinderman, P. (2005). A psychological model of mental disorder. *Harvard Review of Psychiatry*, *13*(4), 206-217.

- Kinderman, P., & Tai, S. (2007). Empirically grounded clinical interventions clinical implications of a psychological model of mental disorder. *Behavioural and Cognitive Psychotherapy*, 35(01), 1-14.
- Kinderman, P., & Tai, S. (2007). Psychological Therapies, Psychological Therapists, Psychological Models of Mental Disorder and the Role of Applied Psychologists. *Mental Health and Learning Disabilities Research and Practice*, 4(2), 190-204.
- Kitwood, T. (1993). Person and process in dementia. *International Journal of Geriatric Psychiatry*, 8, 541 – 545.
- Knapp, M., Comas-Herrera, A., Somani, A., & Banerjee, S. (2007). *Dementia: International Comparisons*. London: Personal Social Services Research Unit.
- Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J. L., ... & Stewart, R. (2007). *Dementia UK—A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society*. London: Alzheimer's Society.
- Koss, E., Weiner, M., Ernesto, C., Cohen-Mansfield, J., Ferris, S. H., Grundman, M., ... & Whitehouse, P. J. (1997). Assessing Patterns of Agitation in Alzheimer's Disease Patients with the Cohen-Mansfield Agitation Inventory. *Alzheimer Disease and Associated Disorders*, 11, 45-50.

- Kovach, C. R., Logan, B. R., Noonan, P. E., Schlidt, A. M., Smerz, J., Simpson, M., & Wells, T. (2006). Effects of the Serial Trial Intervention on discomfort and behavior of nursing home residents with dementia. *American Journal of Alzheimer's Disease and other Dementias*, 21(3), 147-155.
- Kwok, J. Y. C., & Ku, B. H. B. (2016). Elderly people as “apocalyptic demography”? A study of the life stories of older people in Hong Kong born in the 1930s. *Journal of Aging Studies*, 36, 1-9.
- Lai, C. KY. (2014). The merits and problems of Neuropsychiatric Inventory as an assessment tool in people with dementia and other neurological disorders. *Dove Press Journal: Clinical Interventions in Aging*, 9, 1051-1061.
- Laidlaw, K. (2013a). *Adaptation of Kinderman and Tai's (2007) Mediating Psychological Processes Model* [Unpublished Manuscript]. Clinical Psychology Department, University of East Anglia, Norwich.
- Laidlaw, K. (2013b). Understanding distressed behaviour: A person-centred approach. [Training presentation]. Clinical Psychology Department, University of East Anglia, Norwich.
- Laidlaw, K. (2013c). Edinburgh Behaviour Service [Brief]. The University of Edinburgh, School of Health in Social Science. Edinburgh.
- Laing & Buisson. (2009). *Care of Elderly People UK Market Survey 2009*. London: Laing & Buisson.
- Lancaster, G. A. (2015). Pilot and feasibility studies come of age! *Pilot and Feasibility Studies*, 1(1), 1.



- Landreville, P., Dicaire, L., Verreault, R., & Lévesque, L. (2005). A training program for managing agitation of residents in long-term care facilities: description and preliminary findings. *Journal of Gerontological Nursing, 31*(3), 34-42.
- Lawton, M. P., Van Haitsma, K., & Klapper, J. (1996). Observed affect in nursing home residents with Alzheimer's disease. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 51*(1), 3-14.
- Lebowitz, B. D. (2000). Behavioral and psychological symptoms of dementia: A clinical and research update. *International Psychogeriatrics, 12*(S1), 19-21.
- Lefroy, R. B., Hobbs, M. S. T., & Hyndman, J. (1992). Rating scales in residential care for elderly people: The Crichton Royal Behavioural Rating Scale. *Australian Journal on Ageing, 11*(4), 10-15.
- Levene, H. (1960). Robust tests for equality of variances<sup>1</sup>. In I. Olkin (Ed.), *Contributions to Probability and Statistics: Essays in Honor of Harold Hotelling* (pp. 278-292). Stanford University Press.
- Lintern, T., Woods, B., & Phair, L. (2000a). Before and after training: A case study of intervention. *Journal of Dementia Care, 8*, 15-17.
- Lintern, T., Woods, B., & Phair, L. (2000b). Training is not enough to change care practice. *Journal of Dementia Care, 8*, 15-17.
- Lintern, T. (2001). *Quality in Dementia Care: Evaluating Staff Attitudes and Behaviour*. Ph.D. thesis, University of Wales Bangor.

- Lucas, M. D., Atwood, J. R., & Hagan, R. (1993). Replication and validation of anticipated turnover model for urban registered nurses. *Nursing Research, 42*(1), 29-35.
- Luengo-Fernandez, R., Leal, J., & Gray, A. (2010). *Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom*. Cambridge: Alzheimer's Research Trust.
- Luppa, M., Luck, T., Braehler, E., König, E., & Riedel-Heller, S.G. (2008). Prediction of institutionalisation in dementia. A systematic review. *Dementia and Geriatric Cognitive Disorders, 26*(1), 65-78.
- Lyketsos, C. G., Lopez, O., Jones, B., Fitzpatrick, A. L., Breitner, J., & DeKosky, S. (2002). Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: Results from the cardiovascular health study. *The Journal of the American Medical Association, 288*(12), 1475-1483.
- Maas, M. L., Kelley, L. S., Park, M., & Specht, J. P. (2002). Issues in conducting research in nursing homes. *Western Journal of Nursing Research, 24*(4), 373-389.
- Mackenzie, C. S., & Peragine, G. (2003). Measuring and enhancing self-efficacy among professional caregivers of individuals with dementia. *American Journal of Alzheimer's Disease and Other Dementias, 18*(5), 291-299.
- Magai, C., Cohen, C.I., Gomberg, D., (2002). Impact of training dementia caregivers in sensitivity to nonverbal emotion signals. *International Psychogeriatrics, 14*(1), 25-38.
- Maglione, M., Maher, A. R., Hu, J., Wang, Z., Shanman, R., Shekelle, P. G., ... & Motala, A. (2011). *Off-label use of atypical antipsychotics: An update*. Rockville, MD: Agency for Healthcare Research & Quality.

- Maguire, A., Hughes, C., Cardwell, C., & O'Reilly, D. (2013). Psychotropic medications and the transition into care: A national data linkage study. *Journal of the American Geriatrics Society*, *61*(2), 215-221.
- Maher, A. R., Maglione, M., Bagley, S., Suttorp, M., Hu, J. H., Ewing, B., ... & Shekelle, P. G. (2011). Efficacy and comparative effectiveness of atypical antipsychotic medications for off-label uses in adults: A systematic review and meta-analysis. *The Journal of the American Medical Association*, *306*(12), 1359-1369.
- Margallo-Lana, M., Swann, A., O'Brien, J., Fairbairn, A., Reichelt, K., Potkins, D., ... & Ballard, C. (2001). Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments. *International Journal of Geriatric Psychiatry*, *16*(1), 39-44.
- Martin, R., Williams, C., & O'Neill, D. (2009). Retrospective analysis of attitudes to ageing in the economist: Apocalyptic demography for opinion formers. *British Medical Journal*, *339*, b4914.
- Maslach, C., Jackson, S. E., & Leiter, M. P. (1996). *The Maslach Burnout Inventory (3rd ed.)*. Palo Alto, CA: Consulting Psychologists Press.
- Maslach, C., Schaufeli, W. B., & Leiter, M. P. (2001). Job burnout. *Annual Review of Psychology*, *52*(1), 397-422.
- Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, *50*(4), 370.
- Maust, D. T., Kim, H. M., Seyfried, L. S., Chiang, C., Kavanagh, J., Schneider, L. S., & Kales, H. C. (2015). Antipsychotics, other psychotropics, and the risk of death in patients with dementia: number needed to harm. *The Journal of the American Medical Association*, *72*(5), 438-445.

- McCabe, M. P., Davison, T. E., & George, K. (2007). Effectiveness of staff training programs for behavioral problems among older people with dementia. *Aging and Mental Health, 11*(5), 505-519.
- McCallion, P., Toseland, R. W., Lacey, D., & Banks, S. (1999). Educating nursing assistants to communicate more effectively with nursing home residents with dementia. *The Gerontologist, 39*(5), 546-558.
- McCann, J. J., Gilley, D. W., Hebert, L. E., Beckett, L. A., & Evans, D. A. (1997). Concordance between direct observation and staff rating of behavior in nursing home residents with Alzheimer's disease. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 52*(2), P63-P72.
- McCleery, J., & Fox, R. (2012). Antipsychotic prescribing in nursing homes. *British Medical Journal, 344*, e1093.
- Medicines and Healthcare products Regulatory Agency. (2012). *Annual Report and Accounts 2011/12*. London: The Stationary Office.
- Mentes, J. C., & Tripp-Reimer, T. (2002). Barriers and facilitators in nursing home intervention research. *Western Journal of Nursing Research, 24*(8), 918-936.
- Mishara, B. L. (1978). Geriatric patients who improve in token economy and general milieu treatment programs: A multivariate analysis. *Journal of Consulting and Clinical Psychology, 46*(6), 1340.
- Moniz-Cook, E., Agar, S., Silver, M., Woods, R., Wang, M., Elston, C., & Win, T. (1998). Can staff training reduce behavioural problems in residential care for the elderly mentally ill? *International Journal of Geriatric Psychiatry, 13*(3), 149-158.

- Moniz-Cook, E., Stokes, G., & Agar, S. (2003). Difficult behaviour and dementia in nursing homes: five cases of psychosocial intervention. *Clinical Psychology and Psychotherapy*, *10*(3), 197-208.
- Moniz Cook, E. D., Swift, K., James, I., Malouf, R., De Vugt, M., & Verhey, F. (2012). Functional analysis-based interventions for challenging behaviour in dementia. *The Cochrane Library*.
- Moniz-Cook, E., Woods, R., & Gardiner, E. (2000). Staff factors associated with perception of behaviour as 'challenging' in residential and nursing homes. *Aging and Mental Health*, *4*(1), 48-55.
- Moniz-Cook, E., Woods, R., Gardiner, E., Silver, M., & Agar, S. (2001a). The Challenging Behaviour Scale (CBS): Development of a scale for staff caring for older people in residential and nursing homes. *British Journal of Clinical Psychology*, *40*(3), 309-322.
- Moniz-Cook, E., Woods, R. T., & Richards, K. (2001b). Functional analysis of challenging behaviour in dementia: the role of superstition. *International Journal of Geriatric Psychiatry*, *16*(1), 45-56.
- Morris, J. N., Hawes, C., Fries, B. E., Phillips, C. D., Mor, V., Katz, S., ... & Friedlob, A. S. (1990). Designing the national resident assessment instrument for nursing homes. *The Gerontologist*, *30*(3), 293-307.
- Murfield, J., Cooke, M., Moyle, W., Shum, D., & Harrison, S. (2011). Conducting randomized controlled trials with older people with dementia in long-term care: Challenges and lessons learnt. *International Journal of Nursing Practice*, *17*(1), 52-59.

National Audit Office. (2007). *Improving services and support for people with dementia*.

London: National Audit Office.

National Institute for Health and Care Excellence. (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. (NICE guidelines CG42).

Retrieved from: [https://www.nice.org.uk/guidance/cg42/ chapter/person-centred-care](https://www.nice.org.uk/guidance/cg42/chapter/person-centred-care)

National Institute for Health Research. (2012). *NIHR Evaluation, Trials and Studies*

*Coordination Centre: Glossary*. Retrieved from: <http://>

[www.nets.nihr.ac.uk/glossary?result\\_1655\\_result\\_page=F](http://www.nets.nihr.ac.uk/glossary?result_1655_result_page=F)

NHS Education for Scotland. (2012). *Promoting psychological wellbeing for people with dementia and their carers: An enhanced practice resource*. NHS Education for Scotland: Edinburgh.

Nock, M. K., Michel, B. D., Photos, V. I. (2007). Single-Case Research Designs.

Methodological Advances and Data Analysis. In D. McKay (Ed.), *Handbook of research methods in abnormal and clinical psychology* (pp. 337-350). Thousand Oaks, CA: Sage.

Nolan, M., Davies, S., Brown, J., Wilkinson, A., Warnes, T., McKee, K., ... & Stasi, K.

(2008). The role of education and training in achieving change in care homes: A literature review. *Journal of Research in Nursing*, 13(5), 411-433.

Oborne, C. A., Hooper, R., Li, K. C., Swift, C. G., & Jackson, S. H. (2002). An indicator of appropriate neuroleptic prescribing in nursing homes. *Age and Ageing*, 31(6), 435-439.

O'Brien, J. (2008). Antipsychotics for people with dementia. *British Medical Journal*, 337, a602.

O'Donnell, B. F., Drachman, D. A., Barnes, H. J., Peterson, K. E., Swearer, J. M., & Lew, R.

A. (1992). Incontinence and troublesome behaviors predict institutionalization in dementia. *Journal of Geriatric Psychiatry and Neurology*, 5(1), 45-52.

Office for National Statistics, (2013). *Population Estimate for the UK*. London: The Stationary Office.

Oh, H., Hur, M. H., & Eom, M. (2005). Development and analysis of the effects of caregiver training program on aggressive behavior in elders with cognitive impairment. *Taehan Kanho Hakhoe Chi*, 35(4), 745.

Opie, J., Doyle, C., & O'Connor, D. W. (2002). Challenging behaviours in nursing home residents with dementia: A randomized controlled trial of multidisciplinary interventions. *International Journal of Geriatric Psychiatry*, 17(1), 6-13.

Orr, J. M., Sackett, P. R., & DuBois, C. L. Z. (1991). Outlier detection and treatment in I/O Psychology: A survey of researcher beliefs and an empirical illustration. *Personnel Psychology*, 44(3), 473-486

Orsmond, G. I., & Cohn, E. S. (2015). The Distinctive Features of a Feasibility Study Objectives and Guiding Questions. *Occupational Therapy Journal of Research: Occupation, Participation and Health*, 35(3), 169-177.

Osborne, J. W. (2002). Notes on the use of data transformations. *Practical Assessment, Research and Evaluation*, 8(6). Retrieved July 22, 2016 from <http://PAREonline.net/getvn.asp?v=8&n=6>

Pachana, N., Laidlaw, K., & Knight, B. (2010). *Casebook of Clinical Geropsychology: International Perspectives on Practice*. USA: University Press.

- Perneger, T. V. (1998). What's wrong with Bonferroni adjustments? *The British Medical Journal*, 316(7139), 1236-1238.
- Pimm, P. L. (1998). Introduction to challenging behaviour. *The British Journal of Occupational Therapy*, 61(7), 306-310.
- Pitfield, C., Shahriyarmolki, K., & Livingston, G. (2011). A systematic review of stress in staff caring for people with dementia living in 24-hour care settings. *International Psychogeriatrics*, 23(01), 4-9.
- Proctor, R., Burns, A., Powell, H. S., Tarrrier, N., Faragher, B., Richardson, G., ... & South, B. (1999). Behavioural management in nursing and residential homes: a randomised controlled trial. *The Lancet*, 354(9172), 26-29.
- Ray, W. A., Federspiel, C. F., & Schaffner, W. (1980). A study of antipsychotic drug use in nursing homes: Epidemiologic evidence suggesting misuse. *American Journal of Public Health*, 70(5), 485-491.
- Reisberg, B. (1984). *A Guide to Alzheimer's Disease*. New York: Free Press.
- Reisberg, B., Ferris, S.H., Shulman, E., Steinberg, G., Buttinger, C., Sinaiko, E.,... & Cohen, J., (1986). Longitudinal course of normal aging and progressive dementia of the Alzheimer's type: A prospective study of 106 subjects over a 3.6 year mean interval. *Progress in Neuro-Psychopharmacology and Biological Psychiatry*, 10(3), 571-578.
- Richards, K. C., & Beck, C. K. (2004). Progressively lowered stress threshold model: Understanding behavioral symptoms of dementia. *Journal of the American Geriatrics Society*, 52(10), 1774-1775.



- Robert, P. H., Verhey, F. R., Byrne, E. J., Hurt, C., De Deyn, P. P., Nobili, F., ... & Kyriazopoulou, N. (2005). Grouping for behavioral and psychological symptoms in dementia: clinical and biological aspects. Consensus paper of the European Alzheimer disease consortium. *European Psychiatry, 20*(7), 490-496.
- Rodney, V. (2000). Nurse stress associated with aggression in people with dementia: its relationship to hardiness, cognitive appraisal and coping. *Journal of Advanced Nursing, 31*(1), 172-180.
- Rokstad, A. M. M., Røsvik, J., Kirkevold, Ø., Selbaek, G., Saltyte Benth, J., & Engedal, K. (2013). The effect of person-centred dementia care to prevent agitation and other neuropsychiatric symptoms and enhance quality of life in nursing home patients: A 10-month randomized controlled trial. *Dementia and Geriatric Cognitive Disorders, 36*(5/6), 340-353.
- Ryu, S. H., Ha, J. H., Park, D. H., Yu, J., & Livingston, G. (2011). Persistence of neuropsychiatric symptoms over six months in mild cognitive impairment in community-dwelling Korean elderly. *International Psychogeriatrics, 23*(2), 214–220.
- Savva, G. M., Zaccai, J., Matthews, F. E., Davidson, J. E., McKeith, I., & Brayne, C. (2009). Prevalence, correlates and course of behavioural and psychological symptoms of dementia in the population. *The British Journal of Psychiatry, 194*(3), 212-219.
- Schaufeli, W. B. (2003). Past performance and future perspectives of burnout research. *South Africa Journal of Industrial Psychology, 29*(4), 1-15.
- Schaufeli, W. B., Bakker, A. B., & Van Rhenen, W. (2009). How changes in job demands and resources predict burnout, work engagement, and sickness absenteeism. *Journal of Organizational Behavior, 30*(7), 893-917.

Schaufeli, W., & Enzmann, D. (1998). *The Burnout Companion to Study and Practice: A Critical Analysis*. UK: Taylor and Francis.

Schaufeli, W. B., & Greenglass, E. R. (2001). Introduction to special issue on burnout and health. *Psychology and Health, 16*(5), 501-510.

Schaufeli, W. B., & Van Dierendonck, D. (1995). A cautionary note about the cross-national and clinical validity of cut-off points for the Maslach Burnout Inventory. *Psychological Reports, 76*(3c), 1083-1090.

Schneeweiss, S., Setoguchi, S., Brookhart, A., Dormuth, C., & Wang, P. S. (2007). Risk of death associated with the use of conventional versus atypical antipsychotic drugs among elderly patients. *Canadian Medical Association Journal, 176*(5), 627-632.

Schneider, L. S., Dagerman, K. S., & Insel, P. (2005). Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. *The Journal of the American Medical Association, 294*(15), 1934-1943.

Schneider, L. S., Dagerman, K., & Insel, P. S. (2006). Efficacy and adverse effects of atypical antipsychotics for dementia: meta-analysis of randomized, placebo-controlled trials. *The American Journal of Geriatric Psychiatry, 14*(3), 191-210.

Schoenbach, V. J., & Arrighi, M. (1994). Data Management and data Analysis. In V.J. Schoenbach (Ed.), *Understanding the Fundamentals of Epidemiology and evolving text* (pp. 523-549). North Carolina: Chapel Hill. Retrieved from: [www.epidemiolog.net](http://www.epidemiolog.net).

- Schonfeld, L., Cairl, R., Cohen, D., Neal, K. K., Watson, M. A., & Westerhof, C. (1999). The Florida Care College: A training program for long-term-care staff working with memory-impaired residents. *Journal of Mental Health and Aging, 5*(2), 187-199.
- Scottish Social Services Council. (2011). *Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers*. Retrieved from <http://www.scotland.gov.uk/resource/doc/350174/0117211.pdf>
- Scottish Government. (2011). *Scotland's National Dementia Strategy 2013-16*. Edinburgh: Scottish Government. Retrieved from <http://www.scotland.gov.uk/Resource/0042/00423472.pdf>.
- Sedgwick, P. (2014). What is an open label trial? *The British Medical Journal, 348*, g3434.
- Shanahan, N., Orrell, M., Schepers, A. K., & Spector, A. (2013). The development and evaluation of the DK-20: A knowledge of dementia measure. *International Psychogeriatrics, 25*(11), 1899-1907.
- Shah, S. M., Carey, I. M., Harris, T., Dewilde, S., & Cook, D. G. (2011). Antipsychotic prescribing to older people living in care homes and the community in England and Wales. *International Journal of Geriatric Psychiatry, 26*(4), 423-434.
- Shapiro, S. S., and Wilk, M. B. (1965). An analysis of variance test for normality (complete samples), *Biometrika, 52*(3/4), 591-611.
- Sim, K., Gwee, K. P., & Bateman, A. (2005). Case formulation in psychotherapy: Revitalizing its usefulness as a clinical tool. *Academic Psychiatry, 29*(3), 289-292.

- Sink, K. M., Holden, K. F., & Yaffe, K. (2005). Pharmacological treatment of neuropsychiatric symptoms of dementia: A review of the evidence. *The Journal of the American Medical Association*, 293(5), 596-608.
- Skills for Care. (2010). *Common induction standards: Guidance for those responsible for workers in an induction period*. Leeds: Skills for Care.
- Smith, M., Buckwalter, K. C., Garand, L., Mitchell, S., Albanese, M., & Kreiter, C. (1994). Evaluation of a geriatric mental health training program for nursing personnel in rural long-term care facilities. *Issues in Mental Health Nursing*, 15, 149–168.
- Smith, M., Gerdner, L. A., Hall, G. R., & Buckwalter, K. C. (2004). History, development, and future of the progressively lowered stress threshold: A conceptual model for dementia care. *Journal of the American Geriatrics Society*, 52(10), 1755-1760.
- Smyer, M., Brannon, D., & Cohn, M. (1992). Improving nursing home care through training and job redesign. *The Gerontologist*, 32(3), 327-333.
- Spector, A., Orrell, M., & Goyder, J. (2013). A systematic review of staff training interventions to reduce the behavioural and psychological symptoms of dementia. *Ageing Research Reviews*, 12(1), 354-364.
- Spira, A. P., & Edelstein, B. A. (2006). Behavioral interventions for agitation in older adults with dementia: an evaluative review. *International Psychogeriatrics*, 18(02), 195-225.
- Stokes G. (1996). Driven by fear to defend his secure world. *Journal of Dementia Care*, 4(3), 14–15.
- Stokes, G. (2000). *Challenging Behaviour in Dementia: A Person Centred Approach*. Bicester: Winslow Press.

- Streiner, D., & Geddes, J. (2001). Intention to treat analysis in clinical trials when there are missing data. *Evidence Based Mental Health, 4*(3), 70-71.
- Strumpf, N. E., Evans, L. K., Wagner, J., & Patterson, J. (1992). Reducing physical restraints: Developing an educational program. *Journal of Gerontological Nursing, 18*(11), 21-27.
- Swanson, E. A., Maas, M. L., & Buckwalter, K. C. (1993). Catastrophic reactions and other behaviors of Alzheimer's residents: Special unit compared with traditional units. *Archives of psychiatric nursing, 7*(5), 292-299.
- Swanson, E. A., Maas, M. L., & Buckwalter, K. C. (1994). Alzheimer's Residents' Cognitive and Functional Measures Special and Traditional Care Unit Comparison. *Clinical Nursing Research, 3*(1), 27-41.
- Tabachnick, B. G., Fidell, L. S., & Osterlind, S. J. (2014). *Using multivariate statistics*. England: Pearson.
- Tanizaki, H. (1997). Power comparison of non-parametric tests: Small-sample properties from Monte Carlo experiments. *Journal of Applied Statistics, 24*, 603-632
- Tarrier, N., & Calam, R. (2002). New developments in cognitive-behavioural case formulation. Epidemiological, systemic and social context: An integrative approach. *Behavioural and Cognitive Psychotherapy, 30*(03), 311-328.
- Teri, L., Huda, P., Gibbons, L., Young, H., & van Leynseele, J. (2005). STAR: A Dementia-Specific Training Program for Staff in Assisted Living Residences. *The Gerontologist, 45*(5), 686-693.

The House of Commons. (2010). *The House of Commons' Committee on Public Accounts:*

*Improving Dementia Services in England - an Interim Report.* London: The House of Commons.

The Organisation for Economic Co-operation and Development. (2011). *Health at a Glance*

*2011: OECD Indicators.* Organisation for Economic Co-operation and Development Publishing. Retrieved from: <http://www.oecd.org/els/health-systems/49105858.pdf>

Theorell, T., Karasek, R. A., & Eneroth, P. (1990). Job strain variations in relation to plasma

testosterone fluctuations in working men-a longitudinal study. *Journal of Internal Medicine*, 227(1), 31-36.

Thompson, C., Brodaty, H., Trollor, J., & Sachdev, P. (2010). Behavioral and psychological

symptoms associated with dementia subtype and severity. *International Psychogeriatrics*, 22(02), 300-305.

Todd, S. J., & Watts, S. C. (2005). Staff responses to challenging behaviour shown by people

with dementia: An application of an attributional-emotional model of helping behaviour. *Aging and Mental Health*, 9(1), 71-81.

United Nations Population Fund. (2012). *By Choice, Not By Chance: Family Planning,*

*Human Rights and Development.* New York: United Nations Population Fund.

Van der Doef, M., & Maes, S. (1999). The job demand-control (-support) model and

psychological well-being: a review of 20 years of empirical research. *Work and Stress*, 13(2), 87-114.

Visser, S. M., McCabe, M. P., Hudgson, C., Buchanan, G., Davison, T. E., & George, K.

(2008). Managing behavioural symptoms of dementia: effectiveness of staff education and peer support. *Aging and Mental Health*, 12(1), 47-55.

- Volicer, L. (2012). Toward better terminology of behavioral symptoms of dementia. *Journal of the American Medical Directors Association, 13*(1), 3-4.
- Voyer, P., Verreault, R., Azizah, G. M., Desrosiers, J., Champoux, N., & Bédard, A. (2005). Prevalence of physical and verbal aggressive behaviours and associated factors among older adults in long-term care facilities. *BioMed Central Geriatrics, 5*(1), 13.
- Wade, D. T., & Collin, C. (1988). The Barthel ADL Index: a standard measure of physical disability? *International Disability Studies, 10*(2), 64-67.
- Waite, J., Harwood, R., Morton, I., & Connelly, D. (2008). *Dementia care: A practical manual*. Oxford University Press.
- Wang, P. S., Schneeweiss, S., Avorn, J., Fischer, M. A., Mogun, H., Solomon, D. H., & Brookhart, M. A. (2005). Risk of death in elderly users of conventional vs. atypical antipsychotic medications. *New England Journal of Medicine, 353*(22), 2335-2341.
- Weiner, M. F., Martin-Cook, K., Svetlik, D. A., Saine, K., Foster, B., & Fontaine, C. S. (1999). The quality of life in late-stage dementia (QUALID) scale. *Journal of the American Medical Directors Association, 1*(3), 114-116.
- Welsh Assembly Government. (2011). *National Dementia Vision for Wales: Dementia Supportive Communities*. Cardiff: WAG. Retrieved from: <http://gov.wales/docs/dhss/publications/110302dementiaen.pdf>.
- West, S. G., Duan, N., Pequegnat, W., Gaist, P., Des Jarlais, D. C., Holtgrave, D., ... & Mullen, P. D. (2008). Alternatives to the randomized controlled trial. *American Journal of Public Health, 98*(8), 1359-1366.

- Willemse, B. M., de Jonge, J., Smit, D., Depla, M. F., & Pot, A. M. (2012). The moderating role of decision authority and coworker-and supervisor support on the impact of job demands in nursing homes: A cross-sectional study. *International Journal of Nursing Studies, 49*(7), 822-833.
- White, I. R., Horton, N. J., Carpenter, J., & Pocock, S. J. (2011). Strategy for intention to treat analysis in randomised trials with missing outcome data. *British Medical Journal, 342*, d40.
- Wolpe, J., & Turkat, I. D. (1985). Behavioral formulation of clinical cases. In I. D. Turkat (Eds.), *Behavioral Case Formulation* (pp. 5-36). New York: Springer.
- Wood-Mitchell, A., James, I. A., Waterworth, A., Swann, A., & Ballard, C. (2008). Factors influencing the prescribing of medications by old age psychiatrists for behavioural and psychological symptoms of dementia: a qualitative study. *Age and Ageing, 37*(5), 547-552.
- Wood-Mitchell, A., Mackenzie, L., Stephenson, M., & James, I. A. (2007). Treating challenging behaviour in care settings: audit of a community service using the neuropsychiatric inventory. *The Faculty for the Psychology of Older People Newsletter, 101*, 19-23.
- World Health Organisation. (2012). *Dementia: A Public Health Priority*. Retrieved from [http://whqlibdoc.who.int/publications/2012/9789241564458\\_eng.pdf](http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf).
- Wortmann, M. (2012). Dementia: A global health priority-highlights from an ADI and World Health Organization report. *Alzheimer's Research and Therapy, 4*(5), 40.



Zimmerman, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E., &

Sloane, P. D. (2005). Attitudes, stress, and satisfaction of staff who care for residents with dementia. *The Gerontologist*, 45(1), 96-105.

Zuidema, S. U., Derksen, E., Verhey, F. R., & Koopmans, R. T. (2007). Prevalence of neuropsychiatric symptoms in a large sample of Dutch nursing home patients with dementia. *International Journal of Geriatric Psychiatry*, 22(7), 632-638.

Zwijssen, S. A., Smalbrugge, M., Eefsting, J. A., Twisk, J. W., Gerritsen, D. L., Pot, A. M., & Hertogh, C. M. (2014). Coming to grips with challenging behavior: A cluster randomized controlled trial on the effects of a multidisciplinary care program for challenging behavior in dementia. *Journal of the American Medical Directors Association*, 15(7), 531.e1-531.e10.

## Appendices

Appendix A: CAMTED-OP dementia care training and development prospectus 2015-16

Appendix B: Power calculation

Appendix C: Overview of the structure and learning objectives of the two training packages

Appendix C1: Overview of the structure and learning objectives of CAMTED

Appendix C2: Overview of the structure and learning objectives of CAMTED-Plus

Appendix D: The delivery options for training

Appendix D1: The delivery options for CAMTED training package

Appendix D2: The delivery options for CAMTED-Plus training package

Appendix E: A photographic representation of the jigsaw training tool

Appendix F: Outcome Measures

Appendix F1: Approaches to Dementia Questionnaire

Appendix F2: Dementia Knowledge Questionnaire

Appendix F3: The Maslach Burnout Inventory – Human Services Survey

Appendix F4: The English translation of the Swedish Satisfaction in Nursing Care and Work  
Scale

Appendix F5: Stress and Distress Behaviour Scale

Appendix F6: Frequency, Intensity and Confidence Likert Scales

Appendix F7: Participant demographic questionnaire

Appendix F8: Care home demographic questionnaire

Appendix F9: Jigsaw Evaluation

Appendix G: Initial ethical approval letter

Appendix H: Gatekeeper written consent letter

Appendix I: Participant information sheets

Appendix J: Participant consent forms

Appendix K: Procedure for reporting disclosures of malpractice/maltreatment

Appendix L: Ethical approval letters for protocol deviations

Appendix M: Expression of interest forms

Appendix N: Debrief information sheets

Appendix O: Prize draw entry form

Appendix P1: Assessment of normal distribution - Skew and Kurtosis values for variables

Appendix P2: Assessment of normal distribution - Shapiro Wilk test values

Appendix P3: Descriptive data for waiting list group

Appendix P4 Non-parametric data analyses for variables

Appendix P5: Data analysis outputs excluding outliers

Appendix P6: Jigsaw Evaluation qualitative feedback

**Appendix A**

**A subsection of CAMTED-OP's dementia care training and development prospectus**

**2015-16**

Cambridgeshire and Peterborough   
NHS Foundation Trust

# Cambridgeshire Training, Education and Development – Older People (CAMTED-OP)

Dementia care training and development prospectus 2015-16



For care homes and supported  
living and other dementia care  
providers



A member of Cambridge University Health Partners

All training conforms or exceeds minimum training standards set out by Cambridgeshire County Council and Peterborough City Council.

## Our approach

CAMTED-OP aims to offer high-quality, interactive and enjoyable training that enables learners to make a real difference to the quality of care provided to people with dementia.

We believe that dementia care training and practice development should encourage discussion, reflection and sharing of ideas. Our experience suggests that there are many budding person-centred carers waiting to be encouraged and developed. Our training draws strongly upon the principles of the person-centred dementia care approach. The training and practice development sessions are designed using the best available evidence, practice guidance, and our own clinical experience.

Our practice development work is 'hands-on' and practically focussed. We aim to enable teams to make the transition from training to practicing high-quality dementia care.

## The CAMTED-OP team

Our trainers are all qualified health and social care professionals, with years of directly relevant knowledge and clinical experience. As a "hub" for training with the Older People's Mental Health Services, we regularly collaborate with multi-disciplinary colleagues in design and delivery of bespoke training.

## What you can expect from us

We are a highly professional training team that aim to provide a flexible and responsive service according to providers' needs.

The team is happy to discuss your training requirements either face to face or on the phone and will subsequently offer training recommendations that are both relevant to you and in keeping with local and national guidance. This prospectus sets out a range of training opportunities available 'in house' or through accessible centralised locations.

All participants will receive access to full session handouts and a certificate of attendance.

There is no charge to care homes in the Cambridgeshire and Peterborough areas due to centralised funding.

## What we expect from you

- Commitment of regular attendance
- Support for the learning process
- Support after training for application of learning into clinical practice



## Core training

### Location: In-house

Our core dementia care training programme is delivered within your care home or workplace for a consistent group of up to 15 staff. Each session lasts three hours – these are arranged at your convenience, subject to availability.

**Managers** - the core training will support your staff teams' development in keeping with standards 3 and 7 of the common induction standards (Skills for Care, 2010).

This format enables in-depth exploration of key topic

areas related to the provision of high-quality dementia care. At the end of this course, participants should have sufficient knowledge and skills to work confidently with people living with dementia. This method ensures that groups working together also learn together.

The core training approach can be combined with practice development input (Section 2), this goes some way to bridging the gap between learning and practice application.

### What is dementia?

This session will support improved knowledge and understanding of dementia, including an awareness of the common types and their typical presentation. The common 'disabilities' caused by dementia will be explored. Participants will be aware of the similarities and differences between dementia, depression and acute confusion.

### Person-centred care

This session will introduce a model of person-centred care. Participants will be able to discuss the potential benefits to this approach and consider application to their own work. Potential challenges to the successful introduction of the person-centred model of care will be explored.

### Communication

Good communication and supportive relationships are central to high-quality dementia care. This session will enable participants to understand the common communication difficulties experienced by those with dementia. The session will cover effective communication skills and will enable participants to explore responses to common communication dilemmas.

### Purposeful activities

This session will help staff to develop an understanding of the importance of meaningful activity for people with dementia. Participants will be able to consider the selection and matching of activities in accordance with interests and abilities. The workshop will help staff to recognise the emotional significance of helping individuals to engage in activities which are meaningful to them.

### Behaviours that challenge

Participants will be able to recognise different forms of perceived 'challenging behaviour' commonly experienced in dementia care. An appreciation that such behaviours are often caused by unmet needs is a key learning outcome of this session. Staff will be able consider methods of intervening in an attempt to meet or understand the individual's underlying needs.

### Who might benefit from these sessions?

All care staff either in a care home or the community (eg, domiciliary care) would benefit from these in-depth interactive sessions. No prior experience of dementia care is required. Refresher training can be arranged on request. Smaller homes may wish to collaborate with other homes to form a group of staff for training.

To book, please contact CAMTBD-OP on:

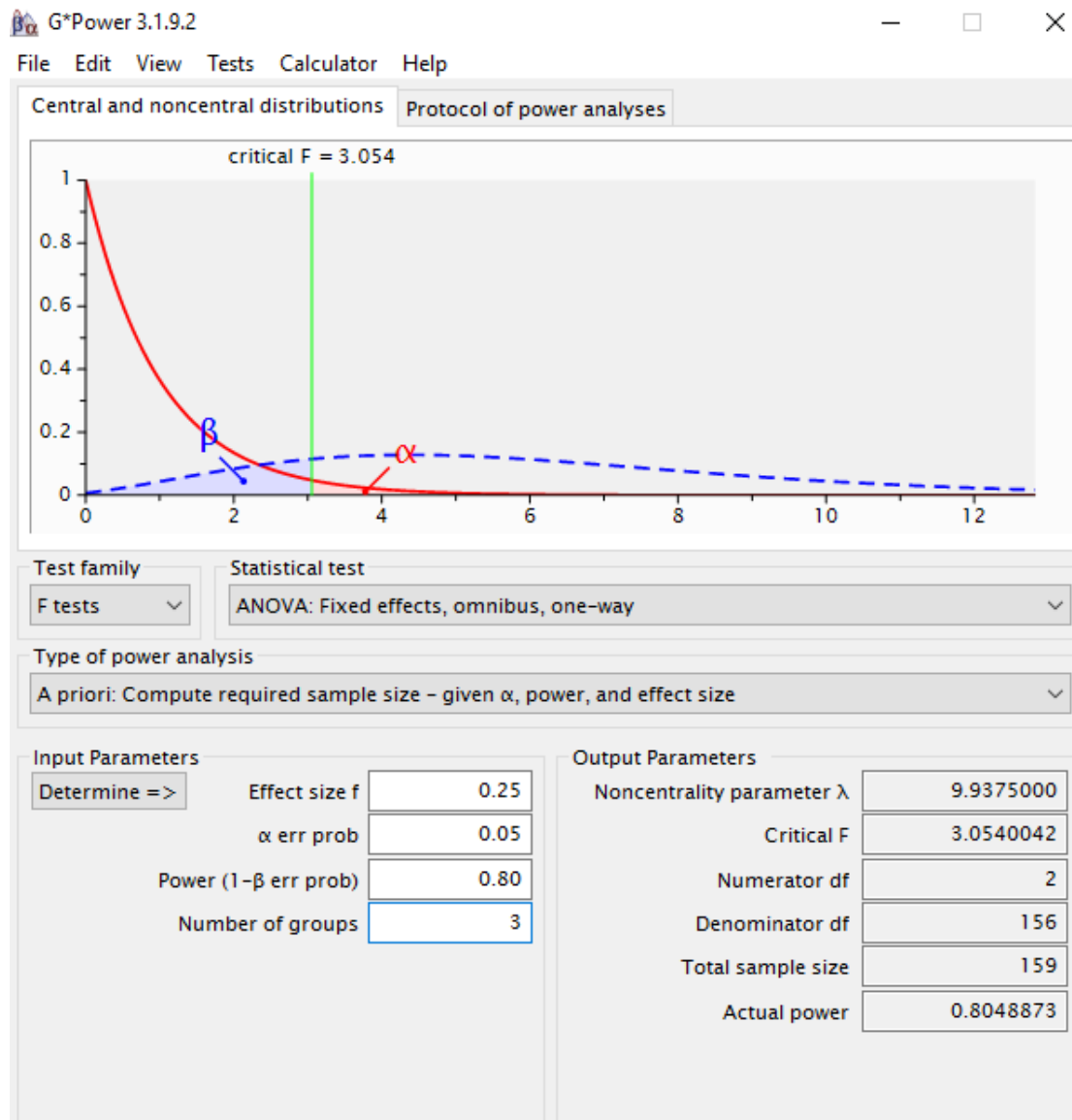
T 01223 218941  
E [camted-op1@cpft.nhs.uk](mailto:camted-op1@cpft.nhs.uk)

There is no charge to care homes in the Cambridgeshire and Peterborough areas due to centralised funding.

## Appendix B

### Power Calculation

Power Calculation conducted using G\*Power (Faul et al., 2009)



## **Appendix C**

### **Structure and learning objectives of training packages**



**Appendix C1****Overview of the structure and learning objectives of CAMTED***CAMTED Standard Training Package*

Session format for intervention		
Session Number	Elements of training	Specific learning objectives
1	What is dementia?	Support improved knowledge and understanding of dementia.  Awareness of the common types of dementia and their presentation.  The common 'disabilities' caused by dementia  Similarities and differences between dementia, depression and acute confusion.
2	Person-centred care	Introduce a model of person-centred care.  Potential benefits to this approach and consider application to their own work.

		Potential challenges to successful introduction of the person-centred model of care.
3	Communication	Understand the common communication difficulties experienced by those with dementia.  What are effective communication skills?  Explore responses to common communication dilemmas.
4	Purposeful Activity	Understanding the importance of meaningful activity for people with dementia.  Selection and matching of activities in accordance with interests and abilities.  Recognise the emotional significance of helping individuals to engage in activities which are meaningful to them.
5	Behaviours that challenge	Recognise different forms of perceived

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‘challenging behaviour’ commonly  
experienced in dementia care.

An appreciation that such behaviours are often  
caused by unmet needs.

Consider methods of intervening in an attempt  
to meet or understand the individual’s  
underlying needs.

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## Appendix C2

### Overview of the structure and learning objectives of CAMTED-Plus

*Person-Centred Approaches to Practice with dementia (PCAP) - Session format for intervention*

<b>Training Session One</b>			
<b>Understanding formulation in stress and distress behaviours with dementia</b>			
Time	Activity	Outline	Learning Points
15 minutes	Group introductions		
	Introduction to the PCAP module.		Understanding of PCAP module e.g. session format, length, in-between session task
	Bridge to previous behaviours that challenge session.		
	Introduce the terms ‘Stress’ and ‘Distress’		Understanding of the terms ‘stress’ and ‘distress’.
	Definitions of SAD-behaviours and behaviours that challenge – bridge these two terms.	Provide definitions of SAD-behaviours and behaviours that challenge. Use diagram to	Understanding how these two terms are interlinked and provide an internal and external

		demonstrate their link.	perspective.
15 minutes	Activity One: Discussion	5 minutes Ask the training group to split into pairs and talk with their partner about a time they have interacted with someone experiencing ‘SAD. This may be at work or outside of work. Discussion points: How did this person feel? What was the impact of SAD on their behaviour? What do they think was going on internally for that person? How did they feel about the person?	Understanding the internal world of the person experiencing ‘SAD’ and how this effects behaviour.  Understanding that SAD-behaviours are not isolated to the individual living with dementia. Care home staff also experience SAD and this can impact on their behaviour.
		10 minutes Training group feedback/reflect on ideas as a whole.	
15 minutes	Understanding dementia from a psychological perspective	Introduction to psychological perspectives for understanding SAD-behaviours:	Understanding psychological perspectives of SAD-behaviours.

		Progressively Lowered Stress Threshold; Unmet Needs; ABC; Functional Analysis.	
15 minutes	Activity Two: Behaviour case vignettes	10 minutes Training group to split into small groups. Handout of three case vignettes and possible needs.	Understanding SAD-behaviours are non-random. There is always a function/meaning behind it
		5 minutes Training group feedback as a group.	
15 minutes	Introduction to ‘formulation’	What is formulation – ‘seeing the bigger picture’  Primacy and Recency effects and impression formation.	Understanding formulation and how it is like a jigsaw.  Understanding that pieces of information on their own can be misleading and lead to snap judgements being made about someone.  Understanding that it is often the

			first and last pieces of information that we retain and use to form a global impression of someone.
15 minutes	Understanding SAD-behaviours in a psychological way.  Bigger Picture Jigsaw Activity - Part 1  'Not the full picture'	See separate handout for theory, development and delivery of the Jigsaw Activity	Case examples of formulation using the Jigsaw tool.
15 minutes	Break	Break	Break
40 minutes	Bigger Picture Jigsaw Activity – Part 2  'Big picture'	See separate handout for theory, development and delivery of the Jigsaw Activity	Case examples of formulation using the Jigsaw tool.
25 minutes	Introduction to Formulation Model	Explain formulation model (10 minutes)  Case examples (Michael)  10 minutes Training group to fill in	Understanding formulation model.    Application of principles using case examples.

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		<p>biological, social and circumstantial information on the formulation model - using Michael's information (provided as handouts)</p> <p>5 minutes</p> <p>Feedback as a group</p>	
10 minutes	In-between session activity	<p>Provide handout</p> <p>Care staff to identify an individual they are currently working with and to collect some details relating to the formulation model that they would be willing to share with their peer group at the next training session.</p> <p>Facilitator to say to the group that we understand that they may not have access to all of the</p>	<p>The purpose of the in-between session activity is to ensure care staff apply learning in situ.</p>

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information and we do not expect all information for each domain to be collected.

If staff could have a go at collecting as much or as little as they can over the next week.

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**Training Session Two**

**Using formulation in stress and distress behaviours with dementia**

Time	Activity	Outline	Learning Points
15 minutes	Recap of previous session (bridge)		
30 minutes	Activity 1: Review in-between session activity	Provide blank handout of the formulation model.	Application of formulation using a clinical case
		<u>15 minutes</u>	
		Group members who have	

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brought details for someone they are working with to have a go at putting the information they collected into the model (just biological, social and circumstantial information and SAD-behaviours)

If only a subset of group members have collected details. Care staff to work in groups and do the above.

If no group members have been able to collect details. Provide handouts on either Michael or Edith from the previous session and individuals to do the above.

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15 minutes

Ask group if someone would share their details to work through as a whole. Group to brainstorm possible unmet needs for this person

If no-one in the group is happy to do this or no group members have brought any details to work through Eva or Michael case – brainstorming possible unmet needs.

30 minutes

Unmet needs ‘Filling in the blanks’

15 minutes

Case study: Ellen

Application of formulation using a clinical case

Describe the case of Ellen and the

intervention.

Provide as handout.

Show formulation model, which provides details on biological, social and circumstantial factors and the behaviours.

Understanding of how an intervention was used to meet an individual's unmet need.

15 minutes

Provide a list of possible unmet needs. Ask the group to identify what unmet needs they think Ellen has and how the intervention met Ellen's needs.

15 minutes

Break

Break

Break

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40 minutes	Making sense – interventions	<u>20 minutes</u>	Understanding of possible interventions for SAD-behaviours.
		Provide a list of types of interventions for SAD-behaviours.	
		Split the group into 2 (each group has 7 interventions each). Ask each group to pick three interventions from their list and generate possible pros and cons for those interventions to share with the other group.	Applying critical thinking skills to evaluate the pros and cons of possible interventions.
		Groups come together and share pros and cons for the interventions selected.	
		<u>20 minutes</u>	
		Case Study: Andrew	

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		Describe Andrew’s case and provide formulation handout (domain factors and behaviours completed)	
		Group consider possible unmet needs from a selection.	
		Group to consider possible interventions from list to meet. Group brainstorm pros and cons of the interventions and how they would meet Andrew’s needs.	
15 minutes	Putting into practice	Group to brainstorm ‘putting into practice’ and possible barriers	Staff are encouraged to think about how they apply the formulation model to their practice.

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To consider possible barriers and ways to overcome these.

Summary

Summary points of training.

Summary:

Main take home messages from training.

One thing group members will take away.

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30 minutes

Outcome measures

Outcome measures

Outcome Measures

Advise group that we will be in touch in 4 weeks' time for them to complete the questionnaires for a final time.

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**Appendix D**  
**Delivery Options for Training**



**Appendix D1**

**Delivery options for CAMTED**

*CAMTED delivery of training breakdown*

	Week 1	Week 2	Week 3	Week 4	Week 5
Option 1	3 hours (half day)	3 hours (half day)	3 hours (half day)	3 hours (half day)	3 hours (half day)
	What is dementia?	Person-centred care	Communication	Purposeful Activity	Behaviours that Challenge
Option 2	6 hours (full day)	6 hours (full day)	3 hours (half day)		
	What is dementia?	Communication	Behaviours that Challenge	-	-
	Person-centred care	Purposeful Activity			

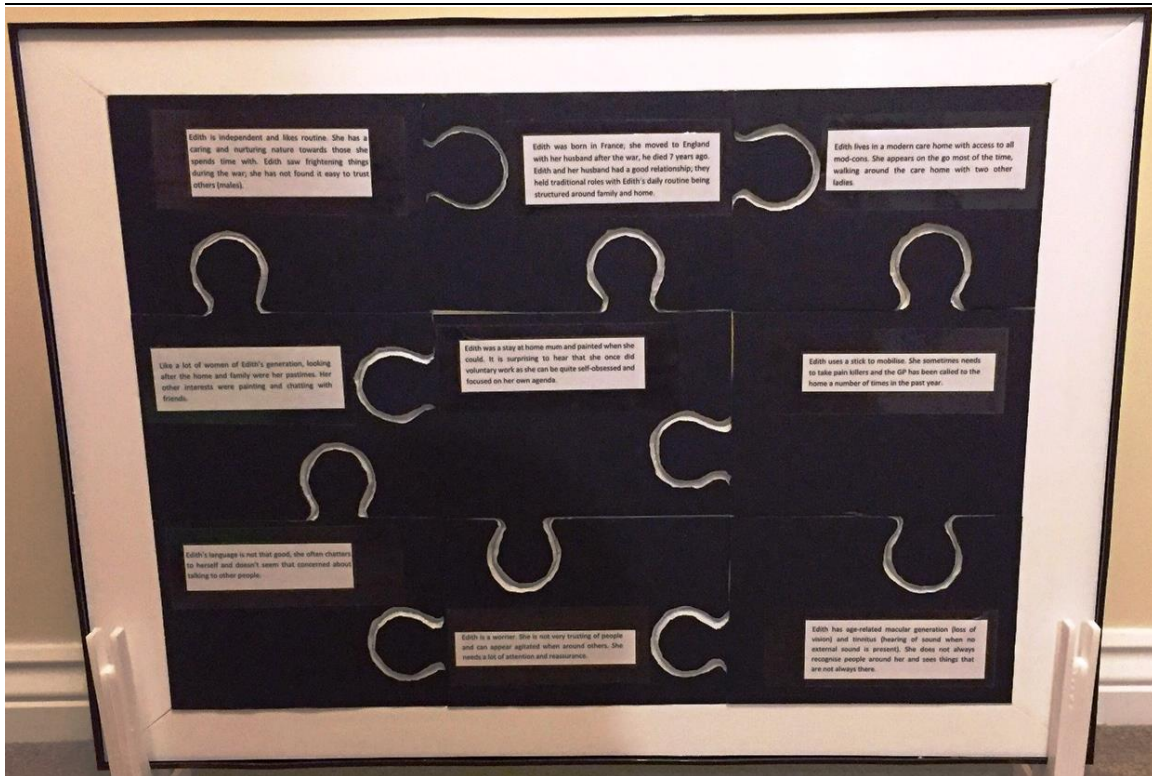
**Appendix D2: Delivery options for CAMTED**

*CAMTED-Plus delivery of training breakdown*

	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7
Option 1	3 hours (half day)	3 hours (half day)	3 hours (half day)	3 hours (half day)	3 hours (half day)	3 hours (half day)	3 hours (half day)
	What is dementia?	Person-centred care	Communication	Purposeful Activity	Behaviours that Challenge	PCAP Session 1	PCAP Session 2
Option 2	6 hours (full day)	6 hours (full day)	3 hours (half day)	3 hours (half day)	3 hours (half day)		
	What is dementia?	Communication	Behaviours that Challenge	PCAP Session 1	PCAP Session 2	-	-
	Person-centred care	Purposeful Activity					

Appendix E

A photographic representation of the Jigsaw tool





Michael's memory is not that good, but is better than other residents in the home and he seems to remember when he wants to.

Michael worked locally as a manager in a factory. He was quite successful and a lot of people will remember him being quite stern. He didn't suffer fools gladly.

Michael is quite an anxious individual and seems to be quite emotional out of the blue (tearful). He is a bit of a worrier and needs a lot of reassurance.

Michael is wheelchair bound, he suffered a stroke 12 years ago that left him paralysed on his left hand side. Recurring skin sores leave him in pain and he regularly experiences chest infections.

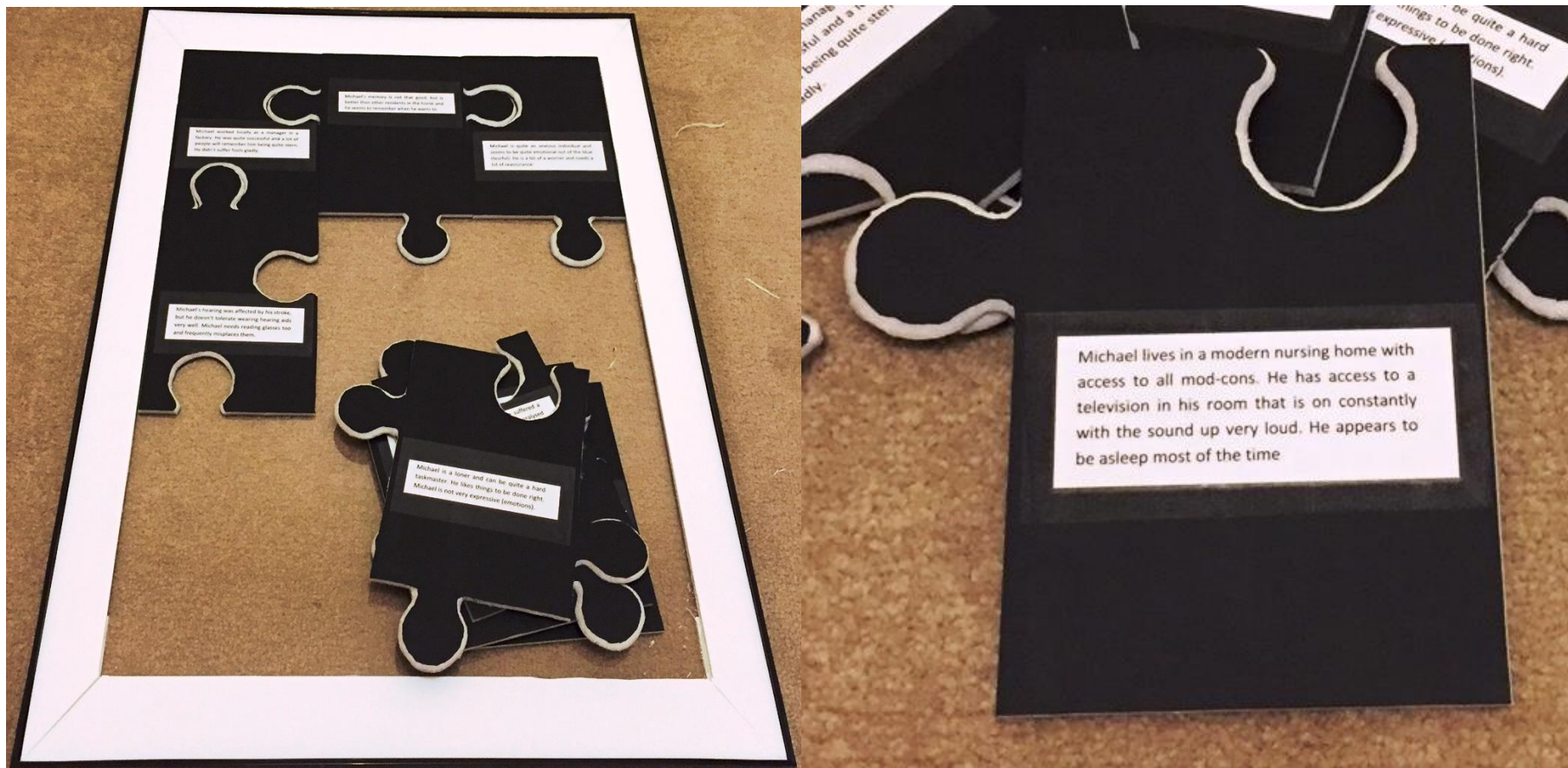
Michael's hearing was affected by his stroke, but he doesn't tolerate wearing hearing aids very well. Michael needs reading glasses too and frequently misplaces them.

Michael is a former and can be quite a hard taskmaster. He likes things to be done right. Michael is not very expressive (emotional).

Michael lives in Southwell, he follows his local team as well as his old team from when he was a boy. He is a keen gardener and used to have a greenhouse where he would grow tomatoes.

Michael lives in a modern nursing home with access to all mod cons, he has access to a television in his room that is an essential with the sound up very loud. He appears to be asleep most of the time.

Most of Michael's generation can be diagnostic and inflexible in their dealings with others, in his generation family may not be as important as before. Michael is a very controlling individual.



**Appendix F**  
**Outcome Measures**

**Appendix F1****Approaches to Dementia Questionnaire**

Please indicate to what extent you agree or disagree with each of the following statements:

- 1. It is important to have a very strict routine when working with dementia sufferers.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

- 2. People with dementia are very much like children.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

- 3. There is no hope for people with dementia.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

- 4. People with dementia are unable to make decisions for themselves.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

- 5. It is important for people with dementia to have stimulating and enjoyable activities to occupy their time.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

- 6. Dementia sufferers are sick and need to be looked after.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

- 7. It is important for people with dementia to be given as much choice as possible in their daily lives.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

- 8. Nothing can be done for people with dementia, except for keeping them clean and comfortable.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

**9. People with dementia are more likely to be contented when treated with understanding and reassurance.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

**10. Once dementia develops in a person, it is inevitable that they will go downhill.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

**11. People with dementia need to feel respected, just like anybody else.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

**12. Good dementia care involves caring for a person's psychological needs as well as their physical needs.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

**13. It is important not to become too attached to residents.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

**14. It doesn't matter what you say to people with dementia because they forget it anyway.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

**15. People with dementia often have good reasons for behaving as they do.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

**16. Spending time with people with dementia can be very enjoyable.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

**17. It is important to respond to people with dementia with empathy and understanding.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

**18. There are a lot of things that people with dementia can do.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree



**19. People with dementia are just ordinary people who need special understanding to fulfil their needs.**

Strongly Agree    Agree    Neither Agree nor Disagree    Disagree    Strongly Disagree

TOTAL:		RP:		H:	
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**Appendix F2****Dementia Knowledge Questionnaire****Dementia Knowledge-20 items (DK-20)**

The questions below aim to gain an understanding of your knowledge and approach to the care of older adults living with dementia. Each question provides you with four possible answers. You may find that some questions appear to have more than one correct answer, in this case please circle the 'best' or 'ideal' answer for the question.

Please try to answer all questions.

- 1. The number of people living with dementia in the UK general population is expected to: *(Circle only one option)***
  - a) Decrease slightly
  - b) Remain approximately the same
  - c) Increase in proportion to the number of people over 65 years of age
  - d) Triple over the next 20 years
  - e) I don't know
  
- 2. There is/are: *(Circle only one option)***
  - a) One type of dementia
  - b) 2-3 types of dementia
  - c) 3-4 types of dementia
  - d) More than 6 types of dementia
  - e) I don't know
  
- 3. Which of the following is always present in Alzheimer's disease? *(Circle only one option)***
  - a) Memory difficulties and incontinence
  - b) Memory and language difficulties
  - c) Incontinence and hallucinations
  - d) Personality changes and dizziness
  - e) I don't know
  
- 4. A person suspected of having dementia should be assessed as soon as possible because: *(Circle only one option)***
  - a) Treating them right away can stop memory problems from becoming worse

- b) Treating them right away may reverse memory problems
- c) It allows the individual more opportunity to make decisions about their care
- d) Drug treatment is only available when the dementia is diagnosed early
- e) I don't know

**5. A person's chances of developing vascular dementia are greater if: (Circle only one option)**

- a) They are above average intelligence
- b) They have blood circulation/blood pressure problems
- c) Their parents or grandparents had a diagnosis of Parkinson's disease
- d) They are female
- e) I don't know

**6. In order to make a diagnosis of dementia (Circle only one option)**

- a) The person must be over 65
- b) The person needs to be showing symptoms of memory loss for over 3 months
- c) Memory and one other area of cognitive function are impaired
- d) The person needs to be in care
- e) I don't know

**7. Drug treatment available through the NHS for Alzheimer's disease: (Circle only one option)**

- a) Can stop symptoms from getting worse
- b) Only works during the early stages of the condition
- c) Can slow down cognitive decline and improve functioning for a period of time
- d) Is not recommended for those over 75 years of age
- e) I don't know

**8. The more complex presenting problems in dementia such as physical aggression, restlessness and wandering could be: (Circle only one option)**

- a) Due to untreated high blood pressure
- b) Behaviours you would typically expect to see in a person with dementia
- c) Behaviours more typical of women with dementia rather than men with dementia
- d) Associated with the moderate/late stages of dementia
- e) I don't know

**9. Mental Health problems such as anxiety and depression: (Circle only one option)**

- a) Are rarely found in people diagnosed with dementia
- b) Are found in all people diagnosed with dementia
- c) Only appear in dementia if the person experienced them before developing dementia
- d) Can appear before, during or after the onset of dementia
- e) I don't know

**10. Behaviours considered to be challenging or aggressive most likely occur: (Circle only one option)**

- a) When a person with dementia is feeling frustrated
- b) If the person with dementia is not getting their needs met in some way
- c) When the person with dementia cannot communicate their needs effectively
- d) All of the above
- e) I don't know

**11. Engaging a person with dementia in a structured activity (such as reminiscence or cognitive stimulation): (Circle only one option)**

- a) Helps them stop losing skills in the long-term
- b) Is a fun way to pass the time but there are no benefits to the person
- c) Can help improve social relationships and quality of life
- d) Often causes further decline
- e) I don't know

**12. A new resident in the care home, Judy, is in the moderate stages of dementia. She is refusing to eat meals in the dining hall with other residents. Judy has language impairment and so it is difficult to communicate with her verbally. In this situation the best option would be to: (Circle only one option)**

- a) Give Judy her food in a separate room to avoid upsetting her and look at her notes, talk to her family and carefully observe her to search for information that might help explain her behaviour
- b) Give Judy all her meals in her bedroom
- c) Not give Judy any dessert until she agrees to eat in the dining hall
- d) Try to make Judy understand that it's important she socialises by eating together with everyone
- e) I don't know

**13. In trying to help a resident with dementia remember to take off their hearing aid at night time, the best option would be to: (Circle only one option)**

- a) Remind them every evening as it will eventually sink in
- b) Provide them with memory aides such as a large reminder beside their bed
- c) If they have forgotten in the morning, gently tell them off (as punishment helps recall)
- d) Take it off for them as this is the only reliable option
- e) I don't know

**14. If a resident with dementia becomes upset asking for a close relative that you know passed away many years ago, the best option would be to: (Circle only one option)**

- a) Be honest, explain that their relative has died and will not be coming, even if it causes distress each time
- b) Tell them that their relative will be coming along soon, as you don't want to upset them any further
- c) Spend time asking them questions and allowing them to speak about their deceased relative, whilst trying to identify what triggered the question
- d) Ignore their behaviour and put on the television as a distracter
- e) I don't know

**15. If a resident becomes agitated because they start to hallucinate (sees or hears things not seen by others) the best thing to do is: (Circle only one option)**

- a) Tell them to calm down as there is nothing there
- b) Comfort their feelings without saying whether or not you think there is something there
- c) Pretend that you too can see and hear them and tell the person there is nothing to worry about
- d) Ignore the behaviour as it will eventually stop
- e) I don't know

**16. When a disoriented person with dementia does not understand what you are saying to them, the best thing to do is: (Circle only one option)**

- a) Speak to them more clearly in a louder voice, using visual prompts if possible
- b) Drop the matter as you are unlikely to get through to them
- c) Repeat what you are trying to say over and over until they understand
- d) Try to get someone else to ask them questions in the future
- e) I don't know

**17. Sally is an 81-year-old resident living with dementia. She has 8 children and 25 grandchildren. Sally was a housewife for most of her life and before moving to the home she nursed her husband through a terminal illness. She very much enjoys helping to clean up after meals, and staff are happy for her to do this. However, recently, Sally is becoming increasingly frail and is at risk of falling and seriously hurting herself. To best manage this situation you should: (Circle only one option)**

- a) Thank Sally for her help but point out that she is too old and frail now
- b) Despite the risk, allow Sally to continue helping as it seems to give her so much pleasure and makes her feel needed
- c) Discuss your concerns about risk with Sally and help her to find a helping/caring role that, although less enjoyable for her, is less physically demanding
- d) Ask one of the other resident's to carry out Sally's role instead
- e) I don't know

**18. Which statement is true of people in the advanced stages of dementia? (Circle only one option)**

- a) They can often see and hear but may not recognise and understand
- b) They can no longer experience emotions
- c) They are unable to form new relationships
- d) None of the above
- e) I don't know

**19. Jenny - an elderly resident with mild dementia, who is able to make her own decisions, is insisting on giving all her jewellery to a charity shop. She has many beautiful and expensive items that she has had for years: In this situation the best thing to do would be to: (Circle only one option)**

- a) Call her relatives informing them of her intention and try to work together to stop Jenny from doing this
- b) Try to convince Jenny otherwise as you feel it is a silly idea and something she might later regret
- c) Have Jenny's jewellery collection removed from her bedroom and put in the office for safe keeping
- d) Once you are sure Jenny understands the consequences and her family have been informed, support her in her decision
- e) I don't know

**20. Disoriented and confused behaviour among residents with dementia becomes a serious risk issue when they:**

***(Circle only one option)***

- a) Wake up at night and want a drink
- b) Ask the same questions over and over
- c) Cannot remember their children's names
- d) Cannot take safe care of themselves
- e) I don't know

**Appendix F3****The Maslach Burnout Inventory – Human Services Survey**

[www.mindgarden.com](http://www.mindgarden.com)

To whom it may concern,

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## MBI-Human Services Survey

How often:	0	1	2	3	4	5	6
	Never month a week	A few times a week or less	Once a week	A few times	Once a year	A few Every day or less	times a month
How Often	0-6	Statements:					
1. _____		I feel emotionally drained from my work.					
2. _____		I feel used up at the end of the workday.					
3. _____		I feel fatigued when I get up in the morning and have to face another day on the job.					

### Appendix F4

#### The English translation of the Swedish Satisfaction in Nursing Care and Work Scale

#### Swedish Satisfaction in Nursing Care and Work Scale

Please indicate to what extent you agree or disagree with each of the following statements:

**1. My duties at work are stimulating**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**2. My duties at work are varied**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**3. I am able to organise my working conditions so that I can work at a pace which is comfortable to me**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**4. I often find that I do not complete everything that I should in my job**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**5. My opinions are considered when changes are made at work**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**6. I worry that my own job situation will change because of changes to the organization**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**7. I am satisfied with the independence I have in my job**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**8. I am satisfied with the responsibility I have in my job**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**9. Our work organization is good**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**10. Our staff work well together**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**11. There is a friendly atmosphere at work**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**12. I often feel that I know too little about the patients'/residents' disease and treatment**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**13. I often feel that I know too little about the patients'/residents' personal background, habits and wishes**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>		<b>Complete Disagreement</b>

**14. There are enough opportunities at work to discuss the psychological stress of the job**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>		<b>Complete Disagreement</b>

**15. The patients/residents at work nearly always receive good care**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>		<b>Complete Disagreement</b>

**16. The patients are given enough information about their disease**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>		<b>Complete Disagreement</b>

**17. The patients/residents are given enough information before examinations and treatment**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>		<b>Complete Disagreement</b>

**18. Newly admitted patients/residents are given enough information about the routine in the place where I work**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>		<b>Complete Disagreement</b>

**19. Relatives are given enough information about care and treatment**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>Complete Disagreement</b>

**20. It is important to try and enter into the way patients experience what happens to them**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>Complete Disagreement</b>

**21. It is too much to expect that I can involve myself with every patient/resident**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>Complete Disagreement</b>

**22. It is difficult to manage the job if you get too involved with the patients/residents**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>Complete Disagreement</b>

**23. I seldom have time to try and understand what the patients/residents think about our care**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>Complete Disagreement</b>

**24. It is boring to work with the same patients/residents every day**

<b>Complete Agreement</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>Complete Disagreement</b>

**25. I enjoy my current work situation**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**26. I feel that I am developing a person from my work here**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**27. I feel that I am developing professionally from my work here**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**28. I often receive encouragement from others for the work I do**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**29. I often receive constructive (i.e. helpful) criticism about the work I do**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**30. My colleagues value what I do at work**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**31. My colleagues often ask me for information I can give about particular patients**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**32. We often discuss ways of improving the care we give (e.g. alternative care methods, setting care goals, changing the work routine)**

Complete Agreement	1	2	3	4	5	Complete Disagreement

**Appendix F5**

**Stress and Distress Behaviour Scale**

**Stress and Distress Behaviour Scale**

We know that behaviours perceived to be challenging with dementia are subjective and very much in the eye of the beholder. Please take a moment to think about a resident you currently care for or have recently cared for that you have found to be challenging or someone you consider to have been the most challenging in your professional context. It would probably be most useful if you think of someone you have cared for who is/was living with dementia. Once you have chosen please complete the scales below by putting a tick in the appropriate box where 0 means a behaviour has not been a challenge at all, and 9 means a behaviour has been challenging to you constantly (all the time).

**1. Physical aggression (e.g. biting, nipping, kicking etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**2. Self-Harm (cuts/hits self, refuses food/starves self-etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**3. Agitated (unable to settle down, pacing, fidgets etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**4. Attention Seeking (demands attention etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time		

**5. Verbal Aggression (insults, swearing, threats etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**6. Manipulative (takes advantage of others, staff etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**7. Non-compliance (deliberately ignores staff requests, refuses food, resists self-care, help etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**8. Please use this scale to rate a behaviour you have found challenging that we have not included above.**

Write the behaviour here: \_\_\_\_\_

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	



**Appendix F5**

**Stress and Distress Behaviour Scale**

**Stress and Distress Behaviour Scale**

We know that behaviours perceived to be challenging with dementia are subjective and very much in the eye of the beholder. Please take a moment to think about a resident you currently care for or have recently cared for that you have found to be challenging or someone you consider to have been the most challenging in your professional context. It would probably be most useful if you think of someone you have cared for who is/was living with dementia. Once you have chosen please complete the scales below by putting a tick in the appropriate box where 0 means a behaviour has not been a challenge at all, and 9 means a behaviour has been challenging to you constantly (all the time).

**9. Physical aggression (e.g. biting, nipping, kicking etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**10. Self-Harm (cuts/hits self, refuses food/starves self-etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**11. Agitated (unable to settle down, pacing, fidgets etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**12. Attention Seeking (demands attention etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time		

**13. Verbal Aggression (insults, swearing, threats etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**14. Manipulative (takes advantage of others, staff etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**15. Non-compliance (deliberately ignores staff requests, refuses food, resists self-care, help etc.)**

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**16. Please use this scale to rate a behaviour you have found challenging that we have not included above.**

Write the behaviour here: \_\_\_\_\_

Not at all	0	1	2	3	4	5	6	7	8	9	All the time	

**Appendix F6**

**Frequency, Intensity and Confidence Likert Scales**

**Frequency and Intensity of Stress and Distress Behaviours Scales**

1. Please rate on the scale below how frequently you come into contact with stress and distress behaviours at your place of work. Place a tick in the appropriate box where 0 means there are no stress and distress behaviours and 6 means there are stress and distress behaviours occurring every hour.

	<b>None</b>	<b>Monthly</b>	<b>Every two to three weeks</b>	<b>Weekly</b>	<b>Every two to three days</b>	<b>Daily</b>	<b>Every hour</b>	
	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	

2. Please rate on the scale below the intensity of stress and distress behaviours at your place of work. Place a tick in the appropriate box where 0 means the stress and distress behaviours are not intense at all and 6 means the stress and distress behaviours are very intense.

	<b>Not intense at all</b>	<b>Not intense</b>	<b>Somewhat not intense</b>	<b>Neither not intense or intense</b>	<b>Somewhat intense</b>	<b>Intense</b>	<b>Very intense</b>	
	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	

**Confidence in managing Stress and Distress Behaviours Scale**

1. Please rate on the scale below how confident you are at managing stress and distress behaviours at your place of work. Place a tick in the appropriate box where 0 means not confident at all and 6 means very confident.

	Not confident at all	Unconfident	Somewhat unconfident	Neither unconfident or confident	Somewhat confident	Confident	Very confident	
0		1	2	3	4	5	6	

**Appendix F7**

**Participant Demographic Questionnaire**

**Demographic Questionnaire**



**Age:** \_\_\_\_\_

**Gender:** \_\_\_\_\_

**Nationality:** \_\_\_\_\_

**Level of education:** \_\_\_\_\_

**Job title:** \_\_\_\_\_

**Length of time in current employment:** \_\_\_\_\_

**Length of time working in services for people living with dementia:** \_\_\_\_\_

**Where do you work in the care home e.g. residential, nursing, dementia care unit:**

\_\_\_\_\_

**Have you had any other training on dementia in the past year? If yes, please provide a few details e.g. number of days:**

\_\_\_\_\_

\_\_\_\_\_

**Appendix F8****Care Home Demographic Questionnaire**

**Lucy de Pfeiffer**  
**Trainee Clinical Psychologist**  
Newtown Centre  
Nursery Road  
Huntingdon  
Cambridgeshire  
PE29 3RJ



Care Home Code:

**Demographic Questionnaire**

1. What is the general age and gender profile of your residents?
  
  
  
  
  
  
  
  
  
  
2. Do you have a 'philosophy of care'? If you do, would you be happy to share with us what this is?
  
  
  
  
  
  
  
  
  
  
3. What is the average length of stay for a resident?
  
  
  
  
  
  
  
  
  
  
4. What is the primary route to becoming a resident?

**Appendix F9**

**Jigsaw Evaluation**

**Jigsaw Evaluation**

**1. Did you enjoy the use of the jigsaw activity in the training?**

<b>Not at all</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>Very much</b>		

**2. Did you understand the purpose of the jigsaw activity?**

<b>Not at all</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>Very much</b>		

**3. Did you find the jigsaw activity helpful in showing the ideas presented in the training?**

<b>Not at all</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>Very much</b>		

4. Do you think the jigsaw activity has changed your attitude/approach to people living with dementia?

Not at all	0	1	2	3	4	5	6	7	8	9	Very much	

If it has changed your attitude/approach, please provide a few details on how it has changed:

---



---



---



---



---

5. Do you think that your practices will change as a result of the jigsaw activity?

Not at all	0	1	2	3	4	5	6	7	8	9	Very much	

If your practice will change, please provide a few details on how it will change:

---



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**Appendix G**  
**Ethical Approval Letter**

Faculty of Medicine and Health Sciences Research Ethics Committee



University of East Anglia

Lucy De Pfeiffer  
MED

Research & Enterprise Services  
West Office (Science Building)  
University of East Anglia  
Norwich  
Research  
Park  
Norwich,  
NR4 7TJ

Telephone: +44 (0) 1603  
591720 Email:  
[fmh.ethics@uea.ac.uk](mailto:fmh.ethics@uea.ac.uk)

Web: [www.uea.ac.uk/researchandenterprise](http://www.uea.ac.uk/researchandenterprise)

15<sup>th</sup> July 2015

Dear Lucy

A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia

20142015-62

The amendments to your above proposal have been considered by the Chair of the Faculty Research Ethics Committee and we can confirm that your proposal has been approved by Chair's Action,

Please could you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance and also that any adverse events which occur during your project are reported to the Committee. Please could you also arrange to send us a report once your project is completed.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Mark Wilkinson'.

Mark Wilkinson  
Chair FMH Research Ethics Committee

**Appendix H****Gatekeeper Written Consent Letter**

**Lucy de Pfeiffer**  
**Trainee Clinical Psychologist**  
Department of Psychological Sciences  
Norwich Medical School  
University of East Anglia  
Norwich Research Park  
Norwich NR4 7TJ

**Care home manager name**  
**Care home manager title**  
Care home address  
Care home contact details

Date

Dear Lucy,

**Re. Study: A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia**

Please accept this letter as confirmation that I have received information about the above study and approve for it to take place at [care home name], at the above address using our care staff.

Yours Sincerely

Care home manager signature

## Appendix I

### Participant Information Sheets

#### Participant Information Sheet Group 1



#### **A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia**

##### **Invitation paragraph**

I would like to invite you to take part in my trainee research study for Clinical Psychology. Before you decide whether you would like to take part, we would like you to understand why the study is being carried out, and what it would mean if you took part. You will be able to speak to a member of the research team either over the phone or in person, who will go through this sheet with you and answer any questions you have. Take time to decide whether or not you wish to take part.

Thank you for reading this.

##### **What is the purpose of the study?**

It is recognised that stress and distress behaviours with dementia (previously known as behaviours that challenge) can cause distress to the person with dementia and care home staff. The purpose of the study is to look at the effects of a dementia care training package for understanding stress and distress behaviours with dementia and how this training affects the frequency and intensity of behaviour within care homes, care home staff thoughts and feelings about their work and knowledge of dementia.

##### **Why have I been invited?**

You have been invited because you work in a care home and care directly for individuals living with dementia. You have worked at your current place of work for at least 1 month and you speak English.

##### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide that you would like to take part you will be given this information sheet to keep and will be asked to sign a consent

form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. If you do withdraw, the data collected up until this point may still be used.

### **What will happen to me if I take part?**

If you decide you would like to take part we will first arrange a session for you to meet a member of the research team. This session will give you the chance to ask any questions you may have about the study. This session will take place at your place of work and there may also be other interested participants at this session to find out more about the research. We will also provide you with the contact details of the researcher and research supervisors if you wish to discuss the study in any further detail.

If it has not been possible to arrange a session at your place of work, as we understand how busy a working environment it can be. We will discuss the study in detail with a manager at your place of work and/or senior member of staff and they will share this information with you. This information sheet also provides contact details of the researchers and research supervisors if you have any questions or wish to discuss the study further.

We will then arrange a further drop-in session at your place of work where you can come and ask any further questions and sign a consent form if you then decide you would like to participate in the study.

If it has not been possible to arrange a drop-in session on a day prior to the start of the training, we will arrange for a session to take place before the first training session starts. If you would like to take part in the study you can come to this session to ask any questions and sign a consent form.

### **What this study is investigating**

We are looking at the effects of different dementia care training sessions. Sometimes we don't know which way is the best. To find out, we need to compare different groups. We put people into groups and give each group a different group. The results are compared to see if one is better than the other. This study has three groups:

#### **Group 1**

In the first group will ask you to attend five, three hour training sessions at your place of work on person-centred dementia care. Before the first training session we will ask you to complete some questionnaires looking at your thoughts and feelings about your work. These will take approximately 20-30 minutes to complete. We will also ask you to complete these at the end of the final training session and four weeks after the training finishes.

#### **Group 2**

The second group will ask you to attend seven, three hour training sessions on person-centred dementia care with an in-between session task to be completed between sessions 6 and 7. Before the first training session we will ask you to complete some questionnaires looking at

your thoughts and feelings about your work. These will take approximately 20-30 minutes to complete. We will also ask you to complete these at the end of the final training session and four weeks after the training finishes.

### Group 3

The third group will be to go on a waiting list to receive person-centred dementia care training once the study has completed. We will arrange to meet with you at your place of work at three time points during your time on the waiting list to complete some questionnaires looking at your thoughts and feelings about your work. These will take approximately 20-30 minutes to complete.

## **YOUR CARE HOME HAS CHOSEN TO JOIN GROUP ONE**

Once the study has come to an end you will receive a debrief sheet. This will provide you with contact details for the primary researcher and research supervisors should you have any questions to discuss. The debrief page will also have information about resources available to you if you found completing the study in anyway distressing.

### **How long will I be involved for?**

Participation in this research will last between nine weeks and twelve weeks. If you are on a waiting list to attend training you will be asked to wait to begin this until the study completion.

### **Will I be paid to take part?**

We cannot offer individual payments to participants, but we will be holding a raffle at the end of the study for three £25 Amazon vouchers as a gesture of thanks for completing the study.

### **What are the possible benefits of taking part?**

Participants may find the study gives them the opportunity to develop knowledge and skills in person-centred dementia care and specifically understanding and managing stress and distress behaviours with dementia.

This training will provide you with up-to-date information on an approach to understanding stress and distress behaviours with dementia. This focuses on understanding the individual in their environment. By attending this training we hope you will develop greater understanding of engaging and supporting people with distress.

### **What are the possible disadvantages of taking part?**

There are potentially a few disadvantages to taking part. You will need to give up some of your time to attend the training sessions. There is a small chance that you may become upset at some of the questions asking about your feelings at work. Should this be the case, please

tell us immediately and together we can decide what to do – for example, you may to take some time out from the study or wish to withdraw from the study. Based on our experience and that of other researchers, we think the likelihood of the study causing you distress is small, but we want to be careful nonetheless, as your safety and wellbeing is most important to us.

**What happens when the research study stops?**

When the research study finishes, participants that have been on the waiting list to receive training will be contacted and offered training.

Once the study is completed a summary of the project will be made available in the format of a newsletter to be displayed on notice boards at your place of work. Contact details will be included if you would like further information.

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

You will be given our contact details so you can contact us at any point during the study to tell us if you have changed your mind about carrying on. As part of the research study you can withdraw from all of the research components at any stage without giving a reason. This includes completing the questionnaires. If you do not want to attend the training sessions, this will need to be discussed with your manager, as these training sessions are not within the control of the research study team as they may form part of your required training and will require approval from your manager to withdraw.

If you withdraw from the research components of the study we will destroy all your identifiable data, but we will need to use the data collected up to your withdrawal. If you withdraw part way through the study, we will unfortunately be unable to include you in the Amazon voucher raffle.

**How will my information be kept safe?**

We will keep your information confidential by giving you an individual participant number. This number will be used to mark all the questionnaires you complete. This means your name will not appear when we look at the data. Your information will not be identifiable in any reports or publications resulting from the study. The questionnaires you complete will be kept in a locked filing cabinet in a locked office on an NHS site.

Exceptions to confidentiality are if a member of the research team is concerned about risk to a participant or someone else (e.g. a resident). If a member of the research team is concerned about the safety of someone during the course of the study they will have to pass their concerns on and seek advice from their research/clinical supervisor on the same day as the concern is raised, who will decide whether other services need to be informed. Your safety as well as individuals receiving care is of paramount importance to us. If confidentiality is breached you will be withdrawn from the study.

If you decide you would like to enter the prize draw. We will ask you to provide your name and the option of either an email address, home address or work address. This data will be

stored securely as previously stated. Once the study is completed, the prize draw has taken place and the three winners picked at random notified. This data will then be deleted.

**Where and for how long will data be stored?**

Data will be stored in locked cabinets in university premises. It will be kept for up to ten years after the completion of the study and then destroyed.

**What will happen to the results of the research study?**

The results of the study will be reported as anonymous data. The study will be seen by colleagues and supervisors at the University of East Anglia, Doctoral programme in psychology and other members of the research team. Results may also become available more publicly if the research is published, however, no identifiable material will be published.

**Who is organising and funding the research?**

The research study is being organised by Lucy de Pfeiffer, Professor Ken Laidlaw, and Dr Paul Fisher, who are part of the Doctorate of Clinical Psychology Programme at the UEA School of Medicine and Alistair Gaskell who is part of Cambridgeshire Training, Education and Development for Older People (CAMTED-OP). It is being funded by the UEA Medical School.

**Who has reviewed the study?**

The research has been considered and approved by UEA Faculty of Medicine and Health Sciences Research Ethics Committee. The research has also been reviewed and approved by the University of East Anglia.

**What if there is a problem?**

If there is a problem and you wish to make a complaint, please contact the primary researcher or senior research tutor at UEA, using the following details:

Lucy de Pfeiffer  
L.de-pfeiffer@uea.ac.uk  
Study mobile: 07934113779

Dr Sian Coker  
S.Coaker@uea.ac.uk  
Tel: 01603 59 3600 (Mon-Fri, 9am – 5pm)

Doctoral Programme in Clinical Psychology  
University of East Anglia  
Queens Building  
Norwich  
Norfolk  
NR4 7TJ



**Further information and contact details**

Thank you for reading this. If you would like any more information about the study or need to contact the researcher, please feel free to contact Lucy de Pfeiffer (Trainee Clinical Psychologist).

Doctoral Programme in Clinical Psychology  
University of East Anglia  
Queens Building  
Norwich  
Norfolk  
NR4 7TJ

Tel: 01603 593600 (Mon-Fri, 9am – 5pm)

Email: [L-De.Pfeiffer@uea.ac.uk](mailto:L-De.Pfeiffer@uea.ac.uk)

Tel: 07934113779 (study mobile number)

*We wish to thank you for taking time to read this information sheet.*

**Participant Information Sheet**  
**Group 2**



**A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia**

**Invitation paragraph**

I would like to invite you to take part in a trainee research study for Clinical Psychology. Before you decide whether you would like to take part, we would like you to understand why the study is being carried out, and what it would mean if you took part. You will be able to speak to a member of the research team either over the phone or in person, who will go through this sheet with you and answer any questions you have. Take time to decide whether or not you wish to take part.

Thank you for reading this.

**What is the purpose of the study?**

It is recognised that stress and distress behaviours with dementia (previously known as behaviours that challenge) can cause distress to the person with dementia and care home staff. The purpose of the study is to look at the effects of a dementia care training package for understanding stress and distress behaviours with dementia and how this training affects the frequency and intensity of behaviour within care homes, care home staff thoughts and feelings about their work and care staff's knowledge of dementia.

**Why have I been invited?**

You have been invited because you work in a care home and care directly for individuals living with dementia. You have worked at your current place of work for at least 3 months and you speak English.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide that you would like to take part you will be given this information sheet to keep and will be asked to sign a consent

form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. If you do withdraw, the data collected up until this point may still be used.

### **What will happen to me if I take part?**

If you decide you would like to take part we will first arrange a session for you to meet a member of the research team. This session will give you the chance to ask any questions you may have about the study. This session will take place at your place of work and there may also be other interested participants at this session to find out more about the research. We will also provide you with the contact details of the researcher and research supervisors if you wish to discuss the study in any further detail.

At the end of this session we will provide ‘expression of interest forms’, which you can complete if you are interested in taking part in the study. An envelope will be provided to place the completed form in. These can be sealed and handed into a member of the research team at the end of the information session or can be sealed in a prepaid envelope provided and sent to the researcher directly if you would like to take the form away to think about participating further.

If it has not been possible to arrange a session at your place of work, as we understand how busy a working environment it can be. We will discuss the study in detail with a manager at your place of work and/or senior member of staff and they will share this information with you and provide you with a ‘participant pack’. This information sheet also provides contact details of the researchers and research supervisors if you have any questions or wish to discuss the study further.

If you are interested in taking part in the study after reading this information sheet, please complete the ‘expression of interest’ form included in this pack and return it to the research team in the prepaid envelope provided. This form is provided for you to express your interest in participating in this study. You will not be consented to participate in this study at this stage.

We will then arrange a further drop-in session at your place of work where you can come and ask any further questions and sign a consent form if you then decide you would like to participate in the study. The consent forms can also be taken away from the drop-in sessions and sealed in a prepaid envelope provided and sent to the researcher directly if you would like to think about participation further before consenting to taking part.

If it has not been possible to arrange a drop-in session on a day prior to the start of the training, we will arrange for a drop-in session to take place 30 minutes before the first training session starts. If you would like to take part in the study you can come to this session to ask any questions and sign a consent form.

### **What this study is investigating**

We are looking at the effects of different dementia care training sessions. Sometimes we don't know which way is the best. To find out, we need to compare different groups. We put people into groups and give each group a different group. The results are compared to see if one is better than the other. This study has three groups:

#### **Group 1**

In the first group will ask you to attend five, three hour training sessions at your place of work on person-centred dementia care. Before the first training session we will ask you to complete some questionnaires looking at your thoughts and feelings about your work. These will take approximately 20-30 minutes to complete. We will also ask you to complete these at the end of the final training session and four weeks after the training finishes.

#### **Group 2**

The second group will ask you to attend seven, three hour training sessions on person-centred dementia care with an in-between session task to be completed between sessions 6 and 7. Before the first training session we will ask you to complete some questionnaires looking at your thoughts and feelings about your work. These will take approximately 20-30 minutes to complete. We will also ask you to complete these at the end of the final training session and four weeks after the training finishes.

#### **Group 3**

The third group will be to go on a waiting list to receive person-centred dementia care training once the study has completed. We will arrange to meet with you at your place of work at three time points during your time on the waiting list to complete some questionnaires looking at your thoughts and feelings about your work. These will take approximately 20-30 minutes to complete.

**YOUR CARE HOME HAS CHOSEN TO JOIN GROUP TWO**

Once the study has come to an end you will receive a debrief sheet. This will provide you with contact details for the primary researcher and research supervisors should you have any questions to discuss. The debrief page will also have information about resources available to you if you found completing the study in anyway distressing.

**How long will I be involved for?**

Participation in this research will last between nine weeks and twelve weeks. If you are on a waiting list to attend training you will be asked to wait to begin this until the study completion.

**Will I be paid to take part?**

We cannot offer individual payments to participants, but we will be holding a raffle at the end of the study for three £25 Amazon vouchers as a gesture of thanks for completing the study.

**What are the possible benefits of taking part?**

Participants may find the study gives them the opportunity to develop knowledge and skills in person-centred dementia care and specifically understanding and managing stress and distress behaviours with dementia.

This training will provide you with up-to-date information on an approach to understanding stress and distress behaviours with dementia. This focuses on understanding the individual in their environment. By attending this training we hope you will develop greater understanding of engaging and supporting people with distress.

**What are the possible disadvantages of taking part?**

There are potentially a few disadvantages to taking part. You will need to give up some of your time to attend the training sessions. There is a small chance that you may become upset at some of the questions asking about your feelings at work. Should this be the case, please tell us immediately and together we can decide what to do – for example, you may take some time out from the study or wish to withdraw from the study. Based on our experience and that of other researchers, we think the likelihood of the study causing you distress is small, but we want to be careful nonetheless, as your safety and wellbeing is most important to us.

**What happens when the research study stops?**

When the research study finishes, participants that have been on the waiting list to receive training will be contacted and offered training.

Once the study is completed a summary of the project will be made available in the format of a newsletter to be displayed on notice boards at your place of work. Contact details will be included if you would like further information.

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

You will be given our contact details so you can contact us at any point during the study to tell us if you have changed your mind about carrying on. As part of the research study you can withdraw from all of the research components at any stage without giving a reason. This includes attending training sessions 6 and 7 and completing the questionnaires. If you do not want to attend training sessions 1-5, this will need to be discussed with your manager, as these training sessions are not within the control of the research study team as they may form part of your required training and will require approval from your manager to withdraw.

If you withdraw from the research components of the study we will destroy all your identifiable data, but we will need to use the data collected up to your withdrawal. If you withdraw part way through the study, we will unfortunately be unable to include you in the Amazon voucher raffle.

**How will my information be kept safe?**

We will keep your information confidential by giving you an individual participant number. This number will be used to mark all the questionnaires you complete. This means your name will not appear when we look at the data. Your information will not be identifiable in any reports or publications resulting from the study. The questionnaires you complete will be kept in a locked filing cabinet in a locked office on an NHS site.

Exceptions to confidentiality are if a member of the research team is concerned about risk to a participant or someone else (e.g. a resident). If a member of the research team is concerned about the safety of someone during the course of the study they will have to pass their concerns on and seek advice from their research/clinical supervisor on the same day as the concern is raised, who will decide whether other services need to be informed. Your safety as

well as individuals receiving care is of paramount importance to us. If confidentiality is breached you will be withdrawn from the study.

Some of the training sessions may be audio recorded for training purposes, any audio recordings of training sessions will be erased from the recording device once loaded onto an NHS computer which will be passcode protected. Once the study has been completed the recordings will be erased.

If you decide you would like to enter the prize draw. We will ask you to provide your name and the option of either an email address, home address or work address. This data will be stored securely as previously stated. Once the study is completed, the prize draw has taken place and the three winners picked at random notified. This data will then be deleted.

#### **Where and for how long will data be stored?**

Data will be stored in locked cabinets in university premises. It will be kept for up to ten years after the completion of the study and then destroyed.

#### **What will happen to the results of the research study?**

The results of the study will be reported as anonymous data. The study will be seen by colleagues and supervisors at the University of East Anglia, Doctoral programme in psychology and other members of the research team. Results may also become available more publicly if the research is published, however, no identifiable material will be published.

#### **Who is organising and funding the research?**

The research study is being organised by Lucy de Pfeiffer, Professor Ken Laidlaw, and Dr Paul Fisher, who are part of the Doctorate of Clinical Psychology Programme at the UEA School of Medicine and Alistair Gaskell who is part of Cambridgeshire Training, Education and Development for Older People (CAMTED-OP). It is being funded by the UEA Medical School.

**Who has reviewed the study?**

The research has been considered and approved by UEA Faculty of Medicine and Health Sciences Research Ethics Committee. The research has also been reviewed and approved by the University of East Anglia.

**What if there is a problem?**

If there is a problem and you wish to make a complaint, please contact the primary researcher or senior research tutor at UEA, using the following details:

Lucy de Pfeiffer  
L.de-pfeiffer@uea.ac.uk  
Study mobile: 07934113779

Dr Sian Coker  
S.Coaker@uea.ac.uk  
Tel: 01603 59 3600 (Mon-Fri, 9am – 5pm)

Doctoral Programme in Clinical Psychology  
University of East Anglia  
Queens Building  
Norwich  
Norfolk  
NR4 7TJ

**Further information and contact details**

Thank you for reading this. If you would like any more information about the study or need to contact the researcher, please feel free to contact Lucy de Pfeiffer (Trainee Clinical Psychologist).

Doctoral Programme in Clinical Psychology  
University of East Anglia  
Queens Building  
Norwich  
Norfolk  
NR4 7TJ

Tel: 01603 593600 (Mon-Fri, 9am – 5pm)  
Email: L-De.Pfeiffer@uea.ac.uk  
Tel: 07934113779 (study mobile number)

*We wish to thank you for taking time to read this information sheet.*



**Participant Information Sheet**  
**Group Three**



**A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia**

**Invitation paragraph**

I would like to invite you to take part in a trainee research study for Clinical Psychology. Before you decide whether you would like to take part, we would like you to understand why the study is being carried out, and what it would mean if you took part. You will be able to speak to a member of the research team either over the phone or in person, who will go through this sheet with you and answer any questions you have. Take time to decide whether or not you wish to take part.

Thank you for reading this.

**What is the purpose of the study?**

It is recognised that stress and distress behaviours with dementia (previously known as behaviours that challenge) can cause distress to the person with dementia and care home staff. The purpose of the study is to look at the effects of a dementia care training package for understanding stress and distress behaviours with dementia and how this training affects the frequency and intensity of behaviour within care homes, care home staff thoughts and feelings about their work and care staff's knowledge of dementia.

**Why have I been invited?**

You have been invited because you work in a care home and care directly for individuals living with dementia. You have worked at your current place of work for at least 3 months and you speak English.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide that you would like to take part you will be given this information sheet to keep and will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. If you do withdraw, the data collected up until this point may still be used.

**What will happen to me if I take part?**

If you decide you would like to take part we will first arrange a session for you to meet a member of the research team. This session will give you the chance to ask any questions you may have about the study. This session will take place at your place of work and there may also be other interested participants at this session to find out more about the research. We

will also provide you with the contact details of the researcher and research supervisors if you wish to discuss the study in any further detail.

If it has not been possible to arrange a session at your place of work, as we understand how busy a working environment it can be. We will discuss the study in detail with a manager at your place of work and/or senior member of staff and they will share this information with you and provide you. This information sheet also provides contact details of the researchers and research supervisors if you have any questions or wish to discuss the study further.

We will then arrange a further drop-in session at your place of work where you can come and ask any further questions and sign a consent form if you then decide you would like to participate in the study.

### **What this study is investigating**

We are looking at the effects of different dementia care training sessions. Sometimes we don't know which way is the best. To find out, we need to compare different groups. We put people into groups and give each group a different group. The results are compared to see if one is better than the other. This study has three groups:

#### Group 1

In the first group will ask you to attend five, three hour training sessions at your place of work on person-centred dementia care. Before the first training session we will ask you to complete some questionnaires looking at your thoughts and feelings about your work. These will take approximately 20-30 minutes to complete. We will also ask you to complete these at the end of the final training session and four weeks after the training finishes.

#### Group 2

The second group will ask you to attend seven, three hour training sessions on person-centred dementia care with an in-between session task to be completed between sessions 6 and 7. Before the first training session we will ask you to complete some questionnaires looking at your thoughts and feelings about your work. These will take approximately 20-30 minutes to complete. We will also ask you to complete these at the end of the final training session and four weeks after the training finishes.

#### Group 3

The third group will be to go on a waiting list to receive person-centred dementia care training once the study has completed. We will arrange to meet with you at your place of work at three time points during your time on the waiting list to complete some questionnaires looking at your thoughts and feelings about your work. These will take approximately 20-30 minutes to complete.

### **YOUR CARE HOME HAS CHOSEN TO JOIN GROUP THREE**

Once the study has come to an end you will receive a debrief sheet. This will provide you with contact details for the primary researcher and research supervisors should you have any questions to discuss. The debrief page will also have information about resources available to you if you found completing the study in anyway distressing.

#### **How long will I be involved for?**

Participation in this research will last between nine weeks and twelve weeks. If you are on a waiting list to attend training you will be asked to wait to begin this until the study completion.

#### **Will I be paid to take part?**

We cannot offer individual payments to participants, but we will be holding a raffle at the end of the study for three £25 Amazon vouchers as a gesture of thanks for completing the study.

#### **What are the possible benefits of taking part?**

Participants may find the study gives them the opportunity to develop knowledge and skills in person-centred dementia care and specifically understanding and managing stress and distress behaviours with dementia.

This training will provide you with up-to-date information on an approach to understanding stress and distress behaviours with dementia. This focuses on understanding the individual in their environment. By attending this training we hope you will develop greater understanding of engaging and supporting people with distress.

#### **What are the possible disadvantages of taking part?**

There are potentially a few disadvantages to taking part. You will need to give up some of your time to attend the training sessions. There is a small chance that you may become upset at some of the questions asking about your feelings at work. Should this be the case, please tell us immediately and together we can decide what to do – for example, you may to take some time out from the study or wish to withdraw from the study. Based on our experience and that of other researchers, we think the likelihood of the study causing you distress is small, but we want to be careful nonetheless, as your safety and wellbeing is most important to us.

#### **What happens when the research study stops?**

When the research study finishes, participants that have been on the waiting list to receive training will be contacted and offered training.

Once the study is completed a summary of the project will be made available in the format of a newsletter to be displayed on notice boards at your place of work. Contact details will be included if you would like further information.

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

You will be given our contact details so you can contact us at any point during the study to tell us if you have changed your mind about carrying on. As part of the research study you can withdraw from all of the research components at any stage without giving a reason. This includes completing the questionnaires.

If you withdraw from the research components of the study we will destroy all your identifiable data, but we will need to use the data collected up to your withdrawal. If you withdraw part way through the study, we will unfortunately be unable to include you in the Amazon voucher raffle.

**How will my information be kept safe?**

We will keep your information confidential by giving you an individual participant number. This number will be used to mark all the questionnaires you complete. This means your name will not appear when we look at the data. Your information will not be identifiable in any reports or publications resulting from the study. The questionnaires you complete will be kept in a locked filing cabinet in a locked office on an NHS site.

Exceptions to confidentiality are if a member of the research team is concerned about risk to a participant or someone else (e.g. a resident). If a member of the research team is concerned about the safety of someone during the course of the study they will have to pass their concerns on and seek advice from their research/clinical supervisor on the same day as the concern is raised, who will decide whether other services need to be informed. Your safety as well as individuals receiving care is of paramount importance to us. If confidentiality is breached you will be withdrawn from the study.

If you decide you would like to enter the prize draw. We will ask you to provide your name and the option of either an email address, home address or work address. This data will be stored securely as previously stated. Once the study is completed, the prize draw has taken place and the three winners picked at random notified. This data will then be deleted.

**Where and for how long will data be stored?**

Data will be stored in locked cabinets in university premises. It will be kept for up to ten years after the completion of the study and then destroyed.

**What will happen to the results of the research study?**

The results of the study will be reported as anonymous data. The study will be seen by colleagues and supervisors at the University of East Anglia, Doctoral programme in psychology and other members of the research team. Results may also become available more publicly if the research is published, however, no identifiable material will be published.

**Who is organising and funding the research?**

The research study is being organised by Lucy de Pfeiffer, Professor Ken Laidlaw, and Dr Paul Fisher, who are part of the Doctorate of Clinical Psychology Programme at the UEA School of Medicine and Alistair Gaskell who is part of Cambridgeshire Training, Education and Development for Older People (CAMTED-OP). It is being funded by the UEA Medical School.

**Who has reviewed the study?**

The research has been considered and approved by UEA Faculty of Medicine and Health Sciences Research Ethics Committee. The research has also been reviewed and approved by the University of East Anglia.

**What if there is a problem?**

If there is a problem and you wish to make a complaint, please contact the primary researcher or senior research tutor at UEA, using the following details:

Lucy de Pfeiffer  
L.de-pfeiffer@uea.ac.uk  
Study mobile: 07934113779

Dr Sian Coker  
S.Coker@uea.ac.uk  
Tel: 01603 59 3600 (Mon-Fri, 9am – 5pm)

Doctoral Programme in Clinical Psychology  
University of East Anglia  
Queens Building  
Norwich  
Norfolk  
NR4 7TJ

**Further information and contact details**

Thank you for reading this. If you would like any more information about the study or need to contact the researcher, please feel free to contact Lucy de Pfeiffer (Trainee Clinical Psychologist).

Doctoral Programme in Clinical Psychology  
University of East Anglia  
Queens Building  
Norwich  
Norfolk  
NR4 7TJ  
Tel: 01603 593600 (Mon-Fri, 9am – 5pm)

Email: L-De.Pfeiffer@uea.ac.uk  
Tel: 07934113779 (study mobile number)

*We wish to thank you for taking time to read this information sheet.*

**Appendix J****Participant Consent Forms****Participant Consent Form**  
**Group 1**

Centre Number:

Participant Number:

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**CONSENT FORM – Group 1**

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Title of Project: A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia

Name of Researcher: Lucy de Pfeiffer

**Please initial all boxes**

1. I confirm that I have read and understand the information sheet dated 06.09.15 (version 5) for the above study.
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw from research parts of the study at any time without giving any reason.
4. I understand that all information collected as part of the study will be treated as completely confidential and that relevant sections of data collected during the study may be looked at by individuals from the University of East Anglia. I give permission to these individuals to have access to my data which will be anonymised.
5. I understand that an exception to confidentiality is if a member of the research team is concerned about the safety of a participant or someone else (e.g. a resident) and that confidentiality may then need to be broken.

6. I understand that the study will involve attending 15 hours of training.

7. I understand that the study will also involve completing some questionnaires at three time points during the course of the study. These questionnaires take approximately 20-30 minutes to complete.

I agree to take part in the above study.

\_\_\_\_\_

Name of Participant

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_

Name of Person

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

taking consent.



**Participant Consent Form**  
**Group Two**

Centre Number:

Participant Number:

---

**CONSENT FORM – Group 2**

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Title of Project: A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia

Name of Researcher: Lucy de Pfeiffer

**Please initial all boxes**

1. I confirm that I have read and understand the information sheet dated (06.09.15) (version 5) for the above study.
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw from research parts of the study at any time without giving any reason. This includes attending training modules 6 and 7 and completing the study questionnaires.
4. I understand that all information collected as part of the study will be treated as completely confidential and that relevant sections of data collected during the study may be looked at by individuals from the University of East Anglia. I give permission to these individuals to have access to my data which will be anonymised.
5. I understand that an exception to confidentiality is if a member of the research team is concerned about the safety of a participant or someone else (e.g. a resident) and that confidentiality may then need to be broken.
6. I understand that the study will involve attending 21 hours of training, which will be delivered as seven, three hour training sessions.



- 7. I understand that the study will also involve completing some questionnaires at three time points during the course of the study. These questionnaires take approximately 20-30 minutes to complete.
  
- 8. I understand that the training sessions I attend may be recorded on an audio device.
  
- 9. I understand that any audio recordings will be stored on a password protected computer
  
- 10. I understand that that any audio recordings will only be listened to by a member of the researcher team, and will be destroyed after use.
  
- 11. I agree to take part in the above study.

Name of Participant	Date	Signature

Name of Person	Date	Signature

taking consent.

**Participant Consent Form**  
**Group 3**

Study Number:

Participant Number:



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**CONSENT FORM – Group 3**

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Title of Project: A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia

Name of Researcher: Lucy de Pfeiffer

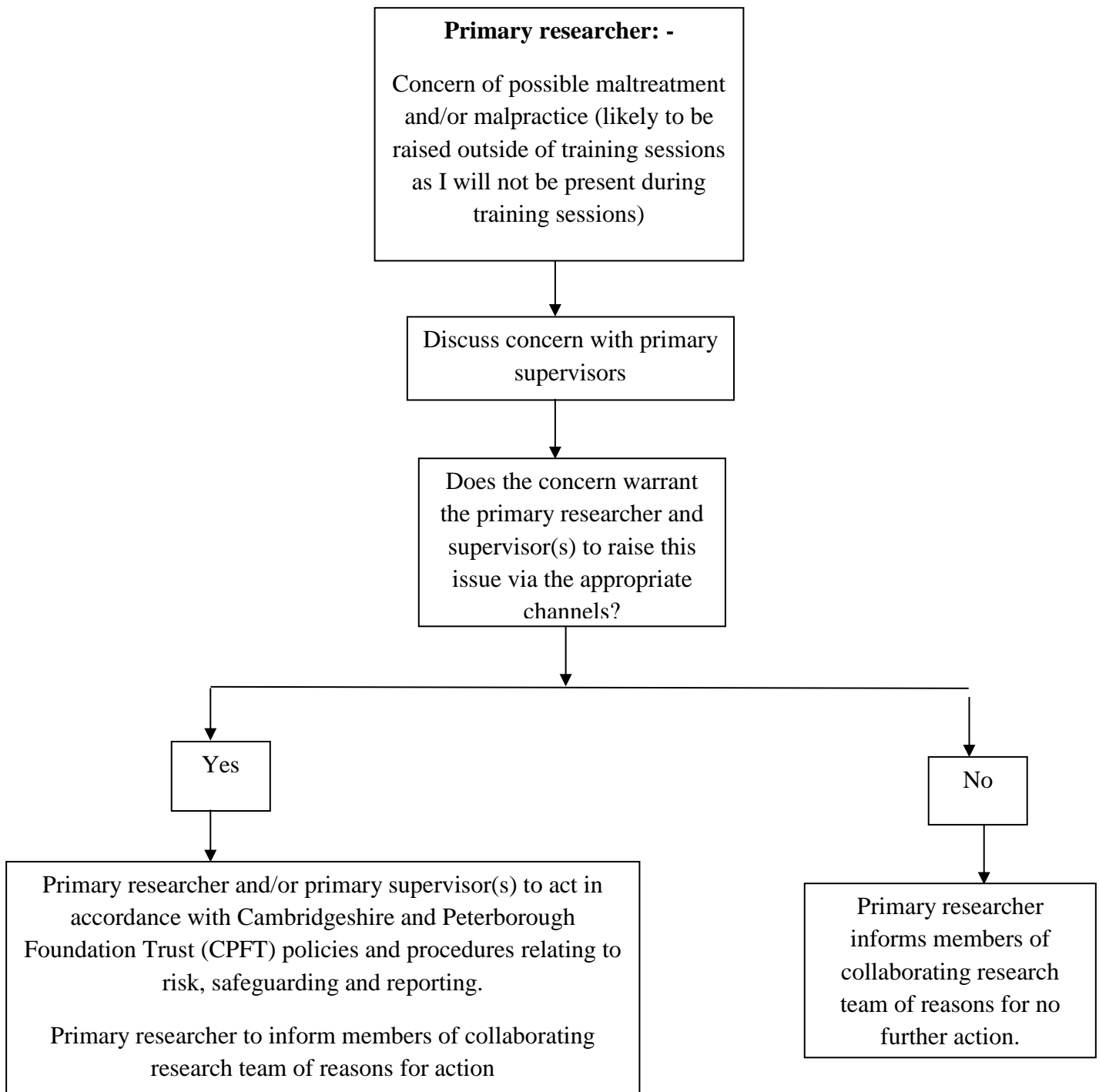
**Please initial all boxes**

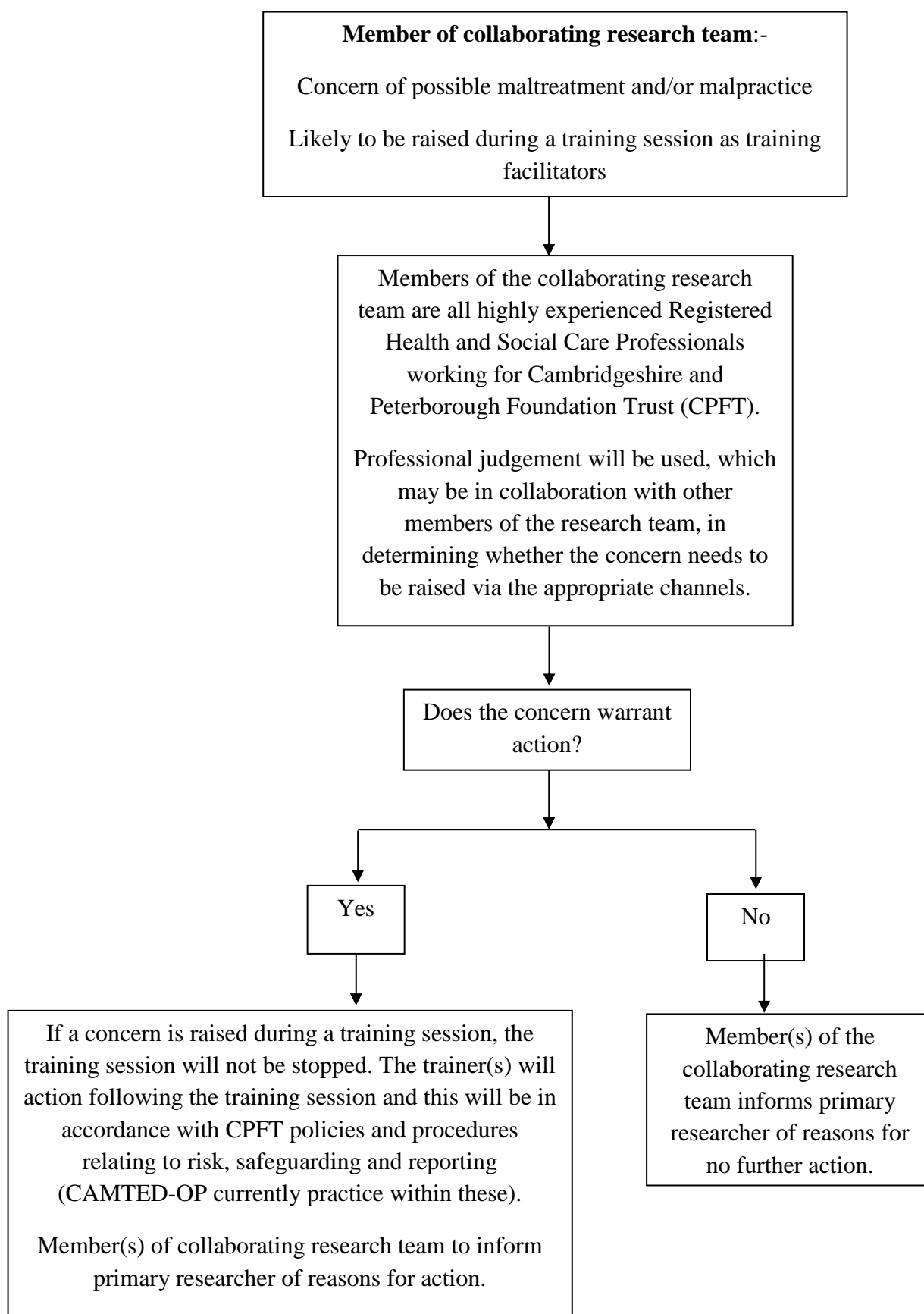
1. I confirm that I have read and understand the information sheet dated 06.09.15 (version 4) for the above study.
  
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
  
4. I understand that all information collected as part of the study will be treated as completely confidential and that relevant sections of data collected during the study may be looked at by individuals from the University of East Anglia. I give permission to these individuals to have access to my data which will be anonymised.
  
5. I understand that an exception to confidentiality is if a member of the research team is concerned about the safety of a participant or someone else (e.g. a resident) and that confidentiality may then need to be broken.
  
6. I understand that the study will involve being on a waiting list to receive training when the study is completed. This will involve me completing some questionnaires at three different time points (approximately 30 minutes per time point)
  
- I agree to take part in the above study.

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

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

taking consent.

**Appendix K****Procedure for Reporting Disclosures of Malpractice/Maltreatment****Procedure 1 - Primary Researcher**

**Procedure 2 – Collaborating research team**

**Appendix L****Ethical Approval Letter for protocol deviations**

Faculty of Medicine and Health Sciences Research Ethics Committee



University of East Anglia

Lucy De Pfeiffer  
MEDResearch & Enterprise Services  
West Office (Science Building)  
University of East Anglia  
Norwich  
Research  
Park  
Norwich,  
NR4 7TJ

Telephone: +44 (0) 1603 591720

Email: [fmh-ethics@uea.ac.uk](mailto:fmh-ethics@uea.ac.uk)Web: [www.uea.ac.uk/researchandenterprise](http://www.uea.ac.uk/researchandenterprise)10<sup>th</sup> September 2015

Dear Lucy

A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia — 20142015-62

Thank you for your email dated 7<sup>th</sup> September 2015 notifying us of the amendments you would like to make to your above proposal. These have been considered and we can now confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee,

Please can you also arrange to send us a report once your project is completed.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Mark Wilkinson', is written over a light blue horizontal line.

Mark Wilkinson  
Chair FMH Research Ethics Committee

Cc Kenneth Laidlaw

Faculty of Medicine and Health Sciences Research Ethics Committee



University of East Anglia

Lucy De Pfeiffer  
MED

Research & Enterprise Services  
West Office (Science Building)  
University of East Anglia  
Norwich  
Research  
Park  
Norwich,  
NR4 7TJ

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Web: [www.uea.ac.uk/researchandenterprise](http://www.uea.ac.uk/researchandenterprise)

8 March 2016

Dear Lucy

A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia

20142015-62

The amendments to your above proposal have been considered by the Chair of the Faculty Research Ethics Committee and we can confirm that your proposal has been approved by Chair's Action.

Please could you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance and also that any adverse events which occur during your project are reported to the Committee. Please could you also arrange to send us a report once your project is completed.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Mark Wilkinson'.

Mark Wilkinson  
Chair FMH Research Ethics Committee

**Appendix M****Expression of Interest Forms****Expression of Interest Form**

Version 2a

08.05.15



**Study title: A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia**

Thank you for attending the information session for this research study. This form is provided for you to express your INTEREST in participating in this study. You will NOT be consented to participate in this study at this stage.

If you are interested in taking part in the above study please complete this form and place it in the envelope provided. This can be sealed and handed into a member of the research team at the end of the information session or it can be sealed in the prepaid envelope provided and sent to the researcher directly, if you would like to take the form away to think about participating further.

**I am interested in taking part in the above study**

**Age:** \_\_\_\_\_

**Gender:** \_\_\_\_\_

**Nationality:** \_\_\_\_\_



**Level of education:** \_\_\_\_\_

**Job title:** \_\_\_\_\_

**Length of time in current employment:** \_\_\_\_\_

**Length of time working in services for people living with dementia:** \_\_\_\_\_

**Where do you work in the care home e.g. residential, nursing, dementia care unit:**

\_\_\_\_\_  
\_\_\_\_\_

**Have you had any other training on dementia in the past year? If yes, please provide a few details e.g. number of days:**

\_\_\_\_\_  
\_\_\_\_\_

**Print Name:**

**Date:**

**Expression of Interest Form**

Version 2b

03.09.15

**Study title: A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia**

Thank you for reading the participant information sheet included in this pack. This form is provided for you to express your INTEREST in participating in this study. You will NOT be consented to participate in this study at this stage.

If you are interested in taking part in the above study please complete this form and place it in the prepaid envelope provided. This can be sealed and sent to the researcher directly.

**I am interested in taking part in the above study**

**Age:** \_\_\_\_\_

**Gender:** \_\_\_\_\_

**Nationality:** \_\_\_\_\_

**Level of education:** \_\_\_\_\_

**Job title:** \_\_\_\_\_

**Length of time in current employment:** \_\_\_\_\_

Length of time working in services for people living with dementia: \_\_\_\_\_

Where do you work in the care home e.g. residential, nursing, dementia care unit:

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Have you had any other training on dementia in the past year? If yes, please provide a few details e.g. number of days:

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**Print Name:**

**Date:**

## Appendix N

### Debrief Information Sheets

#### Debrief Information Sheet Group 1



#### **A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia**

I would like to thank you for taking part in my trainee research study for Clinical Psychology.

Your time as a participant on the study has come to an end. This information sheet provides some further information about the study and includes contact details if you would like to get in touch with the primary researcher to ask any questions about the study.

#### **What was the purpose of the study?**

It is recognised that stress and distress behaviours with dementia can cause distress to the person living with dementia and care home staff. The purpose of the study was to look at the effects of a dementia care training package for understanding stress and distress behaviours with dementia and how this training affects the frequency and intensity of behaviour within care homes and care home staff thoughts and feelings about their work.

We have been looking at the effects of different dementia care training sessions. To help us find out which way is the best, we needed to compare different groups. This study had three groups and your care home decided to join group 1.

#### **Group 1**

In group 1 you were asked to attend 15 hours of dementia care training delivered at your place of work. Before the first training session we asked you to complete some questionnaires looking at your thoughts and feelings about your work. We also asked you to complete these at the end of the final training session.

When you signed a consent form at the beginning of the study to take part, we were also asking if you could complete the questionnaires four weeks after the training finishes. Due to time limitations of the project, I wanted to let you know that we will no longer be carrying out this four week follow-up and you will not be asked to complete the questionnaires again.

### **Prize Draw Raffle**

We were not able to offer individual payments to participants, but we will be holding a raffle at the end of the study for three £25 Amazon vouchers as a gesture of thanks for completing the study.

If you decided to take part in the raffle, once the study is completed, the prize draw will take place and three winners will be picked at random. The winners will be contacted using the details provided on the form completed at the beginning of the study.

### **Resources**

There was a small chance that you may have felt upset at some of the questions asking about your feelings at work. I encourage you to seek additional support if necessary through your line manager or clinical supervision.

### **Contact details**

If you have any questions about the study or would like to speak to a member of the research team, please contact the primary researcher or senior research tutor at UEA, using the following details:

Lucy de Pfeiffer  
L.de-pfeiffer@uea.ac.uk  
Study mobile: 07934113779 (Mon-Fri, 9am – 5pm)

Dr Sian Coker  
S.Coaker@uea.ac.uk  
Tel: 01603 59 3600 (Mon-Fri, 9am – 5pm)  
Doctoral Programme in Clinical Psychology  
University of East Anglia  
Queens Building  
Norwich  
Norfolk  
NR4 7TJ

*We wish to thank you again for taking part in the study*

**Debrief Information Sheet****Group 2****A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia**

I would like to thank you for taking part in my trainee research study for Clinical Psychology.

Your time as a participant on the study has come to an end. This information sheet provides some further information about the study and includes contact details if you would like to get in touch with the primary researcher to ask any questions about the study.

**What was the purpose of the study?**

It is recognised that stress and distress behaviours with dementia can cause distress to the person living with dementia and care home staff. The purpose of the study was to look at the effects of a dementia care training package for understanding stress and distress behaviours with dementia and how this training affects the frequency and intensity of behaviour within care homes and care home staff thoughts and feelings about their work.

We have been looking at the effects of different dementia care training sessions. To help us find out which way is the best, we needed to compare different groups. This study had three groups and your care home decided to join group 2.

**Group 2**

In group 2 you were asked to attend 21 hours of dementia care training delivered at your place of work. Before the first training session we asked you to complete some questionnaires looking at your thoughts and feelings about your work. We also asked you to complete these at the end of the final training session.

When you signed a consent form at the beginning of the study to take part, we were also asking if you could complete the questionnaires four weeks after the training finishes. Due to time limitations of the project, I wanted to let you know that we will no longer be carrying out this four week follow-up and you will not be asked to complete the questionnaires again.

**Prize Draw Raffle**

We were not able to offer individual payments to participants, but we will be holding a raffle at the end of the study for three £25 Amazon vouchers as a gesture of thanks for completing the study.

If you decided to take part in the raffle, once the study is completed, the prize draw will take place and three winners will be picked at random. The winners will be contacted using the details provided on the form completed at the beginning of the study.

**Resources**

There was a small chance that you may have felt upset at some of the questions asking about your feelings at work. I encourage you to seek additional support if necessary through your line manager or clinical supervision.

**Contact details**

If you have any questions about the study or would like to speak to a member of the research team, please contact the primary researcher or senior research tutor at UEA, using the following details:

Lucy de Pfeiffer  
L.de-pfeiffer@uea.ac.uk  
Study mobile: 07934113779 (Mon-Fri, 9am – 5pm)

Dr Sian Coker  
S.Coaker@uea.ac.uk  
Tel: 01603 59 3600 (Mon-Fri, 9am – 5pm)  
Doctoral Programme in Clinical Psychology  
University of East Anglia  
Queens Building  
Norwich  
Norfolk  
NR4 7TJ

*We wish to thank you again for taking part in the study*

**Debrief Information Sheet**  
**Group 3**



**A pilot investigation of the effectiveness of training care home staff in a formulation based functional analysis approach to understanding stress and distress behaviours with dementia**

I would like to thank you for taking part in my trainee research study for Clinical Psychology.

Your time as a participant on the study has come to an end. This information sheet provides some further information about the study and includes contact details if you would like to get in touch with the primary researcher to ask any questions about the study.

**What was the purpose of the study?**

It is recognised that stress and distress behaviours with dementia can cause distress to the person living with dementia and care home staff. The purpose of the study was to look at the effects of a dementia care training package for understanding stress and distress behaviours with dementia and how this training affects the frequency and intensity of behaviour within care homes and care home staff thoughts and feelings about their work.

We have been looking at the effects of different dementia care training sessions. To help us find out which way is the best, we needed to compare different groups. This study had three groups and your care home decided to join group 3.

**Group 3**

In group 3 you were asked to go on a waiting list to receive person-centred dementia care training once the study has been completed. We arranged to meet with you at your place of work on two occasions during your time on the waiting list to complete some questionnaires looking at your thoughts and feelings about your work.

When you signed a consent form at the beginning of the study to take part, we were also asking if you could complete the questionnaires at a third time point. Due to time limitations of the project, I wanted to let you know that you will not be asked to complete the questionnaires again.



**Prize Draw Raffle**

We were not able to offer individual payments to participants, but we will be holding a raffle at the end of the study for three £25 Amazon vouchers as a gesture of thanks for completing the study.

If you decided to take part in the raffle, once the study is completed, the prize draw will take place and three winners will be picked at random. The winners will be contacted using the details provided on the form completed at the beginning of the study.

**Resources**

There was a small chance that you may have felt upset at some of the questions asking about your feelings at work. I encourage you to seek additional support if necessary through your line manager or clinical supervision.

**Contact details**

If you have any questions about the study or would like to speak to a member of the research team, please contact the primary researcher or senior research tutor at UEA, using the following details:

Lucy de Pfeiffer  
L.de-pfeiffer@uea.ac.uk  
Study mobile: 07934113779 (Mon-Fri, 9am – 5pm)

Dr Sian Coker  
S.Coaker@uea.ac.uk  
Tel: 01603 59 3600 (Mon-Fri, 9am – 5pm)  
Doctoral Programme in Clinical Psychology  
University of East Anglia  
Queens Building  
Norwich  
Norfolk  
NR4 7TJ

*We wish to thank you again for taking part in the study*

**Appendix O****Prize Draw Entry Form****Prize Draw Entry Form**

We will be holding a raffle at the end of the study for three £25 Amazon vouchers as a gesture of thanks for completing the study. If you would like to enter the prize draw, please could you print your name below and provide either a contact address (e.g. email address, home address, work address) or a contact number.

The data you provide will be stored securely. Once the study is completed, the prize draw will take place and three winners will be picked at random and notified. This data will then be deleted.

If you withdraw part way through the study, we will unfortunately be unable to include you in the Amazon voucher raffle.

Name: \_\_\_\_\_

Home or work address: \_\_\_\_\_

\_\_\_\_\_

Optional (contact number or email address): \_\_\_\_\_

\_\_\_\_\_

**Appendix P**

**Additional information relating to results section**

**Appendix P1****Assessment of Normal Distribution - Skew and Kurtosis values at baseline and post-intervention***Distribution of variables at baseline*

	CAMTED		CAMTED-Plus	
	S	K	S	K
ADQ	0.31	- 0.66	- 0.66	0.86
ADQ-H	0.87	- 0.61	1.46	*2.72
ADQ-PH	- 0.90	- 0.70	1.37	-.70
DK-20	*- 2.11	0.47	- 1.11	- 0.44
DK-20-DCK	- 1.77	1.94	- 1.21	- 0.10
DK-20-DCaK	- 1.52	0.11	- 1.12	- 0.91
MBI EE	0.34	- 0.08	1.26	- 1.07
MBI DP	1.12	- 0.34	0.71	- 1.15
MBI PA	-1.08	0.26	- 1.18	-1.03
SDBS	0.83	0.81	- 0.21	- 0.61
Frequency Scale	- 0.47	- 0.26	- 0.81	- 1.03
Intensity Scale	0.21	- 1.03	0.25	- 0.35
Confidence Scale	-1.41	0.30	-1.49	- 0.82
SNCW	1.48	1.83	0.90	.28

*Note:* \* deviated significantly from a normal distribution, S = Skew, K = Kurtosis, ADQ = Attitudes to Dementia Questionnaire, ADQ-H = Attitudes to Dementia Questionnaire – Hope subscale (ADQ-H), ADQ-PH = Attitudes to Dementia Questionnaire – Personhood subscale, DK-20 = Dementia Knowledge Questionnaire, DK-20-DCK = Dementia Knowledge Questionnaire – Dementia Core

Knowledge subscale, DK-20-DCaK = Dementia Knowledge Questionnaire – Dementia Care Knowledge subscale, MBI-EE = Maslach Burnout Inventory – Emotional Exhaustion subscale, MBI-DP – Maslach Burnout Inventory – Depersonalisation subscale, MBI-PA = Maslach Burnout Inventory – Personal Accomplishment subscale, SDBS = Stress and Distress Behaviour Scale, Frequency Scale = Frequency of SAD-behaviour Scale, Intensity Scale = Intensity of SAD-behaviour Scale, Confidence Scale = Confidence in managing SAD-behaviour Scale SNCW = Swedish Satisfaction in Nursing Care and Work Scale.

*Distribution of variables post-intervention*

	CAMTED		CAMTED-Plus	
	S	K	S	K
ADQ	0.64	- 1.44	- 1.38	1.32
ADQ-H	0.40	- 0.78	*- 2.78	*2.85
ADQ-PH	- 0.02	- 0.99	0.03	*- 1.57
DK-20	*- 2.33	1.48	*- 2.06	0.34
DK-20-DCK	- 1.11	- 0.29	*- 2.70	*2.10
DK-20-DCaK	*- 3.14	*3.48	*- 2.73	1.06
MBI EE	0.19	1.02	1.40	- 0.53
MBI DP	1.31	0.26	*1.98	0.52
MBI PA	- 0.35	- 0.87	- 0.88	-1.07
SDBS	1.10	0.28	0.11	0.50
Frequency Scale	*- 2.24	*3.71	- 0.83	- 0.66
Intensity Scale	- 0.40	- 0.83	- 0.60	- 0.06
Confidence Scale	-1.37	1.26	*- 2.56	0.17
SNCW	0.71	- 0.19	*2.59	*3.26

*Note:* \* deviated significantly from a normal distribution, S = Skew, K = Kurtosis, ADQ = Attitudes to Dementia Questionnaire, ADQ-H = Attitudes to Dementia Questionnaire – Hope subscale (ADQ-H), ADQ-PH = Attitudes to Dementia Questionnaire – Personhood subscale, DK-20 = Dementia Knowledge Questionnaire, DK-20-DCK = Dementia Knowledge Questionnaire – Dementia Core Knowledge subscale, DK-20-DCaK = Dementia Knowledge Questionnaire – Dementia Care Knowledge subscale, MBI-EE = Maslach Burnout Inventory – Emotional Exhaustion subscale, MBI-DP – Maslach Burnout Inventory – Depersonalisation subscale, MBI-PA = Maslach Burnout Inventory – Personal Accomplishment subscale, SDBS = Stress and Distress Behaviour Scale, Frequency Scale = Frequency of SAD-behaviour Scale, Intensity Scale = Intensity of SAD-behaviour

Scale, Confidence Scale = Confidence in managing SAD-behaviour Scale SNCW = Swedish Satisfaction in Nursing Care and Work Scale.

**Appendix P2****Assessment of Normal Distribution - Shapiro-Wilk values at baseline and post-intervention***Shapiro-Wilk values for variables at baseline*

	CAMTED	CAMTED-Plus
	S-W	S-W
ADQ	.69	.45
ADQ-H	.47	.26
ADQ-PH	.40	.06
DK-20	*.009	.27
DK-20-DCK	.20	.26
DK-20-DCaK	.06	*.01
MBI EE	.76	.02
MBI DP	.17	.11
MBI PA	.62	*.04
SDBS	.78	.37
Frequency Scale	.15	*.02
Intensity Scale	.20	.009
Confidence Scale	*.006	*.001
SNCW	.31	.56

*Note:* \* deviated significantly from a normal distribution, ADQ = Attitudes to Dementia Questionnaire, ADQ-H = Attitudes to Dementia Questionnaire – Hope subscale (ADQ-H), ADQ-PH = Attitudes to Dementia Questionnaire – Personhood subscale, DK-20 = Dementia Knowledge Questionnaire, DK-20-DCK = Dementia Knowledge Questionnaire – Dementia Core Knowledge subscale, DK-20-DCaK = Dementia Knowledge Questionnaire – Dementia Care Knowledge subscale,



MBI-EE = Maslach Burnout Inventory – Emotional Exhaustion subscale, MBI-DP – Maslach Burnout Inventory – Depersonalisation subscale, MBI-PA = Maslach Burnout Inventory – Personal Accomplishment subscale, SDBS = Stress and Distress Behaviour Scale, Frequency Scale = Frequency of SAD-behaviour Scale, Intensity Scale = Intensity of SAD-behaviour Scale, Confidence Scale = Confidence in managing SAD-behaviour Scale SNCW = Swedish Satisfaction in Nursing Care and Work Scale.

*Shapiro-Wilk values for variables post-intervention*

	CAMTED	CAMTED-Plus
	S-W	S-W
ADQ	.04	.29
ADQ-H	.51	*.01
ADQ-PH	.50	*.03
DK-20	*.01	*.02
DK-20-DCK	.11	*.005
DK-20-DCaK	*.002	*.001
MBI EE	.13	.09
MBI DP	.17	.03
MBI PA	.62	.12
SDBS	.87	.98
Frequency Scale	*.009	*.05
Intensity Scale	.35	.06
Confidence Scale	.01	.00
SNCW	.81	.06

*Note:* \* deviated significantly from a normal distribution, ADQ = Attitudes to Dementia Questionnaire, ADQ-H = Attitudes to Dementia Questionnaire – Hope subscale (ADQ-H), ADQ-PH = Attitudes to Dementia Questionnaire – Personhood subscale, DK-20 = Dementia Knowledge Questionnaire, DK-20-DCK = Dementia Knowledge Questionnaire – Dementia Core Knowledge subscale, DK-20-DCaK = Dementia Knowledge Questionnaire – Dementia Care Knowledge subscale, MBI-EE = Maslach Burnout Inventory – Emotional Exhaustion subscale, MBI-DP – Maslach Burnout Inventory – Depersonalisation subscale, MBI-PA = Maslach Burnout Inventory – Personal Accomplishment subscale, SDBS = Stress and Distress Behaviour Scale, Frequency Scale = Frequency of SAD-behaviour Scale, Intensity Scale = Intensity of SAD-behaviour Scale, Confidence

Scale = Confidence in managing SAD-behaviour Scale SNCW = Swedish Satisfaction in Nursing Care and Work Scale.

**Appendix P3****Descriptive data for the waiting list group***Waiting list group descriptive data for variables*

Waiting List (n =7)		
	Mean	SD
Primary Measure		
ADQ		
Pre-Intervention	83	2.02
Post-Intervention	83	2.03
ADQ-H		
Pre-Intervention	33	.68
Post-Intervention	32	1.37
ADQ-PH		
Pre-Intervention	50	1.49
Post-Intervention	51	1.42
DK-20		
Pre-Intervention	13	1.60
Post-Intervention	14	1.16
DK-20-DCK		
Pre-Intervention	7	.80
Post-Intervention	7	.67
DK-20-DCaK		
Pre-Intervention	6	.91

Post-Intervention	7	.75
MBI-EE		
Pre-Intervention	23	4.67
Post-Intervention	18	4.94
MBI-DP		
Pre-Intervention	6	2.35
Post-Intervention	7	2.84
MBI-PA		
Pre-Intervention	37	1.86
Post-Intervention	39	2.30
SDBS		
Pre-Intervention	33	4.56
Post-Intervention	29	4.62
Frequency Scale		
Pre-Intervention	5	.64
Post-Intervention	4	.42
Intensity Scale		
Pre-Intervention	4	.46
Post-Intervention	3	.54
Confidence Scale		
Pre-Intervention	5	.29
Post-Intervention	4	.37

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*Note:* SD = Standard Deviation, ADQ = Attitudes to Dementia Questionnaire, ADQ-H = Attitudes to Dementia Questionnaire – Hope subscale (ADQ-H), ADQ-PH = Attitudes to Dementia Questionnaire – Personhood subscale, DK-20 = Dementia Knowledge Questionnaire, DK-20-DCK = Dementia Knowledge Questionnaire – Dementia Core Knowledge subscale, DK-20-DCaK = Dementia Knowledge Questionnaire – Dementia Care Knowledge subscale, MBI-EE = Maslach Burnout Inventory – Emotional Exhaustion subscale, MBI-DP – Maslach Burnout Inventory – Depersonalisation subscale, MBI-PA = Maslach Burnout Inventory – Personal Accomplishment subscale, SDBS = Stress and Distress Behaviour Scale, Frequency Scale = Frequency of SAD-behaviour Scale, Intensity Scale = Intensity of SAD-behaviour Scale, Confidence Scale = Confidence in managing SAD-behaviour Scale

**Appendix P4****Non-Parametric Analyses***Descriptive statistics for pre and post outcome measures and comparison data*

	CAMTED (n = 13 )		CAMTED-Plus (n = 28)		Statistics	
Primary Measure	Mean	SD	Mean	SD	U	<i>p</i>
ADQ						
Pre-Intervention	72	7.92	72	6.06	.365	.73
Post-Intervention	76	7.27	76	6.98	.421	.69
ADQ-H						
Pre-Intervention	24	5.15	26	3.86	1.688	.10
Post-Intervention	26	3.78	27 <sup>a</sup>	5.03	.225	.84
ADQ-PH						
Pre-Intervention	48	5.07	46	4.47	1.278	.21
Post-Intervention	48	4.23	48 <sup>a</sup>	4.91	.141	.90
DK-20						
Pre-Intervention	13 <sup>a</sup>	3.81	14	3.65	.297	.77
Post-Intervention	15 <sup>a</sup>	2.77	15 <sup>a</sup>	3.36	.071	.94

## DK-20-DCK

Pre-Intervention	7	2.47	7	2.60	.665	.52
Post-Intervention	8	1.27	7 <sup>a</sup>	2.25	.229	.84

## DK-20-DCaK

Pre-Intervention	6	1.91	7 <sup>a</sup>	1.44	1.670	.11
Post-Intervention	7 <sup>a</sup>	2.28	7 <sup>a</sup>	1.66	.131	.90

## Secondary Measure

## MBI-EE

Pre-Intervention	23	13.47	17	12.0	1.154	.26
Post-Intervention	21	11.68	16	11.95	1.299	.20

## MBI-DP

Pre-Intervention	6	4.93	5	3.85	.235	.82
Post-Intervention	4	3.69	5	3.98	.472	.66

## MBI-PA

Pre-Intervention	34	10.43	34 <sup>a</sup>	9.97	.126	.90
Post-Intervention	37	7.76	34	7.17	1.083	.29



## SDBS

Pre-Intervention	25	17.22	31	10.85	1.350	.18
Post-Intervention	26	17.32	28	11.79	.581	.58

## Frequency Scale

Pre-Intervention	3	1.83	4 <sup>a</sup>	1.33	1.802	.08
Post-Intervention	4 <sup>a</sup>	1.38	4 <sup>a</sup>	1.37	.510	.63

## Intensity Scale

Pre-Intervention	3	1.81	3	.84	1.562	.13
Post-Intervention	3	1.66	3	1.08	.299	.78

## Confidence Scale

Pre-Intervention	5 <sup>a</sup>	.87	4 <sup>a</sup>	1.19	1.018	.36
Post-Intervention	5	.80	5	.73	1.271	.28

## SNCW

Pre-Intervention	74	17.95	76	18.16	.512	.63
Post-Intervention	71	19.15	79	19.76	1.247	.22

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*Note:* U = Mann-Whitney test statistic, ADQ = Attitudes to Dementia Questionnaire, ADQ-H = Attitudes to Dementia Questionnaire – Hope subscale (ADQ-H), ADQ-PH = Attitudes to Dementia Questionnaire – Personhood subscale, DK-20 = Dementia Knowledge Questionnaire, DK-20-DCK = Dementia Knowledge Questionnaire – Dementia Core Knowledge subscale, DK-20-DCaK = Dementia Knowledge Questionnaire – Dementia Care Knowledge subscale, MBI-EE = Maslach

Burnout Inventory – Emotional Exhaustion subscale, MBI-DP – Maslach Burnout Inventory – Depersonalisation subscale, MBI-PA = Maslach Burnout Inventory – Personal Accomplishment subscale, SDBS = Stress and Distress Behaviour Scale, Frequency Scale = Frequency of SAD-behaviour Scale, Intensity Scale = Intensity of SAD-behaviour Scale, Confidence Scale = Confidence in managing SAD-behaviour Scale SNCW = Swedish Satisfaction in Nursing Care and Work Scale.

<sup>a</sup> *These variables significantly deviated from a normal distribution*

**Appendix P5****Data analyses excluding outliers***Descriptive statistics and comparison data for post outcome variables excluding outliers*

	CAMTED (n = 13 )		CAMTED-Plus (n = 27)		Statistics	
Primary Measure	Mean	SD	Mean	SD	t / U	p
ADQ						
Post-Intervention	76 <sup>a</sup>	7.27	77	5.89	.471	.64
ADQ-H						
Post-Intervention	27	3.78	28	3.56	.530	.60
DK-20						
Post-Intervention	15 <sup>a</sup>	1.97	16	4.57 <sup>a</sup>	.343	.73
DK-20-DCK						
Post-Intervention	8	1.06	7	1.93 <sup>a</sup>	.58	.57
DK-20-DCaK						
Post-Intervention	8 <sup>a</sup>	1.36	7 <sup>a</sup>	1.66	.655	.52
Secondary Measure						

MBI-EE						
Post-Intervention	21	2.12	16	11.95	1.874	.07
Frequency Scale						
Post-Intervention	4 <sup>a</sup>	.603	4	1.362	.398	.69
Intensity Scale						
Post-Intervention	3	1.66	3 <sup>a</sup>	1.08	.855	.41
Confidence Scale						
Post-Intervention	5	.00	5 <sup>a</sup>	.73	3.140	.16 <sup>b</sup>
SDBS						
Post-Intervention	23	4.01	28	2.51	1.030	.31
SNCW						
Post-Intervention	71	19.15	76	14.81	.888	.41

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*Note:* U = Mann-Whitney test statistic, ADQ = Attitudes to Dementia Questionnaire, ADQ-H = Attitudes to Dementia Questionnaire – Hope subscale (ADQ-H), ADQ-PH = Attitudes to Dementia Questionnaire – Personhood subscale, DK-20 = Dementia Knowledge Questionnaire, DK-20-DCK = Dementia Knowledge Questionnaire – Dementia Core Knowledge subscale, DK-20-DCaK = Dementia Knowledge Questionnaire – Dementia Care Knowledge subscale, MBI-EE = Maslach Burnout Inventory – Emotional Exhaustion subscale, MBI-DP = Maslach Burnout Inventory – Depersonalisation subscale, MBI-PA = Maslach Burnout Inventory – Personal Accomplishment subscale, SDBS = Stress and Distress Behaviour Scale, Frequency Scale = Frequency of SAD-

behaviour Scale, Intensity Scale = Intensity of SAD-behaviour Scale, Confidence Scale = Confidence in managing SAD-behaviour Scale SNCW = Swedish Satisfaction in Nursing Care and Work Scale.

<sup>a</sup>*These variables significantly deviated from a normal distribution, but in each case non-parametric analyses confirmed the reported parametric output.*

<sup>b</sup>*This variable significantly deviated from a normal distribution and the non-parametric analysis did not confirm the reported parametric output. The non-parametric output is therefore reported.*

## Appendix P6

### Jigsaw Evaluation Verbal Feedback

#### *Verbal feedback from jigsaw evaluation*

Item Number	Feedback
Question 4b	More understanding of dementia
If it has changed your attitude/approach, please provide a few details on how it has changed	<p>I understand very well the medical process ... person with dementia (type of dementia) and how manage people with different type of dementia.</p> <p>I'm look at those people only like people who has dementia but come from. All the reasons of the behaviour are serious and must be taken serious.</p> <p>Seeing the bigger picture. Looking at persons past to get a better perception of that person. Why information is helpful/important.</p> <p>This training is very helpful for me because I now understand better people with dementia and my work will be easy in the future.</p> <p>It is ... takes to understand them and look for information.</p> <p>It helped me to understand that there are some of the information more important to provide better care.</p> <p>Understanding what are factual information and what are opinion ... information and to use them on certain models.</p> <p>It has helped me with my day to day activities with my residents and also how to understand them in all area.</p>

---

It has reminded me of the information that I get from people that needs to be reliable. Information to a certain resident or patient might make judgement or assessment to care for them from becoming worse when all that I want is to do good.

It has made me understand that learning a person's background helps in understanding their unmet needs. It can also be wrong to judge person with dementia from just looking or taking statements from other people.

---

Question 5b

If your practice will change, please provide a few details on how it will change

I will try to be calm and understand people with dementia.

I'll try to apply to mt job all the knowledge learned.

Taking the time to find out about a resident in greater detail for you to be able to deliver them better care.

It helps to understand people with dementia

I will try to make time to listen to them, spend more time with them.

I will try to find out more information about residents'

Looking at the bigger picture by knowing the facts so unmet needs can be addressed ?? or potentially de-escalate distressed behaviours

I will apply the jigsaw activity at any time when needed

I will try to remember to gather as much information or data that is relevant and credible to be used in assessing when giving care to a resident

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Treat dementia persons with more care and understanding

I will take into account that unmet needs can lead to distress behaviour - try and identify the unmet needs to improve the quality of life

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Question 7

Childish way of presenting an idea to ADULTS.

Please write below any other comments you would like to share about the jigsaw activity

I learned very much about how to manage people with dementia.

I will use all what I learned in this course every day doing my daily work.

Was very interesting training and is help for my work.  
Dementia training was very important for me.

It is very helpful

It has been very helpful and I understand dementia in a very clearer way.

Helped me understand a person with dementia from where they come from. By looking at their different stages in life. It is important to take into consideration their lives before dementia set in, help to identify their unmet needs and prevent their distress behaviour to make them happier and improve their quality of life and also to keep good care practices.

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*Note:* All comments have been faithfully reproduced including omissions.