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The Carers' Perspective:
loving someone with health issues

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Submitted in the fulfilment of the requirements for the degree of:

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pp. 254-273: **Advanced client study.** Challenging depression and chronic pain: A CBT approach.

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DECLARATION

I grant powers of discretion to the University Librarian to allow this thesis to be copied in whole or in part without further reference to the author. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement.

PREFACE – *'All I know is that I need you'*

The following portfolio comprises of three parts; an empirical research paper, a critical literature review and an advanced case study. Together they form my Doctoral Portfolio prepared as part of the Doctorate of Counselling Psychology at City University, London, UK.

The key theme of the portfolio is the psychological well-being of informal carers. Included in the group are those who care for family members and friends with mental and/or physical health problems.

[redacted]

Most of the current literature on carers focuses on interventions delivered for those caring for someone with a common condition. The empirical study continues in this tradition. Much of my work since entering psychology, as a career change from finance, has been in Older Adult Community Mental Health Teams, primarily working with people diagnosed with dementia and their families. I have found it a privilege to walk alongside people living with such a devastating condition and also those who support them. Yet often the carers are left feeling abandoned as there is no standard support pathway for people who care for those diagnosed with dementia. Many simply muddle their way through while others get first class support. I feel passionate about identifying and developing interventions that will be helpful for all those carers living with dementia and their challenging journey.

The critical literature review addresses whether there are any commonalities in the pathway experienced by carers across different contexts and if a rationalised approach to psychological support for carers is appropriate. I consider the development of a protocol which doesn't pathologize the carer experience but builds on their resilience. It provides them with new skills to manage their role better and be psychologically more resourceful, which fits well with counselling psychology's aims.

The third element is an advanced case study reflecting on my clinical practice and personal journey in becoming a competent practitioner in Cognitive Behavioural Therapy (CBT). Throughout my doctoral training I have had placements within the NHS and consequently

most of my clinical work has been delivering therapy within the CBT model. In practice, my application of CBT incorporates a person centred therapy foundation and third wave CBT techniques and I am looking forward to developing my repertoire of therapeutic skills more broadly in the future.

Together the three elements to the portfolio cover the different aspects of the doctoral requirements. The first two, an empirical research paper and critical literature review, demonstrate my academic capability and area of interest. The third part illustrates my clinical practice and ongoing growth and learning through the presentation of a single case study. Collectively, they demonstrate my growing confidence and competency as a counselling psychologist.

Part 1: The Empirical Research Project

This is an original piece of research adopting a mixed method approach, utilising a quantitative multi-site randomised control trial and qualitative thematic analysis of focus groups. The objective is to evaluate the introduction of a Carer Training Programme, a novel intervention, alongside Cognitive Stimulation Therapy (CST). Group cognitive stimulation is recommended in the NICE guidelines for dementia (2006) for people with mild to moderate dementia. CST is such an intervention and is an evidence based therapy programme for people with dementia demonstrating improved cognitive abilities and quality of life outcomes for those experiencing the therapy.

The rationale for the project comes from previous research literature that suggests joint interventions for people with dementia and their carers are successful. In addition, through my experience of facilitating these groups over the last six years I have learned that many carers ask what happens in the group and what they can do to help/support the attendee at home. When I was offered the opportunity to join this research study with a co-researcher from University College London, I was really excited to be able to work on a project with potential to contribute to the therapeutic understanding and development of a specific intervention for those people I believe are often the last to be remembered, but undertake a valuable and vital role – the informal carer.

In adopting a mixed methodology approach the evaluation of the intervention encapsulates not only the quantitative statistical outcome from standard measures but also feedback from the carers' own voices. Their contributions are insightful and inspiring, reflecting on their

whole experience. They share self-reported changes of the impact of the intervention on their caring role and provide feedback on the detail of the design of the intervention. This is considered in light of clinical practice and service development.

I include an anonymous prayer at the outset of the research section. This piece of literature for me demonstrates the emotional responsibility that carers, especially those living with dementia, carry on a daily basis. It helps me find the right context from which to support the carers in my work and reminds me of the difficult and brave role they undertake.

Part 2: Critical Literature Review

The Critical Literature Review explores the nature of caring for people across a number of different presenting conditions. It asks the question of whether there is a common set of needs across all carers. Most research and services for carers are centred on their needs in relation to the condition of the person being cared for and this is shown to be helpful. I wonder if services are missing an opportunity for rationalisation and efficiency if there are commonalities which could be addressed in a formal care pathway for carers, particularly addressing their psychological well-being.

My doctoral cohort is in an enviable position to be able to choose one element of their portfolio to be a critical literature review or draft a publishable paper based on their research. I consciously decided to include my critical literature review as an element of my doctoral portfolio as I felt it embraced a novel message that would otherwise be lost: That of exploring the commonality of the psychological impact of the caring role independent of the caring context.

From my work in both the critical literature review and the research project I believe that the development of a specific pathway of psychological interventions is worthy of further investigation for informal carers.

There are areas of overlap in the first two parts of this document in the background information which has been kept to a minimum but some unavoidable duplication may be noticed.

Part 3: Advanced Case Study

Throughout my clinical training much of my practice has been in older people services and I have enjoyed working with people who have long histories to integrate into their formulation

and often complex presentations including co-morbid physical difficulties. The acknowledgement of the need and acceptance of support from family members is often integral to therapy progression as one's fragility is addressed.

However, the case study I present is from my working age client work within a Working Age Community Mental Health Team (CMHT). It illustrates that the co-existence of physical and mental health difficulties is not purely within the domain of the elderly. This client presented as focussing on her physical health problems which stopped her achieving her life goals and leaving her depressed and anxious. The therapeutic journey in interpreting her complex history, integrating it into a collaborative formulation and addressing the many contributing factors demonstrates my clinical and professional practice as a Counselling Psychologist.

I chose this client not only because of the therapy content but as I felt it consolidated my learning and competence in my chosen therapeutic model of preference: Cognitive Behavioural Therapy.

Finally, the involvement of the client's mother in her daily living led me to be curious about her thoughts about how her elderly mother managed the continued support of her adult daughter. It also highlighted for me the hidden nature of many carers who would not define themselves as such.

In summary, the path of a carer is a unique one and each individual in this role follows a personal journey and as such will need different types of support at different times. Counselling psychology is in an ideal position to be flexible and responsive to the narrative that each individual brings and offer support in the manner that fits the carer at that time. It is my passion to support carers in my professional career. In practice I have been asked by other therapists how to support carers when their situation is so bleak. A common interpretation is that carers are victims of circumstance. Through the work in this portfolio an alternative perspective has been uncovered of hope and growth and it is one I look to promote in my career through my practice, further research and voice.

PART 1

The impact of the introduction of a Carer Training Programme to Cognitive Stimulation Therapy on the carer: A Mixed Methods Study

Doctoral Research Project

ABSTRACT

Objective: To evaluate the effectiveness of a carer training programme delivered alongside Cognitive Stimulation Therapy (CST).

Design and Subjects: The project used a mixed methodology design. It comprised a single blind, randomised control trial and a thematic analysis of focus group interviews exploring the impact the training had on the carer experience. Sixty-eight people with dementia and their carers were recruited as participant dyads and randomised into one of three conditions; CST plus carer training, CST only or a wait-list control. Carers were administered four questionnaires addressing caregiver burden, self-efficacy, general well-being and carer/patient relationship at baseline and 15 weeks follow up. Focus group interviews were undertaken with eighteen carers who completed the carer training programme alongside their family member with dementia attending a CST group programme.

Setting: Participants were recruited from South Essex Partnership Trust [redacted] across Bedfordshire, UK.

Results: From the quantitative results only one significant result, from the ANCOVA analysis, was found, this was in the quality of the relationship: $F(1, 44) = 12.159$, $p = .001$ ($\eta_p^2 = .225$). The qualitative thematic analysis illustrated a change in carer perception as a result of the training. The participants described an opening position named Pessimism, which included isolation, stigma, lack of support, carer burden, depression and loss. Through adopting strategies shared in the training programme they moved to a position named Mastery with improved understanding, control and self-efficacy leading to hope. This resulted in a third theme named Welfare which reflected improved relationships, interaction and well-being and an ability to facilitate respite.

Conclusions: For carers of people with dementia, in addition to traditional education about dementia, carer training should also consider communication strategies, person-centred interactions and interpretation skills of behavioural and psychological symptoms of dementia. This research found these to be beneficial in enhancing the informal carers' caring experience, resulting in improved relationships. Undertaking specific stimulating activities was more successful when introduced in an organic naturalistic way.

A Prayer

Do not ask me to remember,
Don't try to make me understand.
Let me rest and know you're with me,
Kiss my cheek and hold my hand.

I'm confused beyond your concept,
I'm sad and sick and lost.
All I know is that I need you,
To be with me at all cost.

Do not lose your patience with me,
Do not scold or curse or cry.
I can't help the way I'm acting,
I can't be different though I try.

Just remember that I need you,
That the best of me has gone.
Please don't fail to stand beside me,
Love me till my life is gone.

- *Author Unknown*

1.0. INTRODUCTION

1.1. Carers Overview

In the 2011 Census, 5.8 million people classified themselves as 'carers' by affirming that they provided unpaid care for a family member or friend (Office for National Statistics [ONS], 2013). This number represents approximately 10% of the population of England and Wales and demonstrated an increase in people registered as carers of 600,000 since the previous census in 2001. ONS (2013, p. 1) acknowledges in its summary, '*that the number of carers has increased at a faster pace than population growth between 2001 and 2011*' and this growth is represented across all regions throughout England and Wales, with the exception of London.

A considerable amount of research has been undertaken since the 1950's which has investigated many aspects of being a carer. The research includes establishing how carers manage, what elements of caring add to their burden, identification of coping strategies and carer needs to maintain a good level of care. The UK government has also acknowledged the contribution of carers both practically and financially over the last decade. Consequently, the National Strategy for Carers (Department of Health [DoH], 1999, 2008) was launched. This resulted in a number of initiatives being written into statute and delivering specific 'rights' for carers including, for example, to receive an independent carer's assessment (DoH, 2000) and access to respite (DoH, 2008). Seddon et al. (2007) undertook a review in how these needs are being met in practice and the effectiveness of the services introduced. Their outcomes suggested more work should be carried out to integrate carers in the care process while separately ensuring that the carers' own needs were also being addressed. Knapp and Prince (2007) undertook a review of dementia in the UK for the Alzheimer's Society and suggested that there was a poor level of support for people living with dementia and their carers. My personal experience of carers through my work with people with dementia and their families concurs with this discrepancy between policy and practice. Anecdotally, carers often report feelings of isolation, lack of information and poor support from services once a diagnosis is received. This landscape is also supported by the research of Beeson et al. (2000) reporting that loneliness is a key factor in caring for someone with Alzheimer 's disease and a contributor to carers experiencing depression. Lilly et al. (2012), more recently

through a qualitative study, found a primary theme demonstrated that carers report feelings of abandonment.

Boss (2011, p. xvi) is an American psychologist whose therapeutic approach to carers' challenges aims to reframe their situation as a '*psychological journey toward meaning and hope'*. She too concedes the pervasion of isolation as a serious threat to a carer's emotional and physical well-being.

Brouwer's (2006) commentary revealed that the well-being of carers and the cared for are intertwined and the impact on both should be included in the evaluation of any intervention or service to ensure a full understanding of its effectiveness is obtained.

ONS (2013) acknowledges that, as the population ages, informal care will become more common, with healthy spouses and adult children taking on the responsibility for ensuring the well-being of their frail, physically and/or mentally unwell elderly family members. Thus the development of relevant and comprehensive support for carers in their vital role is critical.

1.2. Carer interventions

A review of carer research highlights that the focus is often given to interventions where carers are caring for family members or friends with the same condition (Jacobi, 2015). This supports the assertion suggested by Smits et al. (2007) that the most effective interventions pay attention to the specific needs of the carer group. Consequently, the current research project focuses on those who are caring for family members or friends living with dementia. Michon et al.'s (2005) critical review of caregiver burden acknowledges the complexity of caring for a family member with dementia, outlining the significant impact it has on the carers' own lives as the demands are significant and time consuming.

Carer interventions, in the dementia arena, primarily fall into three types as Burns and Rabins (2000) identified in their review of caregiver burden. The first type consists of educational programmes which aim to inform carers about dementia and its progression and also cover legal and financial implications. The second type includes more practical solutions supporting the level of caregiving being provided such as respite or introducing practical aids. The third is aimed at improving the carer's well-being and coping skills through psycho-education and skill development, for example around the management of their family

members' challenging behaviours. Ostwald et al. in 1999 noted that interventions which both educated and supported the carers were found to be the most beneficial. This was particularly evident when they were focused on specific situations or challenging behaviours as opposed to describing a more general approach.

Thus, identifying and delivering interventions which provide carers with support and knowledge result in them being better psychologically prepared for the stresses of caring (Quinn et al., 2008). Acquiring improved comprehension of the condition and its impact on their family member, along with skills to help them manage their caring responsibilities effectively, often achieves increased empathy for their family member's predicament (Liddle et al., 2012). It also gives the carer an improved sense of control and self-efficacy which protects their own mental health (Bandura, 1977). These aims fit well with the fundamental philosophy of Counselling Psychology, which Martinelli (2010) explored, highlighting that it leads to the empowerment of individuals and reframes personal experience outside of the medical model.

In 2008, Quinn et al. concluded that supporting carers in understanding dementia was a key 'need' in enabling good caregiving, which was upheld by Schindler, Engel and Rupprecht's (2012) more recent study.

The success of peer support interventions for carers of people with dementia is often discussed in studies, with anecdotal evidence that they are of benefit to carers (Baronet, 1999). Burns and Rabins (2000) noted the importance of peer groups for carers in contributing to stress management by sharing experiences and providing mutual support and advice which was also supported by the findings of Fung and Chien (2002) and Chu et al. (2011). Indeed from my personal experience carers often speak of the support and guidance they have received from others they have met informally. Yet this is an area with little focused research. Even projects which specifically address this issue have reported mixed results. Pillemer and Suitor (2002) explored the success of one-to-one peer support without the surround of education and other services and found no significant effects. Conversely, Fung and Chien's (2002) study of a peer group intervention introduced a trained peer facilitator, and established significant results demonstrating improved quality of life and lower stress levels. Both these studies appear to have used a sound research methodology to capture the impact of their defined intervention, but arguably the intervention design in both projects failed to replicate the 'peer group' support that occurs naturally when carers meet

informally. Arguably, the introduction of a facilitator changes the group dynamic by introducing a power position, and one-on-one interaction loses the breadth of input from a naturally occurring dynamic. This remains a contentious area and both studies reported that more work needs to be carried out in this area to be able to generalise findings. From my personal reflection, a major challenge faced by research designed to capture the effectiveness of peer groups is how to operationalise and deliver the intervention. How can the '*magic*' of people coming together with a common problem be defined without losing the spontaneity and camaraderie between them that formulates organically?

Burns and Rabins (2000) also remind us that the needs of carers change over time as the condition progresses and consequently interventions need to reflect its dynamic course. This important consideration is also emphasized by Beeson et al. (2000), Fontaine and Oyebode (2013) and Zwaanswijk et al. (2013).

1.3. Dementia Background

1.3.1. Prevalence and Economics of Dementia Caregiving

The Alzheimer Research Trust (Luengo-Fernandez, Leal, & Gray, 2010) estimated that over 820,000 people are currently living with dementia in the UK, with costs associated with that care, in the region of £23 billion. Their analysis suggests that 55% (£12.4billion) is attributed to the care provided by family and friends. These costs otherwise would need to be borne by the NHS and other care and social service providers, and do not include costs to support the mental health needs of the carers themselves. Thus failing to care for people with dementia can have consequences which are very real not only for those living with the condition and their families, but for society as a whole, particularly in difficult economic times. Schindler et al. (2012) report dementia as one of the costliest conditions in old age, while Boss (2011) surmises that informal carers are one of the most valuable resources we have in an aging society.

1.3.2. What is Dementia?

Dementia is a biological mental health disorder with a progressive and chronic nature, in which brain cells die off at a quicker rate than in normal aging. There are over 80 different types of dementia. Many lesser well known variants are associated with neurological

diseases such as Parkinson's disease, Huntingdon's disease, Multiple Sclerosis, Creutzfeldt-Jakob disease, AIDS, or from a toxic effect on the brain, for example the effects from long term excessive drinking of alcohol. The third most prevalent variant is Frontal Lobe Dementia, where in many instances personality changes are first noticed by those close to the individual. However, the main and most well-known variants, accounting for over 80% of cases, are Alzheimer's Disease (AD) and Vascular Dementia (VD), including mixed dementia where the individual has elements of both AD and VD present (Boss, 2011; Kitwood, 1997; Lezak, Howieson, & Loring, 2004; Zarit, Orr, & Zarit, 1985).

Alzheimer's Disease is primarily the result of plaques and tangles present in the brain which compromise neuron connections. The effect is a global change in cognitive abilities and individuals present with a gradual decline in abilities noted. Vascular Dementia is generally associated with a vascular incident of some kind such as a transient ischaemic attack (TIA)/mini stroke, or vascular conditions affecting the blood flow to the brain. VD presents with a more localised impact and consequently changes are noted in particular cognitive abilities located in the areas of the brain affected by the vascular incident. The cognitive decline is reported as more "step wise" such that its decline is more obviously defined into discrete stages and often people with Vascular Dementia can have insight and lucid periods (Lezak et al., 2004).

Distinguishing and diagnosing the type of dementia remains a difficult task and often professionals can disagree about the underlying cause (Kitwood, 1997a; Robinson et al., 2008). It can be particularly contentious if the case is complex and the type of changes or course of progression do not fit the standard picture of one dementia. However, progress has been made in facilitating the diagnosis of vascular dementia by identifying a number of specific traits including "step wise" change, history of strokes, little personality change, etc., delivering an 'ischaemic score' (Kitwood, 1997a). But this is not conclusive and thus differential diagnosis is still controversial. More recently technical advances have also assisted this difficult process such as CT and MRI scans which can aid the diagnosis of the specific type of dementia (Lezak et al., 2004).

For family members the main concern at diagnosis is whether there is any medication to slow the process down (Quinn et al., 2008). The diagnosis classification is important at this point as only AD is licensed for medication by National Institute of Clinical Excellence (NICE

CG42, 2006). This is due to the potential complications with respect to heart rhythms associated with the medication (NICE CG42, 2006).

Irrespective of the type of dementia and its underlying cause, once it has been established dementia presents itself as a pervasive loss of cognitive functioning (Lezak et al., 2004). It is diagnosed when there is significant decline in at least two of an individual's cognitive functions, which include memory, language, visuospatial abilities, attention and orientation, motor co-ordination, comprehension, learning capacity, executive functioning including problem solving and judgment making, and has been present for at least six months (World Health Organisation [WHO], 1992). While changes in short term memory is often the first thing noticed by family and friends, it is not this which defines an individual as having dementia. Indeed, some variants such as Frontal Lobe Dementia may not result in any memory difficulties noted initially at all, with personality changes or disinhibited behaviour and poor judgement being early signs of the condition (Lezak et al., 2004). Where only memory difficulties exist, the individual may be diagnosed with Mild Cognitive Impairment (MCI) if no other contributing factors such as depression or a physical problem such as pernicious anaemia exist. If a diagnosis of MCI is given, this is not a dementia, but a separate condition in which there is a 15% likelihood that the individual will go on to develop dementia (WHO, 1992).

Pseudo-dementias should also be ruled out. Depression in older people can lead to poor memory being experienced as a key diagnostic factor, even more so than common elements of depression often seen in younger people such as lack of motivation (Fischer et al., 2008). Whether depression or other reversible memory problem is present needs to be addressed prior to any dementia diagnosis (Kitwood, 1997a; Zarit et al., 1985). Thus, as Robinson et al. (2008) noted, families and friends with concerns that a person close to them is displaying symptoms of dementia are entering a complex arena.

The brief summary in WHO (1992) continues by explaining that cognitive decline is accompanied by an impact on the individual's ability to be able to carry out activities of daily living independently and also by the loss of social functioning. Thus the impact for a carer of someone with dementia, as Andren and Emstahl (2008a) explain, is far reaching. The effect is not only in delivering practical elements in prompting, assisting and provision of personal care, often of the most intimate nature, but also on communication, their social life and economic situation. While there is a lot of media attention currently encouraging people to

get an early diagnosis, Robinson et al. (2008) found there is still a fear of the diagnosis and its associated stigma and perceived hopelessness, not only by families but also from health professionals and doctors.

Dementia is a chronic and progressive illness. In the early stages it presents with primarily cognitive changes, which deteriorate as the disease progresses, and are followed by psychological changes including; agitation, depression, psychosis and behavioural changes which may include; wandering, aggression, incontinence etc., all worsening over time (van der Linde et al., 2013). These changes are commonly referred to as Behavioural and Psychological Symptoms of Dementia (BPSD) and can be very challenging for carers. While all people with dementia deteriorate over time and experience some of these effects, no two people will be identical and, as Etters, Goodall, and Harrison (2008) suggest, each individual's experience of the condition is unique. This results in a difficult task for professionals in supporting carers at the outset as no one pathway can be described, leaving the carers in perpetual uncertainty about what may come next for them and their family member (Conde-Sala et al., 2010b; Robinson et al., 2008). Consequently, education around living with uncertainty and how to manage care in a flexible way may be helpful in setting the carers' expectations and managing their own anxiety. As Boss (2011) suggests, acquiring such skills require a psychological adjustment for the carer, as they challenge the manner in which they have lived their lives previously, leading them to question principles they took for granted, such as abiding by family rules and structure. Consequently, dementia care is an arena in which Counselling Psychology's presence is most appropriate as it works to find meanings in actions and does not look to name unusual but normal reactions to challenging circumstances as pathological.

1.4. What is Dementia Care?

Traditionally, the medical model has been the primary approach to treating dementia. The person is diagnosed following family interviews with medical staff which involve describing the changes in behaviour and memory, undertaking neuropsychological assessment designed to identify changes in cognitive functioning and having a CT or MRI scan. If dementia is diagnosed the individual will be offered medication if appropriate (NICE CG42, 2006). If medication is not viable, there are few alternative options available which can support the family in adjusting to live with the dementia diagnosis and its consequences (Robinson et al.,

2008). More recently research and service development are starting to address how to support carers to engage with the individual with dementia in a different way (Moniz-Cook & Manthorpe, 2009) or help manage the new dynamics present in the family (Fontaine & Oyebode, 2013). Kitwood (1997a) described most support provided is simplistic and functionary with little thought to how the family was experiencing living with dementia.

Tom Kitwood (1997a) was pivotal in challenging how people with dementia are viewed and consequently treated post diagnosis. He pioneered a change in culture in Dementia Care within which care practices were revolutionised. Kitwood (1997a) initially considered how depersonalising the effect of dementia care was, with the individual ultimately seen as being less than human and having to fit into the services available rather than services accommodating the uniqueness of the individual. He illustrated how such treatment would undermine the well-being of an individual. Kitwood (1997a) purported that the deterioration of people with dementia can be impacted as much by the environment they live in and the care treatment they receive, as the neurological changes they are experiencing. He proposed dementia as an interrelationship between the organic changes to the brain and the personal and social factors distinct to each individual and named it the 'dialectical model of dementia'. He argued, and I have seen evidence in my own practice, that the combination of all contributing elements makes the experience of dementia unique for each individual. Kitwood (1997a) described the acceptance of previous thoughtless bad practice, often through ignorance, as 'malignant social psychology'. Historically, there was a community acceptance that people with dementia had lost their humanity and sense of person, and no longer deserved the respect commanded by being human.

Alongside changing dementia care practices, Kitwood (1997a) championed a new view of people with dementia. At the foundation was 'personhood', recognising that the person with dementia still experiences emotion and is capable of relationships and interaction, albeit in a different way. At the basis of personhood is the sense of 'being a person' which Kitwood felt embraced the attributes that Carl Rogers (1961) describes in his book 'On Becoming a Person'. In adopting an alternative way of being with an individual including empathy, congruence, respect etc., as described by Rogers (1961), it allows the individual to become themselves and congruent with their circumstances. In turn, the experience of the relationship between the person with dementia and the other is given priority and Kitwood (1997a) acknowledges Martin Buber's philosophy. Buber proposed two ways of being in the world, with the first being 'I-it' where the second person is objectified; this fitted with

Kitwood's experience of care for those with dementia. The alternative way of being is 'I-thou', where the manner of relating to each other is more encompassing of the whole being and involves creating a more balanced interaction. This symbolises a move from things being done to an individual to things being done with and for an individual. These more experiential and relational approaches were encouraged in Kitwood's (1997a; b) new paradigm of care – 'person centred care'. Indeed, with Rogers' (1961) person centred approach to psychological therapy being the foundation of Counselling Psychology (Blair, 2010) this link suggests person centred care has a particular relevance for counselling psychologists to support the psycho-education of those involved in dementia care.

Kitwood (1997a) postulated the importance of a more balanced relationship model, where the individual with dementia is considered more in the interaction. The loss of cognitive processing can lead to the assumption that the person no longer exists and the subsequent withdrawal from them. This is experienced by the person with dementia and often involves them being unable to articulate their frustration and loneliness. It manifests potentially, as Kitwood (1997b, p. 14) describes, in '*attention-seeking behaviour*s'. Brooker (2007) suggests, a key learning for carers to appreciate is, that any behaviour carries a meaning which is to be interpreted, not simply seen as unhelpful or manipulative. "*Careful listening*", as Kitwood (1997b, p. 15) describes interpreting behavioural cues, is a skill in its own right which once carers have mastered can be very fulfilling for themselves as well as being able to more effectively attend to their family member, a point further supported by Hubbard et al. (2002).

Boss (2011) encourages this shift in the nature of the interaction between carers and individuals with dementia and reflects that participating in a less than perfect relationship '*requires courage and empathy; it deepens your humanity*" (p. 16). She continues that this in turn provides a context where the carer discovers much about themselves and their internal strength and resilience, resulting in a '*new source of hope*' (Boss, 2011). This is a new area of exploration and is congruent with counselling psychology's humanitarian foundations (Martinelli, 2010). It starts to position the carer as having choices and begins to endow them with psychological strength to draw upon rather than simply become 'victims' of their new situation (Boss, 2011). This position is also recognised in the NICE Guideline 42 for dementia (NICE CG42, 2006) which explicitly recognises the importance of person centred care to be delivered to an individual with dementia.

In addition, NICE CG42 (2006) states that its fourth principle is to consider the needs of carers, including informal carers, supporting their ability to care appropriately for people living with dementia. Historically there has been a resistance to sharing 'professional' skills with carers because of a belief that they would not be able to appreciate them or undertake them successfully (Liddle et al., 2012). Yet as Liddle et al. (2012) remind us, most carers are intelligent, well-functioning individuals; hence more recently there is a move towards educating them in key skills and strategies. It is within this context that the current carer training intervention was developed.

Brooker (2004) considers that person centred care has become an overused term and states that it simply does not equate to individualised care. She explains that the key is to understand the life context of the person with dementia. Kitwood (1997b) describes the person living with dementia from a number of perspectives, and considers their condition on both an emotional and social level. This creates an alternative viewpoint so that their actions and perception of the world can be appreciated, their potential encouraged and their personhood respected. Brooker (2004) includes valuing the carers in this model as they will know the person with dementia best when teasing out the critical information to support the person with dementia in their re-scripted world. Thus it is necessary to skill carers to be able to appreciate this aspect of their caregiving role.

Kitwood (1997a, p. 4) describes the task of looking after someone with dementia as a '*near-to-super-human*' task. He continues, stating that it is their '*courage, humour and sheer determination, and by their ability to give friendship and encouragement to others who are in a similar situation'.* I have observed this in all the people I have come in contact with through my work and own personal experience of family members thrown into this role.

1.5. What impacts on carers of people with dementia?

Much has been written about caregiver burden, a term which captures the negative aspects of caregiving (Nijboer et al., 2000). Lockeridge and Simpson (2012) explored its resultant stress and identified some of the coping strategies adopted by carers. It has also been proposed that this additional responsibility will lead to certain feelings which the carer may find hard to admit to, such as guilt (Conde-Sala et al., 2010b; Jarvis, Worth, & Porter, 2006), grief (Boss, 2011), and resentment and bitterness (Beeson et al., 2000; Greenwood et al.,

2009). It is also considered that these unhelpful emotions with no means of release could lead to possible elder abuse (Selwood & Cooper, 2009), the carers own mental health difficulties (Conde-Sala et al., 2010b; Gilliam & Steffen, 2006), physical health difficulties, (Burns & Rabin, 2000; Chang, Chiou, & Chen, 2010; Takai et al., 2009; Vitaliano, Zhang, & Scanlan, 2003), susceptibility to dementia themselves (Alberts et al., 2011; Vitaliano et al., 2011) and premature death (Schulz & Beach, 1999). Indeed, Pinquart and Sorensen (2003) identified that providing care does compromise a carer's mental health, often with the individual not realizing that their ability to cope has deteriorated (McConaghy & Caltabiano, 2005). This in turn compromises the support they can provide for their family member and can lead to earlier institutionalisation (Etters et al., 2008; Moniz-Cook & Manthorpe, 2009). Much research, including that by Andren and Elmstahl (2008a), Smits et al. (2007) and Sorensen, Pinquart, and Duberstein (2002), suggest that such difficult emotions are relevant for all carers.

There is evidence that if a carer is stressed and not managing the situation well, then the person with dementia's behaviour will be worse (Boss, 2011; Michon et al., 2005; Sink et al., 2006), representing a vicious circle. Conversely, the measurement of a person with dementia's awareness is often assessed by reviewing the discrepancy in answers provided by the person and their carer, on such measures such as those addressing activities of daily living or quality of life. Pfeifer et al. (2013) suggest this may be problematic as the carer's answers may be affected by their own experiences and if their perception is that they are experiencing high levels of burden and more stress then the difference could be exaggerated. Concordance of ratings between the carer and recipient of care are used across many contexts and Mitchell et al. (2014) proposed that understanding the relationship dynamic which impacts on the carer's objectivity is critical. Following their study of 258 carers, they concluded that higher secondary stressors, carer depression and sense of caregiver burden all impacted negatively on the carer's ability to assess their family/friends sense of well-being appropriately. Hanson and Clarke (2013) also found that if the carer demonstrated high levels of expressed emotion this compromised their capability to assess the abilities of the person with dementia accurately. This is another argument to support carers' own mental health; otherwise it could lead to people with dementia being judged as more impaired than they actually are. This in turn could lead to misguided treatment choices or early institutionalisation.

1.5.1. Caregiver Burden

Thus a critical question is: *What is caregiver burden and how does it manifest itself*? Baronet (1999) reflects that the phenomenon of 'burden' emerged because, in caring for someone with dementia, the carer has to put their needs behind that of the person with dementia. Michon et al. (2005) outline different elements that contribute to caregiver burden. They propose that the ongoing maintenance of social and professional activities and financial implications collectively are an objective burden, while relationship maintenance and mental and physical well-being of the carer are known as subjective burden. The latter is also captured by Baronet (1999, p. 820), in the sense that the carer is '*carrying a heavy load*'.

Michon et al. (2005) also recognised that burden of care is not necessarily time dependent. They found that higher burden is often experienced immediately following diagnosis when the carers find themselves in an unexpected and unwelcome situation often without support. Then, as the journey of dementia moves from the carer having to take on the higher functioning tasks such as financial management to providing more support in activities of daily living, their stress is seen to increase again. This was confirmed by Takai et al. (2009) who identify that long term challenges in informal dementia care are often not supported by services.

An exploration of contributing factors to caregiver burden identified from research follows. The impact of the key factors is muddled by the specific context of each carer, their personality, personal history and mental and physical well-being (Campbell et al., 2008; Jarvis et al., 2006; Ostwald et al., 1999). This is particularly relevant for this cohort of carers as Schindler et al. (2012) found that higher levels of caregiver burden appear to be experienced by carers of people with dementia more than in other care giving roles.

Pinquart and Sorensen (2003) noted from their meta-analysis of research in this area that higher levels of behavioural and psychological symptoms of dementia (BPSD) by the person living with dementia resulted in higher stress levels being experienced by their carer. This relationship is supported by much research including Baronet (1999), Etters et al. (2008), Kim et al. (2011) and Pillemer and Suitor (2002). Indeed, Conde-Sala et al. (2010b) and Schindler et al. (2012) identified that the impact of BPSD was more of a factor in carer stress than the decline in cognitive abilities. In addition, Burns and Rabins (2000) found that changes in personality contributed to higher levels of burden as the relationship dynamic altered, leaving the carer experiencing a loss of intimacy, communication and emotional

support. This was also supported by the findings of Beeson et al. (2000) and Michon et al. (2005) and addressed by Boss (2011) in her therapeutic approach for those caring for someone living with dementia.

Burns and Rabins (2000) noted that some of the carers' own traits impact on the burden they experience, including their coping style, ability to manage emotions, and attribution style in giving meaning to events. Michon et al. (2005) also identified this important connection in that whether a carer attributes their family member's behaviours as a consequence of their condition or simply as poor or manipulative behaviour can impact on their sense of burden and further supported outcomes demonstrated in Martin-Cook et al.'s (2003) analysis. Other studies including Campbell et al. (2008) and Gallagher et al. (2011) highlighted the carer's personality traits, particularly their level of neuroticism, is an indicator of perceptibility to carer burden.

Ostwald et al. (1999) report that the carers' own perception of their inability to manage their caregiving duties contributes to their sense of burden, which was also supported by Campbell et al. (2008) and Contador et al.'s (2012) studies. It was also noted by Schindler et al. (2012) that knowledge of some of the impacts of dementia, such as services available and behavioural changes lessened a sense of caregiver burden, as did the carer's own assessment of their health status and acknowledging their own need for respite. Thus, Campbell et al. (2008) surmised that delivering interventions which inform and empower carers is vital.

In Burns and Rabins' (2000) review they also noted a difference in gender management of burden. They found that women experience more stress generally, while Akpinar, Kucukguclu, and Yener (2011) noted that men appeared to be affected more by the cognitive losses of their partner. Gender effects were also noted by Zhang, Vitaliano, and Lin (2006) and Etters et al. (2008) where it was found that female carers appear to use emotional strategies to cope while men use more practical solutions. They concluded that problem-solving or mixed approaches appeared to be more beneficial in reducing a sense of carer burden.

Baronet (1999) summarised an interesting association in respect to age and burden, concluding that it appeared that there was no relationship between age and burden if the cared for person was in a stable position, although when families were in crisis there was a negative relationship. This suggested that carers of a younger age, potentially adult children caring for parents, experienced more caregiver burden in that scenario. Given that adult children carers

will often also have other responsibilities such as work and family, this is an important factor to acknowledge as their breakdown may have wider consequences.

There is conflicting evidence in respect to what impact the type of dementia has on the carer. Both Etters et al. (2008) and Burns and Rabins (2000) did not find any effect from the type of dementia. Conversely, Lee et al. (2013) undertook a specific study to address this question and found that carers of those with Lewy Body Dementia (LBD) and Parkinson's disease dementia (PDD) experienced higher levels of stress than those caring for people with Alzheimer Disease or Vascular Dementia. These findings contribute to the argument that higher carer burden is associated with more severe BPSD which are more often found in those with LBD and PDD. Lee et al. (2013) also mentioned that cognitive fluctuations added to carer difficulties as the uncertainty of level of support needed increased.

A final source of stress which appears to contribute to increased caregiver burden is lack of family support (Burns & Rabins, 2000; Etters et al., 2008; Ostwald et al., 1999) or none or poor quality professional support (Baronet, 1999). Pillemer and Suitor (2002) found that if lack of understanding of the carer's plight is experienced or their caring style is challenged or criticised, this potentially results in negative support leading to increased stress and loss of confidence. Etters et al. (2008) report that carers need tangible help from family members and not just platitudes offering encouragement, which could even contribute to the burden experienced by the carer.

1.5.2. Depression

There is a plethora of research which demonstrates the link between the caregiving role and depression in carers (Gilliam & Steffen, 2006), though Burns and Rabin (2000) report that identifying which factors contributes to the depression is less easy to explain. They suggest that it may be a complex picture of many small factors, each individually insignificant, but taken together have a catastrophic impact on the carer's mood.

External factors can contribute to depression, with Etters et al. (2008) recognising that higher levels of BPSD and subsequent experience of increased carer burden impact on feelings of depression in the carer who struggles to manage the difficult changes their family member exhibit, such as wandering and agitation. Michon et al. (2005) also report that over-estimation of the abilities of the family member with dementia can impact on the carer's mood as they are continually disappointed. There is recognition that formal carers can

experience 'burnout' from working with dementia patients and Takai et al. (2009) proposed that this phenomenon could also happen in home environments with family carers, with their study reporting that the consequence is the carer experiencing depression. Indeed there is a move to recognise the impact of caring on informal carers and acknowledge that their need for support is commensurate with that of formal carers as indicated by the National Carers' Strategy documents issued by the Government (DoH, 2000, 2008).

A carer's susceptibility to depression has also been linked to their inherent level of neuroticism (Gallagher et al., 2011; Jang et al., 2004) while Adams (2008) and Beeson et al. (2000) found loneliness, hopelessness and sadness particularly pertinent for those caring for a person living with dementia.

Boss (2011) suggests that naming the carers as depressed may not be helpful as their presentation is actually one of chronic sadness at the situation they find themselves in and at the loss of their family member and previously envisaged life. In labelling them as depressed she suggests that this in turn makes them feel like they have failed and deskills them. Boss (2011) proposes an alternative approach in that carers should be psychologically prepared for the demands likely to be placed on them, with their reactive feelings to this change of circumstance and increased burden normalised. She argues this would in turn empower them. Indeed, Gilliam and Steffen (2006) found a direct relationship between carer's self-efficacy in their role and lower levels of depression.

1.5.3. Physical Illness

Vitaliano et al. (2003) specifically addressed this phenomenon in their meta-analysis and found that the experiences of carer burden and depression exacerbate each other, and in turn have been found to lead to physical conditions. Takai et al. (2009) found similar effects on physical health, for example, carers developing high blood pressure which in turn can lead to far reaching health consequences.

The age of carers themselves is of relevance, as Lavretsky (2005) acknowledges that the majority of carers for people with dementia are older themselves with many being over 65 years old, and thus the physical strain of caring for someone is high, since it is often coupled with physical ailments of their own, leading to exacerbated physical difficulties. Indeed a recent attendee at a Cognitive Stimulation Therapy group I ran was 96 years young – as was his wife and carer!

1.5.4. Stigma

Robinson et al. (2008) found that a common conception of dementia across informal carers and professional services alike was a sense of stigmatisation. Stigma has been found not only to be experienced by the person with dementia but also by their carer.

Moniz-Cook and Manthorpe (2009) align the stigma in dementia to the model espoused by Goffman in 1963. Goffman's conceptualisation identified three types of stigma leading to an individual being seen as less than 'normal', which fits with Kitwood's (1997a) experience of dehumanisation of people with dementia. Moniz-Cook and Manthorpe (2009, p. 16) outline how the three stages are relevant for those living with dementia; first, differences in appearance, which is experienced in dementia, for example, through mobility difficulties; second, that the person no longer fits in with society's norms such that the cognitive decline and associated affects results in a '*spoiled social identity';* and, thirdly, '*tribal stigma*' which refers to the negative perception that society has of the group. Burgener and Berger (2008) concluded, following their comprehensive study, that stigma was experienced by the person living with dementia as a sense of personal shame and rejection by society. The reaction of society, given the entwined nature of the caring role in dementia, also has an impact on those in the caring role (Moniz-Cook & Manthorpe, 2009) in the form of relational stigma. Pinel and Bosson (2013) argue that public stigma impacts on the individual's psychological well-being depending on the amount that they focus on this view of themselves. They explore it in the context of Duval and Wicklund's (1973) objective self-awareness theory that suggests people are more affected by events if their attention is focussed on it. Pinel and Bosson (2013) describe the impact if the social context means the stigmatised trait is acceptable, for example a gay man at a gay pride march. This demonstrates that the individual's perspective and sense of belonging can impact on their well-being, providing further evidence for the need to support carers and normalise their experience.

The government through media campaigns are currently encouraging people to obtain a diagnosis early so that they can access the resources and support that they need. This focus is raising awareness and addressing some of the aspects of stigma described above. However, Devlin, MacAskill, and Stead (2007) hypothesise it is a difficult message to promote, trying to encapsulate empathy and action without causing distress to those living with the condition which, in turn, could compound feelings of stigmatisation.

The early days of diagnosis are often difficult for families, as Robinson et al.'s (2008) research acknowledged. The impact of the diagnosis is absorbed gradually over time and could have implications for how information is provided to carers at this time, when they and their family member are often feeling overwhelmed. Robinson et al. (2008) also reported that families often find that professional services for people with an early diagnosis and their carer is lacking, in both content (such as treatment options) and quality, because GPs and other professionals have few resources available at this crucial time to support them. Moniz-Cook and Manthorpe (2009, p. 17) suggest that the societal narrative, that there is '*little to offer*' those with a dementia diagnosis, results in a stigmatisation within service provision and, consequently, a lack of services offered. This, in turn, could potentially lead to, a reluctance to be diagnosed and labelled or a sense of abandonment, if diagnosis is sought.

Baldwin and Capstick (2007) revisited Kitwood's (1997) question of whether dementia is the result of an individual pathology as a result of neurological deterioration and personal vulnerability or whether it arises as a result of societal pressures. Currently British society appears to value people less as they become old. Bytheway (1994) describes society's reaction to people aging as them becoming a burden on society, and hence less able to contribute. Bytheway (1994) describes this is a phenomenon which pervades society when a group of people are deemed less valuable, and leads to older people perceiving themselves as more burdensome and losing meaning in life. In order to facilitate change, research can challenge these ideas by exploring the value of experience and contributions made throughout a long life to redefine what being old does contribute to society such as wisdom and experience (Bytheway, 1994). Van Orden et al. (2012) report that society's negative view of old age contributes to the poor psychological well-being of carers of those with dementia, which can lead to a greater vulnerability to stress. Kitwood (1997a) discusses that this social context results in too few resources being allocated to the care and services needed by this population, and consequently the employment of people not properly prepared to care for people with dementia or the needs of their family carers. Robinson et al. (2008) established that for carers the lack of resources and difficulties around diagnosis contributed to families experiencing feelings of stigma in the face of dementia.

This is particularly true in the early days following diagnosis, and when the person diagnosed is still relatively well and capable, when sharing the news with extended friends and family is considered. Often people do not let others know, worrying about the stigma of the condition (Robinson et al., 2008). Kitwood (1997a) hypothesised that the negative reaction actually

manifests itself in the anxieties and fear of the recipient of the information who are unconsciously carrying concerns of their own fragility. Either way, the family feel rejected and often withdraw from the social support that research evidence, previously discussed, suggests they need to remain well.

1.5.5. Relationships

Relationships are always complex and the carer/cared for role introduces additional strain. It has been demonstrated that the nature and strength of the pre-morbid relationship impacts on the caring relationship (Campbell et al., 2008; Etters et al., 2008; Fontaine & Oyebode, 2013). Indeed, Quinn, Clare, and Woods (2009) found that the pre-morbid relationship can affect both how the carer adjusts to their new role as well as their ongoing well-being. This was further clarified by Michon et al. (2005) where it was reported the nature of the previous relationship often affected the level of burden experienced.

Conde-Sala et al. (2010a) explored the differences in quality of life of the patient, as reported by carers, which are determined by their relationship to the person with dementia. It was established that female adult child carers perceived themselves as more burdened than spousal carers. Conde-Sala et al. (2010b) found such increased burden led to adult child carers describing less control and more guilt, consequently leading to a higher tendency to mental health difficulties. On reflection this could be the effect of having other commitments such as their own family, work, living apart from their parent and taking on a change in role, leaving limited time to embrace a more empathic relationship.

Campbell et al. (2008) noted that the maintenance of a respectful relationship where both are acknowledged to contribute and maintain warmth between them is important in minimising the burden felt. This relationship was clarified by Fontaine and Oyebode (2013) and Michon et al. (2005) in their respective literature reviews. These findings support the importance of the quality of the relationship to the carer's well-being and in protecting them from stress and depression (Beeson et al., 2000). Fontaine and Oyebode (2013) noted in their systematic review of qualitative relationship studies that, while being together was often spoken about positively, the reality was that it potentially had a long term negative impact on the carer's well-being. Consequently many carers expressed the need for time out to pursue individual interests but often the carer's pursuit of independent time led to disagreement. Hence consideration of relationships is important in designing carer interventions such as

introducing improved communication strategies, as other recent research from Haberstroh et al. (2011), Liddle et al. (2012), and Smith et al. (2012) corroborate.

Fontaine and Oyebode (2013) also caution against taking a biased stance in regards to relationships, by only acknowledging what contributes to better care. Their synthesis of a number of qualitative studies identified a more balanced view, in which their results demonstrated that, not only did good pre-morbid relationships result in positive caring outcomes but conversely poor outcomes could be experienced where past unresolved conflicts in relationships can lead to unhelpful caring dynamics.

Conde-Sala et al. (2010b) found that adult children appear to make more use of external services and their perception of burden decreases when their parent is institutionalised whereas spousal carers feel more stress at this time. They conclude that, given the disparities in different carer relationships, interventions should be designed with its audience in mind and should differentiate content for the carer's specific challenges.

Etters et al. (2008) report the significance of other relationships, such as with extended family and friends, and that tangible support given by the informal support system is seen to be the most helpful. Other research found that good intra-family support can enhance a sense of mastery and control (Baronet, 2003; Skaff, Pearlin, & Mullan, 1996), minimise burden (Michon et al., 2005) and negate depression (Gallagher et al., 2011). Fontaine and Oyedobe (2013) noted it can also delay institutionalisation. Thus the importance of guarding against isolation and being open about the diagnosis to close family and friends is again advocated, although, given the previous discussion around stigma, this can be challenging. This highlights yet another example of the conflict and uncertainty caring for someone living with dementia holds.

The importance of relationships extends to services acknowledging the support the person with dementia needs when interfacing with professional health care providers. Moore (2012) recommended that the carer should not only be present but included in the care management to ensure the person with dementia understands and is compliant with their care plan.

1.5.5.1. Elder Abuse

While the definition of abuse is evasive, the way that people describe abuse can be subjective. Selwood and Cooper (2009) report that carers may not recognise that some of their behaviours are potentially abusive behaviours. Alternatively, there is also the possibility

that some carers may view their behaviours as abusive, adding to their personal levels of stress while the law and health professionals would not classify it that way. Indeed, Michon et al. (2005, p. 49) reflect that a consequence of carer burnout often includes a '*critical and hostile*' attitude, which could be experienced by the carer or the person with dementia as abuse. Although the report "No Secrets" (Hutton, Denham, & Clarke, 2000) suggests that shouting is potentially verbal abuse, government classification outlined in Hutton et al. (2000) and supported by Selwood and Cooper (2009), clarify that there is also an element of repetition which needs to be considered. Hence, such behaviours needed to be assessed on a continuum of increasing occurrence and severity to classify the carer's behaviour as abusive. However, this may not be much consolation for an individual who prior to their caring role would not have reacted in such a manner. Therefore, providing further evidence for the importance in supporting carers to address their carer burden and mitigate difficult feelings and behaviours, often experienced as a consequence of depression and anxiety.

1.5.5.2. Expressed Emotion

As Michon et al. (2005) recognise from their review, carers whose mental health is deteriorating are often more volatile, which subsequently leads to worsening behaviour in the person with dementia. This concept is known as 'expressed emotion' and has been researched since the 1950's following a study by Brown et al. in 1958 (Falloon, 1988). In Falloon's (1988) summary he reports that Brown et al. demonstrated that patients with mental health difficulties who were discharged from hospital into the care of more distant relatives and friends improved at a faster rate than those who went back to their immediate family or care home. The conclusion was that a less emotive environment led to better outcomes for the patient and this is more likely to be found outside of the family home. Falloon (1988) reports that this study was capitalised on and numerous studies replicated its outcome. These studies were particularly pertinent in establishing a contributing factor to relapse in people living with schizophrenia as Vaughn et al. (1982, p. 425) surmise '*relapse is most likely if a patient lives with relatives who are characterised as being high on "expressed emotion.*" More recently this concept has been explored in relation to outcomes for people with other mental health difficulties including those living with dementia (Wearden et al., 2000). Wearden et al. (2000) recognised the uniqueness in dementia in that there is no potential for relapse as it is a progressive condition but they did find an association between high expressed emotion and lower behavioural and cognitive functioning. Michon et al. (2005) describe a link between a carer's emotional response to the person with dementia's behaviour

and their attributional style. Hence, if the carer does not link the difficult behaviour to dementia, they present with higher expressed emotion and sense of caregiver burden. Thus education and training to mitigate this misinterpretation of behaviour and subsequent reaction are also shown to be appropriate.

1.5.6. Grief and Ambiguous Loss

Another area often neglected when researching the experiences of carers generally are the psychological issues around grief and loss (Sanders et al., 2008). Boss (2011) explains that dementia is a series of losses which starts with the loss of cognitive abilities that is in effect an intellectual death which carers are mourning. Worden (2002) describes grief in many ways, including the loss of a dream, of how life could have been, and it is proposed that this may be a common reaction for many carers long before their loved one physically dies (Sanders et al., 2008). Of particular relevance is Worden's (2002) stage of grief, where the relationship between the individual and the person lost is redefined. Salmon (2006) and Boss (2011) acknowledge that the continual losses to dementia result in the relationship dynamics constantly changing, leading to a carer of a person with dementia having to renegotiate their place in the relationship throughout the progression of the condition. Boss (2011) encourages carers to explicitly mourn each loss as it occurs to help them move forward effectively.

Boss (2011) suggests that carers of people with dementia are often pathologized unhelpfully leaving them with a sense of failure. She outlines an alternative hypothesis for the experience of carers of people with dementia as an ambiguous loss. This is where the person is physically present but psychologically absent (Boss, 1999). Boss (2011) explains that as the cognitive awareness of the person with dementia diminishes the expectation of social interaction declines, and carers find this reduction in interaction and support very challenging. Each individual is unique in their experience of dementia (Kitwood, 1997a) and consequently a carer for an individual with dementia faces a future where their ability to take control of situations is compromised leading to a sense of continual uncertainty. Lavretsky (2005, p. 119) suggests this is commensurate to experiencing '*a severe long term chronic stressor*' which in turn leads to hopelessness and depression. It is hypothesised that in acknowledging the carer experiences of loss explicitly through training, and thus normalising and validating the carers' difficult feelings, would provide them with a confidence to seek out support and help (Boss, 2011).

Shapiro et al. (2011) acknowledged that lack of control results in '*poor psychological well-being'* (p. 17), and continue that an individual's ability to exert control over life events is inextricably linked to a positive '*human experience'* (p. 15), but that this can be compromised by the behaviour of others which can lead to stress and burn-out. This phenomenon is tested daily by carers living with dementia. Lavretsky (2005) recognises that this occurs from the moment of diagnosis, as behavioural and cognitive changes early in dementia are often less predictable than in the more severe stages. Sistler and Blanchard-Fields (1993) reported that those with caring duties found that having perceived control in relation to spousal relationships was negative in healthy couples but for those caring for someone with dementia it led to more positive outcomes. As Chattillion et al. (2013) proposed, carers do not always report negative outcomes from the loss of their pre-morbid relationship with the person with dementia, and it is vital that what contributes to a good experience in managing this transition is explored.

1.5.7. Respite

Chang et al. (2010) established that the number of hours a carer spends caring for the person with dementia has a direct link with their mental and physical well-being and sense of burden. The more hours spent in the caring role the higher the sense of burden which is often a precursor to depression (Gallagher et al., 2011) and a sense of 'captivity' which could lead to resentment (Campbell et al., 2008), loss of mastery and control (Skaff et al., 1996) and actions which could potentially be classified as elder abuse (Yan & Kwok, 2011). Yet carers often find it difficult to ask for respite and feel an inflated sense of responsibility to ensure that their family member is supported thus forgoing their own needs (Boss, 2011). Educating carers in the reasons for utilising respite is important to enable them to maintain their own well-being without feeling guilty or that they are letting their family member down (Phillipson, Magee, & Jones, 2013). The reality is that respite actually delays the placement into long term institutionalisation (Lloyd & Stirling, 2011; Phillipson, Magee, & Jones, 2013). In practice, respite utilising residential homes, often occurs in times of crisis when the carer burden can no longer be tolerated rather than as a structured part of their care plan. If respite is introduced in a more controlled way then both the carer and the person living with dementia have a chance to adapt which would lessen the shock impact for both and potentially lessen negative feelings for the carer and minimise challenging behaviour from the person living with dementia (Toot et al., 2013).

Respite can come in many forms and provision of assistive technology to support the caregiving role are just as important in enabling carers to provide their role well and for longer (Toot et al., 2013). Thus Etters et al. (2008) suggested that educating carers to the environmental options is also important in empowering them to make good caring decisions in addition to time away from their family member. Campbell et al. (2008) also recommended that carers be encouraged to undertake activities of their own interest to re-establish a sense of self.

1.5.8. Self-Efficacy

Self-efficacy is one's belief in one's own capability in a given situation. Bandura (1977, p. 194) suggested that this also influences the types of situations into which people place themselves and that people '*tend to avoid threatening situations*' or those they don't feel competent in. Boss (2011) explains, there is often no choice involved in becoming a carer and consequently the individual is placed in a potentially '*threatening situation'* for which the majority have no training or preparation. Not only are they in a position which requires them to support the other person, they also have to take on the responsibilities that the other person had in the healthy relationship. Thus, the carer is put into the position where they have to manage unfamiliar roles and situations which have been the responsibility of their spouse as in their healthy relationship. Bandura (1977) states, that when situations are unfamiliar, people's feelings of incompetence are exacerbated in that area. So unsurprisingly a carer's belief in their ability to cope with this unexpected and unwanted situation can be compromised initially. As time passes and feared situations are managed competently, Bandura (1977) explains that these new experiences of coping reinforce the self-belief that one can manage and subsequently they do cope better. Thus, people begin to believe in themselves and their ability to manage this difficult situation, as carers. Interestingly, there is further evidence that belief in your own personal efficacy can make a difference to the amount of effort you put into a role and how long you will persevere. Indeed, improved self-efficacy has been shown to mitigate stress (Contador et al., 2012; Gallagher et al., 2011) which in turn reduces carer burden (Etters et al., 2008) and depression (Gilliam & Steffen, 2006). Ostwald et al. (1999) noted that the skills carers acquired during their detailed intervention through workshops improved over time and the carer's competence and confidence grew as they applied them in their daily lives effectively. Campbell et al. (2008) also noted that the when a carer believed in their ability in the caring role they experienced lower levels of burden which is supported by Andren and Elmstahl's (2008a) findings.

Rabinowitz et al. (2011) describe self-efficacy in the caregiving role, not in relation to specific tasks, but in having the confidence to address the varying stressors and situations presenting themselves throughout the dementia journey. Rabinowitz et al. (2011) suggest that it is a psychological resource to combat the impact of caregiver burden and offer a barrier to subsequent mental and physical health deterioration. They also suggest that improved self-efficacy appears to counter the use of dysfunctional coping strategies, such as drinking alcohol and eating badly, which in turn supports healthier lives.

There is an alternative perspective and as Boss (2011) and McIntyre (2003) suggest, caring does not have to be all negative. Indeed, Chattillion et al. (2013) acknowledged caring can even be a positive experience. The stressors and depression described above can be addressed by introduction of interventions which re-enable the carers by enhancing their sense of mastery and control (Baronet, 1999; Boss, 2011; Woods & Clare, 2008). This in turn increases the carer's belief in their ability to cope which Skaff et al. (1996) report has been shown to be important in maintaining physical, emotional and mental well-being.

An important justification for the current research project is to introduce an intervention which provides carers with strategies to support them in their caring role, enhancing their self-efficacy and mental and physical health and thus, as Baronet (1999) suggests reducing caregiver burden. The objective is putting the carers back in control and having choices about how they react and manage situations and, in line with Boss' (2011) reframed approach, reinstate hope for the carer. Webb (2012), a carer for her husband who is living with dementia, explains that hope for her is not finding a cure or hoping death comes swiftly and painlessly for her husband, but that in life she has the courage to be able to respond to any situation that sharing life with dementia presents, in the best way she can. With hope she won't give up.

1.6. Exploring joint psychosocial interventions for the carer and cared for

As discussed there are many interventions designed to support the carer in their role and, as Etters et al. (2008) surmised, interventions which address more than one aspect of the caring role have been shown to be the most beneficial. Andren and Emstahl (2008b) also found psychosocial-based interventions for carers were successful. Moniz-Cook et al. (1998) undertook a study which explored the effect of delivering a joint intervention to people with

dementia and their carer, which proved to be successful and resulted in improved outcomes for both; for the carer in their well-being, and in the person living with dementia's memory. This relationship has been supported by more recent research including that of Onder et al. (2005) and Quayhagen and Quayhagen (2001). Brodaty et al. (2003) undertook a meta-analysis of carer interventions and found that those which involved both the carer and person with dementia appeared to be most effective in improving the well-being of both.

Building on these outcomes the current project's design is to introduce a carer training programme to enhance Cognitive Stimulation Therapy (CST) and formally evaluate the impact from the carers' perspective.

1.7. What is Cognitive Stimulation Therapy (CST)?

Group cognitive stimulation is recommended by the Department of Health's NICE Guidance; 'Dementia: supporting people with dementia and their carers in health and social care' (NICE CG42, 2006). Cognitive Stimulation Therapy (CST) is such an intervention and is an evidence-based treatment for people with mild to moderate dementia (Spector et al., 2003).

The use of psychosocial treatments has long been established, in the literature about dementia, as approaches that are helpful in supporting people who are living with dementia (Spector et al., 1998). Historically, however, given the nature of psychosocial interventions, the research evidence underpinning the merits of such approaches, has been challenging to achieve (Moniz-Cook et al., 2011). CST was developed on the basis of a systematic review by Spector et al. (2000) in which they identified the most useful non-pharmacological treatments and synthesised them into a structured stimulation programme. Spector et al. (2003) subsequently undertook a large scale randomised control trial (RCT), primarily involving people with Alzheimer's Disease in day centres and nursing homes, which demonstrated that CST contributed to improved cognition and quality of life for people with dementia.

CST is a structured group programme providing stimulating activities for people living with dementia. The focus is on participation of group members and discussion of personal opinions which are drawn out by taking part in a range of themed creative activities. CST utilises aspects from a range of interventions proven to be effective for people living with dementia including reminiscence therapy, reality orientation, cognitive rehabilitation therapy,

validation models and multisensory stimulation amongst others. The recommendation for group cognitive stimulation for those with mild to moderate dementia was included in NICE CG 42 (NICE, 2006) following the RCT trial of CST (Spector et al., 2003). Spector et al. (2003) also established that CST was as effective as acetyl cholinesterase inhibitors and Knapp et al. (2006) demonstrated it to be a cost effective intervention.

In addition to embracing effective psychosocial therapies for people with dementia, Kitwood's (1997a) concept of person-centred care underpins CST. The research group at University College London developed Kitwood's (1996) dialectical model of dementia further into a bio-psychosocial model (Spector & Orrell, 2010). Kitwood (1996) acknowledged the impact of other factors on dementia in tandem with the neurological changes such as personality, biography, physical health and social psychology. The UCL team broadened the model and suggested that mental stimulation, sensory stimulation, environment and mood all impact on the lived experience of dementia (Spector & Orrell, 2010). Eighteen key principles were established embracing the elements from the bio-psychosocial model of care, effective psychosocial interventions and respectful person-centred interactions, in line with Kitwood's (1997a) dementia care recommendations and Rogers' (1961) person-centred approach. Spector et al. (2006) state that adhering to the eighteen key principles is critical in the delivery of CST, see Appendix A.

The structure of the original CST is a fourteen session programme delivered twice a week over a period of seven weeks. However, while the original programme was assessed in day centres and nursing homes, there are now a number of NHS trusts and third sector providers that deliver CST to individuals living in the community weekly over fourteen weeks. This is to enable a manageable commitment for families living in the community and meet service resource restrictions. Indeed the CST programme offered in Luton and South Beds, South Essex Partnership Trust was a weekly delivery. From my personal experience of delivering such groups over the last five years, the anecdotal feedback from people attending the groups and their family is comparable with that of Spector et al.'s (2003) original study. In addition to the evaluation of the carer intervention delivered alongside CST, this project will also measure outcomes of the participants prior to the commencement of the CST group and after fourteen weeks to ascertain the effectiveness of a weekly programme. This latter part of the programme is part of an associated research project being undertaken by a colleague, a trainee clinical psychologist at University College London, Jenny Cove.

Spector et al. (2003) reiterate that consistency and familiarity are important to the success of the group. Thus a consistent day and time in the week with known facilitators enhances the cognitive and quality of life outcomes for the group.

1.8. Rationale for the Planned Intervention: A Carer Training Programme (CTP)

Olazaran et al. (2010) recommend that non-pharmacological therapy for people with dementia is helpful to both the recipient and their carer. Clare (2002) champions the provision of interventions to support families living well with dementia while minimising conflict and disability as a key objective. McIntyre (2003) ascertains that historically much of the literature around those who provide care informally focuses on the negative aspects of the role which positions the carers as victims. Martin-Cook et al. (2003) describes the scenario as a carer undertaking an undesired role which has been imposed upon them resulting in resentment. In dementia care, Quinn, Clare, and Woods (2012b) propose a shift in focus from understanding what contributes to caregiver burden to exploring elements which can provide positive caregiving experiences (Carbonneau, Caron, & Desrosiers, 2010) and feelings of competence (Brodaty, 2003). This reframes the caring role and provides space which enables the carer to receive benefits and growth from their caring role. These are aims which fit with the objectives of the current research project. Hence, there is a move to develop interventions with the aim to enhance the carer's capabilities, confidence and resilience. McIntyre (2003, p. 474) described her role as a carer and reflected, that acknowledging previously unrecognised personal attributes, as the '*gift of my mother's illness'*. Michon et al. (2005) also acknowledge this shift, and described the challenge as developing interventions that enable an increase in the skills of carers, while Campbell et al. (2008) suggested, that development of communication skills for those where relationship breakdown had occurred could be easily identified and provided. Both of these outcomes fit with the aims of therapeutic interventions and counselling psychology aims. Thus, an alternative narrative for carers is established, from that of victims enduring burden, depression and loss to one of learning and growth, where the '*act of giving care is seen as a worthy activity*' (McIntyre, 2003, p. 475) and resulting in a celebration of caregiving (Michon et al., 2005). Boss (2011) also proposes reframing the carer role, to one where individuals find acceptance that it is difficult and that they will feel sad and lonely, but that this does not define them, for example, as being depressed.

Pinquart and Sorensen (2006) suggest that interventions which support the carer actively engaging in activity with the person with dementia have better outcomes. Teri et al. (1997) also established that undertaking activity previously enjoyed by the person with dementia can lift the mood of both the person and their carer. Hence, in addition to explaining Cognitive Stimulation Therapy (CST) and outlining the person centred strategies that underpin the development and delivery of CST, introduction to the CST activities was also an objective for the carer intervention. Hence, the research's novel intervention encouraged both a change in how interactions with family members are undertaken alongside the introduction of stimulating activities to be carried out jointly.

Spector, Gardner, and Orrell (2011) also found that carers reported not being aware of the content of CST. This resonates with my own experience of carers who have requested information so that they could support their family member between the groups at home.

It was explicitly stated at the outset of the workshop that this would not be a peer support group as the evidence of the usefulness of such programmes has conflicting outcomes (Fung & Chien, 2002; Pillemer & Suitor, 2002). The objectives of the intervention were to enhance understanding of dementia, facilitate providing care utilising the CST key principles and undertaking CST-inspired activities at home. The expectation for carers is that adoption of these newly acquired skills would result in improved self-efficacy and control. This in turn would result in a reduction in carer burden and improved well-being, in line with research discussed, including Burns and Rabins (2000), Contador et al. (2012), Gallagher et al. (2011) and Olazaran et al. (2010).

1.9. Research Objectives and Aims

The objective of the research project was to introduce a novel intervention, a carer training programme (CTP), to be delivered alongside Cognitive Stimulation Therapy (CST).

The research aim was to evaluate what impact, the addition of the carer training programme to CST, would have on the carers and their perception of the caring role.

The aim of the intervention, a carer training programme, was to provide carers with an overview and understanding of the Cognitive Stimulation Therapy (CST) programme; its structure and rationale, but not to become CST facilitators. The programme consisted of four

components: Three developed to facilitate change; firstly, a brief overview of dementia and dementia care; secondly an introduction to the principles underpinning CST, which support improved interaction and communication with someone living with dementia (Spector et al., 2003); and, thirdly, an overview of the CST activities undertaken during sessions with consideration as to how these activities could be amended to be delivered at home. The final section of the intervention was to set out the participant's commitments as part of the research programme.

1.10. Research Questions

1.10.1. Quantitative Hypotheses

Hypothesis 1:

At time 2 and compared with the group who did not receive the carer training programme, the group receiving the CTP should show greater self-efficacy, well-being and relationships, and less burden. Analysis: ANCOVA with scores on these measures at time 1 and time 2 being entered as covariance.

Hypothesis 2:

At time 1 and time 2, more self-efficacy will be associated with reduced burden, higher well-being and better relationships. Analysis: Correlations at time 1 and time 2.

1.10.2. Qualitative Aim

Focus groups were undertaken with those participants who completed the Carer Training Programme, to elucidate the in-depth meaning and understanding attached to, their experience of the intervention, and the impact on their carer role.

1.11. Personal Reflections and connections to the research

I shall now capture my reflections on my opening position and biases. I consider my involvement in this project as an exciting opportunity in a field that I am passionate about. Since undertaking my career change from accountancy, much of the work that I have been involved with as a trainee counselling psychologist has been in the area of older people and

specifically dementia. I have delivered CST groups to individuals with dementia over the past six years and have personally experienced the difference it makes to the lives of those living with dementia. The change in their confidence, mood, sense of self and interaction with others as the weeks pass is tangible. I consider it a real privilege to work in this area.

In working with people with dementia I meet many carers. In my informal discussions with them, it is apparent that the strain of their role is often helped by the ability to share experiences and to understand their loved one's condition. Many carers make the comment as supported by Gilkinson's (2009) findings that their family member with dementia cannot tell them anything about the group and yet they report that the group member is motivated to come to the group. Anecdotally, one carer told me '*We never have any difficulties getting ready on a Tuesday*'. Another carer reflected '*Who would have thought one hour a week would make so much difference*'. Some carers ask for more information, and unfortunately, this has only been provided on an ad-hoc basis and is limited to signposting them to where they can find information on CST themselves. I am excited about the prospect of a formal inclusion of a carer training element to the CST intervention which will provide both knowledge and new skills to help them interact more meaningfully with their family member/friend with dementia.

My empathy with carers has its foundation in my sister's personal experiences. She became a carer when my nephew was born with severe epilepsy which has impacted on his development. Her journey as a carer has been challenging yet rewarding. She undertook some psychological therapy quite early on in her journey but it came at the wrong time and she found that it was unhelpful and never returned. I wonder how many other carers experience such inadequate support which is provided without understanding their needs and where they are in their caring journey.

In undertaking this research I am looking forward to contributing to the research base which explores the needs and requirements of those who provide informal care to a family member. My personal objective is to help provide evidence about the nature and timing of interventions that carers need to support their own psychological well-being. The outcomes can subsequently be integrated into the evidence base which informs professional services and health professionals in how to support informal carers in a structured and responsive way rather than reactive in times of crisis.

2.0. METHOD

2.1. Research Design Strategy

2.1.1 Overview

The current research project was a joint venture with a colleague on the Clinical Doctoral programme from University College London, in training to be a Clinical Psychologist, Jennifer Cove, supervised by Dr Aimee Spector (Reader in Clinical Psychology, UCL). The overall project evaluated the impact of the introduction of a Carer Training Programme alongside Cognitive Stimulation Therapy (CST). The current project's focus was to explore the impact on the carers who undertook the intervention, while my colleague's focus was on any impact the carer training alongside CST may have had on the people with dementia who attended the CST group. The associated research project also examined the effectiveness of CST delivered weekly over 14 weeks. Previous studies evaluating CST (Spector et al, 2003) have focused on the traditional CST format delivered twice weekly over seven weeks. This was a subsequent decision and introduced the need for a third 'waiting list' control condition. This decision was taken as anecdotally some NHS services, which run CST, do weekly programmes because of resource implications and reduction of burden on service users who live in the community. Consequently three conditions will be described in the experimental design. Appendix B outlines each researcher's contribution to the research process.

In the current project there will be two quantitative analyses. The first analysis addresses Hypothesis 1, and will utilise ANCOVAs to explore the impact on carers whose family member attended CST with carer training (Condition 1) compared to those participant dyads who only received CST with no carer training (Condition 2). The second analysis addresses Hypothesis 2, by undertaking correlations on outcomes from all carers, at Time 1 and Time 2 to ascertain the associations between the variables at both time points. Data were analysed using the statistics package SPSS 22. For all analyses a p value less than 0.05 was considered significant.

The current project will also undertake a qualitative study interviewing those carers who undertook the carer training programme. The main aims of the qualitative study are to gain feedback from participants: Firstly, to obtain an evaluation of the effectiveness of the training programme, that is hearing how they experienced the training and if they were able to utilise the techniques; and secondly, to hear their suggestions on how the carer training

programme could be developed and improved. In addition, Quinn et al. (2008) reported that there is relatively little qualitative research which focuses on the carers of people in the early stages of dementia and this project afforded the opportunity to hear those voices, albeit in a specific context, an opportunity not to be missed. The interviews were undertaken in focus groups.

Thus the current project is a Mixed Methodology Design. Over the next few sections, but specifically in section 2.1.2., the justification and appropriateness of adopting this approach are discussed, starting with establishing the epistemological position below, followed by the detailed mixed method rationale in section 2.1.2.

2.1.1.1. Epistemological Rationale

The epistemological position of a research project is the philosophical context that is adopted in respect to the nature of knowledge being explored. One of the key challenges undertaking a mixed methodology project is reconciling the nature of the knowledge being explored in a way that is respectful to all methodologies being adopted, as Breakwell, Smith, and Wright (2012) outlined. Willig (2008) explains that the nature of knowledge rests along a continuum. This moves from a realist position, where it is assumed that information is out there in the world ready to be discovered, through to a relativist position which assumes that there are many variations of knowledge which compete and are socially created through discussion; thus any one individual is only able to access that knowledge created by themselves through conversation or interaction. Willig (2008) explains further that very few psychologists would take either extreme position and would place themselves somewhere in between. The critical realist position is one where both realist and relativist aspects of knowledge are sanctioned.

The basis of quantitative knowledge is found in the positivist position which lies at the realist end of the continuum. Conversely the basis of qualitative research is more subjective as there are a number of different methodologies which adopt varying levels of interpretation of the participant's experience which, as Smith (2008) explains, are the foundation of qualitative psychology. For example, discursive techniques which explore the narrative from the transcript in isolation such as Discourse Analysis fit with a social constructionist view and sit at the relativist end of the spectrum. By contrast, Grounded Theory has a more empirical position and uses the language of the participant to access psychological processes and moves us more towards the middle of the epistemological spectrum (Breakwell et al., 2012; Smith,

2008; Willig, 2008). Madill, Jordan, and Shirley (2000) highlight the importance of qualitative researchers identifying and clarifying their epistemological position and then carrying out their research in a manner that is consistent with that declaration. As such this project has been developed within the critical realist stance.

Collier (1994) describes Bhasker's intention in introducing a critical realist stance was to explore a new epistemology which critiqued and encapsulated both the positivist stance traditionally adopted by quantitative science and the social constructionist position espoused by a more qualitative approach. Bhasker argued that any knowledge gained was only as useful as the sophistication of the variables used to explain it. However, over time as more insight is gained into an area of knowledge, more detailed information becomes available or existing paradigms are challenged and thus the knowledge base broadens and becomes more elaborate. Thus an epistemological stance was needed which accepted both the current knowledge known and was respectful to findings in that context, but also was open to scientific and social development and embodied the different layers of knowledge as they became known, providing a more sophisticated answer to questions (Collier, 1994).

Sayer (1992) proposes that the researcher's epistemological stance should not only align with the methodological approaches undertaken but also fit with the subject matter being explored and the researcher's narrative. Indeed, for families living with dementia, the care and support provided has to be flexible and pragmatic and take into account many different aspects of each individual's bio-psychosocial context (Spector & Orrell, 2010). Each individual's unique experience of dementia is based on, the interaction of hard facts about the condition, such as the physical changes to the brain's structure with the resultant change in cognition and behaviours, intertwined with the particular psychosocial circumstances of the individual (Kitwood, 1997a). Thus dementia is a condition of many levels and one has to be mindful of them all while developing and evaluating interventions.

Jaeger and Rosnow (1988) remind us that people do not exist in a vacuum but that their experience is influenced by factors from the past, present and expectations of the future which, in turn, gives meaning to events that impact on their reality and remains pertinent for those living with dementia. Consequently an individual's perception is impacted by their personal context, affording them a biased view of the world focussing on what their 'filter' prioritises. Hence they propose that the goal of certainty, as pursued by early quantitative scientists from a positivist stance, will always be flawed.

Jaeger and Rosnow (1988) also acknowledge that the researcher will have an impact on their research and should be acknowledged. Willig (2008) clarifies further that the level of interpretation and reflexivity undertaken by any individual researcher is subjective and should be appropriate to the research objectives being explored. The researcher thus acknowledges that her presence would have an impact on the discussions undertaken in the focus groups. However, it is this study's aim to hear the voices of the participants, without further interpretation, in order to evaluate how they were able to utilise the training given and what recommendations they would make to develop it further. In relation to carers of those with dementia, their context is dominated by their family member or friend's condition and their own independent reality is reduced progressively as the condition continues. The questionnaires selected in the quantitative research element identified key areas affected by undertaking a caring role and provided one view of the caring context. The voices of those who experienced the intervention through the focus group adds another tier of knowledge to the evaluation with the synthesis of the outcomes providing a richer explanation overall.

From a personal perspective a critical realist position feels appropriate as I complete my journey from accountancy to psychology. I can appreciate how my education from each perspective now influences my interpretation of events. I am still looking for facts and certainty to explain an event or problem, but now have a greater appreciation of the relevance of context and individual experience.

The acceptance of, and respect for, the many layers of knowledge that contribute to an event and its 'reality' proposed by critical realism fits well with a mixed methodology approach. This is particularly relevant in a research project where neither the quantitative nor the qualitative element is privileged as in the current study. The mixed methodology rationale is now explored in detail.

2.1.2. Mixed Methods Rationale

2.1.2.1. Introduction

Recently research paradigms in psychology have evolved. The traditional focus on quantitative experimental designs has become less popular. This approach looked at exploring the relationship of operationalized terms on a representative sample which provided an understanding of a narrow part of the research question but delivered a result

which could be generalized to the wider population. Breakwell et al. (2006) suggest that psychologists have become more aware of the importance of the depth of individual experience and consequently the use of qualitative techniques has become more accepted. They continue that we should remain mindful that psychology earned its reputation with its foundations in scientific based evidence through the use of experimental psychology.

This research project acknowledges the relevance of both the quantitative and qualitative approaches in psychology. While the two may not sit comfortably with each other and have caused much disagreement within the psychology world, as a critical realist, I recognize, as Langdridge and Hagger-Johnson (2009) suggest, that different methodologies have a contribution to make in different contexts and in answering specific research questions. Thus in order to develop an intervention which is accepted as an integral part of service delivery in the future, the research findings need to be generalizable, hence the quantitative element. To ensure that the experience of the intervention is meaningful and helpful to the individual carers, as Smith, Harre, and Van Langenhove (2008) describe, a more in-depth analysis afforded by qualitative techniques has been included. This will enable an understanding of how carers were able to utilise the training and consider what the intervention should look like.

Creswell and Plano Clark (2011) explain that the nature of the mixed method research design can also impact on the outcome and a number of options were considered. From the outset the researcher was looking to both the qualitative and quantitative aspects of the project to provide a balanced contribution to the evaluation, and thus neither the qualitative nor quantitative outcomes were to be valued over the other. Nor was the information from one strand of the programme expected to provide a foundation for the latter analysis as in a sequential design. The researcher expected that the two strands would provide outcome data which were relevant independently. Subsequently the results would be merged to identify commonalities and differences with the interpretation of the merged results providing a 'more complete understanding' of the evaluation of the intervention. Thus the project adopted a Parallel Convergent Design, further justification for which is described below.

2.1.2.2. Mixed Method Justification

The researcher will now explore the relevance of a mixed method approach for such a research project, where the impact of a novel intervention is being explored.

The underlying objective of the current research project is that it is an evaluation of a novel intervention. The traditional method of analysis supporting such a project design is undertaking an ANCOVA (Dancy & Reidy, 2004; Pallant, 2010). Though of note, Patton (2002) suggested that qualitative research can be particularly useful in a project where something is being evaluated.

Patton (2002) reflects that research studies which evaluate project outcomes originate from when Thorndike evaluated his educational advances, in the early 1900s. Originally, the focus of such a project was the quantitative analysis of changes in predetermined variables as measured by operationalized metrics, which were captured in a systematic way. Patton (2002) asserts that this provides a summative analysis of the success of a programme, that is, whether it is effective or not. He continues that, over time, the evaluation of a programme needs approaches which also capture the quality of the programme and how it may be improved, hence a more formative approach to evaluation. Thus, these contrasting requirements in achieving a balanced and useful evaluation encapsulating both summative and formative elements appears to fit well with a mixed methodology approach as proposed.

The relevance of both qualitative and quantitative information in the evaluation of an intervention is also illustrated in the work of Logghe et al. (2009). In their original RCT paper they concluded that the insignificant quantitative results suggested, that their proposed intervention to minimise falls in the older population, was not effective. Logghe et al. (2011) revisited their study with the team exploring contributing factors from the process in delivering the intervention, as described by the participants. They found that these narratives added a depth to outcomes found in the original RCT which the pure quantitative approach missed. While their conclusion did not change, they were able to outline possible changes to the programme which could be addressed in the future. It was also discussed that self-reported improvements in balance from the participants was not captured in the quantitative analysis (Logghe et al., 2011) but their inclusion could have indicated value received from the intervention. From this latter study, they also recognised that other outcome measures may have been more relevant for the original RCT (Logghe et al., 2009) which could have resulted in a different conclusion.

Thus, the inclusion of a qualitative element in the current research which allows participants to share their experiences, will enable multiple levels of evaluation to emerge. These will

contribute to establishing the overall effectiveness of the intervention and identifying potential improvements for future interventions and research.

Jeppesen (2005) outlined how the critical realist position facilitates many layers of information contributing to the total knowledge achieved, reiterating it an appropriate epistemological stance for the current project. As Creswell and Plano Clark, (2011) describe, in the convergent parallel design adopted in the current project, both the quantitative and qualitative elements contribute to a more in-depth and tiered appreciation of the total research outcomes.

The data for the quantitative and qualitative analyses were collated concurrently and the results are compared and contrasted in the discussion section, exploiting the relative strengths and off-setting the weaknesses of each of the quantitative and qualitative research strands, thus, as Creswell (2009) describes adopting a concurrent triangulation strategy for analysis, which is appropriate in a mixed method study adopting the convergent parallel design (Creswell & Plano Clark, 2011).

2.1.2.3. Mixed Method Summary

Thus the current research has utilised a mixed methodology approach. One element is a randomised control trial exploring the impact on carers of four areas which, previous research, as described in the Introduction section, suggest, are affected by their caring role: self-efficacy, mental and physical health well-being, carer burden and the carer-patient relationship. The second element is the qualitative analysis of focus group interviews with those who attended the carer intervention. Thus a mixed methods approach has been undertaken to evaluate the effectiveness of a new and novel intervention: A carer training programme alongside CST. The research design strategy was adopted to establish both an objective summative measure of effectiveness, but also to hear the voices of the participants, to ascertain any changes they experienced in their caring role after participating in the intervention, and for them to provide formative feedback to improve the intervention for the future. This results in a broader and deeper appreciation of the intervention, as Logghe et al. (2011) identified.

2.1.3. A Unique Opportunity

Another unique and interesting opportunity afforded from the current research project was working alongside a clinical psychology trainee, on a project which was defined prior to my involvement by a clinical psychology research team. Consequently, the philosophical basis of the research project design was rooted in clinical psychology's foundations. It was primarily a randomised control trial to establish the effectiveness of the introduction of a Carer Training Programme alongside the delivery of the Cognitive Stimulation Therapy (CST), fitting with Clinical Psychology's science practitioner model and '*research-oriented training*' (Donn, Routh, & Lunt, 2000, p. 423).

The project consisted of two strands – one focusing on the person with dementia and the other looking at the intervention effect on their carer. My participation in the project arose because a work colleague, who was working towards qualification equivalence in the UK and was an original member of the research team, returned to New Zealand leaving the project with a vacancy. I felt that this project fitted with my interests, as it was the carer element which needed a replacement researcher, and my original research proposal was to explore the experience of male carers looking after a spouse/partner with dementia. In addition, I was delivering a rolling CST programme and often carers would enquire about how they could support their family member in the group. I recognised that, in addition to the objective quantitative findings, this project also afforded an opportunity to explore factors which could contribute to improved well-being for the carers and gain an insight of key factors which impact on this complex relationship dynamic. Lewis and Bor (1998, p. 428) remind us that, in addition to embracing therapeutic congruence and empathy as propounded by person-centred and humanistic therapy models, we must not forget the importance of research as '*an integral part of the training and practice of Counselling Psychology*' as defined by the British Psychological Society. Their debate continues that Counselling Psychology's position in research, which is often cited as a reflective practitioner, can appear to be at variance with traditional quantitative techniques. Indeed, in recent times, there has been a move to more qualitative techniques that embrace this position and to hear the participant's own report of their experiences (Smith, Flowers, & Larkin, 2009; Willig, 2008), which in the current project aimed to capture the nuances of how the intervention was experienced by the carers. Thus, the inclusion of focus groups to hear the carers' voices was critical to my decision to join the project team. The focus group interviews, fit with the art of counselling, in capturing the energy of the individual, to inform change gained from the research

intervention, which they incorporate into their relationships and subsequent personal well-being. The exciting opportunity to develop a multi-layered appreciation of the participant outcomes also fitted with my critical realist epistemological stance, leading to, as described by Blair (2010, p. 28), a '*creative tension'* in the research outcomes. Thus, the enmeshment of qualitative and quantitative research techniques, within counselling psychology's philosophical stance, resulted in creating a unique environment in which the carers were empowered to fulfil their own potential (Martinelli, 2010; Rogers, 1961) and then capture their reflections to credibly inform service development.

2.2. Quantitative Research Study Method

2.2.1. Experimental Design

The experimental design undertaken for this element of the current study was a single blind, multi-site, randomised control trial (RCT) with two independent conditions. Condition 1 is a treatment group in which weekly CST is delivered including the carer training programme intervention. Condition 2 is a treatment group in which weekly CST is delivered with NO carer training. Condition 2 is the control condition for the carer intervention. Data was also collected from participants within the same research protocol for a third condition. Condition 3 was a waiting list control group for the weekly CST intervention analysis. The Condition 3 carer data has been utilised in the correlation analysis to establish the validity of the sample as having been representative of the relationships established in previous studies and detailed in the Introduction.

The data were collected via a respective battery of questionnaires, one battery for the carer and another set for their family member with dementia. It was collected at two time points, pre and post the interventions or wait list period detailed further in the Procedure section. The trial was single-blind - that is, the assessors were blind to the treatment condition of the participants. Participants were aware of the group they had been assigned to as with similar psychosocial interventions studies and thus it was not possible to undertake a double blind trial (Spector et al., 2003). To minimise assessment bias, participants were asked not to share their allocation with the assessors. To ensure equity of treatment for all participants, those participants and carers who had not received the intervention as part of the research were

invited to either the CST Group or Carer Training Workshop respectively following the completion of the research data collection. The project plan is in Appendix C.

The interventions were:

1. Attending the CST Carer Training Programme for the carers allocated to Condition 1.
2. Attending weekly CST for the person with dementia allocated to Conditions 1 or 2.

NOTE: results for participants with dementia, attending the CST intervention, are reported in Cove et al. (2014).

2.2.1.1. Power

The power of a proposed study is the probability that an effect will be detected by the statistical analysis, with the study aim that it will achieve a significant result and the null hypothesis will be rejected (Brace, Kemp, & Snelger, 2006; Tabachnick & Fidell, 2013). The power is calculated based on its relationship with the study's sample size, significance level and effect size. Cohen (1992) suggests that the researcher should aim for a power of 0.8, having a significance level of 5%. Each research study should have an expectation of the effect size they are aiming to achieve in order to be able to establish the sample size required (Cohen, 1992).

As the current study is limited by time and resources the research team aimed to achieve a large effect size of 0.34 or above, which is consistent with effect size guidance outlined in Cohen's (1992) paper. Thus, using G*Power 3.1 (Faul, Erdfelder, Lang, & Buchner, 2007), with power set at 0.8 and using a 5% significance level and an effect size of 0.34, a sample size of 72 dyads, of people with dementia and their primary carers, was determined, hence 144 participants to be recruited. The recruitment of the proposed sample size was considered feasible by the research team in the time scales available to the study for participant recruitment and data collection. Thus, each condition had a potential sample size of 24 people with dementia and 24 carers allocated.

2.2.2. Participants

2.2.2.1. Recruitment Procedure

Participants were recruited in pairs comprising an individual diagnosed with dementia and their primary carer. Participants were recruited from service users who had attended one of the four South Essex Partnership Trust (SEPT) [redacted] across Bedfordshire. Two of the MAS clinics jointly offered CST routinely as part of post-diagnostic treatment, as a combined post-diagnostic CST programme, and thus for the study were considered as one research area. Participants who fitted the study inclusion criteria from the combined CST waiting list were approached. CST was not a routine offering by the other two MAS clinics and they represented a further two research areas independently. Thus, in these two areas an alternative participant identification procedure was adopted, in which the researcher identified people who had been diagnosed with dementia in the previous two years and who met the inclusion criteria. There were specific inclusion criteria respectively, for the person with dementia and their carer, and both had to be met for them to be invited to participate.

2.2.2.2. Inclusion Criteria

The research team developed a set of criteria for the carer participants. The objective was to ensure the carer would have been able to participate in the Carer Training programme and yet was not too onerous, to minimise the exclusion of an individual with dementia from the research programme because of their carer's profile. Carers were considered eligible for participation if they:

1. Had a minimum of three contacts per week with the person they cared for and were able to continue this for the period of the research study;
2. Were aged 18 or above;
3. Could speak and understand English;
4. Did not have major physical illness or disability which could affect participation;
5. Was the main carer for a person living with dementia who fitted the associated research project's inclusion criteria, and had been accepted in the associated project.

The inclusion criteria for the person with dementia were adapted from Spector et al. (2003), the RCT study which demonstrated the efficacy of CST and also established which people are most suitable for CST. People with dementia were eligible for participation if they:

1. Met the Diagnostic and Statistical Manual of Mental Disorder, Fourth Edition (DSM-IV; APA, 1994) criteria for dementia of any type;
2. Scored 18 - 30 inclusively, on the Mini-Mental State Examination (MMSE: Folstein, Folstein & McHugh, 1975) indicating mild to moderate dementia;
   NB: this was adapted from the Spector et al. (2003) research, to include people with a higher level of functioning so that it was consistent with the inclusion criteria for CST in MAS clinics where CST was offered routinely.
3. Could speak English and had some ability to communicate and understand communication;
4. Lived in the community with their family or independently, i.e. not in a residential setting;
5. Were able to see and hear well enough to participate in the group and make use of the material in the CST programme;
6. Could engage in group activity for at least 45 minutes;
7. Did not have a major physical illness or disability which could affect participation;
8. Did not have a diagnosis of learning disability;
9. Had a carer who was willing to take part in the study (and met the respective inclusion criteria as outlined above). NB: This was another adaption to Spector et al. (2003) and was to accommodate the inclusion of carers, specifically for this study.

2.2.3 Procedure

2.2.3.1. Recruitment

The recruitment process was undertaken in three waves, and invited potential participants in each of the research areas as described above. This staggered approach was to facilitate recruitment, enable assessor resources to be utilised effectively and to fit the timing of assessment within the delivery schedule for the research area that already provided routine CST. The same recruitment procedure was adopted across all areas. Each dyad that accepted was allocated a Personal Identification Numbers (PIN) XXXX. It reflected the area they were recruited from XX (Area Code; 01, 02 or 03) and their sequential participant code (XX).

2.2.3.1.1. Invitation Procedure

Potential dyads who met the inclusion criteria outlined above were initially contacted by telephone and provided with a brief explanation of the research project and then asked if they were interested in participating in the research. An outline of the telephone interview script is found at Appendix D. Both the carer and person with dementia were asked to consider the request independently. If they expressed an interest in participating then two Participant Information Sheets were posted out to them for consideration. There were separate schedules for the carer and person with dementia, see Appendix, E and F respectively. All participants were given a minimum of 48 hours to consider the information sheets and make an informed decision to participate or not. They were assured that their decision would not have any influence on the care they received from the [redacted]

After the interested carer-patient dyads had reviewed the respective participant information schedules and agreed to take part in the research project, they were placed on the research accepted list as a confirmed carer-patient dyad participant and a participant identifying number (PIN) was allocated sequentially.

2.2.3.1.2. Randomisation Procedure

Once all the people who had been identified in a given area as meeting the research criteria had been identified, a complete list for the area was finalised. It was at this point that the participant dyads were randomised to their research condition: Condition 1 – CST group plus Carer Training Programme (CTP), Condition 2 – CST group with NO training; CTP Control, Condition 3 – Weekly CST Control. This procedure incorporated a simple block randomisation method (Schulz & Grimes, 2002) using the Random Allocation Software (Saghaei, 2004). Participants were evenly allocated to the three conditions.

Participants were informed of the condition they had been allocated to. They were asked not to share this information with the assessors who attended their homes to complete the assessments to ensure the assessors remained blind to the participant condition. This was to minimise assessor bias so as not to influence the assessment.

2.2.3.2. Assessment Procedure

Data from both the people with dementia and their carers' were collected via a respective battery of questionnaires at two time points. Time 1 (T1) occurred in the two weeks prior to

the commencement of the research interventions. Time 2 (T2) was in the two weeks following the end of the interventions, approximately a 15 week interval. The questionnaire battery details are outlined below in the outcome measure descriptions.

Participants were offered the choice of meeting assessors in their own home or at their local memory clinic. All chose to complete the assessments at home. Two assessors visited each dyad to complete the assessments which enabled the assessments to be run concurrently minimising the impact on participant time. This also ensured the person with dementia was not left alone which may have compromised the carer assessment.

The T1 assessment began with a brief overview of the project and an opportunity for the participants to ask questions or clarify concerns. Following this explanation, and prior to undertaking any assessment, all participants, were asked to complete a written informed consent form, see Appendix G and H for respective consent forms. These were prepared in accordance with the provisions of the Mental Capacity Act (2005) with consideration of potential lack of capacity. A letter was subsequently sent to the General Practitioner (GP) for the participant with dementia outlining their participation in the research, see Appendix I. Participants were reminded that they could withdraw from the research at any point if they wished, without compromising their receipt of the research intervention if they wanted to continue. Carers were also asked to provide demographic details for both the person with dementia and themselves as part of the T1 assessment, included within Appendices G and H.

All carer-patient dyads were informed by letter of the next steps for their involvement in the project, depending on their allocated condition, see Appendix J.

2.2.3.3. Intervention 1: Carer CST Training Programme

In addition to completing the battery of questionnaires the carers allocated to Condition 1 were also asked to attend the Carer Training Programme, which ran over two training sessions, with an optional third session if they required additional support.

Session 1 was a three-hour workshop delivered in the same week that their family member started their CST group. This was the main presentation of information for the carers. It included background information about dementia and an overview of CST which covered a description of its background and development, the underlying key principles and an overview of activities undertaken. The carers were also shown some examples from the CST

DVD, included in the Maintenance CST manual (Aguirre et al., 2012). It concluded with a group discussion on how to incorporate these strategies at home.

The optional support session coincided with CST Session 7 or 8 which was midway through the CST programme. It was a one hour session, which was an optional refresher session, if carers wanted clarify any issues they may have had and share ideas with others about what was working well. Participants were encouraged to attend this session, but some had to work or had other commitments which restricted their ability to attend. They were offered alternative telephone support if required.

Session 2 was at the end of the CST programme. It was a review of the key aspects of the training and was an opportunity for the carers to ask for clarification of the information and share ideas with others.

2.2.3.3.1. Carer Training Programme (CTP) Design

The design of the three hour workshop was a presentation with some interactive elements to enable the carers to undertake some elements of CST experientially. The carer presentation was adapted from the training for health professionals on how to run CST groups and the Maintenance CST manual (Aguirre et al., 2012). The goal of this intervention was not to train carers to deliver CST but to equip them with an understanding of the key underlying principles outlined in Appendix A and provide examples of activities used in delivering CST so that they might adopt them in their own caring role.

Some of the background to dementia and person-centred care was also included in the presentation to give the carers context to the key information being shared which has been shown in previous studies as an important area to improve the efficacy of carers (Clare, 2002; Quinn et al., 2008). Extracts from the Carer Training Programme presentation are illustrated in Appendix K.

Key changes made from the CST health professional training presentation, included removal of the technical research background and development of CST. The language was adapted for a more lay audience, though the Key Principle names were maintained. Some experiential elements were also added to the workshop to allow the carers to experience what was asked of their family members. This included an introduction exercise at the start, an opportunity to take part in an activity discussing ‘famous faces’ and ending the workshop with a verse from a song. The carers were asked to reflect on their experience of these

experiential elements. It was then explained that their family member's level of engagement and experience of such elements was similar to their own. A workshop plan is found in Appendix L.

Each carer was given a workbook with a brief overview of the key elements from the presentation – the key principles and the CST sessions with suggested activities, a carer diary to record any activities that they undertook during the course of their participation in the research and a copy of the Aguirre et al.'s (2012) Maintenance CST Manual.

The Carer Training Programmes were held at locations in the community which were easily accessible for participants. If they needed it, transport was provided and, if required, care was provided for the family member with dementia.

2.2.3.3.2. The structure of the (CTP) intervention

The CTP intervention was designed to encompass training and education in areas, which have been deemed important by previous research, and that impact on the well-being of carers of those living with dementia. Consequently, as previously described the intervention consisted of three key components: 1. Education about dementia and dementia care, 2. Learning skills to improve communication and interaction with the family member living with dementia, 3. Identifying relevant activities to undertake at home.

Firstly, previous studies have identified that an understanding of dementia is an essential requirement to embolden carers in this challenging area, increasing their self-efficacy in managing their caring duties (Clare, 2002; Quinn et al., 2008). Mitchell et al. (2014) noted that it was a lack of understanding of the condition of the cared for, that often led to conflict. Thus the first component of the presentation provided background education on dementia (Ostwald et al., 1999; Schindler et al., 2012), and what constitutes good care, that is the person-centred care approach, when supporting people living with dementia (Brooker, 2004; Kitwood, 1997; Spector et al., 2006).

Quinn, Clare and Woods (2009) established the importance of the relationship between the carer and the cared for, in the provision of good care, when caring for someone living with dementia. Marwit, Meuser, and Bryer (2005) addressed the importance of the relationship dynamics in those living with dementia and reported how communication was a key component to a satisfactory relationship, as well as, physical and emotional health. Arieli (2013) also explored and identified that an alternative approach is needed in communicating

with someone with dementia. The approach needed to be open and flexible to changes in the person with dementia's communicative ability and style – verbal or behavioural, to remain beneficial to both the carer and cared for. Spector et al. (2006) developed a set of key principles which underpinned how a facilitator could improve their interaction with someone living with dementia. Thus, the second component of the intervention introduced these key principles and considered how they could be adopted by the carers in their everyday lives. More recently, Woods (2013) utilised an adaptation of the key principles, and also demonstrated improvement in the carer's well-being and an enhanced relationship with the cared for individual, living with dementia.

The final component, of the training element of the intervention, focused on supporting the carers to identify appropriate activities, based on the CST group interventions, to introduce at home. The activities selected should fit with the interests of themselves and their family member living with dementia and in line with the CST and person-centred care principles. This was important not only to help facilitate an ongoing link with the weekly group sessions, but in undertaking such previously enjoyed activities, Teri et al. (1997) demonstrated that it can result in an improvement in the mood of the carer.

Hence the key areas identified as appropriate to evaluate the intervention were: 1. Self-efficacy, as a result of better understanding of dementia and the nature of care required, 2. A relationship measure, supported by addressing communication skills, 3. Carer mood, by encouraging engagement in meaningful activities and facilitating change through the intervention components attending to relationship dynamics and carer self-efficacy. Fourthly, a caregiver burden measure was also identified as relevant, as this has been demonstrated in the Introduction to be a significant contributor to the level of well-being experienced by carers (Burns & Rabins, 2000; Contador et al., 2012; Gallagher et al., 2011; Olazaran et al., 2010). In addition, Etters et al. (2008) also noted, the impact of caregiver burden on relationship dynamics with the person being cared for.

2.2.3.3.3. Carer Training Workshop Pilot

A pilot workshop was run to establish if the presentation was appropriate in respect of content, language and timing. Ten participants attended, 9 of whom were current carers and whose family members had recently attended a CST group. The tenth person was a carer whose family member had died but has presented on her experience as a carer and remains

very involved in dementia. She is also a lecturer and her view was sought from a professional stance too.

The feedback from the participants was very positive. They reported that all elements of the presentation were valid, appropriate and useful. They also reported no difficulty with the language used in the presentation. The timing of the workshop was the one area which was found to be problematic. It was felt that there was too much content for the length of time. Following this initial presentation, more of the dementia background detail was removed.

A key learning point from the pilot was that the carers often took discussions off at a tangent to talk about specific difficulties and problems they were experiencing. This point was discussed with the research team. It was considered that this may have contributed to the timing issues experienced. As a consequence the introduction was amended to include a statement which asked carers not to bring specific difficulties into the presentation discussions but that, if anything was brought up for them, then there would be an opportunity to discuss it after the presentation had finished on an individual basis.

2.2.3.4. Intervention 2: Delivery of Cognitive Stimulation Therapy

The people with dementia who were allocated to Condition 1 and Condition 2 were invited to attend a Cognitive Stimulation Therapy group, once a week for 14 weeks. The groups started within two weeks of the participants completing their T1 battery questionnaires for the quantitative data collection. Their T2 assessments were undertaken within two weeks of the end of their CST group.

The CST intervention followed the standardised CST manual (Spector et al., 2006) with the adjustment that the 14 sessions were held weekly over 14 weeks rather than the original structure of twice weekly over 7 weeks. Each group session lasted for approximately 1 hour and was held at a regular time and in the same room to ensure continuity, which is an important factor for people living with dementia. Consistency was also supported by each group collectively choosing a unique Group Name and Group Song. Groups were run by two facilitators.

Each session had a different, broad theme which guided the content of the session such as Food, Orientation, Current Affairs etc., see Appendix M for full list of themes. As Spector et al.'s (2006) CST manual offers a choice of activities for each week's theme, the group facilitators met to review the standard structure of the session and agreed the main activity of

each session. This was to ensure a consistent intervention was delivered across the research programme.

People were welcomed to the group by the facilitators and offered a warm drink while they settled. To enhance orientation, a reality orientation (RO) board was located at the front of the room outlining the group name, group session, date, season, location and time of the meeting. The RO board was referenced as part of the introduction to the group and a warm up exercise linked to the week's theme was undertaken to encourage people to relax. This was followed by the group's chosen song and then a discussion about a news article chosen from the day's news. The main activity followed in line with the themed programme agreed previously by the facilitators. The session closed with the group song and individual goodbyes to each group member.

All the CST groups were offered in community settings, within a commutable distance to their homes. Where needed transport was provided.

Waiting list control participants were guaranteed a CST group following their T2 assessment.

2.2.3.5. Waiting List Control

Participants were allocated to the Waiting List Control Group; Condition 3 from all three areas. However, the timing of their assessments in relation to participants in Conditions 1 and 2 varied, depending on the area and if CST was being offered routinely or not.

In an area which did not run CST groups routinely, Condition 3 participants undertook their T1 and T2 assessments during the same assessment period as those randomised into Condition 1 and Condition 2.

It was explained to all participants during the recruitment process and before they signed their consent forms that there was a possibility that, if randomly allocated to the waiting list control, there would be an approximately 15 week waiting period before they or their family member received the Carer Training Workshop or CST respectively. Similarly those carers allocated to Condition 2 would also have to wait for their Carer Training Workshop. While this was out of sync with the CST programme their family member attended, the researchers recognised that a lot of the information contained in the presentation, about background to dementia and communication skills would still be relevant for the carers and they were all offered an opportunity to attend the carer training programme. In addition, a small number of

carers recognised that their family member did not meet the criteria for the CST group but enquired if they could still attend the Carer Training Workshop. This was facilitated following the end of the research project.

The timing of assessments for waiting list participants was different in the areas where CST was being routinely delivered. Schwarz et al. (1997) argued that the ethical position in respect of control groups in social science therapeutic programmes is challenging. They recommended that all participants should receive the best standard therapy available to them, which meant those already on a wait list for a therapy, who had been randomised to the control group, Condition 3, could not have their waiting time increased as a result of the study. Thus the potential participants were only approached where they would have had a 15 week wait or more for CST due to their position on the waiting list. Those recruited to the research and allocated to Condition 3, undertook their respective T1 assessments 15 weeks prior to the commencement of the CST group to which the person with dementia was allocated. They completed their T2 assessments in the week prior to the person with dementia starting the CST group. Thus, carers in Condition 3, the control group, in this area received the Carer Training Programme alongside their family member attending CST as previously described for Condition 1 carers.

2.2.4. Outcome Measures

The outcome questionnaires selected to be completed by the carers, were those found to measure the ways in which carers are affected by their role as identified from the literature review as discussed in the introduction. The main areas identified, which were hypothesised could be impacted by the CTP intervention, were the carers' caregiver burden, mental and physical health, self-efficacy and relationships. The first three areas were also identified by Moniz-Cook et al. (2008) as relevant domains to measure change in carers when evaluating the outcome of psycho-social research interventions. More recently Quinn et al. (2012a) suggested that the nature of the relationship between the carer and their family member/friend also impacts on the success of psycho-social interventions and so a relationship outcome measure was also included. In any study, reliability of the outcome measures is key but often difficult to establish in social sciences and applied research. In order to protect the reliability of the study, standard questionnaires which have been verified were used, and, as recommended by Pallant (2010), the assessors were trained in how to use the instrumentation

competently. The researcher undertook individual training sessions with each of the assessment team to ensure outcome measures were delivered consistently.

2.2.4.1. Caregiver Burden

A key measure in evaluating interventions for carers living with dementia in research programmes is a caregiver burden measure (Campbell et al., 2008). Chou et al. (2003) undertook a review of the various multidimensional measures available to assess caregiver burden; Zarit's Burden Interview (ZBI), Montgomery's Burden Scale (MBS), Vitaliano's Screen for Caregiver Burden (SCB), Novak's Caregiver Burden Inventory (CBI) and Kosberg and Cairl's cost of Care Index (CCI). They concluded that CBI, along with CCI were appropriate for research use and hence CBI was selected for this project.

Novak's Caregiver Burden Inventory (CBI) is a questionnaire developed by Novak and Guest (1989) which assesses caregiver burden and was developed from literature reviews and previous studies. It includes 24 items which are clustered into five sub-factors: 1. Time Dependence Burden, 2. Developmental Burden, 3. Physical Burden, 4. Social Burden and, 5. Emotional Burden. These factors were developed to identify the nature of both subjective and objective burden experienced by carers, so that the results could also help facilitate appropriate strategies to address the carer's caregiver burden, when used in practice (Novak & Guest, 1989). The current project only used the total score generated in the statistical analysis. Each question is scored on a five point scale, scored from 0 (not at all) to 4 (very descriptive), with a total outcome range from 0 to 96. It takes approximately 20 minutes to deliver. Chou et al. (2003) found that good levels of consistency and internal reliability have been reported in the studies they identified. Cronbach alpha values for each sub-factor 1 – 5 were evaluated and reported as .85, .85, .86, .73 and .77 respectively (Novak & Guest, 1989).

2.2.4.2. ***Mental and Physical Health***

The General Health Questionnaire-28 (GHQ-28), (Goldberg & Hillier, 1979) is a self-reported general health questionnaire which assesses the well-being of an individual. Goldberg and Hillier (1979) developed it as a brief assessment tool to address minor psychiatric disorders in the general population. It is appropriate for all age groups above adolescence and for use in non-clinical populations. It consists of 28 questions with four outcomes ranging from 0 (experienced not at all) – 3 (experienced more than normal). Total scores range from 0 – 84 with a high score indicating lower well-being. It takes

approximately 15 minutes to deliver. Goldberg & Hillier (1979) report, that the GHQ-28 has good levels of validity and reliability. Cronbach alpha has been evaluated as 0.70 (Gibbons et al., 2004).

2.2.4.3. *Carer Self-Efficacy*

Self-efficacy was assessed using The Revised Caregiving Self-Efficacy Scale (Revised CSS, Steffen et al., 2002). It consists of 15 questions across three scenarios; how carers could, respond to negative behaviours from the person with dementia, ask for help or respite and control negative thoughts. They are asked to rate their level of confidence in their ability to address an item from 0% - could not do it at all through to 100% if they were certain they could perform the activity to the best of their ability. Each sub-scale is scored independently from the other sub-scales resulting in three outcome scores. Steffen et al. (2002) demonstrated acceptable internal consistency and retest reliability. Factor analysis reported the following Cronbach alphas for each sub-scale: self-efficacy for obtaining respite (CSS:OR) was 0.88, self-efficacy for responding to disruptive patient behaviours (CSS:BPSD) was 0.84, and self-efficacy for controlling upsetting thoughts (CSS:NATs) was 0.86 (Steffen et al., 2002).

2.2.4.4. *Quality of the caregiving relationship*

The relationship quality between the carer and their family member with dementia was assessed using the Scale for the Quality of the Current Relationship in Caregiving (QCRC; Spruytte et al., 2002). It is a 14-item questionnaire used to identify the quality of the relationship including levels of criticism and warmth. There are five response levels to each question which is in the form of an statement asking the respondent to say if they agree strongly, agree, don't know, don't agree and don't agree strongly with scores from 5 (agree strongly) to 1 (don't agree strongly) to a positively biased statement. The total scores range from 0 – 70, with higher scores indicating a stronger relationship. Spruytte et al. (2002) report good reliability and validity have been demonstrated in the development of the scale with an internal consistency Cronbach alpha reported as 0.82.

2.2.5. Ethics

Ethical approval for this study was granted by London South East National Research Ethics Service (NRES) Committee, replicated in Appendix N. This committee is tasked specifically to review research involving adults who may lack capacity under The Mental Capacity Act (2005).

2.2.5.1. Consent Considerations

At the time of initial recruitment, participants with dementia were at the mild-to-moderate stage and would therefore generally be expected to be competent to give informed consent for participation. As dementia is a progressive condition where capacity may change over the duration of the project, consideration was given to the procedures outlined by the British Psychological Society (BPS), (Dobson, 2008) to ensure appropriate consent was being given at all times. This guidance sets capacity in the context of a continuing process as opposed to a one-off decision. Explicit consent is requested at the outset of the research and willingness to continue to participate in interventions is deemed continuing consent. Carers were also asked to countersign the consent forms for their family member at the outset of the research. The research team, facilitators and carers undertook further discussions around continued consent at each assessment and throughout the programme of interventions if circumstances appeared to change.

The following procedures based on the BPS criteria were outlined in the Research Ethics Proposal to assess cases where the capacity of a person with dementia was in doubt;

1. Where the researcher has any doubts regarding the capacity of the person with dementia to provide informed consent, advice from an appropriate clinician will be sought.
2. Where the person with dementia has previously given informed consent to participate, this will provide a good indication of their views regarding the research.
3. All people with dementia participating will be doing so with the full involvement and assent of a family carer; the family carer will be able to withdraw the person with dementia from the study at any time.
4. If a participant lost capacity during the delivery time of the research, a personal consultee (not a carer taking part in the research) will be invited to consider what they think the views of the person with dementia would have been, if they had capacity.

5. Any person with dementia showing verbal or non-verbal indications of refusal or reluctance to participate in group sessions or assessment interviews will be withdrawn from the study.
6. Informed consent from the carer will be sought separately as they are not considered to be a vulnerable group.

2.2.5.2. Confidentiality

All information collected from participants will be kept confidential and anonymised using a coding system (i.e. all participant will be allocated a number which will be used to identify their data). The participant name/number codes will be stored separately from participant data. Data stored on laptops or computers will be protected using a key code and all computers will be password protected. All participant personal data will be stored securely in a locked cabinet kept in a room which is locked when not in use. Only members of the research team will have access to the research data.

2.3. Qualitative Research Study Method

2.3.1. Research Design

The carers who had undertaken the training programme were asked to take part in a semi-structured interview in a focus group format to reflect on their experience of the CST training programme. The objectives were to: ascertain how they had experienced the training programme, explore any impact it had on their caring role, gain insight into their views on the structure and logistics of the programme. The focus groups were an independent exercise to the Carer Training Programme.

To ensure minimal disruption to their caring duties, the focus groups were held immediately following the third carer training session. On completion of the final session refreshments were provided to provide a natural break and change of focus. At this point participants were again invited to attend the focus group or they were free to decline and leave prior to the interview.

Those who agreed to participate were invited to sign a specific consent form for this part of their involvement in the qualitative research interviews, see Appendix O.

2.3.1.1. Focus Groups

Thus, there were three focus group interviews, one for each research area which consisted of the carers from that area who completed the carer training programme and specifically consented to the focus group interview. There were 18 focus group participants in total: Area 1 had 3 participants, Area 2 had 7 participants, Area 3 had 8 participants. Table 1 below illustrates the participant characteristics and flow. Participants across the three focus groups were asked about their experience of the training programme and to reflect on any impact from that training on their interaction with their family member with dementia and other consequences. The interview questions were approved by the Ethics Committee and covered the following:

Focus Group/Qualitative Interview Topics

1. Experience of Training
    - What was your overall experience of the training? – Open question to ascertain the participants initial reaction in their own words
    - What worked well?
    - What didn't work well?

2. Relationship Impact
    - How did your learning impact your interactions with your relative/friend?
    - How did your learning impact on your relationship?

3. Expectations Met
    - Did the training deliver what you were expecting?
    - What would you want to change in the training?
    - What other thoughts do you have?

4. Closure
    - Would you recommend the training to others?

The full focus group schedule is replicated in Appendix P.

Wilkinson (2008) suggests that focus groups are becoming more popular in research possibly because of their flexibility, being appropriate in both a formal research setting or out in the field which is important for applied research.

The literature stresses the importance of planning focus groups to ensure that participants feel relaxed and engaged so that they are able to share their thoughts and ideas and deliver quality data for the research being undertaken (Barbour, 2007; Breakwell et al., 2012; Litosseliti, 2003; Willig, 2008). Barbour (2007) and Litosseliti (2003) emphasise that an important element of focus groups is ensuring the scene is set appropriately, giving consideration to

participants being invited and a pre-interview introduction. In the current research it was considered that as all the participants had agreed to participate in the research and attend all three sessions they demonstrated a commitment to the study. In addition, being carers of people with dementia, they brought a commonality of experience. In order to help the participants feel more comfortable and relaxed, refreshments were provided prior to the focus group interviews and they were given at least half an hour alone to interact without the facilitators' presence.

Wilkinson (2008) stated that it is often suspected that people will not share as much in a group setting. However, researchers have found that the group dynamics often encourage deeper disclosure (Barbour, 2007; Litosseliti, 2003; Liamputtong, 2011). Indeed, my experience in the focus groups undertaken as part of the current project reflected this openness. Participants spoke about their challenges as well as their successes and the narrative included areas which they actually named as 'shameful' – *'I shout at him', 'I get frustrated with her'*. In addition, as Willig (2008) reported, the group dynamics allowed spoken about events actually being demonstrated in the room. For example the participants specifically reported the benefit and help of the peer support that they encountered throughout carer training programme. This was demonstrated, during the focus group interviews (Willig, 2008), by a show of empathy and the sharing of ideas to address difficulties when they were raised during the interview process.

When the groups were asked to return for the focus group, where possible an alternative location was used to help them orientate themselves from the final training session to the focus group agenda. Consent forms were signed and these included agreement that the interview could be taped. A standard introduction to the focus groups, their structure and objectives was given by the facilitator, adapted from that recommended by Litosseliti (2003) reiterating that it was a group discussion and interactive conversation would be encouraged to ensure that all the participant's voices were heard.

2.3.2. Focus Group Participants

The participants for this element of the project were those who had been allocated to Condition 1 in the initial randomisation process and had undertaken the Carer Training Programme intervention as part of the larger study, described above.

Figure 1 is the participant flow diagram for those allocated to Condition 1. Initially 24 people were allocated to Condition 1. As illustrated in Figure 1, this reduced to 21 prior to the T1 assessments. Two dyads withdrew from the project due to the carers' declining health and one participant, with dementia, sadly died. This left 21 participants allocated to Condition 1.

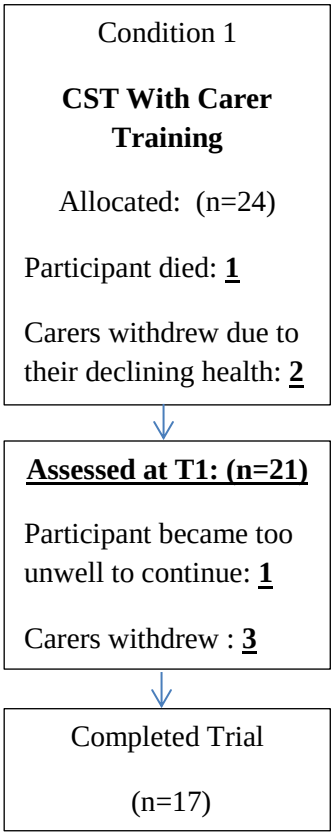


Figure 1: Carers allocated to Carer Training Programme participant flow

Over the course of the project delivery, a further four participant dyads withdrew as a result of health complaints of either the carer or the person with dementia. It is noted that, of the four carers who withdrew, only one of them actually attended the initial Carer Training Workshop. The workshop facilitator reported that this carer was particularly stressed and dominated the carer training session with his concerns. His partner subsequently became very unwell and was hospitalised because of her dementia and both withdrew from the research. Of the remaining three carer withdrawals, they all reported their own challenging health problems, which made it difficult for them to attend the session 1 carer workshop for

three hours. Consequently, they were offered the programme to be delivered at their home on a one-to-one basis. Two accepted this option and had the initial training workshop delivered to them at home, but the third declined. All three subsequently withdrew because of their own health issues and did not complete the T2 assessments.

Female **(F);** Male **(M)**	Condition 1 CST + Training	Withdrew from research	Withdrew from focus group	Siblings attended training & Focus Group only	Focus Group Participants
Total Carers (N)	**21** (13F; 8M)	**-4** (2F; 2M)	**-1** (F)	**+2** (1F; 1M)	**18** (11F; 7M)
Spouse	**17** (9F; 8M)	**-4** (2F; 2M)	**0**	**0**	**13** (7F; 6M)
Daughter	**4** (F)	**0**	**-1** (F)	**+1** (F)	**4** (F)
Son	**0**	**0**	**0**	**+1** (M)	**1** (M)
Area 01 total	**4** (2F; 2M)	**-1** (M)	**0**	**0**	**3** (2F; 1M)
Spouse	**4** (2F; 2M)	**-1** (M)	**0**	**0**	**3** (2F; 1M)
Adult child carer	**0**	**0**	**0**	**0**	**0**
Area 02 total	**11** (7F; 4M)	**-3** (2F; 1M)	**-1** (F)	**0**	**7** (4F; 3M)
Spouse	**9** (5F; 4M)	**-3** (2F; 1M)	**0**	**0**	**6** (3F; 3M)
Daughter	**2** (F)	**0**	**-1** (F)	**0**	**1** (F)
Area 03 total	**6** (4F; 2M)	**0**	**0**	**+2** (1F; 1M)	**8** (5F; 3M)
Spouse	**4** (2F; 2M)	**0**	**0**	**0**	**4** (2F; 2M)
Daughter	**2** (F)	**0**	**0**	**+1** (F)	**3** (F)
Son	**0**	**0**	**0**	**+1** (M)	**1** (M)
Ethnicity					
White British	**17** (10F; 7M)	**-4** (2F; 2M)	**0**	**+1** (F)	**14** (9F; 5M)
Black Caribbean	**2** (2F)	**0**	**-1** (F)	**+1** (M)	**2** (1 F; 1M)
White non-British	**2** (1F; 1M)	**0**	**0**	**0**	**2** (1 F; 1M)

Table 1: Characteristics of Carers in Condition 1 who completed the carer training

NB: The two additional siblings who attended the training and focus group, both attended all three carer training sessions and their mothers, the dementia participant, attended all their CST group sessions.

Ethnicity by research area: Area 01 and Area 02; all attendees were White British, Area 03 attendees' ethnicity breakdown; 4 White British, 2 White Non-British, 2 Black Caribbean.

2.3.3. Qualitative method of analysis review – the most difficult journey

Willig (2008) states the importance of choosing the correct method of qualitative analysis that addresses the research question and fits with the epistemological stance of the project and the researcher. Holloway and Todres (2003) suggested a thoughtful approach to the qualitative method chosen is required as there has been evidence that all methods are seen as a family of approaches in direct contrast to the singular traditional positivist scientific approach. Baker, Wuest, and Stern (1992) report accusations of method slurring, where it is suspected that boundaries around the qualitative methods chosen in research projects are not clearly defined, which could potentially undermine the whole qualitative research paradigm. Indeed, there are many approaches to analysing qualitative data and the clarity around how it is done is variable. Thus ensuring clarity around the rationale and approach chosen is critical.

In order to bring credibility to the practice of qualitative analysis, a clear explanation of the link, between the qualitative approach selected for any given research and the fit with the researcher's philosophical position and methodological underpinnings, are recommended (Holloway & Todres, 2003; Willig, 2008). The consideration of which qualitative methodology to use has presented a particularly challenging element of this research.

I undertook a review of each of the various qualitative method options available in order to select the method which worked within the current research design and was able to provide an analysis which addressed the research objective, to evaluate the impact of a novel intervention.

Interpretative Phenomenological Analysis (IPA) was considered first. The reason for this was because it was the method that had been considered in my original research project proposed; exploring the experience of male carers of partners with dementia. It soon became apparent that this was not appropriate for the current study. Smith et al. (2009, p. 1) describe the method as accessing the experiences of participants in a specific life phenomenon which is found in the '*everyday flow of lived experience*'. While the experience of the training programme is a lived experience it is not part of the 'everyday flow' but a specific one-off event which is quite distinct from everyday experience. One of the main objectives in the evaluation of the training was to hear how the carers used their new information and skills to support their everyday lived experience of being a carer. So, while IPA was not regarded as appropriate in this instance, it was still important to select a qualitative method which encouraged themes to emerge from the data as Willig (2008) describes.

The next methodology to be considered was Grounded Theory. Glaser (1992) originally developed Grounded Theory to be a qualitative methodology which generated theory from the narratives being explored. After consideration it was deemed that Grounded Theory also was not appropriate for the current research design as it was not structured in a way which enables grounded theory to be fully adopted. For example, Grounded Theory looks to identify new themes from current interviews and then identify further participants who can provide further data supporting this new theme through theoretical integration (Corbin & Strauss, 2008). It was not possible to do this in the current project as participant sources were defined and this scope for extension was not possible. Consequently there was no opportunity to explore new areas arising from interviews over the time of the research and undertake theoretical sampling. Glaser (1992) defined theoretical sampling as a key attribute to Grounded Theory. Indeed as Grounded Theory has advanced, Corbin and Strauss (2008) still espouse it as an important element of the process to ensure saturation of contributing themes to an evolving theory.

Willig (2008) and Wilkinson (2008) have suggested that the methods of analysis of interviews, often named Grounded Theory in many research projects, are actually content analysis or thematic analysis. Both, of which, are also qualitative research methods from which common themes are identified and deemed potentially appropriate for the current project.

Thus Content Analysis was also considered and, as this is an evaluative project, there was some merit in identifying the themes which could suggest change from the intervention and exploring the data for them exclusively. This would have had an additional benefit of having a close epistemological fit with the positivist quantitative analysis undertaken, but did not encourage the phenomenological experience to be captured (Elo & Kyngash, 2008).

Guest, MacQueen, and Namey (2012) state that Thematic Analysis has no specific epistemological basis but suggest it is described as consolidating the best bits from a number of robust methodologies. It is thus a pragmatic approach suggesting a philosophical allegiance with Critical Realism. Indeed, identification of the best practices and bringing it together in a coherent programme also fits with the spirit of CST as Spector et al. (2003) identified a number of evidence based interventions for dementia and brought them together into a consolidated programme. As Jaeger and Rosnow (1988) explain, it is important to recognise the context of the experiment in order to understand the knowledge that it

produces. Hence thematic analysis again fits with participants being interviewed in a very particular context which had been developed specifically for the research. While it was important to capture their views on the logistics of the training programme from a practical perspective, the project was also interested in their phenomenological experience of the programme and how that was interpreted by them and applied in their caring role. Thus thematic analysis was the selected method for the qualitative analysis.

2.3.4. Thematic Analysis Methodology

Guest et al. (2012, p.3) provide their favoured description of qualitative analysis as '*Qualitative research involves any research that uses data that do not indicate ordinal values*'. They suggest this as a functional definition that communicates the source of the data for analysis and, does not embroil itself in the quantitative/qualitative debate. Braun and Clarke (2006) report that thematic analysis does not have its roots in any particular epistemology stance and thus it is appropriate within this research as it can be used with less conflict alongside a traditionally positivist quantitative analysis.

Braun and Clarke (2006) report that thematic analysis is often undermined as a methodology in its own right. To counter this claim they wrote a paper to provide clarity to a thematic analysis process. Previously, thematic analysis has been described as, a tool within other qualitative techniques, such as Grounded Theory and IPA. Consequently, the lack of clear guidance on how to use the approach has meant that it is often overlooked as an analytic tool of choice. Interestingly, Charmaz (2006) and Braun and Clarke (2006) suggest that many research papers which purport to be using other methods are actually using thematic analysis. Braun and Clarke (2006, p. 78) stated, it is a versatile tool that can provide a '*rich and detailed*' account of the data, that can encompass a number of different positions simultaneously. Thus it does lend itself to a discourse uncovering the evaluation of an intervention which includes, both, a critique of the experience of the training, as well as uncovering any impact the training may or may not have had on the participants' caring role.

Both Guest et al.'s (2012) applied thematic analysis and Braun and Clarke's (2006) paper endeavour to bring structure and guidance to using thematic analysis in research. This in turn affords the methodology rigour and provides researchers with the confidence to name it as the method of analysis of choice. Following Braun and Clarke's (2006) guidance underpinning

the data analysis in this paper, it is proposed that the Thematic Approach is appropriate for this research project.

Depending on the choices that the researcher makes in respect of their analytic goals, thematic analysis is flexible enough to be used with many different types of data set such as interview scripts, websites or written media. Braun and Clarke (2006, p. 79) at a summary level describe thematic analysis as '*a method for identifying, analysing and reporting patterns (themes) within data*'. From the analysis the data are thus organised and presented in a manner which illustrate the key messages from the script. Braun and Clarke (2006) describe thematic analysis as an active process which incorporates the researcher within that process recognising that the themes which emerge are influenced by the researcher's own perspective. Thus they suggest that the researcher is clear about their own epistemological position and their relationship with the subject matter so that their outcomes can be reviewed in the correct context from which they arose. These are all specific decisions that the researcher has made and have been clarified earlier, that specifically, this research is within a critical realist position which acknowledges different layers of reality all contributing to the overall knowledge of an event.

2.3.4.1. Thematic Analysis Procedure

The proponents of thematic data analysis acknowledge the flexibility of the method as a benefit which allows it to be suitable for many types of projects. In order to give the specific analysis structure and the research project credibility, a number of important structural and analytical design questions need to be answered and clarified so that the reader understands what has been done and on what basis the themes have been developed (Braun & Clarke, 2006; Guest et al., 2012; Patton, 2002).

Braun and Clarke (2006) and Guest et al. (2012) both recommend, that identifying the targeted data unit size for coding, as an initial first step to structuring the data analysis process. Guest et al. (2012) suggest that the data unit can be anything from an interview question asked, to an individual line of the data set. For this analysis, a sentence is defined as the target data unit, for allocating a code to describe it. The size of the data unit can influence the analysis and code book generated, an excerpt is found in Appendix Q. However, the researcher reminds herself that this analysis is looking to evaluate the training from two perspectives: Firstly, how the participants experienced the training and any impact on their caring role, and secondly, a more logistical appreciation of the design and delivery of the

training. Thus, as Guest et al. (2012) and Braun and Clarke (2006) suggest, initially an inductive analysis was undertaken on the whole data set. This process identified codes from within the data set encompassing all elements of the participants' experience. The data were then reviewed again specifically exploring the questions around expectations of the training and its structure to establish feedback on the actual training programme to inform the training programme development.

Patton (2002) recognised that thematic analysis is flexible allowing a wide choice of options to determine themes and their prevalence but it is important that, once defined, the approach should be applied consistently throughout the analysis.

Braun and Clarke (2006) question the relevance of prevalence within qualitative research. On the opposite side of the debate Guest et al. (2012) actively include a numeric count of codes as part of their overall process. However, it is not as structured as one would find in a content analysis where numbers are specifically stated and statistical analysis undertaken on them. They argue that the inclusion of information about the prevalence of themes does suggest that valid decisions about the data have been achieved. Once the thematic analysis had been completed, a count of contributing references within each code and supra theme level was undertaken, see Appendix R (i). However, on reflection this does appear to be hanging on to the traditional positivist approach that there is one identifiable truth which qualitative approaches have challenged from the outset. Given my own personal narrative (previously working in finance), I found it necessary to complete this analysis to verify that a coherent story had been identified from the data set.

For this research the analysis adopted an inductive approach, analysed the data at the semantic, descriptive level and looked to hear what the participants have actually said about the training (Braun & Clarke, 2006; Guest et al., 2012; Patton, 2002; Saldana, 2009). The codes were identified to hear how the participants had evaluated the training programme from both in its delivery and also from their subsequent learning and application in the home environment. The identified themes were deemed relevant by consideration of their validity in line with the literature. This level of analysis also fits with the critical realist approach on which this research is grounded, recognising the relevance of differing layers of knowledge.

The alternative more in-depth latent analysis where the codes are more interpretive, exploring psychological inferences about the participants' contributions would be of great interest to the researcher and I reflect on the early challenge that was experienced in deciding which

qualitative methodology to use. The final decision is again keeping the research question in the foreground. It is an evaluation of the training programme delivered, and thus the relevant information is in hearing the words from the participants and not an interpretation of those words. However, even without reflective interpretation, the current analysis is structured with an intention to identify psychological change and benefits to the carers afforded to them from undertaking the carer training.

Braun and Clarke (2006) state that the analytic process starts as soon as the researcher starts to notice patterns of interest in the data, right from the point of data collection. This was indeed the case in this analysis and I would reflect on the focus groups immediately following their completion and in discussion with my fellow researchers.

Qualitative literature, irrespective of the method of analysis chosen, suggests that you immerse yourself in the data to appreciate the depth and breadth of the information contained within it and to do so in an active way, searching for meanings and patterns (Braun & Clarke, 2006; Saldana, 2009; Smith et al., 2009; Willig, 2008). I listened to the tapes prior to transcription on numerous occasions, listened to the tapes in conjunction with the transcribed scripts to bring life to the words and read the data again. As Patton (2002) explains, these exploratory ventures into the data not only help in acquainting oneself with the data but also enable initial themes and patterns to come forth.

Guest et al. (2012) suggest it is useful to plan the analysis from the outset. There were three questions I asked myself as I read the data:

1. The overall research question – the question that drives the research;
    a. Evaluation of a carer training programme.
2. The questions the participants have responded to;
    a. How did you experience the training?
    b. What was worked well/what did not?
    c. Were you able to utilise the training at home?
    d. Did it change anything about your interaction/relationship?
    e. Would you recommend the training?
3. Questions that guide the coding and analysis;
    a. How was the training programme received?
    b. Did the participants translate their learning into action?
    c. What was the impact on the carer?
    d. How could the training be improved?

The initial themes and patterns identified went on to inform a presentation I was asked to give at a conference and also helped to define the first iteration of my code book (Guest et al., 2012; Patton, 2002), see excerpt in Appendix Q. Braun and Clarke (2006) describe the initial codes as the first steps in sorting the data into meaningful clusters. They are the building blocks of the themes to be generated and as such are an integral part of the process of analysis. Saldana (2009) states that there is no correct way to code and that the methods used should be relevant for the data you are working with and the aims of the project. Saldana (2009) identifies a specific method of coding named evaluation coding which is underpinned by a descriptive naming of the patterns identified by Braun and Clarke (2006). This approach also specifically identifies positive and negative statements about the intervention and notes possible recommendations for change and improvement, which supports the formative intent of the analysis as described by Patton (2002).

In undertaking the initial coding, the whole of the data set was included and worked through thoroughly and systematically, ensuring that each area transcript was given appropriate time and attention. Throughout all three areas there was a lot of agreement noted explicitly. The analysis was undertaken manually with codes to the left of the narrative, thoughts and ideas to the far left, with quotes highlighted. An excerpt is illustrated in Appendix R (ii). The coded data were collated in a summary table, by code by focus group area, also capturing quotes if particularly representative of the code, and then synthesised into a count for each code by area, see Appendix R (i). The specific data item was identified in the table by a reference of [participant pseudonym; area: page: line] e.g. (NICK; 03:63:1125).

Where quotes were allocated to themes in the initial coding more than once, this was recorded, as Braun and Clarke (2006) recognise that it is not a straightforward mapping system and that inconsistencies may occur which are also important to capture. Hence, some quotes were representative of more than one theme and they were recorded in both with reference to the other code. Context of the quotes is also important to maintain so that the themes can be conceptualised in the real world.

Braun and Clarke (2006) explain that the generation of themes from the initial codes is where the interpretative nature of thematic analysis arises and where the links to theory start to form. The list of unconnected codes is reviewed and commonality identified across codes in proposed themes. This is an iterative process where different codes are tried out together in different combinations to explore how they may co-exist as an overarching theme. This

analysis is a complex affair, and each code was placed in a text box, in a word document, and moved about in a mapping exercise experimenting with different combinations of codes. Following the creation of the initial KEY themes, the data extracts supporting each code allocated to a theme were reviewed to establish if a cohesive story for that theme has emerged. If they do not appear to fit, then it is necessary to see if the theme is appropriate and, if they fit in other 'themes' already identified, where they represent a new theme or are discarded from the analysis. Braun and Clarke (2006) named these themes 'candidate themes' which suggests that they are still part of the analytic process rather than the final result. The importance of the themes is then assessed in the production of a thematic map. The thematic maps in the current project endeavoured to establish the effectiveness of the intervention.

The thematic map is where the story and meaning represented by the data set are developed. Saldana (2009) suggests that there is no defined way to do this as the skill, expertise, knowledge, judgement etc. of the researcher is integral in interpreting the data set. Thus, what is an accurate account of the data, depends on the decisions made by the researcher throughout the analytic process but is auditable as the decisions made are clearly defined and documented.

Braun and Clarke (2006) recommend that the thematic map is then reviewed in the context of the original data set. They propose that new themes may emerge which were not originally coded so that these can be considered in light of the full thematic picture of the data, thus recognising that the organic and cyclical process continues to the end of the analytic phase.

Identifying when the full interpretation is complete is a complex challenge due to the cyclical nature of the analysis and the tension between inclusion of data and acknowledging that the analysis is saturated. Braun and Clarke (2006) suggest that a key strategy is to recognise when the changes stop adding something new to the story and are only adding breadth to already established themes.

In line with Braun and Clarke's (2006) theoretical approach to analysis, the literature was reviewed prior to analysis to help identify the key patterns present in the data. As this is a mixed method, project this also fitted with the overall research process as the key areas of interest identified are being measured in the quantitative element of the project. Neither elements of the research project are being privileged over the other, with the outcome from both to be used to synthesise an overall evaluation of the project.

2.3.5. Reliability and Validity

Reliability of qualitative research is a challenging area as Madill et al. (2000) suggest. They undertook a review of a number of qualitative research papers and found that, by comparing and contrasting methodologies used for analysis and subsequent outcomes, they demonstrated that qualitative analysis was being undertaken in a methodical and rigorous manner. This project, being undertaken in a critical realist framework, has adopted the thematic method of analysis as part of a mixed methodology project. It will triangulate the results from the qualitative element with the objective outcomes from the quantitative element of the project to demonstrate reliability of the findings.

It is suggested that it may be appropriate to ask another person to code some of the data to establish reliability of the coding used. Guest et al. (2012) question this approach, as they reflect that each researcher brings their own lens into the analysis. Consequently they ask: just how reliable is the comparison? Alternatively Guest et al. (2012) suggest, that a section of text, which has been analysed by the sole researcher, is returned to after a lapse of time to establish if the coding is being consistently applied. This was the approach adopted within this project. In addition, to provide transparency around the coding and themes identified from the analysis of the transcripts, a codebook has been produced in the format proposed by Guest et al. (2012), see Appendix Q. This defines the codes identified and gives guidance around the nuances of their application to the interviews.

The application of codes is a subjective exercise so by using the structural theme of UTILISATION to illustrate, the development of the code book is described. There were subtle nuances behind the intention in how the carers utilised some of the strategies. Some home activities are specifically linked to CST sessions and within the analysis this was labelled 'FUN/ACTION'. But the carers also spoke about how they 'involved' their family member more in day-to-day activities, so to acknowledge this difference, they were labelled 'INVOLVEMENT'. It was felt important to maintain the different underlying intentions.

Madill et al. (2000) recognised the importance of internal consistency within a qualitative analysis as another way in which reliability is demonstrated in a qualitative study, that is, does the story hang together? This approach resonates with my own style of establishing validity in many scenarios throughout life and fits with the critical realist stance. Jaeger and Rosnow (1988) identify that the many layers in a complex world lend themselves to a level of

coherence in an individual's interpretation, enabling people to function appropriately in different circumstances.

2.3.6. Reflections on the process of analyses.

I was excited by the interviewees' feedback in all areas even during the interviews. From the first interview when I had an emotional pull from one of the statements made in regards to a joint journey – *'we are one'*, I felt privileged to hear the family narratives.

However, my self-doubt then crept in and concern about whether I had done it correctly started to cloud out the messages I had got so excited about. In my immediate reflections there was also concern voiced throughout – Did I let them go off subject too much? Will there be too much talking over each other to be able to hear anyone well enough? Did I allow everyone space to talk? Did I bring the conversation back to the research questions in a helpful and empathic way?

Each area had been a different experience and I reflect on how my presence affected the process. Did the third focus group work more smoothly because it was the third group? Or had the preparation been more thorough through experiential learning from the previous groups or because I knew the participants better through my interaction with them throughout the research? I had only met the three participants from the first area briefly prior to the focus group. I had recruited them in the recruitment drive and run the CST group in that area for a couple of sessions and met them there as they waited for their family member. But we had not had a conversation. In relation to the second area participants, I had undertaken the initial assessments with a number of them and four of the seven participants had family members who attended the CST group that I ran, which meant we had a number of interactions throughout the research process. In the third area I observed the initial training session and ran all the groups in the area, and so had met all the participants and had interactions with them regularly. Did this add to the spontaneity of the focus group or compromise them?

In retrospect I wonder if my reticence to engage with the data was my own fear that I would not do their voices justice. However, I could not deny their stories and, from my first listening of the tapes, key points of interest and patterns across the whole data set became apparent. These formed the basis of my presentation at a CPD conference on 3rd May 2013 where my initial ideas were shared. This was an exciting but worrying experience – Would

people be interested? Would the early patterns make sense? The feedback was positive; people commented on my passion for the project and the key note speaker, who herself had started working with families in an intervention for those living with acquired brain injury, commented on how she had enjoyed the presentation and its early outcomes.

3.0. RESULTS

3.1 Introduction

As this is a mixed method project, the results section explores both the quantitative and qualitative elements of the project in turn and then reviews the independent outcomes together to establish a synthesis of the results.

3.2 Quantitative Analysis

Selecting which statistical test to use is an important decision, as different statistical analyses address different research objectives. For example some tests demonstrate that experimental interventions result in outcomes which achieve statistical significance and support a research hypothesis, while others may provide confirmation of known and expected phenomenon. Thus it is necessary to ensure that the statistical methods chosen are able to answer the desired questions.

The current project was an exploratory project primarily to evaluate the introduction of a Carer Training Programme for carers alongside the delivery of CST to their family members, who are living with dementia. The primary analysis was to undertake ANCOVAs which are a recommended approach in the evaluation of a novel intervention (Dancy & Reidy, 2004; Field, 2013; Pallant, 2010). In addition, the researcher has also undertaken correlations to establish if the data collated from participants are consistent with associations found in previous research.

3.2.1 Recruitment and attrition

Across the four [redacted], one hundred and sixty six dyads (166) were identified as suitable for inclusion and telephoned to invite to take part in the research. Information packs were then sent to 122 dyads, that had consented to receive them and 72 agreed to participate and were randomised into one of the three conditions by area, as described above. Unfortunately before the T1 assessment could be undertaken, 4 dyads withdrew from the study. As no data were held for these dyads, they were excluded from the final analysis. A further 9 dyads withdrew over the course of the study. Figure 2 displays the flow of participants through the research.

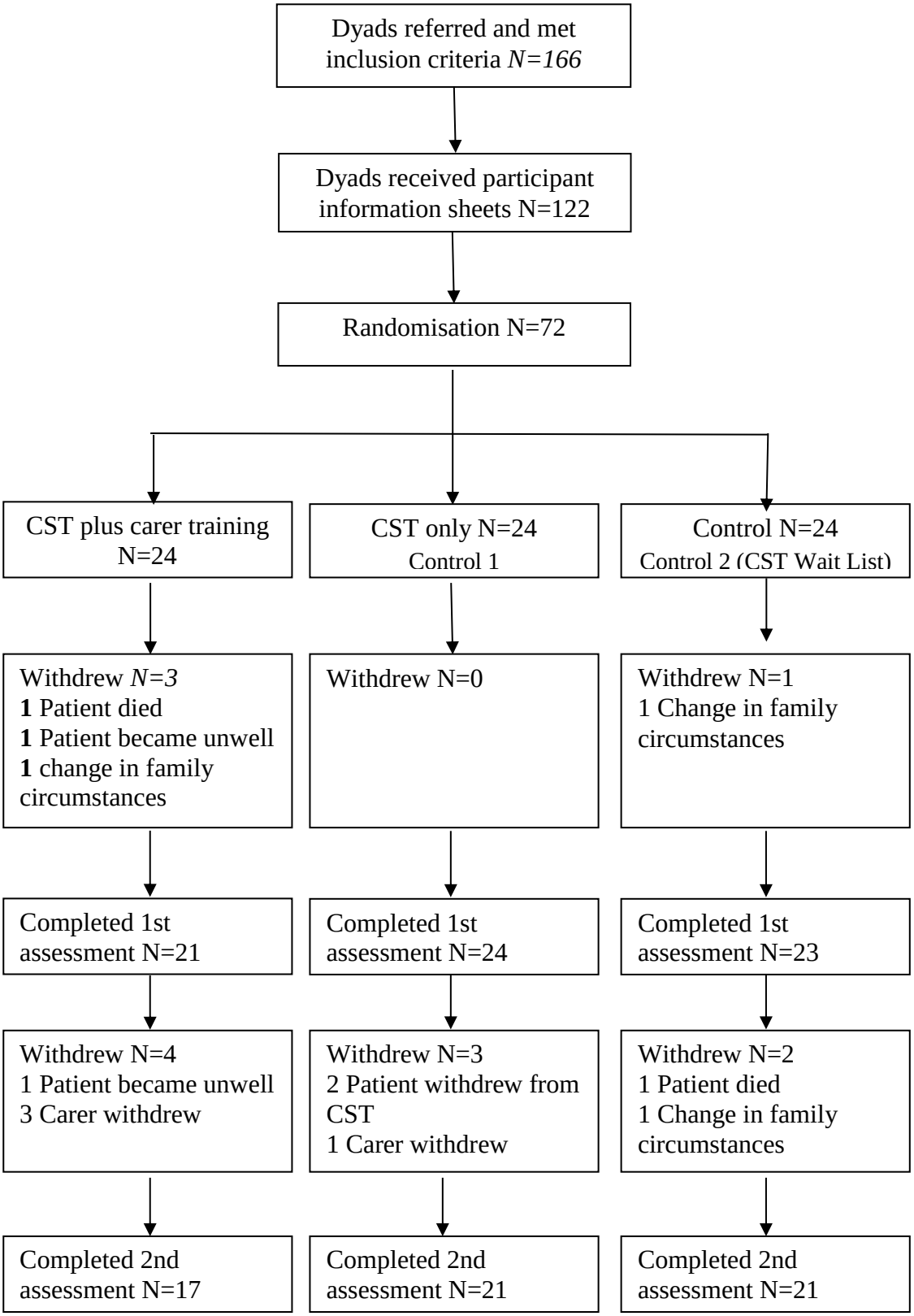


Figure 2: Participant Flow through Research Study

3.2.1.1. Participant Characteristics

The description of the carer characteristics across the three conditions is detailed in Table 2. The description of education was not consistently collected and excluded. In summary, the majority of the carers recruited were White British (85.3%), 82.4% lived with the person they cared for and 76.5% were the spouse/partner of the person living with dementia. One way ANOVAs, t-tests and χ^2 were used to check for differences in baseline characteristics across the three conditions at baseline. There were no significant differences across the three conditions in any of the participant characteristics.

There were also no significant baseline differences across the three conditions on any of the outcome measures: Self-efficacy (CSS) to i) obtain respite (OR), F(2,67)=0.151, p=.86, ii) manage BPSD, F(2,63)=0.428, p=.65, iii) manage negative thoughts (NATs), F(2,65)=1.39, p=.26; GHQ28, F(2,67)=2.02, p=.14; Caregiver Burden (CBI), F(2,67)=0.174, p=.185 and Relationship measure (QCRC), F=1.93, p=.153.

Carer Characteristics	**Condition 1**	**Condition 2**	**Condition 3**	**TOTAL**	F/ χ^2 value, **p-value**
Number of Carers (N)	**21 (30.9%)**	**24 (35.3%)**	**23 (33.8%)**	**68 (100%)**	
Age of Carer in years Mean (sd)	68.8 (10.4)	67.1 (11.3)	70.4 (11.1)	68.8 (10.9)	F=0.54, **p=.59**
Gender					
Male	8 (38.1%)	5 (20.8%)	10 (43.5%)	23 (33.8%)	χ^2 =2.94, **p=.23**
Female	13 (61.9%)	19 (79.2%)	13 (56.5%)	45 (66.2%)	
Relationship to Patient					
Spouse	17 (81%)	17 (70.8%)	17 (73.9%)	51 (75.0%)	χ^2 =7.81, **p=.45**
Partner	0 (0%)	0 (0%)	1 (4.3%)	1 (1.5%)	
Adult Child	4 (19.0%)	5 (20.8%)	4 (17.4%)	13 (19.1%)	
Daughter in Law	0 (0%)	2 (8.3%)	0	2 (2.9%)	
Niece	0 (0%)	0 (0%)	1 (4.3%)	1 (1.5%)	
Living with person with dementia					
YES	18 (85.7%)	19 (79.2%)	19 (82.6%)	56 (82.4%)	χ^2 =1.67, **p=.85**
NO	3 (14.3%)	5 (20.8%)	4 (17.4%)	12 (17.6%)	
Ethnicity					
White British (%)	17 (81%)	21 (87.5%)	20 (87%)	58 (85.3%)	χ^2 =7.25, **p=.51**
White Irish (%)	0	1 (4.2%)	1 (4.3%)	2 (2.9%)	
White Other (%)	2 (9.5%)	1 (4.2%)	0	3 (4.4%)	
Black Caribbean (%)	2 (9.5%)	0	2 (8.7%)	4 (5.9%)	
Indian (%)	0	1 (4.2%)	0	1 (1.5%)	

Baseline Outcome Measures; Means (standard deviation)_					
	Condition 1	**Condition 2**	**Condition 3**	**TOTAL**	F value, **p-value**
CSS (OR)	60.7 (35.3)	63.2 (25.1)	65.6 (30.0)	63.2 (29.8)	F=0.15, **p=.86**
CSS (BPSD)	76.2 (21.7)	73.1 (21.9)	76.6 (15.1)	75.3 (19.4)	F=0.43, **p=.65**
CSS (NATs)	78.3 (16.3)	69.4 (24.8)	78.8 (18.1)	75.5 (20.3)	F=1.39, **p=.26**
GHQ-28	21.7 (10.6)	28.4 (14.2)	20.9 (11.2)	23.76 (12.5)	F=2.02, **p=.14**
CBI	21.6 (16.4)	30.67 (17.7)	25.3 (15.3)	26.03 (16.7)	F=0.17, **p=.19**
QCRC	56.9 (7.8)	50.6 (13.4)	53.74 (7.3)	53.6 (10.2)	F=1.93, **p=.15**

Table 2: Baseline characteristics of all carer participants

Detailed information about the characteristics of the participants with dementia in the study can be found in Appendix S.

As previously illustrated in Figure 1, of the 24 carers allocated to the Carer Training Condition, 3 withdrew prior to T1 assessment which left 21 carers eligible to receive the carer training. Of these 21 carers, 14 (66.7%) attended all three elements of the training, 2 (9.5%) attended 1 and 2 but not the optional middle session, 4 (19%) received only session 1 with two of them receiving it at home. Two siblings of the identified main carer in the study also attended all three elements of the training and also took part in the focus groups. In total, 20 carers attended the carer training workshops and one (4.8%) did not attend any sessions at all.

3.2.2. Hypothesis 1: ANCOVAs

The first analysis of the outcome measures aligned to hypothesis 1 was using ANCOVAs to evaluate the changes in scores over time and across conditions. The ANCOVAs allow for variability in the T1 outcome measures to be controlled for and thus was entered in the analysis as covariates (Dimitrov & Rumrill, 2003). Effect sizes were calculated using Partial Eta^2 (η_p^2). It should be noted that the sample size is small and consequently may compromise the parametric version of the statistical analysis. Dancy and Reidy (2004) suggest in such cases the non-parametric version of the test, should be considered, in this instance the comparative test for an ANCOVA is a Friedman Test. Following consideration, the researcher continued to use the ANCOVA analysis to maintain consistency with the methodology as documented in the original ethics approval documentation. Indeed, as we have only recruited a sample size appropriate to identify a large effect size, this project is in danger of making a type 2 error. This means that if there is an effect, the study may not be

sophisticated enough to capture it; the following analysis is undertaken in this context (Dancy & Reidy, 2004).

To maximise the sample size for the analyses, intention-to-treat analysis was applied. Thus for participants who withdrew from the study before the T2 data collection assessment their T1 outcome was carried forward to T2 for any data missing.

Z-scores were used to check for outliers across each of the questionnaires' outcomes and a number of scores were considered outliers in the self-efficacy elements of behavioural and psychological symptoms management and control of negative automatic thoughts. The relationship measure also had three outliers. However, it was noted that the 5% trimmed mean was comparably close to the overall mean of these three measures, as found in the questionnaires where no outliers were identified; Self Efficacy Obtaining Respite element, GHQ-28 nor the Caregiver Burden questionnaire, and thus no adjustments were made to the outliers, following guidance as described in Tabachnick and Fidell (2013).

All the data sets were assessed using the test for normality, Kolmogorov-Smirnov and levels of skewness and kurtosis. Social science measures often result in data sets which violate normality by being skewed or demonstrating kurtosis. Pallant (2010) explains that this does not mean that the questionnaires are not reliable but suggest that the results are due to the underlying construct being measured. For example people tend to answer low when asked questions about their well-being, leading to positively skewed results; while they tend to score satisfaction measures highly, demonstrating that they are content with their circumstances which lead to a negatively skewed overall result. All of the questionnaires in the current research resulted in skewed data sets as expected.

Tabachnick and Fidell (2013) suggest that statistical solutions are better if the variables are normally distributed and consequently all the data sets which were found not to be normally distributed were transformed. The Self-Efficacy measures and the relationship measure were all found to be negatively skewed and so were transformed using a reflected square root. The GHQ-28 and Caregiver Burden outcomes were found to be positively skewed and were transformed using a square root calculation embedded with SPSS (Pallant, 2010).

MEASURE		Base Line			Post Intervention			ANCOVA	
		CST plus carer training N=21	CST ONLY N=24	All N=45	CST plus carer training N=21	CST ONLY N=24	All N=45	Between group difference at T2, with T1 as covariance *[NB: All Levene's Test passed]*	Effect Size η_p^2
Self-Efficacy; Obtaining respite (CSS:OR)	Mean (SD)	60.7 (35.3)	63.2 (25.1)	62.0 (29.9)	63.1 (36.9)	61.4 (25.3)	62.2 (30.9)		
	Transformed Mean (SD)	5.55 (3.15)	5.71 (2.33)	5.64 (2.71)	5.2 (3.38)	5.9 (2.25)	5.57 (2.83)	F (1,44) =0.977; p=.33	.023
Self-Efficacy; Response to BPSD (CSS:BPSD)	Mean (SD)	76.2 (21.9)	73.1 (22.0)	74.5 (21.6)	77.0 (19.3)	73.6 (18.9)	75.1 (18.9)		
	Transformed Mean (SD)	4.31 (2.56)	4.92 (1.99)	4.64 (2.26)	4.31 (2.40)	4.98 (1.67)	4.66 (2.05)	F(1,40) = 1.157; p=0.29	.030
Self-Efficacy; Negative thoughts (CSS:NATs)	Mean (SD)	78.3 (16.3)	69.4 (24.8)	73.8 (21.3)	76.2 (16.9)	68.5 (24.1)	72.1 (21.2)		
	Transformed Mean (SD)	4.36 (1.97)	5.20 (2.19)	4.79 (2.11)	4.64 (1.89)	5.32 (2.08)	5.00 (1.99)	F(1,42) = 0.075; p=.76	.002
GHQ-28	Mean (SD)	21.7 (10.6)	28.4 (14.2)	25.2 (12.9)	19.7 (9.7)	27.2 (12.7)	23.7 (11.9)		
	Transformed Mean (SD)	4.53 (1.08)	5.15 (1.39)	4.86 (1.28)	1.25 (0.19)	1.39 (0.22)	1.32 (0.21)	F(1,44)=2.05; p=0.16	.047
Caregiver Burden Inventory (CBI)	Mean (SD)	21.6 (16.4)	30.7 (17.7)	26.4 (17.5)	24.1 (16.4)	31.0 (16.9)	27.8 (16.9)		
	Transformed Mean (SD)	4.17 (2.1)	5.29 (1.67)	4.77 (1.94)	4.54 (1.89)	5.37 (1.52)	4.98 (1.73)	F(1,44)=0.86; p=0.36	.020
Carer – Patient relationship (QCRC)	Mean (SD)	56.9 (7.8)	50.6 (13.4)	53.6 (11.5)	56.8 (7.8)	48.3 (12.2)	52.3 (11.1)		
	Transformed Mean (SD)	3.58 (1.15)	4.28 (1.45)	3.96 (1.35)	3.62 (1.08)	4.62 (1.20)	4.15 (1.24)	F(1,44)=12.159; p=.001	.225

Table 3: ANCOVAs: Scores at baseline and follow up for each outcome measure

An analysis of outcomes detailed in Table 3 shows only one significant finding was established between conditions at T2, with the Carer Training Programme intervention having a positive impact on the quality of relationship between the carer and the cared for, as experienced by the carers; $F(1,44) = 12.159$, $p = .001$ ($\eta_p^2 = .225$). There was also a significant change in the carer relationship measure over time from baseline to T2 overall, $t(1,44)=2.7$, $p=.01$. All other measures did not show any significant difference between conditions at follow up. However, although there was no significant difference between conditions at follow up for the GHQ-28, $F(1,44)=2.05$, $p=.36$, there was an overall reduction over time from T1 to T2; $t(1,44)=21.7$, $p<.05$. Conversely, for the caregiver burden (CBI) there was no between condition differences at follow up, $F(1,44)=-.86$, $p=.36$, but there was a significant increase over time between baseline and follow up across the whole dataset, $t(1,44)=2.52$, $p=.016$. There were no significant differences over time from T1 to T2 for any of the self-efficacy measures.

3.2.4. Hypothesis 2: Correlations at time 1 and time 2

The following correlation analyses explore the hypothesis, that at time 1 (T1) and time 2 (T2), more self-efficacy will be associated with reduced burden, higher well-being and better relationships. These analyses will illustrate that the current data set demonstrate associations between outcome measures which are in line with findings established in previous research and outlined in the Introduction. The total T1 and T2 data collected from all participants, across all three conditions, was used as this formed the largest data set.

The non-parametric Spearman's rho correlation was used because the data were not normally distributed. In addition, as Pallant (2010) explains, Spearman's rho correlations are increasingly being used in health and medical literature and psychology research as it is being realised that ordinal level ratings, such as Likert scales, do not translate directly into interval level scaling without issues.

The Spearman's rho correlation results are presented in Table 4 and 5 below, as recommended by Pallant (2010), for ease of reference. The negative correlations arose because high scores meant better outcomes for individuals in the self-efficacy and relationship measures, while high scores in the well-being and caregiver burden measures meant that participants were experiencing more distress.

The correlation results support Hypothesis 2 and illustrate the relationships previously described from earlier research, such that: higher levels of self-efficacy are associated with reduced caregiver burden and consequently increased well-being and improved relationships.

Spearman's rho Correlations	Well-Being GHQ-28	Self-Efficacy - Obtaining Respite (CSS; SE-OR)	Self-Efficacy – Managing BPSD (CSS; SE-BPSD)	Self-Efficacy – Managing negative thoughts (CSS; SE-NATs)	Caregiver burden (CBI)	Relationship Measure (QCRC)
GHQ-28	1	-.34**	-.37**	-.61**	.65**	-.54**
CSS; SE-OR		1	.29*	.45**	-.35**	.27*
CSS; SE-BPSD			1	.70**	-.46**	.46**
CSS; SE-NATs				1	-.61**	.57**
CBI					1	-.60**
QCRC						1

*. Correlation is significant at the 0.05 level (2-tailed). **. Correlation is significant at the 0.01 level (2-tailed).

Table 4: Spearman's rho Correlations of T1 Outcome Questionnaire data

Spearman's rho Correlations	Well-Being GHQ-28	Self-Efficacy - Obtaining Respite (CSS; SE-OR)	Self-Efficacy – Managing BPSD (CSS; SE-BPSD)	Self-Efficacy – Managing negative thoughts (CSS; SE-NATs)	Caregiver burden (CBI)	Relationship Measure (QCRC)
GHQ-28	1	-.33**	-.36**	-.50**	.66**	-.51**
CSS; SE-OR		1	.35**	.22	-.31**	.29*
CSS; SE-BPSD			1	.72**	-.43**	.43**
CSS; SE-NATs				1	-.68**	.60**
CBI					1	-.54**
QCRC						1

*. Correlation is significant at the 0.05 level (2-tailed). **. Correlation is significant at the 0.01 level (2-tailed).

Table 5: Spearman's rho Correlations of T2 Outcome Questionnaire data

3.2.5. Quantitative Results Summary

Hypothesis 1 was not fully supported. The ANCOVA analyses revealed only one significant relationship at T2, demonstrating that only the relationship dynamics were potentially impacted by the intervention. No improvement was observed for carers, in their self-

efficacy, caregiver burden or well-being, between those who received the carer training programme intervention when compared with those carers in the control group, who did not.

Hypothesis 2 was supported. The T1 and T2 correlations analyses revealed associations as hypothesised: more self-efficacy will be associated with reduced burden, higher well-being and better relationships.

3.3. Qualitative Analysis

The qualitative analysis which follows is a narrative exploring the meaning and interpretation of the transcripts from the three focus group interviews in how the Carer Training Programme was experienced and evaluated by the participants. As Patton (2002) explains, evaluating the effectiveness of an intervention involves both summative and formative aspects: Firstly, to ascertain whether it achieved its objective and was effective; and secondly to establish the quality of the intervention and what could be changed to make it more useful.

The analysis that follows has three strands. These three strands align with the three main interview questions, see Appendix P, and provide the structural shape of the results from the thematic analysis of the data, as Guest et al. (2012) recommend. The first structural theme demonstrates how useful the carers found the information and strategies conveyed in the intervention and establish what impact, if any, it has on their caring role and well-being; that is, were they able to utilise the skills shared in the intervention? This, in effect, provided the quality feedback on the training, aligned with Patton's (2002) summative evaluation. The second structural theme explores the participants' experience of the training itself and the third reviews the recommendations of the participants to establish how the intervention could be improved. These are in line with Patton's (2002) formative evaluation.

The three structural themes were named as follows and are illustrated in Figure 3:

1. UTILISATION; Were you able to transfer any of the learning into practise at home? Did it change any relationship dynamics?
2. PERCEPTION; How did you experience the training?
3. APPRAISAL; Was the training as you expected? How would you improve it?

The first detailed analysis will be the UTILISATION structural theme, which provides the summative outcome, of the qualitative evaluation of the intervention.

The structural themes of PERCEPTION and APPRAISAL address the carers' experience of the intervention in a more explicit and practical way. A key output from the latter theme considers what updates to the training programme content and format would make it more fit for purpose. All structural themes also contribute to identifying new areas within the dementia carer field which could prove appropriate for further investigation in the future.

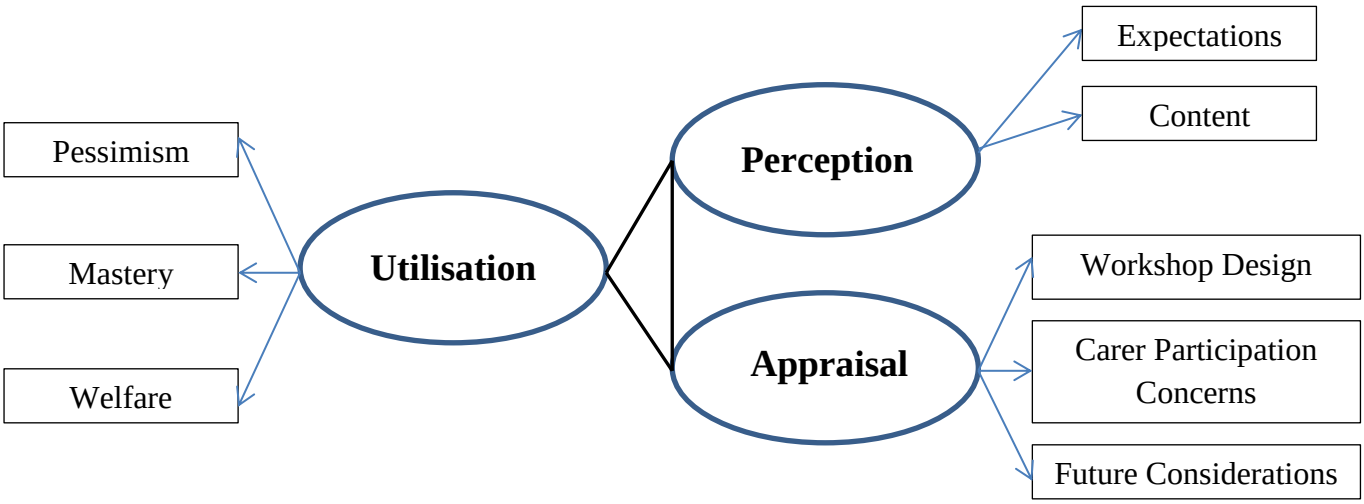


Figure 3: Illustration of Overview of Structural Themes and Master Themes

It is acknowledged that there may be alternative ways to approach the thematic analysis but it is argued that the one undertaken is appropriate given the objective of the current research to establish the effectiveness of the introduction of a novel carer training intervention as outlined in the methodology chapter.

Where quotations from participants are used to illustrate a theme, feedback or recommendation, utterances such as 'erm' have been omitted and if words are repeated they are stated once. If a detailed explanation has been given to clarify an idea by the participant in the middle of a succinct point, this is replaced by '……' to ensure continuity and relevance of the interpretation. All real names and other information which could potentially identify participants have been removed.

3.3.1. Utilisation Structural Theme

The analysis of this structural theme reflects a more traditional Thematic Analysis, starting with the identification of codes that represented themes which were subsequently grouped into psychological key themes and finally master themes. The analysis looked to explore the participants' phenomenological experience of the intervention. Three master themes were identified; PESSIMISM, MASTERY and WELFARE and demonstrate a journey for the carers who undertook the training. Within each master theme, a number of KEY THEMES were identified which support the psychological experience of the carers, and are underpinned by CODES that had emerged from the detailed analysis of data (Braun & Clarke, 2006; Guest et al., 2012; Saldana, 2009). The hierarchy is summarised in Table 6 below.

MASTER THEME (Carer Journey)	KEY THEME (Links to existing Literature)	CODE (see excerpt of Codebook in Appendix *Q*)
PESSIMISM	ISOLATION	*Isolation*
		Services
	UNCERTAINTY	*Denial*
		Helplessness
		Self-doubt
		Uncertainty
		Own Fragility
	STIGMA	*Fear*
		Stigma
		Media
	CAREGIVER BURDEN	*Abuse*
		Frustration
		Enmeshment
	DEPRESSION/ANXIETY	*-ve emotion*
	LOSS	*Loss*
		Responsibility
MASTERY	HOPE	*Hope*
	UNDERSTANDING; re-attribution	*Acceptance*
		Education
		Peer Advice
		Journey
		Unique
	CONTROL	*Control*
		Peer support
	SELF EFFICACY	*Self-efficacy*
		Communication
		Engagement
	INCREASED ACTIVITY	*Fun/Action*
		Involvement
		Potential
WELFARE	IMPROVED RELATIONSHIPS	*Family*
		Humour
		Relationship
	IMPROVED WELL-BEING	*+ve emotion*
		Identity
	RESPITE	*Self-Care*

Table 6: Themes identified in the Structural Code: UTILISATION

Figure 4 below illustrates the relationship between the Utilisation Structural Master and Key Themes.

The flow of the map is numbered and appropriate quotes were selected to support each flow.

The associated quotes are found in Appendix T.

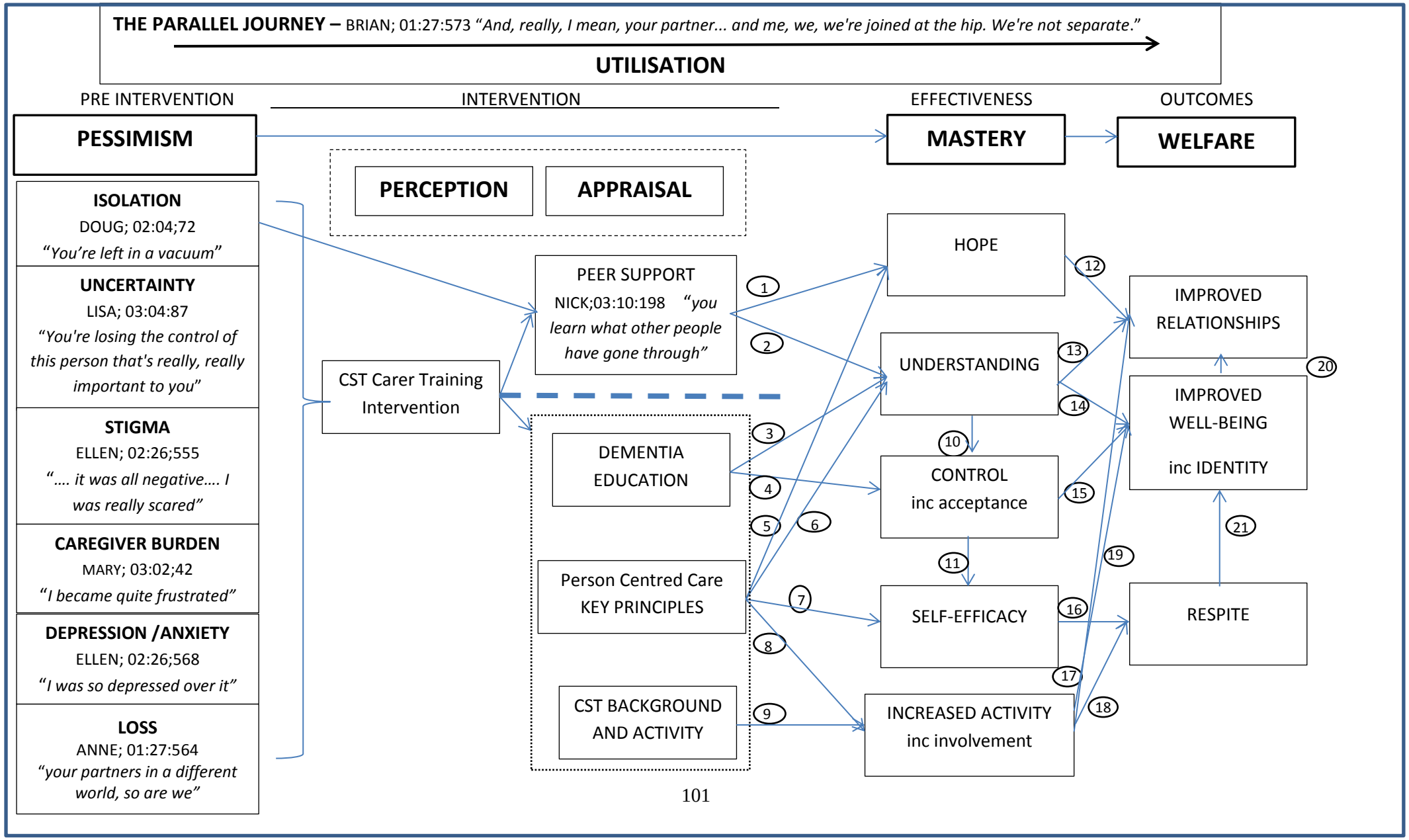


Figure 4: Illustration of the Utilisation Structural Theme

3.3.1.1. Pessimism

An unexpected outcome of the interviews was the reflection from the participants across all three focus groups on how they were managing their caring role prior to being invited to take part in the research. This formed a large part of their discussion and their contributions resonated with the current literature on the experience of being a carer (Michon et al., 2005). An understanding of this position, as described by the participants themselves, provided a base line from which to evaluate the impact of the intervention. Thus, the first master theme to be explored is PESSIMISM.

3.3.1.1.1. Isolation

Many of the participants spoke about feelings of isolation and without exception there would be concurrence from the other focus group members following such an admission.

'*And I don't... I very rarely talk to anybody else, even in the family.*' BRIAN; 01:17:350

Brian's experience suggests that he is managing the situation with his wife on his own, drawing only on his resources.

'it's a hard, quite a very hard, lonely life' RUTH; 03:71:1556

Ruth's description also demonstrates a lack of support from others. Her reflections seem to be alluding to the fact that not only is she isolated from those outside her marriage but within her relationship also.

'I'm at home with him all the time really' IVY; 02:18:370

Ivy's explanation depicts another element of being in this alone, that her time is exclusively taken up by the caring role. It also suggests that opportunities to leave the home become limited, as carers worry about their family member being exposed to the uncertain reactions of others outside of the safe home environment.

'*they drop you like hot bricks'* FRED; 02;30;629

Fred on the other hand specifically references the lack of support he felt from professional services and how he felt abandoned by those he looked to for support by seeking a diagnosis for his wife.

Thus it can be seen that a sense of isolation is a key contributor to the participant's experience of caring for a person with dementia and can take a number of different forms.

The common underlying result is that they feel alone and managing a situation without any support.

This theme is captured by Doug when he reflects:

> '*You're left in a vacuum'* DOUG; 02:04:72

3.3.1.1.2. Uncertainty

This key theme addresses both the initial uncertainty that people reflected on when they notice that something is different but have no explanation of what is happening to their family member, and also how they feel following diagnosis. It leaves them feeling frightened and confused as the person's behaviour changes in subtle ways at first, yet they appear to be physically well. Society's norm is that a physically well looking individual is 'ok'.

> '*you notice all these things before its really diagnosed and you think; 'Is it my imagination or is it not?'* IVY; 02:20:426

Ivy captures the initial realisation that something has changed and how hard it is to articulate what that means. The progress of dementia is slow initially and the changes so subtle that carers can often question their own interpretation of a situation or event.

> '*if you don't accept there's nothing there, you'll be there till the day you die. You think……there's nothing wrong.*' NICK; 03:13:278

Nick speaks about how acknowledging that there is a problem is a critical step in being able to manage dementia. Many of the mistakes and misunderstandings can be explained away and the person diagnosed with dementia often becomes expert in covering them in the early stages.

> '*scary to think your loved one has got that and you know what's going to happen. I think you put it off until someone actually says 'this is what it is''* KAREN; 03:38:813

Karen's comments capture the fear that is felt as family start to acknowledge the changes are real and permanent. They are frightened for their family member and, as Ellen's and Anne's reflections illustrate below, also for themselves:

> '*I was scared of how I would cope'* ELLEN; 02:26:561

Ellen's fear shows a sense of helplessness in the face of dementia, a loss of control and of her ability to manage.

'*I sometimes wonder if I've started on the road'* ANNE; 01:71:1531

While Anne experiences concerns for her own fragility as she recognises some of her husband's behaviours in herself.

> *'you go through all the memory clinic ……. It is very clinical ……. and you sit there and you nod because that's what's expected of you, basically. And, you come away and you think 'right, okay. So I know what the problem is, so... but how do you go forward with the problem?* LISA; 03:03:58

Lisa's description moves onto the post-diagnostic situation. Even with the knowledge of the diagnosis, carers are still at a loss about how to manage the new situation that they find themselves in, and react in a way that they believe is 'expected' of them. Her reflection on how to move forward also suggests how little people hear during the diagnostic process. The memory clinics are full of advice and guidance about where to find help and support and yet carers often leave without absorbing any of that information. The shock of the diagnosis appears to stop them taking in other information.

3.3.1.1.3. Stigma

Stigmatisation of those with dementia is still a concern for many but there does appear to be evidence of change and this is reflected in the focus groups' discussions.

'*I was really scared of Alzheimer's'* ELLEN; 02:26:560

Ellen's fear appears to resonate from society's view of dementia. Her own father actually has a diagnosis of vascular dementia yet her reaction was to the more well-known Alzheimer's variant. The understanding of dementia appears to be clouded by the differentiation society places between Alzheimer's and dementia, with the latter being the lesser evil; anecdotally I have been told by people that they have dementia and not Alzheimer's, apparently to minimise their fear.

> 'I *have to tell her it's the Wednesday Club, if I said, 'you're going to the Alzheimer meeting' she would [not] like it.'* FRED; 02:51:1108

Fred spoke about his wife's acceptance of the condition but not the term.

There were mixed views with regards to the part that the media plays in the role of understanding and dispelling the stigmatisation of dementia.

'[it's] not this alien thing anymore that you have to keep quiet about' MARY; 03:76:1666

Mary in discussing the media feels that there is more awareness of the condition and that this in turn allows families to be more open about it. However, if this is compared to the sense of isolation felt by many carers, as illustrated above, it would seem that, while the shift in understanding is happening, it is slow and often families do not feel empowered to be open about it, as Carol's comment illustrates:

'*we could've been sort of more open about it'*	CAROL; 01:03:60

In addition, as Ivy reflects, the behaviour of people with dementia when out in the community is not understood and people's reactions can be unhelpful and hurtful, taking the confidence away from the individual with dementia and their family member in terms of letting them do things independently:

'The people behind him laughing'	IVY; 02:15:304

However, the group discussions did suggest that there is now an understanding that dementia is a disease of the brain, and not a natural part of aging or an acquisition of strange behavioural traits as you age, as the groups reflected on terms used historically:

'you're old, you forget'	PENNY; 03:06:166
'you get senile'	RUTH; 03:76:1647
'you were eccentric'	LISA; 03:09:176

Also, the media has taken some of the stigma out of the condition by encouraging people to address their concerns and get a diagnosis early, as Fred states:

'*In light of the advertising ….. Get to a doctor quickly – get them diagnosed. But they kept us waiting'*	FRED; 02:24:499

While it would seem that people are acting on the government advice to get help early, it is perceived that services are slow to respond and subsequent support is poor.

3.3.1.1.4. Caregiver Burden

The participants in the focus groups were also very open about the stresses that they encountered in their carer role.

'*we'd be very frustrated with them…… shouting at them'*	JULIA; 02:54:1163

Julia's reflection demonstrates the reality of living with someone with dementia. The behaviours that are constantly being managed by the carer, such as constant questioning and repetition, can become overwhelming and lead to loss of patience and an unhelpful release to deal with the situation.

> *'I get so irritable sometimes. You become not a very nice person'* RUTH; 03:42:904

Ruth's comment suggests the impact that this unhelpful behaviour has on the carer's sense of self, and personal identify.

> '*the DWP say that she doesn't need any attention, she's ok on her own. Which I know is wrong – I can't leave her'.* FRED; 02:29:623

Fred's situation illustrates how the carer's burden is not only from within the relationship but from the lack of support and appreciation of the challenges of living with dementia which non-dementia-specific services appear to have. Many of the criteria for access to support are based on physical difficulties which many people with dementia do not have, though their ability to undertake tasks and be cared for are often even more challenging than those with such disabilities, as the ability to reason and negotiate behaviour has disappeared, as Ruth describes:

> *'if somebody asked you the same thing… Eight times in maybe three minutes, you think 'for goodness sake. When will it stop''* RUTH; 03:42:905

Brian's statement again exhibits the monotony of a carer's situation and the inability to be released from the task at any point in time:

> '*you can't avoid not being involved, cause you are involved'* BRIAN; 01:41:890

This final reflection in the caregiver burden theme also illustrates the psychological connection and enmeshment that occurs when living with and caring for dementia. The carer role is not just a support role but they also become the memory and facilitator of action for the person they care for. Boss (2011) describes this level of involvement in another's life, is usually deemed inappropriate and seen as pathological, but she continues, that when living with dementia, all the normal rules of relationships change.

3.3.1.1.5. Depression and Anxiety

The impact of caring for someone with dementia often leads to feelings and emotions that are named depression and anxiety (Boss, 2012), as the carer finds themselves having difficulties managing their situation. As seen above from Brian's [01:41:890] comment, the relationship between the carer and cared for is enmeshed through necessity.

'*when you do [have time for yourself], you feel kinda guilty.*' OLIVER; 03:72:1562

Oliver reveals the problem that many carers face, the tension between caring for their family member and caring for themselves. The anxiety that is experienced when a carer does take time out for themselves often undermines the benefits. However a continually stressful situation can lead to depression as Ellen states simply:

'I was so depressed over it' ELLEN; 02:27:564

While Ivy's statement demonstrates one of the difficulties that carers experience that is hard for those who do not care for a person with dementia to understand;

'to keep calm is very tiring' IVY; 02:07:144

Many of the challenges that carers face appear simple to manage from the outside, and others find it difficult to see any problem in just answering a question, even though it has been asked many times, or correcting mistakes continually when things are misplaced or tasks are done wrong. The continual monitoring and reaction while remaining calm is draining, as illustrated by Hannah:

'it's non-stop' HANNAH;02:92:2002

Ruth shows another element of the challenge for carers:

'it's quite a scary thing when you are on your own' RUTH; 03:06:123

Often they report that the behaviours can actually be frightening; for example, if their family member does things which are completely out of character or strange and would normally not be acceptable socially, or are outside of 'normal' experiences, such as, when someone reports hallucinations. The fear is exacerbated when the person with dementia then denies the experience happened, as they simply don't remember it. Consequently, the carer has no point of reference or immediate support to try and normalise or rationalise the event.

Other comments reflect the sense of failure when the carer's perception of themselves is threatened as Ruth reflects:

'I didn't realise I was such a nasty person' RUTH; 03:42:908

Such feelings of incongruence with the person that they have defined themselves as throughout their life could contribute to loss of sense of self-esteem and confidence, leading to anxiety and depression.

3.3.1.1.6. Loss

This final sub-theme in pessimism captures the sense of loss that the carers experience in their new role. Loss has many different guises when a family member has dementia. Because the individual is still physically present, it can be very hard for others, who have not experienced dementia, to appreciate the carers' experience of loss.

'*I know your partner's in a different world, but so are we'* ANNE; 01:27:564

Anne's statement captures the totality of the change that carers feel: Their whole world shifts as their life with dementia begins. Many find that their circle of friends change to those who are also living with dementia, because, with this new group, no explanation is required with respect to their family member's behaviour. In addition, the person with dementia is included and acknowledged rather than subtly excluded as they can no longer keep up with the conversation or event. The person that they loved has disappeared and is less able to contribute in decisions, discussions, or activities of life from the routine to those special occasions. Thus, carers find themselves in very challenging and stressful situations, where everything is left to them to facilitate and manage. In addition to practical responsibilities, they may also find themselves having to ensure their family member is not completely ignored, or manage potentially confrontational situations; for example, if the person with dementia offers an opinion in conversation which is biased from their egotistical standpoint.

'*it's a twenty four hour thing – your life changes though you don't realise it.'* RUTH; 03:69:1496

Ruth's comment confirms this world shift and captures another key loss that carers encounter, a loss of any time for themselves. This statement also demonstrates the stealth with which these changes creep into their lifestyle. The consequence is that the carers often take on a sense of responsibility for their family member which permeates every aspect of life.

Thus their own freedom is compromised, as they feel protective of their family member, and guard against any situation which may make them vulnerable, to ensure their well-being is maintained, as reflected in Ivy's comment below:

'*I'll have to go everywhere with him so I can help him with his words.'* IVY; 02:15:305

However, the greatest loss is that of their family member as they knew them, and the injustice of the situation, felt not only by the carer, but by all those who love the person with dementia:

'My youngest son, who's very concerned about his mum is still in the angry stage……. That it shouldn't happen.' OLIVER; 03:38:823

3.3.1.1.7. Pessimism Summary

Initially it felt disruptive that time in the focus group interviews reflected on the period before the research. On reflection I wondered if that was more about my impatience to hear what they thought about the training. The actual function of the comments being aired allowed each of the participants to reconcile the changes that they experienced. Indeed, without a starting position there is nothing to compare where you are now. As many of the carers stated, this was the first contact following diagnosis that they had received from any service and it allowed them a space to be heard. It also demonstrated, that their experiences reflected those outlined in the introduction from previous research, of carers for people with dementia.

3.3.1.2. Mastery

The second master theme, MASTERY, from the Utilisation structural theme explores how the participants reported the usefulness of the strategies and skills communicated, and how changes impacted on their carer experience.

3.3.1.2.1. Understanding

With the introduction of this key theme, it is a timely point to remind the reader that the current project is looking to evaluate the outcome of a novel intervention; that is, to explore whether the carer training programme achieved its objectives. This is an important theme because it demonstrates that people reported: i) a more educated view of dementia and its consequences; ii) an acceptance of the situation that they find themselves in; iii) yet acknowledging that they need to recognise the uniqueness of their particular circumstances

and iv) adapt this learning to their own context and the point in the journey of dementia that their family is living through.

When identifying main themes, Braun and Clarke (2006) warn against the use of a numerical count of references to show that an area is more important than other key themes identified. However, it should be noted that the weighting of the codes captured within this key theme is the most prevalent, as illustrated in Appendix R (i), and that all the participants contributed to comments within this theme.

This theme captures the change that carers have acknowledged over the training period, enabling them to attribute difficulties experienced appropriately, as illustrated by Anne:

'*they're all problems because of the condition'*	ANNE; 01:14:302
'*What it did for me was open my eyes up to my mum's illness'*	MARY; 03:02:41

An improved understanding of the condition itself, which was a key objective of the training, has resulted in more tolerance and acceptance of the behaviours and how they are responded to:

'*you roll with the conversation and don't stop them'*	NICK; 03:29:618

In turn, carers described adopting different interaction styles which acknowledge their family member has changed, such as not challenging or drawing attention to behaviours which are a consequence of the dementia. Conversation is a key area where problems are noticed, for example where a person with dementia will appear to take the conversation off at a tangent; however, by considering what is said in the wider context of the conversation, their contribution will be seen to be relevant, though expressed poorly, enabling the carer to be more understanding of the behaviour as NICK's comment illustrates above.

George recognises, the person with dementia is still present in the interaction with family members and, although they cannot always articulate their needs, it becomes the domain of the carer to ensure that basic needs are appreciated and fulfilled:

'*it's important they don't feel helpless'*	GEORGE; 02:75:1632

Doug's reflection recognises that improved understanding of dementia and more considered ways in which to deal with different circumstances, lead to a much more balanced interaction between the carer and their family member, as he reflects, the latter's frustration is reduced:

'90% of the problems that you seem to get will disappear because it is often the result of frustration'.	DOUG; 02:06:118

In addition, this is a particularly interesting category from the perspective of counselling psychology as the changes identified are those which are often goals as part of an individual's therapeutic journey such as a change of perspective, understanding the triggers to certain behaviours and changing them using thought records (Beck, 1995; Greenberger & Padesky, 1995).

> *'you've listed a whole load of things there now and I can see certain things which I do without even thinking I am doing it'* BRIAN; 01:20:421

Brian acknowledges explicitly that he is doing things already in an appropriate way. Often people undertake tasks and manage events without explicitly acknowledging what is done well. This is a common theme throughout the interviews where carers talk about good behaviours that they are using implicitly with their family member. Therapeutically, it is a strong shift for an individual to appreciate and acknowledge to themselves the positive behaviours they undertake which thus contributes to a sense of competency, control and self-esteem.

> '*you've got to be sensible…. I've reassured myself A's not gonna get any better'* FRED; 02:86:1871

Fred's comment demonstrates that an acceptance and understanding of the behaviours associated with dementia have enabled the carers to relax more in the company of their family member, with more realistic expectations of their abilities which, in turn, has allowed their interactions to be less confrontational and has enabled them to take control of situations in a more helpful way as Fred describes below:

> '*A's got worse at getting up…. So I always make an appointment for the afternoon.'* FRED; 02:85:1844

While Anne's comment reflects the recognition that each family will meet different challenges, depending on their context, personalities and family dynamics which are different for each family challenged with living with dementia.

> *'we're all different personalities. We've got the same problem in common'* ANNE; 01:29:613

But despite the many differences Anne's quote also acknowledges the commonality in each carer's task and that the information that has been shared in the training can be applied by all.

> *'over a period of time, I think we all come to experience the bits and pieces of that which apply.'* STEVE; 03:05:101

As Steve clarifies not everything is relevant from the training all the time, but, as each day brings a unique set of circumstances and events, then the carer may recall a strategy which could be utilised and will become part of their toolkit to manage if the outcome is proven to be helpful.

Thus, the participants made changes to their own situations, in various different guises, as a consequence of the training intervention provided. As Fred reflected:

> *'I feel as if it certainly changed my attitude to her'* FRED; 02:53:1147

Steve and Fred's reflections also bring forth a key aspect of caring for an individual with dementia, that is, the aspect of change and uncertainty. The individual with dementia is on a journey of change as their condition progresses, which is mirrored by the carer's experience being undertaken alongside them. Brian's contribution demonstrates that the current project's intervention is valid for a point in time in that journey, but strategies and learning for the carer is a continuous requirement as their family member's needs change.

> '*Whether these things apply as the situation gets more severe, I don't know. That's a learning curve as well'* BRIAN; 01:70:1521

The analysis above suggests that carers' understanding of the condition did allow them to change their position from blame of their family member for challenging behaviours, to one that recognised the cause was outside of their control and a consequence of the dementia. This allowed them a different space from which more helpful strategies could be adopted.

3.3.1.2.2. Self-Efficacy

Another change described following experiencing the intervention is a sense of confidence in the carer's ability to manage their caring role.

> '*more confident in yourself for dealing with the situation your family member is in'* NICK; 03:10:199

This results in them feeling more able and capable both in the present, but also in the future:

> *'and you feel like you can do something to help'* ELLEN; 02:6:559

A number of carers reported the importance of the key principles, and that, by adopting the behaviours which underpin the principles, they have facilitated change in their caring role:

> '*knowing what you're doing is sort of aligned with some kind of therapy'* ELLEN; 02:56:1197

The carers reported adopting some of the more generic guidance, such as, from DOUG - '*don't argue'*; '*take an answer and don't try to analyse it*'; RUTH – '*we speak to him one to one*' and KAREN – '*not saying 'do you remember?''*, amongst others. Hence, they demonstrated a confidence in their ability to interact with their family member differently.

The focus group discussions also suggested that learning from the intervention provided the carers with a confidence in delivering care to their family member, as illustrated by FRED:

> *'be sensitive to the condition, know what you can and can't do….* FRED; 02:80:1736
> *It's a difficult job, but the training helped.'*

It also appeared to help them simply 'be' in the company of their family member. The dementia stopped being the unspoken problem, which led to many feeling uneasy with their family member, but allowed them to be more relaxed, acknowledging that the person with dementia fundamentally was the same person, and that interactions can occur without preparation or in a defensive reactive context.

> '*I'm not so worried I'll say something wrong'* ELLEN; 02:56:1558

Thus, Ellen's comment also reflected an added confidence that the participants gained, resulting in more freedom and creativity in how they interacted with their family member; there were no defined rules of engagement but exchanges which evolved more naturally.

The learning, also enabled them to challenge their own behaviours, so that they could incorporate more helpful strategies, underpinned by some useful guidance on how their family member was now experiencing the world around them, as HANNAH expresses:

> *'understanding the problems that they are experiencing through* HANNAH; 02:70:1522
> *your training, makes you think yourself "how can I change*
> *what I'm doing? How can I relate to them better? What can I do to help?'*

In addition, there was an increased confidence in recognising their needs, such as when Ruth spoke about having a shower fitted in the home, and recognising that her husband became agitated if there was a lot of activity and strangers being in the house. She reported:

> '*I phoned up and got him the day centre for three days –* RUTH; 03:82:1781
> *I wouldn't have done that…… and it was so easy,*
> *I thought I would do that again'*

The participants also recognised that adopting less challenging strategies lead to a change in their family member's behaviour, which in turn has an impact on them also:

> '*to make life easier for us. Because if you make life easy for your partner then your life's easier*.' ANNE; 01:25:528

An interesting outcome of the focus groups was how the participants reported engaging their family member in activities. The research team had envisaged them ring-fencing some regular time where specific activities would be undertaken. However all three focus groups reported that a more organic method of engagement in activities was needed, otherwise the person with dementia was defensive and would not take part. As Carol stated:

> *'you have to be careful how you feed it to him…. It depends if it's a good or bad day how you go about introducing something. Especially if it's different to something that they've done before.'* CAROL; 01:42:909

As Carol indicates the kind of day that the person with dementia is experiencing also needs to be taken note of; a defined regimented approach to undertaking activities may result in the carer feeling de-skilled as they are setting themselves up to fail if it is 'a bad day'. This is a key learning point, that more can be undertaken if it is introduced naturally:

> '*if I'm doing the crossword.... even though I don't want help, I'll say "oh you might be able to help me with this one''.'* FRED; 02:32:674

In addition, the participants also reflected on the type of activity that is appropriate for their family member and, as Ellen concludes, any activity should be explored rather than making judgements about the level of interest or competence of the person with dementia:

> '*also thinking – can they do that or can't they – we'll try it'* ELLEN; 02:38:806

This 'can do' attitude led to Ellen and others undertaking activities with their family that they would not have done without taking part in the training and provided them with a confidence to be relaxed and creative in the future.

Thus as Bandura's (1977) work in self-efficacy suggests, when people undertake challenging activities successfully with good outcomes for themselves, it gives them confidence for the future and their belief in their own competence thus grows. This was confirmed by Lisa's statement:

> '*I think the training empowers you'* LISA; 03:104:2257

3.3.1.2.3. Control

The debate whether this theme should be subsumed into self-efficacy was given some thought. However, it does appear to demonstrate a different psychological construct to self-efficacy. Where self-efficacy illustrates the carer's confidence in their competency, this theme showed how that confidence was used to galvanise them into action and move from a victim position to a more pro-active position. Thus, supporting carers to alter the nature of their interactions, from a position of 'doing to' their family member, to 'doing with' them, in the spirit of person-centred care.

> *'you've got that mechanism in place and its working…so you feel more prepared and in control'* — LISA; 03:35:758

Thus as LISA illustrated, it led to participants reporting that they did have options, and were now able to be more flexible in their caring role. In addition, with ideas from the training, as OLIVER suggested, they moved to a position where they could accommodate their family member's changing abilities:

> '*it's important that you've got to respond to the situation, just not carry on with it as you used to*.' — OLIVER; 03:37:804

Adopting strategies which they acquired through the intervention has enabled them to build a toolkit of strategies and ideas that improves their interaction with their family member:

> *'You put into practice what you think is best for yourself…. And stick to that as your tool'* — NICK; 03:11:234

They also recognised that, by adopting the techniques discussed in the training, they were taking control of the situation despite the chronic and progressive nature of the condition.

> *'we can sort of do these things and that may not improve things but it'll make things on an even keel……. A bit more control back.'* — LISA; 03:04:67

The participants also reported the introduction of techniques which helped them manage situations in a way which resulted in less distress for their family member. Julia described how previously her husband's anxiety rose if told about appointments, but she changed to:

> '*I can't tell him what we're doing, I can't say 'we're going out tomorrow'. So I never say that we are going anywhere.'* — JULIA; 02:35:738

The participants also stated that by adopting the ideas they were able to manage their own reaction to difficult situations which continue to arise, such as RUTH describes:

‘*Sometimes I go out of the room… you have to walk away’.* RUTH; 02:42:918

While the training has been shown to be helpful for those who completed the whole programme, there did appear to be a particular stage in the carer journey where it was more appropriate. Those carers who had their own health difficulties or, where the family member with dementia had progressed to a later stage of the condition, in which more practical solutions were required, dropped out of the programme. However, the information provided was useful for those with family in the early to moderate stages and, as the participants voiced, could have been useful earlier for their own well-being.

‘[with training] you would have had that [patience] far sooner’ LISA; 03:42:902

Lisa’s statement demonstrates the importance of control in one’s ability to manage situations, leading to more meaningful interactions with their family member.

3.3.1.2.4. Increased Activity

A primary objective of the training intervention was for carers to undertake activity with their family member. The research intervention was designed with the aim of providing carers of those undertaking CST with the skills, strategies, knowledge and activity options which would enable them to support their family member at home. Indeed, participants did report some specific activities linked to the CST programme as described by Fred:

‘after a CST session she came back and mentioned that she’d been doing some matching….. so later that day I just got some cards out and she said ‘I fancy a game of pairs’’ FRED; 02:38:822

While Ellen made great use of the workbooks from the training sessions to think about ideas to engage with her father at home or in the car:

‘*we play in-car eye-spy or word games, and it probably comes naturally. I probably wouldn’t have done that – it would’ve been a much silenter journey.’* ELLEN; 02:37:798

However CST-inspired activity was not the only way that the carers involved their family member in activities as a result of the training programme. The participants spoke about how they involved their family member more in everyday activities:

‘I was doing a lot of Christmas cards and my husband so wanted to help.’ IVY; 02:32:683

Others stated that they would make more of an effort to talk about items from the news or newspaper as a prompt rather than keeping thoughts to themselves:

> *'When the news is on and there's some topic. Afterwards you then mention it again and that gets discussed.'* RUTH; 03:21:438

While other participants encouraged previously enjoyed past-times that had been considered beyond the capability of their family member now they had dementia:

> *'my wife used to play the piano and we put her back to doing a bit of that and she enjoys it.'* DOUG; 02:96:2085

In addition, it became apparent that participants stopped taking responsibility for all of their family member's activities and realised that it was important to allow them to be autonomous in a managed way so that they were able to fulfil their potential:

> *'I used to do probably too much for my dad 'cause it was quick and it was easy and now I'm letting him do more… more for himself.'* ELLEN; 02:12:241

Other participants recognised their family member contributing to discussions if they were included without putting them on the spot and asked challenging questions which resulted in resentment and withdrawal:

> '*They were having a right little conversation… quite normal sounding, mum chatting away. Not this person that couldn't remember anything*.' KAREN; 03:26;555

Involvement in everyday tasks was also reported with participants describing not being so protective of their family member and standing back to allow them to undertake tasks which had previously been taken over, such as clearing the table after a meal. This resulted in improved relationships and less 'challenging' behaviour, as the individual with dementia feels acknowledged and useful:

> '*Which I think helps her, and it doesn't frustrate you quite so much.*' KAREN; 03:16:347

The participants reported engaging with the person with dementia in a number of ways which utilised their strengths, such as, their long term memories, or allowing them to be involved in everyday activities which are well-learned, which with appropriate support, resulted in interactions that were more beneficial to both. In turn, with others relating to the individual in a positive way, as Karen suggests, gave the person with dementia gained confidence and willingness to engage again, and in turn lead to less frustration, improved relationships and well-being for all.

3.3.1.2.5. Hope

Whether to keep 'hope' a separate key theme or subsume it into another key theme was a difficult decision. The final outcome was to keep it separate due to the conclusion that it does represent a shift in the carer's psychological position from that described in PESSIMISM above. It was more than just positive feelings, a sense of control, or confidence, it was a shift in the mind-set of the carers, resulting in an improved personal context, in which they were able to provide care.

> '*without this training I don't know where I would be now. We'd be struggling in the dark not knowing what to do.'* FRED; 02:30:630

Fred's reflections demonstrate the change in the position, moving from the 'dark' into the light. He explicitly mentions the training and the impact that it has on his ability to manage and move forward with his caring role.

> *'it opened my eyes to say - okay, what can I do to help my mum in this situation that can make it easier for me and for us and for her.'* MARY; 03:03:47

Mary's comment illustrates a move to a more hopeful position for the whole family unit. She uses the term 'it opened my eyes' illustrating that a new way of being has been created for the family where a more helpful dynamic can be created.

> *'I'm still not very patient, but I'm coping better.'* ELLEN; 02:10:201

Ellen's contribution shows a change in the way she is persevering in her role as a carer, acknowledging that it is still not an easy role for her, yet following the training and adoption of some of the activities and skills shared has given her a more hopeful outlook on her life with her father and living with dementia.

> *'it certainly helped me, not just from a point of helping our partner, but it's helped me.'* ANNE; 01:29:632

In this quote another shift is illustrated which again puts the carer in an alternative context following receipt of the training. The introduction demonstrated, that as the journey of living with dementia progresses, the person with the condition becomes more egocentric with their requirements and demands, which often means the carer's world can close down to just serving those needs. Here Anne makes a bold statement 'it's helped me' which allowed her to be less confined by the burden of her role and in a position to recognise her own needs.

3.3.1.2.6. Mastery Summary

The conclusion from this key theme is that carers appear to be describing a very different place emotionally from that identified in the PESSIMISM theme which they reported experiencing prior to undertaking the intervention. Their description of change incorporates their learning from the training and utilisation of those strategies in their everyday life or an explicit acknowledgement of things they had been doing well. The result of the acquisition of these skills has resulted in them being more confident in their own abilities to manage their caring duties and take charge of their own needs too.

3.3.1.3. Welfare

The final key theme in the UTILISATION structural theme is that of WELFARE, which captures how the carers are experiencing their role following the intervention. It reflects how their situation is different because they have been able to improve their 'MASTERY' in living with the caring situation that they have found themselves in.

3.3.1.3.1. Improved Relationships

While none of the participants spoke explicitly about a negative relationship with their family member there were indications of strained relationships. As Fred shared:

'*I'd still be frustrated.'* FRED; 02:54:1153

While Nicks reflection suggested that often relations were compromised so as not to upset the family member or cause problems which they were not able to manage:

'*Before the sessions I found myself tip-toeing around the problem.'* NICK; 03:09:187

When reflecting on how relationships changed following the training programme and utilisation of the skills as described above, carers described a different, more open and relaxed interactions with their family members. Ellen's description of her relationship with her father demonstrates both an emotional and practical change in how they are together:

'*I got much closer to Dad and we talk more.'* ELLEN; 03:37:798

While Julia's comment shows a more relaxed and good natured interaction:

'*we'll laugh together'* JULIA; 02:80:1722

Not only did the relationship between the carer and cared for shift, but an improved situation for the whole family was reported:

> '*the DVD has gone round different members of the family… they were impressed and it gave them ideas when they visit.*' DOUG; 02:05:103

As illustrated above, Doug reported that the family now think as a group about what activities that they can undertake together, while Ruth describes how her family also get involved:

> *'involved the family as well, who do the same thing now.'* RUTH; 03:20:436

On a final note, at the end of the focus group he attended, Steve captured the important aspects of the relationship between the carer and cared for to maintain a healthy balance. The training appears to have provided the carers with a new perspective on how their family member experiences the world, which allowed them to facilitate helpful activities and interactions so that they were able to preserve a positive relationship, minimising resentment at having to manage inexplicable changes to behaviour and reducing feelings of animosity:

> *'You have to love the one you are looking after, have a mutual respect for each other.'* STEVE; 03:109:2378

3.3.1.3.2. Improved Well-Being

The participants also described a change in their own emotional experience of caring which demonstrated what a difference it made to them in having knowledge, skills and strategies which enabled them to take control of situations and in having more confidence in their own abilities.

Ruth reflected on her own sense of self and how this has changed after being involved in the intervention. Earlier in the transcript she reflected that she didn't '*realise that I was such a nasty person'*.

> *'I think its learning patience……. It's made me more tolerant.'* RUTH; 03:82:1776

The revised self-report quoted above, of being in a different more accepting place of oneself, will contribute to a more congruent picture of herself in relation to the person she has been throughout her life, enabling her to be more at ease with herself.

Ivy also reported a shift in how she herself was feeling and that the situation was less stressful because of this:

> '*I think it's to do with being more relaxed.*' IVY; 02:79:1569

While Anne's comment reflects that, following the training, the carers were able to be more honest with themselves and others, such that they were able to step out of the shadow of dementia and its negative associations:

> *'You can be a little more truthful and a little bit more open.'* ANNE; 01:16:342

In addition, a more accepting sense of self as 'a carer', and what that involves, was reported as helpful in making changes in the relationship dynamic and enabled the carer to redefine how they interact with their family member:

> '*it's understanding yourself as a carer.'* ANNE; 01:32:682

As Brian elaborates, this realignment brings with it a complete redefinition of oneself in the context of the caring relationship, specifically for those who care for someone living with dementia. Indeed, the carer too is sharing their life with dementia and their contribution to their family member's support is all-encompassing as the individual loses their cognitive abilities to undertake more and more elements of daily living as the condition progresses:

> *'I mean, your partner and me, we're joined at the hip. We're not separate. 'Cause I'm called a carer and she the patient, so we are one.'* BRIAN; 01:27:573

Lisa expands on the idea that it is not only the 'carer' who is affected by the condition or who could benefit from the intervention teaching - but the whole family, so that all experience a more calm and managed environment leading to improved well-being:

> '*This isn't something that's just my mum… My husband and everyone else is sort of going through it to a certain extent. Tell other people if they did it this way round then everyone wouldn't be so frustrated*.' LISA; 03:104:2261

3.3.1.3.3. Respite

The final key theme within WELFARE represents the ultimate outcome for the carer, the recognition of their own importance in the new dynamic caused by their family member's condition. The literature review illustrated the intensity of being a carer living with dementia, describing how many give themselves over to the role completely and, as described in the Introduction, to the detriment of their own well-being (Boss, 2011). Consequently it is important to find ways to look after themselves and to make use of different options. This is fundamental to keeping them well:

> *'Now I go to work three days a week… it helps me and I don't get so frustrated.'* JULIA; 02:13:275

Julia is a spousal carer for a younger person with dementia and returning to work has allowed her to reclaim some of her own sense of identity and interact outside of the caring role.

Older carers report that allowing their family member more autonomy, such as going on short errands alone, gives them some well-needed peace:

> '*It gives me a bit of a break.'* IVY; 02:17:366

Family involvement and more formal care arrangements should be recognised as an important part of ensuring that the caring role is managed well. The carers should feel empowered to access such support and not feel guilty in utilising them. Ruth's quote demonstrated how she makes use of various strategies:

> '*My daughter comes down and takes him out and he goes to a Day Centre once a week now.'* RUTH; 03:75:1625

Many of the participants recognised how key it is to have respite following the training and the implications if they did not ensure they looked after themselves as Steve summarises:

> *'You have to look after yourself because, at the end of the day you're gonna be the important one.'* STEVE; 03:109:2383

This final statement is a critical repositioning of carers in the relationship dynamics. To recognise how important they are in the caring role for someone with dementia, facilitates them valuing themselves more and acknowledging the importance of their contribution. Thus ultimately recognising, that if they become unable to manage their role and are no longer able to care for their family member, the only option is institutionalisation, which is not what they or society would like prematurely.

3.3.1.3.4. Welfare Summary

Thus, in conclusion of the WELFARE key theme, it can be seen that the carers who undertook the training did report change and importantly were able to redefine themselves within their new role. In appreciating their importance in the dynamic, it allows them to take a more proactive role in their own self-care which appears to have been achieved following the intervention.

3.3.1.4. Utilisation Overview

A summary of the outcome from the UTILISATION structural theme and supporting codes can be seen in Figure 4. This illustrates clearly the journey that the carers who completed the

intervention, undertook. Their narrative describes an acquisition of skills and strategies facilitating a sense of MASTERY, which enabled them to feel more confident in their role, thus having more control over how they manage specific situations and a hope for the future. This is a very different psychological context to the PESSIMISM they described in relation to their experience of their caring role prior to the intervention. This resulted in an improved WELFARE so that they can maintain their own well-being, psychological and physical, as their journey continues.

However, while the analysis of the UTILISATION theme above suggests the success of the intervention in achieving its aims in facilitating positive psychological change in the participants, the following reviews of PERCEPTION and APPRAISAL indicate that it is still a work in progress in regards to what is included in the training, its structure, content and delivery. These issues will be summarised below.

3.3.2. Perception Structural Theme: How was the training experienced?

The analysis within this structural theme explores how the intervention was experienced by the participants and explores this against their original expectations. This theme is deemed important as it helps to clarify the information which carers found most relevant for their needs.

MASTER THEME	KEY THEMES	Coding
Expectations	*Expectations of training*	*No expectations*
		Open mind
		Clinical Intervention
Content	*Peer Support*	*Peer Support*
	Training Content	*Practical Advice*
		Dementia Education
		CST Training

Table 7: Themes identified in the Structural Code: PERCEPTION

This theme is shown diagrammatically in Figure 5 below with associated quotes.

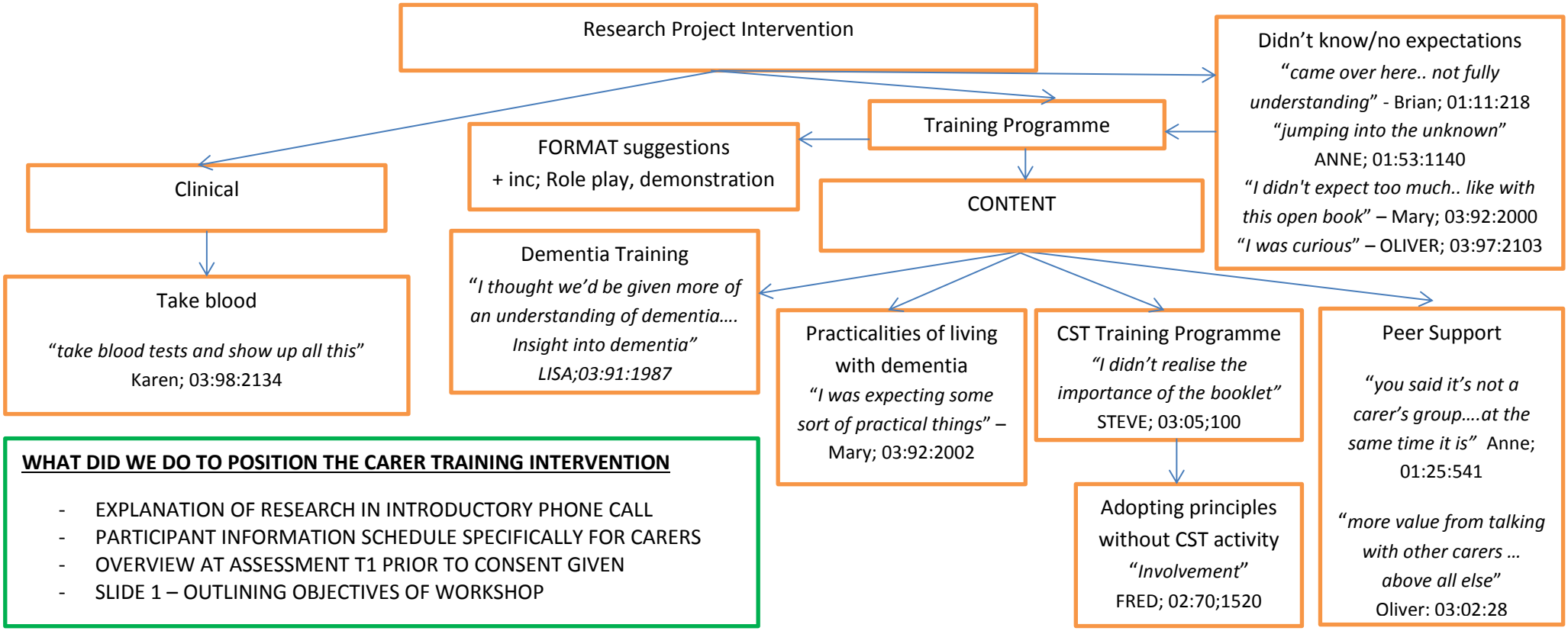


Figure 5: Illustration of the Perception Structural Theme

3.3.2.1. Expectations of training

In summary it can be seen that the expectations of the training, held by the carers at the outset, were in line with the training needs deemed most useful, as identified by Quinn et al. (2008); specifically identifying training on dementia and acquiring practical strategies as key requirements.

The themes underpinning EXPECTATIONS demonstrate that all the carers came with an open mind and a willingness to participate, even though they were unsure of what to expect:

> *'Cause we come over here ……not fully really understanding... what the whole thing is, is going to be about.'* BRIAN; 01:11:217

> *'We didn't really know what to expect, did we, to be quite honest*.' CAROL; 01:53:1137

A surprising outcome from the focus group narratives was the misperception that the participants had in respect to the training, with one participant thinking that her blood was to be analysed:

> '*take blood tests and show up all this…'* KAREN; 03:98:2134

On reflection this would appear to suggest that the medical model is still the most prominent experience of carers as they pass through [redacted] in the diagnostic stages of dementia.

3.3.2.2. Content

3.3.2.2.1 Peer Groups

An interesting outcome from the intervention was the importance that participants placed on being with others in the same situation. Throughout all three focus groups, the importance of peer support appeared to be a key element which all the participants drew on from the carer training programme:

> '*I found more value from talking with other carers above all else.'* OLIVER; 03:02:27

The groups suggested that peer support is useful in finding out information about other local activities and identifying practical strategies to adopt in the home, such as introduction of whiteboards to facilitate memory, and large digital time pieces to help orientation. Other carers suggested that they had not heard about benefits and allowances they were entitled to

prior to meeting with other carers. This is a revealing finding, as the carers would have received much of this information through the memory clinic, which suggests that possibly information is shared with them at a point in time when they are not ready to hear it, following the shock and emotional turmoil of hearing the dementia diagnosis. Anecdotally I have been told that the minute the diagnosis was confirmed '*all I heard was crashing in my ears*', suggesting that any information shared after this would not have been heard.

Much of the discussion about the usefulness of the peer group element was in respect to the normalisation of their fears and recognising they are not the only family dealing with the situation as captured by Ruth:

> *'...come to a group, all got the same problems…. I think you feel you are not alone.'* RUTH; 03:06:118

Interestingly, only focus group 1, talked about concerns about sharing ideas initially and how it would have been useful to have felt more relaxed in each other's company to get the most out of the workshop. While the workshop RUTH attended was in the afternoon, and the participants were given lunch prior to the session where they sat around a table informally interacting, without the facilitators. So, when they sat down for the presentation, connections had been made and they sat with someone they felt comfortable with during the training.

The importance of peer support for this cohort of people resonates further when it is remembered that at the outset of the training it was specifically stated that this is not a 'peer support group'. However, for many they not only had interactions with each other over the three training sessions, but many of the participants met each other for coffee while their family member attended the CST.

As Anne reflected:

> '*Yeah, so I know you said it wasn't a carer's support but I think it has been….. it certainly helped me.'* ANNE; 01:31:658

While the participants in the research noted the importance of this element to the training and were able to articulate the benefits it brought to them, emotionally, psychologically and practically not many had accessed the third party sector offerings previously through carer specific charities, such as the Carers Trust, or the Alzheimer's Society. This would suggest further investigation is needed, to establish what stops people utilising such third sector services, if as suggested in this research, peer support is a key need.

3.3.2.2.2. Training Content

Finally, it would appear that the specific CST focus was not fully appreciated by the participants either before they attended the training or after they completed it. This would appear to demonstrate how important it is to deliver well-defined training to carers who, in a continual stressful situation, are not open to hearing nuances. Interestingly Lisa did reflect on a good time to tell the carers about CST specifically:

> '*The CST bit is almost like a separate thing and you can be told about that when they start the CST.'* LISA 03:64:1390

This quote illustrates how overwhelmed the carers were feeling, in that the fundamental purpose of the training alongside CST was not recognised. Thus, this is a key learning point for professional services, not to make assumptions that key messages are being received.

A key discussion point in all the focus groups, but not explicitly explored in this paper as it did not contribute to the evaluation of the training programme, were the diverse levels of support that different families received, and variations in the appreciation of what support was available to them. This is an area which may be important to be mindful of in future research and service development arenas, but is included in this discussion as it brought forth a key challenge in the training delivery, that is, all the participants were at a different starting points and had different degrees of understanding of dementia and its consequences. This resulted in the specific CST training being less meaningful if the participant's key focus and need was for more generic dementia information if they were in the early stages following diagnosis, or for more practical help and guidance, if they were in the later stages.

3.3.2.3. Perception Overview

A key outcome from this theme is that, despite numerous phone calls, a detailed participation introductory pack and face-to-face explanations, at the initial the participants who attended the training still did not know what to expect when they attended. Reflecting on this I wonder what more could have been done to prepare them for workshop so that they walked in ready and receptive to the information being shared.

The final structural theme is one of appraisal and recommendations from the carers. These are detailed and explored below.

3.3.3. Appraisal Structural Theme: Recommendations for the training structure and content

The final part of the qualitative analysis explores the critique of the workshop training programme, reflecting on its structure and content. As part of the evaluation coding methodology (Saldana, 2009) there is a specific aim to identify and note recommendations. This is the source of the findings within this structural theme. Thus themes did not emerge, as in the previous analyses, but the recommendations were identified throughout the interview scripts and collated into key areas for review.

Without exception the participants said they found the workshops useful and would recommend them to others:

'*For me it was excellent.'* ELLEN; 02:27:564

While the carers were very supportive of the training, they also gave feedback on how it could be improved. Recommendations were thus identified on how to develop the training further and build a programme which is fit for purpose for its objectives and audience.

Table 8 outlines the recommendations for review allocated to key areas identified as follows:

A. WORKSHOP DESIGN
B. CARER PARTICIPATION CONCERNS
C. FUTURE CONSIDERATIONS

A: WORKSHOP DESIGN
1. Review content of the CST Workshop - *'I think maybe we're trying to do too much, with two different things going on. You're trying to explain to us the CST……. And then you have a separate section, the support , the carer part.'* [LISA; 03:60:1297] 2. Review how training objectives communicated - *'I was expecting to come in here and have sessions of people doing scenarios and 'this is what an Alzheimer patient would do, this is how you deal with it and that.'* [FRED; 02:02:38] 3. Review of presentation style - *'maybe some role play, maybe some interaction……'* [MARY; 03:49:1064] 4. Review duration of the workshops - *'this is our life, our family member's life so even though I know I am busy I would rather spend a day and get more out of it, get the emphasis of it than try to cram it into an afternoon – not trying to tailor a days programme into a half day. …'* [MARY; 03:50:1077] 5. Review timing of sessions - *'[follow up meeting] on about the third week, remember what's been done and what the reactions were.'* [ANNE; 01:05:98] 6. Review training materials - *'I was very impressed with the documentation that we were given to take home. That has been helpful.'* [FRED: 02:05:87]

B : CARER PARTICIPATION CONCERNS
7. Consideration of different learning styles - *'..there's different modes of how people learn and how people will take things in, so PowerPoint presentation, reading, interaction.'* [MARY; 03:49:1068] 8. Explore how to ensure participants have a basic level of knowledge about dementia prior to CST training - *'..the only other thing was maybe to have a general question session programmed in at the beginning so that when you start the training, people have asked a lot of the questions.'* [ELLEN; 02:103:2237] 9. Explanation of outcomes from CST – need to set expectations clearly - *'I needed to have a bit more about what these sessions were actually going to give her or not give her or what I should see or not see.'* [LISA; 03:60:1308] 10. To consider how carers can witness their family member in at least one CST session - *'I think you could actually try it with a tape session perhaps, then play tapes when we get together to discuss things….. to see whether…. Because you can pick up your own partner's voice……. To see who's taking part…… You'd get the vibe of what's going on and see what's been said and how the discussion is going.'* [BRIAN; 01:38:826] 11. Consideration of group dynamics to encourage participation - *'I didn't feel part of the group really, on that session.' [1st session]* [BRIAN; 01:12:245]
C : FUTURE CONSIDERATIONS
12. Person centred approach to caring; consider key principles as specific carer training programme– separate from CST - *'And then, gradually, while they are going down the journey……. you've already got that mechanism in place and its working.'* [LISA; 03:35:746] 13. Acknowledge peer support in workshop design - *'Yeah, so I know you said it wasn't a carer's training [sic support], but I think it has been…. It certainly helped me.'* [ANNE; 01:31:658] 14. Ongoing organised activity encourages engagement - *'[reflecting on continuing to meet] 'its good intention but you never do it. But if it's organised for you like a club.'* [FRED: 02:56:1215]

Table 8: Appraisal Structural Theme: Recommendations with supporting quotes

NB: A comprehensive analysis with supporting quotes and areas of influence can be found in Appendix U.

3.3.3.1. Workshop Design

The feedback in regards to the workshop design was also recognised by the research team. The main issue was time, which led to a lot of information being crammed into a half day workshop. The length of the workshop was selected to ensure that carers were not over burdened with the research requirements and to minimise time off work if required. There was also recognition that, if this does prove to be an appropriate adjunct to CST, it should not be too much of a drain on professional's time – a very scarce resource.

However, as was reflected by the comments, the workshops were well received and the information found to be both beneficial and important to the carers and their role. In

hindsight, they reported they would have made themselves available for longer. However, they requested that the training should be split over a number of sessions so that information can be processed better. This commitment was captured by Mary when she stated; '*this is our life, our family's life'*.

It was recognised that there was a tension between the breadth and depth of information shared in the workshops. On reflection it would have been better to concentrate on CST principles and activities and not include the background in dementia, as this background information often led to discussions going off at a tangent to the main agenda.

A key complication was that each of the participants who attended the training all had different levels of knowledge which did lead to some seeking clarification of ideas while others were more informed. In an ideal situation all the carers would start the CST workshop with a working knowledge of dementia and its consequences. How this could be achieved is a point for further investigation.

There was some confusion over the objectives of the training but on reflection this was exacerbated by the amount and different types of information being shared, which led to participants being overwhelmed. It also meant that the amount of time left to focus on the CST activities and the research requirements were limited, as they were at the end of the presentation. With a more focused content the objectives may have been easier to establish.

In developing the training, a lot of thought had gone into making the language user-friendly, yet an issue was raised that too many acronyms were used. Again this highlights the different levels of education in dementia of different carers as none of the carers in the pilot of the workshop suggested that they had any problems with language.

On a positive note the training materials were well received and participants reported that it was useful to have information to take away '*for reference'*. Interestingly some carers reported not realising the relevance of the information given to them. They reported that the time constraints in explaining it to them meant they hadn't appreciated the importance of the documents. In addition, there was mixed feedback in respect of the DVD, which was created to support formal care staff. Again the explanation of how it could be used may need to be explored in further development of the programme.

3.3.3.2. Carer Participation Concerns

The carers all wanted to know what their family member had done in the group, and what they should expect to see as outcomes. This was included in the presentation through a number of quotes from previous family members. However, the carers still wanted to see a more objective measure of their family member's experience. Thus consideration needs to be given as how to set realistic expectations of success for CST group members, that can be understood by the carers and how that progress is communicated in a useful way.

The carers also felt that they needed to see their family member in action and a key request by all of the focus groups was to attend a meeting to see how their family member was in the session:

> '*I think it would have been helpful if we, we as carers, could've been invited to attend one of the sessions.*' FRED; 02:60:1293

This led to a discussion about what impact this may have, recognising that it would mean that the group would have a different context:

> '*…it would put a different slight on them……..she'd want to sit with me so it detracts from that.*' FRED; 02:61:1312

They also recognised that there could potentially be confidentiality issues too:

> '*…we did ask. They said it's not allowed under. Confidentiality rules...'* BRIAN; 01:06:122

Conversely, one family member had asked to attend a session with his wife, but it had been explained to him that it was a closed group. During the focus group discussions he reflected on this. His contribution below, suggested that he had thought about it and came to a very different conclusion:

> '*It was only afterwards, remember I tried to go in, and it was only afterwards it struck me – I could've undone everything.*' GEORGE; 02;61;1318

However, it was a common theme and an emotive one for the family members. One focus debated different ways in which they could get to experience their family member in the group without actually attending the group and interrupting the dynamics. This may be an idea for further deliberation.

> '*I think you could actually try it with a tape session perhaps, then play tapes when we get together to discuss things*' BRIAN; 01:38:826

An area which was highlighted by the carers, that was potentially overlooked in designing the carer training programme was the different learning styles of individuals and a consideration of the fact that many of them are retired and out of practice of being in a learning environment. The carers proposed different learning mediums and possibly less use of a more formal presentation style may be appropriate for this cohort.

A final reflection in this section is the group dynamics. The workshops appeared most effective when carers were at a similar stage in the dementia journey, particularly in the earlier stages. Those who were more distressed or in crisis with their family member were found to dominate the sessions with concerns of a more practical nature which detracted from the messages being shared. Thus it is important to ensure that carers receive the right information at the right time. As Mary reflected:

> *'We've had this now and my mum's had whatever… but what next?* MARY; 03:111:2422
> *I can see that it has helped but now what else can we do?'*

3.3.3.3. Future Considerations

An interesting outcome was the weight that the carers put on the key principles and adopting the strategies outlined within them. Thus the key learning point was the importance of communicating person-centred skills and strategies to carers. Most of the changes reported in the UTILISATION theme arose from implicit and explicit use of adapted key principles rather than the introduction of activity. How this vital information is communicated to carers when it is useful for them is a critical priority, so that they are 'empowered' from the outset of taking on their caring duties.

The importance of peer support was also raised by the carers and use of this resource within the training programme needs to be exploited more. It would appear, that for this cohort, others' stories are useful in identifying techniques which work well but also in normalising their situation and gauging where they are on the dementia journey.

3.3.4. Personal reflections on the qualitative analysis

Undertaking the analysis was challenging and exciting. The key concern I held throughout was 'Am I actually analysing my data? Am I doing it justice?' Braun and Clarke (2006) report that the poorest projects are where no analysis takes place, just paraphrasing of the

extracts resulting in no story being told and no new findings established. The narrative from the participants in the focus groups was rich, covering their incorporation of their learning into their lives, along with their thoughts of how the intervention could be made even more accessible. I felt it was a privilege to hear their ideas and a responsibility to communicate them well and do them justice.

In undertaking the analysis it was difficult to acknowledge instances where there were contradictions and criticism in the data, as described in the Appraisal theme. Guest et al. (2012) warned that it is vital to ensure all the data is considered in the analysis and not to cherry pick the elements which supported the research question or portrayed the intervention in a favourable light. This was a challenge to report, but from the critique came important learning to be considered in future research and the design of similar interventions for carers.

It was also difficult to not use data that was present when it did not address the research question. During the interviews, it was sometimes frustrating as the participants went off at a tangent. When reflecting on this I appreciated that carers do not often get a chance to speak about such issues and it was a forum where they felt safe and heard.

A key area identified is incongruence between the media messages and the subsequent process of diagnosis. The participants reported an inconsistency between the government messages – come and get a diagnosis and we can support you - and the reality they experienced. In practice they reported a long wait to enter into the diagnostic system, a further wait for medication, if appropriate, and then "*they drop you like hot bricks*". This is a narrative I hear in my work and suggests further evidence that a more formal path of support for carers may be appropriate from the moment a diagnosis is received. As Lisa reflected:

> *'[The] training needs to be done sooner……. The minute the person is diagnosed. It would have been a lot more helpful.'* LISA; 03:31:653

4.0. DISCUSSION

The aim of the current project was to evaluate the impact of the introduction of a Carer Training Programme delivered alongside CST Groups on carers of people living with dementia. A mixed methods approach was used to enable both a formative and summative evaluation of the intervention as supported by Patton (2002). The quantitative study is intended to provide an objective view of the intervention's effectiveness. Concurrently the qualitative study provides a rich narrative to hear the carers' experience of, and suggestions to enhance, the CST Carer Training Programme. The synthesised outcomes from the evaluation will be explored to consider any learning in order to inform future research and practice in supporting carers.

A review of the existing research literature revealed that carers experience a number of negative effects as a consequence of their caring role. Namely: caregiver burden, loss of self-efficacy, and a negative impact on both their mental and physical health and the quality of the relationship with the person they care for. Outcome questionnaires which measured these effects were selected for use in the quantitative study to establish if any change occurred following the intervention.

The discussion will start with an overview of the research project's findings, from both the quantitative and qualitative elements of the study, followed by a synthesis of the results found. The outcomes will be explored alongside the existing literature, identifying areas of concordance and difference.

Possible limitations in the current study will then be appraised and potential changes to design considered which may improve the robustness of future similar projects. Recommendations from the current study will be offered, given the outcomes achieved in the context of the limitations identified.

To conclude I will provide a reflection on my personal journey in appreciation of this important group of people and review: How do we 'care for the carer'?

Jeppesen (2005) suggests that we should be mindful and critical of the contribution that our research makes to its field, and this discussion aims to hold this position in mind and identify areas appropriate for further investigation.

4.1. Synthesis of Results

A cursory assimilation of the results appears to demonstrate some conflict between the quantitative and qualitative outcomes. If we start by considering the qualitative Utilisation theme, it would suggest that the Carer Training Programme has been useful for carers. Their narrative illustrates that they have moved from a pessimistic position to one where they have regained some mastery over their situation. This has enabled them to gain a sense of control in challenging situations which occur as a result of their caring role. Reflecting on the adoption of ideas from the workshop that were useful, it is noted that strategies identified through discussion around the CST key principles were employed more often than delivery of specific activities aligned with the CST, as originally hypothesised. This was an unexpected result but one which provides further insight into the kind of information carers find useful.

The findings in the current study support those identified by Ostwald et al. (1999) where it was noted that undertaking a psychoeducation intervention not only enabled carers of those living with dementia to exert more control in their caregiving decisions, but also reduced negative reactions to their family member's behaviours through an improved understanding of the aetiology of the condition. The carers, through their discussions, spoke explicitly about their need to be prepared, to gain '*an acceptance*' (NICK) of the condition and its behavioural consequences, and achieve a '*competence in coping strategies*' (JULIE) to be able to interact better with their family members. They reported that these skills were required before they could consider engaging in interactive activities. Indeed this appears to be the main outcome from the intervention rather than the introduction of CST-specific activity in the home environment.

Thus, the qualitative outcomes seem to suggest the concept of a journey for carers alongside the person living with dementia. The carers who contributed to the focus groups appear to be representative of those caring for people in the earlier stages of dementia, and their feedback from the carer training was that they appreciated learning about person-centred skills to help in their interactions with their family member, in preference to more practical approaches to dealing with behavioural difficulties. This finding is supported by Gilliam and Steffen (2006) and Ornstein et al. (2013) who suggest that when people are in the earlier stages of dementia, as were the person's living with dementia in this study, the behavioural aspects of the condition have less impact on their carers' well-being. This is in contrast to findings identified in the literature research which propose that managing the behavioural aspects of

dementia are an important contributing factor to the carer's well-being (Rabinowitz et al., 2011).

One could consider a hierarchy of needs suggesting that the introduction of person-centred skills is a primary need for carers in the early stages of dementia to equip them with strategies to manage their changed reality and interactions with their family member with dementia. Then, when the relationship is stable, the introduction of more activity based interventions may be useful. In addition, it is also critical to ensure that the intervention is appropriate for the stage of dementia that the family is experiencing. The carers who attended training, where their family member had progressed to the later moderate stages to severe dementia over the duration of the research project, did not benefit at all from the intervention. This was evident from the nature of their engagement with the material and their domination of the discussion in the workshops, demanding practical solutions and support. Thus it is important to keep in mind the carer journey and ensure that people are invited to take part in interventions which are commensurate with their family member's stage in the dementia journey (Burns & Rabin, 2000; Van Mierlo et al., 2011). The training as delivered in the current research would appear to be appropriate for carers of those in the early stages of dementia which is relevant for practice as there is not much support of any nature currently in the immediate post diagnosis period, as Webb (2012) described.

An interesting learning from those who did manage to introduce CST-inspired activity was that it should be delivered in a natural way, rather than asking the person with dementia to take part in an activity which often resulted in them feeling patronised or defensive. They reported that mindfully incorporating CST activity, within everyday activities, was the best way to introduce it: For example, instigating discussions following the news or when reading a newspaper, or including other family members and talking about old family photographs. Another method of successful engagement reported was for the carer to start an activity such as watching a quiz on the television, doing a crossword, playing cards or even computer games and then including the individual in that activity rather than ask them to sit down specifically.

Another noteworthy outcome from the qualitative research was the reported importance of peer support. Oliver from area 03 started the focus group discussion *'I found more value from talking with other carers above all else'.* The value of peer support in the literature is controversial. Anecdotally it is reported as being valued but there are mixed findings if peer

support is operationalised and formally evaluated. Pillemer and Suitor (2002) studied one-to-one peer support where a long term carer trained in counselling techniques to support new carers and found no evidence that this was beneficial. In contrast, Fung and Chien (2002) studied a more traditional support group setting but with a trained facilitator and significant positive outcomes were noted. However, neither captured the more natural interactions as experienced and valued by the carers in this study. Thus, further work needs to be explored in this area to encapsulate what it is that carers value from their peer interactions.

Conversely if the quantitative results are considered in isolation then the findings would have suggested that little benefit has been derived from the intervention. This is similar to the results reported by Logghe et al. (2009) in their original evaluation of an intervention for falls in older adults. This outcome is in contrast to the rich narratives obtained from the carers who took part in the focus groups. Adopting the critical realist stance allowed the study to encapsulate both in the evaluation of the intervention. Hence, hearing the voices of the carers revealing their subjective experience in undertaking the training in conjunction with an objective measure of their feelings, at a specific point in time, when they were asked to complete the questionnaires.

The divergence of outcomes from the quantitative and qualitative elements of the study is explored in more detail below. The brief conclusion is that the difference is potentially the result of design limitations in the quantitative study, which are identified and discussed.

However, the importance of the relationship in the carer/cared for dynamic was the consistent factor in both the quantitative and qualitative outcomes. It was the only significant change in the ANCOVA analysis. It was also a key outcome in well-being felt by the carers as demonstrated in Figure 4: the flow of the journey described by the carers in the Utilisation Structural Theme analysis. As revealed by JULIA if we '*hadn't had this help….. we'd be very frustrated with them……shouting at them*'. This is a relevant finding for the current research in the context of counselling psychology: The foundation of therapy is relationships (Rogers, 1961) and expressed emotion can lead to the break down in relationships, as Michon et al. (2005) reported.

4.2 Critique of the Study

4.2.1 Quantitative Study Review

For the current research the results from the quantitative study demonstrated only one significant change from the ANCOVA results. A number of reasons which may contribute to this outcome have been explored.

Dimitrov and Rumrill (2003) discuss the importance of internal and external validity when undertaking pretest-posttest experimental designs. They outline a number of factors which may undermine the internal and external validity, including for the former; '*..history, pretest effects, instruments, statistical regression towards the mean, differential selection of participants, mortality and a combination of these effects.'* (p. 159). For the external validity they list; '*..interaction effects of selection bias and treatment, reactive interaction effect of pretesting, reactive effect of experimental procedures and a combination of these.'* (p. 159). Many of these do appear to have been present in the current study.

A review of the group base characteristics for each of the conditions illustrates some differences. While participant characteristics were found not to be significantly different across conditions, the carers in the group who did not receive the intervention had higher initial scores in the GHQ-28 and Caregiver Burden on average – a difference of 10 points. This would suggest that they started from a much more stressed position with poorer well-being. Consequently over the course of the 15 weeks, their scores had more opportunity to change naturally. From the qualitative review it appears that most carers prior to their involvement in the research had received little to no contact from professional services. Thus, although this second group did not receive the research intervention, they had effectively received an unplanned intervention in that a professional service had contacted them and they had received an opportunity to talk about their issues. Indeed all the assessors reported anecdotally that carers had spoken at length during their Time 1 assessments which may have implicitly led to a positive change in their well-being.

It was also noted that Condition 1 had more withdrawals from the research than the other two conditions, with most of the carers citing their own physical or family problems as being the reason for withdrawal. Chee et al. (2007) reported that the health status of carers was a key factor in how much they benefitted from interventions. If they were unwell then it was important to address their own health needs as a priority. However, what of those who are

similarly ‘unwell’ in the other conditions? It could be that any potential additional burden from participating in research was minimised for them as they did not have to do anything other than complete questionnaires in their own home. Outside of the research study’s expectations they were able to address their own needs – resulting in an improved position by T2 assessments. Whereas those in Condition 1, who cared for themselves by leaving the research programme, had their T2 assessments replaced by their T1 scores, reducing the impact of the intervention potentially. This provides further support that the type and timing of interventions for people caring for those living with dementia is a critical consideration. A possible correction of the design could be to capture the health status of carers or introduce a threshold criterion addressing the carer’s well-being and physical health, reported in other studies such as Rabinowitz et al. (2011).

As noted in the method section, randomisation is an essential tool in evaluating the efficacy of interventions. Suresh (2011) reiterates that unbiased randomisation is critical to ensure that all participants have an equal opportunity to be allocated to any condition and comparable groups are produced. It would appear for the current study the randomisation of carers into the different conditions has resulted in a skewed bias in characteristics, potentially compromising the analysis. Suresh (2011) reports that in small to medium size projects, simple randomisation can result in a situation where important covariates are not allocated equally across conditions. Due to timing restrictions in the current project, the randomisation was undertaken before any of the initial results from the T1 assessments had been received and reviewed. It is suggested that in future research a stratified randomisation technique may be more appropriate which would control for the influence of important covariates such as the baseline mental and physical well-being of the carers.

Another issue which may contribute to the lack of significant difference is that the power was not large enough for the sample size to detect what may be a small effect size or conversely that due to the dropouts experienced, the sample size reduced, and was no longer large enough to detect a large effect. The qualitative evidence suggests that the intervention was helpful but this is not replicated in the statistical analysis. Thus we need to consider that the effect size was not large enough to be found given the sample size which has led to a Type 2 error – metaphorically, statistically the design was attempting to find a diamond on the beach using a sieve with too large a mesh.

Schwarz et al. (1997) in their discussion of ethical considerations in regards to control groups mention that it is not appropriate to constrain those allocated to the control group in their activities outside of the research. There is evidence that psychosocial interventions for both carers and people living with dementia are helpful with no reported side effects and thus to stop any of the participants taking part in other activities would not have been ethical. This could be a fundamental limitation in the current project's quantitative results. The informed consent that participants signed was only for them to take part in the research, it did not exclude them from seeking out other similar interventions (Hart, 2001). Ostwald et al. (1999) suggested those not receiving the intervention as part of the research may, through their involvement with the project, become more aware of opportunities available to them and identify similar activities themselves and access them. Indeed, the researcher found through discussions with participants that some of them did attend other psychosocial activities and other activity-based meetings with their family member with dementia.

4.2.2. Qualitative Study Review

As can be seen from the Appraisal Theme recommendations, detailed in Table 8, the participants felt overwhelmed by the amount of information that they received at the workshop which influenced the messages that they took from the training.

One of the main issues raised was the perceived lack of clarity around the training programme's objectives. Ostwald et al. (1999, p. 306) concluded that a training programme with '*a clearly defined curriculum*' is beneficial to carers. On reflection, the training programme included in this project was too broad. While in development it was felt important to include more general background of dementia, in reality it led to distraction from the actual task in hand; for carers to understand Cognitive Stimulation Therapy, its key principles and obtain ideas on how to support the CST programme at home.

Unexpectedly the time spent on the key principles was most valued by the carers. While it provided the attendees with key skills and strategies, it did detract from the time spent considering specific activities they may try at home. The research requirements such as writing the diary were reported to be rushed at the end of the presentation and the participants across all three groups reported not appreciating the importance of this request:

> *'We were all a bit naughty – we should've done more than we did, I was…..weren't contributing to, you know what we should have been doing.'* CAROL; 01:03:47

Thus, it would appear that the one of the original key objectives, of informing the carers about CST did not happen, as also illustrated in the Perception theme described earlier. While this is disappointing, the Utilisation theme suggests that carers valued the key principles and were able to introduce these strategies at home, and reporting improved interaction. This is an important finding from the study, which supports Liddle et al.'s (2012) view, that carers can absorb and utilise sophisticated concepts and strategies.

While the carers valued the focus on the key principles, they stated that there were too many principles and they appeared to overlap. This was also reported by research team members who ran the workshops. Of note, there is another CST research project currently being delivered which is exploring Individual CST (iCST) – training carers specifically to deliver CST to their family member at home. Details of this project can be found on the internet (Woods, 2013) and it appears the study has reduced the number of key principles down to 9 from the original 18, to simplify the message for informal carers. This would have saved a lot of time in the first training session, and would have enabled more time to be spent on the CST activities. In addition, the carers could have explored what they may have used at home in more detail during the workshop. The following table is a summary of the revised key principles as used in the iCST project, presented by Woods (2013) on the internet site.

	iCST KEY PRINCIPLES
1	Person Centred Approach
2	Offering Choice
3	Focusing on opinions – rather than facts
4	Using reminiscence
5	Always have a tangible focus
6	Maximising potential
7	Stimulating language
8	Enjoyment and fun
9	Strengthening the caregiving relationship

Table 9: Revised CST Key Principles

While the narratives suggest a shift in the self-efficacy and well-being of the participants, it is not possible to clearly identify which elements of the training programme actually caused

those changes. Although the intervention was designed to illicit changes in these areas, the carers' misperceptions of the aims behind the workshop, may have contributed to different mix of outcomes from the intervention as originally hypothesised. Consequently, the questionnaires selected may not have captured the actual nature of the impact experienced by the carers.

Another limiting factor potentially is the number of participants interviewed. The literature suggests varying opinions in respect to focus group size, with suggestions that groups of four to twelve individuals work well, providing enough voices to create a well-balanced discussion, but not so large that quieter individuals are overwhelmed (Liamputtong, 2011). In the current study, focus group size was dictated by the number of people allocated to and who completed the carer training programme. While in 'area 02' and 'area 03', seven and eight participants respectively attended the focus group interviews, unfortunately in 'area 01' only three participants were interviewed together. It was felt important to interview the carers in their training areas to enhance their interaction by being with people that they had become familiar with throughout the research period (Liamputtong, 2011; Litosseliti, 2003; Willig, 2008). Despite this, a consistency of discussion points was noted across the focus groups and no new codes were identified in the third focus group interview, suggesting the themes emerging appeared to have reached saturation point (Corbin & Strauss, 2008; Willig, 2008). This supports the conclusion that a reliable narrative having been created.

4.2.3. Synthesis of outcomes

In summary, there was only one significant finding from the quantitative analysis yet the carers' narrative in the qualitative analysis revealed a shift in position from one of pessimism to one of mastery and consequently improved welfare. Reflecting on this difference in outcome between the quantitative and qualitative analyses, one consideration was that the measures chosen were not powerful enough in their own right to capture the effect size generated, which is an issue Michon et al. (2005) found in many carer intervention studies. Tabachnick and Fidell (2013) also warn against the risk of not identifying the impact of an intervention because the most sensitive measurement is not used. Reflecting on the measurements selected, they were chosen because they had been shown to be significant in other carer intervention research projects (Moniz-Cook & Manthorpe, 2009). In hindsight, other measures may have been more appropriate for the current project with specific relevance for this cohort of carers, such as considering the importance of the carers'

understanding of dementia and more specific measures of the participant's own well-being. Use of a dementia awareness measure would be recommended in future research and less broad well-being measures. If more specific measures, such as Beck's Depression Inventory had been used rather than the GHQ-28 it may have led to more subtle changes being captured (Aalto, et al., 2012).

When considering the quantitative outcomes from this research, it is pertinent to reflect on Kitwood's (1997b) thoughts on attempting to study the behaviour of a person with dementia within an empiricist method. He suggested that it would lead to simplistic explanations and basic categorisation of complex behaviour. The complexity of the behavioural outcomes elicited from the carers' interviews in this research, suggest that Kitwood's (1997b) concern, is also an issue in assessing the impact of the CTP intervention on the carers'. Reflecting on the outcomes from the quantitative analysis, it may be that in giving the carers a greater sense of self-efficacy and control it also enabled them to assess their sense of burden more objectively. Consequently this increased confidence allowed them to voice their concerns and stresses which previously they would have hidden in the concern that they would be viewed poorly.

The important relationship of the caregiver burden on the feelings of well-being experienced by the carer as described in the literature (Schindler et al., 2012) was demonstrated in correlation analysis. It is also noted in the literature that the carer's perception of competency in managing difficult situations, as noted by Ostwald et al. (1999), is influenced by their attribution style (Burns & Rabin, 2000) and perceived knowledge about dementia (Schindler et al., 2012). Both of these contribute to lower levels of caregiver burden. This provides support for the effectiveness and relevance of the current intervention as these factors are all represented in the journey of change model summarised in the illustration of the Utilisation Structural Theme in Figure 4.

A common theme which ran through all the focus groups was the narrative about 'uniqueness', particularly in reflections about their family members but also about each family's situation. The demographic information unfortunately was not collected in a consistent format and consequently was not fit for purpose, but any future research into the effectiveness of an intervention would benefit from more detail about the participants, including their personality, highest level of education and socio-economic position.

Conde-Sala et al. (2010a, p. 106) conclude that spousal carers appear to have a '*more positive perception*' of their family member's quality of life. An interesting outcome from the qualitative analysis was the reported improvement in interaction between the carer and their family member including a greater appreciation of their capabilities, both from spouses and in particular from the adult child carers. As Nick reflected, '*sometimes you can be a bit too helpful. If you be too over-helpful, it works in a negative way because the other person thinks that they are not doing anything and they're not providing'.* In this, he recognises that his mother still retained a need and an ability to contribute (Kitwood, 1993). Consequently this supports Quinn et al.'s (2008) finding that training and education, around how dementia is experienced by the individual living with it, can change the negative perception of carers.

Ostwald et al. (1999) reflect that a potential limitation of any research is the fact that is part of a research project. By design, it is a stand-alone intervention with no relationship to other services being received and no continuity plan. Thus, at the end of a research programme when post intervention measures and interviews are undertaken, as in therapy, there may be a dip in the well-being of the participants as they potentially feel abandoned. As in Ostwald et al. (1999), the participants did discuss possible continuation of both their own contact as a group and further education needs as the dementia progressed. Thus, it would appear appropriate to consider extended interventions both for the carer and to undertake more longitudinal research programmes.

4.3 Intra study considerations

The data collection gathered a lot more information than has been utilised in this report which has focused on the evaluation of the carer training programme. The participants were asked to complete a diary and, because the returns were obtained only from a few people, they were not analysed in detail. However, a brief overview did highlight some interesting background to the narratives heard in the focus groups. There was evidence that participants had found it difficult to engage their family member in activities if introduced in an overt way. This supports the idea that organic integration of activities is a useful strategy when engaging people with dementia so that they do not feel they are being either tested, infantilised or challenged. One diary was written in great detail and it would be wrong not to acknowledge it at all in this paper. It demonstrated a significant commitment to the research and an incredible journey for the participant and her family member in which their relationship was

redefined very positively. The detail in the diary also described what kinds of activities worked well and which are less helpful for encouraging people with dementia to fulfil their potential. The carer detailed the use of computer packages and games, through to including the person in 'fun' family activities such as helping to train a new puppy. As this participant stated in the focus group, '*it is worth trying things out rather than just thinking they are beyond their capabilities*!'

The feedback from the carers, in respect to the structure and content of the programme, suggested that further work needs to be done on the workshop design. While the information was well received, without exception each focus group felt that there was too much information given in too short a time. This was also recognised by the research team. Analysing the content of the intervention there were three distinct strands; i) what is dementia, ii) the background and development of CST, iii) the explanation of the content and use of CST activities. Both the participants and researchers felt that, in hindsight, each of these areas needed more time in themselves. Indeed, given the journey that the carers embark on, the three areas may even be useful at different time points of their journey. For example the education around dementia might be best delivered close to diagnosis, while the introduction of the person centred principles and associated skills and strategies might better follow when the initial shock of diagnosis has resided. This would provide carers with key competencies to undertake their role better from the outset. Then, the CST element of the training would be relevant and appropriate to be undertaken as and when their family member joins a CST group.

In all three workshops, a lot of time was taken up with questions and concerns outside of the programme agenda and it is proposed that time should also be given to general issues as suggested by the carers. This complexity of needs does highlight that, in order to benefit from the intervention as intended – to understand CST and undertake activity at home, the carers need to have a foundation of knowledge about dementia and already be comfortable interacting with their family member in a person-centred way.

A final thought occurred to me about the data that were obtained from research projects. The development of qualitative research rose from the recognition of qualitative data being discarded in quantitative analysis. A key learning point from this process has been the breadth of interpretation that can be obtained from any and all pieces of data, both qualitative and quantitative, and additional depth and breadth attained from their interaction. Another

important point is the respect that must be given to the choices made in one's research project, and the responsibility to set out the context and assumptions clearly, so that the research can be interpreted appropriately and applied in a useful way to real life settings and in future research.

4.4 Implications for practice

Moniz-Cook and Manthorpe (2009) discuss the nuances of definition around early diagnosis and post diagnosis. As different families have different tolerance levels for unusual behaviour, there will never be a consistent point in dementia's progression when everyone presents for diagnosis. Thus in the post diagnostic period we need to be mindful of the needs of individual families and the stage of the condition at which they have started to ask for assistance. Moniz-Cook and Manthorpe (2009) suggest most evidence-based interventions are focused on more severe dementia but, as the government's awareness schemes gain momentum, more people are coming forward earlier with mild dementia or even before, with concerns about their memory. Thus the psycho-education of carers in gaining an understanding of dementia and its consequences, along with developing the skills and strategies to manage their current difficulties and building self-efficacy in managing more challenging situations, could be introduced immediately. In addition, raising awareness of their own psychological journey at this time would be useful, so that their feelings are normalised and realistic expectations communicated. Recently I attended a one day workshop 'Supporting People with Dementia and their Carer: Messages from Research.' The key message I left with was, that carers need robust and consistent support from services from the moment of diagnosis. If they receive it then, they are better able to manage the journey and stay engaged with services. If they have a bad initial experience, then they withdraw and do not access support until crisis.

Etters et al. (2008) also report that a mixed intervention is found to be the most helpful, where many types of support are incorporated. Indeed, in the current intervention, while it had a specific focus, the participants described their expectation of training and information covering all aspects of their caring role. They also discussed the need for ongoing support/training as the needs and demands of the caring role change as the condition progresses. In addition, Conde-Sala et al. (2010b) remind us to be conscious, in designing interventions, of the particular needs of different types of carers; husbands, wives, adult

children, their gender or ethnicity (Cox, 1995; Yoo, Jang, & Choi, 2010) and other differences such as the person with dementia's level of severity (Schindler et al., 2012). Conversely, as experienced in the current project, a mix of carers with different characteristics, where alternative styles of managing can be shared, has proven to be helpful.

Thus the need for formal support for carers early on in their caring role is vital. Michon et al. (2005) report the experience of burden is not something which grows over time but can be felt acutely immediately following diagnosis, and, as Conde-Sala et al. (2010b) found, continues to be experienced over the course of the dementia journey. Supporting carers to become skilled and find meaning in their role (Farran et al., 1999) from the outset will equip them with a resilience to manage behaviours that challenge and continue to feel empowered (Cohen, Colantonio, & Vernich, 2002) and provide the best care for their family member.

Consideration of the therapeutic needs of carers is also important to support them in their own psychological journey (Boss, 2011). I have had a number of colleagues who know my interest in this area approach me to ask how to support someone who presents with mental health difficulties as a direct result of their caregiving role. The carer's role is diverse and complex and, as Boss (2011) states, is an uncertain and continually changing phenomenon. Addressing ambiguous loss (Boss, 1999) is an important element of the psycho-education for carers and understanding the psychological implications of living with the resultant chronic sadness and continual change may prove helpful. Indeed, the journey of the carers in dementia supports the findings from the critical literature review (Jacobi, 2015). Here it was suggested that different types of therapeutic modalities may be relevant throughout the caring journey to support carers, and is reproduced in Appendix V.

In addition, I was impressed with the use of metaphors by the carers attending the focus groups and how they used it to help rationalise and put their situation into perspective, a helpful approach as Stott et al. (2010) have also noted. Consequently this may be a useful tool to adopt in the therapeutic approach with this cohort. Appendix W illustrates the metaphors identified in the carers' narratives and links them to the Utilisation themes. This could have formed an alternative basis of analysis and contributed to further support of the findings, validating the themes identified.

An important learning for the researcher, and an awareness of the development of similar interventions in the future, is to be mindful of the use of media adopted in workshops and the mode of delivery. The current project adapted a presentation style for health professionals

who are used to receiving information in this format. But in developing interventions for informal carers, consideration should be given to the varied learning styles of participants. Also as they are an older cohort they may not have undertaken any type of training for a considerable time. Such a review and development is not uncommon following practical interventions, as identified by Logghe et al. (2009) and Ostwald et al. (1999).

The well-being of the carers and their family member is an important consideration in deciding for whom this type of intervention is appropriate. It is noted that more people dropped out of the carer training condition than the other two conditions, all reporting declining health issues for themselves or those they care for. Indeed, when carers, who had a family member who was very unwell, attended the workshop their concerns dominated the session. Carers whose family member was in a more advanced stage of dementia or where there were other health and or family issues did find it difficult to engage. People who did not meet the research criteria were invited to attend a carer training workshop outside of the research timetable which also provided interesting learning. Anecdotally one carer whose husband was more advanced in his dementia, who also cared for her mother, simply stated that this information was too late for her – that there was no way she could adopt the principles and when were we going to talk about practical solutions to care! Thus, there does appear to be an appropriate time for the elements in the current intervention to be provided to carers. As previously stated it would appear that such skills need to be delivered to those at the start of their carer journey to support a sense of hope and optimism for their family member/friend and control for themselves.

It is proposed that the nature of the information shared in the current intervention is appropriate for those carers at the outset of their caring journey and for those whose family member is also relatively well and in the early stages of dementia. Once an individual has progressed to the later stages of dementia, more practical and logistical support and strategies are required, while maintaining a person-centred environment.

4.5. Recommendations

In summary the intervention does appear to have been helpful to carers. It is recommended that the nature and format of the CST carer training is explored further, but in the context of the caring role being on a continuum where the carers' needs change over time (Michon et

al., 2005). Psycho-education which outlines 'what dementia is', as previously concluded by Quinn et al. (2008) is key information carers need and was supported in the current project. In addition, it would appear from this intervention that educating informal carers in the key principles of person-centred care and how this translates into helpful interactions with the person with dementia is also appropriate. It resulted in the participants feeling empowered and prepared for their caring role from a more hopeful stance. The practicalities of CST could then be the sole focus of the CST Carer Training delivered alongside CST, if and when a person with dementia attends CST groups. This would give carers the time to appreciate and consider appropriate stimulating activities for their individual circumstances.

Wong et al. (2008) also found that sharing information with carers promptly does contribute to carers feeling more in control of their situation. The timing of information provision of any nature also appeared to need further consideration. The carers in the focus groups all reported '*having no or little information*' yet all had passed through a comprehensive memory assessment service that included information provision. As professionals, it is often easy to become hardened to the effect a diagnosis has on the individual and their family – anecdotally a carer told me: '*as soon as he said dementia I had bells clashing in my head, I didn't hear anything else*.' Thus it is suggested that an information provision process for carers is formally developed to enable carers to feel supported and receive the relevant information when they are in a place to hear it.

Another outcome of this research is the change in the carer's ability to recognise the importance of their welfare. Schindler et al. (2012, p. 131) reported that carers '*not neglecting*' their own needs was important in negating their sense of burden from their caring role. The qualitative outcomes in this research tentatively suggest, that by educating carers in a way that enables them to feel in control, could empower them to make good decisions in addressing their own needs, such as obtaining additional support as necessary; for example, when building work is being undertaken in the home as RUTH reported in the focus group, or accessing respite when required. Hence, in a similar way to Kitwood's (1997) work on providing underlying principles for person-centred care for those living with dementia being the foundation of developing dementia care mapping, by acknowledging the complex needs of carers, as illustrated here, it may be appropriate to develop set of key principles to enable a 'good care environment' and to create a "Carer Support Map". This could deliver a specific programme of information and techniques both of a practical and therapeutic nature to empower them throughout their journey of care.

4.6 Conclusions

In conclusion the mixed methodology resulted in a complex outcome which led to a broad and in-depth appreciation of the impact of the Carer Training Programme. Indeed, neither the quantitative nor the qualitative elements of the study delivered outcomes as originally hypothesised; that is, only the relationship measure had a significant result in the quantitative analysis and carers did not adopt a protected time to undertake specific activities inspired by the CST programme. However these results should be considered in light of the limitations in the research design as discussed previously.

Conversely, the carers' narratives from the focus groups did demonstrate a shift in their self-reported understanding of dementia and attribution of challenging behaviours to the condition rather than the person with dementia's wilfulness; self-efficacy through feeling '*empowered*'; and improved interactions with the person they cared for; '*we talk more*', '*we laugh together*'.

In reflecting on the original objectives of delivering a Carer Training Programme alongside CST as currently structured, it has led to positive outcomes being delivered. However, it should be redesigned, with each component being delivered separately. In order to encourage activity as originally envisaged, the final component could be delivered with a more focussed agenda which concentrates on the CST structure and delivering comparable CST activities in the home environment. It is also recognised from this study that it is most useful for people whose family member is in a relatively early stage of the condition and is stable. In addition, given the nature of the caring role, it is important that carers need to already be well-versed in 'what dementia is' and person-centred principles to benefit most from an activity based intervention. To deliver all this at once was too ambitious in hindsight.

A significant outcome from this review is the importance of peer group support. This research study adds weight to the evidence base that such interventions, for carers of those with dementia are relevant and, should be an element of ongoing support for this cohort. Further research in this area, to identify the relevant elements of peer groups that make them successful, is needed.

The specific cause of change within the current training programme, as described by the participants, appears to have been through the utilisation of the CST key principles. A key recommendation from this project is to create a Dementia Carer Training Programme not

associated with CST based on the learning established. It is suggested that this could incorporate education about dementia, and provide carers with training in person-centred principles of care and interaction strategies for carers of people living with dementia. It is proposed, that such a programme, would be delivered in the period immediately following diagnosis. Currently, with services focused on delivering support in times of crisis, this early period is a time when very little support is available for carers and they often report feeling abandoned (Lilley et al., 2012). As the move towards earlier diagnosis continues, the need for this type of intervention will become greater to enable families to learn to live with dementia well.

Developing such programmes to facilitate peer group interaction and to deliver communication skills, and psycho-education in strategies developed in the context of the person-centred paradigm are fundamental in facilitating the relationship between the carer and cared for to reach its potential. These techniques and objectives align closely with the philosophy and objectives of Counselling Psychology.

4.7. Final Reflections: My Parallel Journey

In this section, I reflect on my personal journey of discovery in undertaking this research project and on what it means to '*share life with dementia'* (Webb, 2012) for the carer and the cared for.

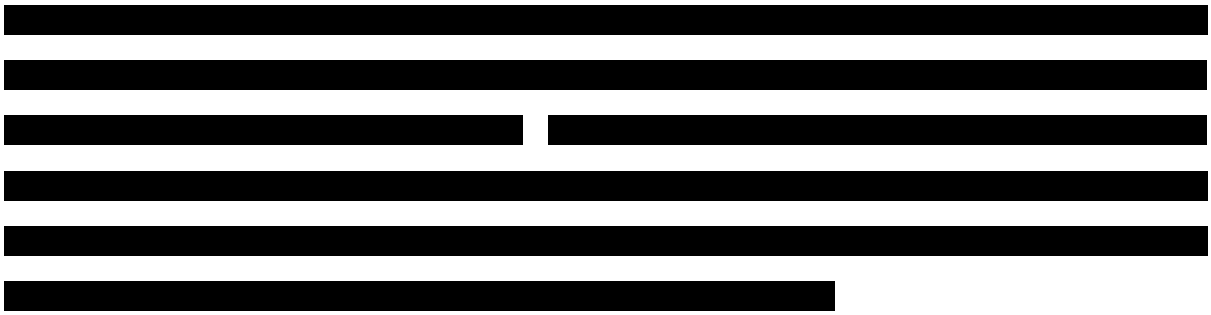
I have worked with people being diagnosed with dementia and in the initial steps of their journey for the past six years and have noticed how my positioning has altered.

As an assistant psychologist, two years on from leaving my Chartered Accountancy career and fresh out of my post-graduate psychology conversion course, my initial experience was within the process of diagnosing the person with concerns about their memory by undertaking neuropsychological assessments with them. In retrospect, I recognise that I fell into the diagnostic medical model approach providing an answer to their experiences but not thinking about the larger picture. Over time, as I met more carers, my appreciation of their task grew. However, initially I believed their needs were very much in line with the medical services model, of providing information and guidance on tasks that should be addressed in the short term, including provision of advice in getting a Lasting Power of Attorney, ensuring that you claim benefits you are entitled to, making links with others in a similar situation with

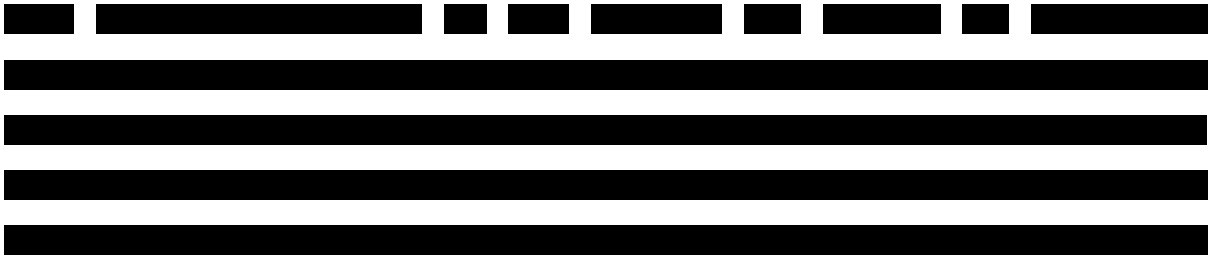
a main focus on continuing to live well and enjoy life including family occasions (Boss, 2011).

On reflection this feels very naïve, and shows a lack of empathy and understanding for the person recently diagnosed with dementia and of the challenge that a carer living with dementia faces (Webb, 2012).

A shift of my approach occurred when I started on my Counselling Psychology Doctorate as I became more mindful of the psychological impact of experience on an individual and their relationship dynamics. I started to wonder why there were not more courses for informal carers which could help them through their own psychological journey (Boss, 2011) in living with dementia and supported them in how to communicate differently with their family member.



Indeed, Webb (2012) reflects on how a joint project with a professional counsellor floundered. While they shared a common passion to write a book about living with dementia in its early stages, they were unable to combine their ideas. The editor pointed out that Dorothy Webb wrote with emotion while the counsellor wrote from a technical position. Both are valid perspectives and they eventually wrote separately. Dorothy Webb's book 'When Goodbye Begins; Sharing Life with Dementia', a book written by a carer about the difficulties faced by carers in the early years, has made me feel like a novice in the field of dementia. Reading her experiences I hear the voices of my mother and the many carers I have met and finally 'get' it – or I think I do.



[redacted] Thus it appears that it is a more organic approach to change that we, as professionals, should adopt, with the introduction of a more rolling agenda of support for carers from the '*moment the diagnosis is given'* as LISA from a focus group stated.

In the focus groups one of the key messages received from the participants was the value they placed on meeting others in the same situation – '*I found more value from talking with other carers above all else*'; '*And then when you are in a group, you realise it is quite natural'.* Reflecting on the half day workshop, provided as part of the research intervention, the informal discussion between the carers was always lively and inclusive and when we restarted the session a different atmosphere filled the space. How this spontaneity can be captured and replicated in order to measure effectively in research is difficult challenge. One group spoke about the wish to remain in contact but recognised, in reality, it would be unlikely. However, they reflected that if it was organised for them it may happen. So it would appear that some level of external organisation is needed for a successful peer group to form.

So the question is; how do we as professionals give support to carers in the early stages of dementia? As Webb (2012) states, most of the advice is for when people are in the latter stages of the condition when it is easy to identify the difficulties that need addressing, such as incontinence, behavioural disturbances, and aggression for example. The solutions are clear, objective and quantifiably deliverable.

There is a wealth of evidence that practical, legal and financial, and psycho-education about dementia is useful (Clare, 2002). But it is not the whole story. There is also a recognised need to provide counselling and therapy for carers, but it is limited and, as Boss (2011) states, for many carers it means labelling them with depression or anxiety, which in itself is unhelpful. She describes it as making them feel deskilled and failing, so possibly the current therapeutic approach is not helpful. The idea of not pathologizing difficulties being experienced is at the root of Counselling Psychology with the objective being that of growth

of the individual within their circumstances (Blair, 2010; Martinelli, 2010; Shorrock, 2011). This is in keeping with recent research, and as supported by Boss (2011) in the therapeutic approach she developed, that caring can reframed with more hope and be a positive experience.

All carers in the current research found the psycho-education and strategies offered through the person centred-care key principles helpful as they integrated some of the ideas into their own skill tool-kit and relationship with their family member and management of situations. Indeed, one carer explicitly stated;

If we had '*actually got some of this information that we've got... on this course at the beginning when it was diagnosed. If I'd have known this information when my mum had actually been diagnosed I would've thought 'oh, right, okay. I could bring those in, we can use that information, we can use those strategies to help out.'*

Through my reading of the literature, my appreciation of the task undertaken by those who provide care informally has also grown. My initial reflections on those carers whom I have met, has always been one of respect and awe, but with a tinge of sadness at the life that they have lost. Yet through my journey with this thesis it does appear that an alternative perspective is possible and can be achieved when caring for someone living with dementia. That the situation can enhance the carers view of themselves, by recognising the capabilities, competence and resilience that comes forth from the caring role, which McIntyre (2003, p. 474) described as the 'gift of my mother's illness'. Thus, an alternative narrative for carers emerges, from that of victims, enduring burden, depression and loss to one of learning and growth and where the act of giving care is seen as a worthy activity. Boss (2011) also proposes a reframing of the carer role, supporting carers in accepting that it is challenging and through therapeutic interventions help them normalise their difficult feelings and reactions. Boss(2011) suggests that acknowledging that an individual will feel sad and lonely, without defining them, will actually give them confidence, with no need to be labelled with terms such as depressed and anxious.

Indeed, normalisation of the possible experiences, emotions and feelings that a carer should expect to encounter at the outset, could help to put them back in control after hearing the diagnosis, enabling them to make choices about how they react to such circumstances. In turn this understanding and self-efficacy could result in minimising some of the

psychological difficulties that carers currently experience and could enable them to carry out their caring activities better. It also provides an immediate focus for the carer as part of their adjustment to their new, re-scripted life (Webb, 2012); sharing life with dementia. Such a programme fits with the foundations and objectives of counselling psychology and is a vital area that, as a counselling psychologist, I hope to remain involved with and develop throughout my career.

5.0. REFERENCES

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6.0. APPENDICES

Appendix A

The 18 KEY PRINCIPLES underlying CST

	Key Principles
1	Mental stimulation
2	New ideas, thoughts and associations
3	Using orientation, both sensitively and implicitly
4	Opinions rather than facts
5	Using reminiscence as an aid to the here-and-now
6	Providing triggers to aid recall
7	Continuity and consistency between sessions
8	Implicit (rather than explicit) learning
9	Stimulating language
10	Stimulating executive functioning
11	Person-centredness
12	Respect
13	Involvement
14	Inclusion
15	Choice
16	Fun
17	Maximising potential
18	Building / strengthening relationships

Appendix B

Researcher's contribution to research delivery

Professor Gary Kupshik (R & D Lead) was the sponsor for this project from South Essex Partnership University NHS Foundation Trust (SEPT). The project was run across a number of sites in Bedfordshire. Dr Helen Donovan (Consultant Clinical Psychologist) was Chief Investigator for the trial, for SEPT, across Bedfordshire.

Research Activity	Nicola Jacobi (City University)	Jennifer Cove (UCL)
Production of Ethics Documentation	X	X
Co-ordination of research Activity	X	
Development of Carer Training Programme with Dr Aimee Spector (UCL)	X	X
Delivery of Caring Training Pilot	X	
Collation of potential participant Lists	X	
Invitation call to participants	X	X
Research Administration	X	
Management and Co-ordination of Assessment visits	X	
Participant Assessments	X Supported by other Assistant Psychologists at SEPT.	X Supported by other Assistant Psychologists at SEPT.
Delivery of CST Groups	X Supported by other Assistant Psychologists and support staff at SEPT.	
Initial Carer Assessment	Carer Training initial workshops undertaken by Dr Helen Donovan (SEPT) to maintain independence of the researcher	
Mid-Session Carer Training	X or Dr Helen Donovan	
Delivery of Final Carer Training Session	X	
Focus Groups	X	
Delivery of Carer Workshops to condition 2 and 3 carers	X	X

Appendix C

CST Carer Training Research Timetable

Task	Owner	Specific Date if known	01-May-12	04-Jun-11	11-Jun-12	18-Jun-12	25-Jun-12	02-Jul-12	09-Jul-12	16-Jul-12	23-Jul-12	30-Jul-12	06-Aug-12	13-Aug-12	20-Aug-12	27-Aug-12	03-Sep-12	10-Sep-12	17-Sep-12	24-Sep-12	01-Oct-12	08-Oct-12	15-Oct-12	22-Oct-12	29-Oct-12	05-Nov-12	12-Nov-12	19-Nov-12	26-Nov-12	03-Dec-12	10-Dec-12	17-Dec-12	24-Dec-12	31-Dec-12	07-Jan-13	14-Jan-13	21-Jan-13	28-Jan-13	04-Feb-13	11-Feb-13	18-Feb-13	25-Feb-13	04-Mar-13	11-Mar-13	18-Mar-13	25-Mar-13	01-Apr-13
NHS Ethics Approval	ALL	23/05/2012																																												
R&D Ethics Approval	JC + NJ																																														
Preparation of data collection documentation	NJ																																														
Carer Training Pilot	NJ	13/06/2012																																													
CST Group and resource planning	Facilitators	10/07/2012																																													
Identification of Participants SEPT	NJ	Ongoing																																													
Recruitment of participants	NJ/HD and team	03 = 25/6/12 02 = 09/7/12 01 = 30/7/12						AREA 03		AREA 01							AREA 02																															
Area 01 Allocation to conditions	NJ																																													
Area 01 pre assessment	Various																																													
Area 01 carer training 1	*HD*	17/08/2012																																												
Area 01 Groups	KC/NJ	Thur 16/08/2012												1	2	3	4	5	6	7	8	9	10	11	12	13	14																				
Area 01 carer training 2	NJ																																													
Area 01 carer training 3	*NJ*																																													
Area 01 Groups post assessment	Various																																													
Area 01 Groups Carer focus Groups Semi Structured interviews	NJ																																													
Area 02 Allocation to conditions	NJ																																													
Area 02 pre assessment	Various																recruitment initial calling	follow up calling																														
Area 02 carer training 1	*HD*																																													
Area 02 Groups	JR/NJ	Mon 15/10/12														BH						1	2	3	4	5	6	7	8	9	10			11	12	13	14										
Area 02 carer training 2	NJ																																													
Area 02 carer training 3	*NJ*																																													
Area 02 Groups post assessment	Various																																													
Area 02 Groups Carer focus Groups Semi Structured interviews	NJ																																													
Area 03 Allocation to Groups	NJ																																													
Area 03 pre assessments	Various											CONTROL																																		
Area 03 carer training 1	*HD/NJ*																																													
Area 03 Groups	NJ	Thur 22/11/12																										1	2	3	4	5		6	7	8	9	10	11	12	13	14				
Control + non qualifying CST Grp	*NJ*	*Mon 19/11/12*												1	2	3	4	5	6	7	8	9	10	11	12	13	14	CONTROL + non qual CST						CONTROL + non qual CST												
Area 03 carer training 2	NJ																																													
Area 03 carer training 3	*NJ*																																													
Area 03 Groups post assessment	Various																									CONTROL + non qual pre																					
Area 03 Groups Carer focus Groups Semi Structured interviews	NJ																																													

XMAS and NEW YEAR

Appendix D

Telephone Interview Script Example

Hello, is this Mr/Mrs <client name>?

My name is <full name>. I am a(n) trainee counselling psychologist/assistant psychologist working with the [redacted] I am calling following on from your appointments with the service in <month, this/last year>.

One of the recommendations at your feedback meeting was to attend a Cognitive Stimulation Therapy group. This is recommended by the department of health, and the groups are an opportunity for people with memory group to meet together and have discussions and enjoyable activities to keep their minds active. Previous research has shown that it can help improve memory difficulties or slow down their progress, and also improve people's quality of life.

The groups will run once a week for 14 weeks for a bit over an hour each time, and we can provide transport there and back if needed. All the people being invited are in a similar situation to you, living in their own homes in the community, and having memory problems in recent times. We've run these groups before, and people find them enjoyable, and many people find it particularly helpful to meet others in a similar situation to themselves.

Do you think you may be interested in finding out more about this?

We are also trialling a new addition to the programme as part of a research project to find out if it is helpful for family members to be provided with information and training about the types of things we do in the groups. They wouldn't be attending the groups at the same time, but will receive a separate training session and some follow up. For this we will need a family member involved, and we are aware that you/your <husband/wife/daughter/son etc.> provided support when you came to the clinic. We would therefore like to ask them to become involved and will need to speak with them as well.

We are going to compare three groups; people waiting to come to the groups, people coming to the groups, and people coming to the groups where their family member receives the extra training.

To evaluate whether the groups and training are effective, we will be carrying out assessments with people and their family member before and after 14 weeks.

For those people who initially are waiting, or don't receive the family training during that initial evaluation period, we will be providing the groups and training to everyone at the end, so no one misses out.

We think this is an important project to help make sure people with memory problems and their families are getting support and help they need, and your help would be very much appreciated, as well as the benefit you will have from taking part.

If you think you might be interested in taking part, we'd like to post you some more detailed written information and then call you in a week or so to see whether you'd like to go ahead.

If you or <family member> don't wish to take part in the new project with the family member training, you are still very welcome to come along to the groups.

<check address info and check best times to get them on the phone>

Appendix E

INFORMATION SHEET FOR CARERS

Pilot study examining the effectiveness of weekly Cognitive Stimulation Therapy (CST) and the additional impact for people with dementia and their carers of including carer training in CST

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this information sheet.

What is the purpose of the study?

In recent years, cognitive stimulation therapy (CST) groups have shown to be an enjoyable and beneficial therapy for people with memory problems. This project will show whether once weekly CST is effective.

Often the carers of those taking part in CST groups request to have more involvement in the treatment so that they can understand the therapy being given and provide support to their relative/friend over the course of the group. This project also aims to show how inclusion of a carer training programme affects the impact of CST for both the person attending CST and their carer.

What happens in a cognitive stimulation group?

Traditionally CST groups are held as a 14 session programme, twice a week for seven weeks. However, in practice NHS services tend to deliver CST once weekly for 14 weeks due to resource limitations. The activities include for example multi-sensory stimulation, word categorisation and discussion of current affairs. The idea is to keep the mind active through enjoyable activities, undertaken as a structured programme facilitated by experienced and trained staff that will look after the group. The sessions include physical games, current affairs discussions, sounds, food, word games, and numbers games.

Why have I been chosen?

You have been invited to take part because of your support for a person who at some point had a memory assessment. We need a large number of people with memory problems to help us evaluate the weekly CST groups – 72 in total. Each CST group may include up to 8 people. In addition, we need each of them to have a carer who has regular contact with them to evaluate impact of adding a carer training programme to CST for both the individual in the CST group and for their carer.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your relative / friend receives.

What will happen to me if I take part?

This study is a randomised trial. We need to have three groups so we can compare the outcomes for each group – a group in which people with dementia receive CST and their carers attend a carer training programme; a group in which people with dementia receive CST but their carers do no attend the carer training programme and a group in which people with dementia do not receive CST and their carers do not attend the carer training programme.

Firstly we need to establish the effectiveness of weekly CST groups, and so we need to compare any changes experienced by people with dementia in CST groups with changes in people with dementia who have not received any treatment.

Secondly we are exploring the impact on both people with dementia and their carers of adding a carer training programme to CST. So we need to compare any changes experienced by carers and people with dementia if the carer receives training with changes experienced by carers and people with dementia if the carer does not receive training. The fairest way of doing this is to select people (the person with dementia and their carer) for each group by chance. The decision is made by an independent computer, which will not have any identifying information about you or your relative/friend.

Those people allocated to the group for which the person with dementia does not receive CST and their carer does not receive training will be asked to complete the interviews described below immediately on entering the project and then after 15 weeks. <u>Your friend/relative will be invited to attend a CST group following their involvement in the research project.</u>

Those allocated to a group in which the person with dementia will receive CST will be interviewed in the two week period prior to the CST group starting and in the two week period following the end of the CST group.

If you decide to take part, your participation in the study will last for a time period of approximately four and half months. Following discussion of any questions you may have with a researcher, and signing the consent form, **all participants** will be asked to:

1. Meet with a researcher for between an hour and an hour and a half to complete some questionnaires. Your relative/friend's questionnaires will cover their cognitive abilities, and their perception about the quality of their life. The questionnaires you will be asked to complete will be about your general health, your feelings of self-efficacy, satisfaction and burden. Both of you will be asked to complete a questionnaire about the quality of your relationship. The time stated to complete the interviews and questionnaires is an estimate;

you and your friend/relative may take as many breaks as you want or feel necessary, and even complete the process over two sessions if preferred.

2. To repeat these questionnaires with the researcher, after 15 weeks
3. Usually, the researcher will come to your home or the home of your relative/friend if you live separately, but will be happy to meet you elsewhere if you would prefer. Usually, the researcher will meet with and interview your relative/friend at the same time as you are completing the questionnaires. Your answers to all the questions will be kept confidential and will not be disclosed to your relative/friend.

Carers allocated to receive carer training (one third of carers) will be also be asked to:

1. Attend two training sessions

    a. The first session will be held at the time the person you care for begins their CST group. This session will last for half a day and introduce you to the key principles of CST and explore ways for you to engage in activities at home based on these principles.
    b. The second session will be held around the time the person you care for finishes their CST group. This session will last for approximately an hour with a focus on maintaining the ideas from the first session into the future.
    c. An optional third session will be offered mid-way through the CST sessions. This session will be one hour long and offer you the opportunity to come and discuss any difficulties you are having and get advice if you need it.

2. To complete a weekly diary reflecting on your thoughts and the activities undertaken. You will be asked to undertake activities as directed in the first training session at least three times a week
3. Participate in either a *focus group or an individual interview* in order to explore in more depth your experience of undertaking the carer training programme. *Focus groups/individual interviews* will last approximately an hour, during which time you will be asked to reflect on your experiences of the carer training programme. An experienced researcher will lead the *focus groups or interviews*.

    The focus groups will be audio recorded in a digital recording format. You will not be identified in the recording. The recordings will be encrypted and password protected and kept on a secure server of the Sponsor organisation (SEPT NHS Trust). They will be retained as research data for a period of 7 years after which time they will be permanently deleted.

4. Refreshments will be provided and transport arranged as needed. Suitable breaks will be scheduled into all groups. Carer training sessions will be led by skilled and trained members of staff who receive regular support and supervision.
5. Those carers who do not get allocated to the carer training programme as part of the research will have an opportunity to undertake some training in CST principles and activities after their involvement in the research has finished. This will be completely voluntary.

Expenses

Any travel expenses incurred by you or your relative/friend will be reimbursed.

What do I have to do?

Taking part in the study does not involve any lifestyle restrictions or changes either for you or your friend, relative. You can carry on your everyday activities as normal while participating in the study.

What if my relative/friend is unable to consent to take part, or loses the ability to consent?

All participants in research are invited to complete a consent form before the research commences. Sometimes people with memory problems are unable to make a decision to consent to a research project because they have difficulty in understanding or retaining the information provided about the project. Sometimes people with memory problems are able to do this at the beginning of the project, but later may not be able to provide their consent. In either of these circumstances, the research team is required to consult with someone who is involved in the person's care, such as a family member, regarding whether the person should participate, or continue to participate, in the project. If concerns do arise regarding the your relatives'/friends' ability to consent, we would seek your advice regarding whether the person with memory problems should participate and what you think the person's feelings and wishes would be regarding taking part. If the person has previously made an advance statement or advanced decision that is relevant, we would not do anything to go against this.

What are the possible disadvantages and risks of taking part?

You may feel that the requirements of your participation appear onerous and time consuming. However, the CST carer training programme has been designed with input from other carers whose family member have been through CST and is based around what they feel they would have liked to receive. Meetings and training sessions will be organized as far as possible to fit around your own commitments.

For your relative/friend CST involves participating in a group programme that aims to be stimulating and enjoyable. Sessions involve discussing themes such as food, childhood and current affairs and it the level of risk in taking part is therefore minimal. If while taking part the participant feels uncomfortable or distressed while taking part in a group, facilitators will be able to give additional one to one support if this is needed

What are the possible benefits of taking part?

If you decide to take part you will receive training which will provide you with a greater understanding of the treatment your relative/friend is involved in, peer support and new communication skills.

We hope that your relative/friend being involved in the CST groups will be of some help to them, and previous group members have indeed reported that they have enjoyed the experience greatly. For all participants, the information we get from this study may help us to treat people with memory problems better in the future.

Will my taking part in the study be kept confidential?

We will request permission to send the person with memory problem's GP a letter explaining that you have both agreed to take part in the study. Otherwise, all information collected about you during the course of the study will be kept strictly confidential. All data is stored without any identifying details under secure conditions.

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

You and your relative/friend will be free to withdraw from the study at any time, without giving a reason. Withdrawing from the study will not affect the standard of care your relative/friend receives. We will need to use any data collected in the study up to the point of withdrawal.

What if something goes wrong?

If you are harmed by taking part in this study, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action, but you may have to pay for your legal costs. Regardless of this, if you wish to make a complaint about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints procedures should be available to you. If you are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution.

What will happen to the results of the research?

The research is being carried out by two trainee psychologists as part of their Doctorate Training. Nicola Jacobi is at City University London and undertaking a Doctorate in Counselling Psychology. Jennifer Cove is at University College London (UCL) and undertaking a Doctorate in Clinical Psychology. Both will produce a research dissertation which forms as part of their final course assessment. It will not be possible to identify individual results specifically, though a summary of the findings will be available if you are interested.

Results will also be published in relevant journals. No participants will be identified in any publication arising from the study without their written consent.

We will make arrangements for participants to be informed of the progress of the research and the results will be summarized in a document following the completion of the project. Please let us know if you would like to receive a copy.

Who has reviewed the study?

All NHS research is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and been given a favourable opinion by the London South East National Research Ethics Committee.

Who can I contact for further information?

For more information about this research, please contact the Chief Investigator:

Dr Helen Donovan
Phone: 01234
Mobile:
Email:

Or if you have any complaints about this study please contact:

R&D Administrator
R& D Department, Disability Resource Centre
Poynters House, Poynters Road,
Dunstable
Bedfordshire, LU5 4TP

Phone: 01582

Email:

Thank you for considering taking part in this research study!

Appendix F

PARTICIPANT INFORMATION SHEET

Pilot study examining the effectiveness of weekly Cognitive Stimulation Therapy (CST) and the additional impact for people with dementia and their carers of including carer training in CST

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this information sheet.

What is the purpose of the study?

In recent years, cognitive stimulation therapy (CST) groups have shown to be an enjoyable and beneficial therapy for people with memory problems. This project will show whether once weekly CST is effective.

Often the carers of those taking part in CST groups request to have more involvement in the treatment so that they can understand the therapy being given and provide support to their relative/friend over the course of the group. This project also aims to show how inclusion of a carer training programme affects the impact of CST for both the person attending CST and their carer.

What happens in a cognitive stimulation therapy (CST) group?

Traditionally CST groups are held as a 14 session programme, twice a week for seven weeks. However, in practice NHS services tend to deliver CST once weekly for 14 weeks due to resource limitations. The activities include for example multi-sensory stimulation, word categorisation and discussion of current affairs. The idea is to keep the mind active through enjoyable activities, undertaken as a structured programme facilitated by experienced and trained staff that will look after the group. The sessions include physical games, current affairs discussions, sounds, food, word games, and numbers games.

Why have I been chosen?

You have been invited to take part because you have at some point had a memory assessment. We need a large number of people with memory problems to help us evaluate the once weekly CST groups – 72 in total. Each CST group may include up to 8 people.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?

This study is a randomised trial. We need to have three groups so we can compare the outcomes for each group – a group in which people with dementia receive CST and their carers attend a carer training programme; a group in which people with dementia receive CST but their carers do no attend the carer training programme and a group in which people with dementia do not receive CST and their carers do not attend the carer training programme.

Firstly we need to establish the effectiveness of weekly CST groups, and so we need to compare any changes experienced by people with dementia in CST groups with changes in people with dementia who have not received any treatment.

Secondly we are exploring the impact on both people with dementia and their carers of adding a carer training programme to CST. So we need to compare any changes experienced by people with dementia and their carer if the carer receives training with changes experienced by people with dementia and their carer if the carer does not receive training. The fairest way of doing this is to select people for each group by chance. The decision is made by an independent computer, which will not have any identifying information about you or your carer.

If you decide to take part, your participation in the study will last for a time period of about four and a half months. Following discussion of any questions you may have with a researcher, and signing the consent form, **all participants** will be asked to:

1. Meet with a researcher for between an hour and an hour and a half to complete some questionnaires covering quality of life, cognition and your relationship with your carer. The time stated to complete the interviews and questionnaires is an estimate; you may take as many breaks as you want or feel necessary, and even complete the process over two sessions if preferred.
2. To repeat these questionnaires with the researcher, after 15 weeks.

Usually, the researcher will come to your home or the home of your relative/friend, but will be happy to meet you elsewhere if you would prefer. Usually, the researcher will meet with and interview your relative/friend at the same time as you are completing the questionnaires. <u>Your answers to all the questions will be kept confidential and will not be disclosed to your relative/friend.</u>

Two thirds of participants entering the trial will be asked to attend CST once a week for fourteen weeks. The CST groups will include up to eight people and each session will last for about an hour. They will be held in a suitable venue within your area and refreshments and transport will be arranged if needed. Those allocated to CST groups will be assessed in the two week period prior to the CST group starting and in the two week period following the end of the CST group.

Those people allocated to the group with no CST (one third of participants) will be asked to complete the assessment immediately on entering the project. They will complete a further assessment approximately 15 weeks later, and will then be offered the opportunity to attend the groups. Therefore everyone who takes part in the research will receive the treatment.

Expenses

Any travel expenses incurred by yourself or your carer will be reimbursed.

What do I have to do?

Taking part in the study does not involve any lifestyle restrictions or changes. You can carry on your everyday activities as normal while participating in the study. All we ask is that you keep your appointments with us during the time that you are taking part.

What are the possible disadvantages and risks of taking part?

CST involves participating in a group programme that aims to be stimulating and enjoyable. Sessions involve discussing themes such as food, childhood and current affairs and the level of risk in taking part is therefore minimal. If the participant feels uncomfortable or distressed while taking part in a group, facilitators will be able to give additional one to one support if this is needed.

What are the possible benefits of taking part?

If you decide to take part, and are involved in the CST Groups we hope that this may be of some help to you, and previous group members have indeed reported that they have enjoyed the experience greatly. For all participants, the information we get from this study may help us to treat people with memory problems better in the future.

Will my taking part in the study be kept confidential?

We will ask for your permission to send your GP a letter explaining that you have agreed to take part in the study. All information which is collected about you during the course of the study will be kept strictly confidential. All data is stored without any identifying details under secure conditions.

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

You will be free to withdraw from the study at any time, without giving a reason. Withdrawing from the study will not affect the standard of care you receive.

What if something goes wrong?

If you are harmed by taking part in this study, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action, but you may have to pay for your legal costs.

Regardless of this, if you wish to make a complaint about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints procedures should be available to you. If you are unhappy or dissatisfied about any

aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution.

What will happen to the results of the research?

The research is being carried out by two trainee psychologists as part of their Doctorate Training. Nicola Jacobi is at City University London and undertaking a Doctorate in Counselling Psychology. Jennifer Cove is at University College London (UCL) and undertaking a Doctorate in Clinical Psychology.

Both will produce a research dissertation which forms as part of their final course assessment. It will not be possible to identify individual results specifically, though a summary of the findings will be available if you are interested.

Results will also be published in relevant journals. No participants will be identified in any publication arising from the study without their written consent.

We will make arrangements for participants to be informed of the progress of the research and the results will be summarized in a document following the completion of the project. Please let us know if you would like to receive a copy.

Who has reviewed the study?

All NHS research is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and been given a favourable opinion by the London South East National Research Ethics Committee.

Who can I contact for further information?

For more information about this research, please contact:
Dr Helen Donovan
Consultant Clinical Psychologist

Phone: 01234
Mobile:
Email:

Or if you have any complaints about this study please contact:

R&D Administrator
R& D Department, Disability Resource Centre
Poynters House, Poynters Road,
Dunstable
Bedfordshire, LU5 4TP
Phone: 01582
Email:

Thank you for considering taking part in this research study!

Appendix G

Carer Participant Consent Form

Participant Identification Number for this trial _____

Pilot study examining the effectiveness of weekly Cognitive Stimulation Therapy (CST) and the additional impact for people with dementia and their carers of including carer training in CST

Name of Researcher:……..

Please Initial Boxes

1. I confirm that I have read and understand the information sheet for carers (Version 2 - 09.05.2012) for the above study and have had the opportunity to ask questions. ☐

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

3. I give permission for my relative's GP to be informed of our participation in the study. ☐

4. I have been consulted regarding the participation of my relative, as required by the Mental Capacity Act, and I believe they would wish to take part / continue to take part in the study. ☐

5. I understand that all information given by me or about me or my relative will be treated as confidential by the research team. ☐

6. I agree to take part in the above study with my relative. ☐

Name of Participant Date Signature

_____ _____ _____

Name of relative

_____

Name of Person taking consent Date Signature

(if different from the researcher)

_____ _____ _____

Researcher Date Signature

_____ _____ _____

Carer Demographics Form

Participant ID Number	
Gender	
Date of birth	
Ethnicity	
Highest level of education achieved	
Relationship to the person you are caring for	
Do you live with the person you are caring for?	
Number of contacts/week with person you care for (if not living with patient?	
Do you consider yourself to be a full time carer?	
Is anyone else involved in the care of the person you care for? (formally or informally?)	
Have you participated in any previous carer training programmes/psychological therapy?	

Appendix H

Participant Consent Form

Participant Identification Number for this trial _____

Pilot study examining the effectiveness of weekly Cognitive Stimulation Therapy (CST) and the additional impact for people with dementia and their carers of including carer training in CST

Name of Researcher:…….. **Please Initial Boxes**

1. I confirm that I have read and understand the participant information sheet (Version 2 - 09.05.2012) for the above study and have had the opportunity to ask questions. ☐

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

3. I give permission for my GP to be informed of my participation in the study. ☐

4. I understand that all information given by me or about me will be treated as confidential by the research team. ☐

5. I agree to take part in the above study. ☐

Name of Participant Date Signature

_____ _____ _____

Name of Person taking consent Date Signature

(if different from the researcher)

_____ _____ _____

Researcher Date Signature

_____ _____ _____

Name of Carer Date Signature

_____ _____ _____

Patient Demographics Form

Participant ID Number	
Gender	
Date of birth	
Ethnicity	
Age at dementia diagnosis	
Highest level of education achieved	
Current living situation	
Current medication	
Relationship to carer	
Does your carer live with you	
Number of contacts/week with carer (if not living with carer	
Who else is involved in your care (formally or informally)	
Participated in any previous psychological therapy for dementia?	
Who else lives with you?	

GP Study Participation Letter **Appendix I**

Clinical Psychology Service
Gilbert Hitchcock House
21 Kimbolton Road
MK40 2AW
Tel: 01234 310241
Fax: 01234 310240

<GP>

13th August 2012

Dear Dr <name>,

GENERAL PRACTITIONER INFORMATION SHEET

Title: Pilot study examining the effectiveness of weekly Cognitive Stimulation Therapy (CST) and the additional impact for people with dementia and their carers of including carer training in CST

Re: <Participant Details>

<participant name> has been invited and consented to take part in a research study. Please let us know if there is anything that is not clear, or if you would like more information.

Dr Gary Kupshik is the sponsor for this project from South Essex Partnership University NHS Foundation Trust (SEPT). The project is being run across a number of sites in Bedfordshire. Dr Helen Donovan is co-ordinating the trial in the Bedfordshire area.

Cognitive Stimulation Therapy (CST) groups are an enjoyable and beneficial therapy for people with memory problems. The idea is to keep the mind active through enjoyable activities, which are undertaken as a structured programme facilitated by experienced and trained staff. The activities include multi-sensory stimulation, for example: physical games, discussion of current affairs, sounds, food, word and number games. Traditionally CST groups are held as a 14 session programme twice a week for seven weeks.

This study aims to show whether weekly CST (14 sessions once weekly for 14 weeks) is effective and whether adding a carer training programme to CST has an impact on the well-being of people with dementia and their carers..

We are interested in including people with any type of dementia. We will interview them and their carer who has also agreed to take part in the study at the start of their involvement with the project and after 15 weeks.

The interviews will use outcome measure which will evaluate:

- Quality-of-life
- Cognition
- Quality of patient-carer relationship

Interviews will also collect information about:

- Personal details (age, relationship, educational level, etc.)

The study will **not** affect your patient's current or future treatment.

The results of this study are expected to be published in relevant journals and at conferences. All interviews are confidential and will not be disclosed to anyone else. The information collected in the study will be anonymous and patients will not be identified in any report/publication.

All proposals for research using human subjects are reviewed by the local Ethics Committee before they can proceed and the appropriate permission.

Thank you for reading this information sheet. Please do not hesitate to contact Dr Helen Donovan [redacted] if you need any further information.

Yours sincerely

Nicola Jacobi
Trainee Counselling Psychologist

Dr Helen Donovan
Consultant Clinical Psychologist

Participant Allocation Letter Example **Appendix J**

Providing Partnership Services in Bedfordshire, Essex and Luton

Clinical Psychology Service

[redacted]

Private & Confidential
<Client Name>
<Client Address>
<Client Address>
<Client Address>

Tel: [redacted]
Fax: [redacted]

<Date>

Dear ,

As we discussed in our telephone conversation, I am writing to confirm the arrangements for your ongoing involvement in the research. Following random allocation, you have been placed in the group receiving the **Cognitive Stimulation Therapy groups for 14 weeks *plus* the Carer Training.**

The groups will commence **in early November 2012**, and we will carry out assessments with you both at your convenience in the week or two before the groups start, and then again after the groups finish. The initial Carer training will take place some time in the first week of the groups.

We will therefore contact you again in a couple of months to arrange the assessments, and to finalise the arrangements for attending the groups (times, days, transport arrangements). However you are very welcome to ring and discuss any queries in the interim.

Once again we would like to thank you for agreeing to take part in this research project, and helping to improve the services we provide to our service users and their families.

If you have any queries please feel free call me on [redacted]].

Yours sincerely

Nicola Jacobi
Trainee Counselling Psychologist

Dr Helen Donovan
Consultant Clinical Psychologist

Extracts of the Carer Training Programme presentation **Appendix K**

Cognitive Stimulation Therapy (CST)

Carer Training Workshop

Nicola Jacobi
Trainee Counselling Psychologist
Tel: [redacted]

Objectives of the training

1. To provide a rationale for introducing Carer Training
2. To give a brief overview of CST design and evaluation
3. To introduce the key underlying principles of CST
4. To show you the content of the 14 CST sessions
5. To think with you about how you might support the CST program at home
6. To review your CST diary for use over the course of the CST program delivery
7. Any questions/issues you would like addressed?

Why introduce a carer training package?

- For you to hear about what is happening in the CST Group
- So you understand how CST works – so you can apply its principles at home…
  - Though we are NOT training you to deliver CST
- For you to have an opportunity to think about how this fits with your experiences at home and the everyday situations/conversations you come across,
- Not a 'carer support' group, but also opportunity to meet people who may have similar experiences, share ideas about the above with each other

Background Information

How is dementia care understood?

- Dementia is an interrelationship between
  - changes in the brain structure
  - personal and social factors unique to the individual
- For the individual this means
  - The disturbance of cognitive functions including memory, orientation, language, learning, judgement
  - Changes in personality, behaviour, walking/stability, irritability, decision making and motivation.
- Treatment plans increasingly take a wider view of other contributing factors outside of the brain
  - Models of care emphasising the importance of 'personhood' and person-centred care
  - Concentrates on the individual rather than the diagnosis
  - It provides opportunity for a more PERSONAL and OPTIMISTIC view of caregiving

How is dementia care understood?

A broader model of dementia encompassing many areas underpins Cognitive Stimulation Therapy, taking into account factors about the individual, and the context around them.

- Neurological Factors
- Personality
- Mood
- Physical Health
- Life Events
- Social Psychology
- Environment
- Mental Stimulation
- Sensory Stimulation

How was CST Developed?

How was CST developed?

- CST was developed through:
  - Systematic reviews of literature of dementia care
- Tested thoroughly
  - Through undertaking large scale research programs
  - asking people directly about their experiences of CST
- CST Research Outcomes demonstrated:
  - Improved Cognition
  - Improved Quality of Life
- Further Research also identified:
  - CST can be as effective in comparison with cholinesterase inhibitors (medication)
  - CST more cost-effective than usual activities, costs generally small

In addition CST Content was designed …..

……embracing the most effective therapies for dementia

- Reality Orientation
  - The presentation and repetition of time, place and person related information often using reality orientation boards to aid memory.
- Reminiscence Therapy
  - Discussion about the past, with groups or individuals often using prompts
- Cognitive Rehabilitation
  - Collaboratively assist a person to achieve individualised goals according to their strengths by use of strategies and adaptations
- Validation Therapy
  - Focus on the emotional meaning of what people say or do, rather than the factual content
- Multisensory Stimulation
  - Stimulating the senses through sound, taste, touch, smell and visual images.

What was the outcome of the research?

NICE (National Institute of Clinical Excellence) guidance on the management of dementia (2006)

"People with mild / moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care workers with training and supervision. This should be delivered irrespective of any anti-dementia drug prescribed for the cognitive symptoms of dementia".

www.nice.org.uk

What does a CST group look like?

What does the programme look like?

- 14 sessions, approximately 1 hour
- Ideally 5-8 people in groups, run by two facilitators.
- A standard structure with group identity (name and song)
- Different theme each week, involving different activities
- Encouraging contributions the individual is comfortable with
- A focus on fun and engagement
- Group members should ideally be at similar stages of dementia.
- Attention is paid to age and gender mix.

What does a session look like?

- Welcome – including tea, coffee and biscuits
- Warm up exercise linked to week's theme
- Group Song
- Current Affairs based on article from days news
- Main Activity – based on the week's theme
- Group Song
- Closure, reminder of next week, individual goodbyes

What does CST look like?

- lets watch some clips from the DVD
  - today we will explore how this dynamic environment is achieved:

Feedback from previous groups

From those attending the group:

- *'Its great to come somewhere and not have to worry'*
- "I didn't know what to expect, but it was very light-hearted"
- *"It's been very enjoyable"*
- "It's nice to come somewhere on my own and feel independent"

And from their family members;

- *'She doesn't call me as much, she appears to be making her own decisions again.'*
- 'After the group she is much more communicative with those around her.'
- *'Who would have thought one hour a week would make that much difference?'*

The important stuff! The KEY PRINCIPLES

The key principles which underpin CST delivery

1	Mental stimulation
2	New ideas, thought and associations
3	Using orientation, but sensitively and implicitly
4	Opinions, rather than facts
5	Using reminiscence, and as an aid to the here-and-now
6	Providing triggers to aid recall
7	Continuity and consistency between sessions
8	Implicit (rather than explicit) learning
9	Stimulating language
10	Stimulating executive functioning
11	Person-centred
12	Respect
13	Involvement
14	Inclusion
15	Choice
16	Fun
17	Maximising potential
18	Building / strengthening relationships

Feedback on the KEY PRINCIPLES Thoughts and ideas?

What is the content of the sessions?

Timetable of CST Sessions

1	Introductions and Physical Games
2	Sounds
3	Childhood
4	Food
5	Current Affairs
6	Faces and Scenes
7	Associated Words
8	Being Creative
9	Categorising Objects
10	Orientation
11	Using Money
12	Number Games
13	Word Games
14	Team Quiz and Endings

What would work for you?

Exercise: working together in pairs:

- Review two or three sessions/themes together
- For each session we consider activities you can do at home to support the group session
- Use the workbook to give you ideas and come up with your own
- Record activities which you think would work for you and your relative/friend
- Share back with the group

What do we need from you?

We need to know what you do?

Keep a weekly diary

- Tell us what activities you use
- When you use them
- Did they work
- What would you do differently
- What are you thoughts about the program
- Have you noticed any changes in your family member?

See example on page 7 of the workbook

THANK YOU

Carer Training Programme Workshop Plan **Appendix L**

Cognitive Stimulation Therapy - Carer Training Programme

Objective

This is a training programme for people who care for someone living with dementia who is currently attending a Cognitive Stimulation Therapy group.
The aim of the training is to:

- Inform the carer of what happens in a group session
- Provide them with some background to the development of the programme
- Identify the key principles which underpin the CST techniques
- Introduce them to how information is shared in the group
- Equip the carer's with key communication skills to improve the quality of their interaction with their friend or relative
- Give them ideas of activities which can be undertaken at home

These aims are met through presentation and experiential activity. We are not asking people to 'role play' but to engage in the activities as themselves.
This starts with the introduction being undertaken as it would in a CST group in the first session.

Room Preparation

The room should be set up as for a CST group.

- At the front place a whiteboard with the key orientation information.
- Teas and coffee should be available
- Projector should be set up to run but the slides should not be visible

Start with Administration

- Exits
- Toilets
- Fire Alarm drill
- Ask people to turn off mobiles etc.
- *Confidentiality – Is confidential – Will be documented as above, discussed within team. We cannot discuss what your relative/friend is doing/saying in CST Group. Boundaries of confidentiality, if concerns about safety – duty to tell someone…*
- Confirm focus of the day + protocol for managing other issues – i.e. facilitator will make a note and speak with individual outside of the workshop

Introduction

Introduce facilitator(s)

- Welcome to the Carer Training Group
- Go over the detail on the orientation board briefly
- Undertake the 'warm up' exercise – invite people to say their name, their connection to the group and a memorable thing about themselves that they are happy to share.
- As people introduce themselves give them a name badge, write their name on the board and their 'memorable thing'.
- Summarise the activity making appropriate links – all like sport/family is key etc.

At this point – stop the discussion and explain that they have just experienced what it is like to be in a CST Group! **Ask them how it felt.**

As people discuss the experience move the orientation board to the side and set up the projector for the presentation.

Presentation Outline

Topic	*Slide No.*	*Key message*	*Facilitator Activity*	*Approx. Time*	*Start Time*
Opening experiential exercise	*N/A*		*Facilitate CST opening activity*	*10 mins*	*10.00*
Feedback + expectations	*2*		*Write suggestions on flip chart*	*5 mins*	*10.10*
Overview of training	*3 - 4*	*Orientation of group to purpose of training*		*5 mins*	*10.15*
How is dementia understood?	*5 - 12*	*Background to dementia and how CST is positioned within that*		*5 mins*	*10.20*
EXERCISE Which of these do you recognise in your situation?	*13–14*	*Encouraging participants to recognise relevance to themselves*	*Write answers on flip chart*	*5 min discussion;*	*10.25*
How was CST developed	*15–18*	*Background information*		*5 mins*	*10.30*
The KEY PRINCIPLES	*19–39*	*Carer's understand that this is a different way of interacting*	*Interactive discussion of 18 key principles. Encouraging personal application and perceived difficulties to be discussed.*	*60 mins*	*10.35*
Break				*10 mins*	*11.35*
What does CST look like?	*40-43*	*Overview of CST Group structure*		*5 mins*	*11.45*
What is the content of the sessions	*44-61*	*Review of themes and activity in each 'theme'*	*Encourage discussion and input in workbook as to activities which could be done at home*	*45 mins (14 sessions approx. 3 min per session)*	*11.50*
What does this look like in practice	*62*	*Bringing together content and key delivery principles*	*Show some clips from DVD Encourage discussion including **'home application'***	*10 mins*	*12.35*
What we need from you	*63-64*	*Research requirements*	*Need them to do activity 2 – 3 times a week Completion of workbook and diary*	*10 mins*	*12.45*
Closing exercise	*65*		*See below*	*5 mins*	*12.55*

Concluding session

Further experiential exercise

- *one round of an activity, use Faces activity – similarities/differences/likes/dislikes*
- *Sing a song! – 'You are my sunshine'*

Feedback

Questions

Summarise and thank you

CST Session Themes **Appendix M**

Session Number	Session Theme
1	Introductions and Physical Games
2	Sounds
3	Childhood
4	Food
5	Current Affairs
6	Faces and Scenes
7	Associated Words
8	Being Creative
9	Categorising Objects
10	Orientation
11	Using Money
12	Number Games
13	Word Games
14	Team Quiz and Endings

1. NRES Approval Letter

Health Research Authority

NRES Committee London - South East

Room 4W/10
4th Floor West
Charing Cross Hospital
Fulham Palace Road
London
W6 8RF

Telephone: [redacted]

23 May 2012

Dr Helen Donovan
Consultant Clinical Psychologist
South Essex Partnership NHS Trust
[redacted]

Dear Dr Donovan

Study title: **Pilot study examining the effectiveness of weekly Cognitive Stimulation Therapy (CST) and the additional impact for people with dementia and their carers of including carer training in CST**

REC reference:

Thank you for your letter of 09 May 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

NHS sites

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

Non-NHS sites

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

Conditions of the favourable opinion

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

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

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

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

Where a NHS organisation's role in the study is limited to identifying and referring potential

participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

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

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

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

Approved documents

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

Document	*Version*	*Date*
Advertisement		
Covering Letter	1	12 March 2012
GP/Consultant Information Sheets	1	07 March 2012
Interview Schedules/Topic Guides		09 May 2012
Investigator CV	1	03 March 2012

Letter from Sponsor		05 March 2012
Other: Summary CV for Nicola Jacobi		05 March 2012
Other: Don Rawson		07 March 2012
Other: Summary CV for Aimee Spector		07 March 2012
Other: Summary CV for Jenny Cove		07 March 2012
Other: Revised scale for caregiving self-efficacy		
Other: carers assessment of satisfaction index		
Other: patient demographics form		
Other: Carer demographics form		
Participant Consent Form	1	07 March 2012
Participant Consent Form: Carer	1	07 March 2012
Participant Consent Form: Carer	1	07 March 2012
Participant Information Sheet: Participants	2	09 May 2012
Participant Information Sheet: Carers	2	09 May 2012
Protocol	1	07 March 2012
Questionnaire: Mini mental state		18 October 2011
Questionnaire: Alzheimer's Disease Assessment Scale		
Questionnaire: Quality of life		
Questionnaire: Quality of the care-giver patient relationship		
Questionnaire: General health questionnaire-28		
REC application	1	16 March 2012
Referees or other scientific critique		18 October 2011
Response to Request for Further Information		09 May 2012

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

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

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

12/LO/0539 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

[redacted]

Email: [redacted]

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Cherie Morgan, South Essex NHS Partnership Trust (SEPT)*

2. Host Organisation Approval Letter

Providing Partnership Services in Bedfordshire, Essex and Luton

14th June 2012

Dr Helen Donovan
Consultant Clinical Psychologist
[redacted]

Research Governance for Bedfordshire and Luton
South Essex Partnership Trust
Disability Resource Centre
Poynters House
Poynters Road
Dunstable, LU5 4TP

Chair: Lorraine Cabel
Chief Executive: Dr Patrick Geoghegan OBE

Dear Dr Helen Donovan,

Re: Effectiveness of weekly CST and the impact of adding carer training (ref RGG-2012 14/06)

Thank you for submitting your research application to the Research Governance Group (RGG) for South Essex Partnership Trust. The RGG considered the above study on the 31st May 2012 and are happy to grant approval for SEPT to be involved with this research as a Patient Identification Centre. The group has asked that the name in section A4, on the R&D form is changed to Ruth Burrell, this will also need to be changed through the Ethics committee.

If you make any changes to your proposal please inform the group of these. If they are substantial changes you will need to resubmit your full proposal for review. We would be grateful for a summary of your findings when your study reaches its conclusion.

Additionally, brief details of your project (title, aim and project lead), may be posted on our internal website and on screens in SEPT buildings to inform and advertise current research to staff, carers and patients to support you with recruitment.

We wish you all the best with your research and look forward to hearing the outcomes of the study.

Best wishes,

Research Assistant to
Prof G A Kupshik
Joint Chair of Research Governance Approvals Group

Carer's Consent Forms for Focus Group **Appendix O**

Participant Consent Form
Audio Taped Focus Group

Participant Identification Number for this trial _____

Pilot study examining the effectiveness of weekly Cognitive Stimulation Therapy (CST) and the additional impact for people with dementia and their carers of including carer training in CST

Exploring the experience of carers who participated in the carer training programme

Name of Researcher:……..

Please Initial Box

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and to have my data returned to me if requested. ☐

I agree to take part in the above study. ☐

I agree to the use of anonymised quotes in publications ☐

Name of Participant	Signature	Date

I, as researcher, confirm that I will keep all information shared confidentially and ensure that it remains anonymous throughout the project. If you decide to withdraw, I will respect your decision and all information will be returned to you or destroyed whichever is your preference. ☐

☐

Name of Person taking consent (if different from the researcher)	Date	Signature

Researcher	Date	Signature

Focus Group Interview Questions — Appendix P

Pilot study examining the effectiveness of weekly Cognitive Stimulation Therapy (CST) and the additional impact for people with dementia and their carers of including carer training in CST

Focus Group exploring the experience of taking part in the CST Carer Training Programme developed as part of this research project

Interview schedule

Introduction and context setting

- Welcome, provide a brief overview:
    - the project
    - the context of the interview;
        - that it is about their experience of the carer training programme,
        - how has being involved in the carer training programme impacted on their own emotions, their caring role, relationship with their family member
        - I am interested in your different views, *I would like to hear why something works well for one person but not so well for others*
- Ask if they have any questions
- Review their signed consent form with them.
- Obtain written confirmation that they are happy for the interview to be taped.

Questions

Thank you for agreeing to take part in this focus group. Can I just remind you that I am audio-taping this conversation so that I can remember accurately what we talk about today. However, you will remain anonymous and you and your partner's name will not be attached to any record of this interview, or in any report I write afterwards.

Focus Group/Qualitative Interview Topics

5. **Experience of Training**
    - What was your overall experience of the training? – Open question to ascertain the participants initial reaction in their own words
    - What worked well?
    - What didn't work well?
        - *How was it to translate the ideas from the training into action at home*
6. **Relationship Impact**
    - How did your learning impact your interactions with your relative/friend?
    - How did your learning impact on your relationship?
        - *Did any relationship dynamics change for you?*
7. **Expectations Met**
    - Did the training deliver what you were expecting?
    - What would you want to change in the training?
    - What other thoughts do you have?
        - *Is there anything you wish you'd done differently/may continue to do?*
8. **Closure**
    - Would you recommend the training to others?

Qualitative Code Book Excerpt				**Appendix Q**
UTILISATION OF LEARNING OR REFLECTIONS FROM LEARNING				
SHORT CODE	Brief Definition	Full Definition	When to use	When not to use
ACCEPTANCE	Participant acknowledging the condition to themselves	Many participants know cognitively that their family member has the diagnosis of dementia but don't acknowledge to themselves. There is a change in their ability to cope if they accept the diagnosis	Use this code if the participant talks about a change in their own acceptance of the condition	Do not use if the participant speaks of their family member's acceptance of the condition E.g. '*She accepts it more now too*' SEE PWD Refl-Accept
COMMUNICATION	Impact from changes in communication skills in the person with dementia	A key difficulty is the reduced communication skills of the person with dementia. This can lead to reduced communication between the carer and person with dementia with discussion reduced to requests and direction only	Use this code if change in communication is mentioned, or if the principles from the training intervention are referenced	Do not use for activities introduced – see FUN, or if responsibilities shared - INVOLVEMENT
CONTROL	Participants experience more control and mastery	Carers often report that they feel they have no control over the condition or how to deal with it, a loss of mastery over the situation (Woods and Clare, 2008). The prognosis of a progressive illness leaves people feeling overwhelmed and not knowing what to do. Intervention desired outcome is participants have strategies they can adopt.	Use this code when participants talk about positive actions, made clear decisions, recognise choices they have undertaken since the intervention.	Do not use when they talk about a change in their ability to manage situations *e.g.: 'I wouldn't have been able to do that before'.* also SEE SELF-EFFICACY
EDUCATION	Carers understand the condition	A key need reported by carers from previous research is that an understanding of the condition is helpful in enabling them in their caregiving role – (Quinn et al. 2008)	Use this code if participants report an increased understanding in what dementia is and how it affects their family member behaviours.	Do not use this code if the participant refers to using the training to improve activity at home – see FUN
EMOTION -	Carers experience many unhelpful emotions	Being a carer is an emotive role. It requires a lot of commitment and often gets no thanks from the person being cared for. It also impacts on the life of the carer resulting in difficult emotions	Use this code when participants mention difficult feelings and emotions including FRUSTRATION	Do not use this code if the reference is to other family member emotions or feelings See FAMILY

Code Book Theme Count Summary **Appendix R (i)**

SHORT CODE	Area 01		Area 02		Area 03		TOTAL	
	No. of quotes	No. of contributors	No. of quotes	No. of contributors	No. of quotes	No. of contributors	No. of quotes	No. of contributors
PESSIMISM								
ISOLATION							**35**	**13**
ISOLATION	4	2	8	5	8	4	20	11
SERVICES	0	0	10	3	5	3	15	6
UNCERTAINTY from LACK OF UNDERSTANDING							**38**	**15**
DENIAL (02 sub)	0	0	1	1	6	4	7	5
HELPLESSNESS	0	0	4	3	4	3	8	6
SELF-DOUBT	1	1	5	3	3	3	9	7
UNCERTAINTY	3	2	2	2	1	1	6	5
OWN FRAGILITY	2	2	2	2	4	4	8	8
STIGMA							**21**	**12**
FEAR	0	0	3	2	1	1	4	3
STIGMA	4	3	4	3	6	4	14	10
MEDIA	0	0	2	2	1	1	3	3
CAREGIVER BURDEN							**11**	**6**
ABUSE	0	0	1	1	1	1	2	2
FRUSTRATION	1	1	3	1	2	2	7	4
ENMESHMENT	1	1	1	1	0	0	2	2
DEPRESSION / ANXIETY							**17**	**11**
EMOTION -ve	1	1	9	6	7	4	17	11
LOSS							**19**	**10**
LOSS	1	1	0	0	2	2	3	3
RESPONSIBILITY	1	1	7	5	8	3	16	9
MASTERY								
HOPE							**18**	**7**

HOPE	4	2	11	3	3	2	18	7
UNDERSTANDING - REATTRIBUTION								**18**
ACCEPTANCE	3	2	12	4	10	3	25	9
EDUCATION	4	3	29	7	24	7	57	17
PEER ADVICE	1	1	5	3	2	2	8	6
JOURNEY	5	3	5	2	8	5	18	10
UNIQUE	4	2	1	1	5	3	10	6
SELF-EFFICACY								**16**
SELF-EFFICACY	7	2	15	6	18	6	40	14
COMMUNICATION	3	1	13	4	8	5	25	10
ENGAGEMENT	1	1	7	3	0	0	8	4
CONTROL								**17**
CONTROL	2	2	8	4	14	6	24	12
PEER	11	3	7	7	15	7	33	17
INCREASED ACTIVITY							**36**	**11**
INVOLVEMENT	1	1	4	3	0	0	5	4
FUN/ACTION	3	1	10	4	7	3	20	8
POTENTIAL	0	0	8	4	3	1	11	5
WELFARE								
IMPROVED RELATIONSHIPS							**23**	**13**
HUMOUR	3	2	3	3	0	0	6	5
FAMILY	0	0	4	3	3	2	7	5
RELATIONSHIP	1	1	4	3	5	4	10	8
IMPROVED WELL-BEING							**22**	**11**
EMOTION +ve	1	1	9	5	6	3	16	9
IDENTITY	4	2	2	2	0	0	6	4
RESPITE							**9**	**6**
SELF-CARE	0	0	2	2	7	4	9	6

Excerpt of transcription from Area 03 (for illustration) **Appendix R (ii)**

Use of principles	COMMUNICATION	468	LISA: ..so that you, you know, that the recognition, the, the using things	the recognition
		469	from the past as a way of bringing them to, into the future, into the	use things from the past
		470	present, and stuff like that I think was really helpful.	help orientate to the present
		471	+ve feedback	was really helpful
Use of everyday activity in proactive way to engage family member	ACTION / FUN	472	RUTH: Yeah. And also when the news is on, you know, and there's some	when the news is on
	ENGAGEMENT	473	topic. Afterwards you then mention it again and, and that gets discussed. I	discuss the topic
		474	find that... we always like watching the news, but sometimes you don't	watch news
	COMMUNICATION	475	think of discussing it afterwards, you just take it in yourself and don't really,	don't think of discussing
		476	but now, uh, I find that I sort of... or we, or I, would start a dis-, you know,	but now I find I would start talking
	EDUCATION	477	talking about it.	
Change in understanding about how to interact		478		
	ENGAGEMENT	479	KAREN: I think you're right because there's, say, when we watched the telly	watch telly
		480	every week...	every week

Participant with dementia Characteristics **Appendix S**

	CST plus carer training	CST	Control	F/t/χ^2 value, ***p-value***
Age, **mean (sd)**	75.4 (5.56)	76.8 (6.62)	77.8 (7.47)	F=0.73, ***p=0.49***
Gender Male (%) Female (%)	 11 (52.4) 10 (47.6)	 15 (62.5) 9 (37.5)	 10 (43.5) 13 (56.5)	χ^2 =1.71, ***p=0.43***
Ethnicity White British (%) White Irish (%) White Other (%) Black Caribbean (%) Indian (%)	 17 (81.0) 0 (0) 2 (9.5) 2 (9.5) 0 (0)	 23 (95.8) 0 (0) 0 (0) 0 (0) 1 (4.2)	 19 (82.6) 2 (8.7) 0 (0) 2 (8.7) 0 (0)	χ^2 =12.78, ***p=0.12***
Living Situation Private Accommodation (%) Sheltered Housing (%) Supported Living (%)	 20 (95.2) 0 (0) 1 (4.8)	 20 (83.3) 1 (4.2) 3 (12.5)	 23 (100) 0 (0) 0 (0)	χ^2 =5.39, ***p=0.25***
Dementia Diagnosis Sub-Type Alzheimer's disease (early onset) (%) Alzheimer's disease (late onset) (%) Alzheimer's disease (atypical/mixed) (%) Vascular dementia (%) Sub-cortical Vascular dementia (%) Dementia in Parkinson's disease (%) Unspecified dementia (%)	 0 (0) 15 (71.4) 1 (4.8) 0 (0) 2 (9.5) 0 (0) 3 (14.3)	 0 (0) 11 (47.8) 2 (8.7) 3 (13.0) 1 (4.3) 4 (17.4) 2 (8.7)	 1 (4.3) 10 (43.5) 6 (26.1) 1 (4.3) 2 (8.7) 1 (4.3) 2 (8.7)	χ^2 =17.12, ***p=0.15***
Dementia Severity Mild (%) Moderate (%)	 15 (71.4) 6 (28.6)	 18 (75.0) 6 (25.0)	 17 (73.9) 6 (26.1)	χ^2 =0.08, ***p=0.96***
No. of medications, **mean (sd)**	5.19 (4.14)	3.88 (2.62)	5.70 (4.16)	F=1.53, ***p=0.22***
Dementia Medication Yes (%) No (%)	 10 (47.6) 11 (52.4)	 16 (66.7) 8 (33.3)	 13 (56.5) 10 (43.5)	χ^2 =1.67, ***p=0.43***
Attended previous dementia intervention Yes (%) No (%)	 1 (4.8) 20 (95.2)	 3 (12.5) 21 (87.5)	 3 (13.0) 20 (87.0)	χ^2 =1.01, ***p=0.60***
No. of CST sessions attended, **mean (sd)**	10.95 (3.64)	10.5 (4.53)	N/A	t=0.37, ***p=0.72***

Utilisation Structural Theme Flow Chart supporting quotes **Appendix T**

Supporting quotes of the intervention process demonstrating evidence for the interventions effectiveness as illustrated in the Utilisation Structural Theme Flow in Figure 4.

1. ANNE; 01:30:654 "You know, makes life a little bit more... light-hearted, if you want"

2. OLIVER; 03:02:28 "... I found more value from talking with other carers……. He told me about the problems he had encountered and how he'd dealt with them"

3. JULIA; 02:27:581 "Do you know, and this session's been really good because, before then, I hadn't got a clue."

HANNAH; 02:71:1539 "And I keep thinking about that, you know, I keep thinking 'his executive function.' You know, and it's really helped."

PENNY; 03:07:151 "Now I know that there is a problem."

4. FRED; 02:53:643 "But I'm able, you know, cope with that now, which I wouldn't have done, I think, without the training."

MARY; 03:03:47 "it opened up my eyes to say 'okay, what can I do to help **my** mum in this situation, that can make it easier for **me** and for **us** and for **her**."

5. BRIAN; 01:27:586 "that list of therapy items makes you realise you can, hopefully, help"

6. FRED; 02:53:1148 "... but I don't know how I'd be treating her now if I hadn't have had the training…….. Not so well I don't think. I'd still be frustrated"

HANNAH; 02:72;1549 "Yeah. 'Cause he can't communicate it necessarily but I'm sort of thinking what... I'm putting myself in his shoes."

7. ELLEN; 02:26:562 "it's shown me what I can do and given me more confidence with Dad"

8. BRIAN; 02:42:900 "some of those things I did…….. I reckon that's useful, let's give that a go.' Everything's worth trying, you know?"

9. ELLEN; 02:38:812 "there's an awful lot you can do and it, it's kind of not just thinking 'oh, that, they can't do that' but trying things and some don't work, but some do work. I mean, I would never thought him playing fantasy gaming..."

10. MARY; 03:12:258 "there are mechanisms in place that can help us, or can assist us"

11. LISA; 03:19:407 "we can use that information, we can use those strategies to help out"

LISA; 03:35:758 "you've got that mechanism in place and its working…….. so you feel…. more prepared and in control"

12. HANNAH; 02:74:1593 "and I laughed and I laughed. And it didn't feel wrong to do that."

MARY; 03:12:256 "that can help us, or can assist us that can help our family members"

13. FRED; 02:69:1485 “it naturally has to because you have changed your attitude towards her”

KAREN; 03:16:347 “Which I thinks helps her, and it doesn’t frustrate you quite so much”

RUTH; 03:22:476 “now I would start talking about it”

14. RUTH; 03:82:1776 “Yes, it has made me more tolerant”

15. KAREN; 03:16:342 “having conversations a different way round. Which I think helps her. And it doesn't frustrate you quite so much.

16. RUTH; 03:82:1783 “I phoned up and I got him into a day centre for three days. I wouldn't have done that.”

17. ELLEN; 02:38:798 “I got much closer to Dad and we talk more”

KAREN; 03;26;555 “They were having a right little conversation. And then I thought hmm……. quite normal-sounding.”

18. IVY; 02:18:366 “Yes. And it gives me a break”

19. ELLEN; 02:55:1179 “Will carry on implementing some of those things……. Cause they made things better”

20. NICK; 03:10:201 “So if you build up the confidence in yourself first”

21. RUTH; 03:84:1832 “and it was so easy, I thought 'ooh, I would do that again”

Appraisal Theme Detail with associated quotes **Appendix U**

Recommendation		01	02	03
WORKSHOP DESIGN				
1. Review content of the CST Workshop		X	X	X
CAROL; 01;02;43	*'we found it was too much to take in on one session'*			
CAROL; 01;09;189	*'Shorter. Not so technical…… And less acronyms.'*			
ANNE; 01:61:1312	*'don't know a think about it and I felt I was bamboozled by science. I know the time element is important but probably in layman's terms more'*			
DOUG; 02:04:68	*'There was nothing given to indicate the do's and don'ts'*			
FRED; 02:58:1241	*'you're going on a three-hour training course, you think ….. somebody gets on the stage in front say 'right this is an Alzheimer patient''*			
ELLEN; 02:104:2246	*'a lot of it was taken up with questions –if you got the general questions out of the way at the beginning there could be more focus on the actual training'*			
MARY; 03:56:1217	*'I felt it was too much for the time we had'*			
MARY: 03:56:1206	*'I couldn't tell you that I digested every single thing… you're not gonna digest everything'*			
	'I can see certain things which I do without even thinking….. that could be important if somehow you get it into us more…..I don't know how you would do that in the training'			
LISA; 03:60:1297	*'I think maybe we're trying to do too much, with two different things going on'* *'You're trying to explain to us the CST…….. And then you have a separate section, the support , the carer part'* *'the CST bit needs half a day and the support group bit needs half a day. I would split them up.'*			
STEVE; 03:57:1237	*'you couldn't absorb it'*			
LISA; 03:105:2291	*'when a professional body puts on a course……., their vocabulary and you think I don't do that… then when you realise what the words mean you say 'yeah, we do that'* *'The wording should become more layman terms.'*			
2. Review how training objectives communicated		X	X	
BRIAN; 01:20:422	*'I can see certain things which I do without even thinking….. that could be important if somehow you get it into us more…..I don't know how you would do that in the training'*			
FRED; 02:02:38	*'I was expecting to come in here and have sessions of people doing scenarios and 'this is what an Alzheimer patient would do, this is how you deal with it and that'*			
ELLEN; 02:103:2237	*'the only other thing was maybe to have a general question session programmed in'*			
3. Review of presentation style			X	X
FRED; 02:02:38	*'I was expecting to come here and have sessions of people doing scenarios'*			
FRED; 02:03:56	*'I was expecting a different form of training'*			
MARY; 03:49:1064	*'maybe some role play , maybe some interaction……'*			
4. Review duration of the workshops		X		X
CAROL; 01:61:1324	*'the time is of the essence…. It was going on and….. in the end when you start looking at your watch to see…. Then you're missing It'*			
ANNE; 01:62:1337	*'when you start fidgeting'*			
MARY; 03:49:1054	*'I know we are all busy but maybe it needs to be a day, that gives us time to digest'*			

MARY; 03:50:1077	*'this is our life, our family member's life so even though I know I am busy I would rather spend a day and get more out of it, get the emphasis of it than try to cram it into an afternoon'*			
RUTH; 03:54:1178	*'Do you not think two half-days would be better than one, because you, I think you get tired…….. you have to watch that'*			
MARY; 03:56:1215	*'The programme tailored to half-days – not trying to tailor a days programme into a half day. …….. '*			
5. Review timing of sessions		X		X
ANNE; 01:05:98	*'on about the third week, remember what's been done and what the reactions were'*			
BRIAN; 01:10:195	*'would've enabled you to absorb information better'*			
BRIAN; 01:11:217	'*Cause we come over here not knowing anybody who's taking part'*			
ANNE; 01:16:333	*'another meeting a couple of weeks down the line, when the ice has broken and we realise we are all in the same boat'*			
RUTH; 03:54:1178	*'Do you not think two half-days would be better than one'*			
6. Review training materials		X	X	X
BRIAN; 01:07:135	*[DVD]* 'but its not individual enough or you want to see, you t see your'			
CAROL; 01:07:138	*[DVD] '*No, it wasn't convincing."			
FRED: 02:05:87	*'I was very impressed with the documentation that we were given to take home. That has been helpful'*			
ELLEN; 02:55:1186	'*Having that book of ideas'*			
FRED; 02:57:1231	*'I think it might've helped if we'd have been shown the video to start with. We only had a snippet – stated so that's what the course is gonna…..'*			
FRED; 02:58:1240	*'the information we took home was very good'*			
STEVE; 03:05:95	*'we didn't really realise the importance of the information that was in this booklet at the time'*			
MARY; 03:94:2050	*[the book] it's a reference point – keep it as a reference'*			
CARER PARTICIPATION CONCERNS				
7. Consideration of different learning styles		X	X	X
ANNE; 01:13:275	*'if it's just you that doesn't understand it'*			
ANNE; 01:60:1307	*'Too concentrate, technical. We're going into the unknown'*			
ANNE; 01:64:1386	*'I think now, what I know by hindsight I'd like to do it again. Cause you would know more about what's involved, I feel I'm more aware of what's expected. I understand more about what's needed from me…… so I could've implemented it earlier'*			
FRED; 02:57:1237	*'there was no hands on stuff, it was all sitting and listening.'*			
MARY; 03:49:1068	*'there's different modes of how people learn and how people will take things in, so powerpoint presentation, reading, interaction.'*			
8. Explore how to ensure participants have a basic level of knowledge about dementia prior to training		X	X	X
FRED; 02:26:546	*'the documentation I read helped me understand A's condition quite a lot more'.*			
ELLEN; 02:103:2237	*'the only other thing was maybe to have a general question session programmed in at the beginning so that when you start the training, people have asked a lot of the questions'*			
ELLEN; 02:105:2286	*'It took a while for me to focus on the training for the cognitive rather than all the other questions I had'*			
MARY; 03:49:1073	*'giving people the opportunity to answer questions'*			

9. Explanation of outcomes from CST – need to set expectations clearly		X	X	X
CAROL; 01:33:705	*'I didn't get enough information from him to sort of decide whether he'd really sort of taken anything from it or not.'*			
ANNE; 01:55:1198	*'probably half way through the session, the people who had helped run the session could have a word with us…. I would have more of an understanding about what went on and how he coped with what went on'*			
CAROL' 01:56;1206	*Of course you don't get the feedback from them….. you're sort of dismissed and you don't get feedback.'*			
ELLEN; 02:58:1253	*'Dad never came home and gave loads of feedback…… it's quite hard to know what he got out of the sessions, he doesn't come back bubbly.'*			
LISA; 03:60:1308	*'I needed to have a bit more about what these sessions were actually going to give her or not give her or what I should see or not see'*			
KAREN; 03:98:2141	*'I was hoping by doing these repetitive things with the relatives…… it would stick a bit but it didn't with us'* *'they can't remember any more because the parts are ill – I don't know what I was expecting'*			
STEVE; 03:99:2167	*'I think it improves their well-being'*			
RUTH; 03:101:2209	*'I think they participated in the group which must be good'*			
10. To consider how carers can witness their family member in at least one CST session		X	X	X
CAROL; 01:06:113	*'would've been helpful – a carer to go into one of the sessions that they were doing?'*			
CAROL; 01:33:719	*'that's why I was saying I would've liked to sat in on a session, not all of us together…… to see how it really worked. I know you had this CD, but it wasn't quite the same'*			
CAROL; 01:37:787	*'could it be tried……. If there is a difference when their partner is there you could say this isn't working because the person reacts totally differently when their partner's there'.*			
BRIAN; 01:38:826	*'I think you could actually try it with a tape session perhaps, then play tapes when we get together to discuss things….. to see whether…. Because you can pick up your own partner's voice……. To see who's taking part…… You'd get the vibe of what's going on and see what's been said and how the discussion is going.*			
ANNE; 01:40:870	*'We'd know how to word things more'*			
FRED; 02:60:1293	"*I think it would have been helpful if we, we as carers, could've been invited to attend one of the sessions*"			
11. Consideration of group dynamics to encourage participation		X		
BRIAN; 01:12:245	*'I didn't feel part of the group really, on that session' [1st session]*			
CAROL; 01:12:255	*'There was so much to take in, you sort of really didn't get to know each other anyway'.*			
FUTURE CONSIDERATIONS				
12. Person centred approach to caring; consider key principles as specific carer training programme– separate from CST		X		X
BRIAN; 01:04:84	'*an introduction could've been done initially…… then go into the depth of the programme [sic CST] at some later date'*			
BRIAN; 01:27:586	*'that list of therapy items makes you realise you can hopefully help'.*			
ANNE; 01:31:672	*'because we've got to train to be carers'*			
BRIAN; 01:69:1504	*'I think – to try and get the understanding of these key principles at the earliest*			

	possible stage and see whether those can be implemented in your day-to-day activities with your relative'			
FRED; 02:70;1497	*'involvement. I find myself because of the training involving her more in everything that I do'*			
MARY; 03:30:646	*'because of these sessions you know and listening you now realise why they're doing that. So because you realise why they're doing that, that's why we roll with it.'*			
LISA; 03:30:653	*'I think, also, going from the training, I think it needs to be done sooner. The minute the person is diagnosed…… I mean, this [sic the training], if it had come sooner, it would've been a lot more helpful'*			
LISA; 03:35:746	*'And then, gradually, while they are going down the journey…….. you've already got that mechanism in place and its working.'*			
NICK; 03:35:752	'*You've got information to help them and yourself.'*			
LISA; 03:35:758	'*As you said before, more prepared and in control'*			
LISA; 03:45:965	'*knowing earlier these steps and how it all works and being able to put in place these mechanisms would've helped us'*			
MARY; 03:111:2422	*'we've had this now and my mum's had whatever… but what next? I can see that it has helped but now what else can we do?*			
13. Acknowledge peer support in workshop design		X	X	X
BRIAN; 01:17:351	*'To be able to talk to people who've got the same problems is so important'*			
ANNE; 01:25:537	*'I know you said it's not a carers' group. But at the same time…. In a way it is'*			
ANNE; 01:31:658	*'Yeah, so I know you said it wasn't a carer's training [sic support], but I think it has been…. It certainly helped me.'*			
14. Ongoing organised activity encourages engagement			X	
FRED: 02:56:1215	*[reflecting on continuing to meet] 'its good intention but you never do it. But if it's organised for you like a club'*			

Carer therapeutic modalities proposal **Appendix V**

In recognition of the journey that a carer embarks upon it would be interesting to explore if different stages of caring are more usefully approached with a range of techniques rather than simply by offering Cognitive Behavioural Therapy (CBT) as recommended in the current NICE guidelines (NICE, 2010).

For illustrative purposes as concluded in Jacobi (2015):

Stage	Proposed Modality (Illustrative)
Prior to recipient diagnosis / condition (if expected)	Person Centred therapy
Initial reaction to change in role	Grief Therapy Trauma based therapy CBT
Acknowledgement of becoming a carer - Adjustment - Change in role/family dynamics	 CBT Systemic Therapy
Ongoing psychological well-being	CBT strategies / problem solving / sleep management Mindfulness techniques
The end of the caring role	CBT – balanced thinking
Palliative care	Mindfulness Bereavement and Grief Therapy

Metaphors with supporting quotes **Appendix W**

Ryan and Bernard (2003) and Saldana (2009) both recognise the use of metaphors in how people represent their ideas. Ryan and Bernard (2003) suggest that if Metaphors and Analogies are identified then a useful exercise is to deduce the themes underlying them. Throughout each of the focus groups the metaphors noticed were collated and explored in light of the coding and themes generated within the primary data analysis. From this alternative analysis of the data, the codes and themes can be applied providing further support to the validity of the themes identified.

Participant	Metaphor/Analogy	Theme
ANNE; 01:03:62	'Breaks the ice'	Stigma; trust to share; Peer support
ANNE; 01:24:519	'We're all in the same boat'	Peer support
BRIAN; 01:27:573	'We are joined at the hip'	Journey Boss (2011) Enmeshment
BRIAN; 01:27:582	'We are one'	Journey Boss (2011) Enmeshment
ANNE; 01:29:618	'Gives us [not a bond]…. a link'	Peer support
ANNE; 01:32:690	'We're in at the deep end'	Ref to caring/isolation
BRIAN; 01:43:936	'more trouble than its worth'	Self Doubt/Frustration
ANNE; 01:44:944	'play each day by ear'	Uncertainty/Flexibility
BRIAN; 01:47:1015	'brassed off'	Self-sacrifice to support - EDUCATION
BRIAN; 01:48:1028	'let her put her two penneth in'	Self-sacrifice to support - EDUCATION
CAROL; 01:51:1093	'let it ride over'	self-sacrifice to support - EDUCATION
CAROL; 01:70:1509	'Keep smiling – and taking the tablets'	Use of humour
BRIAN; 01:70:1526	'That's a learning curve'	Journey of change [Uncertainty]
DOUG; 02:04;72	'You're left in a vacuum'	ISOLATION
ELLEN; 02:10:195	'it's been the big learning curve for me'	Journey of change; acceptance and how to be a carer
FRED; 02;30;629	'they drop you like hot bricks'	Abandoned by services [the government]; ISOLATION
FRED; 02;30;630	"without this training; we'd be struggling in the dark	HOPE
FRED; 02;40;862	"as the old song says – do what comes naturally	ENGAGEMENT
HANNAH; 02;47;1010	meeting other people in the same boat	PEER SUPPORT
GEORGE; 02:53:1132	**"the same way as it does in the trenches; you give your mate the best help you can on your own….. when you see your mate dying, you get down and give him a hand'**	RELATIONSHIP COMMITMENT JOURNEY
HANNAH; 02:71:1550	'I'm putting myself in his shoes'	EDUCATION/CONTROL
MARY; 03:03:47	'opened my eyes'	Better understanding - EDUCATION
Participant	Metaphor/Analogy	Theme

LISA; 03:04:69	'it'll make things on an even keel'	'Strategies for support' – CONTROL
NICK; 03:09:190	"before the training, tip-toeing around the problem'	Denial
NICK; 03:10:208	'deal with it head on'	Understand it yourself – SELF-EFFICACY
NICK; 03:10:211	'the issues get kind of swept under the carpet'.	DENIAL
NICK; 03:11:225	'you kind of build up your barrier'	Coping strategy - CONTROL
NICK; 03:11:235	'stick to that as your tool'	Using strategies for support - CONTROL
NICK; 03:12:261	'if you close your mind to something you won't see it'	ACCEPTANCE
NICK; 03:12:261	'first…… open your eyes, broaden your mind'	ACCEPTANCE
NICK; 03:29:618	"roll with the conversation"	ACCEPTANCE
OLIVER; 03:37:794	'I pussy footed around'	RESPONSIBILITY/DENIAL
NICK; 03:53:1159	'so that is opening your horizons'	EDUCATION/ACCEPTANCE
RUTH; 03:69:1496	'it's a twenty four hour thing'	RESPONSIBILITY/ISOLATION
MARY; 03:76:1666	'It's not this alien thing anymore that you have to keep quiet about'	STIGMA
LISA; 03:81:1755	'go round the houses a bit'	COMMUNICATION – don't use direct questions
STEVE; 03:102:2224	'bottled it all up'	ISOLATION/HELPLESSNESS/-ve EMOTION
NICK; 03:103:2235	'A problem shared, is a problem halved'	PEER SUPPORT
MARY; 03:112:2445	'different strokes for different folks'	UNIQUENESS

Reflections on person with dementia (PwD) Group Experiences **Appendix X**

While this part of the analysis is not specifically included in the evaluation of the carer training programme intervention it was felt that it was important to mention the participant's reflections on their family member's experience of the CST groups. Primarily, because it had an impact on the carers' sense of well-being and secondly as this is an associated research project with another researcher exploring the impact of the weekly CST on the PwD attending the group. The family members with dementia were assessed alongside the carer participants and completed four questionnaires, two to assess their cognitive functioning, the MMSE and ADAS-Cog, a third to assess their quality of life, QOL-AD and the same carer-patient relationship questionnaire as the carers completed.

Cove et al. (2014) undertook a quantitative analysis on the PwD measures and found no significant outcomes concluding weekly CST was not an effective format. Conversely the narrative captured from the focus groups suggests positive outcomes through the PwD's attendance at the groups. It is not often that carers' reflections on their family member's participation in CST are heard and so this appendix is included to ensure this rarely heard view is captured.

"*They were nicer people*" GEORGE; 02:49:1057
"*They really enjoyed I t… [He] was really enthusiastic about that*" JULIA; 02:49:1059
"[She] is really disappointed that it has finished" FRED; 02:49:1062

When reminded the group has finished;

"*Oh dear,……. N's a laugh……. and I used to like to go there*" FRED; 02:50:1072

The importance of this final reflection from a family member with dementia is more poignant when it is recalled that the individual's short term memory is severely compromised and yet the group facilitator and emotional legacy are recalled.

The importance to the CST attendees was also demonstrated by the naming of the group which was adopted by all their family members – 'The Wednesday Club', 'The Club', "going to school tomorrow"

As a final point, the acceptance of the group members of their condition and loss of fear of the stigma of others knowing is shared demonstrating the importance of peer support and normalisation for those with dementia too.

"*he is telling everybody now he is, he's got dementia*" PENNY; 03:15:308

PART 2

Is There A Common Journey for provision of Psychological Intervention when Caring for the Carer?

A Critical Literature Review

Introduction

The importance of informal carers [now referred to as 'carers'] who support a loved one [referred to as the 'recipient'] has been comprehensively researched and documented since the 1950s. A move away from institutionalisation has led to many people with physical and mental health problems living in the community and relying on others to support them in their home environment (Jungbauer, Wittmund, Dietrich, & Angermeyer, 2004). Research has demonstrated that carers have more psychological difficulties than non-carers including depression, stress, lower reported quality of life and poor self-efficacy (Pinquart & Sorensen, 2003)

In the last national census in 2011, 5.8 million carers were registered (Office for National Statistics [ONS], 2013), many reporting that they had health problems themselves. Their contribution has enormous financial implications for the health service (Jarvis, Worth, & Porter, 2006). If these individuals were to stop or become too unwell to continue it would put an untenable economic strain on the National Health Service (Department of Health [DoH], 1999, 2008a). Huckle (1994) makes the point that, with an aging population and the corresponding increase in people living longer with chronic illness (Vitaliano, Zhang, & Scanlan, 2003; Kim et al., 2008), the financial impact carers have on the economy is expected to become even more critical (DoH, 2008a). The Government have recognised this contribution and instigated a National Carers' Strategy (DoH, 1999, 2008a) and have already incorporated some of the recommendations into legislation, such as the right of all carers to a Carers Assessment (DoH, 2000) and carer respite provisions (DoH, 2008a).

While the needs of carers have been defined, the implementation of recommendations into practice in the delivery of care at the point of service provision, and in the delivery of interventions which carers state they require, has been less successful (DoH, 2008c). Seddon et al. (2007) found this was particularly pertinent for emotional support. There also appears to be a disparity in how carers' emotional needs are addressed for different recipient presentations, as outlined in their respective National Institute for Health and Clinical Excellence (NICE, 2010) guidelines.

This paper reviews a number of studies, which explore the experience of carers who provide care to recipients across different presentations, with the aim of identifying the common psychological elements of the caring experience. Most research in this area has addressed the needs of carers in a common context for example, dementia, (Quinn, Clare, Pearce, & van

Dijkhuizen, 2008), strokes (Greenwood, Mackenzie, Cloud, & Wilson, 2009), neurological difficulties (McKeown, Armstrong, & Baxter, 2003), mental health difficulties (Winn et al., 2007), or ageing (Jarvis et al., 2006).

This paper proposes that, if common psychological impacts are identified as affecting carers across different recipient presentations, then the psychological services developed and offered to carers could be rationalised. The aim of this review is to investigate if it is possible to establish common psychological outcomes that could inform the development of psychological protocols to support carers specifically in adjusting to (Aminzadeh et al., 2007), living with (Brereton, Carroll, & Barnston, 2007) and ending (Grande et al., 2009) their carer role irrespective of the recipient's presentation.

This objective is believed to be consistent with the aims of counselling psychology as the breadth of training enables Counselling Psychologists to consider the benefits of different types of therapeutic models, in relation to carers' changing needs. Then by working collaboratively with the carer, through therapy they can provide them with the psychological skills, to be able deal more effectively with the situation they find themselves in, and enhance their own mental health, self-efficacy and effectiveness.

It is proposed that building a knowledge base of therapeutic expertise about carers' psychological requirements, and delivering a specific programme of interventions using evidence-based therapeutic tools, will equip carers with the psychological support they seek (Huckle, 1994; DoH, 1998). The strategies imparted through therapy will provide a strong psychological foundation to build resilience and sense of competency along with understanding, thus making them better prepared for the initial adjustment (Aminzadeh et al., 2007) and challenges facing them at each stage of their carer journey (Li, Seltzer, & Greenberg, 1999; Skaff, Pearlin, & Mullan, 1996). Hence improved mental health of the carer will be achieved through the delivery of psychological strategies and skills to support their personal adjustment to loss (Sanders et al., 2008), sense of efficacy and control (Monin & Schulz, 2009), improved problem solving techniques (Lutz-Stehl et al., 2009) and understanding change in family dynamics (Marriott et al., 2000). This in turn, may ultimately mean less cost for health services and result in better and more consistent care for the recipient (Elliott et al., 2001; Marriott et al., 2000; McKeown et al., 2003). Hence, the 'carer' is at the centre of this review.

Who is a carer and what do they do?

The term ‘carer’ was chosen for this review because it is a term consistent with Government documentation described above and is more commonly used in the UK (Greenwood et al., 2009).

So who is a carer? The Oxford Dictionary definition describes a carer as ‘a person who cares for a sick or elderly person, esp. a relative at home’ (Pearsall & Trumble, 1996). In the 2001 Census, a new question was asked ‘whether people provided unpaid care for a family member or friend and for how many hours’ (Office for National Statistics [ONS], 2013), which would appear to be consistent with the dictionary definition. Of note, carers’ assessments, that are a statutory right for ‘carers’ (DoH, 2000), are only available to those who provide a ‘regular’ and ‘substantial’ amount of care. However, ‘regular’ and ‘substantial’ are not defined and left to each local authority to decide (Seddon et al., 2007). Consequently the number of people who care for others may be underestimated by formal statistical measures (ONS, 2013).

Indeed there is no right way of caring, with individuals developing coping strategies often through trial and error (Huckle, 1994). The subjectivity around the definition and interpretation of care, as described above, is unhelpful and could lead to varying levels of support requirements identified and consequently provided. In Vitaliano et al. (2003), informal caring is described as a way to protect people in poor health by providing unpaid assistance to enable the recipient having difficulties either physically, cognitively or emotionally to sustain themselves. Thus a carer could become involved in any aspect of the recipient’s world, including assisting with financial management, activities of daily living, emotional support, personal care, and decision-making. In fact the list is infinite and quantifying it in terms of ‘regular’ and ‘substantial’ is an impossible task.

There is also some debate about the definition of a carer where there are multiple carers who provide care for one recipient. Harvey and Burns (2003) suggest that psychological stress is experienced similarly by all associated carers whether they are the primary carer, non-primary carer or caring alone. In addition, when the recipient is present in the family environment, there are psychological implications for all family members and therapeutic interventions should be mindful of this dynamic too (Huckle, 1994; Marsh & Johnson, 1997; Wade et al., 2001).

Consequently, there is some ambiguity about who is defined as a carer but, for ease of reference in this paper, the Oxford Dictionary definition shall be adopted (Pearsall & Trumble, 1996).

To conclude the description of terms, a brief explanation for the use of the word 'recipient' to describe the person who is being cared for shall be offered. In practice and throughout the different papers reviewed, they are referred to by many labels such as the 'patient', 'cared for', 'loved one', 'client', or 'service user' etc. It was felt by the author that all these terms put them at the centre of the care management consideration. This is obviously appropriate when considering their needs or the support the carer requires which is dependent on the recipient's presentation, such as, education, training, signposting, and respite etc. (Brereton et al., 2007). However, this paper's aim is to address the impact of the carers' role on their own psychological well-being. Thus, the term 'recipient' lends itself to privileging the carer as the primary consideration.

Rationale for the Review

The Background

The Government has made a commitment to improving the rights and recognition of carers' contributions and needs, and has published a Carers National Strategy (DoH, 1999, 2008a). The process began in 1999 with the Government Paper 'Caring for the Carer' (DoH, 1999). The ideas in this paper have been developed further with a number of initiatives introduced in statute such as the right to a carer's assessment (DoH, 2000). The carer's assessment document includes a statement referring to the assessment of the emotional needs of carers. In 2008, the task force for health and social care update (DoH, 2008b) explored how to address the carer's emotional needs, by investigating the counselling needs of carers, which it concluded were '*expensive and only relevant to a few'*. This is in contrast to the National Carers' Strategy update (DoH, 2008a), which stated that psychological difficulties are experienced by over 50% of carers who deliver more than 20 hours of care a week. The psychological difficulties include depression, disturbed sleep, and stress, in addition to other symptoms experienced which may be indicative of psychological difficulties (WHO, 1992), though not recognised by the carer, including, feeling tired, a loss of appetite and being short tempered.

In addition, while the National Carers' Strategy (DoH, 1999, 2008a) acknowledges the requirement of a specific service addressing the emotional needs of carers, the subsequent task force (DoH, 2008b) recommends this is through third sector organisations. Alternatively the government website for carers (Directgov, 2010) directs individuals who feel they may need additional emotional support to the website for psychotherapists to locate and fund their own therapy. This is in direct contrast to the outcomes collected from carer delegates at the National Carers' Strategy Regional Events (DoH, 2008c) where the key messages included the need for a robust referral pathway to services including talking therapies. It also raised concern around the sustainability of reliance on third sector organisations. Indeed, Robinson et al. (2005, p. 561) reported in their paper, exploring the development of an intervention for carers of stroke recipients, that results in reducing carer stress have been disappointing suggesting that the interventions delivered were '*not grounded in theory nor delivered by an appropriately trained individual'*. Finally peer support is often cited as an appropriate intervention for emotional support and often delivered by third sector organisations. However, Pillemer and Suitor (2002) found that, on its own, it is not sufficient to reduce carer stress.

The carer's perspective on psychological support

Another consideration to these apparent obstacles in obtaining psychological support is the impact on the carer in having to ask for such support. The Attitudes to Mental Illness 2010 Report asked for the first time 'Do you think people with Mental Illness suffer stigma and discrimination? The results revealed that 87% of respondents answered 'YES' (DoH, 2010). A number of other studies also found that carers report social exclusion and stigma as a result of their carer role (DoH, 2008b; Whitney et al., 2007; Winn et al., 2007). Consequently, it would appear that another question for future consideration is: How can carers access psychological support without adding further distress to their situation?

Much is documented in the government strategy papers (DoH, 1999, 2008a) about the diversity and range of carers, with research into the psychological well-being and needs of carers being explored in that context. Further research demonstrates the impact on psychological well-being, from many other factors, including culture (Cox, 1995; Yoo, Jang, & Choi, 2010), gender (Moller et al., 2009), age (Jackson et al., 2009; Jarvis et al., 2006) and spirituality (Greenwood et al., 2009; Speraw, 2006). The nature of the relationship with the recipients may also have an impact psychologically, depending on whether they are a parent

(Byrne et al., 2008; Winn et al., 2007), spouse (Kim et al., 2008; Sussman & Regehr, 2009) or adult-child (Gonyea, Paris, & de Saxe Zerden, 2008; Li et al., 1999). All these factors identify differences in the values and expectations of individuals who become carers and how they consequently experience and respond to that challenge. In addition most research into carers' experience is undertaken in the context of the recipient's presenting issue. However, Whitney et al. (2007, p. 414) noted that research findings investigating such difference, whether '*the role of other illness-related and demographic characteristics*' impact on carers' psychological well-being, are often mixed.

Finally, carers' psychological well-being is not just proven to have an impact on the quality of care the recipient receives, it also has an impact on the carer's own physical health (Vernooij-Dassen & Olde Rikkert, 2004; Vitaliano et al., 2003; Whitney et al., 2007) and, as Schulz and Beach (1999) found, their mortality.

Summary

The objective of this critical literature review is to examine a cross section of research looking at carers' experiences with a view to establish if there is a common psychological experience of being a carer. The aim was to explore if there were commonalities in the psychological experience of carers across different types of recipients, acknowledging that there may also be differences. The differences in the carer's experience, primarily, being a result of the specific challenging aspects of the presentation for the recipient's given condition. The subsequent aim would be to use this insight to assess if there is a need for the development of a specific psychological protocol for carers, which is relevant and appropriate to all carers, irrespective of the recipient's presentation.

MacLennan (1998) reflected that, the effective provision of health care cannot be claimed, until it also acknowledges and meets the needs of carers, and does not add to the burden of those receiving assistance (Sussman & Regehr, 2009). Huckle (1994) noted, the successful delivery of a number of carer interventions addressing carer needs, which are developed with the recipient's presenting difficulties considered; including, practical support, education programmes, signposting, respite facilities and peer groups. Conversely, Seddon et al. (2007) report that there is a lack of interventions offering emotional support for carers specifically, with only 4% of carers reporting receiving such an intervention.

This paper challenges the proposal, to focus new research on exploring the impact of psychological interventions for carers looking after recipients with a common condition (Huckle, 1994; Robinson et al., 2005), as being too narrow. The author recognises the benefits of specific training and education so that carers understand their overall situation and the condition of the recipient (Mitchell et al., 2014). However, it aims to explore the carer's own journey and identify their specific needs, and then consider what is required to support them as they progress through the course of being a carer, as it develops alongside the recipient's condition.

The need for a robust psychological support system for carers is evident from the discussion. Thus, the aim of this review is to identify whether there is a common psychological experience of carers. This would provide evidence to support the development of a therapeutic intervention protocol for carers specifically, which can be established to provide a cost effective solution for all carers in their own right.

Critical Review of Studies

Many studies and reviews have been undertaken which explore the experience of being a carer. However, all analysis undertaken tends to focus on the carers of a particular recipient presentation. This paper reviews a number of more recent publications in the area, examining their findings while considering their limitations, with the aim of establishing if there is a common psychological impact of being a carer.

The research studies were selected, because their objective was to explore the carer experience. The research in each study represented carers of different types of recipient condition, with findings described in their results section and explored in the discussion. Each paper's results and discussion were systematically reviewed to identify the psychological experiences described by the participants, which were consistent with those identified in WHO (1992), as being suggestive of psychological difficulties. The analytic review aimed to identify words and phrases which illustrated a psychological phenomenon which can contribute to reduced carer well-being; adjustment, anger, guilt, anxiety, depression, isolation, uncertainty, grief (WHO, 1992).

The results were collated in a grid of the psychological phenomena identified by research paper, which illustrated where common patterns of experiences existed, across the different recipient conditions. A summary of the findings are found in Table 1.

In order to obtain a breadth of literature, the database search of primarily PsycINFO and PsycArticles, concentrated on the key words of: carer; caregiver; experience. The articles selected were peer reviewed, the full text was available from the database and it was written in English.

Quantitative Studies

Winn et al., 2007; Recipients were adolescents with Bulimia Nervosa [BN]

Winn et al. (2007) undertook a non-experimental design and asked 112 carers of adolescents with BN to complete the GHQ to assess their psychological well-being and a battery of other self-report measures. The measures chosen addressed key contributory factors to the carer experience as identified from an adapted theoretical model of carer experience based on Lazarus and Folkman's cognitive stress theory. They then undertook a regression analysis which established the significant contributing factors to the level of distress the carer was reporting, some of which were identified as psychological implications of caring.

While the results do not demonstrate the breadth of psychological impact, all the key psychological contributors measured had a significant impact on the carers' well-being measure and included expressed emotion, family dynamics and contact, level of dependency, stigma and loss. Interestingly, in their discussion Winn et al. (2007) reflected that the impact of positive carer outcomes should also be considered in a review of carer experience.

It was noted that the study could be made more robust by the inclusion of a larger sample size and a control group. The generalizability of the current study's results may be challenged, as it was not acknowledged that adolescents could be more inclusive of their families than older BN recipients. Consequently some outcomes in regards to family dynamics and dependency potentially could be impacted by the recipient's life stage. Another limitation was that the model they based their research upon was only focused on negative aspects of providing care and so it potentially could give a biased result. It also made the point, that no reference of the carer's mental health status had been made, which may have an implication on their coping abilities.

Winn et al. (2007) also explored whether disturbed behaviour of the recipients is a predictor of carer distress, and found that, unlike in carers of recipients with AIDS/HIV, traumatic brain injury or dementia, there did not appear to be a link. They acknowledged this difference by suggesting that this may be because BN sufferers are more secretive with their maladaptive behaviours. Interestingly the study made a number of comparisons to other studies which had previously reported that carers of BN recipients experienced fewer difficulties than those supporting recipients with Anorexia Nervosa (AN). Winn et al. (2007) stated that their analysis challenged this view, and reported that the level of distress experienced by their cohort was comparable to recipients with chronic AN, or psychosis. Hence this study provides anecdotal evidence that carers' experience across different recipient presentations has some commonality.

Jarvis et al., 2006 – Recipients were people over 75 years

Jarvis et al. (2006) undertook a quantitative study to capture the experience of carers looking after an older person. A set of self-report questionnaires were sent to 247 carers within a single Scottish GP practice, who had previously been identified as supporting an individual over 75 years. These measures examined three strands of the experience of caring; satisfaction, assessment of difficulties and managing. A 70% response rate was achieved [n=172]. The questionnaires used were evidence based and, in the project design, potential recruitment bias as a result of obtaining the sample through a specific caring organisation or via recipient engagement was specifically highlighted. Thus the sample in the study included anyone who defined themselves as a carer. This is consistent with the definition proposed in this review.

The study used a chi-squared test as the information received was of a nominal level to establish the associations between the different measures. The Carers Assessment of Difficulties (CADI) highlighted a number of psychological implications relating to their satisfaction and well-being; poor sleep, guilt, anger, isolation, family dynamics and low emotional well-being. The other measures provided a rounded picture of the carer experience and identified that humour and comparison to others were key coping strategies adopted.

The paper did not undertake a review of its limitations, though it undertook a detailed review of the reliability and validity of the tools it used. However, while significant results were achieved, it should be noted that the majority of respondents answered the questionnaires in a non-committed way – 'This does not apply to me', 'I do not use this' etc. Of note, there was

no reference to whether the recipients had any specific diagnosis, such as dementia, in addition to their age. While this may have provided more detail for the analysis, it is consistent with the current review's objective of establishing carers' experiences irrespective of the recipient's presentation.

Interestingly, the sample included carers who had held that role for different periods of time with a large number being in the early stages of their caring role. Jarvis et al. (2006) reported that this cohort of carers did not appear to include their role as a carer as part of their personal identity. They reflected that this was different to findings from other carer research and stated that it was likely due to the early stage, the current participants, were in their caring journey.

The research found, that the support received, was mostly practical help. This is in line with research findings, described in the Introduction, which suggested that psychological support, to those in the caring role, is less readily accessible than practical support. Jarvis et al. (2006, p. 1457) referred to these '*day to day*' emotional factors as the '*invisible consequences*' of providing care and reflected that they are often not addressed and could evolve into chronic stressors. The report stated that it provided a warning to professionals to be aware of these factors. Jarvis et al.'s (2006) outcomes also provided support to the literature that psychological stress is also experienced by other family members who were not specifically involved in caring.

A final observation from Jarvis et al. (2006) was that they reported that carers also demonstrated a positive view of their role from which rewards of the caring were identified.

Qualitative Study

Quinn et al., 2008 – Recipients were individuals with recently diagnosed Dementia

Quinn et al. (2008) undertook an interpretative phenomenological analysis (IPA) exploring the experience of carers providing care to recipients in the early stages of dementia. The research recruited 34 participants from Memory Clinics across the south of England living in both urban and rural communities. All participants were interviewed using a semi-structured interview which lasted between 20 to 90 minutes long. The interviewees were encouraged to describe the situation from their perspective including their feelings and experiences. The transcripts from these interviews were transcribed and analysed using IPA, which aims to capture the quality of the participant's experience of their lived world.

IPA also takes account of the values and assumptions which the interviewers hold. Consequently, the subsequent analysis could be complicated by the fact that there were three interviewers each at different points in their psychology careers. Another interesting point reported in this study is that, although the recipients were only recently diagnosed, where they were on the path of their dementia was variable. This too is likely to have impacted on the 'new' carer's experience. This highlights an interesting point when exploring carers' experiences, as people have varying tolerance levels which could affect the timing of their transition from family member to carer. It also adds to the debate about whether the critical point for individual carers, is one of transition for the carer in their journey, or level of support the recipient requires.

An interesting outcome from this analysis was the presence of denial. This may be because the interviews being undertaken were with new carers. In addition, although their reported experience coincided significantly with other studies, these participants did not describe more pervasive feelings of depression, psychological morbidity or a poor sense of well-being. Thus again it potentially indicates that the stage of the carer journey has an important impact on the experience reported.

Systematic Reviews

Greenwood et al., 2009 – Recipients were stroke survivors

The objective of this paper was to undertake a systematic review of qualitative studies exploring the experiences of carers for stroke survivors. The analysis covered articles for the period from 1996-2006 identified from medicine, psychology and nursing databases, with seventeen studies fitting the criteria.

The review acknowledged that many experiences are shared by the carer and recipient in this presentation population but stated its intention (page 338) was to identify '*specific carer challenges and experiences*.' The findings suggested that, in addition to the negative aspects often identified in quantitative research, such as burden, stress, reduced quality of life and psychological morbidity, the qualitative studies provided a richer, more balanced picture in detailing positive aspects of caring.

The review detailed quite a breadth of carer needs, identifying, that they wanted information on how to provide best support to the recipient, their need to feel competent in delivering the care required and the need for support from practical services as well as psychological and

emotional interventions. One study reported specifically that 'emotional support' was helpful.

A limitation on the validity of the findings was the diverse nature of the qualitative studies reviewed. Identification of studies that adopted consistent methodologies may have led to more coherent outcomes. As it was, some studies used face-to-face interviews while others were telephone based or a mixture. In addition, there was a discrepancy in when the recipients were interviewed in relation to the incidence of the stroke, both between and within studies. This may have an impact on the reported experience, as discussed previously, though it was stated that the majority were within the first year of becoming a carer. The style of analysis used also varied between studies which could mean that they had foundations in different epistemological stances that could impact on the knowledge identified, although, the majority were described as thematic or content analysis. In respect to the sample selected, Greenwood et al. (2009) did report some concern about the homogeneity of the participants as a description of selection process was either not mentioned or, where it was, they appeared to suggest the samples obtained were convenience or purposive. Lastly the nature of the carer/recipient relationship was not consistent, with different studies including a different mix of gender, age, culture and type of relationship; spousal, adult children, friends etc. As previously discussed, this may have had an impact on reported experience, though for the purpose of this review it is helpful if common threads are identified.

Despite these inconsistencies the report identified a more rounded explanation of carers' experience including both positive and negative experiences. In addition, the findings indicated, that carers embarked on a journey over time which gave rise to different reported experiences at different time points.

McKeown et al., 2003; Recipients were people with a diagnosis of Multiple Sclerosis [MS]

This study was a systematic review of 24 studies. McKeown et al. (2003) identified reports which focused on primary carers, with the majority being spousal carers. The findings suggest that carers of recipients with MS experience a number of the psychological factors consistent with those identified by this review. In addition McKeown et al. (2003) also suggest that the psychological implications are similar to those found in carers of recipients with dementia. Again while limitations were noted, this review identified studies that were consistent in respect to methodologies used and participant profiles.

Overview of outcomes

Thus it would appear that there are similarities between carers' psychological experience irrespective of the recipient's presentation. Where fewer psychological factors were identified, it was primarily because the research was quantitative and had predetermined and operationalised its research outcomes, and thus explored less breadth of experience. The findings would appear to suggest that the differences in carer experiences, are as aligned with the length of time the carer has held that role, and possibly related to critical transition stages in the course of caring, as they are to being impacted by the recipient's behaviours per se, hence demonstrating a journey of care.

While the systematic review focused fundamentally on the more negative psychological impacts of caring, potentially identifying where therapeutic support would be most beneficial, it was also noted that carers reported positive aspects of caring. These included, finding pleasure in bringing happiness to the recipient (Jarvis et al., 2006), and pride in the recipients progress as a result of their care (Greenwood et al., 2009). As Winn et al. (2007) reflected it is important to acknowledge the positive carer experiences too so that they may be harnessed as protective factors against psychological morbidity.

Although coping strategies were not specifically recorded a few repetitive themes became apparent. These included, the use of humour (Jarvis et al., 2006; Greenwood et al., 2009), developing a protected space for themselves (McKeown et al., 2003) and living for the day (Quinn et al., 2008), none of which are currently captured by interventions recommended by professionals. However, these positive strategies may become more prevalent in people's lives if they felt they had the psychological strategies to manage challenging situations well.

It was also noted, though not recorded specifically, that the majority of participants in the studies reviewed were female. Thus it is hypothesised that, the interventions developed to date for carers may be biased in their structure and attract predominantly women carers, which could have the effect of marginalising male carers.

Author	Recipient Presentation	Type of Study	Carer's Psychological Implications identified							
			Adjustment to new role; Change in relationship/ family dynamics	Anger; Bitterness; Lack of personal time;	Burden; Feeling under-valued; Dependency Relentlessness of caring after a period of time Guilt	Anxiety; Stress; Worry; How can I cope?	Depression	Reduced quality of life; Reduced social interaction; Loneliness Stigma	Concern about the future; Uncertainty	Grief Loss
Quantitative Studies										
Winn et al., 2007	Bulimia Nervosa	Quantitative regression analysis	X		X			X		X
Jarvis et al., 2006	People over 75 years	Quantitative Chi squared analysis	X	X	X	X (poor sleep)		X		
Qualitative Studies										
Quinn et al., 2008	Dementia	Interpretative phenomeno-logical Analysis	X	X	X	X		X	X	X
Systematic Reviews										
Greenwood et al., 2009	Stroke survivors	Systemic review of 17 Qualitative Studies	X	X	X	X	X	X	X	X
McKeown et al., 2003	Multiple Sclerosis	Systemic review of 24 Descriptive Studies		X (Wives)	X (physical implications)	X		X	X	X (chronic sorrow)

Table 1: Summary of psychological implications identified from systematic review

Critique of the Literature Review

It is acknowledged that the search criteria were limited, and because of this relevant articles which could have reduced the number of the limitations within the current review were not identified. Consequently, research which explored carers of a similar profile, at a common stage of care career, were not located.

A key difficulty in establishing the validity of the conclusions is the number of different methodologies used by the researchers. Some undertook a quantitative approach to understand the key elements of the carer's experience, while, more recently, qualitative research has looked to achieve more depth and breadth in understanding the carer role. Quantitative research designs are accepted as generally demonstrating more credible conclusions, however, in order to gain more breadth in the analysis, systematic reviews and meta-analysis of carers' experiences were also included (Voss & Rehfuess, 2013). In hindsight given the complexity of such reviews and the significant limitations identified within them, the validity of their analyses, particularly Greenwood et al. (2009), may suggest that their inclusion in establishing evidence for commonality is weak.

Producing a comparative analysis from the studies selected was complicated by the fact that each study specifically named their analysis as being guided around the recipients' presentation. Indeed some of the studies reviewed explicitly, stated that the findings should not be generalised for carers of other recipient presentations. However, given that no research, which explored the carer experience across different recipient presentations, were found, in the limited literature search, it is proposed that this was a compromise which had to be taken in order to explore this novel dimension.

Another difficulty is that the reviews, even within themselves, looked at carers who had been in the role for different lengths of time. Interestingly, this complication gave rise to an unexpected outcome that demonstrated that carers from different presentations experienced a similar journey of experience with a different mix of primary carer experiences and needs depending at which stage they currently were.

Another complication for this review, in establishing its goal to ascertain a common psychological experience in being a carer, is that most of the literature reviewed was not written to identify the psychological characteristics of caring. The papers tended to have broader remits of what the experience of the carer meant or were looking at how to address a

broader set of carers' needs. Thus, much of the systematic analysis arose from subjective identification of the psychological impact on the carers. The descriptions of experience also varied across studies and some subjective alignment was undertaken so that the findings could be rationalised into the key themes documented in Table 1.

The definition of a carer was not consistent across the studies. Some papers focused on primary carers only while others extended definitions to include other family members and friends. However, it has been suggested by Harvey and Burns (2003) that all identified carers, and supported by Jarvis et al. (2006) that family members too, report similar levels of psychological stress to the 'primary' carer.

It is also important to acknowledge any effect carer diversity and/or the relationship with the recipient may have on reported carer experiences. Surprisingly neither of these complexities was referred to in any of the studies reviewed.

Over the course of this review, it has become apparent that there is indeed a carer journey, the implications of which shall be considered in the discussion. However, this gave rise to a difficulty with the current analysis, in that the studies addressed carers at different stages of that journey, and this was noted even within certain studies (Jarvis et al., 2006).

Discussion

The diversity of carers, of their relationship to the recipient, the ongoing nature of the commitment and of the context in which they provide their care, (e.g. a rural or urban setting) (Tommis et al., 2007) makes this area of research very complex. In attempting to ascertain the impact of the many contributing factors to the caring role, it does potentially explain why, most studies limit themselves to focusing on carers of a particular recipient presentation and then to similar carer profiles within that. However, with each clinical field limiting itself to research in its own area, in what is actually universal theme – that of carers' psychological well-being – it could mean that opportunities of shared learning, building expertise and delivering cost efficient services to carers, is being compromised.

An interesting outcome of the review was the suggestion that caring is a journey and may require the development of a toolkit, of alternative therapeutic interventions, accessible at different points in time. Further exploration of this area led to the identification of a number

of carer stages including, immediately following diagnosis (Wade et al., 2001), the first year (Elliott et al., 2001), decline in recipient behavioural symptoms, deciding to end recipient care (Eloniemi-Sulkava et al., 2002) through to palliative care and death (Greenwood et al., 2009; Grande et al., 2009). Though not all carers will experience all stages, adjustment and acceptance of change to one's life, are a common themes experienced.

While much research is based on the needs and concerns of carers resulting in a list of negative experience and implications of burden, some of the research has highlighted positive aspects of providing care (Greenwood et al., 2009; Jarvis et al., 2006; Winn et al., 2007). This new appreciation could also be harnessed in developing psychological interventions for carers to enable them to incorporate a more balanced view of their carer responsibilities. This has been given more focus recently with Boss (2011) acknowledging the caring experience can lead to an appreciation of new self-knowledge by the carer. Indeed, positive psychological interventions may be useful for carers in delivering their role such as developing resilience, self-efficacy and mindfulness. Quinn, Clare and Woods (2012) also propose a shift in focus from understanding what contributes to caregiver burden to how to address the strain, and proposed that more qualitative studies should be adopted to explore lived experience of the comprehensive and complex nature of the carer role.

Tentatively this review has found that the experience described by carers across recipient presentations is comparable. Thus, the development of a specific protocol to structure carer psychological interventions which has relevance for all carers is appropriate. Importantly, as Cox (1995) states, any interventions need to be sensitive to cultural differences.

The next step would be the integration of the delivery of the psychological therapy into current health service provision to deliver a common, early intervention for all carers. It is proposed that this will result in them feeling heard and supported as individuals, separate from the recipient. The timing of the delivery of interventions to carers is critical and even if, at the point of diagnosis, they do not feel it is relevant for them, it is important that they have an opportunity to access it when they need it. Quinn et al. (2008) and Kim et al. (2008) reported that carers often take on their role with little warning or opportunity to decline, but psychologically they are likely to be feeling most capable at this time. It is important to also appreciate that carers are not always able to identify when their mental health and coping skills deteriorate (McConaghy & Caltabiano, 2005) and thus it is essential to build a knowledge base of expertise in professional services, that recognise, the individuality of

carers, incorporates an understanding of the carer journey into their client management plans, and an appreciation that carers may call on psychological support at different times.

The Carers' Strategy Regional Events (DoH, 2008c) stated that an assessment of ongoing carer needs could be monitored through a 'mental health scorecard' and by developing a carers' care pathway. That this is something all carers are entitled to and they could be referred for therapy at a time which is appropriate for them and for a type of therapeutic intervention, which is recognised to be relevant to the stage of the carer's journey that they are experiencing (DoH, 2008c). Counselling psychology with its breadth of training across many therapeutic modalities, experience of different clinical contexts and collaborative style, would be critical in the development and delivery of this dynamic ongoing programme of psychological support.

Ideas for Future Research

It would appear that there is a lack of research which addresses carers as a population in their own right, outside of that associated with the recipient's specific condition. Thus, areas which warrant further investigation may include undertaking research of carers from a number of recipient presentations who are of a comparable carer profile and at the same stage of their carer journey. A qualitative research project asking a common set of questions in an interview style designed to explore carers' psychological experience across a variety of different recipient presentations would seem relevant. This could be analysed through the use of Interpretative Phenomenological Analysis (IPA) to provide additional evidence to establish if there really is a common set of psychological themes for carers.

Another area which may be useful is more longitudinal research to explore specifically how the carer's psychological experience changes over time and/or how it is experienced at different time points along the carer's journey. A research question could be 'What are the critical events in a carer's journey which affect psychological distress?' The latter information could be the key to establishing if alternative psychological treatments are beneficial at different stages of caring. A proposal for illustration is outlined in Appendix A.

Throughout the review there appeared to be limited research exploring the implications of diversity for carers. Thus more research, particularly exploring the impact of becoming carers on men and different cultural groups would be appropriate.

Conclusion

In summary, this critical literature review appears to demonstrate that, carers as a population in their own right, experience similar psychological effects, across different conditions and recipient presentations. It has also been noted that being a carer is not a static position but a journey and that different stressors appear depending on the stage of care the carer is providing.

It is thus proposed that there is a need for more formal psychological interventions for carers to be developed and integrated into their care management plans (DoH, 2008a). This would be in accordance with the spirit of the original National Carers' Strategy (DoH, 1999, 2008a), as highlighted in the studies throughout this review (McKeown et al. 2003, Seddon et al., 2007), as well as derived from the carers' own voices (DoH, 2008c).

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Appendix A

In recognition of the journey that a carer embarks upon it would be interesting to explore if different stages of caring are more usefully approached with a range of techniques rather than simply by offering Cognitive Behavioural Therapy (CBT) as recommended in the current NICE guidelines (NICE, 2010).

For illustrative purposes:

Stage	Proposed Modality (Illustrative)
Prior to recipient diagnosis / condition (if expected)	Person Centred therapy
Initial reaction to change in role	Grief Therapy Trauma based therapy CBT
Acknowledgement of becoming a carer - Adjustment - Change in role/family dynamics	CBT Systemic Therapy
Ongoing psychological well-being	CBT strategies / problem solving / sleep management Mindfulness techniques
The end of the caring role	CBT – balanced thinking
Palliative care	Mindfulness Bereavement and Grief Therapy