DOES ATTENDING A 'THINKING TOGETHER' GROUP HELP PEOPLE FEEL LESS THREATENED BY THEIR DEMENTIA AND LEAD TO A BETTER QUALITY OF LIFE?

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Thesis submitted in partial completion of the requirements of the award of Professional Doctorate in Counselling Psychology

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This is to certify that this research report is my own unaided work.

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Submission Date post viva: November 2019

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ACKNOWLEDGEMENTS

I would like to thank the Avon and Wiltshire Mental Health Partnership NHS Trust for accommodating my research, and to the staff for offering me their support.

I would also like to thank my two supervisors, Richard Cheston and Sarah Voss. Rik, thank you for tirelessly supporting me throughout my research and for all of your encouragement. Your knowledge has been invaluable and I feel incredibly lucky to have had you as my Director of Studies. Sarah, thank you for always making yourself available when I have needed your support and for offering me your pearls of wisdom.

Thank you to my husband, family and friends, who have helped to make this possible and have supported me throughout the whole doctoral process.

Finally, thank you to all of the service users who participated in my research and gave up their time to be involved.

ABSTRACT

Introduction: As we aspire for earlier diagnosis in people affected by dementia, the need for post-diagnostic support has grown. It is therefore important to conduct research on post-diagnostic support and provide evidence about its potential benefits. This study focuses on the 'Thinking Together' groups, which are post-diagnostic groups for people newly diagnosed with dementia along with their carers. The aim of this study was to evaluate these groups to see if and how they work.

Method: A mixed methods approach was used involving three quantitative measures, the Threat of Dementia Scale (ToDS), the Hospital Anxiety and Depression Scale (HADS) and the Dementia Quality Of Life Scale (DEMQOL), alongside semi-structured qualitative interviews. The participants living with dementia completed all three measures pre-group, post-group and at a follow-up eight weeks after the groups had ended. The carers completed the HADS at the same three time points. Full data was collected from 34 participants across all three time points. The semi-structured interviews were conducted after the groups had ended and aimed to establish participants' experiences of the groups. The quantitative measures were analysed using a paired sample t-test and the interviews were analysed using thematic analysis.

Results: Anxiety and threat of dementia reduced in the people living with dementia and quality of life improved between the pre- and post-measures; these changes were maintained at follow-up. There were no significant changes found in carer's anxiety or depression scores. The thematic analysis identified four main themes: 'The splitting of the groups', 'Thinking and feeling differently', 'The perceived threat of a dementia diagnosis' and 'Group dynamics'. To summarise the qualitative findings, the splitting of the groups was found to be more beneficial to the carers than the people living with dementia. The majority of participants reported thinking and feeling differently as a result of attending the groups and enjoyed being able to share experiences, gain knowledge and find out about further support.

Conclusion: The findings indicate that the Thinking Together groups work for different people in different ways. They were effective in reducing anxiety and threat of dementia in the people living with dementia, as well as improving quality of life. Whilst no significant changes were found for the carers, most of the participants reported positive experiences of having attending the groups and changes in thoughts and feelings.

Implications and future research: The findings suggest that the Thinking Together groups are a valuable resource for people newly diagnosed with dementia and their carers. The implications for counselling psychology are that psychologists' input into the designing and overseeing of these groups is essential; the use of a counselling psychologist's skills around managing the split more sensitively may help participants feel more comfortable in future groups. Further research on these groups could be done on a larger scale, possibly with a control group if a waiting list evolves.

INTRODUCTION

The number of people with dementia is steadily increasing in the UK and elsewhere, as an ageing population lives longer (Prince et al, 2009). Much of the current research into dementia focuses on pharmacological interventions; however, research into non-pharmacological interventions is growing (Orrell et al, 2012), reflecting the preference for early diagnosis and the influence of person-centred philosophies within dementia care. Non-pharmacological offerings include psychological interventions such as counselling, psychotherapy and psychosocial interventions, all of which share similar and overlapping techniques.

At the heart of this study is a post-diagnostic group run for people recently diagnosed with dementia called '*Thinking Together*', where attendees are encouraged to bring along a relative or a friend, who is usually also their primary caregiver. The Thinking Together groups are an example of a non-pharmacological intervention and incorporate skills used in counselling, psychotherapy and psychosocial interventions.

Terms used

Throughout this research, the term 'person living with dementia' will be used and the term used for the relative or friend who also attended will be 'carer'. These terms have been chosen because a person with living with dementia is exactly that, and is not just a person defined by their diagnosis with dementia; this term is in line with person-centred dementia care. The relative or friend is referred to as 'carer' because in this research, the relatives or friends who attended were providing care to and supporting the people living with dementia.

Background to Dementia

Dementia represents a diverse category of symptoms characterised by deficits in memory, cognitive function and behaviour (Chapman et al, 2006). The cognitive impairment characterising dementia may include difficulty in understanding or using words, inability to carry out motor activities despite adequate motor function, and failure to identify or to recognize objects (Kaplan et al, 1994). People living with dementia also commonly experience impairments in occupational and social functioning (Andreasen et al, 2001) and may present with behavioural disturbances (Steinberg et al, 2003). Cognitive problems associated with dementia are progressive; while they may begin as localised to one area, and can be hard to distinguish from normal ageing, they then spread to become global deficits affecting almost all areas of day-to-day functioning.

There are currently 850,000 people living with dementia in the UK, with numbers set to rise to over 1 million by 2025 and then to 2 million by 2051 (Alzheimer's Society, 2019). The most common causes of dementia are Alzheimer's disease (affecting 50-80%), vascular dementia (affecting 20-30%), Frontotemporal dementia (affecting 5-10%) and Dementia with Lewy bodies (affecting less than 5%) (Abbott et al, 2011).

There is no cure for dementia at the present time but treatments offered to people living with dementia include drugs to enhance cognitive functioning, which may improve ability to engage in activities of daily living and also more infrequently, talking therapies to help people adjust. It should be noted that not everyone is suitable to take the drugs available; most of them are targeted at people diagnosed with Alzheimer's disease and sometimes they can have side-effects that result in people not wanting to take them. Both pharmacological and psychosocial interventions are important in order to support a person following a diagnosis of dementia (Patel et al, 2014).

The difficulties associated with dementia can have a big impact on a person's well-being; emotionally, mentally and physically. A diagnosis of dementia can therefore be perceived as a threat due to the way it can impact all aspects of a person's life. Individual and group therapy for people living with early-stage dementia has been shown to help with some of these difficulties that people may face (Logsdon et al. 2010; Bakker et al. 2011; Toms et al. 2015; Leung et al. 2015). Other research has found that group psychotherapy may have a role to play in reducing levels of depression and anxiety in people living with mild and moderate levels of dementia (Cheston et al. 2003; Cheston and Ivanecka, 2016).

Early diagnosis

In recent years, there has been a growing preference for early diagnosis in people living with dementia. Early diagnosis provides a chance for people with dementia and their carers to work together, to set goals for care and support, as well as allowing important decisions to be made regarding post-diagnostic support (Scholz, 2009). For these reasons, early diagnosis can be seen as beneficial to both the person living with dementia and their families. There are possible reasons as to why early diagnosis isn't always given and one of the most compelling is that GPs sometimes feel that a diagnosis might do more harm than good, as it raises expectations of effective treatments, which are not there. The skill of the GP, as with so many other conditions, is to recognise with the least distress to their patients those for whom the evidence and their experience indicates a benefit is possible from the potential diagnosis of dementia (Fox et al, 2013).

As an increasing number of people are now being diagnosed with dementia at an earlier stage, there is an increased need for post-diagnostic support to help people adjust to their diagnoses. When adequate post-diagnostic support is provided, this can not only improve quality of life, but can also enable people to make choices about their life, reduces stress for their families and can mean that people are less likely to be admitted to care homes or inpatient wards (Spijker et al. 2008; Brodaty et al. 2003). In order to know whether post-diagnostic support is 'adequate', more research is required for the current support offered, an example of which is the Thinking Together groups.

Threat of dementia

Threat of dementia is a central element of the current study as there is limited evidence into whether non-pharmacological treatments have an impact on the perceived threat of a diagnosis of dementia. A diagnosis of dementia threatens not only many of the core aspects of what it is to be human, but leads, through a progressive deterioration, to death. Dementia thus represents an existential threat that creates profound emotional and psychological challenges for those who are directly affected by the illness (Cheston and Christopher, 2019); support following a diagnosis is therefore essential in order to help people to manage this threat.

Psychological challenges: the role of counselling psychology in dementia care

The researcher conducting the current study is a trainee Counselling Psychologist; therefore, it is important to reflect on how dementia fits within the realm of

Counselling Psychology and in what ways the profession may be helpful when working with people living with dementia.

Counselling psychologists consider how people relate to one another, how they think and behave, their experiences of the world and how they function in everyday life. This will include exploring people's social, economic, cultural, spiritual and physical health experiences. Counselling psychologists use psychological and psychotherapeutic theory and research to guide their practice. They work to reduce psychological distress and to promote the well-being of individuals, groups and families (British Psychological Society, 2019). This definition illustrates how working with people living with dementia fits within the role of a counselling psychologist, as not only is there a physical health problem present, but it is common for mental health difficulties to be associated with a diagnosis of dementia. Amongst the two most common mental health difficulties associated with dementia are anxiety and depression (Huang et al, 2010; Regan et al, 2016), two areas that counselling psychologists regularly work with.

The relationship between dementia and depression can be seen as complex because some of the expressions of dementia and depression overlap, alongside this, the epidemiology and mechanisms are unclear (Enache et al, 2011). A systematic study from 2010 found that in old age there was a definite association between depression and dementia (Huang et al, 2010). Another study estimated that 40% of people with dementia also experience symptoms associated with depression (Alzheimer's Society, 2016). Depression can occur with all forms of dementia and is therefore something that all practioners should be aware of when working with people affected by dementia.

Anxiety is more common in individuals with dementia than those without (Regan et al, 2016). Defining anxiety in people living with dementia is also complex, due to the overlap in symptoms of anxiety, depression and dementia. The prevalence of people living with dementia experiencing anxiety disorders has formed the basis of several recent studies and results range from 5% to 21% (Starkstein et al, 2007; Ferretti et al, 2001). Anxiety is associated with poor quality of life, behavioural disturbances and limitations in activities of daily living (Seignourel et al, 2008). In the later stages of dementia chemical changes in the brain may increase bouts of anxiety and depression (Geriatric Mental Health Foundation, 2015).

Alongside anxiety and depression, dementia may also cause people to feel insecure and lose confidence in themselves and their abilities. They may feel they are no longer in control and may not trust their own judgment. They may also experience the effects of stigma and social 'demotion' – not being treated the same way by people – as a result of their diagnosis. All of this can have a negative impact on the person's self-esteem. Dementia may also have an indirect effect on someone's self-esteem by affecting other areas of a person's life. Health issues, financial circumstances, employment status and, importantly, relationships with those around them may suffer. Some people, however, form new relationships as a result of their diagnosis, through activities such as attending a class or a support group. High self-esteem allows some people to cope better with chronic health conditions (Alzheimer’s Society, 2019)

Psychological Interventions: definitions

The growing literature on post-diagnostic support advocates that it is vital in order to help people adjust to being diagnosed with dementia, and prepare for the future

(Moniz-Cook and Manthorpe, 2009; Selwood et al. 2007; Russell et al. 2013). There are different psychological interventions available for people living with dementia, including psychosocial interventions, support groups, psychotherapy and counselling.

A “psychosocial intervention” is a broad term used to describe different ways to support people to overcome challenges and maintain good mental health, an example being ‘Singing for the brain’ which is run by the Alzheimer’s Society. These interventions draw on techniques from cognitive behavioural therapies (CBT) and educational theories. They assume that there is a complex interplay between biological, environmental and sociological factors and that ambient stress together with certain life events may trigger an onset or relapse of mental health problems in some people (Neuchterlein and Dawson, 1984; Zubin and Spring, 1977). Psychosocial interventions are increasingly available to people who have received a diagnosis of dementia and their families and can help people maintain a good quality of life following diagnosis (Hewitt et al, 2013)

Support groups can be defined as a structured or unstructured group that can be either professionally facilitated, led by a lay facilitator or group members themselves. They can provide opportunities for people living with dementia to communicate and socially interact in some way amongst themselves. This could involve exchanging ideas and providing emotional support (Toms et al, 2015).

Psychotherapy refers to a range of treatments that can help mental health problems, emotional challenges and some psychiatric disorders. Psychotherapy is the informed and intentional application of clinical methods and interpersonal stances derived from established psychological principles for the purpose of assisting people to modify their behaviour, cognitions, emotions, and/or other personal characteristics in directions that the participants deem desirable (Norcross et al, 2013). Psychotherapy places emphasis on helping people to resolve emotional threats, to take greater control of their lives and to adjust to their illness; this means that it has a lot to offer people with dementia (Cheston et al, 2016).

Counselling is a general term for a range of talking therapies. A counsellor listens to a person's concerns in a non-judgemental and supportive manner. The aim of counselling is to help the person seeking support (often called the 'client') to be clearer about their problems. In this way, people are able to come up with their own answers to their problems, rather than being offered answers by someone else. Counselling is often used to help someone cope with recent events that they have found difficult. For someone with dementia, being diagnosed with such a life-changing and life-limiting condition is clearly a major event. There are different types of counselling available, including individual, group or self-help group sessions (Alzheimer’s Society, 2019).

Thinking Together Groups

The Thinking Together groups can be categorised as a psychological intervention that encompasses aspects from a range of existing interventions such as: group psychotherapy, support groups, counselling and psychosocial interventions. More specifically, the Thinking Together groups use person-centred skills and the ‘core conditions’: empathy, congruence and unconditional positive regard. Rogers believed that a therapist who embodies the three core conditions will help liberate their client to more confidently express their true feelings without fear of judgement (Rogers, 1942).

They are available to people who have been given a new diagnosis of dementia or Mild Cognitive Impairment (MCI). They are run by a Memory Service in the South-West of England and last for 90 minutes, taking place on a weekly basis over seven weeks. Three separate groups are run alongside each other on different days, in different locations, so that the waiting lists are kept to a minimum. The groups are run by mental health professionals, including Assistant Psychologists, Occupational Therapists and Memory Nurses.

The Thinking Together groups invite both the person newly diagnosed with dementia and a relative or friend to attend; the relative or friend is usually also the carer. The importance of involving the carer is in line with the 'Triangle of Care' model as proposed by the Carers Trust (2013) in their guide to best practice in dementia care, as well as other research (SCIE: Dementia Gateway, 2013). For a section of each of the seven sessions, the group members are split into two further sub-groups separating the people diagnosed and the carers. This enables people to have a combination of two experiences: of relating to each other in one large group and having the opportunity to speak more freely about the problems they may be experiencing when in the smaller sub-group. Whilst the rationale for splitting the groups in each session is clear, it may create a potential therapeutic issue in how the split is managed, for example, when managing the speculations of what might be being talked about in the other room.

The Thinking Together groups have been designed to offer: the opportunity to talk to others in a similar situation and share experiences, information on memory problems and ways to cope, the chance to learn strategies to enhance living well with dementia, understanding and support from specialist health professionals, the opportunity to get your questions answered by dementia specialists and information about where to get support in the future. The session plan for each of the seven sessions is standardised and can be found in Appendix 17.

The different elements that these groups offer could help people to feel less threatened by their diagnosis of dementia and improve their quality of life in several ways. Firstly, offering information on what dementia actually is might make it less threatening and might make the diagnosis easier to accept. Secondly, the opportunity to share experiences with other people who can relate to them is often helpful as it can normalise a person's response, encourage a dialogue about dementia and group members can experience other people's reactions (Niederhoffer & Pennebaker, 2002). Thirdly, learning coping strategies can help people to adapt to a life with dementia, rather than fear a life with dementia. Finally, offering information on where to get continued support once the groups finish can leave a person feeling less alone in their individual journey and increase feeling of containment once the groups end (Zarit et al, 2004).

The therapeutic elements of these groups include sharing experiences, receiving support from a therapist or specialist, peer support in a safe environment, exploring coping strategies, talking together as a couple and life story work. As the groups have therapeutic elements, they need to be run by skilled practitioners in order to be successful. Practitioners running the groups are required to have many different types of skills, all of which relate to the different elements of the group. For instance, group leaders often need to make use of systemic or family therapy skills in order to help couples understand more about each other's perspectives. The groups allow expression of difficult feelings by the person living with dementia and the carer, both of whom will have had to accommodate change. In order for people to be able to express their feelings, they need to feel that they are in a safe environment; setting up and maintaining an environment which feels safe is one of the key roles of the group facilitators.

There are other similar groups run elsewhere across the UK, but most other groups invite only the person living with dementia **or** the carer of the person living with dementia, not both. Cheston & Ivanecka (2016) set out that the evidence base for these types of interventions is emerging and that all interventions need to find ways of incorporating carers, therefore it is important to evaluate the Thinking Together groups as they offer a different and unique way of working that might inform the development of work in this area.

CRITICAL LITERATURE REVIEW

Following on from the introduction to this research, this narrative literature review will focus on research involving similar group support for people newly diagnosed with dementia in order to draw conclusions about where this study fits with the existing literature and how it can add to it.

The Thinking Together Groups in relation to current research

The Thinking Together groups are offered at an early stage because being given a diagnosis of dementia can be a threat to a person's well-being (Cheston, 2017), and can often be a difficult diagnosis to accept. There is an expanding body of research that indicates that early-stage support groups can be beneficial; some of the key studies conducted on a smaller scale, as in the case of the current study, have been identified below.

Studies have found that early-stage support groups have been beneficial in terms of increasing feelings of confidence, belonging and purpose, as well as creating a space for difficult feelings to be expressed. This was found in a study by Goldsilver and Gruneir (2001), who identified that participants in an eight-session Canadian project, *Circle of Care*, not only reported positive outcomes including camaraderie, affirmation, and improved confidence but were also able to express feelings of helplessness and frustration. These findings were echoed in a study by Snyder et al. (1994), who reported that an eight-session early-stage support group allowed 15 participants to express negative feelings about their symptoms and diagnosis as well as positive feelings of belonging, purpose, and gratification regarding their support group participation.

Other related research has found that groups have been helpful as attendees have been able to feel more connected as a result of being around supportive people. This was the case in a study by Zarit et al. (2004), who reported that 23 participants in a 10-session early-stage dementia “Memory Club” program rated their greatest benefits of the group were being with other supportive people, being able to express their feelings about dementia, and feeling less isolated. Their care partners didn’t attend the groups but reported that they believed the groups helped their relatives become more aware and accepting of their memory problems and that the groups positively facilitated discussions about future planning, decision-making regarding driving and retirement, and discussing the illness with other people.

There has been research conducted on groups that are very similar to the Thinking Together groups and this research has found that participants experienced positive outcomes as a result of attending the groups. Logsdon, McCurry, and Teri (2006) reported that 39 participants and their carers who attended a 9-week Alzheimer’s Association early-stage support group experienced increased emotional support and decreased isolation as a result of attending the group. Carers rated information about community resources and future medical, legal, and financial planning as important group benefits.

Carer involvement

When being compared to most of the other early stage support groups reported in the literature, the Thinking Together groups are quite unique, in that they invite the person with dementia and their relative or friend; more often than not, this person is also the primary carer. Whilst inviting a carer is sensible due to the nature of memory loss in dementia and the impact dementia has on the carers, there aren't any other groups within the South West England memory services that invite the carer to the full cycle of groups. In a recent review of post-diagnostic groups, it was found that carers had some involvement in half of the groups, although involvement ranged from being in solely separate sessions to attending all meetings alongside the person with dementia (Toms et al, 2015).

In a more recent qualitative study (Alzheimer's Research, 2015), it was reported that carers have a limited understanding of dementia with little desire to improve it. This was because the carers included in the study were worried about how they will cope when things deteriorate. They reported that they would prefer not to fully understand the prospects for the future but prefer to live in the now. The study found that caring for someone with dementia changes the dynamic of a relationship. For people caring for someone with dementia there is a sense of loss of the person they once knew. When this is coupled with challenging behaviour and the emotional and physical stress, it can make the act of caring for someone with dementia a significantly emotional experience.

These findings are relevant to the current study and indicate that both the person with dementia and the carer attending the Thinking Together groups could enable an increased understanding between the two people, as well as the opportunity to talk about any difficulties currently in their relationship. Furthermore, ensuring that good relationships are formed between the person living with dementia and those supporting them, is likely to affect how well an individual lives with dementia (Edwards et al. 2016).

A person-centred approach

As previously mentioned, the group facilitators use a person-centred approach within the groups. The person-centred approach was developed from the work of the psychologist Dr Carl Rogers (1902-1987). It was originally described as non-directive and moved away from the idea that the therapist was the expert and more towards a theory that trusted the innate tendency of human beings to find the fulfilment of their personal potentials. These personal potentials include sociability, the need to be with other human beings and a desire to know and be known by other people. It also includes being open to experience, being trusting and trustworthy, being curious about the world and being creative and compassionate. Rogers said that these personal potentials could only be achieved in a psychological environment where a person felt free from threat, both physically and psychologically. The Thinking Together groups aim to be groups where this psychological environment can be achieved.

The person-centred approach has been researched within the field of dementia, predominantly by Tom Kitwood; he first used the term in 1988 to distinguish a certain type of care approach from more medical and behavioural approaches to dementia. Kitwood repeatedly drew on Rogers' framework to describe the therapeutic and containing qualities of good dementia care. Kitwood (1998) proposed that dementia could be best understood as an interplay between neurological impairment and psychosocial factors, namely, health, individual psychology, and the environment, with particular emphasis on social context. He believed that the environment has as much effect on the brain as the brain has on a person's abilities.

Kitwood and Bredin (1992) found a need for high-quality interpersonal care that affirms personhood; one that implies recognition, respect, and trust. They looked at what people living with dementia need and determined that the answer began with love at the centre surrounded by the following five offshoots: comfort, attachment, inclusions, occupation and identity (Kitwood, 1997). The facilitators of the Thinking Together group aim to act in a way that aligns with these five offshoots by providing an environment that encompasses these different elements.

Kitwood and Bredin (1992) also explored how due to Alzheimer's disease, a dependence on others is essential for people living with dementia. The carer becomes an absolute necessity, both physically and psychologically. They described how the carer is needed to offset degeneration and fragmentation and sustain personhood. The carer is needed to hold the pieces together to become the memory; this therefore provides a rationale for why it important that the carer is involved, as they are in the Thinking Together groups.

Existing research into psychological interventions for people with dementia

In an attempt to be able to provide people with dementia the time and space they need to make sense of the changes that might occur in their lives, there has been an increase in the use of psychotherapy and counselling with people with dementia. A wide range of individual psychotherapeutic work with people with dementia has been described including psychodynamic (e.g. Sinason, 1992), cognitive-behavioural (e.g. Teri and Gallagher-Thomson, 1991) and humanistic approaches (e.g. Goudie and Stokes, 1989; Stokes and Goudie, 1990). However, therapists are costly and the NHS aren't equipped with the money or resources to be able to offer such a service to everyone, so one of the most common ways of intervening with people with dementia is through group work (Cheston, 2003). The Thinking Together groups are an example of group work that uses skills found in psychotherapy and counselling. The groups are run by mental health professionals who have been trained to be able to use certain therapeutic skills, such as person-centred skills and skills found in couples therapy, without always having to be trained therapists themselves. The groups are overseen by the psychology department and have been designed to incorporate aspects from different types of therapies and interventions, allowing for an affordable service for the NHS, as well as an accessible service for people affected by dementia.

Psychosocial interventions

In a review of psychosocial interventions for dementia, Olazaran et al. (2010) reviewed 179 randomised control trials (RCTs) published up until September 2008. Olazaran and colleagues grouped the studies according to the target of the intervention (person with dementia, caregiver, 'other') and, within these groups, categorised them according to the type of intervention (eighteen, five and three types, respectively, in each group). They concluded that there was consistent high-quality evidence from multiple RCTs that multi-component interventions for caregivers delayed moves of those with dementia to institutional care. They also found that there was consistent evidence from at least two lower quality RCTs that multi-component interventions for those with dementia have positive effects on cognitive functioning, activities of daily living, behaviour and mood; multi-component interventions for those with dementia and caregivers have benefits for quality of life; cognitive training and cognitive stimulation enhance cognitive functioning; and training of professional caregivers enhances behaviour and reduces use of restraints.

A more recent review by Oyebode & Parveen (2016) looked at the efficacy of various psychosocial interventions for people with dementia and aimed to provide an up-to-date snapshot of the current state of the field by focusing on pertinent reports of high-quality research and reviews, which have been published since Olazaran et al.'s (2010) comprehensive overview of RCTs. This review was described by the researchers as 'a 'helicopter view' that aims to give a high level coherent narrative of current trends, gaps and issues in this broad and disparate field'. Only studies which considered psychosocial outcomes (cognitive functioning, emotional well-being, behaviour, level of functioning in everyday activities and quality of life) were included, with these outcomes for people with dementia being the same as those employed by Olazaran et al. (2010) for their review. Their findings were that a range of multi-component and specific interventions had benefits for cognitive, emotional and behavioural well-being of people with dementia in residential settings, as well as for quality of life. Overall, interventions tended to be short term with impact only measured in the short term. They recommended further research on interventions to promote living well in the community post-diagnosis and to address end-of-life care. Development of psychosocial interventions would benefit from moving beyond the focus on control of behaviours to focus on wider aspects of life for people with dementia.

This review has a number of limitations. The researchers report that it is possible that search terms may have led to the omission of research in specialist areas that were not captured by the relatively general search terms. In addition, although they focused on controlled studies and systematic reviews, they did not carry out methodological evaluation of the papers that were included in the many reviews.

Support groups

A recent review by Toms et al. (2015) looked into the effects of support groups for people living with dementia. In this study, 17 studies that met the above definitions for a support group were identified and reviewed. The findings indicated that groups are rated positively and people are observed to enjoy meeting together and often form close bonds. When participants provided feedback on groups, it was found that, on the whole, respondents reported positive experiences and satisfaction.

When looking specifically at time-limited groups: one study found improved mood (Logsdon et al. 2010), one study found increased dementia knowledge (McAfee et al. 1989) and two studies found enhanced quality of life (Logsdon et al. 2007; 2010) following participation in the groups. They reported that this evidence represents some positive psychosocial outcomes from RCTs, between-group studies and repeated measure designs. However, despite the corroborating evidence from different study designs, the evidence base for time-limited groups is not strong. Only two RCTs (the highest level of evidence included in the review) found evidence for positive outcomes and these trials lacked detailed information about randomisation procedures and so had potential methodological limitations. The papers using a repeated measure design also had variable reporting quality with Roberts and Silverio (2009) meeting 71% of reporting criterion but McAfee et al. (1989) only meeting 47% of criterion. Evidence for improved mood is particularly limited with three studies reporting no improvement or trends only (McAfee et al. 1989; Marshall et al. 2005; Logsdon et al. 2007).

Prior to Toms' review, Leung et al. (2015) conducted a systematic review which also concluded that support groups may have psychological benefits for people with dementia and mild cognitive impairment. However, they only focused on outcomes from RCTs and therefore only two papers were included. A narrow focus on trial design eliminates the majority of the available evidence and other study designs may be more informative about how interventions perform in "real life" conditions.

The Toms et al. (2015) review had several limitations. The literature search did not access unpublished data or non-English papers, which will mean that several studies were excluded. Four studies were included although not all participants had clearly received a diagnosis: 95% of the sample were diagnosed in Gaugler et al. (2011), the majority had dementia in Goldsilver and Gruneir (2001), a small subset of participants were still undergoing diagnostic assessment in Billington et al. (2013) and in the study by Örulv (2012) two of the seven participants had been re-diagnosed with mild cognitive impairment, though they were originally diagnosed with dementia and self-identified as having dementia. Also, the generalizability of the review findings is limited. Most studies were conducted in the West and in 63% of the studies reviewed participants were predominantly in the early stages of dementia.

Psychotherapy and counselling

Research that is more closely linked to the nature of the current study is a randomised controlled clinical trial conducted by Logsdon et al. (2010). This research was included in the Toms et al. (2015) review as a support group but was included in a review by Cheston & Ivanecka (2016) as an example of psychotherapy, which illustrates how blurred the distinction can be in practice. At the centre of Logsdon's (2010) randomised control trial was an Early Stage Memory Loss (ESML) group that Logsdon et al. had conducted previous research on. The ESML sessions were similar in nature to the Thinking Together groups; they averaged 90 minutes in duration and met weekly for nine weeks. Each session included both individuals with early-stage dementia and a care partner, who met together for part of the session and separately for part of the session. Findings of this study demonstrated that, for individuals with early-stage memory loss, participating in a nine-session Early-Stage Memory Loss support group resulted in significantly better quality of life and decreased depressive symptoms compared with a waiting list control condition. Although the amount of change seen in these outcomes is modest, these findings are consistent with qualitative reports of the benefits of early-stage support groups and provide empirical support for the efficacy of these groups on areas of clinical importance to individuals living with dementia. Furthermore, these results indicate that individuals who were experiencing more distress at baseline experienced greater improvement in quality of life following participation in ESML groups and that improved quality of life was associated with improved mental health, family communication, and self-efficacy. Participants who were more distressed may have had a poorer quality of life to begin with and therefore more room to improve it.

Interestingly in Logsdon's study, they found that care partners who attended the ESML groups along with the person diagnosed with early-stage dementia did not report significant changes in their own quality of life. The ESML groups evaluated in this investigation were designed primarily to meet the needs of the person with early-stage dementia and focused on concerns of the diagnosed individual. Care partners are included to support the participants, and many care partners in the early stages did not consider themselves to be “caregivers.” They recommended that additional research is needed to evaluate other types of early-stage interventions for both persons with dementia and family care partners.

The final review to be discussed was conducted by Cheston & Ivanecka (2017) and focused on the use of psychotherapy in post-diagnostic dementia care. 1397 papers were screened evaluating the impact of group or individual psychotherapy with people affected by dementia. Out of the 1397 papers screened, 26 papers using randomised, non-randomised controlled trials or repeated measured designs were included. A broad mix of therapeutic modalities, types, lengths and settings were described, focusing largely on people with mild levels of cognitive impairment living in the community. In their review, one study provided evidence that post-diagnostic group therapy improved quality of life and reduced depression. Where participants were in the early stages of dementia, the strongest evidence found in a review of the literature was from the above mentioned study conducted by Logsdon et al. (2010), which demonstrated that a 9-week group intervention delivered by experienced therapists significantly reduced levels of depression and improved quality of life. The results of this review suggest that interventions with psychotherapeutic values at their core can go a long way into helping someone adjust to their diagnosis of dementia. However, this review did have certain limitations. Firstly, the researchers only reviewed papers which reported in English and thus excluded a range of reports of psychotherapy (e.g. Fabris, 2006; Scheurich et al. 2008; Scheurich and Fellgiebel, 2009); they also excluded both support groups and family therapy because they had been addressed in other reviews.

The literature demonstrates that a variety of names can be used for the different types of groups provided to people living with dementia, for example, support groups, group psychotherapy, post-diagnostic groups, psychosocial interventions and non-pharmacological interventions. There are two possibilities as to why many different names are used, either that different names mean that different things are being done, or that the same things are being done but in different ways. Another factor when thinking about what name to give a group could be that different names carry different connotations, for example calling an intervention support group might mean it is more appealing to the public when compared with psychotherapy. Each of these types of groups share similarities in that they all provide a chance for people living with dementia, and sometimes their partners, to have a chance to share their experiences and receive support following a dementia diagnosis.

Summary of evidence: the need for further research

Existing research has concluded with a number of different future research suggestions, some of which the current study aims to address. Logsdon et al. (2010) stated that additional research is needed to evaluate other types of early-stage interventions for both people living with dementia and their care partners. The current study aims to follow this suggestion as the Thinking Together groups are an example of an early stage intervention that involves both the person living with dementia and the caregiver. Oyebode & Parveen (2016) recommended further research on interventions to promote living well in the community post-diagnosis. The current study will also follow this suggestion as the Thinking Together groups invite people living in the community and create a space where people can think about how to live well with dementia. Finally, Toms et al. (2015) reported that there are significant gaps in the evidence base for time-limited groups. Toms and colleagues state that there is currently no evidence as to whether benefits are maintained in the medium or longer term and this limits what conclusions can be drawn about how effective support groups are. The current study on the Thinking Together groups includes an 8-week follow-up measure, so it will be able to point to whether or not groups such as these have short to medium-term effects. Toms et al. (2015) also reported in their study that there is limited evidence of positive outcomes based on quantitative data. The current study incorporates quantitative measures into data collection, so will be adding to the limited evidence base.

It should also be noted that in the NICE (2018) guidance for dementia, the only type of non-pharmacological intervention recommended is cognitive stimulation therapy; this further indicates that more evidence is needed for all other types of non-pharmacological interventions.

RESEARCH RATIONALE, AIMS AND QUESTIONS

The main aim of the current study is to evaluate the Thinking Together groups in order to see if they help participants living with dementia to feel less threatened by their dementia, lead to decreased levels of anxiety and depression and in turn a better quality of life. A secondary aim is to see if the groups have an effect on the carer's depression and anxiety levels as they are also attendees of the groups. There has been little research into the effectiveness of the Thinking Together groups so the current research aims to address this, as well as adding to the existing literature on the evidence base for non-pharmacological interventions.

These aims will be addressed through a mixed methods approach. Quantitative measures that assess threat of dementia levels, anxiety, depression and quality of life will be used. Qualitative semi-structured interviews will be used to examine these elements in depth and will also be used to investigate which aspects of the Thinking Together groups may be helpful or unhelpful. The qualitative and quantitative measures will answer different questions and will be used to complement each other.

If the current study provides evidence which indicates that these groups are an effective intervention, this will strengthen the case for future funding from the Clinical Commissioning Group (CCG) so that the Avon and Wiltshire Mental Health Partnerships (AWP) continue to be commissioned to provide these groups, as well as raising awareness that these groups are available and are an evaluated intervention.

Through the use of qualitative methods, the research will also contribute to our understanding about the process of the groups, for example, what aspects of the groups are helpful, which aspects could be improved and who benefits from attending. Having an evidence base behind an intervention can be useful in encouraging people who are offered the service to attend. This study highlights the importance of continuing to move towards person-centred dementia care, which involves tackling the cognitive and mood difficulties with medications, as well as offering knowledge and post-diagnostic support to people living with dementia and their families.

Research Questions

1. Are the participants living with dementia less threatened by their dementia at the end of the intervention than they were at the start?

2. Are the participants living with dementia feeling less anxious and depressed at the end of the intervention than they were at the start?

3. Do participants report a better quality of life at the end of the intervention than they did at the start?

4. Are the carers feeling less anxious and depressed at the end of the intervention than they were at the start?

5. Which elements of the group did the participants find the most and least useful?

METHODS

Epistemological position

The researcher has conducted this research using a pragmatic approach. Morgan (2007) presents pragmatism as an alternative to positivism and ''metaphysical'' thinking. Pragmatism is outcome-orientated and focuses on the product of research (Biesta, 2010). Pragmatism places emphasis on shared meaning-making and communication in order to create practical solutions to social problems, for example with the current study, the psychological treatment of dementia has been explored in order to look at what does or doesn't work. Pragmatism places primary importance on the research question (Tashakkori & Teddlie, 2003), which is why the outcome measures used in this research directly relate to the research questions and the research questions were used to guide the thematic analysis.

Pragmatism is based on the belief that theories can be both contextual and generalisable by analysing them for 'transferability' to another situation. The pragmatic researcher is similarly able to maintain both subjectivity in their own reflections on research and objectivity in data collection and analysis. Pragmatism has been described as offering specific ideas as to what constitutes knowledge, but does not purport to present an entirely encompassing world view (Biesta, 2010). Morgan (2007) emphasises that pragmatism centres on creating shared meanings and joint action, which points to the underlying belief in complementarity, that is, qualitative and quantitative approaches can be combined in order to 'complement' the advantages and disadvantages presented in each. A pragmatic, complementary approach to research allows for 'shared meanings' to be created when the quantitative and qualitative data seem inconsistent with one another

(Arnon & Reichel, 2009). This reflects the intersubjectivity that pragmatism offers mixed methods researchers, as the two sets of data can be integrated through cross-validation or triangulation in order to emphasise the shared meanings created as the results of integration.

Pragmatism breaks down the hierarchies between positivist and constructionist ways of knowing in order to look at what is meaningful from both (Biesta, 2010). Addressing the connections between theory and data, pragmatism uses 'abduction' which moves back and forth between induction and deduction – first converting observations into theories and then assessing the theories through action (Morgan, 2007). Also, pragmatism utilises transferability to consider the implications of research. Transferability in qualitative research refers to the possible local and external connections that data can reveal about a phenomenon (Jensen, 2008). In other words, transferability allows the researcher to investigate the factors that affect whether the knowledge we gain can be transferred to other settings (Morgan, 2007).

Ensuring good quality qualitative research

The tests and measures used to establish the validity and reliability of quantitative research cannot be applied to qualitative research and there are ongoing debates about whether terms such as validity, reliability and generalisability are appropriate to qualitative research (Rolfe, 2006; Sandelowski, 1993; Long and Johnson, 2000). In the broadest context these terms are applicable, with validity referring to the integrity and application of the methods undertaken and the precision in which the findings accurately reflect the data, while reliability describes consistency within the employed analytical procedures (Long and

Johnson, 2000). However, if qualitative methods are inherently different from quantitative methods in terms of philosophical positions and purpose, then alterative frameworks for establishing rigour are appropriate (Sandelowski, 1993).

Lincoln and Guba (1985) offer alternative criteria for demonstrating rigour within qualitative research namely truth value, consistency and neutrality and applicability. Truth value refers to the researcher recognising that multiple realities exist, the researcher's personal experience and viewpoints may have resulted in methodological bias and that the researcher needs to clearly and accurately present participant's perspectives. Consistency relates to the trustworthiness by which the methods have been undertaken and is dependent on the research maintaining a decision 'trail' so that the researcher's decisions are clear and transparent. Neutrality is achieved when truth value, consistency and applicability has been reached. It centres on acknowledging the complexity of prolonged engagement with participants and that the methods undertaken and findings are intrinsically linked to the researcher's philosophical position, experiences and perspectives; these should be made clear. The final criterion is applicability, which gives consideration to whether findings can be applied to other contexts, settings or groups. These criteria have been used as a guide for the qualitative research part of the current study in order to address the common issues with qualitative research and ensure good quality research.

Design

Randomised control trials (RCTs) are the most stringent way of determining whether a cause-effect relationship exists (Kendall, 2003). However, for pragmatic reasons, it wasn't possible to run a control group. This study uses a one-group pre-test–post-test research design, which is an important non-experimental design and is a reasonable option for an evaluation. Although it suffers from many threats to internal validity, it can, in many cases, provide preliminary evidence for intervention effectiveness, especially when supplemented with complementary information (Robson et al, 2001).

This study also uses a mixed-methods approach to data collection, incorporating three quantitative measures and brief qualitative semi-structured interviews. The rationale behind 'brief' semi-structured interviews is that dementia affects concentration, meaning that people living with dementia will be able to focus more effectively during a shorter time period.

A mixed-methods approach was chosen because quantitative data alone wouldn't reflect the depth of the topic being researched. Qualitative data will be able to provide richer, more exploratory data that will be tailored to the research questions. Quantitative data wouldn't allow for people to express personal opinions on their experiences of the group, which is important to see if, how and why they are effective. The qualitative and quantitative data will be used to complement each other so as to explore shared or opposing findings.

Participants

Participants involved in this research attended the seven-week Thinking Together groups and had a recent diagnosis of dementia (in the last 18 months). On average, each group contained six people newly diagnosed with dementia plus their carer. Two or three sets of groups were run simultaneously on different days, in different locations in each cycle of seven weeks. A sample size of between 24 -50 participants (12-25 pairs made up of the person living with dementia and their carer) was used in this study, which is in the range recommended for pilot studies (Browne, 1995; Sim & Lewis, 2012; and Julious, 2005). The current study can be described as a pilot study as it is research done on a small scale, with the potential to be researched on a larger scale in the future.

The researcher allowed ten months for data collection and recruited 42 participants in total. Out of the 42 participants, eight participants stopped attending the groups due to various personal circumstances, so were withdrawn from the study and their data has not been used. In total, full data across all three time points was collected from 34 participants. Of these, 20 were female and 14 were male; 10 of the females and seven of the males had dementia.

Recruitment

In terms of recruitment to the study, participants that met the inclusion criteria were given a letter of invitation (Appendix 6) by the group facilitators and then the participants informed the group facilitators if they would like to take part. If participants agreed to take part, they consented to their details being passed to the researcher, who sent the participants information sheets (Appendix 7 and 8) in the post and phoned to arrange an initial visit. In the first visit, participants had the opportunity to ask any questions they may have had about the research, before signing a consent form if they were happy to take part in the research.

Inclusion Criteria

The participants living with dementia needed to:

1. Have a diagnosis of Alzheimer's disease, vascular dementia, dementia with Lewy bodies or mixed dementia and this had to be diagnosed within the last 18 months
2. Live in the local area
3. Have mild/moderate level of cognitive impairment as assessed by a cognitive assessment such as the MOCA (Nasreddine et al, 2005) or ACE-R (Mioshi et al, 2006)
4. Have capacity to give informed consent to take part in the research study

Exclusion Criteria

Participants would be excluded if they are deemed to be either*:

1. Emotionally vulnerable (e.g. if they have a significant pre-morbid history of mental health problems such that being interviewed about their dementia might cause undue distress); OR
2. Physically frail; OR
3. Currently experiencing significant levels of emotional distress; OR
4. Have complex family circumstances that would otherwise make participation inadvisable; OR
5. Lacking in capacity to provide informed consent

* as determined collaboratively by the memory service and the researcher.

Ethical considerations

A central ethical issue of the present research is to ensure that enough information is provided at appropriate points so that consent from participants is meaningful and continues throughout the research process. To help participants in giving informed consent, all participants in the study were provided with an information sheet explaining the nature of the study and were all given the contact details of investigators involved in the study and/or memory clinic staff facilitating groups, so that at any point they can ask any questions they may have. Furthermore, the information sheet and informed consent form made it clear to participants that their participation in the study is entirely voluntary and that they may withdraw from the study at any time without any consequence to themselves or their on-going care/future treatment.

Capacity to provide informed consent is always an important issue when working with people living with dementia. All of the participants in this study had capacity to provide informed consent. Judgements about capacity were made by a health professional working in the clinical team who was independent of the researcher, who knew the person and who had access to the person's clinical notes including cognitive assessments collected as part of their dementia assessment. The clinical team continued to be involved in caring for the individual with dementia over the course of the group sessions and were therefore well placed to monitor and identify any fluctuations in capacity over the course of the study. Anyone deemed to have lost capacity before the end of data collection would have been withdrawn from the study. Any identifiable data collected from them would have been withdrawn from the study and would not have been included. There was not anyone who lost capacity during the study, but these were the measures in place if that had happened.

Full ethical approval was granted for this study by the appropriate governing bodies on the following dates:

Research Ethics Committee approval granted: 26th June 2017 REC ref: 17/WA/0200
Health Research Authority approval granted: 25th July 2017 IRAS ID: 229665
Research & Development approval granted: 11th August 2017
Faculty Research Ethics Committee approval granted: 31st October 2017
UWE Health & Applied Sciences application number: HAS.17.10.039

Gaining ethical approval required that all the relevant forms for the study were created and approved, for example: participant information sheets, consent forms, interview schedules, letter of invitation, a protocol and copies of the three measures used in this research. The relevant documents can be found in the appendices 6-16.

Data Collection

All data was collected at the participants' homes across the different time points between September 2017 and May 2018. Home visits allowed for increased engagement as the participants didn't have to travel anywhere and felt comfortable in the safety of their own home. In total, the researcher made 54 home visits over ten months in order to collect all the data needed for the study. During this time frame, the group facilitators included an occupational therapist, an assistant psychologist and a memory nurse; they followed a standardised session plan, an overview of which can be found in Appendix 17.

The data collection measures included three quantitative methods: Threat of Dementia Scale (ToDS), Hospital Anxiety and Depression Scale (HADS) and Dementia Quality of Life Scale (DEMQOL). A limitation of quantitative methods is that they limit the range of responses from the participants (McLeod, 2008), so to counteract this limitation, a qualitative method comprising of brief semi-structured interviews was also used.

Quantitative data collection

ToDS is a newly formed scale (Cheston et al, 2019) which comprises 13 statements relating to how threatening the changes that dementia causes are. Participants are asked to rate how their sense of well-being would be threatened in relation to each statement. It is a well-fitted measure for this research as the threat of dementia will be a key component looked at over the course of the groups. The Cronbach's alpha for the scale was 0.911 with all 13 items having a high-corrected item-total correlation. The ToDS is a valid measure of the extent to which an individual feels threatened by dementia and it has good psychometric properties, including acceptable test-retest reliability after one month.

HADS is a scale formed by Zigmond and Snaith (1983), and was created as a tool to detect anxiety and depression in people with health problems. It is a 14-item scale which generates ordinal data. Although not originally designed for use with people living with dementia, it has been widely used as a self-report measure in studies exploring the impact of therapy with people with mild levels of dementia (Cooper et al 2008; Wands et al, 1990). As the participants in this study are all over 70 years of age and considered as older adults, it should be noted that the internal consistency of the HADS in a sample of older adults was as satisfactory as it is in samples with younger persons (Helvik et al, 2011). It will be useful in the current study to look at whether people's anxiety levels change over the course of the Thinking Together groups.

DEMQOL is a patient reported outcome measure which is designed to enable the assessment of health-related quality of life of people living with dementia. It was developed according to the best quality psychometric principles by a multidisciplinary team including the London School of Hygiene and Tropical Medicine, the London School of Economics and Nottingham and Sheffield Universities. DEMQOL is designed to work across dementia subtypes and can be used at all stages of dementia. DEMQOL is a 28-item interviewer-administered questionnaire answered by the person living with dementia and measures quality of life over three main domains: feelings, memory and everyday life. It also has one question at the end where participants are asked to rate their overall quality of life. Anxiety, fear and quality of life are closely linked (Ferrans et al, 2005) so it is rational to use these three measures alongside each other.

All of the people with dementia received the ToDS, HADS, DEMQOL and the carers received the HADS. There were three points of data collection using these measures. The three time points were within two weeks before the groups started (T1), within two weeks after the groups had ended (T2) and follow-up measures which were eight weeks after the groups ended (T3). The researcher arranged appointments as close to each time point as possible, but allowed a maximum of a two-week time frame so that appointments could be scheduled and attended.

The ToDS, HADS and DEMQOL were administered by the researcher. The HADS and the ToDS were self-ratings, whereas the DEMQOL is designed to be read to the participant so that verbal responses can be recorded. In cases where the participants struggled with speech, they indicated their answers by pointing to them.

Qualitative data collection

A smaller sub set of 20 participants (10 pairs) received brief semi-structured interviews, which were recorded on a digital voice recorder and were then transcribed. Participants received interviews if they had indicated that this was something they felt comfortable doing and had given consent; the researcher continued to interview participants until the desired number of 20 interviews had been reached.

Each individual of each pair was interviewed separately during the second visit after they had attended a full cycle of the groups. The interview schedule can be found in Appendix 11-12. It contained questions about how each of the participants experienced the groups and also included questions about which aspects of the groups they found the most and least helpful. The interviews were conducted by the researcher in the participants' homes and were carried out in separate rooms to the other person, for example, the dining room or kitchen, so that each member of the pair had the opportunity to speak freely.

Semi-structured interviews are often used in order to delve deeply into a topic and to understand thoroughly the answers provided (Margaret et al, 2009), so it is an appropriate measure to use in the current study. Semi-structured interviews allow individuals to disclose thoughts and feelings (Newton et al, 2010); this is ideally fitted to the personal and sensitive nature of dementia. Using a semi-structured interview enabled the researcher to ask questions tailored to the research questions and also meant that the data could be used to further explore the quantitative data, and vice versa.

Whilst this method is suitable for the current study, it is important to recognise and address the weaknesses that this method can have. Denscombe (2007) discusses research which demonstrates how people respond differently depending on how they perceive the interviewer, '*the interviewer effect'.* Gomm (2004) further describes demand characteristics in which participants' responses are based on what they perceive the interviewer wants to hear. In order to take this into account and to attempt to counteract it, it was made clear before each interview that the researcher does not work for the memory service and is looking for honest feedback in order to aid further running of the groups.

Data Analysis

Data was stored on a password-protected file and paper documents were kept in a locked filing cabinet. Consent forms and participant data were stored in separate folders. Participant names did not appear on interview transcripts and randomisation numbers were employed to label data in order to keep it confidential.

Quantitative data analysis

During data analysis, the data from the quantitative measures was entered into an SPSS spreadsheet and analysed using paired sample t-tests. A paired sample t-test is a parametric test that compares two means that are from the same individual, object, or related units. The two means typically represent two different times (for example, pre-test and post-test with an intervention between the two time points). The purpose of the test is to determine whether there is statistical evidence that the mean difference between paired observations on a particular outcome is significantly different from zero.

Qualitative data analysis

The qualitative data was analysed using thematic analysis. Thematic analysis is the process of identifying patterns or themes within qualitative data. Braun & Clarke (2006) suggest that it is the first qualitative method that should be learned as 'it provides core skills that will be useful for conducting many other kinds of analysis' (p.78). A further advantage is that it is a method rather than a methodology (Braun & Clarke 2006; Clarke & Braun, 2013), which means that, unlike many other qualitative methodologies, it is not tied to a particular epistemological or theoretical perspective, making it a flexible method to use.

The interviews were transcribed and the transcripts were entered into NVivo 12; they were then coded using the same programme. From here, initial patterns were identified and these were later redefined into themes and subthemes. The identification of the themes and subthemes was guided by the original research questions. The themes and subthemes were then summarised and interpreted, using relevant quotes to evidence them. Braun & Clarke's (2006) six-stage guide to thematic analysis was followed and has been summarised in Table 1.

Table 1: Braun & Clarke's six-stage framework for doing a thematic analysis

Step 1: Become familiar with the data	**Step 4:** Review themes
Step 2: Generate initial codes	**Step 5:** Define themes
Step 3: Search for themes	**Step 6:** Write-up

Braun and Clarke (2006) distinguish between two levels of themes: semantic and latent. Semantic themes '...within the explicit or surface meanings of the data and the analyst is not looking for anything beyond what a participant has said or what has been written.' (p.84). In contrast, the latent level looks beyond what has been said and '...starts to identify or examine the underlying ideas, assumptions, and conceptualisations – and ideologies – that are theorised as shaping or informing the semantic content of the data' (p.84). The thematic analysis in this study was done at a semantic level. The analytic process involved a progression from description, where the data has simply been organised to show patterns in semantic content, and summarised, to interpretation, where there is an attempt to theorise the significance of the patterns and their broader meanings and implications (Patton, 1990), often in relation to previous literature.

Recruitment, data collection and analysis took place concurrently, and it was judged that theoretical saturation had been reached when no further attributional themes arose. An inductive approach was used which means the themes identified are strongly linked to the data themselves (Patton, 1990).

Public involvement work

In order for the researcher to fully understand the Thinking Together groups, the researcher attended a seven-week cycle of groups before data collection began. The researcher observed the group dynamics and was able to speak to attendees; this allowed an initial insight into how the groups were run and how people attending the groups responded to them. After attending the groups, the researcher concluded that the current studies research into the groups would be useful to further explore the effects of the groups and whether they are a beneficial intervention to those that attend.

REFLEXIVITY STATEMENT

I am a 27 year old, white British female, training to be a counselling psychologist. My interest in the area of dementia started with my own grandparents and has continued to progress throughout my working life. I have worked with people living with dementia in a clinical role and was part of a project that involved creating a dementia-friendly ward.

Several years ago, three of my grandparents showed signs of having dementia; one of them has since been diagnosed with Alzheimer's and has been living with this diagnosis for several years. At the time of his diagnosis, my father wasn't sure what to make of it all and could have really done with some further support. My granddad attended a cognitive group for people living with dementia but was unable to remember the content of the sessions on his return home. This sparked my interest in looking for other groups that were available, which is how I discovered the Thinking Together groups. I noticed that the Thinking Together groups were the only groups in the local area that invited both the person diagnosed with dementia and a relative or friend to attend. In terms of my own experiences, a group like this would have been ideal for my family, as my father would have been able to gain support as well as my granddad; it would have also meant that the content could have been relayed to other people involved in my granddad's care. I was intrigued as to whether these groups are experienced as beneficial and if they were, wanted to know more about what was helpful or not helpful about them.

Having family members with dementia and experiencing a lack of support after a diagnosis naturally means that I am inclined to lean towards wanting the Thinking Together groups to be an effective treatment, as in the absence of a cure, non-pharmacological treatments are essential. I have been mindful of this inclination throughout the research and have used my reflective capacity, alongside regular supervision to remain as neutral as possible when conducting the interviews and analysing the content.

QUANTITATIVE RESULTS

Participants

There were 60 people (30 dyads) who attended the Thinking Together groups between September 2017 and March 2018 who met the criteria to be involved in the research; that is that one person in the dyad had a diagnosis of dementia, had mild/moderate cognitive impairment as assessed by a cognitive assessment such as the MOCA or ACE-R and had capacity to provide informed consent.

Out of the 30 dyads, 21 dyads gave consent to be involved in the research. Of the 21 consenting dyads, four dyads were seen at T1 and then stopped attending the groups; three dyads dropped out due to illness and one dyad dropped out as the person living with dementia had been taken into short-term residential care. This resulted in these four pairs being withdrawn from the research as they no longer met the criteria of needing to have attended a cycle of the groups and their data wasn't used.

In total, full data across all three time points was collected from 17 dyads, the baseline demographic and clinical characteristics for the 17 dyads can be found in Appendix 1. To summarise, 20 participants were female and 14 were male; 10 of the females and seven of the males had dementia. The carers were either friends or relatives and most of them lived with the person living with dementia, apart from two. The Consort Diagram located in Appendix 2 provides more information regarding the participant flow.

Diagnosis

Each of the dyads consisted of a person living with dementia and a carer. Out of the 17 people diagnosed with dementia, 12 had a diagnosis of Alzheimer's disease; two had a diagnosis of vascular dementia; two had a diagnosis of dementia with Lewy-bodies and one had a diagnosis of mixed Alzheimer's and vascular dementia.

Statistical data

The data for the different measures at the three different time points can be found in the two tables below. Table 2 shows the outcomes for the participants living with dementia and Table 3 shows the outcomes for the carers.

Table 2: Participants living with dementia outcomes

	Pre-intervention: T1 (n=17)	**Post-intervention: T2 (n=17)**	***t*-score for T1 vs T2**	**Eight week follow-up: T3 (n=17)**	***t*-score for T1 vs T3**
Anxiety (HADS-A)	4.24 (3.40)	3.53 (2.93)	2.94**	2.59 (2.85)	3.45**
Depression (HADS-D)	4.29 (2.95)	4.38 (3.06)	1.12	3.65 (3.00)	1.86
DEMQOL overall	89.53 (15.11)	98.64 (10.06)	-4.44**	103.12 (9.75)	-4.14**
DEMQOL feelings	37.06 (7.39)	41.65 (5.60)	-3.78**	44.06 (5.66)	-4.28**
DEMQOL memory	19.18 (3.56)	21.53 (1.84)	-4.24**	21.59 (2.79)	-2.68*
DEMQOL everyday	30.18 (5.43)	32.41 (3.57)	-3.65**	34.18 (2.04)	-3.86**
DEMQOL QoL	3.18 (0.95)	3.06 (0.90)	0.70	3.29 (0.59)	-0.52
ToDS	73.71 (11.18)	48.59 (12.60)	8.96**	41.00 (14.39)	9.54**

(**= 0.01 or less and *=0.05 or less)

Table 3: Carer outcomes

	Pre-intervention: T1 (n=17)	Post-intervention: T2 (n=17)	*t*-score for T1 vs T2	Eight week follow-up: T3 (n=17)	*t*-score for T1 vs T3
Anxiety (HADS-A)	4.47 (3.50)	5.06 (3.11)	-0.979	3.88 (3.35)	0.979
Depression (HADS-D)	3.89 (2.50)	4.82 (3.13)	-1.610	3.94 (2.49)	-0.108

(**= 0.01 or less and *=0.05 or less)

The differences between quantitative outcome measures at: pre, post and follow-up.

The quantitative data was analysed on SPSS and paired sample t-tests were used; the findings are detailed below.

Hospital Anxiety and Depression Scale: Anxiety (HADS-A)

Participants living with dementia

The anxiety scores (as measured by the HADS-A) for the participants living with dementia were found to be significantly decreased between T1 (baseline/pre-intervention) ($M = 4.00$, $SD = 3.39$) and T2 (post-intervention) ($M = 2.00$, $SD = 1.73$), $t(16) = 2.94$, $p = 0.01$. The anxiety scores remain significantly decreased for the participants living with dementia at follow-up T3 compared to T1 ($M = 1.29$, $SD = 1.40$), $t(16) = 3.45$, $p = 0.003$.

These differences demonstrate that the anxiety levels for the participants living with dementia decreased between T1 and T2 and that they remained significantly less anxious at follow-up.

Carers

There were no significant changes found in the anxiety scores for the carers at T1 and T2; there were also no significant differences found between T1 and T3 either.

Hospital Anxiety and Depression Scale: Depression (HADS-D)

Participants living with dementia

There were no significant differences found between T1 and T2 depression scores (as measured by the HADS-D) for the participants living with dementia. There were also no significant differences found between T1 and T3 depression scores for the participants living with dementia.

Carers

There were no significant differences found between T1 and T2 depression scores (as measured by the HADS-D) for the carers. There were also no significant changes found in depression scores between T1 and T3 for the carers.

Threat of Dementia Scale (ToDS)

There was a significant decrease found between the ToDS scores for the participants living with dementia between T1 (M = 73.71, SD = 11.18) and T2 (M = 48.59, SD = 12.60), $t(16) = 8.96$, $p<0.001$. It was also found that the ToDS scores remained significantly decreased at follow-up T3 compared to T1 (M = 41.00, SD = 14.39), $t(16) = 9.54$, $p<0.001$. A lower score on the ToDS represents feeling less threatened, therefore the results suggest that the participants living with dementia felt less threatened at T2 when compared to T1 and that this decrease was maintained at the T3 follow-up.

Dementia Quality Of Life scale (DEMQoL)

The DEMQoL questionnaire is split into four sections that can each be scored and the overall score can then be obtained; all mean scores across the time points for the different sections can be seen in Table 2.

Feelings

The first section is DEMQoL feelings and a significant increase in scores was found between T1 (*M* = 37.06, *SD* = 7.39) and T2 (*M* = 41.65, *SD* = 5.60), $t(16) = -3.78$, $p = 0.002$. DEMQoL feelings scores remained significantly increased at T3 compared to T1 (*M* = 44.06. *SD* = 5.66), $t(16) = -4.28$, $p = 0.001$.

Memory

The second section is DEMQoL memory and a significant increase in scores was found between T1 (*M* = 19.18, *SD* = 3.56) and T2 (*M* = 21.53, *SD* = 1.84), $t(16) = -4.24$, $p = 0.001$. DEMQOL memory scores remained significantly increased at T3 compared to T1 (*M* = 21.59, *SD* = 2.79), $t(16) = -2.68$, $p<0.02$.

Everyday

The third section is DEMQoL everyday and a significant increase was found for scores between T1 (*M* = 30.18, *SD* = 5.43) and T2 (*M* = 32.41. *SD* = 3.57), $t(16) = -3.65$, $p = 0.002$. DEMQOL everyday scores remained significantly increased at T3 compared to T1 (*M* = 34.18, *SD* = 2.04), $t(16) = -3.86$, $p = 0.001$.

Quality of life question

The fourth section is one question that asks participants to self-rate their quality of life. No significant differences were found between scores at T1 and T2 . There were also no significant differences found between T1 and T3.

DEMQoL overall score

A significant increase was found in the DEMQoL overall scores for the participants living with dementia between T1 (M = 89.53, SD = 15.12) and T2 (M = 98.65, SD = 10.06), $t(16) = -4.44$, $p<0.001$. DEMQoL overall scores remained significantly increased at T3 compared to T1 (M = 103.12, SD = 9.75), $t(16) = -4.14$, $p = 0.001$.

An increased score on the DEMQoL indicates a better quality of life, so this means that the DEMQOL scores on the feelings, memory, everyday and overall increased between T1 and T2 and that these increased scores were maintained at the T3 follow-up.

QUALITATIVE RESULTS: A THEMATIC ANALYSIS

Interviews were conducted with 10 dyads; each member of the dyad had their own individual interview, so there were 20 interviews in total. All names have been changed to protect participant confidentiality. Demographic information for the participants whose quotes have been used can be found in Appendix 3.

The interviews were analysed using thematic analysis; Braun and Clarke's (2006) six-stage approach to thematic analysis was followed. These six stages consist of: becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining themes and then writing up. In the initial coding stage, 126 codes were found in total. These were then grouped into seven initial patterns, which were then redefined into four themes with sub themes. A diagram of the thematic analysis process can be found in Appendix 4 and a coded interview transcript can be found in Appendix 5. The final themes and sub-themes identified can be found in Table 4.

Table 4: Overview of themes and sub-themes

Theme	**Subtheme**
1. The splitting of the groups	1a. Getting more out of a big group 1b. Safety 1c. Suspicions 1d. Carers were freer to converse 1e. Will they remember?

Theme	Subtheme
2. Thinking and feeling differently	2a. Gaining knowledge 2b. Further support 2c. Acceptance 2d. Shared experiences
3. The perceived threat of a dementia diagnosis	3a. Feeling less threatened 3b. Participants had never felt threatened by a diagnosis of dementia 3c. Threat levels stayed the same
4. Group dynamics	4a. Not enough opportunity to talk 4b. Group facilitators utilised person-centred skills

1. The splitting of the groups

This first theme focuses on the different experiences people had when the Thinking Together groups were split into two groups; this happened in each of the seven sessions. All participants remained together for the first half an hour of each session, for the next 45 minutes the carers went into another room and then for the last 15 minutes of each session all participants came back as one big group again. The Thinking Together groups are unique in encouraging the person living with dementia to bring a relative or friend along to the group and are also unique in then splitting the groups for part of each session. This theme has several sub-themes that detail the different experiences and identify distinct aspects of this theme.

1a. Getting more out of a big group

This sub-theme looks at people's experiences of preferring the group when it was one big group, rather than when it was split into two. There were seven people in total that expressed this preference and there were varying reasons for this; these people were a mixture of both carers and people living with dementia.

Some attendees preferred the group as a whole because they felt that they got more out of it when everyone was together. They felt it was important to hear the experiences of the people living with dementia. This is indicative of some people feeling that they would gain more from this or find this more interesting than they would from only listening to the experiences of the carers.

> 'Ben: It didn't worry me particularly but I think when we were all together I think I felt I got more from it when we were all together'. **(Ben, person living with dementia)**

> 'Jean: No, I preferred the big group.
>
> Interviewer: You preferred the big group. Why was that, why did you prefer the big group?
>
> Jean: Because I could hear the other people who have the dementia, when they were talking of their own experiences'. **(Jean, carer)**

Other attendees expressed preference for one big group, but for different reasons. As well as everyone being together for the first half an hour of each session, it was also when the psychoeducation elements of the group took place. It was found that some of the group members found the information-based part of the session the most useful, even though they found the split 'interesting'. The psycho-education elements of the group consisted of information about the different types of dementia, the different ways it can affect individuals and support available for those diagnosed and their carers.

> 'Barb: It was far more useful when we were one group together because that was mainly information-based. And when you were in the other part, whilst it was quite nice to have the opportunity to say something more individually, it was the first half that was the most useful'. **(Barb, carer)**

As described in this sub-theme, some of the group attendees preferred taking part when all participants (both the person living with dementia and their carer) stayed together in a larger group rather than the group was split up into two. However not everyone shared this opinion, as demonstrated in some of the other sub-themes.

1b. Safety

Some of the participants noticed that the people living with dementia didn't always feel that safe when the groups were split into two. Dementia is an illness that can often make people feel vulnerable because of the way it affects people's ability to retain information and people can often begin to rely on their partners; it therefore understandable that when their support is taken away, people can feel unsafe.

Some of the people living with dementia described feeling more comfortable when they had their partners in the room because they were concerned that they might start to feel unwell and worried about not having their partner there to support them.

> ‘Pat: No, I would rather he’s in the room.
>
> Interviewer: You’d rather he was in the room, okay. And why is that, why do you prefer if he’s in the room?
>
> Pat: Because I’ve got this awful giddy feeling and I suddenly think, well, if something happens to me and I really can’t face any more, then he’s there to help me’. **(Pat, person living with dementia)**

Other participants didn’t feel unsafe themselves but observed some of the people living with dementia feeling uncomfortable when their carers were out of the room. There are participants that attended different courses of the Thinking Together groups that observed or experienced this, which suggests that it wasn’t something that was isolated to one single course of the Thinking Together groups.

> ‘Jean: Only that some of the people who have the dementia don’t like being left for any period at all on their own. And apparently, one of them, when her husband goes out, she tends to go out looking for him outside the front door, that type of thing. And it makes you think, yes’. **(Jean, carer)**

This observation that some of the people living with dementia felt unsafe was observed by other participants, who then go on to describe having to spend time comforting the people who were distressed. This participant below also says that the group he was in, which consisted of the people living with dementia, was told a different reason to that of his carer about why the groups were split; from here, suspicions started to generate, which is explored in the next sub-theme.

> ‘Ben: Well, it’s a bit off-putting in many ways because a lot… I accept it for what it was, they go into the other room, but the whole group, including this lady who got very uptight about it and I had to say to her well don’t worry your partner has gone in the room with them as well and said that he'll be back soon and I spent most of that time with her, sort of talked to her about it. But the group generally weren't very happy with that. We were told that they were split because the room wasn’t big enough for all of us but my wife suggests that wasn’t the reason we were split’. **(Ben, person living with dementia)**

As described in the methodology, the participants are told about the structure of the group in the first session so they are aware a split will happen, but it could be that some of the groups were told a mixture of reasons and they have retained different information, which in this case was when suspicions started to generate.

1c. Suspicions

It was identified that suspicions started to generate when the groups were split into two; these suspicions only played out in the group of people living with dementia. The previous sub-theme described how some of participants living with dementia reported being told that the groups were split due to lack of room and that they found out their carers were told a different reason. Naturally, if people feel that they aren’t being told the truth they can start to become suspicious about what is going on and this can impact the therapeutic process.

> ‘Ben: And the general consensus was what are they doing out there? What are they being told out there that we're not being told? I accepted what was

> going to happen and it wasn't going to be anything really serious but a lot of people in the group were quite…
>
> Interviewer: Struggling with that.
>
> Ben: Yes. We were told we were split because the room wasn't big enough for the complete group and they had to move the other half to the other room to give everybody time to talk. And I accepted that but that wasn't the reason I was told afterwards by my wife.
>
> Interviewer: And in a sense it is so everyone can talk but it's also so that you feel more able to talk freely and some people in front of their partners might struggle to say certain things.
>
> Ben: The group as a group were suspicious.
>
> Interviewer: Yes, okay, suspicious of what's going on in the other room.
>
> Ben: Yes, yes'. **(Ben, person living with dementia)**

These suspicions continued to develop when some of the people living with dementia described feeling as though they were being talked about, however, this particular participant also coupled this with an understanding that their partner needs time to talk.

> 'Lisa: I felt that I was being talked about. It was obviously what they were doing but I can understand why because my husband needs to know. He's looking after me. Apart from that it was great. I really enjoyed it'. **(Lisa, person living with dementia)**

As well as suspicions, worries were expressed by participants living with dementia about what the carers were talking about. The worries continued to grow in a different way when some of the people living with dementia expressed worrying about whether they would remember what to say without their partner in the room.

> ‘Barb: I think the people that were left, the people with dementia, well, they were worried about what was going on in the other room’. **(Barb, carer)**

> ‘Mel: When he was out I was okay. I was just thinking well am I going to remember to answer the questions that they ask me, but I did.’ **(Mel, person living with dementia)**

The suspicions and worries arose in the group consisting of the people living with dementia, but the group of carers reported different experiences, as explored in the next sub-theme.

1d. Carers were freer to converse

Some carers identified that they found that they were ‘freer to converse’ when their partners weren’t in the room. As well as being freer to converse, participants reported that they found the split beneficial. The reasons for this varied, however one reason was that the carers found that they could share experiences about day-to-day life, so that they could gain knowledge on other peoples' experience of living with someone who has dementia.

> 'Interviewer: Yes? Okay. That's good. So the groups, you went in for a bit together and then they got split into two. So how did you find it when the groups were split into two?
>
> Matt Oh, beneficial.
>
> Interviewer: Yes? And when you said it was beneficial to split into two what did you find beneficial about it?
>
> Matt: The group I was in was freer to converse'. (**Matt, carer)**

> ‘Fran: I thought it was a good idea because the carers could talk among themselves about different aspects of their daily life, and it gave you an insight into what problems they had with more disabled people, should we say’. **(Fran, carer)**

Some of the carers reiterated that they were able to speak more openly when the groups were split, but go on to say that the reasoning behind this was because there were some things that they wanted to say that they wouldn’t be able to say in front of their partners because of concerns that they might upset them. Due to the nature of dementia, carers can often find it difficult living with someone with dementia and from what the carers reported, it appears that the split allowed a chance for them to gain support over their shared experiences. Being a carer of someone living with dementia can often be lonely and isolating, so meeting others in a similar position might help them to feel less alone.

> ‘Sammy: Well some of the others were able to sort of say things that they hadn’t wanted to say in front of their particular partner. And one couple in particular I felt very sorry for because the husband, who was the carer, was a sick man himself. It was interesting to see how they were coping’. **(Sammy, carer)**

> ‘Jean: I think it was probably more open because probably, the carers didn’t want to discuss some things in front of their partners as it may have upset them. And they were able to do that, particularly one of the groups, was a daughter, she was there with her father. And

> obviously, it was easier for her if she was talking with us in a room on our own, that type of thing'. **(Jean, carer)**

These experiences of the carer contrast with the accounts of the people living with dementia who didn't like the split because they were filled with suspicions that they were being talked about. This suggests that whilst the split serves as a potentially beneficial function for some of the carers, it might not be as beneficial to some of the people living with dementia. These findings indicate that it might sometimes be challenging for therapists to meet the emotional needs of both sets of participants in one therapeutic context, a point that I will return to in the discussion section.

1e. Will they remember?

Another topic that was identified centred on the way dementia affects people's memory, in particular their short-term memory, which can make it difficult to retain information.

Some of the carers expressed concern that the people living with dementia won't remember what is being said when the groups are split. Some of the group members talk about witnessing the way that dementia can affect short term memory within the group setting and also picked up on the fact that some of the people living with dementia didn't acknowledge that they had dementia.

> 'Interviewer: Okay, so as one big group, it was more helpful, okay. So we've covered different aspects of the group. Are there any other comments that you want to make about the groups that you don't think you've been able to say or we haven't covered?

> Barb: No, I don't think so. I did notice at one time, it was only the people with dementia that went. Well, I would have thought that was next to useless because half the time, they're not going to remember what's suggested or what's said, and some of them don't acknowledge really that they've got it. There was one particular fellow there that evidently kept on asking his wife to repeat what they were going to be doing that day, but of course, because he didn't remember, he didn't realise just how many times he had been asking this particular thing'. **(Barb, carer)**

Dementia does affect memory, so this is an interesting point, but from this research it has been found that the people living with dementia have been able to recount their experiences of the group, whether this is in the form of thoughts or feelings. A worked example of this was seen when both the people living with dementia and the carers were able to recount the reasons they were told regarding the split, which runs counter to the narrative that people living with dementia will not be able to remember much. This and other evidence from the interviews suggests that memories are retained from the group and that emotionally salient material might be easier for participants to recall. The group facilitators also give out paper copies of the things explored in the groups so that the people living with dementia can recap the material if needed.

A statement which focuses on whether people living with dementia will remember much potentially undermines the whole group and the value of having groups for the people diagnosed. Coupled with this, feelings that people living with dementia won't remember anyway may affect the therapeutic process and how the people living with dementia are regarded by the carers.

2. Thinking and feeling differently

This theme encapsulates the ways in which people reported that the Thinking Together groups enabled them to think and feel differently. This theme contains several sub-themes that distinguish the different ways that people say that their thoughts and feelings have changed or altered in some way after having attended the groups.

2a. Gaining knowledge

Both the people living with dementia and the carers identified that one of the most useful aspects of the group was receiving information on the different types of dementia. Dementia is caused by many different illnesses and is a syndrome in which there is progressive cognitive impairment resulting from Alzheimer's disease, vascular dementia and Lewy-body dementia, amongst others.

Participants talked about not being aware of the different types of dementia and that the learning enabled them to put things into focus. This was further elaborated when both the people living with dementia and carers described that learning about the different types of dementia allowed them to know more about what to expect in the future. Often when someone gets a diagnosis of dementia, all that they know is that there is no cure and it is a progressive illness. The groups allow for the opportunity to find out more accurate information about the prognosis and also enable people to see how they can live well with a diagnosis of dementia.

> 'Sammy: Well, having dementia sort of defined more because it does seem to be quite a few different types of dementia which I didn't realise and just sort of getting to know a little bit more about the future, the support out there and what we can do and what we can't do and things like that. It put it a little bit more into focus I thought'. **(Sammy, carer)**

The carers describe finding it useful to know about more about the future and further support, whereas the people living with dementia describe other information useful.

> 'Ben: Yes I did. The doctor we had that talked about various types of dementia and how it affects the brain and that I found very useful because you know more about it then and you know what's actually happened'. **(Ben, person living with dementia)**

Some of the people living with dementia said that finding out about the different types of dementia was useful because they were able to find out more about what had happened to them and how dementia might be affecting their brain.

2b. Further support

The carers said that the information provided in the group enabled them to understand their partner's path and also allowed them to gain knowledge on the further support available. From attending the groups, carers described feeling that they now know what benefits are available as a carer of someone living with dementia. As many older people don't always have access to the internet, it can be difficult to find out about the benefits available, so hearing the information in a group can be a useful way of distributing this information.

> 'Matt: Understanding what odd advice or information is available. I didn't realise it was such a wide amount available. Understanding other people's problems and my wife's own path. The financial benefits. When it gets to that stage do I need to get a carers, things of that nature, the steps to take, the benefits of it. Yes, the general information that they give you. Of course there's pages and pages of it at home. I didn't realise there were so any different types of dementia'.
> **(Matt, carer)**

This point is further expanded on when some of the group members spoke about learning about specific benefits such as the carer's card. There is also a blue card that is mentioned, this is something that is given out in the groups that the person living with dementia can carry around with them, in case they become lost or confused. These practical measures are simple yet effective and are not that well known about.

> 'Jean: They were helpful with things like getting the carer's card in case anything happened. We do carry that, and he carries a blue card now with my telephone number on it. And I think it was a lady in one of the groups, who suggested getting a badge for the car because my husband can't walk very far.

> Interviewer: Yes, so that was useful, I guess, knowing what support is out there as well?
>
> Jean: Yes'. **(Jean, carer)**

2c. Acceptance

The topic of acceptance was identified in some of the participants. Both the people living with dementia and the carers shared that the groups allowed them to feel differently about the situation in terms of learning how to accept it. One of the carers described that the groups were useful in helping him to understand his wife's perception. This participant talked about learning to accept the situation, which has helped them to not get as annoyed as they had been getting before. This group member goes on to say that they had started to 'let things go' because they had been able to acknowledge that a dementia diagnosis is unfortunately not something that can be changed and instead has to be adapted to in order to live well with a diagnosis of dementia.

> 'Matt: Oh, definitely, yes.
>
> Interviewer: Are you able to expand on that at all? Any particulars?
>
> Matt: Yes, understanding you're in a process position and the fact that… How can I put it? Mainly understanding the other person's perception of what's happening and how… Not to get annoyed at what's happening. So let some things go because you're not going to change it. You've just got to accept it. That situation's there and try and alter the conversation if that's necessary and turn it into something else. That's about it, it's the main thing.
>
> Interviewer: So there's an element around acceptance then?

> Matt: Yes, being able to accept things and let them go a little bit more’.
> **(Matt, carer)**

One of the people living with dementia described actively making a decision to accept the situation after finding out that there wasn’t anything that can be done to change the diagnosis.

> ‘Ben: When the doctor said to me you’ve got dementia I said what can you do about it? He said nothing. I thought you can't do anything. I said what happens? You just get worse. I thought well in that case I'll just have to put up with it and that's when I decided to accept it… I've always had a quite good sense of humour and I thought well I'll keep my sense of humour and I've found that very helpful, and I can't remember what your original question was, you know. **(Ben, person living with dementia)**

Other participants also described becoming more accepting of the situation and said that they have been able to do this by meeting other people in a similar position. Often carers can feel very alone, so being able to find acceptance in meeting others in similar situations is something that the groups can offer. Sharing experiences also bought comfort as well as acceptance to participants; this is looked at in the next sub-theme.

> ‘Jean: No, I don’t think so. Probably, I’ve become a bit more accepting of the situation because of knowing that other people are in the same position’.
> **(Jean, carer)**

As well as acceptance of the situation, attendees also describe the groups helping them to feel more confident. If acceptance results in people feeling that the situation is easier to deal with, then this could be why confidence increased.

> 'Dan: It actually made me feel quite confident'. **(Dan, person living with dementia)**

2d. Shared experiences

Participants often spoke about being able to share experiences and this was shown to be useful in different ways for different people. Some of the people living with dementia found comfort in realising that they weren't alone and that it wasn't just them in this situation; one participant also seeks comfort in the fact that others were worse off than him. Participants also describe finding it helpful meeting others so that they could see how other people coped, which suggests that comfort was found in knowing that other people do cope.

> 'Dan: It made us aware that everybody there had a whole group of problems, and the fact that it wasn't just you was comforting'. **(Dan, person living with dementia)**

> 'Ben: Yes, meeting the other people. I like meeting people in any case
> but to meet people who were struggling more than I was in many
> ways with the problem I found that very helpful.
>
> ....
>
> Ben: So listening to these various people and what they had to say and how they were coping with it I found very useful. Because as far as I'm

> concerned I don’t think I've got any real problem. My wife might say oh a problem perhaps than I recognise. But I know I've got dementia and I know it's going to get worse. I hope it doesn’t get too bad. But I listened to these other people and I thought well I could be a lot worse off than they are.
>
> Interviewer: Okay. So that aspect of it kind of made you feel maybe a sense of relief that you were more okay?
>
> Ben: Yes, more comfortable perhaps.
>
> Interviewer: More comfortable, yes okay. So what about the other things the group covers, kind of like the information on different memory problems?
>
> Ben: That was very good’. **(Ben, person living with dementia)**

A carer expands on this point and talked about it being helpful hearing about how people were managing day to day, which has links to learning about how other people cope. This participant also said that they noticed that the male carers had a different outlook on how to cope compared with the female carers. It is interesting to begin to think about how gender differences may play a role in how people cope and manage with a diagnosis of dementia.

> ‘Jean: The listening to other people with their experiences of the same thing, and the people running the group would answer any questions very thoroughly. They were being very helpful.
>
> Interviewer: Okay, and when others shared their experiences, how was that helpful to you?
>
> Jean: I hadn’t talked to anyone else. And so I was able to hear how they were managing day-to-day, and the different ways. I noticed particularly

> that the men who were the carers had an entirely different outlook on the whole thing'. **(Jean, carer)**

3. The perceived threat of a dementia diagnosis

3a. Feeling less threatened

Some of the carers and people living with dementia reported that their threat levels lessened as a result of attending the group and that this was due to varying reasons. One carer reported that they felt less threatened by their diagnosis because they realised that they aren't alone and now had ways of getting further support. It is important to note that a threat of a dementia diagnosis can be experienced by the person diagnosed and the people close to them who also have to adapt to a chance in circumstances.

> 'Interviewer: So do you feel less threatened by your husband's diagnosis of dementia after the groups?
>
> Deana: I think yes, you don't feel alone. You know there are people out there now who can help you and so that's very good. **(Deana, carer)**

Some of the participants living with dementia described feeling less threatened by their dementia because in comparison to some of the other attendees, they didn't think they 'had it too bad'. Being around people at varying stages of dementia can usually have one of two effects, either people are glad that they aren't as far along as others, or people can worry about what the future holds. In this case, it is the former, which has led to threat of dementia levels lessening in some participants.

> ‘Interviewer: So now the groups have finished do you feel less threatened by your memory problems?
>
> Mel: Yes.
>
> Interviewer: And why is that?
>
> Mel: Well, I didn’t think I had it too bad. And when I got there I realised how bad some people are.
>
> Interviewer: Okay.
>
> Mel: Makes you feel better because you aren’t as bad as they are’. **(Mel, person living with dementia)**

In this case, seeing that others were further progressed with their dementia led to threat levels lessening, however, this also leaves open the possibility that things will get worse, which could alter threat levels in different ways for different individuals.

3b. Participants had never felt threatened by a diagnosis of dementia

A few of the people living with dementia talked about how they had never felt threatened by their diagnosis of dementia. An assumption made in this research is that people are likely to feel threatened by a diagnosis of dementia because of the nature of it and because there is no cure; however, on a conscious level some people report to not feeling threatened by it. One participant living with dementia described not feeling threatened by their diagnosis of dementia, but described this as a conscious choice after receiving the diagnosis. This suggests that the threat of dementia may be linked to the acceptance of it. One group member described deciding ‘to just put up with it’ after finding out that there isn’t anything you can do to change it or stop it.

> ‘Ben: No, I never felt threatened in the first place. When the doctor said to me you’ve got dementia I said what can you do about it? He said nothing. I thought you can't do anything. I said what happens? You just get worse. I thought well in that case I'll just have to put up with it and that's when I decided to accept it… I've always had a quite good sense of humour and I thought well I'll keep my sense of humour and I've found that very helpful, and I can't remember what your original question was, you know.
>
> Interviewer: It was about feeling less threatened by the diagnosis. But I guess if you…
>
> Ben: Yes, but I never felt threatened by it. **(Ben, person living with dementia)**

3c. Threat levels stayed the same

Some of the carers reported that their threat levels stayed the same after having attended the groups. A carer reported that their threat levels had stayed the same, but that actually seeing people in the groups who were ‘further down the line’ made them realise that it is likely that life will get harder as time goes on. This suggests that threat levels may change if the situation gets progressively worse.

> ‘Barb: I don’t think it’s changed because you do see too, in our particular group, whilst they were meant to be all in the early stages of dementia, there were two ladies there that were very much, I

> don’t know how far down the line, but down the line. And so really, you do realise that it’s highly likely life will get harder.
>
> Interviewer: Okay, so there is that aspect of it.
>
> Barb: It’s that aspect as well’. **(Barb, carer)**

Another carer described the threat of dementia not changing but said they feel that they now have more information about it. This suggests that for this participant, more information neither increased nor decreased the threat levels.

> ‘Matt: Yes, we call it memory problems.
>
> Interviewer: Memory problems. Okay. So the group aims to kind of help people with their memory problems. Do you now feel less threatened by that kind of diagnosis of having a memory problem?
>
> Matt: No, I feel the same as before. It's just that I've got a little more knowledge about it. **(Matt, carer)**

4. Group dynamics

There were different aspects of the group dynamics that were identified through listening to participants’ accounts. One of the research questions aimed to look at what people experienced as helpful and unhelpful within the group; this research aims to evaluate the Thinking Together groups, so this theme should provide useful feedback for the running of future groups.

4a. Not enough opportunity to talk

Some participants reported feeling that there was no discipline to the group and that people ‘butted in’. Some of the other participants reported finding that some attendees 'dominated' the group. Within group settings, there will always be group members who speak too much and some who speak too little. It sounds like some of the group members felt that they didn't get to contribute as much as they would have liked to.

> 'Jim: Well, they didn't come up like that. It was an open group and people said what they liked when they butted in. So, there was virtually no discipline to the group. But, having said that, it was not a bad thing. It just means that everybody was saying their bit and perhaps for too long, some of them'. **(Jim, person living with dementia)**

> 'Jean: No, I don't think there was anything, not that I can think of. The only thing, obviously some people are more outgoing than others, and they would tend to dominate the group. But that was all'. **(Jean, carer)**

This experience was shared by others, who also would have liked more opportunity to talk. Fred reports feeling that the group facilitator wasn't particularly concerned with hearing him. Fred's dementia had affected his speech, making it more difficult for people to understand him; it could be that the group facilitators were struggling to hear what he said and so in turn he wasn't given as much opportunity to talk as other people. As dementia manifests in several different ways, it is important that the group sessions are adapted to meet the individual needs of the participants.

> 'Fred: I think there wasn't enough opportunity for talking.

Interviewer: Okay. So you would have liked more opportunity to be able to talk?

Fred: Yes.

Interviewer: And why do you think there wasn't enough opportunity? Was it to do with how many people were in the group or were the groups not long enough?

Fred: I think she didn't… She wasn't particularly concerned with hearing me.

Interviewer: Okay. So you would have liked the chance to maybe talk a little bit more about your experiences.

Fred: Yes'. **(Fred, person living with dementia)**

4b. Group facilitators utilised person-centred skills

A common pattern identified in many of the interviews was the positive experiences of the group facilitators, in terms of how they related to the participants interpersonally. The group facilitators aim to use person-centred skills in order to develop a safe space in which participants can explore the impact of a diagnosis of dementia. A range of responses were found that indicated people felt that the person-centred skills of empathy, congruence and unconditional positive regard were being used by the group facilitators, with good effect.

'Cat: Very good. They really listened and helped us all to feel comfortable'. **(Cat, person living with dementia)**

'Lisa: No, I don't think. We both said to all of them how good they were

> and how helpful they were because they were helpful for my husband as well. Yes, I thought they were great, they always cared and listened to us.
>
> Interviewer: So it was a positive experience?
>
> Lisa: Yes, it definitely is. It was a big help yes'. **(Lisa, person living with dementia)**

> 'Sammy: Oh they ran it very well I thought. They were very helpful and empathised with our situation. **(Sammy, carer)**

Active empathic listening is a core person-centred skill and participants demonstrated that this skill was being utilised by the group facilitators. Person-centred skills are utilised so that people can feel confident in discussing difficult topics whilst knowing that they won't be rejected. Ron describes how the group facilitators allowed a space where 'difficult subjects' could be explored, which suggests that the person-centred skills used within the groups were effective.

> 'Ron: Oh, very good, all of them. Yes, every single person who was running that group was very, very good, yes. They allowed an opportunity to talk about really difficult subjects'. **(Ron, carer)**

Having a space in which the people living with dementia and the carers can explore the more difficult aspects of a diagnosis of dementia is one of the main aims of the Thinking Together groups and Ron explains that he experienced precisely this.

DISCUSSION

In summary, the findings of the results were that the participants living with dementia were feeling significantly less threatened by their diagnosis of dementia, alongside feeling less anxious and reporting a better quality of life at the end of the intervention than they were at the start. There were not any significant differences found in the carers' anxiety and depression scores at the end of the intervention when compared to the start. Themes identified in the qualitative analysis included participants reporting that they were feeling and thinking differently after having attended the intervention and that they had varying experiences of when the group was split.

Within this discussion, the research questions will be addressed, the findings of the current study will be explored, the study will be critically evaluated in relation to existing research and final conclusions will be drawn. The research questions were answered by employing the use of quantitative and qualitative measures; the two different approaches will be discussed in relation to each other when looking at the findings.

Are the participants living with dementia less threatened by their dementia at the end of the intervention than they were at the start?

The quantitative results showed that the scores on the Threat of Dementia Scale decreased between the pre and post measures, so this indicates that attending the Thinking Together groups had an impact on how threatened people felt about their diagnosis. The decrease in threat levels was maintained at the follow-up measure, which was taken eight weeks after the groups finished. Within the qualitative findings, people’s experiences of whether their threat levels changed varied. Some people reported finding that the threat decreased because they now know more about dementia; this reflects one of the key elements of the group which is psycho-education about the different types of dementia and the progression of them. Research has found that dementia is the most feared health condition in the UK and that 62% of people surveyed felt a diagnosis would mean their life was over (Alzheimer’s Society, 2016). Some people will most likely walk into post-diagnostic groups thinking that they are going to die sooner than they had expected alongside possible feelings guilt, shame, the loss of social contact and knowing the process of decline (Cheston & Christopher, 2019). If they then attend the groups and realise that they can actually live well with dementia this could be one of the factors that contributes to the threat of dementia decreasing.

Interestingly in the qualitative findings, one of the sub-themes identified was ‘Participants had never felt threatened by a diagnosis of dementia’. As dementia is the most feared health condition in the UK, there is an assumption that a diagnosis of this kind would therefore be a threat to the person in some way. Within the above sub-theme, several interviewees stated that they haven’t ever perceived a diagnosis of dementia as a threat. The interviews uncovered that one of the participants made a conscious decision that dementia isn’t something that can be medically cured and they therefore decided to ‘put up with it’ and use their sense of humour to get them through it. Research has found that people who have good self-esteem, social connectedness and meaning in life are more able to think about the nature of threat without becoming overwhelmed with anxiety (Cheston et al, 2015), so it is possible that the participants in this study who don’t experience a dementia diagnosis as a threat may score highly on these three factors or that they may just choose not to think about the diagnosis.

Another sub-theme identified was ‘threat levels stayed the same’; here some people identified that they felt the same about the diagnosis, but that they now feel that they have more knowledge on it and therefore are more able to cope with it. This suggests that more knowledge will not always change the threat levels, but may leave people feeling more ‘in the know’. Another participant said that their threat levels didn’t change, but that that the groups made them realise that it is ‘highly likely that life will get harder’. It is interesting that knowing life will get harder didn’t change how threatening the diagnosis was, but may mean that ‘threat’ is something that develops as the progression of dementia continues.

Whilst the quantitative results show a clear decrease in the threat of dementia, these results are not completely in line with the qualitative findings. This could be for several reasons; one of these being that it is possible that the threat of dementia is not necessarily felt on a conscious verbal level, but rather a felt sense that can’t be articulated. The threat of dementia scale asks participants to rate how threatened they feel by some of the things that can happen following a dementia diagnosis, so by breaking down the different elements, it could also be that people are able to break down the potential threat further than being asked about the threat in an interview. Another possibility is that not verbally expressing dementia as a threat may also be a defence strategy employed by people to distance them from the distressing reality that a dementia diagnosis could bring.

Are the participants feeling less anxious and depressed at the end of the intervention than they were at the start?

People living with dementia

Two of the research questions relate to whether the groups help all the attendees feel less anxious and depressed. These questions were investigated using both qualitative and quantitative methods. The quantitative measured used was the Hospital Anxiety and Depression Scale (HADS), which asks participants to decide how much each statement in the questionnaire relates to them; the statements are either associated with anxiety or depression and are scored separately at the end.

The findings in the current study demonstrated that the anxiety scores for the people living with dementia were significantly decreased between the pre and post measures and that the scores remained significantly decreased at the follow-up measure. This finding indicates that the people living with dementia felt less anxious after attending the groups and some of the reasons were identified in the qualitative findings; these can be found in the theme 'Thinking and feeling differently'. A sub-theme within this theme is 'Gaining knowledge', which included the people living with dementia speaking about finding it helpful to be given information about the different types of dementia because they can then make sense of what has happened to them. The fear of the unknown has been linked to many anxiety disorders (Gorka et al, 2016), so increased knowledge may go hand in hand with decreased anxiety. Within this theme, a further sub-theme of 'finding comfort in a shared experience' was identified and the people living with dementia describe how they no longer feel alone as they have met people in a similar position. Loneliness has been found to be strongly associated with anxiety (Jones et al, 1990), so therefore people reporting to feel less lonely and more connected fits with the current literature on how anxiety can be reduced.

The quantitative findings showed no significant difference in the depression scores between pre, post and follow-up in the people living with dementia; this has also been found in other studies that assessed mood in participants attending dementia support groups (McAfee et al. 1989; Marshall et al. 2005; Logsdon et al. 2007). Whilst there are no quantifiable findings for a change in depression scores, there were elements identified in the qualitative findings that suggest that mood may have been impacted in the people living with dementia. As discussed above, one of the themes identified within the qualitative data included a subtheme in which people living with dementia reported that they found comfort in sharing experiences with others in a similar situation. A recent study found that helping others regulate emotions through sharing experiences, predicts decreased symptoms of depression (Dore et al, 2017). Whilst the scores on the depression element of the HADS didn't decrease significantly, it doesn't necessarily mean that participants felt sense of depression didn't change, but it could indicate that changes were potentially not captured on quantitative measures.

Carers

On the quantitative measure, the carers showed no significant changes in their scores for anxiety or depression, however, when looking at the qualitative findings, the carers report changes to their lives that might suggest that symptoms associated with anxiety and depression did potentially alter in some way. Some of the carers described that the groups helped them to become more accepting of the situation, which has led to them feeling less annoyed and being able to 'let things go'. As can be seen in the efficacy of Cognitive Behaviour Therapy (CBT) research, if healthier thoughts and behaviours can be utilised, this can directly impact mood in a positive way (Hofmann et al, 2012). Other people echoed the feeling of acceptance of the situation as they had met others in a similar situation and now realised they were not on their own. As can be seen in Acceptance and Commitment Therapy (ACT), choosing to accept a situation for what it is, rather than fight it, is a skill that has been shown to lower levels of anxiety and depression (Fledderus et al, 2012). A working example of this skill in action can be found in a book called 'Dear Alzheimer's that was written by Keith Oliver; in this book, Keith describes how helpful ACT was, for precisely these reasons.

ACT has been found to be effective in reducing symptoms of anxiety and depression and research has found that one of the ways the outcomes were mediated was through acceptance (Forman et al, 2007). This suggests that if people attending the group reported being able to feel more acceptance of the situation, this could have mediated reduced symptoms of anxiety and depression, even though these changes may not have been captured on the quantitative measure used. This highlights the importance of taking a pragmatic approach to this research, as a positivist paradigm would have simply found a null finding.

Do participants report a better quality of life at the end of the intervention than they did at the start?

Another of the research questions aimed to look at whether quality of life was affected in the people living with dementia as a result of attending the Thinking Together groups. This was researched primarily by using the Dementia Quality Of Life scale (DEMQOL).

The DEMQOL is split into four sections. The first section asks participants to state how often they have experienced a variation of feelings in the past week. The feelings that are asked about range from more positive feelings, for example, confident, cheerful and enjoyment and then includes some more negative feelings such as sadness, loneliness and frustration. The results show that there was a significant increase in scores in this section and that this was sustained for the follow-up measure. This indicates that in some way, the groups may have changed how people were feeling and that the groups enabled more positive emotions to be accessed. This was further demonstrated in the qualitative findings as the theme 'Thinking and feeling differently' identified some of the ways that people were feeling differently. Increased confidence was one of the feelings identified by a participant that they attributed to attending the groups. Participants also describe feeling less frustrated and irritated at the situation after having attended the groups. The quantitative and qualitative findings can be seen to complement each other in terms of participant's feelings having changed after attending the groups.

The second section asks participants to rate how worried they felt about different aspects of their memory. There was a significant increase in these scores which suggests that people felt less worried about their memory after having attended the group. This was sustained at follow-up which indicates that these effects weren't just short-term. The qualitative findings identified feelings of acceptance; increasing acceptance of internal experiences has been found to be negatively associated with worry (Roemer et al, 2008), so the findings of acceptance in the current study supports the quantitative findings of the DEMQOL that worry decreases. The qualitative findings also included a sub-theme that looked at people having gained knowledge on the different types of dementia. People described finding it useful to learn about what has happened or is happening to them. Findings from other studies have found that increased knowledge about the future in elderly people was consistently associated with lower worry scores (Neikrug, 1998). This suggests that increased knowledge on dementia may also result in people feeling less worried.

The third section asks people how worried they have felt by different aspects of everyday life; these aspects include having enough company, getting support when needed and how the participants feel in themselves. There was a significant increase in these scores between the first and second time point which indicates that people felt less worried about aspects of everyday life after attending the groups. This was sustained at follow-up which suggests that the worries are less present after the groups had ended. Within the qualitative findings, it was found that as well as finding comfort in other's experiences, participants were also able to listen to how other people coped in order to aid with their own ways of coping. Increased coping skills will lead to a better quality of life in relation to day to day activities, so the qualitative findings appear to support the quantitative findings.

The last section is a single question asking participants to rate their quality of life. There were no significant differences in these scores across any of the time points, which suggests that quality of life changes were more easily detected when questions were split into different areas of life, rather than one overall rating. This is a similar pattern to the findings of threat of dementia, in that changes seem to be more easily detected when the area is split up into its components, rather than as an overall rating.

Which elements of the group did the participants find the most and least useful?

The final research question focused on which aspects of the group participants found most and least useful. This question was explored using the semi-structured interviews and a range of findings were identified.

The splitting of the groups

One of the main themes identified in the interviews centred on participant's experiences of when the groups split into two in each of the sessions. There was a mixture of responses regarding people's experience of the split; some found it beneficial whilst others didn't.

Some of the people living with dementia and the carers said that they found that they got more out of the group when everyone was together. Several of the participants described finding it more useful as one big group because they wanted to hear everyone's experiences, not just the people in a similar position to them. There were some further sub-themes identified that were unique to either the experience of only the people living with dementia or only the carers.

There were two patterns identified that were unique to the people living with dementia and these were feelings of lack of safety and feelings of suspicions when the groups split. In terms of safety, it was reported by participants that some of the people living with dementia felt unsafe when their partners were out the room; this was either because they were worried about not having their carer's support or that they were worried about forgetting what to say. Research has shown that people living with dementia can become reliant on their carers to make decisions for them, so when carers are absent, it could indicate that the people living with dementia may feel unsafe in some way as the person they rely on is absent (Samsi and Manthorpe, 2013). Other research stipulates that a dependence on a carer is a necessity for people living with dementia as they become needed both physically and psychologically (Kitwood and Bredin, 1992).

As well as feelings of being unsafe, feelings of suspicions started to generate amongst the people living with dementia when their carers were in a different room; a potential explanation behind this came to light in the interviews. One of the participants living with dementia described that he was told a different reason behind the rationale for the split compared to the reason his wife was given. It either could be the case that indeed the two sets of participants were given different reasons, or that participants retained different information about what they were told. Other participants talked about feeling like they were being talked about, which isn't something that will generate positive feelings. The researcher asked about the rationale for the split when they attended some of the groups pre-data collection and was informed that it is so both the people living with dementia and the carers have space to talk freely without worrying about upsetting their partner; this needs to be stated clearly at the outset so that all of the participants know that the split is designed to be beneficial to both parties. Even if this is done, there is still a possibility that this won't resolve the therapeutic conflict that splitting the groups may create, and further consideration may need to be given about meeting the emotional needs of both parties in one group.

A pattern unique to the carers was that some of them reported that the split of the group led to more open conversations amongst them. The carers describe how they were able to say things that they hadn't wanted to say in front of their partner when the groups were split because of fears of upsetting their partners; this suggested that the rationale behind the split played out effectively in the group of carers. It was also identified that the carers were able to hear about how the other carers coped, which was helpful when thinking about how they were going to cope with the changes that dementia may bring to their lives.

The reported differences in the experiences of the people living with the dementia and the carers might potentially reflect the difficulties of trying to meet individual needs of the people diagnosed with dementia and the carers within one group. Whilst the split was described as beneficial for most of the carers as they were able to talk more freely and gain further support, it didn't present as a beneficial experience for many of the people living with dementia. As the group is predominantly based around dealing with a diagnosis of dementia, it is a possibility that the worries or suspicions arose in the people living with dementia because their diagnosis is being talked about when they aren't present and they might feel that they should be part of the discussions.

Gaining knowledge

A useful aspect of the group that was identified across both the people living with dementia and the carers was the opportunity to gain new knowledge as a result of attending the group. Psychoeducation is a key element of these groups as people affected by a diagnosis of dementia are usually not aware of all the information available about the illness itself and also the support available. There has been some research into how psychoeducation helps the carers of people living with dementia, but little research exists on whether psychoeducation is useful to the people living with dementia. The people living with dementia spoke about increased dementia knowledge as a result of attending the groups, which was found in other studies (McAfee et al. 1989). More specifically, the participants talked about it being useful to learn about how dementia affects the brain, so that they can then make sense of what has happened to them. The carers speak about the psychoeducational aspects being useful so that they know more about the prognosis of dementia and how to plan for the future; this has also been found to be useful in other research (Zarit et al. 2004).

The carers spoke about it being useful to learn about how and where to get further support if needed. They went on to report that it was useful to learn more about the practical elements of support, for example, an identity card for the person living with dementia to carry with them, a blue badge for the car and financial benefits such as a carer's allowance. The group allows the opportunity for this information to be distributed easily; these practical elements may not have been discovered without the group as many of the elderly people attending the group didn't have regular access to the internet, which is where a lot of this information is widely available.

Shared experiences

Another theme that was identified across both the people living with dementia and carers was that it was useful to have a space where experiences could be shared. The people living with dementia describe finding it useful to hear that it wasn't just them and that others were experienced similar things. The research into whether sharing experiences is useful in people living with dementia is very sparse, so these findings offer something new to the existing literature and provide further evidence as to why post-diagnostic groups can be a useful intervention to a person living with dementia.

Yalom (1995) describes universality, which is that in a brief group experience, attendees encounter other individuals who have faced similar problems. They become aware that they are not alone in life and can feel tremendous satisfaction in this connection. The sense that their pain is not exclusive or unique and that others with similar problems are willing to support them can be profoundly healing. It helps individuals move beyond their isolation, and it gives further energy to hope, which helps to fuel the change process. Universality can be seen as one of the central mechanisms of therapeutic change within these groups and is demonstrated in this sub-theme.

The carers also describe sharing experiences as being a useful aspect of the group. The findings from this set of participants demonstrate that the reasoning behind this was that they were able to listen to how people were managing and coping day to day. One person says that the groups were the first opportunity they had ever had to talk about how they were managing with their partner's diagnosis of dementia. There is more research into the experiences of carers in dementia diagnosis support groups and these findings are in line with existing research for dementia carer support groups (Chien et al, 2011).

Group facilitators utilised person-centred skills

The Thinking Together groups are run by facilitators who use person-centred skills in order to create a safe therapeutic environment and to help people feel comfortable in a group setting. One of the patterns identified in the data was that participants gave accounts of person-centred skills being utilised. The majority of participants said that they felt listened to and that the group facilitators were able to empathise with their situations. Participants also explained that the group facilitators created an environment in which some difficult topics could be explored, which suggests that participants felt safe enough to do this.

Within the data, empathy was identified as a skill used by the group facilitators and this has been shown to be an important aspect of the delivery of care in people living with dementia (Norman, 1996). Empathy is considered essential to therapy because for any therapeutic tactic to work, the therapist has to make the person feel understood. To do this, the therapist must not only understand what a person says in a therapy session but also understand what the person is not saying and communicate this understanding. Therapists who are highly empathic can help people face past experiences and obtain a greater understanding of both the experience and feelings surrounding it. A good therapist will generally be able to sense another person's emotion through concentration and active listening, but the process requires continued engagement (GoodTherapy, 2019).

Participants identified that the group facilitators 'really listened', which can be seen as an example of active listening, another person-centred skill. It is important within the Thinking Together groups that people are able to share experiences and have these experienced listened to. Research has found that one of the most common fears in people living with dementia is not being listened to (Husband, 2000), so for the majority of participants attending these groups to come out feeling that they have been listened to may go some way to reduce this fear and increase confidence for future interactions.

Not enough opportunity to talk

A key theme identified across participants in terms of the least useful aspects of the group was that participants would have liked more free space to talk; this was a pattern present in both the participants living with dementia and the carers. The groups themselves are quite structured, which can sometimes mean the opportunity for free conversation when together as one big group can be limited. Some of the attendees describe there not being much discipline to the group in terms of equal opportunities to talk, which led to some people talking a lot more than others. In a time-limited group, it is important that people are offered an equal opportunity to talk, so as to avoid people not feeling heard. One of the participants who attended the groups had speech difficulties and felt that the group was not concerned with hearing him; it is important that extra care is taken that even those who can't verbally communicate as well are given an equal opportunity as dementia can affect speech.

As can be seen in the findings of this particular theme, the only unhelpful aspects identified amongst the interviewees centre around some of the group dynamics. Group dynamics was a term coined by Kurt Lewin (1947), who used the term to describe the powerful and complex social processes that emerge in groups. Issues with group dynamics are usually unavoidable as naturally when a group of strangers come together, there will be differences in how people engage in a group setting. It is therefore vital that the experienced group facilitators running these groups pay attention to any issues, in particular the quieter members of the group, and work out how to resolve them going forward.

Linking findings to existing research

The most closely linked research to the current study is work conducted by Logsdson et al. (2006; 2007; 2010), which involved an Early Stage Memory Loss (ESML) support group. Each session of the ESML groups lasted for 90 minutes and met weekly for nine weeks. Similar to the Thinking Together groups, each session included both the people living with dementia and a carer, who met for part of the session and then met separately for part of the session. Logsdon's study only included participants with a diagnosis of Alzheimer's disease whereas the current study also included participants with vascular dementia, Lewy-body dementia and a mixed diagnosis of Alzheimer's and vascular.

Prior to a randomised controlled clinical trial conducted in 2010 which involved the ESML groups, Lodgson et al. had conducted previous work on a smaller scale looking at these groups. Lodgson, McCurry and Teri (2006) reported that 39 participants experienced increased emotional support and decreased isolation as a result of attending the group. Within the current study, participants who were interviewed also reported feeling supported as a result of attending the group, as well as feeling less lonely. On top of this, the current study also found that participants now felt supported for the future, as well as during the course of the groups. There weren't any issues detected with the group splitting in Logsdon et al.'s study, as only quantitative measures were employed, meaning this phenomenon wasn't explored as has been in the current study. This piece of research was a similar size to the current study and acted as a base for future research, much as is the hope for future research on a larger scale for the Thinking Together groups.

Logsdon et al. (2010) went on to conduct a randomised controlled trial that included 142 dyads; the dyads were randomised into either the ESML group or a waiting list. Within the current study, there wasn't a sufficient waiting list to be able to have a control group because anyone deemed suitable for the Thinking Together groups is offered the chance to join with minimal wait time; it wouldn't be ethical to put people on a waiting list if there was no requirement for one. Logsdon's (2010) study assessed outcomes at baseline and post-treatment; there was no follow-up measure, as in the current study, which was deemed important to look at the longevity of any outcomes.

Results of Logsdon's randomised controlled clinical trial found that participants with early-stage memory loss who participated in the nine-session group had significantly better quality of life and decreased depressive symptoms when compared to the control condition. Logsdon and colleagues found that care partners who attended the group along with the person living with dementia reported no significant changes in their own quality of life. The current study didn't quantifiably measure quality of life in carers; however, it did use quantitative measures to look at anxiety and depression, both of which correlate with quality of life (Brenes, 2007). There were no significant differences found in levels of anxiety and depression in carers, which potentially mean that the current study's findings were similar to Logsdon (2010) in terms of carer's quality of life not changing, as the two of the aspects associated with quality of life did not change.

Toms et al. (2015) reviewed 17 different support groups for people living with dementia and found that on the whole, participants rated them positively, which has also been found in this study. When looking specifically at time-limited groups, one study found increased dementia knowledge (McAfee et al. 1989), two studies found enhanced quality of life (Logsdon et al. 2007; 2010) following participation in the groups. Both of these findings were also found in this study along with decreased anxiety and decreased threat of dementia; the latter is a phenomenon which hasn't yet been widely researched, but this study's positive findings indicate that further research on the threat of dementia would be useful.

In another review conducted by Olazaran et al. (2010), consistent evidence was found that multi-component interventions for people living with dementia had positive effects on cognitive functioning, activities of daily living, behaviour and mood. Within the current study, decreased worry about activities of daily living and increased positive emotions was found in the people living with dementia, as measured by the DEMQOL.

Oyedobe and Parveen (2016) then completed a more recent review of psychosocial interventions and found that these interventions had benefits for cognitive, emotional and behavioural well-being of people living with dementia, as well as for quality of life. The current study found significant increases in quality of life for the participants living with dementia across all three areas: feelings, memory and everyday life. Oyedobe and Parveen concluded that the studies they included in their review only measured short-term effects; the current study had a follow-up measure eight weeks after the intervention finished, which could be classed as a medium-term effect. They recommended further research on interventions to promote living well with dementia in the community, as well as research focusing on wider aspects of life, rather than just a behavioural focus, which is what the current study achieved.

Cheston & Ivanecka (2016) reviewed 1397 papers that studied group or individual psychotherapy with people living with dementia and found that post-diagnostic group therapy improved quality of life and reduced depression. The improved quality of life finding is echoed in the current study and whilst the quantitative measure didn't show reduced depression, the findings from the qualitative measure indicate that mood would have been altered in some way as people report feeling less lonely and more connected to others. Loneliness can lead to depression (Mushtaq et al, 2014), so feeling less lonely and more connected are amongst some of the findings that indicate that depression levels may have decreased.

The role of counselling psychology in the Thinking Together groups

As mentioned in the introduction, the Thinking Together groups are overseen by the psychology department and the psychologists within the service play a key role in the design of the groups, training and supervision of the facilitators, as well as making sure the groups are run in line with what current research tells us about what might be useful from such groups. Within the realm of counselling psychology, leadership is an important aspect of a counselling psychologist's training; leadership is an important skill when overseeing the Thinking Together groups as ultimately the psychologists in the service hold the responsibility to ensure that they are run well and that the facilitators are trained to manage difficult dynamics sensitively. As can be seen from the current study, difficult dynamics do arise, so a counselling psychologist's skill set will be essential in skilling facilitators up to manage these dynamics.

LIMITATIONS OF THE CURRENT STUDY

The participants in this study were all white British which results in the current study lacking cultural diversity. However, in the time the data was collected, all of the participants that gave consent to participate were white British, so this was unavoidable. The findings of this study are a true reflection of the Thinking Together groups and the people that usually attend, so an evaluation of the groups can still be accurately made.

The number of participants studied was in line with that expected of a pilot study (Browne, 1995; Sim & Lewis, 2012; and Julious, 2005), but the lack of a control group can also be seen as a potential limitation. The researcher investigated whether a control group could be used when looking at the study design but the waiting list for the groups was minimal, as anyone deemed suitable is usually put into the next group running, which is normally only a matter of weeks. It would have been unethical to make people wait to attend the groups for the sake of a control group, as these groups are designed to be attended as soon after a diagnosis as possible. If the waiting list for the Thinking Together groups was longer, a control group could have been used. This could be considered for future research if a waiting list is established.

The design used for this study was a one-group pre-test–post-test research design, which does not account for many confounding variables that may threaten the internal validity of a study. In particular, this research design is susceptible to seven distinct threats to internal validity that may promote inaccurate conclusions regarding the effectiveness of a treatment or intervention. The first type of threat is history effects, which acknowledges that events or experiences outside the scope of a study may influence the changes in a dependent variable from pre-test to post-test. The second threat is a maturation effect, which recognises that any changes in the dependent variable between the pre-test and post-test may be attributed to changes that naturally occur within a sample. The third type of threat is the Hawthorne effect, which acknowledges the possibility that participants' awareness of being included in a study may influence their behaviour. The fourth threat is participant mortality, which occurs when a considerable number of participants withdraw from a study before completing the post-test. Throughout most research designs, it is inevitable that some participants will not finish, but when mortality becomes excessive, it can alter the relationship between the pre-test and post-test assessments, however, this was not the case in the current study. The fifth threat is instrument reactivity, which occurs when the implementation of the pre-test uniquely influences participants' performances on the post-test. Pre-tests can prime participants to respond to the post-test in a manner that they otherwise would not have if they did not receive the pre-test. The sixth threat is an instrumentation effect, which recognises that changes in how the dependent variable is assessed during the pre-test and post-test, rather than the treatment or intervention, may explain observed changes in a dependent variable. The final threat is regression to the mean, which recognises that participants with extremely high or low scores on the pre-test are more likely to record a score that is closer to the study average on their post-test. Despite the one-group pre-test–post-test research design potentially being a weak experimental design, under particular conditions, it can be useful, such as when only one group of participants is available to the researcher or when creating a control group is unethical (Allen, 2017).

The current study also has other potential limitations in how the research was conducted, for example, the sample was self-selected by the researcher and the same researcher administered the interviews, transcribed them and analysed them. There are also possible limitations associated with using a semi-structured interview, such as ‘the interviewer effect’, which is when the participants provide answers that they think are desirable to the interview. To counteract this, participants were told that the researcher did not work for the memory service and was looking for open and honest feedback.

Whilst a variety of different types of dementias were present in this study, the majority of people had been diagnosed with Alzheimer’s, meaning that applicability to other types of dementias is limited.

SUGGESTIONS FOR FURTHER RESEARCH

This research was designed to be a pilot study with the hope that further research can be conducted on the Thinking Together groups. Recommendations for further research on these groups would be to conduct it on a larger scale and hopefully with a control group, if the demand grows and a waiting listing evolves. Further research may also include longer interviews where possible so that some of themes identified in this research can be explored more fully. Being able to use longer interviews will be dependent on people's cognitive capabilities; in the current research, shorter semi-structured interviews were deemed the most suitable for the participants included in the study.

The threat of dementia was one of the key topics looked at in this research and a recommendation would be to have more research that explores this phenomenon. This study was one of the first of its kind to use the 'Threat of Dementia Scale' and it found some promising results in terms of post-diagnostic groups being able to reduce the threat of dementia. Further research using this scale would be useful in order to establish whether other post-diagnostic groups also have a positive impact on people's perceived threat of a dementia diagnosis.

IMPLICATIONS FOR PRACTICE

This research suggests that the Thinking Together groups are a valuable intervention that can be offered to people newly diagnosed with dementia and their carers. In terms of potential considerations, the research suggests that in order for service users diagnosed with dementia to get the most out of the groups, the split of the participants in each session may need some more thought and consideration so that the people living with dementia aren't left feeling vulnerable when their carers leave the room.

A counselling psychologist would be well placed to advise on how to manage the split more sensitively and could provide a platform for discussion about whether the split is necessary at all, and if it is, how it can be communicated so that the people living with dementia feel more contained and also find the split beneficial.

The groups being run by mental health professionals such as assistant psychologists, occupational therapists and memory nurses allow them to be an affordable intervention for the NHS to offer, however, the difficulties that can arise in the group dynamics highlights the need for these groups to be overseen by psychologists who are trained to effectively manage difficult group dynamics. Alongside this, the groups being managed by the psychology department ensures that the group design is in line with the current evidence base for post-diagnostic support.

There is a lack of dementia research that incorporates qualitative interviews with people living with dementia; this could possibly be due to the myths around whether people living dementia will remember attending a group. This research demonstrates that the participants diagnosed with dementia were able to recount information about the groups, as well as emotionally salient memories, so this research directly challenges the myth that people living with dementia won't remember. This is good evidence that can be used for future research and indicates that conducting qualitative research with people living with dementia is not only important, but very informative for what is useful versus what isn't useful in post-diagnostic groups.

CONCLUSIONS

The overall evaluation of the Thinking Together groups is that they appear to work for people in different ways. Quantitative results demonstrate that the groups significantly reduce anxiety and threat of dementia, alongside increasing quality of life for the people living with dementia. The results showed that the quantitative measures didn't demonstrate a reduction in the carer's anxiety and depression scores.

In terms of qualitative findings, people's overall experiences of the groups are positive and suggest that both the people living with dementia and the carers experience being able to think and feel differently as a result of having attended the group. Thinking differently came from participants gaining knowledge on the different types of dementia, finding out about support available in the community and practical benefits such as identity cards and blue badges. A theme of acceptance was also identified which reflects how participants had begun to feel differently in terms of being able to accept their diagnosis and adapt to life with it. Feeling differently came from participants being able to meet others in a similar situation, being listened to, learning new coping skills and from the realisation that people do live well after a diagnosis of dementia. All of these findings can be linked to how the group facilitators ran the groups and that by using person-centred skills, they were able to create a safe therapeutic environment so that the people attending the groups found them beneficial.

A unique aspect of the Thinking Together groups is that they invite both the carer and the person living with dementia and then split the groups each session; this was a key topic that was explored in the current study. From the results, it can be concluded that the split may be beneficial to the carers in terms of them being able to talk more freely, but may not be as beneficial to some of the people living with dementia. A majority of the interviews with the people living with dementia indicated that during the split, they felt unsafe without their partner, felt suspicious of what was going on in the other room and felt like they were being talked about. These findings may reflect the challenges of trying to meet the needs of both carers and the people living with dementia within one group; further considerations of splitting the groups need to be made for future groups as the split was an area that proved problematic for the people living with dementia.

As discussed, the threat of dementia scores significantly reduced between the pre-group measure and the post-group measure; this finding suggests that the Thinking Together groups help people to feel less threatened by their diagnosis and this could have been due to a number of factors. If the people living with dementia were able to find out more about their diagnosis and realise that it doesn’t mean life is over, naturally it would become less threatening. Alongside this, meeting and getting support from others and knowing that they are not alone in this journey could have also helped to reduce the threat of dementia. Some of the participants said that the groups were the first time they had talked about their diagnosis, which may have also helped to ease the fear surrounding it. The scores remained significantly reduced at the follow-up measure, which indicates that these changes are not just short-term, but seem to be longer lasting.

In terms of conclusions for the world of counselling psychology, this study demonstrates how a counselling psychologists clinical and leadership skills are essential for the effective running of the Thinking Together groups. Counselling psychologists are able to offer guidance on the design of the groups, as well as training, mentoring and coaching the group facilitators so that the groups don’t need to be run by psychologists themselves; this makes the Thinking Together groups an affordable intervention for the NHS to run.

Word count: 26,438

REFERENCES

Abbott, A. (2011). A problem for our age. *Nature*, *475*(7355), S2.

Antoine, C., Antoine, P., Guermonprez, P., & Frigard, B. (2004). Awareness of deficits and anosognosia in Alzheimer's disease. *L'Encephale*, *30*(6), 570-577

Allen, M. (Ed.). (2017). *The SAGE encyclopedia of communication research methods*. SAGE Publications.

Alzhemier's Research (2015) *Dementia in the family: the impact on carers*. Alzheimers Research UK.

Alzheimer's Society (2017) Apathy, depression and anxiety. Factsheet 444LP.

Bakker, A. B., & Oerlemans, W. (2011). Subjective well-being in organizations. *The Oxford handbook of positive organizational scholarship*, 178-189.

Billington, J., Carroll, J., Davis, P., Healey, C., & Kinderman, P. (2013). A literature-based intervention for older people living with dementia. *Perspectives in public health*, *133*(3), 165-173

Black, D. W., & Andreasen, N. C. (2014). *Introductory textbook of psychiatry*. American Psychiatric Pub.

Brandt, J., Spencer, M., & Folstein, M. (1988). The telephone interview for cognitive status. *Neuropsychiatry Neuropsychology Behaviour Neurology*, *1*(2), 111-117.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Brenes, G. A. (2007). Anxiety, depression, and quality of life in primary care patients. *Primary care companion to the Journal of clinical psychiatry*, *9*(6), 437.

Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, *51*(5), 657-664.

Browne, R. H. (1995). On the use of a pilot sample for sample size determination. *Statistics in medicine*, *14*(17), 1933-1940.

Bryan, K., & Maxim, J. (1998). Enabling care staff to relate to older communication disabled people. *International journal of language & communication disorders*, *33*(S1), 121-125.

Campbell, L. F., Norcross, J. C., Vasquez, M. J., & Kaslow, N. J. (2013). Recognition of psychotherapy effectiveness: The APA resolution. *Psychotherapy*, *50*(1), 98.

Chapman, D. P., Williams, S. M., Strine, T. W., Anda, R. F., & Moore, M. J. (2006). PEER REVIEWED: Dementia and its implications for public health. *Preventing chronic disease*, *3*(2).

Cheston R (2019) Improving care: the next step forward - a commentary, in D. Brooker, (Editor) and T. Kitwood (2019). *Dementia Reconsidered, Revisited: The person still comes first*. London, Open University Press

Cheston, R., & Christopher, G. (2019). Dementia as an Existential Threat. In *Confronting the Existential Threat of Dementia* (pp. 27-43). Palgrave Pivot, Cham.

Cheston, R., Christopher, G., & Ismail, S. (2015). Dementia as an existential threat: the importance of self-esteem, social connectedness and meaning in life. *Science progress*, *98*(4), 416-419.

Cheston, R., & Ivanecka, A. (2017). Individual and group psychotherapy with people diagnosed with dementia: a systematic review of the literature. *International journal of geriatric psychiatry*, *32*(1), 3-31.

Cheston, R., Jones, K., & Gilliard, J. (2003). Group psychotherapy and people with dementia. *Aging & mental health*, *7*(6), 452-461.

Snow, K., Cheston, R., & Smart, C. (2016). Making sense of dementia: Exploring the use of the Markers of Assimilation of Problematic Experiences in Dementia scale to understand how couples process a diagnosis of dementia. *Dementia*, *15*(6), 1515-1533.

Chien, L. Y., Chu, H., Guo, J. L., Liao, Y. M., Chang, L. I., Chen, C. H., & Chou, K. R. (2011). Caregiver support groups in patients with dementia: a meta-analysis. *International journal of geriatric psychiatry*, *26*(10), 1089-1

Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist*, *26*(2), 120-123.

Clarke, A., Jane Hanson, E., & Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of clinical nursing*, *12*(5), 697-706.

Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International journal of geriatric psychiatry*, *23*(9), 929-936.

Della Penna, R. D., Heumann, K. S., Gade, G., & Venohr, I. (2002). Evidence-based clinical vignettes from the Care Management Institute: Alzheimer’s disease and dementia. *Perm J*, *6*, 43-50.

Denscombe, M. (2007) The good research guide: for small-scale social research. Buckingham. Open University Press

de Souza, L. C., Sarazin, M., Goetz, C., & Dubois, B. (2009). Clinical investigations in primary care. In *Dementia in Clinical Practice* (Vol. 24, pp. 1-11). Karger Publishers.

Doré, B. P., Morris, R. R., Burr, D. A., Picard, R. W., & Ochsner, K. N. (2017). Helping others regulate emotion predicts increased regulation of one’s own emotions and decreased symptoms of depression. *Personality and Social Psychology Bulletin*, *43*(5), 729-739.

Dubois, B., Picard, G., & Sarazin, M. (2009). Early detection of Alzheimer's disease: new diagnostic criteria. *Dialogues in clinical neuroscience*, *11*(2), 135.

Edwards, H. B., Savovic, J., Whiting, P. F., Leach, V. A., Richards, A. C., Cullum, S. J., & Cheston, R. (2016). Quality of relationships as predictors of outcomes in people with dementia: a systematic review protocol. BMJ Open, 6(4)

Enache, D., Winblad, B., & Aarsland, D. (2011). Depression in dementia: epidemiology, mechanisms, and treatment. *Current opinion in psychiatry*, *24*(6), 461-472.

Fabris, G. (2006). Psychotherapeutic groups for elderly people suffering from Alzheimer’s disease or dementia. *Gruppi*, *8*(1), 75-85.

Ferrans, C. E., Zerwic, J. J., Wilbur, J. E., & Larson, J. L. (2005). Conceptual model of health-related quality of life. *Journal of nursing scholarship*, *37*(4), 336-342

Ferretti, L., McCurry, S. M., Logsdon, R., Gibbons, L., & Teri, L. (2001). Anxiety and Alzheimer's disease. *Journal of Geriatric Psychiatry and Neurology*, *14*(1), 52-58.

Fledderus, M., Bohlmeijer, E. T., Pieterse, M. E., & Schreurs, K. M. G. (2012). Acceptance and commitment therapy as guided self-help for psychological distress and positive mental health: a randomized controlled trial. *Psychological medicine*, *42*(3), 485-495.

Forman, E. M., Herbert, J. D., Moitra, E., Yeomans, P. D., & Geller, P. A. (2007). A randomized controlled effectiveness trial of acceptance and commitment therapy and cognitive therapy for anxiety and depression. *Behaviour modification*, *31*(6), 772-799.

Fox, C., Lafortune, L., Boustani, M., & Brayne, C. (2013). The pros and cons of early diagnosis in dementia. *British Journal of General Practice*, *63*(612), e510-e512.

Geriatric Mental Health Foundation (2015) Anxiety in older adults http://www.gmhfonline.org/gmhf/consumer/factsheets/anxietyoldradult.html

Goudie, F., & Stokes, G. (1989). Dealing with confusion. *Nursing Times*, *20*, 38.

Gomm, R. (2008). *Social research methodology: A critical introduction*. Macmillan International Higher Education.

Gorka, S. M., Lieberman, L., Shankman, S. A., & Phan, K. L. (2017). Startle potentiation to uncertain threat as a psychophysiological indicator of fear-based psychopathology: An examination across multiple internalizing disorders. *Journal of abnormal psychology*, *126*(1), 8.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of qualitative research*, *2*(163-194), 105.

Harrell, M. C., & Bradley, M. A. (2009). *Data collection methods. Semi-structured interviews and focus groups*. Rand National Defence Research Institute, Santa Monica, California.

Hedman, R., Hansebo, G., Ternestedt, B. M., Hellström, I. and Norberg, A. (2014a). Expressed sense of self by people with Alzheimer's disease in a support group interpreted in terms of agency and communion. *Journal of Applied Gerontology*, 14, 1–23. doi: 10.1177/0733464814530804.

Helvik, A. S., Engedal, K., Skancke, R. H., & Selbæk, G. (2011). A psychometric evaluation of the Hospital Anxiety and Depression Scale for the medically hospitalized elderly. *Nordic journal of psychiatry*, *65*(5), 338-344.

Hewitt, P., Watts, C., Hussey, J., Power, K., & Williams, T. (2013). Does a structured gardening programme improve well-being in young-onset dementia? A preliminary study. *British Journal of Occupational Therapy*, *76*(8), 355-361.

Hofmann, S. G., Asnaani, A., Vonk, I. J., Sawyer, A. T., & Fang, A. (2012). The efficacy of cognitive behavioral therapy: A review of meta-analyses. *Cognitive therapy and research*, *36*(5), 427-440.

Huang, C. Q., Wang, Z. R., Li, Y. H., Xie, Y. Z., & Liu, Q. X. (2011). Cognitive function and risk for depression in old age: a meta-analysis of published literature. *International Psychogeriatrics*, *23*(4), 516-525.

Husband, H. J. (2000). Diagnostic disclosure in dementia: an opportunity for intervention?. *International Journal of Geriatric Psychiatry*, *15*(6), 544-547

Jones, W. H., Rose, J., & Russell, D. (1990). Loneliness and social anxiety. In *Handbook of social and evaluation anxiety* (pp. 247-266). Springer, Boston, MA.

Julious, S. A. (2005). Sample size of 12 per group rule of thumb for a pilot study. *Pharmaceutical Statistics: The Journal of Applied Statistics in the Pharmaceutical Industry*, *4*(4), 287-291.

Kaplan, H. I., Sadock, B. J., & Grebb, J. A. (1994). *Kaplan and Sadock's synopsis of psychiatry: Behavioural sciences, clinical psychiatry*. Williams & Wilkins Co.

Kendall, J. M. (2003). Designing a research project: randomised controlled trials and their principles. *Emergency Medicine Journal*, *20*(2), 164-168.

Kitwood, T. (1997). Dementia reconsidered: The person comes first. Berkshire, UK: Open University Press.

Kitwood , T. (1998). Toward a theory of dementia care: ethics and interaction . The Journal of Clinical Ethics, 9, 23–34.

Kitwood T., & Bredin, K.(1992). Towards a theory of dementia care: personhood and well-being. *Ageing and Society*, 12, 269-287.

Leung, P., Orrell, M. and Orgeta, V. (2015). Social support group interventions in people with dementia and mild cognitive impairment: a systematic review of the literature. *International Journal of Geriatric Psychiatry*, 30, 1–9. doi: 10.1002/gps.4166.

Lewin, K. (1947). Frontiers in group dynamics: Concept, method and reality in social science; social equilibria and social change. *Human relations*, *1*(1), 5-41.

Linehan, M. (1993). *Skills training manual for treating borderline personality disorder* (Vol. 29). New York: Guilford Press.

Logsdon, R. G., Pike, K. C., McCurry, S. M., Hunter, P., Maher, J., Snyder, L., & Teri, L. (2010). Early-stage memory loss support groups: outcomes from a randomized controlled clinical trial. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *65*(6), 691-697.

Logsdon, R. G., McCurry, S. M., & Teri, L. (2007). Time-limited support groups for individuals with early stage dementia and their care partners: Preliminary outcomes from a controlled clinical trial. *Clinical Gerontologist*, *30*(2), 5-19.

Logsdon, R. G., McCurry, S. M. and Teri, L. (2007). Time-limited support groups for individuals with early stage dementia and their care partners. *Clinical Gerontologist*, 30, 5–19. doi: 10.1300/J018v30n02_02.

Long, T., & Johnson, M. (2000). Rigour, reliability and validity in qualitative research. *Clinical effectiveness in nursing*, *4*(1), 30-37.

Marshall, A., Bucks, R. and Mander, H. (2005). A long-term support group for people with dementia. *Journal of Dementia Care*, 13, 36–37.

McAfee, M. E., Ruh, P. A., Bell, P., & Martichuski, D. (1989). Including persons with early stage Alzheimer's disease in support groups and strategy planning. *American Journal of Alzheimer's Care and Related Disorders & Research*, *4*(6), 18-22.

McEvoy, P., & Richards, D. (2006). A critical realist rationale for using a combination of quantitative and qualitative methods. *Journal of research in nursing*, *11*(1), 66-78.

McLeod, S. A. (2008). Qualitative quantitative. *Simply Psychology*.

Mioshi, E., Dawson, K., Mitchell, J., Arnold, R., & Hodges, J. R. (2006). The Addenbrooke's Cognitive Examination Revised (ACE-R): a brief cognitive test battery for dementia screening. *International journal of geriatric psychiatry*, *21*(11), 1078-1085.

Moniz-Cook, E., & Manthorpe, J. (Eds.). (2009). *Early psychosocial interventions in dementia: evidence-based practice*. Jessica Kingsley publishers.

Mushtaq, R., Shoib, S., Shah, T., & Mushtaq, S. (2014). Relationship between loneliness, psychiatric disorders and physical health? A review on the psychological aspects of loneliness. *Journal of clinical and diagnostic research: JCDR*, *8*(9), WE01.

Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., ... & Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, *53*(4), 695-699.

Niederhoffer, K. G., & Pennebaker, J. W. (2002). *Sharing one's story: On the benefits of writing or talking about emotional experience.* The Oxford Handbook of Positive Psychology (2 ed.)

Neikrug, S. M. (1998). The value of gerontological knowledge for elders: A study of the relationship between knowledge on aging and worry about the future. *Educational Gerontology: An International Quarterly*, *24*(3), 287-296.

Newton, N. (2010). The use of semi-structured interviews in qualitative research: strengths and weaknesses. *Exploring qualitative methods*, *1*(1), 1-11.

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-based nursing*, *18*(2), 34-35.

Norman, K. D. (1996). The role of empathy in the care of dementia. *Journal of psychiatric and mental health nursing*, *3*(5), 313-317.

Olazaran, J., Reisberg, B., Clare, L., Cruz, I., Pen˜ a-Casanova, J., del Ser, T., Lai, C. (2010). Nonpharmacological therapies in Alzheimer’s disease: A systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders*, 30(2), 161–178.

Orrell, M. (2012). The new generation of psychosocial interventions for dementia care. *The British Journal of Psychiatry*, *201*(5), 342-343.

Örulv, L. (2012). Reframing dementia in Swedish self-help group conversations: constructing citizenship. *International Journal of Self-Help and Self-Care*, 6, 9–41. doi: 10.2190/S.H.6.1.c.

Patel, B., Perera, M., Pendleton, J., Richman, A., & Majumdar, B. (2014). Psychosocial interventions for dementia: from evidence to practice. *Advances in psychiatric treatment*, *20*(5), 340-349.

Prince, M., Ali, G. C., Guerchet, M., Prina, A. M., Albanese, E., & Wu, Y. T. (2016). Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer's research & therapy*, *8*(1), 23.

Regan, M. (2016) The interface between dementia and mental health: an evidence review. London: Mental Health Foundation.

Roberts, J. S. and Silverio, E. (2009). Evaluation of an education and support program for early-stage Alzheimer's Disease. *Journal of Applied Gerontology*, 28, 419–435. doi: 10.1177/0733464809333883.

Robson, L. S., Shannon, H. S., Goldenhar, L. M., & Hale, A. R. (2001). Before-and-after design: A simple evaluation design. *Guide to Evaluating the Effectiveness of Strategies for Preventing Work Injuries*, pp-17.

Roemer, L., Orsillo, S. M., & Salters-Pedneault, K. (2008). Efficacy of an acceptance-based behavior therapy for generalized anxiety disorder: Evaluation in a randomized controlled trial. *Journal of consulting and clinical psychology*, *76*(6), 1083.

Rogers, Carl R. (1942). Counselling and psychotherapy. Cambridge, MA: Riverside Press.

Rolfe, G. (2006). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of advanced nursing*, *53*(3), 304-310.

Russell, P., Banerjee, S., Watt, J., Adleman, R., Agoe, B., Burnie, N., ... & Davies, D. (2013). Improving the identification of people with dementia in primary care: evaluation of the impact of primary care dementia coding guidance on identified prevalence. *BMJ open*, *3*(12), e004023.

Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *International psychogeriatrics*, *25*(6), 949-961.

Sandelowski, M. (1993). Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *ANS. Advances in nursing science*, *16*(2), 1-8.

Scheurich, A., Schanz, B., Müller, M. J., & Fellgiebel, A. (2008). Early interventional group therapy for patients with incipient Alzheimer disease and their relatives. *Psychotherapie, Psychosomatik, medizinische Psychologie*, *58*(6), 246-252.

Scholz, S. (2015). Early diagnosis of dementia through the expansion of memory clinics. *Diffusion-The UCLan Journal of Undergraduate Research*, *2*(2).

Seignourel, P. J., Kunik, M. E., Snow, L., Wilson, N., & Stanley, M. (2008). Anxiety in dementia: a critical review. *Clinical psychology review*, *28*(7), 1071-1082

Selwood, A., Johnston, K., Katona, C. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders* 101: 75-89

Sim, J., & Lewis, M. (2012). The size of a pilot study for a clinical trial should be calculated in relation to considerations of precision and efficiency. *Journal of clinical epidemiology*, *65*(3), 301-308.

Sinason, V. (1992). *Mental handicap and the human condition* (Vol. 38). London: Free Association Books.

Starkstein, S. E., Jorge, R., Petracca, G., & Robinson, R. G. (2007). The construct of generalized anxiety disorder in Alzheimer disease. *The American Journal of Geriatric Psychiatry*, *15*(1), 42-49.

Steinberg, M., Sheppard, J. M., Tschanz, J. T., Norton, M. C., Steffens, D. C., Breitner, J. C., & Lyketsos, C. G. (2003). The incidence of mental and behavioral disturbances in dementia: the cache county study. *The Journal of neuropsychiatry and clinical neurosciences*, *15*(3), 340-345.

Spijker, A., Vernooij-Dassen, M., Vasse, E., Adang, E., Wollersheim, H., Grol, R., & Verhey, F. (2008). Effectiveness of nonpharmacological interventions in delaying the institutionalization of patients with dementia: a meta-analysis. *Journal of the American Geriatrics Society*, *56*(6), 1116-1128.

Stokes, G., Goudie, F. (1990), Counselling confused elderly people. Working with Dementia, Bicester, Oxon: Winslow.

Teri, L., & Gallagher-Thompson, D. (1991). Cognitive-behavioral interventions for treatment of depression in Alzheimer's patients. *The Gerontologist*, *31*(3), 413-416.

Toms, G. R., Clare, L., Nixon, J., & Quinn, C. (2015). A systematic narrative review of support groups for people with dementia. *International psychogeriatrics*, *27*(9), 1439-1465.

Wands, K., Merksey D, M,. Vladimir, C., Fisman, M, B., Fox, H., Boniferro, M. (1990) A questionnaires investigation of anxiety and depression in early dementia. *Journal of the American Geriatrics Society*. Volume 38, Issue 5, Pages 535–538.

Zarit, S. H., Femia, E. E., Watson, J., Rice-Oeschger, L., & Kakos, B. (2004). Memory club: A group intervention for people with early-stage dementia and their care partners. *The Gerontologist*, *44*(2), 262-269.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta psychiatrica scandinavica*, *67*(6), 361-370.

Journal Article

Does attending a ‘Thinking Together’ group help people feel less threatened by their dementia and lead to a better quality of life?

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Word count (6228, excluding abstract and references)

Abstract

Objectives

To evaluate the 'Thinking Together' groups, which are post-diagnostic dementia groups run in the South West England.

Method

A mixed methods design was used. Three quantitative measures were used alongside semi-structured interviews.

Results

Anxiety and threat of dementia levels significantly decreased between the pre and post measures, and quality of life improved; all of which were maintained at follow-up. No changes were found in the carer's scores. The semi-structured interviews revealed four main themes: the splitting of the groups, thinking and feeling differently, the perceived threat of a dementia diagnosis and group dynamics.

Conclusions

The Thinking Together groups work for different people in different ways. The findings indicate that for the people living with dementia, the groups lessened feelings of anxiety and threat of dementia, as well as improving quality of life. The majority of participants reported positive experiences of the groups and found them beneficial.

Introduction

The number of people with dementia is steadily increasing in the UK and elsewhere, as an ageing population lives longer (Prince et al, 2009). Much of the current research into dementia focuses on pharmacological interventions;

however, research into non-pharmacological interventions is growing (Orrell et al, 2012), reflecting the drive for early diagnosis and the influence of person-centred philosophies within dementia care. Non-pharmalogical interventions include counselling, psychotherapy and psychosocial interventions, all of which share similar and overlapping techniques.

At the heart of this study is a post-diagnostic group run for people recently diagnosed with dementia called '*Thinking Together*', where attendees are encouraged to bring along a relative or a friend, who is usually also their primary caregiver. The Thinking Together groups are an example of a non-pharmalogical intervention and incorporate skills used in counselling, psychotherapy and psychosocial interventions.

Background to Dementia

Dementia represents a diverse category of symptoms characterised by deficits in memory, cognitive function and behaviour (Chapman et al, 2006). The cognitive impairment characterising dementia may include difficulty in understanding or using words, inability to carry out motor activities despite adequate motor function, and failure to identify or to recognize objects (Kaplan et al, 1994). People living with dementia also commonly experience impairments in occupational and social functioning (Andreasen et al, 2001) and may present with behavioural disturbances (Steinberg et al, 2003).

There are currently 850,000 people living with dementia in the UK, with numbers set to rise to over 1 million by 2025 and then to 2 million by 2051 (Alzheimer's

Society, 2019). The most common types of dementia are Alzheimer's disease (affecting 50-80%), Vascular dementia (affecting 20-30%), Fronto Temporal dementia (affecting 5-10%) and Dementia with Lewy bodies (affecting less than 5%) (Abbott et al, 2011).

There is no cure for dementia at the present time but treatments offered to people living with dementia include drugs to slow down the progression of the disease and, increasingly, talking therapies to help people adjust. Both pharmacological and psychosocial interventions are important in order to support a person following a diagnosis of dementia (Patel et al, 2014).

The difficulties associated with dementia can have a big impact on a person's well-being; emotionally, mentally and physically. A diagnosis of dementia can therefore be perceived as a threat due to the way it can impact all aspects of a person's life. Individual and group therapy for people living with early-stage dementia has been shown to help with some of these difficulties that people may face (Logsdon et al. 2010, Bakker et al, 2011). Other research has found that group psychotherapy may have a role to play in reducing levels of depression and anxiety in people living with mild and moderate levels of dementia (Cheston et al, 2003).

Psychological interventions

A "psychosocial intervention" is a broad term used to describe different ways to support people to overcome challenges and maintain good mental health. Psychosocial interventions are increasingly available to people who have received a diagnosis of dementia and their families. They are designed to help people maintain a good quality of life following diagnosis (Hewitt et al, 2013). Psychosocial interventions are becoming more popular as society moves towards the view that a good quality of life can be had beyond a diagnosis of dementia. Also, the drive for an early diagnosis in dementia has meant that there is now more of a need for interventions to help people adjust to the diagnosis. These interventions can be used in a wide-range of settings, including residential and community. The Thinking Together groups are an example of a psychosocial intervention and are part of the movement that emphasises the importance of ‘living well’ with dementia, which is the central element of the government’s policy over the last five years.

Thinking Together Groups

The Thinking Together groups are post-diagnostic and are available to people who have been given a new diagnosis of dementia or Mild Cognitive Impairment (MCI). They are run by a memory service in the South West England and last for 90 minutes weekly for seven weeks. There are other similar groups run elsewhere in the AWP and across the UK, but most other groups invite only the person living with dementia **or** the carer of the person living with dementia, not both.

Three groups are run alongside each other so that the waiting lists are kept to a minimum, and the groups are run by mental health professionals. The Thinking Together groups invite both the person newly diagnosed with dementia and a relative or friend to attend; the relative or friend is usually also the carer. The importance of involving the carer is in line with the ‘Triangle of Care’ model as proposed by the Carers Trust (2013) in their guide to best practice in dementia care, as well as other research (SCIE: Dementia Gateway, 2013). For the middle section of each of the seven groups, the group members are split into two further sub-groups separating the people diagnosed and the carers. This enables people to have a combination of two experiences: of being able to relate to each other in one large group and of being able to speak more freely about the problems they may be experiencing when in the smaller sub group.

The Thinking Together groups have been designed to offer:

1. The opportunity to talk to others in a similar situation and share experiences.
2. Information on memory problems and ways to cope.
3. The chance to learn strategies to enhance living well with dementia.
4. Understanding and support from specialist health professionals.
5. The opportunity to get your questions answered by dementia specialists.
6. Information about where to get support in the future.

The different elements that these groups offer could help people to feel less threatened by their diagnosis of dementia and improve their quality of life in several ways. Firstly, offering information on what dementia actually is can make it less threatening and can make the diagnosis easier to accept. Secondly, having somewhere an individual can share their experiences with people who can relate to what they are going through is often helpful as it can normalise a person's response, encourage a dialogue about dementia and group members can experience other people's reactions. Thirdly, learning coping strategies can help people to adapt to a life with dementia, rather than fear a life with dementia. Finally, offering information on where to get continued support once the groups finish can leave a person feeling less alone in their individual journey and increase feeling of containment once the groups end.

The central function of the groups is to facilitate the process of adjustment to the diagnosis of dementia for both the people living with dementia and their carers. There is an educational element to the groups, as well as a therapeutic element. These two elements combined create a therapeutic group that is designed to make a real difference with how people move forward after a diagnosis of dementia.

Review of the current literature

In an attempt to be able to provide people with dementia the time and space they need to make sense of the changes that might occur in their lives, there has been an increase in the use of psychotherapy and counselling with people with dementia. A wide range of individual psychotherapeutic work with people with dementia has been described including psychodynamic (e.g. Sinason, 1992), cognitive-behavioural (e.g. Teri and Gallagher-Thomson, 1991) and humanistic approaches (e.g. Goudie and Stokes, 1989; Stokes and Goudie, 1990). However, therapists are costly and the NHS aren't equipped with the money or resources to be able to offer such a service to everyone, so one of the most common ways of intervening with people with dementia is through group work (Cheston, 2003). The Thinking Together groups are an example of group work that uses skills found in psychotherapy and counselling. The groups are run by mental health professionals who have been trained to be able to use certain therapeutic skills, without always having to be trained therapists themselves. The groups are overseen by the psychology department and incorporate aspects from different types of therapies and interventions, allowing for an affordable service for the NHS, as well as an accessible service for people affected by dementia.

A recent review by Toms et al. (2015) looked into the effects of support groups for people living with dementia. The findings reported that groups are rated positively and people are observed to enjoy meeting together and often form close bonds. When participants provided feedback on groups, it was found that on the whole respondents reported positive experiences and satisfaction.

When looking specifically at time-limited groups, they found that one study found improved mood (Logsdon et al. 2010), one study found increased dementia knowledge (McAfee et al. 1989) and two studies found enhanced quality of life (Logsdon et al. 2007; 2010) following participation in the groups. They reported that this evidence represents some positive psychosocial outcomes from randomised control trials (RCTs), between-group studies and repeated measure designs. However, despite the corroborating evidence from different study designs, the evidence base for time-limited groups is not strong. Only two RCTs (the highest level of evidence included in the review) found evidence for positive outcomes and these trials lacked detailed information about randomization procedures and so had potential methodological limitations. The papers using a repeated measure design also had variable reporting quality with Roberts and Silverio (2009) meeting 71% of reporting criterion but McAfee et al. (1989) only met 47% of criterion. Evidence for improved mood is particularly limited with three studies reporting no improvement or trends only (McAfee et al. 1989; Marshall et al. 2005; Logsdon et al. 2007).

Research that is more closely linked to the nature of the current study is a randomised controlled clinical trial conducted by Logsdon et al. (2010). At the centre of this randomised control trial was an Early Stage Memory Loss (ESML) support group that Logsdon et al. had conducted previous research on. The ESML groups were similar in nature to the Thinking Together groups; sessions averaged 90 min in duration and met weekly for nine weeks. Each session included both individuals with early-stage dementia and a care partner, who met together for part of the session and separately for part of the session. Findings of this study demonstrated that, for individuals with early-stage memory loss, participating in a nine-session Early-Stage Memory Loss support group resulted in significantly better quality of life and decreased depressive symptoms compared with a waiting list control condition. Although the amount of change seen in these outcomes is modest, these findings are consistent with qualitative reports of the benefits of early-stage support groups and provide empirical support for the efficacy of these groups on areas of clinical importance to individuals living with dementia.

Interestingly in Logsdon's study, they found that carer partners who attended the ESML groups along with the person diagnosed with early-stage dementia did not report significant changes in their own quality of life. The ESML groups evaluated in this investigation were designed primarily to meet the needs of the person with early-stage dementia and focused on concerns of the diagnosed individual. Carer partners are included to support the participants, and many care partners in the early stages did not consider themselves to be "caregivers." They reported that additional research is needed to evaluate other types of early-stage interventions for both persons with dementia and family care partners.

Research aims

The main aim of the current study is to evaluate Thinking Together groups in order to see if they help participants to feel less threatened by their dementia, lead to decreased levels of anxiety and depression and in turn a better quality of life. A secondary aim is to see if the groups have an effect on the carer's depression and anxiety levels as they are also attendees of the groups. There has been little research into the effectiveness of these particular groups, so the current research aims to fulfil this, as well as adding to the existing literature on the evidence base for non-pharmalogical interventions.

Research Questions

1. Do the Thinking Together groups help people attending to feel less threatened by a diagnosis of dementia?
2. Do the Thinking Together groups help the people living with dementia feel less anxious and depressed?
3. Do the Thinking Together groups lead to a better quality of life for the people living with dementia?
4. Do the Thinking Together groups help the carer feel less anxious and depressed?
5. Which elements of the groups did the participants find most/least useful?

Methods

This study is a quasi-experimental study, which uses a repeated measures design and a mixed methods approach to data collection, incorporating three quantitative measures and brief semi-structured interviews.

Participants

Participants involved in this research attended the seven-week Thinking Together groups and had a recent diagnosis of dementia (in the last 18 months) or was a carer to someone with a dementia diagnosis. On average, each group contained six people newly diagnosed with dementia plus their carer. Two or three groups were run simultaneously in each cycle of seven weeks. A sample size of between 24 -50 participants (12-25 pairs made up of the person living with dementia and their carer) was been used in this study, which is in the range recommended for pilot studies (Browne, 1995; Sim & Lewis, 2012; and Julious, 2005). In total, full data across all three time points was collected from 34 participants. Of these, 20 were female and 14 were male; 10 of the females and seven of the males had dementia.

Ethical considerations

A central ethical issue of the present research is to ensure that enough information is provided at appropriate points so that consent from participants is meaningful and continues throughout the research process. To help participants in giving informed consent, all participants in the study were provided with an information sheet explaining the nature of the study and were all given the contact details of investigators involved in the study and/or memory clinic staff facilitating groups, so that at any point they can ask any questions they may have. Furthermore, the information sheet and informed consent form made it clear to participants that their participation in the study is entirely voluntary and that they may withdraw from the study at any time without any consequence to themselves or their on-going care/future treatment.

Data Collection

The data collection measures included three quantitative methods: Threat of Dementia Scale (ToDS), Hospital Anxiety and Depression Scale (HADS) and Dementia Quality of Life scale (DEMQOL). A limitation of quantitative methods is that they limit the range of responses from the participants (McLeod, 2008), so to counteract this limitation, a qualitative method comprising of brief semi-structured interviews was also used.

Data Analysis

During data analysis, the data from the quantitative measures was entered into an SPSS spreadsheet and analysed using a paired sample t-test. The qualitative data was analysed using thematic analysis. Thematic analysis is the process of identifying patterns or themes within qualitative data. Braun & Clarke (2006) suggest that it is the first qualitative method that should be learned as 'it provides core skills that will be useful for conducting many other kinds of analysis' (p.78). A further advantage is that it is a method rather than a methodology (Braun & Clarke 2006; Clarke & Braun, 2013), which means that, unlike many other qualitative methodologies, it is not tied to a particular epistemological or theoretical perspective, making it a flexible method to use.

The interviews were transcribed and the transcripts were entered into NVivo 12; they were then coded using the same programme. From here, initial patterns were identified and these were later redefined into themes and sub-themes. The identification of the themes and subthemes was guided by the original research questions. The themes and sub-themes were then summarised and interpreted, using relevant quotes to evidence them. Braun & Clarke's (2006) six-stage guide to thematic analysis was followed and has been summarised in Table 1.

Table 1: Braun & Clarke's six-stage framework for doing a thematic analysis

Step 1: Become familiar with the data	**Step 4:** Review themes
Step 2: Generate initial codes	**Step 5:** Define themes
Step 3: Search for themes	**Step 6:** Write-up

Quantitative Results

Statistical data

The data found for the different measures at the three different time points can be found in the two tables below. Table 2 shows the outcomes for the participants living with dementia and Table 3 shows the outcomes for the carers. Each of the 17 dyads consisted of a person living with dementia and a carer. Out of the 17 people diagnosed with dementia, 12 had a diagnosis of Alzheimer's disease; two had a diagnosis of vascular dementia; two had a diagnosis of dementia with Lewy-bodies and one had a diagnosis of mixed Alzheimer's and vascular dementia.

Table 2: Participants living with dementia outcomes

	Pre-intervention: T1 (n=17)	**Post-intervention: T2 (n=17)**	***t*-score for T1 vs T2**	**Eight week follow-up: T3 (n=17)**	***t*-score for T1 vs T3**
Anxiety (HADS-A)	4.24 (3.40)	3.53 (2.93)	2.94**	2.59 (2.85)	3.45**
Depression (HADS-D)	4.29 (2.95)	4.38 (3.06)	1.12	3.65 (3.00)	1.86
DEMQOL overall	89.53 (15.11)	98.64 (10.06)	-4.44**	103.12 (9.75)	-4.14**
DEMQOL feelings	37.06 (7.39)	41.65 (5.60)	-3.78**	44.06 (5.66)	-4.28**
DEMQOL memory	19.18 (3.56)	21.53 (1.84)	-4.24**	21.59 (2.79)	-2.68*
DEMQOL everyday	30.18 (5.43)	32.41 (3.57)	-3.65**	34.18 (2.04)	-3.86**
DEMQOL QoL	3.18 (0.95)	3.06 (0.90)	0.70	3.29 (0.59)	-0.52
ToDS	73.71 (11.18)	48.59 (12.60)	8.96**	41.00 (14.39)	9.54**

(**= 0.01 or less and *=0.05 or less)

Table 3: Carer outcomes

	Pre-intervention: T1 (n=17)	**Post-intervention: T2 (n=17)**	***t*-score for T1 vs T2**	**Eight week follow-up: T3 (n=17)**	***t*-score for T1 vs T3**
Anxiety (HADS-A)	4.47 (3.50)	5.06 (3.11)	-0.979	3.88 (3.35)	0.979
Depression (HADS-D)	3.89 (2.50)	4.82 (3.13)	-1.610	3.94 (2.49)	-0.108

(**= 0.01 or less and *=0.05 or less)

The differences between quantitative outcome measures at: pre, post and follow-up.

The quantitative data was analysed on SPSS and paired sample t-tests were used; the different findings are detailed below.

Hospital Anxiety and Depression Scale: Anxiety (HADS-A)

Participants living with dementia

The anxiety scores (as measured by the HADS-A) for the participants living with dementia were found to be significantly decreased between T1 (baseline/pre-intervention) (*M*=4.00, *SD*=3.39) and T2 (post-intervention) (*M*=2.00, *SD*=1.73), *t*(16)=2.94, p=0.01. The anxiety scores remain significantly decreased for the participants living with dementia at follow-up T3 (*M*=1.29, *SD*=1.40), *t*(16)=3.45, p=0.003.

These differences demonstrate that the anxiety levels for the participants living with dementia decreased between T1 and T2 and that the participants living with dementia remained significantly less anxious at follow-up.

Carers

There were no significant changes found in the anxiety scores for the carers at T1 and T2; there were also no significant differences found between T1 and T3 either.

Hospital Anxiety and Depression Scale: Depression (HADS-D)

Participants living with dementia

There were no significant differences found between T1 and T2 depression scores (as measured by the HADS-D) for the participants living with dementia. There were also no significant differences found between T1 and T3 depression scores for the participants living with dementia.

Carers

There were no significant differences found between T1 and T2 depression scores (as measured by the HADS-D) for the carers. There were also no significant changes found in depressions scores between T1 and T3 for the carers.

Threat of Dementia Scale (ToDS)

There was a significant decrease found between the ToDS scores for the participants living with dementia between T1 (*M*=73.71, *SD*=11.18) and T2 (*M*=48.59, *SD*=12.60), *t*(16)=8.96, p<0.001. It was also found that the ToDS scores remained significantly decreased at follow-up T3 (*M*=41.00, *SD*=14.39), *t*(16)=9.54, p<0.001.

A lower score on the ToDS represents feeling less threatened, so the results suggest that the participants living with dementia felt less threatened at T2 compared to T1 and that this decrease was maintained at the T3 follow-up.

Dementia Quality Of Life scale (DEMQoL)

The DEMQoL questionnaire is split into four sections that can each be scored and the overall score can then be obtained; all mean scores across the time points for the different sections can be seen in Table 2.

Feelings

The first section is DEMQoL feelings and a significant increase in scores was found between T1 (*M*=37.06, *SD*=7.39) and T2 (*M*=41.65, *SD*=5.60), t(16)=-3.78, p=0.002. DEMQoL feelings scores remained significantly increased at T3 (*M*=44.06. *SD*=5.66), t(16)=-4.28, p=0.001.

Memory

The second section is DEMQoL memory and a significant increase in scores was found between T1 (*M*=19.18, *SD*=3.56) and T2 (*M*=21.53, *SD*=1.84), t(16)=-4.24, p=0.001. DEMQOL memory scores remained significantly increased at T3 (*M*=21.59, *SD*=2.79), t(16)=-2.68, p<0.02.

Everyday

The third section is DEMQoL everyday and a significant increase was found for scores between T1 (*M*=30.18, *SD*=5.43) and T2 (*M*=32.41. *SD*=3.57), t(16)=-3.65, p=0.002. DEMQOL everyday scores remained significantly increased at T3 (*M*=34.18, *SD*=2.04), t(16)=-3.86, p=0.001.

Quality of life question

The fourth section is one question that asks participants to self-rate their quality of life. No significant differences were found between scores at T1 and T2. There were also no significant differences found between T1 and T3.

DEMQoL overall score

A significant increase was found in the DEMQoL overall scores for the participants living with dementia between T1 (*M*=89.53, *SD*=15.12) and T2 (*M*=98.65, *SD*=10.06), *t*(16)=-4.44, p<0.001. DEMQoL overall scores remained significantly increased at T3 (*M*=103.12, *SD*=9.75), *t*(16)=-4.14, p=0.001.

An increased score on the DEMQoL indicates a better quality of life, so this means that the DEMQOL scores on the feelings, memory, everyday and overall increased between T1 and T2 and that these increased scores were maintained at the T3 follow-up.

Qualitative Results: A Thematic Analysis

Interviews were conducted with ten dyads; these dyads were purposively selected until the desired number had been reached and the selection was based on whether participants indicated that they would feel comfortable being interviewed. Each member of the dyad had their own individual interview, so there were 20 interviews in total. All names have been changed to protect participant confidentiality. In the initial coding stage of the thematic analysis, 126 codes were found in total. These were then grouped into seven initial patterns, which were then redefined into four themes with sub-themes. The final themes and sub-themes identified can be found in Table 4.

Table 4: Overview of themes and sub-themes

Theme	**Subtheme**
1. The splitting of the groups	1a. Getting more out of a big group 1b. Safety 1c. Suspicions 1d. Carers were freer to converse 1e. Will they remember?
2. Thinking and feeling differently	2a. Gaining knowledge 2b. Further support 2c. Acceptance 2d. Shared experiences
3. The perceived threat of a dementia diagnosis	3a. Feeling less threatened 3b. Participants had never felt threatened by a diagnosis of dementia 3c. Threat levels stayed the same
4. Group dynamics	4a. Not enough opportunity to talk 4b. Group facilitators utilised person-centred skills

Discussion

Threat of dementia

The quantitative results showed that the scores on the Threat of Dementia Scale decreased between the pre and post measures, so this indicates that attending the Thinking Together groups had an impact on how threatened people felt about their diagnosis. The decrease in threat levels was maintained at the follow-up measure, which was taken eight weeks after the groups finished.

Within the qualitative findings, people's experiences of whether their threat levels changed varied. Some people reported finding that the threat decreased because they now know more about dementia; this reflects one of the key elements of the group which is psycho-education about the different types of dementia and the progression of them. Research has found that dementia is the most feared health condition in the UK and that 62% of people surveyed felt a diagnosis would mean their life was over (Alzheimer's Society, 2016). Some people will most likely walk into post-diagnostic groups thinking that they are going to die sooner than they had expected, if they then attend the groups and realise that they can actually live well with dementia this could be one of the factors that contributes to the threat of dementia decreasing.

Anxiety and depression

People living with dementia

The findings in the current study demonstrated that the anxiety scores for the people living with dementia were significantly decreased between the pre and post measures and that the scores remained significantly decreased at the follow-up measure. This finding indicates that the people living with dementia felt less anxious after attending the groups and some of the reasons were identified in the qualitative findings; these can be found in the theme ‘Thinking and feeling differently’. A sub-theme within this theme is ‘Gaining knowledge, which included the people living with dementia speaking about finding it helpful to be given information about the different types of dementia because they can then make sense of what has happened to them. The fear of the unknown has been linked to many anxiety disorders (Gorka et al, 2016), so increasing the known through information giving correlates with decreased anxiety.

The quantitative findings showed no significant difference in the depression scores between pre, post and follow-up in the people living with dementia; this has also been found in other studies that assessed mood in participants attending dementia support groups (McAfee et al. 1989; Marshall et al. 2005; Logsdon et al. 2007). Whilst there are no quantifiable findings for a change in depression scores, there were elements identified in the qualitative findings that suggest that mood may have been impacted in the people living with dementia. As discussed above, one of the themes identified within the qualitative data included a sub-theme in which people living with dementia reported that they found comfort in sharing experiences with others in a similar situation.

Carers

On the quantitative measure, the carers showed no significant changes in their scores for anxiety or depression, however, when looking at the qualitative findings, the carers report changes to their lives that might suggest that symptoms associated with anxiety and depression did potentially alter in some way. Some of the carers described that the groups helped them to become more accepting of the situation, which has led to them feeling less annoyed and being able to 'let things go'. As can be seen in the efficacy of Cognitive Behaviour Therapy (CBT) research, if healthier thoughts and behaviours can be utilised, this can directly impact mood in a positive way (Hofmann et al, 2012).

Quality of life in the people living with dementia

The DEMQOL is split into three sections: feelings, memory and everyday life. The first section asks participants to say how often they have experienced a variation of feelings in the past week. The results show that there was a significant increase in scores in this section and that this was sustained for the follow-up measure. This indicates that in some way, the groups may have changed how people were feeling and that the groups enabled more positive emotions to be accessed. This was further demonstrated in the qualitative findings as the theme 'Thinking and feeling differently' identified some of the ways that people were feeling differently. The second section asks participants to rate how worried they felt about different aspects of their memory. There was a significant increase in these scores which suggests that people felt less worried about their memory after having attended the group. This was sustained at follow-up which indicates that these effects weren't just short-term. The qualitative findings identified feelings of acceptance; increasing acceptance of internal experiences has been found to be negatively associated with worry (Roemer et al, 2008), so the findings of acceptance in the current study supports the quantitative findings of the DEMQOL that worry decreases. The third section asks people how worried they have felt by different aspects of everyday life; these aspects include having enough company, getting support when needed and how the participants feel in themselves. There was a significant increase in these scores between the first and second time point which indicates that people felt less worried about aspects of everyday life after attending the groups. This was sustained at follow-up which suggests that the worries are less present after the groups had ended. Within the qualitative findings, it was found that as well as finding comfort in other's experiences, participants were also able to listen to how other people coped in order to aid with their own ways of coping. Increased coping skills will lead to a better quality of life in relation to day to day activities, so the qualitative findings appear to support the quantitative findings.

The most and least useful aspects of the group

The splitting of the groups

The participant's experiences of when the groups split varied depending on whether they were in the group of people living with dementia or the carer group. The people living with dementia reported that some of them felt unsafe without their partner in the room and that they felt suspicious of what was being talked about. Research has shown that people living with dementia can become reliant on their carers to make decisions for them, so when carers are absent, it could indicate that the people living with dementia may feel unsafe in some way (Samsi and Manthorpe, 2013). The carers however, reported that the split was beneficial as they were able to talk more openly without a fear of upsetting their partners. The reported differences in the experiences of the people living with the dementia and the carers might potentially reflect the difficulties of trying to meet individual needs of the people diagnosed with dementia and the carers within one group.

Gaining knowledge

A useful aspect of the group that was identified across both the people living with dementia and the carers was the opportunity to gain new knowledge as a result of attending the group. Psychoeducation is a key element of these groups as people affected by a diagnosis of dementia are usually not aware of all the information available about the illness itself and also the support available. There has been some research into how psychoeducation helps the carers of people living with dementia, but little research exists on whether psychoeducation is useful to the people living with dementia. The people living with dementia spoke about increased dementia knowledge as a result of attending the groups, which was found in other studies (McAfee et al. 1989). More specifically, the participants talked about it being useful to learn about how dementia affects the brain, so that they can then make sense of what has happened to them. The carers speak about the psychoeducational aspects being useful so that they know more about the prognosis of dementia, where to get support and how to plan for the future; this has also been found to be useful in other research (Zarit et al. 2004).

Shared experiences

Another theme that was identified across both the people living with dementia and carers was that it was useful to have a space where experiences could be shared. The people living with dementia describe finding it useful to hear that it wasn't just them and that others were experienced similar things. The research into whether sharing experiences is useful in people living with dementia is very sparse, so these findings offer something new to the existing literature and provide further evidence as to why post-diagnostic groups can be a useful intervention to a person living with dementia.

The carers also describe sharing experiences as being a useful aspect of the group. The findings from this set of participants demonstrate that the reasoning behind this was that they were able to listen to how people were managing and coping day to day.

Limitations of the current study

The participants in this study were all white British which results in the current study lacking cultural diversity. However, in the time the data was collected, all of the participants that gave consent to participate were white British, so this was unavoidable. The results of this study are a true reflection of the Thinking Together groups and the people that usually attend, so an evaluation of the groups can still be accurately made.

The number of participants studied was in line with that expected of a pilot study (Browne, 1995; Sim & Lewis, 2012; and Julious, 2005), but the lack of a control group can also be seen as a potential limitation. The researcher investigated whether a control group could be used when looking at the study design but the waiting list for the groups was minimal, as anyone deemed suitable is usually put into the next group running, which is normally only a matter of weeks. It would have been unethical to make people wait to attend the groups for the sake of a control group, as these groups are designed to be attended as soon after a diagnosis as possible. If the waiting list for the Thinking Together groups was longer, a control group could have been used. This could be considered for future research if a waiting list is established.

Whilst a variety of different types of dementias were present in this study, the majority of people had been diagnosed with Alzheimer's, meaning that applicability to other types of dementias is limited.

Suggestions for further research

This research was designed to be a pilot study with the hope that further research can be conducted on the Thinking Together groups. Recommendations for further research on these groups would be to conduct it on a larger scale and hopefully with a control group, if the demand grows and a waiting listing evolves. Further research may also include longer interviews where possible so that some of themes identified in this research can be explored more fully. Being able to use longer interviews will be dependent on people's cognitive capabilities; in the current research, shorter semi-structured interviews were deemed the most suitable for the participants included in the study.

The threat of dementia was one of the key topics looked at in this research and a recommendation would be to have more research that explores this phenomenon. This study was one of the first of its kind to use the 'Threat of Dementia Scale' and it found some promising results in terms of post-diagnostic groups being able to reduce the threat of dementia. Further research using this scale would be useful in order to establish whether other post-diagnostic groups also have a positive impact on people's perceived threat of a dementia diagnosis.

Conclusions

The overall evaluation of the Thinking Together groups is that they appear to work for people in different ways. Quantitative results demonstrate that the groups significantly reduce anxiety and threat of dementia, alongside increasing quality of life for the people living with dementia. The results showed that the quantitative measures didn't demonstrate a reduction in the carer's anxiety and depression scores.

In terms of qualitative findings, people's overall experiences of the groups are positive and suggest that both the people living with dementia and the carers experience being able to think and feel differently as a result of having attended the group. Thinking differently came from participants gaining knowledge on the different types of dementia, finding out about support available in the community and practical benefits such as identity cards and blue badges. A theme of acceptance was also identified which reflects how participants had begun to feel differently in terms of being able to accept their diagnosis and adapt to life with it. Feeling differently came from participants being able to meet others in a similar situation, being listened to, learning new coping skills and from the realisation that people do live well after a diagnosis of dementia. All of these findings can be linked to how the group facilitators ran the groups and that with their use of person-centred skills, they were able to create a safe therapeutic environment so that the people attending the groups found them beneficial.

A unique aspect of the Thinking Together groups is that they invite both the carer and the person living with dementia and then split the groups each session; this was a key topic that was explored in the current study. From the results, it can be concluded that the split may be beneficial to the carers in terms of them being able to talk more freely, but may not be as beneficial to some of the people living with dementia. A majority of the interviews with the people living with dementia indicated that during the split, they felt unsafe without their partner, felt suspicious of what was going on in the other room and felt like they were being talked about. These findings may reflect the challenges of trying to meet the needs of both carers and the people living with dementia within one group; further considerations of splitting the groups need to be made for future groups as the split was an area that proved problematic for the people living with dementia.

As discussed, the threat of dementia scores significantly reduced between the pre-group measure and the post-group measure; this finding suggests that the Thinking Together groups help people to feel less threatened by their diagnosis and this could have been due to a number of factors. If the people living with dementia were able to find out more about their diagnosis and realise that it doesn’t mean life is over, naturally it would become less threatening. Alongside this, meeting and getting support from others and knowing that they are not alone in this journey could have also helped to reduce the threat of dementia. Some of the participants said that the groups were the first time they had talked about their diagnosis, which may have also helped to ease the fear surrounding it. The scores remained significantly reduced at the follow-up measure, which indicates that these changes are not just short-term, but seem to be longer lasting.

References

Abbott A. 2011. Dementia: A problem for our age. Nature 475, S2–S4

Alzheimers Society (2016) Depression and anxiety. http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=139

Bakker, A. B., & Oerlemans, W. (2011). Subjective well-being in organizations. In K. Cameron & G. Spreitzer (Eds.), Handbook of positive organizational scholarship (pp. 178–190). New York, NY: Oxford University Press.

Black, D. W., & Andreasen, N. C. (2014). *Introductory textbook of psychiatry*. American Psychiatric Pub.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology, 3 (2). pp. 77-101

Browne, R. H. (1995). On the use of a pilot sample for sample size determination. *Statistics in medicine*, *14*(17), 1933-1940.

Chapman, D. P., Williams, S. M., Strine, T. W., Anda, R. F., & Moore, M. J. (2006). PEER REVIEWED: Dementia and its implications for public health. *Preventing chronic disease*, *3*(2).

Cheston, R., Jones, K., & Gilliard, J. (2003). Group psychotherapy and people with dementia. *Aging & mental health*, *7*(6), 452-461.

Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The psychologist*, *26*(2), 120-123.

Gorka, S. M., Lieberman, L., Shankman, S. A., & Phan, K. L. (2017). Startle potentiation to uncertain threat as a psychophysiological indicator of fear-based psychopathology: An examination across multiple internalizing disorders. *Journal of abnormal psychology*, *126*(1), 8.

Goudie, F. and Stokes, G. (1989) Dealing with Confusion. Nursing Times

Hewitt, P., Watts, C., Hussey, J., Power, K., & Williams, T. (2013). Does a structured gardening programme improve well-being in young-onset dementia? A preliminary study. *British Journal of Occupational Therapy*, *76*(8), 355-361.

Hofmann, S. G., Asnaani, A., Vonk, I. J., Sawyer, A. T., & Fang, A. (2012). The efficacy of cognitive behavioral therapy: A review of meta-analyses. *Cognitive therapy and research*, *36*(5), 427-440.

Julious, S. A. (2005), Sample size of 12 per group rule of thumb for a pilot study. Pharmaceut. Statist., 4: 287–291

Kaplan, H. I., Sadock, B. J., & Grebb, J. A. (1994). *Kaplan and Sadock's synopsis of psychiatry: Behavioral sciences, clinical psychiatry*. Williams & Wilkins Co.

Logsdon, R. G., McCurry, S. M. and Teri, L. (2007). Time-limited support groups for individuals with early stage dementia and their care partners. *Clinical Gerontologist*, 30, 5–19. doi: 10.1300/J018v30n02_02.

Logsdon, R. G., Pike, K. C., McCurry, S. M., Hunter, P., Maher, J., Snyder, L., & Teri, L. (2010). Early-stage memory loss support groups: outcomes from a randomized controlled clinical trial. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *65*(6), 691-697.

Marshall, A., Bucks, R. and Mander, H. (2005). A long-term support group for people with dementia. *Journal of Dementia Care*, 13, 36–37.

McAfee, M. E., Ruh, P. A., Bell, P. and Martichuski, D. (1989). Including persons with early stage Alzheimer’s disease in support groups and strategy planning. *American Journal of Alzheimer’s Disease and Other Dementias*, 4, 18–22. doi: 10.1177/1533331758900400605

Orrell, M. (2012). The new generation of psychosocial interventions for dementia care. *The British Journal of Psychiatry*, *201*(5), 342-343.

Patel, B., Perera, M., Pendleton, J., Richman, A., & Majumdar, B. (2014). Psychosocial interventions for dementia: from evidence to practice. *Advances in psychiatric treatment*, *20*(5), 340-349.

Prince, M., Ali, G. C., Guerchet, M., Prina, A. M., Albanese, E., & Wu, Y. T. (2016). Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer's research & therapy*, *8*(1), 23.

Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *International psychogeriatrics*, *25*(6), 949-961.

Sim, J., & Lewis, M. (2012). The size of a pilot study for a clinical trial should be calculated in relation to considerations of precision and efficiency. *Journal of clinical epidemiology*, *65*(3), 301-308.

Sinason, V. (1992). *Mental handicap and the human condition* (Vol. 38). London: Free Association Books.

Steinberg, M., Sheppard, J. M., Tschanz, J. T., Norton, M. C., Steffens, D. C., Breitner, J. C., & Lyketsos, C. G. (2003). The incidence of mental and behavioral disturbances in dementia: the cache county study. *The Journal of neuropsychiatry and clinical neurosciences*, *15*(3), 340-345.

Stokes, G., Goudie, F. (1990), Counselling confused elderly people. Working with Dementia, Bicester, Oxon: Winslow.

Teri, L., & Gallagher-Thompson, D. (1991). Cognitive-behavioral interventions for treatment of depression in Alzheimer's patients. *The Gerontologist*, *31*(3), 413-416.

Toms, G. R., Clare, L., Nixon, J., & Quinn, C. (2015). A systematic narrative review of support groups for people with dementia. *International psychogeriatrics*, *27*(9), 1439-1465.

Zarit, S,H., Femia, E, E., Watson, J., Rice-Oeschger, L., Kakos, B. (2004). Memory club: a group intervention for people with early-stage dementia and their care partners. Gerontologist 44(2): 262–269.

Appendix Section

Appendix 1: baseline demographic data and clinical characteristics

Table 1: Participants living with dementia: baseline demographic and clinical characteristics.

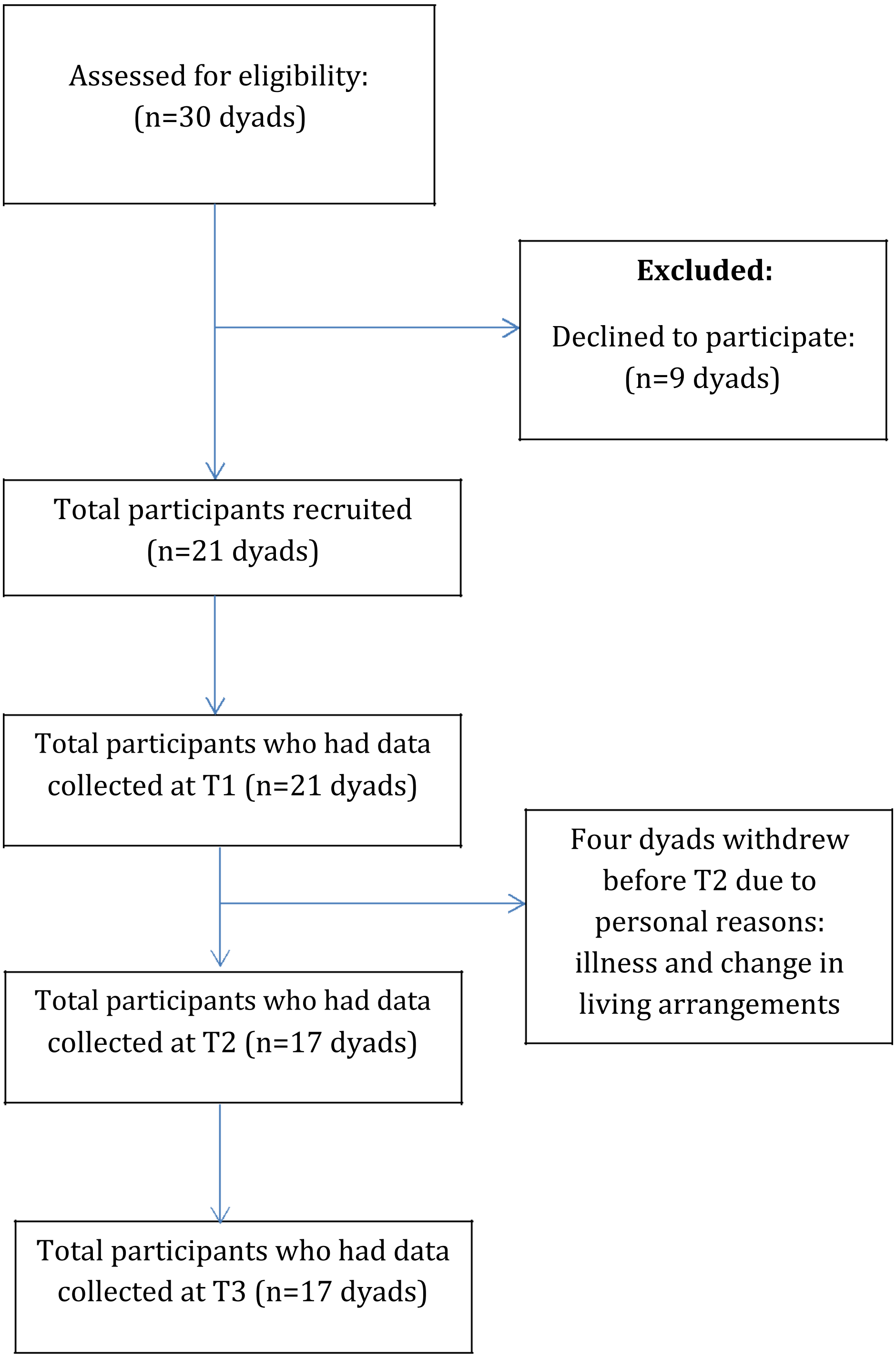
	Participants living with dementia (n=17)
Gender	
Female	10
Male	7
Age	
Mean age (years)	77.88 (5.42)
Age range (years)	65 - 87
Ethnicity	
White British	17
Living status	
Living with carer	15
Living alone	2
Relationship to carer	
Spouse husband	7
Spouse wife	7
Mother	1
Friend	2
Dementia Diagnosis	
Alzheimer’s	12
Vascular	2
Lewy-body dementia	2
Mixed	1

Table 2: Carers: baseline demographic and clinical characteristics.

	Carers (n=17)
Gender	
Female	10
Male	7
Age	
Mean age (years)	72.82 (10.39)
Age range (years)	42 - 89
Ethnicity	
White British	17
Living status	
Living with participant	15
Living alone	2
Relationship to participant	
Spouse husband	7
Spouse wife	7
Daughter	1
Friend	2

Appendix 2: Consort Diagram

Diagram One: Consort diagram of the participant flow



Appendix 3: demographic data for interviewees used in the Thematic Analysis write up

Name*	Age	Diagnosis if applicable	Participant type
Ben	65	Vascular	Person living with dementia
Jean	77		Carer
Barb	64		Carer
Pat	76	Alzheimer’s	Person living with dementia
Lisa	78	Alzheimer’s	Person living with dementia
Mel	75	Alzheimer’s	Person living with dementia
Matt	76		Carer
Fran	79		Carer
Sammy	68		Carer
Dan	78	Alzheimer’s	Person living with dementia
Deana	73		Carer
Jim	81	Mixed	Person living with dementia
Fred	80	Alzheimer’s	Person living with dementia
Cat	76	Lewy-body	Person living with dementia
Ron	77		Carer

*pseudonyms

Appendix 4: Process of thematic analysis

Interviews were transcribed, the researcher then read and re-read the transcripts and fully immersed themselves in the data

The data was then coded and a total of 126 codes were identified

The codes were then grouped into different initial patterns; a total of seven patterns were identified

The seven initial patterns were then redefined into themes that addressed the research questions

A total of four final themes were found; all of which have sub-themes that help to further clarify the areas of interest

Appendix 5: Example coded interview

Ben's* Interview

Interviewer: So how did you come to attend the group?

Ben: How did I physically get there do you mean?

Interviewer: No. How did it come about that you came to the group?

Ben: Oh, through the memory clinic.

Interviewer: Okay. And did you get referred to the memory clinic by your GP?

Ben: Yes. I said to the GP I want to go to the memory clinic.

requested the memory clinic

Interviewer: Okay, good. And then they referred you and then the memory clinic asked you about groups?

Ben: Yes.

Interviewer: Okay. So you finished the groups recently and how do you feel now the group has finished?

Ben: About the group?

Interviewer: Yes, how do you feel now it's finished? That the groups are over.

Ben: I was very pleased with the groups.

— pleased. satisfied

Interviewer: Okay. So finishing them, how do you feel about finishing them?

Ben: A bit disappointed really. I'd like it to go on.

would have liked to go on longer

disappointed they're over.

Interviewer: Okay. Would have been better if there was more of them?

Ben: A longer period, yes.

Interviewer: Okay. So what name do you use for the difficulties that the group was helping you with?

remembering

Ben: Well, it was probably remembering things. At the same time I found it very useful that you could meet people and talk to people in more or less the same position and see what their problem was. So listening to these various people and what they had to say and how they were coping with it I found very useful. — how people were coping

Similar situation

Same position.

sharing experiences

Interviewer: Yes. So in terms of the name of the difficulty the groups were helping you with, what do you use? What name do you feel comfortable using?

Ben: Dementia I think. — dementia.

Interviewer: Dementia? Yes, okay. So after attending the groups do you now feel less threatened by your diagnosis of dementia?

Ben: No, I never felt threatened in the first place.

never felt threatened.

Interviewer: Never felt threatened in the first place, okay.

active choice

Ben: When the doctor said to me you've got dementia I said what can you do about it? He said nothing. I thought you can't do anything. I said what happens? You just get worse. I thought well in that case I'll just have to put up with it and that's when I decided... I've always had a quite good sense of humour and I thought well I'll keep my sense of humour and I've found that very helpful, and I can't remember what your original question was, you know.

acceptance

conscious decision

Interviewer: It was about feeling less threatened by the diagnosis. But I guess it you...

Ben: Yes, but I never felt threatened by it.

Interviewer: No, because you made that choice at the beginning not to be. Okay, that's good. So on a scale of one to five, one's very unhelpful, and five's very helpful, where would you rate the groups?

Ben: Very helpful.

very helpful.

Interviewer: Yes? Five, okay. So were there particular aspects of the group that you found most helpful?

found comfort in meeting others who were struggling more.

Ben: Yes, meeting the other people. I like meeting people in any case but to meet people who were struggling more than I was in many ways with the problem I found that very helpful. There was one lady in the group, who had dementia a lot worse than I've got. She didn't think she had it. Her husband had it but she became very friendly with me. We used to sit each time and I used to refer to her as my girlfriend. She was older than I was and that's saying something. But she sort of took to me and I thought well I'll take to her as well because there's nothing to it really.

But her husband got terminal cancer and he was really worried about what's going to happen. So I thought well I'll give her what support I can while I'm there. But it was interesting as well to listen to the other people. There were some people there who said there's nothing wrong with me, I don't know why I'm here, and another man saying well how do they know I've got it. And when the nurses I presume, I don't know what title they give them, said we've had all the tests but how do they know those tests are right. And he was a mathematician and I think he wanted a mathematical answer.

wanting to support others

little insight

Interviewer: Yes, equation to... Yes, yes.

Ben: So listening to these various people and what they had to say and how they were coping with it I found very useful. Because as far as I'm concerned I don't think I've got any real problem. My wife might say oh a problem perhaps than I recognise. But I know I've got dementia and I know it's going to get worse. I hope it doesn't get too bad. But I listened to these other people and I thought well I could be a lot worse off than they are.

listening to how others coped.

accepting the situation

accepting it's going to get worse

Interviewer: Okay. So that aspect of it kind of made you feel maybe a sense of relief that you were more okay.

Ben: Yes, more comfortable perhaps.

Interviewer: More comfortable, yes okay. So what about the other things the group covers, kind of like the information on different memory problems?

Ben: That was very good.

Interviewer: Yes, what about stuff like that? Did you find those aspects helpful?

gaining more information

Ben: Yes I did. The doctor we had that talked about various types of dementia and how it affects the brain and that I found very useful because you know more about it then and you know what's actually happened.

find out what happened.

Interviewer: You can understand it better.

Ben: Yes, I didn't realise there were so many different types, well four or five different types. And that was very useful.

surprised on how many types

new information

Interviewer: Yes. Okay, that's good. So were there any aspects of the group that you didn't find helpful? Was there anything that you didn't like?

longer groups

Ben: There was nothing I didn't like. The only thing I'd like was if it was longer.

Interviewer: Okay, so that would be your...

Ben: Because I enjoyed it. – enjoyable experience

Interviewer: Yes, so you would have liked it to be a longer course than seven weeks yes?

Ben: Yes.

Interviewer: Okay, perfect. So you started the groups a few months ago, six/seven weeks whatever it is. Have you noticed any changes to your life in those last few months?

better understanding

Ben: I don't think any changes. Just a better understanding of the problem and the disease.

Interviewer: So leading on from that did the group help you to think about things differently or approach things in different ways?

thinking differently

Ben: I think it helped me to think about it differently. Whether I approach things differently I don't think so.

Interviewer: Okay, so with the thinking it might have helped with...?

Ben: Yes, a better understanding. ← understanding

Interviewer: Yes, okay, that's good. So how did you find the group facilitator, the people who ran the groups?

Ben: Very good. — good group facilitators.

Interviewer: Yes? And did you think they ran the group well? Did they start and end on time stuff like that?

Ben: Yes, started on time. The only problem, but it wasn't a problem to me but it was a problem to some of the other groups is they split the group in two halves.

Interviewer: Yes, I'm coming on to that.

Ben: Oh, we'll come to that then.

Interviewer: Well that's my next question is when the groups were split into two, so you all started as a group and then you split into two, how did you find that? What was your experience of that?

- off-putting

people felt unsafe?

Ben: Well, it's a bit off-putting in many ways because a lot... I accept it for what it was, they go into the other room, but the whole group, including this lady who got very uptight about it and I had to say to her well don't worry your partner has gone in the room with them as well and said that he'll be back soon and I spent most of that time with her, sort of talked to her about it. But the group generally weren't very happy with that. We were told that they were split because the room wasn't big enough for all of us but my wife suggests that wasn't the reason we were split. — suspicious?

had to take on comforting role

not the real reason

Interviewer: No.

Appendix Five – example coded interview

suspicions.

Ben: And the general consensus was what are they doing out there? What are they being told out there that we're not being told? I accepted what was going to happen and it wasn't going to be anything really serious but a lot of people in the group were quite...

what's going on in the other room

being deceived?

Interviewer: Struggling with that.

Ben: Yes. We were told we were split because the room wasn't big enough for the complete group and they had to move the other half to the other room to give everybody time to talk. And I accepted that but that wasn't the reason I was told afterwards by my wife.

different groups, told different reasons

compared reasons → different?

Interviewer: And in a sense it is so everyone can talk but it's also so that you feel more able to talk freely and some people in front of their partners might struggle to say certain things.

Ben: The group as a group were suspicious.

suspicious.

Interviewer: Yes, okay, suspicious of what's going on in the other room.

Ben: Yes, yes.

Interviewer: Yes, okay. So did you prefer it when your wife and all the other partners were in the room or when it was split?

Ben: It didn't worry me particularly but I think when we were all together I think I felt I got more from it when we were all together.

got more from one big group

Interviewer: Yes, okay, that's a good comment to make. Okay. So we've covered different bits about the group, is there anything else that you want to say?

Any other comments you want to make about the group or do you feel that we've covered it?

useful experience

Ben: I think that we've covered it all really. I found I got a lot of use from it. I'd like it to have gone on longer for two reasons; first of all, whether there was further aspects of dementia that could be covered in the group and secondly I really enjoyed it. — positive experience.

wanted more info. →

Interviewer: Yes, well that's really nice. Nice to hear you enjoyed it and hopefully when the team comes to visit you'll get some other forms of support and other things that you can carry on with.

Ben: That's the other point, I mean nothing to do with that but I'm amazed at the support I have got from the medical profession generally. It's been quite surprising really. And that's nothing to do with the group.

Interviewer: No, but that's good. That's good.

Ben: I forget. Just remind me.

Interviewer: Yes, so it was just about whether there was any other comments. I think you said about it would have been nice for it to go on longer and there might have been other bits.

Ben: Yes, I think there was some people in the group who may not agree with that, but personally...

Interviewer: Okay, but this is your perception.

Ben: I like meeting people and talking to people.

sociable person
- sociable aspects

Interviewer: Its good, it sounds like it was a good experience.

Ben: Yes, it was, yes. good experience

Interviewer: Okay, perfect.

*pseudonym used

Appendix 11: Interview schedule for person living with dementia

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Interview Schedule for the person living with dementia

1. How did you come to attend the group?
2. How do you feel now the group has finished?
3. What name do you use for the difficulties the group has been helping you with?
4. Do you now feel less threatened by your diagnosis of dementia*?
5. How helpful did you find the group on a scale of 1-5? 1 = very unhelpful to 5 = very helpful.
6. Which aspect(s) of the group did you find the most helpful?

PROMPTS

- The opportunity to talk to others in a similar situation and share experiences.
- Information on memory problems and ways to cope.
- The chance to learn strategies to enhance living well with dementia.
- Understanding and support from specialist health professionals.
- The opportunity to get your questions answered by dementia specialists.
- Information about where to get support in the future.

7. Which aspect(s) of the group did you find least helpful?
8. Have there been any changes to your life over the past few months?
9. Do you think the group has helped you to think about or approach things in a different way?
10. How did you find the group facilitator?

PROMPTS

- Do you think the group was run well?
- Did things start/end on time?
- Were appropriate boundaries maintained by the facilitator?

11. How did you find it when the groups were split into two?
12. Did you prefer it when your relative/friend was there or when they were in the other room? Why was this?
13. Do you have any other comments you wish to make?

*The interviewer will use the word that the participant has said in the previous question

Appendix 12: Interview schedule for carer

Interview Schedule for family member/friend

14. How did you come to attend the group?
15. How do you feel now the group has finished?
16. What name do you use for the difficulties the group has been helping your relative/friend with?
17. Do you now feel less threatened by their diagnosis of dementia*?
18. How helpful did you find the group on a scale of 1-5? 1 = very unhelpful to 5 = very helpful.
19. Which aspect(s) of the group did you find the most helpful?

PROMPTS

- The opportunity to talk to others in a similar situation and share experiences.
- Information on memory problems and ways to cope.
- The chance to learn strategies to enhance living well with dementia.
- Understanding and support from specialist health professionals.
- The opportunity to get your questions answered by dementia specialists.
- Information about where to get support in the future.

20. Which aspect(s) of the group did you find least helpful?
21. Have there been any changes to your life over the past few months?

22. Do you think the group has helped you to think about or approach things in a different way?
23. How did you find the group facilitator?

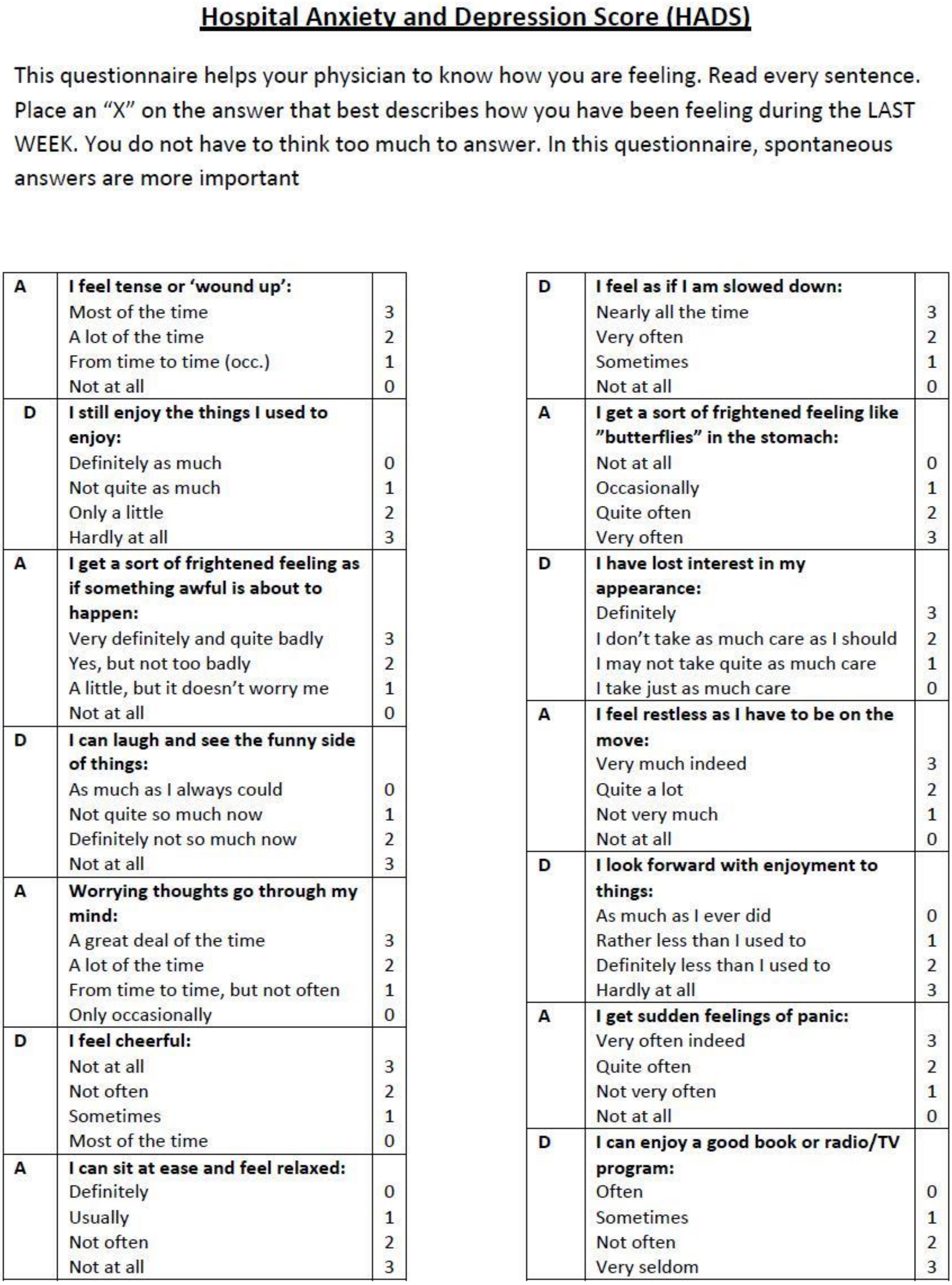
PROMPTS

- Do you think the group was run well?
- Did things start/end on time?
- Were appropriate boundaries maintained by the facilitator?

24. How did you find it when the groups were split into two?
25. Did you prefer it when your family member/friend was there or when they were in the other room? Why was this?
26. Do you have any other comments you wish to make?

*The interviewer will use the word that the participant has said in the previous question

Appendix 13: Hospital Anxiety and Depression Scale



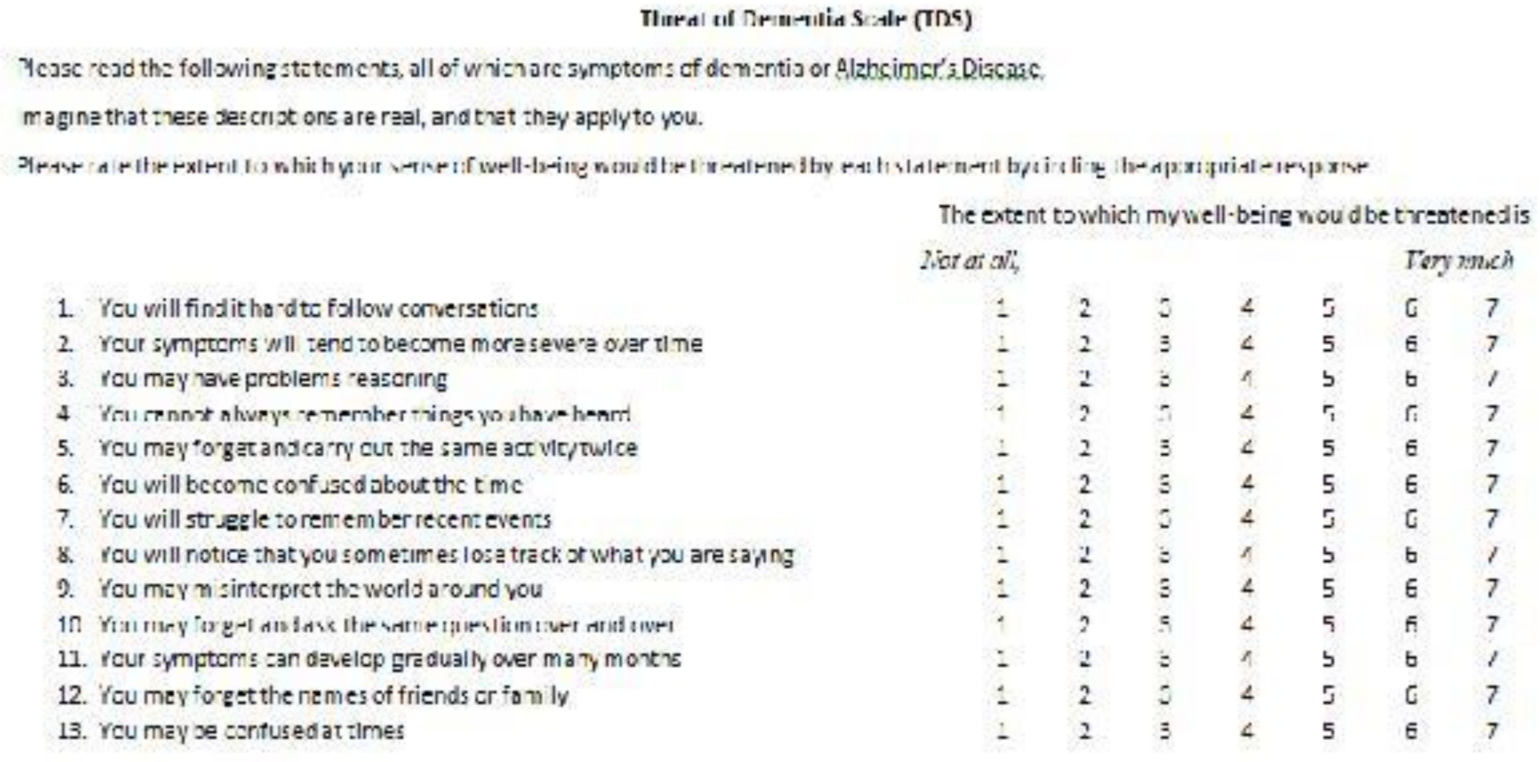
Hospital Anxiety and Depression Score (HADS)

This questionnaire helps your physician to know how you are feeling. Read every sentence. Place an "X" on the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important

A	**I feel tense or 'wound up':**	
	Most of the time	3
	A lot of the time	2
	From time to time (occ.)	1
	Not at all	0
D	**I still enjoy the things I used to enjoy:**	
	Definitely as much	0
	Not quite as much	1
	Only a little	2
	Hardly at all	3
A	**I get a sort of frightened feeling as if something awful is about to happen:**	
	Very definitely and quite badly	3
	Yes, but not too badly	2
	A little, but it doesn't worry me	1
	Not at all	0
D	**I can laugh and see the funny side of things:**	
	As much as I always could	0
	Not quite so much now	1
	Definitely not so much now	2
	Not at all	3
A	**Worrying thoughts go through my mind:**	
	A great deal of the time	3
	A lot of the time	2
	From time to time, but not often	1
	Only occasionally	0
D	**I feel cheerful:**	
	Not at all	3
	Not often	2
	Sometimes	1
	Most of the time	0
A	**I can sit at ease and feel relaxed:**	
	Definitely	0
	Usually	1
	Not often	2
	Not at all	3

D	**I feel as if I am slowed down:**	
	Nearly all the time	3
	Very often	2
	Sometimes	1
	Not at all	0
A	**I get a sort of frightened feeling like "butterflies" in the stomach:**	
	Not at all	0
	Occasionally	1
	Quite often	2
	Very often	3
D	**I have lost interest in my appearance:**	
	Definitely	3
	I don't take as much care as I should	2
	I may not take quite as much care	1
	I take just as much care	0
A	**I feel restless as I have to be on the move:**	
	Very much indeed	3
	Quite a lot	2
	Not very much	1
	Not at all	0
D	**I look forward with enjoyment to things:**	
	As much as I ever did	0
	Rather less than I used to	1
	Definitely less than I used to	2
	Hardly at all	3
A	**I get sudden feelings of panic:**	
	Very often indeed	3
	Quite often	2
	Not very often	1
	Not at all	0
D	**I can enjoy a good book or radio/TV program:**	
	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3

Appendix 14: Threat of Dementia Scale



Threat of Dementia Scale (TDS)

Please read the following statements, all of which are symptoms of dementia or Alzheimer's Disease.

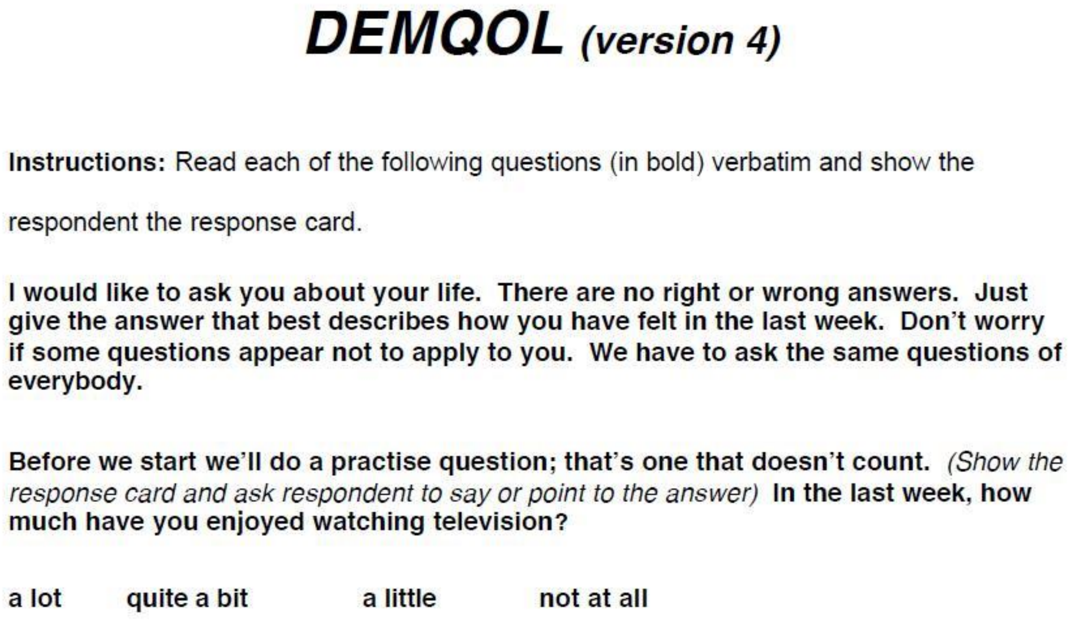
Imagine that these descriptions are real, and that they apply to you.

Please rate the extent to which your sense of well-being would be threatened by each statement by circling the appropriate response.

The extent to which my well-being would be threatened is

	Not at all,						*Very much*
1. You will find it hard to follow conversations	1	2	3	4	5	6	7
2. Your symptoms will tend to become more severe over time	1	2	3	4	5	6	7
3. You may have problems reasoning	1	2	3	4	5	6	7
4. You cannot always remember things you have heard	1	2	3	4	5	6	7
5. You may forget and carry out the same activity twice	1	2	3	4	5	6	7
6. You will become confused about the time	1	2	3	4	5	6	7
7. You will struggle to remember recent events	1	2	3	4	5	6	7
8. You will notice that you sometimes lose track of what you are saying	1	2	3	4	5	6	7
9. You may misinterpret the world around you	1	2	3	4	5	6	7
10. You may forget and ask the same question over and over	1	2	3	4	5	6	7
11. Your symptoms can develop gradually over many months	1	2	3	4	5	6	7
12. You may forget the names of friends or family	1	2	3	4	5	6	7
13. You may be confused at times	1	2	3	4	5	6	7

Appendix 15: Dementia Quality Of Life Scale



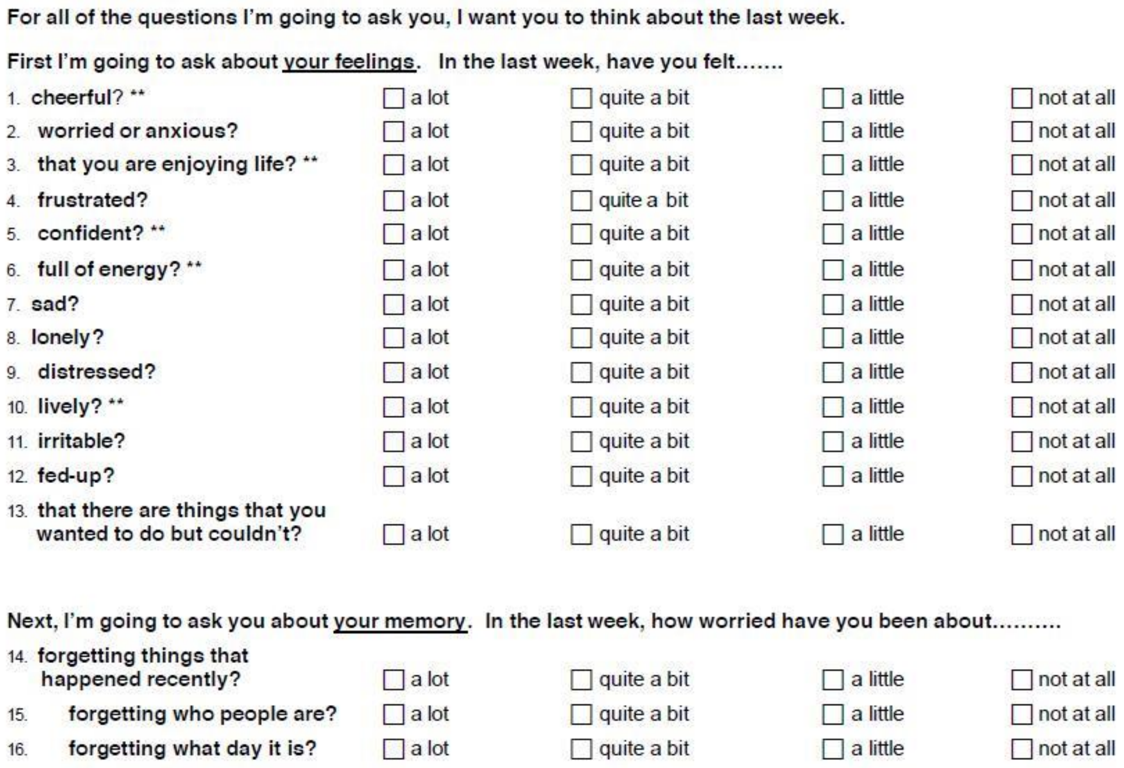
DEMQOL *(version 4)*

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

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

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

a lot quite a bit a little not at all



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

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

1. **cheerful? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
2. **worried or anxious?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
3. **that you are enjoying life? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
4. **frustrated?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
5. **confident? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
6. **full of energy? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
7. **sad?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
8. **lonely?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
9. **distressed?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
10. **lively? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
11. **irritable?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
12. **fed-up?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
13. **that there are things that you wanted to do but couldn't?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

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

14. **forgetting things that happened recently?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
15. **forgetting who people are?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
16. **forgetting what day it is?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

17. your thoughts being muddled?	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
18. difficulty making decisions?	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
19. poor concentration?	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

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

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

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

29. your quality of life overall? **	☐ very good	☐ good	☐ fair	☐ poor

** items that need to be reversed before scoring

Appendix 17: Overview of the Thinking Together group session plan

Session 1: Introduction to the groups and information on the different diagnoses

Session 2: Useful memory strategies that can help with memory difficulties

Session 3: A session on communication

Session 4: A session on occupation

Session 5: Life story work

Session 6: Q&A with a dementia specialist

Session 7: What's next? Information about further support for the future