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EXPLORING MINDFULNESS INTERVENTIONS FOR PEOPLE WITH DEMENTIA AND THEIR FAMILY CAREGIVERS

Section A: A review of the effectiveness of mindfulness-based interventions on the wellbeing of people living with dementia and their family caregivers
Word Count: 7955 (279)

Section B: Exploring the experiences of people with dementia and their family caregivers completing a MBSR intervention
Word Count: 8000 (321)

Overall Word Count: 15955 (600)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2017

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements

I would like to thank all the couples who took part in the research, for their time and commitment to the project. It has been an honour spending time with you and learning about your lives.

Thank you to my supervisors Dr Asesha Morjaria-Keval and Dr Kate Foxwell for all their support help and encouragement. To the course facilitators who dedicated their time to the successful running of the group Asesha, Miranda Weller and David Smith, thank you.

Most importantly I would like to thank my partner Paul for his endless support and patience.

Summary of the MRP portfolio

Section A

A critical review of all the empirical literature addressing the impact MBI has on the wellbeing of people with dementia and their caregivers. The review evaluates thirteen papers for either people with dementia, their caregivers or both as a dyad. It explores the strengths and limitations of this research and the clinical and research implications.

Section B

This research aimed to explore dyads' experiences of attending an eight week MBSR intervention. Five couples were recruited using a mixed method multiple case-study pre- and post- measure design with follow-up. Data was collected using self-report measures, group observations and semi-structured interviews. Thematic analysis and statistics analysed the data. Results were inconclusive from self-report measures but qualitative analysis suggested participants found the intervention a positive experience. They benefitted from completing it as a dyad and with people with related problems, specific mindfulness benefits were also found. Research and clinical implications are also discussed.

Section C

Includes all the appendices and supporting material from the research.

Table of Contents

Section A: A review of the effectiveness of mindfulness-based interventions on the wellbeing of people living with dementia and their family caregivers

Section B: Exploring the experiences of people with dementia and their family caregivers completing a MBSR course

Table of Figures and Tables

Table of Appendices

Section A: A review of the effectiveness of mindfulness-based interventions on the wellbeing of people living with dementia and their family caregivers

Word Count: 7955 (279)

Abstract

Background: Dementia affects the wellbeing for people with the disorder and their families. The Department of Health recommends intervening therapeutically with both the person with dementia and caregiver, but there is limited research around effective psychological interventions. Mindfulness based interventions (MBI) have become popular treatment options for wide-ranging difficulties, including dementia.

Methodology: A systematic review of the literature was carried out to find empirical research addressing the impact MBI has on the wellbeing of people with dementia and their caregivers.

Results: Thirteen papers were assessed for either people with dementia, their caregivers or both as a dyad. All bar one noted significant improvement in aspects of wellbeing. The most common improvements for caregivers were decreased caregiver burden, stress and depression, while for people with dementia it was greater quality of life and decrease in depression. The studies reviewed a range of methodologies, a key limitation was small samples.

Conclusions: Current literature suggests MBI might support the wellbeing of caregivers and people with dementia. More rigorous research is needed, involving larger sample sizes and exploring the specific mechanisms of change through which MBI impacts on participants' wellbeing. Caution is needed when considering MBI in clinical practice over more researched psychological interventions.

Key words: Dementia, Mindfulness, Wellbeing, Caregiving, Alzheimer's

Introduction

Dementia

Dementia is an umbrella term used for a range of organic brain disorders, which result in progressive and irreversible multiple impairments to functioning (Holmes, 2012). These impairments include memory loss, executive functioning problems, personality changes and communication difficulties (NICE/SCIE, 2006). The most prevalent dementias are Alzheimer’s disease (approximately 60% of all cases), vascular dementia (20%), dementia with Lewy bodies (10%) and frontotemporal dementia (2%) (Holmes, 2012). Diagnoses with multiple types of dementia (mixed dementia) are common (Holmes, 2012). Age is the main risk factor for dementia, with frequency increasing from one in fourteen in those over 65, to one in six in the over 80s (Alzheimer’s Society, 2014).

Estimates suggest over 850,000 people (7.1% of over 65s) have dementia in the UK. Due to an ageing population, this is forecast to exceed one million by 2025, and two million by 2051 (Alzheimer’s Society, 2014). Globally in 2015, there were estimated to be 46.8 million people living with dementia and is expected to double every twenty years (Alzheimer’s Disease International, 2015), meaning that dementia will have an increased burden on families and societies living with the disease.

Current guidance and policies aimed at supporting people with dementia and their families include the National Institute for Health and Care Excellence and Social Care Institute for Excellence (NICE / SCIE, 2006) report highlighting the need for early diagnosis, interventions for the cognitive and psychological symptoms associated with dementia, and collaborative work with families. The Department of Health (DoH) subsequently published living well with dementia (2009) and the (UK) national dementia strategy (2012) both setting out guidelines to increase awareness of dementia, early diagnosis and developing better services for people with dementia and their families.

For those diagnosed, dementia can have devastating effects due to its degenerative prognosis and impacts on wellbeing and identity (Kitwood, 1990; Lyketsos et al., 1997; Woods, 2001). Psychological symptoms such as anxiety and depression are common in people with dementia, with the Alzheimer's Society (2014) stating 61% of people with dementia felt anxious or depressed. Farrand, Matthews, Dickens, Anderson and Woodford (2016) highlight the stigma associated with mental health issues in older adults, suggesting this as a barrier to seeking help, and therefore higher rates of mental health difficulties in people with dementia and their family caregivers may exist.

In the UK, dementia has an overall annual economic burden of £26.3bn (Alzheimer's Society, 2014). Two-thirds of people with dementia live in the community (Alzheimer's Society, 2014). The cost of dementia to families living with dementia lies at around £17.4bn, with £11bn being the cost of unpaid care (Alzheimer's UK, 2014).

Family caregivers of people with dementia are likely to feel more stressed than caregivers of other disorders, which could be due to the chronic and degenerative nature of dementia disorders (Russo, Vitaliano, Brewer, Katon, & Becker, 1995). Caregivers may experience further burden if the person with dementia is experiencing anxiety and depression (Kang et al., 2014). This correlation may be because caregivers deal with more behavioural disturbances from the person with dementia (Allegri et al., 2006). Furthermore, increased caregiver stress leads to the person with dementia being more likely to require care or residential home support (Gaugler, Yu, Krichbaum, & Wyman, 2009; Mittelman 2005; Yaffe et al., 2002).

O'Shaughnessy, Lee and Lintern (2010) highlighted the negative impact dementia has systemically on couples' relationships and role identities. Therefore, it is apparent the impact of dementia on individuals and families is great and services need to support the psychological wellbeing in both, as outlined by government reports (DoH, 2009; 2012).

Understandings of ‘wellbeing’ in dementia

Understandings of dementia based on a medical or disease model can overlook the ways the psychological wellbeing of people with dementia can be supported (Farrand et al., 2016). Although there is no defining consensus of wellbeing in dementia (Algar, Woods, & Windle, 2014), Kitwood (1997) argued it is possible to have dementia and still be in a state of wellbeing, which he named ‘personhood’. He suggested dementia is a dialectical process between neurological impairment, identity (psychological factors) and social environment, and that positive social interactions and a nourishing social environment maintain ‘personhood’. Kitwood (1990; 1997) suggested that maintaining the ‘personhood’ of the individual consists of personal worth, social confidence, hope and agency. However, the psychological wellbeing of the person with dementia is often overlooked (Nolan, Ryan, Enderby, & Reid, 2002), or its deterioration thought of as an inevitable part of the dementia’s course, even though it has been argued that social processes have greater impact on wellbeing than neurological decline (Kitwood, 1997).

Research into community art interventions, such as viewing gallery art, have increasingly shown wellbeing benefits for people with dementia (Kinney & Rentz, 2005; Young, Camic, & Tischler, 2015). From this, a theoretical understanding of how art galleries can have a positive effect on people with dementia and their caregivers was developed (Camic, Baker, & Tischler, 2016). This area of research has enabled the development of the Canterbury wellbeing scale (Johnson, Culverwell, Hulbert, Robertson & Camic, 2017), an ‘in the moment’ measure of wellbeing in people with dementia. This can be used to broaden our understanding of wellbeing in dementia and the different ways it can be supported.

Aspects of the national dementia strategy (DoH, 2009, 2012), such as increasing the rate of diagnosis, have been given greater attention than supporting the mental wellbeing of the people diagnosed and their caregivers (DoH, 2015). There is a clear argument for the need to refocus recourses, not only identifying dementia but also promoting understanding and help to support and improve the dementia journey for individuals and their families.

Interventions to support people with dementia and their caregivers

There is currently a lack of research focused on interventions for people with dementia aimed at improving wellbeing and limited reviews examining this evidence base (Farrand et al., 2016). Smits et al. (2007) completed a review highlighting the effects of twenty-two interventions supporting either people with dementia or their caregivers. This review found interventions supporting the caregiver and person with dementia could improve some aspects of functioning and wellbeing for both. However, this review was very broad and included all interventions, including psychological. Therefore, it lacked detail on the helpfulness of specific interventions and the ways it supported the participants.

The review by Orgeta, Qazi, Spector and Orrell (2014) found evidence that psychological treatment for people with dementia can help reduce clinician-rated anxiety symptoms and depressive symptoms, for example counselling, cognitive behavioural therapy and interpersonal psychodynamic therapy. Robinson, Clare and Evans (2005) recommends when working with a person with dementia, involving caregivers is integral as it can help with adjustment to dementia, role transitions and identity issues. Nolan et al. (2002) also highlights the importance of ‘relationship centred care’. Dyadic interventions that involve both the person with dementia and caregiver can have practical benefits as caregivers can aid inter-sessional practice and support the person with skills learnt.

Mindfulness

One psychological intervention, which may be helpful for families living with dementia, is mindfulness. Mindfulness is described as a state of awareness ‘paying attention, characterized by intentional and non-judgmental observation of present moment experiences’ (Piet & Hougaard, 2011, p.1033). The practice of mindfulness and mindful meditation originated from Eastern contemplative practices and Buddhism. Kabat Zinn (2003) introduced mindfulness as a clinical intervention for stress reduction within the mindfulness based stress reduction (MBSR) programme. The MBSR programme consists of eight 2.5 hour, weekly, structured sessions and a retreat day around the sixth session. Sessions consist of formal and informal mindfulness practices. Participants are expected to complete 45 minutes of daily practice (Kabat Zinn, 2003).

Mindfulness and mindful meditation techniques have been adapted and utilised in various therapy programmes and models including mindfulness based cognitive therapy (MBCT, Teasdale, Segal, & Williams, 1995). MBCT usually consists of eight two hour, weekly sessions, incorporating elements of MBSR and cognitive behavioural therapy (Teasdale et al., 1995). Other common models including mindfulness are dialectical behaviour therapy (DBT, Lineham, 1993) and acceptance and commitment therapy (ACT, Davis & Hayes, 2011).

Many disorders, including recurrent depression, have been shown to benefit from Mindfulness based interventions (MBI) (Galante, Iribarren, & Pearce, 2013; Piet & Hougaard, 2011), with MBCT recommended as a relapse prevention treatment (NICE, 2009). MBI have been shown as beneficial for people with anxiety and bipolar disorder (Sipe & Eisendrath, 2012), and for improving the psychological health of people with physical health conditions such as cancer (Wood, Gonzalez, & Barden, 2015). Grossman, Nieman, Schmidt and Walach (2004) argued MBI could be applied to a multitude of long-term disorders including heart disease and chronic pain. More generally, a recent review has found MBI helpful in improving the physical and mental wellbeing of older people (Geiger et al, 2016), and having a positive impact on couples’ relationships (Bihari & Mullan, 2014). Though still being researched, Greeson (2009) argues that MBI may benefit individuals’ and couples’ wellbeing through instigating change in three areas: regulating awareness, attention, and emotion.

MBI for people with dementia and their caregivers

Psychological wellbeing has not been a focus for the majority of research conducted on MBI. However, research has shown, with adaptation, mindfulness can be taught to people with dementia (McBee, 2003), MBI can lead to cognitive improvements (Hernández et al., 2014; Innes, Selfe, Brown, Rose, & Thompson-Heisterman, 2012; McBee, 2003; Newberg, Wintering, Khalsa, Roggenkamp, & Waldman, 2010) and MBI may be beneficial for attentional rehabilitation (Robinsons, 2015).

Starts to investigating the usefulness of MBI for people with dementia and their caregivers are recent. Mcbee (2003) argues MBI can be helpful for caregivers of people with dementia in reducing stress and somatic complaints, and increasing the satisfaction of their role as caregivers. Mackenzie and Poulin (2006) highlighted MBI may be helpful as they can: give space to process feelings around being a caregiver; help participants notice when they are stuck in unhelpful ways of reacting and thinking around their caregiving role; and help develop non-judgemental and compassionate attitudes, as well as enable greater attention and kindness towards their own and loved one’s needs. Finally, the authors noted MBI might be helpful in enabling caregivers to live in the moment non-judgementally, rather than trying to ‘fix’ difficulties, which is not necessarily always possible in dementia care.

A recent systematic review by Hurley, Patterson and Cooley (2014) reviewed eight studies and tentatively suggested that MBI can reduce depressive symptoms and burden in caregivers, indicating the potential for this type of intervention to improve psychological wellbeing. However, no reviews have been undertaken that consider the way MBI may benefit both the wellbeing of caregivers, individuals with dementia and both together as a dyad.

Aims

This paper systematically reviewed all available research using MBI to improve the psychological wellbeing of people with dementia and their family caregivers. The review aimed to answer the following questions:

What does the current literature tell us about how effective MBI are at supporting the wellbeing of people with a diagnosis of dementia and their family caregivers?

Does the current literature highlight any further areas of research needed to explore the effectiveness of MBI for people with a diagnosis of dementia and their family caregivers?

Methodology

Scope

This systematic review was interested in papers using MBI, MBSR, MBCT or interventions adapted from these programmes. The larger field of psychological interventions using meditation and yoga was not included as, although they may have included meditation, they were not based on the principles of mindfulness. Papers with participants only diagnosed with mild cognitive impairment (MCI) will not be included as this is not a type of dementia, and not everyone with MCI will subsequently be diagnosed with dementia (Summers & Saunders, 2012). As this is a new area of investigation and research, this review will not limit the papers to ones found in peer-reviewed journals.

Literature search

A search on the following databases was carried out in August 2016: PsycINFO, MEDLINE, Web of Science, ASSIA, Google Scholar and the Cochrane Library. For studies exploring the use of MBI with caregivers, the search terms included: Carer OR Caregiver AND dementia OR Alzheimer AND mindfulness OR MBCT OR MBSR. For studies exploring the use of MBI with people with dementia, the search terms included: dementia OR

Alzheimer AND mindfulness OR MBCT OR MBSR. The search dates were 1990 to present and only included English language papers. From this initial search, articles were screened by reading their titles and abstracts, identifying articles focused on MBI aimed to improve any aspect of psychological wellbeing, for example, reduction in negative symptoms of mental health difficulties, improvement in quality of life, or reduction in caregiver burden.

Following this the articles were read in full for their suitability and their references searched for further papers missed from the original search. Follow-up papers and papers using the same participants were highlighted (see Figure 1).

Inclusion/Exclusion criteria

Inclusion criteria: papers using MBI with either people with dementia, caregivers or the dyad; primary outcome measures focused on psychological wellbeing, distress, caregiver burden or symptoms of psychological disorders such as depression or anxiety.

Exclusion criteria: papers where the majority of participants did not have a diagnosis of dementia; where the primary aim of the paper is to assess change in cognition or neurological performance; and finally, conceptual papers which did not involve an intervention.

Review structure

Thirteen studies were deemed to fulfil the inclusion criteria and of these, three papers were not published in peer-reviewed journals. Due to the variety of designs and heterogeneous nature of the papers, a meta-analysis could not be performed. The Downs and Black’s checklist (1998, see Appendix A) was utilised to help assess the randomised and non-randomised controlled trials. The critical skills appraisal programme was used to help assess the other studies (CASP, 2013 see Appendix B).

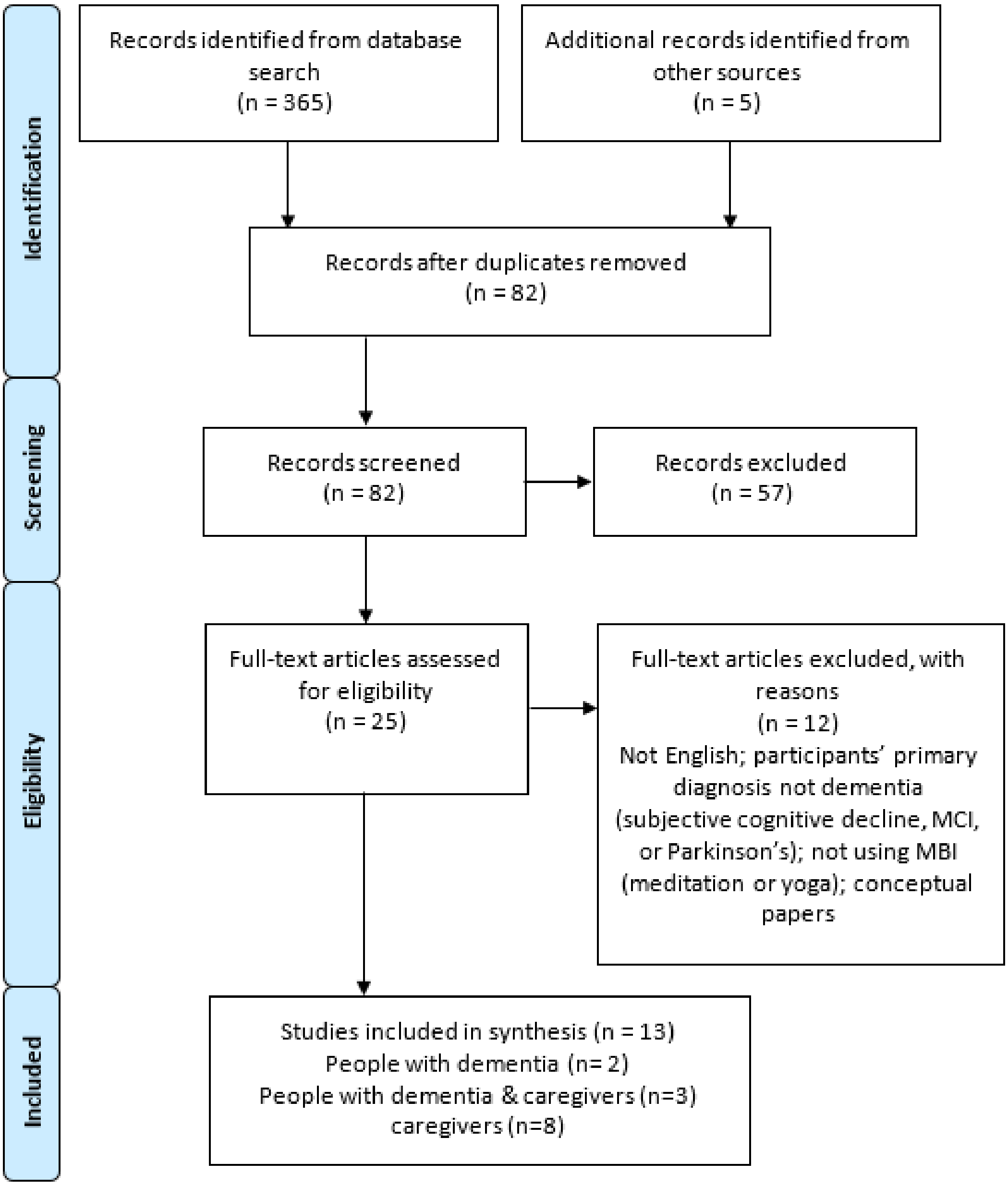

Figure 1. Flow Diagram of articles included in review based on PRISMA (2009).

Literature review

The literature review was divided into three subsections: papers exploring MBI interventions for people with dementia, for caregivers or for both as a dyad. Within the three subsections, papers were introduced with their results summarised to highlight the main findings before acritical review of the participant samples, intervention used, data collection and analysis was completed. Quality improvement tools aided this review.

MBI for people with dementia

Two papers were found that explored MBI for people with dementia. Lantz, Buchalter and McBee (1997) reported the benefits of mindfulness for fourteen people with moderate to severe dementia using a modified MBSR intervention called ‘The Wellness Group’. This research was a pre-test post-test non-randomised controlled trial. Chan (2015) detailed a pilot RCT in London conducted as part of the author’s unpublished doctoral thesis. This an adapted mindfulness programme, for thirty-one people with mild to moderate dementia, in care homes (see Table 1 for details on the intervention and participant demographics).

Summary of results. Both studies found some significant results that indicate MBI may be beneficial to people with a diagnosis of dementia. Lantz et al. (1997) found significant improvements in the Cohen-Mansfield agitation inventory (Cohen-Mansfield, Marx, & Rosenthal, 1989) completed by care home staff. Chan (2015) found a significant increase in quality of life through self-report measures with a medium effect size, however no significant improvements in cognition and stress levels were found at follow-up (see Table 1). Both studies reported difficulty in having available staff to support participants to practise in-between sessions. This suggests that MBI within care homes is resource intensive and therefore not a viable intervention if staff are unable to provide support to practise.

Table 1

People with dementia studies

				Sample for Active intervention / Control group											
First author and year	Country	Design	Mode of MBI	Size	% participants which were Female	Age (mean)	Diagnosis	Dementia severity	Ethnicity	Sessions	Follow up (months post intervention)	Measures used	Self report Measures	Comparison group intervention	Findings
Chan, 2015	UK	Single Blind Randomized controlled trial	MBSR & MBCT	Active 20 /Control 11	Active 60%/ Control 27.3%	Active 81.39/ Control 79.36	Alzheimer's= Active 4/ Control 2, Vascular= Active 3/ Control 3, Alcohol related= Active 2/ Control 0 , Dementia unspecified type= Active 11/ Control 6	Mild= Active 1/ Control 2, Moderate= Active 19 / Control 9	White British' Active 15/ Control 9 , 'Black Caribbean' Active 4/ Control 1, 'White European' Active 1/ Control 0, 'Black African' Active 0/ Control 1	Group, 10 consecutive weeks, 1 hour sessions	None	Self assess measures, feasibility by record of attendance, drop outs, home practise sheets , sessional rating forms.	QoL-AD, Cornell , ADS, MCAMS-R, MBAS, MMSE, PSS-13	Treatment as usual	At follow-up improvements in QOL-AD scale in intervention group and decline in the control.
Lantz, 1997	USA	Pretest-posttest non Randomized controlled trial	Modified MBSR	Active 8/ Control 6	Active 62.5% / Control 83.3%	Active 81/ Control 82	Not reported	MMSE (mean score) Active 8/ Control 9	Not reported	Group, 10 consecutive weeks, 1 hour sessions	3 months	Interviews and observational measures with nursing staff	CMAI completed by the primary nursing assistant	None	Reduction in agitation

* All findings reported in this table were statistically significant at p

QoL-AD= The Quality of Life – Alzheimer's Disease scale, Cornell=Cornell Scale of Depression in Dementia, ADS= Anxiety in Dementia Scale, MCAMS-R=Mindfulness Cognitive and Affective Mindfulness Scale Revised, MBAS= Meditation Breath Attention Score CMAI=The Cohen-Mansfield Agitation Inventory, PSS-13=Perceived Stressed Scale, MMSE= Mini Mental State Examination.

Participants. These were the first two papers reporting on MBI for people with dementia, both with small sample sizes. From reviewing the checklist (see Appendix A), a strength of Chan (2015) was the consort flowchart highlighting the participant recruitment and retention process. Participants for both appeared to be recruited through convenience sampling. While Chan's (2015) study reported on a range of demographic information (see Table 1), a limitation of Lantz et al. (1997) was that only severity of dementia was reported. Important information such as type of dementia diagnosis, were not reported or considered in data analysis. Dementia can affect people in wide ranging ways depending on details such as specific diagnosis or its severity.

Both papers reported using the Mini-Mental State Exam (MMSE) to measure severity of dementia. Chan (2015) reported each participant's type of dementia and Lantz et al. (1997) grouped participants to interventions according to severity. However, no further details were given on how the dementia did or did not affect the results gained. This review therefore cannot establish how important type and severity of dementia are as confounding variables affecting the utility of MBI in dementia.

Intervention. Lantz et al. (1997) used a modified MBSR group intervention. Sessions were reduced to sixty minutes and ran over ten weeks, with no retreat session. Staff from the nursing home attended the group with the aim of learning the techniques and incorporating mindfulness practice into their daily care work. Adaptations included having a facilitator to support residents needing extra 1-to-1 support. The authors described the flexibility they used in teaching the programme. They reduced or changed the session practices depending on the needs of participants. However, this would affect the authenticity of the model and ability for the study to be replicated in future (CASP checklist, see Appendix B).

Chan’s (2015) intervention included aspects of MBSR, MBCT and techniques from ‘The Wellness group’ (Lantz et al., 1997). A strength was its development, which was guided by a literature search and expert consultation. The main adaptations were to the structure, based on the Lantz et al. (1997) paper. Other adaptations included facilitators’ increased modelling, repetition and the simplification of language. Chan (2015) noted a limitation of the study was that a standardised adherence checklist was not used to assess fidelity, which would affect how reliably the study could be replicated (Downs and Black checklist, 1998 see Appendix A).

Data collection and analysis. Lantz et al. (1997) used a single measure, an assessment of observed agitation, to assess changes in wellbeing for people with dementia. This measured was completed by caregiving staff.. Staff completing the measure took part in the MBI, meaning that the changes in agitation cannot reliably be attributed to changes in the person with dementia. Staff’s involvement in the MBI may have led to them developing different ways of interacting with resident leading to a reduction in agitation.

This critique is also applicable to Chan’s (2015) study where staff attended the intervention. A strength of Chan’s (2015) study was the multiple ways that data was collected from the participants (i.e. observational measures, self-report measures and different attendance measures, see Table 1 for more information). To help support the reliability of the measures used, Chan (2015) chose self-report measures which had previously been used in research with people with dementia. A limitation of Chan’s (2015) study, noted by the author, was the sample size being under power so results should be taken with caution.

Chan’s (2015) study reported that there was no attrition, whereas Lantz et al. (1997) did not report on attrition rates.

MBI for caregivers of people with dementia

Eight papers were found that explored MBI for caregivers of people with dementia. The first two pilot studies of MBI interventions for family caregivers were completed by Oken et al. (2010) and Epstein-Lubow, McBee, Darling, Armey, and Miller (2011). Both aimed to assess the effectiveness of MBI, with Oken et al. (2010) also aiming to refine the protocol for MBI in larger future trials and Epstein-Lubow et al. (2011) piloting a MBSR intervention with minor adaptions.

Following this, two further studies assessed the effectiveness of different variations of MBI interventions. Hoppes, Bryce, Hellman, and Finlay (2012) assessed a low dose MBSR protocol, and Norouzi, Golzari and Sohrabi (2014) assessed a MBCT intervention specifically for female caregivers.

Three studies then went on to complete RCTs on MBSR interventions (Brown, Coogle, & Wegelin, 2016; O’Donnell, 2013; Whitebird, Kreitzer, Crain, Lewis, Hanson, & Enstad, 2013).

Finally, Ho et al. (2016) reported an intervention study exploring the effectiveness of MBSR at improving resilience and identifying predictive biomarkers of resilience in caregivers.

Summary of results. All eight studies found some significant improvements in psychological measures for caregivers attending MBI. The most common areas of significant improvement were decreases in self-reported stress (Brown et al., 2016; Epstein-Lubow et al., 2011; Ho et al., 2016; Oken et al., 2010; Whitebird et al., 2013), depression (Epstein-Lubow et al., 2011; Norouzi et al., 2014; O’Donnell, 2013) and burden (Epstein-Lubow et al., 2011; Hoppes et al., 2012; Norouzi et al., 2014; Whitebird et al., 2013). This supports Hurley et al.’s (2014) conclusion that MBI can reduce caregiver depression and burden. Note that all the studies used different self-report measures of depression and burden so direct comparisons cannot be made and any overall findings can only be tentatively suggested.

Areas of improvement not highlighted in past reviews included reductions in self-reported anger, tension (Brown et al., 2016) and feelings of isolation (O’Donnell, 2013), and increased hope (Hoppes et al., 2012).

Two studies collected qualitative data (Epstien-Lubow et al., 2011; Hoppes et al., 2012). Hoppes et al., (2012) reported that participants felt increases in acceptance, awareness, peace, and had decreased reactivity to stressful caregiving situations. These findings support some of Mackenzie and Poulin (2006) hypotheses’ on the benefits of mindfulness for caregivers, such as increased awareness of the way caregivers think about and react to caregiving situations. In addition, participants of both Epstien-Lubow et al. (2011) and Hoppes et al. (2012) reported perceived benefits and desire to continue to practise the skills learnt.

Of the studies completing follow-up measures, time since intervention completion ranged from one to six months. All but one study (Epstein-Lublow et al., 2011) found that significant improvements appeared to be maintained at follow-up (Brown et al., 2016; Norouzi et al., 2014; Oken et al., 2010). Four studies compared MBI with active controls of similar in time and length (Brown et al., 2016; O’ Donnell, 2013; Oken et al., 2010; Whitebird et al., 2013). From the active control studies, three reported significant differences, reductions in symptoms of stress (Brown et al., 2016; Whitebird et al., 2013) and depression (O’ Donnell, 2013; Whitebird et al., 2013) the most common. Oken et al. (2010) did not report a difference between active interventions. From this small number of studies, it could be suggested MBI may be superior to other active interventions assessed at reducing caregiver stress and depression.

Of the eight studies, six used mindfulness measures in the research, and of these, only two found a significant increase in mindfulness post intervention (Epstein-Lublow et al., 2011; Ho et al., 2016). Either these findings suggest methodological limitations in the ability to assess the change in the mindfulness measures, or that the moderators of change may not be related specifically to the intervention’s mindfulness aspects.

Participants. The sample sizes of the eight studies were small, ranging from nine to seventy-eight participants. From reviewing the critical appraisal checklists (see Appendix A and Appendix B) a general weakness of all studies was the recruitment and retention of participants. From the limited information gathered, it appeared the majority of studies used convenience sampling. O’Donnell (2013) highlighted the difficulty in recruiting participants not already actively engaged in community services. The under representation of certain participant’s samples and the selection bias this causes would affect the validity of results to a wider population. Only three papers reported on their recruitment and retention process (Ho et al., 2016; O’Donnell, 2013; Whitebird et al., 2013). Whitebird et al. (2013) separately documented the recruitment and retention process (Whitebird et al., 2011).

Table 2
Caregivers of people with dementia studies

				Sample Active/ Control										
First Author and year	Country	Design	Mode of MBI	Size	% participants which were Female	Age (mean)	Relationship to person with dementia %	Ethnicity	Intervention format times and lengths	Follow up (months post intervention)	Measures used	Self-report Measures	Comparison group intervention	Psychological Wellbeing Findings *
Brown, 2016	USA	Pilot RCT	MBSR	Active 23/ Control 15	84.2%	Not reported	Spouse=Active 52.2% / Control 26.7% , Parent= Active 47.8% /Control 53.3%, Other= Active 0% /Control 20%	Caucasian' 75.7%, 'African American' 21.6%, 'Hispanic/ Latino'2.7%	Group, 8 consecutive weeks, 1.5-2 hours	2 & 3 months	Subjective self-report measures and salivary cortisol	PSS, AAQ, POMS, MOS-SF-36, FCI-MS, ZBI	Standard Social Support	Post intervention compared to SSS, MBSR group had lower levels of anger, tension and perceived stress
Norouzi, 2012	Iran	Quasi-experimental method	MBCT	Active 10/ Control 10	100%	Not reported	Not reported	Not reported	Group, 8 consecutive weeks, 2.5 hours	2 months	Subjective self-report measures	Hamilton , SF-36(V2) , CBI	Waiting list	At follow-up decrease in depression and burden of life
Oken, 2010	USA	Pilot controlled Trial	Adapted from MBSR & MBCT	Active 10/ Active Control 11 /Control 10	Active 80% / Active Control 88% / Control 90%	Active 62.5/ Active Control 67.09/ Control 63.80	Spouse= Active 70%/ Active Control 73%/ Control 80%, Parent= Active 30%/ Active Control 27%/ Control 20%	White' =Active 8/ Active Control 10/ Control 10 'African American'= Active 1/ Active Control 0/ Control 0 'Asian'= Active 1/ Active Control 1/ Control 0	Group, 8 consecutive weeks, 1.5 hours	6 weeks	Subjective self report measures, hand held digital device measuring perceived stress and ability to cope, cognitive measures, salivary cortisol, homework logbooks	Primary measure RMBPC Secondary measures, CAT, PSS , CES-D , SF-36, GPSES ,CPI, PSQI ESQ Other measures CEQ , Global Impression of Change scale Neuro measures- NI, RMBPC Mindfulness measures ,FFMQ & MAAS	6 week 'Powerful Tools for Caregivers' group or 3 hours per week Respite only	Compared to respite, reduction in RMBPC for both active interventions as well as intervention effect on caregiver self -efficacy and cognitive measures. Correlations between mindfulness and mood and stress.
Hoppes, 2012	USA	Mixed method parallel model	Adapted from 'low dose' MBSR	11	88%	63.9	Parents 36%, Spouses 74%	'Caucasian' 100%	Group, 4 consecutive weeks, 1 hour	1 month	Self-report measures & semi-structured interviews	FMI, SHS, LOT and ZBI short	None	Self report measures reported decrease in sense of burden and increase in sense of hope, themes from the interviews included increased acceptance, increased awareness, increased peace and decreased reactivity to difficult behaviours

				Sample Active/ Control									
First Author and year	Country	Design	Mode of MBI	Size	% participants which were Female	Age (mean)	Relationship to person with dementia %	Ethnicity	Intervention format times and lengths	Follow up (months post intervention)	Measures used	Self-report Measures	Comparison group intervention	Psychological Wellbeing Findings *
Whitebird, 2012	USA	RCT	MBSR	Active 38/ Control 40	Active 86.8%/ Control 90%	Active 57.2/ Control 56.4	Parents= Active 68.4%/ Control 80%, Spouse, Sibling or Friend= Active 31.6% / Control 20%	White' Active 100%/ Control 97.5 % 'American Indian' Active 0% / Control 2.5%, 'Hispanic' Active 0%/ Control2.5 %	Group, 8 consecutive weeks of 2.5 hour sessions and 5 hour retreat day	2 months & 6 months	Self-report measures	PSS, CES-D, MBCBS, SSS	CCES community caregiver education and support same time limits	MBSR group reduction in stress and depression
Epstein-Lubow, 2011	USA	Pilot	MBSR	9	100%	56.2	Parents 78%, Spouse 22%	'Caucasian' 6, 'African American' 3	Group, 8 consecutive weeks of 1.5 hours	1 month	Self-report measures, written comments & verbal feedback to instructors	The primary measure CES-D; Secondary measures ZBI, STAI, ICG, PSS; SF-36 (V2) KIMS	None	Self-reported depression, perceived stress, and burden decreased following intervention. At follow-up stress and burden remained reduced. Mindful attention and calmness increased post intervention of the study. Qualitatively, participants reported continued use of acquired skills and personal benefits from the training.
Ho, 2016	USA	Prospective single arm behavioural intervention study	MBSR	20	95%	60.9	Parents 65%, Spouse 20%, Other 15%	'Caucasian' 16, 'African American' 3, 'Hispanic' 1	Group, 8 consecutive weeks, 1.5 hour & 4 hour retreat	None	Self-report measures and blood samples for gene expression analysis.	CSAQ, CES-D, PSS, ITGPL, FFMQ	None	CSAQ self report measures improved post intervention. Mindfulness skills improved post intervention
O'Donnell, 2013	USA	2 by 3 mixed model repeated measures design	MBSR	24	Active 83.3%/ Control 100%	Active 70.42 / Control 72.15	Not reported	Not reported	Group, 8 consecutive weeks, 3 hours & 7.5 hour retreat	2 months	Self-report measures, salivary cortisol, systolic blood pressure & log books of homework	CEQ, MAAS, SCS; PSS; GDS	Progressive Muscle Relaxation intervention	MBSR group greater reductions in depression and isolation from pre- to post-intervention, and at follow up.

* All findings reported in this table were statistically significant at p

PSQ= Pittsburgh Sleep Quality Index, ESQI= Epworth Sleep Questionnaire Inventory , GDS= Geriatric Depression Scale, RSCB= Rapid Screen for Caregiver Burden, ITGPL= Inventory of Traumatic Greif Pre-Loss, ICG= Inventory of Complicated Grief, STAI= State-Trait Anxiety Inventories =Caregiver Self-Assessment Questionnaire, MBCBS= Montgomery Borgatta Caregiver Burden Scale, SCS= Self compassion Scale, GPSES =General Perceived Self-Efficacy Scale, SSS= Social Support Survey, NI= Neuropsychiatric Inventory, CPI= Coping Responses Inventory, CEQ =Expectancy / Credibility VAS scale, CES-D = Centre for Epidemiologic studies Depression Scale, CAT= Caregiver Appraisal Tool, RMBPC = Revised Memory and Behaver Problems Checklist, CBI= Caregiver Burden Inventory, Hamilton= Hamilton ranking scale for depression PSS= Perceived Stress Scale, AAQ= Experimental Avoidance, Acceptance and Action Questionnaire II, POMS= The Profile of Mood States, MOS-SF-36= The Medical Outcomes Study Short-Form Health Survey, SF-36(V2) = Short-Form Health Survey, FCI-MS= Mutuality Scale of the Family Care Inventory, ZBI= Zarit Burden Interview , 1980 ZBI Short= The Zarit Burden Interview : A new short version, SHS= State Hope Scale, LOT= Life Orientation Test,

FFMQ= Factor Five Mindfulness Questionnaire, MAAS= Mindful Attention Awareness Scale, KIMS= Kentucky Inventory of Mindfulness Skills, FMI= Freiburg Mindfulness Inventory

All studies apart from that by Norouzi et al. (2014) contained inclusion and exclusion criteria, with minimal detail given on the impact this had on their recruitment process. Therefore, this report is unable to rule out selection bias occurring.

From the limited demographic details, there appear to be similarities between the samples. The majority of participants were from the US, ‘white’ or ‘Caucasian’ ethnicity, and female (80%-100%, see Table 2). O’Donnell (2013) gave limited information on basic participant demographics that could be confounding variables (e.g. relationship the caregiver had to the person with dementia). The limitations of the papers would affect the generalisability of the results to a wider population.

Intervention. Five papers based the intervention on MBSR (Brown et al., 2016; Epstein-Lubow et al., 2011; Ho et al., 2016; O’Donnell, 2013; Whitebird et al., 2013), one on MBCT (Norouzi et al., 2014) and one on mixed MBSR and MBCT interventions (Oken et al., 2010). Hoppes et al. (2012) used the Klatt, Buckworth and Malarkey (2009) adapted MBSR low dose intervention, with adaptations including shorter sessions over four weeks, and requiring less home practice than the standard MBSR intervention.

The groups ranged from four to eight weeks and the length of sessions varied from one to 3.5 hours. Rationales given for shorter sessions included time restrictions of the caring role (Hoppes et al., 2012; Oken et al., 2010) and a review by Carmody and Baer (2009) that reported ‘lower dose’ MBSR could be as effective for people who are experiencing stress and are time limited.

In the traditional MBSR sessions, participants complete a whole day silent retreat around the 6th week. Three of the six studies using MBSR included a retreat but this varied from four hours (Ho et al., 2016) to a full day (O’Donnel, 2013). The papers’ adaptations were the time spent completing mindfulness practices (Brown et al., 2016; Epstein-Lubow et al., 2011) and focusing discussions around the caring role (Brown et al., 2016;Oken et al., 2010). Adaptations to the yoga poses and length of time in a practice were made by O'Donnell (2013) to consider physical difficulties. Norouzi et al. (2014) gave no information on the protocol or adaptations of the model.

These papers show a wide variation of differences in the ways MBI may be offered to caregivers, which could affect efficiency, authenticity to the model and make it difficult to identify what components of the interventions are important for change.

To ensure the fidelity of the studied interventions, checklists can be used to ensure the intervention is true to the model and trained mindfulness practitioners teach the interventions (Santorelli, 2014; UK Mindfulness-Based Teacher Trainer Network, 2011). Only four of the studies reported using facilitators trained in mindfulness (Brown et al., 2016; Epstein-Lubow et al., 2011; O' Donnell, 2013; Oken et al., 2010), while no papers reported using fidelity checklists. This missing information is significant as it means we are unsure if the intervention is true to the model, and therefore would affect the ability to replicate the studies and evaluate its quality (CASP checklist, see Appendix B).

Data collection and analysis. The majority of data collected was using self-report measures. Using the critical appraisal tools as guidance (see Appendix A and Appendix B), all studies reported the validity of measures used, and the aims of the papers appeared related to these measures. However, thirty-three different measures were used, and therefore direct comparisons between the papers' findings are unable to be completed.

Interestingly, most papers did not aim to look at the impact MBI had on the levels of mindfulness in its caregiver participants, and two studies did not administer a mindfulness measure. Four different self-report mindfulness measures were used in the six studies where one was administrated. Park, Reilly-Spong, and Gross (2013) highlight a limitation of using mindfulness measures because of the lack of evidence around construct validity of available measures. Park et al. (2013) and Bohlmeijer, ten Klooster, Fledderus, Veehof, and Baer

(2011) recommend the Five Facet Questionnaire Short Form (Baer, Smith, Hopkins, Krietemeyer, & Toney, 2006) over other measures because of its internal consistency, however this measure was only used by Ho et al. (2006) and Oken et al. (2010).

Daily practice is regarded as one essential aspect of mindfulness (Kabat-Zinn, 1996) and has been reported as instrumental for clinical change, however data regarding adherence to home practice was not always collected (Vettese, Toneatto, Stea, Nguyen, & Wang, 2009). Oken et al. (2010), Whitebird et al. (2013) and O'Donnell (2013) were the only papers that collected diaries or logbooks from participants on their daily practice. The above highlights limitations around the validity of the results, lack of clarity around possible mediators and moderators of change found, and if any change can be attributed to mindfulness and mindfulness practice.

The Downs and Black checklist (1998) and CAPS checklist (see Appendix A and Appendix B) note the need for research to report on the attrition of the study as high dropout can affect the reliability of results. All studies did so and had low attrition rates, varying from 0% (Epstien – Ludlow et al., 2010; Hoppes et al., 2012; Norouzi et al., 2014; Oken et al., 2010) to 14% (O'Donnell, 2013). Reasons for dropout were given in some papers and included health problems and the person receiving the care entering a home and scheduling difficulties (Brown et al., 2016; Whitebird et al., 2013). Reasons for dropout were not given by all (O'Donnell, 2013; Ho et al., 2016).

All studies had small sample sizes, which may have affected their power and therefore make it more likely for type one and two errors to occur, however only Oken et al. (2010), considered this. Most studies acknowledged a need for future trials to include larger samples to help identify the effects of mindfulness interventions on this group.

Hoppes et al. (2012) was the only study that used qualitative interviews as part of their research and from the CASP checklist (see Appendix B) these appeared to be conducted to a good standard. They reported using thematic analysis and this appears to have been completed rigorously.

Overall, qualitative data is limited. At this stage of investigation into the effectiveness of MBI it may be that more studies need to be completed using qualitative methods, to gain a more in-depth understanding of caregivers' experiences.

MBI for people with dementia and their caregivers

Three studies explored MBI supporting people with dementia and their caregivers. Litherland and Robertson (2014) conducted a pilot MBSR group in three different locations around the UK. The primary aim of this research was to study the feasibility of teaching mindfulness to people with dementia and if it is an effective intervention at improving their quality of life. Studying the effects of the intervention on caregivers was the secondary aim. In two locations, the participants with dementia attended with their family caregiver. In one location, day centre staff attended in a support role.

Paller et al. (2015) conducted a pilot pre- and post-test study in the US, aiming to develop a mindfulness programme for people with dementia and their caregivers, to test the main hypothesis that participants would experience increased wellbeing and mood following the intervention. Kemp, Wilkinson, Cambray, and Johansson (2016) reported on a case of a couple living with dementia and their experiences of MBI. The aim of the intervention was to help the couple with acceptance of negative feelings associated with the dementia and foster a focus of being within the present moment.

Summary of results. Of the quantitative data assessed, Paller et al. (2015) found significant improvement in quality of life and depression for both caregivers and people with dementia. Similarly, using case study methodology, Kemp et al. (2016) found lower anxiety and depression scores and higher self-compassion scores for both participants with dementia and their caregivers. These findings could support previous research indicating that MBI can reduce symptoms of depression and anxiety (Galante et al., 2013) for both members of a dyad. While Litherland and Robertson (2014) reported some improvements, they did not find significant changes in measures used to assess mental wellbeing.

Concerning relationship-based outcomes, Paller et al. (2015) reported half the participants rated improvements in their relationships. Bihari and Mullan (2014) reported this in previous mindfulness research. Although Kemp et al. (2016) did not report improvements in their relationship, the couple reported some positive relationship outcomes from completing the intervention together.

Each study collected qualitative data, with similar themes identified by all papers; that participants held an intention to continue to use the practices learnt from the MBI, and that they reported an increase in skills to be able to cope with dementia and stressful situations. Two papers reported an increase in quality of life (Litherland & Robertson, 2014; Paller et al., 2015). In addition, Litherland and Robertson (2014) reported participants' increased ability to regulate emotions, which could support Greeson's (2009) review highlighting regulating emotions as one of the ways mindfulness can benefit wellbeing.

Participants. Sample size in the studies varied; Kemp et al. (2016) had one couple, Litherland and Robertson (2014) twelve participants, and Paller et al. (2015) thirty-seven. A strength of Litherland and Robertson's (2014) paper was the three UK locations the study was completed in. This enabled a larger and broader participant sample. However, there was very limited information on demographics on all the studies, and critical information was missing from Litherland and Robertson's (2014) paper around gender, type of caring role and participants' type of dementia. This meant that when reviewing the study, we are not able to assess if important confounding variables were considered in the data analysis (CAPS checklist, see Appendix B) Recruitment varied across the studies and appeared to be from convenience samples. Reviewing the checklist (see Appendix B), a limitation of all the studies was the lack of information given on the recruitment and retention of the studies and what, if any, potential participants were excluded. This affects the ability to generalise the results of these studies to any given population.

Intervention. Different interventions were used in the three studies. Litherland and Robertson (2014) used an eight-week MBSR course without adaptations. This was to identify adaptations to the traditional format for future groups of people with dementia. From not adapting the intervention, they reported a need to make future course material ‘dementia friendly’ as their findings suggested participants with dementia struggled to cognitively engage and understand some of the material given, especially material explaining the conceptual basis of MBI.

In Paller et al.’s (2015) study, the intervention was based mainly on a MBSR programme, drawing on elements of DBT and ACT. However, no details were given on the intervention or the theoretical or empirical rationale for these adaptations, therefore a critical appraisal of the need for these adaptions cannot be made.

Kemp et al.’s (2016) intervention was based on the MBCT self-help manual by Williams and Perryman (2011). There were eight sessions, one and a half hours long, and a follow-up and introduction session.

Table 3

People with dementia and caregivers studies

				Sample People with Dementia (PWD) / Caregivers										
First author and year	Country	Design	Mode of MBI	Size	% participants which were Female	Age (mean)	Caregiver relationship to PWD	Diagnosis of person being cared for	Ethnicity	Intervention format times and lengths	Follow up (months post intervention)	Measures used	Self report Measures	Findings
Litherland, 2014	UK	Pilot study	MBSR	PWD 12/ Caregivers 8	Not Reported	Not Reported	Not Reported	Not Reported	Not Reported	Group,8 consecutive weeks, 2 hours	3 months	Self report measures, observations, interviews	FFMQ , BASQID, HADS, EQ5D, SF12 , WEMWBS	Interviews results, beneficial intervention, mindfulness improved their quality of life, reduced pain and anxiety and improved ability to cope with dementia, regulating emotions, majority of carers will continue to practise mindfulness
Paller, 2015	USA	pre and post test	MBSR	PWD 17/ Caregivers 20	PWD 29.4%/ Caregivers 80%	PWD 72/ Caregivers 62.5	Spouses 13, Adult Children 5, Daughter-In-Law 1, Mother-In-Law 1	Alzheimer's disease 9, MCI 2, Memory loss due to Stroke, 2 Frontotemporal Dementia 1	Caucasian' 31, 'Hispanic' 2 , African American 1	Group, 8 consecutive weeks,1.5 hours	None	Self report measures	QOL-AD, GDS, PSQI , BAI , Trail Making test , RBANS , RMPBC, SF- 34, ADLQ , 5 Point scale strongly agree / strongly disagree subjective benefit from the programme.	Increased quality of life, fewer depressive symptoms, better subjective sleep quality
Kemp, 2016	UK	Case report	MBCT	2	50%	Not Reported	Spouse	Alzheimer's	Not Reported	Couple session 10 consecutive weeks 1.5hours	6 months	Oral and written feedback, self report measures	SCS, PHQ-9 & GAD-7	At follow-up both had lower scores on SCS, PHQ-9 & GAD-7

* All findings reported in this table were statistically significant at p

PSQI = Pittsburgh Sleep Quality Index, GDS= Geriatric Depression Scale, SCS= Self Compassion Scale, FFMQ= Factor Five Scale, RMBPC = Revised Memory and Behaver Problems Checklist, SF-36(V2) = Short-Form Health Survey, BASQID= Bath Assessment of Subjective Quality of Life in Dementia HADS=Hospital Anxiety and Depression Scale, WEMWBS= Warwick- Edinburgh Mental Wellbeing Scale, EQ5D= EQ5D The Euro Qol Group, SF-12= 12-Item Short Form Health Survey, QOL-AD= Quality of life in Alzheimer’s Disease, BAI= Becks Anxiety Inventory Beck, ADLQ= Activities of Daily Living Questionnaire, Trail Making test= Trail Making test A and B, RBANS= Repeatable Battery for the assessment of Neuropsychological Status, PHQ-9=Patient Health Questionnaire- 9, GAD-7= Generalised Anxiety Disorder -7 .

Two papers commented on the teachers of the intervention being qualified in mindfulness (Kemp et al., 2016; Litherland & Roberson, 2014). Similar to the papers for caregivers and people with dementia, a limitation was that no fidelity checklists were used. As these are the only three papers, each using different MBI, it would be difficult to draw any conclusions on which type of MBI or elements of the interventions would be most beneficial to use with couples with dementia. A benefit highlighted by both Kemp et al. (2016) and Litherland and Robertson (2014) was that the intervention was joint and caregivers reported being able to help and prompted the person with dementia to complete the home practice.

Data collection and analysis. A limitation of all three papers was they did not report on the validity of the measures for people with dementia. Paller et al. (2015) discussed the potential reliability issue, and to improve reliability had the participants with dementia complete the forms in an interview format. The inclusion of qualitative interview data was a strength as it enabled an exploration of what elements of the intervention participants found helpful. Only Litherland and Roberson (2014) reported any difficulties participants had with the practices. From reviewing the checklist (see Appendix B), none of the papers report how data analysis was conducted and if any guidelines were used to ensure rigour.

A further limitation was high attrition rates, 33% dropped out for Litherland and Roberson (2014), and 16 % for Paller et al. (2015), both with no reason given. With such high rates in the dyad studies there is potential that difficulties with the intervention could have led to the dropout and therefore raises concerns over validity of the results found. It is important to acknowledge the lower attrition rates of the papers with just caregivers or people with dementia. Therefore, other factors may need to be taken into consideration for the high rates such as if one of the dyad was unwell and could no longer continue, both may dropout..

Discussion

This review found thirteen papers aimed to see if MBI improved the wellbeing of people with dementia and/or their family caregivers. The papers described a variety of study designs including; five RCTs; one case study; one mixed methods; two pilot studies; three pre and post-test designs; and one single group pre-post-test design with follow-up. All bar one, reported significant improvement in some aspects of wellbeing for participants. The one study (Litherland & Roberson, 2014) that did not find significant results from quantitative data still reported benefits identified from their interview data. However, as all the studies used different participant samples, data analysis, and intervention, it is not feasible to make any overarching conclusions about the effectiveness of MBI on the wellbeing of people with dementia and their family caregivers. Therefore, the main findings summarised below can only give a tentative suggestion on the helpfulness of MBI for these populations.

Two small-scale studies used people with dementia as the participants, both finding significant results, which may indicate MBI to be beneficial to people with a diagnosis of dementia. Lantz et al. (1997) found a reduction in agitation measured by care home staff and Chan (2015) found a significant increase in quality of life through self-report measures. Importantly, both identified that the people with dementia needed support to practise the interventions and that staff availability for this support was limited.

All eight papers researching MBI for caregivers found some significant improvements in aspects of wellbeing. The most common areas of improvement were around caregiver burden, stress and decrease in depressive symptoms. This supports a previous similar review's findings (Hurley et al., 2014). Of the studies that completed qualitative data, it could be suggested improvements noted are associated with key aspects of mindfulness such as increased acceptance, and awareness and decreased reactivity to stressful caregiving situations, supporting Greeson (2009) argument on how MBI may instigate change. An important finding was that seven of the studies maintained the improvements at follow-up, suggesting these improvements for caregivers may continue after the programme. When controlled against active interventions, three out of the four studies reported significant differences in support of the MBI, around a reduction in stress and depression.

Of the three studies where participants were people with dementia and their caregivers, two studies reported significant improvements in aspects of the participants' wellbeing; Paller et al. (2015) in quality of life and depression, and Kemp et al. (2016) reported lower anxiety and depression and higher self-compassion. Interestingly, Paller et al. (2015) reported improvements in the relationships of the caregiver and person with dementia following the intervention.

This review highlighted a variety of methodological rigour in the thirteen papers with the support of critical appraisal tools. The most significant methodological issues identified, in the majority of the papers, were around small sample sizes. The papers' samples ranged from two to 78 participants. The small sample sizes may have affected results' power and therefore make it more likely for type one and two errors to occur. Another limitation of this research was participant recruitment and retention; all participants appeared to be recruited from convenience sampling. However, it is important to take into consideration the challenges involved in recruiting people with dementia and their caregivers in research. Some challenges identified have been gaining access to willing participants within communities (Whitebird et al., 2011) and negotiating the ethics of including people with dementia in research where capacity to consent may not always be possible. These limitations of the papers would affect the generalisability and replicability of the results to a wider population. There were also substantial differences found in the details the papers gave on participant demographics, flow through of participants and reasons for dropout. With recruitment a known challenge in this field, studies documenting the participant flow through may help future research develop different or more effective ways of recruiting participants.

The papers reported on different MBI, the most popular being MBSR used by eight studies. Another significant critique highlighted by this review, was the limited information reported on the justification for the intervention and modifications used. By not reporting on the theoretical or empirical reasons for adaptations, further research would need to consider if they want to include these without clear rationale. This could hinder the progression of robust research in this area. The majority of the studies did not report how they maintained fidelity to the model, (such as using trained mindfulness practitioners, supervision or standardised adherence checklists) affecting reliability.

Finally, a limitation in the majority of the papers around data collection and analysis was the limited use of a measure aimed to show mindfulness change. Only eight studies used a self-report mindfulness measure, and of them, only two found significant changes in mindfulness following the intervention. Furthermore, the two studies that used a mindfulness measure on participants with a diagnosis of dementia did so with measures not yet shown to be valid for those with this diagnosis. These points highlight limitations around the certainty to which the papers and this review can suggest the significant changes to wellbeing noted in the results are associated with the mindfulness aspects of the intervention, or if other mediators and moderators may have also influenced the change found.

Research implications

This review highlights a new and developing area of research consisting of a wide range of small-scale studies. While this makes it difficult to report any robust outcomes regarding the effectiveness of MBI for people with dementia and their caregivers, the review suggests that MBI may be helpful for this population.

The papers providing MBI for caregivers of people with dementia was the largest area of research. It could be suggested that MBI may be helpful for caregivers compared to other active interventions, such as social support, progressive muscle relaxation, and caregiver education sessions (Brown et al., 2016; O' Donnell, 2013; Oken et al., 2010; Whitebird et al., 2013). MBI appeared to be better at reducing stress and depression. However, due to the small number of studies it can only be tentatively suggested that it is the more superior intervention.

Further research is needed using larger sample sizes, more robust designs and greater clarity regarding the intervention's design. Using similar active interventions as controls (e.g. progressive muscle relaxation, or cognitive behavioural therapy), it may be possible to identify if MBI are effective for caregivers and if the mindfulness elements are the moderators of change (rather than other confounding variables such as generic therapeutic benefits of a psychological intervention). Future research should include reliable and valid measures of mindfulness and report on adherence to mindfulness practice. However, as stated earlier, further qualitative research could explore the aspects of the intervention the caregivers found beneficial so as to gain a deeper understanding of the processes of mindfulness or the aspects of MBI that contribute to improvement in wellbeing.

There is a lack of focus in research around improving the wellbeing of people with dementia. This could be due to many reasons including no consensus on defining wellbeing in dementia (Algar, et al., 2014), and more of a focus in research in understanding the causes of dementia or improving the persons cognitive functioning rather than focusing on the importance of maintaining the person's overall wellbeing (Farrand et al., 2016). Compared to studies for caregivers, there are more confounding variables which could affect the results gained and are needed to take into consideration when studying people with dementia and joint interventions for caregivers and people with dementia (such as stage of dementia, type of dementia and type of relationship). Therefore, more exploratory research is needed using both qualitative and quantitative methods taking into consideration all the different variables before, studies with control groups, longitudinal studies and possibly RCTs can be completed, enabling more concrete findings to be drawn from research, and to further grow and support the wider field of research into the wellbeing of people with dementia.

Further research using MBI is needed to explore different ways of measuring wellbeing for people with dementia. In particular, researching the impact mindfulness may have relationally on the person with dementia could be an important area for further understanding, as theory highlights the importance of the relationships in dementia care and understanding of wellbeing (Kahana & Young, 1990; Kitwood, 1997). Research should also use measures shown to be reliable for people with dementia to ensure the reliability of results.

This review has highlighted the difficulties people with dementia can have in remembering to practise mindfulness, considering this it can further support more research exploring joint interventions for people with dementia and caregivers.

In summary, suggested next steps in this area of research could explore MBI for caregivers using larger samples and more robust RCTs, given the greater literature in this area. Studies, for example, using mixed method design MBI for both people with dementia and caregivers would be valuable to understand the effects when both members of the dyad are included. It is suggested that this research should use measures that have been shown to be reliable for people with dementia and include measures of mindfulness.

Clinical and professional implications

As this is a new area of research, there is insufficient evidence currently for substantial recommendations to be made; therefore, caution is needed when considering MBI in clinical practice over other interventions that have more robust research findings (Orgeta, et al., 2014).

If future research highlights the effectiveness of MBI for people with dementia and their family caregivers it could be a beneficial intervention to use in clinical practice, being a time limited, low cost intervention, much needed within the current NHS climate. There are challenges around NHS services being able to run MBI interventions. Current austerity policies affecting the NHS means work being undertaken needs to have a clear clinical focus to justify the use of resources, for example diagnosis of dementia or symptom management. Focusing resources on improving the wellbeing of people with dementia, which is less understood and therefore does not have as clear a clinical focus, could be seen as a less important use of resources.

However, caution is needed to maintain the integrity of the model making sure the intervention does not drift into a more generic relaxation intervention. One way to ensure this is to run MBI by trained mindfulness practitioners (Santorelli, 2014).

There are potentially multiple clinical benefits of a group MBI for people with dementia and caregivers together. Policies discuss the need to involve the family more in the care of people with dementia (DoH 2009; 2012), and services need to be seen to be offering caregivers support when needed (the Care Act, 2014). Another possible benefit for services offering group MBI for couples is supporting effective use of clinical resources. Research shows that the wellbeing of the person with dementia or caregiver can affect the caregiving relationship (Allegri et al., 2006; Kang et al., 2014). By using a MBI to improve the wellbeing of both it could potentially reduce the need for more intensive support later on, or even support the caregiver to able to care better, for longer.

Conclusion

This review set out to highlight and critically evaluate all available research exploring MBI aimed to improve the psychological wellbeing of people with dementia and their family caregivers. The review found evidence that MBI may be beneficial for caregivers of people with dementia in improving psychological wellbeing, supporting a previous review’s findings (Hurley et al., 2014). Some evidence was found suggesting MBI might be beneficial for people with dementia at improving their psychological wellbeing. When including both the caregiver and person with dementia in the MBI, further benefits found suggest caregivers were able to act as a support for the person with dementia to practise mindfulness and the intervention had a positive impact on the dyad's relationship. However, this is a new area of research, with limited small-scale studies, demonstrating a variety of methodological rigour.

A major criticism of the current research available is that the improvements to psychological wellbeing found in the research cannot be confidently attributed to the MBI. Changes in mindfulness and adherence to the practice were not always measured and adaptations made to structured MBI programmes were not always clearly stated. Therefore, the underlying mechanisms by which the change came about remain unclear.

Recommendations include that future research should measure participants' perceived changes in mindfulness using reliable measures of mindfulness change. Future research looking specifically at caregivers and people with dementia should focus on larger more rigorously completed RCTs controlled against active interventions. The next steps for research addressing MBI for people with dementia is to include caregivers, and use designs that would allow further exploration of the mediators and moderators of change that MBI could bring to the psychological wellbeing of this group.

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Section B: Exploring the experiences of people with dementia and their family caregivers completing a MBSR course

Word Count: 8000 (321)

Abstract

Evidence highlights the need to support people with dementia and their family caregivers together as a dyad and mindfulness has been suggested as one intervention. This research aimed to explore dyads' experiences of attending an eight-week MBSR intervention. Five couples were recruited, using a mixed method multiple case study design with a four-week follow-up.

Data was collected using self-report standardised measures, group observations and semi-structured interviews. Thematic analysis, descriptive and parametric statistics were used to analyse the data. Although quantitative analysis was inconclusive, qualitative analysis suggests some participants found the intervention a positive experience, benefitting from completing the intervention as a dyad and attending with people with related problems. Specific mindfulness benefits were also reported. Further larger scale research is needed to support these findings and explore specific benefits mindfulness interventions has over other interventions, before being suggested as a helpful clinical intervention.

Dementia, Mindfulness, Wellbeing, Caregivers, MBSR

Introduction

Worldwide, dementia is one of the major causes of disability and dependency (World Health Organisation, WHO, 2012). Their families support the majority of people with dementia in communities (Alzheimer’s UK, 2014). Due to the progressive, chronic nature of dementia, caregivers experience more burden than those who care for other older adults (Moise, Schwarzinger, & Um, 2004), directly affecting their ability to care for loved ones (Gaugler, Yu, Krichbaum, & Wyman, 2009; Mittelman, 2005). Living well with dementia (2009), the (UK) National Dementia strategy (2012) and Prime Minister's challenge on dementia 2020 (2015) highlight needs to develop better services for people with dementia and their families. In addition, the Care Act (2014) acknowledges caregivers’ right to their own individual support.

Wellbeing for people with dementia and caregivers

People with dementia can live well, with Kitwood (1997) arguing a nourishing social environment and positive social interactions can maintain wellbeing. However, their wellbeing can often be overlooked (Farrand, Matthews, Dickens, Anderson, & Woodford, 2016; Nolan, Ryan, Enderby, & Reid, 2002) and there remains no consensus defining wellbeing in dementia (Algar, Woods, & Windle, 2014). Research addressing caregiver wellbeing has historically positioned itself from a model of deficit rather than highlighting psychological wellbeing (Chappell & Reid, 2002).

Systemic models allow us to assess the impact of dementia on the caregiver and the person together as a dyad, with Ablitt, Jones and Muers (2009) proposing a theoretical framework to understand the impact dementia has on the couple and their relationship. It proposes the quality of relationship prediagnosis can determine how dementia can affect the couple’s wellbeing, relationship and the experience of living with dementia.

Hellstrom, Nolan and Lundh (2005; 2007) highlight nonlinear changes within the couple’s relationship with progression of the disease. Three phases of the dyads’ relationship were identified; ‘sustaining couplehood’, ‘maintaining involvement’, and ‘moving on’. In the beginning, both parties are actively maintaining and sustaining the relationship, with a gradual letting go and taking over of roles as the dementia progresses. They argue the couple need to work together to help the each other have a sense of agency to live positively with dementia. Robinson, Clare and Evans (2005) research found couples have a shared experience and response to receiving a dementia diagnosis, highlighting the importance of the dyad working together to help make sense of their journey.

Berg and Upchurch (2007) developed a theory on dyadic coping highlighting the way couples living with chronic illness cope and adjust. Haussler et al. (2016) research highlights dyadic coping as a mediator in quality of life in couples including a person with dementia and suggest dyadic interventions to cope with this.

There is a growing area of research looking at psychosocial interventions including psychological to support both people with dementia and their families (Smits et al., 2007; Van’t Leven et al., 2013). Although these reviews suggest dyadic interventions can be beneficial, there is no consensus on what is more helpful, with Van’t Leven et al. (2013) suggesting a need to target individual difficulties the dyad is having with a specific intervention.

Mindfulness

One psychological intervention widely used and with a growing base of empirical research showing benefits for a range of difficulties and disorders (Grossman, Nieman, Schmidt, & Walach, 2004), is mindfulness. The concept of mindfulness is ‘paying attention, characterized by intentional and non-judgmental observation of present moment experiences’ (Piet & Hougaard, 2011, p.1033). In 1979, Kabat Zinn developed the mindfulness based stress reduction (MBSR) programme, which uses mindfulness concepts and practices to reduce stress (Kabat Zinn, 2003). Since then, a variety of other mindfulness based interventions (MBI) have developed such as mindfulness based cognitive therapy (MBCT, Teasdale, Segal, & Williams, 1995).

Evidence suggests the benefits of MBI for older adults (Geiger et al., 2016) and couples (Bihari & Mullan, 2014). Smith, Jones, Holttum and Griffiths (2014) reported dyads who completed a MBCT intervention found attending together helped facilitate home practice, regularity of attendance and indicated they gained mutual support and sense of responsibility for the other’s wellbeing. Cognitive improvements have also been reported from practicing MBI (Hernández et al., 2014; Innes, Selfe, Brown, Rose, & Thompson-Heisterman, 2012; McBee, 2003; Newberg, Wintering, Khalsa, Roggenkamp, & Waldman, 2010). Mindfulness has also been used with people with dementia (McBee, 2003), and Robertson(2015) recommended its use in attentional rehabilitation.

Mindfulness for people with dementia and caregivers

Research has just started exploring the potential benefits of MBI for people with dementia and their caregivers. One advantage of MBI for people with dementia is it empowers them by giving techniques to use with their abilities rather than focusing on problems (Smith, 2006). For caregivers, a recent systematic review tentatively suggested MBI could reduce depressive symptoms and burden (Hurley, Patterson & Cooley, 2014). Since this review, two further randomised control trials (RCTs) have found positive benefits of MBI for caregivers of people with dementia (Brown, Coogle, & Wegelin, 2016; Whitebird et al., 2013).

Three small-scale studies have explored MBI for people with dementia and their caregivers. Following MBSR group interventions, qualitative interviews found improvements to wellbeing (Litherland & Robertson, 2014) and increases in quality of life using self-reported measures (Paller et al., 2015). Kemp, Wilkinson, Cambray, and Johansson (2016) reported lower anxiety and depression and higher self-compassion self-report scores for one couple who completed a MBCT dyad intervention. Positive impacts on the dyads relationship following the MBI were also found by Kemp et al. (2016) and Paller et al. (2015). Although the results from these small-scale studies are promising, significant limitations have affected drawing any substantial conclusions. More exploratory research, using both qualitative and quantitative methods, could identify mediators of change from attending MBI interventions, particularly the effect MBI may have relationally on the dyad. If research highlights benefits for MBI for both people within the dyad, it could be a clinically beneficial intervention to use in NHS services and in line with national government strategies (DoH, 2012; 2015) and NHS Healthcare Values of developing high quality care and improving lives for all patients and communities.

Research Questions

The main aim of this research was to explore the experiences of participants with dementia and their family caregivers attending a MBSR course. Further aims included: What benefits and/or difficulties were experienced in attending the course and practising mindfulness? How do participants describe the course's effects on their wellbeing and their acceptance of and adjustment to the diagnosis of dementia? What changes did participants identify in the other person in the dyad and their relationship following the intervention?

Methodology

Participants

Participants with a diagnosis of dementia were recruited from three community mental health services for older people (CMHSOP's) in the South East of England using convenience sampling. The inclusion criteria were participants had a diagnosis of dementia;

scored 60 or above on a cognitive abilities screening tool, Addenbrooke's Cognitive Examination III (ACE III, Hsieh, Schubert, Hoon, Mioshi, & Hodges, 2013); had a main caregiver supporting them regularly; and both were willing to participate in the MBSR programme and practice homework. Participants were excluded if any person was experiencing a current co-morbid serious mental health disorder; were a risk to themselves or others, or were experiencing any other systemic or external difficulties, which would affect attending the MBSR course or completing homework (see Figure 2).

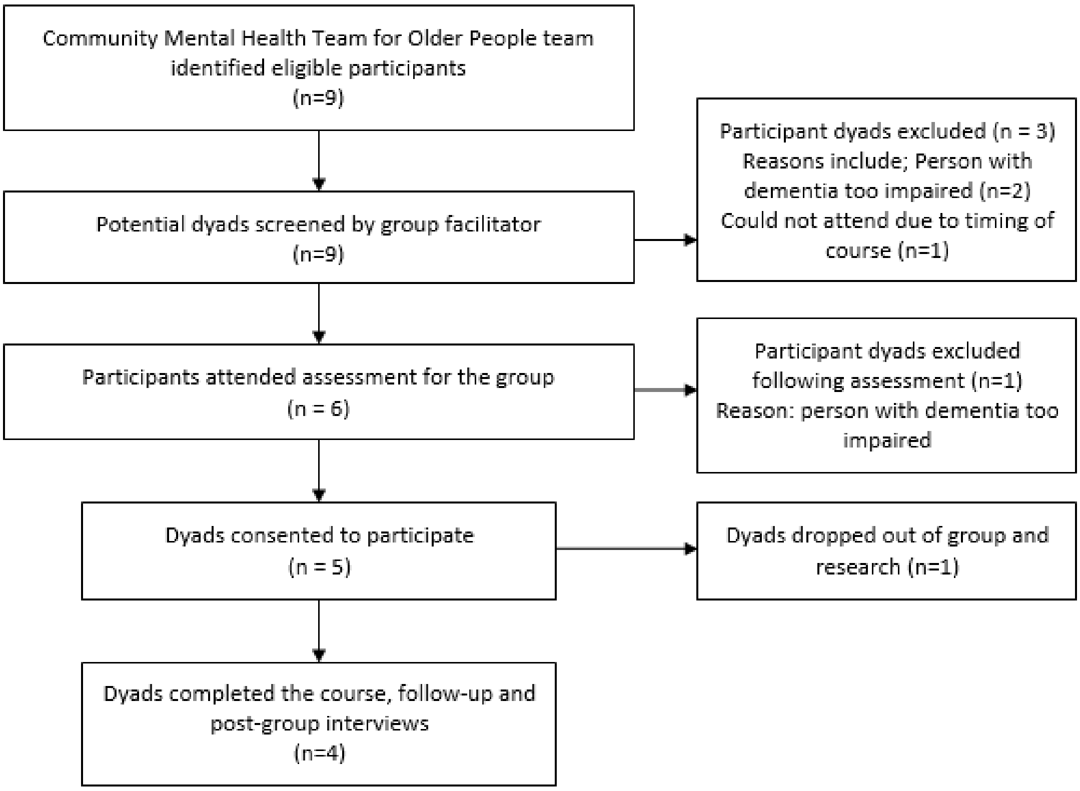

Figure 2. Flow diagram of participant recruitment and retention.

Five dyads agreed to participate in the research. All were married, with the husband having a diagnosis of dementia. Anne B had also recently been diagnosed with dementia, and although her ACE III (Hsieh et al., 2013) was lower than Robert's she positioned herself in the role of a caregiver. All described their ethnicity as 'White British'. The mean age of caregivers was 66.0 and participants with dementia was 73.8 (see Table 4).

Table 4

Participant demographics and course attendance

Participant	Gender Male/Female	Age	Relationship status	Years married	Ethnicity	Dementia diagnosis	ACE III score	Sessions attended	Follow-up attended?
Jane A	Female	66	Married	25	White British			7	No
Jack A	Male	76			White British	Mixed Dementia	86		
Anne B	Female	59	Married	28	White British	Mixed Dementia	69	8	Yes
Robert B	Male	56			White British	Vascular Dementia	78		
Mary C	Female	69	Married		White British			3	No
Paul C	Male	71		17	White British	Mixed Dementia	85		
Julia D	Female	77	Married	44	White British			7	Yes
Dez D	Male	86			White British	Mixed Dementia	92		
Pauline E	Female	59	Married	40	White British			7	Yes
Charles E	Male	80			White British	Alzheimer's	59		

Design

This study uses a multiple case study design with follow-up using a sequential explanatory mixed-methods strategy (Creswell, 2014). Mixed method designs allow an in-depth investigation of a particular area (Bergen & While, 2000; Yin, 2014), needed in this developing area of research.

Ethics

An NHS ethics committee and host trust approved this research (see Appendix D and E). This research complied with British Psychological Society code of conduct (BPS, 2009). Half the participants had a diagnosis of dementia; therefore, their capacity to consent to take part in the research was continually assessed throughout the intervention and research process following the principles of process consent (Dewing, 2007).

Materials and Measures

Wellbeing and mindfulness self-report measures were administered at baseline for participants to act as their own control, and at follow-up to assess the longevity of any change made. A time-series of the wellbeing measures were completed during the MBSR intervention (Borckardt et al., 2008). Audio-recorded semi-structured interviews were completed with each dyad preintervention to gather a current understanding of the dyad's relationship, wellbeing and expectations as difficulty with recall was anticipated for the participants with dementia at follow-up. Follow-up interviews were conducted as a dyad and then individually, similar to Camic, Williams and Meeten's (2011) research. Finally, the researcher conducted direct observations and field notes were written for seven of the eight sessions of the MBSR intervention to help gain validity through triangulation (Mays & Pope, 2000; Yin, 2014) (see Table 5).

Table 5
Data collection timeline

Time point	Baseline	S1	S1 (P)	S2	S2 (P)	S3	S3 (P)	S4	S4 (P)	S5	S5 (P)	S6	S6 (P)	S7	S7 (P)	S8	S8 (P)	Follow-up
Date collected	CWS	CWS	CWS	CWS	CWS	CWS	CWS	CWS	CWS	CWS	CWS	CWS	CWS	CWS	CWS	CWS	CWS	CWS
Quantitative data	WHO-5 FFMQ-SF	WHO-5		WHO-5		WHO-5		WHO-5		WHO-5		WHO-5		WHO-5		WHO-5		WHO-5 FFMQ-SF
Qualitative data	Joint Interviews	Obs		Obs		Obs		Obs		Obs		Obs		Obs		Obs		individual and joint interviews

Key: CWS= Canterbury Wellbeing Scale, WHO-5= World Health Organisation-5 scale, FFMQ-SF= Five Facets Mindfulness Questionnaire -Short Form, Obs = Observations, Baseline=3 weeks pre MBSR intervention, Follow-up= 4 weeks post MBSR intervention, S1= Start of session one, S1 (P) = post session one.

Canterbury Wellbeing Scale. The Canterbury wellbeing scale (CWS) assesses in the moment subjective wellbeing in people with dementia and their caregivers (Johnson, Culverwell, Hulbert, Robertson & Camic, 2017, see Appendix F). CWS was administered at the start and end of each session to explore changes during this period. Based on the visual analog scale (Bond & Lader, 1974), it asks participants to score an X anywhere on a vertical from 0 to 100 to describe how they are feeling at that very moment for five items; happy/sad, well/unwell, interested/bored, confident/not confident, and optimistic/not optimistic. After scoring each individual scale, a composite score can be given by adding all the items together (0 to 500). The CWS has been shown to be effective in measuring change in people with mild to moderate dementia and family caregivers over short periods of time (Camic, 2014; Camic, Hulbert & Kimmel, 2017; Johnson et al., 2017) and to not be cognitively burdensome for participants (Johnson et al., 2017).

WHO-5. The World Health Organisation-5 (WHO-5) is a five item self-report questionnaire assessing peoples' subjective wellbeing (WHO, 1998; see Appendix G). Participants score, on a 6-point Likert scale, which most closely represented how they felt over the last two weeks. The higher the total percentage score the higher the person's wellbeing. Topp, Østergaard, Søndergaard and Bech's, (2015) review of the WHO-5, concluded the measure was reliable at detecting clinical change in many client groups including older adults. The WHO-5 is currently used within the service and is easy to administer due to its short length.

Five Facets Mindfulness Questionnaire-short form. The Five Facets Mindfulness Questionnaire-short form (FFMQ- SF, Bohlmeijer, ten Klooster, Fledderus, Veehof, & Baer, 2011, see Appendix H) is a shorter version of the original thirty-nine item FFMQ (Baer, Smith, Hopkins, Krietemeyer, & Toney, 2006). The 24 item self-report questionnaire aims to identify five facets of mindfulness; observe, describe, act aware, non-judge, non-react. Using a 1-5 Likert scale from 'never or very rarely true' to 'very often or always true', it asks for participant's frequency of experience over the last month. Higher scores on each factor indicate greater mindfulness.

The FFMQ-SF has been shown to have high internal consistency (Park, Reilly-Spong, & Gross, 2013), with the FFMQ shown as one of the most valid and reliable and more sensitive to change of existing mindfulness measures (Bohlmeijer et al., 2011). Currently, validity or reliability measures of mindfulness scales for people with dementia and older adults are not available; therefore, the FFMQ- SF was only administered at baseline and follow-up to reduce questionnaire fatigue affecting the reliability of the more evidenced wellbeing measures.

Interview Schedule. Supervisors supported the interview schedule development, ensuring the interview had content validity, did not include leading questions and was able to help retrieve participants' experiences of the course. Following this revision, service user consultants were asked for feedback before submission to ethics (see Appendix I).

Procedure

Following university proposal approval, two service users with dementia and one caregiver were consulted from service user forums in the South of England on the initial research idea, data collection and interview questionnaires. Suggestions incorporated were using the shorter FFMQ, including researcher's pictures in the information sheet, giving participants time to digest information before consenting to the research and completing individual and joint interviews to ensure all participants voices where heard.

Following ethical approval, the lead facilitator introduced the researcher to members of the CMHTOP teams (see Appendix J for information sheet, referral form, course pamphlet and consent form). The lead facilitator invited suitable participants to an initial assessment, following MBSR standards of practice (Santorelli, 2014, see Figure 2**Error! Reference source not found.**). Consent to participate was signed at initial interview with the researcher; £10 was available to each participant dyad for travel expenses. Participants attended the 8 weeks MBSR intervention. The CWS and WHO-5 questionnaires were administered to participants on arrival. At the end of each session before leaving the CWS was again administered and completed by participants. At the final session, participants were invited to book a follow-up interview held in the same week as the follow-up session. Due to other commitments, Couple A were unable to attend the follow-up and were interviewed two weeks later.

Intervention

The intervention was based on a MBSR course outline (Kabat Zinn, 2003) with the following adaptations: sessions shortened from the 2.5 hour to 90 minutes with a 5-minute silent break; home practice commitment shortened from 60 to 40 minutes per day; individual practices shortened to a maximum of 30 minutes from 45 minutes; and no full-day retreat was provided. These adaptions were in line with previous research using MBI for people with dementia (Chan, 2015; Lantz et al., 1997), managing attentional difficulties and time limitations of participants (Hoppes Bryce, Hellman, & Finlay, 2012; Oken et al., 2010).

The lead facilitator recorded guided meditations onto CDs with more concrete use of language and briefer silences than traditional MBSR practices. Litherland and Robertson (2014) recommended information to be made more accessible for participants with dementia, so adapted information on stress and dementia was provided from the Warwickshire Living Well with Dementia website. As well as guided practice, sessions included inquiry about the practice, readings or poems and reflections on these. Two extra exercises were included, a ‘mindful communication exercise’ as found beneficial in previous MBSR research for dyads experiencing stress from lung cancer (Schellekens et al., 2014) and a loving and kindness meditation used in previous research for caregivers of people with dementia (Epstein-Lubow, McBee, Darling, Armey & Miller, 2011), (see Appendix L for session details). All participants received a folder with the adapted written materials to take away and read with optional record forms for home practice.

Three facilitators, (a clinical psychologist and two CBT therapists working in older adult services and practicing mindfulness) ran the course. Three facilitators enabled extra support for participants if needed. Two facilitators had completed the appropriate mindfulness teacher training qualifications.

Data Analysis

Statistical data analysis. Quantitative analysis was completed in Excel and SPSS Statistics 23. Descriptive statistics were completed for all participants with dementia, all caregivers, and then each participant individually. The preintervention and postintervention measures, patterns across the sessions and between sessions were analysed. A reliable change index (RCI) using the Leeds reliable change indicator (Morley & Dowzer, 2014) was calculated on the WHO-5 as population norms were available. To support the descriptive statistics, parametric group-level tests were performed on the CWS and WHO-5 measures.

Qualitative data analysis. Case study research allows for different epistemological orientations (Yin, 2014). Data was collected and analysed from a critical realist orientation (Mcevoy & Richards, 2006). This allows exploration of the quantitative and qualitative data, and is compatible with methodological triangulation (Mcevoy & Richards, 2006). Interviews were analysed using thematic analysis (Braun & Clarke, 2006) (see Table 6). Thematic analysis was done separately for the preintervention and postintervention data.

Table 6
Six stages of thematic analysis

Phase	Name	Description
1	Familiarisation with the data	Conducting interviews, listening to audio-recordings, transcribing data, reading data and re-reading data, noting any analytic observations
2	Coding	Coding and labelling the data set using QSR NVivo 11 software
3	Searching for themes	Searching for coherent and meaningful themes in the data codes
4	Reviewing themes	Checking the themes by repeatedly exploring the codes and whole data set. Themes where then reviewed by the internal supervisor using 2 out of the 10 transcripts discrepancies explored before themes were refined. Once the themes were revised and reviewed again by the primary researcher an impartial external researcher reviewed another 2 transcripts and themes
5	Defining and naming themes	Writing a detailed analysis of each theme and naming them
6	Writing up	Weaving' the data together using data extracts to tell a coherent story about the data in relation to the literature

Quality assurance and reflectivity

The lead supervisor assessed the thematic analysis for quality assurance and coding reliability followed by a revision by a researcher independent of the study (see Table 6). A research diary documented thought processes around analysis (see Appendix M). Observations and field notes supported data analysis accuracy through triangulation of data from multiple sources (Yin, 2014). Potential biases in data analysis are considered when conducting thematic analysis from a critical realist orientation. For example, both supervisors were trained mindfulness practitioners and the researcher practiced mindfulness and therefore had a relationship to the topic. The effect this relationship to mindfulness could have on the analysis was taken into consideration and an external researcher with no relationship to mindfulness was consulted to review the themes.

Results

The results are from four couples, who completed the MBSR intervention, self-report questionnaires and attended follow-up interviews. Data from the fifth couple, Mary and Paul C, who dropped out after session three were not included (see Appendix N for telephone interview following dropout). Statistics for the whole group will be presented, followed by qualitative and quantitate data analysis for each couple and the thematic analysis for the whole group's postinterview data. To fully describe experiences and expectations of the course, precourse interview data will be briefly mentioned when discussing each couple (see Appendix O). Field notes will be discussed when appropriate throughout the results.

Quantitative Data Overview

Overall, participants with dementia showed no clear increase or decrease in scores on the WHO-5 postintervention but a reduction from final session to follow-up was evident, indicating deterioration in wellbeing. Compared to the people with dementia, caregivers' wellbeing scores on the WHO-5 remained more stable postintervention and at follow-up (see Table 7**Error! Reference source not found.**).

Table 7
WHO-5 baseline, preintervention, postintervention, and follow-up scores and RCI results.

Participants with dementia	Baseline	Pre	Post	Follow-up	Pre - post	Post - follow-up	RCI pre - post	RCI pre - follow-up
Jack A	52	40	48	32	8	-16	No change	No change
Robert B	28	44	44	40	0	-4	No change	No change
Dez D	40	80	76	24	-4	-52	No change	Deteriorate
Charles E	68	48	52	48	4	-4	No change	No change
All participants (Mean)	47	53	55	36	2	-19		
Caregivers	**Baseline**	**Pre**	**Post**	**Follow-up**	**Pre - post**	**Post - follow-up**	**RCI pre - post**	**RCI pre - follow-up**
Jane A	40	40	40	48	0	8	No change	No change
Anne B	28	40	12	12	-28	0	Deteriorate	Deteriorate
Julia D	64	64	60	68	-4	8	No change	No change
Pauline E	36	32	48	40	16	-8	Improve	No change
All participants (Mean)	42	44	40	42	-4	2		

Key: Pre = Preintervention, Post = Postintervention.

For participants with dementia, CWS scores increased postintervention, however reduced at follow-up. For caregivers, CWS scores postintervention increased, however they decreased at follow-up (see Table 8). Interestingly, some participants scored higher on the CWS at baseline than preintervention postintervention.

Table 8
CWS baseline, preintervention, postintervention and follow-up scores.

Participants with dementia	Baseline	Pre	Post	Follow-up	Pre – post	Post - follow-up
Jack A	370	340	385	390	45	5
Robert B	345	325	365	360	40	-5
Dez D	470	470	455	405	-15	-50
Charles E	420	430	480	330	50	-150
All participants (Mean)	401.25	391.25	421.25	371.25	30	-50
Caregivers	**Baseline**	**Pre**	**Post**	**Follow-up**	**Pre - post**	**Post - follow-up**
Jane A	325	285	315	295	30	-20
Anne B	385	390	415	405	25	-10
Julia D	380	425	445	390	20	-55
Pauline E	365	425	460	440	35	-20
All participants (Mean)	363.75	381.25	408.75	382.5	27.5	-26.25

Key: Pre = Preintervention, Post = Postintervention

Time Series Data. When analysing patterns across the sessions for the WHO-5 and CWS, no clear patterns emerged for participants with dementia or caregivers (see Figure 3, 4, 5 and 6; gaps indicate the participant did not attend the session).

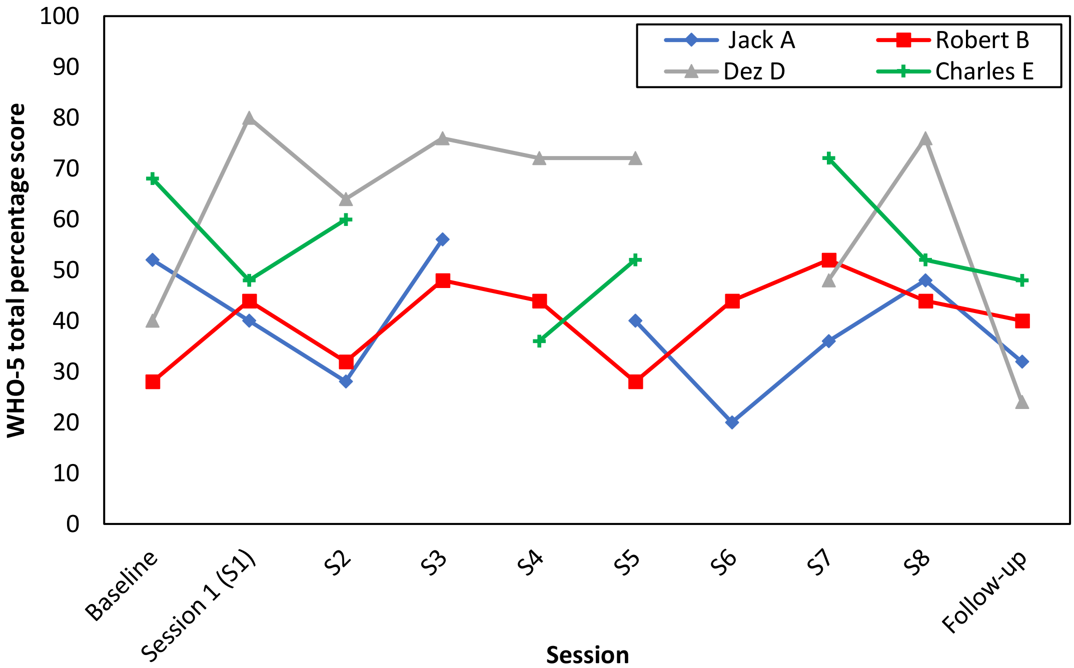

Figure 3. WHO-5 time series data for PWD.

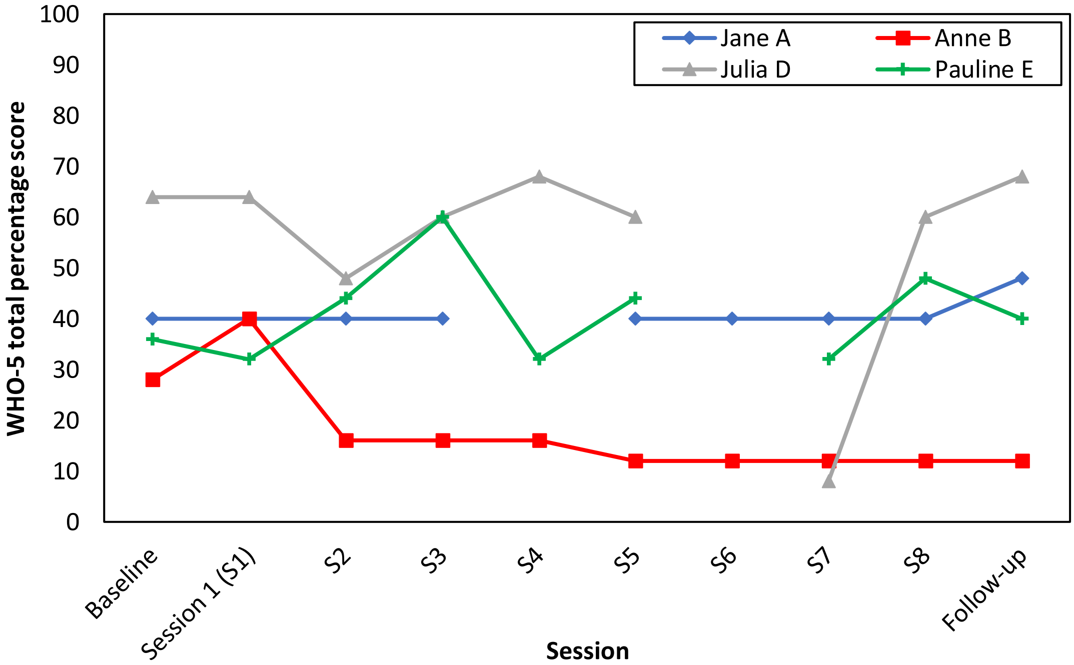

Figure 4. WHO-5 time series data for caregivers.

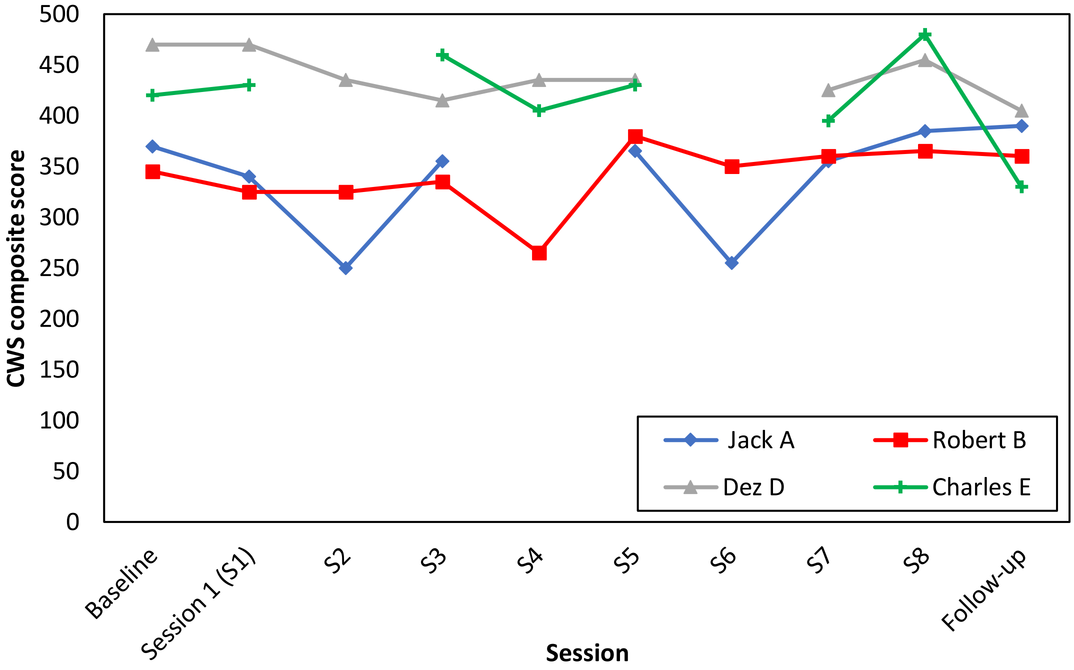

Figure 5. CWS time series data for PWD.

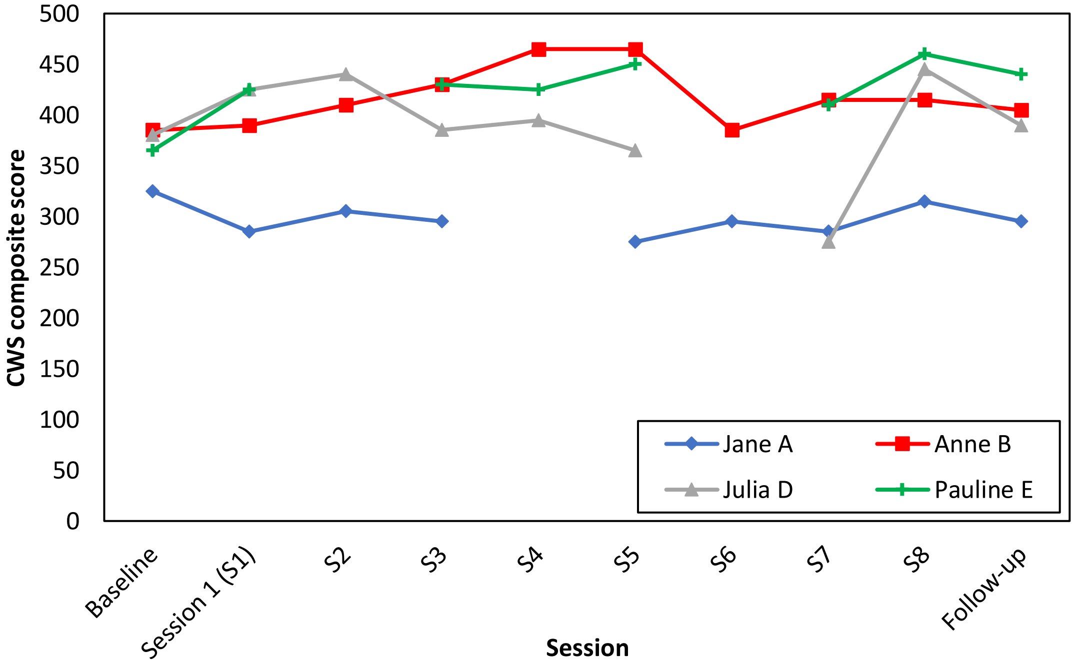

Figure 6. CWS time series data caregivers.

Presession to postsession CWS scores increased for the majority of participants with dementia and was more evident with the caregiver group (see Figure 7 and 8).

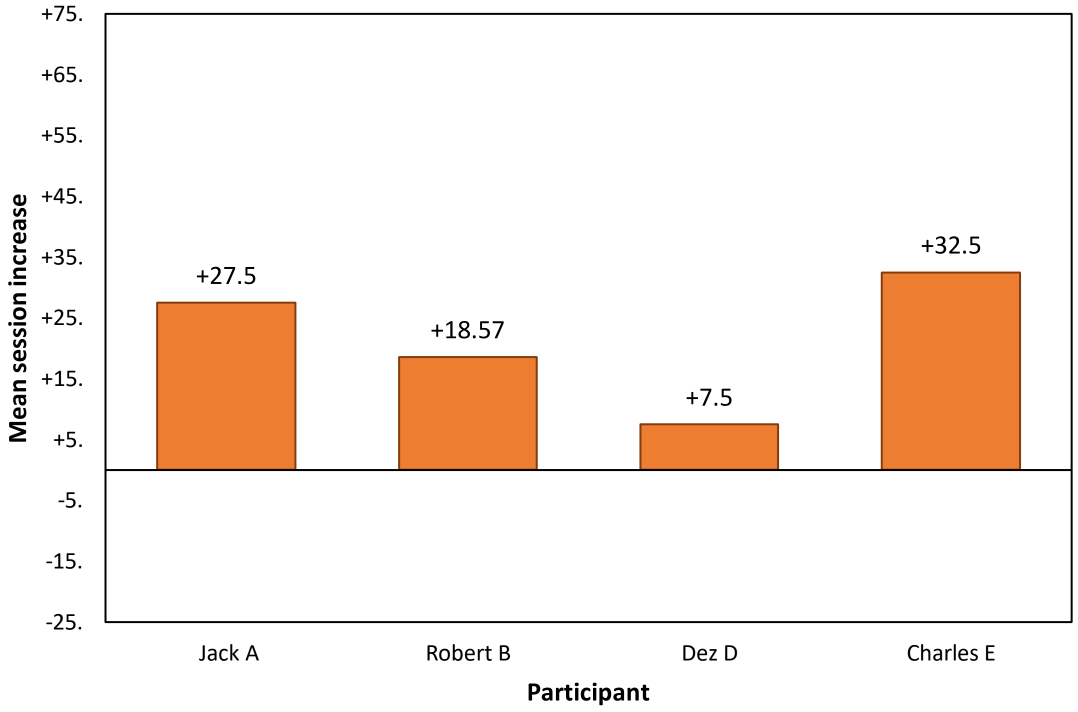

Figure 7. Mean increase in CWS composite scores presession to postsession for PWD.

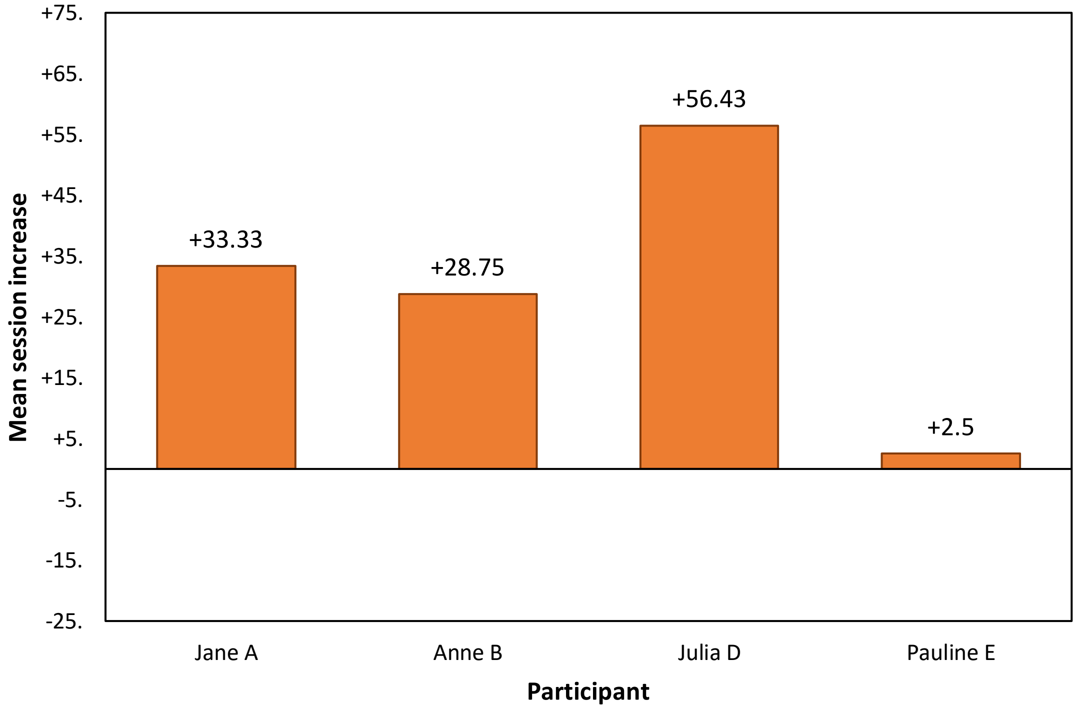

Figure 8. Mean increase in CWS composite scores presession to postsession for caregivers.

For participants with dementia and caregivers, the largest two subscale increases were for, respectively: ‘Well/Unwell’ and ‘Interested/Bored’; and ‘Confident/Not Confident’ and ‘Optimistic/Not Optimistic’ (see Figure 9 and 10).

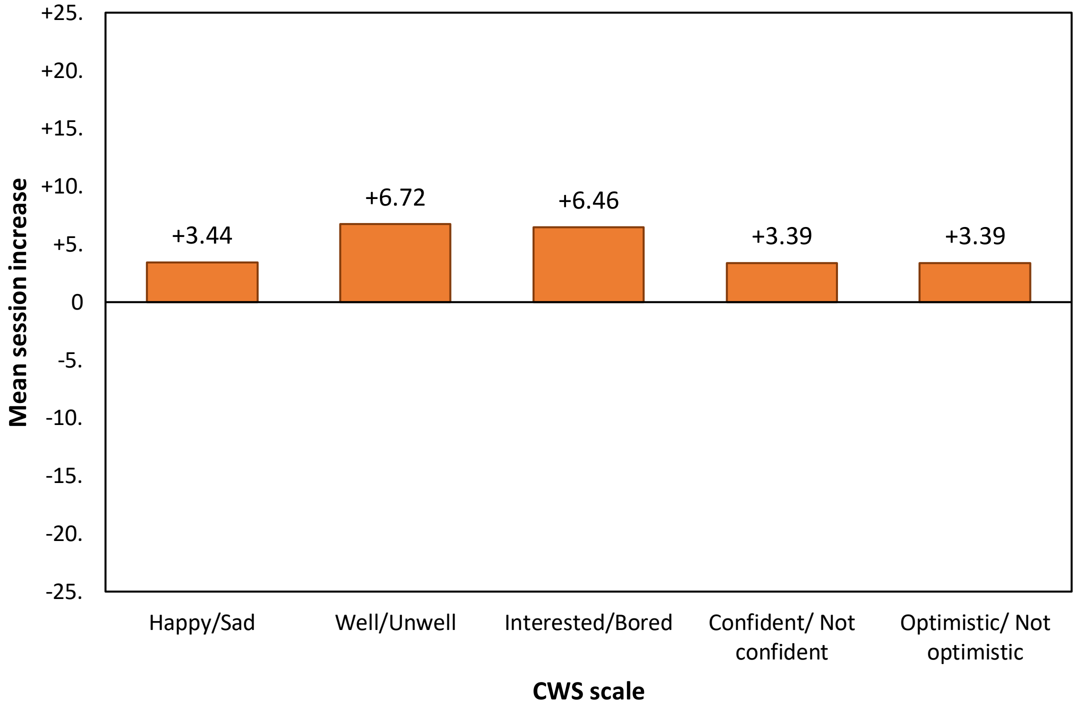

Figure 9. Mean increase in individual CWS scale scores presession to postsession for PWD.

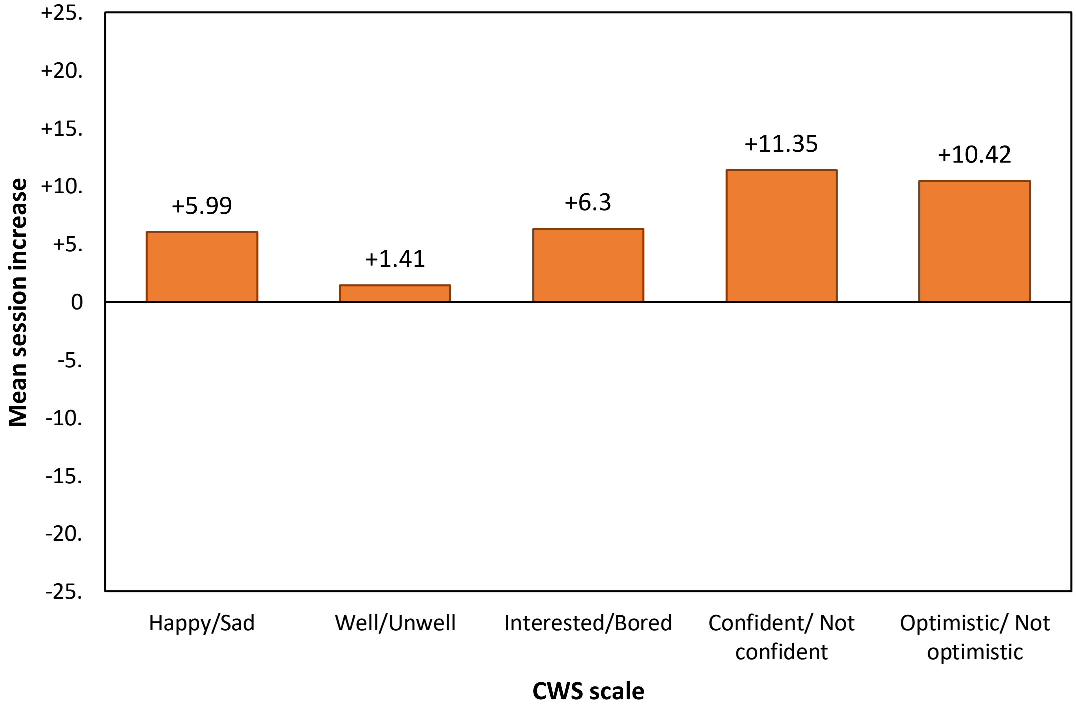

Figure 10. Mean increase in individual CWS scale scores presession to postsession for caregivers.

Reliable Change Indicator. A RCI was conducted on the WHO-5 data to analyse whether changes in each participants' scores were statistically significant, based on the reliability of the measure (Morley & Dowzer, 2014). To ensure reliability, the Cronbach's Alpha from Allgaier, et al. (2013) rather than Krieger et al. (2014) was used, as the clinical sample was comparable to this studies participant's demographics of older adults. However, Allgaier, et al. (2013) sample did not include people with dementia, so results should be interpreted with caution.

The RCI showed reliable deterioration in scores from preintervention to postintervention for Anne B, which remained at follow-up. Dez D had a reliable deterioration in self-reported wellbeing from postintervention to follow-up. Pauline E had a reliable increase in wellbeing score preintervention to postintervention, not remaining at follow-up (see Table 7).

Paired t-test. Paired-samples t-tests were conducted to compare WHO-5 and CWS scores preintervention to postintervention and preintervention to follow-up. As the CWS is a measure of 'in the moment' wellbeing, paired t-tests were completed comparing before and after each session. Due to the small sample size, it could not be assumed that data was normally distributed therefore all tests were bootstrapped.

Preintervention to postintervention, no significant increases or decreases in scores were found for the WHO-5 for participants with dementia and caregivers (see Appendix P results tables). For the CWS, no significant increases or decreases in scores were found for participants with dementia (see Appendix Q results tables). For caregivers, there was a significant increase in the scores for the CWS postintervention ($M = 408.75$, $SD = 65.24$) and preintervention ($M = 381.25$, $SD = 66.25$) conditions; $t(3) = 8.521$, $p = 0.003$. However, no significant difference was found for the CWS follow-up (M = 382.5, SD = 61.98) and preintervention (M = 381.25, SD = 66.25) conditions; t(3) = 0.103, p = 0.924.

Presession to postsession, for participants with dementia, there was a significant increase for session five in the scores for the CWS postsession (M = 420, SD = 35.12) and presession (M = 402.5, SD = 35.24) conditions; t(3) = 5.422, p = 0.012.

For caregivers, there was a significant increase in the CWS scores for two sessions; postsession three (M = 433.75, SD = 79.41) and presession (M = 385, SD = 63.64) conditions; t(3) = 3.239, p = 0.048, and postsession eight (M = 445, SD = 54.16) and presession (M = 408.75, SD = 65.24) conditions; t(3) = 3.394, p = 0.043.

These results need to be taken with caution due to the small sample, but can support the descriptive statistics.

FFMQ-SF. The FFMQ-SF results for participants with dementia and caregivers from baseline to follow-up show a mixed picture, with no overall clear increases or decreases in scores.

Participants with dementias' largest changes were increases in the facets 'non-react' and 'non-judge', and a decrease in 'describe'. Caregiver changes on the individual facets were smaller (see Table 9).

Table 9
FFMQ-SF change in scores from baseline to follow-up.

	Score change from baseline to follow-up				
Participants with dementia	Non-react	Observe	Act aware	Describe	Non-judge
Jack A	-4	-1	-4	-1	1
Robert B	5	-1	0	-6	-1
Dez D	1	1	3	-3	-2
Charles E	7	-2	-5	-2	11
All participants (Mean)	2.25	-0.75	-1.5	-3	2.25
Caregivers	Non-react	Observe	Act aware	Describe	Non-judge
Jane A	1	-3	1	0	0
Anne B	0	9	1	-2	7
Julia D	5	0	-6	2	-7
Pauline E	-1	-1	0	-4	-1
All participants (Mean)	1.25	1.25	-1	-1	-0.25

Jack and Jane A

Initial interview. Jack and Jane described a happy marriage; however, the diagnosis of dementia affected them considerably. Jack reported substantial losses due to the dementia and depending more on his wife. This led to significant changes in their relationship roles.

Both reported emotional effects of the dementia. Jack felt lower in mood and more tearful, while Jane reported increased irritation and frustration. Jane hoped the course would increase Jack's activities out of the house, and give her coping strategies for now and the future.

Postinterview and field notes. The couple attended seven of eight sessions, but were unable to attend the follow-up. The couple were "united in our hatred" of the home practice. Jane also reported it felt like a chore or burden. They completed the home practice together, 3-4 times every week. Jack reported struggling with the concept of the course and because of his cognitive difficulties, it became a frustration. Both were unsure if mindfulness would benefit someone with dementia. Jack reported meeting people with similar difficulties was a benefit (also noted as a reflection in the 4th session field notes). Jane found the informal practice helpful, and reported feeling improvements in acceptance and attention. Finally, as an important confounding variable, Jack had an accident between the final session and follow-up and reported this affected their moods negatively.

Quantitative results. Jack's FFMQ-SF scores decreased on four of the five facets at follow-up with largest in 'non-react' and 'act aware'. Neither Jack nor Jane showed a reliable change in the WHO-5 RCI.

Jack had a large increase in wellbeing in the CWS presession to postsession, compared to Janes' slight increase. Caution is needed when looking at Jack's results as his baseline was not stable on both wellbeing measures and due to his accident between final session and follow-up (see Table 10).

Table 10
Jack and Jane preintervention, postintervention and follow-up data

Participant	Measure	Facet	Baseline	Preintervention	Postintervention	Follow-up	Mean change presession to postsession
Jack A	WHO-5		52	40	48	32	
	CWS		370	340	385	390	27.5
	FFMQ-SF	Non-react	17			13	
		Observe	13			12	
		Act aware	21			17	
		Describe	13			12	
		Non-judge	16			17	
Jane A	WHO-5		40	40	40	48	
	CWS		325	285	315	295	5
	FFMQ-SF	Non-react	13			14	
		Observe	19			16	
		Act aware	16			17	
		Describe	15			15	
		Non-judge	10			10	

Key: RI= RCI reliable change

Robert and Anne B

Initial interview. Robert and Anne described their marriage as 'equal', both working and raising children together. Anne was still working and Robert primarily remained at home. They reported having their own hobbies and not often spending time together.

Robert described the difficult process of being diagnosed with dementia as a young older adult due to limited expertise of some professionals involved in his care. Robert described negative experiences in his local community disclosing his diagnosis, and now finds social situations difficult. Anne reported they were both less argumentative since Robert's diagnosis. Anne indicated she avoids talking about her own recent diagnosis of dementia and tries to "take every day as it comes". Robert wanted to attend the course, as the CMHSOP is somewhere he had previously found supportive.

Postinterview and field notes. The couple attended every session. Robert completed both shorter and longer practices each morning. Anne completed the informal practices walking to work and the 3-minute breathing space in her breaks. She reported struggling to complete the practice due to work commitments.

Both found the course helpful, the practices relaxing and enjoyed socialising with others. They felt less emotionally reactive. Robert reported the course might have positively affected his blood sugar levels. Anne reported mindfulness increased her awareness, and the course made her face-up to her own dementia diagnosis.

Importantly, they reported the course positively affected their relationship. They felt the mindful communication exercise was a big contributor to this as they confronted and discussed Robert's difficulty with word finding, allowing them to have open conversations about the impact of dementia on their lives.

Quantitative results. Robert recorded a FFMQ-SF decrease at follow-up in 'describe' and an increase in 'non-reactive'. This is consistent with the qualitative data (see later) around Robert struggling with word finding and feeling less emotionally reactive. Anne recorded an increase in 'observe' and 'non-judge', which is also consistent with the qualitative results.

Anne showed reliable wellbeing deterioration, in WHO-5 RCI, which remained at follow-up. Furthermore, Anne's wellbeing deteriorated following the first session and remained low until the follow-up (see Figure 4), indicating she had an early reduction in wellbeing. It is important to look at this reduction in the context of Anne's report the course made her face-up to her own diagnosis of dementia.

Table 11
Robert and Anne preintervention, postintervention and follow-up data

Participant	Measure	Facet	Baseline	Preintervention	Postintervention	Follow-up	Mean change presession to postsession
Robert B	WHO-5		28	44	44	40	
	CWS		345	325	365	360	18.57
	FFMQ-SF	Non-react	14			19	
		Observe	16			15	
		Act aware	12			12	
		Describe	18			12	
		Non-judge	14			13	
Anne B	WHO-5		28	40	12RI	12RI	
	CWS		385	390	415	405	28.75
	FFMQ-SF	Non-react	16			16	
		Observe	7			16	
		Act aware	11			12	
		Describe	15			13	
		Non-judge	7			14	

Key: RI= RCI reliable change

Both showed increased scores on the CWS. It is important to consider both Robert and Anne's scores on the WHO-5 and CSW did not remain stable between baseline and preintervention so results need to be taken with caution (see Table 11).

Dez and Julia D

Initial interview. Dez and Julia described their longstanding, happy relationship with traditional roles. Although different people, they feel they complemented each other. Dez reported currently dementia was not having a significant impact on his life, and other long-term conditions were causing him more difficulty. Julia reported having to take on more of

Dez's roles in the relationship. They both reported they now have greater reliance on each other. Dez wanted to participate as he enjoys helping with research, while Julia wanted to do something together.

Postinterview and field notes. The couple attended seven of eight sessions and completed the home practice together. Dez reported the practices might have helped with his concentration. Both commented on enjoying practising and attending the course 'together'.

Both struggled to engage with the presentation style and presenters, which appeared particularly important as they both came from teaching backgrounds. Julia found being around others with similar problems helpful, and reported after the course being less judgemental of herself and emotionally reactive. An important confounding variable was Dez reported at the follow-up significant recent physical health complications. Both acknowledged this had affected his wellbeing.

Quantitative results. Julia's scores for the FFMQ- SF showed an increase in 'non-react' and decreases in 'act aware' and 'non-judge' at follow-up. Dez showed decreases in wellbeing scores postintervention and at follow-up for both the WHO-5 and CWS. He showed a reliable deterioration in wellbeing on the WHO-5 RCI at follow-up. These results should be taken with caution due to confounding variables and scores at baseline not being stable. Both showed increases on the CSW presession to postsession with Julia having a larger increase (see Table 12).

Table 12
Dez and Julia preintervention, postintervention and follow-up data

Participant	Measure	Facet	Baseline	Preintervention	Postintervention	Follow-up	Mean change presession to postsession
Dez D	WHO-5		40	80	76	24 RI	
	CWS		470	470	455	405	7.5
	FFMQ-SF	Non-react	12			13	
		Observe	12			13	
		Act aware	11			14	
		Describe	23			20	
		Non-judge	24			22	
Julia D	WHO-5		64	64	60	68	
	CWS		380	425	445	390	56.4
	FFMQ-SF	Non-react	15			20	
		Observe	20			20	
		Act aware	14			8	
		Describe	13			15	
		Non-judge	14			7	

Key: RI= RCI reliable change

Charles and Pauline E

Initial interview. Pauline and Charles described a happy and supportive relationship. Charles did not feel the dementia was having a big impact on him and liked to take each day as it came.

Pauline felt that the dementia was having more of an impact. She sometimes found the caring role difficult as she was supporting her husband along with other family members and missed their past relationship and the conversations they had together.

Charles wanted to take part as he wanted to do more activities and meet people, whereas Pauline hoped to learn some skills to help her better control her emotions.

Postinterview and field notes. The couple attended 7 of 8 sessions. They reported completing the home practice together, Pauline initiated the practice and that due to other commitments, sometimes found it difficult to find the time to practice. Both reported enjoying attending the course, and Charles found the exercises relaxing.

Pauline reported being more aware of her surroundings following the MBSR course, and used mindfulness as a coping strategy during times of high emotion, whilst sometimes helpful, she reported that sometimes the high emotion could make mindfulness difficult to practice. Both enjoyed the social aspect of the course and spending time together. Both reported wanting to continue to practice mindfulness.

Quantitate data results. Charles increased at follow-up for FFMQ- SF (Bohlmeijer et al., 2011) 'non-react' and 'non-judge' facets, but decreased for 'act aware',

Pauline also decreased in the facet of 'describe'. Pauline's scores reliably improved on the WHO-5 (WHO, 1998) postintervention (Morley & Dowzer, 2014) but which was not maintained at follow-up.

Charles' CWS scores improved postintervention but decreased at follow-up. Pauline's scores on the CSW increased postintervention and although reduced at follow-up remained higher than preintervention (see Table 13).

Table 13
Pauline and Charles preintervention, postintervention and follow-up data

Participant	Measure	Facet	Baseline	Preintervention	Postintervention	Follow-up	Mean change presession to postsession
Dez D	WHO-5		68	48	52	48	
	CWS		420	430	480	330	32.5
	FFMQ-SF	Non-react	18			25	
		Observe	15			13	
		Act aware	12			7	
		Describe	15			13	
		Non-judge	9			20	
Julia D	WHO-5		36	32	48 RI	40	
	CWS		365	425	460	440	22.8
	FFMQ-SF	Non-react	16			15	
		Observe	15			14	
		Act aware	15			15	
		Describe	20			16	
		Non-judge	15			14	

Key: RI= RCI reliable change

Thematic analyses

Thematic analysis of the follow-up interviews revealed three overarching themes: Experiences of MBSR, Maintaining wellbeing in the dementia journey and Completing MBSR as a couple (see Table 14). The summary of the thematic analysis is organised according to these themes (for theme descriptions and transcript coding example see Appendices O and R).

Table 14
Follow-up interview themes

Themes	Experiences of MBSR	The dementia journey	Completing MBSR as a couple
Sub themes	"It was just helpful" A therapeutic space to gain support Group intervention challenges "It's [MBSR] a benefit, and it's a tool" MBSR challenges A mindful future?	"Everything else going on" "In one ear and out the other" A shrinking social world Gaining support from others	Coping together or apart "United in our hatred" Maintaining the relationship

Theme one: Experiences of MBSR

Six subthemes were identified from participants' descriptions of the benefits and challenges associated with MBSR.

"It was just helpful". This subtheme highlighted the overall positive experience and gains participants reported from attending MBSR, although answers often lacked detail, for example, what elements they found beneficial, or contributed to gains made. This could be due to general difficulty people may have had in defining the sometimes intangible gains made due to mindfulness. This could be harder for older adults with a lack of previous exposure to psychological interventions, and for people with cognitive impairments.

Dez D (PWD): No expectations, I had to go and look up the word… err…

Julia D (Caregiver): What word? Not mindfulness?

Dez D (PWD): Mindfulness, it was, yes

A therapeutic space to gain support. Participants described the importance of attending a course alongside people with similar problems and feeling listened to and supported by the facilitators and other participants. One participant highlighted this aspect as most beneficial:

> Julia D (caregiver): So it was just nice to know we had something, where the people were similar… and umm it was more that than anything else really, more than the course was about [laugh].

Group intervention challenges. Participants felt the quality of the presentation of material and facilitation of the group was sometimes lacking, with facilitators not making enough adaptations (e.g., for those hard of hearing). Others felt refreshments such as coffee or tea were lacking.

> Pauline E (Caregiver): The first few times it was quite unsettling for [Charles]. He kept asking 'what are we doing, what are we doing'. I was ok about it really, but he, well he said oh no but we didn't get a cup of tea [laugh] that's the first thing he said, and he didn't quite understand. But I think, you know, for people with Alzheimer's, it's nice to have that cup of tea and it's a safe place as you know a cup of tea is always a friendly thing, isn't it?

For participants to name these challenges highlighted the importance of generic group therapy skills, making participants feel safe and welcome, especially for people with dementia. It is important to note some participants who most strongly reported facilitation difficulties were both from teaching backgrounds.

"It's [MBSR] a benefit, and it's a tool". Participants spoke about the benefits regarding mindfulness. Field notes highlighted the important benefit of reducing emotional reactivity. Participants talked about feeling calmer, relaxed and better equipped to deal with stressful situations.

> Robert A (PWD): Calming me down a bit, yeah. I say, I could say a few years ago I would of got angry, but I get frustrated more than anything now. And err that is... coming to this course, is helping me settle things settle things down in that way.

Another important benefit from mindfulness was focusing attention to the here and now, one participant being struck with how much she was paying attention

> Anne B (Caregiver)It's fascinating really, that you walk around on auto-pilot, and it's started making me look at things instead of tunnel vision, and it is, it's making a difference I think.

Some caregivers reported effects the course had on their cognitions, feeling they gained new perspectives and became less judgemental.

> Julia D (Caregiver) If your thoughts have strayed that is ok that is fine and normal and and be gentle with yourself and bring your mind back, if it happens again and again don't worry and that sort of thing. You know umm very sort of soothing having someone say things like that be non-judgemental.

MBSR challenges. Participants reported difficulty with heightened emotions; either struggling to practice in highly emotional times, or the practice brought up strong negative emotions. Another difficulty was motivation to practice. Some found the mindfulness concepts hard to follow or understand.

> Dez D (PWD): I did find it very, very difficult to think about breathing through my right [laugh] foot, I mean it seemed so implausible.

A mindful future? Participants were mixed regarding their future with mindfulness. Some reported continuing with formal practice; others that mindfulness informally became part of their lives. All participants wanted to continue having monthly follow-up group sessions. This highlighted the group's importance as a source of support generally and supporting further mindfulness practice.

> Anne B (Caregiver): I mean as a whole group we said if we could carry on doing it even if it is just once a month for an hour, we think it would help all of us, and us carers as well. And it brings you back to that sort of discipline about doing it, you know meditation, and it's nice to you know… get back together with these people.

Theme two: Maintaining wellbeing in the dementia journey

Four subthemes were identified associated to the dementia journey in participants' lives and its relationship to their experience of attending the course.

"Everything else going on". Participants spoke about living with dementia alongside other difficulties and demands. These included health difficulties, family dynamics and other responsibilities. They reported how these affected their MBSR practice, and how the practices sometimes helped them cope with these wider demands.

"In one ear and out the other". Participants discussed the impact cognitive decline had on being able to practice MBSR. This varied from remembering to practice, to being unable to hold on to, or understand, the concept of mindfulness. Some participants felt it improved their concentration, while others felt it was not beneficial for people with dementia. Jane A (Caregiver) reported: "I don't see how it can help people with dementia if it's you know in one ear and out the other…"

Being in the group with others with similar problems enabled them to explore the dementia and the role it plays in their lives, with some reporting it helped them accept the diagnosis. Field note observations highlighted when participants discussed cognitive difficulties (most notably in sessions 4 and 5) and how the group discussed this shared experience supportively.

> Robert talked about his negative thoughts again, about the anger and frustration he feels not recognising people he knows, and the negative impact dementia has on his relationships with others in the community. Dez and Jack in the group acknowledged

> this happening to them, and supportive feedback was given to Robert from the group (Field notes, Session 5).

A shrinking social world. Participants talked about dementia affecting their social world and how the course was one way they were able to improve this. It appeared the caregivers wanted socialising to remain an important aspect in their lives.

> Julia D (Caregiver): But he can't even do that sort of thing now [holidays], so our world has really closed down, so it was just nice to know we had something, where the people were similar.

Gaining support from others. Participants talked about the importance of support from others and being introduced to different provisions available to them from other participants and facilitators. This varied from referrals in service to caregivers finding out about available financial support.

Theme three: Completing MBSR as a couple

Three subthemes were identified, highlighting the importance of the relationship in the experience of attending the course.

Coping together or apart. Coping and supporting each other appeared an important part of experiencing the course. Participants talked variedly about how the course helped them cope as individuals or as a dyad. The majority reported it allowed them to better support one another. An example from Couple B was around their experiences of the communication exercise, feeling participating helped them open up and explore how they cope and support each other.

> Robert B (PWD): Since that 1:1 [communication exercise] she err as I say, we have started to talk about it, and she will step in and help me out.
>
> Anne B (Caregiver): He is opening up more now, he is accepting more that he needs help, you know, and he doesn't mind me umm… finishing his sentences whereas

> before, it would be "oh you're butting in" whereas now he accepts the fact that he can't find his words umm he is more open to me helping him in that respect... so… yeah. It has helped a lot.

Another participant spoke of the importance of doing the intervention, sharing and learning together as a dyad:

> Julia D (Caregiver): Possibly if I had been on my own, getting back home, back to my normal situation, it probably wouldn't have affected me so much, I am sure the fact we did it together has made a big difference.

One caregiver felt the MBSR gave her individual strategies to support her partner better. Jane A: "And I don't get quite so irritated by Jack."

"United in our hatred". Interestingly, all couples noted either attending the course or completing the practices together had some effect on how connected they felt as a couple. Some reported they held more positive feelings for the other:

> Anne B (Caregiver): I think we have more of an understanding of each other, and appreciate each other more, and we definitely appreciate [laugh] time together, whereas before it was just you know getting on with day to day life, whereas now umm… we sit we sit and talk more, you know when we can.

One couple who struggled with the practices reported they felt more connected through shared hatred of the practices.

> Jane A (Caregiver): umm I think we… I think we were [laugh] united in our hatred of the practice [Jack and Jane laughing]. In the 'omming'.

Maintaining the relationship. This subtheme was mainly evident from the caregivers' interviews. Participants talked about how spending time together doing an activity helped maintain their dyad couple relationship, rather than being a caregiver and supported person.

One participant acknowledged the important aspects of the course were different for her as her husband but doing something together was important.

> Pauline E (Caregiver): It does make a difference, well because life is so different anyway, but it does connect you, because, because we are doing it together, we may be doing it for different reasons and things, we are still doing it together and still a nice memory.

Discussion

Summary of main findings

The research aimed to explore how people with a diagnosis of dementia and their caregivers experienced a MBSR course. Further aims sought to explore the benefits and difficulties participants had attending MBSR and practising mindfulness, how participants described effects the course had on their wellbeing and relationships, and acceptance and adjustment to the diagnosis of dementia.

The main findings from self-report measures of wellbeing, found no clear patterns of improvements or deteriorations from the time series data or preintervention to postintervention, for both caregivers and participants with dementia. The majority of changes found postintervention were not maintained at follow-up.

Presession to postsession, all participants showed patterns of improvements in wellbeing using the CWS, indicating wellbeing improved during each session, with parametric tests suggesting significant improvements in session five for people with dementia and sessions three and eight for caregivers.

The FFMQ-SF showed a mixed picture for all participants, with no overall clear changes in mindfulness scores for each facet.

Thematic analysis of the follow-up interviews showed overall participants reported positive experiences of the course and felt they benefitted from attending. The theme ‘It was just helpful' highlighted the course's usefulness, but also the lack of explicit reasons or explanations as to why. Participant's inability to articulate what was helpful could be due to many reasons including age, cognitive impairment, or the fact that mindfulness is a complex, difficult to define concept. This remains a limitation within current research (Chiesa, 2013).

All participants reported generic benefits to attending a therapeutic course. For example, the importance of a containing space where they felt supported and listened to by facilitators and other participants. Participants wanting to attend future sessions, and feedback on the importance of good facilitation reinforced this.

Specific MBSR benefits were found with aspects varying in importance. Caregivers reported engaging more with cognitive elements, such as acceptance and being non-judgemental. This finding supports Smith's (2006) argument that mindfulness is beneficial as it draws on people's specific abilities rather than focusing on problems. An important benefit for all was the impact practices had on emotional reactivity. This is consistent with Litherland and Robertson (2014) research that a benefit of mindfulness to wellbeing is its ability to help regulate emotions. Finally, three of the four couples reported mindfulness being beneficial enough to want to continue, as reported in previous research (Kemp et al., 2016; Litherland & Robertson, 2014; Paller et al., 2015).

Although improvements in wellbeing for participants with dementia were not verbally reported in the interviews, the subthemes 'A therapeutic space to gain support', and 'A shrinking social world' highlighted the importance of the group having a space to socialise, while feeling heard and being supported. An important consideration is the inevitable deterioration associated with dementia and the impact this will have on couples' wellbeing, which Jane A (caregiver) highlighted in the preintervention interview: "I don't believe in living well with dementia I think that's a load of rubbish, dementia is a ghastly disease…. You have been dealt this blow in life, but don't tell me you can live well with it because you live as best as you can". Therefore, there are limitations to the impact any intervention can have to the wellbeing of the person with dementia and caregiver.

The role of the relationship within the course was highlighted as important for multiple reasons, including helping to facilitate and support practice for participants, as previously reported by Smith et al, (2014) in research with couples attending MBCT interventions. Findings highlighted the courses' positive effect on the dyad relationship, with participants reporting feeling more connected as a couple (reported also by Bihari & Mullan 2014; Paller et al., 2015). Participants actively sought engagement in activities together to maintain the relationship. As described by Hellstrom, Nolan and Lundh (2005; 2007), the importance of doing something together maintained couplehood, and helped to live positively with dementia.

Finally, participants reported feeling they were able to cope better with dementia after the course, consistent with Litherland and Robertson's (2014) findings. Where some dyads appeared to cope as before the course, others noticed they were supporting each other more as a couple; with one dyad feeling this was one of the most important benefits. This is similar to Häusler et al. (2016) findings suggesting dyadic interventions could help couples living with dementia and dealing with stress.

Strengths and Limitations

This study was unique, looking at a new and developing area of research. Using a mixed method design, it allowed for in-depth exploration of participants' experiences, while quantifiably measuring changes to wellbeing.

The self-report measure CWS is able to show changes in people with mild–moderate dementia. As this questionnaire and the WHO-5 were simple to administer, there was minimal impact on questionnaire fatigue, which is important for participants with cognitive difficulties. Because measures were not burdensome to administer, collecting time series data enabled an exploration of patterns across each session and throughout the intervention. The qualitative data gave a richer exploration of participants' and couples' individual experiences and benefits, which the quantitative data would not have found.

However, this study had limitations. Statistical analysis results can only suggest improvements due to the small sample size and lack of statistical power. Furthermore, the results are not generalizable due to the heterogeneous and small sample size.

Unlike the wellbeing measures, available mindfulness measures were not deemed valid for older adults, or people with dementia. Due to its length, the FFMQ-SF was only completed at baseline and follow-up to reduce cognitive fatigue and the potential effect this could have on participants completing the more valid wellbeing measures. It is important to consider MBSR aims to encourage heightened awareness, which could increase participants' awareness of their difficulties and may have negatively affected the results from the questionnaires (especially the FFMQ-SF). For example, Anne B reported feeling the course made her less avoidant of her own diagnosis, and all participants with dementia had reduced scores on the 'describe' facet at follow-up, possibly highlighting this increased awareness. Due to reliability and validity issues of the FFMQ-SF, the results need to be taken with caution.

It was not possible to conduct a later follow-up, which would have been helpful in exploring longer-term benefits from the course. Although two facilitators were trained practitioners, a standardised adherence checklist, such as the Mindfulness-Based Interventions-Teaching Assessment Criteria (Crane et al., 2013), would have supported treatment fidelity.

Theoretical implications

This research tentatively supports the three aspects of Greeson's (2009) theory regarding how MBI benefits wellbeing, through regulating awareness, attention, and emotion.

However, limitations of participants' difficulty articulating clearly the benefits from mindfulness do not allow making strong supportive theoretical links. The generic benefits around the social aspects of the course appear to support Kitwood's (1997) theory on wellbeing with dementia, and that wellbeing 'personhood' is maintained by positive social environments.

Hellstrom, Nolan and Lundh's (2005; 2007) theory on couples' relationships with dementia highlights a phase of the dyads relationship called 'Sustaining couplehood' where both of the dyad are actively involved in trying to preserve the relationship. This phase appears to be supported by the subtheme 'Maintaining the relationship' where dyads reported wanting to maintain the relationship through engaging in activities as a couple, even with the difficulties associated with dementia.

Finally, participant's discussions around the ways the couple coped following the course appear to support theory around dyadic coping (Berg & Upchurch 2007). This theory is in the context of dyads living with chronic illness and cancer, and as such, further research is needed to explore these theories in relation to coping as a dyad with dementia.

The connections of the findings to multiple theoretical models highlight the complex way the course was of benefit to participants and supports the need for research to explore this further.

Clinical implications

With limited research in the area, MBSR would not be considered for clinical practice over other more researched interventions. However, this study highlights the importance of working together as a dyad in supporting people with dementia and their caregivers within older adult mental health services. This recommendation is supported by others (Robinson, Clare, & Evans, 2005) and in line with government guidance (DoH, 2009; 2012; 2015). Following more in depth research, psychological interventions such as MBI for participants with dementia and caregivers together, may be a cost-effective way for services to support this group, and help reduce the burden on caregivers to find alternative care if they were to attend a course themselves. Caution is needed when considering MBI in clinical practice, so it is not used as just a relaxation technique. Crane et al. (2017) highlighted the need to maintain the integrity of the MBI, to adapt interventions to support the client group but keep the fundamental aspects of mindfulness. This can be done by using specifically trained facilitators and basing interventions on original MBCT and MBSR programs.

Future Research

Further research is needed to build on these findings. Although qualitative results highlight benefits from the course, the results cannot argue MBSR is superior to other interventions, including generic support groups for improving the wellbeing of people with dementia and caregivers. Conducting further research with larger participant samples and more qualitative research exploring, in-depth, participants' experiences of MBI may help support these findings.

Dementia is a degenerative disorder and the difficulties people with dementia and their caregivers will face will continually change, therefore it is important to produce research that can conduct longer-term follow-ups to explore how, if at all MBSR can support dyads throughout the dementia journey. To help explore the benefits of mindfulness for participants, research will need to include more standardised measures shown to be suitable for people with dementia.

Conclusion

This research explored the experiences of four couples living with dementia attending a MBSR intervention. Quantitative results from self-report measures highlighted wellbeing increased during each session, but other quantitative results were inconclusive with no clear improvements or deteriorations in wellbeing or mindfulness found. Thematic analysis of follow-up interviews found a broad range of ways participants experienced the MBSR course; highlighting generic therapeutic benefits, improvements to the dyads relationship and varying ways the mindfulness techniques benefitted participants.

Before recommending MBSR over other dyad interventions or generic support groups for clinical settings, further research is needed. However due to the multiple ways this intervention has been shown to support a variety of participants, it could be argued MBI may have wide ranging benefits than more targeted interventions. Further research using larger samples and using qualitative and quantitative data is needed to gain more robust findings on the benefits of mindfulness for people with dementia and their caregivers.

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Section C: Appendix of Supporting Material

Appendix A
Downs and Black checklist (1998)

Downs & Black’s (1998) checklist

	Reporting										External Validity						Internal Validitiy confounding (selection bias)										
First Author and Date	1. Hypothesis / Aims	2. Outcomes	3. Sample	4. Intervention	5. Principle Confounders	6. Main findings	7. Estimates of random variability	8. Adverse Effects	9. Lost at follow up (Characteristics)	10. Actual probability values	11. Source of population representative?	12. Sample representative?	13. Setting Representative?	15. Measures blinded?	16. Analysis planned?	17. Follow up times for control and intervention the same?	18. appropriate statistical tests?	19. Intervention compliance	20. valid and reliable outcome measures?	21. population recruitment	22. recruitment time?	23. group randomisation	24. blinded randomisation	25. Adjustment of main confounders	26. follow up loses recorded?	27. sufficient power?	Total
Lantz, 1997	N	N	Y	Y	?	Y	Y	N	N	Y	N	N	N	?	?	Y	?	?	Y	Y	?	?	N	?	?	N	8
Brown, 2015	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	?	?	Y	Y	Y	Y	Y	Y	?	Y	?	Y	Y	?	20
Norouzi, 2012	Y	Y	N	N	N	Y	Y	N	Y	Y	?	N	?	?	Y	?	Y	?	Y	Y	?	Y	?	Y	Y	?	13
Oken, 2010	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	?	?	?	Y	Y	Y	Y	?	Y	Y	Y	Y	Y	Y	Y	?	20
Whitebird, 2012	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	?	?	Y	Y	Y	Y	Y	Y	Y	Y	?	Y	Y	?	21
O'Donnell, 2013	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	?	?	Y	Y	Y	Y	Y	Y	Y	Y	?	Y	Y	N	21
Chan, 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	?	Y	?	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	23

y= yes N= No ?= unable to determine

*note item 14 removed from the checklist as it is not relevant for psychological studies

Appendix B
CASP Qualitative Research checklist

First Author and Date	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	Total
Litherland, 2014	Y	?	Y	Y	?	?	Y	?	N	**4**
Kemp, 2016	Y	?	?	?	Y	N	?	?	N	**2**
Epstein-Lubow, 2011	Y	N	Y	?	Y	N	?	N	Y	**3**
Hoppes, 2012	Y	Y	Y	Y	Y	Y	?	Y	Y	**8**

y= yes N= No ?= Can't tell

* note item 10 not included in table as it not a closed question

First Author and Date	1. Did the study address a clearly focused issue?	2. Was the cohort recruited in an acceptable way?	3. Was the exposure accurately measured to minimise bias?	4. Was the outcome accurately measured to minimise bias?	5. (a) Have the authors identified all important confounding factors?	(b) Have they taken account of the confounding factors in the design and/or analysis?	6. (a) Was the follow up of subjects complete enough?	(b) Was the follow up of subjects long enough?	9. Do you believe the results?	10. Can the results be applied to the local population?	11. Do the results of this study fit with other available evidence?	**Total**
Litherland 2014	Y	Y	N	?	N	N	Y	Y	Y	?	?	**5**
Kemp 2016	Y	?	?	Y	?	?	Y	Y	Y	?	?	**5**
Paller 2015	Y	?	Y	Y	Y	Y	N/A	N/A	Y	?	?	**6**
Hoppes 2012	Y	Y	?	Y	?	?	Y	N	Y	?	?	**5**
Epstein-Lubow 2011	Y	?	Y	Y	N	?	Y	N	Y	N	?	**5**
Ho 2016	Y	?	Y	?	Y	?	N/A	N/A	Y	?	?	**4**

y= yes N= No ?= Can't tell

* note items 7, 8 and 12 are not included in table as they are not closed questions

Appendix C
Timeline

Timeline of the research

- 31st July 2015: Approval of research proposal
- October-December 2015: Service user consultation
- 27th January 2016: NHS ethics panel meeting
- 15th March 2016, 24th April 2016 and 1st August 2016: NHS ethics and R&D approval
- May- June 2016: Recruitment
- 30th May- 9th June 2016: Pre-interviews
- June-August 2016: Transcribing of pre- course interviews
- 20th June 2016-8th August 2016: 8 week MBSR course
- 5th September 2016: Follow up session of MBSR course
- 6th September-22nd September: Follow up interviews
- September- November 2016: Transcribing follow up interviews
- November -December 2016: Coding of the data & Analysing the descriptive statistics
- January 2017: Initial themes and codes shared with supervisor
- February 2017: Revision of themes and subthemes
- 17th-19th February 2017: Themes and subthemes shared with external researcher
- 23rd February 2017: Naming of themes
- January-April 2017: Write up of the research
- March 2017: Informing HRC NHS Ethics end of study.

Appendix D

Ethics approval letter

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Appendix E

R&D access to site approval letters

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Appendix F
Canterbury Wellbeing Scale

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Appendix G
WHO-5

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Appendix H

5 facet questionnaire: short form

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Appendix I
Interview procedure

Interview procedure and questions.

Pre interview procedure

- Introduce the researcher, research and interview
    - ‘My name is Emily Swannell and I am a Trainee Clinical Psychologist at Salomons Centre for Applied Psychology, Canterbury Christ Church University. I will be interviewing you today as part of my research which is looking to explore the impact of mindfulness for people with a diagnosis of dementia and their main caregiver’.
- Housekeeping
    - ‘Before we start, I wanted to let you know that we can stop at any time if you need a break.’ (For the interviews held in NHS buildings show the participants where the toilets and exits are and fire drill procedure).
- Recap on consent and withdrawal procedure and check that they still have capacity to consent to continue with the research
    - ‘You have given consent to take part in this research by completing the consent form. By giving consent (show the participants a blank consent form as a reminder) you are agreeing to participate in three audio recorded interviews and complete some self-report questionnaires. You are also giving permission for me to attend the mindfulness course as an observer. With the data you provide you are agreeing for me and my supervisors to access this data, which will be anonymised, and for any anonymised quotations from the interviews to be used in published reports in the study.’
    - ‘You can withdraw from the research at any time and this will not impact on the care you or the person you are caring for have’
    - ‘Can I ask you to feedback your understanding of what you will be asked to do as part of the study?
- Explain the structure of the interview
    - ‘In this interview I will be asking you some questions. Please answer them as best as you can. The questions are intended to explore your experiences so there are no right or wrong answers. This interview should take no more than 30 minutes (interview1) / 1 hour (interview 2 & 3) and I will be recording it on this dictaphone and occasionally I will take some notes to aid my memory. During your answers I may interrupt you to make sure I have understood your answer correctly. I might also go back to something previously said for clarification. Do you have any questions before we start the interview?’

Interview Schedule

Interview 1: Pre-course joint interview

- Can you describe your relationship? Prompt: how would you describe your roles in the relationship? Prompt: How long have you been in this relationship for? [1]

- What help have you had so far? [4] What has been your experiences of the professionals involved in your care? (e.g. mental health services/ GP)? Prompt: After receiving this diagnosis what support have you both had already? [4]
- Can you tell me about some things that you enjoy doing together?
- Can you tell me about a difficult time in your relationship recently?
- What was your life like for both of you before the diagnosis? How has it changed? Prompt: Are you still working? What are your current occupations/ what was your previous occupations? [2]
- How would you describe yourself now? Prompt: Do you feel that dementia has had any impact on who you are as a person, and if so, how? How are you managing to maintain who you are as a person despite this diagnosis / being a caregiver?
- How, if at all, has your relationship changed since the diagnosis?
- How, if at all, has the diagnosis affected the wellbeing of both of you? Are there any other physical, mental health difficulties or life events which are also impacting on the wellbeing of both of you? [3]
- Can you tell me what has made you decide to attend the 8 week mindfulness course? What are you hoping to gain from attending?
- What do you understand about mindfulness? Prompt: have you come across the concept of mindfulness before? How do you think this might be relevant to the experiences you are having currently?

Interview 2: Post-course joint interview

- How did you find the experience of attending this course? Prompt: Are there any parts or aspects that stand out as most important? Was it what you expected?
- What, if anything, did you find helpful? What did you find unhelpful or difficult?
- Have you noticed any change in how you manage on a day to day basis? Do you have any examples of this?
- Since attending the course have you noticed any changes in the way you view the diagnosis of dementia and yourselves?
- How did you experience the home practice? Prompt: did you complete it together or independently? (If practiced together) Who initiated the practice or took responsibility for this? How did it feel to do the practice together?
- Are you still practicing the techniques? If so, what and why? Prompt: Are you still practicing independently / together?
- Did you notice any change in your relationship after the course? Prompt: Did you notice any changes in each other? In your roles? In how connected you feel?
- Have you noticed any change in how likely it would be for you to request help/ view support from professionals? (e.g. mental health services/ GP)?
- If at all, has the course had any impact on you and your wellbeing?
- Thinking about the future, how, if at all, might mindfulness be helpful for you? Prompt: will you continue to practice independently or together?

Interview 3: Post-course individual interview

‘Thank you for attending this final interview. In the joint interviews we talked about how you found practising mindfulness, attending the course, you as a person and your relationship.

This final interview is to give you some space to discuss anything which you didn't get a chance to say in the joint interviews'

Questions for participants with the diagnosis of dementia

- How did you find attending the course and practising mindfulness? Prompt: What, if anything, did you find anything helpful, unhelpful or difficult?
- If at all, did attending the course have any effect on who you are as a person, and if so, how? Prompt: What about to your well-being? Or your experience of being a person with a diagnosis of dementia?
- Since attending the course have you noticed any changes in your relationship? If so how? Prompt: What about feeling more or less connected to your… (for example wife/ husband/ daughter)? What if any changes have you noticed in your…(for example wife/ husband/ daughter)?

Questions for participants who are the carer.

- How did you find attending the course and practising mindfulness? Prompt: What, if anything, did you find anything helpful, unhelpful or difficult?
- If at all, did attending the course have any effect on who you are as a person, and if so, how? Prompt: What about to your well-being? Or your experience of being a caregiver to a person with a diagnosis of dementia?
- Since attending the course have you noticed any changes in your relationship? If so how? Prompt: What about feeling more or less connected to your… (for example wife/ husband/ daughter)? What if any changes have you noticed in your… (for example wife/ husband/ daughter)?

Debrief Information following each interview

- Debrief the participants, and highlight consent and withdrawal procedure and check capacity again.
  - 'This is the end of the interview.'
  - 'Do you have any questions or is there anything that we haven't talked about that you wanted to mention before we finish?'
  - 'At the beginning of the interview I recapped on what you have consented to, in being involved with this study (show the participants a blank consent form as a reminder). I also reminded you that you can withdraw from the research at any time and that this will not impact on the care you or the person you are caring for have. Do you have any questions about this? Are you happy to continue your involvement with the study?'
  - 'Do you have a copy of the information sheet or would you like another one to take home?'
  - 'The information sheet has contact details for me, the older adult service and other services which may be of use to you. If you have any further questions please do get in contact with me.'
  - (At final interview) 'Would you like a copy of the final report?'

Demographic information (collected in first interview)

(Tick box once information is collected)

- ☐ Length of relationship [1]
- ☐ Previous or current occupation [2]
- ☐ Any co-morbid mental or physical health issues, or other stressors (e.g., life events), which are currently impacting on their wellbeing? (for both patient and carer) [3]
- ☐ Support they have had pre-course following the diagnosis (for both patient and carer)?[4]

Demographic information (collected before the interview in the MBSR assessment)

- Gender
- Age
- Ethnicity
- Type of relationship (for example marriage, parent/ child, siblings)
- When was the diagnosis?
- What was the diagnosis?
- Score of the **ACE III** at last testing (and date at which **ACE** completed)

Appendix J
Information sheet, referral form, course pamphlet and consent form

Canterbury Christ Church University

Salomons Centre for Applied Psychology

Version 2 08.03.2016

Information about the research

Exploring mindfulness for older adults with dementia and their carers

Hello. My name is Emily Swannell and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide if you wish to participate, it is important that you understand why the study is being carried out and what it would involve from you.

You are welcome to talk to others about the study if you wish, including staff in the [redacted] who are not part of the research.

The information below is divided into two parts. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1:

What is the purpose of the study?

Mindfulness has been proven to benefit the wellbeing of a wide range of people. It has been shown that a diagnosis of dementia can have an impact on the wellbeing of both the individual diagnosed and that of their caregiver. This research is aiming to explore the impact of mindfulness for people with a diagnosis of dementia and their main caregiver and

Version 2
08.03.2016

to find out if practicing mindfulness together has any impact on the relationship. In this study the term 'caregiver' is shorthand being used to refer to a nonprofessional who is supporting a person with dementia. It is acknowledged that this term may not reflect how the relatives, partners, children, and friends explain their relationship or role. This study is also a part of the requirements of completing my doctorate in Clinical Psychology.

Why have I been invited?
You have been invited to take part in this research as you have been identified as someone who is either a service user or who is a main caregiver for someone with a diagnosis of dementia and you are both being offered an 8-week mindfulness course.

Do I have to take part?
No it is up to you to decide whether or not to join the study. Before agreeing to take part in this research you can ask me (Emily Swannell, lead researcher) any questions about the research. If you agree to take part, I will ask you to sign a consent form to indicate that you understand what is involved in the study, and would like to take part. You are free to withdraw from the study at any time, without giving a reason. This would not affect any care that you or your loved one would receive from [redacted] If you wish to take part in the research I will ask you to complete the consent form and bring it with you to the initial interview.

What will happen to me if I decide take part?

Before the course

- You have given permission for me (Emily Swannell, lead researcher) to contact you via the telephone to book an initial interview and discuss the research in more detail.

- You will be asked to attend a joint interview (service user and caregiver) with the researcher to discuss your expectations of attending the course, your current well-being and any current difficulties you are having individually or in your relationship. This will be up to an hour long and can be conducted at home if you wish.

Version 2
08.03.2016

- At this initial interview you will also be asked to complete some brief self-report questionnaires assessing wellbeing and mindfulness (three questionnaires, two with five questions in each and a one questionnaire with 15 questions). You will also be asked to provide some demographic information; this will include age, previous or current occupation, type of relationship (for example, marriage/ parent & child/ siblings) length of relationship, length of time since diagnosis.

During the mindfulness course

- You will attend an initial mindfulness taster session followed by the eight session mindfulness course. The sessions will last 90 minutes and you will be expected to practise homework in-between sessions. You will be asked to complete two brief self-report questionnaires assessing wellbeing at every mindfulness session.

- The lead researcher will attend the mindfulness course as an observer/ co-participant. This is to gather general field notes on the group to identify things which may not necessarily be picked up in the interviews.

After the course

- You will be asked to attend a final joint interview (service user and caregiver) and individual interviews with the researcher to discuss your experiences of attending the course and to explore if the course has impacted on your well-being and relationship. Each interview might be up to an hour long. These interviews and can be conducted at home if you wish. In these final interviews you will be asked to complete all three questionnaires, one last time.

Managing your information

- The interviews will be audio recorded on a Dictaphone. Immediately after the interview the recording will be transferred on to an encrypted memory stick and deleted from the Dictaphone. The audio recording will then remain on the encrypted memory stick until the time at which it is transcribed and anonymised. Once transcribed the audio recordings will be deleted from the memory stick. Your interviews will be analysed to look for key themes around experiences of attending the mindfulness course. These themes and some anonymised quotations from your interview will be used in the report to help make sense of people's

Version 2
08.03.2016

- experiences. After the research has been completed the transcripts will be stored on an encrypted CD within Canterbury Christ Church University building in a locked cabinet for 10 years before being destroyed. This is part of Canterbury Christ Church University policy on storage of data for theses.

- At the assessment you will be asked if the lead researcher can contact you in the circumstances that you do not complete the course. We will ask for your permission to contact you as this will enable us to offer you an interview which can help us gain valuable information on the limitations or difficulties of attending this course.

Expenses and payments

If you wish to complete the study you will be given £10 towards the cost of travel to attend each interview however unfortunately no other payment can be made.

What will I have to do?

If you feel you want to take part in the research please contact the lead researcher, Emily Swannell. You have the right to change your mind at any point.

What are the possible disadvantages and risks of taking part?

The interviews we will be asking you about your experiences of attending the course and any impact this may have on your relationship. These can be sensitive topics and as a consequence may cause some distress to participants.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this project will add to a growing area of research into interventions which aim to improve the wellbeing of people with a diagnosis of dementia and their caregivers.

Version 2
08.03.2016

What if there is a problem?

Any complaint about the way you have been dealt with/ treated during the study or any possible harm you might have suffered will be addressed. The detailed information on this is given below in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1.

Department of Psychology, Politics and Sociology
Faculty of Social and Applied Sciences

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www.canterbury.ac.uk

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Registered Charity No: 1098136

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Canterbury Christ Church University

Salomons Centre for Applied Psychology

Version 2
08.03.2016

Part 2:
What will happen if I don't want to carry on with the study?

You have the right to withdraw from the study at any point. If only one of you wants to discontinue the study once it has started this is possible, and this will not impact on the other person continuing to take part in the course or research. If you or your loved one are currently receiving support from the [redacted] withdrawing will not impact on the care received.

If you decide during an interview that you do not wish to continue, the interview will be stopped immediately and you will have the option to have the data collected destroyed. All questionnaires and data collected in the interviews can also be destroyed up until the report is finished. After this point all data will be non-identifiable.

At the beginning of the study you will be asked to give permission for the lead researcher to contact you if you decide for any reasons not to continue with the mindfulness course. All feedback and experience about an intervention is helpful, however it will be your choice whether you would like to provide this information

What if there is a problem?

Complaints

If you have a concern about any aspect of this study, please ask to speak to me (Emily Swannell, lead researcher) and I will do my best to answer your questions. You can contact me by leaving a voicemail message on [redacted] your contact details or on my -[redacted] you back to discuss your concerns.

If you remain unhappy and wish to complain formally, you can do this in two ways; if it is a complaint about the course[redacted] complaints department (Tel: [redacted] if it is a complaint about the research you can contact Canterbury Christ Church University Applied Psychology Research Director ------[redacted]

Version 2
08.03.2016

Will my taking part in this study be kept confidential?

Yes.

- The interview will take place in a confidential interview room in [redacted] service building or, if more convenient, at your home. A dictaphone will be used to tape the interviews and this will then be transferred onto a password accessed, encrypted memory stick. All field notes from the lead researcher will not include any identifiable information and will also be transferred onto the password accessed, encrypted memory stick.

- Only the researcher will be able to identify each participant's interview and questionnaires. Each interview will be transcribed and all identifiable information from this will be anonymised. All data will then be held on a secure password accessed, encrypted memory stick. During the study all written data will be kept in a locked filing cabinet at [redacted] service.

- All data collected from self-report questionnaires will be kept in a locked filing cabinet at the [redacted]. As soon as possible this will be transferred onto a password accessed, encrypted memory stick and at this point all participant data will be anonymised. These paper questionnaires will not leave the NHS building and will then be destroyed in a NHS confidential waste disposal.

- Following the completion of the research, the interviews and questionnaire data will be deleted from the memory stick but the research study report will be available in the university library. In the final report non identifiable sections of the transcript from the interviews may be included in the report to highlight an area of interest.

All information which is collected about you during the course of the research will be kept strictly confidential. You have the right to check the accuracy of data held and correct any errors.

The information you provide during the interview will be held in strict confidence. Under the Data Protection Act 1998, should the researchers become concerned that information has been disclosed which might result in potential harm to yourself or others, they will need to notify the relevant authority. Wherever possible, this will be discussed with you first.

Canterbury Christ Church University

Salomons Centre for Applied Psychology

Version 2
08.03.2016

What will happen to the results of the research study?

This research will be [redacted] and the university. It will also be stored on university campus, and may be published in a relevant journal.

Who is organising and funding the research?

Canterbury Christ Church University.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South Central-Hampshire B Research Ethics Committee.

Contact details
If you would like to speak to me and find out more about the study or have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line [redacted] ---[redacted] Please say that the message is for me Emily Swannell and leave a contact number so that I can get back to you.

Contact Details of support services
Should you need any further support

[redacted]

Lead Researcher Emily Swannell
Canterbury Christ Church University
Runcie Court
David Salomons Estate
Broomhill Road
Kent
TN3 0TF
Tel: [redacted]

Department of Psychology, Politics and Sociology
Faculty of Social and Applied Sciences

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www.canterbury.ac.uk

Version 2
08.03.2016

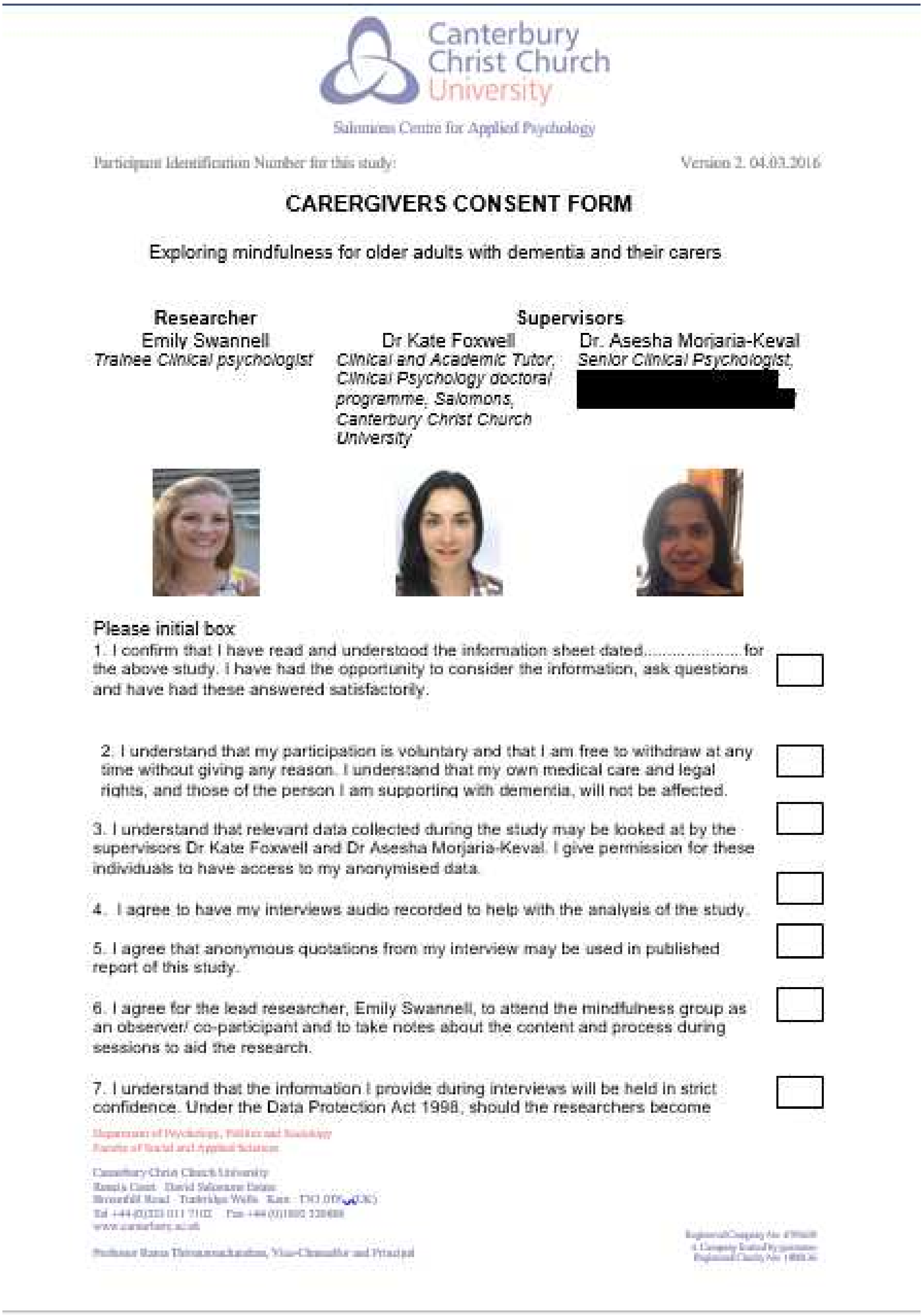
Samaritans
Tel[redacted]
Email: jo@samaritans.org

Alzheimers UK
Tel: [redacted]
[redacted]

Carers UK
Tel: [redacted]. (Monday to Friday, 10am-4pm)
Email: advice@carersuk.org

[redacted]

Consent form



Participant Identification Number for this study:

Version 2. 04.03.2016

CARERGIVERS CONSENT FORM

Exploring mindfulness for older adults with dementia and their carers

Researcher
Emily Swannell
Trainee Clinical psychologist

Supervisors
Dr Kate Foxwell
Clinical and Academic Tutor, Clinical Psychology doctoral programme, Salomons, Canterbury Christ Church University

Dr. Asesha Morjaria-Keval
Senior Clinical Psychologist,
[redacted]

Please initial box

1. I confirm that I have read and understood the information sheet dated.................... for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. I understand that my own medical care and legal rights, and those of the person I am supporting with dementia, will not be affected. ☐

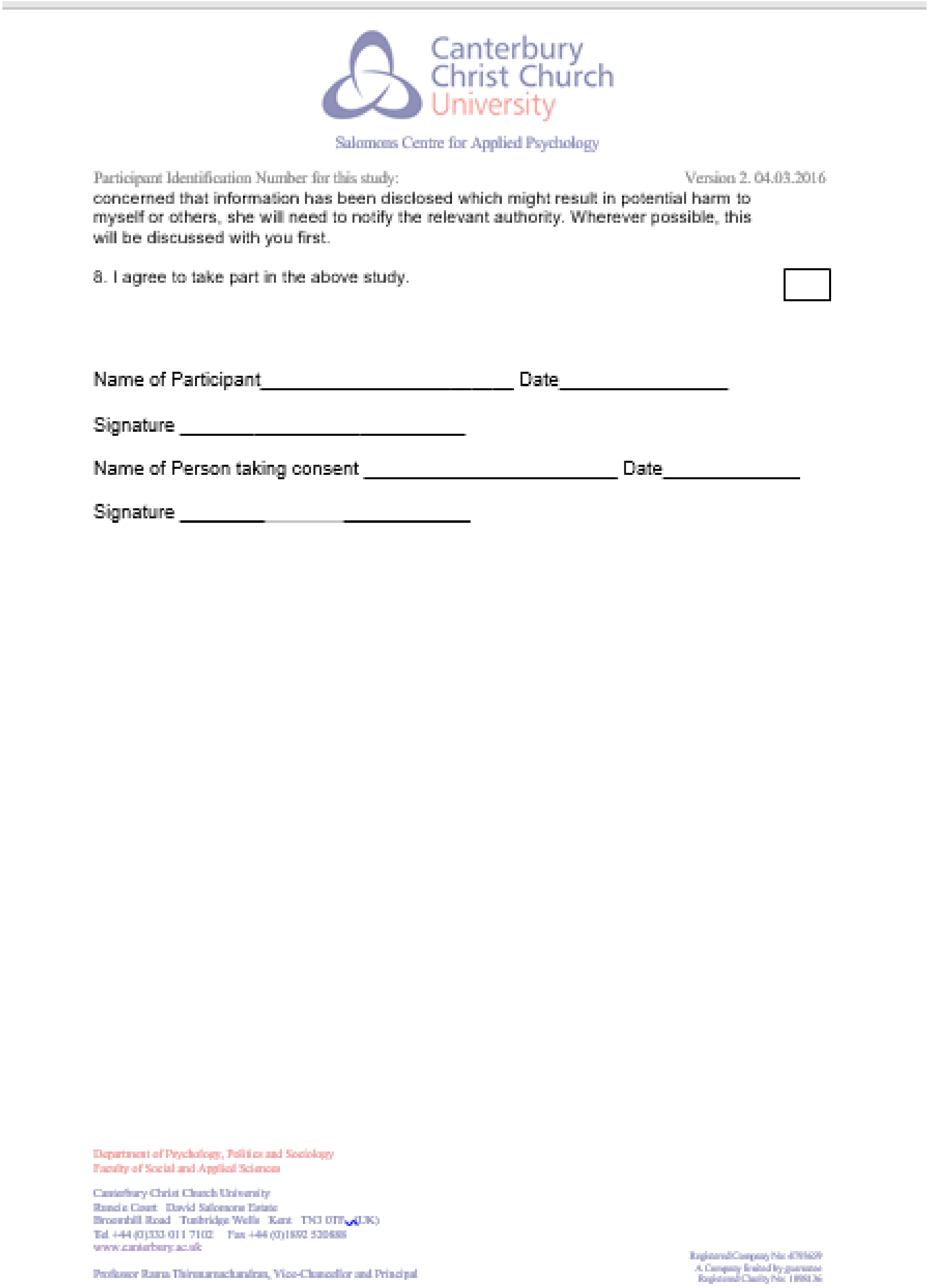
3. I understand that relevant data collected during the study may be looked at by the supervisors Dr Kate Foxwell and Dr Asesha Morjaria-Keval. I give permission for these individuals to have access to my anonymised data. ☐

4. I agree to have my interviews audio recorded to help with the analysis of the study. ☐

5. I agree that anonymous quotations from my interview may be used in published report of this study. ☐

6. I agree for the lead researcher, Emily Swannell, to attend the mindfulness group as an observer/ co-participant and to take notes about the content and process during sessions to aid the research. ☐

7. I understand that the information I provide during interviews will be held in strict confidence. Under the Data Protection Act 1998, should the researchers become ☐



Canterbury Christ Church University

Salomons Centre for Applied Psychology

Participant Identification Number for this study: Version 2. 04.03.2016

concerned that information has been disclosed which might result in potential harm to myself or others, she will need to notify the relevant authority. Wherever possible, this will be discussed with you first.

8. I agree to take part in the above study. ☐

Name of Participant________________________ Date________________

Signature ___________________________

Name of Person taking consent ________________________ Date_____________

Signature ___________________________

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Faculty of Social and Applied Sciences

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Professor Rama Thirunamachandran, Vice-Chancellor and Principal

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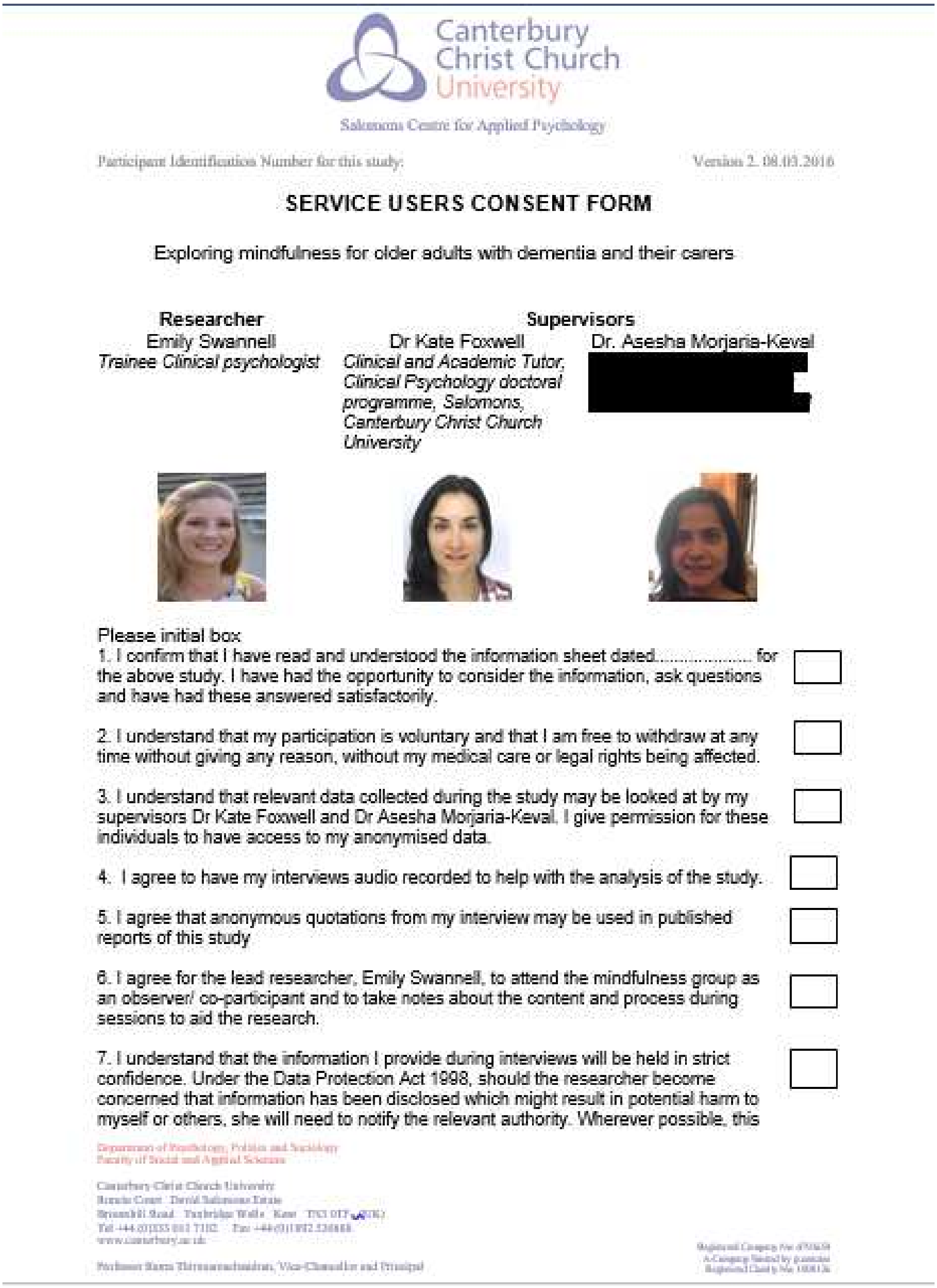
Registered Charity No 1098136



Salomons Centre for Applied Psychology

Participant Identification Number for this study: Version 2. 08.03.2016

SERVICE USERS CONSENT FORM

Exploring mindfulness for older adults with dementia and their carers

Researcher	**Supervisors**	
Emily Swannell	Dr Kate Foxwell	Dr. Asesha Morjaria-Keval
Trainee Clinical psychologist	*Clinical and Academic Tutor, Clinical Psychology doctoral programme, Salomons, Canterbury Christ Church University*	[redacted]

Please initial box

1. I confirm that I have read and understood the information sheet dated................... for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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

3. I understand that relevant data collected during the study may be looked at by my supervisors Dr Kate Foxwell and Dr Asesha Morjaria-Keval. I give permission for these individuals to have access to my anonymised data. ☐

4. I agree to have my interviews audio recorded to help with the analysis of the study. ☐

5. I agree that anonymous quotations from my interview may be used in published reports of this study ☐

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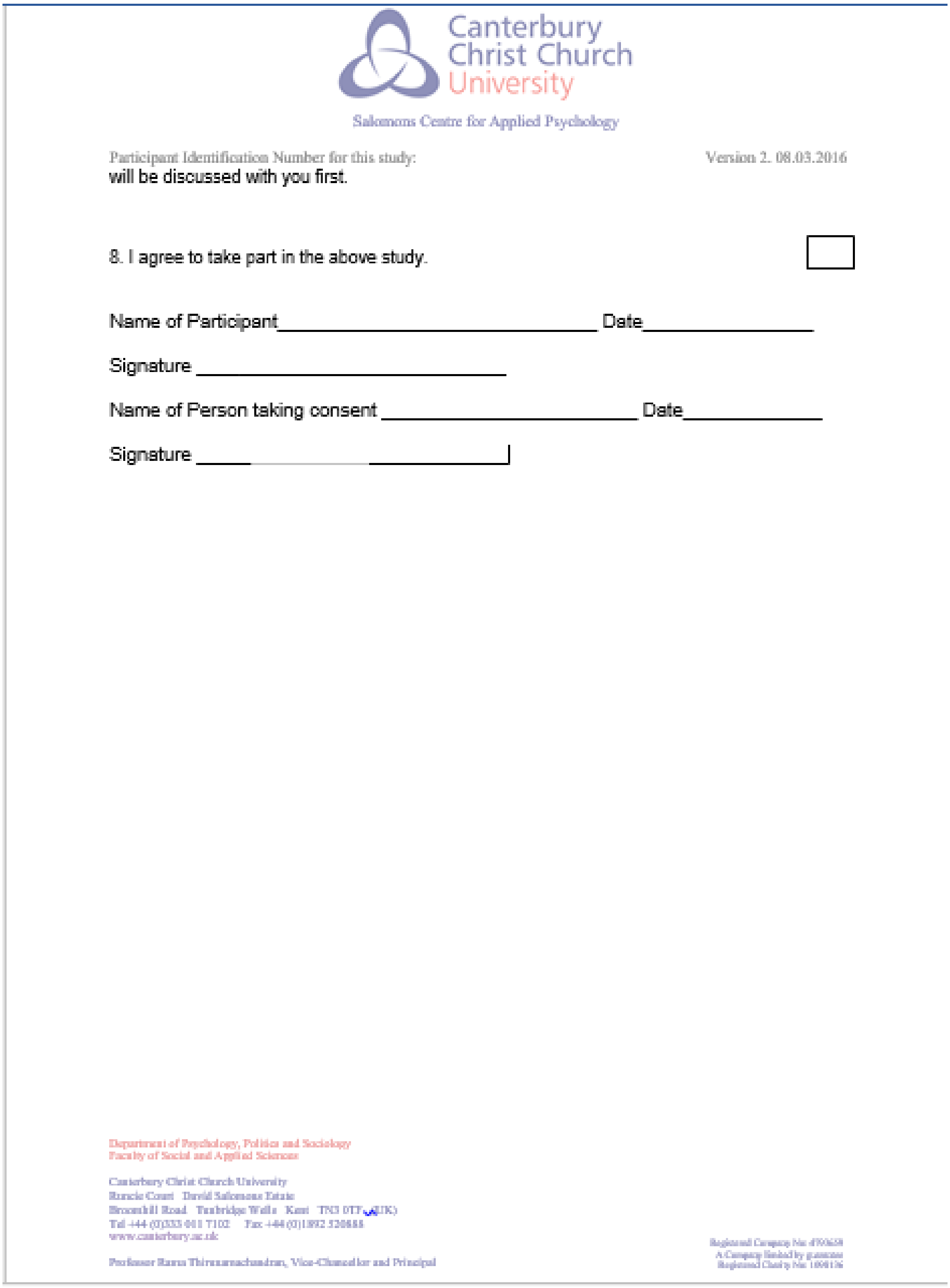

Canterbury Christ Church University

Salomons Centre for Applied Psychology

Participant Identification Number for this study:

Version 2. 08.03.2016

will be discussed with you first.

8. I agree to take part in the above study. ☐

Name of Participant______________________________ Date________________

Signature _____________________________

Name of Person taking consent ________________________ Date_____________

Signature _____________________________

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Faculty of Social and Applied Sciences

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Referral form

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Course Pamphlet

Mindfulness-based Stress Reduction Course

Courses for couples where one person has a diagnosis of dementia and their main carer

INFORMATION LEAFLET

Mindfulness means paying attention in a particular way;
on purpose
in the present moment,
and
non-judgementally

Jon Kabat-Zinn

Clinical Psychology Services
[redacted]

What is Mindfulness-based Stress Reduction?

Mindfulness is concerned with deliberately noticing how you think and feel, rather than about thinking or feeling in a particular way. It can help people who have formed unhelpful patterns of thinking to be less influenced by them.

We do this by practicing together bringing our attention to the present moment using a variety of different methods. In the course, we combine traditional meditation exercises and techniques to help manage stress. These techniques are not difficult, but do require a commitment to practice them regularly in order to benefit from them. Maintaining our attention on the present moment is important as many of us miss out on certain aspects of our lives, lost in worries about the future or regrets about the past.

The course aims to help people to foster a kinder, more compassionate and non-judgemental attitude towards themselves, their thoughts and feelings as we practice together. The idea of this is to help you to be able to choose the most skilful response to any unpleasant thoughts, feelings or situations you might meet.

Who is the course for?

Mindfulness has helped thousands of people across the world. Research has demonstrated that it can help people to cope with chronic pain and physical illness, reduce the likelihood of depression recurring and reduce anxiety.

This course is for people who are receiving treatment and accessing support from the [redacted], have received a diagnosis of dementia recently and want to attend with their main carer. We would meet with both the person with the diagnosis of dementia and their carer who are interested in completing the course prior to it starting to ensure that their problems would not interfere with their ability to participate in a group. Part of the course involves mindful movement adapted to suit a range of physical abilities.

Facing difficulties

The classes and the homework sessions teach you how to be more fully aware and present in each moment of life. This can make life more interesting, vivid and fulfilling. On the other hand, this means facing what is present, even when it is unpleasant and difficult. In practice, you will find that turning to face and acknowledge difficulties is the most effective way, in the long run, to reduce unhappiness. It is also central to preventing further psychological discomfort.

Seeing unpleasant feelings, thoughts, or experiences clearly, as they arise, means that you will be in a much better position to “nip them in the bud,” before they progress to be more intense or persistent. In the classes, you will learn ways to face difficulties and will be supported by the instructor and other team members.

Course information

The course consists of eight sessions, each lasting approximately 90 minutes. It is not what would be traditionally associated with group therapy as we would not sit discussing problems at length. Rather, we practice mindfulness meditation together and spend time reflecting on this experience. We also complete exercises in the whole group or in smaller groups.

This approach depends on your willingness to complete the homework tasks between the weekly meetings. This will take up to 40 minutes per day, six days per week for the eight weeks. It will involve listening to tapes or CDs and performing brief exercises. Rest assured that the course instructors will be completing the homework tasks! We do appreciate that it can be very difficult to find that amount of time, but your commitment to spend the time doing this homework is essential.

The courses are led by Clinical Psychologist [redacted].

If you are interested in finding out more, please contact us.

Note

Research is being conducted alongside this course. Information on the research will be available on the information sheet:

‘Information about the research
Exploring mindfulness for older adults with
dementia and their carers’

Appendix K

Field note example

Appendix L
MBSR session details

Session		**Silent Break 5 mins**		**Home practise assignment**
1 **'Awareness'**	Establish the orientation of the class. Set ground rules and introductions (15 mins) Raisin exercise (5 mins) Feedback and discussion of Raisin Exercise. (10 mins)		Body Scan Practice – starting with a short breath focus (20 mins) Feedback and Discussion of Body Scan. (10 mins) Home practice assignment setting. (5 mins) Discussing in pairs time for home practice, what obstacles may arise and how to deal with them (5 mins) End the session with a short breath focus, 2 minutes on the breath (2 mins)	Body Scan for 6 out of 7 days. Mindfulness of a routine activity. (5 mins)
2 **'Awareness of breath and body'**	Body Scan Practice (20 mins) Practice Review (10mins) Homework Practice Review – identifying difficulty with home practice (10mins)		Awareness of pleasant activities (15 mins) 10-minute sitting meditation. (10mins) Discussion of sitting meditation (5mins) Distribute session 2 participant handouts and discuss home practise (5mins) 2-minute breathing exercise	Body Scan, 6 out of 7 days 10 minutes' mindfulness of the breath, 6 out of 7 days Pleasant Events Calendar (one example daily)
3 **'Observing Limits'**	Seeing or hearing exercise with discussion (5 mins & 5mins) 20-minute sitting meditation (awareness of breath and body; how to respond to intense physical sensations). Practice Review (10mins)		Introduce yoga poses and discussion (15 mins) Awareness of unpleasant experiences (10 minutes) Distribute Session 3 participant handouts. End the session with a short breath focus, 2-3 minutes on the breath	Unpleasant experiences calendar (a different experience each day) Stretch & breath follow with 10-minute sitting meditation Mindfulness of routine activity- choose one activity for the week
4	20-minute sitting		Mindful Walking (10	Sitting Practise (20

Session		**Silent Break 5 mins**		**Home practise assignment**
'Noticing stress'	meditation, awareness of sight, breath, body (end with reading a poem). Practice review and Homework review (15mins)		mins) Enquiry (5 mins) 3-minute breathing space and review (Using hour glass analogy) Distribute Session 4 handouts. Explain stress bucket (15 mins) 2 min ending mindfulness of breath	mins) 3-minute breathing space x3 daily – everyday instructions (morning, noon and night) Stress Bucket Mindful walking (as everyday activity- optional)
5 **'Responding to stress'**	25-minute sitting meditation – awareness of breath and body; sounds and thoughts noticing how we relate to our experiences through the reactions we have to whatever thoughts, feelings, or body sensations arise. Practice review including homework (and stress bucket) (15 mins)		3-minute Breathing space and review (5 mins) A story of wrong perceptions discussion (10mins) Read Rumi's poem, 'The Guest House' and discussion (10mins) 2-minute ending meditation (5 mins)	Sitting practise breath, body, sounds and thoughts (20 mins) 3-minute breathing space 3 x daily and times of unease/stress
6 **Exploring difficulty and Mindful communication**	20-minute sitting meditation – exploring difficulty meditation (20mins) Practice and homework review(15mins)		Breathing space and review (10mins) Mindful communication exercise- 5 minutes each (10mins) Discussion (10mins) 3-minute breathing space & review (5mins) Distribute session 6 handouts and discuss homework practise (5mins) Ending meditation (2mins)	20 minutes of sitting practice (exploring difficulty) Informal practise of awareness of communication 3-minute breathing space every day x 3 daily and at times of unease/stress
7 **'Taking care of yourself'**	20-minute sitting meditation –breath, body, sounds, thoughts then choiceless awareness. Practice review and Home Practice Review (10 mins)		loving and Kindness meditation (20mins) Discussion of practise and idea of taking care of ourselves (15mins) Discussion on self-directed homework (5 mins)	Self-directed practise (20-30 mins) 3 Minute Breathing Space – as needed

Session		**Silent Break 5 mins**		**Home practise assignment**
			3-minute breathing space and review (5mins)	
8 **‘The Rest of your life’**	Body scan practice (30mins) Brief practice review (5mins)		Home practice review (10mins) Review whole course: (10mins) Discuss how best to keep up momentum and discipline etc…(10mins) End the class with a concluding meditation (marble, stone or bead) or with participants wishing each other well. (10mins)	
Follow-up session	Body scan or sitting meditation (20mins) Reflection following meditation (10mins)		What was it like being back in the group? (10mins) Discussion about homework practice (10mins) How to practice in the future – sharing tips and advice from each other (10mins) Mountain meditation-end(10mins)	

Appendix M

Abridged research diary

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Appendix N

Couple C drop out telephone interview

Mary and Paul C telephone interview post course drop out (notes from the telephone conversation)

Both gave consent to have the notes from this conversation included in the research

What were the reasons to not attend the group anymore?
Things got too much, stressed struggling to cope with too much going on, not a good time for me (Mary, caregiver). It started to become a burden, reducing what we were doing helped ease the pressure felt like had to do the course and homework rather than wanted to do it.

Feedback on the course
It was run quite well, easy to follow.
Paul (PWD) Didn't enjoy the body scan, knew it would take a while to do, didn't get any sensations which was strange, just waiting for it to end.

What they found helpful
Found it quite relaxing, made me more aware of my body, things that you take for granted. Breathing was helpful, sometimes I still do it, Nice atmosphere, go with the flow was quite happy with that idea. Liked the breathing ones found it relaxing, it was helpful to become more aware.

Still practising?
When I am uptight I sit, shut my eyes breath and it helps. Sit in the garden look at the water and birds and it is helpful. Will continue to do this.

Would like a copy of the final report? Yes

Appendix O

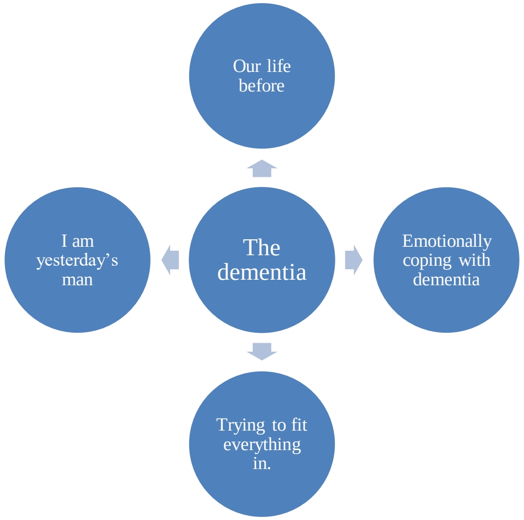
Thematic analysis: themes, codes and descriptions

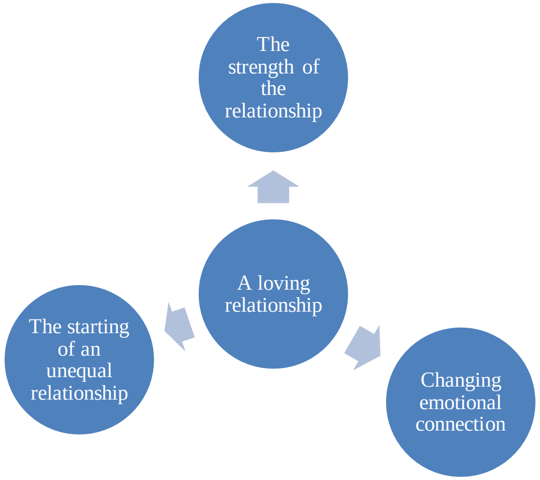
Follow-up interviews thematic analysis, themes, subthemes and descriptions

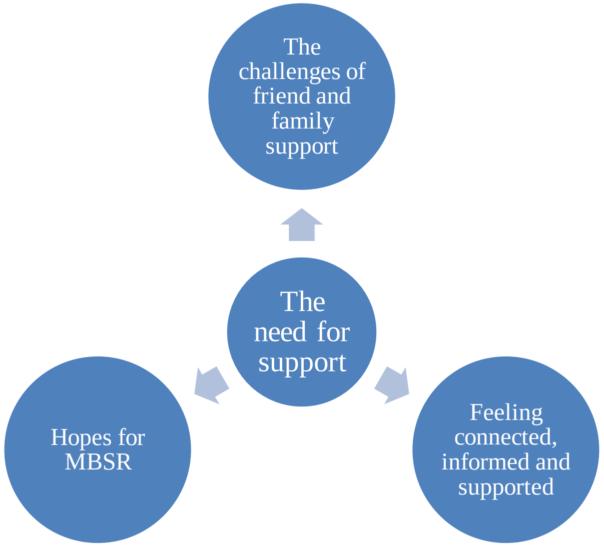
Theme	Sub themes	Sub theme description	Sub theme code examples
Experiences of MBSR	It was just helpful	Overall positive experience and gains reported, but lack of detail given in explaining what aspects where helpful.	‘As I said before, I found it very interesting and very enlightening and useful, very useful’ 'The bits I found most enjoyable where the exercises …'
	A therapeutic space to gain support	The importance of generic therapeutic skills such as empathy and containment of problems gained from the facilitators and other group members.	‘it’s nice to be around people who understand and see it, who know what it’s like, because I don’t think you can ever know what it is like until you see what happens to people’ ‘the most help I got was listening to the other people, there how they were dealing with it, and I could empathise, and them with me’
	Group intervention challenges	Challenges, highlighted the importance of good facilitation, a need to feel safe and welcome, and accommodate all participants needs. Varying views on the course content and session length.	‘just a bit of irritation with not being able to hear well’ ‘feel it was necessary for 3 of them to be there [facilitators] I didn’t think if it had just been xxx on her own I think it would have been better.’
	It’s [MBSR] a benefit, and it’s a tool	Gains included reduction in emotional reactivity, improvements to attention, increased awareness and concentration, for caregivers also an increase in acceptance and less judgemental.	‘and I don’t lose my temper as much, and I don’t get as frustrated as I did when [husband] was first diagnosed’ ’focusing my attention a little more continually on a subject, yes it did help my concentration.’
	MBSR challenges	Challenges included, with motivation, practising with heightened emotions, and difficulty relating or understanding the concepts of mindfulness.	‘if you can’t grasp the concept and what it’s all about there isn’t much point to it.’ ‘found the homework tedious and really had to be motivated to do it, thinking of [Teacher] and her getting cross if we didn’t do it… umm so that I did find difficult to do and to get [husband] to do…’
	A mindful future?	Most participants wanted to continue to meet up and practice with the group. Some reported wanting to continue formal practice, and some to practising informally.	‘yes we are [still practising], but we haven’t got into a routine yet’ ‘To be honest with you no. We stopped practising as soon as the course finished I think’

The dementia journey	Everything else going on	How MBSR interacted with the wider difficulties of coping with dementia alongside other demands, such as health issues family dynamics and role changes.	‘But it is fitting it in with everything else which is going on, you know, [husband] has a couple of appointments and I have the children, it is finding that time, and that’s why it’s nice to go somewhere and actually do it, because you do it [laugh]’ ‘Yeah yeah, as I say it calms me, I can get angry with some of the things which go on in this house between the other two [children]’
	In one ear and out the other	The challenges of the cognitive impairment to participating in MBSR, and the benefit of exploring the impact of dementia with the group.	‘most of the time I was off with the fairies trying to understand but very rarely could’ ‘Umm as I say at first [wife] was in denial about having it, or not denial she was frightened about having it, but she is coming to terms now coming on this course’
	A shrinking social world	The impact dementia has on reducing their social lives and the opportunity attending the course brought to gain back some of this loss.	‘that’s something which I find frustrating with [husband] as he shuts himself away, and that’s why I am glad he has got [CMHTOP] and can go to different groups and talk to people.' ' But as I say, I was looking forward to coming out every week and doing it, as its now finished I dunno [laugh] umm couldn’t answer that as such, feel a bit lost now it has come to an end, even though we have learnt something.'
	Gaining support from others	A need to be able to gain emotional and practical support from others and how the group facilitated this.	‘I have, I have done a lot probably coincidently but I have had a carers assessment, I’ve found out about crossroads yes I have done a lot, I think it was a combination of a lot of things coming together, and other carers saying have you done this that or the other, you know and that’s what’s good about when you meet others ‘
The whole point of this was to do it together wasn’t it?	Coping together or apart	Coping was discussed it was in the context of coping together as a dyad, or apart as individuals. For some the course enabled them cope or support each other together as a dyad.	’ ‘We are helping one another more aren’t we?’ ‘We had to do it together for [wife] to explain it to me so I would understand’
	United in our hatred	From attending the course and completing the practices either together or apart it appeared to have a positive impact on how connected emotionally the dyad felt to the other.	‘I think we have grown closer because, of knowledge and the situation has needed for time and err concern for each other.’' ‘but if we hadn’t of had that 1:1 thing, it wouldn’t have entered my head to ask him, we have got a bit more of an understanding of each other now haven’t we?’
	Maintaining the relationship	The importance of 'doing something together' as a couple and how this helped maintained the relationship.	‘it was something we both could do; we do so little together now’ ‘enjoyment of this was doing it together, a very nice thing.’

Pre-course interviews thematic analysis themes and subthemes







Thematic analysis, themes, subthemes and descriptions

Theme	Sub themes	Sub theme description	Coding examples
The dementia	Emotionally coping with dementia	The varying emotional impact of dementia, becoming more irritated, worrying more and lower moods.	'I am up and down one-minute I can be devastated and then next minute I am fine and I am coping'.
	I am yesterday's man	Due to the dementia, participants experienced multiple losses and the impact this had on their identity.	'The frustrating thing was I look at that car every day and I can't go out and drive it …. I can't even go down the dump, so it's taken away my freedom' 'I use to draw and paint a lot but now it's just not quite right I can't express it sometimes'.
	Trying to fit everything in.	Juggling the demands placed on the caregivers, to take on new roles and caring responsibilities on top of ones already held.	'It's just working around how [Husband] is really yeah so… and being there making sure he can get dressed and you know and things so'.
	Our life before	The positive experience gained from the researcher and participants discussing different times in their lives before the diagnosis.	'He had a very responsible job' 'Well-travelled, you know. Came home every yeah and err yeah various diversions to see the world' 'I was a graduate of a tiny two room school'.
A loving relationship	The strength of the relationship	The importance of the relationship, and maintaining this even when faced with the dementia.	'That's because I love you (laughs) you are my everything you are my right hand to my left' 'I still feel it is the same I mean I try and keep it as normal as possible'.
	Changing emotional connection	The mixed view of some feeling more supportive and tolerant of each other, others missing important emotional connections with the other.	'We don't laugh as much as we use to …. Xxx use to say and do funny things but you don't say as much as you use to' 'We have been nicer to each other [laugh]'.
	The starting of an unequal relationship	The impact of dementia is starting to have on the roles within the relationship, and the difficulty the dyad had with this adjustment.	'It's a very one unbalanced relationship in as much as he always use to do …, was always very active always did cooking, housekeeping gardening, umm book keeping all the household accounts err and now that 'cause the position has reversed I do most of that'.

The need for support	The challenges of friend and family support	The difficulty in being able to gain support from friends and family, with their own demands and challenges, and confronting other people's understanding and biases about dementia.	'But it's difficult because they are so busy everyone is busy nowadays it's just having time really and that's that what people haven't got'.
	Feeling connected, informed and supported	Overall positive experience from formal support, from keeping active, learning about dementia and opportunities to interact with others with dementia.	'COGS cognitive stimulation I had was absolutely fantastic, the group gelled and the lady in charge was so good yes revelation likeminded sufferers and I found it such a good help'.
	Hopes for MBSR	Participants want to attend a supportive group, caregivers hoped to learn techniques to support their role going forward.	'Learning to say in control of my feeling a bit more and stop going on this up and down sort of feeling'.

Appendix P
WHO-5 data

Reliable change index table

	Caregivers		Participants with Dementia	
	pre-post	pre-follow-up	pre-post	pre-follow-up
Summary and Effect Size				
Sample size	4	4	4	4
Pre-treatment mean	44	44	53	53
Pre-treatment SD	13.86	13.86	18.29	18.29
Posttreatment mean	40	42	55	36
Posttreatment SD	20.40	23.21	14.38	10.33
Pre-post Effect Size	-0.29	-0.14	0.11	-0.93
Reliable Change Index				
Standard Error of Measurement	3.10	3.10	4.09	4.09
RCI value	8.59	8.59	11.34	11.34
Number "No change"	2	3	4	3
Number "Deteriorate"	1	1	0	1
Number "Improved"	1	0	0	0

WHO-5 raw total scores for Participants with dementia and caregivers

Participant	Baseline	Session 1 (S1)	S2	S3	S4	S5	S6	S7	S8	Follow-up
Jane A	40	40	40	40		40	40	40	40	48
Anne B	28	40	16	16	16	12	12	12	12	12
Julia D	64	64	48	60	68	60		8	60	68
Pauline E	36	32	44	60	32	44		32	48	40

Participant	Baseline	Session 1 (S1)	S2	S3	S4	S5	S6	S7	S8	Follow-up
Jack A	52	40	28	56		40	20	36	48	32
Robert B	28	44	32	48	44	28	44	52	44	40
Dez D	40	80	64	76	72	72		48	76	24
Charles E	68	48	60		36	52		72	52	48

Paired Samples Statistics (WHO-5) PWD

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	Session 8	55.00	4.00	14.38	7.19
	Session 1	53.00	4.00	18.29	9.15
Pair 2	Follow-up	36.00	4.00	10.33	5.16
	Session 1	53.00	4.00	18.29	9.15

Paired Samples Test (WHO-5) PWD

		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	CI				
					Lower	Upper			
Pair 1	Session 8 - Session 1	2.00	5.16	2.58	-6.22	10.22	0.775	3	0.495
Pair 2	Follow-up - Session 1	-17.00	26.20	13.10	-58.70	24.70	-1.297	3	0.285

Note. CI is 95% Confidence Interval of the Difference

Paired Samples Statistics (WHO-5) Caregivers

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	Session 8	40.00	4.00	20.40	10.20
	Session 1	44.00	4.00	13.86	6.93
Pair 2	Follow-up	42.00	4.00	23.21	11.60
	Session 1	44.00	4.00	13.86	6.93

Paired Samples Test (WHO-5) Caregivers

		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	CI				
					Lower	Upper			
Pair 3	Session 8 - Session 1	-4.00	18.18	9.09	-32.94	24.94	-0.440	3	0.690
Pair 4	Follow-up - Session 1	-2.00	17.44	8.72	-29.74	25.74	-0.229	3	0.833

Note. CI is 95% Confidence Interval of the Difference

Appendix Q
Canterbury Wellbeing Scale (CWS) data

CWS total composite score raw data for participants with dementia and caregivers

Participants	Baseline	Session 1 (S1)	T3	S2	T5	S3	T7	S4	T9	S5	T11	S6	T13	S7	T15	S8	T17	Follow-up
Jane A	325	285		305	305	295	315			275	305	295	335	285	345	315	365	295
Anne B	385	390	420	410	410	430	480	465	460	465	480	385	435	415	455	415	465	405
Julia D	380	425	480	440	390	385	475	395	415	365	445			275	435	445	485	390
Pauline E	365	425	415		415	430	465	425	465	450	465			410	340	460	465	440

Participants	Baseline	Session 1 (S1)	T3	S2	T5	S3	T7	S4	T9	S5	T11	S6	T13	S7	T15	S8	T17	Follow-up
Jack A	370	340		250	220	355	440			365	385	255	335	355	355	385	395	390
Robert B	345	325	275	325		335	315	265	385	380	395	350	395	360	390	365	355	360
Dez D	470	470	465	435	425	415	470	435	445	435	445			425		455	440	405
Charles E	420	430	475		350	460	480	405	460	430	455			395	425	480	500	330

* S1= start of session one

*T3= end of session one

Each 5 item scores for the CWS for Caregivers

Happy/Sad	Baseline	1st session	Final Session	Follow up
Jane A	55	45	55	60
Anne B	85	90	85	75
Julia C	80	100	95	65
Pauline E	55	85	95	85
Total Mean	68.75	80.00	82.50	71.25

Well/Unwell	Baseline	1st session	Final Session	Follow up
Jane A	55	65	65	60
Anne B	95	90	75	85
Julia C	80	75	95	85
Pauline E	55	55	75	65
Total Mean	71.25	71.25	77.50	73.75

Interested/Bored	Baseline	1st session	Final Session	Follow up
Jane A	65	55	65	60
Anne B	95	100	85	95
Julia C	100	100	95	90
Pauline E	85	95	100	100
Total Mean	86.25	87.50	86.25	86.25

Confident/ Not confident	Baseline	1st session	Final Session	Follow up
Jane A	95	65	65	60
Anne B	65	50	85	65
Julia C	60	65	75	65
Pauline E	85	95	95	95
Total Mean	76.25	68.75	80.00	71.25

Optimistic/ Not optimistic	Baseline	1st session	Final Session	Follow up
Jane A	55	55	65	55
Anne B	45	60	85	85
Julia C	60	85	85	85
Pauline E	85	95	95	95
Total Mean	61.25	73.75	82.50	80.00

Each 5 item scores of the CSW for People with dementia

Happy/Sad	Baseline	1st session	Final Session	Follow up
Jack A	90	50	75	60
Robert B	85	55	65	85
Dez D	95	95	95	85
Charles E	80	100	95	100
Total Mean	87.50	75.00	82.50	82.50

Well/Unwell	Baseline	1st session	Final Session	Follow up
Jack A	50	50	75	70
Robert B	45	55	45	50
Dez D	75	85	75	75
Charles E	90	45	95	55
Total Mean	65.00	58.75	72.50	62.50

Interested/Bored	Baseline	1st session	Final Session	Follow up
Jack A	50	80	85	90
Robert B	85	75	85	75
Dez D	100	95	95	95
Charles E	80	95	100	85
Total Mean	78.75	86.25	91.25	86.25

Confident/ Not confident	Baseline	1st session	Final Session	Follow up
Jack A	90	80	75	90
Robert B	65	75	85	75
Dez D	100	95	95	75
Charles E	80	95	95	45
Total Mean	83.75	86.25	87.50	71.25

Optimistic/ Not optimistic	Baseline	1st session	Final Session	Follow up
Jack A	90	80	75	80
Robert B	65	65	85	75
Dez D	100	100	95	75
Charles E	90	95	95	45
Total Mean	86.25	85.00	87.50	68.75

Paired Samples Statistics (CWS) PWD

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	Session 8, pre	421.25	4.00	54.98	27.49
	Session 1, pre	391.25	4.00	70.04	35.02
Pair 2	Follow-up	371.25	4.00	33.26	16.63
	Session 1, pre	391.25	4.00	70.04	35.02
Pair 3	Session 1, post	405.00	3.00	112.69	65.06
	Session 1, pre	408.33	3.00	74.89	43.24
Pair 4	Session 2, post	322.50	2.00	144.96	102.50
	Session 2, pre	342.50	2.00	130.81	92.50
Pair 5	Session 3, post	426.25	4.00	76.09	38.04
	Session 3, pre	391.25	4.00	57.06	28.53
Pair 6	Session 4, post	430.00	3.00	39.69	22.91
	Session 4, pre	368.33	3.00	90.74	52.39
Pair 7	Session 5, post	420.00	4.00	35.12	17.56
	Session 5, pre	402.50	4.00	35.24	17.62
Pair 8	Session 6, post	365.00	2.00	42.43	30.00
	Session 6, pre	302.50	2.00	67.18	47.50
Pair 9	Session 7, post	390.00	3.00	35.00	20.21
	Session 7, pre	370.00	3.00	21.79	12.58
Pair 10	Session 8, post	422.50	4.00	62.25	31.12
	Session 8, pre	421.25	4.00	54.98	27.49

Paired Samples Test (CWS) PWD

		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	CI				
					Lower	Upper			
Pair 1	Session 8, pre - Session 1, pre	30.00	30.28	15.14	-18.18	78.18	1.982	3	0.142
Pair 2	Follow-up - Session 1, pre	-20.00	73.82	36.91	-137.47	97.47	-0.542	3	0.626
Pair 3	Session1, post - Session1, pre	-3.33	47.52	27.44	-121.38	114.72	-0.121	2	0.914
Pair 4	Session2, post - Session2, pre	-20.00	14.14	10.00	-147.06	107.06	-2.000	1	0.295
Pair 5	Session3, post - Session3, pre	35.00	45.28	22.64	-37.05	107.05	1.546	3	0.220
Pair 6	Session4, post - Session4, pre	61.67	55.30	31.93	-75.71	199.04	1.931	2	0.193
Pair 7	Session5, post - Session5, pre	17.50	6.45	3.23	7.23	27.77	5.422	3	0.012
Pair 8	Session6, post - Session6, pre	62.50	24.75	17.50	-159.86	284.86	3.571	1	0.174
Pair 9	Session7, post - Session7, pre	20.00	17.32	10.00	-23.03	63.03	2.000	2	0.184
Pair 10	Session8, post - Session8, pre	1.25	16.52	8.26	-25.04	27.54	0.151	3	0.889

Note. CI is 95% Confidence Interval of the Difference

Paired Samples Statistics (CWS) Caregivers

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	Session 8, pre	408.75	4.00	65.24	32.62
	Session 1, pre	381.25	4.00	66.25	33.13
Pair 2	Follow-up	382.50	4.00	61.98	30.99
	Session 1, pre	381.25	4.00	66.25	33.13
Pair 3	Session 1, post	438.33	3.00	36.17	20.88
	Session 1, pre	413.33	3.00	20.21	11.67
Pair 4	Session 2, post	368.33	3.00	55.75	32.19
	Session 2, pre	385.00	3.00	70.89	40.93
Pair 5	Session 3, post	433.75	4.00	79.41	39.71
	Session 3, pre	385.00	4.00	63.64	31.82
Pair 6	Session 4, post	446.67	3.00	27.54	15.90
	Session 4, pre	428.33	3.00	35.12	20.28
Pair 7	Session 5, post	423.75	4.00	80.45	40.23
	Session 5, pre	388.75	4.00	87.69	43.85
Pair 8	Session 6, post	385.00	2.00	70.71	50.00
	Session 6, pre	340.00	2.00	63.64	45.00
Pair 9	Session 7, post	393.75	4.00	59.77	29.89
	Session 7, pre	346.25	4.00	76.63	38.32
Pair 10	Session 8, post	445.00	4.00	54.16	27.08
	Session 8, pre	408.75	4.00	65.24	32.62

Paired Samples Test (CWS)Caregivers

		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	CI				
					Lower	Upper			
Pair 1	Session 8, pre - Session 1, pre	27.50	6.45	3.23	17.23	37.77	8.521	3	0.003
Pair 2	Follow-up - Session 1, pre	1.25	24.28	12.14	-37.39	39.89	0.103	3	0.924
Pair 5	Session 1, post - Session 1, pre	25.00	32.79	18.93	-56.45	106.45	1.321	2	0.317
Pair 6	Session 2, post - Session 2, pre	-16.67	28.87	16.67	-88.38	55.04	-1.000	2	0.423
Pair 7	Session 3, post - Session 3, pre	48.75	30.10	15.05	0.85	96.65	3.239	3	0.048
Pair 8	Session 4, post - Session 4, pre	18.33	22.55	13.02	-37.67	74.34	1.408	2	0.294
Pair 9	Session 5, post - Session 5, pre	35.00	30.82	15.41	-14.04	84.04	2.271	3	0.108
Pair 10	Session 6, post - Session 6, pre	45.00	7.07	5.00	-18.53	108.53	9.000	1	0.070
Pair 11	Session 7, post - Session 7, pre	47.50	94.30	47.15	-102.55	197.55	1.007	3	0.388
Pair 12	Session 8, post - Session 8, pre	36.25	21.36	10.68	2.26	70.24	3.394	3	0.043

Note. CI is 95% Confidence Interval of the Difference

Appendix R

Section of transcript with codes identified

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Appendix S
HRA end of study letter
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Summary for ethics panel and R&D committee

Exploring the experiences of people with dementia and their family caregivers completing a MBSR intervention using a multiple case study

Background: Estimates suggest over 850,000 people (7.1% of over 65s) have dementia in the UK. Due to an ageing population, this is forecast to exceed one million by 2025, and two million by 2051 (Alzheimer's Society, 2014). Evidence highlights the need to support people with dementia and their family caregivers together as a dyad and mindfulness has been suggested as one intervention.

Aim: This research aimed to explore dyads experiences of attending an adapted eight-week Mindfulness Based Stress Reduction MBSR intervention (Kabat Zinn, 2003).

Method: Five married couples were recruited from three Community Mental Health Service for Older People (CMHSOP) in the South East of England. The design was a mixed method multiple case study pre- and post-measure design with follow-up (Yin, 2014). Data was collected using self-report standardised measures, group observations and semi-structured interviews. Data collection time points included; three weeks before the intervention (self-report wellbeing and mindfulness measures and interviews) Time series data of wellbeing measures was collected during the intervention. Four weeks post-intervention follow-up all self-report measures and semi-structured interviews. Measures included The Canterbury Wellbeing Scale (Johnson, Culverwell, Hulbert, Robertson & Camic, 2017), which looks to assess in the moment subjective wellbeing in people with dementia and their caregivers, the WHO-5 (WHO, 1998) and The Five Facets Mindfulness questionnaire- short form (FFMQ- SF, Bohlmeijer, ten Klooster, Fledderus, Veehof, & Baer, 2011).

Results: Four of the five couples completed the course and attended the follow-up interviews. Thematic analysis and descriptive statistics analysed the data. The main findings from self-report measures of wellbeing, found no clear patterns of improvements or deteriorations from the time series data or pre-intervention to post-intervention, for both caregivers and participants with dementia.

The majority of the changes found post-intervention were not maintained at follow-up. Clear patterns of improvements to wellbeing were found pre-session to post-session on CWS (Johnson et al., 2017) for all participants, indicating that wellbeing improved during each session.

The FFMQ-SF (Bohlmeijer et al., 2011) showed a mixed picture for all participants, with no overall clear increases or decreases in mindfulness scores for the five facets.

Thematic analysis of follow-up interviews found a broad range of ways the MBSR course was experienced by participants, highlighting generic therapeutic benefits, improvements to the dyads relationship and varying ways the mindfulness techniques benefitted participants.

Recommendations: When considering MBSR in clinical settings over other dyad interventions or generic support groups, further research is needed before being recommended. However, due to the multiple and complex ways this intervention has been shown to support participants, it could be argued MBI may have more benefits than more targeted interventions. Further research using larger samples with active control groups is needed to gain more robust findings on the benefits of mindfulness for people with dementia and their caregivers.

Next steps: The full research report will be made available on the university thesis database. Participants were all given a summary of the main findings and a copy of the full report. The research is also aimed to be published within a peer review journal such as Dementia Journal published by SAGE.

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Appendix T
Author guideline notes for chosen journal

Dementia Journal

Sage Publishing

Details below available from https://uk.sagepub.com/en-gb/eur/journal/dementia#HOWTOSUBMITYOURMANUSCRIPT

Dementia publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

1. Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

1.1 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2. Article types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words.

Appendix U
End of study report for participants

Canterbury Christ Church University
Salomons Centre for Applied Psychology

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** Draft to be sent out once MRP viva is completed***

Dear xxxx

I am writing to you as the research you took part in has come to an end. This research aimed to explore the experiences of people with dementia and their main family caregiver attending a mindfulness course.

I wanted to thank you both for giving up your time to take part in this research. Thank you for not only attending the course and interviews but also completing all the questionnaires. All your feedback has been so valuable in this research.

Please see attached a brief summary of the research and the full report. This full report was submitted into the university and will be made available on the university thesis database. The next step is to get this research published in a journal. This will enable other researchers to benefit from these findings and to continue to research interventions to support people with dementia and their families.

It was a pleasure to meet you both and I wish you all the best for the future.

Kind regards

Emily Swannell
Trainee Clinical Psychologist
Salomons Centre of Applied Psychology
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Exploring the experiences of people with dementia and their family caregivers completing a MBSR course

Summary of the Study

There are estimated to be over 850,000 people with dementia in the UK. This is expected to rise to over one million by 2025 (Alzheimer's Society, 2014). Most people with dementia are supported by their families (Alzheimer's UK, 2014). Although people with dementia can live well, their wellbeing can often be overlooked. Caregivers wellbeing, and their experience of caregiver burden can also be overlooked. The Department of Health (DoH) developed guidelines highlighting the need to develop better services for people with dementia and their families (2009; 2012; 2015). It is important to conduct research to find different effective ways of supporting the wellbeing of people with dementia and their families.

Aim of the research

This research explored the experiences of four couples living with dementia attending a MBSR (mindfulness) intervention. It aimed to find out how participants experienced the course. To find out what participants found helpful, and unhelpful about the course. Finally, to see if the course had any impact on their wellbeing, their relationships and feelings about having a diagnosis of dementia or feelings about being a caregiver.

What we did

Participants attended a pre-course interview; this aimed to find out about the participants' experiences of dementia so far and their expectations for the course. Participants then attended the eight week MBSR course, the researcher also attended as an observer. Finally, participants attended a follow-up meeting and follow-up interview. At every step participants also completed questionnaires either about their wellbeing or about mindfulness.

Findings

The results from the questionnaires did not find any increase or decrease in wellbeing or mindfulness during the course or after the course for most participants. We did however find that wellbeing for most participants increased during each session. So, people had higher wellbeing after the sessions than the beginning.

Results from the follow-up interviews found that participants found attending a therapeutic course helpful, especially the aspect of socialising with people with similar difficulties. Participants noticed different types of changes and improvements to their relationship. Finally, participants found the mindfulness techniques benefitted them in different ways from helping with emotions and relaxation, to helping them to be more aware of their surroundings. Participants also talked about the difficulty of practising mindfulness due to different things including remembering to practice, understanding the concepts of mindfulness, or having other demand which take priority.

Conclusions and next steps for research

More research is needed before recommending mindfulness courses as a helpful intervention for people with dementia and caregivers in Older People Mental Health Services. This research will need to involve more participants so that we can find more robust evidence that mindfulness will be helpful over other interventions such as generic support groups.

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