

THE UNIVERSITY OF HULL

**Mindfulness and Meditation Interventions in Dementia: Experiences,  
Adaptations and Effects on Well-being**

Being a Thesis submitted in partial fulfilment of the requirements for the  
degree of Doctor of Clinical Psychology  
in the University of Hull

by Jennifer Adams, BSc (Hons) Psychology, University of York

June 2018

## **Acknowledgements**

Firstly, I would like to thank the participants who took part in this research, for giving up their time across a whole summer. It has been a privilege to have shared in your experiences and to see how the research has benefitted you. I wish you all the very best in your futures.

To Susie and Alison, you have shown an incredible level of dedication, time, expertise and willingness over these past two years. It certainly would not have been possible to have carried out this research without the two of you. You went above and beyond, and I am truly grateful. I would also like to thank Jill, for stepping in and co-facilitating one week, and Stuart and Annette, for volunteering your time and energy to support the group. Also, thank you to the York Common Good Trust for providing us with the additional funding which made this course happen.

I would like to thank Dr Chris Clarke and Dr Emma Wolverson, my thesis supervisors. Your expertise and knowledge in this area and research generally have been inspiring and your encouragement has spurred me on each step of the way. Thank you for providing me with motivation and guidance throughout.

To my wonderful partner Anthony, for your unending patience and belief in my abilities, and for putting my needs first by giving me the space I needed to complete this piece of work. I would also like to thank my fellow trainees and friends, both for their collective support, but particularly to Jade, for keeping me balanced and reminding me of the importance of down-time, and to Lucy, for always being a step ahead, and your support with the research and write-up.

I would finally like to thank my mum for giving me so many experiences of care and acceptance throughout my life, not only towards myself, but towards others. These experiences have shaped the person and professional that I have become.

## **Overview**

This portfolio thesis consists of three parts: a systematic literature review, an empirical paper and a set of appendices. The thesis as a whole considers the effects of meditation-based interventions for people living with dementia and age-related cognitive impairments, and their caregiver on wellbeing, including their experiences of meditation-based interventions and appropriate adaptations to these interventions.

The first section is a systematic literature review that explores the domains of wellbeing which have been targeted and measured in studies of meditation-based interventions for people living with dementia and mild and subjective cognitive impairment, and the effects of these interventions. The review also considers the methodological quality of the evidence in this area. Fourteen papers were identified and synthesised using a narrative approach. The findings are discussed within the context of previous literature relating to meditation interventions for people living with dementia and age-related cognitive impairments. The clinical and research implications for these findings are also considered.

The second section is an empirical study that explores how dementia dyads experience and engage with an adapted mindfulness-based intervention and what the impact of this is on subjective wellbeing. The research used a qualitative method, gathering data using a Grounded Theory approach, which due to not meeting data saturation was analysed using Thematic Analysis. Four superordinate and 11 subordinate themes emerged from the data. The results of this analysis are discussed in the context of previous literature relating to mindfulness-based interventions for people living with dementia and their caregivers, previous adaptations, the impact of these interventions on dyadic wellbeing

and dyadic conceptualisations of mindfulness. The clinical and research implications for these findings are also discussed.

The third section consists of a set of appendices which relate to the systematic literature review and empirical paper. Within these appendices are a reflective and epistemological statement, which includes the primary researcher's reflections on the journey of these pieces of research, and the philosophical position and underlying assumptions of the research.

**Total Word Count: 36, 013** (including tables, appendices and references)

## Table of Contents

Acknowledgements.....	1
Overview.....	3
List of Tables.....	8
List of Figures.....	8
<b>Part One: Systematic Literature Review.....</b>	<b>9</b>
Abstract.....	11
Introduction.....	13
Method.....	16
Search Protocol.....	16
Inclusion and Exclusion Criteria.....	17
Data Extraction.....	18
Quality Assessment.....	18
Data Analysis.....	19
Results.....	20
Characteristics of Included Studies.....	21
Quality of Included Studies.....	25
Meditation-based Intervention for People Living with Dementia.....	25
Meditation-based Interventions for People Living with Mild Cognitive Impairment (MCI) .....	28
Meditation-based Interventions for People Living with Subjective Cognitive Impairment (SCI) .....	30
Meditation-based Interventions for Mixed Samples.....	33
Discussion.....	36
Strengths and Limitations.....	39
Implications for Research and Practice.....	40
Conclusions.....	40
Disclosure of Interest.....	41
References.....	42
<b>Part Two: Empirical Paper.....</b>	<b>53</b>
Abstract.....	5
Introduction.....	53
Method.....	57
Sample.....	57

Design & Data Collection.....	59
Procedure.....	60
Facilitators.....	60
Materials and Measures.....	61
Introductory Session/Focus Group.....	61
Intervention.....	61
Dyad Interviews.....	62
Analysis.....	62
Results.....	63
Theme One: Making Sense of Mindfulness.....	66
Theme Two: Impact on Wellbeing.....	71
Theme Three: Group Processes.....	74
Theme Four: Essentials of Mindfulness for Dementia Dyads.....	76
Discussion.....	82
Summary of Findings.....	82
Strengths and Limitations.....	85
Clinical Implications and Future Research.....	87
Conclusions.....	88
Declaration of Conflicting Interests.....	88
Acknowledgements.....	88
Funding.....	88
Description of Author’s Roles.....	88
References.....	89
<b>Part Three: Appendices.....</b>	<b>94</b>
Appendix A: Instruction for Contributors to the Journal Aging & Mental Health.....	95
Appendix B: Data Extraction Tool.....	107
Appendix C: Adapted Quality Assessment Tool & Description of Process....	108
Appendix D: Summary Table of Quality Assessment Scores for Included Studies.....	111
Appendix E: Instructions for Contributors to the Journal Dementia.....	113
Appendix F: Participant Demographic Questionnaire.....	126
Appendix G: Participant Information Sheet.....	127
Appendix H : Participant Consent Form.....	134
Appendix I : Documentation of Ethical Approval .....	132

Appendix J: Recruitment Poster.....	134
Appendix K: Sources of Support Handout.....	140
Appendix L: Focus Group Schedule.....	141
Appendix M: Focus Group Handouts for Participants.....	142
Appendix N: Example of Weekly Measures Handout.....	143
Appendix O: Example Email to Participants Before Each Session .....	144
Appendix P: Dyad Post-Course Interview Schedule.....	145
Appendix Q: Dyad Follow-up Interview Schedule.....	146
Appendix R: Facilitators Interview Schedule.....	147
Appendix S: Overview of Intervention Session Content .....	148
Appendix T: Adapted Supplementary Material Example.....	152
Appendix U: Adaptations to Intervention List.....	154
Appendix V: Data Analysis Example & Supporting Quotes for Themes.....	155
Appendix W: Development of Themes.....	169
Appendix X: Reflective Statement.....	172
Appendix Y: Epistemological Statement.....	177

## **List of Tables**

**Table 1.** Inclusion and exclusion criteria for studies in review.

**Table 2.** Characteristics of included studies in review.

**Table 3.** Inclusion and exclusion criteria for empirical study.

**Table 4.** Characteristics of participants recruited to empirical study

**Table 5.** Process of thematic analysis.

**Table 6.** Summary of superordinate themes, subordinate themes and illustrative quotes.

## **List of Figures**

**Figure 1.** Flowchart to illustrate the process of selection

## **Part One: Systematic Literature Review**

**Wellbeing and Adaptations in Meditation-based Interventions for People Living  
with Dementia and Age-associated Cognitive Impairments: A Systematic  
Literature Review and Narrative Synthesis**

Jennifer Adams\*, Dr Chris Clarke and Dr Emma Wolverson

School of Health and Social Work  
University of Hull, Hull, United Kingdom, HU6 7RX

\*Corresponding Author: Tel +7794154253

Email Address: [J.Adams@2015.hull.ac.uk](mailto:J.Adams@2015.hull.ac.uk)

This paper is written in the format reading for submission to the journal *Aging & Mental  
Health*. Please see Appendix A for the Guidelines for Authors

This research received no specific grant from any funding agency in the public,  
commercial, or not-for-profit sectors.

Word Count: 5,851 (excluding references and tables)

## **Abstract**

### ***Objectives***

Meditation-based interventions are known to improve wellbeing. Research has highlighted the negative relationship between living with dementia and wellbeing, but little is known about the impact on wellbeing of these interventions for this group, or how they ought to be adapted. The aims of this review were to identify what domains of wellbeing have been measured in studies of meditation-based interventions for people living with dementia, and mild and subjective cognitive impairments, and their effects on wellbeing.

### ***Method***

A systematic search of the literature was conducted using the electronic databases: PsycINFO, MEDLINE, CINAHL Complete, Web of Science and EThOS. Fourteen studies were identified and synthesised using a narrative approach.

### ***Results***

The review suggests positive trends in wellbeing from pre-post intervention, with some significant findings. Qualitative findings were generally positive. Commonly measured wellbeing domains included quality of life, anxiety, depression and mood, although the measures used lacked consistency. Common adaptations, particularly for people living with dementia, included shorter practices, sessions and day retreats, increased sessions and repetition, using adapted materials and involving caregivers.

### ***Conclusions***

Meditation-based interventions have a positive impact on the wellbeing of people living with dementia, and mild and subjective cognitive impairments. Future research might

utilise larger samples, more qualitative data collection, standardised measures and explore other meditation types.

**Key words:** Meditation, dementia, cognitive impairment, wellbeing

## Introduction

Recent years have seen the development of a number of meditation-based clinical interventions (MBIs) that show evidence of effectiveness with respect to a wide range of clinical outcomes (see Baer, 2006; Chiesa & Serretti, 2009; Hofmann, Sawyer, Witt & Diana, 2010). Mindfulness-based Stress Reduction (MBSR; Kabat-Zinn, 1990) and Mindfulness-based Cognitive Therapy (MBCT; Teasdale, Segal, Williams, Ridgeway, Soulsby & Lau, 2000) are among the most ubiquitously delivered and researched MBIs but relatively little is currently known about their impact on wellbeing and quality of life (QoL) in dementia, or which factors might influence their effectiveness and how they ought to be adapted.

Interventions have often focused on preventing cognitive decline in people living with dementia (PLwD), such as cognitive stimulation therapy (Spector, Thorgrimsen, Woods & Orrell, 2006), overshadowing the need for interventions which target wellbeing more broadly. ‘Living well with dementia’ has become a practice and policy priority in dementia care (e.g. Department of Health, 2009), suggesting a societal shift away from negative discourses, towards a focus on retained strengths and subjective wellbeing. At present there is little consensus as to what living well with dementia entails. Global definitions of wellbeing include ‘the state of being comfortable, healthy, or happy’ (Stevenson & Soanes, 2008, p.1698) and ‘how people feel and how they function, both on a personal and societal level, and how they evaluate their lives as a whole’ (New Economics Foundation, 2012, p. 6). One model of wellbeing in dementia developed by Kaufmann and Engel (2016) involves a conceptual framework based on Kitwood’s (1997) model of psychological needs and wellbeing in dementia, centred on personhood. Kitwood (1997) identified five domains of subjective wellbeing in dementia care including *comfort, inclusion, identity, occupation and attachment*, with

Kaufmann and Engel providing further evidence for the model and including *agency* as a sixth domain. The domains consist of 30 components, suggesting wellbeing for PLwD is both diverse and individual. These findings are consistent with broader models of wellbeing within positive psychology, such as the PERMA model (Seligman, 2011) which categorises psychological wellbeing within five domains: *positive emotions, engagement, relationships, meaning and accomplishment*.

The empowerment of PLwD has become a prominent feature in dementia care, with reference to including PLwD in decisions about their own care and the development of dementia services and dementia-focused research (DoH, 2009; Dementia Action Alliance, 2018). Kaufmann & Engel's addition to Kitwood's aforementioned framework highlights the importance of *agency*, which involves self-determination, freedom of action and independence. This suggests it is imperative to include PLwD in all aspects of wellbeing interventions, and for practitioners to understand which adaptations are appropriate for people with cognitive impairments.

Current interventions are often targeted towards PLwD alone and typically include reminiscence therapy (Cotelli, Manenti & Zanetti, 2012), cognitive training, physical exercise and music (Vernooij-Dassen, Vasse, Zuidema, Cohen-Mansfield & Moyle, 2010). Psychological interventions generally and MBI's in particular have received relatively less research attention but a significant body of research has emerged in recent years which documents the effectiveness of MBIs for dementia caregivers (for a review see Kor, Chien, Liu & Lai, 2017) which is noteworthy given the increasing recognised notion that the wellbeing of carers and PLwD is inter-dependent.

A considerable body of evidence has highlighted the negative relationship between living with dementia and wellbeing (e.g. Wilson, Boyle, Segawa, Begency, Anagnos & Benett, 2013). Existing evidence indicates that both Subjective Cognitive Impairment (SCI) and Mild Cognitive Impairment (MCI) can be predictors of progression to dementia and also have a detrimental impact on wellbeing (Reisberg & Gauthier, 2008). Annually, 7-10% of individuals with SCI convert to a MCI or dementia diagnosis (Innes & Selfe, 2014), and more than 50% of individuals with MCI receive a diagnosis of dementia within five years (Gauthier et al., 2006). These conversion rates suggest a clear trajectory of cognitive deterioration for some individuals with cognitive impairments, and therefore a window in which early psycho-social intervention may be appropriate.

Previous reviews in this area have highlighted the effectiveness of specific MBIs for certain groups (e.g. Robertson, 2015), whereas others have focused on cognitive rehabilitation and underlying physiological mechanisms (e.g. Innes & Selfe, 2014). To the best of the authors' knowledge, no review to date has attempted to compare, synthesise and evaluate research that has investigated the wellbeing effects of MBIs for people living with dementia, MCI and SCI in order to take a trajectory approach. As such, this review sought to answer the following questions:

1. What domains of wellbeing have been targeted and measured in studies of MBIs in dementia/MCI/SCI to date?
2. What effects on particular domains of wellbeing do MBIs have in dementia/MCI/SCI and what is the current methodological quality of the evidence in this area?

## **Method**

### ***Search Protocol***

The primary researcher conducted a systematic search in February 2018, across four electronic databases: PsycINFO, MEDLINE, CINAHL Complete and Web of Science, due to their relevance to psychology, dementia and MBIs. To extend the inclusiveness of this review, further searches were run on the EThOS database to explore appropriate unpublished theses (see Figure 1). The included studies were also searched by hand for further appropriate literature.

The following terms were searched for in the text of articles. They were included to identify literature that has explored the use of any meditation based interventions for people living with dementia or cognitive impairment:

*mindfulness* OR *MBSR* OR *MBCT* OR *MBI* OR *third wave* OR *meditation*  
AND *memory* OR *mild cognitive impairment* OR *dementia* OR *Alzheimer's*.

In addition, the search terms *meditation* OR *mindfulness* AND *dementia* were used on the EThOS database. The filter 'journal articles' was applied to the searches.

## ***Inclusion and Exclusion Criteria***

Table 1 shows the inclusion and exclusion criteria for studies in the review.

Table 1. *Inclusion and exclusion criteria for studies in review.*

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Studies involving a meditation-based intervention, defined as those which focus on meditative practices e.g. MBSR, MBCT, Kirtan Kriya	Participants in the intervention did not include person living with cognitive impairment or dementia (e.g. staff/caregivers only)
Participants of the studies had subjective or mild cognitive impairment, dementia (self-reported or diagnosed) or encompass multiple groups of these	Studies measured cognitive change without measuring wellbeing directly
Studies have measured wellbeing directly via self-report as a primary or secondary outcome. Wellbeing was operationalised broadly in terms of the presence of positive affect, life satisfaction or quality of life and/or the relative absence of stress, anxiety and depression.	Studies where the participants had cognitive impairment explicitly linked to other diagnosable health issues (e.g. cancer)
	Reviews or discussion papers
	Conceptual papers i.e. a future intervention is outlined but results have not yet been published

## Data Extraction

A data extraction form (Appendix B) was used by the lead author to identify the salient points from each study in relation to the aims of the review.

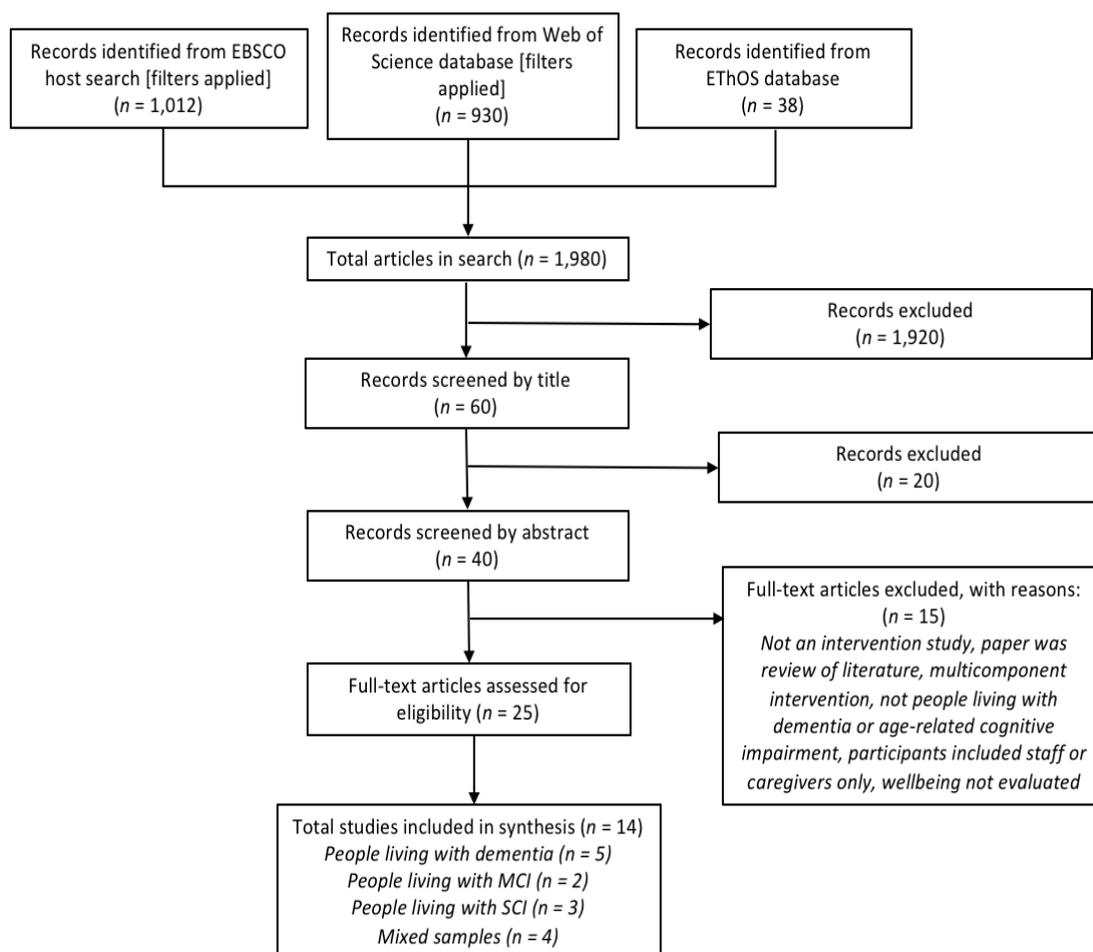


Figure 1. Flowchart to illustrate the process of selection.

## Quality Assessment

A key element to a systematic literature review is the inclusion of a quality assessment of the literature in order for the reader to assess both reliability and validity of the body of literature (Parahoo, 2006). For the purpose of this review, a bespoke checklist (see Appendix C) was developed by the lead author, combining questions from the Downs and Black (1998) quantitative quality checklist, the Mixed Methods Assessment Tool

(MMAT; Pluye et al., 2011) and one of the authors own questions designed to address issues of quality in relation to the acknowledgement of limitations (see Appendix C). This tool encompassed the multiple designs and methodological approaches across the studies. Questions 1-8 applied to all studies, whereas question 9-11 involved specific criteria depending on study design, which was appropriate as the studies in the review were quantitative, quantitative with informal exit interviews/questionnaires, or mixed methods. Studies were not excluded from this review based on checklist scores, rather methodological quality was integrated into the final synthesis.

The lead author conducted the quality scoring. A second impartial rater also scored five studies using the checklist. Discrepancies between scores were considered and the lead author re-scored studies as necessary.

### ***Data Analysis***

Studies included in the review varied in design, measurements of wellbeing and methods of analysis which meant a meta-analysis was not appropriate. Therefore, a narrative synthesis was used to develop a preliminary synthesis of the studies' findings, relationships in the data and methodological robustness (Popay et al., 2006). Narrative syntheses are used to answer a range of research questions in order to 'tell a story' of the findings (Popay et al., 2006). In line with the procedure for conducting a narrative synthesis (Popay et al., 2006), relevant information from each study was extracted using a data extraction form (Appendix B) and an initial written narrative of relationships within the data was constructed to critique the body of literature by comparing similarities and differences in the approaches, effects and quality of the studies. Comparisons were also made regarding the robustness of the studies and overall body of literature.

## **Results**

### ***Characteristics of Included Studies***

Fourteen studies from a range of sources were synthesised and divided into four categories dependent on the type of cognitive impairment (dementia, MCI, SCI and mixed samples).

Four interventions were delivered on a one to one basis ( $n=4$ ), whereas 10 were group-based. Three were delivered to dyads (person with cognitive impairment and caregiver), and two allowed a support person to attend alongside the person with cognitive impairments. Most studies delivered an MBSR or MBCT program ( $n=11$ ) whereas others delivered a Kirtan Kriya intervention ( $n=3$ ). The age of participants included in the studies varied significantly from 45-85; several studies ( $n=5$ ) recruited only older samples (aged 50+). Most recruited from community samples ( $n=12$ ), however a small number were from care home settings ( $n=2$ ). All studies were completed with Western cultures. For details of features of included studies see Table 2. The total sample of this review was 283.

Table 2. *Characteristics of included studies.*

<b>Authors, Date, Location</b>	<b>Relevant Aims</b>	<b>Participants</b>	<b>Cognitive Impairment</b>	<b>Setting</b>	<b>Methodology &amp; Intervention</b>	<b>Wellbeing Measures</b>	<b>Quality Score</b>
<b>Churher-Clarke et al. (2017) UK</b>	To develop a manual for a group-based mindfulness-based intervention  To assess feasibility and outcomes of the intervention	Intervention ( <i>n</i> = 20) Age range 61-95, mean age 81.30  Control ( <i>n</i> = 11) Age range 64-93, mean age 79.36	Mild-moderate dementia	Carehomes	Quantitative  Adapted MBSR/MBCT	Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young & Shamoian, 1988) Rating Anxiety in Dementia Scale (RAID; Shankar, Walker, Frost & Orrell, 1999) Perceived Stress Scale (PSS-13; Cohen, Kamarck & Mermelstein, 1983)	100%
<b>Paller et al (2015) USA</b>	Implement mindfulness program to create model for future  Patients and caregivers would experience improvement in wellbeing and mood	Patients ( <i>n</i> = 17) Age range 55-81, mean age 72.0  Caregivers ( <i>n</i> = 20) Age range 31-98, mean age 62.5)  ( <i>n</i> = 29 part of a pair)	Dementia (9), MCI (2) Memory loss due to strokes (2) Memory complaints without clinical diagnosis (3) FTD (1)	Community	Quantitative  Adapted MBSR	Quality of Life Alzheimer's Disease (QoL-AD; Logsdon, Gibbons, McCurry & Teri, 2002) Geriatric Depression Scale (GDS; Yesavage et al., 1982) Pittsburg Sleep Quality Inventory (PSQI; Buysse, Reynolds, Monk, Berman & Kupfer, 1989) Short Form Health Survey (SF-36; Brazier et al., 1992) Activities Daily Living Questionnaire (ADLQ; Johnson, Barion, Rademaker, Rehkemper & Weintraub, 2004)	90.1%
<b>Innes et al (2016) USA</b>	Efficacy of relaxation practices for improving psychological outcomes and preclinical memory loss assessed effects of two relaxation	KK group ( <i>n</i> = 30) Age range 50-84, mean age 60.93	Subjective cognitive decline	Community	Quantitative  Kirtan Kriya vs. Music Listening	PSS SF-36 PSQI Psychological Wellbeing Scale (PSWB; Ryff & Keyes, 1995)	100%

	programs on stress, sleep, mood, health related QoL	ML group ( $n = 30$ ) Mean age 60.23					
<b>Moss et al (2012) USA</b>	Assess outcomes of mood and affect and spirituality	KK group ( $n = 15$ ) Mean age 62  ML group ( $n = 5$ ) Mean age 69	Age associated memory impairment ( $n = 7$ ), MCI ( $n = 5$ ), moderate impairment with AD ( $n = 3$ )	Community	Quantitative  Kirtan Kriya vs Music listening	Spielberger state and trait anxiety inventory (Spielberger, Gorsuch & Lushene, 1970) Profile of Mood States (POMS; McNair, Lorr & Droppleman, 1992) Purpose in life scale (Marsh, Smith, Piek & Saunders, 2003)	75%
<b>Wong et al (2017) Australia</b>	Can mindfulness practices improve health outcomes of older people with MCI  Does degree of improvement in outcomes vary with duration/level of mindfulness  Are improvements maintained at one year follow up	Intervention ( $n = 13$ )  Age range 60-89, mean age 76.5	MCI	Community	Mixed-methods  Adapted mindfulness training program	Depression Anxiety Stress Scale (DASS-21; Henry & Crawford, 2005) Bayer Activities of Daily Living Scale (B-ADL; Hindmarch, Lehfeld, De Jongh & Erzigkeit, 1998) Demographic Health and Lifestyle Questionnaire (DHL; Wong, Hassed, Chambers & Coles, 2016)	100%
<b>Berk et al (2017) The Netherlands</b>	Feasibility and acceptability of MBSR for middle aged and older adults with cog complaints including qualitative assessment of experiences  Conducted hypothesis generating analyses on cog and psychological indicators of sensitivity to MBSR including QoL, psychological distress, self-compassion	$n = 13$ Age range 45-85, mean age 59	SCI	Community	Mixed-methods  MBSR	Self-compassion Scale (SCS-SF; Neff, 2003) Health Related Quality of Life (EuroQoL; EuroQol Group, 1990) DASS-21	77.8%
<b>Lenze et al (2014) USA</b>	Does MBSR need to be lengthened for late-life anxiety to provide clinical benefits	Standard MBSR ( $n =$	Cognitive dysfunction	Community	Quantitative	Penn State Worry Questionnaire (PSWQ-A; Meyer, Miller, Metzger & Borkovec, 1990)	

		16) Mean age 70.9			Standard MBSR vs Adapted MBSR		
		Adapted MBSR ( <i>n</i> = 18) Mean age 70.4					
<b>Innes et al (2012)</b> USA	Investigating the effects of meditation on perceived stress and related indices of psychological morbidity and sympathetic activation in caregiver dyads	<i>n</i> = 12 (6 dyads) Age range 45-85, mean 73.3	MCI or early stage AD	Community	Quantitative  Kirtan Kriya	PSS POMS Positive and Negative Affect Scale (PANAS; Watson, Clarke & Tellegen, 1988) Dispositional Resilience Scale (DRS; Bartone, Ursano, Wright & Ingraham, 1989) General Sleep Disturbance Scale (GSDS; Lee, 1992) SCS	100%
<b>Wells et al (2013)</b> USA	Explore effects of MBSR on wellbeing	<i>n</i> = 14 Age range 55-90	MCI	Community	Mixed-methods  2:1 MBSR or usual care	Resilience Scale (Wagnild & Young, 1993) PSS QoL-AD Herth Hope Index (Herth, 1988) Life Orientation Test-revised (Scheier, Carver & Bridges, 1994) Center of Epidemiologic Studies Depression Scale (Radloff, 1977)	66.7%
<b>Swannell et al (2017)</b> UK	Explore the experiences of dyads on MBSR course  What benefits and or difficulties?  How do participants describe effects on wellbeing and acceptance and adjustment to diagnosis of dementia?	<i>n</i> = 10 (5 dyads) Age range 56-86	Dementia diagnosis	Community	Mixed-methods  Adapted MBSR	Canterbury Wellbeing Scale (CWS; Johnson, Culverwell, Hulbert, Robertson & Camic, 2017) World Health Organisation-5 (WHO-5; WHO, 1998)	77.8%

What changes did they identify in the other person/relationship?							
<b>Leader et al (2013) UK</b>	Do mindfulness techniques make a difference to PLwDs wellbeing and quality of life	<i>n</i> = 20 (12 PLwD, 8 caregivers)  Age not reported	Dementia diagnosis	Community	Mixed-methods  Adapted MBSR	Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant, 2007)	72.2%
<b>Lantz et al (1997) USA</b>	Reducing disruptive behaviour while enhancing emotional state	Quantitative study ( <i>n</i> =8) TAU ( <i>n</i> = 6)  Nursing IVs ( <i>n</i> = 8)  Age range 72-94	Dementia	Carehome	Mixed-methods  Meditation based intervention (10 structured sessions)	Cohen Mansfield Agitation Inventory (CMAI; Cohen Mansfield, Marx & Rosenthal, 1989)	36.3%
<b>Wetherell et al (2017) USA</b>	Whether clinical outcomes can be enhanced by mindfulness intervention	<i>n</i> = 103  MBSR Mean age 70.4 HE Mean age 73.3	Subjective neurocognitive difficulties	Community	Quantitative  MBSR vs health education	PSWQ PROMIS Scales (Cella et al., 2010)	83.3%
<b>Kemp et al (2016) UK</b>	To help the person with dementia and caregiver foster a constructive acceptance of the negative emotions associated with the experience of dementia	<i>n</i> = 2 (one dyad)  Age not reported	Mr D – Alzheimer’s disease	Community	Mixed-methods  Adapted MBCT	Patient Health Questionnaire 9 (PHQ9; Kroenke et al., 2001) Generalised Anxiety Disorder 7 (GAD 7; Spitzer et al., 2006) SCS	50%

### ***Quality of Included Studies***

Quality varied greatly across and within the sample types. Five studies addressed the use of MBIs on PLwD, which was the most methodologically varied area, with study quality ranging from 36-100%. This may be because the three studies not published in peer-reviewed journals were in this section (Leader, Litherland, Mason, Pilchick, Sansom & Robertson, 2013; Kemp, Wilkinson, Cambray & Johnsson, 2016, Swannell, 2017). Two studies were identified for people with MCI, with methodological quality ranging from 67-100%. Studies of MBIs for SCI had quality ratings of 75-83%. Mixed sample studies quality ranged from 75-100%; this section had the consistently highest quality scores across the review (mean 91.5%). Studies with high methodological quality were often RCTs (Churcher-Clarke et al., 2017; Innes et al., 2016; Wells et al., 2013; Wetherell et al., 2017), whereas low were not published in peer-reviewed journals, did not acknowledge the limitations of their studies (Lenze et al., 2014; Wells et al., 2013; Lantz et al., 1994; Kemp et al., 2016), and did not provide a rationale for the integration (or lack thereof) of quantitative and qualitative data (Paller et al., 2015; Kemp et al., 2016). (See Appendix D for breakdown of quality scores).

### ***Meditation-based Interventions for People Living with Dementia***

The most researched group in the review was PLwD, consisting of five studies (Leader et al., 2013, Swannell, 2017, Kemp et al., 2016, Churcher-Clarke, Chan, Stott, Royan & Spector, 2017, Lantz et al., 1997, Buchalter & McBee, 1997).

### ***Participants***

Most studies involved both the PLwD and carers to facilitate engagement of the PLwD (Swannell, 2017, Kemp et al., 2016, Leader et al., 2013). Two were dyadic case studies (PLwD and caregiver) (Swannell, 2017  $n = 10$ ; Kemp et al., 2016  $n = 2$ ), therefore their

findings lack generalisability. Three studies recruited only PLwD (Churcher-Clarke et al., 2017  $n = 31$ ; Lantz et al., 1997  $n = 14$ ). Dementia type was not always reported (Leader et al., 2013, Lantz et al., 1997), whereas Churcher-Clarke et al. (2017) recruited people with mild-moderate cognitive impairment, Mr. D in Kemp et al. (2016) had Alzheimer's disease, and Swannell (2017) recruited four dyads with mixed dementia and one with Alzheimer's.

### *Intervention*

Four studies (Leader et al., 2013, Churcher-Clarke et al., 2017, Kemp et al., 2016, Swannell, 2017) delivered a standardised mindfulness-based intervention, with adaptations. Several studies increased the number of sessions to 10 (Churcher-Clarke et al. 2017, Kemp et al., 2016) to accommodate problems in memory and learning. Churcher-Clarke et al. (2017) also held sessions twice a week for five weeks.

Most studies reduced the length of sessions to less than 90 minutes, shortened practices and adapted materials (Churcher-Clarke et al., 2017, Kemp et al., 2016 & Swannell, 2017). Adaptations were decided by researchers, although a strength of two studies was involving PLwD in decisions about intervention delivery (Churcher-Clarke et al., 2017; Swannell, 2017). Lantz et al. (1997) ran a meditation programme developed by a psychiatrist and social worker, including elements of MBSR such as deep breathing, awareness training and promoting sense of self.

There was little consistency regarding the qualifications of mindfulness practitioners. Facilitators in two studies had mindfulness teacher training qualifications (Kemp et al., 2016; Swannell, 2017). The remaining interventions did not report the facilitator's mindfulness qualifications or experience.

One study involved a randomised control group (Churcher-Clarke et al., 2017; intervention plus treatment as usual vs. TAU), allowing researchers to compare outcomes. As such, this study received the highest possible quality rating (100%). Lantz et al. (1997) also utilised a control group in their small-scale study of nurses' perceptions of agitation in residents, although the group's characteristics are not described. The lack of detail and integration of quantitative and qualitative data translated to a lower quality score (36%).

#### *Domains of wellbeing and findings*

Some domains of wellbeing were consistent across studies, but used different measures. Common domains were Quality of Life (QoL) (Leader et al., 2013, Churcher-Clarke et al., 2017), wellbeing (Leader et al., 2013), and anxiety and depression (Leader et al., 2013, Kemp et al., 2016, Churcher Clarke et al., 2017) where lower rates of anxiety and depression were regarded as improvements to wellbeing. Other domains including stress were measured in single studies (see Table 2.).

Two studies measured wellbeing in PLwD via proxy ratings. Lantz et al. (1997) administered an agitation measure to nursing assistants at pre-post, revealing a significant improvement in the intervention group. Churcher-Clarke et al. (2017) administered standardised and dementia specific wellbeing measures at pre-post, with anxiety and depression measures involving interviews with people PLwD and care staff. They found a significant improvement in QoL in the intervention group compared to controls from pre-post, as well as non-significant differences between the groups on depression, anxiety and stress.

The remaining studies administered self-report wellbeing measures. In Swannell's (2017) study, PLwD and caregivers showed improvements in wellbeing from pre-post, although not at follow-up. No other significant wellbeing improvements for PLwD were revealed. One study involved a three-month follow-up (Leader et al., 2013) to investigate whether effects were sustained, whereas others did not (Churcher-Clarke et al., 2017; Lantz et al., 1997).

Two studies ran descriptive statistics and were therefore unable to detect and report the significance of changes in wellbeing. Leader et al. (2013) found self-reported wellbeing improvements which were slightly greater for PLwD compared to caregivers, though similarly to Swannell's (2017) findings these gains were not upheld at follow-up. Kemp et al. (2016) administered measures at pre-intervention and 6 month follow-up, which also suggested an improvement in anxiety and depression.

Four studies collected some form of qualitative data, reporting common themes such as feeling calmer (Lantz et al., 1997; Kemp et al., 2016), increased awareness (Kemp et al., 2016; Leader et al., 2013), coping with dementia better (Leader et al., 2013; Swannell, 2017), enjoyment of shared dyadic experiences (Kemp et al., 2016; Swannell, 2017) and improved relationships (Leader et al., 2013; Swannell, 2017).

### ***Meditation-based Interventions for People Living with Mild Cognitive Impairment (MCI)***

Two studies (Wells et al., 2013; Wong, Coles, Chambers, Wu & Hased, 2017) in the review evaluated meditation-based interventions for people living with MCI.

### *Participants*

Both studies had small samples ( $n = 14$ ; Wells et al., 2013; Wong et al., 2017); a common issue throughout this review. One study invited a family member to support the person living with cognitive impairments (Wong et al., 2017), possibly because participants in this study were older and had more physical and/or cognitive difficulties, therefore required additional support.

### *Intervention*

Both interventions were based on a standardised MBSR program (Wells et al., 2013; Wong et al., 2017). Session content was similar in both interventions, including formal mindfulness meditations focused on the breath and body, and yogic exercises, with advised daily home practice.

Wells et al. (2013) did not explicitly report adaptations and retained most elements of the standardised protocol, however they encouraged only 30 minutes of homework a day. By contrast, Wong et al. (2017) adapted specifically for difficulties common in MCI such as attention, memory, daily functioning, psychological health and sleep, and reduced session length (90 minutes). Two trained mindfulness facilitators delivered the intervention in one study (Wong et al., 2017), whereas this was not reported in Wells et al. (2013).

A significant strength of the Wells et al. (2013) study was the incorporation of an RCT design, comparing the MBSR group (randomised 2:1) to TAU, to isolate the effects of the intervention.

### *Domains of wellbeing and findings*

Both studies measured depression but they differed significantly on other domains (see Table 2).

Both administered measures at pre-post. In Wells et al. (2013), analyses revealed no statistically significant results, however non-significant trends suggested improvement in the MBSR group on resilience, perceived stress, QoL, hope and life orientation. Interviews with participants identified themes of wellbeing, acceptance and decreased stress reactivity. A strength of this study was that measures were administered by a neuropsychologist blind to allocation. Wong et al. (2017) found significant positive correlations between length of meditation and ADL functioning. Wellbeing scores did not significantly change, however positive trends were found in depression, anxiety, stress and ADL functioning. This study did not involve a control group, but followed up participants one year post-intervention, finding greater improvements in ADLs which is the longest follow-up in this review.

### ***Meditation-based Interventions for People Living with Subjective Cognitive***

#### ***Impairment (SCI)***

Three studies (Berk, Hotterbeekx, van Os & van Boxtel, 2017, Lenze et al., 2014, Wetherell et al., 2017) in the review delivered MBIs to people with SCI.

#### *Participants*

In these studies, cognitive impairments were subjectively reported. Two studies had inclusion criteria of psychological distress; Lenze et al. (2014) recruited participants with co-occurring anxiety related distress and Wetherell et al. (2017) with clinically

significant anxiety or depression. All three studies excluded participants with a dementia diagnosis.

The number of participants in the studies varied significantly from smaller samples ( $n=13$  -Berk et al., 2017;  $n=34$  - Lenze et al., 2014) to comparatively larger samples ( $n=103$  - Wetherell et al., 2017).

### *Intervention*

All three studies delivered standardised interventions. Each split participants into multiple groups. Berk et al. (2017) analysed data as a whole from two groups, who were delivered the same intervention six months apart ( $n=6$  and  $7$ ), whereas the other studies compared two different groups; Standard MBSR vs Adapted MBSR (Lenze et al., 2014), to identify whether adaptations were necessary, and MBSR vs. Health Education (HE) (Wetherell et al., 2017), to see whether MBSR was more effective than HE. Participants in Wetherell et al. (2017) were recruited from the same two sites as in the Lenze et al. (2014) study, as this was a continuation study, with a broader range of outcomes and a comparison group.

Minimal adaptations were applied to this group of interventions. Lenze et al.'s (2014) adapted group contained the same content as standard MBSR, but delivered 12 sessions and included more repetition. A commonly adapted feature was reducing the intensity of yoga and shortening the retreat (Lenze et al., 2014; Wetherell et al., 2017). Again, two studies reduced session length (90 minutes) (Wetherell et al., 2017 et al; Berk et al., 2017).

All studies were delivered by certified MBSR trainers, with two being facilitated by the same group of researchers with their own mindfulness-practice, experience of delivering MBSR groups and were overseen by the director of the UCSD Center for Mindfulness who supervised instructors (Lenze et al., 2014; Wetherell et al., 2017 et al). Sessions in both these studies were reviewed by a supervisor to ensure intervention quality, which is a major strength of these studies.

#### *Domains of wellbeing and findings*

Worry was measured in all three studies and depression and anxiety in two (Berk et al., 2017, Wetherell et al., 2017). Berk et al. (2017) also administered measures of self-compassion and QoL (see Table 2 for complete list).

Each study administered measures at pre-post, two including a follow-up at five weeks (Berk et al., 2017) and 3 and 6 months (Lenze et al., 2014). Significant reductions in worry were revealed in MBSR compared to HE (Wetherell et al., 2017) and also in Lenze et al.'s (2014) study. This finding was comparable to interventions using antidepressants or Cognitive-Behavioural Therapy (Lenze et al., 2014). Berk et al. (2017) found no significant changes in wellbeing, but there were trends towards improvement in depression and QoL scores.

Qualitative findings identified five themes; 'positive effects of training' which implicated wellbeing as participants enjoyed attending, experiencing a calming effect, coping with stressful situations, less worry about memory and accepting difficult situations (Berk et al., 2017). The integration of mixed data which supported each other in the study was a strength. However, 30% of participants screened were unable to take part due to the time commitment.

### *Meditation-based Interventions for Mixed Samples*

Four studies (Paller et al., 2015; Inne, Selfe, Brown, Rose & Thompson-Heisterman., 2012; Innes, Selfe, Khalsa & Kandati., 2016; Moss et al., 2012) recruited mixed samples of persons living with various cognitive impairments.

#### *Participants*

Two studies recruited participants as dyads with MCI or early stage Alzheimer's disease; one consisting of six dyads, (five spouses and one parent-daughter) (Innes et al., 2012). Another consisted of 17 people with cognitive impairments and 20 caregivers (13 spouses, five adult children, one daughter-in-law and one mother-in-law) with varying cognitive difficulties including Alzheimer's ( $n=9$ ), MCI ( $n=2$ ), stroke-related memory loss ( $n=2$ ), memory complaints ( $n=3$ ) and fronto-temporal dementia ( $n=1$ ) (Paller et al., 2015). Another study recruited participants with SCI or MCI, but allowed a 'study buddy' to attend for people with MCI (Innes et al., 2016). The last study only recruited individuals with cognitive impairments; mild memory impairment ( $n=7$ ), MCI ( $n=5$ ) and Alzheimer's ( $n=3$ ) (Moss et al., 2012).

A limitation of all these studies is that by including mixed samples it is difficult to know which adaptations were appropriate for people with different cognitive impairments, however the findings may also suggest that similar adaptations are appropriate for all.

#### *Intervention*

Paller et al. (2015) delivered an adapted MBSR programme for several groups over eight weeks, which was adapted to meet the needs of people with memory loss and carers by shortening meditations and reducing session length to 90 minutes, incorporating exercises from other therapies, slower instruction, reduced physical

exertion, and less homework. The remaining three delivered Kirtan Kriya (KK) meditation training (Innes et al. 2012; Innes et al.; 2016, Moss et al., 2012), taught in an initial 30-40 minute in-person training session of the simple meditation practice lasting 11 minutes. This involves chanting sounds, visualising energy and complimentary finger movements, with comparably fewer adaptations being made to these studies. Participants were given CDs of the meditation and advised to complete it once (Innes et al., 2016; Moss et al., 2012) or twice (Innes et al., 2012) a day. Innes et al. (2016) gave participants a portable CD player to improve accessibility of the meditations. Two of the KK studies compared the participants to music groups (Innes et al., 2012; Moss et al., 2012), which involved listening to classical music for the same length of time each day, to compare the effects of KK meditation to relaxation. Two studies advised participants to complete this for eight weeks (Innes et al., 2012; Moss et al., 2012), whereas another advised 12 (Innes et al., 2016).

One study used an RCT design (Innes et al., 2016) and another involved a comparison group, to which participants were not randomised (Moss et al., 2012), whereas the remaining studies (Innes et al., 2012; Paller et al., 2015) included no comparison or control group. Both studies by Innes et al. (2012; 2016), and Paller et al. (2015) scored very highly on the review quality checklist (100%, 100% and 91% respectively), whereas Moss et al. (2012) scored much lower (75%) as although the methodological quality of the study was good, the authors did not sufficiently describe the limitations of the intervention.

Facilitators of these interventions were not specified as trained in the meditation techniques delivered, which may be due to the simplistic instruction necessary to deliver KK compared to mindfulness interventions.

### *Domains of wellbeing and findings*

Across the four studies, consistently measured domains of wellbeing included QoL (Paller et al., 2015, Innes et al., 2016), sleep (Paller et al., 2015; Innes et al.; 2012, Innes et al., 2016), mood states (Innes et al., 2012; Innes et al., 2016; Moss et al., 2012), perceived stress (Innes et al., 2012; Innes et al., 2016) and health outcomes (Paller et al., 2015; Innes et al., 2016). Individual studies also measured resilience self-compassion, psychological wellbeing, and purpose in life (see Table 2).

All four studies administered standardised measures pre-post, with the addition of a 12 and 26 week follow-up in Innes et al. (2016). Significant findings included improvement in QoL and depression scores (Paller et al., 2015), and stress, sleep quality and mood impairment (Innes et al., 2012) for all participants. Innes et al. (2012) also found significant correlations between perceived stress and changes in mood and sleep, as well as improvement in sleep being strongly correlated with mood improvement. Innes et al. (2016) found significant improvements in psychological wellbeing, mood and sleep quality for both Kirtan Kriya and Music Listening groups, as well as perceived stress and mental health for the KK group at 12 weeks, the benefits of which were sustained or strengthened at follow-up. In addition, the KK group had significantly greater gains in perceived stress and mood than ML at 12 and 26 weeks, suggesting these benefits were specific to the meditation-based intervention. Other significant findings included improvements in fatigue and state anxiety for the KK group, and improvements in tension and fatigue subcategories for KK when compared to ML (Moss et al., 2012).

## **Discussion**

This review aimed to establish what domains of wellbeing have been targeted and measured in MBI research for people living with dementia, MCI and SCI, and what effects MBIs have on these domains. Overall, the research suggests positive trends in wellbeing from pre-post intervention, with some significant findings, although the degree to which they were effective varied. The results of the qualitative data suggest participants experienced improvements in their wellbeing. These trends support the findings of reviews which have focus on the wellbeing of dementia caregivers in MBIs (Hurley, Robyn, Patterson & Cooley, 2014; Li, Yuan & Zhang, 2016; Kor, Chien, Liu & Lai, 2017). However, the lack of significant quantitative findings when compared to positive qualitative findings may suggest that more sensitive outcomes measures need to be considered to measure how MBIs affect the wellbeing of people living with cognitive impairments.

The most commonly identified wellbeing domains included standardised measures of QoL, anxiety, depression and mood. Although multiple studies measured the same, or similar, domains of wellbeing, there was a general lack of consistency as to which domains were measured, and in what way, however the measures used in these studies were not synthesised, as this was beyond the scope of this review. Most of the studies did not specify that the measures they administered related to 'wellbeing'. This lack of specificity alongside a lack of consensus about the definition of wellbeing (Dodge, Daly, Huyton & Sanders, 2012) and how to measure it made it difficult to integrate the findings of the included studies. In addition, it is noted that overall wellbeing was not measured in the reviewed studies by the domains identified in models of wellbeing in dementia and positive psychology (Kaufmann & Engel, 2016; Seligman, 2011).

Wellbeing was most frequently measured by the absence or alleviation of depression or

anxiety, rather than the existence of positive experiences as these models suggest. A small minority of papers included measures which may map on to domains from the aforementioned models, for example ‘purpose in life’ and ‘health outcomes’ may map on to the domain of ‘identity’ identified by Kitwood (1997). Some qualitative data also made reference to ‘enjoyment of shared dyadic experiences’ and ‘improved relationships’ which may map on to ‘attachment’ in Kitwood’s model.

A further limitation is that two of the studies of PLwD (Lantz et al., 1997; Churcher-Clarke et al., 2017) relied on proxy measures completed by care staff which does not support current understandings of wellbeing in dementia as being about independence and agency (Kaufmann & Engel, 2016).

Adaptations were a common theme across the studies, particularly for PLwD, which is likely to be due to the additional needs of people with more severe cognitive impairments and attention difficulties. The rationale for including adaptations was not always clear, but those that did specify often cited using existing literature of MBIs for older people and people with cognitive impairments (Churcher-Clarke et al., 2017; Swannell., 2017; Wetherell et al., 2017; Kemp et al., 2016). The most common adaptations across the review were specific to aiding learning for people with cognitive impairments such as shorter practices, sessions and day retreats, increased number of sessions and repetition, fewer physical exercises and the inclusion of adapted materials. These adaptations are consistent with MBIs which have been adapted for people living with cognitive impairments and similar difficulties of attention and memory, such as for people living with Parkinson’s (Cash, Ekouevi, Kilbourn & Lageman, 2016), and brain injuries (Bedard et al., 2003). However, it is less clear from this review which adaptations are most effective for which groups of people, and how these affect

learning. Some of the studies have included their participants in deciding how the interventions should be delivered, utilising a more person-centred approach which has become an important element of dementia-care (National Institute for Health and Care Excellence, 2016).

A further adaptation was the inclusion of dyads. This was more common for PLwD, however some studies also encouraged a familial caregiver to support the person with cognitive impairments. Dyadic interventions recognise the value of relationship-centred care and the reciprocal relationship between dyadic wellbeing (Holst & Edberg, 2011). However it is not possible in this review to directly compare the effects of dyadic vs. individual interventions due to the lack of consistency of outcomes measured, which may be a useful venture for future research.

The review reveals a range of MBIs which were either mindfulness-based or Kirtan Kriya, which vary greatly in their methods, with MBSR/MBCT interventions involving group sessions over several weeks, qualified facilitators to deliver the intervention, practising a range of meditative exercises and extensive homework periods (up to an hour per day), whereas KK takes only one brief session to deliver and 11 minutes per day of meditation, potentially making it more cost-effective in clinical settings. In addition, mindfulness-based interventions encompass much more learning and practice, and often incorporate psychoeducation, stress management and how to use mindfulness in daily life (Teasdale et al., 2000). Studies delivering both types of MBI had positive effects on wellbeing related outcomes, which may suggest that the type of meditation is less important, and perhaps people living with cognitive impairments should choose which intervention suits them best. Studies which compare the use of these two interventions and their outcomes on wellbeing may be useful to explore in the future.

### *Strengths and Limitations*

This review is a useful summary of wellbeing in MBIs for people living with dementia/MCI/SCI. A strength of several studies was the use of control groups, and whether these were compared to treatment as usual or an alternative intervention. However, the number of control groups across the review were limited, which is important for future research.

A limited range of interventions, primarily mindfulness-based or Kirtan Kriya were reviewed which additionally led to difficulties comparing two interventions whose methods varied greatly. No studies were found which directly compared the effectiveness of the two interventions.

The review was limited by the homogeneity of samples, often consisting of white, educated, females, which limits the generalisability of its findings. It was also difficult to compare the included studies due to the extensive variability in design, wellbeing outcomes, and measurement of outcomes and data collection methods.

Several studies collected follow-up data, but the length of time post-intervention varied greatly from a few weeks to a year, with most being within three months. This is an important element of high quality studies, as the maintenance of mindfulness practice and the effects of this on wellbeing over a long period of time has not been explored.

Finally, it remains unclear from the results of this review at which point in the trajectory of cognitive impairment there would be the most clinical utility for a meditation-based intervention in relation to improving wellbeing.

## ***Implications for Research and Practice***

This review has highlighted that further research is needed in the following areas:

- The (lack of) standardisation of measures used in MBIs to evaluate wellbeing, and the validity and reliability of these
- Whether engagement in MBIs at earlier stages of the trajectory (i.e. SCI/MCI) positively impact wellbeing in the long-term, particularly for those who later develop dementia
- Whether other types of meditation (e.g. transcendental meditation) are effective in improving wellbeing for people living with cognitive impairments and whether different types of meditation are more effective or cost-effective than others
- Whether there are common factors (aside from meditation) across MBIs which affect wellbeing for people living with cognitive impairments, such as being in a group, having a routine, doing something as a dyad etc.
- Larger scale studies need to be conducted in this area with a longer follow-up period and control groups
- More mixed-methods and qualitative studies need to be conducted to understand the experience of these interventions for people living with cognitive impairments, and to help identify which components people enjoy and find the most important/effective.

## **Conclusions**

This review found that most MBIs have a positive impact on the wellbeing of people living with dementia, MCI and SCI, although how wellbeing is measured varies considerably between studies. Future research in this area might utilise larger samples,

more qualitative data, standardised definitions and measures of wellbeing and explore the use of other meditation types.

### **Disclosure of Interest**

The authors report no conflict of interest.

## References

- Alexopoulos, G. S., Abrams, R. C., Young, R. C., & Shamoian, C. A. (1988). Cornell scale for depression in dementia. *Biological psychiatry*, *23*(3), 271-284.
- Baer, R. A. (2003). Mindfulness training as a clinical intervention: A conceptual and empirical review. *Clinical psychology: Science and practice*, *10*(2), 125-143.
- Bartone, P. T., Ursano, R. J., Wright, K. M., & Ingraham, L. H. (1989). The impact of a military air disaster on the health of assistance workers. *Journal of nervous and mental disease*, *177*(6), 317-328.
- Bedard, M., Felteau, M., Mazmanian, D., Fedyk, K., Klein, R., Richardson, J., ... & Minthorn-Biggs, M. B. (2003). Pilot evaluation of a mindfulness-based intervention to improve quality of life among individuals who sustained traumatic brain injuries. *Disability and Rehabilitation*, *25*(13), 722-731.
- Berk, L., Hotterbeekx, R., van Os, J., & van Boxtel, M. (2017). Mindfulness-based stress reduction in middle-aged and older adults with memory complaints: a mixed-methods study. *Aging & mental health*, 1-8.  
<https://doi.org/10.1080/13607863.2017.1347142>
- Brazier, J. E., Harper, R., Jones, N. M., O'cathain, A., Thomas, K. J., Usherwood, T., & Westlake, L. (1992). Validating the SF-36 health survey questionnaire: new outcome measure for primary care. *Bmj*, *305*(6846), 160-164.
- Buysse, D. J., Reynolds, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh Sleep Quality Index: a new instrument for psychiatric practice and research. *Psychiatry research*, *28*(2), 193-213.
- Cash, T. V., Ekouevi, V. S., Kilbourn, C., & Lageman, S. K. (2016). Pilot study of a mindfulness-based group intervention for individuals with Parkinson's disease and their caregivers. *Mindfulness*, *7*(2), 361-371.

- Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S., ... & Cook, K. (2010). The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. *Journal of clinical epidemiology*, *63*(11), 1179-1194.
- Chiesa, A., & Serretti, A. (2009). Mindfulness-based stress reduction for stress management in healthy people: a review and meta-analysis. *The journal of alternative and complementary medicine*, *15*(5), 593-600.
- Churcher Clarke, A., Chan, J. M. Y., Stott, J., Royan, L., & Spector, A. (2017). An adapted mindfulness intervention for people with dementia in care homes: feasibility pilot study. *International journal of geriatric psychiatry*, *32*(12), e123-e131.
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of health and social behavior*, *24*(4), 385-396.
- Cohen-Mansfield, J., Marx, M. S., & Rosenthal, A. S. (1989). A description of agitation in a nursing home. *Journal of gerontology*, *44*(3), M77-M84.
- Cotelli, M., Manenti, R., & Zanetti, O. (2012). Reminiscence therapy in dementia: A review. *Maturitas*, *72*(3), 203-205.
- Dementia Action Alliance. (2018). *Who we are*. Retrieved from [https://www.dementiaaction.org.uk/who\\_we\\_are](https://www.dementiaaction.org.uk/who_we_are)
- Department of Health. (2009). *Living Well With Dementia: a national dementia strategy*. Retrieved from <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>
- Dodge, R., Daly, A., Huyton, J., & Sanders, L. (2012). The challenge of defining wellbeing. *International Journal of Wellbeing*, *2*(3), 222-235.  
doi:10.5502/ijw.v2i3.4

- Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology & Community Health*, 52(6), 377-384.
- EuroQol, G. (1990). EuroQol--a new facility for the measurement of health-related quality of life. *Health policy (Amsterdam, Netherlands)*, 16(3), 199-208.
- Gauthier, S., Reisberg, B., Zaudig, M., Petersen, R. C., Ritchie, K., Broich, K., ... & Cummings, J. L. (2006). Mild cognitive impairment. *The Lancet*, 367(9518), 1262-1270.
- Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British journal of clinical psychology*, 44(2), 227-239.
- Herth, K. (1991). Development and refinement of an instrument to measure hope. *Research and Theory for Nursing Practice: An International Journal*, 5(1), 39-51.
- Hindmarch, I., Leffeld, H., de Jongh, P., & Erzigkeit, H. (1998). The Bayer activities of daily living scale (B-ADL). *Dementia and geriatric cognitive disorders*, 9(2), 20-26.
- Hofmann, S. G., Sawyer, A. T., Witt, A. A., & Oh, D. (2010). The effect of mindfulness-based therapy on anxiety and depression: A meta-analytic review. *Journal of Consulting and Clinical Psychology*, 78(2), 169-183.
- Holst, G., & Edberg, A. K. (2011). Wellbeing among people with dementia and their next of kin over a period of 3 years. *Scandinavian journal of caring sciences*, 25(3), 549-557.
- Hurley, R. V., Patterson, T. G., & Cooley, S. J. (2014). Meditation-based interventions for family caregivers of people with dementia: a review of the empirical literature. *Aging & mental health*, 18(3), 281-288.

- Innes, K. E., & Selfe, T. K. (2014). Meditation as a therapeutic intervention for adults at risk for Alzheimer's disease—potential benefits and underlying mechanisms. *Frontiers in psychiatry*, 5, 40.
- Innes, K. E., Selfe, T. K., Brown, C. J., Rose, K. M., & Thompson-Heisterman, A. (2012). The effects of meditation on perceived stress and related indices of psychological status and sympathetic activation in persons with Alzheimer's disease and their caregivers: a pilot study. *Evidence-Based Complementary and Alternative Medicine*, 2012, 1-9.
- Innes, K. E., Selfe, T. K., Khalsa, D. S., & Kandati, S. (2016). Effects of meditation versus music listening on perceived stress, mood, sleep, and quality of life in adults with early memory loss: a pilot randomized controlled trial. *Journal of Alzheimer's Disease*, 52(4), 1277-1298.
- Johnson, J., Culverwell, A., Hulbert, S., Robertson, M., & Camic, P. M. (2017). Museum activities in dementia care: Using visual analog scales to measure subjective wellbeing. *Dementia*, 16(5), 591-610.
- Johnson, N., Barion, A., Rademaker, A., Rehkemper, G., & Weintraub, S. (2004). The Activities of Daily Living Questionnaire: a validation study in patients with dementia. *Alzheimer disease & associated disorders*, 18(4), 223-230.
- Kabat-Zinn J. (1990). *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness*. New York: Delacorte.
- Kaufmann, E. G., & Engel, S. A. (2016). Dementia and wellbeing: A conceptual framework based on Tom Kitwood's model of needs. *Dementia*, 15(4), 774-788.
- Kemp, E., Wilkinson, P., Cambray, L., & Johnsson, M. (2016). Case report: Accepting what is present: Could learning mindfulness together be a useful intervention for a couple living with dementia? *FPOP Bulletin*, 134, 20-24.
- Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health*, 1(1), 13-22.

- Kor, P. P., Chien, W. T., Liu, J. Y., & Lai, C. K. (2017). Mindfulness-Based Intervention for Stress Reduction of Family Caregivers of People with Dementia: A Systematic Review and Meta-Analysis. *Mindfulness*, 9(1), 1-16.
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The phq-9. *Journal of general internal medicine*, 16(9), 606-613.
- Lantz, M. S., Buchalter, E. N., & McBee, L. (1997). The wellness group: a novel intervention for coping with disruptive behavior in elderly nursing home residents. *The Gerontologist*, 37(4), 551-557.
- Leader, G., Litherland, R., Mason, T., Pilchick, T., Sansom, S., & Robertson, G. (2013). Mindfulness and dementia: Report of a pilot study. *Innovations in Dementia and Positive Ageing Associates*.
- Lee, K. A. (1992). Self-reported sleep disturbances in employed women. *Sleep*, 15(6), 493-498.
- Lenze, E. J., Hickman, S., Hershey, T., Wendleton, L., Ly, K., Dixon, D., ... & Wetherell, J. L. (2014). Mindfulness-based stress reduction for older adults with worry symptoms and co-occurring cognitive dysfunction. *International journal of geriatric psychiatry*, 29(10), 991-1000.
- Li, G., Yuan, H., & Zhang, W. (2016). The effects of mindfulness-based stress reduction for family caregivers: systematic review. *Archives of psychiatric nursing*, 30(2), 292-299.
- Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic medicine*, 64(3), 510-519.
- Marsh, A., Smith, L., Piek, J., & Saunders, B. (2003). The purpose in life scale: Psychometric properties for social drinkers and drinkers in alcohol treatment. *Educational and Psychological Measurement*, 63(5), 859-871.

- McNair, D. M., Lorr M., & Droppleman, L. F. (1992). *Manual for the Profile Mood States*. San Diego: EdITS/Educational and Industrial Testing Service.
- Meyer, T. J., Miller, M. L., Metzger, R. L., & Borkovec, T. D. (1990). Development and validation of the penn state worry questionnaire. *Behaviour research and therapy*, 28(6), 487-495.
- Moss, A. S., Wintering, N., Roggenkamp, H., Khalsa, D. S., Waldman, M. R., Monti, D., & Newberg, A. B. (2012). Effects of an 8-week meditation program on mood and anxiety in patients with memory loss. *The Journal of Alternative and Complementary Medicine*, 18(1), 48-53.
- National Institute for Health and Care Excellence. (2016). *Dementia: supporting people with dementia and their carers in health and social care*. Retrieved from <https://www.nice.org.uk/guidance/cg42/chapter/personcentred-care>
- Neff, K. D. (2003). The development and validation of a scale to measure self-compassion. *Self and identity*, 2(3), 223-250.
- New Economics Foundation. (2012). *Measuring Wellbeing: A guide for practitioners*. London: New Economics Foundation.
- Paller, K. A., Creery, J. D., Florczak, S. M., Weintraub, S., Mesulam, M. M., Reber, P. J., ... & O'Hara, M. (2015). Benefits of mindfulness training for patients with progressive cognitive decline and their caregivers. *American Journal of Alzheimer's Disease & Other Dementias®*, 30(3), 257-267.
- Parahoo K (2006) *Nursing Research – principles, process and issues* (2nd ed.). Palgrave, Houndsmill.
- Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'cathain, A., Griffiths, F., ... & Rousseau, M. C. (2011). Proposal: A mixed methods appraisal tool for systematic mixed studies reviews. *Montréal: McGill University*, 2, 1-8.

- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., ... & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version, 1*, b92.
- Radloff, S.L. (1997). The CES-D Scale: A Self-Report Depression Scale for Research in the General Population. *Applied Psychological Measurement*, 1(3), 385-401.
- Reisberg, B., & Gauthier, S. (2008). Current evidence for subjective cognitive impairment (SCI) as the pre-mild cognitive impairment (MCI) stage of subsequently manifest Alzheimer's disease. *International psychogeriatrics*, 20(1), 1-16.
- Robertson, G. (2015). Spirituality and ageing—the role of mindfulness in supporting people with dementia to live well. *Working with Older People*, 19(3), 123-133.
- Ryff, C. D., & Keyes, C. L. M. (1995). The structure of psychological well-being revisited. *Journal of personality and social psychology*, 69(4), 719.
- Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a reevaluation of the Life Orientation Test. *Journal of personality and social psychology*, 67(6), 1063.
- Seligman, M. E. P. (2011). *Flourish*. New York, NY: Simon & Schuster.
- Shankar, K. K., Walker, M., Frost, D., & Orrell, M. W. (1999). The development of a valid and reliable scale for rating anxiety in dementia (RAID). *Aging & Mental Health*, 3(1), 39-49.
- Spector, A., Thorgrimsen, L., Woods, R. T., & Orrell, M. (2006). *Making a difference: an evidence-based group programme to offer Cognitive Stimulation therapy (CST) to people with dementia*. London: Hawker Publications.
- Spielberger, C. D., Gorsuch, R. L., Lushene, R. E., Vagg, P. R., & Jacobs, G. A. (1970). *State-trait anxiety inventory*. Palo Alto, CA: Consulting Psychologists Press.

- Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of internal medicine*, 166(10), 1092-1097.
- Stevenson, A., & Soanes, C. (2008). *Concise Oxford English Dictionary* (11<sup>th</sup> ed., Revised). Oxford University Press, USA.
- Swannell, E. (2017). *Exploring mindfulness interventions for people with dementia and their family caregivers* (Doctoral dissertation, Canterbury Christ Church University).
- Teasdale, J. D., Segal, Z. V., Williams, J. M. G., Ridgeway, V. A., Soulsby, J. M., & Lau, M. A. (2000). Prevention of relapse/recurrence in major depression by mindfulness-based cognitive therapy. *Journal of consulting and clinical psychology*, 68(4), 615.
- Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S., ... & Stewart-Brown, S. (2007). The Warwick-Edinburgh mental well-being scale (WEMWBS): development and UK validation. *Health and Quality of life Outcomes*, 5(1), 63.
- Vernooij-Dassen, M., Vasse, E., Zuidema, S., Cohen-Mansfield, J., & Moyle, W. (2010). Psychosocial interventions for dementia patients in long-term care. *International Psychogeriatrics*, 22(7), 1121-1128.
- Wagnild, G. M., & Young, H. M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of nursing measurement*, 1(2), 165-178.
- Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: the PANAS scales. *Journal of personality and social psychology*, 54(6), 1063.
- Wells, R. E., Kerr, C. E., Wolkin, J., Dossett, M., Davis, R. B., Walsh, J., ... & Phillips, R. S. (2013). Meditation for adults with mild cognitive impairment: a pilot randomized trial. *Journal of the American Geriatrics Society*, 61(4), 642-645.

- Wetherell, J. L., Hershey, T., Hickman, S., Tate, S. R., Dixon, D., Bower, E. S., & Lenze, E. J. (2017). Mindfulness-Based Stress Reduction for Older Adults With Stress Disorders and Neurocognitive Difficulties: A Randomized Controlled Trial. *The Journal of clinical psychiatry*, 78(7), e734-e743.
- Wilson, R. S., Boyle, P. A., Segawa, E., Yu, L., Begeny, C. T., Anagnos, S. E., & Bennett, D. A. (2013). The influence of cognitive decline on wellbeing in old age. *Psychology and aging*, 28(2), 304.
- Wong, W. P., Coles, J., Chambers, R., Wu, D. B. C., & Hased, C. (2017). The Effects of Mindfulness on Older Adults with Mild Cognitive Impairment. *Journal of Alzheimer's Disease Reports*, 1(1), 181-193.
- Wong, W. P., Hased, C., Chambers, R., & Coles, J. (2016). The effects of mindfulness on persons with mild cognitive impairment: Protocol for a mixed-methods longitudinal study. *Frontiers in aging neuroscience*, 8(1), 156.
- World Health Organization: Regional Office for Europe (1998) *WellBeing measures in primary health care: The DepCare Project*. Consensus meeting, Stockholm
- Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M., & Leirer, V. O. (1982). Development and validation of a geriatric depression screening scale: a preliminary report. *Journal of psychiatric research*, 17(1), 37-49.

## **Part Two: Empirical Paper**

**A Mindfulness-based Intervention for Dementia Dyads: Understanding Dyadic  
Experience and Possible Adaptations**

Jennifer Adams\*, Dr Chris Clarke and Dr Emma Wolverson

School of Health and Social Work  
University of Hull, Hull, United Kingdom, HU6 7RX

\*Corresponding Author: Tel +7794154253

Email Address: [J.Adams@2015.hull.ac.uk](mailto:J.Adams@2015.hull.ac.uk)

This paper is written in the format reading for submission to the journal *Dementia*.

Please see Appendix E for the Guidelines for Authors

Word Count: 7,393 (excluding references and tables)

## **Abstract**

People living with dementia have often been excluded from research of mindfulness-based interventions. The journey of dementia is also increasingly being recognised as an interpersonal process that unfolds between the person living with dementia and their caregiver, and wider relationships, which suggests the importance of including dyads in psychological wellbeing interventions. The preliminary findings of some studies that investigate the use of mindfulness with people living with dementia are promising, and highlight some wellbeing benefits can be gained. This study sought to understand how mindfulness might impact on wellbeing for people living with dementia and their caregivers, and their experience of this from their perspectives. Three dementia dyads were recruited to the study and engaged in an adapted mindfulness-based intervention, with qualitative data collected before, during and after. Data was analysed using thematic analysis, which led to the identification of four superordinate and eleven subordinate themes. The findings describe a process of integrating mindfulness into daily life, which led to a broader understanding of mindfulness as ‘a way of life’. Wellbeing effects were also identified, including positive effects on the relationship, improved stress, increased awareness and increased gratitude. The study also highlights the importance of not only dementia and ageing related adaptations, but also person-centred adaptations. The essential personal resources of dyads before engaging in such an intervention are also considered. The findings are discussed in the relation to wider literature on dementia, ageing and mindfulness and the clinical and research implications for future interventions.

**Keywords:** dementia, dementia dyads, mindfulness, wellbeing

## **Introduction**

Historically, the subjective wellbeing of People Living with Dementia (PLwD) has largely been overlooked, in light of the assumption that wellbeing will inevitably decline as neurodegeneration progresses. Alternative discourses suggest wellbeing in dementia can be understood using a person-centred approach, whereby personhood is sustained through social relationships (Kitwood, 1997).

Psychosocial interventions, such as cognitive stimulation, physical activities and behavioural management (Vernooij-Dassen, Vasse, Zuidema, Cohen-Mansfield & Moyle, 2010) have been demonstrated to improve wellbeing in dementia, but less is known about the applicability of specific wellbeing focused interventions. Mindfulness-based interventions (MBIs), based on training mindfulness skills through meditation exercises (Baer, 2003) such as Mindfulness Based Stress Reduction (MBSR; Kabat-Zinn, 1990) and Mindfulness Based Cognitive Therapy (MBCT; Teasdale, Segal, Williams, Ridgeway, Soulsby & Lau, 2000), have been adapted to meet the needs of multiple populations including people living with physical illnesses and psychiatric diagnoses, resulting in improved Quality of Life (QoL) and wellbeing (Fjorback, Arendt, Ørnbøl, Fink & Walach, 2011).

Evidence for using MBIs with older people is steadily growing (Young & Baime, 2010). However, this has often excluded people with cognitive impairments (e.g. Meeten, Whiting & Williams 2015). Research has begun to investigate the effects of mindfulness with older people in relation to cognitive functioning (for example see Smart, Segalowitz, Mulligan, Koudys & Gawryluk, 2016), the potential of MBIs to improve PLwD's wellbeing has yet to be thoroughly investigated. The rationale for this exclusion is rarely provided, but may reflect assumptions about the ability of PLwD to

follow a mindfulness protocol. Research has suggested adults with cognitive impairments as a result of brain injury have engaged well with mindfulness and reported wellbeing benefits when appropriate adaptations have been implemented (Bédard et al., 2014).

A pilot study assessed the feasibility and impact of a standard MBSR course for 12 PLwD and eight caregivers (Leader, Litherland & Mason, 2013). PLwD learned mindfulness and experienced increased wellbeing across various domains (Leader, Litherland & Mason, 2013). In a more formal evaluation, Churcher-Clarke, Chan, Stott, Royan & Spector (2017) randomly allocated PLwD in care homes to intervention plus treatment as usual (TAU) ( $n = 20$ ) or TAU ( $n = 11$ ). Analysis revealed a significant improvement in Quality of Life (QoL) for the intervention group compared to controls. This study made adaptations including increased modelling, modified scripts, more frequent sessions and smaller groups, which demonstrates the potential for developing an effective yet tailored intervention. However, the experiences of PLwD when practising mindfulness have not yet been thoroughly explored.

The journey of dementia is increasingly being recognised as an interpersonal process that unfolds between the PLwD and their primary caregivers, and wider relationships. Living with dementia affects both individual and shared factors in the caregiving relationship, including reciprocal interactions and interdependence (Moon & Adams, 2012). Several studies have demonstrated the effectiveness of MBIs for dementia caregivers (for a review see Hurley, Patterson & Cooley, 2014). As dementia research focuses more on dyads, this approach is becoming more widely recognized as key to understanding the wellbeing of PLwD, by involving both members in interventions (see Daniels, Lamson & Hodgson, 2007), which is in keeping with Kitwood's theory that

PLwD need to connect with others socially to maintain wellbeing. A study by Paller et al. (2015) delivered an adapted MBSR protocol to dyads, which led to QoL and depression scores significantly improving for patients and caregivers from pre-post intervention. In addition, 50% of participants reported improvements in relationships, which suggests MBIs impact the dyadic relationship.

Whilst the findings of these studies are promising, a key question which has not yet been completely addressed is: *how* might mindfulness impact on wellbeing for PLwD and their caregivers, from their perspectives? This has implications for the implementation of MBIs in dementia, such as what aspects affect the success of these programmes and how to maximise engagement in them.

In this study, data was collated from the perspective of the dyads, facilitators and researcher, in accordance with a Participatory Action Research (PAR) approach (McIntyre, 2008) which values the perspectives of everyone involved equally. Over the past two decades the active involvement of service users in designing, delivering and disseminating research in health and social care has become a priority with one reason being to improve the relevance of research for those it is aimed to benefit by creating more meaningful results (Szmukler, Staley & Kabir, 2011). Trivedi & Wykes (2002) suggest studies which aim to increase user empowerment are particularly suitable for involving users as partners in research. Allowing service users to make decisions about the design and measures of a study can be a move towards liberating those service users from stigma and exclusion (Smukler, Stanley & Kabir, 2011), which corresponds to a principle of PAR which is to give a voice and power to disenfranchised populations (McIntyre, 2008).

The aim of the study was to provide not only an understanding of *how* mindfulness impacts on wellbeing for dementia dyads, but also how facilitators experience developing and delivering the intervention, so that future interventions can be tailored to meet everyone's needs. The two primary questions this study sought to answer were: (1) How do dyads (where one person is living with dementia) engage with and experience the practice of mindfulness over the course of an adapted mindfulness intervention? (2) How does practising mindfulness impact on subjective wellbeing in the context of dementia and how do dyads experience this? An overview of the intervention sessions and the adaptations made to standardised MBSR will also be outlined.

## **Method**

### ***Sample***

Participants were recruited from the community via posters, word of mouth, and social media in the North of England. Table 3 shows the inclusion and exclusion criteria for participants recruited to the study. The study aimed to recruit no more than five dementia dyads to optimise group engagement and learning.

Table 3. *Inclusion and Exclusion Criteria for Study*

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
<p>Participants included both one person with dementia and their primary caregiver. Caregiver status was self-reported by dyads, rather than based on criteria such as number of hours caregiving.</p>	<p>Being assessed to not have capacity to consent to partake as judged by the primary research.</p>
<p>One member had a self-reported diagnosis of dementia.</p>	<p>Not wanting to take part (including if only one member of the dyad was not willing).</p>
<p>Both members had mental capacity to make the decision to participate and remain involved in the study.</p>	<p>And having previously taken part in a formal mindfulness intervention such as MBSR or MBCT.</p>
<p>Both must have been willing participants and engage in the intervention voluntarily.</p>	
<p>Sufficient fluency in English to contribute to the focus group and understand the content of the course.</p>	

Table 4 shows the characteristics of participants recruited to the study.

Table 4. *Summary of Participant Demographics.*

<b>Pseudonym</b>	<b>Ethnicity</b>	<b>Status</b>	<b>Relationship</b>	<b>Age</b>	<b>Years together</b>	<b>Diagnosis</b>	<b>Years since diagnosis</b>
<b>Stephen</b>	White British	Carer	Husband	70	48y		
<b>Rose</b>	White British	PLwD	Wife	72		Alzheimer's	5y 8m
<b>George</b>	White British	Carer	Husband	72	46y		
<b>Elizabeth</b>	White British	PLwD	Wife	68		MCI/ Alzheimer's	10y
<b>Sarah</b>	White British	Carer	Daughter	46	n/a		
<b>Martin</b>	White British	PLwD	Father	81	n/a	Mixed dementia	10y

### **Design & Data Collection**

This study took a qualitative design, guided by principles of Participatory Action Research (PAR), whereby through the cyclical process of exploration, knowledge construction and research, research questions are re-contextualised in terms of participant's involvement (McIntyre, 2008). The approach combines the research expertise of the researcher with the expertise of experience of the participants, which this study sought to do by determining adaptations to the intervention as indicated by researcher, facilitators and participants. See Appendix U for complete adaptations list.

Qualitative data was collated from a range of sources at multiple time points. An iterative and constant comparative approach was utilised whereby data was coded and

analysed in parallel with the intervention, as informed by Grounded Theory (Charmaz, 2006), in order to build an account of the dyads and facilitators experiences of the course, and to understand the effects of this on wellbeing.

### **Procedure**

The study was reviewed and approved by the School of Health and Social Work Research Ethics Committee, University of Hull (see appendix I). The primary researcher met each dyad to explain the purpose of the research, assess capacity and gain written informed consent.

### ***Facilitators***

Two qualified facilitators delivered the sessions. Both had completed mindfulness teacher training, engaged in their own mindfulness practice, and had personal experiences of dementia. On one occasion another experienced facilitator substituted. The facilitators were jointly supervised during the set-up and delivery of the course through the UK Mindfulness Association. The facilitators were interviewed about their experiences after the intervention (see Appendix R for schedule).

Two volunteers with their own mindfulness practice and qualifications were also present, serving refreshments and participating in sessions.

The primary researcher was a Trainee Clinical Psychologist who had attended an MBSR course and engaged in their own mindfulness practice. They attended all sessions, engaged in the group and recorded written observations and reflections.

### ***Materials and Measures***

Schedules for the focus group and subsequent interviews were developed based on key codes identified in the data throughout the course. A handout containing two questions was developed and distributed to dyads at the end of each session. Each dyad received a free copy of the book 'Finding Peace in a Frantic World' and a CD alongside handouts developed by the facilitators summarising corresponding chapters of the book and homework tasks (see Appendix T for example). The facilitators also recorded and distributed another CD with additional practices including 'kindness for self and other' recorded by the facilitators, and two recordings from the Mindfulness Association including 'self-compassion break' and 'R.A.I.N. practice for dealing with difficulties'.

### ***Introductory Session/Focus Group***

An introductory session held by the two facilitators lasted one hour. During which a focus group was held for one hour involving the primary researcher, course facilitators, two additional volunteers and three dementia dyads. The session was audio recorded and transcribed for analysis. This explored the group's expectations of practising mindfulness and what support they anticipated to ensure the intervention was person-centred. This information was used to adapt the intervention. See Appendix L for focus group schedule.

### ***Intervention***

All sessions took place in a quiet setting, in a local community church hall.

The intervention was based on an established MBSR protocol (Williams & Penman, 2011). Eight two-hour sessions were delivered including a short break. The day before each session dyads received an email reminder (see Appendix O). Each session included a check-in, an introduction to a new aspect of mindfulness, formal practices such as

Mindful Breathing, and informal practice such as homework tasks and specified meditations. Participants were encouraged to try and practice for an hour each day. See Appendix S for summary of intervention content.

At the end of each session, the researcher presented each dyad two printed questions (see Appendix N):

1. How have you found the course so far?
2. What effects, if any, have you noticed since starting the course?

### ***Dyad Interviews***

The primary researcher interviewed dyads after the final session and one month post-intervention. Interviews were semi-structured (see Appendices P & Q for interview schedules) and covered topics such as the effects of practising mindfulness, evaluations of the course, the practice of mindfulness and understanding mindfulness.

### ***Analysis***

Thematic analysis was used to analyse the data which was combined from all sources. Data from the various sources and time-frames of the intervention (i.e. pre, during and post) were analysed as a whole, as this was consistent with the PAR approach. This led to the identification of superordinate and subordinate themes (Braun & Clarke, 2006). See Table 5 detailing the analytic process. The approach was inductive, meaning themes were identified from the data, rather than being informed by theories and models (Patton, 1990). This analysis was informed by a Constructivist Grounded Theory approach (Charmaz, 2006), underpinned by the use of a constant comparative method being taken to the data, which guided data collection and analysis. The primary

researcher identified initial codes based on the data gathered at the focus group and each session, which informed how the intervention was delivered and the interview topics.

Table 5. *Process of thematic analysis (Braun and Clarke, 2006, p87).*

<b>Phase</b>	<b>Description of the process</b>
<b>1. Familiarizing yourself with your data:</b>	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
<b>2. Generating initial codes:</b>	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
<b>3. Searching for themes:</b>	Collating codes into potential themes, gathering all data relevant to each potential theme.
<b>4. Reviewing themes:</b>	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis.
<b>5. Defining and naming themes:</b>	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
<b>6. Producing the report:</b>	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

## **Results**

Only one dyad attended the full course (George and Elizabeth). Sarah and Martin withdrew after Week 1 due to health problems. Stephen and Rose withdrew after Week 4, also due to health problems, but participated in Week 5 at home. They stated they would continue using mindfulness where possible while unable to attend the course, therefore materials for each week were emailed.

The recruitment of only three dyads and a high attrition rate during the intervention led to data saturation not being sufficiently reached, which is fundamental for developing a theory using Constructivist Grounded Theory (Charmaz, 2006). Therefore, a Thematic Analysis approach (Braun & Clarke, 2006) was adopted as a more conservative way to analyse the data and answer the research questions. The Thematic Analysis was guided by Grounded Theory principles and approaches using a constant comparative analysis during the course.

Thematic analysis revealed four overarching themes in the data: *Making Sense of Mindfulness, Impact on Wellbeing, Group Processes* and *Essentials of Mindfulness for Dementia Dyads*. Each theme was represented longitudinally within the data set. The processes they described developed over time from pre-intervention to post-intervention. Table 6 shows the superordinate and subordinate themes and an illustrative quote from each.

Table 6. *Summary of superordinate themes, subordinate themes and illustrative quotes*

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>	<b>Illustrative Quote</b>
Making Sense of Mindfulness	Incorporating mindfulness into life	<i>'We have also incorporated mindfulness into our daily walks, which has provided a clearer appreciation of our surroundings; the dawn chorus, the geese with their young...'</i> (Stephen, carer & Rose, PLwD)
	Meanings of mindfulness	<i>'I do think it's a way of living...'</i> (Elizabeth, PLwD)
Impact on Wellbeing	Noticing the effects	<i>'We're working together better.'</i> (George, carer)
	Gratitude	<i>'...we're in a pretty fortunate position that we've got good physical health...'</i> (George, carer)
	Facilitator benefits	<i>'I found it really quite humbling...'</i> (Facilitator 2)
Group Processes	Being in a group	<i>'...so many nice people... I'm not alone in this.'</i> (Martin, PLwD)
	Mindfulness as a dyad	<i>'...it's a very good opportunity for us both to work together.'</i> (Rose, PLwD)
Essentials of Mindfulness for Dementia Dyads	Adaptations and accommodations	<i>'They're very good [foam blocks] ... it's more comfortable.'</i> (Elizabeth, PLwD)
	Preparedness	<i>'...we didn't think that the subject was as extensive...'</i> (Stephen, carer)
	Difficulties	<i>'...you could see how that noise level was sort of making [Martin] feel agitated...'</i> (Facilitator 1)
	Motivation to practice	<i>'..[mindfulness] could be powerful enough to undo things... physical problems, medical problems...'</i> (George, carer)

### ***Theme One: Making Sense of Mindfulness***

The superordinate theme *Making Sense of Mindfulness* captures participants' individual and shared experiences of meaning-making with respect to the construct of mindfulness.

This underpinned their evolving engagement in the practice of mindfulness.

#### *Incorporating Mindfulness into Life*

To develop and make sense of mindfulness, dyads had to *incorporate it into their lives*.

This was done through a structured approach and embedding mindfulness into their routines as a dyad. Particularly for Stephen and Rose, this process began early on in the course and developed throughout as they continued to find new ways to incorporate mindfulness into their lives after the course had finished

‘Mindfulness is now becoming part of our daily routine...’ (Week 1, Stephen, carer &  
Rose, PLwD,

‘...we could use time set aside for our nap...’ (Post-course, Stephen, carer

Initially, dyads engaged in mindfulness practices as instructed by facilitators, but over time they tailored this, engaging more in the practices that suited them as a couple and using mindfulness in line with their values:

‘We have practised regularly ’10 breaths’... and the ‘body scan’ meditation.’ (Week 2,  
Stephen, carer & Rose, PLwD)

‘This just is unnecessary you’ve got to find somebody who’s a problem...’ (Post-  
course, George, carer,

‘I still prefer that kindness one, especially to do with in our situations.’ (Post-course,  
George, carer,

After the course, dyads continued developing more ways to incorporate mindfulness into their lives, but also by making room for mindfulness by changing their routines. An example of this was by finding times in the day when the benefits of the practices were most useful to them, or places they had visited where they would enjoy meditating:

‘...a good time for me to practice which was around 4...’ (Post-course, Stephen, carer)

‘And those waves... a good place to meditate I think.’ (Post-course, Stephen, carer)

The dyads also gave examples of using mindfulness informally, and applying mindfulness to novel situations which had not been covered during the course, such as by becoming more aware and appreciative of their natural environment. This was made possible by their developing their understanding of mindfulness and how it worked for them. Stephen and Rose began this process very early in the course, whereas George and Elizabeth developed their understanding more slowly and showed greater awareness later in the course. Both couples made reference to applying mindfulness to novel situations more frequently after the course. Evidence of this process can be seen below:

‘We have also incorporated mindfulness into our daily walks, which has provided a clearer appreciation of our surroundings; the dawn chorus, the geese with their young...’ (Week 2, Stephen, carer & Rose, PLwD)

‘Noticing the difference between the pleasure of being near trees compared to traffic fumes...’ (Week 7, George, carer; Elizabeth & PLwD)

‘...you can get frustrated and want to put your foot down on the motorway but, the thought then is just to ease off and settle down...’ (Post-course, Stephen, carer)

### *Meanings of Mindfulness*

It was through the repetitive practice of both formal and informal mindfulness that participants made sense of what mindfulness was and how it was or could be important to them across the course. This longitudinal process can be seen in the data:

‘... developing a clearer understanding...’ (Week 2, George, carer & Elizabeth, PLwD)

‘...now I know more about it with doing the course... I might be able to understand [the book] more.’ (Post-course, George, carer)

After the course, the couples and facilitators regarded it as having been an introduction to mindfulness which would remain in their lives beyond the course, with the intention that personal practice in the future would lead to more sense-making and understanding of mindfulness:

‘...it’s long enough to plant a seed that could take root ...’ (Post-course, Facilitator 1)

‘...you would regard it as an introduction...’ (Post-course, Stephen, carer)

Throughout the intervention process, participants were asked about their understanding of mindfulness. Prior to the course, they referred to it as a skill, ‘I’m really looking forward to learning a new skill’ (pre-course, Sarah, carer), which reflected how it was introduced by the facilitators. Both dyads who participated in the post-course interviews found describing mindfulness difficult, but their definitions of mindfulness had shifted, suggesting it was much broader –a way of living. This broader understanding seemed to reflect that they were able to learn about mindfulness by doing it, rather than just learning about it from a book: ‘I do think it’s a way of living...’ (Post-course, Elizabeth,

PLwD)

...‘I just knew that it’s a nice way of living...’ (Post-course, George, carer)

Mindfulness was also conceptualised as a tool for managing difficulties, particularly in relation to living with dementia as a dyad, which developed through consistent practice.

This understanding was mirrored by the facilitators:

‘It’s the toolbox for erm, handling circumstances...’ (Post-course, Stephen, carer)

‘...giving people a tool that helps them live with it [dementia] is the bottom line...’

(Post-course, Facilitator 1)

Both Stephen and Rose, and George and Elizabeth repeatedly spoke about mindfulness as increasing awareness and living in the present moment, consistent with standard definitions:

‘...being in the present rather than the past...’ (Post-course, George, carer)

After the course, Elizabeth expressed a different understanding of mindfulness to her husband. She understood mindfulness as being ‘cautious’ in new situations. George initially disagreed, wondering if Elizabeth had misunderstood. However, George’s understanding began to align with Elizabeth’s when he drew parallels with his interpretations of mindfulness being about developing awareness. This suggested that although the dyads had their own understandings of what mindfulness meant to them personally, their understanding developed into a shared dyadic experience when they shared their interpretations:

George (carer): ‘...it’s two different meanings ...’

Elizabeth (PLwD): ‘...it’s about being conscious of of people around also mindful of  
what you want to do...’

George (carer): ‘I suppose it does come into it... I suppose you’re right...’

Throughout the course the dyads expressed concerns about whether they were practising mindfulness ‘well enough’ and that there might be a right or wrong way, which continued after the course. Stephen highlighted his experiences of attempting to ‘succeed’ in meditation before the course even began. The dyads expressed their commitment to using mindfulness to improve their lives, which they continued to do whilst tolerating doubts about their shared ability to ‘master’ it. They also showed less criticism of themselves after the course, as their understanding of there not being a wrong way to practice developed

‘I tried to get into it, but I haven’t succeeded...’ (Pre-course, Stephen, carer)

‘...[mind wandering] that’s where I was going wrong...’ (Post-course, George, carer)

‘...the important bit it... don’t be hard on yourself, just gradually bring the mind back.’

(Post-course, George, carer)

### ***Theme Two: Impact on Wellbeing***

The second superordinate theme relates to the reported *impact on wellbeing*, for both participants *and* facilitators, which appeared reciprocally linked with the first superordinate theme. As participants developed their understanding and practice of mindfulness, individually and together, this led to positive effects on their wellbeing. This strengthened their practice, which led to further development of their understanding.

### *Noticing the Effects*

There was a general sense that practising was beneficial, but also some uncertainty in regard to what impact mindfulness practice had, and would have in the future. The dyads and facilitators also commented on a range of effects they had recognised, which fell into several categories. These included specific benefits to carers, involving increased awareness and becoming a better carer. These possible effects were reflected on throughout the course, but were clearer to the participants upon completion.

‘Feel confidence that mindfulness will help me be happier and more relaxed.’ (Week 6,  
George, carer)

‘It has provided me and us with a more clear understanding of where we’re at ...’ (Post-  
course, Stephen, carer)

After the course, both couples commented on the positive impact on their dyadic relationships:

‘We’re working together better.’ (George, carer)

Stephen (carer): ‘We are spending more time together now...’

Rose (PLwD): ‘... We’re getting there aren’t we?’

Stephen and Rose repeatedly spoke about how their development of mindfulness led them to re-evaluate their lives and reprioritise what was important in their relationship. Since Rose’s diagnosis, they had continued their lives as normal, which they later understood as being ‘in denial’ of how living with dementia may affect them. They

stated that since gaining greater clarity and awareness of the challenges they faced as a result of practising mindfulness, they decided on some significant changes, including Stephen retiring so they could spend more time together:

‘...the idea is that we spend our days together, we get up together... get dressed together...’ (Post-course, Stephen, carer)

Some more wellbeing benefits were experienced by individuals, such as a growing awareness, confidence, feelings of relaxation and calmness:

‘[Stephen] Noticed feeling of being connected with whole body...’ (Week 3, Researcher observation)

‘I have time to consider myself and other people.’ (Post-course, Elizabeth, PLwD)

### *Gratitude*

Throughout the intervention, dyads described increasing feelings of gratitude which appeared to be facilitated by broadening awareness of the positive aspects of their lives and environments. Things people were grateful for included the aspects of the intervention, health and the environment. The things the dyads described feeling grateful for increased as they progressed through the course:

‘...we are grateful for [the facilitators] commitment’ (Week 1, Stephen, carer & Rose, PLwD)

‘Dyads experienced gratitude for fitness compared to peers’ (Week 3, Researcher observation)

‘...we’re in a pretty fortunate position that we’ve got good physical health...’ (Post-course, George, carer)

‘...how they could appreciate nature.’ (Post-course, Facilitator 1)

### *Facilitator Benefits*

Although the course was delivered to the dyads to provide them with skills to positively affect their wellbeing, the facilitators also experienced benefits, on a personal and professional level, which they spoke about after completing the course:

‘...we’re getting more skilled.’ (Facilitator 1)

‘I found it really quite humbling...’ (Facilitator 2)

### ***Theme Three: Group Processes***

Themes three and four are also connected, in that they describe the dyads and facilitators experiences of the course itself, which have been separated into group processes (theme three) and content (theme four). This theme conveyed the experiences of the course and the group for the participants, and in particular the importance of connecting with others.

### *Being in a Group*

All dyads made reference to preferring being in a group and the benefits of this. There was also a sense of people connecting within the group, as a result of their shared experiences of living with dementia and finding other people with similar values. Although Martin sometimes struggled to remember the purpose of the course, the positive experience of feeling connected to others was evident from even before the course began and continued throughout:

‘...so many nice people... I’m not alone in this.’ (Pre-course, Martin, PLwD)

‘Dad enjoys being part of a group’ (Week 1, Sarah, carer)

‘...it’s helpful for me... to go to places where other people with dementia are...’ (Post-course, Rose, PLwD)

### *Mindfulness as a Dyad*

Particularly after the course had ended, participants commented on their experiences of attending and practising mindfulness as a dyad. Early on, the researcher observed that both Stephen and Rose, and George and Elizabeth, reported practising mindfulness meditations together; however, as time went on and life became hectic because of work, Stephen and Rose began practising at different times. They commented at the end of the course ‘...we need to do it together really don’t we?’ which aligned with their newly envisaged way of living together. Generally the dyads spoke about how it worked to practice together and the positive impact of this on their relationships:

‘...it’s a very good opportunity for us both to work together.’ (Post-course, Rose, PLwD)

George (carer): ‘...you know we’re happy to do it together...’

Elizabeth (PLwD): ‘It’s worked.’ (Post-course)

All participants preferred attending the intervention together. Several had experiences of other groups which did not allow them to do so, whereas being able to attend together benefitted their shared sense of wellbeing:

[attending together] ‘...that’s how we wanted it.’ (Post-course, George, carer)

Within this theme was the only instance of conflict in opinion between participants and facilitators. Although the facilitators recognised the self-reported benefits of dyads attending together, the facilitators framed their plans for a future course as separating dyads to enable both parties to speak more freely about the difficulties living with dementia may cause within their relationships

‘...the carers didn’t get an opportunity to talk about how they deal with day to day frustrations...’ (Post-course, Facilitator 2)

#### ***Theme Four: Essentials of Mindfulness for Dementia Dyads***

The fourth theme can be understood as aspects of the course and dyads’ shared resources that were essential for them to engage with the adapted intervention, which were described by both dyads and facilitators.

##### *Adaptations and Accommodations*

Through a person-centred approach, adaptations were made to the intervention. Some adaptations were established prior to the course, such as the worksheets which two dyads deemed helpful, whereas others were implemented throughout as a result of weekly feedback. Finally, some were decided based on feedback after the course. Dyads reviewed their experiences of engaging with the adapted mindfulness resources as generally positive and that they benefitted both members of the dyad (not just those living with dementia) by facilitating their understanding of some difficult concepts, particularly as those living with dementia often struggled to retain information from the book. This feedback was most frequently given after the course

...‘the worksheets really provided clarity...’ (Post-course, Stephen, carer)

‘[George] would remember more about the book than I would... I found it interesting reading.’ (Post-course, Elizabeth, PLwD)

Creating a sense of safety and comfort was important within the group. It was often attention to a very small person-centred adaptation which allowed an individual to be supported. For example, Elizabeth commented on the foam blocks the facilitators provided which enabled her to reach the floor, making meditations more comfortable:

‘They’re very good [foam blocks]... it’s more comfortable.’ (Post-course, Elizabeth, PLwD)

Participants also commented on the use of ground rules set collaboratively by the group before the course began, which the facilitators would not usually include:

‘...you should start the ground rules to say that what is said here doesn’t go any further.’  
(Post-course, George, carer)

One adaptation the facilitators decided before the course began was the use of additional visual prompts and ‘anchors’, to facilitate the learning of PLwD:

‘...the more anchors that you have er the better...’ (Post-course, Facilitator 2)

‘We used the whiteboard and diagrams a lot...’ (Post-course, Facilitator 1)

The facilitators shared more stories about their own difficulties with the group than usual. The purpose of this was to balance power between themselves and the dyads, so they felt comfortable to share and to apply mindfulness to difficult situations:

‘...tried to be honest about things going on in our life to encourage them to see that it’s ok to talk about those things.’ (Post-course, Facilitator 2)

### *Preparedness*

One theme dyads and facilitators spoke about was preparedness. Dyads did not feel prepared for the course before it began, particularly the intensity of learning and content covered, and how much was required of them between sessions. Unexpectedly, this was highlighted most by the carers at several time points, including during the initial taster session and after the course had finished:

‘I’m conscious of the amount of information....’ (Pre-course, Sarah, carer)

‘...we didn’t think that the subject was as extensive...’ (Post-course, Stephen, carer)

Again, small actions led to people feeling more prepared on smaller, person-centred levels. This had not been explicitly considered by the facilitators when designing the intervention, but was experienced as important by the participants both during and after:

‘...I was pleased that you told us that we’d take our shoes off...’ (Post-course, George, carer)

### *Difficulties*

Dyads commented on another feature they had not anticipated, which was struggling to find time to practice mindfulness. Dyads actively set aside dedicated time for their mindfulness practice throughout the course, fitting it into their current routines:

‘...it’s setting aside the time to do it...’ (Post-course, Elizabeth, PLwD)

Dyads seemed to find difficulty setting aside a regular time, as general life got in the way, for example housework and illness:

‘I was too busy tidying the house up.’ (Post-course, George, carer)

They commented on when it was more or less possible to find time to practice. George and Elizabeth were retired and had stable health, which meant they had more flexibility and time, whereas Stephen and Rose were still working and Stephen experienced health problems, which they reflected made finding time more difficult:

‘...now I’m older I’ve got time to sit down and meditate...’ (Post-course, George, carer)

‘You’re going to be retired very soon we’d have much more time.’ (Post-course, Rose, PLwD)

Not only did the dyads have difficulties finding time to practice, but difficulties ran through the course, due to the challenges living with dementia presents, but also more generally in relation to making changes in the dyads lives. Most difficulties were reflected on after the course had ended, however Sarah pre-empted some possible difficulties for her dad at the beginning

‘Distractions make it difficult for Dad...’ (Week 1, Sarah, carer)

However, the dyads managed these difficulties and overcame them through their learning and practice. The majority of concerns and difficulties were actually identified by the facilitators, in relation to their expectations and anxieties about how the PLwD might manage the course:

‘...you could see how that noise level was sort of making [Martin] feel agitated...’

(Post-course, Facilitator 1)

Upon reflection, the facilitators commented on how these anxieties which they thought were specific to running a mindfulness course for PLwD were anxieties you might have with *any* mindfulness course, irrespective of the participants:

‘We knew it was going to be challenging the inquiry, but you never know what’s going to come in inquiry...’ (Post-course, Facilitator 1)

‘...how to respond to people when they erm, actually all of us do it, but when you think ‘where’s the thread going?’ (Post-course, Facilitator 2)

### *Motivation to Practice*

Essential to engaging with the practice was motivation. Participants shared their hopes and expectations about how mindfulness might impact their lives, help them to manage anxiety and stress, and increase their shared happiness, particularly in the context of living with dementia:

‘Hoping that I deal with stress better...’ (Pre-course, Sarah, carer)

‘Frustration at Alzheimer’s. Hoping mindfulness will help.’ (Week 2 Researcher observation)’

There was also a sense that the course was the beginning of a journey of mindfulness. Dyads had hopes and expectations at the start, but also at the end of the course, and they spoke about how being able to use mindfulness gave them a sense of hope for the future:

‘..[mindfulness] could be powerful enough to undo things... physical problems, medical problems...’ (Post-course, George, carer)

After the course, dyads reviewed whether these expectations had been met. Experiencing the effects of mindfulness, particularly in relation to what they had initially hoped to get from it increased their motivation to continue practising together:

‘It’s probably done better than I’d expected’ (Post-course, George, carer)

‘...I put “to learn to be an effective carer”... it’s certainly done that.’ (Post-course, George, carer)

Interestingly, both dyads who were interviewed mentioned close friends or family who also practiced mindfulness, and how they had seen the positive effects of this, which may be linked to their expectations of what benefits mindfulness might have for them and therefore increased their motivation to continue their practice. Stephen and Rose’s family member had practiced mindfulness for a long time, and they felt they could learn more from them about mindfulness and practice together. George and Elizabeth also

spoke of a friend who practiced mindfulness for their mental health difficulties and they were moved by the profound impact of this:

‘... the one thing she says that did it was mindfulness...’ (Post-course, George, carer)

Another motivating factor was preparing for the future. Dyads expressed an expectation that things may become more difficult due to age- and dementia-related challenges and that mindfulness would be an important tool to have:

‘...especially if we became less mobile...’ (Post-course, George, carer)

‘...I think it’s important for me to carry on [mindfulness] to handle that sort of thing.’

(Post-course, Stephen, carer)

## **Discussion**

### ***Summary of Findings***

The purpose of this research was to address gaps in the literature focusing on the experiences of dementia dyads during and after an adapted mindfulness intervention and to understand how practising mindfulness impacts on dyadic wellbeing in the context of dementia.

Participants described positive experiences of attending and learning mindfulness.

Themes 1 and 3 describe how dementia dyads experienced the intervention. These themes outline a cyclical learning process for dyads involving learning information during the sessions, reflecting on these experiences in inquiry, integrating this into their understandings of mindfulness and then applying this to novel situations. This process is reflected in literature pertaining to learning cycle theories, whereby learning is

understood as an experiential process, grounded in continued experience (Kolb, 2014). This process is also consistent with literature that states considerable repetition and practice are key to learning new skills for PLwD (Ries, 2018), which may have implications for how MBIs are adapted to aid learning for PLwD in future.

Another important finding is that although the MBSR-protocol this intervention was based on portrays secular mindfulness as a skill, dyads understood mindfulness as a 'way of life', which bears a strong resemblance to ancient Buddhist conceptualisations (Gunaratana, 1993). This suggests that taking part in a mindfulness course can be a process of learning and discovery for dementia dyads, which goes beyond their initial expectations of simply learning a new skill.

The only instance of a significant difference of opinion between the various parties involved was that all dyads had commented on the benefits of attending the course as a couple, whereas the facilitators planned to separate dyads in a future course as they felt carers needed time to 'off-load' about the challenges of dementia in light of their relationships without the PLwD being present. This issue was not highlighted by any of the participants, although this could have been because the two couples who were interviewed post-intervention had not encountered significant relational problems in light of living with dementia. Additionally, the purpose of the intervention was to learn mindfulness, rather than be a support group.

This is also important to consider when designing MBIs in the future as a recent review of dyadic vs. carer-focused multicomponent interventions in dementia did not identify a significant difference in outcomes (Laver, Milte, Dyer & Crotty, 2017), therefore the dyads' reported benefits of attending together are important to note

The wellbeing effects described by participants, such as improved stress and increased awareness, are consistent with the extensive literature on the impact of MBIs for dementia caregivers (Kor, Chien, Liu & Lai, 2017). The theme of gratitude, notably increased appreciation of health, highlights a strength of the dyads and their resilience in the face of the challenges of living with dementia (Harris, 2008). Gratitude is known to be foundational to wellbeing and mental health by increasing positive affect (Emmons & Mishra, 2011). Recent research on the role of gratitude in dementia suggests more gratitude in familial dementia caregivers leads to better coping and psychological resources and lower levels of psychological distress (Lau & Cheng, 2017). These findings suggest that incorporating gratitude exercises into future MBIs for dementia dyads could positively impact their shared wellbeing and ability to cope.

There has been much interest in the necessary adaptations needed to engage PLwD in mindfulness. A manual for delivering an adapted MBI to PLwD has been developed (Chan, Churcher Clarke, Royan, Stott & Spector, 2017) which suggests adaptations should be made to the intervention itself. This is consistent with the current findings and the experiences of the dyads. However, this study also emphasises the importance of individual adaptations which had a significant effect on how participants experienced the course. This study used principles from Participatory Action Research, allowing dyads the opportunity to shape and tailor the adaptations, rather than utilising a one-size-fits-all approach. The findings from this study indicate that adaptations can be co-produced with dyads and applied alongside them, rather than to them. Adaptations were not necessarily dementia or even ageing-specific, but highlights how crucial person-centred adaptations can be, and therefore the importance of not assuming all PLwD, or

carers, have the same needs, as is in keeping with Kitwood's (1997) domains of wellbeing.

An aspect that manuals have not included to date is the importance of the personal resources of dementia dyads engaging in such an intervention, such as finding time, both to attend the intervention and to practice at home. This is consistent with other studies which have commented on the high number of possible participants unable to engage in their study due to the time commitment (e.g. Berk, Hotterbeekx, van Os & van Boxtel, 2017). The dyads in this study emphasised the intensity of the course and a lack of preparedness, which may indicate future studies should consider screening participants for resources such as motivation before they engage in an MBI. This may in part explain why recruitment and retention were challenges in this study. Furthermore, if dyads need to find ways to incorporate mindfulness into their lives, this may not be appropriate for carers with high levels of burden and stress, or facilitators may be required to support dyads with this directly.

### ***Strengths and Limitations***

A strength of this study is the use of PAR principles, within the practical restrictions of a time-limited research project. The expertise of the researcher, facilitators and participants were integrated to identify the most appropriate way to deliver the intervention, which changed over time in light of their combined experiences with the course. This study highlights the capacity of PLwD to not only take part in research, but to be involved in the design and delivery.

As MBIs become more popular criticisms have emerged about the quality of research (Davidson & Kaszniak, 2015). Recent literature suggests the quality of mindfulness

research is not improving (Goldberg, Tucker, Greene, Simpson, Kearney & Davidson, 2017). In this regard, a strength of this study was the qualifications of the facilitators and their engagement in supervision, as this should have increased the quality of the intervention. Most research in this area has gathered largely quantitative data using standardised measures, with the inclusion of some exit interviews, the results of which have often not been integrated into the analysis (see Paller et al., 2015). Therefore this study has provided a rich account of the experiences of dyads and *how* wellbeing effects occur, rather than only a description of what they are. A final strength was the far-reaching implications of the course for participants. Both dyads who were interviewed conceptualised mindfulness as a ‘way of life’, and this led one couple to prioritise their relationship in light of living with dementia, rather than continuing to focus on work.

A clear limitation of this study was the small sample size, which limits the transferability of the findings and prevented the planned use of a Grounded Theory analysis. The dyads that were recruited may have had similar characteristics, which also means the data may not be applicable to other dyads, such as those with more advanced cognitive impairments or physical disabilities. However, the study did generate rich qualitative accounts which has provided insight into the experience of mindfulness for dementia dyads. Social desirability may have affected the responses of participants and facilitators, as the researcher was both a participant of the group *and* conducted the interviews. However, literature suggests being an ‘insider’ can allow participants to be more open with the researcher due to an assumption of a shared understanding, which leads to richer data (Dwyer & Buckle, 2009).

Overall, the outcomes of the intervention were positive for the dyads, and the reported benefits were recognised by everyone involved in the intervention, although it is

difficult to establish what the active agents of change were. In some instances dyads directly attributed practising mindfulness to the changes they reported such as increased sense of awareness. Other factors, several of which were highlighted in theme three, such as psycho-education, being in a group and practising an activity as a dyad may have also contributed to the reported benefits. Confounding factors such as pharmacology were not controlled for, but this was beyond the scope of this study.

### ***Clinical Implications and Future Research***

This study highlights the importance of involving both members of the dyad in dementia interventions, as living with dementia is experienced within the context of a caregiving relationship. It also builds on current literature about what adaptations are appropriate to mindfulness interventions; however, this study emphasises the importance of person-centred adaptations, which may not be specific to dementia or ageing. The findings also suggest what dementia dyads need to have in place prior to engaging in an MBI which may affect whether they are screened as appropriate.

Future research which involves administering MBIs in fewer sessions, as both dyads that did not attend all sessions still acknowledged wellbeing benefits, may prove to be more cost-effective and require less time and effort from dyads which was a difficulty in this study. In terms of difficulties encountered with time commitments in this study and others, future research may explore whether MBIs can be delivered to dyads at home, perhaps through an online course or distance learning. The use of a non-mindfulness comparison group in a future study may also lead to identifying which factors lead to the reported positive outcomes in mindfulness interventions with this population. Finally, future research can build on this by involving a greater number of

participants, with a wider range of dyad types and a greater range of cognitive impairments which would improve the generalisability of findings in this area.

## **Conclusions**

This study explored the experiences and effects on wellbeing of an adapted MBI for dementia dyads. The findings highlighted the positive wellbeing effects of the intervention, and suggest how dyads developed an understanding of mindfulness through practice. The study emphasised the importance of dyads attending interventions together and implementing both standardised and individual adaptations to interventions. Future research may involve larger and more diverse samples, and attempts to deliver interventions in different settings and via other modalities.

## **Declaration of Conflicting Interests**

None Declared.

## **Acknowledgements**

The authors would like to acknowledge the contribution of the facilitators and volunteers who delivered and supported the running of the course.

## **Funding**

This work was supported by The York Common Good Trust's small grants fund.

## **Description of Authors' Roles**

J. Adams designed the study, carried out the data collection and analysis and wrote the paper. C. Clarke and E. Wolverson supervised data collected and analysis, and assisted in preparing the paper.

## References

- Baer, R. A. (2003). Mindfulness training as a clinical intervention: A conceptual and empirical review. *Clinical psychology: Science and practice, 10*(2), 125-143.
- Bédard, M., Felteau, M., Mazmanian, D., Fedyk, K., Klein, R., Richardson, J., ... & Minthorn-Biggs, M. B. (2003). Pilot evaluation of a mindfulness-based intervention to improve quality of life among individuals who sustained traumatic brain injuries. *Disability and rehabilitation, 25*(13), 722-731.
- Berk, L., Hotterbeekx, R., van Os, J., & van Boxtel, M. (2017). Mindfulness-based stress reduction in middle-aged and older adults with memory complaints: a mixed-methods study. *Aging & mental health, 1*-8.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.
- Chan, J., Churcher Clarke, A., Royan, L., Stott, J., & Spector, A. (2017). A Mindfulness Program Manual for People With Dementia. *Behavior modification, 41*(6), 764-787.
- Charmaz, K. (2006). *Constructing Grounded Theory: A practical guide through qualitative analysis*. London: SAGE Publications.
- Churcher Clarke, A., Chan, J. M. Y., Stott, J., Royan, L., & Spector, A. (2017). An adapted mindfulness intervention for people with dementia in care homes: feasibility pilot study. *International journal of geriatric psychiatry, 32*(12).
- Daniels, K. J., Lamson, A. L., & Hodgson, J. (2007). An exploration of the marital relationship and Alzheimer's disease: One couple's story. *Families, Systems, & Health, 25*(2), 162.
- Davidson, R. J., & Kaszniak, A. W. (2015). Conceptual and methodological issues in research on mindfulness and meditation. *American Psychologist, 70*(7), 581.

- Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International journal of qualitative methods*, 8(1), 54-63.
- Emmons, R. A., & Mishra, A. (2011). Why gratitude enhances wellbeing: What we know, what we need to know. *Designing positive psychology: Taking stock and moving forward* (pp. 248-262) in Sheldon, K. M., Kashdan, T. B., & Steger, M. F. (2010). *Designing positive psychology: Taking stock and moving forward*. New York: Oxford University Press.
- Fjorback, L. O., Arendt, M., Ørnbøl, E., Fink, P., & Walach, H. (2011). Mindfulness-Based Stress Reduction and Mindfulness-Based Cognitive Therapy—a systematic review of randomized controlled trials. *Acta Psychiatrica Scandinavica*, 124(2), 102-119.
- Goldberg, S. B., Tucker, R. P., Greene, P. A., Simpson, T. L., Kearney, D. J., & Davidson, R. J. (2017). Is mindfulness research methodology improving over time? A systematic review. *PloS one*, 12(10), e0187298, <https://doi.org/10.1371/journal.pone.0187298>
- Gunaratana, H. (1993). *Mindfulness in plain English*. Boston: Wisdom Publications
- Harris, P. B. (2008). Another wrinkle in the debate about successful aging: The undervalued concept of resilience and the lived experience of dementia. *The International Journal of Aging and Human Development*, 67(1), 43-61.
- Hurley, R. V., Patterson, T. G., & Cooley, S. J. (2014). Meditation-based interventions for family caregivers of people with dementia: a review of the empirical literature. *Aging & mental health*, 18(3), 281-288.
- Kabat-Zinn J. (1990). *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness*. New York: Delacorte.

- Kaufmann, E. G., & Engel, S. A. (2016). Dementia and wellbeing: A conceptual framework based on Tom Kitwood's model of needs. *Dementia, 15*(4), 774-788.
- Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health, 1*(1), 13-22.
- Kolb, D. A. (2014). *Experiential learning: Experience as the source of learning and development*. FT press.
- Kor, P. P., Chien, W. T., Liu, J. Y., & Lai, C. K. (2017). Mindfulness-Based Intervention for Stress Reduction of Family Caregivers of People with Dementia: A Systematic Review and Meta-Analysis. *Mindfulness, 9*(1) 7-22.
- Lau, B. H. P., & Cheng, C. (2017). Gratitude and coping among familial caregivers of persons with dementia. *Aging & mental health, 21*(4), 445-453.
- Laver, K., Milte, R., Dyer, S., & Crotty, M. (2017). A systematic review and meta-analysis comparing carer focused and dyadic multicomponent interventions for carers of people with dementia. *Journal of aging and health, 29*(8), 1308-1349.
- Leader, G. Litherland, R. [and] Mason, T. (2014). *Mindfulness and dementia: report of a pilot study. A joint project by Innovations in Dementia and Positive Ageing Associates*.
- McIntyre, A. (2008). *Qualitative Research Methods: Participatory action research*. CA: SAGE Publications.
- Meeten, F., Whiting, S., & Williams, C. M. (2015). An exploratory study of group mindfulness-based cognitive therapy for older people with depression. *Mindfulness, 6*(3), 467-474.
- Moon, H., & Adams, K. B. (2012). The effectiveness of dyadic interventions for people with dementia and their caregivers. *Dementia, 12*(6), 821-839.
- Paller, K. A., Creery, J. D., Florczak, S. M., Weintraub, S., Mesulam, M. M., Reber, P. J., ... & O'Hara, M. (2015). Benefits of mindfulness training for patients with

- progressive cognitive decline and their caregivers. *American Journal of Alzheimer's Disease & Other Dementias*®, 30(3), 257-267.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Thousand Oaks, CA: SAGE Publications, Inc.
- Ries, J.D. (2018). Rehabilitation for Individuals with Dementia: Facilitating Success. *Current Geriatrics Reports*, 7(1), 59-70
- Smart, C. M., Segalowitz, S. J., Mulligan, B. P., Koudys, J., & Gawryluk, J. R. (2016). Mindfulness Training for Older Adults with Subjective Cognitive Decline: Results from a Pilot Randomized Controlled Trial. *Journal of Alzheimer's Disease, (Preprint)*, 1-18.
- Szmukler, G., Staley, K., & Kabir, T. (2011). Service user involvement in research. *Asia-Pacific Psychiatry*, 3(4), 180-186.
- Teasdale, J. D., Segal, Z. V., Williams, J. M. G., Ridgeway, V. A., Soulsby, J. M., & Lau, M. A. (2000). Prevention of relapse/recurrence in major depression by mindfulness-based cognitive therapy. *Journal of consulting and clinical psychology*, 68(4), 615.
- Trivedi, P., & Wykes, T. (2002). From passive subjects to equal partners: qualitative review of user involvement in research. *The British Journal of Psychiatry*, 181(6), 468-472.
- Vernooij-Dassen, M., Vasse, E., Zuidema, S., Cohen-Mansfield, J., & Moyle, W. (2010). Psychosocial interventions for dementia patients in long-term care. *International Psychogeriatrics*, 22(7), 1121-1128.
- Williams, M., & Penman, D. (2011). *Mindfulness: a practical guide to finding peace in a frantic world*. London: Hachette UK.

Young, L. A., & Baime, M. J. (2010). Mindfulness-based stress reduction: Effect on emotional distress in older adults. *Complementary Health Practice Review, 15*(2), 59-64.

## **Part Three: Appendices**

## **Appendix A: Instruction for Contributors to the Journal *Aging & Mental Health***

### **Instructions for authors**

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website.



**SCHOLARONE MANUSCRIPTS™**

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the guide for ScholarOne authors before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

### **Contents**

- About the Journal
- Peer Review
- Preparing Your Paper
  - Style Guidelines
  - Formatting and Templates
  - References
  - Checklist
- Using Third-Party Material

- Disclosure Statement
- Clinical Trials Registry
- Complying With Ethics of Experimentation
  - Consent
  - Health and Safety
- Submitting Your Paper
- Data Sharing Policy
- Publication Charges
- Copyright Options
- Complying with Funding Agencies
- Open Access
- My Authored Works
- Reprints

### **About the Journal**

*Aging & Mental Health* is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

*Aging & Mental Health* accepts the following types of article:

- Original article
- Short report

### **Peer Review**

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer reviewed by independent, anonymous expert referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

### **Preparing Your Paper**

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

#### **Original article**

- Should be written with the following elements in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list)
- Should be no more than 5000 words, inclusive of figure captions, footnotes, endnotes.
- Should contain a structured abstract of 250 words. A structured abstract should cover (in the following order): : Objectives, Method, Results, and Conclusion. Read tips on writing your abstract.
- Between 3 and 5 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

#### **Short report**

- Should be written with the following elements in the following order: title page; main text; acknowledgments; declaration of interest statement; references.
- Should be no more than 2000 words, inclusive of figure captions, footnotes, endnotes.

### **Style Guidelines**

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript.

Please use single quotation marks, except where ‘a quotation is “within” a quotation’.

Please note that long quotations should be indented without quotation marks.

### **Formatting and Templates**

Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the template via the links (or if you have any other template queries) please contact [authortemplate@tandf.co.uk](mailto:authortemplate@tandf.co.uk).

### **References**

Please use this reference guide when preparing your paper.

An EndNote output style is also available to assist you.

### **Checklist: What to Include**

1. **Author details.** Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) requirements for authorship is included as an author of your

paper. Please include all authors' full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

2. A structured **abstract** of no more than 250 words. A structured abstract should cover (in the following order): Objectives, Method, Results, and Conclusion. Read tips on writing your abstract.
3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:

*For single agency grants*

This work was supported by the [Funding Agency] under Grant [number xxxx].

*For multiple agency grants*

This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

5. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.

6. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
7. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
8. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
9. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, GIF, or Microsoft Word (DOC or DOCX). For information relating to other file types, please consult our Submission of electronic artwork document.
10. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
11. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
12. **Units.** Please use SI units (non-italicized).

### **Using Third-Party Material in your Paper**

You must obtain the necessary permission to reuse third-party material in your article.

The use of short extracts of text and some other types of material is usually permitted, on

a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on requesting permission to reproduce work(s) under copyright.

### **Disclosure Statement**

Please include a disclosure statement, using the subheading “Disclosure of interest.” If you have no interests to declare, please state this (suggested wording: *The authors report no conflict of interest*). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the declaration of interest statement. Read more on declaring conflicts of interest.

### **Clinical Trials Registry**

In order to be published in a Taylor & Francis journal, all clinical trials must have been registered in a public repository at the beginning of the research process (prior to patient enrolment). Trial registration numbers should be included in the abstract, with full details in the methods section. The registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the WHO International Clinical Trials Registry Platform (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the ICMJE guidelines.

### **Complying With Ethics of Experimentation**

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report in vivo experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the Declaration of Helsinki.

### **Consent**

All authors are required to follow the ICMJE requirements on privacy and informed consent from patients and study participants. Please confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any research, experiment, or clinical trial described in your paper has given written consent to the inclusion of material pertaining to themselves, that they acknowledge that they cannot be identified via the paper; and that you have fully anonymized them. Where someone is deceased, please ensure you have written consent from the family or estate. Authors may use this Patient Consent Form, which should be completed, saved, and sent to the journal if requested.

### **Health and Safety**

Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the International Association of Veterinary Editors' Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

### **Submitting Your Paper**

This journal uses ScholarOne Manuscripts to manage the peer-review process. If you haven't submitted a paper to this journal before, you will need to create an account in ScholarOne. Please read the guidelines above and then submit your paper in the relevant Author Centre, where you will find user guides and a helpdesk.

Please note that *Aging & Mental Health* uses Crossref™ to screen papers for unoriginal material. By submitting your paper to *Aging & Mental Health* you are agreeing to originality checks during the peer-review and production processes.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about sharing your work.

### **Data Sharing Policy**

This journal applies the Taylor & Francis Basic Data Sharing Policy. Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and

recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see this information regarding repositories.

Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

### **Publication Charges**

There are no submission fees or page charges for this journal.

Colour figures will be reproduced in colour in your online article free of charge. If it is necessary for the figures to be reproduced in colour in the print version, a charge will apply.

Charges for colour figures in print are £300 per figure (\$400 US Dollars; \$500 Australian Dollars; €350). For more than 4 colour figures, figures 5 and above will be charged at £50 per figure (\$75 US Dollars; \$100 Australian Dollars; €65). Depending on your location, these charges may be subject to local taxes.

### **Copyright Options**

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. Read more on publishing agreements.

### **Complying with Funding Agencies**

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders' open access policy mandates here. Find out more about sharing your work.

### **Open Access**

This journal gives authors the option to publish open access via our Open Select publishing program, making it free to access online immediately on publication. Many funders mandate publishing your research open access; you can check open access funder policies and mandates here.

Taylor & Francis Open Select gives you, your institution or funder the option of paying an article publishing charge (APC) to make an article open access. Please contact [openaccess@tandf.co.uk](mailto:openaccess@tandf.co.uk) if you would like to find out more, or go to our Author Services website.

For more information on license options, embargo periods and APCs for this journal please go [here](#).

### **My Authored Works**

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmetric data) via My Authored Works on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your free eprints link, so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to promote your research.

### **Article Reprints**

You will be sent a link to order article reprints via your account in our production system. For enquiries about reprints, please contact the Taylor & Francis Author Services team at [reprints@tandf.co.uk](mailto:reprints@tandf.co.uk). You can also order print copies of the journal issue in which your article appears.

### **Queries**

Should you have any queries, please visit our Author Services website or contact us at [authorqueries@tandf.co.uk](mailto:authorqueries@tandf.co.uk).

*Updated 29-01-2018*

### **Appendix B: Data Extraction Tool**

<b>Participants</b> – age, <i>n</i> =, community vs residential, gender	
<b>Cognition status</b>	

<b>Inclusion/exclusion criteria</b>	
<b>Dyads or individual</b>	
<b>Recruitment</b>	
<b>Intervention type</b>	
<b>Who ran it?</b>	
<b>Adaptations?</b>	
<b>No. sessions/per week</b>	
<b>Length of sessions</b>	
<b>Control group?</b>	
<b>Follow-up?</b>	
<b>Quant/qual/mixed?</b>	
<b>Data collection methods</b>	
<b>Statistical analyses</b>	
<b>Wellbeing outcomes</b>	
<b>Outcome measures</b>	
<b>When administered</b>	
<b>Main findings</b>	
<b>Limitations</b>	
<b>Strengths</b>	

**Appendix C: Adapted Quality Assessment Tool & Description of Process**

<b>Study Design</b>	<b>No.</b>	<b>Criteria</b>	<b>Response</b>			
			<b>Yes</b>	<b>No</b>	<b>Can't tell</b>	<b>N/A</b>

			1	0	0	
<b>All studies</b>	1	Is the hypothesis/aim/objective of the study clearly described?				
	2	Are the main outcomes of interest clearly described in the Introduction or Methods section?				
	3	Are the characteristics of the patients included in the study clearly described?				
	4	Are the interventions of interest clearly described?				
	5	Are the main findings of the study clearly described?				
	6	Have the characteristics of patients lost during the study or to follow-up been described?				
	7	Does the study discuss the generalisability of the findings in the discussion? (external validity)				
	8	Were the limitations of the study acknowledges in the discussion?				
<b>Qualitative only</b>	9.1	Are the sources of qualitative data relevant to address the research question?				
	9.2	Is the process for analysing qualitative data relevant to address the research question?				
	9.3	Is appropriate consideration given to how findings relate to the context? E.g. the setting, in which the data were collected?				
	9.4	Is appropriate consideration given to how findings relate to researchers' influence e.g. through their interactions with participants?				
	10.1	Is there a clear description of randomisation (or an appropriate sequence generation?) (RCTs only)				

<b>Quantitative only</b>	10.2	Are participants recruited in a way that minimises selection bias? (Non-randomised studies only)				
	10.3	Are appropriate measures used in relation to validity and reliability?				
	10.4	If groups are being compared, are the participants comparable, or do researchers control for the difference between these groups?				
	10.5	Are there complete outcome data (80% or above) and an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies?				
<b>Mixed methods only</b>						
<b>Mixed methods only</b>	11.1	Is the mixed methods research design relevant to address the quantitative and qualitative research questions?				
	11.2	Is the integration of qualitative and quantitative data relevant to address the research question?				
	11.3	3. Is appropriate consideration given to the limitations of this integration?				
<i>Appropriate criteria for the qualitative component (9.1-9.4) and the quantitative component (10.1-10.4), must also be applied for mixed methods studies, depending on the nature of the study.</i>						
Total (divided by)						
Total Possible Score						
=						
x100						
Total Score						

### *Description of Process*

Questions 1-7 have been taken and adapted from the Downs and Black (1998) checklist, which encompasses generic quality aspects across all studies including clear descriptions of the hypothesis/aim, participant's outcomes, interventions and findings. Question 8 was included from the lead author as multiple studies in the review did acknowledge the limitations of their interventions. Questions 9-11 were taken from the MMAT (Pluye et al., 2011) and involve specific criteria for studies which have been quantitative, qualitative or mixed methods. These questions involved whether the data had been synthesised appropriately for mixed-methods studies, whether control groups were utilised for quantitative studies, and the use of qualitative analysis in relation to the research question. Questions from the Downs and Black (1998) checklist which were not included such as those pertaining to quantitative methodologies were not included due to the inclusion of grey literature and varying methodological quality of the studies in the review. This led to more generic questions about methodological quality being chosen.

A point scoring system which integrated scoring from both checklists was used - 0 for 'no' or 'can't tell' and 1 for 'yes', or 'N/A' if the criteria did not apply. The total possible quality score for each study varied depending on the design (quantitative RCT – 12, quantitative non-randomised/no control – 11, qualitative – 12, mixed methods – 19). The total score and total possible score were used to calculate a percentage so that scores could be compared across studies.

**Appendix D: Summary Table of Quality Assessment Scores for Included Studies**

	1	2	3	4	5	6	7	8	9.1	9.2	9.3	9.4	10.1	10.2	10.3	10.4	10.5	11.1	11.2	11.3	Total	Total Possible	%	
<b>Article</b>	<b>All studies</b>								<b>Qualitative only</b>				<b>Quantitative only</b>				<b>Mixed-methods</b>							
<b>Churcher-Clarke et al. (2017)</b>	1	1	1	1	1	1	1	1	/	/	/	/	1	/	1	1	1	1	1	1	1	12	12	100%
<b>Paller et al. (2015)</b>	1	1	1	1	1	1	1	1	/	/	/	/	/	1	1	/	0	/	/	/	10	11	90.1%	
<b>Innes et al. (2016)</b>	1	1	1	1	1	1	1	1	/	/	/	/	1	/	1	1	1	/	/	/	12	12	100%	
<b>Moss et al. (2012)</b>	1	1	1	1	1	0	1	1	/	/	/	/	/	0	1	1	0	/	/	/	9	12	75%	
<b>Wong et al. (2017)</b>	1	1	1	1	1	1	1	1	/	/	/	/	/	1	1	1	1	/	/	/	11	11	100%	
<b>Berk et al. (2017)</b>	1	1	1	1	1	1	1	1	1	1	0	0	/	0	1	/	1	1	1	1	0	14	18	77.8%

<b>Lenze et al. (2014)</b>	1	1	1	1	1	1	1	1	0	/	/	/	/	0	/	1	0	1	/	/	/	9	12	75%
<b>Innes et al. (2012)</b>	1	1	1	1	1	1	1	1	1	/	/	/	/	/	1	1	/	1	/	/	/	11	11	100%
<b>Wells et al. (2013)</b>	1	1	1	1	1	0	1	0	/	/	/	/	/	1	/	1	0	0	/	/	8	12	66.7%	
<b>Swannell et al. (2017)</b>	1	1	1	1	1	1	1	1	1	1	1	0	0	/	0	1	/	1	1	1	0	14	18	77.8%
<b>Leader et al. (2013)</b>	1	1	1	1	1	1	1	1	1	1	0	0	0	/	1	1	/	0	1	1	0	13	18	72.2%
<b>Lantz et al. (1997)</b>	0	1	0	1	1	0	0	0	/	/	/	/	/	0	1	/	0	/	/	/	4	11	36.3%	
<b>Wetherell et al.(2017)</b>	1	1	1	1	1	0	0	1	/	/	/	/	1	/	1	1	1	/	/	/	10	12	83.3%	
<b>Kemp et al. (2016)</b>	1	/	1	1	1	/	1	0	1	0	0	0	/	0	1	/	1	0	0	0	8	16	50%	

## **Appendix E: Instructions for Contributors to the Journal *Dementia***

This Journal is a member of the Committee on Publication Ethics.

**Please read the guidelines below then visit the Journal's submission site <http://mc.manuscriptcentral.com/dementia> to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.**

Only manuscripts of sufficient quality that meet the aims and scope of *Dementia* will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. What do we publish?
  - 1.1 Aims & Scope
  - 1.2 Article types
  - 1.3 Writing your paper
2. Editorial policies
  - 2.1 Peer review policy
  - 2.2 Authorship
  - 2.3 Acknowledgements
  - 2.4 Funding

- 2.5 Declaration of conflicting interests
- 2.6 Research ethics and patient consent
- 3. Publishing policies
  - 3.1 Publication ethics
  - 3.2 Contributor's publishing agreement
  - 3.3 Open access and author archiving
- 4. Preparing your manuscript
  - 4.1 Formatting
  - 4.2 Artwork, figures and other graphics
  - 4.3 Supplementary material
  - 4.4 Reference style
  - 4.5 English language editing services
- 5. Submitting your manuscript
  - 5.1 ORCID
  - 5.2 Information required for completing your submission
  - 5.3 Permissions
- 6. On acceptance and publication
  - 6.1 SAGE Production
  - 6.2 Online First publication
  - 6.3 Access to your published article
  - 6.4 Promoting your article
- 7. Further information

## **1. What do we publish?**

### **1.1 Aims & Scope**

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

## **1.2 Article Types**

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

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 2,500-3,000 words. Innovative practice papers should include the words 'Innovative Practice' after the title of their article when submitting to the journal. For further information about innovative practice papers, please refer to the guidelines.

The journal also publishes book reviews.

## **1.3 Writing your paper**

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

### ***1.3.1 Make your article discoverable***

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

Back to top

## **2. Editorial policies**

### **2.1 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.

### **2.2 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.

### **2.3 Acknowledgements**

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

### **2.4 Funding**

Dementia requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

### **2.5 Declaration of conflicting interests**

It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a ‘Declaration of Conflicting Interests’ statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that ‘The Author(s) declare(s) that there is no conflict of interest’. For guidance on conflict of interest statements, please see the ICMJE recommendations [here](#).

## **2.6 Research ethics and patient consent**

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

Back to top

### **3. Publishing Policies**

4.

#### **3.1 Publication ethics**

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

##### ***3.1.1 Plagiarism***

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

##### **3.1.2 Prior publication**

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published

material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

### **3.2 Contributor's publishing agreement**

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

### **3.3 Open access and author archiving**

Dementia offers optional open access publishing via the SAGE Choice programme. For more information please visit the SAGE Choice website. For information on funding body compliance, and depositing your article in repositories, please visit SAGE Publishing Policies on our Journal Author Gateway.

[Back to top](#)

## **4. Preparing your manuscript for submission**

### **4.1 Formatting**

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

*Language and terminology.* Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. demented). Language that might be deemed sexist or racist should not be used.

*Abbreviations.* As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

#### **4.2 Artwork, figures and other graphics**

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

#### **4.3 Supplementary material**

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

#### **4.4 Reference style**

Dementia adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

#### **4.5 English language editing services**

4.6 Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

Back to top

### **5. Submitting your manuscript**

Dementia is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts.

Visit <http://mc.manuscriptcentral.com/dementia> to login and submit your article online.

**IMPORTANT:** Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

Innovative Practice papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Jo Moriarty [jo.moriarty@kcl.ac.uk](mailto:jo.moriarty@kcl.ac.uk).

Books for review should be sent to: Book Review Editor, Dementia, Caroline Swarbrick University of Manchester, UK [caroline.swarbrick@manchester.ac.uk](mailto:caroline.swarbrick@manchester.ac.uk)

#### **5.1 ORCID**

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a persistent digital identifier that distinguishes researchers from every other researcher and, through integration in key research workflows such as manuscript

and grant submission, supports automated linkages between researchers and their professional activities ensuring that their work is recognised.

We encourage all authors to add their ORCID to their SAGE Track accounts and include their ORCID as part of the submission process. If you don't already have one you can create one here.

## **5.2 Information required for completing your submission**

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

## **5.3 Permissions**

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway.

[Back to top](#)

## **6. On acceptance and publication**

### **6.1 SAGE Production**

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

### **6.2 Online First publication**

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

### **6.3 Access to your published article**

SAGE provides authors with online access to their final article.

### **6.4 Promoting your article**

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice. In addition, SAGE is partnered with Kudos, a free service that allows authors to explain, enrich, share, and measure the impact of their article. Find out how to maximise your article's impact with Kudos.

[Back to top](#)

## **7. Further information**

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Dementia editorial office as follows:

[dem.pra@sagepub.com](mailto:dem.pra@sagepub.com)

**Appendix F: Participant Demographic Questionnaire**

**Demographic Questionnaire**

**1. What are both of your names and ages?**

Name of person with dementia:

Age:

Name of caregiver:

Age:

**2. What ethnicity are you?**

Person with dementia:

Caregiver:

**3. How long have you been in your relationship for?**

.....  
.....  
.....  
.....

**4. What is your diagnosis of dementia (if known)?**

.....  
.....  
.....  
.....

**5. Can you tell me roughly when you got your diagnosis of dementia- this doesn't need to be exact?**

.....  
.....  
.....  
.....

## Appendix G: Participant Information Sheet

### **Participant Information Sheet**

Version 3 Date 26.07.2017

**We would like to invite you to take part in a research study looking at the experience of learning mindfulness meditation for people living with dementia and their partners.**

**Title of the study:** A Mindfulness Intervention for Dementia Dyads (people living with dementia and their partners or family members): Understanding Dyadic Experiences and Possible Adaptations.

This sheet will provide you with some information about the study, to help you decide whether you'd like to participate. We would also like you to understand what it will involve for you if you make the decision to take part. If you have any questions about the study and your involvement, the researcher will be able to answer them once you have read this sheet.

#### **What is the purpose of the study?**

Mindfulness involves deliberately paying attention to particular things (for example, one's own breathing) in the present moment. There is now over 20 years of research showing that practising mindfulness can improve wellbeing and be of benefit to different people. Some recent research suggests this may be the case for people living with dementia but further research is needed to understand how mindfulness might help.

#### **Why have I been invited?**

We are recruiting people with dementia and their partner or chosen family member / carer to complete an adapted mindfulness course and to be involved in deciding what changes should be made and how we should research the experience and impact of the mindfulness course.

You have been invited because you are in a couple or caring relationship whereby one person is currently living with dementia and the other is their spouse or partner or family member / carer.

If you have had previous experience of mindfulness, either by attending a mindfulness intervention, or as a part of psychological therapy, unfortunately you will not be able to take part in the study. This is because the study is exploratory and previous experience

may affect your experience. You must also speak sufficiently fluent English, as the course will be delivered in this language.

### **Do I have to take part?**

No, you do not have to take part. Participation in this study is entirely voluntary and it is up to you if you would like to participate. You can withdraw from the study at any point up to where the results are analysed by the researcher and written up. You do not have to provide a reason for withdrawing. If you decide to withdraw from the research study, you may still attend the mindfulness course, and your data from the course will not be included in the final write-up. However, your data cannot be withdrawn following participation from the focus group (though this will be anonymised in the final write-up).

If one person in a couple / dyad decides to withdraw, both members will be excluded from the data research process (with the exception of the focus group). However the remaining person has the right to continue attending the mindfulness group if they wish to without being involved in the research aspect.

### **What will happen if I decide to take part?**

Firstly, you will be asked to provide some general information about yourself such as your age, gender, how long you have lived with dementia for, what your experience of mindfulness/meditation is, and whether you consider your relationship to be a couple or caregiving / family relationship. This will be done by meeting with the researcher who will fully explain the process of the study. At this point the researcher will discuss consent and withdrawing from the study with you and answer any questions you may have.

The course will run for eight weeks between July – September 2017, so it important to consider if you will be available during this time.

We hope to recruit a group of 10-12 people who will attend the focus groups and course. All meetings will take place in a dementia-friendly community venue. Refreshments will be provided at each session. Unfortunately, we are unable to provide reimbursement for travel due to funding, however attending the course will be free. We estimate that the focus groups and course will take approximately 19 hours in total. We acknowledge that this is a large amount of your time, and that the course will require some effort and dedication, however we hope that there will also be benefits to attending the course. If you have concerns regarding this, please speak to the researcher who will be happy to answer any queries.

Next, you will be invited to a ‘focus’ group meeting at a community venue in xxxx along with all of the participants who are going to take part. A focus group is a meeting where people are asked specific questions and asked to share their views and experiences together. Focus group meetings will be attended by the course leader (xx) who will run the course and deliver the mindfulness training, and will be led by the primary researcher (Jennifer Adams, Trainee Clinical Psychologist). This first meeting will last 1.5 hours (with a tea break) and the researcher and course leader will begin with a discussion about mindfulness and how the course will run. They will ask for your views and how you think the course would best be run to suit your needs.

After this, a manual will be created from your joint decisions in the focus group. The mindfulness course will run according to this manual. The course will take place weekly for eight weeks and we ask that you try your best to attend every session. Each session will last 1.5 hours, with a break in between. You will have the opportunity to learn about mindfulness and practice it, with full instruction from two very experienced practitioners of mindfulness. At the end of each session the researcher will ask you to write down some information about your experience of mindfulness. You will have the opportunity to take this home and complete it, and bring it back to the next session. If you would prefer, this information could also be typed on a laptop or recorded via the researcher’s Dictaphone at the end of the session. Some ‘at-home practice’ of mindfulness may also be part of the course.

After the eight weeks, once the course is completed, a final focus group will run. This will last 1.5 hours. You will have the opportunity to discuss what went well, what didn’t, what could be improved in future, and what your overall experience of the course was.

### **What are the possible disadvantages and risks of taking part?**

There has been some research which has investigated the risks of mindfulness meditation. In a few extreme instances, people who have participated in intensive meditation have experienced some psychotic symptoms, particularly when they have had a history of schizophrenia. There is also the possibility that meditation may cause some difficult thoughts and emotions to rise to the surface for some people. This is why it is important that we discuss with you and the other participants what changes could be made to the course before it runs in order to minimize any difficulties which may occur. All exercises in the classes and suggestions for home practice are voluntary. Guidance and alternatives will be offered by course leaders to ensure that practice is safe and easy. If at any time you feel uncomfortable or unable to take part in a meditation, you may sit out.

On occasion, some people can find specific meditations discomforting. Any difficulties with the exercises will be discussed and explored as part of the course. This is a standard part of learning mindfulness in a group, however if you do not want to participate in any exercises for any reason then you can sit out at any time and join in again when you feel ready.

There are possible risks of partaking in the focus groups before and after the course. Although the researchers will not intentionally choose topics for the groups which could cause upset, it is important to be aware that personal topics may come up through discussions in the groups. The researchers acknowledge that topics around what people are able to manage and how this may relate to living with dementia are likely to be discussed. Should you find this difficult, you would not have to voice your opinions or thoughts if you did not feel comfortable to. You would also be free to leave the room, or the study, at any time if you found certain topics distressing.

In addition, you would be free to discontinue your participation in the study at any point. If necessary, the researcher will offer support and help you gain access to further help if needed e.g. from your GP or an appropriate source. If you are concerned about any of the risks, please discuss this with the researcher.

### **What are the possible benefits of taking part?**

Previous research has shown that mindfulness courses such as this one have the effect of improving wellbeing and quality of life and reducing stress. However, this research has not been conducted with couples who are living with dementia. Therefore, we do not currently know what the particular benefits could be for you.

Lots of mindfulness groups in the past have found that group learning is supportive and enjoyable, and members of other groups have been known to make long-term connections. In addition, your participation has the potential to improve knowledge about mindfulness for people living with dementia and whether involving couples and family members in the approach is a good way to help both people involved gain benefit from mindfulness. This will eventually help professionals and organisations working with people who are living with dementia and their spouse/partner and families.

### **What will happen if I decide I no longer wish to take part?**

If you decide that you no longer wish to take part, you should inform the researcher. You do not have to provide a reason as to why you wish to withdraw. When discussing this with the researcher they will ask you if you would like to continue attending the course, and not have your data used in the analysis or final write-up of the study, or whether you wish to withdraw completely. If your partner/spouse would like to continue

to participate then they can. As mentioned, if one of the couple decides to withdraw, both members will be excluded from the data research and analysis process.

### **What if there is a problem?**

If you have any concerns about the study you can speak to the researcher (Jennifer Adams), or you can contact Dr Chris Clarke at the University of Hull whom is overseeing this research in a supervisory role.

### **Will my taking part in this study be kept confidential?**

Yes. When the researcher gains written consent from you and your partner/spouse, a code will be assigned to your data. No names will be used in written reports. Any data from yourselves, including your participation in the focus groups and your written data after each session will be anonymised using this code. Any identifiable information about yourselves including names, contact details and personal information will be stored in a locked cabinet at the University of Hull to which only the researcher and their supervisor have access. Recordings of the focus groups will be transcribed electronically and the original recording destroyed. The transcription will be stored on an encrypted memory stick with password protection.

All information will be stored securely for 10 years and then destroyed. We will follow ethical and legal practice and all information about yourselves will be handled in confidence.

### **What will happen to the results of the study?**

The overall results of the study will be presented in a University doctoral thesis (June 2018), submitted for publication in an academic journal and may be presented at conferences. No individual participant details will be identified in any of these presentations. If you are interested, you can receive a short summary of the findings of the study – please let the researcher know if you are interested.

### **Who is organising and funding the research?**

The research is being carried out as part of a doctorate level training program in Clinical Psychology via the University of Hull. Additional funding has been secured from the York Common Good Trust to help with running costs of the study; however they will not have access to any confidential data.

### **Who has reviewed the study?**

This study has been reviewed by the researcher's supervisor at the University of Hull on a monthly basis, members of the research team at the University and the School of Health and Social Work Research Ethics Committee at the University.

**Further information and contact details**

Miss Jennifer Adams and Dr Chris Clarke will be happy to answer questions about this study at any time.

Email: [j.adams@2015.hull.ac.uk](mailto:j.adams@2015.hull.ac.uk) /  
[Phone : 07794 154253](tel:07794154253) /

Address: Miss Jennifer Adams / Dr Chris Clarke, Department of Psychological Health and Wellbeing, University of Hull, Cottingham Road, Hull, HU6 7RX

Thank you for taking the time to read this letter.

Yours sincerely,

Jennifer Adams  
Trainee Clinical Psychologist

Supervised by,  
Dr Chris Clarke  
Clinical Psychologist

If you are interested in taking part in the study please leave your contact details in the space provided below. You will be contacted by the researcher to arrange a meeting at a convenient place and time.

Name:

.....

Address:

.....

.....

.....

.....

Telephone Number:

.....

Mobile Phone Number:

.....

Are there any times of the day that you prefer to be contacted?

.....

Do you have any further comments?

.....

.....

Signature:.....

Date:.....

**Thank you very much for your interest!**

## Appendix H: Participant Consent Form

Centre Number:

Study Number:

Patient Identification Number for this trial:

---

### CONSENT FORM

---

Title of Project: [A Mindfulness-based Intervention for Dementia Dyads: Understanding Dyadic Experience and Possible Adaptations](#)

Name of Researcher: [Jennifer Adams](#)

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated **09.03.2017** (version **ONE**) 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 agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person  
taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## **Audio Taping of Focus Groups Consent Form**

### **Audio Taping**

You have been asked whether you to participate in two ‘focus groups’ (one before the mindfulness course, and one after it is finished) and for these to be audio recorded by the researcher. Information gathered at the focus group meetings forms part of the data used for this study.

This sheet provides you with information about why and how this data will be stored and kept confidential. If you have any questions, the researcher (Jen Adams, Trainee Clinical Psychologist) will be happy to help after you have read this information sheet, or via email/phone if you have questions later (j.adams@hull.2015.ac.uk/07794154253)

### **Why will the sessions be recorded?**

The primary researcher (Jen Adams) will be present at the two focus group meetings and will be leading and also participating in the discussions. This means that the groups will need to be recorded so that the researcher can review the session afterwards to help adapt the mindfulness course. As such, an accurate representation of what was said needs to be available, rather than written notes or relying on memory. In addition, the researcher will need the transcripts (written versions of what is said) of the two meetings to help with the data analysis stage of the study.

### **What will happen to the recording?**

The recording will be made on an electronic and password-protected Dictaphone and stored immediately in a lockable bag to which only the primary researcher (Jen Adams) has access. At the earliest possible convenience, the electronic recording will be transferred to a secure encrypted memory stick and the recording will be transcribed and saved on the same stick. As soon as the written transcription is complete, the original recording will be destroyed. The written transcription will be stored as a password-protected computer file at the University of Hull for a period of 10 years.

### **Will it remain confidential?**

Yes.

It may be the case that personal details such as people’s names are used in discussions and therefore appear on the recording. However, when the recording is being transcribed into an electronic written document, pseudonyms will replace real names and any other personally identifiable information will not be recorded on the transcript.

When writing-up the final report of the research project, pseudonyms will also be used to keep information confidential.

**Do I have to agree to being recorded during the focus groups?**

No. You do not have to agree to being recorded. However, you will unfortunately be unable to take part in the focus groups if you do not wish to be recorded during the group meetings.

**Consent to audio taping of focus groups**

*Please initial all boxes*

*Please read this information and sign below if you are in agreement:*

The primary researcher (Jen Adams) has asked me whether I would be willing to engage in the focus groups which will be recorded.

I have read the information sheet on this and had the opportunity to discuss this with them.

I understand that the information on the recording will be kept confidential and under secure conditions. The original copy will be destroyed at the earliest convenience.

I understand that if I do not feel comfortable to give consent then I do not have to, however I will be unable to participate in the focus group.

I understand that If I decide to withdraw from the study at a later date, the researcher will review with me whether I would like my participation in the focus groups to be removed from the research process.

**Name of Participant:**

.....  
....

**Date:** .....

**Participant Signature:**

.....

**Appendix I: Documentation of Ethical Approval**

**REMOVED FOR FINAL SUBMISSION**

**REMOVED FOR FINAL SUBMISSION**

## **Mindfulness Meditation and Dementia Study**

We are looking for couples (one of whom is living with dementia) to participate in an eight-week course where they can learn to practice mindfulness together.



Research shows practising **mindfulness can improve wellbeing, physical and mental health**. We are interested in how couples living with dementia find practising mindfulness, how it affects their wellbeing and how they think the course should run.

The course will be held at a community venue in xxxx running over summer 2017. It will involve eight 2 hour sessions, plus a meeting before and after the course.

**If you think you might be interested please contact Jen Adams  
(Trainee Clinical Psychologist)**

**[j.adams@2015.hull.ac.uk](mailto:j.adams@2015.hull.ac.uk) / 07794154253**

## Sources of support and information regarding Dementia

**Dementia Forward** offers information and advice regarding Dementia:

Websites: <http://www.dementiaforward.org.uk/>

Confidential Helpline: **01904 692473**

The **Alzheimer's Society** also offer advice, information and online forums regards Dementia:

Website: <https://www.alzheimers.org.uk/>

**Age UK:**

Website: <http://www.ageuk.org.uk>

Should you have any specific issues regarding the research of the mindfulness course that taking part in this study has raised you can call the **researcher** on:

Jen Adams: 07794154253

**You can also seek advice from your GP**

## Appendix L: Focus Group Schedule

### **Focus group – Mindfulness & Dementia Study (60 minutes)** 07.07.2017

#### **Notes to researcher pre-focus group:**

- *Explain about participatory action research and how this fits with having a focus group before and after the course has taken place*
- *What the purpose of the focus group is – to think about how best to run the course for the all involved*

- 1. What are people's expectations of this course? What do they want to get from it? (10 mins)**
- 2. What type of support will be most helpful throughout the group? (10 mins)**
- 3. How would you like to be supported in the weeks we don't have a session? (10 mins)**
- 4. How would you like to do the enquiry process? Explain this – feedback/discussion after exercises/meditations. (10 mins)**
- 5. Some adaptations already made (visual prompts, structure, link to book, certain practices from earlier groups). Are there are needs people have that we might need to take in to account? (10 mins)**
- 6. Aim is to build a theory of how dementia dyads experience a mindfulness course together and the effect of this on their joint wellbeing. Measure at the end of sessions – what do you think would be most useful for me to research? (10 mins)**

## **FOCUS GROUP – MINDFULNESS & DEMENTIA STUDY**

1. Expectations
2. Support during group
3. Support between sessions
4. Discussions after exercises
5. Adaptations
6. What to ask/research

**A Mindfulness-based Intervention for Dementia Dyads:  
Understanding Dyadic Experience and Possible  
Adaptations**

**Session 7 – Friday 22<sup>nd</sup> September 2017**

This research is being conducted with the aim to understand how dyads (one person living with dementia and their partner/spouse/family member) experience attending a mindfulness course together and how this affects their well-being as a couple/pair. We also want to find out what changes to a standard course may be helpful to make for this group of people.

**Please answer the following questions after the session has ended. You may take this home to complete and bring it back next week if you prefer. You may use more paper if needed.**

---

*As a couple/pair:*

**1. How have you found the course so far?**

**2. What effects, if any, have you noticed since starting the course?**

Dyad ID: \_\_\_\_\_

## **Appendix O: Example Email to Participants before Each Session**

Hi all,

Here is your email reminder for our **week 3** of the mindfulness group tomorrow.

Tomorrow we will look at how we are getting on so far, do some mindful movements and try out some new practices. At the end of the mindfulness group I will give you a sheet of paper with a couple of questions about how you've found the group so far. We will do this after every session. You can either fill it in at the end, or take it away with you to bring back the next week.

As usual, we'll be starting at 10am at xxxxxxxxxxxxxxxx. We anticipate that tomorrow's session should finish by 12.30pm.

If you have any issues or questions my mobile number is 07794 154253. Or you can email me. I will be there early and the door should be open and on the latch.

xxxxxx and xxxxxx will be facilitating the group.

### **Please bring with you:**

- your folders with all the sheets in so far**
- your filled in answers from last week if you took them home**
- an open mind**
- optional socks - as we will be encouraging you to take your shoes off for some of the exercises**

Looking forward to seeing you all again tomorrow.

Best wishes,

Jen Adams  
Trainee Clinical Psychologist

## **Appendix P: Dyad Post-Course Interview Schedule**

What is your understanding of the connection between mindfulness and living with dementia?

Has the course met your initial hopes and expectations?

What has it been like learning mindfulness as a group?

What do you think of the idea that mindfulness is a skill? Or do you think it is something else?

How have you gone about practising mindfulness between sessions?

What resources have you found helpful or unhelpful?

How have you found the practical elements of the course? E.g. pace, length of practices, venue, room, chairs, refreshments, volunteers

How have you found attending the course as a dyad/couple? Pros and cons?

Do you see mindfulness playing a role in your life after the course?

## **Appendix Q: Dyad Follow-up Interview Schedule**

What does mindfulness mean to you?

What is your understanding of what mindfulness is? Is it a skill? Or something else?

How have you been practising since the course ended? Without the support of the group?

What has been your motivation to continue?

What was it like when the facilitators shared information from their own lives?

Have you noticed more effects since starting the course?

Have you noticed anything you don't like, or any disadvantages of practising mindfulness?

How are you finding the resources we gave you at the course?

How do you see mindfulness playing a role in your future, if any?

## **Appendix R: Facilitator Interview Schedule**

What initially made you interested in taking part in the research and running the course?

What role do you think mindfulness could have for people living with dementia?

What was your experience of having both dyads present at the group?

What was your process for making adaptations to the group?

What was your experience of group processes and changes throughout the course?

What were your hopes and expectations of the course, and how were they met?

What was it like running the group as a pair?

What were the barriers to delivering this course to people living with dementia and their caregivers?

Did you notice any effects of benefits for either the participants in the group, or yourselves?

Any disadvantages to attending?

What did you think about how the course was evaluated and how it could be in future?

What would you change if you ran the course again?

## Appendix S: Overview of Intervention Session Content

<p><b>Week 1</b></p>	<p>Welcome and check-in (weather report)          Revisit learning agreement          Posture and sitting – 10 breaths exercise – brief inquiry          Raisin exercise – small group inquiry – feedback to whole group  <i>Tea break</i>          Chapter 4: Paying attention – mind is like a puppy, autopilot          Body and breath exercise – small group inquiry – feedback to whole group          Talk about home practice          Collection of data for research (Jen)</p>
<p><b>Week 2</b></p>	<p>Welcome and check in          Short breathing space          Remind group agreement          Questions and feedback on home practice          Keeping the body in mind (chapter 6) internal awareness  <i>Tea break</i>          Body scan meditation – inquiry          Movement meditation          Home practice          Collection of data</p>
<p><b>Week 3</b></p>	<p>Welcome and check-in          Short breathing space          Remind group agreement          Questions and feedback on home practice          Introduce mindful movement          Mindful movement practice – inquiry  <i>Tea break</i>          Body and breath practice – inquiry          Breaking space – inquiry          Uses of breathing space          Questions, home practice          Collection of data</p>

<b>Week 4</b>	<p>Welcome and check-in</p> <p>Short breathing space</p> <p>Remind group agreement</p> <p>Questions and feedback on home practice</p> <p>Sitting movements</p> <p>Thinking about thinking – Headspace video</p> <p>Sounds and thoughts practice – inquiry</p> <p><i>Tea break</i></p> <p>Share stories about using breathing space in daily life</p> <p>Breathing space for everyday life practice – inquiry</p> <p>Home practice and ideas for “gap” activities e.g. walking meditation, habit release</p> <p>Collection of data</p>
<b>Week 5</b>	<p>Welcome and check in</p> <p>Short breathing space</p> <p>Remind group agreement</p> <p>Questions and feedback on home practice</p> <p>Foot exercises – inquiry</p> <p>Rumi poem – read out and invite responses</p> <p>Working with difficulties – model the R.A.I.N. practice – questions</p> <p><i>Tea break</i></p> <p>R.A.I.N. meditation – inquiry</p> <p>Soothing exercise – hand tracing meditation activity to introduce self-compassion</p> <p>Home Practice</p> <p>Collection of data</p>

<b>Week 6</b>	<p>Welcome and check in</p> <p>Short breathing space</p> <p>Remind group agreement</p> <p>Questions and feedback on home practice</p> <p>Self-compassion and soothing system introduction (Handling a storm, analogy of tree)</p> <p>Hand tracing exercise – inquiry</p> <p><i>Tea break</i></p> <p>Loving-kindness practice – inquiry</p> <p>Self-critical comments discussion</p> <p>Home practice</p> <p>Collection of data</p>
<b>Week 7</b>	<p>Welcome and check in</p> <p>Short breathing space</p> <p>Remind group agreement</p> <p>Questions and feedback on home practice</p> <p>Explore breathing space options</p> <p>Handout exercise – what nourishes/depleted you?</p> <p>Sharing in group</p> <p><i>Tea break</i></p> <p>Practice – what nourishes you? Incorporate into breath and body practice – inquiry</p> <p>Handout – attending to the balance/rebalancing</p> <p>Questions – preparing for next week</p> <p>Home practice</p> <p>Collection of data</p>

<b>Week 8</b>	Welcome and check in Short breathing space Remind group agreement Questions and feedback on home practice Chapter 12 – the rest of your life Reading from volunteers and facilitators 7 tenets of mindfulness (Rob Nairn) Challenges and difficulties Revisiting intention practice – inquiry <i>Tea break</i> Groups, resources and online support Gratitude and flower watering Closing practice Collection of data
---------------	--

## Appendix T: Adapted Supplementary Material Example

### WEEK 7 –WHEN DID YOU STOP DANCING? Chapter 11

*Mindfulness: Finding Peace in a Frantic World* by Mark Williams and Danny Penman.



#### Balancing Nourishing and Depleting Activities

The first theme of this chapter is about how we can become depleted in our busy lives. The stress system gets activated and we then start to think that we have no time for the activities that attend to our soothing systems or that give us a sense of satisfaction. This can become a downward spiral, illustrated by the Exhaustion Funnel on page 211. The chapter asks us to reflect on ourselves: What do you find depleting? What do you find nourishing? How is the balance at the moment? This is an exercise that can be helpfully repeated on a regular basis. We will give you a few blank copies of this.

#### Mindfulness Bells



On page p.233 the book talks about ‘Mindfulness Bells’ - activities or occurrences in everyday life that we can use as reminders to come back to the present moment, using the everyday things to develop helpful habits of bringing our attention into the now. Overleaf is an extended list of suggestions - which ones appeal to you? Which might work best in your life? How might you remind yourself to be mindful?

#### *Some Tips for Everyday Mindfulness* by Madeline Klyne

- When you first wake up in the morning, before you get out of bed, bring your attention to your breathing. Observe five mindful breaths.

- Notice changes in your posture. Be aware of how your body and mind feel when you move from lying down to sitting, to standing, to walking. Notice each time you make a transition from one posture to the next.
- Whenever you hear a phone ring, a bird sing, a train pass by, laughter, a car horn, the wind, the sound of a door closing – use any sound as the bell of mindfulness. Really listen and be present and awake.
- Throughout the day, take a few moments to bring your attention to your breathing. Observe five mindful breaths.
- Whenever you eat or drink something, take a minute and breathe. Look at your food and realize that the food was connected to something that nourished its growth. Can you see the sunlight, the rain, the earth in your food? Pay attention as you eat, consciously consuming this food for your physical health. Bring awareness to seeing your food, smelling your food, tasting your food, chewing your food and swallowing your food.
- Notice your body while you walk or stand. Take a moment to notice your posture. Pay attention to the contact of your feet with the ground under them. Feel the air on your face, arms and legs as you walk. Are you rushing?
- Bring awareness to listening and talking. Can you listen without agreeing or disagreeing, liking or disliking, or planning what you will say when it is your turn? Can you notice how your mind and body feel?
- Whenever you wait in a line, use this time to notice standing and breathing. Feel the contact of your feet with the floor and how your body feels. Bring attention to the rise and fall of your abdomen. Are you feeling impatient?
- Be aware of any points of tightness in your body throughout the day. See if you can breathe into them and as you exhale, let go of excess tension. Is tension stored anywhere in your body? For example, your neck, shoulders, stomach, jaw, or lower back? If possible, stretch or do yoga once a day.
- Focus attention on your daily activities such as brushing your teeth, washing up, brushing your hair, putting on your shoes, doing your job. Bring mindfulness to each activity.
- Before you go to sleep at night, take a few minutes and bring your attention to your breathing. Observe five mindful breaths.

<http://simpleandfree.ca/some-tips-for-everyday-mindfulness-madeline-klyne/>

Learning Mindfulness: week by week study guide

©Mindful Support Ltd 2017

## Appendix U: Adaptations to Intervention List

### Content:

- Extra practices – 10 breaths practice, hand-tracing exercise, self-compassion break, range of movement routines (particularly seated)
- Simplified practices – R.A.I.N., simpler form of befriending (drawing on material from mindfulness association)
- Visual support for learning – week by week course guide with pictures, information sheets for folders, laminated reminders – drawing on teaching materials from other programmes and the mindfulness association
- Handouts on neuroscience where relevant, particularly compassion focused e.g. old brain new brain, drive systems

### Teaching style:

*Due to nature of the group (couple living with dementia), and because it was a small group (or might even say shrinking group – and that is common on courses)*

- Inquiry – normal teaching method is to ask people to share experiences in couples or three's, then ask for feedback to whole group. This was not appropriate for the group so we always did whole group inquiry as it enabled people to hear a range of experiences.
- Tried to allow people with dementia to contribute as much as possible, aware that in first few sessions they did not open up and talk much – this did change
- Questions asked to a person with dementia about what they are experiencing, or have experienced during a practice need to be sensitive and very open (and with awareness that at certain stages of dementia asking questions is not best form of interaction), tended to stick to “How are you feeling now?” or “How was that for you?” rather than more probing inquiry about specific aspects of the practice
- Focused inquiry on body sensation, breathing, emotions and compassion (Less on the cognitive aspects of mindfulness, though patterns, stress, habits)
- Having a small group enabled us to focus on the needs of individuals present – tailor teaching to issues raised by them, their interests and questions
- as the group dwindled to just one couple, this meant a lot tailored teaching to that couple and the person with dementia did open up and talk about past experiences that had come up in her practice (and we were aware of themes that emerged from that inquiry – such as a theme around food and food preparation, and memories of friends going through difficult time)

## V: Data Analysis Example

Transcript Extract	Emergent Themes	Exploratory Notes
<p>Stephen and Rose - Post-course Interview</p> <p><i>Lines 62-188</i></p>		
<p>Stephen - It has from that very first session erm, I realized a certain clarity of of greater understanding of where we are.</p> <p>Researcher – Okay.</p>	<p>Noticing effects of mindfulness</p>	<p><i>S noticing greater understanding of relationship in context of living with dementia</i></p> <p><i>Effects noticed from very early on in course</i></p>
<p>Stephen - Erm if I can give the example of [x time ago] there was a long article written about us in [dementia]</p>	<p>New way of living</p>	<p><i>S reflecting on past/current approaches of living with dementia and re-evaluating</i></p>

magazine [chair creaks], it was I think it was called [article name] and it was all about us leading our lives as before the diagnosis maintaining independence and now looking back on that and as a result of the course I think you get this wider understanding of where we're at and erm what we should be doing is we should've been spending more time together erm, enjoying each day as it comes, whereas it's been a trudge with that hasn't it—  
Rose - Mmm, mmm.

Stephen - So I I think that the consequence of that clearer and wider understanding of where we're at has directed us to, a new erm way of spending our days, which I'm intending on giving up work at the earliest opportunity

Reprioritising relationship

New way of living

Effects on relationship

*whether this is appropriate as a result of mindfulness intervention and increased awareness. Shifting perspective, focus moving away from work and onto relationship*

*S reflecting on importance of spending time together, impact on wellbeing and relationship, reprioritising relationship*

and erm we'll spend the idea is that we spend our days together we get up together we have our wash get dressed together go make meals together clean the house do the decorating build the extension together as the erm—

Researcher - So mine- so coming to the course right from the beginning was helpful in it sounds like making some quite big decisions about you know work and about you know how you want to spend time together?

Elizabeth - Yes.

Stephen - Quite. I think that it erm, it will relieve erm pressure by doing things together erm, things that could be problem for others, if we're doing them together they're not a problem.

Noticing effects of mindfulness

Noticing effects of mindfulness

Effects on relationship

*S noticing positive effects of mindfulness on stress and pressure and on relationship, new ways of approaching situations*

Researcher - Yeah, there's something about connection and unity there and about yeah, almost like stronger doing it together than on your own.

Rose – Yes. Yeah.

Researcher - And I was thinking you kind of touched on this that erm if you're living with dementia and you're reading the book and trying to keep up, I was wondering how that how that is because some people might find it more difficult some people might find it okay?

*Things easier to do if doing together –  
shared approach vs individual?*

*Mindfulness brought closer together?*

Rose - I don't find it difficult erm, but... erm, you know it takes a while for everything to sort of be focused—

Researcher - Yeah, for it to fall into place? But reading the book has been okay?

Rose – Yes yes, it's fine.

Researcher - It sounds like with you going to your reading group and reading a book a month, that's more than I read!

[all laughing] I struggle to get through a book in a month.

Evaluation of mindfulness resources

Resources in context of living with dementia

*R possibly describing difficulties with attention/retention? Resources difficult to engage with when living with dementia?*

Stephen - I think another point there is that erm, is that the sessions themselves, reading the book and then the sessions it's all intense learning isn't it?

Researcher: Yeah.

Stephen – And I think that that might help you absorb?

Rose – Mmm.

Stephen – Absorb the material better.

Rose – Mmm.

Evaluation of course

Intense learning/learning mindfulness

Learning mindfulness

Accommodating for living with dementia

Learning mindfulness

Accommodating for living with dementia

*S multiple components to learning,*

*highlights intensity*

*Good or bad for PLwD?*

*S multicomponent way of learning helpful*

*for learning when living with dementia?*

Researcher - So having multiple things like the CD and the book and the course and the worksheets, lots of different resources quite helpful?

Rose – Yes.

Stephen – Yes.

Researcher - Yeah okay. And er and you know still kind of on that theme I was thinking about maybe if either of you have noticed any effect that mindfulness has had on living with dementia?

Stephen - I think it's a difficult one that isn't it because erm... I don't know quite how to explain it but you don't, I think you know you don't know how you'd feel if we weren't doing this you know, would we still feel the same

Uncertainty of effects

about my diagnosis and erm. But I think you know it's certainly a lot of these things like the practical pros and cons that kind of thing. It's helpful isn't it?

Rose - Yes. Yes we don't know what would've happened if we hadn't been doing it.

Researcher – Yeah.

Stephen - But erm, the point that I just made... of erm if focusing on nothing if you just try to leave your mind empty erm, by some means that seems to me to have provided that clearer understanding of where we're at, yeah to sort of just think about that subject, I remember years and years ago to go see do you remember [friends name]'s wife?

Rose - Oh, [name]? Sorry—

Uncertainty of effects

Noticing effects of mindfulness

Understanding

Stephen - She she held meditation classes.

Rose – Right, yes. It was a long time ago [laughing].

Stephen - And I remember saying, her saying quakers you know people who spend an hour every week just meditating in this group erm, so in parallel to that the mindfulness I think would erm, it it gives you that opportunity to reflect on where you're at erm, whereas previously I just kept my nose down and it was work work work.

Noticing effects of mindfulness

Time to reflect

New way of living

*S – change in way of living, moving focus from work to relationship and spending time together*

*Examples of Supporting Quotes for Themes*

Superordinate Theme	Subordinate Theme	Example of quotes to support theme (Selection of quotes included)
Impact on wellbeing	Noticing the effects	<p>“It is perhaps too early in the course to notice any effects.” (Stephen, carer &amp; Rose, PLwD)</p> <p>“...we don’t know what would’ve happened if we hadn’t been doing it.” (Rose, PLwD)</p> <p>“I think you know you don’t know how you’d feel if we weren’t doing this you know, would we still feel the same about my diagnosis...” (Rose, PLwD)</p> <p>“...however the practice of mindfulness I think does have a calming effect.” (Stephen, carer)</p> <p>“...four or five sessions that [inaudible] they were especially important erm, stress erm, relieving stress erm, and on addressing concerns and anxieties.”(Stephen, carer)</p> <p>“...we go to the theatre once a week it was, well I found it for the first time ever quite claustrophobic, I think that was part of the illness really, and I had become a bit unsettled,</p>

		<p>and focusing on breathing helped to get through that.” (Stephen, carer)</p> <p>“I think it is helping” (George, carer)</p> <p>“We’re working together better” (George, carer)</p> <p>“I have been getting better over these past three months. Erm, but I don’t know why...it could be simply the mindfulness...” (Elizabeth, PLwD)</p> <p>[use of mindfulness in future purpose] “ Keeping well. Supporting one another and anybody else that needs support” (George, carer)</p> <p>“I think that we are spending more time together now aren’t we?” (Stephen, carer)</p> <p>“I would hope that our routine would, we would get closer...” (Stephen, carer)</p>
	Gratitude	<p>“We are grateful for the commitment and experience of the trainers, and their skill in conveying their knowledge.”(Stephen, carer)</p>

		<p>“We have also incorporated Mindfulness into our daily walks, which has provided a clearer appreciation of our surroundings; the dawn chorus, the geese with their young, sunrise over the towers of the Minster, which has provided a greater awareness of our situation and how fortunate we are.” (Stephen, carer &amp; Rose, PLwD)</p> <p>“[F1] and [F2} are clearly very skilled trainers, knowledgeable about their subject, patient and anxious to convey their teaching successfully; we are grateful for their commitment.” (Stephen, carer &amp; Rose, PLwD)</p> <p>“ Introducing Mindfulness into our daily walks has made us aware of how fortunate we are in terms of our health and especially the environment through which we pass.” (Stephen, carer &amp; Rose, PLwD)</p> <p>Both dyads expressed feeling of gratitude of fitness in early 70s compared to peers. [Both dyads] (Researcher observation)</p>
--	--	--

		<p>“...it is a way of saying erm er I’m thankful that I can do this I can almost stand on one leg in a way it’s a sign of say look after yourself and in a way I think mindfulness is looking after yourself I think...” (George, carer)</p> <p>“I’ve seen people in their 80s and 90s and they’re just nothing to do and I just think mindfulness could give a bit of hope, it could erm er, because it must be parts of your body that are good even when you’re that age and you can rejoice on the fact that you’ve still got good parts left...” (George, carer)</p> <p>“...there was a moment I think certainly both of [P1] and [P3] mentioned that thing of appreciating what they have got.” (Facilitator 1)</p> <p>[dyads appreciative of] “Health, how they can go walking how they could appreciate nature, erm celebrating the things they could do rather than focusing on what you can’t do...” (Facilitator 1)</p>
--	--	--

	Facilitator benefits	<p>“I found it really humbling at the beginning...” (Facilitator 2)</p> <p>“Oh gosh so did I. I found it humbling at the end.” (Facilitator 1)</p> <p>“I found that really moving” (Facilitator 2)</p> <p>“...we’re getting more skilled all the time in terms of finding out what works and what doesn’t and what’s going to be the right way to do this...” (Facilitator 1)</p> <p>“I’d reached that point where giving back to the dementia community was a very important part of er what I was looking towards, in terms of my own development, I was looking, I was already planning to retire, thinking I’d like to teach mindfulness, and specifically wanted to try and bring, the use of mindfulness to er, people in the what I call the dementia community.” (Facilitator 1)</p>
--	----------------------	--

## Appendix W: Development of

### Themes

#### Initial codes & possible groups (Version

1)

- Experiences of course/facilitators
- Experiences of course
- Resources
- Preparedness
- (Course as introduction? Move from meanings of M?)
- Practising at home
- Understanding mindfulness
- Understandings/definitions/meanings of mindfulness
- Cautious/mindful
- Purpose of mindfulness?
- Difficulty describing?
- Right/wrong way
- No harm
- Tool?
- Effects
- Expectations/hopes
- Positive outcomes
- Benefits to carers
- Gratitude
- Lifestyle change
- Routine
- Mindfulness Practice
- Motivation to continue
- Right/wrong way
- Making it fit
- Togetherness/connectedness
- Togetherness/connectedness
- Practising as a group
- Practising as a dyad
- Attending as a dyad
- Mindfulness effects on others
- Helping others
- Frustration and barriers
- Frustrating experiences
- Barriers
- Essentials for dementia dyads practising mindfulness
- Essentials
- Adaptations/accommodations
- Modelling
- Prompts

- Flexibility
- Uncertainty
- Learning mindfulness with dementia
- Mindfulness and dementia connection
- Time
  - Future courses/improvements
- Improvements/suggestions

## Initial Themes Maps Versions 2 and 3



## **Appendix X: Reflective Statement**

### ***Empirical Research***

#### *The prequel*

I have fond memories of my mum taking me to the older people's day centre and residential home she managed. I spent countless school holidays roaming free, happily chatting to the residents and being treated as their collective granddaughter. I also had some understanding that my presence had a positive effect. I have one particular memory of being about six or seven years old and “helping” to collect orders for lunch. My mum’s co-worker explained to me, “some of the people here find it hard to answer questions like ‘what do you want for lunch?’ because it’s lots of choices, so I’d like you to go and ask them ‘would you prefer a sandwich or a jacket potato?’ because that’s easier for them”. Although I accepted this without question, as young children often do, what I wasn’t aware of at the time is that I was learning about what it’s like to be living with severe cognitive impairments as a result of dementia, and these experiences have stayed with me into adulthood.

#### *The beginning*

Something that really stood out to me during the first few weeks on teaching on the course was mindfulness. I’d always been interested in trying some form of meditation and had become loosely interested in spirituality during my late teens. So, I attended a mindfulness based stress reduction course with a fellow trainee. Around this time I had begun my first clinical placement working with older people, which I really enjoyed, and was just beginning to start my enduring passion for third-wave therapies. I worked with some people living with dementia, both on a ‘functional’ level, but also therapeutically, using compassion focused techniques, which involved mindfulness.

Although the content of what we had discussed the previous week wasn't always retained, something was changing – they seemed less stressed, calmer and it was having a positive impact on their relationships. By now I was certain I wanted to research mindfulness, and a combination of my clinical and early experiences made me certain about doing this with people with dementia.

### *The middle*

I remember meeting for the first time with Chris and Emma to discuss possible research options and leaving feeling inspired. I reached out to psychologists and specialists using mindfulness in other areas to see what they thought of the project. Most feedback was that I was taking on a monumental task by trying to conduct an intervention for PLwD and their carergivers, but this seemed like the most useful way of finding out about their experiences. I found two incredibly dedicated qualified mindfulness teachers who had personal experiences of PLwD and they had wanted to run an intervention for PLwD for years, but hadn't had the resources. So, we pooled our expertise (mine feeling comparably limited) and overcame what seemed like a never-ending tirade of obstacles to acquire additional funding, early ethical approval, the resources, the participants and the venue, to make it all work. So many times I felt like giving up and doing some interviews or administering some questionnaires about experiences people had already had, but I seem to have a tendency for the taking on more than everyone around me, and so being the only trainee in my year to do an intervention seemed fitting.

We finally got it all together and just as it seemed everything had slotted into place... life happened. We had managed to recruit just enough people to run the group, but after the first week one dyad had some major health problems and was hospitalised, unable to return to the course. This had a significant impact on myself, the facilitators and the rest

of the group, and was a stark reminder of the medical difficulties that often accompany living with dementia; something I had essentially managed to avoid in my research, focusing on improving wellbeing. I think this is something about psychologists generally; we have a tendency to focus on strengths and positive experiences. And then again half way through the intervention, another dyad fell ill and couldn't return. I had spent a lot of time with the members of the group at this point and I found it upsetting that two of three had fallen ill. I also panicked about what this meant for the research and how I would run a focus group with just two people at the end of the course. After my catastrophizing passed, I reminded myself to use the skills we were teaching on the course and made a conscious effort to not let the panic overwhelm me.

### *The end*

We made it to the end and I conducted all the interviews. I was amazed at how welcoming the group members were, allowing me into their homes, always providing (proper) coffee, biscuits and cakes each time I arrived. They all wished me the very best in the research and were so pleased they had taken part. They had wanted to take part for themselves, but mostly for the sake of helping others in similar situations in the future. They had such high hopes for this research and what it might do for PLwD, and I found their belief in me inspiring, if a little too ambitious.

I began this research from a selfish perspective, needing a topic to investigate so I could sign myself off as Dr Adams in three years, but it had a much more profound effect on the people who took part, and on myself, than I could have anticipated. My appreciation for qualitative research has also grown. I never before considered that I might connect so much with my participants. That I would be so in-awe of the stories they had to tell. And I now appreciate the insurmountable challenge of wanting to relay the entire story,

but having to pick the highlights, to turn it into something readable and publishable. I realise it's impossible to tell all of the stories I've heard now, but it feels like an honour that I'm the only one who has the whole book.

### ***Systematic Literature Review***

#### *The beginning*

I am writing about my SLR second because to me it always felt less important. This is a discourse that trainees who have completed their theses have perpetuated year on year; however, I have come to realise this is not the case. My SLR felt like a tag along to my empirical research, which I felt so passionate about. I was even told by my supervisors that I needed to find some motivation for my SLR, because it was clear it wasn't there.

#### *The middle*

Countless times I found a review topic that was applicable to my empirical research and I felt was achievable to conduct. And then hours or days later, I would find it had already been done. This was probably when I felt the most stressed during the entire process. It was beginning to feel like I would never find a topic. Of course, eventually I found one, and knowing this was set allowed for some relief (for a short period anyway). I then realised I had chosen a topic which would mean sifting through thousands of possible papers, which felt like a hopeless search. I cannot describe the release when I found my final set of papers. As I read more and more I realised how interested in this topic I was. I still set my empirical research as a priority, as those were real people I had personally connected with, but my SLR helped to inform my empirical research and gave me countless ideas of things that needed to be discussed and researched in the future.

*The end*

I now recognise the value of systematic reviews, and the time and effort that goes into them. I will not perpetuate the myth that your SLR is not as important as your empirical to newer trainees, as I realise this made me complacent about starting my SLR much later. I appreciate the energy that goes into the entire process, and the difficulty of writing an actual synthesis of findings, rather than a list! I also learned how to use the word 'however', through endless trial and tribulation. And although I probably won't be planning my next systematic review for any time soon, I've certainly caught the research bug, and I know this is something I want to make time for in my future career.

## **Appendix Y: Epistemological Statement**

Ontology is ‘concerned with the nature of what exists’, whereas epistemology is ‘concerned with the nature of knowledge and how it can be acquired’ (Ritchie, Lewis, Nicholls & Ormston, 2013). Epistemology is thought to influence the methodology (i.e. how the research should be conducted) and methods (i.e. techniques used to conduct the research) of research, and the ways in which the researcher and participants relate (Carter and Little, 2007).

The intended purpose of this research was to give a voice to people living with dementia (PLwD) and their caregivers, to understand their experiences from their own perspective and to develop an emerging theory of these experiences and processes within this area of research. The principles by which this research was guided were from Participatory Action Research (PAR), a methodology whereby through the cyclical process of exploration, knowledge construction and action research, research questions are re-contextualised in terms of participant’s involvement (McIntyre, 2008). The PAR approach combines the research experience of the researcher with the experiential expertise of the participants through frequent communication. A further purpose of PAR is to make a commitment to and to make heard the voice of groups who have been traditionally exploited or oppressed (Maguire, 1987). Behuniak (2011) reflects that dehumanising discourses such as “the living dead” to describe PLwD are still prominent. People with a dementia diagnosis have historically been negatively stereotyped, which has led to all subsequent behaviours of an individual being interpreted as dysfunctional (Scholl & Sabat, 2008). As such, this study sought to add to the increasing literature which empowers the voices of PLwD and highlights their capacity to actively engage in research and psychological interventions. In order to do

this, the authors decided to use methodology which would lead to an emergent theory of the experiences of PLwD, which meant a qualitative approach was required.

In addition, a considerable issue which is debated within epistemology, and is pertinent to this study, is theories around 'truth' and whether this is objective (i.e. positivist stance) or subjective (constructivist stance) (Ritchie, Lewis, Nicholls & Ormston, 2013). A positive stance come from empiricism, whereby reality is understood and experienced as objective and quantifiable, and researcher bias is not thought to influence the research (Ponterotto, 2005). This approach did not fit with the research questions or aims, nor PAR principles, therefore was rejected for the current study.

By contrast, a constructivist stance assumed there is no objective truth, therefore the researcher acts as a detective, and building an inductive theory from the subjective truths they experience (Gergen, 1999). This fit with the current study's aims and PAR principles, as this would incorporate the subjective realities of the participants, facilitators and researcher, to build an emergent theory.

The authors examined the available qualitative methodologies which will each be considered here: Interpretative Phenomenological Analysis (IPA), Thematic Analysis (TA) and Grounded Theory (GT).

### *IPA*

IPA methodology is about understanding the 'lived experience' and 'subjective meaning' of experiences for participants (Smith & Osborn, 2008).

The current study aimed to build a generalisable theory for PLwD and their caregivers, rather than understanding the lived experience of previous experiences which they had reflected on. This study planned to explore ‘in the moment’ experiences of mindfulness and possible future expectations, therefore IPA was not used.

### ***Thematic Analysis***

Thematic analysis is used to identify, analyse and report patterns within a set of data (Braun and Clarke, 2006). Data is categorised into themes, collated from participant’s accounts, rather than acknowledgement of their individual experiences (Anderson, 2007). This therefore limits the depth of understanding around the experiences of participants within a study, which was not suitable for the present study as this would not lead to the development of an emergent theory.

### ***Grounded Theory***

Constructivist Grounded Theory was selected by the authors of this research. Grounded Theory methods intend to construct theories that are grounded in collected data (Glaser & Strauss, 1967). This begins with the process of qualitative coding which allows the researcher to separate and synthesise the data and allow for comparisons. From these, preliminary analytic notes are formed, which define the ideas that best fit and interpret the data as tentative analytic categories. Then, through successive levels of analysis, these categories become theoretical (Charmaz, 2006). The authors planned to use this approach in the study by identifying initial qualitative codes based on the data gathered at the focus group, each session and the post-course interviews, which would inform what was most suitable to ask and measure in the final focus group, and how the intervention progressed based on the experiences of the participants, facilitator and researcher.

This process fit well with PAR principles, as participants would provide information before the course, such as what would be most important for the researcher to measure during the intervention. Grounded Theory utilises the process of moving back and forth between the data and emerging analysis in real time (Bryant & Charmaz, 2007), which in the context of this research involved the emerging analysis informing what data was gathered. In addition, the emphasis on data and analysis being derived from shared experiences and relationships with participants, and that the analysis should be contextually situations in culture, time, place and situations (Charmaz, 2006) aligns well with PAR principles (McIntyre, 2008).

### *Final Analysis*

Due to the data not meeting saturation, as is a key principle of Grounded Theory analyses (Charmaz, 2006), not enough data was available from which to develop an emerging theory. The authors therefore utilised a reflexive approach, choosing to complete a Thematic Analysis of the data. Grounded Theory informed the approach, data collection and analysis of the study, but the final write-up of the data was presented as superordinate and subordinate themes.

An inductive approach was taken to the Thematic Analysis, which meant the themes were strongly linked to the data themselves (Patton, 1990), which bears resemblance to the initial coding stages of a Grounded Theory approach. By contrast, deductive Thematic Analysis involves data being driven by current theories and the analytic interest of the researcher in the area (Braun & Clarke, 2006). An inductive approach fit with the current study as the aims of the research were to give a voice to PLwD and their caregivers, in light of PAR principles, and to understand their experiences and

realities, therefore the themes were developed directly from the data. In addition, the Thematic Analysis utilised a social constructivist approach, as is similar to Constructivist Grounded Theory, which informed how meaning was conceptualised. Social constructivism suggests ‘meaning and experience are socially produced and reproduced’ (Burr, 2015), therefore the analysis of this research did not focus on just individual realities, but on sociocultural contexts (Braun & Clarke, 2006).

Finally, the role of the research should be considered within the current study. PAR principles involve the expertise of the researcher combining with the experiential expertise of the participants (McIntyre, 2008). And, just as the participants and facilitators have their own subjective realities, so too does the researcher, therefore this research is a collaboration of the combined subjective realities of all involved, and can only be read as one possible version of the data, rather than an objective truth.

## References

- Anderson, R. (2007). *Thematic Content Analysis (TCA): Descriptive Presentation of Qualitative Data*. Retrieved from [www.wellknowingconsulting.org/publications](http://www.wellknowingconsulting.org/publications).
- Behuniak, S. M. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society*, 31(01), 70-92.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Bryant, A., & Charmaz, K. (Eds.). (2007). *The Sage handbook of grounded theory*. London: Sage.
- Burr, V. (2015). *Social constructionism*. Sussex/New York: Routledge.
- Carter, S. M., & Little, M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. *Qualitative Health Research*, 17(10), 1316-1328.
- Charmaz, K. (2006). *Constructing Grounded Theory: A practical guide through qualitative analysis*. London: SAGE Publications.
- Gergen, K. (1999). *An invitation to social construction*. London: Sage
- Glaser, B. & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.
- Maguire, P. (2006). Uneven ground: Feminisms and action research (pp. 60-70). In Reason, P. & Bradbury, H. (2006) *Handbook of action research*. SAGE Publications.
- McIntyre, A. (2008). *Qualitative Research Methods: Participatory action research*. CA: SAGE Publications Ltd.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. SAGE Publications Ltd.

- Ponterotto, J. G. (2005). Qualitative research in counselling psychology: A primer on research paradigms and the philosophy of science. *Journal of Counselling Psychology, 52*(2), 126-136.
- Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (Eds.). (2013). *Qualitative research practice: A guide for social science students and researchers*. SAGE Publications.
- Scholl, J. M., & Sabat, S. R. (2008). Stereotypes, stereotype threat and ageing: implications for the understanding and treatment of people with Alzheimer's disease. *Ageing and Society, 28*(01), 103-130.
- Smith, J. A. & Osborn, M. (2008). *Interpretative Phenomenological Analysis*. In J. A. Smith, *Qualitative Psychology* (2nd ed). London: Sage.