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Author

Murfield, Jenny, Moyle, Wendy, O'Donovan, Analise

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Submission to special issue: Self-care in long term conditions

Mindfulness- and compassion-based interventions for family carers of older adults: a scoping review

Jenny Murfield BSc(Hons)^{a,b*} (j.murfield@griffith.edu.au) ORCID: 0000-0001-9595-4242

Wendy Moyle PhD^{a,b} (w.moyle@griffith.edu.au) ORCID: 0000-0003-3004-9019

Analise O'Donovan PhD^{a,c} (a.odonovan@griffith.edu.au) ORCID: 0000-0002-0776-0956

^aMenzies Health Institute Queensland, Griffith University, Nathan, Brisbane, Queensland, Australia

^bSchool of Nursing and Midwifery, Nathan Campus, Griffith University, Nathan, Brisbane, Queensland, Australia

^cSchool of Applied Psychology, Mt Gravatt Campus, Griffith University, Mt Gravatt, Brisbane, Queensland, Australia

***Corresponding Author:** Jenny Murfield, School of Nursing & Midwifery, Menzies Health Institute Queensland, Griffith University, Health Sciences (N48), 170 Kessels Road, Nathan, Brisbane, Queensland, 4111, Australia. Tel: +61 7 3735 7855; Email: j.murfield@griffith.edu.au

Mindfulness- and compassion-based interventions for family carers of older adults: a scoping review

Abstract

Objectives: To provide an overview of the current use of mindfulness- and compassion-based interventions with family carers of older adults, to aid primary healthcare practitioners in their decision-making around referral to wider healthcare services. The study was guided by four research questions: what interventions are currently used; whom they are used with; why they are used; and their evidence-base in terms of acceptability and effectiveness.

Design: A scoping study using the methodological frameworks of Arksey and O'Malley and Levac et al.

Data sources: Searches of electronic databases (MEDLINE, CINHALL, PsycINFO), reference lists of relevant articles, and journal websites were conducted in June 2019. Search terms were developed via an iterative process, and included medical subject headings and keywords relating to mindfulness and compassion, interventions, and family carers.

Review methods: Articles were included if: written in English; published in a peer-reviewed journal; employed quantitative, qualitative, or mixed-method research designs; and described a mindfulness- and/or compassion-based intervention for adults identified as a family carer of an older adult. Data from included studies were charted (using a purposively-designed template), and descriptively analysed in relation to the study's research questions.

Results: From 2,005 unique records, 32 primary studies were included. Seven types of mindfulness- or compassion-based interventions were broadly described within studies, including: mindfulness-based stress reduction (n=13), mindfulness-based cognitive therapy (n=3), meditation interventions (n=9), acceptance and commitment therapy (n=1), dialectical behaviour therapy (n=1), compassion-focused therapy (n=1), and study-specific interventions involving a combination of mindfulness and/or compassion (n=4). Studies sampled a total of n=991 participants and targeted

six family carer sub-groups: dementia (n=23), cancer (n=5), amyotrophic lateral sclerosis (n=1), chronic conditions (n=1), cirrhosis (n=1), and Parkinson's disease (n=1). A variety of health outcomes were assessed across interventions, with the most common being depression (n=26), anxiety (n=15), burden (n=15), quality of life (n=14), and stress (n=11). The evidence-base for each intervention was insufficient and too heterogeneous to make clear statements regarding effectiveness. However, based on these findings, interventions show some potential utility in supporting family carers in their role and, given a collective rate of attrition (18%), may do so in a way that is acceptable to carers.

Conclusions: This scoping study highlighted the nascent use of mindfulness- and compassion-based interventions with family carers of older adults, and provided important substantive detail about what each intervention entails. Based on current evidence, a number of implications for research and practice are presented.

Keywords: Acceptance and Commitment Therapy; Compassion; Family Caregiver; Mental Health; Mindfulness; Self-Care.

What is already known about the topic?

- Caring for an older family member can negatively impact the mental and physical health of both the family carer and care recipient.
- Carers need to be better supported in their role, and quantitative reviews and meta-analyses have highlighted the potential benefit of interventions that develop emotion regulation strategies for family carers of older adults, including mindfulness- and compassion-based interventions.
- As interest in mindfulness and compassion grows, it is important to provide primary healthcare practitioners with enough detail about what such interventions entail, in order to help inform their clinical decision-making around referral to wider healthcare services.

What this paper adds

- Over the last fifteen years, 32 published studies have researched the use and effect of seven mindfulness- or compassion-based interventions with six family carers subgroups on the main outcomes of depression, anxiety, burden, stress, and quality of life.
- While it is premature to make clear statements about the effectiveness and acceptability of mindfulness- and compassion-based interventions, early findings suggest some potential utility in supporting family carers in their role, and in a way that is acceptable to carers.
- The current use of mindfulness- and compassion-based interventions with family carers of older adults are substantively described within this scoping study to aid primary healthcare practitioners in their decision-making around referral to wider healthcare services.

1. Introduction

Caring for an older family member is no easy task, and extensive research conducted over the last three decades shows that many carers find it a stressful and challenging experience (Adelman et al., 2014, Schulz and Sherwood, 2008). When compared to non-caregiving populations, family carers report significantly more psychological health problems (Roth et al., 2009), and have higher levels of depression and stress, and lower levels of self-efficacy and subjective wellbeing (Pinquart and Sorensen, 2003). In addition, poorer carer mental health has been identified as a key risk factor for increased neglect and abuse of older adults (Kohn and Verhoek-Oftedahl, 2011) and, in carers of people with neurodegenerative diseases specifically, is a predictor of mortality (Lwi et al., 2017). These data present a compelling case to better support carers in their role, and efforts to do so are borne out in the plethora of support services currently available. However, despite these efforts, services remain largely under-utilised, and many family carers of older adults report that what is available does not adequately meet their wants or needs (Heath et al., 2018, Stockwell-Smith et al., 2010, Temple and Dow, 2018). Such incongruence between provision and uptake has been explored in research focused on better understanding the needs of family carers, and self-care has emerged as an important issue (Silva et al., 2013). Specifically, family carers of older adults have self-identified a need for better access to professional emotional support services to help with coping strategies and stress management (Silva et al., 2013), and there is evidence from online family carer blogs that various health and wellness strategies (including mind-body practices) are incorporated into and/or recognised as important in many carers' self-care routines (Anderson et al., 2018). Early-stage research also supports the potential of self-care practices to provide protective emotional adaption in the caregiving role, with higher levels of self-compassion in family carers of people with dementia associated with lower levels of burden and greater use of emotion-focused coping strategies (Lloyd et al., 2018). Such findings highlight the potential benefit of interventions that seek to intentionally develop emotion

regulation strategies for family carers of older adults, and in providing them with skills to manage the stresses of their role in the longer-term.

The last few decades has seen the emergence of a number of psychological therapies and interventions (often referred to as ‘third-wave’ therapies) that have evolved from traditional cognitive behavioural therapy treatments, and which focus on issues such as mindfulness, acceptance, and compassion (Hofmann et al., 2010). These interventions, albeit differing in their method and the outcomes they target, are considered transdiagnostic, and are focused on addressing thought patterns and how the individual relates and responds to symptoms and experiences. In mindfulness-based approaches this is generally achieved through focusing on the non-judgmental awareness and acceptance of present-moment experiences (Kabat-Zinn, 1994), while compassion-based approaches tend to focus on the cultivation of compassion for self and others (Gilbert, 2009). Growing evidence from reviews and meta-analyses demonstrate the potential of mindfulness- and compassion-based interventions to reduce psychopathology in various clinical and subclinical populations (Khoury et al., 2013, Kirby et al., 2017). Similarly promising findings have been evidenced in reviews of older family carer populations, particularly carers of people with dementia, with improvements reported for depression, burden, stress, and anxiety (Berk et al., 2018, Collins et al., 2018, Dharmawardene et al., 2016, Guichen et al., 2016, Hurley et al., 2014, Jaffray et al., 2016, Kor et al., 2018, Liu et al., 2017, Liu et al., 2018).

As interest in the area of mindfulness and compassion continues to grow, the importance of quantifying potential effects cannot be under-estimated. However, it is also important, at a practical level, to provide practitioners with enough detail about what mindfulness- and compassion-based interventions entail, including what is available, what they involve, whom they are used with, and why. A broader description of the evidence may help inform clinical decision-making further, and this may be particularly useful for primary healthcare practitioners whom are typically the first point of contact for family carers about health-related issues, and facilitate access to wider healthcare services.

The purpose of this scoping study is to provide a broad but substantive overview of the current use of mindfulness- and compassion-based interventions with family carers of older adults, with a view to aiding primary healthcare practitioners in their understanding and decision-making around referral to wider healthcare services.

2. The Scoping Study

2.1 Research question

The broad exploratory research question guiding the study was: *What is known about the use of mindfulness- and compassion-based interventions with family carers of older adults?* Four specific research questions were then developed after undertaking initial searches: 1) *What types of mindfulness- and compassion-based interventions are used?* 2) *What subgroups of family carers are mindfulness- and compassion-based interventions used with?* 3) *What target health outcomes are mindfulness- and compassion-based interventions used for?* 4) *What evidence is there for the acceptability and effectiveness of mindfulness- and compassion-based interventions?*

2.2 Design

The purpose of a scoping study is to map the literature on either a broad or emerging research area, and to identify gaps in knowledge to inform future research, policy, and practice (Arksey and O'Malley, 2005, Levac et al., 2010). It is a useful way of examining the extent, range and nature of a research area, and in mapping current knowledge in areas that have limited randomised controlled trial evidence available (Levac et al., 2010). As such, the scoping study was considered the most appropriate approach for this study given: 1) the potential breadth of the research area (i.e., number of different interventions); 2) the relative infancy of compassion-based intervention research specifically (i.e., limited randomised controlled trials) (Kirby et al., 2017); 3) the study's aim of providing primary healthcare practitioners with substantive detail about what each intervention entails and how they are currently used with the family carer population; and 4)

and the recently identified difficulties in combining different mindfulness- and compassion-based therapy/intervention modalities together as an homogeneous group for quantitative systematic review and meta-analyses (for a fuller discussion see Kirby and Gilbert, 2019).

The study used the five stages outlined in the methodological frameworks of Arksey and O'Malley (2005) and Levac et al. (2010), involving: identification of the research question; identification of relevant studies; selection of studies; charting of the data; and collation and summary of results.

2.3 Search strategy

The scoping study methodological framework (Arksey and O'Malley, 2005, Levac et al., 2010) does not assess study quality, given that the focus of the method is on 'mapping' the breadth and depth of a research area. However, to ensure a minimum level of evidence quality, only primary studies reported in peer-reviewed journals were permitted. Articles were identified via searches of electronic databases, reference lists of shortlisted full-text articles, and journal websites. An iterative process was undertaken to identify search terms, which involved: reading titles and abstracts of known studies to identify initial search terms; sourcing previous reviews of mindfulness- and compassion-based interventions in other populations to identify existing interventions and previously used keywords; trialing Medical Subject Headings (MeSH) and keyword combinations for accuracy; and ongoing consultation with a healthcare librarian. MEDLINE (via EBSCO), CINAHL Plus with Full Text (via EBSCO), and PsycINFO (via Ovid) were searched on June 21 2019, using a combination of terms in searches of titles, abstracts, and database-specific subject headings (Table 1). Searches were restricted to articles written in English. No date limitations were applied.

Table 1

Medical subject headings (MeSH) and keywords used in searches.

#	MeSH (in subject headings)	Key words (in title and abstract)
#1	(“mindfulness” ^a OR “compassion” ^b OR) OR	(mindful* OR “mindfulness-based” OR “self compassion” OR self-compassion OR compassion OR “compassion-based”) AND (program* OR intervention* OR train* OR therap* OR group* OR self-help OR “self help” OR self-care OR “self care”) AND
	“caregivers” ^a OR	(caregiver* OR carer* OR famil* car* OR famil* member* OR informal car* OR relative* OR spous* OR partner* OR *kin OR couple* OR dyad*)
#2	(“meditation” ^a OR “acceptance and commitment therapy” ^b) OR	(“mindfulness based stress reduction” OR “mindfulness-based stress reduction” OR “mindfulness based cognitive therapy” OR “mindfulness-based cognitive therapy” OR “acceptance and commitment therapy” OR “dialectical behaviour therapy” OR “dialectical behavior therapy” OR meditation’ OR “loving kindness meditation*” OR “loving-kindness meditation” OR “compassion meditation” OR “mindful self compassion” OR “mindful self-compassion” OR “compassion focused therapy” OR “compassion-focused therapy” OR “compassion focussed therapy” OR “compassion-focussed therapy” OR “compassionate mind training” OR “compassion cultivation training” OR “cognitively based compassion training” OR “cognitively-based compassion training” OR “cultivating emotional balance) AND caregiver* OR carer* OR famil* car* OR famil* member* OR informal car* OR relative* OR spous* OR partner* OR *kin OR couple* OR dyad*
#3		Search #1 OR Search #2

Note: ^aSubject headings used in all database searches (MEDLINE, CINAHL, and PsycINFO) ^bSubject headings used only in searches of CINAHL.

2.4 *Study selection*

Articles were selected for inclusion if they were: written in English; published as a full-text article in a peer-reviewed journal; primary research with a quantitative, qualitative, or mixed-method design; and a mindfulness- and/or compassion-based intervention for adult carers of an older adult family member, friend, or neighbour. In the absence of a universal definition of an older adult (World Health Organization, 2002), a broad age parameter was applied, seeing studies eligible if the reported mean age of care recipients was 60 years or older, and/or presented with a condition associated with older age (e.g., dementia). After removing duplicates, the first author reviewed titles and abstracts. The first and second author then independently assessed the full-texts of shortlisted articles against the described criteria. Further detail about the age of the care recipient was required for 11 studies, and six corresponding authors responded. Consensus between authors was absolute, with independent agreement reached on all 66 studies (Figure 1).

2.5 *Charting data and synthesis*

A purposefully designed template was used to record information from included studies about the author, intervention, design, sample, measures, and key findings. Data were descriptively analysed and presented narratively in relation to the study's four guiding research questions.

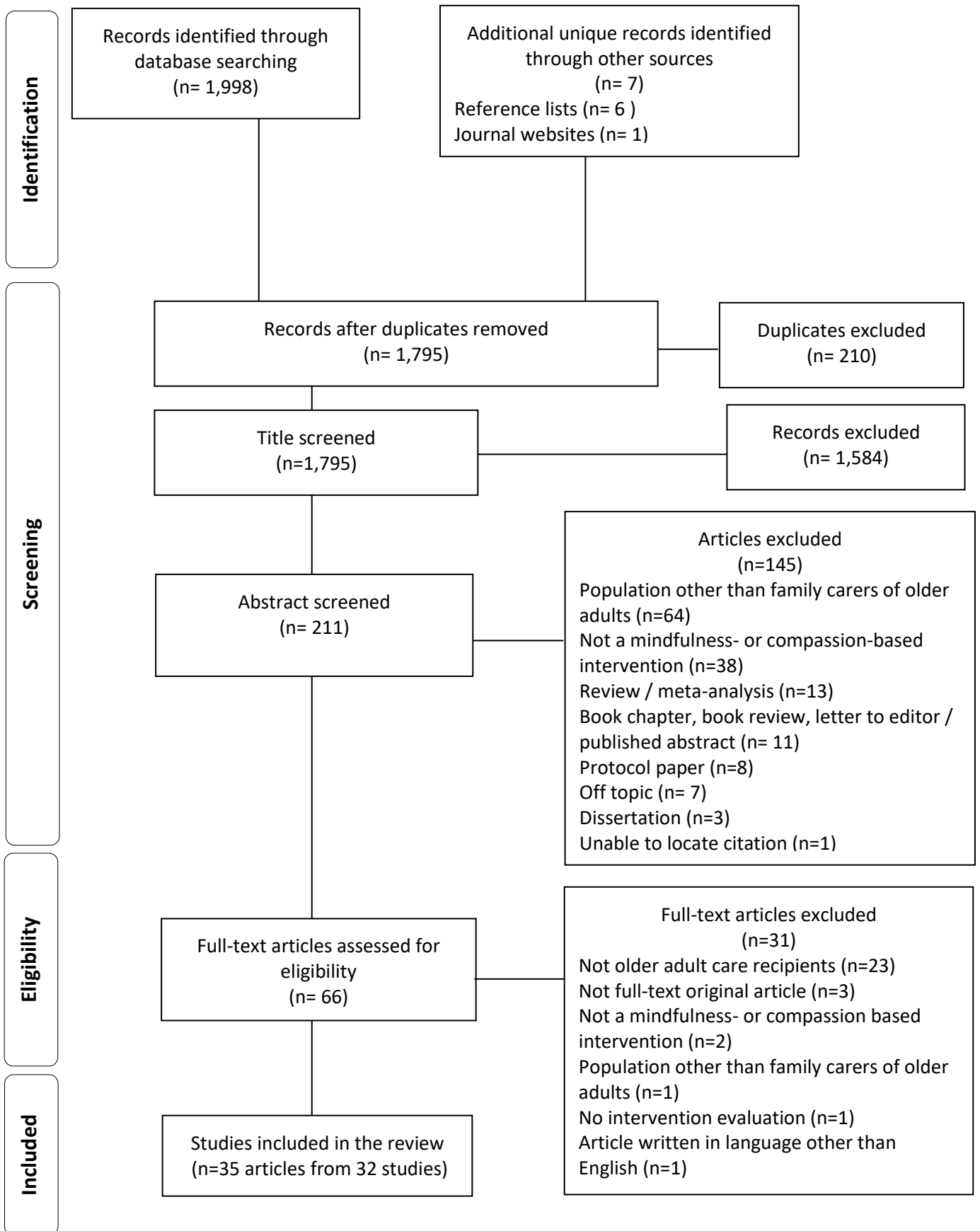


Fig. 1. Literature search process.

3. Results

The search process yielded a total of 2,005 unique records. After eligibility screening, 35 articles, reporting findings from 32 primary studies, were included (Table 2 and supplementary data file). Studies were published within the last fifteen years (2004-2019), and were conducted in ten countries (United States n=21; Hong Kong n= 2, Netherlands n=2, Australia n=1, Brazil n=1, Canada n=1, Iran n=1, Italy n=1, Spain n=1, United Kingdom n=1). Twenty-three studies employed a quantitative design, seven used mixed-methods, and two were qualitative. Approximately 40% of all studies were randomised controlled trials (20% fully powered; 20% pilot/exploratory). Seven types of mindfulness- or compassion-based interventions were described within studies, including: mindfulness-based stress reduction (n=13), mindfulness-based cognitive therapy (n=3), meditation interventions (n=9), acceptance and commitment therapy (n=1), dialectical behaviour therapy (n=1), compassion-focused therapy (n=1), and study-specific interventions involving a combination of mindfulness and/or compassion (n=4). Studies sampled a total of n=991 participants, and were targeted at six family carer sub-groups: dementia (n=23), cancer (n=5), amyotrophic lateral sclerosis (n=1), chronic conditions (n=1), cirrhosis (n=1), and Parkinson's disease (n=1). A variety of outcomes were assessed across studies, with the most common being depression (n=26), burden (n=15), anxiety (n=15), quality of life (n=14), and stress (n=11). The evidence-base for the effectiveness of interventions varied in number and quality, and reflected a research field still in its infancy. However, the collective attrition rate across studies was 18%, suggesting general levels of acceptability.

Table 2

Overview of included studies by intervention, design, and family carer population sub-group

Intervention	Design	Sub-group
Mindfulness-based stress reduction (n=13)		
Bajaj et al., 2017	Pre-post	Cirrhosis (<i>dyadic</i>)
Berk et al., 2019	Pilot mixed-methods	Dementia (<i>dyadic</i>)
Birnie et al., 2010	Pre-post	Cancer (<i>dyadic</i>)
Brown et al., 2016	Pilot RCT	Dementia
Cash et al., 2016	Pilot pre-post	Parkinson's disease (<i>dyadic</i>)
Epstein-Lubow et al., 2011	Mixed-methods	Dementia
Ho et al., 2016	Pre-post	Dementia
Hoppes et al., 2012	Mixed-methods	Dementia
Hou et al., 2014	RCT	Chronic conditions
Marconi et al., 2016	Qualitative	ASL (<i>dyadic</i>)
Paller et al., 2015	Pre-post	Dementia (<i>dyadic</i>)
van den Hurk et al., 2015	Pilot mixed-methods	Cancer (<i>dyadic</i>)
Whitebird et al., 2013 & 2011	RCT	Dementia
Mindfulness-based cognitive therapy (n=3)		
Kor et al., 2019	Pilot RCT	Dementia
Norouzi et al., 2013	Quasi-experimental	Dementia
Oken et al., 2010	Pilot RCT	Dementia
Meditation interventions (n=9)		
Black et al., 2013 & Lavretsky et al., 2013	RCT	Dementia
Bormann et al., 2009	Mixed-methods	Dementia
Innes et al., 2012	Pilot pre-post	Dementia (<i>dyadic</i>)
Jain et al., 2014	Feas mixed-methods	Dementia
Kubo et al., 2018	Feas mixed-methods	Cancer (<i>dyadic</i>)
Leach et al., 2015	Pilot RCT	Dementia
Pomykala et al., 2012	Pilot RCT	Dementia
Waelde et al., 2017	RCT	Dementia
Waelde et al., 2004	Pre-post	Dementia
Acceptance and commitment therapy (n=1)		
Losada et al., 2015	RCT	Dementia
Dialectical behaviour therapy (n=1)		
Drossel et al., 2011	Pre-post	Dementia
Compassion-focused therapy (n=1)		
Collins et al., 2018	Pre-post	Dementia (<i>dyadic</i>)
Study-specific interventions (n=4)		
Cottingham et al., 2018	Qualitative	Cancer (<i>dyadic</i>)
Danucalov et al., 2013, 2017	RCT	Dementia
Dowling et al., 2014	Pilot RCT	Dementia
Milbury et al., 2015	Pilot pre-post	Cancer (<i>dyadic</i>)

Note. RCT: randomised controlled trial; Feas = feasibility; ASL = Amyotrophic lateral sclerosis

3.1 Mindfulness-based interventions

3.1.1 Mindfulness-based stress reduction

Mindfulness-based stress reduction is a structured psychoeducational and skills-based program that uses contemplative mindfulness meditation practices to facilitate better emotional coping (Kabat-Zinn, 1990, Kabat-Zinn, 2003). First developed in the late 1970s for people experiencing chronic pain, it has since been adapted and has shown some efficacy in reducing stress, depression, and anxiety in family carers of various conditions (Guichen et al., 2016), and in reducing stress for carers of people with dementia (Kor et al., 2018). While drawing on Buddhist philosophy, mindfulness-based stress reduction is delivered as a secular, group-based intervention, involving 2.5 hour weekly sessions over eight weeks, a 7-hour silent retreat, and 45-minute daily homework. The program focuses on three main practices – mindfulness meditation, body scanning, and Hatha yoga (focused on moment-to-moment awareness) – and sessions involve guided practice, shared experiential enquiry, and psychoeducation/theoretical discussion.

Interventions: Thirteen studies described adapted mindfulness-based stress reduction programs (Table 2). Eight were quantitative studies (n=5 pre-post interventions studies; n=3 randomised controlled trials), four were mixed-methods, and one was qualitative. All studies tailored the content to the sub-group population, and typically reduced intensity via shorter sessions over fewer weeks, less homework practice, and no retreat. Only three studies kept the original duration (Berk et al., 2019, van den Hurk et al., 2015, Whitebird et al., 2013), while 11 studies reduced intensity, the shortest being 60 minute weekly sessions over four weeks (e.g., Bajaj et al., 2017, Hoppes et al., 2012). Six studies specifically omitted the inclusion of a retreat (Bajaj et al., 2017, Epstein-Lubow et al., 2011, Hoppes et al., 2012, Hou et al., 2014, Marconi et al., 2016, Paller et al., 2015), and others reduced duration from a full day to a 3-4 hour half-day (e.g., Birnie et al., 2010, Cash et al., 2016, Ho et al., 2016). When the amount of homework practice was specified, it ranged from 30 to 60 minute daily

practice (Berk et al., 2019, Cash et al., 2016, Epstein-Lubow et al., 2011, Hou et al., 2014, Paller et al., 2015, van den Hurk et al., 2015).

Sub-groups: Studies sampled a total of n=443 family carers from six sub-groups: dementia (n=7), cancer (n=2), amyotrophic lateral sclerosis (n=1), chronic conditions (n=1), cirrhosis (n=1), and Parkinson's disease (n=1). Half of the studies were dyadic (n=7), involving the family carer and care recipient. However, for interventions targeting dementia (n=5/7), and the study involving chronic conditions, interventions typically included the family carer only. Studies varied in the demographic information provided; however, where reported, family carers were typically female spouses or offspring, with an average age of 61 years. There was a general paucity of information reported about care recipients.

Target outcomes: Intervention effects were assessed on a plethora of health outcomes, the most common being: depression (n=10), burden (n=8), mindfulness (n=8), anxiety (n=8), stress (n=7), and quality of life (n=6). All studies assessed short-term effects from baseline to intervention end. However, six studies also assessed sustained effects, and these were chiefly at 3-month follow-up after an 8-week intervention (Brown et al., 2016, Epstein-Lubow et al., 2011, Hou et al., 2014, van den Hurk et al., 2015), but also included a 1-month follow-up after a 4-week intervention (Hoppes et al., 2012), and at 6-months after an 8-week intervention (Whitebird et al., 2013).

Evidence-base: From the host of significant effects reported (supplementary data file), there was most evidence to support the effectiveness of mindfulness-based stress reduction in reducing depression (Bajaj et al., 2017, Epstein-Lubow et al., 2011, Ho et al., 2016, Hou et al., 2014, Paller et al., 2015, Whitebird et al., 2013) and burden (Bajaj et al., 2017, Epstein-Lubow et al., 2011, Ho et al., 2016, Hoppes et al., 2012, van den Hurk et al., 2015). Findings were less conclusive for improvements in mindfulness – whereby five studies found evidence of improvements post-intervention, but three did not – and for positive changes in anxiety,

quality of life, stress, and general wellbeing. In addition, support for sustained effects was generally weak – either not studied (n=7) or not found (Brown et al., 2016, Hoppes et al., 2012) – although effects were reported at 3-months for burden (Epstein-Lubow et al., 2011, van den Hurk et al., 2015), depression (Hou et al., 2014), and calmness and mindful attention (Epstein-Lubow et al., 2011), and at 6-months for overall wellbeing (Whitebird et al., 2013).

When looking at the best evidence available in the three randomised controlled trials, mindfulness-based stress reduction was more effective than a social support group (matched to duration, frequency, and length) in improving stress, tension, and anger in family carers of people with dementia after an 8-week intervention (Brown et al., 2016). However, the social support group was more effective in improving burden, and there was no evidence of sustained effects on any outcome. In a similar randomised controlled trial involving family carers of people with dementia and a education support comparison group, mindfulness-based stress reduction was more effective in improving overall mental health both at week eight and 6-months follow-up, and in improving stress and depression at post-intervention only (Whitebird et al., 2013). Both groups, however, were similarly effective in improving anxiety, social support, and burden. Finally, in a randomised controlled trial that compared mindfulness-based stress reduction with a self-help education booklet control group (Hou et al., 2014), mindfulness-based stress reduction was more effective in improving depression and anxiety at week eight in family carers of chronic conditions, and in improving depression, mindfulness, and self-efficacy at 3-months.

There was a collective attrition rate of 17%. Family carers generally noted that it was helpful and supportive to participate dyadically (Berk et al., 2019, Marconi et al., 2016, van den Hurk et al., 2015), and in groups (Berk et al., 2019, van den Hurk et al., 2015). However, some carers expressed difficulty in completing homework practice due to limited time and external distractors (Berk et al., 2019, Marconi et al., 2016, van den Hurk et al., 2015). The

logistics of getting to sessions (Marconi et al., 2016), and scheduling conflicts with medical appointments (Cash et al., 2016), was also a barrier for some. One study participant also noted increased feelings of sadness during practices within group sessions (Berk et al., 2019).

3.1.2 Mindfulness-based cognitive therapy

Mindfulness-based cognitive therapy is an adaption of mindfulness-based stress reduction, matched to structure and duration, but adapted specifically for the treatment and prevention of recurrent depression (Segal et al., 2002). With an explicit focus on exploring low mood and negative thought patterns, recent years have seen MBCT used to address a range of health issues other than recurrent depression, including anxiety (Strege et al., 2018) and bipolar disorder (Lovas and Schuman-Olivier, 2018).

Interventions: Three studies described use of an adapted mindfulness-based cognitive therapy intervention, two of which were pilot randomised controlled trials, and one a non-randomised trial (see Table 2). All interventions adapted the mindfulness-based cognitive therapy program for use with a dementia carer population, and all excluded a silent retreat. While the study by Norouzi et al. (2014) most closely resembled the original format (2.5 hours once a week for eight weeks), homework practice was not specified. In contrast, Oken and colleagues (2010) reduced the length of each weekly session to 1.5 hours, as well as reduced the intervention duration to seven weeks, but kept daily homework practice. Kor et al. (2019) reduced session length to 2 hours, which were conducted weekly for the first four weeks, and then bi-weekly from weeks five through seven, with additional weekly telephone support (total duration 10 weeks). Expected homework practice varied as the intervention progressed, but generally included 45-minutes practice six days a week.

Sub-groups: A total of n=87 family carers of people with dementia were sampled. The demographic information provided varied but, where reported, family carers had an

average age of 60 years, and were typically either a spouse or offspring. Information about the care recipient was not reported in any study.

Target outcomes: A host of health outcomes were assessed using a variety of measures that were self-report, but also included assessment of cognition and physiological stress (Oken et al., 2010). The most common target outcome was depression, which was assessed in all studies, followed by burden and quality of life (Kor et al., 2019, Norouzi et al., 2014), and stress and mindfulness (Kor et al., 2019, Oken et al., 2010). Short-term effects from baseline to intervention end were assessed in all studies, and two also assessed longer-term effects at 2- (Norouzi et al., 2014) and 3-month follow-up (Kor et al., 2019). One study also used experiential-based sampling to assess changes over the course of a day when in the home environment (Oken et al., 2010).

Evidence-base: In the randomised controlled trials, when compared to a weekly dementia education group, mindfulness-based cognitive therapy was significantly more effective in improving stress, depression, and mindfulness in the short-term and at 3-months, but had no effect on anxiety, resilience, or quality of life at any point (Kor et al., 2019). However, when compared to an active intervention (Powerful Tools for Caregiving education and social support group), as well as a respite-only control group, the unique effect of mindfulness-based cognitive therapy was less clear: both the mindfulness-based cognitive therapy and active intervention were similarly more effective than the control in improving stress and cognition post-intervention (Oken et al., 2010), but there was no effect on depression, mindfulness, or physiological stress (supplementary file for all outcomes assessed). In the non-randomised trial, when compared to a wait-list control (Norouzi et al., 2014), mindfulness-based cognitive therapy was significantly more effective in improving depression and burden immediately after the intervention and at 2-month follow-up, but had no effect on quality of life.

There was a relatively low rate of attrition across studies (9%). Kor et al. (2019) also noted that the average weekly homework practice was three hours (ranged from 1 to 5 hours), and that the intervention was enjoyable and helpful for carers.

3.1.3 Meditation interventions

The term meditation is used to encompass an array of different mind-body practices, some of which are spiritual and religiously contemplative, while others are secular and involve cognitive-related activities of reflection, monitoring, and awareness (Awasthi, 2013). The method used in each type of meditation can vary significantly, and may include more mindfulness-based techniques (i.e., present moment attention), or more concentrative forms involving repetition of a word/mantra or focused imagery (Hurley et al., 2014). A multitude of studies have explored the effects of meditation, and some positive effects have been reported, such as the treatment of major depressive disorders (Zou et al., 2018), pain intensity in headaches (Gu et al., 2018), and symptoms of post-traumatic stress disorder (Gallegos et al., 2017).

Interventions: Nine studies broadly described meditation interventions (Table 2). Six were quantitative studies (n=4 randomised controlled trials; n=2 pre-post intervention), and three were mixed-methods. There was heterogeneity in the type of meditation used, which included: yogic Kirtan Kriya mediation (Black et al., 2013, Innes et al., 2012, Lavretsky et al., 2013, Pomykala et al., 2012); spiritually-based mantra repetition with cognitive behavioural skills (Bormann et al., 2009); transcendental meditation (Leach et al., 2015); Headspace™ mindful mediation app (Kubo et al., 2018); Central Mediation and Imagery for Caregivers (Jain et al., 2014); and an Inner Resources program for Caregivers involving meditation, breathing techniques, imagery, and mantra repetition, either with hatha yoga (Waelde et al., 2004), or without (Waelde et al., 2017). Delivery format, frequency, and

duration of interventions varied significantly, ranging from 11-minutes of twice daily Kirtan Kriya meditation using a guided CD for eight weeks (Innes et al., 2012), to 90-minute group sessions once a week for eight weeks and daily homework practice (Jain et al., 2014).

Sub-groups: Studies sampled a total of n=176 family carers. These were predominantly carers of people with dementia (n=8), and one study of carers of people with cancer. Interventions typically targeted the family carer only (n=7), although two studies involved both the family carer and care recipient (Innes et al., 2012, Kubo et al., 2018). While there was variation across studies in the level of demographic information provided, family carers were typically female spouses or offspring, with an average age of 70 years. Information about care recipients was lacking, with only the dyadic studies including some detail, albeit varying.

Target outcomes: Intervention effects were assessed on a range of self-report health outcomes, the most common being depression (n=7), quality of life (n=4), anxiety (n=3), burden (n=3), and sleep (n=3). Effects were also explored in terms of cognitive functioning (Black et al., 2013, Lavretsky et al., 2013, Leach et al., 2015), and physiology (Black et al., 2013, Innes et al., 2012, Lavretsky et al., 2013, Pomykala et al., 2012, Waelde et al., 2017). Seven studies assessed short-term effects from baseline to intervention end, while two only assessed effects from baseline to 1-month follow-up after 5- and 8-week interventions (Waelde et al., 2017, Waelde et al., 2004). Three studies also assessed longer-term effects on health outcomes of up to two years (Bormann et al., 2009, Jain et al., 2014, Leach et al., 2015).

Evidence-base: Across studies, there was strongest evidence for meditation interventions to reduce levels of depression in family carers (Black et al., 2013, Bormann et al., 2009, Innes et al., 2012, Jain et al., 2014, Kubo et al., 2018, Lavretsky et al., 2013). However, findings for most other health outcomes were less clear (supplementary data file).

When isolating results from the four randomised controlled trials specifically, while there was some preliminary evidence of physiological changes post-intervention, very limited effects were shown for self-report measures. When comparing 8-weeks of Kirtan Kriya meditation with relaxation involving listening to music (matched to session duration and frequency), there was evidence of positive increases in telomerase activity (Black et al., 2013), altered gene expression and immune response (Lavretsky et al., 2013), and metabolic changes in the brain (Pomykala et al., 2012). In the randomised controlled trial that compared an Inner Resources program to psychoeducational telephone support, concentration of salivary cortisol was found to be lower, and life satisfaction higher, at 1-month follow-up (Waelde et al., 2017). Finally, when a 12-week transcendental meditation group was compared to a wait-list control group, there was a quicker response speed post-intervention; however, there were no changes in distress, depression, anxiety, sleep, fatigue, and quality of life (Leach et al., 2015).

The rate of attrition across studies was reasonable at 14%. Generally, family carers reported good levels of satisfaction after interventions (Bormann et al., 2009, Innes et al., 2012, Kubo et al., 2018), although some suggested that they need to be longer (Bormann et al., 2009), and highlighted difficulties in finding time to meditate, particularly when attending regular medical appointments (Innes et al., 2012, Kubo et al., 2018). Some carers also noted that the meditation activities required mental effort (Jain et al., 2014), and carers from one study experienced short-lived (<3 hours), moderate neurological effects during the intervention, including headaches, pins and needles, shoulder pain, and restless feet (Leach et al., 2015).

3.1.4 Acceptance and commitment therapy

Acceptance and commitment therapy is a form of action-orientated behaviour psychotherapy that uses mindfulness and acceptance-based strategies to enhance psychological flexibility to improve mental health (Hayes et al., 1999). The approach has been used to treat a variety of different psychological issues across various population groups, such as chronic pain (Hughes et al., 2017), and suicidal ideation and depression (Walser et al., 2015). Acceptance and commitment therapy is centred on relational framework theory (Hayes et al., 2001), a complex approach that is beyond the scope of this paper, but which essentially premises that the human capacity to relate concepts to each other under arbitrary contextual control is the foundation of communication (Hayes, 2004). Acceptance and commitment therapy is structured on the three core functions of accepting thoughts and feelings within the present moment, choosing a valued direction, and taking committed action. To achieve this and overcome the common processes of cognitive fusion (i.e., dominance of thoughts over behaviour) and experiential avoidance (i.e., avoiding, suppressing, or escaping internal experience), six therapeutic processes – often referred to as the hexaflex – are used: contacting the present moment; cognitive diffusion; acceptance; self-as-context/the observing self; values; and committed action. Exercises within acceptance and commitment therapy focus on the use of metaphors, stories, and experiential activities, with mindfulness, diffusion, and acceptance skills used throughout. Acceptance and commitment therapy has flexible delivery and can be applied as individual psychotherapy or within a group, and can be a brief or prolonged intervention.

The study: An acceptance and commitment therapy intervention with family carers of people with dementia was reported in one published study (Losada et al., 2015). Using a three-group randomised controlled trial design, 135 participants were randomised to an acceptance and commitment therapy, cognitive behaviour therapy, or control group. Active

intervention arms were delivered as individual therapy, involving 90-minute sessions once a week, for eight weeks, with homework practice. The control group participated in a 2-hour, non-therapeutic, psychoeducation workshop about dementia. The acceptance and commitment therapy intervention was modeled on the original approach, but adapted for use with family carers of people with dementia. All participating carers had clinically indicative levels of depression, and were typically female spouses or offspring, with an average age of 62 years. Intervention effects were assessed at week-8 post-intervention and 6-months for the primary outcomes of depression and anxiety, and the secondary outcomes of frequency of leisure activities, experiential avoidance, and dysfunctional thoughts. Findings showed that, although both interventions produced clinically significant reductions in depression at week eight post-intervention, only cognitive behaviour therapy had sustained effects at 6-months. However, acceptance and commitment therapy was significantly more effective than both cognitive behaviour therapy and the control in reducing anxiety immediately after the intervention, yet had no longer-term effect. When compared to control, both acceptance and commitment therapy and cognitive behaviour therapy significantly improved short-term engagement in leisure activities and dysfunctional thoughts, but only acceptance and commitment therapy improved short-term experiential avoidance. It was proposed that this showed greater utility of training family carers in acceptance-based coping strategies (mostly taught in acceptance and commitment therapy) rather than control/change coping strategies (mostly taught in cognitive behaviour therapy). Both acceptance and commitment therapy and cognitive behaviour therapy were similarly rated in terms of satisfaction. However, acceptance and commitment therapy exercises were rated as more difficult than cognitive behaviour therapy, and attrition across the trial was high at 30%.

3.1.5 Dialectical behaviour therapy

Dialectical behaviour therapy was first developed in the late 1980s as a specific type of cognitive behaviour therapy to treat women with borderline personality disorder and suicidal or self-harm behaviour (Linehan, 1993). It has since been used with various populations and targeting different psychopathologies, including the treatment of eating disorders (Bankoff et al., 2012), and anger, aggression, and violent behaviour (Frazier and Vela, 2014). Dialectical behaviour therapy is grounded in a framework of dialectical philosophy and validation, which sees the manualised approach involve continual orchestration between change-oriented strategies and acceptance. Through a focus on skills-based learning and psychoeducation, dialectical behaviour therapy aims to improve quality of life, and consists of four core modules that cover training in mindfulness, interpersonal effectiveness, distress tolerance, and emotion regulation. Typically delivered over a minimum of six months, each module takes around six weeks to complete, and involves weekly 1-hour individual therapy sessions, weekly 1.5 to 2.5 hour groups skills sessions, homework practice, and access to 24/7 telephone support/coaching.

The study: The use of dialectical behaviour therapy with family carers of people with dementia was reported in one published study (Drossel et al., 2011). Using a pre-post intervention design, 24 family carers of people with dementia took part in a 9-week group-based dialectical behaviour therapy skills training program. The program was modeled on the original dialectical behaviour therapy manual, but with adaptations largely relating to interpersonal skills training for dementia carers, and a reduction in program duration. Sessions ran for 2.5 hours, once a week, for eight weeks, plus homework practice. Family carers were also encouraged to undertake individual sessions with their usual therapist during the program. In response to requests, small ‘booster’ group sessions that repeated the program were conducted three weeks after completion of the original program. Eight family

carers took part in this. All family carers were identified as at risk of abusing a family member with dementia, and were predominantly female offspring with a mean age of 59 years. Intervention effects were assessed at week-9 post-intervention for the outcomes of depression, burden, wellbeing, coping, burden, number of reports to elder protection services, and individual therapy session attendance. While dialectical behaviour therapy effectively improved psychosocial adjustment of family carers post-intervention (in terms of improved problem-focused coping, emotional wellbeing, and fatigue), findings were inconclusive, as there were no significant improvements for depression, burden, and burnout. Greater utilisation of individual therapy sessions during the intervention also precluded determination of whether the gains observed were due to the dialectical behaviour therapy group specifically, or additional individual therapy sessions. While the request from some family carers for ‘booster’ sessions indicated a desire to continue the program, there was a high rate of attrition (33%).

3.2 Compassion-based interventions

3.2.1 Compassion-focused therapy

Compassion-focused therapy is an integrative approach that focuses on improving emotional wellbeing through the development and application of compassionate self-to-self, self-to-other, and other-to-self relating (Gilbert, 2010). Developed over 20 years ago as a psychotherapy for people presenting with high levels of shame and self-criticism, it has since been used with a number of different population groups to improve various health outcomes, including depression, anxiety, and psychological distress (Kirby et al., 2017, Leaviss and Uttley, 2015). The approach incorporates cognitive behaviour therapy techniques with theory and learning from across evolutionary, developmental, social, and Buddhist psychology, as well as affective neuroscience, and highlights the importance of the three basic emotion-

regulation systems within mental health (Gilbert, 2010): 1) the threat and self-protection system; 2) the drive-reward system; and 3) the soothing- affiliative system. Compassion-focused therapy posits that the development of a compassionate mind enables activation of caregiving processing systems during times of stress, and that this can facilitate adaptive physiological emotional regulation (i.e., parasympathetic nervous system activity) (Gilbert, 2014). Compassion-focused therapy includes psychoeducation on the evolution of the brain and emotion-regulation systems, as well as a range of guided exercises intended to activate the physiology and neurobiology underpinning the soothing system. This includes soothing rhythm breathing, safe space imagery, and the development of an ideal, compassionate self. Given the origins of compassion-focused therapy as a form of psychotherapy, there is no limit regarding program duration. However, a group-based approach – Compassionate Mind Training (Irons and Beaumont, 2017) – has been developed, which typically includes two-hour weekly group sessions over eight weeks.

The study: Only one published study reported use of compassion-focused therapy with family carers of people with dementia (Collins et al., 2018). Within this pre-post intervention study, the population target was dyadic, involving n=34 community-dwelling people with dementia and their spousal family carer. The compassion-focused therapy group was based on the original compassion-focused therapy model, but adapted for use with people with dementia. Each session ran for two hours, once a week for a total of six weeks. All care recipients had dementia, varying from early to late stage, and had a mean age of 74 years. Nearly two-thirds (62.5%) of participating family carers were female. Intervention effects were assessed at week-6 post-intervention for the outcomes of anxiety, depression, and respiratory rate. While a clinically significant reduction in carers' respiratory rate was observed at week six post-intervention, suggestive of improved psychological wellbeing, there were no significant or clinically meaningful reductions in anxiety or depression.

However, the intervention was well tolerated, with a low rate of attrition (6%), and most family carers rated all six sessions as helpful. Carers highlighted the usefulness of attending as a dyad, although some felt there was too much focus on compassion, and would be most useful to people with early stage dementia.

3.3 Other mindfulness- and/or compassion-based interventions

3.3.1 Study-specific interventions

Interventions involving elements of mindfulness and/or compassion were described in four studies: two were randomised controlled trials (Danucalov et al., 2017, Danucalov et al., 2013, Dowling et al., 2014), one a pre-post intervention study (Milbury et al., 2015), and one a qualitative study (Cottingham et al., 2018). Intervention programs included yoga and compassion (Danucalov et al., 2017, Danucalov et al., 2013), Tibetan yoga (Milbury et al., 2015), positive affect (Dowling et al., 2014), and mindfulness (Cottingham et al., 2018). Each study is discussed individually.

In the randomised controlled trial by Danucalov and colleagues (2017, 2013), a yoga and compassion program was compared against a wait-list control group in a sample of family carers of people with dementia (n=53) on the following outcomes at week-8 post-intervention: stress, anxiety, depression, quality of life, vitality, attention, self-compassion, and salivary cortisol levels. Involving a combination of traditional hatha yoga poses, breathing exercises, and mindfulness and compassion meditations, sessions ran for 75 minutes, three times a week for eight weeks. One weekly group session was delivered face-to-face, while the other two sessions were undertaken at home using a guided DVD. At week-8 post-intervention, the yoga and compassion intervention group showed significant improvements compared to control in quality of life, vitality, mindfulness, self-compassion, stress, anxiety, depression, and concentration of salivary cortisol. Attrition was 13%.

A Tibetan yoga program was the focus of Milbury et al's. (2015) pilot pre-post intervention study, which was developed for use with people undergoing active treatment for cancer and their partners (n=14 dyads). Involving breathing exercises and visualization, mindfulness and compassion meditations, and *Tsa Lung* upper body movements, sessions lasted between 45 to 60 minutes, and were conducted 2 to 3 times a weeks over a 5 to 6 week period (total of 15 sessions). CD-guided homework practice was encouraged on non-intervention days. Intervention effects were assessed at week-6 post-intervention for the outcomes of depression, anxiety, sleep, fatigue, health-related quality of life, spiritual wellbeing, and finding meaning. At intervention end, carers reported intervention utility, and there were significant improvements in family carers' fatigue and anxiety, and non-significant trends in improved sleep quality. No significant effects were seen for depression, quality of life, spiritual wellbeing, or finding meaning. Attrition was 29%.

In the randomised controlled trial by Dowling et al. (2014), a positive affect intervention – Life Enhancing Activities for Family Caregivers – was evaluated against an attention control group with family carers of people with frontotemporal dementia (n=12 in each intervention arm). The intervention was skills-based, involving didactic and practice elements focused on cultivating greater positive affect. Each session was conducted individually, either face-to-face or via videoconference, for one hour once a week for five weeks. Weekly homework practice was expected, as well as completion of daily experience worksheets. The control group was comparable in frequency and length, but involved one-on-one discussion around topics such as life history and social networks, and the completion of an emotions rating scale. Homework practice consisted of daily affect reports. Intervention effects were assessed at week-6 post-intervention and week-10 follow-up for the outcomes of affect, depression, stress, distress, and burden. At week-6 post-intervention, the intervention was significantly more effective than control in improving stress, and effects were seen for

positive affect and burden at 1-month post-intervention. Family carers positively evaluated the intervention, and found the videoconference delivery easy to use and comparable to face-to-face. Attrition was 17%.

In the qualitative study by Cottingham and colleagues (2018), a mindfulness intervention – the Mindfully Optimising Delivery of End-of-Life Care – was assessed for use with 13 dyads of people with advanced-stage cancer and their carers. Drawing on methods from mindfulness-based stress reduction, compassion meditation, and mindful speaking and listening, each session was conducted in groups, and ran for 2-hours, once a week for six weeks. Homework practice was set each week. In interviews conducted at week-6 post-intervention, dyad members positively evaluated the intervention, perceiving it improved: adaptive coping, emotion reactivity, relationships between dyad members, and communication. Attrition was 8%.

4. Discussion

Over the last fifteen years, 32 published studies have researched the use of seven mindfulness- or compassion-based interventions with six family carer subgroups. The most commonly studied interventions were mindfulness-based stress reduction, mindfulness-based cognitive therapy, and various forms of meditation. The most commonly studied population subgroups were family carers of people with dementia and cancer. Across studies, intervention effects were assessed on a heterogeneous group of health outcomes, but most frequently included family carers' self-report assessments of depression, anxiety, burden, stress, and quality of life. For interventions related to mindfulness-based stress reduction, mindfulness-based cognitive therapy and meditation, there was most evidence of effectiveness, although interpretation remains cautiously tempered given that studies were mainly uncontrolled pre-post intervention trials, with effects on individual outcomes

inconsistently replicated, and mainly evidenced in the short-term only. In addition, evidence related to acceptance and commitment therapy, dialectical behaviour therapy, and compassion-focused therapy remain limited to individual small-scale studies. In light of this current evidence-based, therefore, it is premature to make general statements regarding intervention effectiveness overall. However, these early findings tentatively suggest that mindfulness- and compassion-based interventions have some potential utility in supporting family carers in their role and, given a reasonable rate of attrition (18%), may do so in a way that is acceptable to carers. As such, further research is warranted in the area of mindfulness- and compassion-based interventions for this population, and a number of implications for such work are presented in the following subsection.

4.1 Implications for research and clinical practice

In terms of design, future research should evaluate individual mindfulness- and compassion-based interventions within a randomised controlled trial, including both an active and control group so that nuanced effects can be compared against similar interventions. In addition, given the emerging evidence on the neurobiological effects within some studies, a combination of self-report, cognitive, and physiological measures should be considered, and these should assess potential effects at both short- and long-term (i.e., of up to 12-months). Studies should also seek to better collect and report demographic and clinical information about both the family carer and the care recipient. Despite extensive research showing that these characteristics can impact on family carers' physical and mental health (Schulz and Sherwood, 2008), this information remains inconsistently, and often poorly, reported. Finally, mindfulness- and compassion-based studies need to build in more overt measures to assess and report potential adverse effects. Insufficient assessment and reporting of harmful outcomes in mindfulness research has recently been highlighted (Baer et al., 2019, Van Dam

et al., 2018), and future studies should seek ways to monitor individual data and measure this aspect explicitly.

Regarding the structure of mindfulness- and compassion-based interventions, the potential utility of conducting longer but less intense programs is warranted. Some studies showed that there was a desire for a longer duration of support – lengthier programs were called for, and ‘booster’ sessions after the original program were held in response to carers’ requests. However, delivery of interventions through a more flexible approach, such as remote connection, needs to be explored, as there were practical challenges in attending face-to-face sessions.

In terms of clinical decision-making around referral to wider healthcare services, it is important to recognise that these interventions may not be suited to every carer as, with any mind-body practice, individual receptiveness to the intervention is a major factor in uptake and sustained attendance (Whitebird et al., 2011). Nevertheless, of the interventions published to date, these have been used most often with older female spouses or offspring of people with dementia or cancer, and most particularly for depression, anxiety, stress, burden, and quality of life. Interventions have been chiefly delivered in a group-based format, and this may appeal to carers whom feel particularly isolated or seeking social connection. Similarly, dyadic interventions that target both the family carer and care recipient might also encourage uptake by carers who would not otherwise attend sessions due to the need for respite care services (van Boxtel et al., 2019).

4.2 Limitations

As consistent with the scoping study methodology, a formal appraisal of study quality was not undertaken, and the inclusion of only published peer-reviewed journal articles written in English may have introduced publication bias. The study was also broad in its

conceptual discussion of mindfulness, mediation, and compassion, and did not delve into the ongoing definitional debates and nuanced complexities of these concepts (as a starting point see Awasthi, 2013, Chiesa, 2013, Gilbert, 2015).

5. Conclusion

This scoping study highlighted the nascent use of mindfulness- and compassion-based interventions with family carers of older adults, and showed, based on preliminary evidence, their potential to help family carers cope in their role. A number of implications for research and practice are presented to help advance understanding of how such interventions can support the self-care needs of family carers.

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Conflict of Interest

This scoping study was undertaken as part of Jenny Murfield's PhD research program, under the supervision of Professor Wendy Moyle and Professor Analise O'Donovan. No author has any source of financial support or relationship that may pose a conflict of interest to the study.

Ethical Approval

Ethical approval was not required for this scoping study.

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Supplementary data

Table 1

Characteristics of included studies: mindfulness-based stress reduction

Author	Country	Intervention	Design	Sample	Measures	Assessment	Key findings
Bajaj et al., (2017)	United States	Adapted MBSR & Supportive Group Therapy 1hr once a wk for 4wks, plus daily CD-guided meditation	Pre-post	Dyads - depressed men with cirrhosis & co-dwelling FC Recruited (n = 20 dyads) Completed (n=20 dyads)	Depression = BDI-II Anxiety = BAI Sleep: PSQI & ESS Health related quality of life = SIP Burden = ZBI-SF & PCB	Baseline Wk4 post-intervention	Sig. improvement in scores for depression (p=0.03), burden (PCB p=0.05; ZBI-SF p=0.04) & sleep quality (PSQI p<0.001) Non-sig. improvements in scores for anxiety (p=0.80) health related quality of life (p=0.52) & sleepiness (ESS p=0.11)
Berk et al., (2019)	Netherlands	Adapted MBSR 'TANDEM' 2.5hrs once a wk, for 8wks, with 4-hr silent day, plus 45 min daily home practice using guided CD	Pilot mixed methods	Dyads – people with a dementia diagnosis & FC Recruited (n=7 dyads) Completed (n= 7 dyads)	<u>Self-report</u> Quality of life = WHOQOL-BREF Caregiver burden = SPPIC Caregiver self-esteem = CRA-SE Self-compassion = SCS-SF Positive mental health = MHC-SF	<u>Self-report</u> Baseline Wk8 post-intervention <u>Qualitative</u> Within 1-3 wks of intervention completion	Large increase in FC mindfulness (d=2.86), & small-medium improvements in FC QOL (d=0.47), self-esteem (d=0.46), self-compassion (d=0.39), & worry (d=0.25) Qualitative feedback: intervention positively

					Worry = PSWQ Psychological distress = DASS-21 Mindfulness = FFMQ-SF		increased relaxation, awareness, acceptance and resilience. Value of participating as a dyad was noted
					<u>Qualitative</u> Interviews		
Birnie et al., (2010)	Canada	MBSR 90mins once a wk for 8wks, plus a 3hr weekend silent retreat	Pre-post	Couples - people with cancer & romantic partner Recruited (n = 41 couples) Completed (n=21 couples)	Affective states: POMS Stress: C-SOSI Mindfulness: MAAS	Baseline Wk8 post- intervention	Sig. reduction in mood disturbance overall (POMS total score p<0.05) and in subscales of tension/anxiety p<0.01) & fatigue (p<0.05), & improvements in mindfulness (p<0.05) No sig. change in stress levels overall, but sig. decrease on subscales muscle tension (p<0.01), neurological/GI (p<0.05), and upper respiratory symptoms (p<0.01)

Brown et al., (2016)	United States	Adapted MBSR 1.5-2hrs once a wk for 8wks in either MBSR (plus 1-day intensive retreat) vs. standard social support group (same duration)	Pilot RCT	FC (spouse or blood-relative) of people with dementia Recruited (n=38) Completed (n=38)	<u>Self-report</u> Stress: PSS Avoidance: AAQ-II Mood: POMS Mental & physical functioning: SF-36 Caregiver burden: ZBI Caregiver-recipient relationship quality: FCI-MS <u>Physiology</u> Salivary cortisol	Baseline Wk8 post-intervention 3mth follow-up At each time-points, salivary cortisol was taken 6 times: before rising; 45mins, 2.5hr, 8hr and 12h post-awakening; bedtime	Sig. reduction wk8 post-intervention favouring MBSR vs. social support group for stress (p=0.03), tension (p=0.02), anger (p=0.016) Sig. reduction wk8 post-intervention favouring social support vs. MBSR for burden (p=0.046) No sig. differences between groups on self-reported outcomes at 3-mth follow-up No sig. diff in either group at any time-point in diurnal cortisol response curve
Cash et al., (2016)	United States	Adapted MBSR 1.5hrs once a wk for 8wks, plus 45mins meditation home practice 6 days per wk, plus 4hr silent	Pilot pre-post	Dyads – people with Parkinson’s disease & FC Recruited (n=52; FC=18)	<u>Self-report</u> Apathy: AS Depression: PHQ-9 Anxiety: GAD-7 Daily cognitive functioning: ECQ Quality of life: PDQC Mindfulness: FFMQ	Baseline Wk8 post-intervention	Sig. improvement in mindfulness (p=0.007) No sig. improvements in depression (p=0.34) & daily cognitive functioning (p>0.05)

		retreat 1wk post-intervention		Completed (n=39; FC = 10)	<u>Cognition</u> Processing speed: TMT-A Basic attention: DS Complex attention: ACT Working memory & mental flexibility: COWA, TMT-B		Other outcomes were analysed collectively for FC and people with Parkinson's disease; findings are not reported here
Epstein-Lubow et al., (2011)	United States	Adapted MBSR 75mins once a wk for 8wks, with 30mins daily home practice	Mixed-methods	FC of people with dementia Recruited (n=9) Completed (n=9)	<u>Self-report</u> Depression: CES-D Burden: ZBI Anxiety: STAI Grief: ICG Stress: PSS General Health: SF-36 Mindfulness: KIMS <u>Qualitative</u> Informal verbal feedback & written comments	<u>Self-report</u> Baseline Wk8 post-intervention Wk12 follow-up CES-D & KIMS completed at wk4 mid-intervention <u>Qualitative</u> After every session	Sig. reduction in depression (p=0.001) & down-heartedness (p=0.016) from baseline to post-intervention, but returned to baseline levels at wk12 Sig. improvement in burden (p=0.007), calmness (p=0.017) & mindful attention (p=0.048) from baseline to wk12. Similar non-sig trend for stress (p=0.058) No sig. effects found for grief, anxiety, general health, or overall mindfulness

							Post-intervention, all FC reported continued use of mindfulness-based exercises & benefits of intervention, but wanted support longer than 8wks
Ho et al., (2016)	United States	Adapted MBSR 90mins once a wk for 8wks, with daily home practice, plus 4-hr retreat during wk6	Pre-post	FC of people with dementia Recruited (n=26) Completed (n=20)	<u>Self-report</u> Stress: PSS Depression: CSAQ & CES-D Burden: RSCB Grief: ITGPL Mindfulness: FFMQ <u>Physiology</u> Peripheral venous blood	Baseline Wk8 post-intervention	<p>Sig. improvement in mindfulness (p=0.0081) depression (CSAQ p<0.001), stress (nr), burden (nr), and grief (nr).</p> <p>MBSR beneficial to ~75% of FC in sample</p> <p>913 genes differentially expressed post MBSR</p> <p>Identified 91 predictor biomarkers associated with the likelihood of caregivers to benefit from MBSR, enriched for functional biological pathways relating to immune responses, toll signaling & insulin signaling</p>

							194 MBSR-responsive genes were enriched for cellular pathways relating to inflammation, stress response and depression
Hoppes et al., (2012)	United States	Adapted MBSR 1hr once a wk for 4 wks	Mixed methods	FC of people with dementia Recruited (n=11) Completed (n=10)	<u>Self-report</u> Burden: ZBI-SF Hope: SHS Optimism: LOT-R Mindfulness: FMI <u>Qualitative</u> Interviews	<u>Self-report</u> Baseline Wk4 post-intervention Wk8 follow-up <u>Qualitative</u> Wk8 follow-up	Sig. improvement in burden (p<0.01) & hope (p<0.01) post-intervention, but only hope was sustained at wk8 follow-up No sig. improvement in optimism & mindfulness FC reported increased acceptance of dementia post-intervention, as well as increase sense of presence, sense of peace, and decreased reactivity

Hou et al., (2014)	Hong Kong	Adapted MBSR 2hrs, once a wk for 8 wks, with 30-45min daily CD-guided home practice vs. control group - self-help education information booklets	RCT	FC of people with chronic conditions Recruited (n =141) Completed (n = 113)	Self-compassion = SCS-SF Depression = CES-D Anxiety = STAI Stress = PSS Self-efficacy = CRSE-OR & CRSE-UT Quality of life = SF-12 Mindfulness = FFMQ Monthly use of health services	Baseline Wk8 post-intervention 3mth post-intervention	MBSR group vs. control = sig. improvement for depression at wk 8 & at 3-mths follow-up (p<0.01 both) MBSR group vs. control = sig. improvement in anxiety (state (p<0.01) & trait (p<0.05)), & reduction in traditional Chinese medicine service use at wk8 (p<0.01), but not at 3-mths follow-up MBSR group vs. control = sig. improvement in mindfulness & self-efficacy at 3mths (both p<0.05) No sig. improvements in self-compassion, stress, quality of life, or health service use
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Marconi et al., (2016)	Italy	Adapted MBSR 90mins once a wk for 8wks, plus daily homework exercises	Qualitative	Dyads – FC of people with ASL Recruited (n =18 FC) Completed (n = 18)	Semi-structured interview	Wk8 post-intervention	Dyads reported positive impact of intervention on psychological well-being, promoting increase in acceptance & non-judgmental attitudes, & improving coping strategies & positively affecting resilience skills Logistical & practical issues were highlighted as barriers to uptake (limited practice & psychological resistance to meditation)
Paller et al., (2015)	United States	Adapted MBSR 90mins once a week, for 8wks, plus 30-60 mins daily home practice with guided CD	Pre-post	Dyads – people with dementia & FC Recruited (n = 20 FC) Completed (n = 20 FC)	<u>Self-report</u> Quality of life: QOL-AD Depression: GDS Sleep: PSQI Anxiety: BAI Wellbeing: SF-36 Behaviour & carer distress: RMPBC Activities of daily living: ADLQ <u>Cognition</u> TMT-A, TMT-B, RBANS	Baseline Wk8 post-intervention	Sig. improvements post-intervention for quality of life (p<0.05) & depression (p<0.05) only FC reported being grateful to attend intervention & recommend to others

van den Hurk et al., (2015)	Netherlands	Adapted MBSR 2.5hrs once a wk, for 8wks, with 1 day silent retreat, plus 45 min daily home practice using guided CD	Pilot mixed methods	Partners – people with lung cancer & partners Recruited (n = 16 partners) Completed (n = 13 partners)	Self-report Psychological distress: HADS Quality of life: QLQ-LC13 Psychological stress reaction: IES Worry: PSWQ Mindfulness: MAAS Burden: SPPIC Self-esteem: CRA-SE <u>Qualitative Interviews</u>	Self-report Baseline Wk8 post-intervention 3-mth follow-up <u>Qualitative</u> Within 1yr of intervention completion	Sig. improvements in caregiver burden at post-intervention & follow-up (p<0.05 both) No sig. improvement in other measures at post-intervention or follow-up Qualitative feedback: intervention started process of change, with couples developing greater awareness & insight into thoughts, feelings and bodily sensations
Whitebird et al., (2011) (2013)	United States	Adapted MBSR 2.5hrs once a wk for 8 wks, with home practice, plus 5-hr retreat with daily practice vs. community & caregiver education support group (same duration)	RCT	FC of people with dementia Recruited (n = 78) Completed (n = 72)	Stress: PSS Depression: CES-D Anxiety: STAI Wellbeing: SF-12 Burden: MBCBS Social support: MOSSSS	Baseline Wk8 post-intervention 6-mth follow-up	MBSR more effective than education/support group at post-intervention (p=0.007) & follow-up (p=0.04) in improving overall mental health (SF-12 mental health subscale) MBSR more effective than education/support group post-intervention in stress (p=0.007) & depression (p=0.005),

but not at 6-mth follow-up

Both interventions similarly effective in improving anxiety, social support, and burden

Note. MBSR = mindfulness-based stress reduction; hr = hour; wk = week; FC = family carers; BDI-II = Beck Depression Inventory; BAI = Beck Anxiety Inventory; PSQI = Pittsburgh Sleep Quality Index; ESS = Epworth Sleepiness Scale; SIP = Sickness Impact Profile; ZBI-SF = Zarit Burden Interview Short-Form; PCB = Perceived Caregiver Burden; sig. = significant; TANDEM = Attention Training for People with Dementia and their Caregivers; WHOQOL-BREF = World Health Organization Quality of Life Questionnaire; SPPIC = Self-Perceived Pressure from Informal Care; CRA-SE = Caregiver Reaction Assessment; SCS-SF = Self-Compassion Scale – Short Form; MHC-SF = The Dutch Mental Health Continuum Short Form; PSWQ = Penn State Worry Questionnaire; DASS-21 = Depression Anxiety Stress Scales-21; FFMQ-SF = Five Facets Mindfulness Questionnaire Short-Form; mins = minutes; POMS = Profile of Mood States; C-SOSI = Calgary Symptoms of Stress Inventory; MAAS = Mindful Attention Awareness Scale; vs. = versus; RCT = randomised controlled trial; PSS = Perceived Stress Scale; AAQ-II = Acceptance and Action Questionnaire II; SF-36 = Medical Outcomes Study Short-Form Health Survey 36; ZBI = Zarit Burden Interview; FCI-MS = Mutuality Scale of the Family Care Inventory; mth = month; AS = Apathy Scale; PHQ-9 = Patient Health Questionnaire-9; GAD-7 = Generalised Anxiety Disorder-7; ECO = Everyday Cognition Questionnaire; PDQC = Parkinson’s Disease Questionnaire Carer; FFMQ = Five Facets Mindfulness Questionnaire; TMT- A = Trail Making Test-Part A; DS = Digit Span; ACT = Auditory Consonant Trigams; COWA = Controlled Oral Word Association Test; TMT-B = Trail Making Test-Part B; CES-D = Centre for Epidemiological Studies Depression Scale; STAI = State Trait Anxiety Inventory; ICG = Inventory of Complicated Grief; KIMS = Kentucky Inventory of Mindfulness Skills; CSAQ = Caregiver Self-Assessment Questionnaire; RSCB = Rapid Screen for Caregiver Burden; ITGPL = Inventory of Traumatic Grief Pre-Loss; nr = not reported; SHS = State Hope Scale; LOT-R = Life Orientation Test – Revised; FMI = Freiburg Mindfulness Inventory; SF-12 = Health Survey Short Form-12; CRSE-OR = Revised Caregiving Self-Efficacy Scale – Obtaining Respite; CRSE – UT = Revised Caregiving Self-Efficacy Scale – Upsetting Thoughts; ALS = amyotrophic lateral sclerosis; QOL-AD = Quality of Life in Alzheimer’s Disease; GDS = Geriatric Depression Scale; RMPBC = Revised Memory Problem and Behaviour Checklist; ADLQ = Activities of Daily living Questionnaire; RBANS = Repeatable Battery for the Assessment of Neuropsychological Status; HADS = Hospital Anxiety and Depression Scale; QLQ-LC13 = Core Quality of Life Questionnaire for Lung Cancer-13; IES = Impact Event Scale; MBCBS = Montgomery Borgatta Caregiver Burden Scale; MOSSSS = Medical Outcomes Study Social Support Survey

Table 2

Characteristics of included studies: mindfulness-based cognitive therapy

Author	Country	Intervention	Design	Sample	Measures	Assessment	Key findings
Kor et al., (2019)	Hong Kong	Adapted MCBT 2 hrs, 7 session for 10 wks (1-4 session wkly, 5-7 bi-wkly) MBCT, plus homework practice vs. usual care with brief education on dementia group (same duration)	Pilot RCT	FC of people with dementia Recruited (n =36) Completed (n = 31)	<u>Self-report</u> Stress: PSS Depression: CES-D Anxiety: HADS-A Resilience: BRS Quality of life: SF-12v2 Burden: ZBI Mindfulness: FFMQ-SF <u>Qualitative</u> Focus group to discuss MBCT group strengths, limitations, & difficulties	Baseline Wk 10 post-intervention (FFMQ-SF end of wk 3 session) 3-mth follow-up	Sig. improvement in stress (p=0.05) & depression (p=0.02) at wk 10 post-intervention compared to control Sig. improvement in stress (p=0.01), depression (p=0.03) & burden (p=0.006) at 3-mth follow-up compared to control Sig. improvement in mindfulness in MBCT group from baseline to wk 3 (p=0.01) and 3-month follow-up (p=0.01) Focus group MBCT participants reported: increased self-awareness, feelings of relaxation, concentration & sleep quality; improved

							behavioural changes of the person with dementia, & increased interactions between FC and person with dementia.
							Challenges included: time constraints, caregiving commitments, & disturbance in practice by person with dementia
Norouzi et al., (2013)	Iran	Adapted MBCT 2.5 hrs, once a wk, for 8 wks MBCT vs. wait-list control	Quasi-experimental	Depressed FC of people with dementia Recruited (n = 20) Completed (n = 20)	Depression: HRSD Quality of life: SF-36v2 Burden: CBI	Baseline Wk 8 post-intervention 2 mth follow-up	Sig. improvement in depression (p=0.001) & burden (p=0.001) at wk8 post-intervention compared to control Sig. sustained effects in MBCT group for depression (p=0.005) & burden (p=0.005) at 2-mth follow-up No sig. improvement in quality of life at wk 8 or 2-mth follow-up
Oken et al., (2010)	United States	Adapted MBCT	Pilot RCT	FC of people with dementia	<u>Self-report</u> Stress: RMBPC, PSS, Depression: CES-D	<u>Self-report & cognition</u> Baseline	Sig. improvement in stress (p=0.030) & cognition (stroop)

<p>90 mins, once a wk, for 7 wks, plus daily home practice MBCT vs. Powerful Tools for caregiving education/social group (same duration) vs. respite-only control (3 hr wkly respite care)</p>	<p>Recruited (n = 31) Completed (n = 28)</p>	<p>Fatigue: SF-36 Self-efficacy: GPSES Sleep: PSQI, ESQ Perception of change: GICS Coping: CRI Mindfulness: MAAS, FFNJ Improvement expectancy & credibility: 6-item VAS</p> <p><u>Cognition</u> Cognitive function: ADAS-CS, Stroop test, ANT</p> <p><u>Physiology</u> Salivary cortisol</p> <p><u>Experience-based sampling</u> Rated current situation in terms of stress, coping, focus, fatigue, & demand level using 1-6 LRS</p>	<p>Wk7 post-intervention</p> <p><u>Physiology</u> 1 day during baseline & post-intervention: 5 mins after waking, 30 mins before eating, & bedtime (~10-11pm)</p> <p><u>Experience-based</u> 1 day during baseline & post-intervention: 5 semi-random time-points during wake times</p>	<p>p=0.038; ANT alerting p=0.045) for the 2 active groups compared to control post-intervention</p> <p>No sig. improvement in all other measures over time or between groups</p>
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Note. MBCT = mindfulness-based cognitive therapy; hr= hour; wk = week; vs. = versus; RCT = randomised controlled trial; FC = family carers; PSS = Perceived Stress Scale; CES-D = Centre for Epidemiological Studies Depression Scale; HADS-A = Hospital Anxiety & Depression Scale- Anxiety; BRS = Brief Resilience Scale; SF-12v2 = 12-item Short-form Health Survey Version 2; ZBI = Zarit Burden Scale; FFMQ-SF = Five Facets Mindfulness Questionnaire Short-Form; mth = month; sig. = significant; HRSD = Hamilton’s Raking Scale of Depression; SF-36v2 = 36-item Health Survey Version 2; CBI – Caregiver Burden Inventory; RMBPC = Revised Memory and Behaviour Problems Checklist; GPSES = General Perceived Self-Efficacy Scale; PSQI = Pittsburgh Sleep Quality Index; ESQ = Epworth Sleep Questionnaire; GICS =

Global Impression of Change Scale; CRI = Coping Responses Inventory; MAAS = Mindful Attention Awareness Scale; FFNJ = Five Factor; VAS = Visual Analogue Scale; ADAS-CS = Alzheimer's Disease Assessment Scale-Cognitive Subscale; ANT = Attentional Network Test; LRS = Likert rating scale

Table 3

Characteristics of included studies: meditation interventions

Author	Country	Intervention	Design	Sample	Measures	Assessment	Key findings
Black et al., (2013) & Lavretsky et al., (2013)	United States	Kirtan Kriya Meditation (yogic meditation) 12mins daily at the same time for 8wks in either CD-guided KKM vs. relaxing music (same duration). Both groups received an educational manual about dementia & maintaining good health	RCT	FC of people with dementia Recruited (n = 45) Completed (n=39)	<u>Physiology</u> Genome-wide transcriptional profiles collected from peripheral blood leukocytes Telomerase activity <u>Self-report</u> Depression: HRSD-24 Mental health wellbeing: SF-36 Illness: CIRS <u>Cognition</u> Functioning: MMSE Verbal memory: CVLT II Attention information & speed: TMT-A Executive function: TMT-B	Baseline Wk8 post-intervention	KKM vs. relaxing music: 68 genes differentially expressed (19 up-regulated, 49 down-regulated) after adjusting for sex, illness burden, and BMI. KKM participants showed reduced expression of genes bearing NF-kB-response elements (p = 0.006) and increased expression of genes bearing IRF1 response elements (p = 0.040). Plasmacytoid dendritic cells (p=0.002) and B lymphocytes (p=0.002) identified as primary cellular context of alterations KKM vs. relaxing music: sig. improvements in depression (p<0.05); mental health wellbeing

							(all $p < 0.05$); cognitive functioning (MMSE $p < 0.001$; TMT-B $p < 0.01$); & telomerase activity compared ($p = 0.05$)
Bormann et al., (2009)	United States	Mantram repetition with cognitive-behavioural skills group training 1hr once a wk for 8wks (wk 1 & 8 f2f, wks 2-7 teleconf. calls), plus reading assignments Wks10, 12 & 14 – telephone calls to assess adherence & encourage practice	Mixed-methods	FC of veterans with dementia Recruited (n = 21) Completed (n=16)	<u>Self-report</u> Caregiver burden: ZCBS Stress: PSS Depression: CESD-SF Rumination: RS Anger: STAS Quality of life: QOLESQ-SF Mindfulness: MAAS <u>Interviews</u> Client satisfaction survey	<u>Self-report</u> Wk1 pre-intervention Wk8 post-intervention Wk16 follow-up <u>Interviews</u> Wk10, 12, 14 & 36	Sig. improvements from pre- to wk8 post-intervention for burden ($p = 0.02$), stress ($p = 0.001$), depression ($p = 0.02$), rumination ($p = 0.005$), quality of life ($p = 0.04$) No sig. improvements from pre- to 8 wks post-intervention for anger ($p = 0.68$) and mindfulness ($p = 0.99$) At wk8 post-intervention, FC were satisfied with the program ($p = 0.046$); satisfaction levels did not change from wk 8-16. At 36-wks, FC expressed need for support longer than 16 wks: wanted group calls fortnightly

Innes et al., (2012)	United States	Kirtan Kriya Meditation (yogic meditation) 11mins twice daily practice at the same time for 8 wks in CD-guided KKM	Pilot pre-post	Dyads – people with dementia & co-dwelling FC Recruited (n =12) Completed (n = 10)	<u>Self-report</u> Stress: PSS Mood: POMS Affect: PANAS Stress hardiness: DRS Sleep quality: GSDS Self-compassion: SCS Cognitive status: MFQ Treatment expectancy questionnaire <u>Physiological</u> Blood pressure Heart rate	<u>Self-report</u> Baseline Wk8 post-intervention <u>Physiological</u> Each session – taken 3 times with 5 mins in between, then averaged	Sig. improvement in stress (p=0.03), mood (depression p=0.01), sleep quality (p=0.02), retrospective memory function (p=0.04), systolic blood pressure (p=0.004) post intervention No sig. improvement in affect, stress hardiness, or self-compassion FC reported enjoyment of the intervention
Jain et al., (2014)	United States	Central Meditation & Imagery Therapy for Caregivers 90mins once a wk for 8wks, plus daily exercises for home practice	Feasibility mixed-methods	FC of people with dementia Recruited (n =12) Completed (n = 10)	Depression: CES-D Anxiety: ZAS Insomnia: ISI Quality of life: QOLESQ-SF Mindfulness: FFMQ Credibility of therapy	Baseline Wk8 post-intervention 3mth follow-up (CES-D; ZAS; QLESQ-SF)	Sig. improvements for depression, anxiety, & insomnia (p<0.05 all) post-intervention & at follow-up Sig. improvements in mindful awareness, non-judgment, and observation post-intervention (p<0.05 all)

							No sig. improvement in quality of life over the study
							FC completed home practices regularly
							FC reported the exercise required mental effort & not purely relaxing, but resulted in greater understanding and compassion, improved ability to cope day-to-day, and reduced arguing
Kubo et al., (2018)	United States	Mobile-app based mindfulness intervention 10-20min daily practice using Headspace™ app for 8wks	Feasibility mixed methods	Dyads – people with cancer & primary FC Recruited (n =14 FC) Completed (n = 9 FC)	<u>Self-report</u> Distress: NCCNDT Depression: HADS Anxiety: HADS Sleep: PSQI Fatigue: BFI Quality of life: PROMIS <u>Qualitative</u> Interviews	Baseline Wk8 post-intervention	Sig. improvement in distress (p<0.05), depression (p<0.05), quality of life (physical domains p<0.001), & fatigue (p<0.05) No sig. improvement in anxiety, quality of life (mental health domain), or sleep quality FC reported ease in use of the app, & appreciated convenience of accessing the program any time

Leach et al., (2015)	Australia	Transcendental Meditation 12-wk TM: (wk1 = 1hr introductory session with 30-min personal instruction plus 3 x 1.5hr sessions; wk2-4 = 3 wkly 1hr classes; wk 5-12 = 4 x bi-wkly 1hr classes) vs. 24-week wait-list control	Pilot RCT	FC of people with dementia Recruited (n =17) Completed (n = 16)	<u>Self-report</u> Health-related quality of life: AQoL-8D <u>Cognition</u> Stress: WebNeuro test	Baseline Wk12 post-intervention Wk 24 follow-up	TM vs. wait-list control = sig. improvements in WebNeuro response speed (p=0.03) No sig. improvement in other outcomes; but a trend toward greater improvement in WebNeuro stress, depression and negativity bias scores in the TM group. Adverse events reported in 63% of TM participants, but events generally transient, of mild-moderate intensity and only ‘possibly’ related to intervention
Pomykala et al., (2012)	United States	Kirtan Kriya Meditation (yogic meditation)	Pilot RCT	FC of people with dementia Recruited (n =10)	<u>Self-report</u> Mental wellbeing: SF-36 Depression: HRSD-24 Burden: ZBI <u>Physiology</u>	Baseline Wk8 post-intervention	No sig. difference between groups on self-report measures Sig. difference between groups post-intervention

		12mins daily practice at the same time for 8wks in either CD-guided KK vs. relaxing music (same duration). Both groups received an educational manual about dementia & maintaining good health		Completed (n = 9)	Resting metabolism: PET scan		in regional cerebral metabolism: bilateral cerebellum (p<0.0005), right inferior lateral anterior temporal (p<0.0005), right inferior frontal (p=0.001), left superior frontal (p=0.001), left associative visual (p=0.002), & right posterior cingulate (p=0.002) cortices
Waelde et al., (2017)	United States	Inner Resources for Stress (mindfulness meditation & mantra training <u>without</u> hatha yoga)	RCT	FC of people with dementia Recruited (n =31) Completed (n = 31)	<u>Self-report</u> Life satisfaction: SWLS Depression: CES-D Self-efficacy: SE-UT Subjective improvement: LRS <u>Physiology</u> Diurnal cortisol in saliva	<u>Self-report</u> Baseline 1-mth follow-up <u>Physiological</u> Baseline & follow-up: daily at awakening, 5pm, 9pm on 2 consecutive days	IR vs. control = sig. improvements in diurnal cortisol slope (p=0.018) & life satisfaction (p=0.028) No sig. differences in depression or self-efficacy IR vs control = participants rated more highly overall IR intervention benefits (p=0.009) & benefits for

		1.5hrs, once a wk for 8wks IR group, with 30 min home practice 6 days, plus 3hr retreat in wk7. A booster session was held in wk12 vs. 10-15min biwkly psycho-education telephone support calls (6 in total)					coping and stress (p=0.04)
Waelde et al., (2004)	United States	Inner Resources for Stress (mindfulness meditation & mantra training <u>with</u> hatha yoga) 6 sessions - 90mins, once a wk for 5wks, & 3hr session in	Pre-post	FC of people with dementia Recruited (n =14) Completed (n = 12)	Depression: CES-D Self-efficacy: SE-UT Anxiety: STAI Burden: RMBPC Subjective improvement: LRS	Baseline 1-mth follow-up	Sig. improvement in depression (p<0.01), anxiety (p<0.05), & self-efficacy (p<0.05) No sig. improvement in burden FC reported intervention useful & reported improvement in physical & emotional functioning

wk5, with
30mins home
practice for 6
days

Note. min = minute; wk = week; KKM = Kirtan Kriya Meditation; vs = versus; RCT = randomised controlled trial; FC = family carers; HRSD-24 = Hamilton Rating Depression Scale -24; SF-36 = Medical Outcomes Study Short-Form Health Survey 36; CIRS = Cumulative Illness Rating Scale; MMSE = Mini-Mental State Examination; CVLT II = California Verbal Learning Test II; TMT- A = Trail Making Test-Part A; TMT-B = Trail Making Test-Part B; sig. = significant; hr = hour; f2f = face-to-face; teleconf. = teleconference; ZCDS = Zarit Caregiver Burden Scale; PSS = Perceived Stress Scale; CESD-SF = Clinical Epidemiology Study for Depression-Short Form; RS = Rumination Scale; STAS = Spielberger Trait-Anger Subscale; QOLESQ-SF= Quality of Life Enjoyment and Satisfaction Questionnaire Short Form; MAAS = Mindfulness Attention Awareness Scale; POMS = Profile of Mood States; PANAS = Positive and Negative Affect Scale; DRS = Dispositional Resilience Scale; GSDS = General Sleep Disturbance Scale; SCS = Self-Compassion Scale; MFQ = Memory Functioning Questionnaire; CES-D = Centre for Epidemiological Studies Depression Scale; ZAS = Zung Anxiety Scale; ISI = Insomnia Severity Index; FFMQ = Five Factor Mindfulness Questionnaire; mth = month; NCCNDT = National Comprehensive Cancer Network Distress Thermometer; HADS = Hospital Anxiety and Depression Scale; PSQI = Pittsburg Sleep Quality Index; BFI = Brief Fatigue Inventory; PROMIS = PROMIS Global Health Scale; TM = Transcendental Meditation™; AQoL-8D = Assessment of Quality of Life – 8 Dimension; ZBI = Zarit Burden Interview; IR Inner resources mindfulness meditation & mantra program; SWLS = Satisfaction with Life Scale; SE-UT = Self-Efficacy for Controlling Upsetting Thoughts about Caregiving (subscale of the Revised Scale for Caregiving Self-Efficacy); LRS = Likert rating scale; RMBPC = Revised Memory and Behaviour Problem Checklist

Table 4

Characteristics of included studies: acceptance and commitment therapy

Author	Country	Intervention	Design	Sample	Measures	Assessment	Key findings
Losada et al., (2015)	Spain	Adapted ACT 90 mins once a wk for 8 wks of individual therapy of either ACT or CBT vs. minimal support control group (2hr dementia education workshop)	RCT	Depressed FC of people with dementia Recruited (n = 135) Completed (n=94)	Depression: CES-D Anxiety: Tension-anxiety subscale POMS Leisure activities: LTSS Experiential avoidance: EACQ Dysfunctional thoughts about caregiving: DTCQ Satisfaction with intervention, therapist, content & if would recommend: 0-10 LRS Knowledge & skills related to content & exercises: 0-10 LRS Quantity & quality of homework: 0-5 LRS	Baseline Wk8 post-intervention 6 mth follow-up	Sig. improvement in depression after ACT (p<0.01) & CBT (p<0.01) vs. control at wk 8, but only maintained for CBT at 6 mth follow-up (p=0.02) Sig. improvement in anxiety after ACT (p<0.05) vs. CBT & control at wk 8 only, but no effects at 6 mth follow-up Sig. improvement for ACT & CBT at wk 8 in leisure (p<0.05) & dysfunctional thoughts (p<0.05) compared to control, but not at 6-mth Sig. improvement in experiential avoidance in ACT vs. control at wk 8 (p=0.01), but not at follow-up & not sig. different to CBT at any time-point ACT & CBT similarly rated

in satisfaction with
intervention, therapist, &
content; perceived increases
in knowledge & skills; &
quantity & quality of
homework

ACT exercises rated sig.
more difficult than CBT
($p < 0.01$)

Note. ACT = acceptance and commitment therapy; min = minute; wk = week; vs. = versus; CBT = Cognitive Behaviour Therapy; hr = hour; RCT = randomised controlled trial; FC = family carers; CES-D = Centre for Epidemiological Studies Depression Scale; POMS = Profile of Mood States; LTSS = Leisure Time Satisfaction Scale; EACQ = Experiential Avoidance in Caregiving Questionnaire; DTCQ = Dysfunctional Thoughts about Caregiving Questionnaire; LRS = Likert rating scale; mth = month; sig. = significant

Table 5

Characteristics of included studies: dialectical behaviour therapy

Author	Country	Intervention	Design	Sample	Measures	Assessment	Key findings
Drossel et al., (2011)	United States	Adapted DBT 2.5 hr once a wk for 9 wks, with ongoing individual therapist sessions & homework. Training sequence repeated in requested 'booster' groups	Pre-post	FC of people with dementia, identified as high risk for abuse (referred by individual therapists) Recruited (n = 24) Completed (n=16)	Depression = CES-D Burden: CBI Wellbeing = SF-36 Coping: WoC-R Burnout: MBI Individual therapy session attendance Number of reports to elder protection services	Baseline Wk 9 post-intervention 'Booster' groups reassessed at start and end of group (i.e., wk 12, and 9 wks later)	Sig. improvement in problem-focused coping (p<0.05), emotional wellbeing (p<0.05), & energy level (p<0.05) Individual therapy rates increased during intervention 'Booster' group analysis (n=5/8): depression scores returned to baseline levels

Note. DBT = dialectical behaviour therapy; hr = hour; wk = week; FC = family carers; CES-D = Centre for Epidemiological Studies Depression Scale; CBI = Caregiver Burden Inventory; SF-36 = Medical Outcome Studies Short-Form 36-Item Health Survey; WoC-R = Ways of Coping Checklist (Revised); MBI = Maslach Burnout Inventory; sig. = significant

Table 6

Characteristics of included studies: compassion-focused therapy

Author	Country	Intervention	Design	Sample	Measures	Assessment	Key findings
Collins et al., (2018)	United Kingdom	Adapted CFT 2 hrs once a wk for 6 wks	Pre-post	Dyads - people with dementia & spousal FC Recruited dyads (n =34) Completed dyads (n=32)	Anxiety: HADS Depression: HADS RR: n= inhalations per/min Intervention appraisal: each 6 sessions rated on ascending 1-10 helpfulness scale	Baseline Wk6 post-intervention	Sig. reduction in respiratory rate (p=0.02), but no sig. reduction in anxiety (p=0.10) & depression (p=0.30) All sessions rated most as '7' helpful, but intervention too focused on compassion, & may benefit people with early stage dementia

Note. CFT = compassion focused therapy; hr = hour; wk = week; FC = family carer; HADS = Hospital Anxiety and Depression Scale; RR = respiratory rate; min = minute; sig = significant.

Table 7

Characteristics of included studies: study-specific interventions involving a combination of mindfulness and/or compassion

Author	Country	Intervention	Design	Sample	Measures	Assessment	Key findings
Cottingham et al., (2018)	United States	MODEL Care intervention 2 hrs once a wk for 6 wks, plus weekly home practice	Qualitative	Dyads - people with advanced cancer & FC Recruited (n=13) Completed (n=12)	Interviews Open response survey	<u>Interviews</u> Wk6 post-intervention <u>Survey</u> Wk6 post-intervention 4-wk follow-up	Dyad members reported intervention: 1) enhanced adaptive coping practices; 2) lowered emotional reactivity; 3) strengthened relationship with each other; & 4) improved communication, including communication about disease
Danucalov et al., (2013) (2017)	Brazil	Yoga & compassion meditation 75mins, 3 times a wk for 8wks (1wkly in person, 2 wkly at home DVD) vs. waitlist control	RCT	FC of people with dementia Recruited (n = 53) Completed (n = 46)	<u>Self-report</u> Self-compassion = SCS Quality of life = WHOQOL-BREF Vitality = SVS Mindfulness = MAAS Stress = LSSI Depression = BDI Anxiety = BAI <u>Physiology</u> Salivary cortisol	<u>Self-report</u> Baseline Wk8 post-intervention <u>Physiology</u> 8 samples (under fasting): 4 pre-intervention (2x 2 consecutive days of immediately before & 30	Sig. improvements at wk 8 for YMCP group vs. control: quality of life (p<0.01); vitality (p<0.01); mindfulness (p<0.00001); self-compassion (p<0.05); stress (p<0.05), anxiety (p<0.000001), depression (p<0.00001) & concentration of salivary cortisol (p<0.05)

						mins after waking); & 4 post-intervention (as above)	
Dowling et al., (2014)	United States	LEAF Intervention 1hr, one-on-one, once a wk for 5wks in either LEAF (in-person or video-conference), plus homework exercises & daily work sheets or interview-based control (completion of DES, with daily affect reports as home practice)	Pilot RCT	FC of people with frontotemporal dementia Recruited (n = 26) Completed (n = 24)	Affect: DES Depression: CES-D Stress: PSS Distress: NPI Burden: ZBI Intervention evaluation survey: LRS	Baseline Wk6 post-intervention Wk10 follow-up Intervention evaluation during wk2 & 6 sessions	LEAF group vs. control = sig. improvements in stress (p<0.05) from baseline to wk6 post-intervention; and positive affect (p<0.05) & burden (p<0.05) from baseline to wk10 follow-up. LEAF intervention positively evaluated by FC, including the videoconference delivery format that was rated as easy and the same as interacting in person
Milbury et al., (2015)	United States	Tibetan yoga 45-60 mins, 2-3 times a wk for 5-6 wks (15	Pilot pre-post	Dyads – people with lung cancer and FC	Depression: CES-D Anxiety: Anxiety subscale of BSI-18 Sleep: PSQI	Baseline Wk5-6 last wk of intervention	Sig, improvements in FC fatigue (p=0.03), anxiety (p=0.04) post-intervention. Similar non-sig. improvements in

sessions total),
plus CD-guided
homework
practice on non-
intervention
days

Recruited
(n =14 dyads)
Completed
(n = 10 dyads)

Fatigue: BFI
Health-related
quality of life: SF-
36
Spiritual
wellbeing:
FACTSWBS-4
Finding meaning:
FMCS

sleep disturbance
(p=0.08)

No sig. findings for all
other outcomes

Dyads reported
intervention as very
useful

Note. MODEL = Mindfully Optimising Delivery of End-of-Life Care; hr = hour; wk = week; FC = family carers; min = minutes; RCT = randomised controlled trial; SCS = Self-Compassion Scale; WHOQOL-BREF = World Health Organisation Quality of Life Questionnaire; SVS = Subjective Vitality Scales; MAAS = Mindful Attention Awareness Scale; LSSI = Lipp’s Stress Symptoms Inventory for Adults; BDI = Beck Depression Inventory; BAI = Beck Anxiety Inventory; vs. = versus; LEAF = Life Enhancing Activities for Family Caregivers; DES = Differential Emotions Scale; CES-D = Centre for Epidemiological Studies Depression Scale; PSS = Perceived Stress Scale; NPI = Neuropsychiatric Inventory; ZBI = Zarit Burden Interview; LRS = Likert rating scale; BSI-18 = Brief Symptom Inventory-18; PSQI = Pittsburg Sleep Quality Index; BFI = Brief Fatigue Inventory; SF-36 = Medical Outcomes Study 36 item Short Form; FACTSWBS-4 = Functional Assessment of Cancer Therapy Spiritual Wellbeing Scale Version 4; FMCS = Finding Meaning in Cancer Scale