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**Meditation-Based Interventions for Family Caregivers of People with Dementia:
A Review of the Empirical Literature**

Objectives: Providing care for a family member with dementia is associated with increased risk of adverse mental health sequelae. Recently, interventions utilising meditation-based techniques have been developed with the aim of reducing psychological distress among dementia caregivers. The present review aimed to critically evaluate the extant empirical literature in order to determine: (1) whether meditation-based interventions can reduce depression among dementia caregivers and (2) whether meditation-based interventions can reduce subjective burden among dementia caregivers. Method: After adhering to inclusion and exclusion criteria, a total of eight studies were included in the present review.

Methodological quality was assessed using one of two scales dependent on study design.

Results: The results provide tentative evidence that meditation-based interventions do indeed improve levels of depression and burden in family dementia caregivers. Conclusions: The review highlighted the strengths and weakness of the studies' methodological designs. While this novel review offers evidence in support of meditation-based interventions to improve the psychological distress of family dementia caregivers, future research should direct efforts to conduct larger scale, more rigorous studies. Clinical implications of the findings are also discussed.

Keywords: *mindfulness; dementia caregivers; depression; burden*

Introduction

The Department of Health reported that over 700,000 individuals in the UK are currently living with a diagnosis of dementia and prevalence is increasing (DoH, 2009). The impact of caring for a family member with a chronic illness has long been an area of interest in the field of psychology. When reviewing the literature regarding the effects of caring for a person with dementia, Schulz et al. (1990) identified a significant increase in psychiatric illness, as well as an increased vulnerability to physical illness, although these effects were less clear-cut. In a more recent meta-analysis, Pinquart and Sorensen (2003) concluded that caregivers were significantly more depressed and stressed than non-caregivers; they also reported significantly lower levels of self-efficacy and subjective well-being. Interestingly, a greater difference in these variables was observed between dementia caregivers and non-caregivers, when compared to a heterogeneous sample of different types of caregivers versus non-caregivers. Furthermore, dementia caregivers have been shown to face additional challenges compared to other caregivers, such as providing significantly more hours of care, as well as assisting with significantly more daily activities and facing a higher level of behavioural issues from patients (Ory et al. 1999).

Gallicchio et al. (2002) explored gender differences among 327 informal dementia caregivers, and found that significantly more female caregivers experienced a high level of burden, whilst likelihood of depression did not differ between genders. In light of this observed gender difference in caregiver burden, the authors hypothesised that in adhering to social norms, it is more likely that females feel obliged to assist with activities of daily living and take on a caregiver's role. This is consistent with previous research, which found that female caregivers spend more time assisting the care recipient than male caregivers and this is associated with higher risk of psychiatric morbidity (Yee & Schultz, 2000).

In addition to psychological distress, recent literature suggests that dementia caregivers themselves may experience reduced cognitive performance. Oken et al. (2011) found that, when compared to non-caregiving controls, dementia caregivers performed significantly worse on cognitive tasks and mediation analysis revealed that impaired sleep was the sole mediator of impaired cognitive performance.

The aforementioned studies emphasise the importance of providing effective interventions to address the psychological needs of dementia caregivers. One such intervention involves the use of meditation.

Meditation-Based Practice

Meditation, often described as a contemporary mind-body intervention, can take one of two distinct forms: concentration meditation or mindfulness meditation.

Mindfulness has been defined as “the awareness that emerges through paying attention on purpose, in the present moment, and non-judgementally to the unfolding of experience moment by moment” (Kabat-Zinn 2003, p145). Mackenzie and Poulin (2006) remarked that whilst the majority of interventions designed to reduce stress in caregivers adhere to a medical model, there is an evidence-base, albeit limited by the small number of studies, which indicates that mindfulness training is an alternative and promising caregiver intervention. In contrast to some cognitive-behavioural and psycho-educational approaches, which encourage activities designed to distract patients from distressing thoughts, mindfulness promotes an individual’s ability to focus their awareness on the present moment.

Dunn et al. (1999) commented that concentration, the second type of meditation, encourages the individual to focus their attention on a single object, such as an image or a mantra. Although this is considered to be a distinct approach to meditation, aspects of concentration meditation such as mindfulness of breathing also form part of mindfulness-based approaches (Segal et al., 2002).

Feasibility of Meditation-Based Interventions for Dementia Caregivers

Mindfulness-based approaches are recommended for those who are experiencing stress within a current role as they can serve to enhance an individual's ability to alleviate "excessive role stress" (Kabat-Zinn, 1996, p381). Consequently, they are considered suitable for caregivers of people with dementia.

In order to assess the practical feasibility of mindfulness-based stress reduction (MBSR) for family caregivers of people with dementia, Whitebird et al. (2011) conducted a randomised control trial to explore challenges to the recruitment and retention of participants. The study surpassed the goal sample size with 78 caregivers participating in the trial, suggesting that the range of recruitment sources was successful. Further, a low attrition rate was observed, with 92% of the caregivers completing the trial and 2-month follow up; this low rate of attrition indicates that the content of the sessions was acceptable and useful for participants. Taken together, the successful recruitment and retention of family dementia caregivers suggest that mindfulness is an acceptable intervention for this population. Additionally, Puymbroeck et al. (2007) found that informal caregivers who completed a concentration meditation intervention in the form of yoga, described the intervention as enjoyable and there was a 25% attrition rate, which was attributed to time commitments rather than limitations of the intervention. The study demonstrated that meditation-based interventions are beneficial to informal caregivers as they facilitate coping, improve physical health and are deemed acceptable by those who participate.

Rationale for current literature review

Given that extensive literature indicates negative psychological sequelae associated with caring for a family member with dementia (e.g., Ory et al., 1999; Pinquart & Sorenson, 2003), there is a clear need to explore interventions that may serve to reduce or ameliorate psychological distress where it occurs in this population. Despite being shown to be a

feasible intervention, no previous review has examined the evidence for meditation-based interventions in dementia caregivers. Furthermore, as the literature field is not yet densely populated with relevant studies, a review is also required to guide the future research in this area.

Aims

The present literature review aims to:

- i. explore whether meditation-based interventions alleviate symptoms of depression among dementia caregivers
- ii. explore whether meditation-based interventions reduce levels of burden among dementia caregivers
- iii. critically appraise the methodologies of studies reviewed to inform future research

Method

Inclusion Criteria and Search Strategy

To be eligible for inclusion in the review, studies were required to meet the following criteria:

- Be an empirical study of a meditation-based intervention
- Have been published in a peer-reviewed journal
- Participants were family caregivers of people with dementia.
- Levels of depression and/or burden must have been included as a dependent measure.
- Quantitative, pre-post findings must have been reported for depression and/or burden.

Electronic searches were carried out in October 2012 using four databases: PsychInfo, Medline, Scopus and Embase, which retrieved 14, 9, 19 and 27 studies respectively. The keywords used to identify relevant articles were: (“Mindfulness” OR “MBCT” OR “MBSR” OR “Meditation” OR “Mantra”) AND (“Dementia” OR “Alzheimer’s” OR “Frail Elderly”)

AND (“Caregiver*”). These search terms were identified in the title, abstract or keyword list of journal articles on each database. After completing the search, the abstracts of the identified articles were read and studies that met the inclusion criteria outlined above were selected. This resulted in a total of eight studies included in the review. Seven were written using the English language and one was written in Spanish language.

Analysis of Methodological Quality

Methodological quality of the studies was systematically assessed using one of two quality appraisal scales. Of the eight studies included in the review, five were case series studies; a case series design is defined as a study that employs an experimental group that receives an intervention but does not include a comparison or control group (Cochrane Collaboration, 2012). Methodological quality for the case series studies was assessed using a quality design checklist developed specifically for the evaluation of cased series research by Moga et al. (2012). The checklist items include elements of study recruitment, methodology and statistical analysis.

The other three studies included in the review employed a randomised control design. The PEDro scale (Maher et al., 2003) was designed to assess the methodological quality of randomised control trials (RCTs). The PEDro scale is an 11-item measure with items scored as either one or zero depending on whether the study has met the required criteria. The PEDro scale was used in the current review as recent research has found it to be a valid measure for assessing the methodological quality of clinical studies that employ an RCT design (de Morton, 2009).

When employing the scales discussed above, two independent researchers rated each study. Inter-rater reliability was high for both the quality design checklist for case series (Moga et al. 2012) and the PEDro scale for RCTs (Maher et al. 2003), with interclass correlation coefficients (ICC) of .80 ($p=.364$) and .923 ($p=.423$) respectively. Vincent (1999)

reported that an acceptable inter-rater reliability score includes those with an ICC greater than .70.

Results and Discussion

Descriptive Statistics

Eight studies, published between 2004 and 2012, were included in the review. Three followed an RCT design and five used a case series study design. The total number of participants included in the studies was 181 (M=22.63, SD=15.59), with a grand mean age of 61 years (SD=8.12). There was an uneven distribution of gender, with a higher proportion of recruited participants being female (M=87.25%, SD=16.43). This is congruent with research showing that the majority (73%) of dementia caregivers are female (Ory et al., 1999). In terms of attrition, percentages ranged from 0-24%, with a mean of 12% (SD=8.47). Information regarding each study's sample, demographic and attrition data is displayed in Table 1.

(Table 1 inserted here)

Summary of Studies and Findings

An overview of the eight studies included in this review is displayed in Table two, which shows the studies' findings regarding depression and burden only, serving to address the first two aims of the current review.

(Table 2 inserted here)

Do Meditation-Based Interventions Reduce Levels of Depression Among Dementia Caregivers?

Of the eight studies included in the review, seven assessed participants' levels of depression pre- and post-intervention. Five found significant reductions in depression score from pre- to post-intervention (Epstein-Lubow et al., 2011; Franco et al., 2010; Innes et al., 2012; Lavretsky et al., 2012; Waelde et al., 2004), whilst two identified a non-significant trend for reduced scores in depression (Bormann et al., 2011 & Oken et al., 2010).

Three of the seven studies conducted a follow-up assessment to explore whether the effects of the intervention had been maintained; the first study, which had not observed significant changes pre to post, found a significant reduction in depressive symptoms between the pre-intervention and follow-up scores (Bormann et al., 2011). The second study found that the depression levels had returned to baseline, following the significant reduction, which was observed immediately post-intervention (Epstein-Lubow et al., 2011). The third study found that the improvements in depression scores were maintained at follow-up, however, the differences were greater from pre to post than from post to follow up (Franco et al., 2010); the authors attempted to explain this result by suggesting that the caregivers did not spend a sufficient amount of time practicing the mindfulness techniques after the intervention was complete. However, the authors did not state or propose a minimum level of practice, highlighting a weakness in their design.

Do Meditation-Based Interventions Reduce Levels of Burden Among Dementia Caregivers?

Of the eight studies, five assessed participants' levels of burden pre- and post-intervention. Three found a significant reduction pre- to post- intervention (Epstein-Lubow et al., 2011; Franco et al., 2010; Hoppes et al., 2012) and the data of a fourth study showed a non-significant trend for reduced levels of burden among participants (Bormann et al., 2009). The final study revealed no significant pre-post changes (Waelde et al., 2004).

Four of these five studies conducted a follow-up assessment to explore whether the effects of the intervention had been maintained; the findings of three studies revealed that the levels of burden had continued to reduce since the post-intervention measures (Bormann et al., 2009; Epstein-Lubow et al., 2011; Franco et al., 2010), whilst the fourth study found that levels of burden had increased at the four-week follow-up when compared to post-intervention scores, but that they still remained lower than baseline (Hoppes et al., 2012).

Research has highlighted the importance of alleviating burden as long-standing feelings of burden among dementia caregivers have a negative impact on an individual's mental health. In a longitudinal study, Epstein-Lubow et al. (2008) found that high levels of burden significantly predicted subsequent depressive symptoms. Consequently, meditation-based interventions that effectively alleviate feelings of burden in dementia caregivers may also result in reduced levels of depression.

Methodological Considerations

Quality of design. Three of the reviewed studies employed a randomised controlled trial (RCT) design and were scored for methodological quality using the PEDro Scale (Maher et al., 2003). The three RCTs include, Franco et al. (2010), Lavretsky et al. (2012) and Oken et al. (2010), which scored, 5/11, 7/11 and 6/11 respectively (M=6/11).

The three RCTs scored highly on items including random allocation, baseline similarity between conditions and the statistical tests used. All three neglected to blind subjects and therapists or to conduct intention-to-treat analysis. Two of the studies were able to gain marks for collecting data from over 85% of participants that were initially recruited; Franco et al. (2010) narrowly failed on this score as their study experienced an attrition rate of 18%. These findings are consistent with research conducted by de Morton (2009), who selected 200 clinical trials at random in order to formulate the PEDro items into a hierarchy, depicting the most and least adhered to items. The results reflect those observed in the present literature review and revealed that the majority of studies fail to blind therapists and subjects, whilst many are successful in the following items: random allocation; using a statistical test to compare groups; reporting the mean and variability of data; checking that group are similar at baseline; blinding the assessor; and obtaining data from at least 85% of participants at post-intervention time points.

The other five studies reviewed here adopted a case series design and were assessed using the 18-item checklist devised by Moga et al. (2012). These five studies, including Bormann et al. (2009), Epstein-Lubow et al. (2011), Hoppes et al. (2012), Innes et al. (2012) and Waelde et al (2004), received scores of 11/18, 12/18, 11/18, 14/18 and 13/18 respectively (M=12.2/18).

The five case series studies scored highly on the items that require the study's objective to be clearly stated and appropriate outcome measures and statistical tests to be employed; however, some studies failed to specify participant characteristics, including the number of hours spent caring, as well as the current stage of the person with dementia. These characteristics are deemed important as they could mediate intervention efficacy to alleviate depression and burden among the dementia caregivers. Additionally, all five studies failed to report whether or not there were any competing interests in the study or to state any sources of financial support.

Validity of outcome measures used. There were inconsistencies between the studies with regard to the measures used to assess depression and burden. Levels of depression were assessed using four different measures across the eight studies; these include the Centre for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977), Hamilton Depression Rating Scale (HDRS; Hamilton, 1960), Symptom Checklist 90 (SCL-90; Derogatis & Cleary, 1977a) and Profile of Mood States (POMS; McNair et al., 1992). The psychometric properties of these measures differ greatly. The CES-D, a 20 item self-report questionnaire, was found to have high validity and reliability scores when tested among middle-aged women (Knight et al., 1997), as well as when tested amongst community-dwelling older adults (Lewinsohn et al., 1997). These two samples reflect a large proportion of the participants recruited in the studies included in the current literature review. However, research into the psychometric properties of the HDRS has suggested that this measure is less

robust; Bagby et al. (2004) conducted a literature review of studies that explored the psychometrics of the scale, and revealed that its validity and reliability is poor, including its test-retest reliability. The authors concluded that what had been the gold standard measure of depression had become a “lead weight” (p2163). The implications of Bagby’s findings suggest that the findings of Lavretsky et al. (2012), the only included article to measure depression with the HDRS, should be interpreted with some caution, despite the study having a strong methodology and employing an RCT design.

With regard to subjective burden, which was assessed in five of the eight studies included in the present review, four measures were utilised. Epstein-Lubow et al. (2011) used the Zarit Burden Interview (ZBI; Zarit, 1980) to measure caregiver burden pre- and post-intervention. Vitaliano et al. (1991) conducted a review of burden measures employed with dementia caregivers and reported sound psychometric properties for the ZBI. The authors did however suggest that this measure of subjective burden, namely caregiver distress, would be complemented by the use of the Memory and Behaviour Problems Checklist (Zarit & Zarit, 1987), which is designed to measure frequency of behavioural issues displayed by the person with dementia. Bormann et al. (2009) and Hoppes et al. (2012) both employed the shorter, 12-item ZBI, originally developed by Bedard et al. (2001). The psychometric properties of this version have been established by Higginson et al. (2010), who found it to be valid for use with dementia caregivers. Franco et al. (2010) administered the Spanish version of the ZBI, ‘Escala de Sobrecarga del Cuidador de Zarit’, originally translated by Martin-Carrasco et al. (1996); the psychometric properties have been established and are reported as being appropriate for use with a Spanish caregiving population (Martin-Carrasco et al., 2010). Lastly, Waelde et al. (2004) employed the Revised Memory and Behaviour Problem Checklist (Teri et al. 1992), though it was not clear why the authors employed this measure

alone as it is not a direct measure of subjective burden and is therefore, not as widely used as the ZBI.

Sample

Defining caregivers. One area of ambiguity surrounds the definition of a “caregiver”; all eight studies included in the current review recruited family caregivers of people with dementia but the criteria used to identify appropriate caregivers varied. The minimum amount of time spent caring for a family member with dementia ranged from being in contact with the individual for at least three days per week (Lavretsky et al., 2012), to spending a minimum of 12 to 20 hours per week caring (Oken et al., 2010 and Epstein-Lubow et al., 2011 respectively) and providing at least four hours per day of care (Waelde et al., 2004). Additionally, four of the eight studies did not refer to an amount of time spent caring for the individual in their inclusion criteria (Bormann et al., 2009; Franco et al., 2010; Hoppes et al., 2012; Innes et al., 2012).

Recruitment bias. A further consideration is that of sample bias. Dura and Kiecolt-Glaser (1990) explored the frequently observed selection bias in research that involves dementia caregivers. Their research suggested that studies regarding dementia caregivers may unintentionally recruit a non-representative sample. Employing those who are willing to travel may limit participation to less depressed individuals, whose family member is significantly less impaired and presenting with significantly fewer dementia-related behavioural problems. The authors suggested that to address this sample bias, future studies should include an at-home assessment option where appropriate. Such findings are relevant to the studies included in the present review. Whilst none of the mindfulness-meditation studies employed at-home delivery of the intervention, two of the four concentration-meditation studies (Lavretsky et al., 2012; Innes et al., 2012) did not require participants to travel to a clinical site, but instead to complete the required practice at home. Additionally, one of the

concentration-based interventions was delivered via teleconference (Bormann et al., 2011). Both styles of intervention serve to facilitate minimal disruption of the caregivers' routines and do not add further burden to the already heavy time constraints experienced by many informal dementia caregivers.

Implications for Clinical Practice

The meditation-based approaches explored as part of the present literature review have demonstrated significant improvements in depression among dementia caregivers, consistent with the application of such interventions to other populations with depression (Segal et al., 2002; Smith et al., 2007; Splevins et al., 2009). Additionally, the interventions have been shown to alleviate burden, a finding that is congruent with Kabat-Zinn (1996) who identified “excessive role stress” (p381) among caregivers and suggested that mindful practice could help caregivers to cope with this stress. Consequently, it appears that meditation-based interventions offer a feasible and effective intervention for dementia caregivers experiencing burden or depression. After the tentative results from these studies have been confirmed with larger trials boasting high levels of rigorous methodological quality, the National Institute of Clinical Excellence may wish to incorporate such approaches into their current recommendations for supporting caregivers.

Whilst the short-term outcomes of the reviewed studies reflect the benefits of meditation-based approaches, the longer-term follow-up results suggest that gains are not always maintained, indicating that interventions should consider whether caregivers may benefit from *booster* sessions to support maintenance of their meditation-based practice.

Recommendations for Future Research

Two of the studies included in the current review supplemented their findings with qualitative data (Epstein-Lubow et al., 2011; Hoppes et al., 2012). Both demonstrated participants' increased awareness of the present moment, as well a greater acceptance for

‘what is’, rather than striving to achieve a desired situation. These results suggest that, at least in part, the goals of mindfulness have been achieved. However, it would be useful for future research to gather qualitative data for participants who took part in a concentration-meditation intervention to identify whether participants experience a similar shift to focusing on the present moment. Additionally, it may be beneficial for researchers, who may wish to conduct similar studies, to use qualitative data to explore aspects that participants found most useful, as well as to provide an opportunity to feed back constructive proposals for change; this may serve to reduce attrition rates, as well as helping to tailor future clinical practice to meet the needs of dementia caregivers.

Whilst some of the studies measured adherence to at-home practice of meditation-based techniques, this was done during the intervention period. It may be useful for future research to explore the relationship between practice and maintained gains following completion of the intervention. Additionally, encouraging at-home practice and considering providing booster / maintenance sessions, may serve to improve follow-up outcomes.

As previously described, three of the concentration-meditation studies reviewed here utilised a design that did not require participants to leave their homes, ensuring that participation in the studies did not make additional time on the caregivers. However, none of the mindfulness-based studies explored in the present review offered an at-home intervention. It would be interesting for future studies to explore the feasibility of employing a tele-conference or online-based design, facilitating teaching of mindfulness techniques whilst remaining sensitive to the needs of the caregivers. This may serve to partially address the recruitment bias identified by Dura and Kiecolt-Glaser (1990), that dementia caregivers who take part in research are generally those who care for individuals with less severe dementia and can therefore travel to participate in studies.

Furthermore, some of the reviewed studies did not report key information regarding either the stage of dementia in the person cared for or the amount of time spent caring, i.e. the number of years spent caring and the approximate number of hours per week providing direct care. Such factors have been shown to be significantly related to behavioural disturbance in the person with dementia, as well as poorer caregiver physical health (Gallicchio et al., 2002) and it is therefore recommended that future studies gather and report this information.

Conclusion

The aim of the present review was to explore whether meditation-based interventions can reduce depression and burden in dementia caregivers. The studies reviewed here offer a valuable insight into the potential benefits of meditation-based interventions for informal dementia caregivers while providing evidence that generally supports the benefits of such interventions in terms of reduced levels of both depression and burden for participants.

The Oxford Centre for Evidence Based Medicine outlines the quality of evidence provided by different research designs; case series studies are not as methodically robust as randomised control trials (Howick et al., 2011). The majority of the studies in this review used a case series design and consequently the findings should be interpreted with some caution. Future research would benefit from employing large-scale randomised-control designs. Finally, given the relatively low attrition rates across the studies reviewed ($M=12\%$, $SD=8.7$), it would appear that meditation-based interventions are both feasible and acceptable to the dementia caregiving population.

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