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Which intervention work for dementia family carers?: An updated systematic review of
randomised controlled trials of carer interventions

Dr Naoko Kishita¹⁾, Laura Hammond²⁾, Celina M. Dietrich³⁾, Professor Eneida Mioshi¹⁾

¹⁾ School of Health Sciences, University of East Anglia

²⁾ Research Development Programme, Norfolk and Suffolk NHS Foundation Trust

³⁾ Norwich Medical School, University of East Anglia.

Correspondence concerning this article should be addressed to Dr Naoko Kishita,
School of Health Sciences, University of East Anglia, Norwich, NR4 7TJ, UK

Phone: 01603 593599 Email: N.Kishita@uea.ac.uk

Abstract

Objective: The aim of this study was to update the literature on interventions for carers of people with dementia published between 2006 and 2016 and evaluate the efficacy of psychoeducational programmes and psychotherapeutic interventions on key mental health outcomes (depression, anxiety, burden, and quality of life).

Methods: A meta-analysis was carried out of randomised controlled trials of carer interventions using MEDLINE, PsycINFO, Scopus, and Cochrane Central Register of Controlled Trials.

Results: The majority of studies were conducted in Western and Southern Europe or the United States and recruited carers of people with Alzheimer's disease or dementia grouped as a whole. The most commonly used outcome measures were depression and burden across studies. The updated evidence suggested that psychoeducation-skill building interventions delivered face-to-face can better impact on burden. Psychotherapeutic interventions underpinned by Cognitive Behaviour Therapy (CBT) models demonstrated strong empirical support for treating anxiety and depression and these effects were not affected by the mode of delivery (i.e., face-to-face vs technology). A modern CBT approach, Acceptance and Commitment Therapy (ACT), seemed to be particularly beneficial for carers experiencing high levels of anxiety.

Conclusions: Future research needs to explore the efficacy of interventions on multiple clinical outcomes and which combination of interventions (components) would have the most significant effects when using CBT. The generalisation of treatment effects in different countries and carers of different types of dementia also need to be addressed. More research is needed to test the efficacy of modern forms of CBT such as ACT.

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Introduction

Elevated symptoms of anxiety, depression, and burden in dementia carers are very common and are associated with poor quality of life (QoL) (Abdollahpour *et al.*, 2015; Cooper *et al.*, 2007; Cuijpers, 2005). Not surprisingly, dementia carers are considered to be a high-risk group for death by suicide, and this risk does not appear to be diminished by the death or institutionalisation of the care recipient (Joling *et al.*, 2017; O'Dwyer *et al.*, 2016). As such, establishing effective interventions that can help caregivers maintain their emotional wellbeing (i.e., anxiety, depression, and burden) across the care trajectory is critically important.

There are several existing meta-analyses focused on assessing the efficacy of carer interventions on emotional wellbeing. However, most of these reviews target one specific approach such as Cognitive Behaviour Therapy (CBT) (Vernooij-Dassen *et al.*, 2011), , educational interventions (Jensen *et al.*, 2015), support groups (Chien *et al.*, 2011), technology-based CBT (Scott *et al.*, 2016), and telephone counselling (Lins *et al.*, 2014). The conclusion about differential efficacy of treatments using separate meta-analyses is problematic as it is unclear how valid these comparisons are given differences in methodology and levels of heterogeneity.

An earlier comprehensive review by Pinquart and Sörensen (2006) has compared the efficacy of different types of carer interventions on emotional wellbeing with non-active control conditions within their single meta-analysis. This meta-analysis integrated the results of 127 carer intervention studies published between 1982 and 2005 and demonstrated that interventions had, on average, significant but small immediate effects on carer outcomes such as burden, depression, and QoL. The main limitation of this study was the inclusion of both randomised and non-randomised trials and the authors have concluded that non-randomised studies may have overestimated the efficacy of interventions.

Gallagher-Thompson and Coon (2007) have also conducted a comprehensive review of carer intervention studies published between 1980 and 2005. Unlike the previous review (Pinquart and Sörensen, 2006), this study only included Randomised Controlled Trials

(RCTs). They identified three categories of psychologically derived interventions: psychoeducational programmes ($N = 14$ studies), psychotherapy (CBT) ($N = 3$), and multicomponent interventions (family counselling with support group) ($N = 2$). The main limitation of this study was the relatively small number of studies identified, partly due to studies only being included if they showed beneficial treatment effects in target problems, a criterion proposed by Yon and Scogin (2007). The largest effect size was found in the psychotherapy category (CBT). An overall effect size of CBT for psychological distress was 1.20. However, there may have been a reporting bias due to the aforementioned criterion as a recent review on CBT based interventions for carers demonstrated only a small effect on anxiety (0.21) and a medium effect on depression (0.66) (Vernooij-Dassen *et al.*, 2011).

Recently, Elvish *et al.* (2013) has conducted a comprehensive review to update the literature on carer interventions published between 2005 and 2011. This study also only included RCTs. However, the authors included studies that used both active and non-active control conditions and both quantitative and qualitative methodologies. Thus, effect sizes were not reported in the review. Similar to the previous review (Gallagher-Thompson and Coon, 2007), this study identified four categories of psychologically derived interventions: psychoeducational programmes, psychotherapy (no quantitative study was identified for this category), multicomponent interventions, and technology-based interventions.

The main limitation of this review (Elvish *et al.*, 2013) was not only a large heterogeneity in the study designs, but also the categories of interventions used. For example, multicomponent interventions included two distinct types of interventions (i.e., family counselling with support group, pharmacological therapy for people with dementia combined with psychosocial intervention). Technology-based interventions included both technology-based psychoeducational programmes and CBT. The categorisation of interventions needs to be theory-driven rather than driven by the mode of delivery. Gallagher-Thompson and Coon (2007) particularly highlighted the importance of distinguishing studies grounded in CBT theories from psychoeducational programmes in that

the former place emphasis on the development of therapeutic relationship as part of the treatment process.

Reaching a valid conclusion based on a more appropriate comparison metric will help direct focus on the important clinical task of understanding the efficacy of different types of carer interventions. Therefore, the aim of the current study is to conduct an up-to-date systematic review and evaluate the efficacy of carer interventions on emotional wellbeing (i.e., depression, anxiety, and burden). The current review particularly focuses on psychoeducational programmes and CBT based psychotherapeutic interventions as previous comprehensive reviews (Elvish *et al.*, 2013; Gallagher-Thompson and Coon, 2007) suggested that these approaches can better impact on emotional wellbeing of dementia carers among other approaches.

One might argue that some techniques used in these two approaches overlap. CBT is an active, directive, time-limited, structured approach based on the cognitive model: the way that individuals perceive a situation is more closely connected to their reaction than the situation itself (Beck, 1967; 1979). Various cognitive and behavioural strategies are used in CBT. However, CBT is not defined by its use of these strategies but by whether the specific therapeutic techniques employed are utilised within the framework of the cognitive model (Beck, 1979). To be categorised as CBT based psychotherapeutic interventions in the current review, the intervention needed to be delivered by CBT therapists or trainers who received CBT training or there needed to be a clear reference to the cognitive model in the intervention protocol.

The recent comprehensive review (Elvish *et al.*, 2013) treated technology driven interventions as an independent intervention category regardless of the underlying theoretical framework. This review does not omit a spectrum of delivery modes, but rather it will be treated as a covariate in each intervention category. In addition, a strict approach to sorting studies based on control conditions is essential in systematic reviews and researchers should avoid categorising active and non-active controls into a generic control group as separating these different control conditions is paramount to achieve meaningful

estimates of treatment efficacy (Karlsson and Bergmark, 2015). Therefore, in order to reduce the heterogeneity of included studies and to obtain an empirically derived index of interventions for dementia carers, the current study only includes RCTs that used a treatment condition that solely focused on carers and utilised non-active control conditions (e.g., waiting list) as comparators.

Methods

Inclusion and Exclusion Criteria

Studies were included if they (a) recruited dementia family carers; (b) randomised participants to either a treatment condition or a non-active control condition; (c) reported the efficacy of an intervention on either depression, anxiety, or burden as a primary outcome; (d) were published in peer-reviewed journals; (e) were written in English; and (f) were published after 2006. When means, standard deviations, and sample size for one of the targeted outcomes were not reported, we contacted the first author of the study for further details. Studies were excluded if further information was not available.

Studies were excluded if they (a) provided an intervention to both carers and care recipients; or (b) reported data that overlapped with data from other included studies (e.g., secondary analysis of existing data). Non-active control conditions were defined as a control condition that did not receive any treatment (e.g., waiting list, treatment as usual) or a control condition that provided a brief information based support (e.g., a brief educational leaflet, a brief information session). The latter conditions were included as these types of support are often provided as routine care in the community. However, in order to be eligible, these control conditions had to be intended solely to provide general information about dementia (e.g., clinical and pharmacological information about dementia, symptoms). Control groups could not receive any skill building or therapeutic techniques even if fewer sessions than the intervention group.

Search Strategies

The following electronic databases were searched: MEDLINE (all text), PsycINFO (all text), Scopus (title, abstracts, keywords), and Cochrane Central Register of Controlled Trials (title, abstracts, keywords) on 10 November 2016. We used terms for dementia (dementia, Alzheimer*), family carers (caregiver*, caregiving, carer*, famil*, relative*), intervention studies (intervention*, support, training, program*, therap*), randomised control trials (RCT, random*, control* trial*), and psychological outcomes (depression, anxiety, burden, distress, stress).

Coding Procedure

Information was extracted independently by two authors (NK and LH) using a purposely designed electronic data extraction sheet for the current review. Agreement between the two coders was 85.9%. Disagreements were resolved through discussion, and consensus was obtained.

For each included study, information was recorded on (a) the country where research was conducted; (b) participants' age range and mean age; (c) care recipients' diagnosis; (d) proportion of spouse carers; (e) proportion of female carers; (f) format of treatment (e.g., individual face-to-face, group face-to-face, online); (g) number of sessions; (h) length of each session; (i) professional background of interventionists (e.g., nurse, clinical psychologist); (j) outcome measure of depression, anxiety, or burden used (measure of QoL was also recorded as a secondary outcome where available); and (j) means, standard deviations, and sample size for the outcome measures in treatment and control conditions at pre-test and post-test. Means and standard deviations were extracted from intention-to-treat samples when available.

To compare methods used for data analysis and treatment assignment and investigate adherence and acceptance of the treatment, the following information was also extracted: (a) type of data analyses (i.e., intention-to-treat, completers only); (b) randomisation method; (c) method of treatment adherence reporting, (d) whether treatment was manualised; (e) provision of training and supervision for trainers; and (f) attrition rate.

Intervention Categories

The use of the following approaches in the treatment conditions for each study was recorded: (a) case management; (b) provision of information on dementia and care-related issues; (c) communication training; (d) CBT techniques for managing carers' emotional difficulties; (e) non-CBT techniques for managing difficulties related to caregiving (e.g., coping skill training with no reference to the cognitive model); and (f) behaviour modification training for managing behavioural and psychological symptoms of dementia. This was completed independently by authors NK and LH. Agreement was 87.5% and disagreements were resolved through discussion, and consensus was obtained. Subsequently, studies were divided up into two categories. The studies not falling into either category were further excluded due to irrelevance to the review question.

Psychoeducation-skill building interventions. This category included studies that focused on increasing carers' knowledge of dementia and teaching them specific coping skills for managing common emotional distress and/or behavioural changes associated with dementia.

CBT based psychotherapeutic interventions. To be included in this category it was necessary for an intervention to employ cognitive and behavioural strategies that are utilised within the framework of the cognitive model. Some examples of such strategies included standard cognitive and behavioural techniques aimed at testing the individual's specific misconception and maladaptive assumptions (Beck, 1979) or more modern cognitive and behavioural techniques aimed at accepting distressing thoughts and emotions (Hayes *et al.*, 1999).

Statistical Methods

All data were analysed using the Open Meta-Analyst (Wallace *et al.*, 2012). The effect size for the difference between treatment and control conditions were calculated for each included study using the Hedge's *g*. A fixed-effect model was used to provide a pooled estimated effect for each intervention category, and a test for heterogeneity was performed using the *Q*-statistic and the *I*² statistic. Where there was evidence of heterogeneity of the treatment effect a random-effects model was used. If data were clearly heterogeneous, a

leave-one-out sensitivity analysis was conducted to test whether any individual study had a significant influence on the overall estimate of the rest of the studies. A subgroup analysis was also performed to test whether the mode of delivery (i.e., face-to-face and technology) had a significant impact on the overall estimated effect. The overall effect size was reported only if there were data available for three or more studies for the outcome of interest (i.e., depression, anxiety, burden, or QoL).

Results

Study Selection

Figure 1 presents a flow diagram illustrating the study selection process. Our search yielded 1,279 titles and abstracts. Two authors (NK and CD) excluded 1,144 articles based on the abstracts as they were clearly irrelevant to the present research question. The same authors reviewed the remaining 135 full articles independently. Applying the inclusion and exclusion criteria resulted in the identification of 40 original studies.

Finally, a further 10 studies were excluded due to the intervention not meeting any of the intervention categories. These 10 studies used the following interventions: case management (Xiao *et al.*, 2016), support group (Chu *et al.*, 2011; Winter and Gitlin, 2006), information provision (Kurz *et al.*, 2010), meditation (Danucalov *et al.*, 2013; Leach *et al.*, 2015), resourcefulness training (Gonzalez *et al.*, 2014), physical exercise (Connell and Janevic, 2009; Hirano *et al.*, 2011), and self-help decision aids (Stirling *et al.*, 2012). The details of these excluded studies are provided in Supplementary Table S1. Of the 30 identified studies, one had two CBT conditions (Losada *et al.*, 2015) resulting in a total of 31 eligible studies.

Study Characteristics

Psychoeducation-skill building interventions ($n = 16$). Table 1 contains descriptions of the 16 studies in this category. The majority of the studies were conducted in either Asia ($n = 5$), Europe ($n = 5$), or the United States ($n = 4$). Other studies were conducted in Australia ($n = 1$) and Peru ($n = 1$). Of the 16 studies, six studies recruited carers

of people with Alzheimer's disease. Most studies involved carers of people with various diagnoses of dementia grouped as a whole.

The details of Interventions are summarised in Supplementary Table S2. Studies in this category used a structured programme that provided information about dementia and services, and lectures on how to effectively respond to symptoms of the disease and/or better take care of themselves. Twelve studies used a face-to-face mode of delivery. Four studies used technology as a significant vehicle for delivery of the intervention (i.e., telephone, internet, DVD).

The number of face-to-face treatment sessions ranged from 5 to 12, with more than half of the studies (58.3%) providing six or less sessions. The trainers had various backgrounds including nurses, doctors, occupational therapists, social workers, counsellors, and psychologists. Seven studies (58.3%) used a treatment manual to deliver the intervention. Three studies (25%) provided supervision to trainers during the trial and audio recorded treatment sessions for checking treatment adherence. The attrition rate during the treatment period ranged from 0% to 25%, with an average rate of 8.7% (See Supplementary Table S3 for additional study characteristics).

The number of technology driven treatment sessions ranged from 2 to 23. One study used a completely self-help approach with no trainer contact (i.e., a fully automated website to be used in an individual fashion at home). Of the three studies that involved trainer contact, two studies used a treatment manual and one study provided supervision during the trial and audio recorded treatment sessions for checking treatment adherence. The attrition rate during the treatment period ranged from 18% to 45%, with an average rate of 23%.

Eleven of the 16 studies (87.5%) used an intention-to-treat analysis. The main outcome measure for studies in this category was burden. Fourteen studies reported the efficacy of interventions on burden. The majority of studies used the Zarit Burden Interview (ZBI) (Zarit *et al.*, 1980). Data were available to calculate the effect size for six of the eight studies that included depression as one of the outcome measures. The most commonly used measure was the Centre for Epidemiologic Studies Depression Scale (CESD) (Radloff,

1977). Although eight studies reported the efficacy on QoL, there was wide variance in QoL indices used. Some studies reported the total scores while other studies reported the scores of each individual subscale of the measure (e.g., social relationship, physical pain). The effect size was calculated using four studies that reported the total scores. The majority of studies used the WHOQoL-BREF (Skevington *et al.*, 2004). Only two studies reported the efficacy on anxiety and thus the effect size was not calculated.

CBT based psychotherapeutic interventions (n = 15). Table 2 contains descriptions of the 15 studies in this category. Most studies were conducted in Spain ($n = 6$) or the United States ($n = 5$). Other studies were conducted in the United Kingdom ($n = 1$), Netherlands ($n = 1$), and Hong Kong ($n = 2$). Six studies recruited mostly carers of people with Alzheimer's disease. The remaining 10 studies involved carers of people with various diagnoses of dementia grouped as a whole.

All studies included an interventional component based on cognitive and behavioural principles, which aim to reduce carers' psychological difficulties. Other approaches included were (a) education on dementia; (b) communication skill training (e.g., learning to ask for help from other family members); and (c) training on managing the behaviours of the care recipient, or promoting exercises in the care recipient. The combined use of these approaches varied across studies. More than half of the studies (56.3%) combined a standard CBT component with all three additional components. One study used a modern CBT approach, Acceptance and Commitment Therapy (ACT). Ten studies used a face-to-face mode of delivery. Five studies used technology as a significant vehicle for delivery of the intervention (i.e., telephone, internet, DVD).

The majority of the studies that utilised the face-to-face approach provided eight or more treatment sessions (90%) and recruited trainers with a psychology background (80%). All studies, except for one, used a treatment manual to deliver the intervention (90%). Five studies (50%) provided supervision to trainers during the trial and two studies (20%) audio recorded treatment sessions for checking treatment adherence. The attrition rate during the

treatment period ranged from 9% to 32%, with an average rate of 21.1% (Supplementary Table S3)

All studies that used technology provided nine or more sessions except for one study which used a completely self-help approach with no trainer contact (i.e., the DVD vignettes illustrating coping strategies with the accompanying workbook). Four studies that involved trainer contact did not provide any information on the use of a treatment manual or supervision during the trial. The attrition rate during the treatment period ranged from 8% to 43%, with an average rate of 22.6%.

Six of the 15 studies (40%) used an intention-to-treat analysis. The main outcome measure for studies in this category was depression. Data were available to calculate the effect size for 13 of the 14 studies that included depression as one of the outcome measures. The most commonly used measure was the CESD (Radloff, 1977). Six studies reported the efficacy of interventions on anxiety and burden. There was wide variance in anxiety indices used (See Table 2). The majority of studies used the ZBI (Zarit *et al.*, 1980). Only two studies reported the efficacy on QoL and thus the effect size was not calculated.

Effects of interventions

Psychoeducation-skill building interventions. A fixed model was used to evaluate the efficacy of interventions on depression and burden as heterogeneity was not significant. The pooled data revealed no significant effect on depression ($g = 0.12$, $p = 0.14$; 95% CI = -0.04-0.29; Figure 2-a). An overall effect size on burden was small ($g = 0.18$, $p < 0.01$; 95% CI = 0.06-0.29; Figure 2-b). A random effect model was used for QoL as there was statistically significant high heterogeneity between study effect sizes ($Q(3) = 45.81$, $p < 0.01$; $I^2 = 93.45$). The pooled data revealed no significant effect on QoL ($g = 0.60$, $p = 0.15$; 95% CI = -0.21-1.42; Figure 2-c).

CBT based psychotherapeutic interventions. A random effect model was used for anxiety and depression as there was statistically significant high heterogeneity between study effect sizes. An overall effect size for anxiety was large ($g = 0.84$, $p < 0.01$; 95% CI = 0.27-1.41; Figure 3-a). There was high heterogeneity between study effect sizes ($Q(5) =$

76.72, $p < 0.01$; $I^2 = 93.48$). The results of a leave-one-out meta-analysis showed that the study that used ACT (Losada *et al.*, 2015) had a large impact on the overall effect size. If this study was excluded, the effect size for anxiety would decrease from 0.84 to 0.38. An overall effect size for depression was moderate ($g = 0.53$, $p < 0.01$; 95% CI = 0.22–0.84; Figure 3-b). High heterogeneity was observed among the studies ($Q(16) = 164.213$, $p < 0.01$; $I^2 = 90.26$). The results of a leave-one-out meta-analysis showed that CBT and ACT studies extracted from a single trial (Losada *et al.*, 2015) had a large impact on the overall effect size. If these two studies were excluded, the effect size for depression would decrease from 0.53 to 0.15. A fixed model was used to evaluate the efficacy of interventions on burden as heterogeneity was not significant. The pooled data revealed no significant effect on burden ($g = 0.09$; 95% CI = -0.03-0.21, $p = 0.14$; Figure 3-c).

Discussion

The current review found psychoeducation-skill building interventions to be an effective treatment for burden among dementia carers ($g = 0.18$). There was no significant heterogeneity among the studies suggesting that the observed effect sizes are likely to be robust. Results demonstrated no significant effect on depression and QoL which contradict the findings from the previous review (Pinquart and Sörensen, 2006). This may be due to the limited number of studies that reported targeted outcomes, and thus the results need to be interpreted with caution.

The largest effect sizes were found for CBT psychotherapeutic interventions (anxiety $g = 0.84$; depression $g = 0.53$). However, greater heterogeneity was evident in the included studies indicating that these effect sizes may not be robust. The overall effect size for anxiety was larger than the effect size demonstrated in the recent review (Vernooij-Dassen *et al.*, 2011). A major difference between the data reported here is the inclusion of a modern CBT approach (ACT). Unlike the previous review which evaluated the efficacy of standard CBT approaches, the current review included both *standard* and *modern* CBT approaches. The current review showed that the effect size for anxiety would decrease from 0.84 to 0.38 if the

study that utilised ACT (Losada *et al.*, 2015) was excluded from the sample. A recent review conducted by Collins and Kishita (2018) has also demonstrated that mindfulness- and acceptance-based interventions are acceptable and beneficial for informal carers of people with dementia. These suggest that ACT may be a useful alternative for dementia carers experiencing high levels of anxiety. However, the results of the current review need to be interpreted with caution as there was only one RCT which utilised ACT. Similar to the previous review (Vernooij-Dassen *et al.*, 2011), the effect size for burden was not significant.

The current study highlighted areas that have improved in the last 10 years and areas that still need improvement. First, the existing research on dementia carers is still largely focused on treating depression and burden and this trend has not changed substantially since earlier systematic reviews (Gallagher-Thompson and Coon, 2007; Pincart and Sørensen, 2006). Considering that anxiety disorders and anxiety symptoms may be the most common mental health problems among dementia family carers (Mahoney *et al.*, 2005; Ostojic *et al.*, 2014), current research may not reflect the needs of this group.

Second, QoL measures have been used more frequently in psychoeducation-skill building interventions compared to the early review (Pincart and Sørensen, 2006). In the current review, although the measure of burden was the most common outcome in this category, more than half of psychoeducational studies included a QoL measure. However, these studies used either the 12-Item Short Form Health Survey (Ware *et al.*, 1996) or the WHOQOL-BREF (Skevington *et al.*, 2004) to assess QoL of carers. In the area of care provision, such “health-related” or “generic” QoL measures (e.g., the assessment of mobility problems) may not be the most suitable to detect key areas of need for carers (Reed *et al.*, 2017). Instead, more recently developed specific measures of carer QoL such as the Carer Experience Scale (Al-Janabi *et al.*, 2008) and the Care Related Quality of Life (CarerQoL) (Brouwer *et al.*, 2006) (e.g., the assessment of activities outside caring, carer-recipient relationship) may be more appropriate as it can detect the broader impact of caring on a carers’ life (Jones *et al.*, 2012).

Recently, increased attention has been given to outcome measures that can assess positive experiences in dementia caregiving such as self-efficacy, resilience, and rewards in carer intervention studies. It is recommended that future prospective studies in any of the intervention categories to investigate the efficacy of interventions on anxiety and carer-specific QoL as well as positive experience outcomes. However, although there are some robust positive measures in existence for dementia carers, the quality of many scales may not be ideal due to lack of reporting of their psychometric properties (Stansfeld *et al.*, 2017). There is still work to be done to develop more high quality positive outcome measures for this population.

Third, the largest effect sizes were found for CBT based psychotherapeutic interventions, supporting previous findings (Elvish *et al.*, 2013; Piquart and Sørensen, 2006). In this category, the quality of treatment delivery was high across studies, all but one study used a treatment manual to train trainers and deliver the face-to-face intervention (90%), and clinical supervision was provided throughout the trial for 50% of studies that utilised the face-to-face approach (only 25% did so in the psychoeducation-skill building category). These factors may have contributed to the positive results.

The large effect size observed for anxiety was strongly influenced by one study that used ACT (Losada *et al.*, 2015). Over the last 25 years, mindfulness- and acceptance-based behavioural interventions have emerged as an evolution of the CBT tradition (Hayes *et al.*, 2004). Rather than addressing a specific symptom or disorder with an outcome-focused goal of symptom reduction, ACT aims to foster greater psychological flexibility in the face of challenges while optimising active engagement in one's own life (i.e., the end result is greater life satisfaction in the face of a wide variety of realistic challenges) (Dindo *et al.*, 2017). Future studies should examine the efficacy of modern CBT approaches such as ACT with dementia carers.

Interestingly, both CBT and ACT studies extracted from a single trial (Losada *et al.*, 2015) had a large impact on the overall effect size for depression. One possible contributing factor is that the protocol used in these two studies included the least number of intervention

components (i.e., CBT and communication training only or ACT only) while the majority of included studies used the combination of three or more components. More research is needed to explore whether simpler focused interventions with fewer components are more effective when using CBT with dementia carers.

Fourth, the majority of identified studies were conducted in Western and Southern Europe or the United States. Although there were a few studies that directly addressed the effects of ethnic background on the efficacy of interventions (Belle *et al.*, 2006; Gallagher-Thompson *et al.*, 2008), studies from Asian, African, and South American countries were scarce. Therefore, it is unclear how findings are generalizable across various culture as cultural beliefs play an important role, potentially, affecting the impact of interventions (Losada *et al.*, 2006; Montoro-Rodriguez and Gallagher-Thompson, 2009). This may be partly due to the fact that we limited our search to studies published in English. Therefore, the conclusion has to be drawn with greater caution.

On a related note, the majority of studies recruited carers of people with Alzheimer's disease or dementia in general. It has been found that frontotemporal dementia can lead to greater carer burden and depression than Alzheimer's disease (Mioshi *et al.*, 2009; Nunnemann *et al.*, 2012), and lack of support is more concerning for these carers especially when behavioural symptoms are severe (Gorno-Tempini *et al.*, 2011; Rascovsky *et al.*, 2011). The question remains whether observed positive effects can be generalised to carers of people with other types of dementias. These gaps in literature have not changed significantly over the last 10 years.

Finally, the current review included both face-to-face and technology driven interventions. To accommodate the expected increased needs for the future, developing and maximising the use of technology enabled care seems critically important. In the current review, the mode of delivery did not seem to affect the efficacy of interventions on emotional wellbeing. However, the average attrition rate of psychoeducation-skill building interventions was higher for the technology driven programmes (23%) compared to the face-to-face programmes (8.7%). This indicates that psychoeducation-skill building interventions may be

more acceptable when delivered face-to-face over the short period (i.e., six or fewer sessions). Unlike psychoeducation-skill building interventions, the average attrition rate of CBT based interventions was relatively similar between two delivery modes (face-to-face 21.1%, technology 22.6%).

The current study has some methodological limitations. We did not contact the research team for missing information except for the data needed to calculate effect sizes. The main characteristics of studies were fully reported in the majority of studies as summarised in Table 1 and 2. Some or all study characteristics related to adherence to treatment (e.g., assessment of treatment integrity, and supervision during the trial) were not reported in 77% of the studies. This raises questions regarding the quality of treatment used in identified studies. A literature search was conducted using four major electronic databases and no hand search was performed, which could have resulted in missing some relevant papers. Study quality was not assessed using a standardised tool, and only key potential moderator variables (e.g., randomisation methods, type of data analysis, treatment adherence and attrition rate) were evaluated.

Conclusion

Despite some methodological limitations, the updated evidence suggests that psychoeducation-skill building interventions delivered face-to-face can better impact on burden. Psychotherapeutic interventions underpinned by CBT models seem to demonstrate strong empirical support for treating anxiety and depression and these effects seem not to be affected by the mode of delivery. A modern CBT approach (ACT) may be particularly beneficial for carers experiencing high levels of anxiety. Future research needs to explore (i) the efficacy of interventions on multiple clinical outcomes including anxiety, carer-specific QoL, and positive experiences, (ii) which combination of intervention components would have the most significant effects when using CBT, (iii) the efficacy of a modern CBT approach (ACT), and (iv) the generalisation of treatment effects in different countries and carers of different types of dementia.

Conflict of interest declaration

None

Description of authors' roles

N. Kishita was principal investigator for the study. N. Kishita designed the study and developed the search protocol. N. Kishita, L. Hammond, and C. Dietrich carried out screening, selection, and data extraction. N. Kishita wrote the first draft of the article, and L. Hammond and E. Mioshi contributed to the interpretation of results and refining of the paper. All authors have seen and approved the final draft.

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Figure Captions

Figure 1. Flow chart of the selection of studies of dementia carer interventions. Note. QoL = quality of life

Figure 2. Effect sizes (Hedge's g) derived from studies examining the efficacy of psychoeducational skill building interventions — a) Depression, b) Burden, and c) Quality of life

Figure 3. Effect sizes (Hedge's g) derived from studies examining the efficacy of CBT—a) Anxiety, b) Depression, and c) Burden

Supplementary Material Captions

Supplementary Table 1. The contents of interventions employed in excluded studies

Supplementary Table 2. The contents of psychoeducational-skill building interventions

Supplementary Table 3. Additional study characteristics of included studies

Table 1. Psychoeducational-skill building interventions

First author, year	Country	Dementia type of care-recipient	Format of therapy	Length of each session (min)	No of sessions	Trainers	Self-report outcomes (Standardised measures)
Face-to-face psychoeducational-skill building interventions							
Chen, 2015	Taiwan	Dementia (AD 66.7%, VD 32.6%)	Individual	–	6	Research nurses	Burden (CBI)
Chien, 2011	Hong Kong	AD	Individual	120	10	Case managers, experienced family caregivers	Burden (CBI) QoL (WHOQoL-BREF)
Gaugler, 2015	US	Dementia (People with dementia in long term care)	Individual	60-120	6	Transition counsellors	Depression (CESD, GDS) Burden (ZBI)
Gavrilova, 2009	Russia	Dementia	Individual	30	5	Newly qualified doctors	Burden (ZBI) QoL (WHOQoL-BREF)
Gitlin, 2010	US	Dementia	Individual	–	11 ^{b)}	OTs and nurse	Depression (CESD) Burden (ZBI)
Guerra, 2011	Peru	Dementia	Individual	30	5	Junior psychologists and social workers	Burden (ZBI) QoL (WHOQoL-BREF)
Joling, 2012	Netherlands	Dementia (AD 57.3%)	Individual	73 ^{a)}	6	Counsellors with an advanced degree in nursing, social work, psychology or an allied profession	Anxiety (HADS-A) Depression (CESD) QoL (SF-12)
Pahlavanzadeh, 2010	Iran	Dementia	Group	90	5	–	Burden (ZBI)
de Rotrou, 2011	France	AD	Group	120	12	Psychologists	Depression (MADRS) Burden (ZBI)
Sepe-Monti, 2016	Italy	AD	Group	120	6	Psychologists	Anxiety (STAI-Y) Depression (CESD) Burden (CBI) QoL (SF-12)
Wang, 2011	Hong Kong	AD	Group	120	8	Psychiatric nurse, experienced family caregivers	Burden (CBI) QoL (WHOQoL-BREF)

Wang, 2012	China	Dementia (Mainly AD)	Group	90	12	Psychiatric nurse (group leader) and co-group leaders (qualification not known)	QoL (WHOQoL-BREF)
Technology based psychoeducational-skill building interventions							
Cristancho-Lacroix, 2015	France	AD	Internet (Individual)	15-30	12	(No therapist-participant interactions)	Depression (BDI) Burden (ZBI)
Liddle, 2012	Australia	Dementia (AD 41.4%, VD 13.8%, FTD 6.9%)	DVD (Individual)	45	2	Researchers with either psychology or speech pathology qualifications monitored how the training was received, encouraged discussion, answered questions regarding the DVD training.	Burden (ZBI)
Martindale-Adams, 2013	US	Dementia	Telephone (Group)	14h in total	15	Master's-prepared group leaders	Depression (CESD) Burden (ZBI) QoL (GWS)
Tremont, 2008	US	Dementia	Telephone (Individual)	15-30 ^{a)}	23	Master's level therapists	Depression (GDS) Burden (ZBI)

Note. AD = Alzheimer's disease, VD = Vascular dementia, OT = occupational therapist, QoL = quality of life, Y = Yes. Measures: BDI = Beck Depression Inventory II, CBI = Caregiver Burden Inventory, CESD = The Center for Epidemiologic Studies-Depression scale, GDS = Geriatric Depression Scale, GWS = General Well-Being Scale, HADS-A = Hospital Anxiety and Depression Scale-Anxiety subscale, MADRS = Montgomery and Asberg Depression Rating Scale, SF-12 = The 12-Item Short Form Health Survey, STAI-Y = The State-Trait Anxiety Inventory Self-Evaluation Questionnaire, Form Y, WHOQoL-BREF = The World Health Organization Quality of Life Scale-BREF, ZBI = Zarit Burden Interview.

- a) The length of each session was 74 minutes on average (range 47-105 min).
- b) The treatment consisted of nine OT session, two nursing sessions (one delivered at home and one over the phone), and three brief OT telephone contacts during the maintenance phase.
- c) 12h of contact in total (Initial contacts lasted approximately 60 minutes and follow-up contacts lasted about 15–30 minutes)

Table 2. CBT based psychotherapeutic interventions

First author, year	Country	Dementia type of care-recipient	Main treatment components	Format of therapy	Length of each session (min)	No of sessions	Trainers	Self-report outcomes (Standardised measures)
<i>Face-to-face interventions informed by standard CBT</i>								
Au, 2010	Hong Kong	AD	Information CBT Communication Behaviour management	Group	120	13	Clinical psychologists-in-training	Depression (CESD)
Belle, 2006	US	Dementia	Information CBT Communication Behaviour management	Individual + Group	30-90 ^{a)}	17 ^{a)}	Certified interventionists with at least a bachelor's degree	Depression (CESD) Burden (ZBI)
Gallagher-Thompson, 2008	US	Dementia	Information CBT Communication Behaviour management	Group	120	13	Postdoctoral fellows and advanced graduate students in psychology or related fields	Depression (CESD)
Livingston, 2013	UK	Dementia	Information CBT Communication Behaviour management	Individual	–	8	Psychology graduates with no clinical training	Anxiety (HADS-A) Depression (HADS-D) Burden (ZBI)
Losada, 2011	Spain	Dementia	Information CBT Communication Promoting exercises in People with dementia	Group	90-120	12	Psychologists (group leader) and OT (co-therapist)	Depression (CESD)
Losada, 2015	Spain	Dementia (AD 75.8%)	CBT Communication	Individual	90	8	Master's or doctoral level clinical psychologists trained in CBT	Anxiety (POMS) Depression (CESD)
Márquez-González, 2007	Spain	Dementia	CBT Communication	Group	120	8	Psychologists	Depression (CESD)
Martín-Carrasco, 2009	Spain	AD	Information CBT Behaviour management	Individual	90	8	Clinical psychologist, nurse or social worker	Anxiety (GHQ28) Depression (GHQ28) Burden (ZBI) QoL (SF-36)

Martín-Carrasco, 2014	Spain	Dementia (AD 53.8%, VD 14.7%)	Information CBT Behaviour management	Group	90-120	7	–	Anxiety (GHQ28) Depression (GHQ28) Burden (ZBI) QoL (SF-12)
Face-to-face interventions informed by third wave CBT								
Losada, 2015	Spain	Dementia (AD 74.5%)	Acceptance and commitment therapy (ACT)	Individual	90	8	Master's or doctoral level clinical psychologists trained in ACT	Anxiety (POMS) Depression (CESD)
Technology based CBT interventions								
Blom, 2015	Netherlands	Dementia (AD 73.5%)	Information CBT Communication Behaviour management	Internet (Individual)	–	9 ^{b)}	Psychologist trained in CBT monitored the progress of participants, evaluated the homework, and provided electronic feedback.	Anxiety (HADS-A) Depression (CESD)
Finkel, 2007	US	Dementia (AD 94%, VD 4%)	Information CBT Communication Behaviour management	Computer phone system ^{d)} (Individual + Group)	–	14 ^{c)}	Clinical social workers (the role of therapists not known)	Depression (CESD)
Gallagher-Thompson, 2010	US	Dementia	Information CBT Communication Behaviour management	DVD (Individual)	2.5h in total	NA	(No therapist-participant interactions)	Depression (CESD)
Glueckauf, 2007	US	Dementia (AD 57.1% VD 42.9%)	Information CBT Communication	Telephone (Individual + Group)	45-60 ^{d)}	12 ^{d)}	Trained doctoral or master's-level counsellor	Depression (CESD) Burden (CAI)
Kwok, 2013	Hong Kong	Dementia	Information CBT Communication Behaviour management	Telephone (Individual)	30	12	Social workers	Burden (ZBI)

Note. AD = Alzheimer's disease, VD = Vascular dementia, Information = Interventions aimed at increasing carers' knowledge, CBT = Interventions based on cognitive and behavioural principles aimed at reducing caregiver psychological difficulties, Communication = Interventions aimed at teaching carers to improve their communication skills (e.g., learning to ask for help from others), Behaviour management = Interventions aimed at teaching carers to manage behavioural changes of the care recipient, OT = occupational therapist, QoL = quality of life, Y = Yes. Measures: CAI = Caregiver Appraisal Inventory, CESD = The Center for Epidemiologic Studies-Depression scale, GHQ28=General Health Questionnaire-2, HADS-A = Hospital Anxiety and Depression Scale-Anxiety subscale, HADS-D = Hospital Anxiety and Depression Scale-Depression subscale, POMS = The

Tension-Anxiety subscale from the Profile of Mood States, SF-12 = The 12-Item Short Form Health Survey SF-36 = The 36-Item Short Form Health Survey, ZBI = Zarit Burden Interview.

- a) The treatment consisted of nine 90-min in home sessions, three 30-min telephone individual sessions, and five telephone group sessions (the length of groups were not specified).
- b) The treatment consisted of eight sessions and one booster session.
- c) The treatment consisted of 2 in-home sessions and 12 sessions over the computer-telephone system.
- d) 7 x 45 min group session, 5 x 1h individual sessions

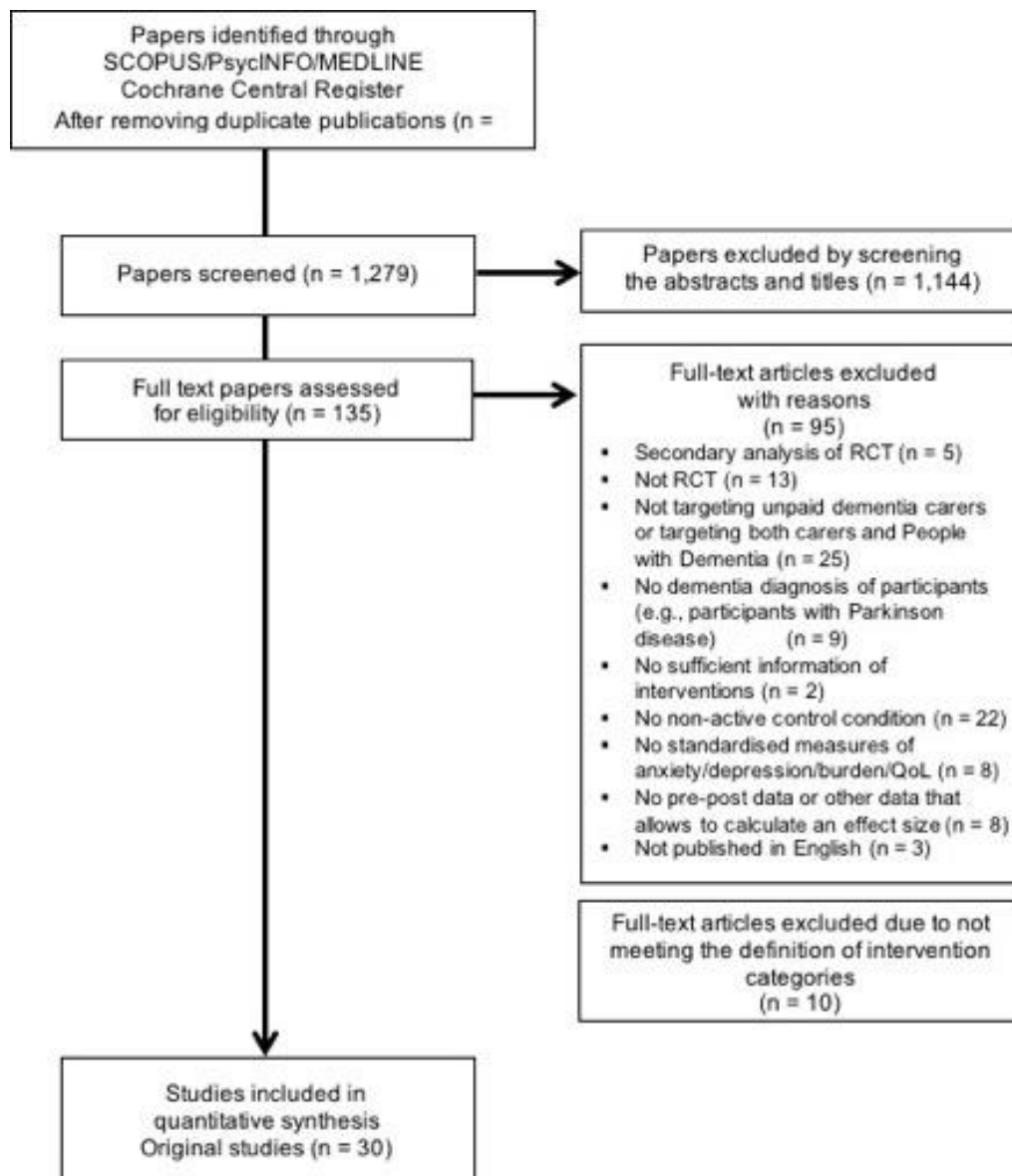


Figure 1

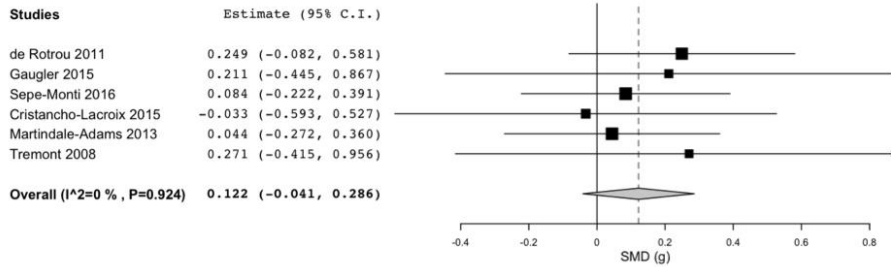


Figure 2- a Depression

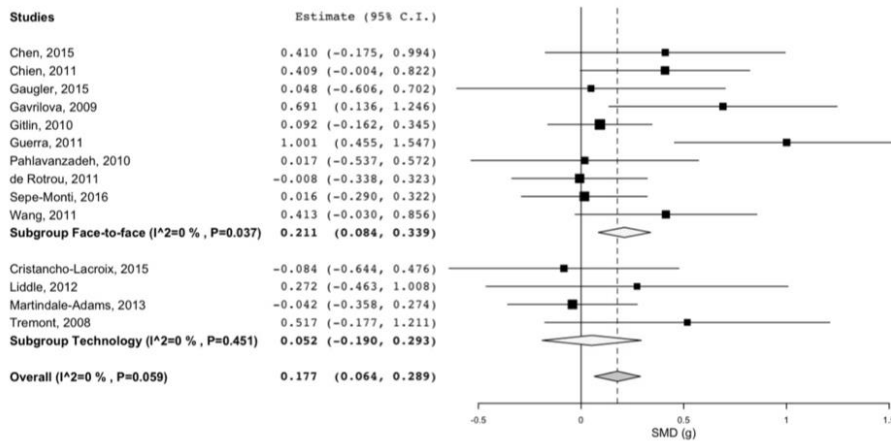


Figure 2- b Burden

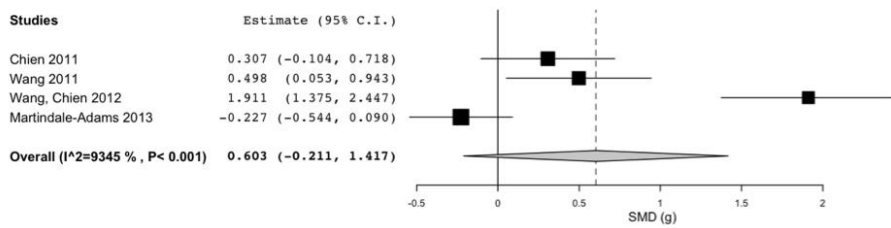


Figure 2- c Quality of life

Figure 2

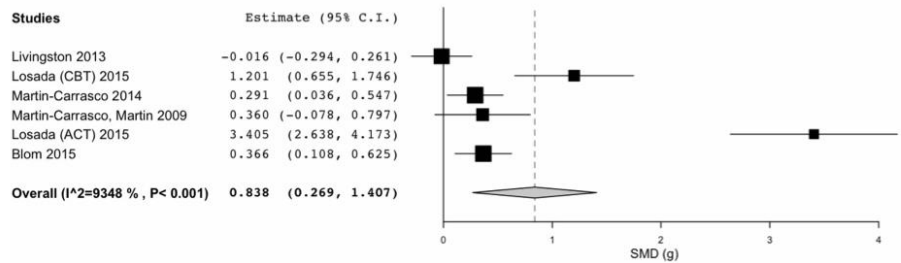


Figure 3- a Anxiety

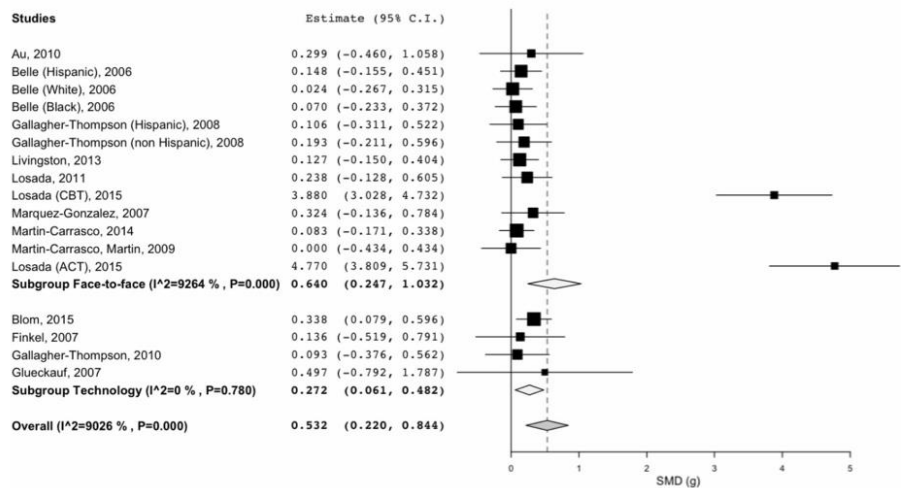


Figure 3- b Depression

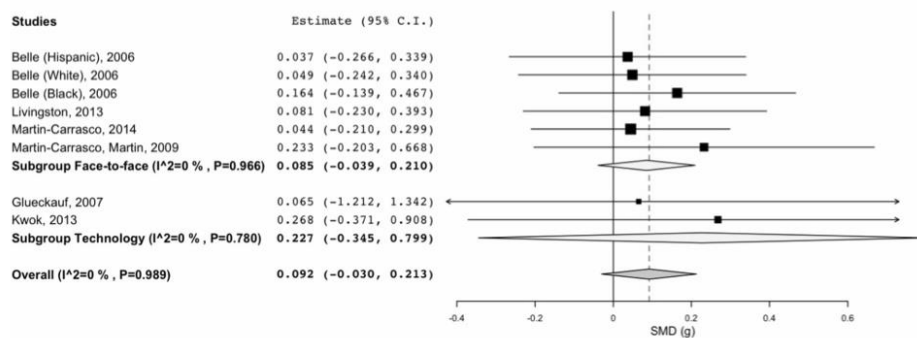


Figure 3- c Burden

Figure 3