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A systematic review and meta-analysis comparing carer focussed and dyadic multicomponent interventions for carers of people with dementia

Introduction

Most people with dementia live in their own homes and rely on assistance to manage activities of daily living (ADL) from family and friends (carers) (Australian Institute of Health and Welfare, 2012; National Alliance for Caregiving, 2009). Assistance is commonly required to support personal ADLs (e.g., washing, dressing, grooming, toileting, eating) and instrumental ADLs (e.g, cooking, shopping and managing finances and healthcare) as well as providing general surveillance to ensure the safety and wellbeing of the person with dementia (Alzheimer's Disease International, 2009). A review of studies that provided information on caregiving reported that carers spent an average of 3.7 hours per day assisting with ADLs and additional time spent providing supervision (Wimo, Winblad, & Jonsson, 2007). Although caring for someone with dementia can be rewarding, it is also challenging (Thompson, 2013) and associated with high levels of burden (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014), depression (Clare et al., 2002) and reduced quality of life (Argimon, Limon, Vila, Cabezas, 2004). Carers have reported that they want more education, skills counselling, emotional support and respite to help them in their caring role (Black et al., 2013; Hughes et al., 2014). There are now many trials demonstrating the efficacy of nonpharmacological interventions where the interventionist predominantly works with the carer with the aim of supporting them to provide care and cope more effectively (Brodaty & Arasaratnam, 2012; Elvish, Lever, Johnstone, Cawley, & Keady, 2013; Gallagher-Thompson et al., 2012; Jones, Edwards, & Hounsome, 2012; Kales, Gitlin, & Lyketsos, 2015; Maslow, 2012; Olazaran et al., 2010; Schoenmakers, Buntinx, & DeLepeleire, 2010; Van't Leven et al., 2013). Interventions for carers are often multicomponent and tend to involve a

combination of education, support, problem solving and skills training (Kales et al., 2015).

Although carer interventions are widely considered to be effective, studies are heterogeneous and involve different participant groups, interventions, comparison conditions and outcomes.

This leads to difficulty in interpreting the evidence and ascertaining which interventions are most effective and should be translated into clinical practice.

One of the distinctions between caregiver intervention programs is whether they work with the person with dementia and carer (dyad) or whether they focus the intervention on the carer alone. A number of the interventions that have been tested are considered dyadic interventions (Van't Leven et al., 2013). Dyadic interventions may include joint counselling, problem solving and use of strategies to try and increase independence in activities of daily living and engagement in meaningful activities. Working with the dyad is thought to be more effective because of the synergistic relationship between the person with dementia and the caregiver. Existing systematic reviews have examined the effect of one type of carer intervention or the effect of carer interventions more broadly on a single outcome (Brodaty & Arasaratnam, 2012; Kales et al., 2015; Maslow, 2012).

The aim of this paper was to examine the efficacy of carer interventions that involve multiple components (e.g., education, problem solving, skills building, support) and compare effects based on whether or not they were dyadic in nature.

Methods

Background to the review

This review stemmed from work that was completed in the development of clinical practice guidelines for dementia in Australia (Guideline Adaptation Committee, 2016). Clinical practice guidelines should include the most recent literature and be developed in a way that is timely and resource efficient while maintaining methodological quality of the systematic reviews (World Health Organisation, 2012). In order to manage this, guidelines typically use

existing systematic reviews as a source of primary studies and update these reviews with more recent studies where required (Woolf, Schunemann, Eccles, Grimshaw, & Shekelle, 2012). As a component of guideline development we conducted a systematic review of the efficacy of interventions for carers of people with dementia in comparison to usual care. We identified the most recent, comprehensive, high quality systematic review and used this as a source of primary studies (Olazaran et al., 2010). We then updated this by identifying any newer studies meeting the inclusion criteria and combined all results to present an overall measure of efficacy. This work is available in the Guideline Technical Report (Guideline Adaptation Committee, 2016). Subsequent to development of the guideline, we have examined the effectiveness of multicomponent interventions that were dyadic in nature in comparison to those that were not. We have updated the searches conducted during the guideline development work, included new studies, completed additional data extraction and conducted novel meta-analyses.

Inclusion criteria

We included randomised controlled trials published in English. Participants in the included studies were carers of people with any type of dementia. Multicomponent interventions were defined as those that involved a number of different intervention techniques. These interventions techniques included, but were not limited to, education, counselling, information regarding services, enhancing carer skills to provide care, problem solving and strategy development and increasing resilience and coping skills in the carer. Interventions that were conducted with the carer alone or those that also involved the person with dementia (dyad) were included. Studies were required to compare the intervention to usual care. We also searched for studies that directly compared carer focussed with dyadic interventions. The outcomes included were those measuring direct impact for the carer (depression, quality of life and carer burden and caregiver upset in relation to behavioural and psychological

symptoms of dementia) and the person with dementia (activities of daily living function, behavioural and psychological symptoms of dementia).

Search methods

We identified the most recent and comprehensive high quality systematic review. The review was updated by searching for additional randomised controlled trials published after September 2008. Databases searched were Health Technology Assessment, the Cochrane Library (Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects), Medline, EMBASE, PsycINFO and PubMed using terms including: Alzheimer's, dementia, caregiver, carer, family, assess, treatment, therapy, intervention, support, psychosocial, nonpharmacologic, education (see Appendix 1 for full search strategy). Searches for the guideline were conducted on 9th of May 2014 and updated on the 7th of October 2015.

Data collection and analysis

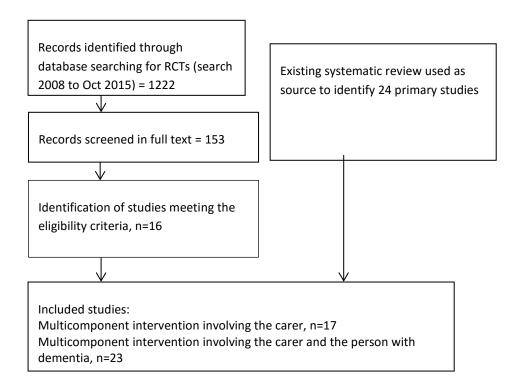
One review author (KL) ran the searches and reviewed titles and abstracts to select articles for full text review. Two authors (KL and RM) conducted full text review to determine which studies met the criteria for inclusion in the review. One author (KL) extracted data into the tables and into RevMan version 5.2 for analysis and a second person checked the data extraction accuracy. Two authors (KL and RM) independently completed an assessment of risk of bias using the Cochrane Collaboration Risk of Bias tool (Higgins & Green, 2011). This included assessment of: (1) Random sequence generation, (2) Allocation concealment, (3) Blinding of participants and personnel, (4) Blinding of outcome assessment, (5) Incomplete outcome data, (6) Selective reporting. Items were classified as being 'low risk', 'high risk' or 'unclear risk of bias'. We did not contact authors to obtain missing information regarding study data or methods.

Study outcomes were pooled in a meta-analysis in RevMan version 5.2 when means and standard deviations were reported or could be calculated. Where authors did not report means and standard deviations (or these could not be calculated based on the data provided) studies were described narratively. A random effects model was used for pooling all outcomes due to statistical heterogeneity ($I^2 \ge 50$) and obvious heterogeneity observed on forest plot. Where it was not possible to pool data for an outcome (due to data not presented in an appropriate form for use in meta-analysis) the study results were synthesized in a narrative summary.

Results

The study selection process is presented in Figure 1.

Figure 1: Search for studies



The most recent high quality systematic review was conducted by Olazaran and colleagues in 2010 (Olazaran et al., 2010). This review included all forms of carer interventions and did not exclude studies based on outcomes reported. The review included six multicomponent

interventions involving the carer and 18 multicomponent interventions involving the carer and the person with dementia. The review included studies published to 2008.

We searched for additional studies published from 2008 to October 2015; 11 studies of multicomponent interventions involving only the carer and five multicomponent dyad interventions were identified. Thus, the total number of studies included in the review was 40. We did not identify any studies that compared carer focussed interventions with dyadic interventions. Characteristics of included studies are summarised in Table 2.

Summary of included studies

The characteristics of carers were similar across all studies. Studies typically recruited more females than males; in most studies approximately two thirds of the caregivers were female. Caregivers were typically aged in their 60s and 70s. The severity of symptoms in people with dementia varied widely across studies although most participants had mild to moderate dementia as indicated by Mini-Mental State Examination scores. A summary of the different interventions provided, the follow-up time for the studies and the outcomes contributing to this review is shown in Table 2. In the dyadic interventions, the person with dementia was involved in various activities including: education about dementia, joint problem solving, joint counselling, cognitive stimulation, engagement in pleasant activities, modification of the environment or tasks, peer support and general case management duties.

Methodological quality of the included studies

Overall, the quality of included studies was considered moderate as presented in Table 2. Due to unclear reporting it was often difficult to determine methods of randomisation and allocation concealment. Few studies had published protocols or were registered on clinical trial registries making it difficult to determine the presence of selective reporting. Four studies appeared to use outcome assessors who were not blinded to allocation and in a further 16 studies it was unclear as to whether the outcome assessor was aware of allocation.

Impact on the carer's depressive symptoms

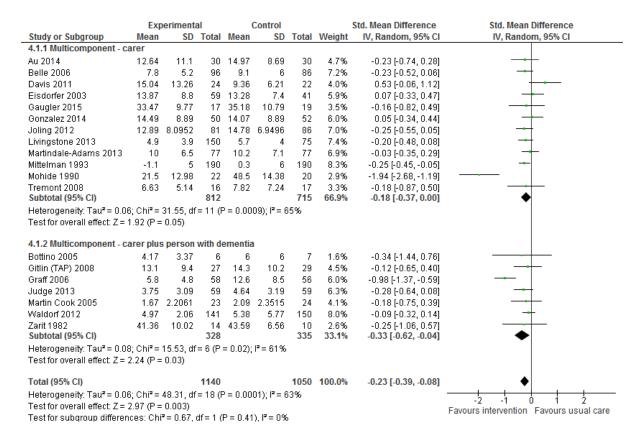
Carer only interventions

Multicomponent interventions involving only the carer tended to reduce depressive symptoms although this was of borderline statistical significance (SMD -0.18, 95%CI -0.37 to 0.00, 12 trials, N=1527 participants). Two studies could not be included in the meta-analysis; one of these studies reported no effect on depression following treatment (Finkel et al., 2007) whereas the other study reported that carers receiving the intervention had decreased risk of depression (odds ratio =0.15, confidence interval 0.04 to 0.65, p<0.013) (Kuo et al., 2013).

Dyadic interventions

Multicomponent interventions involving both the carer and the person with dementia significantly reduced depressive symptoms (Figure 2, SMD -0.33, 95%CI -0.62 to -0.04; 7 studies, N=663). Four studies did not provide data that could be included in the meta-analysis. One of these studies reported no significant effect associated with intervention (Chu, Edwards, Levin, & Thompson, 2000) whereas the other three studies reported a statistically significant improvement in depressive symptoms as a result of the intervention. Buckwalter and colleagues found that those in the intervention group were significantly less depressed than caregivers receiving usual care at 6 months (p=0.0007), but outcome at 12 months did not reach statistical significance (Buckwalter et al., 1999). Two other studies reported an improvement in depressive symptoms as a result of the intervention (Gitlin. Winter, Dennis, Hodgson, & Hauck, 2010; Logsdon et al., 2010), with Gitlin and colleagues reporting that 53% of carers in the intervention group reported depressive symptoms versus 68% in the control group (p=0.02). There was no statistically significant difference between carer only interventions and dyadic interventions (p=0.41).

Figure 2. Multicomponent intervention versus usual care: effect on depression post intervention



Impact on the carer's quality of life

Carer only interventions

Although the overall effect on quality of life was not statistically significant, there was a trend in favour of intervention (SMD 0.14, 95%CI -0.06 to 0.34, three studies, N=412). One study that did not report data suitable for contributing to the meta-analysis found no significant improvements in quality of life of carers post intervention (Davis, Tremont, Bishop, & Fortinsky, 2011).

Dyadic interventions

Analysis revealed a trend towards improved quality of life associated with intervention (Figure 3); however, the confidence intervals were wide and the effect was not statistically significant (SMD 0.32, 95%CI -0.04 to 0.68, four studies, N=589). A study conducted by Logsdon and colleagues could not be included in the analysis; this study found no significant differences between treatment and control groups in quality of life (Logsdon et al., 2010).

When considering all multicomponent interventions (carer only plus dyadic), the analysis demonstrated an overall positive effect (SMD 0.24, 95%CI 0.04 to 0.44). There was no statistically significant difference between carer only interventions and dyadic interventions (p=0.39).

Std. Mean Difference Experimental Control Std. Mean Difference IV, Random, 95% CI Study or Subgroup Mean SD Total Mean SD Total Weight IV, Random, 95% CI 4.2.1 Multicomponent - carer Joling 2012 88.71 18.2708 81 86.96 17.5373 16.7% 0.10 [-0.21, 0.40] 86 Livingstone 2013 6.5 137 5.8 คค 17.1% 0.14 [-0.15, 0.44] 30.7 29.8 Mohide 1990 22 0.41 20 7.7% 0.29 [-0.32, 0.90] Subtotal (95% CI) 240 172 41.4% 0.14 [-0.06, 0.34] Heterogeneity: $Tau^2 = 0.00$; $Chi^2 = 0.31$, df = 2 (P = 0.85); $I^2 = 0\%$ Test for overall effect: Z = 1.37 (P = 0.17) 4.2.2 Multicomponent - carer plus person with dementia Chien 2008 75.1 16.8 44 69.8 16.7 44 12.3% 0.31 [-0.11, 0.73] Chien 2011 80.4 15 46 65.2 17.5 46 12.0% 0.92 [0.49, 1.36] Judge 2013 10.92 3.04 59 10.69 3.4 59 14.4% 0.07 [-0.29, 0.43] Waldorf 2012 141 150 20.0% 0.07 [-0.16, 0.30] 81.6 16.4 80.3 18.2 Subtotal (95% CI) 58.6% 0.32 [-0.04, 0.68] 290 299 Heterogeneity: $Tau^2 = 0.10$; $Chi^2 = 12.64$, df = 3 (P = 0.005); $I^2 = 76\%$ Test for overall effect: Z = 1.75 (P = 0.08) Total (95% CI) 471 100.0% 0.24 [0.04, 0.44]

-0.5 -0.25

Favours usual care Favours intervention

Figure 3. Multicomponent interventions versus usual care: effect on quality of life post intervention

Impact on level of carer burden

Test for overall effect: Z = 2.33 (P = 0.02)

Heterogeneity: $Tau^2 = 0.04$; $Chi^2 = 13.45$, df = 6 (P = 0.04); $I^2 = 55\%$

Test for subgroup differences: $Chi^2 = 0.75$, df = 1 (P = 0.39), $I^2 = 0\%$

Carer only interventions

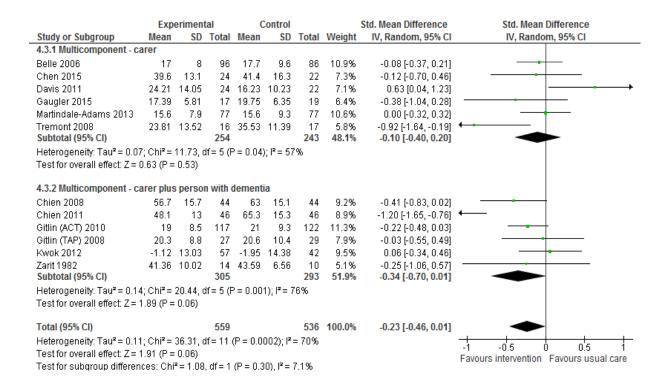
The analysis found there was no significant effect on carer burden (Figure 4, SMD -0.10, 95%CI -0.40 to 0.20, six studies, N=497). A study conducted by Logsdon and colleagues which could not be included in the analysis similarly found no significant reduction in levels of burden (Logsdon et al., 2010).

Dyadic interventions

Six studies were pooled to examine the efficacy of dyadic training on carer burden. The result was statistically not significant due to wide confidence intervals. However, there was a strong trend suggesting efficacy of intervention (SMD -0.34, 95%CI -0.70 to 0.01, six studies, N=598). One study that could not be included in the analysis found that following

intervention there was a significant reduction in carer burden in the intervention group relative to those in the control group. However, at six months there were no differences between groups (Chu et al., 2000). There was no statistically significant difference between carer only interventions and dyadic interventions (p=0.30).

Figure 4. Multicomponent interventions versus usual care: effect on carer burden post intervention



Impact on behavioural and psychological symptoms of dementia

Carer only interventions

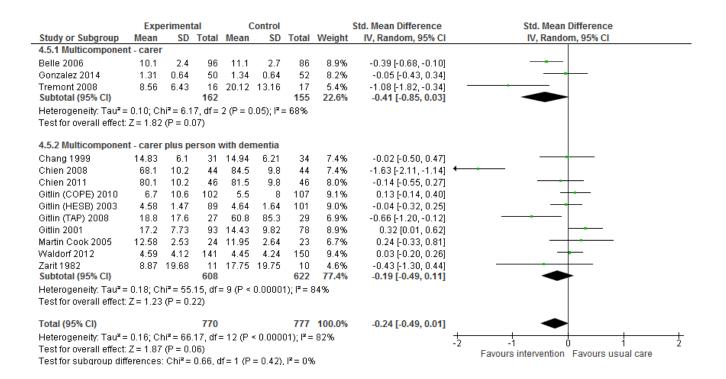
We pooled three studies evaluating the effects of intervention on behavioural and psychological symptoms of dementia measured using a tool such as the Neuropsychiatric Inventory or the Revised Memory and Behaviour Problem Checklist (Figure 5). Overall, the effect was not significant although the analysis suggested positive effects on intervention (SMD -0.41, 95%CI -0.85 to 0.03, three studies, N=317).

Dyadic interventions

We also found that dyadic interventions appeared to be beneficial. However, the results were statistically not significant (SMD -0.19, 95%CI -0.49 to 0.11, ten studies, N=1230).

Overall, the meta-analysis suggested a reduction in behavioural and psychological symptoms of dementia (SMD -0.24, 95%CI -0.49 to 0.01). There was no statistically significant difference between carer only interventions and dyadic interventions (p=0.42).

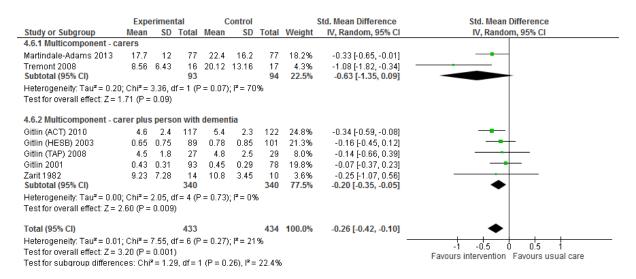
Figure 5. Multicomponent interventions versus usual care: effect on behavioural and psychological symptoms of dementia post intervention



Impact on caregiver upset with behavioural and psychological symptoms of dementia

Fewer studies examined caregiver reaction or upset with symptoms. Overall, we found that multicomponent interventions were effective in reducing caregiver reaction or upset (Figure 6, SMD -0.26, 95%CI -0.42 to -0.10, 7 studies, 867 participants). The statistical heterogeneity in the analysis was lower than in the other analyses ($I^2=21\%$).

Figure 6. Multicomponent interventions versus usual care: effect on caregiver upset with behavioural and psychological symptoms of dementia post intervention



Impact on independence in activities of daily living

Nine studies reported outcomes for activities of daily living in the person with dementia, of which eight of these studies were dyadic in nature. Overall, the effect was not significant although the direction of effect was positive (Figure 7, SMD 0.17, 95%CI -0.15 to 0.57, N=1465).

Figure 7. Multicomponent interventions versus usual care: effect on activities of daily living post intervention

Study or Subgroup Mean SD Total Mean SD Total Weight IV, Random, 95% Cl IV, Random, 95% Cl		Ex	perimenta	ı		Control			Std. Mean Difference	Std. Mean Difference
Belle 2006 3.5 2 86 3.7 2.3 86 12.4% -0.09 [-0.39, 0.21] Subtotal (95% CI) 86 12.4% -0.09 [-0.39, 0.21] Heterogeneity: Not applicable Test for overall effect: Z = 0.61 (P = 0.54) 4.4.2 Multicomponent - carer plus person with dementia Bottino 2005 10.83 2.71 6 10.57 2.43 7 5.3% 0.09 [-1.00, 1.19] Chang 1999 19.2 8.17 34 19.72 8.41 31 10.5% -0.06 [-0.55, 0.42] Gitlin (COPE) 2010 3.7 1.3 102 3.3 1.3 107 12.7% 0.31 [0.03, 0.58] Gitlin (HESB) 2003 3.67 1.72 89 3.75 1.89 101 12.5% -0.04 [-0.33, 0.24] Gitlin 2001 3.24 1.59 93 3.57 1.38 78 12.4% -0.22 [-0.52, 0.08] Graff 2006 1.2 0.7 68 0.2 0.8 67 11.7% 1.32 [0.95, 1.70] Martin Cook 2005 39.08 15.6277 24 31.05 15.9701 23 9.5% 0.50 [-0.08, 1.08] Waldorf 2012 58 13.4 141 60.5 13.5 15.0 13.0% -0.19 [-0.42, 0.05] Subtotal (95% CI) 557 564 87.6% 0.21 [-0.15, 0.57] Heterogeneity: Tau* = 0.22; Chi* = 56.74, df = 7 (P < 0.00001); i* = 88% Test for overall effect: Z = 1.13 (P = 0.26) Total (95% CI) 643 650 100.0% 0.17 [-0.15, 0.49] Heterogeneity: Tau* = 0.19; Chi* = 58.40, df = 8 (P < 0.00001); i* = 86% Test for overall effect: Z = 1.06 (P = 0.29)	Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI	IV, Random, 95% CI
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Graff 2006 1.2 0.7 68 0.2 0.8 67 11.7% 1.32 [0.95, 1.70]	Gitlin (HESB) 2003	3.67	1.72	89	3.75	1.89	101	12.5%	-0.04 [-0.33, 0.24]	
Martin Cook 2005 39.08 15.6277 24 31.05 15.9701 23 9.5% 0.50 [-0.08, 1.08]	Gitlin 2001	3.24	1.59	93	3.57	1.38	78	12.4%	-0.22 [-0.52, 0.08]	
Waldorf 2012 58 13.4 141 60.5 13.5 150 13.0% -0.19 [-0.42, 0.05] Subtotal (95% CI) 557 564 87.6% 0.21 [-0.15, 0.57] Heterogeneity: Tau² = 0.22; Chi² = 56.74, df = 7 (P < 0.00001); I² = 88% Test for overall effect: Z = 1.13 (P = 0.26) Total (95% CI) 643 650 100.0% 0.17 [-0.15, 0.49] Heterogeneity: Tau² = 0.19; Chi² = 58.40, df = 8 (P < 0.00001); I² = 86% Test for overall effect: Z = 1.06 (P = 0.29)	Graff 2006	1.2	0.7	68	0.2	0.8	67	11.7%	1.32 [0.95, 1.70]	→
Subtotal (95% CI) 557 564 87.6% 0.21 [-0.15, 0.57] Heterogeneity: Tau² = 0.22; Chi² = 56.74, df = 7 (P < 0.00001); i² = 88% Test for overall effect: Z = 1.13 (P = 0.26) Total (95% CI) 643 650 100.0% 0.17 [-0.15, 0.49] Heterogeneity: Tau² = 0.19; Chi² = 58.40, df = 8 (P < 0.00001); i² = 86% Test for overall effect: Z = 1.06 (P = 0.29) Test for overall effect: Z = 1.06 (P = 0.29)	Martin Cook 2005	39.08	15.6277	24	31.05	15.9701	23	9.5%	0.50 [-0.08, 1.08]	+
Heterogeneity: Tau² = 0.22; Chi² = 56.74, df = 7 (P < 0.00001); I² = 88% Test for overall effect: Z = 1.13 (P = 0.26) Total (95% CI) 643 650 100.0% 0.17 [-0.15, 0.49] Heterogeneity: Tau² = 0.19; Chi² = 58.40, df = 8 (P < 0.00001); I² = 86% Test for overall effect: Z = 1.06 (P = 0.29) O.17 [-0.15, 0.49] -1 -0.5 0 0.5 1 Favours usual care Favours intervention	Waldorf 2012	58	13.4		60.5	13.5	150			
Test for overall effect: Z = 1.13 (P = 0.26) Total (95% CI) 643 650 100.0% 0.17 [-0.15, 0.49] Heterogeneity: Tau² = 0.19; Chi² = 58.40, df = 8 (P < 0.00001); i² = 86% Test for overall effect: Z = 1.06 (P = 0.29) Test for overall effect: Z = 1.06 (P = 0.29)	Subtotal (95% CI)			557			564	87.6%	0.21 [-0.15, 0.57]	
Total (95% CI) 643 650 100.0% 0.17 [-0.15, 0.49] Heterogeneity: Tau² = 0.19; Chi² = 58.40, df = 8 (P < 0.00001); i² = 86% Test for overall effect: Z = 1.06 (P = 0.29) Total (95% CI) 0.17 [-0.15, 0.49] -1 -0.5 0 0.5 1 Favours usual care Favours intervention	Heterogeneity: Tau² =	: 0.22; CI	hi² = 56.74	df = 7	$(P \le 0.1$	00001); l² :	= 88%			
Heterogeneity: Tau ² = 0.19; Chi ² = 58.40, df = 8 (P < 0.00001); i ² = 86% Test for overall effect: Z = 1.06 (P = 0.29) Test for overall effect: Z = 0.19; Chi ² = 58.40, df = 8 (P < 0.00001); i ² = 86% Test for overall effect: Z = 1.06 (P = 0.29)	Test for overall effect:	Z = 1.13	(P = 0.26)							
Test for overall effect: Z = 1.06 (P = 0.29) -1 -0.5 U 0.5 1 Favours usual care Favours intervention	Total (95% CI)			643			650	100.0%	0.17 [-0.15, 0.49]	-
Test for overall effect: Z = 1.06 (P = 0.29) Favours usual care Favours intervention	Heterogeneity: Tau² =	0.19; CI	hi² = 58.40	df = 8	$(P \le 0.1$	00001); l² =	86%			1 05 0 05 1
Test for subgroup differences: Chi ² = 1.58, df = 1 (P = 0.21), I ² = 36.9%	Test for overall effect:	Z = 1.06	(P = 0.29)							
	Test for subgroup diff	ferences	: Chi² = 1.5	8, df=	1 (P = 0)	0.21), $I^2 = 3$	36.9%			1 avours usual care 1 avours litterverition

Effect of interventions based on the severity of symptoms of the person with dementia

There were too few studies to further compare the effect of carer focussed and dyadic interventions based on the severity of the symptoms in the person with dementia. However, we did conduct sensitivity analyses to examine whether severity of symptoms was a moderator of effect of caregiver interventions for each outcome. Results are presented in Table 1. It can be seen that studies involving people with milder severity symptoms of dementia appeared to be more effective in reducing levels of depression and burden in carers. Whereas, studies involving people with moderate to severe symptoms of dementia appeared to be more effective in improving the quality of life of the carer.

Table 1: Effect of interventions for carers on different outcomes based on the severity of symptoms of the person with dementia

Outcome	Milder severity group	Moderate to severe group
Carer depression	-0.31 (95%CI -0.51 to -0.10)*	-0.30 (95%CI -0.64 to 0.04)
	8 studies (1008 participants)	7 studies (630) participants
Carer quality of life	0.12 (95%CI -0.02 to 0.25)	0.65 (95%CI 0.03 to 1.26)*
	5 studies (867 participants)	2 studies (134 participants)
Carer burden	-0.43, 95%CI -0.81 to -0.05)*	-0.25 (95%CI -0.53 to 0.04)
	3 studies (167 participants)	7 studies (858 participants)
ADL (person with	0.45 (95%CI -0.43 to 1.33)	0.06 (95% CI -0.19 to 0.31)
dementia)	4 studies (486 participants)	3 studies (571 participants)
BPSD global measure	-0.59 (95%CI -1.49 to 0.30)	-0.18 (95%CI -0.42 to 0.07)
	4 studies (459 participants)	5 studies (729 participants)
BPSD upset	-1.08 (95%CI -1.82 to -0.34)*	-0.27 (95%CI -0.42 to -0.11)*

*significant

Discussion

Family members and friends (informal carers) play an important role in the day to day assistance and support of people with dementia. Informal carers typically have poorer outcomes in terms of wellbeing, depression, quality of life, health status, and use of healthcare resources (Argimon, Limon, Vila, & Cabezas, 2004; Bremer et al., 2015; Spector, Orrell, Charlesworth, & Marston, 2015). This review included 40 studies evaluating multicomponent interventions for carers of people with dementia. Meta-analysis demonstrated that multicomponent interventions can reduce caregiver depressive symptoms, decrease burden, reduce caregiver's upset with symptoms of dementia and improve the caregiver's quality of life. Multicomponent interventions can also reduce behavioural and psychological symptoms of dementia, and our analyses suggested beneficial effects in terms of delaying functional decline although some interventions did this more effectively than others.

There were no statistically significant differences between the effects of carer focussed interventions and dyadic interventions for any of the outcomes although inspection of the forest plots suggests that dyadic interventions appeared to reduce carer burden to a greater extent. Furthermore, studies evaluating carer focussed interventions rarely collected outcome measures relating to the functional independence of the person with dementia suggesting that this is not one of the aims of treatment. Qualitative research has found that the quality of the relationship between the person with dementia and the carer depends not only on the presence of depression or anxiety in the carer, but also the presence of depression, irritability, behavioural disturbances and quality of life status of the person with dementia, emphasising

the need for interventions targeting both parties to improve mood and quality of life (Spector et al., 2015). Given the interdependent nature of the health and quality of life of people with dementia and their family members it is plausible that providing multicomponent interventions that target the dyad, rather than just the caregiver or person with dementia themselves, would be more effective. We did not identify any studies that directly compared carer focussed with dyadic interventions. Studies to compare direct differences between carer focussed interventions and dyadic interventions are required.

We also examined whether effects varied based on the severity of symptoms of the people with dementia included in the population. Studies were categorised rather arbitrarily based on the average Mini-Mental State Examination score of participants which provided an overall reflection of the study group. The analyses suggest that there is more potential to reduce depressive symptoms and carer burden when the person has milder severity dementia. Interestingly, there appeared to be more capacity to improve the carer's quality of life when the person with dementia had moderate to severe symptoms. Quality of life is difficult to change through intervention. It may be that carer quality of life quickly deteriorates when the symptoms of dementia change from mild to moderate /severe and so there is more potential to make a difference at this point. Caution should be applied in interpreting these findings because of the relatively small number of studies involved in the analyses.

This review supports the findings of other reviews of caregiver interventions (Brodaty & Arasaratnam, 2012; Olazarán et al., 2010; Van't Leven et al., 2013) but adds to the body of literature by examining effect on a number of outcomes, including meta-analysis and comparing different forms of multicomponent interventions. The effect sizes found for all outcomes are considered small (Cohen, 1992). However, living with dementia and providing care for someone with dementia is challenging, hence even small improvements may be

considered clinically significant. This is particularly important in dementia care where there are few effective treatments for the person with dementia.

The total worldwide cost of dementia in 2015 was US\$\$18 billion and this is projected to rise (Prince et al., 2015). This estimate reflects direct medical costs (approx. 20% of global costs), direct social care costs (approx. 40%) and the costs of informal care (valued using an opportunity cost approach and accounting for approx. 40%) (Prince et al., 2015).

Governments have identified the need to invest money to identify a cure for dementia and to delay onset of dementia. In 2013, the G7 (United States, Japan, Germany, France, UK, Italy, Canada) launched the 'Global Action Against Dementia'. The initiative was designed to increase research funding, promote participation in trials and enhance collaboration and data sharing. The group declared an ambition to identify a cure, or a disease modifying therapy for dementia by 2025. However it has been acknowledged that this is an ambitious target and that we cannot and should not delay implementation of treatment and care that has been shown to be effective in improving outcomes for people with dementia (Prince et al., 2015). While caregiver interventions may not be disease modifying they have been shown to improve outcomes for both the person with dementia and their carer and there is some evidence of cost-effectiveness (Knapp, Iemmi, & Romeo, 2013).

Nonpharmacological interventions for people with dementia and their carers are heterogeneous in terms of content, dose and the person delivering the treatment. Studies also involve participants with different severities of dementia and from different cultural backgrounds though the majority of studies were conducted in the United States. Pooling studies in the presence of clinical heterogeneity can be problematic but the reality in clinical practice is that most of these interventions are not replicated 'as per protocol'. Clinicians are most likely to provide their own form of multicomponent intervention based on what they have been taught, their organisational culture and their previous clinical experiences. The

benefit of the meta-analyses presented within this review is that they provide an overall indication of the magnitude and types of effect. Indeed, a number of translational studies of caregiver interventions have demonstrated differences between intervention delivery in the context of a highly structured research trial and delivery in 'real world' settings (Döpp, Graff, Rikkert, Nijhuis van der Sanden, & Vernooij-Dassen, 2013; Gitlin, Jacobs, & Earland, 2010). In this review we did not look at effects on all outcomes (e.g. service use) and we pooled different outcome measures to calculate the standardised mean difference which is more difficult to interpret. We also did not conduct subgroup analyses based on intervention dose, content and different populations. Subgroup analyses can be insightful but can also be difficult when considering complex interventions as it is hard to determine clinically meaningful cut-off points. For example, how should one compare low and high dose interventions when intervention duration within the studies is consistently spread between two and ten hours?

One of the limitations of this review is that we used an existing systematic review to source studies published until 2008 and then updated searches for more recent studies. Thus, there were two slightly different methods used to source studies. The existing systematic review included all nonpharmacological interventions whereas we were only interested in caregiver intervention. Our search term was developed based on terms used by the Cochrane Dementia and Cognitive Impairment Group and the BMJ Clinical Evidence terms for study design (BMJ Clinical Evidence, 2016). Furthermore, we relied on the details describing the interventions provided in the publications to categorise studies. This may have led to us categorising studies as being 'education focussed' or 'support focussed' and thus excluded from this review when they actually involved additional content that was poorly described or omitted.

In conclusion, there is a substantial body of evidence that multicomponent interventions can improve a range of important outcomes for both the person with dementia and their carer.

There was no evidence that the dyadic approach offered an advantage.

Table 2: Characteristics of Included Studies

MULTICOMPONENT CARER

MULTICOMPONENT CARER					
Reference Country	N carers	Participants	Intervention	Length of followup	Risk of bias ¹
Lawton 1989 (Lawton, Brody, & Saperstein, 1989) United States	632	Carers: Mean age 60 80% female PWD: Mean cognitive symptom severity was 14/30 in the control group and 13/30 in the intervention group (moderate severity).	Intervention included respite, case management, and counselling. A social worker discussed the carer's needs, assisted where needed in procuring services, and maintained regular contact (at client's request at any time, with a 2-month maximum interval, initiated by the social worker if necessary) through the 12 months following the baseline interview. Case management and counseling continued where needed, throughout the year and the respite offer was made when appropriate.	12 months	1. Unclear 2. Unclear 3. High 4. Unclear 5. Unclear 6. Unclear
Mohide 1990 (Mohide et al., 1990) United States	60	Carers: Mean age 66 in the intervention group and 69 in the control group Gender 70% in the experimental group and 73% in the control group PWD: Mean MMSE was 13 in the intervention group and 11 in the control group (moderate severity)	The aim of intervention was to enhance carer competence and achieve a sense of control. Caregiver support nurses scheduled home visits which were initially weekly. Carers undertook a health assessment, were provided with education, a copy of 'The 36-Hour Day', problem solved strategies to reduce excessive disability and enhance functional capacity in the person with dementia. Carers were offered a four hour block of in home respite weekly. Carers were encouraged to attend a monthly 2 hour support group.	3,6 months	1. Low 2. Unclear 3. High 4. Low 5. High 6. Unclear
Eisdorfer 2003 (Eisdorfer et al., 2003) United States (REACH Miami study)	225	Carers: Mean age 69 years, 75% female PWD: Across the subgroups the average MMSE ranged from 10-19/30 (moderate severity)	A structural family therapy intervention plus technology system designed to facilitate linkages of the carers with both their family and supports outside of the home. The system also provided the therapist with enhanced access to the carer and their family members. Intervention took place over 12 months with weekly sessions for the first 4 months, biweekly sessions for the next 2 months and monthly sessions for the final 6 months. Each session lasted 60-90 minutes.	6 and 18 months	1. Unclear 2. Unclear 3. High 4. Unclear 5. Unclear 6. High
Mittelman 2004 (Mittelman, Roth, Coon, & Haley, 2004; Mittelman, Roth, Haley, & Zarit, 2004) Gaugler 2008 United States	406	Carers: Mean age 71 60% female PWD: The majority of participants had a Global Deterioration Scale score of 4 (mild severity)	Caregivers in the treatment group received a comprehensive intervention that was designed to maximize the support provided to them. They agreed to participate in individual and family counselling sessions and to join and regularly attend an AD caregiver support group. They and their families could request additional help, advice, or counselling at any time. Education was a key element of the intervention. There was no predefined endpoint to the treatment. Formal counselling was the central structured component of the	4,8,12 months	 Low Unclear High High High Unclear

			treatment. There were two sessions with the caregiver alone		
Belle 2006 (Belle et al., 2006) Nichols United States	642	Carers: Mean age was 57-64 in the various treatment and participant groups 81-90% female depending on treatment and participant groups PWD: Mean MMSE ranged from 8-10/30 across the different subgroups (moderate severity)	and four sessions with the caregiver and the family The intervention addressed caregiver depression, burden, self-care, and social support and care recipient problem behaviours through 12 in-home and telephone sessions over 6 months. Key strategies for intervention included education about pleasant events and wellbeing, stress management techniques, importance of looking after own health, social support and the symptoms of dementia. Carers were supported to manage BPSD and given prescriptions with step-by-step strategies to manage these.	6 Months	1. Low 2. Unclear 3. High 4. Low 5. High 6. Unclear
Finkel 2007 (Finkel et al., 2007) United States	46	Carers: Mean age 65; 68% female PWD: severity not reported	Primary component of intervention delivery was the Computer-Telephone Integration System. Carers could 1) place and receive calls, 2) send and retrieve messages, 3) access information and services, 4) conference with several people simultaneously. Intervention was provided over 6 months and included 2 in-home sessions and 12 sessions conducted over the CTIS. Eight individual educational skill building sessions and six support group sessions were interspersed.	6 months post intervention	 Unclear Unclear High Low High Unclear
Tremont 2008 (Tremont, Davis, Bishop, & Fortinsky, 2008) United States	33	Carers: Mean age Intervention group 66 Control group 61 Gender not reported PWD: 22 care recipients had mild dementia and 11 had moderate dementia. (mild severity)	Telephone based psychosocial intervention (called FITT-D). 23 phone calls over one year. Involved emotional support, direction to resources, encouraging families and carers health and teaching families and carers strategies	1 year	1. Unclear 2. Unclear 3. High 4. Low 5. High 6. High
Davis 2011 (Davis et al., 2011) United States	46	Carers: Mean age intervention group 57, control group 61 Gender intervention group 83% female, control group 68% female PWD: severity not reported	FITT-NH intervention. Delivered via 10 phone calls over 3 months for families and carers who's loved one had moved into a care home. Incorporated emotional adjustment, families and carers-staff interaction, family functioning, health behaviours and social support and role change.	Post-intervention	1. Unclear 2. Unclear 3. High 4. Low 5. Low 6. High
Kuo 2012 (Kuo et al., 2013) Taiwan	129	Carers: Mean age 80, 54% female PWD: 36% had mild dementia, 34% had moderate dementia, 30% had severe dementia (moderate severity)	Intervention comprised a two session, in-home training program. Each session was 1 wk apart. Sessions lasted 2-3 hrs. BPSD were identified and a plan formulated to minimise stimuli, modify daily schedule and environment. The second session involved education and confirming the action plan. One week after the second visit then once a month for up to 6 months, the research nurse made follow-up phone calls.	2 weeks, 3 months and 6 months post intervention	 Unclear Unclear High Unclear High Unclear Unclear
Joling 2012 (Joling et al., 2012)	192	Carers: Mean age intervention group 68, control group 71	Six sessions were held over a year. Intervention was tailored to the needs of the families and carers and included psycho-	Month 12 post- intervention	1. Unclear 2. Unclear

Netherlands		Gender 70% female PWD: Mean MMSE was 21/30 (mild severity)	education, problem solving techniques and engaging family networks in order to enhance support. Issues such as management of behavioural problems and coping with feelings of guilt were addressed. Ad hoc telephone counselling was available beyond the scheduled sessions.		3. High 4. Low 5. Unclear 6. High
Gaugler 2013 (Gaugler, Reese, & Mittelman, 2013) United States	107	Carer: mean age 50, gender: all female PWD: Mean severity on the Global Deterioration Scale was 4.97. (moderate severity)	Individual and family counselling, support group participation and ad hoc counselling over a 4 month intervention period.	Quarterly during year 1 and then every 6 months for a minimum of 2 years	1. Low 2. Unclear 3. High 4. Low 5. Unclear 6. Unclear
Livingston 2013 (Livingston et al., 2013) Knapp 2013 United Kingdom	260	Carers: Mean age intervention group 62, control group 56 Gender intervention group 67% female, control group 71% female PWD: Mean severity on the clinical dementia scale was 1.3 indicating mild to moderate severity (mild severity)	A manual based coping intervention comprising eight sessions. The program consisted of psychoeducation about dementia, carers' stress, and where to get emotional support; understanding behaviours of the family member being cared for, and behavioural management techniques; changing unhelpful thoughts; promoting acceptance; assertive communication; relaxation; planning for the future; increasing pleasant activities; and maintaining skills learnt. Carers practised these techniques at home, using the manual and relaxation CDs.	Months 4, 8	1. Low 2. Low 3. High 4. Low 5. High 6. Low
Martindale-Adams 2013 (Martindale-Adams, Nichols, Burns, Graney, & Zuber, 2013) United States	154	Carers: Mean age intervention group 66, control group 65 Gender intervention group 82% female, control group 86% PWD: mean MMSE 15/30 (moderate severity)	Telephone support groups involving 5-6 families and carers and a group leader. The group met for 14 sessions over 1 year. Families and carers were provided with written materials on managing behaviours of concern and coping with stress. The intervention focussed on education, skills-building and support.	Months 6 and 12	1. Unclear 2. Unclear 3. High 4. Unclear 5. Low 6. High
Gonzalez 2014 (Gonzalez, Polansky, Lippa, Gitlin, & Zauszniewski, 2014) United States	102	Carers: Mean age 62 in the intervention group and 58 in the control group Gender: all female PWD: severity not reported	Six group sessions on resourcefulness training in groups of 5 to 7 carers who met for 2 hours weekly. The training taught and reinforced cognitive behavioural skills, coping strategies, problem solving, priority setting and decision making.	Post intervention and 12 weeks after the intervention	1. Unclear 2. Unclear 3. High 4. Unclear 5. Unclear 6. Unclear
Au 2014 (Au, Wong, Leung, Leung, & Wong, 2014) Hong Kong	60	Carers: Mean age 58 in intervention group and 55 in control group. Gender: 78% female PWD: Mean MMSE 15.5 in intervention group and 12.9 in the control group (moderate severity)	Pleasant event scheduling for the caregivers and discussion and support around coping with caregiving.	Post intervention and 1 month following intervention	1. Unclear 2. Unclear 3. High 4. Low 5. Unclear 6. Unclear

Chen 2015	46	Carers: Mean age 55	Study nurses provided the intervention of 6 sessions over 3	Post intervention	1. Low
(Chen, Huang, Yeh, Huang, &		Gender; 67% female	months. Sessions included improving knowledge of		2. Unclear
Chen, 2015)			dementia, providing information regarding support services,		3. High
Taiwan		PWD: Approximately 63% had	techniques to manage BPSD or cognitive difficulties, support		4. Unclear
		CDR score of 1 and 37% had a	in relaxation and coping and establishing a caregiver self-		5. Unclear
		CDR score of 2 (mild severity)	support system.		6. Unclear
Gaugler 2015	36	Carers: Mean age 63, 81%	Residential Care Transition Module to help families manage	At 4 months and 8	1. Unclear
(Gaugler, Reese, & Sauld, 2015)		female	their emotional and psychological distress following	months	2. Unclear
United States			residential care placement of a cognitively impaired relative.		3. High
		PWD: NPI-Q severity mean 9.89	Intervention included psychoeducation, communication,		4. High
		out of 30 in the total group	problem solving, behaviour management strategies,		5. Unclear
		(moderate severity)	concrete planning and counselling.		6. Unclear

MULTICOMPONENT CARERS PLU	MULTICOMPONENT CARERS PLUS PEOPLE WITH DEMENTIA							
Reference	N carers	Participants	Intervention	Length of followup	Risk of bias ¹			
Country								
Zarit 1982	35	Carers: Not reported	Classes with problem-solving training involving taking	Post intervention	1. Unclear			
(Zarit, Zarit, & Reever, 1982)			practical steps to manage day-to-day problems caused by		2. Unclear			
United States		PWD: not reported	the memory loss. Participants, including both the individuals		3. High			
			with dementia and the caregivers, were asked to talk about		4. Unclear			
			specific instances of 'forgetting' that were troublesome.		5. Unclear			
			Suggestions for managing these problems were made by		6. Unclear			
			group leaders or other participants, taking into account an					
			individual's severity of memory loss, living arrangements,					
			and personal resources. The classes met twice a week for					
			1.5 hours a session for 3.5 weeks, or seven sessions					
Chang 1999	65	Carers: Mean age 67	The intervention was designed to provide the caregiver with	4,8,12 weeks	1. Unclear			
(Chang, 1999)		All females	knowledge and skills to improve the PWD's eating and		2. Unclear			
United States			dressing abilities. It involved a) videotapes demonstrating		3. High			
		PWD: not reported	assisted modeling behavior (eating and dressing); and (b) a		4. Unclear			
			Nurseline support program to reinforce the video		5. Unclear			
			information and assist the caregiver to explore coping		6. Unclear			
			strategies.					
Quayhagen 2000	103	Carers: Mean age 72	Dyadic counselling, namely problem (conflict) identification,	Post intervention	1. Unclear			
(Quayhagen et al., 2000)		63% female	stress reduction, anger / frustration management,		2. Unclear			
United States			communication enhancement, and conflict resolution The		3. High			
		PWD: severity not reported	family (caregiver and PWD) focused on problems and/or		4. Low			
			conflicts that reduced their ability to interact effectively		5. Unclear			
			accompanied by tasks oriented to increasing communication		6. Unclear			
			and problem-solving skills and enhancing the relationship.					
			The dual participation continued to offer cognitive					
			stimulation to the patient while working on social and					
			emotional issues of concern to the couple. Each of the					
			intervention programs was conducted for 8 weeks and					
			included the participation of both members of the					

			caregiving dyad. Three of the four programs were 1.5 hours in length, while the fourth program, the early-stage day care, was conducted for 4 hours weekly for the patients, but had only two sessions for the caregivers, with respite time an intended aspect of this intervention.		
Buckwalter 1999 (Buckwalter et al., 1999) Gerdner 2002(Gerdner, Buckwalter, & Reed, 2002) Stolley 2002(Stolley, Reed, & Buckwalter, 2002) United States	245	Carers: Mean age 65 years 75% female PWD: severity not reported	Community based psychoeducational nursing intervention to teach carers to manage BPSD. The individualized plan of care based on the PLST model was presented and practiced utilizing examples with return demonstration during the inhome sessions. The care plan was reviewed, techniques taught, and written materials summarizing the care plan were provided at the second in-home session one week later. Referrals for support groups, legal counseling, and case management services were provided as indicated. Experimental subjects received a total of approximately 3 to 4 hours of in-home intervention following baseline assessment, and biweekly follow-up phone calls from a research team member for the first 6 months of the study.	6 months, 12 months	1. Unclear 2. Unclear 3.High 4. Low 5. Unclear 6. Unclear
Chu 2000 (Chu et al., 2000) Canada	78	Carers: 68% of carers over75 Equal numbers of males and females PWD: Mean MMSE 22/30 (mild severity)	The Early Home Care Program provided case management, occupational therapy, physiotherapy, social work, nursing, respiratory therapy, respite, home making, personal care assistance, volunteer service and psychiatric consultation. The objectives were to 1) initiate long term planning early to issues such as housing, finance, legal matters and caregiving support, 2) increase the early use of home care and other community services, 3) improve the coping strategies related to psychosocial issues which often hinder long term planning and service utilisation, and 4) improve caregiving strategies related to functional and BPSD.	3,6,10,14,18 months	1. Unclear 2. Unclear 3. High 4. Unclear 5. Unclear 6. Unclear
Gitlin 2001 (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001) United States	171	Carers: Mean age 61 73% female PWD: severity of dementia not reported	Intervention was a targeted, multicomponent program led by an occupational therapist. It involved educating caregivers about the impact of the environment on dementiarelated behaviors and helping caregivers simplify objects in the home (e.g., remove clutter), break down tasks (e.g., one-or two-step commands, lay out clothing in the order in which it is to be donned), and involve other members of the family network or formal supports in daily caregiving tasks. For example, occupational therapists provided education about dementia and the relationship between excess stimulation (auditory and visual) and behavioral disturbances such as agitation or resistance to assistance with self-care. Strategies such as removing objects to simplify the home and breaking down tasks provided primary control mechanisms by which caregivers could	3 months	1. Unclear 2. Unclear 3. High 4. Unclear 5. Unclear 6. Unclear

	T	T			
			manage problems areas, such as agitation or the inability to		
			follow directions or initiate tasks by the person with		
			dementia. The program consisted of five 90-min sessions		
			that were spaced approximately every other week over 3		
			months.		
Garand 2002	39	Carers: Mean age 65	Intervention involved two consultations, each lasting	Post intervention; 6	1. Unclear
(Garand et al., 2002)		92% female	approximately 3 hours. During the first home visit, the	months	2. Unclear
United States			interventionist focused on developing a therapeutic		3. High
		PWD: severity of dementia not	relationship with the caregiver while teaching underlying		4. High
		reported	principles of the PLST model and instructing caregivers in the		5. Unclear
			use of behavioral logs. At the second home visit, the plan of		6. Unclear
			care was reviewed, specific behavioral techniques were		
			taught, and the therapeutic relationship was reinforced. A		
			plan for home safety was also outlined during this phase of		
			the intervention and supporting literature was left with the		
			caregiver. Referrals for support groups, legal counsel, and		
			case management were provided. Phase two of the		
			intervention consisted of telephone contacts with subjects		
			(by the same interventionist), approximately every other		
			week, for 6 months. Throughout both phases of the		
			intervention, caregivers were encouraged to discuss feelings		
			associated with the caregiving experience, as well as general		
			life stressors they encountered, and to be actively involved		
			in the care planning process.		
Gitlin 2003	255	Carers: Mean age 61	"Home Environmental Skill Building Program"	6, 12 months	1. Low
(Gitlin, Hauck, Dennis, &		76% female	Occupational therapists provided caregivers with education,		2. Low
Winter, 2005; Gitlin et al.,			problem-solving and technical skills (task simplification,		3.High
2003)		PWD: Mean MMSE 12/30	communication), and simple home modifications. The goal		4. Unclear
Gitlin 2005		(moderate severity)	was to help caregivers modify the environment to support		5. Unclear
United States			care recipient physical functioning and reduce behavioural		6. Unclear
			occurrences as well as to reduce caregiver burden. Active		
			treatment, consisting of five 90-minute home visits and one		
			telephone session, occured over 6 months. Maintenance,		
			consisting of one home visit and three brief telephone		
			sessions to reinforce strategy use and obtain closure, occurs		
			over the subsequent 6 months.		
Nobili 2004	69	Carers: Mean age 53 in the	Structured intervention involving one home visit with an OT	6, 12 months	1. Unclear
(Nobili et al., 2004)		intervention group and 59 in the	and one with a psychologist.		2. Unclear
Italy		control group. Gender: 74%	1. Analysis of the data collected by researchers during the		3. High
		female in the control group and	baseline assessment of patients and principal carer		4. Unclear
		89% female in the intervention	2. Home visit by the psychologist to assess and give advice		5. Unclear
		group.	on: Relationships within the family, care burden of carer and		6. Unclear
			psychological consequences, changes in personality, verbal		
		PWD: Mean MMSE 12 in the	and nonverbal communication, how problems are dealt by		
		control group and 11 in the	the family and carer, psychological support and training to		

D.W 2005		intervention group (moderate severity)	carer, 3. Home visit by the occupational therapist to suggest: strategies for the control of reactive behaviors and to maintain or improve residual functional ability, modification to home barriers, adaptation of the environment to meet the patient's needs in order to limit dangerous situation.		4 Usalara
Bottino 2005 (Bottino et al., 2005) Brazil	13	Carer details not reported PWD: Mean MMSE was 23.5 in the intervention group and 21.3 in the control group (mild severity)	Cognitive rehabilitation consisted of 90-min group sessions, once a week, designed to stimulate patients' cognitive functions and to enhance ADL and social interaction. Simultaneously, caregivers (either a familiar or a professional caregiver) attended support group sessions. This group aimed to offer support and to prevent early stress caused by the strain and burden of dementia caregiving, sharing information about the disease and how to take care of the patient. Caregivers were always instructed to repeat some exercises at home in between the group sessions at least three times a week.	Post intervention	 Unclear Unclear High Low Low Unclear
Martin-Cook 2005 (Martin-Cook, Davis, Hynan, & Weiner, 2005) United States	49	Carers: Age not reported 70% female PWD: Mean MMSE 19/30 (mild severity)	Intervention involved four weekly skills-training sessions In Session 1, the TFLS was administered to the patient while observed by the caregiver. In Session 2, the TFLS was readministered with the addition of breaking tasks into smaller steps, as well as other visual, auditory, tactile, or multimodal cues and prompts to facilitate improved performance. Caregivers were told that the goal was for patients to complete as many of the IADL tasks as independently as possible, but that assistance should be rendered when patients seemed unable to proceed on their own. In Session 3, the caregiver administered the TFLS, using facilitative prompts and cues as appropriate. The study coordinator offered suggestions and input as needed to assist caregivers in cueing specific tasks. Session 4 integrated the experience of the previous three sessions. Individualized suggestions to enhance communication and specific strategies to facilitate cueing on ADL were reviewed. Practical advice regarding home safety and information about community resources, companion service agencies, and other home health services was offered.	Post intervention; 10 weeks post intervention	1. Unclear 2. Unclear 3. High 4. Unclear 5. Unclear 6. Unclear
Graff 2006 (Graff et al., 2008; Graff et al., 2007; Graff et al., 2006) Graff 2007 Graff 2008 The Netherlands	135	Carers: Mean age 66 in intervention group; mean age 61 in control group 70% female Mean MMSE 19/30 (mild severity)	Treatment consisted of 10 one hour sessions delivered by OTs and held over five weeks and focused on both patients and their primary care givers. In the first four sessions of diagnostics and goal defining, patients and primary care givers learnt to choose and prioritise meaningful activities they wanted to improve. The occupational therapist evaluated the possibilities for modifying patients' homes and environment and observed patients' ability to perform	Post intervention (6 weeks) and 12 weeks	1. Low 2. Low 3. High 4. Low 5. Low 6. Low

			relevant daily activities and to use compensatory and environmental strategies. Therapists also observed primary care givers' supervision skills. In the remaining six sessions, patients were taught to optimise these compensatory and environmental strategies to improve their performance of daily activities. Primary care givers were trained, by means of cognitive and behavioural interventions, to use effective supervision, problem solving, and coping strategies to sustain the patients' and their own autonomy and social participation. The total time spent for the intervention, including the time spent for treatment at home (10 hours), narrative analysis, reports, and multidisciplinary briefing, was about 18 hours per patient and care giver together.		
Stocking 2007 (Stocking et al., 2007) United States	149	Caregiver details not reported PWD: Mean MMSE 20/30 (mild severity)	Joint completion of the Planning Ahead Together document, a research advance directive.	Post intervention, 2 years	 Unclear Unclear High Unclear Unclear Unclear Unclear
Chien 2008 (Wai Tong Chien & Lee, 2008) Hong Kong	88	Carers: Mean age 44 64% female PWD: 80% of the patients presented with low to moderate impairments in ADLs (mild severity)	Education and support group for family members that lasted for six months. A multidisciplinary committee—including a psychiatrist, a social worker, a case manager (nurse) from each center, and the researchers— selected 25 intervention objectives from dementia guidelines and designed an information and psychological support system linking case managers and dementia care services, health professionals, and referrals. Case managers coordinated all levels of family care according to the results of a structured needs assessment. Each family was assigned one case manager who prioritized problem areas and formulated a multidisciplinary education program for each family on effective dementia care— for example, cognitive stimulation. The program consisted of 12 sessions that were held every other week and lasted two hours each. It consisted of five phases— orientation to dementia care (one session), educational workshop about dementia care (three sessions), family role and strength rebuilding (six sessions), community support resources (one session), and review of program and evaluation (one session). The case managers also conducted home visits and brief education about dementia care every other week and family health assessment once per month.	6, 12 months	1. Unclear 2. Unclear 3. High 4. Low 5. Low 6. Unclear
Gitlin 2008 (Gitlin et al., 2008)	60	Carers: Mean age 65 88% female	Tailored Activity Program: 6 x 90 minute home visits and two 15 minute telephone contacts by occupational therapists	4 months	1. Low 2. Unclear

United States		PWD: Mean MMSE 12/30 (moderate severity)	over 4 months. Three activities per patient were developed based on assessments that identified the person's capacities. The interventionist developed a brief written activity prescription. Carers were instructed in how to facilitate the activity and also in stress reducing techniques to establish a calm emotional tone. As activities were mastered, interventionists generalised strategies to care problems and instructed then on how to downgrade activities for future declines.		3. High 4. Low 5. Unclear 6. Low
Eloniemi-Sulkava 2009 (Eloniemi-Sulkava et al., 2009) Finland	125	Carers: Mean age intervention group 78, control group 77 Gender: Approximately ¾ were female PWD: Mean MMSE 13 in the intervention group and 14 in the control group (moderate severity)	Family care coordinator, education sessions, geriatrician, support groups for families and carers and individualised services. Program lasted for up to 24 months	Months 6, 12 and 24	1. Low 2. Low 3. High 4. High 5. Low 6. High
Logsdon 2010 (Logsdon et al., 2010) United States	142	Carers: Mean age intervention group 71, control group 62 Gender 68% PWD: Mean MMSE 23/30 (mild severity)	Alzheimer's Association Early Stage Memory Loss Program Involves 9 sessions for the person with dementia and families and carers on topics such as information about the condition, relationships, daily living skills, self-esteem, future planning, legal and financial considerations	Post intervention	1. High 2. High 3. High 4. Unclear 5. Unclear 6.Unclear
Gitlin 2010 United States	272	Carers: Mean age 66 Gender 82% female PWD: Mean MMSE 13/30 (moderate severity)	Intervention occurred over 24 weeks and involved up to 9 occupational therapy sessions and 2 nursing sessions plus 3 phone calls. Goal setting, home assessment, problem solving and action plans, strategies to reduce families and carers stress were used and assistive devices provided. The nurse addressed any potential causes of behavioural symptoms related to medical conditions (eg pain, dehydration)	Months 4 and 6	1. Low 2. Low 3. High 4. Low 5. Unclear 6. Unclear
Gitlin 2010 (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010) United States	237	Carers: Mean age 82 Gender: 68% female PWD: Mean MMSE 13/30 (moderate severity)	"COPE" intervention: Assessment (patient capability, medical testing, home environment, family carer communication, concerns), family carer education (patient capabilities, potential effects of medications, pain, constipation, dehydration) and family carer training to address concerns and help reduce stress. Training in problem solving, communication, engaging patients in activities and simplifying tasks was tailored to the needs of the dyad. Dyads received up to 10 sessions over 4 months with an occupational therapist	Months 4 and 9	1. Low 2. Low 3. High 4.Low 5. Unclear 6. Low
Chien 2011 (Chien & Lee, 2011) Hong Kong	92	Carers: Mean age 45 Gender 66%	Program was conducted fortnightly over 5 months. A multidisciplinary group identified intervention goals. The program included case management, education, support and problem solving, information about relationships,	Week 1, Month 12 and Month 18	1. Unclear 2. Unclear 3. High 4. Low

		PWD: Severity ranged from mild (17%), moderate (50%) to severe (33%) (moderate severity)	community resources and improvement of home care and finance skills. Peer mentors helped with problem solving.		5. Low 6. Unclear
Kwok 2012 (Kwok, Lam, & Chung, 2012) Hong Kong	102	Carers: Mean age 78 Gender intervention group 59%, control group 56% PWD: Mean MMSE 18/30 (moderate severity)	Support from case manager via home visits and phone calls, home based cognitive stimulation activities for the person with dementia and a telephone hotline to access the case manager. An OT advised on coping strategies, skills training and behavioural management and linked the person with local services.	Months 4 and 12	1. Unclear 2. Unclear 3. High 4. Unclear 5. High 6. Unclear
Waldorff 2012 (Waldorff et al., 2012) Phung 2013 Sogaard 2014 Denmark	330	Carers: Mean age 66 Gender intervention group 53% female, control group 55% female PWD: Mean MMSE 24/30 (mild severity)	"DAISY" intervention. Tailored program conducted over 8- 12 months. Involved up to 7 counselling sessions, (4-5 with the families and carers present), a group education course about the condition building in peer support, phone call support, written information and a journal.	12 Month	1. Low 2. Low 3. High 4. Low 5. High 6. Low
Judge 2013 (Judge, Yarry, Looman, & Bass, 2013) United States	128	Carers: Mean age 65 Gender 74% female PWD: Mean MMSE 23/30 (mild severity)	Combines educational skills and cognitive rehabilitation training. Six sessions provided to the dyad covering: educational information, effective communication, managing memory, staying active, recognising emotions and behaviours	Month 3	1. Unclear 2. Unclear 3. High 4. Low 5. High 6. Unclear

Abbreviations: AD=Alzheimer's disease; CG=caregiver education; CSDD= Cornell Scale for Depression in Dementia; hr=hour(s); NPI=Neuropsychiatric inventory; OT= occupational therapist; PWD=person with dementia; RCT=randomised controlled trial; wk=week(s)

1. Risk of bias: (1) Random sequence generation, (2) Allocation concealment, (3) Blinding of participants and personnel, (4) Blinding of outcome assessment, (5) Incomplete outcome data, (6) Selective reporting

Note that populations were categorised based on severity. The mean MMSE (or similar) was used where MMSE 19-23 was considered mild and MMSE 10-18 was considered moderate.

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Appendix 1: search strategy

Database: Ovid MEDLINE(R)

- 1 exp Dementia/
- 2 Wernicke Encephalopathy/
- 3 Delirium, Dementia, Amnestic, Cognitive Disorders/
- 4 dement*.mp.
- 5 alzheimer*.mp.
- 6 (lewy* adj2 bod*).mp.
- 7 (chronic adj2 cerebrovascular).mp.
- 8 ("organic brain disease" or "organic brain syndrome").mp.
- 9 ("normal pressure hydrocephalus" and "shunt*").mp.
- 10 "benign senescent forgetfulness".mp.
- 11 (cerebr* adj2 deteriorat*).mp.
- 12 (cerebral* adj2 insufficient*).mp.
- 13 (pick* adj2 disease).mp.
- 14 (creutzfeldt or jcd or cjd).mp.
- 15 huntington*.mp.
- 16 binswanger*.mp.
- 17 korsako*.mp.
- 18 or/1-17
- 19 (review or review, tutorial or review, academic).pt.
- 20 (medline or medlars or embase or pubmed or cochrane).tw,sh.
- 21 (scisearch or psychinfo or psycinfo).tw,sh.
- 22 (psychlit or psyclit).tw,sh.
- 23 cinahl.tw,sh.
- 24 ((hand adj2 search\$) or (manual\$ adj2 search\$)).tw,sh.
- 25 (electronic database\$ or bibliographic database\$ or computeri?ed database\$ or online database\$).tw,sh.
- 26 (pooling or pooled or mantel haenszel).tw,sh.
- 27 (peto or dersimonian or der simonian or fixed effect).tw,sh.
- 28 (retraction of publication or retracted publication).pt.
- 29 or/20-28
- 30 19 and 29
- 31 meta-analysis.pt.
- 32 meta-analysis.sh.
- 33 (meta-analys\$ or meta analys\$ or metaanalys\$).tw,sh.
- 34 (systematic\$ adj5 review\$).tw,sh.
- 35 (systematic\$ adj5 overview\$).tw,sh.
- 36 (quantitativ\$ adj5 review\$).tw,sh.
- 37 (quantitativ\$ adj5 overview\$).tw,sh.
- 38 (quantitativ\$ adj5 synthesis\$).tw,sh.39 (methodologic\$ adj5 review\$).tw,sh.
- 40 (methodologic\$ adj5 overview\$).tw,sh.
- 41 (integrative research review\$ or research integration).tw.
- 42 or/31-41
- 43 30 or 42
- 44 18 and 43
- 45 Caregivers/
- 46 (family or caregiver* or carer*).ti,ab.
- 47 (assess* or treatment* or therap* or counsel* or intervention* or support or support group* or psychosocial* or nonpharmacologic* or relax* or educat* or psychoeducat* or advice).ti,ab.
- 48 46 and 47
- 49 45 or 48
- 50 44 and 49
- 51 limit 50 to (english language and humans and yr="2005 2014")

We then conducted a search using a randomised controlled trial filter as follow for studies between January 2008 and 2014.

- 1 "randomized controlled trial".pt.
- 2 (random\$ or placebo\$ or single blind\$ or double blind\$ or triple blind\$).ti,ab.
- 3 (retraction of publication or retracted publication).pt.
- 4 1 or 2 or 3
- 5 (animals not humans).sh.
- 6 ((comment or editorial or meta-analysis or practice-guideline or review or letter or journal correspondence) not "randomized controlled trial").pt.
- 7 (random sampl\$ or random digit\$ or random effect\$ or random survey or random regression).ti,ab. not "randomized controlled trial".pt.
- 8 4 not (5 or 6 or 7)