The effects on carer well-being of carer involvement in cognition-based interventions for people with dementia: A systematic review and meta-Analysis

Abstract

Objectives: To investigate the effects on carer well-being of carer involvement in cognition-based interventions (CBIs) for people with dementia.

Methods: A review and meta-analysis were performed. We searched electronic databases for randomised controlled trials (RCTs). Two reviewers worked independently to select trials, extract data and assess the risk of bias.

Results: A total of 4737 studies were identified. Eight randomised controlled trials (RCTs) met the inclusion criteria. Only seven studies with 803 dyads of people with dementia and carers were included in the meta-analysis. Evidence indicated that carer involvement in CBIs for people with dementia had a beneficial effect on carers' QoL with effect size Hedges' g=0.22; 95% CI of 0.02 to 0.42, z=2.19 and p=0.03. Carers' depression levels were reduced in the intervention group with effect size Hedges' g=0.17; 95% CI of 0.02 to 0.32, z=2.19 and p=0.03. No significant differences were observed in levels of anxiety symptoms, caregiving relationship and carer burden in the intervention group compared to the control group.

Conclusions: Since CBIs are designed to deliver benefit for people with dementia, the collateral benefits for carers have potential implications for the importance of CBIs in service delivery and may contribute to cost effectiveness. However, there remains a lack of quality of research in this area. Particularly, in some outcomes, there was a lack of consistency of results, so the findings should be interpreted with caution. Future studies of the impact of CBIs on carers with larger samples and high-quality RCTs are warranted.

Introduction

Psychosocial interventions such as cognition-based interventions (CBIs) have been predominantly developed to improve cognition and enhance the quality of life (QoL) for people with dementia (Clare et al., 2010; Neely, Vikstrom, & Josephson, 2009; Spector et al., 2003). However, it has recently been suggested that this focus needs to be broadened to include family carers (Gitlin & Earland, 2010). A recent review showed that engaging carers in psychosocial interventions may increase mutual understanding and enhance the caregiving relationship (Moon & Adams, 2013). Taking part in CBIs provides an environment for carers to interact and understand the cognitive needs of the person with dementia and thus increase their cognitive support (Gitlin & Earland, 2010). For example, carer involvement in reality orientation sessions provides them with opportunities to engage with the person with dementia in reality-based communication such as discussion of personal, time and space orientation (Onder et al., 2005). Carers who engaged in mutual sharing of meaningful activities (Cartwright et al., 1994) and cognitive tasks (Cavanaugh et al., 1989) may have positive effects on the caregiving relationship. However, the inclusion of carers in CBIs can be very challenging as carers may report increased depressive symptoms when they participate in interventions alongside their relative (Zarit, Zarit, & Reever, 1982).

Caregiving has a high interpersonal stress component which can adversely affect the relationship quality of the carer and the person with dementia (Quinn, Clare, & Woods, 2009). The Stress Process Model (SPM) of Pearlin et al., (1990) is one of the most comprehensive and influential models of dementia caregiving. Pearlin and colleagues (1990) propose four domains which include the background and context of caregiving history, stressors, potential mediators and carer outcomes to explain the dementia caregiving stress process. In the SPM (Pearlin 1990) social support and carers' coping strategies are two principal mediators of the relationship between carer stress and carer well-being. However, the SPM does not explicitly state how dyadic interpersonal interactions between the carer and the person with dementia could act as a mediator to buffer the impact of stressors (Sanders, 2005; Zarit, 2012).

In order to examine the effects of carer involvement in CBIs, it is important to consider the dyadic interpersonal aspects of the caregiving relationship. For example, the positive effects of caregiving include feelings of reward, enjoyment and gratification (Kramer, 1997), whereas negative experiences include lack of motivation (Ablitt 2010). Due to the lack of dyadic interpersonal interactions in the SPM (Pearlin et al., 1990), we revised this model to accommodate three key components (Figure 1) that include a) dyadic interpersonal interactions in the caregiving relationship, b) opportunities to engage in pleasurable and meaningful activities and c) cognitive support provided by carers as potential mediators of the SPM of dementia caregiving. We have further developed and conceptualised a framework of carer involvement in CBIs (Figure 2). The conceptual underpinnings of this model lie in the binding ties theory (Townsend & Franks, 1995), the enrichment process theory (Cartwright, et al., 1994) and the scaffolding process theory (Cavanaugh et al., 1989). Townsend & Franks (1995) examined the closeness and conflict in adult children's caregiving relationship with their cognitively impaired parents. Closeness was assessed by feelings of affirmation, affection and fundamental facets of intimate ties (House & Kahn, 1985; Reis & Shaver, 1988). Conflict was measured by frequency of communicating negative affect, negative evaluations, or social undermining (Reis & Shaver, 1988; Vinokur & van Ryn, 1993). The binding ties theory emphasises the importance of considering not only the cognitive impairment of the person with dementia but also positive and negative interpersonal ties in the caregiving relationship. An existing positive relationship helps carers to encounter stress by adapting to the changing needs of the person with dementia, in order to protect them from experiencing negative consequences. Therefore, when carers fail to adapt to these changes, it may lead to a further negative impact on the caregiving relationship. The dementia caregiving literature suggests that mutuality is associated with positive relationships and lowers level of carer strain (Archbold, Stewart, Greenlick, & Harvath, 1990; Hirschfeld 1983). Therefore, Cartwright and colleagues (1994) applied a theory of enrichment in family caregiving that explains how some families use pleasurable and meaningful experiences to adapt and cope with the caregiving role. Their findings suggested that the enrichment process only occurs either within the context of an existing positive relationship or being motivated to improve the relationship. As dementia is a progressive disease, Cavanaugh and colleagues (1989) adopted the scaffolding process theory, which emphasises the importance of carers' cognitive support that can contribute to enhance interpersonal interactions in the caregiving relationship.

In dementia care, dyadic interpersonal interactions play a major role in the caregiving process. Therefore, the proposed conceptual framework of carer involvement in CBIs for people with dementia may broaden the understanding of dyadic interpersonal interactions (Townsend & Franks 1995), mutual sharing of pleasurable and meaningful activities (Cartwright et al., 1994) and cognitive support by carers (Cavanaugh et al., 1989) in relation to carer well-being. It also highlights that the key components of dyadic interpersonal interactions are interrelated and may act as mediators on carer well-being. However, no theoretical model has adopted and conceptualised these theories in relation to carer involvement in CBIs. Furthermore, there has been limited research examining the effects of carer involvement in CBIs for people with dementia on carer well-being.

Aim

To investigate the effects on carer well-being of carer involvement in CBIs for people with dementia

Methods

Criteria for considering studies for this review

Types of studies

- Studies in which carers were involved in a CBI for the person with dementia.
- Randomised controlled trials that provided adequate information in terms of results and description of the study (i.e. means, standard deviations (SDs), t-test or F-test, p and n-values).
- On-going trials were included if data were available and could be provided by authors.

Types of participants

- Carers of people with dementia; the main diagnostic categories for people with dementia included Alzheimer's disease, vascular dementia or mixed Alzheimer's and vascular dementia
- Any setting (e.g. community, day centre or care home)

Types of interventions

For the purposes of this review, CBIs were defined as interventions that used Cognitive Stimulation (CS), Cognitive Rehabilitation (CR) and Cognitive Training (CT) approaches (Clare & Woods, 2004). CS provides a range of activities and opportunities for discussion that aim to engage the individual in general stimulation of memory and enhance social function, usually conducted in a group setting (Clare & Woods, 2004; Woods & Aguirre et al., 2012). CR is an individualised approach that focuses on reducing functional disability in people with dementia and maximising their engagement in everyday activities by identifying meaningful goals and developing strategies to address these goals (Clare et al., 2010). CT aims to maintain or improve cognitive function in people with dementia by using repeated and guided practice via a set of standardised tasks. These tasks target specific areas of cognitive function such as attention, memory, learning, executive function, language, perceptual-motor skills or social cognition (Sitzer, Twamley, & Jeste, 2006). Multicomponent interventions were considered as eligible as long as the intervention was based on a CBI for people with dementia and involved carers.

Studies were included if comparison conditions included 1) carers were not involved in CBIs alongside people with dementia receiving placebo, 'no treatment', 'usual care' or 'treatment as usual'. 'Usual care' or 'treatment as usual' stands for a treatment normally provided to the person with dementia such as medication, clinic consultations, day care or other types of support and 2) people with dementia received CBIs, but carers were not involved in the intervention.

Types of outcome measures

- Primary outcomes: carer well-being (including QoL, mood, physical and mental health)
- Secondary outcomes: the caregiving relationship and carer burden

Search methods and identification of studies

Electronic databases and key articles were searched for randomised controlled trials (RCTs) published up to 18th December 2015 inclusive. Search was carried out in MEDLINE, Embase, Pubmed, PsycINFO, Alois (www.medicine.ox.ac.uk/alois), Cumulative Index of Nursing and Allied Health Literature (CINAHL) and the Cochrane Library in order to identify RCTs.

Search terms included people with dementia, dementia, dementia*, Alzheimer*, Alzheimer's disease, cognitive impairment, cognitive stimulation, cognitive rehabilitation, cognitive training, cognitive retraining, cognitive support, memory rehabilitation, memory therapy, memory aid, memory group, memory training, memory retraining, memory support, memory stimulation, memory strategy, reality orientation, rehabilitation training and cognitive psychostimulation, carer, caregiver*, randomised controlled trial or random*.

Data extraction and management

Two reviewers (PL and VO) extracted data independently using a standardised data extraction form. Differences in the quality ratings of the papers were resolved by the third reviewer (MO) to reach a consensus. The information included data on methods, participants, type of intervention, model of delivery, outcome and results. Study authors were contacted for data not provided in the papers.

Analyses

Effect size Hedges' g (Hedges, & Vevea, 1998) of continuous data was calculated as the standardised mean difference (SMD) with 95% confidence intervals (CI) between the intervention and control group. When means and standard deviation were not available, effect sizes were computed from exact p-values, t-values or F-values (Comprehensive Meta-analysis, Software-Version 2). The random effect model was used to decide whether an effect size was statistically significant (Hedges, & Vevea, 1998). The weighted average effect size was calculated by the inverse of its variance (RevMan 5).

Results

Results of the search

Selection of studies

A total of 4721 studies was identified through database searching which was conducted during the period of 1st July to 18th December 2015. A total of 16 additional studies was identified via other sources. After removal of duplicates and irrelevant studies by title, 302 studies remained to be screened. A total of 257 studies was discarded as not relevant, and 45 studies remained for further screening. Nine of these studies were retrieved via full text, and 36 were excluded. A total of 23 RCTs and one ongoing trial did not report carer outcomes and carers were not involved in the intervention. Three RCTs did not involve carers in the intervention, but carer outcomes were examined. Two RCTs reported carer involvement, but carer outcomes were not examined. The remaining seven studies did not employ an RCT, but carers were involved in the intervention. Four of these studies assessed carer outcomes. Amongst the nine included studies, one was an ongoing trial (Clare et al., 2013) (data not available). Only seven studies in the remaining eight included studies were included in the meta-analysis as a data of one study was not available. Figure 3 shows the PRISMA flow diagram detailing the search process.

Included studies

1. Participant characteristics

Table 1 shows the characteristics of the eight included studies. The included studies were conducted during 2000 to 2015. One study was conducted in the USA (Quayhagen 2000), two in the UK (Clare 2010; Orgeta 2015), one in Germany (Kurz 2012), one in Sweden (Neely, 2009), two in Italy (Onder 2005; Onor 2007) and one in Brazil (Bottino 2005). All the people with dementia were diagnosed with mild to moderate dementia with mean Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) scores ranging from 19.8 (Neely 2009) to 25.1 (Kurz 2012). The mean age of people with dementia ranged from 70.0 years (Onor 2007) to 78.2 years (Orgeta 2015). The mean age of carers ranged from 56.8 years (Onder 2005) to 73.8 years (Neely 2009).

2. Intensity, frequency and duration of the interventions

The intensity of the sessions was either 30-minutes (Onder 2005; Orgeta 2015) or 60-minutes (Clare 2010; Kurz 2012; Neely 2009; Onor 2007; Quayhagen 2000) or 90-minutes (Bottino 2005). The frequency of the sessions included one session weekly (Neely 2009; Clare 2010; Kurz 2012; Bottino 2005), three sessions weekly (Onor 2007; Orgeta 2015; Onder 2005) and five sessions weekly (Quahagen 2000). The duration of the interventions was eight weeks (Quayhagen 2000, Neely 2009; Clare 2010), twelve weeks (Kurz 2012), sixteen weeks (Onor 2007), twenty weeks (Bottino 2005) or twenty-five weeks (Onder 2005; Orgeta 2015).

3. Types of carer involvement

   The included studies were categorised into three groups according to types of carer involvement.

A) Carers delivered/led the CBI

In four of the included studies Neely (2009), Onder (2005), Orgeta (2015) and Quayhagen (2000), carers were trained to deliver the interventions. For example, carers helped people with dementia with their problem-solving techniques, cognitive stimulation and conversational fluency activities (Neely 2009; Quayhagen 2000). They were encouraged to engage their relative in reality-based communications (Onder 2005) and mutual sharing of mentally stimulating activities (Orgeta 2015).

B) Therapist delivered CBIs plus carers attending some sessions

In the study by (Clare 2010), the intervention was delivered by occupational therapists and carers were invited to join the last 15 minutes of each training session to support between-session implementation. In the study by Kurz (2012), behavioural therapists delivered the intervention and carers attended one in every two sessions during the 12-week intervention period. Carers were trained to apply the transfer of newly learned strategies into everyday life when communicating about memories with the person with dementia.

C) Therapist delivered CBI plus carers repeating some activities at home

In the study by Bottino (2005), neuropsychologists delivered the intervention and carers were trained to repeat some activities between the sessions at least three times a week at home. In the study by Onor (2007), psychologists delivered the intervention and carers were trained to repeat some of the activities at various times of the day at home.

Quality assessment of included studies

The Cochrane Risk of Bias tool (Cochrane Handbook for Systematic Reviews of Interventions) (Higgins and Green, 2008) was used to assess risk of bias in included studies. This addresses six specific domains: 1) sequence generation, 2) allocation concealment, 3) blinding, 4) incomplete outcome data, 5) selective reporting and 6) other issues. Each of these domains was rated as a ‘low risk’, ’high risk’ or ’unclear risk’ of bias. The review authors worked independently in relation to input of entries in a risk of bias table. Differences of judgement of risk of bias were resolved by discussion or by involving the third author (MO). Figure 4 presents the summarised results for risk of bias assessment of included studies.

1) Sequence generation

The studies by Onder (2005), Orgeta (2015), Clare (2010), Kurz (2012) and Bottino (2005) specified how random sequence generation was generated. These studies were classified as low risk. The study by Quayhagen (2000), Neely (2009) and Onor (2007) did not provide details of sequence generation. Therefore, these studies were classified as having unclear bias in this domain.

2) Allocation concealment

All studies reported the use of randomisation. However, descriptions and details by individual studies varied. Five studies reported group allocation was concealed from blind assessors (Onder 2005, Orgeta 2015, Clare 2010, Kurz 2012 and Bottino 2005). These studies were classified as low risk of bias in this domain. Quayhagen (2000), Neely (2009) and Onor (2007) did not describe any details of allocation; therefore, these studies were classified as having unclear risk.

3) Blinding

The studies by Quayhagen (2000), Onder (2005), Orgeta (2015), Clare (2010), Kurz (2012) and Bottino (2005) reported the assessors being blind to outcome assessments. Therefore, these studies were classified as being at low risk of bias. Neely (2009) and Onor (2007) did not report details of blinding assessment; therefore, these studies were classified as being of unclear risk.

4) Incomplete outcome data

Onder (2005), Orgeta (2015), Clare (2010), Kurz (2012) and Onor (2007) reported attrition for both treatment and control groups. They were therefore classified as low risk. Quayhagen (2000), Neely (2009) and Bottino (2005) were judged as having unclear risk in this domain because they did not provide attrition details.

5) Selective reporting

All studies reported all pre-specified outcomes and were classified as low risk of bias in this domain

6) Other potential sources of bias

No additional risk of biases was identified in each of the included studies

Carer outcome measures

- *Primary outcome measures*

Carer quality of life

The study of Onder (2005) employed the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36) (Ware & Sherbourne, 1992) and Orgeta (2015) used the Short Form Health Survey Questionnaire-12 items (SF-12); physical and mental components (Ware et al., 1996) to measure carer QoL. Orgeta (2015) also assessed carer QoL by using the Health-related Quality of Life (HR-QoL) EQ5-D (Brooks, 1996). Clare (2010) evaluated carer QoL by using the short-version of the World Health Organization Quality of Life questionnaire (WHOQOL-BREF); 5 subscales (Skevington, Lotfy, & O'Connell, 2004). Quayhagen (2000) measured life satisfaction by using the Philadelphia Geriatric Center Morale Scales (PGCMS) (Lawton, Moss, Fulcomer, & Kleban, 1982).

Carer anxiety/depression

Both Quayhagen (2000) and Onor (2007) measured anxiety and depressive symptoms using the subscales of the Brief Symptom Inventory (BSI) (Derogatis & Melisaratos, 1983). The study of Onder (2005) employed the 21-item Hamilton Rating Scale for Anxiety to measure anxiety (HRSA) (Hamilton, 1959) and depressive symptoms (HRSD) (Hamilton, 1967). Clare (2010) and Orgeta (2015) employed the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) to assess anxiety and depressive symptoms. In the study of Bottino (2005), the Montgomery-Asberg Depression Rating Scale (Montgomery 1979) was used to measure depressive symptoms and the Hamilton Anxiety Rating Scale (HAM-A) (Bruss, Gruenberg, Goldstein, & Barber, 1994) to assess anxiety. Neely (2009) and Kurz (2012) measured depressive symptoms using the Beck Depression Inventory (BDI) (Beck, Steer, & Carbin, 1988).

Carer physical health and mental health

Quayhagen (2000) evaluated physical health status by using the Health Assessment Scale (Rosencranz & Pihlblad, 1970). Clare (2010) employed the General Health Questionnaire GHQ-28 (Goldberg & Hillier, 1979) to measure carers' mental health.

- *Secondary outcome measures*

The carer/person with dementia relationship

Quayhagen (2000) assessed relationship functioning by using the Marital Needs Satisfaction Scale (MNSS) (Stinnett, Collins, & Montgomery, 1970). Orgeta (2015) used the Quality of the Carer Patient Relationship (QCPR) scale (Spruytte, Van Audenhove, Lammertyn, & Storms, 2002) to evaluate the carer/person relationship.

Carer burden/relative stress

Four studies measured levels of carer burden. Onder (2005), Onor (2007) and Neely (2009) used the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989), and Kurz (2012) employed the Zarit Burden Interview (ZBI) (Zarit, Reever, & Bach-Peterson, 1980) to rate carer burden. Clare (2010) employed the Relative's Stress Scale (RSS) (Greene, Smith, Gardiner, & Timbury, 1982) to evaluate carer stress.

Effects of carer involvement in CBIs

Seven included studies with 803 dyads of people with dementia and carers were included in the meta-analysis. A study of Neely (2009) was not included in this meta-analysis, due to no data being available.

- *Primary outcomes*

Carer quality of Life

Three studies measuring carer QoL were included in the meta-analysis (Quayhagen 2000; Onder 2005; Orgeta 2015). The findings indicated a significant improvement in carer QoL in the intervention group. The effect size was g=0.22; 95% CI of 0.02 to 0.42, z=2.19 and p=

0.03. The heterogeneity between studies was I^2=9 % (Figure 3). The data of Health Survey SF-12 in the study by Orgeta (2015) and the WHOQOL-BREF in the study by Clare (2010) can not be pooled in the meta-analysis because only the subscale scores of these measures were reported.

Carer anxiety and depression

Seven studies assessed carers' depressive symptoms (Onder 2005; Orgeta 2015; Quayhagen 2000; Clare 2010; Kurz 2012; Bottino 2005; Onor 2007), and the meta-analysis showed a significant effect favouring the intervention group with g=0.17; 95% CI of 0.02 to 0.32, z=2.19 and p=0.03. There was no heterogeneity between studies I^2=0% (Figure 4). Six studies examined anxiety symptoms (Quayhagen 2000; Onder 2005; Orgeta 2015; Clare 2010; Bottino 2005; Onor 2007). The meta-analysis showed no evidence of a significant effect size for anxiety symptoms in carers in the intervention group compared with the control, g=0.08; 95% CI of -0.09 to 0.26, z = 0.92, and p=0.36. There was no heterogeneity between studies I^2=0%.

Carer physical health and mental health

Two studies evaluated physical health (Quayhagen 2000; Orgeta 2015), two studies assessed mental health (Orgeta 2015; Clare 2010) and one study measured general health. Due to outcomes varying widely across studies, the data could not be pooled for the meta-analysis.

- *Secondary outcomes*

The carer/person with dementia relationship

Two studies evaluated the quality of relationship functioning between carers and people with dementia (Quayhagen 2000; Orgeta 2015). The meta-analysis showed no significant effects on the quality of relationship between carers and the person with dementia in the intervention group with an effect size of g=0.01; 90% CI of -0.23 to 0.24, z=0.05 and p=0.96. There was no heterogeneity between studies I^2=0%.

Carer burden/stress

Five studies measured the level of carer burden/stress (Onder 2005; Quayhagen 2000; Clare 2010; Kurz 2012; Onor 2007). The meta-analysis indicated no significant differences in carer burden/stress between the intervention and control groups with an effect size of g=0.03; 95% CI of -0.27 to 0.32, z=0.17 and p=0.86. The heterogeneity between studies was I^2=39 %.

Discussion

To our knowledge, this is the first systematic review evaluating the effects on carer well-being of carer involvement in CBIs for people with dementia compared with carers and people with dementia not involved in CBIs. The results indicate that carer involvement in CBIs may improve carers' QoL and depressive symptoms. Although the effect sizes are small, the findings are consistent with the theoretical predictions of binding ties theory (Townsend 1995), enrichment process theory (Cartwright et al., 1994) and scaffolding process theory (Cavanaugh et, al., 1989).

The findings of the meta-analyses indicate that carer involvement in CBIs had no positive effects on the caregiving relationship. It is consistent with the binding ties theory that alongside the benefits of positive ties, there is evidence of the influence of negative social ties (Townsend & Franks, 1995). For example, an increased closeness in a relationship could be too emotionally demanding for some carers, which might lead to responses of frustration or withdrawal. This adverse experiences might influence the quality of caregiving relationship (de Vugt et al., 2003; Fauth et al., 2012). The meta-analyses also show that carer involvement in CBIs had no effects on anxiety symptoms or carer burden. However, Clare (2010) found a small effect size of 0.25 on a reduction of carer burden for the intervention group, whereas Kurz (2012) found an effect size of 0.30 towards carers in the control group.

This review identified four non-RCTs that involved carers in the CBI and examined carers' outcomes. Moniz-Cook and colleagues (1998) evaluated carer involvement in an individual home-based memory orientation programme, in which carers received psycho-education and counselling. The study found that carer well-being was worse in the control group. Clare (2000) conducted a multiple single case study to investigate the effects of errorless learning principles for people with dementia and their carers. There was no evidence of effects for carers' anxiety or depressive symptoms when carers were involved in the CBI activities. Viola et al. (2011) conducted a multicomponent CR for people with dementia and involved carers repeating some of the activities at home. Carers also received psychoeducation and counselling sessions. Their findings showed that carers in the interventions group reported fewer depressive symptoms and lower carer burden. In contrast, the study by Milders and colleagues (2013) examining the effects of carer-delivered CS intervention reported increased levels of burden in carers in the intervention group when compared with the control group.

Amongst the 36 excluded studies, three RCTs reported carer outcomes, but carers were not involved in the intervention (Aguirre et al., 2014; Chapman et al., 2004; Spector, Orrell, Davies, & Woods, 2001). The study by Aguirre and colleagues (2014) examining the effects of group CST for people with dementia on carer QoL showed that there was no evidence of improvement in carers’ physical and mental health components (Health Survey SF-12) and HR-QoL (EQ5-D). Chapman and colleagues (2004) examined the effects of cognitive communication stimulation for people with dementia. This study however measured carers’ distress by using the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994), which is not a validated measure for carer distress (Lai, 2014). The study by Spector (2001) described the development and implementation of group CS therapy for people with dementia. Their findings showed that the caregiving stress (Relative’s Stress Scale (RSS)) increased both in the intervention group and the control group, however, carers in the intervention group reported an improvement in their general psychological distress (General Health Questionnaire12 (GHQ-12)). The data for these outcomes can not be pooled in the meta-analysis as the outcome measures used vary in terms of what was being measured and underlying concepts.

A Cochrane review by Woods et al., (2012) examining the effects of CS on people with dementia identified three studies in which carer outcomes were examined. Two of these studies involved carers in the interventions (Bottino 2005; Onder 2005), but a study by Spector et al., (2001) did not. Their findings showed no significant differences in carer anxiety, depression, carer burden and general health. Another Cochrane review by Bahar-Fuchs, Clare, & Woods (2013) evaluating the effects of CT and CR in people with dementia identified five studies in which carers were involved in the interventions. Of these three studies examined carer outcomes (Clare 2010; Neely 2009; Quayhagen 2000) but two studies did not (Davis, Massman, & Doody, 2001; Quayhagen et al.,1995). However, this Cochrane review did not statistically examine carer outcomes.

Limitations

The interpretation of these effects is not straightforward, due to the diverse range of studies with small sample sizes, which may have been unable to achieve statistical power. Results may be therefore misinterpreted or fail to produce reliable outcomes (Hackshaw, 2008). For example, of the seven studies included in the meta-analysis, two studies had small samples which ranged from 13 to 16 dyads (Bottino 2005; Onor 2007). Studies with small sample sizes combined with a lack of acceptable standards of sequence generation, allocation concealment, blinding and dropout rates limit conclusions of the analysis undertaken. A combination of different interventions, various types of carer involvement and duration, intensity and follow-up of the intervention makes results difficult to interpret. Publication bias was not assessed, as there were too few studies within each meta-analysis group. Therefore, there would not be sufficient power to detect true asymmetry (Higgins and Green, 2008).

Since CBIs have been predominantly developed to improve cognition and QoL for people with dementia, there is a lack of RCTs comparing two similar interventions where one includes carer involvement and the other does not. Therefore, it is hard to be specific about the impact of carer involvement on carer well-being.

Conclusion

The findings suggest that carer involvement in CBIs may improve carers' QoL and reduce carers' depressive symptoms. These results support the theories of carer involvement where interpersonal interaction, mutual sharing of meaningful experiences and cognitive support by carers may act as mediators of carer well-being. Nevertheless, there remains a lack of quality of research in this area. Particularly, for some outcomes, there was a lack of consistency of results, so the findings should be interpreted with caution.

This review also highlights that the current evidence base for carer involvement in CBIs is limited with most of the studies reporting results based on small sample sizes. There are insufficient studies to examine differences between carer involvement in CS, CR and CT. Therefore, larger samples and further high-quality RCTs of carer involvement in CBIs are warranted. Future research should examine the effects of carer involvement where people with dementia in the control group also receive CBIs. Since CBIs are designed to deliver benefit for people with dementia, the collateral benefits for carers have potential implications for the importance of CBIs in service delivery and may contribute to cost effectiveness of dementia care.

Key points

- Carer involvement in cognition-based interventions may improve carer quality of life and reduce carers' depressive symptoms.
- Since cognition-based interventions are designed to deliver benefit for people with dementia, the collateral benefits for carers have potential implications for the importance of cognition-based interventions in service delivery and may contribute to cost effectiveness.
- There remains a lack of quality, consistency of results and small sample size in some studies. Therefore, the findings should be interpreted with caution.

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Conflicts of Interest

None

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Table 1 The characteristics of included studies

Study	**Country**	**Sample**		**Intervention group**	**Control group**	**Carer outcomes**
		People with dementia	**Carers**			
Quayhagen (2000)	USA	n = 36 Mean age:74.5 Inclusion criteria: - Diagnosis of Alzheimer's disease or/and cardiovascular dementia and Parkinson's disease dementia - Mattis Dementia Rating Scale ≥100	n=36 Mean age: 71.8 Relation to person with dementia: Spousal carers	Individual CT: memory stimulation, problem solving and conversation fluency tasks. - Intensity: 60 -minute sessions - Frequency: 5 sessions weekly - Duration: 8 weeks - Carers were trained to deliver the intervention	People with dementia - Wait-list Carers - No treatment	**QoL** Life satisfaction (PGCMS) **Mood** Anxiety (BSI) Depression (BSI) **Caregiving relationship** Marital Needs Satisfaction (MNSS) **Physical health** Health Assessment (HAS)
Onder (2005)	Italy	n = 156 Mean age: 75.7 Mean MMSE: 20.0 Inclusion criteria: - Diagnosis of dementia (NINCDS–ADRDA) - MMSE (14-27) - Received donepezil for at least 3 months	n = 156 Mean age: 56.8 Relation to person with dementia: not provided	Individual CS: space orientation tasks, historical events, famous people and exercises of memory, visuospatial orientation and communication - Intensity: 30-minute sessions - Frequency: 3 sessions weekly - Duration: 25 weeks - Carers were trained to deliver the intervention	People with dementia - Treatment as usual Carers - No treatment	**QoL** Health survey (SF-36) **Mood** Anxiety (HRSA) Depression (HRSD) **Burden** CBI burden (CBI)
Neely (2009)	Sweden	n = 20 Mean age: 75.4 Mean MMSE: 19.8 Inclusion criteria: - Diagnosis of dementia	Carers: n = 20 Mean age: 73.8 Relation to person with dementia: Not	Individual CT: practice strategies to support everyday mnemonic and occupational performance, cognitive training strategies of spaced retrieval and face name tasks	People with dementia - Treatment as usual Carers	**Mood** Depression (BDI) **Burden** Carer Burden (CBI)

		(DSM-IV)	provided	- Intensity: 60-minute sessions - Frequency: 1 session weekly - Duration: 8 weeks - Carers were trained to deliver the intervention	- No treatment	
Orgeta (2015)	UK	n = 356 Mean age = 78.2 Mean MMSE: 21.2 Inclusion criteria: - Diagnosis of mild to moderate dementia (DSM-IV) - MMSE ≥10	n= 356 Mean age: 65.7 Relation to person with dementia: Spouses (63%), adult children & siblings (32%), Other relatives (5%)	Individual home-based CS therapy consisting of orientation activities and structured themes in each session (i.e. current affairs, words games, music quizzes) - Intensity:30-minute sessions - Frequency: 3 sessions weekly - Duration: 25 weeks - Carers were trained to deliver the intervention	People with dementia - Treatment as usual Carers - No treatment	**Primary outcome** **QoL** Health survey (SF-12): 2 subscales **Secondery outcomes** HR-QoL EQ5-D **Relationship functioning** Quality Carer/Patient Relationship (QCPR) **Mood** Anxiety (HADS-A) Depression (HADS-D)
Clare (2010)	UK	n = 45 Mean age 77.8 Mean MMSE: 23.0 Inclusion criteria: - Diagnosis of dementia (NINCDS/ADRAD) - MMSE ≥18 - Taking AChEIs at least 4 weeks	n = 25 Mean age: 70.0 Relation to person with dementia: Spouses: (73%), adult children: (20%), Other relatives: (7%)	Individual CR: practical aids, strategies and techniques for learning new information, maintaining attention and concentration and techniques of stress management - Intensity: 60-minute sessions - Frequency: 1 session weekly - Duration: 8 weeks - Occupational therapists delivered the intervention - Carers attended the last 15 minutes of each CR session if they were available	People with dementia - Usual care Carers - No treatment	**QoL** WHOQOL-BREF: 5 sub-scales. **Mood** Anxiety (HADS-A) Depression (HADS-D) **Carer burden** Relative's Stress (RSS) **Mental health** General Health (GHQ-12)

Kurz (2012)	Germany	n = 201 Mean age: 73.7 MMSE: 25.1 Inclusion criteria: - Dementia diagnosis (ICD-10) - MMSE ≥21	N=201 Mean age: 64.9 Relation to person with dementia: Spouses: (72%), other relatives (28%)	Individual multi-component cognitive behaviour therapy (CBT) & CR programme of 6 modules (12 sessions), including use of external memory aids, coping with memory-related problems, reminiscence and activity planning. - Intensity: 60-minute sessions - Frequency: 1 session weekly - Duration: 12 weeks - Behavioural therapists delivered the intervention - Carers attended six sessions with the person with dementia	People with dementia - Usual care Carers - No treatment	**Mood** Depression (BDI) **Burden** Burden (ZBI)
Bottino(2005)	Brazil	n = 13 Mean age: 73.7 Mean MMSE: 22.3 Inclusion criteria: - Diagnosis of dementia (NINCDS-ADRDA) - Taking Rivastigmine for 2 months	n = 13 - Mean age: not provided - Relation to person with dementia: not provided	Group CS: orientation activities, discussion of themes, reminiscence and planning of daily activities via use of calendars and clocks or other external memory aids - Intensity: 90-minute sessions - Frequency: 1 session weekly - Duration: 20 weeks - Neuropsychologists delivered the intervention - Carers were trained to repeat some activities at home in between the group sessions for at least three times a week	People with dementia - Treatment as usual Carers - No treatment	**Mood** Anxiety (HAM-A) Depression (MADRS)
Onor (2007)	Italy	n = 16 Mean age: 70.0 Mean MMSE: 22.4	Carers: n=16 Mean age: Not provided	CS group programme: RO therapy (memory events, people, objects, songs and rhymes) and implicit	People with dementia - Treatment as	**Mood** Anxiety (BSI) Depression (BSI)

	Inclusion criteria: - Mild-moderate dementia (DSM-IV and NINCDS/ADRAD) - Received AChEIs ≥ 6 months	- Relation to person with dementia: Not provided	memory stimulation tasks (i.e. daily personal care and activities) through occupational therapy - Intensity: 60-minute sessions - Frequency: 3 sessions weekly - Duration: 16 weeks - Psychologists delivered the intervention - Carers were trained to repeat some activities at home at various times of the day	usual Carers - No treatment	**Burden** Carer Burden (CBI)

PGCMS: Philadelphia Geriatric Center Morale scale; BSI: Brief Symptom Inventory (Anxiety, Depression); MNSS: Marital Needs Satisfaction Scale; HAS: Health Assessment Scale; SF-36 Health Survey Short Form; HRSA: Hamilton Rating Scale for Anxiety; HRSD: Hamilton Rating Scale for Depression; CBI: Carer Burden Inventory; BDI: Beck Depression Inventory; SF-12: Health Survey Short Form; EQ5-D VAS: Europe Quality of Life Visual Analogue Scale; QCPR: Quality caregiver/patient Relationship; HADS-A: Hospital Anxiety and Depression Scale; HADS-D: Hospital Anxiety and Depression Scale; WHOQOL-BREF: World Health Organisation Quality of Life Assessment Short Version; RSS: Relative's Stress Scale; GHQ-12: General Health Questionnaire; ZBI: Zarit Burden Interview; HAM-A: Hamilton Anxiety Scale; MADRS: Depression Montgomery-Asberg; BSI-A: Brief Symptom Inventory-Anxiety; BSI-D: Brief Symptom Inventory-depression; CBI: Carer Burden Inventory.

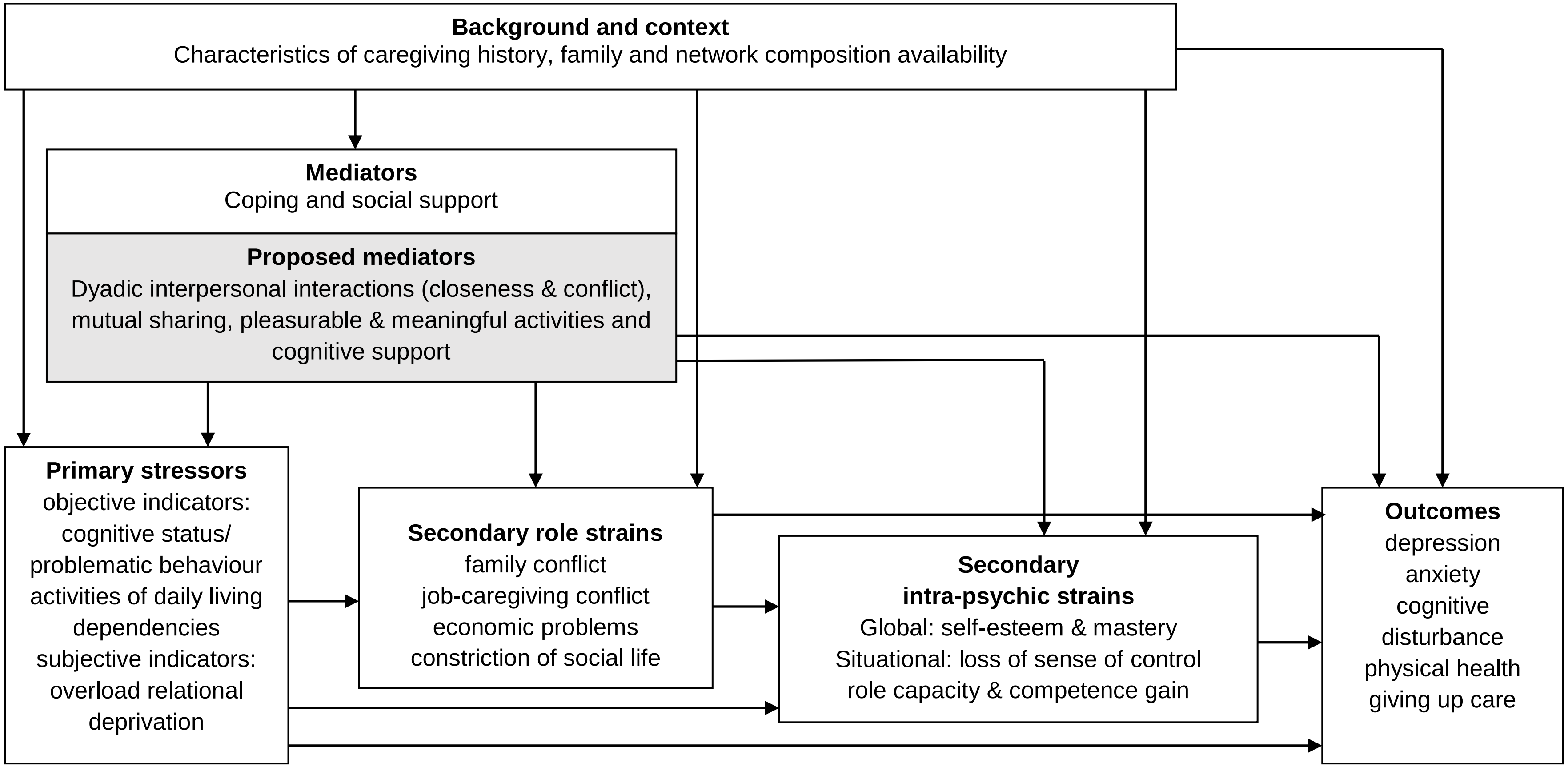


Figure 1 Caregiving Stress Model Revised (Pearlin 1990)

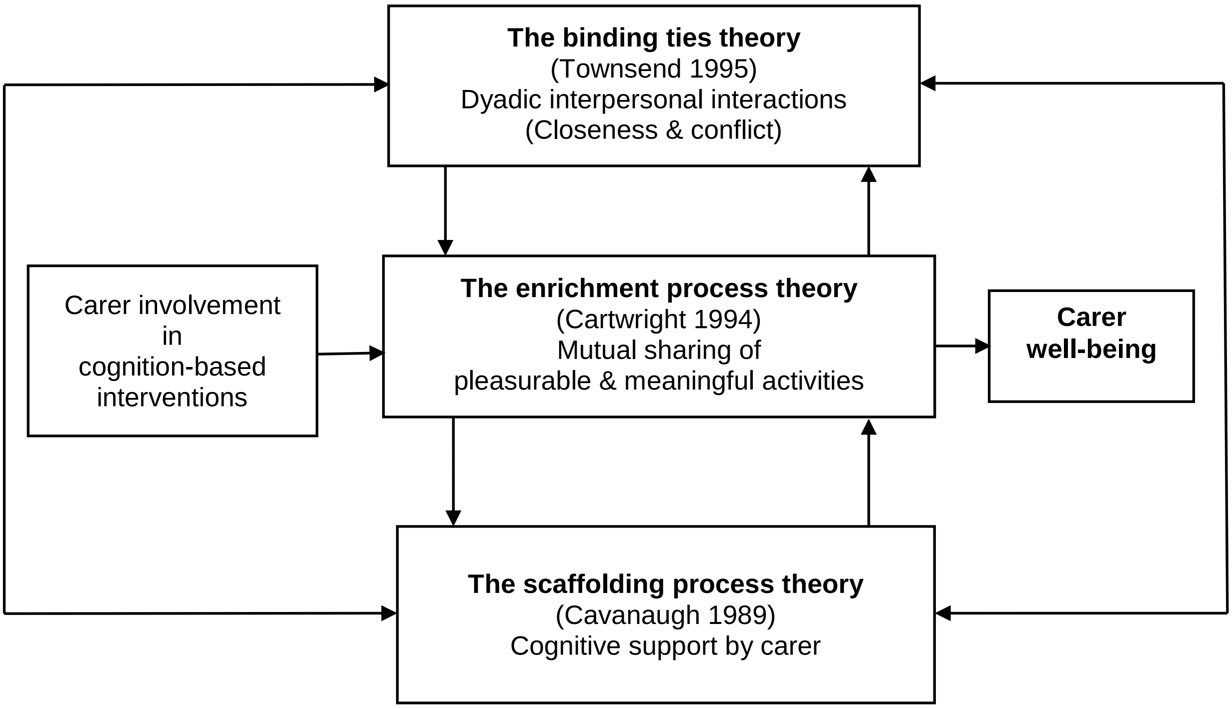


Figure 2 A Conceptual Framework of Carer Involvement in CBIs for People with Dementia

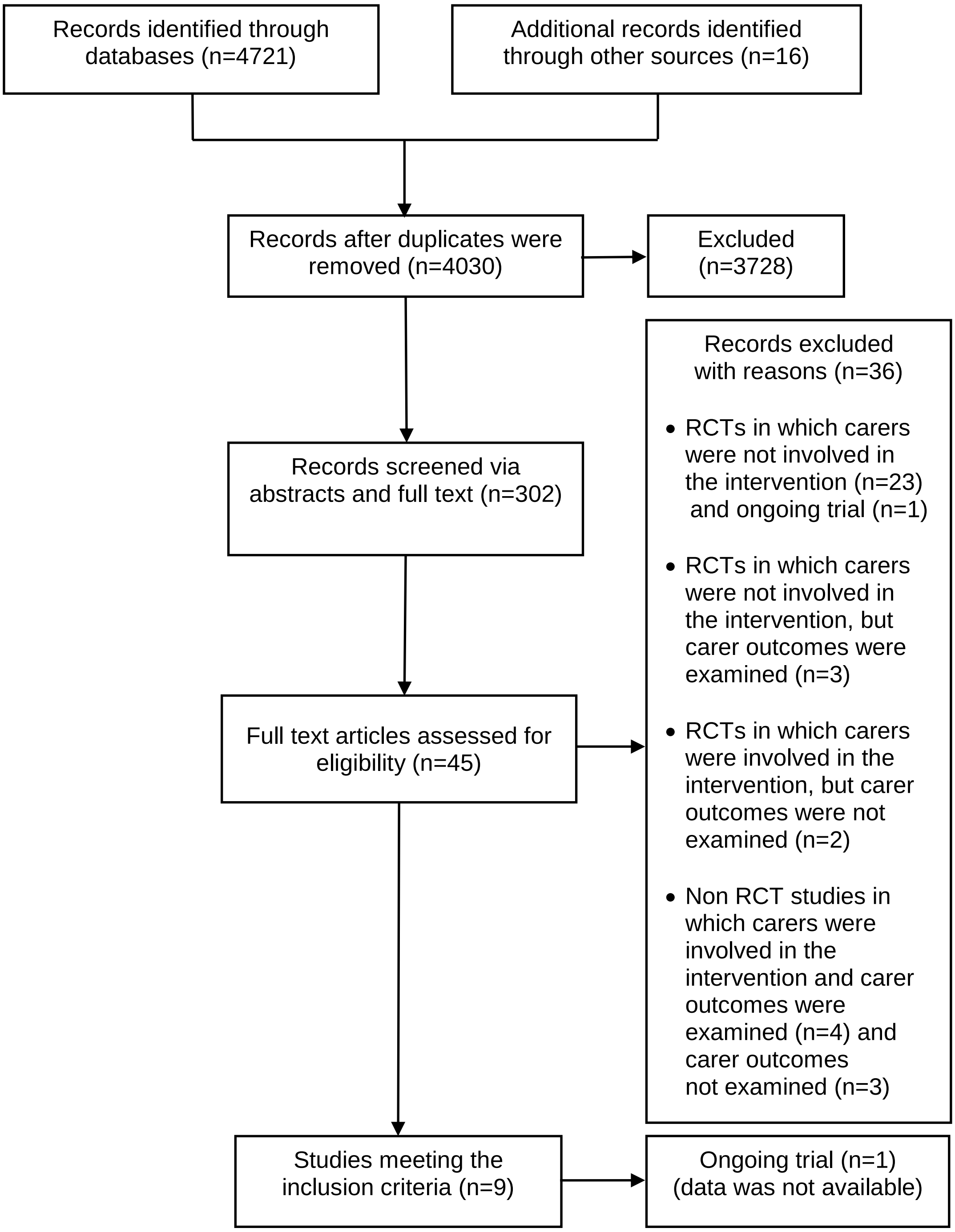
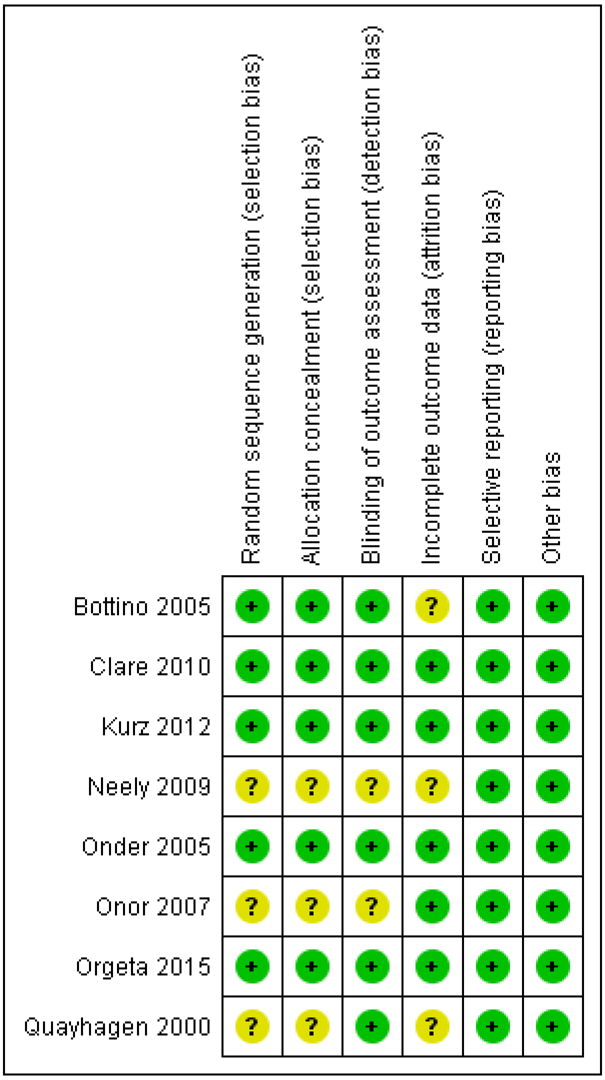
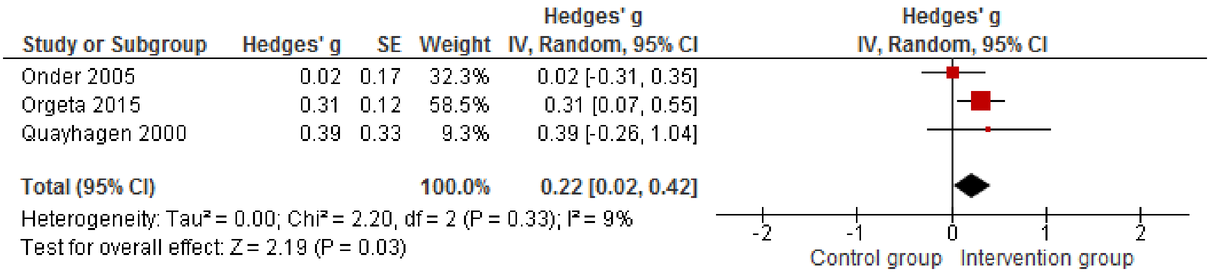


Figure 3 The PRISMA Flow Diagram of the review



	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Bottino 2005	+	+	+	?	+	+
Clare 2010	+	+	+	+	+	+
Kurz 2012	+	+	+	+	+	+
Neely 2009	?	?	?	?	+	+
Onder 2005	+	+	+	+	+	+
Onor 2007	?	?	?	+	+	+
Orgeta 2015	+	+	+	+	+	+
Quayhagen 2000	?	?	+	?	+	+

Figure 4 The summarised results for risk of bias assessment.



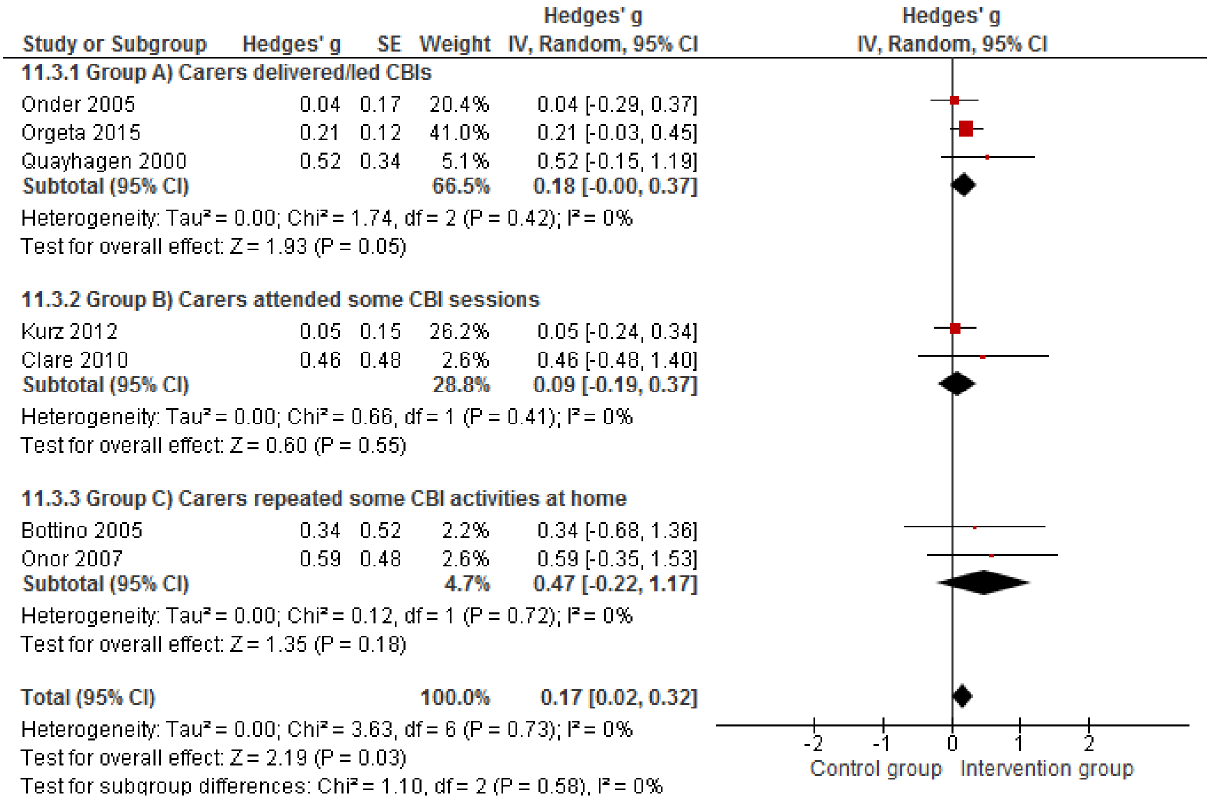
Study or Subgroup	Hedges' g	SE	Weight	Hedges' g IV, Random, 95% CI
Onder 2005	0.02	0.17	32.3%	0.02 [-0.31, 0.35]
Orgeta 2015	0.31	0.12	58.5%	0.31 [0.07, 0.55]
Quayhagen 2000	0.39	0.33	9.3%	0.39 [-0.26, 1.04]
Total (95% CI)			**100.0%**	**0.22 [0.02, 0.42]**

Heterogeneity: Tau² = 0.00; Chi² = 2.20, df = 2 (P = 0.33); I² = 9%

Test for overall effect: Z = 2.19 (P = 0.03)

Figure 5 Forest plot of carer quality of life

Carer involvement in CBIs for people with dementia vs no CBIs at follow-up for carer QoL



Study or Subgroup	Hedges' g	SE	Weight	Hedges' g IV, Random, 95% CI
11.3.1 Group A) Carers delivered/led CBIs				
Onder 2005	0.04	0.17	20.4%	0.04 [-0.29, 0.37]
Orgeta 2015	0.21	0.12	41.0%	0.21 [-0.03, 0.45]
Quayhagen 2000	0.52	0.34	5.1%	0.52 [-0.15, 1.19]
Subtotal (95% CI)			**66.5%**	**0.18 [-0.00, 0.37]**
Heterogeneity: Tau² = 0.00; Chi² = 1.74, df = 2 (P = 0.42); I² = 0%				
Test for overall effect: Z = 1.93 (P = 0.05)				
11.3.2 Group B) Carers attended some CBI sessions				
Kurz 2012	0.05	0.15	26.2%	0.05 [-0.24, 0.34]
Clare 2010	0.46	0.48	2.6%	0.46 [-0.48, 1.40]
Subtotal (95% CI)			**28.8%**	**0.09 [-0.19, 0.37]**
Heterogeneity: Tau² = 0.00; Chi² = 0.66, df = 1 (P = 0.41); I² = 0%				
Test for overall effect: Z = 0.60 (P = 0.55)				
11.3.3 Group C) Carers repeated some CBI activities at home				
Bottino 2005	0.34	0.52	2.2%	0.34 [-0.68, 1.36]
Onor 2007	0.59	0.48	2.6%	0.59 [-0.35, 1.53]
Subtotal (95% CI)			**4.7%**	**0.47 [-0.22, 1.17]**
Heterogeneity: Tau² = 0.00; Chi² = 0.12, df = 1 (P = 0.72); I² = 0%				
Test for overall effect: Z = 1.35 (P = 0.18)				
Total (95% CI)			**100.0%**	**0.17 [0.02, 0.32]**
Heterogeneity: Tau² = 0.00; Chi² = 3.63, df = 6 (P = 0.73); I² = 0%				
Test for overall effect: Z = 2.19 (P = 0.03)				
Test for subgroup differences: Chi² = 1.10, df = 2 (P = 0.58), I² = 0%				

Figure 6 Forest plot of carer depressive symptoms

Carer involvement in CBIs for people with dementia vs no CBIs at follow-up for carer depressive symptoms