

EVIDENCE SYNTHESIS

Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review

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Executive summary

Objectives The objective of this review was to assess the effectiveness of interventions that assist caregivers to provide support for people living with dementia in the community.

Inclusion criteria

Types of participants Adult caregivers who provide support for people with dementia living in the community (non-institutional care).

Types of interventions Interventions designed to support caregivers in their role such as skills training, education to assist in caring for a person living with dementia and support groups/programs. Interventions of formal approaches to care designed to support caregivers in their role, care planning, case management and specially designated members of the healthcare team – for example dementia nurse specialist or volunteers trained in caring for someone with dementia.

Types of studies This review considered any meta-analyses, systematic reviews, randomised control trials, quasi-experimental studies, cohort studies, case control studies and observational studies without control groups that addressed the effectiveness of interventions that assist caregivers to provide support for people living with dementia in the community.

Search strategy The search sought to identify published studies from 2000 to 2005 through the use of electronic databases. Only studies in English were considered for inclusion. The initial search was conducted of the databases, CINAHL, MEDLINE and PsychINFO using search strategies adapted from the Cochrane Dementia and Cognitive Improvement Group. A second more extensive search was then conducted using the appropriate Medical Subject Headings (MeSH) and keywords for other available databases. Finally, hand searching of reference lists of articles retrieved and of core dementia, geriatric and psycho geriatric journals was undertaken.

Assessment of quality Methodological quality of each of the articles was assessed by two independent reviewers using appraisal checklist developed by the Joanna Briggs Institute and based on the work of the Cochrane Collaboration and Centre for Reviews and Dissemination.

Data collection and analysis Standardised mean differences or weighted mean differences and their 95% confidence intervals were calculated for each included study reported in the meta-analysis. Results from comparable groups of studies were pooled in statistical meta-analysis using Review Manager Software from the Cochrane Collaboration. Heterogeneity between combined studies was tested using standard chi-square test. Where statistical pooling was not appropriate or possible, the findings are summarised in narrative form.

Results A comprehensive search of relevant databases, hand searching and cross referencing found 685 articles that were assessed for relevance to the review. Eighty-five papers appeared to meet the inclusion criteria based on title and abstract, and the full paper was retrieved. Of the 85 full papers reviewed, 40 were accepted for inclusion, three were systematic reviews, three were meta-analysis, and the remaining 34 were randomised controlled trials. For

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the randomised controlled trials that were able to be included in a meta-analysis, standardised mean differences or weighted mean differences and their 95% confidence intervals were calculated for each. Results from comparable groups of studies were pooled in statistical meta-analysis using Review Manager Software and heterogeneity between combined studies was assessed by using the chi-square test. Where statistical pooling was not appropriate or possible, the findings are summarised in narrative form.

The results are discussed in two main sections. Firstly it was possible to assess the effectiveness of different types of caregiver interventions on the outcome categories of depression, health, subjective well-being, self-efficacy and burden. Secondly, results are reported by main outcome category. For each of these sections, meta-analysis was conducted where it was possible; otherwise, a narrative summary describes the findings.

Effectiveness of intervention type Four categories of intervention were included in the review – psycho-educational, support, multi-component and other.

Psycho-educational

Thirteen studies used psycho-educational interventions, and all but one showed positive results across a range of outcomes. Eight studies were entered in a meta-analysis. No significant impact of psycho-educational interventions was found for the outcome categories of subjective well-being, self-efficacy or health. However, small but significant results were found for the categories of depression and burden.

Support

Seven studies discussed support only interventions and two of these showed significant results. These two studies were suitable for meta-analysis and demonstrated a small but significant improvement on caregiver burden.

Multi-component

Twelve of the studies report multi-component interventions and 10 of these report significant outcomes across a broad range of outcome measures including self-efficacy, depression, subjective well-being and burden. Unfortunately because of the heterogeneity of study designs and outcome measures, no meta-analysis was possible.

Other interventions

Other interventions included the use of exercise or nutrition which resulted in improvements in psychological distress and health benefits. Case management and a computer aided support intervention provided mixed results. One cognitive behavioural therapy study reported a reduction in anxiety and positive impacts on patient behaviour.

Effectiveness of interventions using specific outcome categories In addition to analysis by type of intervention it was possible to analyse results based on some outcome categories that were used across the studies. In particular the impact of interventions on caregiver depression was available for meta-analysis from eight studies. This indicated that multi-component and psycho-educational interventions showed a small but significant positive effect on caregiver depression.

Five studies using the outcome category of caregiver burden were entered into a meta-analysis and findings indicated that there were no significant effects of any of interventions. No meta-analysis was possible for the outcome categories of health, self-efficacy or subjective well-being.

Implications for practice From this review there is evidence to support the use of well-designed psycho-educational or multi-component interventions for caregivers of people with dementia who live in the community. Factors that appear to positively contribute to effective interventions are those which:

- Provide opportunities within the intervention for the person with dementia as well as the caregiver to be involved
- Encourage active participation in educational interventions for caregivers
- Offer individualised programs rather than group sessions
- Provide information on an ongoing basis, with specific information about services and coaching regarding their new role
- Target the care recipient particularly by reduction in behaviours

Factors which do not appear to have benefit in interventions are those which:

- Simply refer caregivers to support groups
- Only provide self help materials
- Only offer peer support

Key words: Dementia, caregivers, meta-analysis, systematic review, interventions.

Background

In 2005, the number of Australians with dementia passed the 200 000 mark (and reached 1.0% of the population). By 2050, the total number will exceed 730 000 (2.8% of the projected population) – a fourfold increase since 2000. By 2050, there are projected to be over 175 000 new cases every year.¹ The average time a person will live with dementia is 4–5 years and 55% of people with moderate to severe dementia live in the community, in their homes or the home of a carer.¹

Demand for access to high-quality care for people living with dementia in the community will rise exponentially over the coming decade. Already, prior to the onset of the foreseeable ‘epidemic’, there is a significant gap between supply and demand for such care; and on too many occasions the quality of care available and the outcomes achieved lag behind our knowledge of what should be done and what could reasonably be expected.

People living in the community with dementia are frequently supported by informal caregivers: spouses, other family members, friends or neighbours. Caregivers can experience negative mental and physical consequences as a result of the pressures of caregiving. Problems can include depression and strain, social isolation, financial burden and disruptions to sleep.²

A 1998 Cochrane review investigating support for carers of people with Alzheimer’s type dementia³ did not find conclusive evidence of the most effective support for carers. Since then other systematic reviews have been conducted to evaluate interventions for caregivers.^{4–6} The review by Acton and Kang⁴ used meta-analytic techniques to evaluate intervention strategies designed to help caregivers of adults with dementia cope with the burden of caregiving. They reviewed articles published from 1982 to 1999 that tested an intervention to reduce the burden of caregiving. Interventions were categorised into support group, education, psycho-education, counselling, respite care and multi-component interventions (e.g. sleep, support, stress management and education intervention). A total of 1254 participants were included in the meta-analysis of which 866 were in experimental groups and 388 in control groups. Seventeen studies used both a treatment and control group, and seven studies used a one-group pre-/post-test design. Outcome measures focused on caregiver burden predominantly measured by the Zarit Burden Interview or the Burden Scale. No significant effect on caregiver burden was found for the pooled effect studies but looking at effect by intervention type, the multi-component intervention category ($n = 3$) showed a small significant positive effect on caregiver burden. The other intervention categories had no significant effect on burden. The authors comment that burden may not be the best outcome measure to choose to demonstrate effectiveness of caregiver interventions as it lacks conceptual clarity. The review by Cooke *et al.*⁵ aimed to identify the components that have been utilised in psychosocial/psycho-educational interventions for dementia caregivers of people with dementia. Components found to be effective were the

inclusion of social components such as social support and cognitive training such as problem-solving.

The review by Brodaty, Green and Koschera⁶ was a meta-analysis of articles published from 1985 to the end of 2000 that included interventions for caregivers (excluding respite care). Thirty studies included a total of 2040 caregivers, predominantly spouses. Main outcomes were categorised as psychological morbidity and burden. Other outcomes included coping skills, social support, knowledge of Alzheimer’s disease and time till institutional placement. Effect sizes were calculated for each study. For continuous data an effect size of 0.2 was rated as a weak effect, 0.5 moderate and 0.8 strong. Statistical significance and study success were deemed for those with effect sizes of greater than 0.5. Odds ratio was used for dichotomous outcomes. An effect size of greater than 0.5 for caregiver psychological morbidity was found in five of the 20 studies that used this as a measure. Only one of the 20 studies measuring burden showed a statistically significant effect and this was for a social skill-training program conducted in 1988. Seven studies used time until nursing home placement as an outcome, and in four studies, a significantly longer time in home care was found in the intervention groups, therefore, delaying the need for institutionalisation. These authors conclude that some psychosocial interventions can reduce psychosocial morbidity in caregivers, and may help people with dementia to stay in their own homes for longer. Study limitations of variability in outcomes, follow-up times and sample sizes may have contributed to interventions not showing statistically significant effects.

Despite an increasing literature considering interventions for caregivers of people with dementia, the number of systematic reviews addressing this topic is small. This review will extend work already published^{3–6} by considering literature from 2000 to 2005.

Objectives

The objective is to assess the effectiveness of interventions that assist caregivers to provide support for people living with dementia in the community. Interventions are those which directly affect the caregivers’ ability to provide support for a person living with dementia. Specific interventions of interest are:

- Interventions designed to support caregivers in their role through education and/or skills training about caring for someone with dementia in the community
- Interventions of formal approaches to care delivery designed to support caregivers in their role such as case management, support programs or the use of specially designated members of the healthcare team such as dementia nurse specialists or volunteers
- Interventions that have multi-components of the above interventions.

Inclusion criteria

Types of participants

The review considered caregivers who provide support for people with dementia living in the community

(non-institutional care). Caregivers are defined as individuals taking responsibility for the care of a person with dementia. The relationship of the caregiver to the person with dementia may be biological, by acquisition (related by marriage/contract) or by choice (not related biologically or marriage/contract). This review included Alzheimer's disease, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, Wernicke Encephalopathy, Creutzfeldt-Jakob Syndrome and Korsakoff Syndrome.

Types of intervention

Only interventions involving caregivers of people with dementia living in the community (non-institutional care) were considered. Definitions of specific intervention types were not provided at this stage of the searching process. Three broad categories reflected intervention types from published^{5,6} reviews. These included:

- 1 Interventions designed to support caregivers in their role
 - Skills training
 - Education to assist in caring for a person living with dementia
 - Support groups/programs
- 2 Interventions of formal approaches to care designed to support caregivers in their role
 - Care planning
 - Case management
 - Specially designated members of the healthcare team – for example dementia nurse specialist or volunteers trained in caring for someone with dementia
- 3 Multi-component interventions that involve any of the above

Types of studies

Studies include systematic reviews, meta-analyses, randomised control trials, quasi-experimental studies, cohort studies, case control studies and observational studies without control groups. Studies from 2000 to 2005 were considered for inclusion as studies published prior to that date have been included in other, similar reviews. Only studies published in English were considered for inclusion.

Types of outcomes

The following outcomes were considered to be the most valid measures of impact on the caregiver.

- Health service utilisation – outcomes impacting on the caregiver
 - Health service utilisation – outcomes for the person with dementia that are specifically related to a caregiver intervention
 - Caregiver satisfaction with health service utilisation
 - Psychological morbidity of caregivers measured by valid and reliable instruments
 - Caregiver quality of life measured by valid and reliable instruments
 - Caregiver self reported perception of knowledge or competence in caring for someone with dementia in the community
- Excluded are outcomes concerning respite care

Search strategy

- 1 The initial phase consisted of searches of the databases CINAHL, MEDLINE and PsycINFO using search strategies adapted from the Cochrane Dementia and Cognitive Improvement Group (see Appendix I).
- 2 A second more extensive search was performed using the appropriate headings and keywords for each of the following databases:

Cochrane (CDSR, DARE, CCTR and CENTRAL)

All systematic review protocols and reviews from the Cochrane Dementia and Cognitive Improvement Group

APAIS Health

Search terms (Keywords) Dementia and caregivers

Current Contents

Search terms Topic/Subject (Dementia) and Topic/Subject (Caregiver)

ERIC

Search terms (Keywords) -Dementia and caregivers

Professional Development Collection

Search terms (Subject terms) – Dementia and caregivers

Psycarticles

Search terms (Keywords) – Dementia and caregivers

Dissertation and Thesis Abstracts

Search terms (Keywords) – Dementia and caregivers

NHMRC guidelines

Search terms (Keywords) – Dementia and caregivers

Social Science Citation Index

Search terms (Keywords) – Dementia and caregivers

Ageline, Econlit, Sociological Abstracts

See search strategy used for Medline (Appendix I)

Literature resources from the following web sites using the search terms – Dementia and caregivers:

National Institute of Clinical Studies Australian Centre for Evidence Based Clinical Practice (<http://www.acebcp.org.au>)

Centre for Clinical Effectiveness (<http://www.med.monash.edu.au/healthservices/cce/index.html>)

Joanna Briggs Institute (<http://www.joannebriggs.edu.au>)

National Institute for Health and Clinical Excellence (<http://www.nice.org.uk>)

National Guidelines Clearing House (<http://www.guidelines.gov>)

Alzheimer's Disease Education and Referral Centre Clinical Trials Database host: Food and Drug Administration and the National Institute on Aging (<http://www.alzheimers.org/trials/index.html>)

National Institutes of Health (NIH) Clinical Trials Database host: NIH (<http://clinicaltrials.gov/ct/gui>)

3 The third stage involved

Hand searching reference lists of articles retrieved, foundation works older than five years referred to in the literature were also be included in the review. Systematic hand searching (prospectively) of core dementia, geriatric and psycho geriatric journals, comprising:

Age and Ageing

Ageing and Society

Ageing and Mental Health

Alzheimer's Disease and Associated Disorders

American Journal of Geriatric Psychiatry
 Archives of Gerontology and Geriatrics
 Biological Psychiatry
 Clinical Therapeutics
 Dementia and Geriatric Cognitive Disorders
 European Neurology
 Experimental Gerontology
 Gerontologist
 Geriatrics
 Gerontology
 International Journal of Geriatric Psychiatry
 Journal of the American Geriatrics Society
 Journal of Gerontology – Series A, Biological Sciences and Medical Sciences
 Journal of Gerontology – Series B, Psychosocial Sciences and Social Sciences

Methodological quality

Data collection

Six hundred and eighty-five articles were identified by database searches and hand searching, and were assessed for relevance to the review based on the title and abstract. Eighty-one papers appeared to meet the inclusion criteria and the full paper was retrieved and assessed for relevance to the review criteria. Each of the articles were assessed by two independent reviewers for methodological quality prior to inclusion in the review using the appraisal checklist instrument developed by the Joanna Briggs Institute and based on the work of the Cochrane Collaboration and Centre for Reviews and Dissemination (Appendix II).

Critical appraisal

There was a high level of agreement between the two reviewers and of the 81 studies retrieved, 40 were accepted. Data from these articles were extracted using a data extraction tool developed by the Joanna Briggs Institute (Appendix III).

Data synthesis

Standardised mean differences or weighted mean differences (WMD) and their 95% confidence intervals were calculated for each included study reported in the meta-analysis. Results from comparable groups of studies were pooled in statistical meta-analysis using Review Manager Software from the Cochrane Collaboration. Heterogeneity between combined studies was tested using standard chi-square test.

Where statistical pooling was not appropriate or possible, the findings have been summarised in narrative form.

In order to group the findings in a meaningful way, for each of the studies (excluding the meta-analysis and systematic reviews) the category of intervention was identified, and the intervention was classed as either group or individual based (this was to aid in the determination of which studies to include in a meta-analysis). Intervention type was based on the categories used by Pinquart and Sorensen.⁷ Each study was independently classified by two reviewers.

- Psycho-educational – Consists of structured presentation of information about dementia and caregiver issues and includes applying new knowledge to problems. Support may be part of a psycho-educational group but is secondary to the education content.
- Support – Provides support for problems that inhibit caregiving and provide opportunities for sharing personal feelings and overcome social isolation.
- Multi-component – A combination of at least two of the above categories.
- Other – (including cognitive behavioural therapy (CBT) and exercise).

Excluding the meta-analysis and systematic review articles, the remaining studies employed the following interventions:

- Psycho-educational – 13
- Support – 7
- Multi-component – 12
- Other – 2

Of the 34 Randomised Controlled Trials (RCTs), 16 conducted the interventions with caregivers individually, 13 in group settings and the remaining five had both individual and group components.

Each of the studies was given a study-quality rating based on a 5-point scale as used by Pinquart and Sorensen.⁷

- Random Assignment (Yes = 1, No/not reported = 0)
- The intervention and control groups did not differ by sample characteristics at baseline (Yes = 1, No = 0)
- Both groups had at least 10 participants (Yes = 1, No = 0)
- Attrition rate < 10% (Yes = 1, No = 0)
- Well-validated outcome measure used (Yes = 1, No = 0)

A sum measure for the five questions was computed with a higher rating indicating better quality.

Of the 34 studies considered here, 21 had a study quality rating of 5/5, 12 had ratings of 4/5, and only one study had a rating of 3/5. For the studies that scored a rating of four, the majority marks lost because of an attrition rate in excess of 10% (10 studies), the intervention and control groups were not equivalent (one study) or, the outcome measurement tools were either not well validated or modified for the individual study (one study). For the study that was rated 3/5 this was due to the intervention, control groups were not equivalent, and attrition rate was in excess of 10%.

For the three systematic review and three meta-analysis articles, the Scottish Intercollegiate Guidelines Network methodology checklist for systematic reviews and meta-analysis was used to determine suitability of the study for inclusion (<http://www.sign.ac.uk/>). All systematic reviews and meta-analysis were independently assessed by two raters as suitable for inclusion.

Results

In addition to the two meta-analysis and one systematic review discussed in the introduction to this paper,⁴⁻⁶ two systematic reviews and one meta-analysis were found.^{2,7,8}

The review by Pusey and Richards⁸ looked at the effectiveness of psychosocial intervention for carers of people with

dementia. Their search yielded 391 studies, of which, 30 studies matched the inclusion criteria. These studies were given a quality score according to their methodological quality and divided into four intervention types, being: group, individual, service and technology. The authors conclude that individualised interventions using a problem solving approach and behaviour management demonstrated the best evidence of effectiveness. They also suggest that efforts should be made to conduct future studies with larger sample sizes and adopt randomised allocation design in order to increase the weight of evidence.

Charlesworth was critical that neither the review by Pusey and Richards⁸ nor Cooke *et al.*⁵ provide a synthesis using meta-analysis.

Peacock and Forbes² conducted a systematic review of all interventions for caregivers of persons with dementia published between 1992 and 2002. Their search yielded 36 relevant studies and these studies were rated strong, moderate or weak according to their methodological quality. Only 11 of these studies were rated as strong and the paper focuses on those studies. The most common outcome measure among these studies ($n = 6$) was institutionalisation of the care recipient. Overall, there are few significant effects for the interventions. Case management was found to be an effective method for increasing the use of formal services. The authors suggest that tailoring individual approaches to the particular needs of both caregivers and care recipients may be more successful than a single, group intervention.

While outside the original search scope, during the review a meta-analysis by Pinquart and Sorensen⁷ was published. These authors conducted a meta-analysis to discover which interventions for caregivers were effective and how significant these effects are. The studies were divided into categories of intervention types, these being: Psycho-educational, Cognitive-Behavioural, Counselling/Case Management, General Support and Respite. A total of 127 intervention studies were included in the meta-analysis and the authors concluded that, on average, the interventions had small, but significant effects on burden, depression, subjective well-

being and symptoms of the care recipient. They reported that psycho-educational interventions requiring active participation of the caregiver demonstrated the broadest effects. The authors also conclude that most interventions have domain-specific effects and therefore, interventions should be tailored to the specific needs of caregivers.

Table 1 provides a summary of the details of the randomised controlled trials included in the current review. Not all studies reported all characteristics. Of the studies, 21 had one intervention group only, eight had two intervention groups, and one study had four intervention groups. Two of the 30 studies did not have a control group. All studies were of caregivers who provided support at home for people with dementia. The number of intervention sessions ranged from one to 38. The study by King, Baumann, O'Sullivan, Wilcox and Castro⁹ with 204 interventions was treated as a statistical outlier and excluded from this calculation. The number of participants in the intervention condition ranged from 14 to 203 (mean = 63.7), for nine studies more than one intervention condition was reported and the mean number of participants in this condition was 54.9. The number of participants in the control condition ranged from 14 to 203 (mean = 57.6).

Time to first follow-up ranged from 1 to 24 months (mean = 5.1 months), to second follow-up ranged from 3 to 24 months (mean = 8.83 months), to third follow-up 6–36 months (mean = 16.29 months). Mean age of caregivers where reported was 63 (standard deviation (SD) = 6.48), 76% of caregivers were women, and 52% were spouse caregivers. Non-white ethnicity was reported for 13 studies (26.5%). The caregivers had been providing care on average for 42 months (SD = 7.75).

Five categories were used to classify the wide range of outcome measures reported in the articles (Table 2). Measures of depression, health and self-efficacy are easily categorised, while measures of subjective well-being and burden are more complex. Diener, Napa Scollon and Lucas¹⁰ define well-being as the person's evaluation of their life. Four components of subjective well-being are positive affect

Table 1 Descriptive characteristics of the randomised controlled studies

	No of studies	Mean	SD	Median	Min	Max
No of participants – 1st intervention condition	30	63.7	45.89	52	14	203
No of participants – 2nd intervention condition	9	54.9	30.92	49	14	105
No of participants control condition	27	57.6	48.64	45	14	203
Number of interventions sessions	25	8.64	8.26	7	1	38
Time to post test-months	30	5.1	4.8	3.5	1	24
Time to 2nd post test – months	18	8.83	5.1	6.5	3	24
Time to 3rd post test – months	7	16.29	10.08	18	6	36
Gender – Female	24	76				
Gender – Male	24	24				
Carer Age	24	63	6.48	63.35	45.2	72.5
Spouse carer	23	52				
No of months providing care	11	40.8	8.17	40.7	27	52
Ethnicity– White	13	72.2			37	94
Ethnicity- Other	13	26.5			6	61

SD, standard deviation; Min, minimum; Max, maximum.

Table 2 Outcome categories and outcomes measured reported in the 34 RCTs

Category	Outcome measures	Outcome measures
Depression	Beck Depression Inventory	Geriatric Depression Scale
Health	Center for Epidemiologic Studies Depression Scale,	Hamilton Depression Rating Scale
	Caregiver Health Index	Modified General Well-being Scale
Subjective well-being	Caregiver Sleep questionnaire	Multilevel Assessment Inventory
	Health Assessment Scale,	Pittsburgh Sleep Quality Index
	Brief Symptom Inventory	Revised Bradburn Affect Scale
	Beck Anxiety	Rosenberg Self Esteem Scale
	Bradburn Affect Scale	Steinmetz Control Scale
	Caregiver Distress Measure	Satisfaction with Social Support Network
	Caregiver Hassles Scale	Social Support Questionnaire
	Geriatric Center Morale Scale	Spielberger Anger Expression Scale
	General Well-being	Spielberger Anxiety Inventory
	Hamilton Anxiety Scale	State Trait Anger Expression Inventory
	Inventory of Socially Supportive Behaviours	Perceived Change in Affect
	Multiple Affect Adjective Checklist	State Trait Anxiety Inventory
	Ifield Psychiatric Symptoms Index	Thomas Assessment of Communication Inadequacy
Perceived Stress Scale	World Health Organisation Quality of Life Measure – WHOQOL-BREF	
Self-efficacy	Relatives Stress Scale	Personal Self-Efficacy Scale
	Caregiver Self-Efficacy Assessment	Self-efficacy and behaviour upset scale
	Revised Scale of Caregiving Self-Efficacy	
	Agitation Management Self-Efficacy Scale	
Burden	Assessment of Awareness about Communication Strategies Test	Neuropsychiatric Inventory of Distress (NPI-D)
	Beliefs about Caregiving Scale	Philadelphia Geriatric Center Caregiving Appraisal Scale
		Revised Memory Behaviour Problem Checklist
	Carer resentment scale	Screen for Caregiver Burden
	Carer Strain Scale	Task Management Strategy Index
	Coping Strategies Inventory Revised	Ways of Coping Checklist Revised
	Caregiving Mastery Scale	Zarit Burden Interview
	Memory of Behaviour Problem Checklist	
	NPI	

WHOQOL-BREF, World Health Organisation Quality of Life Measure-Brief Version.

(joy, contentment, etc.), negative affect (anger, stress, etc.), global life judgements (life satisfaction, fulfilment) and domain satisfaction (marriage, work, health, leisure). A large number of outcome measures are included in this category. Zarit¹¹ defines caregiver burden as the extent to which caregivers perceived their emotional or physical health, social life and financial status as suffering as a result of caring for their relative. Some burden scales such as the Zarit Burden Interview have two subscales; a measure of subjective (perception) and objective (tasks) burden, while others only have one subscale (Caregiving Mastery Scale).

Effects of different types of interventions on caregiver outcomes

Psycho-educational interventions

Thirteen studies used a psycho-educational intervention and reported outcome measures of depression, health, subjective well-being, self-efficacy and burden.

The reported results are quite variable, although with the exception of the study reported by Martin-Cook, Remakel-Davis, Svetlik, Hynan and Weiner,¹² all report some positive effects of psycho-educational interventions. Most studies report findings only at the completion of the intervention and evidence of sustained impact of the intervention is

limited. It is, therefore, possible that these effects may not be maintained if further follow-up analysis had been conducted. The studies also varied in the length and exposure to the intervention with some studies reporting on a one off single exposure while others treat caregivers with weekly sessions over several months. These differences may explain variability in reported effectiveness.

Seven studies report interventions that were conducted for at least a 6-week period, with two studies 4 years apart by the same author showing development of the intervention strategy over time.^{13,14}

A 2001 article by Hepburn, Tornatore, Center and Ostwald¹⁴ reports on a community-based 14-h training program over 7 weeks designed to provide the caregiver with the knowledge, skills and beliefs required to function effectively in their caregiving role. The training had five components – information provision, concept development, role clarification, belief clarification and mastery-focused coaching. The mastery-focused coaching provided opportunity for caregivers to put what they had been taught into practice. A day-care-like group was available for care recipients during each of these 2-h periods. Outcome measures included the Revised Memory Behaviour Problem Checklist (RMBPC), Center for Epidemiologic Studies Depression Scale

(CES-D) and Beliefs about Caregiving Scale (BACS). Caregivers in the intervention group reported improved outcomes on all three measures 3 months after completion of the training program. The authors conclude that three key aspects of the training were important to the successful outcomes. These are information provided on an ongoing basis, specific information about services and coaching regarding their new role. A major short-coming of this study was the lack of linking of the training to the caregiver's usual medical or other care providers.

The more recent study published in 2005 by Hepburn, Lewis, Narayan, Center, Tornatore, Lindstrom and Bremer¹³ of a randomised control trial which had two intervention groups and one control group also found positive short-term results. The two intervention groups participated in the Partners in Caregiving Program. One group had an intervention aimed at improving strategies for day-to-day care of a person with dementia. Participants in the second intervention group were provided with a decision-making framework. Both interventions were over a period of 6 weeks for 2 h per week. Six outcome measures were used over two data points – 6 months and 12 months. Positive findings for caregiver distress and caregiving attitude was evident at 6-month follow-up for both intervention groups but these effects had diminished at 12 months. No significant differences were found between the two intervention groups. The authors highlight that this study, similar to that reported in the 2001 article (Hepburn, Tornatore, Center and Ostwald), was not conducted in conjunction with any clinical services.

Teri, McCurry, Logsdon and Gibbons¹⁵ conducted a study using a problem solving-based intervention to approach behaviour change. The intervention consisted of eight weekly in home sessions followed by monthly phone calls. The first three sessions concentrated on problem solving approaches to behaviour change with subsequent sessions focused on improving caregiver communication and increasing pleasant strategies to improve mood. Outcome measures included the CES-D, the Hamilton Depression Rating Scale, the Caregiver Sleep Questionnaire, the Perceived Stress Scale, Screen for Caregiver Burden and the RMBPC. Outcomes were measured immediately post-intervention and again at 6 months. Caregivers in the intervention group showed significant decrease in levels of depression, burden and reactivity to problem behaviours, and these findings were maintained at 6-month follow-up.

Coon, Thompson, Steffen, Sorocco and Gallagher-Thompson¹⁶ conducted a study comparing the effectiveness of two different intervention groups, an Anger Management Class or Depression Management Class against a waitlist control group for female-only caregivers. The interventions were delivered via a small group workshop format, 2 h per week for 8 weeks and two follow-up skill reinforcement sessions at 1-month intervals. Outcomes measured included the Revised Scale for Caregiving Self-Efficacy, the State-Trait Anger Expression Inventory, the State Anger Scale and the Multiple Affect Adjective Checklist hostility and depression subscales. Assessments were conducted at the completion of the intervention and then 3 months later. The reported find-

ings include a small effect for both intervention groups in reduction of anger and depression along with increases in self-efficacy for managing behavioural problems and controlling upsetting thoughts. The anger management group also reported increases in positive coping.

Gallagher-Thompson, Coon, Solano, Ambler, Rabinowitz and Thompson¹⁷ conducted an intervention as part of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study that compared a psycho-educational intervention – the Coping with Caregiving Class (CWC), an enhanced support group (ESG) and a minimal support condition as the control group. The CWC was designed to teach caregivers cognitive-behavioural mood management skills particularly reducing negative affect and increasing positive mood. The intervention period was over 10 weeks and outcomes reported reflect assessment at the completion of this time. The ESG was designed to provide peer support on a weekly basis. Outcome measures included depression using the CES-D, coping using the Revised Ways of Coping Checklist (RWCCCL) which has positive and negative subscales, perception of support using the Inventory of Socially Supportive Behaviours and burden using the RMBPC. Both groups included only female caregivers. The authors report a significant reduction in depression measured by the CES-D for the CWC group in comparison with the ESG and control group. A significant result on the positive coping scale of the RWCCCL was found for the CWC group but not for the ESG or control group; however, no differences between groups were found for the negative coping subscale. Both intervention groups showed a significant improvement on the RMBPC scale but no significant differences across groups for the perception of social support. The authors conclude that a psycho-educational intervention based on CBT can decrease depression and increase effective coping strategies of female caregivers for someone with dementia.

A study comparing two intervention groups and a control group is reported by Bourgeois, Schultz, Burgio and Beach.¹⁸ One intervention group attended patient change workshops while the other intervention group attended self-change workshops. Interventions were conducted over a 12-week period. The self-change workshop provided three self-change strategies – increasing pleasant events, problem solving and relaxation techniques. For 9 weeks following this workshop a project staff member visited the caregiver in their home for 1 h each week for individualised skills training. In the patient-change group the weekly visits helped caregivers to identify problem behaviours and develop a management plan. Outcome measures included the Caregiver Strain Scale, the Spielberger Anger Expression Scale, the Spielberger Anxiety Inventory, the Caregiver Self-Efficacy Assessment, the Perceived Stress Scale, the CES-D and the Caregiver Health Index, and were measured at the completion of the treatment phase and at 3- and 6-month post-intervention. Results indicate that both treatment groups learned skills that helped reduce problem behaviours and had some effect on other outcomes including temporary effects on depression and perceived stress along with delayed effects on perceived strain. The authors note that

future interventions should assess the caregiver's specific training requirements and tailor interventions accordingly.

A study conducted by Hebert, Levesque, Vezina, Lavoie, Ducharme, Gendron *et al.*¹⁹ reports on an intervention where the intervention group participated in 15, 2-hour-weekly sessions that focused on stress appraisal (four meetings) and coping (11 meetings). Outcome measures were administered at the completion of the intervention and included the RMBPC, the Zarit Burden Interview, the Spielberger State-Trait Anxiety Inventory, the Bradburn Revised Affect Scale, the Inventory of Socially Supportive Behaviours and the Ifield Psychiatric Symptoms Index. The intervention group reported a significant effect for reactions to behavioural problems but no effect could be demonstrated on more general outcomes such as burden, stress, psychological distress, affect and social support.

The remaining six studies discussed in this section had interventions which were shorter in length. Four of these studies only involved one or two intervention sessions. The study by Done and Thomas²⁰ was a one off workshop and three studies²¹⁻²³ only provided two intervention sessions in which training and materials were provided.

Done and Thomas²⁰ compared the effectiveness of a communication techniques workshop and an information booklet for improving communications skills. Outcomes measures included the Assessment of Awareness about Communication Strategies (AACCS Test), the Relatives Stress Scale and the Thomas Assessment of Communication Inadequacy (TACI). They report that the workshop group demonstrated greater awareness of communication strategies measured by the AACCS Test than the 'booklet only' group at 6-week follow-up. There were no significant differences on the measure of relative stress or the TACI and no conclusions are drawn here as to the possible flow on effects on depression, burden or self-efficacy.

Huang, Lotus Shyu, Chen, Chen and Lin²¹ employed a two session in-home caregiver training program with a control group receiving only written information. The training program was designed to help caregivers identify problem behaviours of their family member and plan environmental modifications. The outcome measure was the Agitation Management Self-Efficacy Scale which was measured 3-week post-intervention and then at 3 months. Significant increases for caregiver self-efficacy and management of problem behaviours were noted and these effects were maintained at 3-month follow-up post-intervention.

Two articles by Gerdner, Buckwalter and Reed²² and Stolley, Reed and Buckwalter²³ report on the Progressively Lowered Stress Threshold intervention. This intervention is aimed at assisting the caregiver to manage care recipient problem behaviour. For those in the intervention group an individualised plan of care was constructed with the caregiver and focused on environmental modifications with a review visit scheduled 1 week later. The control group received two visits and were given general information about caregiving and support groups available. Outcomes were reported for 3-, 6-, 9- and 12-month post-intervention. The outcome measure used by Gerdner *et al.*²² was the

Memory and Behaviour Problems Checklist (MBPC) and the intervention group showed positive effects for appraisal of the caregiving situation. Stolley *et al.*²³ used the Philadelphia Geriatric Center Caregiving Appraisal Scales (PGCCAS) and found that while the intervention resulted in reduction of burden and increased caregiver satisfaction no effects were demonstrated for improving caregiving mastery.

The only multimedia intervention was conducted by Beauchamp, Blair Irvine, Seeley and Johnson.²⁴ This intervention involved a web-based program allowing individually tailored information that included knowledge, cognitive and behavioural skills, addressed caregiving challenges, affective issues and common concerns. Outcomes were measured immediately at the completion of the 30-day intervention and included the Caregiver Strain Instrument, CES-D and the State-Trait Anxiety Inventory. Results show improved caregiver appraisals and decreased depression, anxiety and strain. No longitudinal affects are available.

Martin-Cook *et al.*¹² provided a longer 4-week psycho-educational intervention and found no significant intervention effects for caregiver attribution, resentment or depression. The four sessions included an overview of Alzheimer's disease, behaviour management and communication strategies, environmental and safety issues, legal and financial issues, community resources and cognitive behaviour therapy approach to address negative feelings. Outcome measures included the Caregiver Resentment Scale, the CES-D, the Steinmetz Control Scale and the Neuropsychiatric Inventory (NPI) and were administered 2 weeks after completion of the intervention (week 6) and week 14.

Meta-analysis

Of the 13 studies that report a psycho-educational intervention eight had outcome measures that were suitable for meta-analysis. Of the five studies excluded Gallagher-Thompson *et al.*¹⁷ did not include a control group and Gerdner *et al.*,²² Martin-Cook *et al.*¹² and Stolley *et al.*²³ did not have data available. The study by Coon *et al.*¹⁶ did not have outcome measures compatible for meta-analysis.

Table 3 summarises the eight studies that were suitable for meta-analyses by outcome category. Six of these studies had a quality rating of 5/5, while the articles by Hepburn *et al.*¹⁴ and Teri *et al.*¹⁵ had a quality rating of 4/5, each losing a point for a drop-out rate of >10%. Statistically significant results in favour of the intervention were found for the outcome depression and subjective well-being but not for caregiver health, self-efficacy and burden.

Psycho-educational interventions and caregiver depression

Four studies that demonstrate the effect of a psycho-educational intervention on depression were entered for meta-analysis with 262 subjects in the intervention group and 236 in the control group.^{14,15,18,24} With the exception of the study by Beauchamp *et al.*²⁴ which had a 30 day intervention, all interventions were conducted over at least 7 weeks and follow-up data were collected between 3- and 6-month post-intervention.

Table 3 Psycho-educational interventions by outcome measures

Outcome category	Studies	Participants	Statistical method	Effect size
Depression	4	498	WMD (random), 95%CI	-1.93 (-3.79, -0.07)
Health	3	220	SMD (random), 95%CI	0.05 (-0.38, 0.48)
Subjective well-being	5	625	SMD (random), 95%CI	-0.16 (-0.32, 0.00)
Self-efficacy	4	548	SMD (random), 95%CI	0.30 (-0.04, 0.65)
Burden	7	824	SMD (random), 95%CI	0.02 (-0.37, 0.42)

WMD, weighted mean differences; SMD, standard mean differences; CI, confidence intervals.

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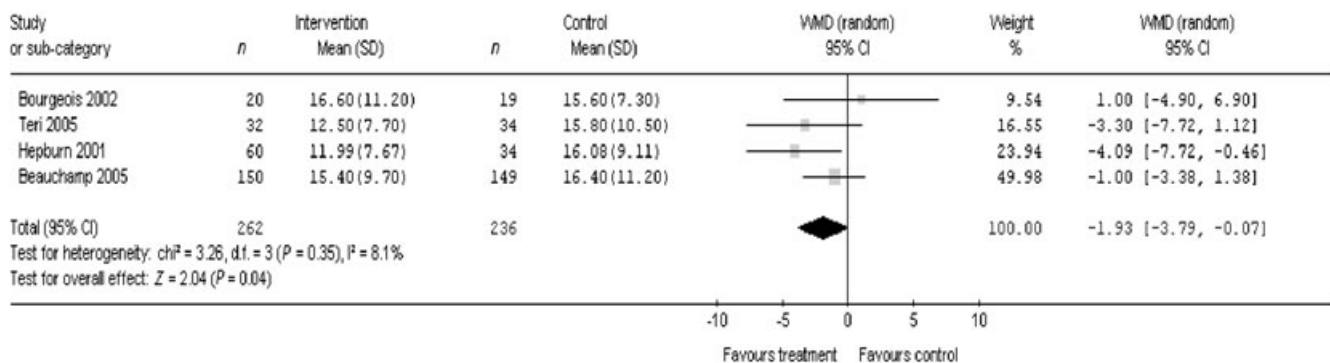


Figure 1 Forest plot of psycho-educational intervention effects on caregiver depression. SD, standard deviation; CI, confidence intervals; d.f., degree of freedom; WMD, weighted mean differences.

Analyses were adjusted to the random effects model because of heterogeneity of the trials, and WMD were used because the same outcome measure, the CES-D was used for all for studies. To maximise analysis of effect of interventions over time, the follow-up data point furthest from the commencement of the intervention were used in each study. The pooled results of the total scores were significant and favouring the intervention. The WMD were -1.93 and a 95% confidence interval $(-3.79, -0.07)$ $P = 0.04$ (Fig. 1).

The study by Hepburn *et al.*¹⁴ does not pass through the line of no effect indicating that the result was individually and statistically significant; however, the confidence interval is quite large. The intervention in this study was a comprehensive 7-week program and the outcome was measured approximately 3 months after program completion. The study by Beauchamp *et al.*²⁴ has the smallest confidence interval and also accounts for the most weight in the analysis. The intervention used in this study was a multimedia program but outcomes were measured immediately at the completion of the 30-day intervention and no results of longitudinal effect are available. The study by Bourgeois *et al.*¹⁸ shows the least convincing results with low weighting and a large confidence interval.

Psycho-educational interventions and caregiver subjective well-being

Five studies that demonstrate the effect of a psycho-educational intervention on caregiver subjective well-being

were entered for meta-analysis with 346 subjects in the intervention group and 279 in the control group.^{13,18–20,24} Analyses were adjusted to the random effects model because of heterogeneity of the trials, and standard mean differences (SMD) were used because different outcome measures were used. Done *et al.*²⁰ used the Relatives Stress Scale, Hebert *et al.*¹⁹ and Beauchamp *et al.*²⁴ used the State Trait Anxiety Scale, Bourgeois *et al.*¹⁸ used the Perceived Stress Scale, and Hepburn *et al.*¹³ used a Caregiver Distress Measure constructed specifically for the study. Intervention times for each of the six studies varied from 30 days²⁴ to 12 weeks¹⁸ and only the study by Hepburn *et al.*¹³ had follow-up data for 12 months.

The pooled results of the total scores were significant and favouring the intervention. The SMD were -0.16 and a 95% confidence interval $(-0.32, -0.00)$ $P = 0.04$ (Fig. 2). However, all five studies pass through the line of no effect, although the study by Beauchamp *et al.*²⁴ which has the most weight has a narrow confidence interval. This is similar to the results reported for depression (Fig. 1) and may be attributable to immediate effects that may not be sustained.

Summary of psycho-educational interventions

From this analysis of randomised controlled trials the use of a psycho-educational intervention program does appear to have a small and immediate impact on reducing caregiver depression and improving caregiver subjective well-being;

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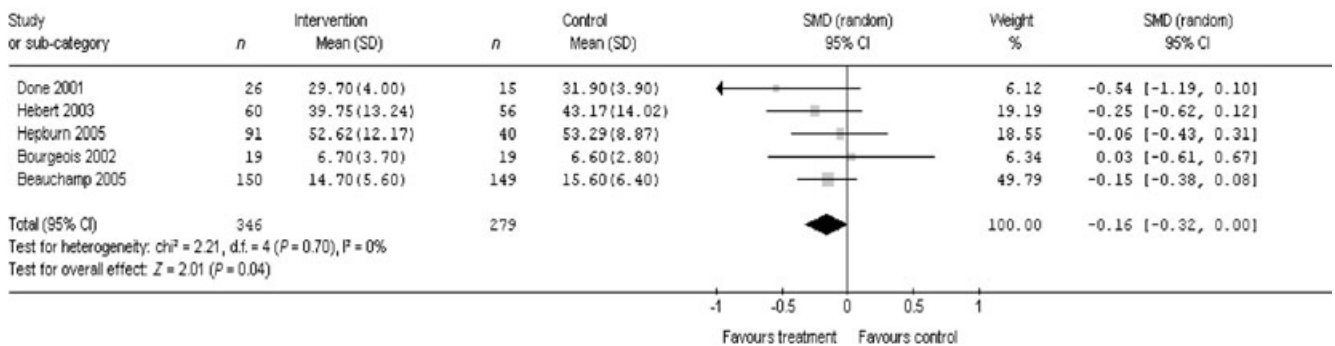


Figure 2 Forest plot of psycho-educational interventions and caregiver subjective well-being. SD, standard deviation; CI, confidence intervals; d.f., degree of freedom; SMD, standard mean differences.

however, as all but one of the studies included in the meta-analysis cross the line of effect, more studies using standardised measures and adequate sample sizes are required. Also the lack of longitudinal studies precludes further conclusions for long-term effects of these interventions. The absence of significant effects on outcomes of health, self-efficacy and burden may reflect the wide range of outcome measures.

Two of the meta-analysis articles examined the impact of psycho-educational interventions. Acton and Kang⁴ who reviewed studies published up to 1999 using the outcome measure of burden found no significant impact of psycho-educational interventions. The more recent article by Pinquart and Sorensen⁷ which included studies from 1982 up to 2005 found that psycho-educational interventions had significant effects on caregiver burden, depression, subjective well-being, caregiver knowledge or ability and care receiver outcomes but not time to institutionalisation. These authors divide psycho-educational interventions according to whether the caregiver is involved in an active role such as role play or if information only is provided. The most significant effect is those in which there is active participation by the caregiver. Pinquart and Sorensen⁷ argue that their significant findings on the positive effect of psycho-educational interventions on caregiver burden which are contrary to that found by Acton and Kang⁴ are a result of including more recent studies that have found significant impacts on caregiver burden.

Support interventions

Seven studies report support interventions and similar to the psycho-educational interventions outcomes vary, with some studies reporting no main effects from the intervention and others reporting significant positive effects. Five of seven studies^{25–29} showed no significant effects. The studies by Fung *et al.*³⁰ and Dooley *et al.*³¹ indicate positive impacts of their interventions on decreasing caregiver burden and improving quality of life.

Dooley and Hinojosa³¹ measured burden and quality of life for caregivers receiving an individualised Occupation Therapy-based intervention. This intervention included one visit by an occupational therapist that made recommendations for environmental modifications, caregiver approaches to the care recipient and community-based assistance. Caregiver burden using the Zarit Burden Interview was the outcome measured between 1 and 6 months after the intervention visit. Caregivers who received the intervention reported lower feelings of burden.

A study by Fung and Chien³⁰ conducted an intervention that used a mutual support group approach. The group sessions were facilitated by a nurse trained in group facilitation and were conducted for 12 weeks. Sessions included education, psychological support and problem solving. The control group received the conventional services provided by dementia centres. Outcomes were measured using the Neuropsychiatric Inventory Caregiver Distress Scale (NPI-D) and the World Health Organisation Quality of Life Measure-Brief Version (Hong Kong) and were completed after 12 group sessions. The intervention group had lower levels of distress and improvement in quality of life. No longitudinal effects are reported.

Pillemer and Sutor²⁷ implemented a social support enhancement program with volunteers who had been caregivers. The volunteers were given training in providing support and a toolkit of exercises and activities for use with caregivers. Support meetings were provided for 2 hours over a period of 8 weeks. Outcome measures included the CES-D and Rosenberg Self-Esteem Scale and were administered approximately 3–4 months after the final visit. The authors found no significant improvements on caregiver depression or self esteem and suggest that peer support enhancement should be part of a multi-component intervention rather than one that stands alone.

A 1-year nurse delivered program of education and counselling is reported by Wright, Litaker, Laraia and DeAndrade.²⁶ Caregivers were provided with supportive

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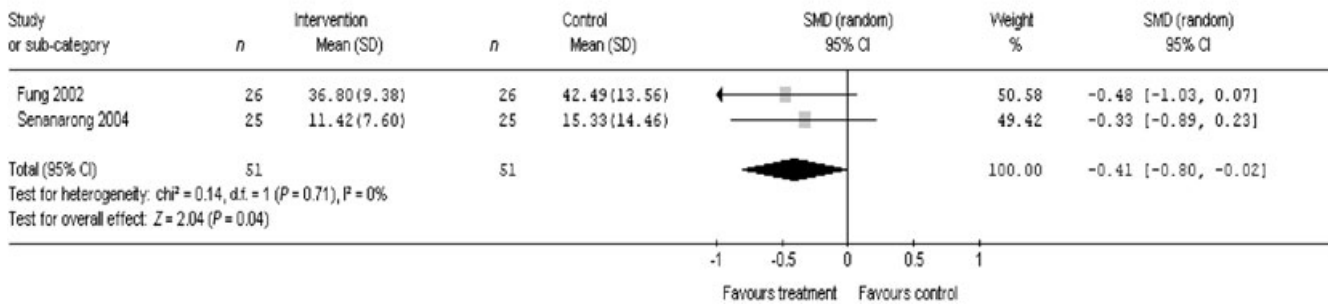


Figure 3 Forest Plot of Support interventions and caregiver burden. SD, standard deviation; CI, confidence intervals; d.f., degree of freedom; SMD, standard mean differences.

counselling as well as asked to identify troublesome behaviours of the person with dementia. The nurse would then provide strategies for handling these behaviours. Outcome measures included the Caregiving Hassle Scale, the CES-D and the Multilevel Assessment Inventory and were conducted at 2 weeks, 6 weeks, 12 weeks, 6 and 12 months. No significant effects on caregiver stress, depression and physical health were found.

Nobili, Riva, Tettamanti, Lucca, Liscio, Petrucci *et al.*²⁵ report on a structured intervention which included a home visit with a psychologist and an occupational therapist. The psychologist discussed with caregivers what behaviours people with dementia may exhibit and offered psychological support and training. The occupational therapist suggested strategies for dealing with care recipient behaviours and modifications to the home. Outcome was measured by the Relatives Stress Scale at 6 months and 12 months. No significant impact on relative stress was found between the intervention and control group.

Senanarong, Jamjumras, Harmphadungkit, Klubwongs, Udomphantharak, Pongvarin *et al.*²⁹ conducted a group counselling and support intervention which included a 45-minute group session conducted by two nurses. A total of five sessions were held approximately 6–8 weeks apart. Outcome assessments occurred at 3 and 6 months using the NPI. No significant differences were evident between the intervention and control group although there were significant differences between baseline measures and 6-month follow-up for the intervention group only. The authors conclude that small sample size and non-significant findings between groups limit generalisability of these findings. Mahoney, Tarlow and Jones²⁸ report on findings from a 12-month study trialling the use of a computer automated interactive voice response system. The system was designed to provide caregiver stress monitoring, counselling information and a voice-mail telephone support group. Outcome measures included the RMBPC, the State Anxiety Inventory (STAI) and the CES-D and were administered at 6, 12 and 18 months. There were no significant intervention effects as measured by the RMBPC, the CES-D or the STAI.

The meta-analysis by Acton and Kang⁴ found no significant results of support interventions on caregiver burden. In the meta-analysis by Pinquart and Sorensen,⁷ only one support intervention was reported and this was found to have a significant effect on improving caregiver subjective well-being but no significant effects for burden, depression, caregiver ability/knowledge, symptoms of the care recipient or time to institutionalisation were found.

Meta-analysis

Of the seven studies that report a support intervention two had outcome measures that were suitable for meta-analyses^{29,30} and both had a quality rating of 5/5. The studies by Fung and Chien³⁰ and Senanarong *et al.*²⁹ which demonstrate the effect of a support intervention on caregiver burden were entered for meta-analysis with 51 subjects in the intervention group and 51 in the control group.^{29,30} Analyses were adjusted to the random effects model because of heterogeneity of the trials, and SMD were used because different outcome measures were used, the NPI was used by Senanarong *et al.*,²⁹ and the NPI-D was used by Fung (2002). The pooled results of the total scores was significant and favouring the intervention. The SMD were -0.41 with a 95% confidence of interval -0.80 to -0.02 ($P = 0.04$). These two studies have small sample sizes and both results cross the line of no effect. More studies are required to increase confidence in these results (Fig. 3). No studies were suitable for meta-analysis for the outcomes of depression, caregiver health, subjective well-being or self-efficacy.

Summary of support interventions

Two of the seven studies reviewed report significant effects on caregiver burden. Dooley and Hinojosa³¹ provided occupational therapy expertise for environmental modifications and the study by Fung and Chien³⁰ was a support program provided by a nurse. The five studies that did not report significant findings varied in their interventions. Unfortunately only two studies had data suitable for meta-analysis. Despite this, significant results were found that indicate support interventions may be effective in decreasing

caregiver burden. These findings indicate that a support program may be beneficial for caregivers, although more studies are required in this area.

Multi-component interventions

Twelve of the studies employed multi-component interventions and four of these were part of the REACH project, a 6-year study conducted over several states in the United States.³²⁻³⁵ A further four were from the New York University study led by Professor Mittelman.³⁶⁻³⁹

No studies were suitable for meta-analysis. Of these studies seven had a quality rating of 5/5, and five had a quality rating of 4/5.

The study by Gitlin, Corcoran, Winter, Boyce and Hauck⁴⁰ conducted prior to the REACH project examined the effectiveness of a Home Environmental Intervention on self-efficacy and upset in caregivers. The intervention consisted of five home visits by an occupational therapist that provided education and environmental modifications. No significant improvements for caregivers were demonstrated between the intervention and control group although subgroup analysis indicated positive effects of the intervention for self-efficacy for women caregivers.

The two later studies by Gitlin, Winter, Cororan, Dennis, Schinfeld and Hauck and Gitlin, Hauck, Dennis and Winter^{32,33} report the effects of the Home Environmental Skill Building Program. This program is a more intense program than reported in the Gitlin *et al.*⁴⁰ study. This included more time in the home and availability of equipment and environmental strategies. The intervention spanned 12 months with the first 6 months being the active phase and the subsequent phase being the maintenance phase. The article published in 2003 reports results of outcomes after the active phase only using the outcome measures – the RMBPC, the Caregiving Mastery Index, the Task Management Strategy and the Perceived Change Index. Results indicate that caregivers in the intervention group reported less upset with memory-related behaviours, less need for assistance from others, better affect and enhanced management ability and mastery. In the 2005 article the authors report outcomes at 12 months. At this point there is a reported loss of intervention effect for the need for help, for upset with memory-related behaviours and for task management. Improvement in caregiver affect was maintained at the 12-month point.

A different intervention from the REACH study is reported by Eisdorfer, Czaja, Lowenstein, Rubert, Arguelles, Mitrani *et al.*³⁴ This study has one group of participants involved in a family therapy intervention, one group receiving the family therapy intervention in addition to a computer telephone-support system and a minimal support control group. Outcomes are reported at 6 months and 18 months post-baseline. Six-month data indicated significant reductions in depressive symptoms for the combined family therapy and technology intervention. The family therapy intervention alone did not have a significant effect.

Another REACH study by Burns, Nichols, Martindale-Adams, Graney and Lummus³⁵ compared two interventions (no control group) of 24 months duration. One intervention

targeted patient behaviour modification and the other included patient behaviour modification in addition to stress-coping management. Both groups reported improvements in how they felt bothered by associated with problem behaviours. The stress-coping management group maintained their depression scores as measured by the CES-D, while the group receiving only the patient behaviour modification intervention had higher scores, indicating higher risk of depression.

Following the success of these REACH studies a follow-up study known as REACH II was undertaken. No published articles from this study were available at the time of this review; however, an article published in November 2006⁴¹ reports the first findings from this study. The study conducted across five sites in the United States included 692 caregivers of people with dementia divided into three groups by race (Latino, Caucasian and African-American) and then assigned to either the intervention or control group. The intervention included provision of information, didactic instruction, role playing, problem solving, skills training, stress management techniques and telephone support. The primary outcomes were five dimensions of quality of life – depression (CES-D), caregiver burden (Zarit Caregiver Burden Interview), self-care, social support and problem behaviours of the person with dementia (RMBPC). Results indicated significant improvements in the quality of life measures for Caucasian and Latino caregivers but not for African-American caregivers. Unfortunately this study only had follow-up data collected at 6 months, and therefore, no longitudinal effects are reported.

The most comprehensive multi-component study is that reported by the research group led by Mittelman.³⁶⁻³⁹ These authors provide the only longitudinal evidence of the impact of a comprehensive multi-component intervention including growth curve analysis and structural equation modelling.

This study, spanning 19 years involved 406 caregivers, 203 in both the control group and the intervention groups. The intervention included individual and family counselling sessions (six sessions over 4 months), weekly support groups (indefinitely) and ongoing access to a counselling service.

The first published article by Mittelman³⁶ reports on results of the first phase of recruitment which had 206 caregivers enrolled into the study. They found a positive effect on reducing admission to nursing home for the intervention group and particularly for care recipients with early to moderate dementia. The authors also assessed caregiver depression using the Geriatric Depression Scale (GDS) and management of behavioural problems using the MBPC. Positive benefits were found for reducing depression and caregiver reaction to care recipient behaviour problems. These effects were sustained over 12 months.

The subsequent articles report on both phases of recruitment and include 406 caregivers. The article by Roth, Mittelman, Clay, Madan and Haley³⁹ used structural equation modelling to determine whether level of social support impacted on stress appraisal as measured by the MBPC or depression measured using the GDS 12 months after inclusion in the study. The authors conclude that counselling and

support have positive impacts on social support. However, only increased satisfaction with social support predicted reductions in stress appraisal of behaviours and decrease depression. They suggest future studies should target the existing social support resources and the caregivers' satisfaction with those resources.

Sustained intervention effects of caregiver depression are discussed in the article by Mittelman, Roth, Coon and Haley.³⁷ Caregiver depression at 1-year follow-up was lower for those in the intervention group. Growth curve analysis over a 5-year period indicated that caregivers in the intervention group had significantly lower depression scores 3 years and 1 month after enrolment into the study. This result remained constant despite the severity of the care recipient's dementia and independent of caregiver gender. These results indicated that impact on caregiver depression was greater, the longer the period of follow-up indicating that a sustained intervention can have significant effects. The authors, however, warn that simply referring caregivers to support groups and providing self-help materials is not adequate. Similarly, the article by Mittelman, Roth, Haley and Zarit³⁸ reports on sustained intervention effects over 4 years of caregivers' appraisal of care recipient behaviours using the MBPC. Using growth curve analysis the authors report caregivers in the intervention group had lower reaction scores to care recipients' behaviours and this effect increased over time. In contrast caregivers in the control group had increased, and therefore, there are more negative reactions to care recipients' behaviours over time. A further article published by Mittelman, Haley, Clay and Roth⁴² which was not available during the review process provides further support for their multi-component intervention. This article specifically concentrates on reduction in the rate of nursing home placement. People with dementia whose caregivers received the intervention had a 28.3% reduction in the rate of nursing home placement and a difference in median time to placement of 557 days. More importantly the extension of time in the community rather than institutional care did not come at the expense of the caregiver. The intervention group had greater levels of caregivers' satisfaction with social support, response to problem behaviours and decreased symptoms of depression than the control group.

A study reported by Eloniemi-Sulkava, Notkola, Hentinen, Kivela, Sivenius and Sulkava⁴³ examines the effect of a 2-year-long intervention including comprehensive support by a Registered Nurse, advocacy for caregiver and patient, counselling, access to training courses and in home visits. The main measure was the time to institutionalisation. At the end of the intervention period the number of patients institutionalised was similar between intervention and control groups. However, the median time staying in the community for the intervention group was 647 days and for the intervention group, 396 days.

Marriott, Donaldson, Tarrier and Burns⁴⁴ report on a family-based intervention incorporating education, stress management and the management by using CBT. This study had a quality rating of 5/5. In this study caregivers were allocated to one of three groups, the family intervention

group or one of two control groups. Those in the intervention group were provided with three components over 14 sessions conducted over a 28-week period provided by a clinical psychologist – carer education, stress management and coping skills training. Booklets with information about Alzheimer's disease, the intervention topics and available services were provided. Neither of the two control groups received the intervention; however, one control group was provided with an assessment interview while the other was not. Post-test assessments using the Beck Depression Inventory and the General Health Questionnaire were completed at 9 months after trial entry and 12 months after trial entry. Results indicated significant reductions in caregiver depression as well as having a positive impact on patient behaviour.

Quayhagen, Quayhagen, Corbeil, Hendrix, Jackson, Snyder *et al.*⁴⁵ compare the effects of four different interventions: cognitive stimulation, dyadic counselling, dual supportive seminar, early stage day care and a wait list control group. Outcome measures included the Marital Needs Satisfaction Scale, the Brief Symptom Inventory, the Geriatric Center Moral Scale, the Health Assessment Scale and MBPC and were administered at the completion of the 1 month after the two-month intervention. Three interventions were home based and one was respite. The cognitive stimulation intervention trained caregivers to cognitively stimulate the patient by memory provoking, problem-solving and conversational fluency activities. The dyadic counselling used a systems and cognitive behavioural approach to identify problems between the caregiver/care recipients and implement stress reduction, anger management, communication enhancement and conflict resolution. In the dual supportive seminar group seminars were provided for support, discussion and problem solving. The fifth group was a wait-list control. Caregiver outcomes include improved communication from the dyadic counselling group, decreased hostility from the early stage day care group and a decrease in morale in the dual supportive seminar group. Patients in the cognitive stimulation intervention group had a greater improvement over time in cognitive outcomes and caregivers depression decreased. In the respite group and dual supportive seminar group it reported a decrease in hostility and a decrease in use of negative coping strategies.

Summary of multi-component interventions

Of the 12 articles reviewed, 10 report significant findings across a variety of outcome measures. An inherent difficulty with synthesising results from multi-component interventions is the eclectic nature of the components with the interventions. However, a common feature of the multi-component interventions reviewed is that they are provided over an extended period of time at least 6 months.

The four articles reported on the REACH study and the four articles from the New York University study provide evidence to support the use of multi-component interventions particularly on the outcomes of depression and caregiver burden. In particular the New York study was able to

demonstrate longitudinal effects on depression for up to 3 years, on appraisal for up to 4 years, and in extending the time to nursing home placement by more than 1.5 years.

The meta-analysis by Acton and Kang⁴ found mixed results with only one of the three multi-component interventions that they included having a small but significant effect on caregiver burden. The meta-analysis by Pinquart and Sorensen,⁷ which required corroborating evidence from more than one study, found that multi-component interventions only had a significant outcome on time to institutionalisation but not on burden, depression, subjective well-being, caregiver ability/knowledge or symptoms of the care recipient.

Other interventions

A study by Akkerman and Ostwald⁴⁶ using CBT specifically recruited anxious family caregivers. This study had a quality rating of 4/5. The intervention included 9-week didactic skill-training and incorporated strategies to address physical, cognitive and behavioural components associated with caregiver anxiety. Review of the use of these strategies was provided to caregivers in 2-hour weekly meetings over a 3-week period. Outcomes specifically concentrated on anxiety with caregivers completing both the Beck Anxiety Inventory and the Hamilton Anxiety Scale at the completion of the intervention, 10-week post-intervention and 16-week post-intervention. The findings report that the intervention specifically designed for anxious caregivers was successful at reducing anxiety in this group immediately following the intervention period and at a further 6-week follow-up assessment. Unfortunately a high attrition rate limited results to only 12 caregivers in the intervention group and 11 in the control group. The authors conclude that the findings suggest a need for additional investigation into the efficacy of the CBT model they developed. The meta-analysis by Pinquart and Sorensen⁷ found small to moderate effects of CBT on improving caregiver burden and large effects on improving caregiver depression. However, no effect was found for subjective well-being, caregiver ability/knowledge or symptoms of the care recipient.

One study by King, Baumann, O'Sullivan, Wilcox and Castro⁹ compared the effects of two interventions, a moderate intensity exercise program and a nutrition education program. This study only had a quality rating of 3/5. They report both groups experienced improvements in psychological distress, while the exercise group benefited from a reduction in stress induced cardiovascular reactivity and improvement in rated sleep quality.

Peacock and Forbes² report on 11 studies that used four types of interventions – education, case management, psychotherapy and computer assistance. Mixed results were found with one of the education studies showing a positive influence in reducing caregiver depression, one case management study showed that caregivers were more likely to use formal support, two studies found that psychotherapy delayed time to institutionalisation and one study found improved decision-making by using a computer network. The authors comment that methodological limitations of these studies indicate results should be interpreted with caution.

Summary of results by intervention type on measures of depression and burden

Caregiver depression

Six studies that used the CES-D as an outcome measure of caregiver depression were entered for meta-analysis with 252 subjects in the intervention group and 219 in the control group^{14,15,18,24,28,34} (Table 4). Five of the six studies had a quality rating of 5/5 with only the study by Eisdorfer *et al.*³⁴ having more than 10% of the sample not available for follow-up. The type of interventions varied between multi-component,³⁴ support²⁸ and psycho-educational.^{14,15,18,24} Analyses were adjusted to the random effects model because of heterogeneity of the trials, and WMD were used because the same outcome measure (the CES-D) was used for all studies.

Figure 4 shows the effect of interventions on carer depression using the outcome measure, the CES-D. Data for 6-month follow-up was available for all six studies and two studies had 18-month follow-up data. At 6 months a significant effect of the intervention was found – the WMD were -2.26 and a 95% confidence interval ($-3.82, -0.69$) $P = 0.005$. However, at 18-month follow-up the effects are not significant – WMD were -2.64 and a 95% confidence interval ($-6.50, 1.23$) $P = 0.18$. The pooled data of the two follow-up points indicate an overall significant effect of the intervention using all follow-up time points, WMD were -2.31 and a 95% confidence interval ($-3.76, -0.86$) $P = 0.002$. The study by Hepburn *et al.*¹⁴ is the only study that is individually significant, all the remaining studies cross the line of no effect.

Analysis was undertaken of all studies with different interventions that used a measure of depression. Six studies (as reported above) used the CES-D,^{14,15,18,28,34} Marriott *et al.*⁴⁴ used the Beck Depression Inventory, and Roth *et al.*³⁹ used the GDS. The type of interventions varied between multi-component³⁴ support,^{28,39} psycho-educational^{14,15,18,24} and

Table 4 Effect of interventions using the CES-D as an outcome measure

Follow-up time	Studies	Participants	Statistical method	Effect size
Up to 6 months	6	637	WMD (random) 95% CI	-2.26 ($-3.82, -0.69$)
18 months	2	133	WMD (random) 95% CI	-2.64 ($-6.50, 1.23$)
All follow-up	8	770	WMD (random) 95% CI	-2.31 ($-3.76, -0.86$)

CES-D, Center for Epidemiologic Studies Depression Scale; WMD, weighted mean differences; CI, confidence intervals.

Review: Effectiveness of interventions that provide support for carers of people with dementia in the community (Version 02)
 Comparison: 01 Carer support and training
 Outcome: 01 Depression - CES-D 6, 18mths

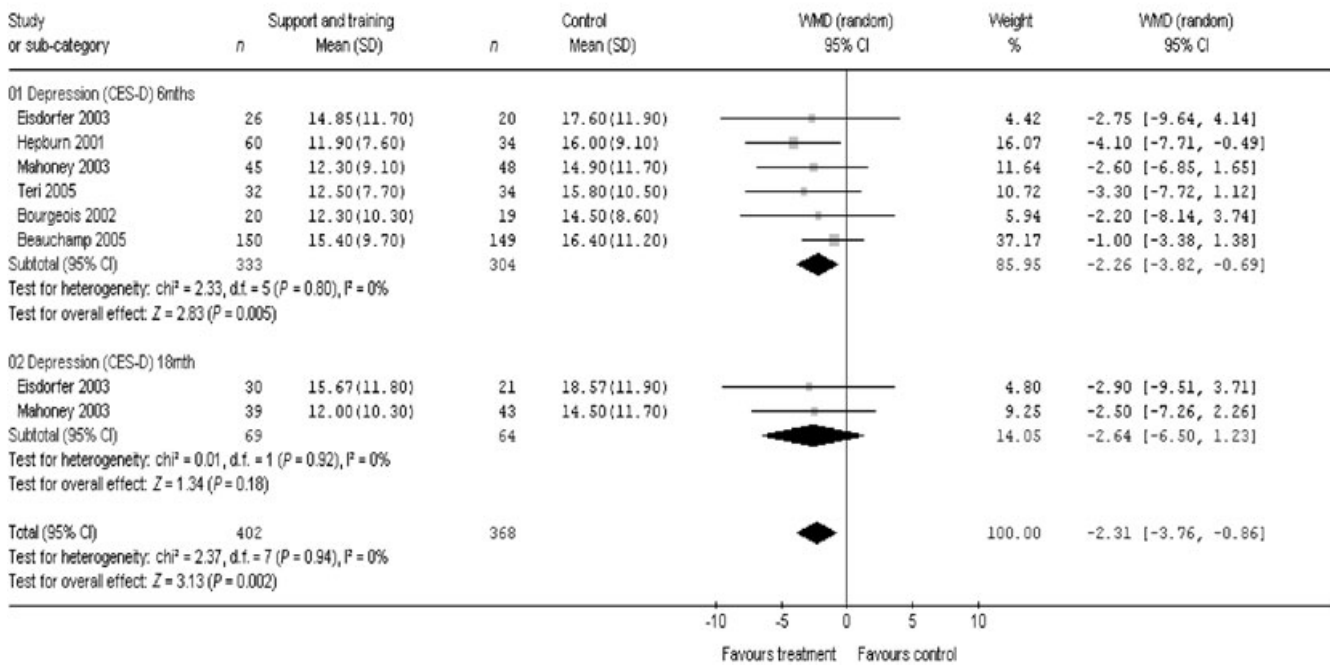


Figure 4 Forest Plot of Effect of interventions using the CES-D as an outcome measure. CES-D, Center for Epidemiologic Studies Depression Scale; SD, standard deviation; CI, confidence intervals; d.f., degree of freedom; WMD, weighted mean differences.

Table 5 Effect of interventions using the CES-D, BDI and GDS as an outcome measure

Follow-up time	Studies	Participants	Statistical method	Effect size
2–6 months	6	637	SMD (random) 95% CI	-0.22 (-0.37, -0.06)
9 months	2	80	SMD (random) 95% CI	-0.23 (-0.67, 0.22)
12 months	3	439	SMD (random) 95% CI	-0.35 (-0.54, -0.16)
All follow-up	11	1156	SMD (random) 95% CI	-0.27 (0.38, 0.15)

CES-D, Center for Epidemiologic Studies Depression Scale; BDI, Beck Depression Inventory; GDS, Geriatric Depression Scale; SMD, standard mean differences; CI, confidence intervals.

CBT.⁴⁴ Follow-up measures were recorded at a variety of intervention times (Table 5).

Analyses were adjusted to the random-effect model because of heterogeneity of the trials, and SMD were used because different outcome measures were used.

Figure 5 shows the effect of carer support and training on carer depression using different measures of depression (CES-D, BDI and GDS). At 6-month follow-up a significant effect of the intervention was found with the SMD being -0.22 and a 95% confidence interval (-0.37, -0.06) $P = 0.007$. The only study to be individually significant is by Hepburn *et al.*¹⁴ At 9-month follow-up the effects are not significant when SMD were -0.22 and a 95% confidence interval (-0.86, 0.42) $P = 0.49$. For these follow-up points there is heterogeneity between the two studies ($\chi^2 = 2.09$, d.f. = 2, $P = 0.22$, $I^2 = 52.1\%$) and this has impacted on the results.

Using 12-month follow-up data a significant effect is again found with the SMD being -0.35 and a 95% confidence interval (-0.63, -0.08) $P = 0.01$. The studies by Roth *et al.*³⁹ and Marriott *et al.*⁴⁴ show individually significant results. The pooled data of the three follow-up points indicate an overall significant effect of the intervention (SMD = -0.27 and a 95% confidence interval (-0.38, -0.15) $P = 0.00001$).

Of the three meta-analysis articles^{4,6,7} included in the review two used depression as an outcome measure. Brodaty *et al.*⁶ reported that five of the 20 studies that used depression as an outcome measure had statistically significant results. However, the effect sizes were weak and all of these studies were conducted between 1990 and 1999. The meta-analysis by Pinquart and Sorensen⁷ found depression was improved through psycho-educational interventions, CBT and respite but not counselling/case management interventions, multi-component or support interventions. Of

Review: Effectiveness of interventions that provide support for carers of people with dementia in the community (Version 02)
 Comparison: 01 Carer support and training
 Outcome: 03 Depression measures range of outcome points

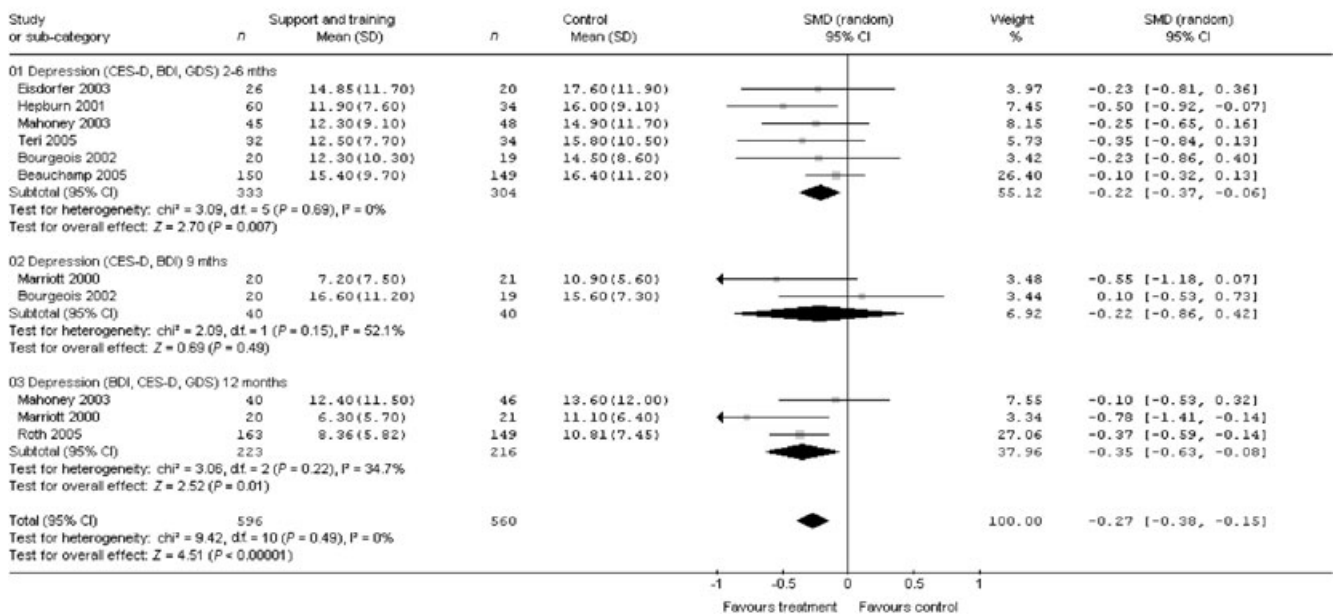


Figure 5 Overall effects of interventions on carer depression using the CES-D, BDI and GDS over a range of time points. CES-D, Center for Epidemiologic Studies Depression Scale; BDI, GDS, SD, standard deviation; CI, confidence intervals; d.f., degree of freedom; SMD, standard mean differences.

the systematic reviews Cooke *et al.*⁵ analysed psychological outcomes (which included depression) on different caregiver interventions based on the year the study was published. They found that for studies conducted pre 1990, 38% of interventions had a positive impact on psychological outcomes but for studies published from 1990 onwards, 50% showed positive impacts. Peacock and Forbes in their systematic review report that only the study by Marriott *et al.*,⁴⁴ which is also reported in this current review, indicated a positive effect of an education intervention on depression. However, in the original article Marriott *et al.*⁴⁴ they state that providing information only to the carer had no effect on carer burden or health. Pusey and Richards⁸ systematic review only included psychosocial interventions with nine studies measuring depression as an outcome measure. Only three of these studies showed significant results.

Caregiver burden

Twenty-three studies used a measure of caregiver burden as an outcome. Wide variation in the measures made meta-analysis difficult. Five studies used the Zarit Burden Interview^{13,14,18,19,31} but only three had data that could be used in the meta-analysis. Ten studies used the RMBPC^{9,14,15,17,19,28,32-35} but only three studies had data suitable for meta-analysis. For three studies no control group data were available and for four studies only a subscale of the RMBPC was reported.

Six studies used the MBPC^{22,36,37,39,40,45} but only two studies had data suitable for meta-analysis, one study only had subscale data, and the other three studies did not provide data.

Other caregiver burden outcome measures used included the NPI and NPI-D,^{29,30} BACS,^{13,14} Carer Strain Instrument,^{18,24} Caregiver Resentment Scale,¹² Caregiver Mastery Index,³² Coping Strategy Inventory Revised,⁴⁵ PGCCAS; PGCCAS,²³ Perceived Change Index,³² Screen for Caregiver Burden,^{9,15} Task Management Strategy Index^{32,33} and the Ways of Coping Checklist Revised.^{16,17,24}

Figure 6 shows the effect of interventions on carer burden using the Zarit Burden Interview. Data were available for 6-month follow-up. Results indicate no significant effect of the intervention with WMD -1.09 with a 95% confidence interval of $(-6.37, 2.6)$ $P = 0.41$. This result is most likely due to the heterogeneity of the studies $\chi^2 = 6.64$, $df = 2$ ($P = 0.04$), $I^2 = 69.9\%$.

Figure 7 shows the effect of interventions on carer burden using the RMBPC. Data were available for 6-month follow-up. Results indicate no significant effect of the intervention WMD -1.60 with a 95% confidence interval of $(-3.25, 0.05)$ $P = 0.06$. However, these results favour the intervention and approach significance with the study by Hepburn *et al.*¹⁴ approaching individual significance.

The three meta-analysis articles^{4,6,7} all include analysis of interventions on caregiver burden. The article by Acton and Kang⁴ found that multi-component interventions had a

Review: Effectiveness of interventions that provide support for carers of people with dementia in the community (Version 02)
 Comparison: 02 Carer support and training
 Outcome: 02 Burden (Zarit) up to 6 months

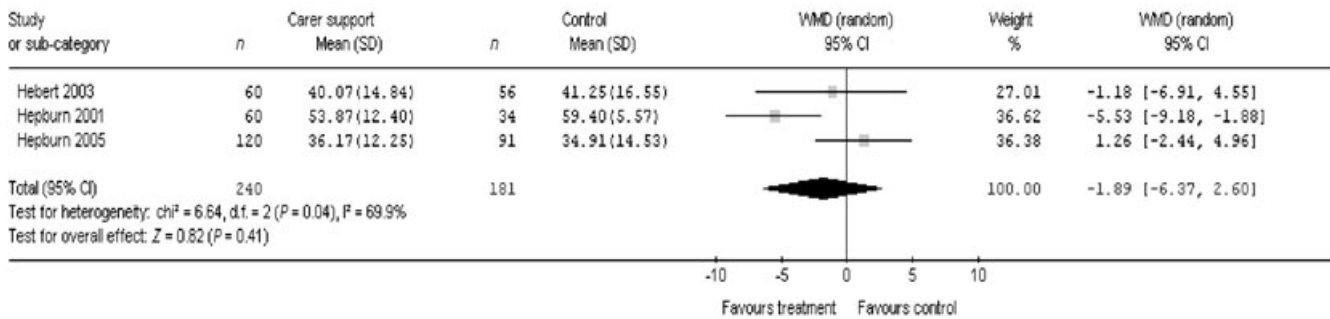


Figure 6 Effect of interventions on carer burden using the Zarit Burden Interview at 6 months post intervention. SD, standard deviation; CI, confidence intervals; d.f., degree of freedom; WMD, weighted mean differences.

Review: Effectiveness of interventions that provide support for carers of people with dementia in the community (Version 02)
 Comparison: 02 Carer support and training
 Outcome: 01 Burden (RMBPC) up to 6 months

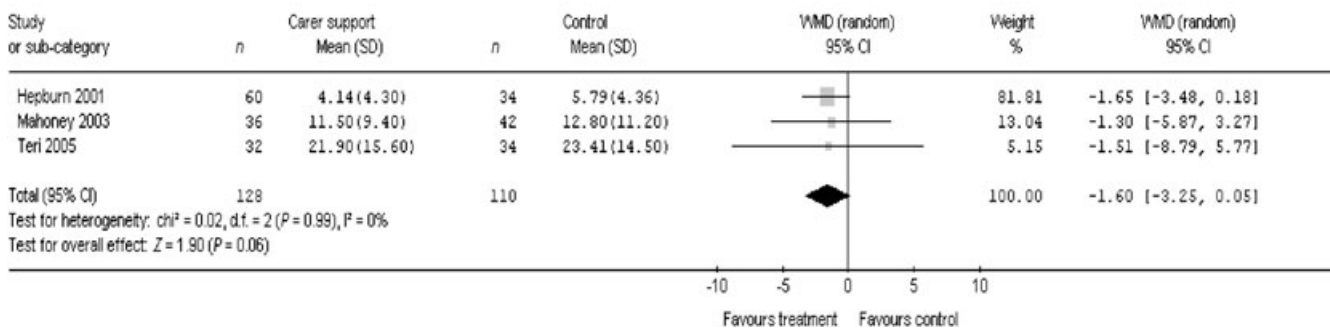


Figure 7 Effect of interventions on carer burden using the RMBPC at 6 months post intervention. RMBPC, Revised Memory Behaviour Problem Checklist; SD, standard deviation; CI, confidence intervals; d.f., degree of freedom; WMD, weighted mean differences.

small but significant effect on caregiver burden. However, these authors are cautious about these results as they believe that the concept of burden lacks conceptual clarity, with some measures containing subscales for objective and subjective burden and others only containing one of these. These authors independently evaluated the subjective and objective impact of burden. While no significant differences were found, they argue that measures of subjective burden which report caregivers' reactions are more likely to demonstrate an effect than objective burden measures. Brodaty *et al.*⁶ included burden as one of their main outcome categories but found that only one of 20 studies that used this measure had a significant effect. The meta-analysis by Pinquart and Sorensen⁷ found burden was improved through psycho-educational interventions, CBT, counselling/case management and respite interventions but not multi-component or support interventions. In the systematic review by Pusey and Richards,⁸ 14 studies used caregiver burden as an outcome measure but only two studies had significant results. The systematic review by Cooke *et al.*⁵

included caregiver burden as an outcome measure and they report that nine out of 22 studies had improved levels of caregiver burden with the majority of those with significant results conducted between 1998 and 1999. They argue that caregiver burden is difficult to influence as an outcome measure as it is a concept that is insensitive to change. Pinquart and Sorensen attribute the more positive results than that found by Acton and Kang and Brodaty *et al.*^{4,6} to the inclusion of different Burden Outcome Scales and more recently published articles that have found burden significantly improved.

Conclusion

Effectiveness of interventions on caregivers

Of the 34 randomised controlled trials, 26 indicate that the intervention had positive effects for caregivers. For psycho-educational interventions, 12 of the 13 studies indicated some positive effects. For the eight studies that were suitable for meta-analysis, it appears that psycho-educational inter-

ventions have a positive impact on caregiver depression although no studies provided follow-up analysis for more than 6 months. The study by Hepburn *et al.*¹⁴ was independently significant. This intervention was a community-based 14-h training program which included a day care group for care recipients. There were also indicators that psycho-educational interventions have a positive impact on caregiver subjective well-being although only one study had follow-up analysis for 12 months and no study was independently significant.

Of the seven studies reporting a support intervention, two had significant effects. More studies are needed to provide evidence of effect of support interventions.

Of the 12 multi-component interventions, 10 indicated positive results. Four of these were part of the REACH program. Three of the studies report on Home Environmental Intervention programs which at 6-month follow-up indicated improvements in caregiver well-being and ability to provide care; however, by 12 months these had decreased. A further four articles reported on the New York University study.³⁶⁻³⁹ This study provided six counselling sessions in a 4-month period, support groups and *ad hoc* counselling. It is one of the studies that provide longitudinal results indicating a positive impact on caregiver depression for up to 3 years, on appraisal for up to 4 years, and in extending the time to nursing home placement by more than 1.5 years. Other multi-component interventions could not sustain longitudinal effects. Limitations on suitability of studies for meta-analysis limit the strength of evidence available.

Brodaty *et al.*⁶ found that the most significant intervention type was one in which the person with dementia as well as the caregiver was involved in a structured program. While not statistically significant, qualitative findings indicate that intervention techniques such as practical support, involvement of the extended family, individual counselling and a primary case manager are beneficial.

Peacock and Forbes² found few positive results in their systematic review. While one study found case management increased the use of formal support services, another found no effect on strain or caregiver depression. One education intervention reduced caregiver depression but two other studies showed no effect on psychological well-being, the use of computer networking while improving decision-making confidence did not decrease social isolation, improve decision-making skills, or increase use of formal supports. Two studies indicated that psychotherapy may delay institutionalisation of care recipients.

The meta-analysis by Pinguart and Sorensen⁷ provides a comprehensive analysis of the impact of different types of interventions on caregiver outcomes. They report that the most effective interventions are psycho-educational and explicitly those which include active participation of caregivers. These interventions showed significant results for caregiver burden, depression, subjective well-being, caregiver ability/knowledge and symptoms of the care recipient. The next most successful intervention was CBT which showed significant improvements in caregiver burden and depression. Multi-component interventions showed significant

results only for delaying institutionalisation, and support interventions showed significant results only for subjective well-being.

Effect of interventions based on specific outcome measures

In this review caregiver depression appeared to be an outcome measure that was useful to assess the effectiveness of interventions. From the meta-analysis significant results indicated that caregiver depression can be positively influenced by caregiver interventions particularly psycho-educational interventions regardless of the depression measure used (CES-D, GDS or BDI).

Caregiver burden was a good outcome predictor in the meta-analysis for support interventions but not other types of interventions. Despite this, caregiver burden as an outcome measure has been popular in caregiver research. Sixteen different measures of caregiver burden were reported with the most popular being the Zarit Burden Interview, the RMBPC or the modified version of this checklist, the MBPC. Unfortunately standardised use or reporting of these scales was limited with some studies modifying questions or only reporting subscales. Other authors^{4,5} have argued that the construct of caregiver burden is poorly defined and may be insensitive to change and more research on the suitability of measures of caregiving burden is required. Pusey and Richards⁸ argue that measures such as the Brief Symptom Inventory or the Depression and Anxiety Inventory are more sensitive to change than the Zarit Burden Interview. Pinguart and Sorensen⁷ found more significant improvements in caregiver burden for more recently conducted studies and those of higher quality. In the present review the outcome category of subjective well-being is used to describe a range of psychological morbidity measures such as anxiety, distress, anger, affect and morale. These extensive measures which this category included limited the effect of its use in meta-analysis, although it was found to be significant for psycho-educational interventions.

While some articles have used the construct of self-efficacy because no other consistent measurement was available it was not possible based on the results in this review to advocate whether self-efficacy is a useful outcome measure. However, the exception may be for interventions based on the theory of self-efficacy. Previous reviews have not highlighted this as an outcome measure.

The limited inclusion of caregiver health measures and lack of quality of life measures is surprising particularly as many caregivers may themselves have health problems and given the exhaustive and longitudinal nature of caring for someone with dementia. The dearth of health measures used in these studies may be due to most of the interventions having potentially limited impact on caregiver physical health. An exception is the study by King *et al.*⁹ whose focus was nutrition and exercise effects.

Choice of outcome measures should also be realistic in terms of what may be possible to influence with the intervention provided. Brodaty, Green, Banerjee, Mittelman, Schulz, Whitehouse *et al.*⁴⁷ highlight the importance of

understanding how close (proximal) or far (distal) the outcome selected is to the goal of the intervention. Outcomes such as burden and knowledge are proximal outcomes whereas depression and quality of life are distal outcomes.⁶

The duration and intensity of interventions and follow-up may impact on outcome measures. Pinquart and Sorensen⁷ argue that the longer the intervention, the greater likelihood of improvement in caregiver depression and delay of institutionalisation.

These authors identify that more emphases should be placed on outcome measures of positive aspects of caregiving such as subjective well-being and finding benefit in being in the caregiver role. Peacock and Forbes² advocate that a measure such as quality of life might be more appropriate than caregiver strain, depression or time to institutionalisation. Similarly, Acton and Kang⁴ who are critical of the use of burden as an outcome measure suggest caregiver well-being or life satisfaction might be appropriate.

Methodological quality of studies

Overall the methodological quality of the studies was good with 21 of the 34 randomised controlled trials having a quality rating of 5/5. Two of the studies did not have a control group, instead comparing two interventions and this limited their application as they were not suitable for meta-analysis. Of the remaining studies, nine had more than one intervention group and in these instances the subjects that were included in the most comprehensive intervention group were considered for meta-analysis. While 21 studies had a control group the definition of what was usual care also varied between studies, some studies using wait list control and others a limited version of the intervention. Pusey and Richards⁸ argue that using wait list controls poses ethical issues particularly if the intervention is of long duration. They also note that a wait list control loses the opportunity for a long-term comparison group. The number of participants in intervention control groups also differed although the median number in the intervention condition was 52 and in the control condition 45. Loss to follow-up also had an impact on results as for 10 studies this was greater than 10%. Other methodological difficulties in comparing results in this review were the wide range of outcome measures and outcome time points. These issues have been raised by other authors.^{2,4,6-8}

Recommendations

In summary this systematic review has built upon previous systematic reviews and meta-analyses that together provide an opportunity for clinicians and researchers to begin to understand which interventions may impact positively on caregivers for people with dementia in the community. However, those designing interventions should take note of the myriad of outcome measures reported in the literature and be cognisant of consulting best practice guidelines where available to determine the most appropriate outcome measures for the intervention design. A symposium by world experts in caregiver research and caregivers

convened in 2000 in the United States recommended a minimum data set of caregiver outcomes that should be considered by researchers in this area. Similarly interventions should be based upon theoretical constructs and have adequate commitment from those who are providing the intervention for it to be sustained over a long period of time and longitudinal follow-up provided to assess continuation. This symposium also highlighted the different priorities of outcomes of interventions from caregivers and health professionals. Top priorities for caregivers were improvements on practical and financial outcomes and interventions that improved quality of life and provided practical assistance. In contrast health professionals identified psychological outcome such as depression and subjective burden. The article provides suggestions of outcome measures for researchers based on a model of caregiver strain inclusive of physical, financial, social and psychological influences. Psychological outcome measures recommended include the Zarit Burden Interview, Screen for Caregiver Burden, Satisfaction with Life Scale, CES-D, BDI, Hamilton Rating Scale for Depression, Positive and Negative Affect Scale and the General Health Questionnaire. Recommended measures of social support include the Instrumental and Expressive Social Support Scale, Norbeck's Social Support Questionnaire, Stokes Social Network Scale and the Social Support Questionnaire. Physical health may be measured by self-perception of health using the Subjective Overall Physical Health Questionnaire or measures such as the The MOS 36-item short-form health survey (SF-36). No specific scales for financial outcomes are suggested but a list of pertinent issues that can impact financially is provided. Other factors that may impact on caregivers are severity of problem behaviours of the person with dementia and how the caregiver reacts to these behaviours. Two scales which measure this are the RMBPC and the NPI. Comparison between this list of recommended outcome measures and those used in the articles in this review, indicates a high proportion used measures of psychological outcomes, and the RMBPC or a modified version the MBPC was extensively used. Limited use of the recommended social and health measures was evident.

At present choice of outcome measures appears *ad hoc*, however, depression, and measures of subjective well-being do appear to be useful outcome measures. The concept of burden may not be sensitive enough for use in short-term interventions although recent studies which are more rigorous report significant results using this measure.

From this review there is evidence to suggest that well-designed psycho-educational or multi-component interventions may assist caregivers of people with dementia who live in the community. Factors that appear to positively contribute to effective interventions are those which:

- Provide opportunities within the intervention for the person with dementia as well as the caregiver to be involved
- Encourage active participation in educational interventions for caregivers which is more effective rather than didactic teaching

- Offer individualised programs as well as group sessions
 - Provide information on an ongoing basis, with specific information about services and coaching regarding their new role
 - Target the care recipient particularly by reduction in behaviours
- Factors which do not appear to have benefit in interventions are those which:
- Simply refer caregivers to support groups
 - Only provide self-help materials
 - Only offer peer support

Implications for research

This review is based upon the best available evidence in an area in which randomised-controlled trials are increasing in popularity. This review extends previous evidence in this area by including within the parameters a variety of interventions and providing synthesis of results by outcome measure. Earlier reviews by Pusey and Richards⁸ and Cooke *et al.*⁵ focused specifically on psychosocial interventions. The review by Acton and Kang⁴ focused on one outcome measure – burden. Similarly an earlier review by Brodaty *et al.*⁶ had only two primary outcome measures – psychological morbidity and burden. Both encompassed a wide variety of constructs and as indicated by this review a large number of different measures are considered to measure burden and results indicated that only one intervention of 20 showed a significant impact on burden. More encouraging results in this review regarding effect of interventions on caregiver burden are linked to more recent studies which are supported by Pinquart and Sorensen.⁷

This review provides increasing evidence that psycho-educational or multi-component interventions may assist in supporting caregivers of people with dementia living in the community. This review provides information across different intervention types and attempts to categorise different outcome measures to enable synthesis of data. An important finding from the analysis of intervention type on the outcome measure of caregiver depression and burden is that there is a consistent effect regardless of the intervention type or outcome used.

In the present review the inclusion within a 5-year period of 34 randomised controlled trials conducted for caregivers of people with dementia in a community setting illustrates that this is an area that can generate high quality evidence to inform practice and improve outcomes. As such it is irresponsible and unethical for researchers embarking on intervention studies to ignore the methodological issues raised by this review and previous reviews conducted over the previous 10 years.

Priorities for future research in this area therefore include:

- Well-designed and conducted-randomised-controlled trials that have adequate sample sizes, well-defined intervention and control groups and adequate follow-up periods.
- Interventions which are conceptually and theoretically sound.

- Outcome measures that adequately measure the constructs within the intervention.
- Outcome measures that are reliable and valid within the population studied.

To assist in the synthesis of evidence using meta-analysis all randomised control trials published should be reported according to the guidelines set out in the CONSORT⁴⁸ Statement which outlines essential criteria for readers to determine validity and reliability of results.

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Appendix I

Medline, Ageline, Econlit, Sociological Abstracts

- 1 exp Alzheimer Disease/mo, nu, cl, co, pa, pp, di, pc, px, ec, rh, th [Mortality, Nursing, Classification, Complications, Pathology, Physiopathology, Diagnosis, Prevention & Control, Psychology, Economics, Rehabilitation, Therapy]
- 2 exp Creutzfeldt-Jakob Syndrome/mo, cl, nu, pp, di, pc, dh, px, rh, th [Mortality, Classification, Nursing, Physiopathology, Diagnosis, Prevention & Control, Diet Therapy, Psychology, Rehabilitation, Therapy]
- 3 exp Dementia, Vascular/mo, cl, nu, di, pp, dh, pc, px, rh, th [Mortality, Classification, Nursing, Diagnosis, Physiopathology, Diet Therapy, Prevention & Control, Psychology, Rehabilitation, Therapy]
- 4 exp Lewy Body Disease/cL, mo, nu, dt, pp, px, rh, th [Classification, Mortality, Nursing, Drug Therapy, Physiopathology, Psychology, Rehabilitation, Therapy]

- 5 exp Wernicke Encephalopathy/mo, nu, di, pp, dh, pc, px, rh, th [Mortality, Nursing, Diagnosis, Physiopathology, Diet Therapy, Prevention & Control, Psychology, Rehabilitation, Therapy]
- 6 **#1 OR #2 OR #3 OR #4 OR #5**
- 7 dement\$.mp
- 8 Alzheimer\$.mp
- 9 lewy\$ near bod\$.mp. [mp = title, original title, abstract, name of substance word, subject heading word]
- 10 ((cognit\$ or memory\$ or mental\$) and (declin\$ or impair\$ or los\$ or deteriorat\$)).mp. [mp = title, original title, abstract, name of substance word, subject heading word]
- 11 exp Korsakoff Syndrome/co, nu, di, dh, pp, px, rh, th [Complications, Nursing, Diagnosis, Diet Therapy, Physiopathology, Psychology, Rehabilitation, Therapy]
- Dementia/or alzheimer disease/or dementia, vascular/or lewy body disease/or 'pick disease of the brain'/
- 12 **#8 OR #9 OR #10 OR #11**
- 13 **#7 or #12**
- 14 randomi\$ed-controlled trial.pt.
- 15 controlled-clinical trial.pt.
- 16 randomi\$ed-controlled trials.mp. [mp = title, original title, abstract, name of substance word, subject heading word]
- 17 random-allocation.mp. [mp = title, original title, abstract, name of substance word, subject heading word]
- 18 double-blind method.mp. [mp = title, original title, abstract, name of substance word, subject heading word]
- 19 single-blind method.mp. [mp = title, original title, abstract, name of substance word, subject heading word]
- 20 clinical-trial.pt.
- 21 clin\$ near trial\$.ab,ti.
- 22 random\$.ab,sh,ti.
- 23 research-design.mp. [mp = title, original title, abstract, name of substance word, subject heading word]
- 24 cohort stud\$.mp
- 25 longitudinal stud\$.mp [mp = title, original title, abstract, name of substance word, subject heading word]
- 26 follow-up.stud\$.mp [mp = title, original title, abstract, name of substance word, subject heading word]
- 27 prospective stud\$.mp [mp = title, original title, abstract, name of substance word, subject heading word]
- 28 comparative stud\$ [mp = title, original title, abstract, name of substance word, subject heading word]
- 29 interrupted time series.mp [mp = title, original title, abstract, name of substance word, subject heading word]
- 30 case control stud\$.mp [mp = title, original title, abstract, name of substance word, subject heading word]
- 31 #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR 30
- 32 #14 AND #31
- 33 limit 32 to (humans and English language and year = '2000–2005')
- 34 Exp Caregive\$
- 35 34 AND 31
- 36 limit 35 to (humans and English language and year = '2000–2005')
- Psych INFO**
- 1 explode 'Presenile-Dementia'
- 2 explode 'Senile-Dementia'
- 3 explode 'Vascular-Dementia'
- 4 'Huntingtons-Disease' in DE
- 5 'Wernickes Syndrome' in DE
- 6 'Korsakoffs-Psychosis' in DE
- 7 'Alzheimers-Disease' in DE
- 8 'Progressive-Supranuclear-Palsy' in DE
- 9 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8
- 10 #dement*
- 11 alzheimer*
- 12 lewy* and bod*
- 13 (cognit* or memory* or mental*) and (declin* or impair* or los* or deteriorat*)
- 14 chronic and cerebrovascular
- 15 'orhanic brain syndrome*' or 'organic brain disease*'
- 16 'supra nuclear palsy'
- 17 'normal pressure hydrocephalus' and shunt*
- 18 'benign senescent forgetfulness'
- 19 cerebr* and deteriorat*
- 20 cerebr* and insufficien*
- 21 confusion* or confused
- 22 'Pick's disease' in TI, AB, KP, DE
- 23 (Creutzfeldt or JCD or CJD) in TI, AB, KP, DE
- 24 Huntington* in TI, AB, KP, DE
- 25 Binswanger* in TI, AB, KP, DE
- 26 Korsako* in TI, AB, KP, DE
- 27 (Wernicke* and syndrome) in TI, AB, KP, DE
- 28 #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27
- 29 #9 or #28
- 30 'randomi?ed controlled trial' or 'clinical controlled trial'
- 31 random*
- 32 placebo*
- 33 control* or prospective* or volunteer*
- 34 (singl* or doubl* or trebl* or tripl*) and (blind* or mask*)
- 35 cross-over* or crossover*
- 36 'latin square'
- 37 between groups design/or clinical trials/or cohort analysis/or follow-up studies/or hypothesis testing/or longitudinal studies/or repeated measures/
- 38 #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37
- 39 #29 and #38
- 40 exp Caregivers
- 41 limit 40 to (human and english language and year = '2000–2005')
- Cinahl**
- 1 explode 'Dementia-Presenile'/all topical subheadings/all age subheadings

- 2 explode 'Dementia-Senile'/all topical subheadings/all age subheadings
- 3 explode 'Dementia-Multi-Infarct'/all topical subheadings/all age subheadings
- 4 explode 'Huntington's-Disease'/all topical subheadings/all age subheadings
- 5 #1 or #2 or #3 or #4
- 6 dement*
- 7 alzheimer*
- 8 lewy* and bod*
- 9 (cognit* or memory* or mental*) and (declin* or impair* or los* or deteriorat*)
- 10 chronic and cerebrovascular
- 11 'organic brain syndrome' or 'organic brain disease'
- 12 'supra-nuclear palsy'
- 13 'normal pressure hydrocephalus' and shunt*
- 14 'benign senescent forgetfulness'
- 15 cerebr* and deteriorat*
- 16 cerebr* and insufficien*
- 17 confusion* or confused
- 18 'Pick's disease' in TI, AB, DE
- 19 (Creutzfeldt or JCD or CJD) in TI, AB, DE
- 20 Huntington* in TI, AB, DE
- 21 Binswanger* in TI, AB, DE
- 22 Korsako* in TI, AB, DE
- 23 (Wernicke* and syndrome) in TI, AB, DE
- 24 #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23
- 25 #24 in TI, AB, DE
- 26 #5 or #25
- 27 random*
- 28 placebo*
- 29 control* or prospective* or volunteer*
- 30 ((singl* or doubl* or trebl* or tripl*) and (blind* or mask*))
- 31 cross-over* or crossover*
- 32 'normal control*' or 'healthy control*' or 'healthy volunteer*' or 'normal volunteer*'
- 33 experimental studies/or clinical trials/or community trials/or double-blind studies/or factorial design/or non-randomized trials/or one-shot case study/or pretest-post-test design/or single-blind studies/or repeated measures/
- 34 #27 or #28 or #29 or #30 or #31 or #32 or #33
- 35 #26 and #34
- 36 limit 35 to (english and year = '2000-06')
- 37 exp caregivers
- 38 36 and 37 limit to (English and year = '2000-2005')

Appendix II

Appraisal form

Reviewer _____ Date _____

Author _____ Year _____ Record No _____

1. Was the assignment to treatment groups random?
 Yes No Not clear NA
2. Were the participants blinded to treatment allocation?
 Yes No Not clear NA
3. Was allocation to treatment groups concealed from the allocator?
 Yes No Not clear NA
4. Were the outcomes of people who withdrew described and included in the analysis?
 Yes No Not clear NA
5. Were those assessing the outcomes blind to the treatment allocation?
 Yes No Not clear NA
6. Were control and treatment groups comparable at entry?
 Yes No Not clear NA
7. Were groups treated identically other than for the named interventions?
 Yes No Not clear NA
8. Were outcomes measured in the same way for all groups
 Yes No Not clear NA
9. Were outcomes measured in a reliable way?
 Yes No Not clear NA
10. Was there adequate follow-up of participants (>80%)
 Yes No Not clear NA
11. Was appropriate statistical analysis used?
 Yes No Not clear NA

Overall appraisal: Include Exclude Seek further info

Comments (including reasons for exclusion) _____

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Appendix III**Extraction form****JBI Data Extraction Form for Experimental/Observational Studies**

Reviewer _____ Date _____

Author _____ Year _____ Record No _____

Study Method RCT Quasi RCT Longitudinal
 Retrospective Observational Other

Participants

Setting _____

Population _____

Sample size

Intervention 1 _____ Intervention 2 _____ Intervention 3 _____

Interventions**Intervention 1** _____**Intervention 2** _____**Intervention 3** _____**Clinical Outcome Measures**

Outcome Description	Scale/measure

Study results**Dichotomous data**

Outcome	Intervention () Number/total number	Intervention () Number/total number

Continuous data

Outcome	Intervention () Mean and SD (number)	Intervention () Mean and SD (number)

Author conclusions

Reviewer conclusions /comments

Include Exclude Seek further info

Appendix IV

Caregiver articles included in the review (*n* = 40)

No	Title	Year	Author	Study quality	Type of study sample	Intervention	Measures	Intervention length	Follow up	Findings
1	Effectiveness of cognitive behavioural family intervention in reducing the burden of carers of patients with Alzheimer's disease	2000	Marriott	5	RCT Intervention 1 – Camberwell Family Interview + skills training <i>n</i> = 14 Control 1 Family Interview <i>n</i> = 14 Control 2 – No interview <i>n</i> = 14	Multi-component/ Individual	Beck Depression Inventory	7 months	3 months post	Cognitive behavioural intervention significantly reduced carer stress; interventions resulted in modification of behavioural disturbances in the patient. Little benefit from cathartic interview with the patient. Some interventions can reduce psychological morbidity and help keep patients at home longer. Programs involving families, are more intensive and modified to care giver need may be more successful.
2	Meta analysis of psychosocial interventions for caregivers of people with dementia	2003	Brodsky		Meta-Analysis					Includes good breakdown of intervention components. 40 studies included in review, 2/3 of interventions did not show improvement of any outcome measures, of those that did show improvements inclusion of social components or a combination of social and cognitive components seemed to be relatively effective. Collectively, interventions had no effect on caregiver burden. Only interventions that were effective were those using multi component interventions.
3	Psychosocial interventions for caregivers of people with dementia: a systematic review	2001	Cooke		Systematic review					
4	Interventions of reduce the burden of caregiving for an adult with dementia: A meta analysis	2001	Acton		Meta-analysis					

Appendix IV Continued

No	Title	Year	Author	Study quality	Type of study sample	Intervention	Measures	Intervention length	Follow up	Findings
7	Effects of supporting community living demented patients and their caregivers: A randomised trial	2001	Eloniemi-Sulkava	4	RCT Intervention – support by family coordinator <i>n</i> = 53 Control <i>n</i> = 47	Multi component/ Individual	Days of enrolment to long term care	2 years	At 2 year follow up	Intervention, of systematic, comprehensive support by dementia family care coordinator. No effect demonstrated after 2 years, numbers similar in intervention and control groups.
9	A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia	2001	Pusey		Systematic review					Conclusions, most effective interventions were those that used problem solving and a behavioural component.
10	A randomised control trial of a home environmental intervention: Effect on efficacy & upset in caregivers & on daily function of persons with dementia	2001	Gitlin	4	RCT Intervention – environmental program <i>n</i> = 100 Control – education materials <i>n</i> = 102	Multi component/ Individual	Self efficacy Behaviour upset	3 months	At completion intervention	Intervention resulted in a positive effect for African/American and spousal caregivers but very little with male or non spousal caregivers.
15	The effect of a family therapy and technology based intervention on caregiver depression	2003	Eisdorfer	4	RCT, Intervention 1 – SET <i>n</i> = 75 Intervention 2 – SET+CTIS <i>n</i> = 77 Control – minimal support <i>n</i> = 73 Part of the REACH program.	Multi component Group	RMBPC CES-D	1 year	Post Test – 6 months and 18 months	Combined therapy resulted in decrease in reported depression at 6 months and 18 months but results differed according to ethnicity and type of caregiver. Results indicate that information technology has a promising role in reducing distress and depression among groups of caregivers.
16	Primary care interventions for dementia caregivers: 2 year outcomes from the REACH study	2003	Burns	4	RCT Intervention 1 – behaviour care <i>n</i> = 85 Intervention 2 – enhanced care <i>n</i> = 82 No control 2 year follow up, part of the REACH program. Enhanced care (including patient behaviour management and stress-coping strategies)	Multi component/ Individual	CES-D RMBPC General well being	2 years	6, 12, 18, 24 months	Intervention was effective in reducing caregiver stress and burden in the long term management of patients with dementia.

18	Effects of the home environmental skill building program on the caregiver-care recipient dyad: 6 month outcomes from the Philadelphia REACH initiative	2003	Gitlin	5	RCT – Part of the REACH program, Intervention, Environmental Skill Building Program, structured home visit and telephone contact providing education, problem solving and adaptive equipment. n = 89 Control – information n = 101	Multi component/ Individual	Task Management Strategy Index, Caregiving mastery index, RMBPC, Perceived Change Index	1 year	Post Test – 6 months post intervention	Results, caregivers in the intervention group showed less upset with problem behaviours, less need for assistance, better affect and overall well being.
20	Effects of an automated telephone support system on caregiver burden and anxiety. Findings from the REACH for TLC intervention study	2003	Mahoney	5	Part of the REACH program. RCT, automated telecare application providing information, interactive messaging with peers and professionals n = 49 Control n = 51	Support/ Individual	CES-D, RMBPC, STAI	1 year	Post Test – 6 months and 18 months	No significant effect in reducing burden (RMBPC), although those with low mastery skills at baseline displayed less burden.
21	Change in indices of distress among Latino & Anglo female caregivers of elderly relatives with dementia: site specific results from the REACH national collaborative study	2003	Gallagher-Thompson	5	Part of the REACH program. Intervention 1 – Psycho-educational program n = 147. Intervention 2 – Enhanced Support n = 210 Control – minimal support condition	Psycho-educational/ Group	CES-D, RMBPC, RWCCL, Inventory of Socially Supportive Behaviours	10 weeks	Post Test – 3 months	Psycho-educational group intervention reduced depressive symptoms, increase in adaptive coping strategies compared to Enhanced Support Group (modelled on typical caregiver support group).
22	Maintenance effects of the home environmental skill building program for family caregivers & individuals with Alzheimer's disease and related disorders	2005	Gitlin	4	Part of the REACH program. 12 month follow up of the ESP, (Article 18) Intervention n = 65 Control n = 65	Multi component/ Individual	Reach modified RMBPC Task management strategy	6 months	Post Test – 1 year	Effects of reduced upset with problem behaviours and needing less help with daily care were not maintained but improved affect was maintained at follow up.
23	The effects of a structured intervention on caregivers of patients with dementia and problem behaviours	2004	Nobili	4	RCT Intervention – home visits impact on caregiver stress and institutionalisation rate of patient n = 36 Control – helpline, information n = 34	Support/ Individual	Relative Stress Scale	2 visits, 1 psych, 1 OT	6 months and 1 year	Caregiver stress main determinate of institutionalisation.

Appendix IV Continued

No	Title	Year	Author	Study quality	Type of study sample	Intervention	Measures	Intervention length	Follow up	Findings
24	Effects of moderate intensity exercise on physiological, behavioural and emotional responses to family caregiving. A randomised control trial	2002	King	3	RCT – Intervention 1 -exercise <i>n</i> = 51 Intervention 2 – nutritional advice <i>n</i> = 49	Other (Exercise) Individual	Beck Depression Inventory, Pittsburgh Sleep Quality Index RMBPC Screen for caregiver burden	1 year	Post Test – completion of intervention	Intervention groups experienced reduced stress increased cardiovascular reactivity and improvements in sleep quality.
25	Impact of a psycho-educational intervention on caregiver response to behavioural problems	2002	Gerdner	5	RCT Caregivers receive an individualised plan of care to modify environment, and develop activities for care recipient <i>n</i> = 132 Control group – some support <i>n</i> = 105 Same study as No 33	Psycho educational/ Individual	MBPC	2 home visits	Post Test – 1 year	Findings, Positive impact on caregiver response to problem behaviours among spousal patients.
26	Training in communication skills for informal carers of people suffering from dementia: a cluster randomised clinical trial comparing a therapist led workshop and a booklet	2001	Done	5	RCT Communication training program aimed at workshop. <i>n</i> = 30 Control group received information booklet, intervention group to workshop sessions <i>n</i> = 15	Psycho-educational/ Group	Relative Stress Scale Thomas Assessment Inadequacy	6 weeks	Post Test – intervention completion	Both groups reported some reduction in the frequency of communication problems and in the associated level of distress.
31	Dementia family caregiver training: Affecting beliefs about caregiving and caregiver outcomes	2001	Hepburn	4	RCT Intervention – Community based training program based of stress and coping skills <i>n</i> = 72 Wait list control <i>n</i> = 45	Psycho-educational/ Group	RMBPC BACS, Zarit, CES-D	7 weeks	Post Test – 5 months	Intervention group had improved scores for depression, burden and reactions to problem behaviours compared to control group.
32	Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease	2004	Mittelman	5	RCT Intervention consisted of individual and family counselling sessions followed by weekly support groups and ad hoc telephone counselling <i>n</i> = 203 Control <i>n</i> = 203 Follow up of previous study, 42	Multi component/ Both group and individual	Geriatric Depression Scale	7 weeks	Post test – 6 monthly	Intervention group had significantly fewer depressive symptoms than the control group. Effects were sustained for over 3 years post baseline.

33	Caregiving appraisal and interventions based on the progressively lowered threshold model	2002	Stolley	5	RCT Intervention – Caregivers receive an individualised plan of care to modify environment and develop activities for care recipient <i>n</i> = 133 Control group – some support <i>n</i> = 108 Same study as No 25	Psycho-educational individual and component group	PGCCAS	Intervention ongoing	Post Test – 3 monthly up to 12 months	Findings showed that the PLST was effective in decreasing perceived burden at 12 month follow up.
34	Reducing anxiety in Alzheimer's disease family caregivers: The effectiveness of a 9 week cognitive behavioural intervention	2004	Akkerman	4	RCT, Intervention – CBT <i>n</i> = 18 Wait list control <i>n</i> = 17	CBT Group	Hamilton Anxiety Rating Scale, Beck Anxiety Inventory	9 weeks	Post Test – 6 weeks	Study conducted on anxious caregivers, intervention: a group cognitive behavioural therapy. Intervention group reported less anxiety and improved sleep.
36	A pilot study on a home based caregiver training program for improving caregiver self efficacy and decreasing the behavioural problems of elders with dementia in Taiwan	2003	Huang	5	RCT Intervention – Caregiver training program based on the PLST <i>n</i> = 24 Control – written education <i>n</i> = 24	Multi component/ Individual	Agitation Management Self efficacy Scale	2 sessions	Post test 3 months	Behavioural problems significantly reduced and caregivers reported increased self efficacy.
39	Efficacy of a psycho educative group program for caregivers of demented persons living at home: A randomised control trial	2003	Hebert	5	RCT Intervention cognitive appraisal and coping strategies <i>n</i> = 60 Control <i>n</i> = 58	Psycho-educational /Group	Zarit, RMBPC, STAI, Ifield Symptom, Bradburn Revised Affect, Inventory of Social Support	4 months	Post test –completion intervention	The program decreased the frequency and reactions to disruptive behaviours.
41	Anger and depression management: Psycho-educational skill training interventions for women caregivers of a relative with dementia	2003	Coon	4	RCT Intervention 1 – anger management <i>n</i> = 41 Intervention 2 – depression management <i>n</i> = 45 Wait list control <i>n</i> = 44	Psycho-educational/ Group	State Trait Anger Expression inventory, Multiple Affect Adjective Checklist (MAACL) Revised Scale Caregiving Self Efficacy, WCCL-R Positive Aspects of Caregiving	4 months	Post test – completion intervention	Participants in both intervention groups had reductions in levels of anger or hostility in comparison to the control group. Positive cognitive coping strategies increased in the anger management group only. Self efficacy increased in both intervention groups.

Appendix IV Continued

No	Title	Year	Author	Study quality	Type of study sample	Intervention	Measures	Intervention length	Follow up	Findings
42	Effects of a caregiver intervention on negative caregiver appraisals of behavioural problems in patients with Alzheimer's disease: Results of a randomised trial	2004	Mittelman	5	RCT Intervention consisted of individual and family counselling sessions followed by weekly support groups and ad hoc telephone counselling <i>n</i> = 203 Control <i>n</i> = 203 Same study as 32	Multi component/ Both group and individual	MBPC	Ongoing	Post Test – 4 Years	Findings, decreased reactions to problem behaviour, reduced depression and greater feelings of self efficacy.
44	Continuum of Care for Alzheimer's Disease: A nurse Education and Counselling Program	2001	Wright	4	RCT Intervention –education and counselling <i>n</i> = 68 Control <i>n</i> = 25	Support/ Counselling/ Individual	CES-D, Caregiving Hassle Scale, Multilevel Assessment Inventory	12 month	Post Test – several measures, last one at intervention completion	No significant effects from intervention.
46	The effectiveness of a mutual support group for family caregivers of a relative with dementia	2002	Fung	5	RCT Intervention –mutual support group <i>n</i> = 26 Control <i>n</i> = 26	Support /Group	NPI-D, WHOQoL-BREF	3 months	1 month	Intervention group had significant improvements in distress levels and quality of life over the control group.
47	Website based Internet multimedia program for family caregivers of persons with dementia	2005	Beauchamp	4	RCT Intervention multimedia work based program <i>n</i> = 150 Waitlist control <i>n</i> = 149	Psycho-educational/ Individual	CES-D, State Trait Anxiety Instrument, Caregiver Strain Instrument WCCL-R Self efficacy	One off	Post Test – 1 month	Gains in depressive symptoms, anxiety, strain.
48	Training community consultants to help family members improve dementia care: A randomised controlled trial	2005	Teri	4	RCT Intervention behavioural therapy program <i>n</i> = 47 Control <i>n</i> = 48	Psycho educational/ Individual	CES-D, Hamilton Depression Rating Scale, Caregiver sleep Questionnaire, Screen for Caregiver Burden RMBPC	6 months	Post Test – 6 months post intervention	Results showed reduction in self reported depression, burden and reactivity.
51	Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's Disease	2005	Roth	5	RCT Intervention consisted of individual and family counselling sessions followed by weekly support groups and ad hoc telephone counselling <i>n</i> = 163 Control <i>n</i> = 149 Same study as 42 and 32 but different outcomes measured,	Multi component/ Both individual and group	Geriatric Depression Scale, MBPC	Ongoing	Post test 1 year after	Positive effects on key measures of social support. Caregivers' satisfaction with social support networks improved as well as the amount of support they were receiving.

61	Coping with Dementia: Evaluation of four non pharmacologic interventions	2000	Quayhagen	5	Comparison of 4 different interventions incorporated into the one study. Intervention 1 Intervention 2 Intervention 3 Intervention 4 Control – Wait list control	Multi component/ Group	Caregiver Health Index Health Assessment Scale, BSI MBPC Geriatric Morale Scale Social Support Questionnaire	2 months	1 month post intervention	Measures both patient and caregiver outcomes.
62	Skills training for spouses of patients with Alzheimer's disease: Outcomes of an intervention study	2002	Bourgeois	5	RCT Intervention 1 patient behaviour change <i>n</i> = 22 Intervention 2 caregiver self change <i>n</i> = 21 Control <i>n</i> = 20	Psycho educational /Group	CES-D Caregiver Strain Scale, Spielberger Anger Expression Scale, Spielberger Anxiety Scale, Caregiver Self Efficacy Assessment Perceived Stress Scale	3 months	Post test – completion intervention then 6mth, 9mths	Results refer to Intervention 2 and control group. Intervention groups showed weak effects for depression, perceived stress, caregiver strain and self efficacy.
63	Peer support for Alzheimer's caregivers	2002	Pillemer	4	RCT Intervention testing social support for caregivers <i>n</i> = 54 Control <i>n</i> = 61	Support/ Individual	CES-D, Rosenberg Self Esteem Scale	2 months	Post Test – 6 months	No main effects found for either depression or self esteem.
66	Caregiver attribution and resentment in dementia care	2003	Martin-Cook	5	RCT, Psycho-educational sessions Intervention <i>n</i> = 19 Control <i>n</i> = 18	Psycho-educational/ Group	CES-D, NPI, Steimetz Control Scale Caregiver resentment scale	4 weeks	Post Test – 14 weeks	No significant impact from intervention found.
68	Partners in caregiving: A Psycho-educational program affecting dementia family caregivers distress and caregiving outlook	2005	Hepburn	5	RCT, Psycho-educational intervention Intervention 1 <i>n</i> = 79 PIC – Day to Day Intervention 2 <i>n</i> = 72 Control <i>n</i> = 64	Psycho-educational/ Group	BACS Caregiver Distress Measure, Zarit	6 weeks	Post Test – 6 months and 12 months	The 2 interventions were similar and analysis is based on combining these 2 groups. Positive effects demonstrated on reducing carer distress at 6 months but had diminished by 12 months.
75	Improving quality of life for persons with Alzheimer's disease and their family caregivers: Brief Occupational Therapy Intervention		Dooley	5	RCT Intervention –occupational therapy <i>n</i> = 40 Control <i>n</i> = 40	Support/ Individual	Zarit	One off	Post Test – 1 month	Positive effect shown for reduction in caregiver burden from this OT based intervention.
78	A counselling intervention for caregivers: effect on neuropsychiatric symptoms	2004	Senanarong	5	RCT Intervention – counselling and support groups <i>n</i> = 25 Control <i>n</i> = 25	Support /Group	NPI	6 months	Post Test –completion intervention	Group counselling and support intervention, no significant effects.

Appendix IV Continued

No	Title	Year	Author	Study quality	Type of study sample	Intervention	Measures	Intervention length	Follow up	Findings
83	Helping caregivers of persons with Dementia: which interventions work and how large are their effects?	2006	Pinquart		Meta analysis					Conclusions, interventions, on average have small but meaningful effects of reducing burden and depressive symptoms and Subjective Well Being and for multi component therapy, reducing the risk of institutionalisation.
85	Effect of Support and Counselling on Caregivers of patients with Alzheimer's Disease	2000	Mittelman	5	Intervention consisted of individual and family counselling sessions followed by weekly support groups and ad hoc telephone counselling <i>n</i> = 203 Control <i>n</i> = 203 Same study as 32, 42	Multi component/ individual and Group	GDS MBPC	Ongoing	Post test – 1 year	Use only for Caregiver Depression outcome.
87	Interventions for Caregivers of persons with Dementia: A Systematic Review	2003	Peacock		Systematic review					Few significant effects for caregiver interventions. Positive finding include: case management increased likelihood of using formal support, and educational intervention decreased depression at 3 month F/U, psychotherapy delayed patient placement. Non significant finding more common.

Appendix V

Caregiver articles excluded in the review (n = 41)

No	Title	Year	Author	Type of study	Reason for exclusion
6	Depressive disorders in caregivers of dementia patients: A systematic review	2005	Cuijpers	Systematic review	Review of the prevalence of depressive disorders.
11	Loneliness & depression in spousal caregivers of those with Alzheimer's disease versus non caregiving spouses	2003	Beeson	Questionnaire	Outcomes of interventions by carer relationship only.
12	Behavioural change in persons with dementia; Relationships with mental and physical health of caregivers	2002	Hooker	Questionnaire	Descriptive only, no intervention.
13	Impact of 2 psychosocial interventions on white and African caregivers of individuals with dementia	2003	Burgio	RCT	Results on reported on cultural differences.
17	The Cleveland Alzheimer's managed care demonstration: Outcomes after 12 months of implementation	2003	Bass	RCT	Sample includes patient without dementia.
19	Home care for demented subjects: new models of care and home care allowance	2004	Fabris	RCT	Study involves some subjects admitted to inpatient facility and is not caregiver specific.
27	A pilot study of immune and mood outcomes of a community based intervention for dementia caregivers: The PLST intervention	2002	Garland	RCT	Pilot study, small sample, poor design and power, n = 37.
28	The resources for enhancing Alzheimer's caregiver health (REACH): Project design and baseline characteristics	2003	Wisniewski	RCT	Only describes the REACH program.
29	Exercise program for women who are caring for relatives with dementia	2002	Castro	RCT	Main outcomes related to adherence to exercise program.
30	End of life care and the effects of bereavement on family caregivers of persons with dementia	2003	Schulz	Observational	No intervention.
35	Perceived helpfulness of telephone calls	2004	Chang	RCT	Only reports qualitative results from larger study.
37	Providing education about Alzheimer's disease	2001	Sullivan	RCT	Participants are professional carers.
38	Outcomes for patients with dementia from the Cleveland Alzheimer's managed care demonstration	2004	Clark	RCT	Reports patient outcomes only.
40	Understanding the outcomes of a Psycho-educational group intervention for caregivers of persons with dementia living at home: A process evaluation	2005	Lavoie	Pre and Post test	Outcomes are related to assess the educational process of the intervention.
43	Alzheimer's disease caregiving information and skills. Part 2: Family caregiver issues and concerns	2004	Farran	Descriptive	Data is collected from professional carers views.
45	Structured intervention in family caregivers of the demented elderly and changes in their immune function	2003	Hosaka	Pre and post test	Immune function is main outcome measure.
50	Introduction to the Special section on Resources for Enhancing Alzheimer's Caregiver Health (REACH)	2003	Schulz	Descriptive	No outcomes of the intervention reported.
52	Effect of meeting centres support program on feelings of competence of family carers and delay of institutionalisations of people with dementia	2004	Droes	Quasi experimental	Control group includes respite care.
53	Adult day service use and reductions in caregiving hours: effects on stress and psychological well being for dementia caregivers	2003	Gaugler	Longitudinal	Intervention is respite care.
54	How effective are interventions with caregivers, an updated meta – analysis	2002	Sorensen	Meta-analysis	Not dementia specific.
55	Effect of combined support for people with dementia and carers vs regular day care on behaviour and mood of persons with dementia: results from a multi centre implementation study	2004	Droes	Quasi-experimental	Intervention includes respite care.

Appendix V Continued

No	Title	Year	Author	Type of study	Reason for exclusion
58	The mediating effects of situational control on social support and mood following a stressor: a prospective study of dementia caregivers in their natural environments	2001	Atienza	Pre and post test	No intervention, measures perceived stress over time.
59	Evaluation of Geriatric day care units: Effects on patients and caregivers	2002	Zank	Quasi-experimental	Intervention includes respite care.
60	Psychosocial intervention for dementia caregivers: What can it accomplish	2003	Mittelman	Observational	No intervention outcomes reported.
64	Relationship matters in dementia caregiving	2005	Lewis	Cohort study	Not an intervention.
65	A randomised controlled study of an Alzheimer's caregiver skills training program	2005	Martin-Cook	RCT	Sample includes patients living in care facilities.
67	The effects of duration of caregiving on institutionalisation	2005	Gaugler	RCT	Secondary analysis of modelling effects.
69	Helping the family carers of Alzheimer's patients: from theory to practice. A preliminary study	2000	Millan-Calenti	Pre and post test	Descriptive results only.
70	Alzheimer's Disease caregiving information and skills, Part III: Group process issues and concerns	2004	Perraud	Descriptive	Look at process outcomes only.
71	A relaxation training program to increase self efficacy for anxiety control in Alzheimer family caregivers	2001	Fisher	Pre and post test	No control group.
72	Carer training project for the management and psychological symptoms of dementia (BPSD) by home based carers: Phase 2	2005	Dicker	Pre and Post test	Measures caregiver learning gains from the intervention rather than caregiver well being.
73	Carer training project for the management of behavioural and psychological symptoms of dementia by home based carers	2001	Dicker	Qualitative	Not an intervention, article is a review of a training package pre implementation.
74	Health status and work burden of Alzheimer patients informal caregivers. Comparisons of 5 different care programs in the European Union	2002	Colvez	Descriptive	Compares the effectiveness of various different programs including respite care.
76	Provider Assessment of interactions with Dementia Caregivers: Evaluation and Application of Therapeutic Engagement index	2005	Chee	Evaluation	Measures the level of caregiver engagement in program, not a measure of caregiver outcomes.
77	Effects of a comprehensive educational program on quality of life and emotional issues of dementia patient caregivers	2005	Kuzu	Pre and Post test	No control group.
79	Evaluating the effect of care programs for elderly persons with dementia on caregivers well-being	2004	Gramain	Modelling	Comparison of day centres and group living.
80	The Kingston Dementia Café: The benefits of establishing an Alzheimer café for carers and people with Dementia	2005	Capus	Descriptive	No intervention.
81	A Program Evaluation of the Caregiver Assistance Program,	2002	Bourgard	Quasi RCT	Small sample size, underpowered, post test conducted within 1 week, not enough to observe outcome change
82	Generalisation of the effects of a Cognitive-Behavioural Intervention for family caregivers of individuals with Dementia	2004	Buchanan	RCT	Dissertation, small study, sample size 8 both intervention and control.
84	Alzheimer's Disease Caregiving Information and Skills: Part 1: Care Recipient Issues and Concerns	2003	Farran	RCT	Descriptive report. No intervention outcomes.
86	Educational Support Groups for Male Caregivers of individuals with Alzheimer's Disease	2000	McFarland	Focus group	Descriptive report of developing an intervention.