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Respite care for people with dementia and their carers (Review)

Maayan N, Soares-Weiser K, Lee H

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[Intervention Review]

Respite care for people with dementia and their carers

Nicola Maayan[1], Karla Soares-Weiser[1], Helen Lee[2]

[1]Enhance Reviews Ltd, Wantage, UK. [2]Oxford, UK

Contact: Helen Lee, Hidcote, Radley, Oxford, Oxfordshire, OX14 3BL, UK. helencharlottelee@yahoo.co.uk.

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ABSTRACT

Background

Caring for someone with dementia can be emotionally and physically demanding. Respite care is any intervention designed to give rest or relief to caregivers. It is not clear what positive and negative effects such care may have on them, or on people with dementia.

Objectives

To assess the benefits and harms of respite care for people with dementia and their caregivers, in particular the effect of respite care on rates of institutionalisation.

Search methods

The trials were identified from a search of ALOIS, the Specialized Register of the Cochrane Dementia and Cognitive Improvement Group, using the terms respite* OR daycare OR caregiver* relief. ALOIS contains up-to-date records from all major healthcare databases and many ongoing trial databases.

Selection criteria

Randomised controlled trials comparing respite care with a control intervention for people with dementia.

Data collection and analysis

Two review authors carried out study selection independently and reached a consensus through discussion. Data were extracted by a single review author. The review authors contacted all investigators for methodological details not reported in the text and for additional data for three studies included in the previous version of the review.

Main results

Four trials are now included in the review, with 753 participants. They were different in many ways including the intervention, duration, outcomes and control group so pooling of data was not possible. Overall, the quality of the evidence was rated as very low. Re-analysis of outcomes using data from the published studies found no significant effects of respite care compared to no respite care on any caregiver variable. When respite care was compared to polarity therapy a significant effect was found in favour of polarity therapy for caregiver perceived stress (n = 38, MD 5.80, 95% CI 1.43 to 10.17), but not for other measures of psychological health and other caregiver outcomes. No studies reported evaluable data on outcomes related to the people with dementia.

Authors' conclusions

Current evidence does not demonstrate any benefits or adverse effects from the use of respite care for people with dementia or their caregivers. These results should be treated with caution, however, as they may reflect the lack of high quality research in this area rather

than an actual lack of benefit. Given the frequency with which respite care is advocated and provided, well-designed trials are needed in this area.

PLAIN LANGUAGE SUMMARY

Respite care for people with dementia and their carers

Review question

This review aims to see whether respite care can reduce caregiver burden and stress, and increase the length of time for which a person with dementia can continue living at home.

Background

Caring for someone with dementia can be emotionally and physically demanding. Respite care is any intervention designed to give rest or relief to caregivers and it is not clear what positive and negative effects such care may have on them, or on people with dementia.

Study characteristics

Four studies with 753 participants were included in this review. Three compared respite care to no respite care and one compared respite care to polarity therapy, a type of touch therapy. All studies included people with dementia and their caregivers. We were not able to pool the results of the studies as there were so few studies and they measured the outcomes in different ways. All the studies reported outcomes for the caregiver, but only one reported outcomes for the person with dementia.

Key results

The three studies that compared respite care to no respite care found no evidence of any benefit of respite care for people with dementia or for their caregivers for any outcome, including rates of institutionalisation and caregiver burden. The study that compared respite care to polarity therapy found that polarity therapy decreased caregiver perceived stress but that there was no difference between polarity therapy and respite care for other measures of psychological health and other caregiver outcomes.

Quality of the evidence

A host of methodological problems were identified in the available trials. One study did not report data that could be analysed, the remaining three studies were very small and had a very short duration. Further methodologically sound research is needed before any firm conclusions can be drawn.

Summary of findings for the main comparison. Respite care versus no respite care for people with dementia and their carers

Respite care versus no respite care for people with dementia and their carers

Patient or population: patients with people with dementia and their carers
Settings: outpatients
Intervention: Respite care versus no respite care

Outcomes	Illustrative comparative risks* (95% CI)		Relative effect (95% CI)	No of Participants (studies)	Quality of the evidence (GRADE)	Comments
	Assumed risk	Corresponding risk				
	Control	Respite care versus no respite care				
Rate of institutionalisation	See comment	See comment	Not estimable	_	See comment	No studies reported data for this outcome
Mortality of people with dementia - not reported	See comment	See comment	Not estimable	-	See comment	No studies reported data for this outcome
Physical health of people with dementia - not reported	See comment	See comment	Not estimable	-	See comment	No studies reported data for this outcome
Quality of life of people with dementia - not reported	See comment	See comment	Not estimable	-	See comment	No studies reported data for this outcome
Caregiver Burden Zarit's Caregiver Burden Scale Follow-up: 6 weeks		The mean caregiver burden in the intervention groups was **5.51 lower** (12.38 lower to 1.36 higher)		21 (1 study)	⊕⊝⊝⊝ **very low** [1,2,3]	
Caregiver psychological stress and health Various scales Follow-up: 2 weeks	See comment	See comment	Not estimable	55 (1 study)	⊕⊝⊝⊝ **very low** [2,3,4]	Grant 2003 measured this outcome on 3 scales, none of which showed a significant difference between respite care and no respite care.[5]

Caregiver quality of life - not reported	See comment	See comment	Not estimable	-	See comment	No studies reported data for this outcome

*The basis for the **assumed risk** (e.g. the median control group risk across studies) is provided in footnotes. The **corresponding risk** (and its 95% confidence interval) is based on the assumed risk in the comparison group and the **relative effect** of the intervention (and its 95% CI).
CI: Confidence interval; **RR:** Risk ratio

GRADE Working Group grades of evidence
High quality: Further research is very unlikely to change our confidence in the estimate of effect.
Moderate quality: Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.
Low quality: Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.
Very low quality: We are very uncertain about the estimate.

[1] Risk of bias - serious: Wishart 2000 had an unclear risk of bias for blinding and incomplete data.
[2] Imprecision - serious: this outcome had very wide confidence intervals.
[3] Publication bias - strongly suspected: only one study reported data for this outcome.
[4] Risk of bias - serious: Grant 2003 had an unclear risk of bias for allocation concealment, blinding and incomplete data.
[5] The scales used were: Hamilton Depression scale, Hamilton Anxiety scale and the Brief Symptoms Inventory.

Summary of findings 2. Respite care versus polarity therapy for people with dementia and their carers

Respite care versus polarity therapy for people with dementia and their carers

Patient or population: people with dementia and their carers
Settings: outpatients
Intervention: Respite care versus polarity therapy

Outcomes	**Illustrative comparative risks* (95% CI)**		**Relative effect (95% CI)**	**No of Participants (studies)**	**Quality of the evidence (GRADE)**	**Comments**
	Assumed risk	**Corresponding risk**				
	Control	**Respite care versus polarity therapy**				
Rate of institutionalisation - not reported	See comment	See comment	Not estimable	-	See comment	No studies reported data for this outcome
Mortality of people with dementia - not reported	See comment	See comment	Not estimable	-	See comment	No studies reported data for this outcome

Physical health of people with dementia - not reported	See comment	See comment	Not estimable	-	See comment	No studies reported data for this outcome
Quality of life of people with dementia - not reported	See comment	See comment	Not estimable	-	See comment	No studies reported data for this outcome
Caregiver burden - not reported	See comment	See comment	Not estimable	-	See comment	No studies reported data for this outcome
Caregiver psychological stress and health Various scales Follow-up: 8 weeks	See comment	See comment	Not estimable	38 (1 study)	⊕⊖⊖⊖ **very low** [1,2,3]	Korn 2009 measured this outcome on 4 scales, one of which showed a significant difference favouring polarity therapy between respite care and no respite care.[4]
Caregiver quality of life Quality of Life - AD (Caregiver version) Follow-up: 8 weeks		The mean caregiver quality of life in the intervention groups was **1.8 lower** (5.74 lower to 2.14 higher)		38 (1 study)	⊕⊖⊖⊖ **very low** [1,2,3]	

*The basis for the **assumed risk** (e.g. the median control group risk across studies) is provided in footnotes. The **corresponding risk** (and its 95% confidence interval) is based on the assumed risk in the comparison group and the **relative effect** of the intervention (and its 95% CI).
CI: Confidence interval

GRADE Working Group grades of evidence
High quality: Further research is very unlikely to change our confidence in the estimate of effect.
Moderate quality: Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.
Low quality: Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.
Very low quality: We are very uncertain about the estimate.

[1] Risk of bias - serious: Korn 2009 had an unclear risk of bias for randomisation, allocation concealment, and incomplete data.
[2] Imprecision - serious: this outcome had very wide confidence intervals.
[3] Publication bias - strongly suspected: only one study reported data for this outcome.
[4] The scales used were: Perceived Stress scale, CES Despression scale, Penn State Worry Questionnaire and SF-36 Mental component summary.

BACKGROUND

Description of the condition

Dementia is a common and serious mental health problem affecting 6.4% of the population. It increases in prevalence with age, from 0.8% in 65 to 69 year olds to 28.5% in people aged 90 years or older (Lobo 2000). In the coming years an exponential increase in numbers of people who are affected is anticipated as populations age (Mura 2009).

The clinical features of dementia include an acquired global impairment of intellect and memory; there may be changes in personality and most cases of dementia result in progressive impairment of language, insight and judgement (APA 1994). Most affected individuals demonstrate difficulties with executive functions and later develop difficulties with activities of daily living. As a result of these impairments, people with dementia require assistance with many aspects of their lives and progressively more care over time. Such care is initially provided by family members (Karlawish 2002; Shaji 2003). Because of the long duration and increasing severity of their disorder, people with dementia may be institutionalised.

Remaining in the community is generally preferable for people with dementia (Levin 1994), who may remain more socially connected, have better physical functions and experience higher levels of quality of life (Nikmat 2013) and, when not overly demanding, can be emotionally satisfying and rewarding for caregivers. In some systems of health and social care delaying institutionalisation can also reduce costs to the system (Johnson 2000). Providing care for a person with dementia in the community commonly places stress on the primary caregiver (Brodaty 2009). The stress can have many causes including the need to be available to the person with dementia at all times as well as problems with communication and behaviour associated with the dementia. It is reported that the primary sources of strain to caregivers of people with dementia are the behavioural problems and incontinence (Grant 2003). The stress of caring can also be exacerbated by lack of a supportive response from local health and social services, and by lack of support and sometimes criticism from other family members (Shaji 2003). Such stress can have a range of adverse effects including the breakdown of the relationship between patient and caregiver, a poorer quality of care, and physical and psychological morbidity for both the patient and caregiver (Neufield 2003; Parks 2000). In extreme cases, violence and other forms of abuse may be precipitated.

Description of the intervention

In an attempt to prolong the time that people with dementia can remain in the community, respite care has been advocated. Respite care is the temporary provision of care for a person with dementia, at home or in an institution, by people other than the primary caregiver. Respite care is a blanket term used to describe a very diverse set of services which vary over a number of dimensions. The first of these dimensions is place; respite care can take place in the home of the person with dementia, a daycare centre or a residential setting. Respite care can also vary in terms of who provides the care; this may be by trained and untrained staff or volunteers. The care provided may also differ in duration, ranging from a couple of hours to a number of weeks. Respite care may be planned or unplanned and may involve overnight care or daytime-only care. Ideally the patient and caregiver should be able to choose the type of respite care that suits them, but in reality often only one type of care is available in any one geographical area.

How the intervention might work

The temporary provision of care is to give primary caregivers respite from their caregiving responsibilities and hopefully ameliorate, to some degree, the stresses associated with being a caregiver. The provision of respite care is based on the assumption that the reduction in the stress of the caregiver produced by a temporary relief from caregiving will allow the person with dementia to remain in the community for longer, to have a better relationship with his or her caregiver, and to receive better care while in the community. In an ideal situation, the periods of respite can also be used to offer professional re-evaluation of the needs of a person with dementia and to provide rehabilitation.

The different types of respite care are so diverse that they are likely to vary in the extent to which they are useful to what is an equally diverse set of users. People with dementia and their caregivers vary in many factors including age, sex, severity of disease, employment status, education, socioeconomic status and physical health. All of these factors could be expected to impact on the type of respite care that may be most desirable and efficacious for any particular person with dementia and their carer.

Increased availability and flexibility of respite care are very common requests in surveys of caregivers (Levin 1994). Thus we can assume that caregivers value respite services. Many users report that they would not be able to cope without such support (Levin 1994).

Why it is important to do this review

Although respite care is advocated by many and has a rational basis, its efficacy has been called into question, particularly because when offered respite care only "slightly over half of caregivers" avail themselves of this service (Lawton 1989). Publications suggest that the limited use of respite care may arise because most families cope reasonably well with the demands of caregiving and therefore do not need this service. Many caregivers may be using informal types of respite care such as help from family and friends. Alternatively, caregivers may think, rightly or wrongly, that respite care has adverse consequences which outweigh its benefits. Reports have found that caregivers regard respite care as providing benefits of self-care and relief to themselves at the cost of the safety and comfort of their family members during the respite care episodes; they feel torn between the necessity to have a break and their anxiety about the impact of institutional respite care on the person with dementia (Gilmour 2002; Perry 2001). Other perceived adverse effects of respite care are the disruption in routine (Hirsch 1993) and the feelings of guilt, despondency, being 'let-down' or emotional devastation some caregivers experience when a respite care period ends (Strang 2000). A further possibility is that the type of respite care preferred by the caregiver is not available in their area of residence, implying that it is not respite care in general but the mode of service delivery the efficacy of which may be being questioned. This explanation would fit in with the earlier observation that respite care is a much requested service.

Respite care services are advocated by health and social care providers from a wide range of backgrounds and have been

provided for over 20 years around the world. In addition, numerous publications evaluate the effects of respite care (Gottlieb 2000; Lawton 1989; Zarit 1998; Zarit 1999) and have given rise to reviews of caregiver interventions in general and one concerning daycare programmes alone. These papers have focused on outcomes for the caregiver. A systematic review of the literature and data which specifically assess the benefits and adverse effects of respite care on the quality of life, morbidity or mortality of people with dementia and their caregivers has not been published.

OBJECTIVES

The aim of this review was to assess the benefits and harms of respite care for people with dementia and their caregivers, in particular the effect of respite care on rates of institutionalisation.

METHODS

Criteria for considering studies for this review

Types of studies

All randomised controlled trials in which respite care was given as an intervention for people with dementia and their caregivers.

Types of participants

1. People of any age and either sex with dementia of any type, including Alzheimer's disease and multi-infarct dementia, who lived in the community and who had a full-time caregiver. The operational definition of dementia was based on the criteria used in the Diagnostic and Statistical Manual of Mental Diseases-IV (DSM-IV) (APA 1994), International Classification of Diseases-10 (ICD-10) (WHO 1992), or National Institute of Neurologic and Communicative Disorders and Stroke - Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) (McKhann 1984). Where this information was unavailable, the review authors deemed other standardized approaches to diagnosis acceptable.
2. The full-time caregivers of the people with dementia included above.

Types of interventions

This review included all interventions that provided respite care, defined as any service or group of services designed to provide temporary periods of relief or rest, or both, for caregivers. Control groups included those receiving otherwise similar care without respite, but who were eligible and willing to participate in such care, or a comparison with an alternative intervention.

Episodes of respite care might have lasted any amount of time but cumulatively must have amounted to less than 50% of total care time. Respite care could be provided in the community or in an institution.

Types of outcome measures

Positive and negative outcomes for people with dementia and their caregivers were assessed.

Primary outcomes

The primary outcome for this review was rate of institutionalisation.

Secondary outcomes

Secondary outcomes for people with dementia included:

- mortality*;
- physical health*;
- use of medications;
- cognition;
- other aspects of mental function;
- behaviour and activities of daily living;
- quality of life*;
- evidence of abuse.

Secondary outcomes for caregivers included:

- caregiver burden*;
- psychological stress and health*;
- physical health;
- economic impact;
- quality of life*.

The rate of institutionalisation and the outcomes marked with an asterisk (*) were included in the summary of findings tables (see 'Summary of findings' table 1; 'Summary of findings' table 2).

Search methods for identification of studies

See Cochrane Dementia and Cognitive Improvement Group methods used in reviews.

Electronic searches

See Appendix 1 for details of the update search and Appendix 2 for details of previous searches.

We searched ALOIS (www.medicine.ox.ac.uk/alois), the Cochrane Dementia and Cognitive Improvement Group Specialized Register on 3 December 2012. The search terms used were: respite* OR daycare OR caregiver* relief.

ALOIS is maintained by the Trials Search Co-ordinator of the Cochrane Dementia and Cognitive Improvement Group and contains studies in the areas of dementia prevention, dementia treatment and cognitive enhancement in healthy people. The studies are identified from the following.

1. Monthly searches of a number of major healthcare databases: MEDLINE, EMBASE, CINAHL, PsycINFO and LILACS.
2. Monthly searches of a number of trial registers: International Standard Randomised Controlled Trial Number Register (ISRCTN); UMIN (Japan's Trial Register); the World Health Organization (WHO) Clinical Trials Registry Platform portal (which covers ClinicalTrials.gov; ISRCTN; the Chinese Clinical Trials Register; the German Clinical Trials Register; the Iranian Registry of Clinical Trials; and the Netherlands National Trials Register, plus others).
3. Quarterly searches of the Central Register of Controlled Trials (CENTRAL) in *The Cochrane Library*.
4. Six-monthly searches of a number of grey literature sources: ISI Web of Knowledge Conference Proceedings; Index to Theses; Australasian Digital Theses.

To view a list of all sources searched for ALOIS see About ALOIS on the ALOIS website.

Details of the search strategies used for the retrieval of reports of trials from the healthcare databases, CENTRAL and conference proceedings can be viewed in the 'methods used in reviews' section within the editorial information about the Dementia and Cognitive Improvement Group.

We performed additional searches in many of the sources listed above to cover the timeframe from the last searches performed for ALOIS to ensure that the search for the review was as up-to-date and as comprehensive as possible. The search strategies used can be seen in Appendix 1.

The latest search (December 2012) retrieved a total of 771 results. After a first assessment and de-duplication of these results the authors were left with 35 references to further assess.

Searching other resources

We also checked the reference lists of included studies for relevant trials.

Data collection and analysis

Methods used for this update of the review are reported below. See Appendix 2 for details of the methods used in the previous version of this review.

Selection of studies

For the 2013 update, NM and KSW independently screened the titles and abstracts extracted by the searches for their eligibility for potential inclusion in the review based on the above criteria. We obtained full texts for all relevant studies and again independently screened them. We resolved any disagreements by consensus.

In the previous version of the review, one review author (HL) studied the titles and abstracts of those references identified by the search, discarding those that were clearly not relevant and retrieving the remaining ones in hard copy. Two review authors independently assessed the resulting references and preliminarily divided them into excluded and included categories on the basis of the predefined inclusion criteria. We sought additional information from study authors if appropriate. The review authors reached a final consensus through discussion.

Data extraction and management

For the 2013 update, NM extracted data from the new included published reports and KSW checked the data. In the previous version, one review author (HL) extracted the data from the published reports.

Assessment of risk of bias in included studies

NM undertook assessment of the risk of bias of all the included trials according to the methods in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2011) and KSW checked these.

The risk of bias tool examines five key domains for bias: selection bias, performance bias, attrition bias, detection bias and reporting bias. We assessed each domain and classified it as either at low or a high risk of bias and where insufficient detail was reported in a study to assess the risk we reported this as 'unclear'. In addition, we reported any other forms of bias noted in the studies.

We used the Cochrane 'Risk of bias' tool in RevMan 5.1 (RevMan 2011).

Measures of treatment effect

For continuous outcomes we collected the mean change from baseline, the standard deviation of the mean change, and the number of patients for each treatment group at each assessment. The baseline assessment was defined as the latest available assessment preceding randomisation, but no longer than two months before.

Where changes from baseline were not reported, we extracted the endpoint mean and standard deviation at each time point. We estimated the mean difference (MD) between groups and its 95% confidence interval (CI).

For binary data we sought the numbers in each treatment group and the numbers experiencing the outcome of interest, and calculated a standard estimation of the risk ratio (RR) and its 95% CI. If the only data reported were the treatment effects and their standard errors, then these were extracted.

Unit of analysis issues

The outcomes measured in clinical trials of dementia and cognitive impairment often arise from ordinal rating scales. Where the rating scales used in the trials had a reasonably large number of categories (more than 10) we treated the data as continuous outcomes arising from normal distributions. Summary statistics (n, mean and standard deviation) were required for each rating scale at each assessment time for each treatment group in each trial for the change from baseline.

When changes from baseline results were not reported, we calculated the required summary statistics from the baseline and assessment time treatment group means and standard deviations. In this case a zero correlation between the measurements at baseline and assessment time was assumed. This method overestimates the standard deviation of the change from baseline, but this conservative approach is considered to be preferable in a meta-analysis.

One trial apparently used clustering but did not report enough information for us to be sure and the data were not reported in a usable form. If cluster studies had been appropriately analysed taking into account intra-class correlation coefficients and the relevant data documented in the report, synthesis with other studies would have been possible using the generic inverse variance technique.

Dealing with missing data

We extracted data to allow an intention-to-treat analysis in which all randomised participants were analysed in the groups to which they were originally assigned. For continuous outcomes, we calculated missing standard deviations from other available data such as CIs, standard errors, P, T or F values as detailed in Deeks 2009.

Assessment of heterogeneity

We explored heterogeneity by examining factors that may be influential, such as the care setting and duration of follow-up. In the absence of clinical heterogeneity we assessed statistical heterogeneity using the I^2 statistic and the Chi^2 test.

Assessment of reporting biases

Had there been more than 10 included studies we would have assessed reporting bias by constructing a funnel plot.

Data synthesis

We used a fixed-effect model unless there was heterogeneity (see 'Assessment of heterogeneity'). If the I^2 statistic indicated substantial heterogeneity (values of 50% or greater), we presented the results using a random-effects model meta-analysis.

Subgroup analysis and investigation of heterogeneity

We did not plan to undertake any subgroup analyses.

Sensitivity analysis

There were not sufficient studies reporting data for each outcome to allow a meaningful sensitivity analysis to be carried out.

RESULTS

Description of studies

See Characteristics of included studies and Characteristics of excluded studies for details of the studies considered for this review.

Results of the search

The December 2012 update search identified 35 records, and for eight studies we obtained the full texts. After examining the full texts of these articles, we included one additional study (Korn 2009). This review now includes four studies.

Included studies

Four randomised studies met the inclusion criteria for this review. Three studies compared outcomes for a group provided with an intervention aimed to provide rest or respite for the primary caregiver with a control group. There were few other similarities between the studies and this had consequences for the extent to which the studies were able to be compared. One further study (Korn 2009) compared respite care to polarity therapy.

1. Additional information

The review authors requested additional study data from the authors of the three trials included in the previous version of this review. Data were no longer available from the Lawton and Wishart studies (Lawton 1989; Wishart 2000). Investigators in the Grant study (Grant 2003) agreed to forward data to the review authors but these have not been received to date. Professor J Roberts supplied information about the diagnostic criteria in the Wishart study (Wishart 2000). We did not request additional data from the authors of Korn 2009.

2. Study design

Three included studies were parallel group randomised controlled trials and one was apparently cluster randomised (Lawton 1989).

3. Duration

Three of the studies were short term, lasting two weeks (Grant 2003), six weeks (Wishart 2000) and eight weeks (Korn 2009). Lawton 1989 was a long term study lasting 12 months.

4. Participants

Grant 2003: the participants were 55 people with probable Alzheimer's disease and their spousal caregivers. Diagnosis of Alzheimer's disease was established through neurological and neuropsychological tests or from an existing diagnosis made by a physician. Baseline information about the people with dementia was limited to a Clinical Dementia Rating: 38% were classified as mild, 44% as moderate and 18% as severe. The caregivers were stratified into two groups according to criteria developed by the investigators, vulnerable and non-vulnerable. The vulnerable classification was made in those persons who provided more than 12 hours of care per day and who had received in-home respite care less than once per month in the six months preceding the baseline. Non-vulnerable caregivers were those who received more respite care than this, although those who received more than eight hours per week were not considered for the study. Caregivers all lived with the person with dementia. There were 21 male and 34 female caregivers.

Korn 2009: the participants were 42 American Indians or Alaskan natives who were caregivers of family members with dementia. The mean age of the caregivers was 50 years, ranging from 27 to 69 years, and there were 38 women and 4 men. The care recipients' age ranged from 32 to 89 years and 57% were 70 years and older. The two care recipients who were younger than 35 years were diagnosed with dementia due to a stroke and to the sequelae of a failed suicide attempt.

Lawton 1989: the participants were 632 people with dementia and their caregivers. Eligibility criteria were that the caregiver took primary responsibility for the care of the patient who was diagnosed with Alzheimer's disease or a related disorder by a physician. This diagnosis was confirmed using the Mental Status Questionnaire (Kahn 1961). The average age of the care recipients was 76.2 years and of the caregivers it was 59.9 years; 377 people with dementia were female and 255 were male. There were 501 female and 131 male caregivers.

Wishart 2000: the participants were 24 people with dementia who were living in the community and their caregivers. Demographic information was not fully reported but the mean ages of the participants for whom the data were available were 80.2 and 57.6 years for the care recipients and caregivers respectively. Correspondence with the author revealed that the diagnosis of dementia was an existing diagnosis made by a physician. Sixteen care recipients were female and 4 were male. There were 18 female and 3 male caregivers.

5. Interventions

Grant 2003: the intervention group were entitled to up to 60 hours of respite care over a two-week period. The respite intervention was care of the person with dementia in the home of the caregiver and

person with dementia, provided by professionals who were trained in the care of people with Alzheimer's disease. Respite care could total no more than six hours per day. The actual amount of respite care used was up to the discretion of the caregiver. Members of the control group were given no respite care.

Korn 2009: the respite intervention provided a trained companion to stay at home with the care recipient for eight sessions, and lasted for three hours. The caregivers were encouraged to participate in activities and were given transportation, admission costs and supplies for the activities they chose, which included music therapy, yoga, swimming and basket-making, activities with friends and gardening, and lasted between 60 to 120 minutes. The control group were given polarity therapy, a type of touch therapy that uses gentle pressure on energy points and biofields to help the client achieve physiological relaxation. They were provided with eight 50-minute sessions, and care recipients also received three hours of trained care to allow for travel to and from the therapy.

Lawton 1989: experimental participants were given access to three types of respite care, in-home respite, daycare or institutional respite. The different forms were not mutually exclusive as participants were eligible to use any of the different forms in any combination. Funding for the respite care was provided as needed. This meant that those caregivers able to pay for the respite care did so, and those that could not were given a subsidy by the respite programme, government or other organisation. The duration of the intervention was one year. Those in the control group were not given access to respite care but were given a list of services available for those with dementia and their families.

Wishart 2000: the respite intervention consisted of a weekly visit by a trained volunteer who provided assistance and companionship to the care recipient through a visiting or walking programme, so relieving the caregiver. The visits lasted an average of 2.5 hours and the intervention was provided for six weeks. Those randomised to the control group received no visits but were given the intervention after the study had finished and so constituted a waiting list control.

6. Outcomes

Grant 2003: there were no outcomes reported for the person with dementia. Baseline and one-month post-baseline scores were obtained for caregivers in the following.

- Structured Interview Guide for the Hamilton Depression and Anxiety Scale: this is a validated two-part scale with 17 depression items and 13 anxiety items administered by a structured interview. It measures symptoms of depression and anxiety. Each item is rated by the interviewer on a scale of 0 to 2, 0 to 3 or 0 to 4 depending on the item. Higher scores indicate more severe symptoms (Williams 1988).
- Brief Symptom Inventory - Global Severity Index: the BSI is a validated self-reported assessment of psychological distress comprising 53 items. Each item is rated on a five-point scale (0 to 4) where higher scores indicate higher levels of distress. Items are grouped into nine primary symptom dimensions. The Global Severity Index combines information on the number and severity of the symptoms to give a single score of distress (Derogatis 1983).

Physiological measures of stress markers such as plasma adrenaline levels were also reported but were not in the scope of this review.

Korn 2009: outcomes were only reported for caregivers.

- Perceived stress scale (PSS): this is a 10-item scale that measures the perception of stress. Higher scores indicate increased perception of stress (Cohen 1988).
- Center for Epidemiological Studies Depression Scale: this validated 20-item scale consists of statements describing positive and negative emotions and behaviours, each of which is rated from 0 to 3 corresponding to the frequency of the emotion or behaviour. Higher scores indicate increased depression (Radloff 1972).
- Short form (SF)-36: this is a validated scale that measures health-related quality of life using eight health attributes. Higher scores indicate better health-related quality of life (Ware 2000).
- Quality of Life–AD (Caregiver Version): this is a validated 13-item checklist that covers additional domains not addressed by the SF-36. Higher scores indicate higher quality of life (Logsdon 2002).
- Pittsburgh Sleep Quality Index(PSQI): this validated self-rated questionnaire measures the quality and patterns of sleep in older adults. Higher scores indicate worse sleep quality (Buysse 1989).
- Penn State Worry Questionnaire (PSWQ): this is a validated 16-item self-report measure that assesses the generality, excessiveness, and uncontrollability of worry without focusing on specific domains of worry. Higher scores indicate high levels of worry (Meyer 1990).

Lawton 1989: for those with dementia the following were measured.

- Severity of illness, 20 symptoms were rated by the caregiver on 5-point scales according to the severity of the problem they caused. This measure was unvalidated (Lawton 1989).
- Mortality, determined through monthly telephone contact with caregivers.
- Number of days living in the community, number of days preceding institutionalisation or death (whichever happened first).

For the caregiver the following were measured.

- Caregiver attitudes: an unvalidated set of five scales derived from 47 items from existing scales measuring subjective caregiving burden, impact of caregiving, caregiving mastery, caregiving satisfaction and cognitive reappraisal (Lawton 1989).
- Caregiver Physical Health: measured with the four-item health subindex of the Philadelphia Geriatric Center Multilevel Assessment Instrument (MAI) (Lawton 1982).
- Psychological wellbeing. Two scales were used:
  a. Center for Epidemiological Studies Depression Scale (CESD), this validated 20-item scale consists of statements describing positive and negative emotions and behaviours, each of which is rated from 0 to 3 corresponding to the frequency of the emotion or behaviour. Higher scores indicate increased depression (Radloff 1972);

b. Bradburn Affect Balance Scale (ABS), this is a 10-item scale made up of five items describing positive affect and five describing negative affect. Responses are yes or no (Bradburn 1969).

Wishart 2000 measured the following outcomes.

- Zarit's Caregiver Burden Scale: this is a validated 22-item scale which aims to measure the extent to which caregivers perceive how their emotional or physical health, social life and financial status are suffering as a consequence of caring for a person with dementia. Each item is rated on a five-point scale with higher scores indicating increased levels of burden (Zarit 1986).
- Duke-UC Functional Support Questionnaire: this validated eight-item scale yields two separate scores of social support, one of confident support summed from six items, and one of affective support from three items (Broadhead 1988).
- Health and social service utilization: this was measured using an unvalidated scale consisting of questions about the use of medical services over the preceding six weeks (Browne 1990).

Excluded studies

Twenty-five studies were excluded: in seven studies the intervention was not respite care or both groups received some form of respite care; in one study respite care was compared to nursing home placement; two studies did not include people with dementia; and 15 studies were not randomised. See also Characteristics of excluded studies.

Risk of bias in included studies

See Characteristics of included studies, Figure 1 and Figure 2.

Figure 1. Risk of bias graph: review authors' judgements about each risk of bias item presented as percentages across all included studies.

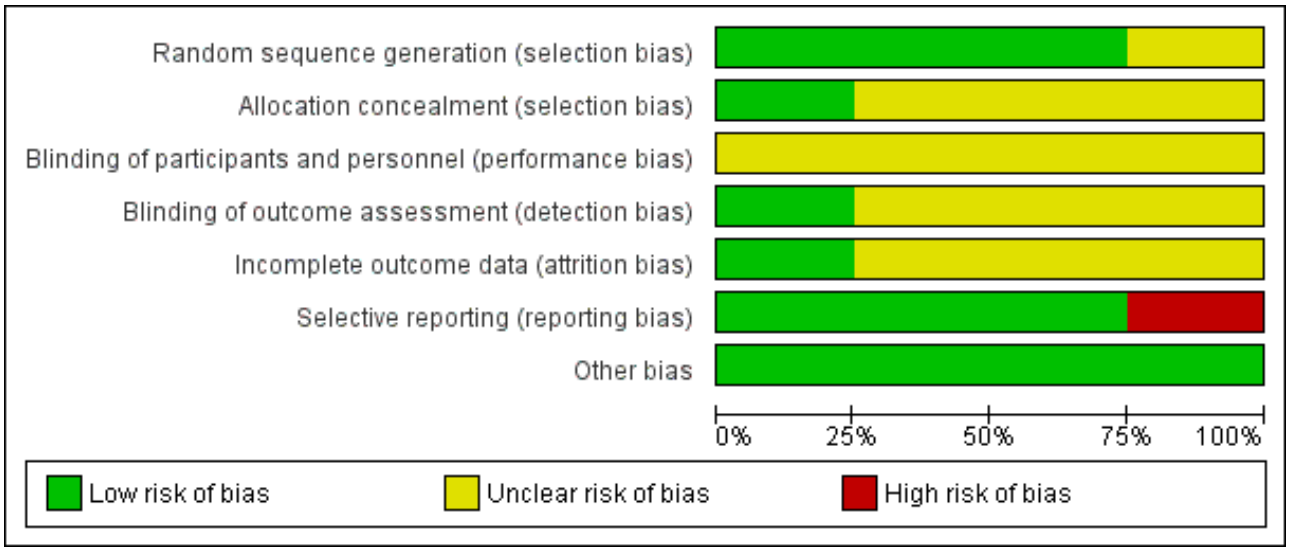
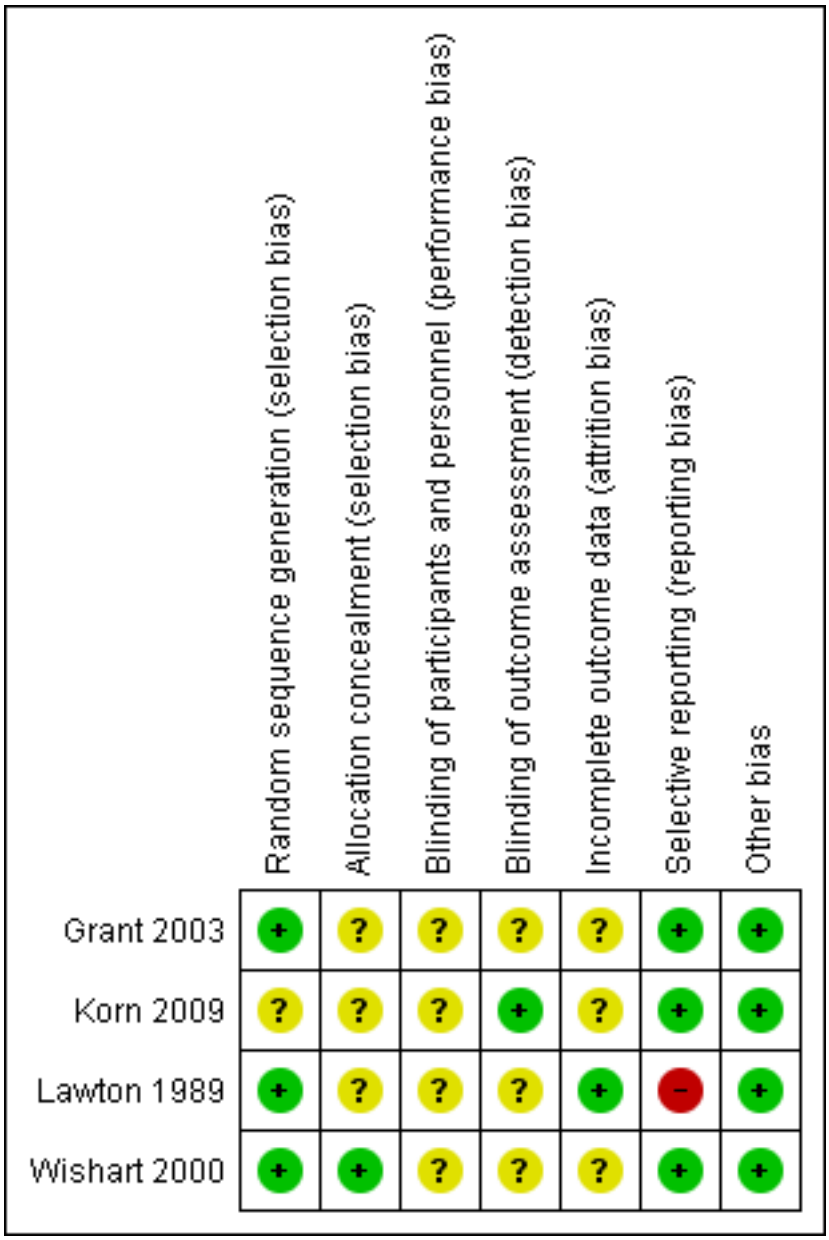


Figure 2. Risk of bias summary: review authors' judgements about each risk of bias item for each included study.



Allocation

Grant 2003 and Lawton 1989 described the allocation to treatment group as being by using random number tables, and Wishart 2000 described a computer-generated randomisation process with group numbers being placed in sealed opaque envelopes to conceal allocation. All three studies were rated as low risk of bias for randomisation. Korn 2009 stratified participants according to Perceived Stress Scale scores but did not report the randomisation procedure and was rated as at unclear risk of bias. Only Wishart 2000 reported allocation concealment measures and was rated as low risk of bias; the remaining three studies were rated as having unclear risk of bias for allocation concealment. As mentioned in the description of the studies, the caregivers in the Grant study were divided into two groups, vulnerable and non-vulnerable, according to how much respite care they received and how many hours a day they were engaged in caregiving tasks. Grant and colleagues used stratified randomisation to ensure that similar numbers of vulnerable and non-vulnerable caregivers were in the treatment and control groups.

Blinding

No double blinding was reported in any of the studies. Blinding is virtually impossible with this type of intervention for the participants and the experimenters. However, it is feasible for those who are measuring outcomes to be blind to treatment allocation. Lack of blinding in this type of study diminishes the methodological quality due to the possibility that the researchers' or participants' preconceptions about the efficacy of respite care may result in bias when performing the assessments. All studies were rated as unclear for blinding of participants; only Korn 2009 reported that

the outcome assessors were blinded and was rated as low risk, the remaining three trials were rated as at unclear risk of bias.

Incomplete outcome data

No information on dropouts was given in the Grant 2003 publication. There were three dropouts in Wishart 2000 (12.5%), two in the respite group and one in the control group. The reasons given were death and increased severity of illness. There was a 20% mortality rate in Lawton 1989 but no details of further dropouts were given. Five people from the enhanced respite group and two from the polarity therapy left the study early due to lack of time in the Korn 2009 trial. The dropouts from deaths were similar in the treatment and control groups.

Selective reporting

Three studies were rated as low risk of bias as all outcomes that were stated in the studies were reported.

Lawton 1989 used two different approaches to randomisation depending on where the participants were recruited from. Those recruited from Alzheimer's disease support groups were allocated as a group whereas those recruited through the media were allocated individually. This method of randomisation does not reduce the validity of the methodology per se but means that any statistics must use the support group as the unit of analysis and not the individual. It was not reported how many support groups there were and how many of the sample came from this source. Data in this study were not reported in a useable form and the study was rated as at high risk of bias.

Other potential sources of bias

All studies had a low risk of bias for other biases, as there were no other apparent sources of bias.

Effects of interventions

See: **Summary of findings for the main comparison** Respite care versus no respite care for people with dementia and their carers; **Summary of findings 2** Respite care versus polarity therapy for people with dementia and their carers

Respite care versus no respite care

Primary outcome

None of the three studies that compared respite care with no respite care reported on the rate of institutionalisation, which was the primary outcome of this review.

Secondary outcomes

Only Grant 2003 and Wishart 2000 contributed data to the analysis. Data from Lawton 1989 were not reported in a usable form. No pooling of study data was possible because the interventions and outcomes were too dissimilar. There were suitable data for the analysis of six outcomes, none of which showed a significant treatment effect. These outcomes were Caregiver Burden (Analysis 1.1), Hamilton-Depression (Analysis 1.2), Hamilton Anxiety (Analysis 1.3), Global Severity Index from the Brief Symptom Inventory (Analysis 1.4), Social Support-Affective Support (Analysis 1.5) and Social Support-Confidant Support (Analysis 1.6). Wishart 2000 reported a significant effect in favour of the respite group on caregiver burden; however, using the data reported in the paper we found a non-significant result. This indicated an error either in the reporting of the results or in the analysis itself.

Respite care versus polarity therapy

Primary outcome

The study that compared respite care with polarity therapy did not report on the rate of institutionalisation.

Secondary outcomes

Korn 2009 found a significant difference in favour of polarity for caregiver psychological stress and health measured on one scale: Perceived Stress Scale (n = 38, MD 5.80, 95% CI 1.43 to 10.17, Analysis 2.1). However, no significant treatment effect was seen on the Center for Epidemiological Studies - Depression Scale (Analysis 2.2), the Penn State Worry Questionnaire (Analysis 2.3) and the SF-36 Mental component summary (Analysis 2.4). Furthermore, no significant treatment effects were found for the SF-26 Physical component summary (Analysis 2.5), the Pittsburgh Sleep Quality Index (Analysis 2.6) and quality of life (Analysis 2.7).

DISCUSSION

Summary of main results

The aim of this review was to evaluate the benefits and adverse effects of respite care for people with dementia and their caregivers. See Summary of findings for the main comparison and Summary of findings 2.

Analysis of the available data showed no significant effects on caregiver outcomes when respite care was compared with no respite care in three studies, and there was no evaluable data for people with dementia. When respite care was compared to polarity therapy, a type of touch therapy that uses gentle pressure on energy points and biofields to help the client achieve physiological relaxation, a significant treatment effect was found in favour of polarity therapy for caregiver perceived stress, however, other measures of psychological health and other outcomes showed no significant effects. Again, there were no evaluable data for people with dementia.

Overall completeness and applicability of evidence

There are two possible explanations for these results, firstly, that in reality respite care has no effects on caregivers or, secondly, that any resultant effects are imperceptible due to the small sizes of the trials. In order to establish which of these is the case one must systematically assess the validity of the studies included in the review. There are three main issues to address here, the intervention, the people to whom the intervention was given and the outcomes of the intervention.

The interventions tested in the included studies were very different, although they all met our criteria for respite care by providing relief for the caregiver. The duration of the intervention for three of the trials was extremely short, consisting of two, six and eight weeks for Grant 2003, Wishart 2000 and Korn 2009, respectively. Given the prolonged and degenerative course of the diseases that cause dementia, even the year-long study by Lawton and colleagues could be considered too short. The intensity of the intervention also varied between studies. Participants in the Wishart study were

provided with respite care for only two hours per week, in Korn 2009 they received three hours per week, while those in the Grant 2003 trial had 10 days of care (up to six hours per day). The frequency and amount of respite provided in the Lawton 1989 study depended on how much care the caregiver both wanted and felt able to afford. To use an analogy coined by Zarit in his extensive writings on this subject, it is possible that the respite care given in these studies was at a subclinical dosage.

The actual respite care received was also qualitatively different. The intervention in both Grant 2003 and Korn 2009 was in-home respite only, Lawton 1989 allowed the choice between in-home, daycare and institutional respite, and in Wishart 2000 the person with dementia was taken from the home on a walk. Different kinds of respite care are likely to have very different effects on both the caregivers and recipients and may be used in very different ways. Daycare and in-home respite care are likely to be used on a regular basis whereas institutional care is likely to be used on a more infrequent basis, and can be planned or unplanned in the case of, for example, caregiver illness. In-home respite care is said to be the most requested service while out of home daycare may increase the workload for caregivers by requiring them to prepare and transport the person with dementia (Berry 1991). It is recommended that future studies evaluate a single type of respite care and that future reviews consider each type of respite care separately.

A problem specific to the Lawton 1989 study was that caregivers were only given the opportunity to purchase respite care and were not provided with it free-of-charge as with the other three studies, although it should be noted that there were means-tested subsidies available. This introduces a further confounding factor to the study as only those who were able to afford respite care may have used it. This may have partly explained the low utilization of the intervention on offer. A further criticism of the Lawton 1989 study is that on examination of the range of hours of in-home respite used by participants in the control group in the year preceding baseline, some caregiving dyads were receiving full-time in-home care. This shows that the definition of respite care as being a temporary relief for caregivers was confounded in this study.

The Korn 2009 study compared respite care to a very specific alternative treatment, and only one of the four caregiver psychological health and stress outcomes were in favour of the alterative therapy, which could mean that either the trial was underpowered to find a difference on these outcomes or that respite care was equally as good as polarity therapy in improving the psychological and physical health of caregivers. It is unclear whether this trial has wider applicability as it was conducted in a very specific population, American Indians and Native Alaskans.

In terms of participants, the sample sizes in three of the studies were small. If an effect of respite care does exist it is likely to be small and may not be identified in studies of such limited size and quality. The samples of people with dementia were poorly defined, with none of the three included studies using any standard diagnostic tools. There was wide variation in the severity of cognitive impairment, which was likely to translate into a similarly large variation in the need for respite care. It has been shown that many caregivers do not make use of respite care early on in their relative's illness but wait until they have been caring for them for many years (Gottlieb 2000). If a large proportion of the sample were caring for a mildly impaired person then respite care might not have been expected to have a significant impact. Conversely, some researchers have suggested that not using respite care until the care recipients are severely impaired may mean that the caregivers are beyond help. Grant and colleagues split the caregivers in their sample into vulnerable and non-vulnerable subgroups according to the number of hours they spent on caregiving tasks on an average day and the amount of respite they had received in the preceding six months. It is probable that measurable differences in caregiver outcomes are more likely in vulnerable groups.

The relationships between the caregivers and those with dementia also differed among the studies. The caregivers in the Grant 2003 study were all the spouses of those with dementia and in Korn 2009 they were spouses and other family members. Caregivers in the Lawton 1989 and Wishart 2000 studies were enrolled irrespective of their relationship with the caregiver. Caregivers who are spouses of patients and those who care for their parents are said to have very different needs (Zarit 1999).

The validity of any randomised controlled trial also depends on the choice of control intervention. Wishart 2000 used a wait-list control group. This type of control has been criticised because the participants in the control group know that they will receive the intervention at some time, and this may have an impact upon their psychological wellbeing (Basham 1986). Grant 2003 and Lawton 1989 both used a no-treatment control. A problem with all of these designs is that the respite care provided as the intervention is not the only respite care available to the caregivers. Some caregivers in the control group of the Lawton 1989 study actually received more hours of respite care than those in the intervention group. This has been criticised in the literature as confounding the study (Gottlieb 2000; Zarit 1998; Zarit 1999) but may rather suggest that the way in which respite care was offered in the study was not as effective as the ways in which caregivers located it independently. In this case one would be evaluating a service designed to deliver respite care rather than respite care per se. Korn 2009 used respite care as the control, with participants engaging in a range of activities, and polarity therapy, a specific form of touch therapy, was the intervention. This is likely to have influenced the results and makes it difficult to compare the effects of respite care in this study with the other included studies.

Regarding outcomes, only one of the studies included any outcomes for the person with dementia (Lawton 1989). One of the most widely quoted statistics in the respite care literature is the reported 22-day increase of days spent in the community by the experimental group in the Lawton 1989 study. As already discussed the analysis in this publication was flawed due to the cluster randomisation process. This is one of the few studies to report a positive effect on rates of institutionalisation. Lawton 1989 also reported measures of functional status and mortality rates for the people with dementia, none of which were significantly different between the intervention group and the control group. In not reporting outcomes for the care recipient in the other three trials, a lack of consideration for the recipient is reflected in the wider literature of respite care; this point should be noted by researchers designing further trials.

In addition to the limitations of the outcomes measured for people with dementia, some of the measures used for assessment of the caregivers may have been inappropriate for that population. For example, the Hamilton scales were designed to monitor the progress of those diagnosed with depression or anxiety. It is unrealistic to expect a change by measuring populations such

as those in the Grant 2003 study who largely have subclinical scores. A similar objection can be lodged against the use of the Global Severity Index of the Neuropsychiatric Inventory, which showed low baseline values. The Duke UNC Functional Support Questionnaire was also a questionable choice. It measures perceived social support and may not be sensitive enough to pick up changes in these populations.

Quality of the evidence

Overall the quality of the evidence, based on GRADE, was very low. One study did not report data that could be used in the analysis, the remaining three studies were very small and had short lengths of follow-up. Only Korn 2009 mentioned blinding of the outcome assessor. This means that preconceived ideas about the efficacy of respite care might have been allowed to influence the results.

Potential biases in the review process

We tried to identify all relevant trials through our search, however it is possible that we may have failed to identify some studies.

Agreements and disagreements with other studies or reviews

To counteract the problems regarding insufficient amount of respite and the need for a suitable control group, Zarit and colleagues carried out a quasi-experimental study comparing caregivers living in two different regions of the USA which were similar demographically but which provided different access to daycare facilities (Zarit 1998). The treatment group comprised 121 carers living in New Jersey, which has a well-developed, subsidised daycare programme, who had enrolled their relatives in this programme. The control group comprised 203 caregivers from Ohio and Pennsylvania where there are very limited daycare programmes. The choice of caregivers for the control group was restricted to those who stated that they would use daycare if it was available. Zarit and colleagues claim that the caregivers in the two groups were similar in all respects apart from their access to daycare; the control group also used very small amounts of other types of respite. The treatment group caregivers showed improvements at three months and 12 months on measures of caregiving-related stress and psychological wellbeing. An advantage of this study over some previous research is that large amounts of respite care were utilized by the treatment group, preventing the possibility that respite was received in amounts that were too small to be of value. However, the lack of randomisation to groups means that we cannot be sure that the differences between the groups were due to the daycare or whether they reflected differences between the groups in other ways that might have affected the results. Zarit indicates that the demographic characteristics of the two regions were similar on per capita income, education, proportion of the population over 65 years, unemployment rates, population density and proportion of minorities. The advantage of randomisation is that as well as controlling for factors that are known to affect relevant outcomes it controls for factors that are not known (Higgins 2008).

AUTHORS' CONCLUSIONS

Implications for practice

No meaningful conclusions for practice can be drawn with the available evidence. This review has raised the possibility that studies of respite care focus too much on caregivers since only one of the four included studies and a minority of the literature reported any outcomes for the care recipient. We must ensure that at the same time as monitoring and nurturing caregivers, the lack of attention paid to people with dementia in the literature does not translate into a similar lack of attention in practice.

Implications for research

Current evidence does not allow one to make any reliable conclusions about the efficacy of respite care for people with dementia and their caregivers. This reflects a lack of high quality research in this difficult area. Future research should consider some of the methodological issues discussed and include outcomes for the care recipients as well as their caregivers.

As mentioned previously, utilization of respite care has been very low in many studies; some caregivers in the Lawton 1989 study used no respite care at all. As well as establishing any efficacy or harm associated with respite care, future research needs to explore why such services are not utilized when freely available. There are likely to be multiple reasons for this but one important reason may be the caregiver's anxiety that their relative will not receive care of the highest standard. Thus, it remains an imperative part of future research to evaluate whether any actual harm is associated with provision of respite care for people with dementia.

We present suggestions for future research based on this Cochrane review and the thematic synthesis, and using the EPICOT+ structure (Brown 2006) in Table 1.

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* Indicates the major publication for the study

CHARACTERISTICS OF STUDIES

Characteristics of included studies *[ordered by study ID]*

Grant 2003

Methods	RCT comparing one intervention group with a control in a parallel group design Duration: 2 weeks
Participants	N=55 Country: USA Mean age ˜73 years 62% female Inclusion criteria: spousal caregivers of people with a diagnosis of "probable" or "possible" AD
Interventions	Intervention group: 10 days of in-home respite of up to 6 hours per day over a 2 week period (N=27) Control group: no respite provided (N=28)

Grant 2003 *(Continued)*

Outcomes	For the caregiver: 1. Structured Interview Guide for the Hamilton Depression and Anxiety Scales 2. Brief Symptom Inventory 3. Physiological measures
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	"Randomly assigned with a table of random numbers"
Allocation concealment (selection bias)	Unclear risk	No information reported
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	Participants were not blinded
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	No information reported
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Leaving the study early not reported and Ns not reported in the results
Selective reporting (reporting bias)	Low risk	All outcomes stated in the study are reported
Other bias	Low risk	Supported by a National Institute on Aging grant No conflicts of interest reported

Korn 2009

Methods	RCT comparing one intervention group with an alternative treatment group in a parallel group design Duration: 8 weeks
Participants	N=42 Country: USA Mean age 50 years, range 27-69 90% female Inclusion criteria: American Indians or Alaskan Natives who had been the primary caregiver of a family member with dementia for at least 6 months, currently providing at least 4 hr of direct assistance per day, access to a telephone, and plan to remain in the community for at least 6 months. No medical conditions that would preclude the use of polarity therapy including acute infection, deep vein thrombosis, diabetic neuropathy, current substance abuse, cardiac arrhythmia, or other conditions associated with severe disability or high risk of death.

Korn 2009 *(Continued)*

Interventions	Intervention group: enhance respite care, eight sessions ranging from 60 to 120 minutes (N= Control group: polarity therapy, trained practitioners administered the standard 21-point protocol to participants during eight 50-min sessions (N= Both PT and ERC provided the same amount of time (3 hr) of paid care for the care recipient.
Outcomes	For the caregiver: 1. Perceived stress scale 2. Center for Epidemiological Studies–Depression Scale 3. SF-36 4. Quality of Life–AD (Caregiver Version) 5. Pittsburgh Sleep Quality Index 6. Penn State Worry Questionnaire
Notes	All participants who enrolled in the study received a choice of a fresh salmon or a small gift basket (value $30.00) following their participation.

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	"Randomization was carried out separately in each of two strata defined by baseline scores on the Perceived Stress Scale", no further details reported
Allocation concealment (selection bias)	Unclear risk	No information reported
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	Participants were not blinded
Blinding of outcome assessment (detection bias) All outcomes	Low risk	"Caregivers were instructed not to reveal which treatment they had received; a protocol deviation log was maintained by the nurse and clinical coordinator to record if blinding was broken and in no case did that occur."
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Five people from the enhanced respite group and two form the polarity therapy left the study early due to lack of time "All outcomes were analyzed on an intent-to-treat basis using data from all participants who could be assessed. Of 42 participants, 35 completed the entire course of PT or ERC and the posttreatment assessment, three dropouts did not complete their assigned treatment but did complete the posttreatment assessment (and were included in the outcome analysis), and four dropouts completed neither their assigned treatment nor the posttreatment assessment. Thus, the change in outcome measures from baseline until the end of the trial is based on 38 of 42 participants"
Selective reporting (reporting bias)	Low risk	All outcomes stated in the study are reported
Other bias	Low risk	Funding from the National Institutes of Health, National Center for Complementary and Alternative Medicine (NIH-NCCAM) No conflicts of interest reported

Lawton 1989

Methods	RCT comparing one intervention group with a control in a cluster randomised design Duration: 12 months
Participants	N=632 Country: USA Mean age: caregiver 60 years, person with dementia 76 years 79% female caregivers, 60% female with dementia Inclusion criteria: people with "AD and related disorders" and their caregivers
Interventions	Intervention group: access to institutional respite, daycare and in-home respite over a 12 month period. The choice of which type or types of respite used was made by the caregiver Control group: no access to respite via the programme
Outcomes	For the person with dementia: 1. Amount of formal respite used 2. Amount of informal respite used 3. Institutionalisation 4. Severity of Illness 5. Mortality For the caregiver: 1. Caregiver wellbeing 2. Physical health - Philidelphia Geriatric Center Multilevel Assessment Instrument 3. Depression - Center for Epidemiological Studies Depression Scale (CESD) 4. Bradburn Affect Balance Scale (ABS)
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	"Assignment of a given participant by a random number"; "randomisation of people from support groups was accomplished by using the random number to assign each whole support group either to the E or C condition"
Allocation concealment (selection bias)	Unclear risk	No information reported
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	Participants were not blinded
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	No information reported
Incomplete outcome data (attrition bias) All outcomes	Low risk	"Ten experimental subjects dropped out too early to serve as subjects and one control subject heard about, requested, and was given the experimental respite experience, requiring deletion from the study. Over the course of the year 19% of the experimental and 21% of the control subjects died"
Selective reporting (reporting bias)	High risk	Data was not reported in a useable form, and the two different approaches to randomisation means that any statistics must use the support group as the

Lawton 1989 *(Continued)*

		unit of analysis and not the individual. It was not reported how many support groups there were and how much of the sample came from this source
Other bias	Low risk	Supported by a grant from the John A Hartford Foundation inc of New York and by the Pew Charitable Trusts of Philadelphia No conflicts of interest reported

Wishart 2000

Methods	RCT comparing one intervention group with a control in a parallel group design Duration: 6 weeks
Participants	N=24 Country: Canada Mean age 58 years 86% female Inclusion criteria: caregivers of clients with cognitive impairment referred to the Special Steps Program who were able to go on outings
Interventions	Intervention group: weekly 2-hour visit by trained volunteers taking the person with dementia out of the house on a walk or another activity (N=13) Control group: waiting list - people in this group received the intervention 6 weeks later (N=11)
Outcomes	For the caregiver: 1. Caregiver burden - Zarit 2. Social support
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	"Randomisation was carried out by computer-generated random assignment to group", "grouping was blocked after every four assignments so that groups would not differ greatly in
Allocation concealment (selection bias)	Low risk	"Group numbers were placed in sealed opaque envelopes"
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	Participants were not blinded
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	No information reported
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	"At 6 weeks there were three dropouts due to death or illness, two in the experimental group and one in the control group", ITT was not used

Wishart 2000 *(Continued)*

Selective reporting (reporting bias)	Low risk	All outcomes stated in the study are reported
Other bias	Low risk	Supported by a New Horizons Grant, Partners in Aging Project, Health Canada, and the System-Linked research Unit, McMaster University. No conflicts of interest reported

Characteristics of excluded studies *[ordered by study ID]*

Study	Reason for exclusion
Beattie 2012	Cross-sectional study about respite use and non-use in carers of people with dementia
Brodaty 1989	Allocation to intervention was sequential by date of postal application
Burdz 1988	Experimental and control groups were not assigned by the experimenters
Cameron 2011	Review article about assessing and helping carers of older people
Conlin 1992	Allocation to experimental and control groups was by alternation
Droes 2000	Assignment to groups was not random
Engedal 1989	The intervention did not fit the inclusion criteria for the review because it wasn't designed to provide temporary periods of rest or relief for the caregivers
Hedrick 1993	Participants did not have dementia. Inclusion was based on those elderly people who met criteria predicting who would be admitted to a nursing home
Howe 2009	Commentary on suboptimal take-up of respite care
Kosloski 1993	Non-equivalent control group design
Lee 2007	Prospective case series study with no control group
Lukas 2012	Intervention was individual advice about available treatment options for dementia patients
Mavall 2007	Observational study with no control group
Mohide 1990	Respite given as one part of a multi-component caregiver support programme
Montgomery 1989	The participants did not meet the inclusion criteria because only a small proportion were diagnosed with dementia
Neville 2006	Observational study with no control group
Newcomer 1999	Intervention was case management with community care service benefit
Quayhagen 2000	Caregivers randomised to the daycare group were also enrolled in support groups
Stirling 2012	Intervention was decision aids for respite service choices
Thiel 2012	Not randomised

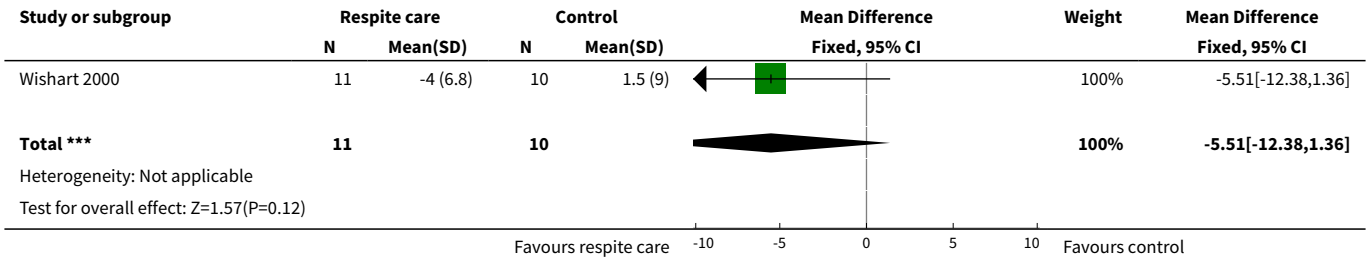
Study	Reason for exclusion
Wells 1987	Compared respite care with nursing home placement
Wells 1990	The experimental and control groups were not assigned by the researchers. They were made up of a group that were already receiving daycare and a group that were about to receive it
Whitebird 2011	Intervention was mindfulness-based stress reduction and control group was community caregiver education and support. Participants could apply for additional financial help up to $200 to obtain respite care or travel assistance
Wimo 1993	Assignment to groups was not random
Zarit 1998	Assignment to groups was not random

DATA AND ANALYSES

Comparison 1. Respite care versus no respite care

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
1 Caregiver Burden	1	21	Mean Difference (IV, Fixed, 95% CI)	-5.51 [-12.38, 1.36]
2 Hamilton-Depression	1	55	Mean Difference (IV, Fixed, 95% CI)	-0.18 [-3.82, 3.46]
3 Hamilton-Anxiety	1	55	Mean Difference (IV, Fixed, 95% CI)	0.05 [-3.76, 3.86]
4 Brief Symptom Inventory	1	55	Mean Difference (IV, Fixed, 95% CI)	0.04 [-0.29, 0.37]
5 Affective Support	1	19	Mean Difference (IV, Fixed, 95% CI)	-0.44 [-2.85, 1.97]
6 Confidant Support	1	19	Mean Difference (IV, Fixed, 95% CI)	1.3 [-1.04, 3.64]

Analysis 1.1. Comparison 1 Respite care versus no respite care, Outcome 1 Caregiver Burden.



Analysis 1.2. Comparison 1 Respite care versus no respite care, Outcome 2 Hamilton-Depression.

Study or subgroup	Respite care N	Respite care Mean(SD)	Control N	Control Mean(SD)	Mean Difference Fixed, 95% CI	Weight	Mean Difference Fixed, 95% CI
Grant 2003	32	0.5 (6.8)	23	0.7 (6.8)		100%	-0.18[-3.82,3.46]
Total ***	**32**		**23**			**100%**	**-0.18[-3.82,3.46]**
Heterogeneity: Not applicable							
Test for overall effect: Z=0.1(P=0.92)							

Analysis 1.3. Comparison 1 Respite care versus no respite care, Outcome 3 Hamilton-Anxiety.

Study or subgroup	Respite care N	Respite care Mean(SD)	Control N	Control Mean(SD)	Mean Difference Fixed, 95% CI	Weight	Mean Difference Fixed, 95% CI
Grant 2003	32	0.6 (7.6)	23	0.6 (6.7)		100%	0.05[-3.76,3.86]
Total ***	**32**		**23**			**100%**	**0.05[-3.76,3.86]**
Heterogeneity: Not applicable							
Test for overall effect: Z=0.03(P=0.98)							

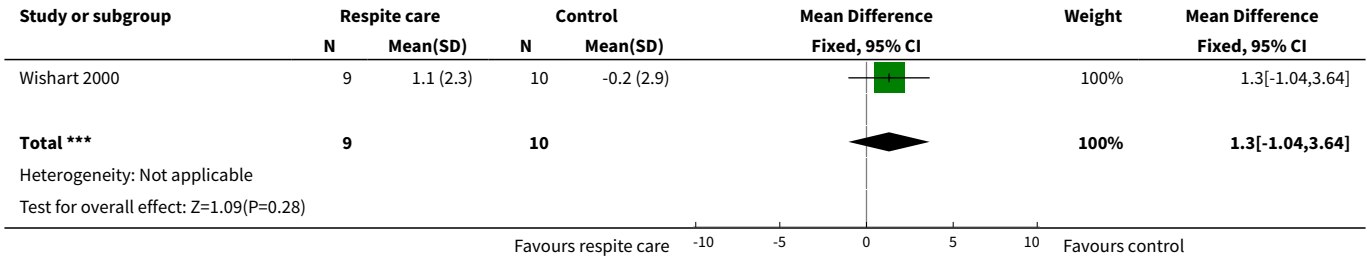
Analysis 1.4. Comparison 1 Respite care versus no respite care, Outcome 4 Brief Symptom Inventory.

Study or subgroup	Respite care N	Respite care Mean(SD)	Control N	Control Mean(SD)	Mean Difference Fixed, 95% CI	Weight	Mean Difference Fixed, 95% CI
Grant 2003	32	0.1 (0.6)	23	0 (0.7)		100%	0.04[-0.29,0.37]
Total ***	**32**		**23**			**100%**	**0.04[-0.29,0.37]**
Heterogeneity: Not applicable							
Test for overall effect: Z=0.24(P=0.81)							

Analysis 1.5. Comparison 1 Respite care versus no respite care, Outcome 5 Affective Support.

Study or subgroup	Respite care N	Respite care Mean(SD)	Control N	Control Mean(SD)	Mean Difference Fixed, 95% CI	Weight	Mean Difference Fixed, 95% CI
Wishart 2000	9	-0.4 (2.9)	10	0 (2.4)		100%	-0.44[-2.85,1.97]
Total ***	**9**		**10**			**100%**	**-0.44[-2.85,1.97]**
Heterogeneity: Not applicable							
Test for overall effect: Z=0.36(P=0.72)							

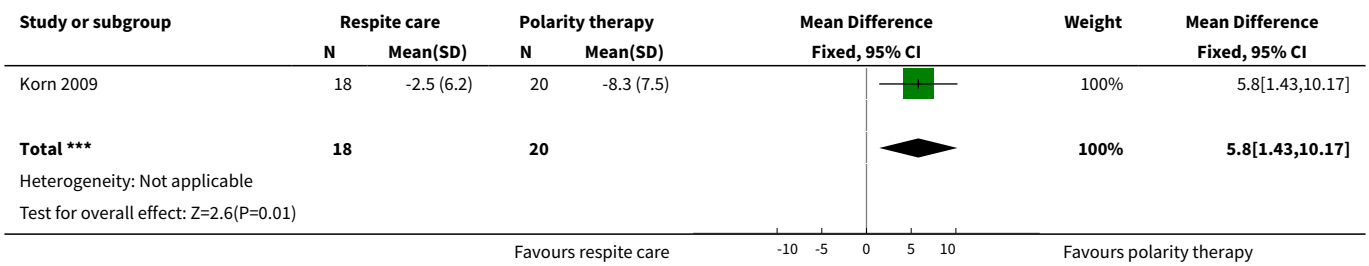
Analysis 1.6. Comparison 1 Respite care versus no respite care, Outcome 6 Confidant Support.



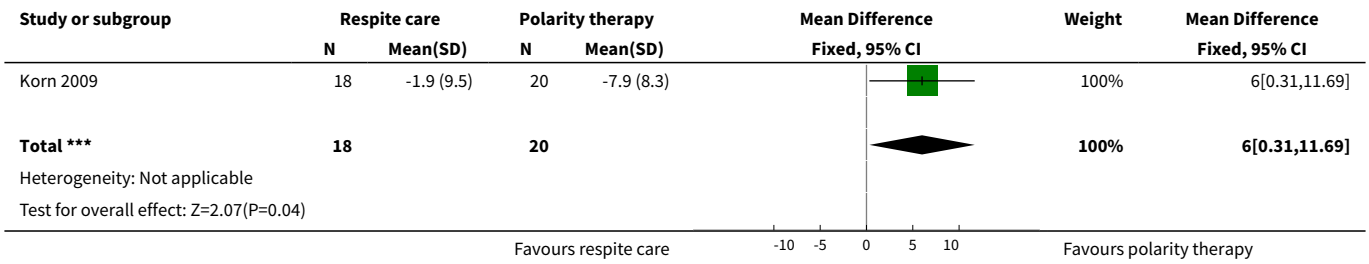
Comparison 2. Respite care versus polarity therapy

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
1 Perceived Stress Scale	1	38	Mean Difference (IV, Fixed, 95% CI)	5.80 [1.43, 10.17]
2 Center for Epidemiological Studies - Depression Scale	1	38	Mean Difference (IV, Fixed, 95% CI)	6.0 [0.31, 11.69]
3 Penn State Worry Questionnaire	1	38	Mean Difference (IV, Fixed, 95% CI)	8.1 [-3.14, 19.34]
4 SF-36 Mental component summary	1	38	Mean Difference (IV, Fixed, 95% CI)	-0.90 [-6.35, 4.55]
5 SF-36 Physical component summary	1	38	Mean Difference (IV, Fixed, 95% CI)	-4.5 [-9.69, 0.69]
6 Pittsburgh Sleep Quality Index	1	38	Mean Difference (IV, Fixed, 95% CI)	1.70 [-0.55, 3.95]
7 Quality of Life - AD	1	38	Mean Difference (IV, Fixed, 95% CI)	-1.80 [-5.74, 2.14]

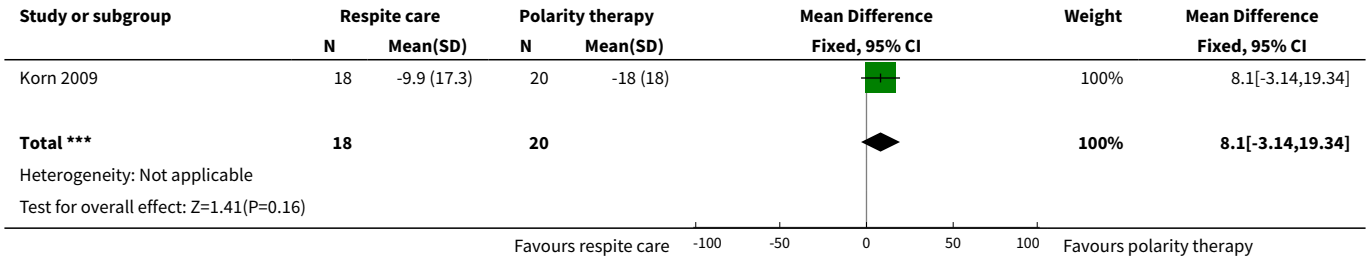
Analysis 2.1. Comparison 2 Respite care versus polarity therapy, Outcome 1 Perceived Stress Scale.



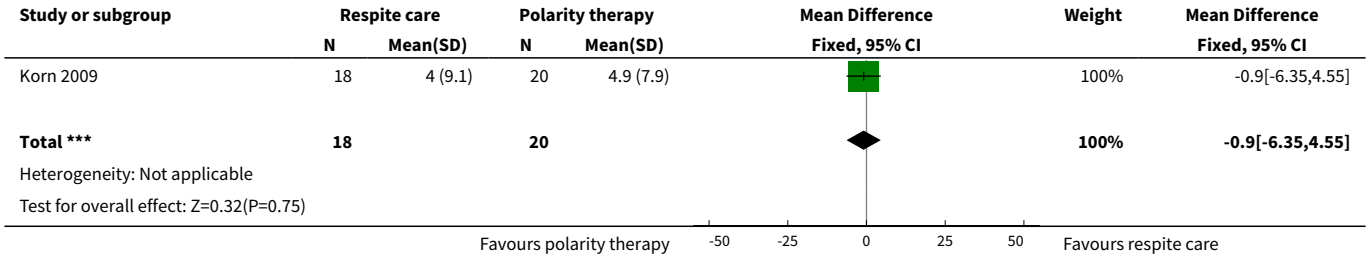
Analysis 2.2. Comparison 2 Respite care versus polarity therapy, Outcome 2 Center for Epidemiological Studies - Depression Scale.



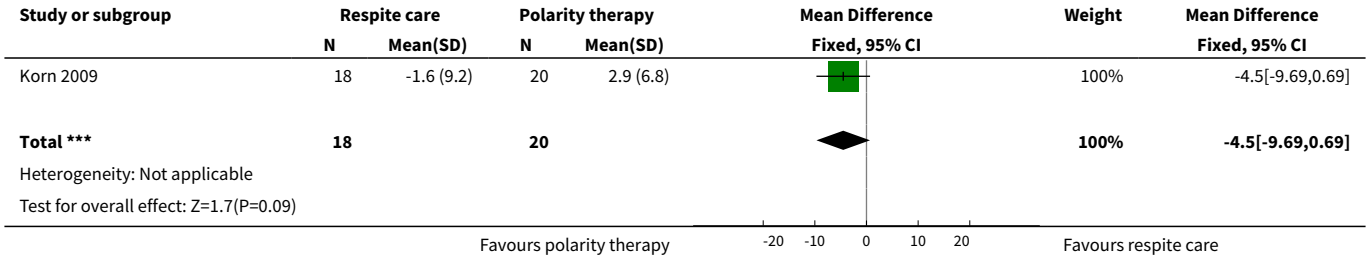
Analysis 2.3. Comparison 2 Respite care versus polarity therapy, Outcome 3 Penn State Worry Questionnaire.



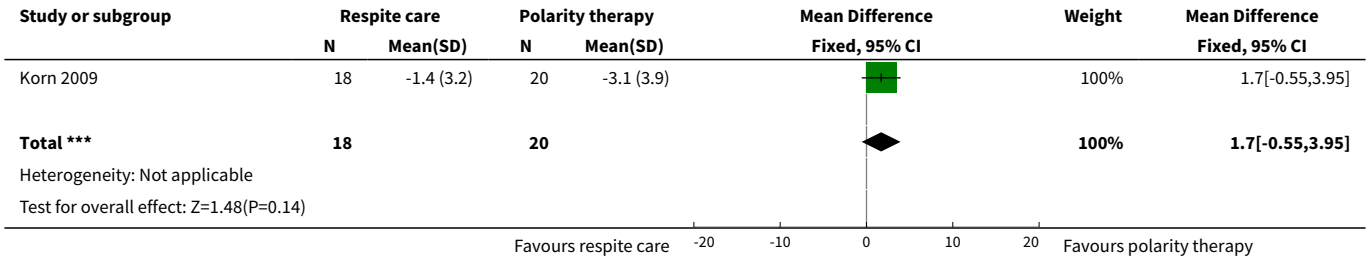
Analysis 2.4. Comparison 2 Respite care versus polarity therapy, Outcome 4 SF-36 Mental component summary.



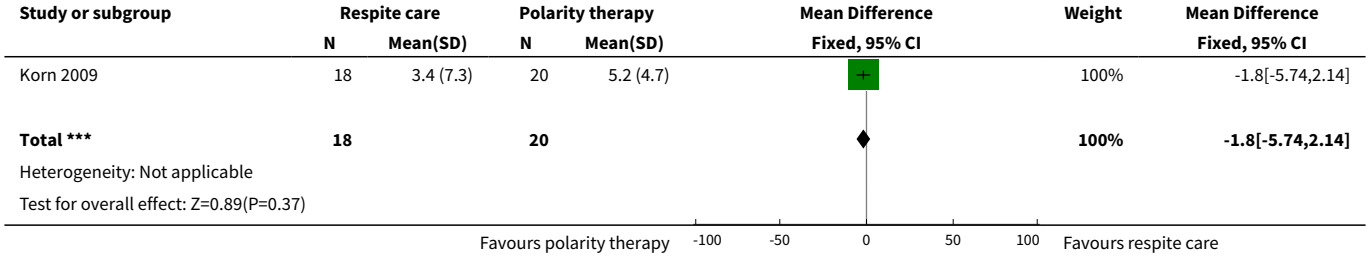
Analysis 2.5. Comparison 2 Respite care versus polarity therapy, Outcome 5 SF-36 Physical component summary.



Analysis 2.6. Comparison 2 Respite care versus polarity therapy, Outcome 6 Pittsburgh Sleep Quality Index.



Analysis 2.7. Comparison 2 Respite care versus polarity therapy, Outcome 7 Quality of Life - AD.



ADDITIONAL TABLES

Table 1. EPICOT+ research recommendations

Element to consider in future research	Implications and suggestions for future research arising from Cochrane review
Evidence	Current evidence does not allow one to make any reliable conclusions about the efficacy of respite care for people with dementia and their caregivers. This reflects a lack of high quality research in this difficult area
Population	1. People of any age with dementia of any type 2. Full-time carers of people with dementia
Intervention	Respite care, i.e. a service or group of services designed to provide temporary periods of relief and/or rest for caregivers
Comparison	An alternative intervention, waiting list or no respite care
Outcomes	For people with dementia - rate of institutionalisation, mortality, physical health, quality of life; for caregivers – caregiver burden, psychological stress and health, and quality of life
Time stamp	November 2013
Disease burden	Dementia is a common and serious mental health problem affecting 6.4% of the population, and increasing in prevalence with age, from 0.8% in 65 to 69 year olds to 28.5% in people aged 90 years or older. In the coming years an exponential increase in numbers of people affected is anticipated as populations age (Lobo 2000). Providing care for a person with dementia in the community commonly places stress on the primary caregiver. Such stress can have a range of adverse effects including the breakdown of the relationship between patient and caregiver, a poorer quality of

Table 1. EPICOT+ research recommendations *(Continued)*

	care, and physical and psychological morbidity for both patient and caregiver (Neufield 2003; Parks 2000).
Timeliness	Mean age of population: over 65 years Duration of intervention: minimum 1 month Length of follow-up: minimum 3 months. Dementia is a chronic condition, and most studies in the review were between two and six weeks long, and showed no difference between groups, which could be due to the short duration
Study type	Randomised controlled trial

APPENDICES

Appendix 1. Sources searched and search strategies

Source	Search strategy	Hits retrieved
1. ALOIS (www.medicine.ox.ac.uk/alois)	respite* OR daycare OR caregiver* relief	15
2. MEDLINE In-Process and other non-indexed citations and MEDLINE 1950-present (OvidSP)	1. exp Dementia/ 2. Delirium/ 3. Wernicke Encephalopathy/ 4. Delirium, Dementia, Amnestic, Cognitive Disorders/ 5. dement*.mp. 6. alzheimer*.mp. 7. (lewy* adj2 bod*).mp. 8. deliri*.mp. 9. (chronic adj2 cerebrovascular).mp. 10. ("organic brain disease" or "organic brain syndrome").mp. 11. ("normal pressure hydrocephalus" and "shunt*").mp. 12. "benign senescent forgetfulness".mp. 13. (cerebr* adj2 deteriorat*).mp. 14. (cerebral* adj2 insufficient*).mp. 15. (pick* adj2 disease).mp. 16. (creutzfeldt or jcd or cjd).mp. 17. huntington*.mp. 18. binswanger*.mp. 19. korsako*.mp.	121

(Continued)

	20. or/1-19	
	21. respite.ti,ab.	
	22. daycare.ti,ab.	
	23. ("caregiver* relief" or "carer* relief").ti,ab.	
	24. Respite Care/	
	25. (care adj3 relief).ti,ab.	
	26. or/21-25	
	27. 20 and 26	
	28. (2007* or 2008* or 2009* or 2010* or 2011* or 2012*).ed.	
	29. 27 and 28	
3. EMBASE 1980-2012 November 30 (OvidSP)	1. exp dementia/ 2. Lewy body/ 3. delirium/ 4. Wernicke encephalopathy/ 5. cognitive defect/ 6. dement*.mp. 7. alzheimer*.mp. 8. (lewy* adj2 bod*).mp. 9. deliri*.mp. 10. (chronic adj2 cerebrovascular).mp. 11. ("organic brain disease" or "organic brain syndrome").mp. 12. "supranuclear palsy".mp. 13. ("normal pressure hydrocephalus" and "shunt*").mp. 14. "benign senescent forgetfulness".mp. 15. (cerebr* adj2 deteriorat*).mp. 16. (cerebral* adj2 insufficient*).mp. 17. (pick* adj2 disease).mp. 18. (creutzfeldt or jcd or cjd).mp. 19. huntington*.mp. 20. binswanger*.mp. 21. korsako*.mp. 22. CADASIL.mp. 23. or/1-22 24. respite.ti,ab.	304

(Continued)

	25. (daycare or "day care").ti,ab.	
	26. ("caregiver* relief" or "carer* relief").ti,ab.	
	27. respite care/	
	28. (care adj3 relief).ti,ab.	
	29. or/24-28	
	30. 23 and 29	
	31. (2007* or 2008* or 2009* or 2010* or 2011* or 2012*).em.	
	32. 30 and 31	
4. PsycINFO 1806-November week 4 2012 (OvidSP)	1. exp Dementia/ 2. exp Delirium/ 3. exp Huntingtons Disease/ 4. exp Kluver Bucy Syndrome/ 5. exp Wernickes Syndrome/ 6. exp Cognitive Impairment/ 7. dement*.mp. 8. alzheimer*.mp. 9. (lewy* adj2 bod*).mp. 10. deliri*.mp. 11. (chronic adj2 cerebrovascular).mp. 12. ("organic brain disease" or "organic brain syndrome").mp. 13. "supranuclear palsy".mp. 14. ("normal pressure hydrocephalus" and "shunt*").mp. 15. "benign senescent forgetfulness".mp. 16. (cerebr* adj2 deteriorat*).mp. 17. (cerebral* adj2 insufficient*).mp. 18. (pick* adj2 disease).mp. 19. (creutzfeldt or jcd or cjd).mp. 20. huntington*.mp. 21. binswanger*.mp. 22. korsako*.mp. 23. ("parkinson* disease dementia" or PDD or "parkinson* dementia").mp. 24. or/1-23 25. respite.ti,ab. 26. (daycare or "day care").ti,ab.	173

(Continued)

	27. ("caregiver* relief" or "carer* relief").ti,ab. 28. (care adj3 relief).ti,ab. 29. exp Respite Care/ 30. or/25-29 31. 24 and 30 32. (2007* or 2008* or 2009* or 2010* or 2011* or 2012*).up. 33. 31 and 32	
6. ISI Web of Knowledge [includes: Web of Science (1945-present); BIOSIS Previews (1926-present); MEDLINE (1950-present); Journal Citation Reports]; BIOSIS Previews	Topic=(respite OR daycare OR "caregiver$ relief" OR "carer relief") AND Topic=(dement* OR alzheimer* OR FTLD OR FTD OR "primary progressive aphasia" OR "progressive non-fluent aphasia" OR "frontotemporal lobar degeneration" OR "frontolobar degeneration" OR "frontal lobar degeneration" OR "pick* disease" OR "lewy bod*") AND Year Published=(2008-2013) Timespan=All Years. Search language=English	134
7. LILACS (BIREME)	respite OR break OR (carer AND relief) OR (caregiver AND relief) [Words] and Demências OR dementia OR dementias OR demência OR Alzheimer OR Alzheimers OR Alzheimer's OR cognitive OR cognitive OR cognitive OR cognition OR "déficit cognitive" OR cognición OR cognição OR Memória OR memory OR Memoria OR "Frontotemporal Lobar Degeneration" OR FTLD OR FTD [Words]	9
8. CENTRAL (*The Cochrane Library*) (Issue 8 of 12, 2012)	#1 MeSH descriptor: [Dementia] explode all trees #2 MeSH descriptor: [Delirium] this term only #3 MeSH descriptor: [Wernicke Encephalopathy] this term only #4 MeSH descriptor: [Delirium, Dementia, Amnestic, Cognitive Disorders] this term only #5 dement* #6 alzheimer* #7 "lewy* bod*" #8 deliri* #9 "chronic cerebrovascular" #10 "organic brain disease" or "organic brain syndrome" #11 "normal pressure hydrocephalus" and "shunt*" #12 "benign senescent forgetfulness" #13 "cerebr* deteriorat*" #14 "cerebral* insufficient*" #15 "pick* disease" #16 creutzfeldt or jcd or cjd #17 huntington*	11

(Continued)

	#18 binswanger* #19 korsako* #20 #1 or #2 or #3 or #4 or #5 or #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 #21 respite #22 daycare #23 "day care" #24 "caregiver* relief" #25 "carer* relief" #26 #21 or #22 or #23 or #24 or #25 #27 #20 and #26 from 2007 to 2012, in Trials (Word variations have been searched)	
9. Clinicaltrials.gov (www.clinicaltrials.gov)	respite care OR daycare | Interventional Studies | dementia	4
TOTAL before de-duplication		771
TOTAL after de-duplication and first assessment		35

Appendix 2. Previous methods

Search methods for identification of studies

See Cochrane Dementia and Cognitive Improvement Group methods used in reviews.

The Specialized Register of the Cochrane Dementia and Cognitive Improvement Group (CDCIG) was searched on 10 December 2007 for all years up to December 2005. This register contains records from the following major healthcare databases: *The Cochrane Library*, MEDLINE, EMBASE, PsycINFO, CINAHL and LILACS, and many ongoing trial databases and other grey literature sources. The following search terms were used: respite OR daycare OR caregiver* relief.

The Cochrane Library, MEDLINE, EMBASE, PsycINFO, CINAHL and LILACS were searched separately on 10 December 2007 for records added to these databases after December 2005 to December 2007. The search terms used to identify relevant controlled trials on dementia, Alzheimer's disease and mild cognitive impairment for the Group's Specialized Register can be found in the Group's module in *The Cochrane Library*. These search terms were combined with the following search terms and adapted for each database, where appropriate: respite* OR daycare OR "caregiver* relief.

On 10 December 2007, the Specialized Register consisted of records from the following databases.

Healthcare databases

- CENTRAL (*The Cochrane Library* 2006, Issue 1)
- MEDLINE (1966 to 2006/07, week 5)
- EMBASE (1980 to 2006/07)
- PsycINFO (1887 to 2006/08, week 1)
- CINAHL (1982 to 2006/06)
- SIGLE (Grey Literature in Europe) (1980 to 2005/03)
- LILACS, Latin American and Caribbean Health Science Literature (http://bases.bireme.br/cgi-bin/wxislind.exe/iah/online/?IsisScript=iah/iah.xis&base=LILACS&lang=i&form=F) (last searched 29 August 2006)

Conference proceedings

- ISTP (http://portal.isiknowledge.com/portal.cgi) (Index to Scientific and Technical Proceedings) (to 29 August 2006)

- INSIDE (BL database of Conference Proceedings and Journals) (to June 2000)

Theses

- Index to Theses (formerly ASLIB) (http://www.theses.com/) (UK and Ireland theses) (1716 to 11 August 2006)
- Australian Digital Theses Program (http://adt.caul.edu.au/): (last update 24 March 2006)
- Canadian Theses and Dissertations (http://www.collectionscanada.ca/thesescanada/index-e.html): 1989 to 28 August 2006)
- DATAD - Database of African Theses and Dissertations (http://www.aau.org/datad/backgrd.htm)
- Dissertation Abstract Online (USA) (http://wwwlib.umi.com/dissertations/gateway) (1861 to 28 August 2006)

Ongoing trials
UK

- National Research Register (http://www.update-software.com/projects/nrr/) (last searched issue 3/2006)
- ReFeR (http://www.refer.nhs.uk/ViewWebPage.asp?Page=Home) (last searched 30 August 2006)
- Current Controlled trials: Meta Register of Controlled trials (mRCT) (http://www.controlled-trials.com/) (last searched 30 August 2006)
- ISRCTN Register - trials registered with a unique identifier
- Action medical research
- Kings College London
- Laxdale Ltd
- Medical Research Council (UK)
- NHS Trusts Clinical Trials Register
- National Health Service Research and Development Health Technology Assessment Programme (HTA)
- National Health Service Research and Development Programme 'Time-Limited' National Programmes
- National Health Service Research and Development Regional Programmes
- The Wellcome Trust
- Stroke Trials Registry (http://www.strokecenter.org/trials/index.aspx) (last searched 31 August 2006)

Netherlands

- Nederlands Trial Register (http://www.trialregister.nl/trialreg/index.asp) (last searched 31 August 2006)

USA/International

- ClinicalTrials.gov (http://www.ClinicalTrials.gov) (last searched 31 August 2006) (contains all records from http://clinicalstudies.info.nih.gov/)
- IPFMA Clinical trials Register: www.ifpma.org/clinicaltrials.html. The Ongoing Trials database within this Register searches http://www.controlled-trials.com/isrctn, http://www.ClinicalTrials.gov and http://www.centerwatch.com/. The ISRCTN register and Clinicaltrials.gov are searched separately. Centerwatch is very difficult to search for our purposes and no update searches have been done since 2003
- The IFPMA Trial Results databases searches a wide variety of sources among which are:
- http://www.astrazenecaclinicaltrials.com (seroquel, statins)
- http://www.centerwatch.com
- http://www.clinicalstudyresults.org
- http://clinicaltrials.gov
- http://www.controlled-trials.com
- http://ctr.gsk.co.uk
- http://www.lillytrials.com (zyprexa)
- http://www.roche-trials.com (anti-abeta antibody)
- http://www.organon.com
- http://www.novartisclinicaltrials.com (rivastigmine)
- http://www.bayerhealthcare.com
- http://trials.boehringer-ingelheim.com
- http://www.cmrinteract.com
- http://www.esteve.es
- http://www.clinicaltrials.jp

This part of the IPFMA database is searched and was last updated on 4 September 2006:

- Lundbeck Clinical Trial Registry (http://www.lundbecktrials.com) (last searched 15 August 2006);
- Forest Clinical trial Registry (http://www.forestclinicaltrials.com/) (last searched 15 August 2006).

The search strategies used to identify relevant records in MEDLINE, EMBASE, PsycINFO, CINAHL and LILACS can be found in the Group's module in *The Cochrane Library*.

Data collection and analysis

Selection of studies

One review author (HL) studied the titles and abstracts of those references identified by the search, discarding those that were clearly not relevant and retrieving the remaining ones in hard copy. Both review authors independently assessed the resulting references and preliminarily divided them into excluded and included categories on the basis of the predefined inclusion criteria. Additional information was sought from study authors if appropriate. The review authors reached a final consensus through discussion.

Quality assessment

The review authors assessed the quality of the methods used in each selected trial by looking at randomisation, blinding, patient selection, selection of control group, reporting of results and statistical analysis.

Data extraction

One review author (HL) extracted data from the published reports. The summary statistics required for each trial and each outcome for continuous data were the mean change from baseline, the standard error of the mean change, and the number of patients for each treatment group at each assessment. Where changes from baseline were not reported she extracted the mean, standard deviation and the number of patients for each treatment group at each time point. The baseline assessment was defined as the latest available assessment preceding randomisation, but no longer than two months prior.

For binary data the review authors sought the numbers in each treatment group and the numbers experiencing the outcome of interest. If the only data reported were the treatment effects and their standard errors, then these were extracted. For each outcome measure the reviewers sought data on every patient assessed. To allow an intention-to-treat analysis, the data were sought irrespective of compliance, whether or not the patient was subsequently deemed ineligible, or otherwise excluded from treatment or follow-up. If intention-to-treat data were not available in the publications, the reviewers sought 'on-treatment' data, or the data of those who completed the trial, and indicated it as such.

Data analysis

The outcomes measured in clinical trials of dementia and cognitive impairment often arise from ordinal rating scales. Where the rating scales used in the trials had reasonably large number of categories (more than 10) the data were treated as continuous outcomes arising from normal distributions.

Summary statistics (n, mean and standard deviation) were required for each rating scale at each assessment time for each treatment group in each trial for change from baseline.

When changes from baseline results were not reported, the review authors calculated the required summary statistics from the baseline and assessment time treatment group means and standard deviations. In this case a zero correlation between the measurements at baseline and assessment time was assumed. This method overestimates the standard deviation of the change from baseline, but this conservative approach is considered to be preferable in a meta-analysis.

WHAT'S NEW

Date	Event	Description
9 December 2013	New citation required but conclusions have not changed	New authors; conclusions unchanged
3 December 2012	New search has been performed	An update search was performed for this review on 3 December 2012; one new study was added to the review

HISTORY

Protocol first published: Issue 3, 2003
Review first published: Issue 4, 2003

Date	Event	Description
3 December 2012	New search has been performed	An update search was performed for this review on 3 December 2012
14 May 2008	Amended	Converted to new review format
14 May 2008	New search has been performed	May 2008: The update search of 10 December 2007 did not find any new studies that met the inclusion criteria so the review remains unchanged. Three excluded studies have been added
14 May 2005	New search has been performed	May 2005: the update search did not reveal any new trials or additional references and so the review's conclusions have remained the same
10 October 2003	New citation required and conclusions have changed	Substantive amendment

CONTRIBUTIONS OF AUTHORS

For the 2004 version of this review
Helen Lee: searching, selection and assessment of studies, extraction of data, analysis, drafting of review, all correspondence, updating of review
Michelle Cameron: inclusion and exclusion of studies, commenting on drafts
Dymphna Hermans and Vittoria Lutje: update searches
Contact Editor: Linda Clare
Consumer Editor: Mike Hadden
This review has been peer reviewed by two external peer reviewers.

For the current updated version of this review
Nicola Maayan and Karla Soares-Weiser performed all tasks for the updated version of this review

DECLARATIONS OF INTEREST

The Enhance Reviews team were contracted to update this review.

SOURCES OF SUPPORT

Internal sources

- Division of Clinical Geratology, Nuffield Department of Clinical Medicine, University of Oxford, UK.

External sources

- No sources of support supplied

NOTES

While Michelle Cameron was the main review author for the protocol, Helen Lee has taken over as the main review author for the review. All correspondence should be directed to Helen Lee.

INDEX TERMS

Medical Subject Headings (MeSH)

Caregivers [*psychology]; Dementia [*nursing] [psychology]; Randomized Controlled Trials as Topic; Respite Care [*psychology]; Stress, Psychological [*therapy]; Therapeutic Touch

MeSH check words

Aged; Humans