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<https://doi.org/10.1111/j.1532-5415.2006.01037.x>

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Title: The Effectiveness and Cost-effectiveness of Respite for Caregivers of Frail Older People

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This article was published in February 2007:

Mason, A., Weatherly, H., Spilsbury, K., Golder, S., Arksey, H., Adamson, J. and Drummond, M. (2007) The effectiveness and cost-effectiveness of respite for caregivers of frail older people, *Journal of the American Geriatrics Society*, 55, 2, 290-99

This is an author produced version of the article published. This paper has been peer-reviewed but does not include the final publisher proof-corrections or journal pagination.

The definitive version is available at www.blackwell-synergy.com: <http://www.blackwell-synergy.com/doi/abs/10.1111/j.1532-5415.2006.01037.x>

DOI: 10.1111/j.1532-5415.2006.01037.x

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Funding sources: UK Department of Health's National Coordinating Centre for Health
Technology Assessment (NCCHTA)

Running head: A Systematic Review

ABSTRACT

The proportion of frail elderly people in the industrialized world is increasing. Respite care is a potentially important way of maintaining the quality of life for both these people and their caregivers. The objective of this systematic review was to determine the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their caregivers. To identify relevant studies, 37 databases were searched and reference checking and citation searches were undertaken. Well-controlled effectiveness studies were eligible for inclusion, with uncontrolled studies admissible only in the absence of higher-quality evidence. Studies assessed the impact of community-based respite, relative either to 'usual care' or to another support intervention, on caregivers of frail elderly people. Eligible economic evaluations also addressed costs. Where appropriate, data were synthesized using standard meta-analytic techniques. Ten randomized controlled trials, seven quasi-experimental studies and five uncontrolled studies were included in the review. For all types of respite, the effects upon caregivers were generally small with better-controlled studies finding modest benefits only for certain subgroups. However, many studies reported high levels of caregiver satisfaction. No reliable evidence was found that respite care either delays entry to residential care or adversely affects frail older people. The economic evaluations all assessed day care, which tended to be associated with similar or higher costs than usual care. Given the increasing numbers of frail elderly people and the lack of up-to-date, good-quality evidence for all types of respite care, better-quality evidence is urgently needed to inform current policy and practice. (250)

KEY WORDS

Respite Care, Frail Elderly, Caregivers, Review, Costs and Cost Analysis

INTRODUCTION

Over the last four decades, the industrialized world has seen a substantial change in the age composition of older people. For example, the proportion of the population aged over 85 increased almost three-fold between 1960 and 2000 in both the United States (US) and the United Kingdom (UK), and is projected to double in both countries by 2030.^{1, 2} Most people who are older or who have disabilities live in the community, and are cared for mainly by family, friends or neighbors.³ In the UK, there are at least six million adults providing care for sick or disabled relatives or friends.^{4, 5} In the States, latest estimates indicate that 22 million unpaid informal caregivers look after elderly persons; this figure is projected to rise to 40 million by 2050.⁶

Frailty is an important concept, used by geriatricians to describe older patients in poor health, vulnerable to trauma and environmental stressors, and at high risk of adverse health outcomes including worsened morbidity, disability, institutionalization and mortality⁷ - ‘the weakest and most vulnerable subset of older adults’.⁸ However, the concept is recognized to be complex⁹ and evolving,^{8, 10} and a standard definition of frailty in the elderly has not been agreed.⁹ Frailty may encompass physical, physiological, social and /or psychological dimensions, with debate ongoing over whether frailty should be conceptualized as a single syndrome or as a cluster of distinct traits that are better considered separately.⁸ While some maintain that functional dependence may be equated with,¹⁰ or at least partly explain, frailty,^{9, 11} others suggest that frailty is better seen as a precursor to disability¹² or argue that frailty may be present in the absence of disease or disability.⁸ It appears then that dependence and cognitive impairment may be *sufficient* but not *necessary* markers of frailty.¹³ However, it is clear that people who are frail

and older may require high levels of support, which can adversely affect caregivers' quality of life. For example, caregivers report high levels of stress, anxiety and depression, as well as general health problems and physical injuries such as strained backs associated with lifting. Caregivers of people with dementia are likely to have higher than normal levels of stress and burden, and to report higher levels of depression or fatigue.¹⁴⁻¹⁷

'Respite care' is not a discrete intervention, but encompasses a range of services 'provided in the home or institution intermittently in order to provide temporary relief to the family home caregiver'.¹⁸ Respite services may include (adult) day care, in-home respite, video respite, institutional respite or host-family respite, where the older person stays for a short period in a service provider's home, with or without their caregiver. Respite may also be offered as a combination of these services ('respite packages') or in the context of other support services ('multidimensional packages').

A recent national US survey identified large differences in the availability and accessibility of publicly-funded caregiver support services, both within and between states.¹⁹ The Lifespan Respite Care bill (HR 3248) was introduced to address these anomalies, but has yet to become law.^α Intuitively, providing a break might be expected to particularly benefit those caring for frail older people. However, the effectiveness and cost-effectiveness of respite care remain unclear.²⁰

^α <http://www.govtrack.us/congress/bill.xpd?bill=h109-3248>, accessed 05/05/06

Previous reviews have either addressed particular disease areas,^{21, 22} rather than examining the impact on the frail elderly population more generally, or have not focused on respite but considered support services more broadly.^{20, 23} Given the growing numbers of older people and the potentially important role of respite services, the identification of service models that provide effective and cost-effective breaks for caregivers of frail older people is essential. A comprehensive search for evidence that would address these issues was undertaken.

METHODS

Thirty-seven databases were searched for references for relevant studies relating to respite for caregivers of frail elderly people, including databases of systematic reviews, old age and aging, health and social care, economics, conference proceeds, ongoing research, dissertations and other gray literature (further details are available from the authors). To ensure relevant literature was identified, search strategies were broad, incorporating terms for caregivers and respite (both free text and indexing). No terms for elderly were added due to inconsistent terminology use, poor reporting and inadequate indexing. The searches were not restricted by study design, outcome measure or disease area and no language limits were applied. Databases were searched from 1980 onwards, or from inception. All searches were conducted in March 2005. In addition, citation searches for key papers and reference checking were undertaken.

Inclusion criteria related to study design; respite setting; care receiver age (i.e. older person aged at least 65); and whether caregiver outcomes were assessed. *Effectiveness studies* had to be well-controlled, with uncontrolled studies included only in the absence of higher quality evidence for a type of respite or particular disease area (e.g. cancer). *Economic evaluations* had to compare at least two options and consider both costs and consequences. Studies assessing the impact of community-based respite services on caregivers of older people were eligible for inclusion. Respite services provided in acute hospital settings and studies where caregiver outcomes were not assessed were excluded from the review. Multidimensional packages of care that included a respite component were eligible only if the distinct impact of respite could be evaluated.

For the effectiveness and economic studies, data were extracted and the study quality assessed²⁴ by one reviewer (AM, KS, HW) and checked by another (KS, HW, AM). Any disagreements were resolved through discussion, with a third reviewer (JA, MFD) acting as arbiter where necessary. Similarly, the quality of uncontrolled studies was assessed by one reviewer (KS) and checked by a second (JA) using a quality appraisal checklist.²⁵

Meta-analysis is a formal method of synthesizing evidence from controlled trials that makes explicit assumptions about study quality and the relative importance attached to each study that may remain implicit or unclear in a narrative synthesis. Where sufficient clinically and statistically similar data were available, data were pooled using appropriate statistical techniques. For the controlled trials, two reviewers (AM, JA) examined findings for each outcome category (e.g. quality of life; mental health) to explore whether studies reported similar measures and whether these could be pooled. Effect sizes were estimated using standardized mean differences (SMDs) and shown graphically on forest plots constructed using Review Manager 4.2. SMDs are an effect size measure for continuous variables, computed as the difference between two means divided by the variability of that difference. They are used as a summary statistic in meta-analysis when the trials assess the same outcome, but use different scales. Statistical heterogeneity was measured using the I-square statistic, which describes the percentage of the variability in effect estimates that is due to heterogeneity rather than chance. A value greater than 50% may be considered to represent substantial heterogeneity. Where pooling was associated with statistical heterogeneity, a random effects model was fitted: this method gives wider confidence intervals than fixed-effect models, because it incorporates within- *and* between-study variation. Studies in the meta-analysis were quality assessed by concealment of

allocation score: adequate concealment (A); inadequate concealment (C); concealment unclear (B); concealment not applied (D).

RESULTS

A total of 12,927 titles and abstracts were screened for relevance and full copies of 379 references were retrieved and assessed for eligibility. Bibliography checking identified an additional 91 references. Table 1 provides an overview of the studies included in the review.

(TABLE 1 HERE)

Although searches were not limited by disease area, most of the 22 effectiveness studies included older people with cognitive impairment, either exclusively (13) or in part (7). However, in some studies the proportion with cognitive impairment was low, for example this comprised just 22% in the study by Burch (2001).²⁶ Physical impairment also seemed common, though this was inconsistently reported. Owing to the absence of controlled evidence, two uncontrolled studies of respite services for caregivers of cancer sufferers were reviewed, one assessing a multidimensional package²⁷ and the other in-home respite.²⁸ Of the five economic evaluations, two included a proportion of people with cognitive impairment and three had dementia as an eligibility criterion for inclusion in the study. Table 2 summarizes the populations covered by the included studies.

(TABLE 2 HERE)

Findings are reported by type of respite, covering adult day care; respite packages; in-home respite; host family respite; institutional respite; multi-dimensional packages; and video respite. For each type of respite, evidence from randomized trials (RCTs), quasi-experimental studies and uncontrolled studies is presented separately. Drawing on a meta-analysis, the effects of respite care on specific caregiver outcomes are then explored.

Adult day care

The effectiveness of ('adult') day care was evaluated in eight studies,^{26, 29-35} five of which also incorporated economic evaluations.^{29, 30, 32, 34, 35} Studies offered diverse services to older people, including rehabilitative and educational activities, outings and entertainment. Some day care centers also provided caregiver support services such as counseling.^{29, 31} All but two studies^{31, 35} provided transportation.

Evidence from randomized trials

Of the four randomized trials, neither the US study by Hedrick (1993)³⁰ nor the Canadian study by Baumgarten (2002)²⁹ found a difference in caregiver outcomes when day care was compared with 'usual care' in the study setting. The UK study by Burch and colleagues (2001)²⁶ compared day care center with a rehabilitation hospital, and found that caregiver strain diminished in both groups. However, this effect may reflect the high baseline stress levels for caregivers of people recently admitted to hospital following fracture or acute illness. Only one randomized trial found a statistically significant between-group difference. The US study by Quayhagen (2000)³¹ compared early-stage day care with three other 'active' interventions (counseling; seminars; cognitive stimulation) and one control. Quayhagen's study found a significant decrease in 'carer hostility' for caregivers in the day care group, but no difference was identified in depression, anxiety or stress. 'Hostility' was one of three emotions measured on the Brief Symptom Inventory (Derogatis & Spencer, 1982), in which feelings or problems indicative of hostility were assessed on a 5-item, 4-point Likert scale. However, the large number of outcomes measured in this study and the small numbers of participants in each group (day care group: N=16; control group: N=15) limit the reliability of these findings.

Randomized evidence suggests that day care generally neither benefited nor harmed the *care receivers*. One study found benefits for certain subgroups of older people: those who were not married, those who were not hospitalized at enrolment and those who were very satisfied with social support had better health outcomes than those receiving usual care.³⁰ Two studies assessed the impact of day care upon institutionalization, but found no significant difference.^{26, 30}

Evidence from quasi-experimental studies

Findings from quasi-experimental studies were generally more positive than those from randomized trials. The UK study by Donaldson (1989) found that the Family Support Unit prolonged life at home and increased caregivers' sense of freedom and relaxation.³⁴ In the German study by Zank (2002), day care was reported to have a significant positive effect on care receiver well-being and dementia symptoms, relative to controls.³³ No effect upon caregiver outcomes was observed, but high levels of satisfaction were reported. The US study by Zarit (1998)³² found that caregivers using 'substantial' amounts (at least twice a week for at least 3 months) of day care benefited significantly more than those using no day care, in terms of caregiver depression and caregiver burden ('overload') and that day care appeared to delay entry to institutional care. The Spanish study by Artaso Irigoyen (2002) of psycho-geriatric day care found no between-group difference in caregiver outcomes, although satisfaction levels were consistently higher in the intervention group throughout the duration of the study.³⁵

Evidence from these quasi-experimental studies is difficult to interpret, with the internal validity of findings uncertain because comparison groups differed at baseline in demographic or clinical

characteristics. In addition, the studies by Zank³³ and Zarit³² reported findings only for treatment completers rather than for all study participants.

Only five economic evaluations of respite care services were identified, all of which compared day care with usual care.^{29, 30, 34-36} Day care tended to be associated with higher costs. One study found that the cost of day care was statistically significantly higher compared with usual care, when based on local and national unit costs.³⁰ However, when the data were reanalyzed using either local *or* national prices, there was no statistically significant difference at the 5% level.³⁷ Day care tended to be associated with either similar or a slight increase in benefits, relative to usual care. The majority of studies assessed health and social service use and cost, but inadequate reporting limits the potential for exploring applicability to other settings. No study included generic health-related quality of life measures, making cost-effectiveness comparisons with other healthcare programs problematic.

Respite Packages

Four studies of interventions involving more than one type of respite (respite packages) were identified, all set in the US. Two studies were randomized and two were quasi-experimental. Three offered a package that included day care, in-home respite or institutional respite;³⁸⁻⁴⁰ in the fourth study, caregivers in the intervention arm chose between in-home respite and institutional respite.⁴¹ 'Usual care' was a comparator in all four studies, although the 12-month study by Lawton (1989) supplemented this with counseling and information at enrolment³⁹ and the Montgomery (1989)⁴⁰ study randomized patients to one of six groups. No economic evaluation of respite packages was identified.

Evidence from randomized studies

Of the two randomized studies, the Montgomery trial (1989)⁴⁰ compared various packages of support with respite or no intervention. The published papers^{40, 42-44} report few data and attempts to retrieve the full report to the sponsoring body were unsuccessful. Overall, the trial identified few benefits for caregivers: respite group caregivers were slightly more relieved and more satisfied with support (from any sources) relative to the control group. Although there was no statistically significant difference between groups in the rate of institutionalization at 12 months or at 20 months, subgroup analyses suggested that adult child caregivers in treatment groups were *less* likely to institutionalize care receivers than caregivers in the control group, whereas spouse caregivers in the treatment groups were *more* likely to institutionalize care receivers, relative to the control group. In the other randomized study (Lawton, 1989),³⁹ the statistical analysis was flawed: while the unit of randomization was a mixture of (support) group and individual, the unit of analysis was the caregiver or care receiver. This assumes each allocation is independent and takes no account of the group-level allocation, which makes findings almost impossible to interpret.

Evidence from quasi-experimental studies

Both quasi-experimental studies reported positive findings for caregiver outcomes. Conlin's (1992)⁴¹ comparison of in-home or institutional respite with usual care found that respite was associated with significant reductions in caregiver stress, but had no impact upon entry to long-term care. However, the small sample size (15 dyads) and baseline differences in demographic characteristics between groups undermine the reliability of this finding. The other

nonrandomized study (Kosloski 1993)³⁸ reported benefits for caregiver morale and subjective burden. However, the groups differed at baseline in both racial composition and income, which casts doubt on the validity of findings.

In-home respite

Four studies of in-home respite met our inclusion criteria, of which three were randomized⁴⁵⁻⁴⁷ and one quasi-experimental⁴⁸ in design. No economic evaluation of in-home respite was identified. In addition, an uncontrolled study of in-home respite for caregivers of cancer patients was retrieved.²⁷ In one study, respite was provided by qualified home health aides, trained in the management of Alzheimer's disease;⁴⁵ the other four studies were staffed exclusively,^{46, 48} or in part,^{27, 47} by volunteers.

Evidence from randomized studies

In addition to the comparison between those receiving and not receiving respite, Grant and colleagues (2003) explored the impact of caregiver 'vulnerability', defined as "a severe mismatch between caregiving demand and help received in the preceding 6 months".⁴⁵ Based on findings from 55 dyads, in-home respite in this US study had no effect upon anxiety or depression, but appeared to moderate stress-related chemical levels in the subgroup of 'vulnerable' caregivers. Although the Canadian study by Wishart and colleagues (2000)⁴⁶ reported a significant reduction in caregiver burden, doubt has been cast on the validity of this finding.²¹

The US study by Montgomery and colleagues (1985)⁴⁷ experienced severe staff recruitment and retention difficulties. The authors found no significant between-group differences in caregiver

burden, although subgroup analysis of those still having an elder in the community found a statistically significant decrease in objective burden over the study period for *spouses* in the respite group and for *adult child* caregivers in the control group. Inadequate reporting of full results by allocation group makes this finding difficult to interpret.

Evidence from quasi-experimental studies

One quasi-experimental study of in-home respite was identified (Niebuhr, 1989).⁴⁸ In this US study, the population was frail (persons whose level of impairment required care comparable to intermediate or skilled nursing care), but 16% were aged under 65. No significant between-group differences were found in terms of impact on caregivers' psychological distress, but the non-comparability of the study groups at baseline means that the interpretation of the finding is unclear.

Evidence from uncontrolled studies

The UK study by Johnson and colleagues (1988) examined a Relative Support Scheme.²⁷ Malignant disease was the principal reason for referral to the scheme in 85% of cases. A postal survey of caregivers revealed that they were generally very satisfied with the service, with 90% describing the scheme as vital or of great help. However, one third of those responding believed they had been offered the service 'too late'.²⁷ No objective assessment of caregiver outcomes was reported.

Host Family Respite

No controlled study or economic evaluation of host family respite was identified. Our searches identified one (uncontrolled) study of host family respite.⁴⁹ In addition, bibliography checking identified an unpublished Master's thesis,⁵⁰ and contact with the author identified a related poster presentation.⁵¹

Evidence from uncontrolled studies

The Australian study by Ziguras (2003)⁴⁹ examined a 'host-home' respite program for older people with dementia who had problems accessing center-based respite due to communication and language difficulties. The program provided a range of activities, including occasional outings. Groups were run by two care-workers with extensive professional caring experience, with volunteers also supporting some of the larger groups.

Telephone interviews were conducted with seven caregivers. Three had prior experience of respite and thought the small group setting was beneficial, appreciated the homelike location and the attitudes of the care-workers and activities, '*Wonderful, doing a great service...*'. The caregivers also recognized benefits for themselves in terms of getting a break and being confident their relative was being well cared for and safe. They also commented on benefits for their relative, '*Loves it. Just loves the people. So happy to be involved*' (p.143).⁴⁹

Care receivers described the program as an important part of their week and highlighted the benefits to the smaller host-home program, '*...here you see the same people each week and get to be friends*' (p.143). Care receivers enjoyed the activities, being able to socialize and form friendships.

The study on host family respite by (2002)⁵⁰ evaluated a service provided in Scotland (UK) for people with dementia and their caregivers. Entitled 'Time to Share', the scheme provided joint family breaks for both caregiver and care receiver in the service provider's home. The service provider offered hospitality to the couple, and other activities offered according to need and preference. Service providers received initial and ongoing training on a range of issues including dementia awareness, communication, food hygiene and first aid, and were paid a fee for their services.^{50, 51} The breaks generally lasted between 5 and 7 days, and took place every two months.

All participants described the experience as "a happy one". For caregivers and care receivers, the homelike 'normal' environment, companionship, emotional and practical support were important features. Most couples enjoyed the joint nature of the respite offered. Overall, participants reported feeling relaxed, happy and refreshed.

Institutional Respite

No trial comparing institutional respite with usual community care was identified. Besides the studies that examined institutional respite as part of a respite package, just one study of institutional respite met the eligibility criteria for the review. Wells and colleagues (1987)⁵² undertook an RCT to compare full-time nursing home care with community care that included the option of periodic institutional respite. No economic evaluation of in-home respite was identified.

Evidence from randomized studies

Set in Australia, the 12-week trial by Wells (1987) examined 26 caregivers of persons in 'reasonable' physical health, but whose dementia made them highly dependent.⁵² At baseline, caregivers in the control group had significantly better psychological health than those in the intervention group.

The authors found that full-time institutional care had no adverse effect upon care receiver health, but reduced caregivers' psychological symptoms and improved caregiver quality of life relative to the control group who received periodic respite.

Although the authors adjusted their statistical analyses to take account of baseline differences in caregiver health, the existence of these differences raise the possibility that randomization method was flawed. If this were so, there may have been other, unknown, differences between the groups at baseline that could account for the findings. The reliability of the authors' conclusions is therefore uncertain and so these should be treated with caution.

Multidimensional packages

Several studies evaluating respite as part of a multidimensional package of care (i.e. involving respite in addition to other support services) were found, none of which met our inclusion criteria because the distinct impact of respite was unclear. The randomized study by Montgomery and colleagues (1989)⁴⁰ compared respite with and without other interventions, but as a control group was also evaluated, the study is classified as reporting a respite package. However, an uncontrolled study of caregivers of *cancer patients* was eligible for inclusion, because no

controlled study evaluating this patient group was identified. No economic evaluation of respite as part of a multidimensional package of care was identified.

Evidence from uncontrolled studies

Clark and colleagues (2000) evaluated a pilot initiative known as the “Macmillan Carers Schemes.”²⁸ Developed in the 1990s as an extension of a nursing service run by a charitable organization (Macmillan), the service was provided at seven sites in England (UK).

The pilot scheme offered respite as part of a multidimensional package. A team of healthcare assistants provided practical support, personal care (for patients) and emotional support to patients with cancer and their caregivers. In addition to in-home respite and companionship, support might include help with washing, dressing, cooking and other activities of daily living. The evaluation of 624 service users found that respite for caregivers was the principal reason for referral (42% of all referrals), but reasons also cited included emotional support (15%), enabling the patient to die at home (11%) and support following discharge from hospital (11%). On average, each patient received seven visits (range: one to 56). When surveyed about their satisfaction with the respite services, 86% of the 121 caregivers who responded felt able to go out and leave the assistant in charge.

Video Respite

Only one study of video respite met the inclusion criteria for the review.⁵³ No economic evaluation of video respite was identified.

Evidence from uncontrolled studies

The paper by Lund and colleagues (1995)⁵³ describes interim findings from a US study of video respite, used by informal caregivers at home (no report of the final results was identified). All care receivers had Alzheimer's disease.

Care receivers watched two tapes: the 'Favorite Things' tape and a 'Lawrence Welk' tape (an American television program). Attention and participation levels were compared for the two tapes, either at home or in a laboratory setting.

Two-thirds (67%) of caregivers used video respite at least once over the one-month study period. Summary measures of caregiver satisfaction are not reported, but views of two of the 31 caregivers are cited. One caregiver said "it's very good, and nearly every time she watches it is the first time for her." Another commented, "He enjoyed it so much. I like him to be using his mind instead of just sitting doing nothing." Caregiver views on the Lawrence Welk tape were not reported.

Overview of respite services: meta-analysis

Of the 17 controlled trials included in the review, all but one⁵² compared the impact of a respite intervention with usual care. The remaining 16 controlled trials provided useable data for only two caregiver outcomes (burden and depression). Figure 1 illustrates the process for study eligibility for the meta-analysis. As studies reported a variety of scales, effect size was calculated using the standardized (weighted) mean difference (SMD). The forest plots are graphical illustrations of the effect sizes, with the black diamonds showing the pooled effects.

(FIGURE 1 HERE)

Findings by outcome: caregiver burden

Four randomized trials and four quasi-experimental studies contributed data on caregiver burden from 989 caregivers (Figure 2). Five studies assessed day care (Baumgarten 2002;²⁹ Burch 2001;²⁶ Hedrick 1993;³⁰ Artaso 2002³⁵; Zarit 1998³²), two studies were of in-home respite (Niebuhr 1989;⁴⁸ Wishart 2000⁴⁶) and the study by Kosloski 1993³⁸ assessed a respite package. Two studies, both quasi-experimental, found a statistically significant effect on caregiver burden in favor of respite. The significant pooled overall effect of respite is explained by these two studies.

(FIGURE 2 HERE)

Findings by outcome: caregiver depression

One randomized study and two quasi-experimental studies contributed data on depression scores for 295 caregivers (Figure 3). Two studies assessed in-home respite (Grant 2003;⁴⁵ Niebuhr 1989⁴⁸) and one evaluated day care (Zarit 1998³²). Pooled findings found a statistically significant effect upon caregiver depression, but Figure 3 shows that the positive overall effect was due to Zarit's trial of day care.³² The methodological flaws associated with this study, including the application of a strict per-protocol approach and an unconventional statistical analysis, undermine the reliability of these findings.

(FIGURE 3 HERE)

DISCUSSION

Evidence from this review suggests that respite for caregivers of frail elderly people generally has a small effect upon caregiver burden, caregiver mental or physical health. There is tentative

evidence that some caregivers benefit more than others. However, caregiver satisfaction levels for all types of respite are generally high and caregivers appear to be more satisfied with respite than with usual care. No reliable evidence was found that respite care either delays entry to residential care or adversely affects frail older people. Economic evidence suggests that day care is at least as costly as, and may be more expensive than, usual care. The cost-effectiveness of in-home respite, institutional respite, host-family respite, respite packages and video respite remains unclear, as does the cost-effectiveness of adding respite to a multidimensional package of care. Based on these findings, what implications for policy and practice can be drawn? Can policy makers or providers be confident in this evidence and use it to shape the way that respite services are configured and delivered?

The existing evidence base does not allow any firm conclusions on effectiveness or cost-effectiveness to be drawn and is unable to inform current policy and practice. There are two principal reasons for this. First, there are serious problems with the methodological quality of many studies underpinning the evidence base, which makes findings from these evaluations extremely difficult to interpret. Second, where better quality evidence exists, the implications for other populations are unclear. The quality assessment²⁴ used in this review identified three ‘better quality’ studies.²⁹⁻³¹ None of these studies was designed to examine an impact on caregiver outcomes: one study estimated in advance the sample size needed to detect a difference in outcomes, but this was based on a measure of *care receiver* health.³⁰ Furthermore, the relative effects of these studies are highly dependent on how the intervention and comparator services (e.g. ‘usual care’) were configured, resourced, delivered and accessed; this can vary internationally as well as nationally and - even if adequately reported - makes attempts to

synthesize the evidence problematic. For example, financial barriers, eligibility criteria and the availability of other formal and informal support services may vary, potentially influencing effectiveness and cost-effectiveness.

How should these issues be addressed? Studying the effectiveness and cost-effectiveness of respite care using conventional RCT designs is challenging because respite is a complex intervention, for which it is difficult to identify the ‘active’ ingredients and to determine how these interact. However, poorly controlled studies present enormous analytic challenges and are typically very difficult to interpret. A trade-off needs to be struck between good quality studies with findings that apply only within their local context and those with a more pragmatic approach that can be usefully applied more widely.

In view of the complexity of the intervention, the recruitment challenges posed by existing access methods and the diversity of the study population, the primary research need is for good pilot studies that can inform full-scale controlled trials. Pilot studies could identify one or more target groups (i.e. caregiver and care receiver dyads) suitable for study; establish clear definitions of the services to be compared; and determine the main outcomes to be measured, such as caregiver quality of life or institutionalization rate. Although the phenomenon of low levels of utilization amongst study participants offered respite is well documented,⁵⁴ the factors affecting uptake are still poorly understood. Identifying reasons for caregiver behavior is intrinsically difficult: self-reported evidence from qualitative research may be biased by the way the questions are framed or by respondents’ expectations of how the information they provide will be used. On the other hand, regression analyses of observational datasets are limited by the

quality and breadth of data analyzed, making it difficult to identify true causal effects.⁵⁴ As any single approach is unlikely to provide satisfactory data, there may be scope for ‘marrying’ different methodologies within a single study to enable both qualitative and quantitative approaches to compensate for their respective shortcomings. Once these issues have been addressed and resolved, the prospects of successfully conducting a full-scale, well-controlled trial would be greatly enhanced. Long-term surveillance could complement findings from these trials. For example, longitudinal data on service use, potentially accessible through the US National Family Caregiver Family Support Program,¹⁹ could help establish the real-world effectiveness and economic viability of the respite intervention.

CONCLUSION

This review provides some evidence that respite for caregivers of frail elderly people may have a small positive effect upon caregivers in terms of burden and mental or physical health. Caregivers were generally very satisfied with respite. No reliable evidence was found that respite care either delays entry to residential care or adversely affects frail older people. Economic evidence suggests that day care is at least as costly as usual care.

However, much of the existing literature is unable to inform current policy and practice: there are many important gaps in the knowledge base, with a lack of recent, good-quality, controlled evaluations for all types of respite care and no economic evidence for any type of respite other than day care. Given the changing demographics of the industrialized world, the ever-pressing need to ensure that limited resources are spent wisely and effectively, and the moral imperative

to properly support frail older people and their caregivers, high-quality, robust research is urgently needed.

Acknowledgments

We wish to thank Yolanda Bravo (University of York) for translation assistance, Jeremy Miles (University of York) for statistical support, the Expert Reference Group for helpful comments on an earlier draft and Dan Myers for proof reading the manuscript. All remaining errors or omissions are our own. The study was funded by the UK Department of Health through its Health Technology Assessment Programme. The opinions and conclusions expressed here are those of the authors and do not necessarily reflect those of the UK National Health Service or the Department of Health.

Conflict of interest

Anne Mason: received funding for this project from the UK Department of Health's National Coordinating Centre for Health Technology Assessment (NCCHTA).

Helen Weatherly: received funding for this project from the UK Department of Health's National Coordinating Centre for Health Technology Assessment (NCCHTA).

Karen Spilsbury: received funding for this project from the UK Department of Health's National Coordinating Centre for Health Technology Assessment (NCCHTA).

Hilary Arksey: received funding for this project from the UK Department of Health's National Coordinating Centre for Health Technology Assessment (NCCHTA).

Su Golder: received funding for this project from the UK Department of Health's National Coordinating Centre for Health Technology Assessment (NCCHTA).

Joy Adamson: received funding for this project from the UK Department of Health's National Coordinating Centre for Health Technology Assessment (NCCHTA).

Mike Drummond: received funding for this project from the UK Department of Health's National Coordinating Centre for Health Technology Assessment (NCCHTA).

Author Contributions

Anne Mason: lead reviewer, analysis and interpretation of data, preparation of manuscript

Helen Weatherly: review of economic literature, analysis and interpretation of data, preparation of manuscript

Karen Spilbury: study design, reviewer of effectiveness literature (controlled and uncontrolled studies), preparation of manuscript sections and commented on other sections

Hilary Arksey: helped design the study, managed the Expert Reference Group and commented on the manuscript

Su Golder: literature searching, wrote sections of manuscript and commented on other sections

Joy Adamson: screening of abstracts, moderator for disagreements relating to the inclusion/exclusion of studies, collaborated in the meta-analysis, commented on manuscript.

Mike Drummond: helped design the study, advised on economic issues and commented on the manuscript

Sponsor's Role

The project was sponsored by the UK Department of Health's National Coordinating Centre for Health Technology Assessment (NCCHTA). The NCCHTA specified the scope for the review and the methodology to be undertaken.

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Table 1: Overview of the evidence on respite care for carers of frail elderly people

Type of respite	Number of studies included in the effectiveness review				Number of studies included in the cost-effectiveness review ^b				Country ^c					Publication year (range)	
	RCTs ^d	Quasi-experimental	Uncontrolled studies	All	Cost effectiveness	Cost consequence	Other	All	Australia	Canada	Germany	Spain	UK		US
All studies	10	7	5	22	2	3	0	5	2	2	1	1	5	11	1985-2003
Day care	4	4	0	8	2	3	0	5	0	1	1	1	2	3	1989-2002
Host family respite	0	0	2	2	0	0	0	0	1	0	0	0	1	0	2002-2003
In-home respite	3	1	1	5	0	0	0	0	0	1	0	0	1	3	1985-2003
Institutional respite	1	0	0	1	0	0	0	0	1	0	0	0	0	0	1988
Multidimensional packages	0	0	1	1	0	0	0	0	0	0	0	0	1	0	2000
Respite packages	2	2	1	4	0	0	0	0	0	0	0	0	0	4	1989-1993
Video respite	0	0	1	1	0	0	0	0	0	0	0	0	0	1	1995

^a included because no controlled study was identified for this type of respite or patient group

^b all cost-effectiveness studies also contributed to the effectiveness review

^c cost-effectiveness studies were set in Canada (n=1), Spain (n=1), the United Kingdom (UK; n=1), and the United States (US; n=2)

^d Randomized Controlled Trials

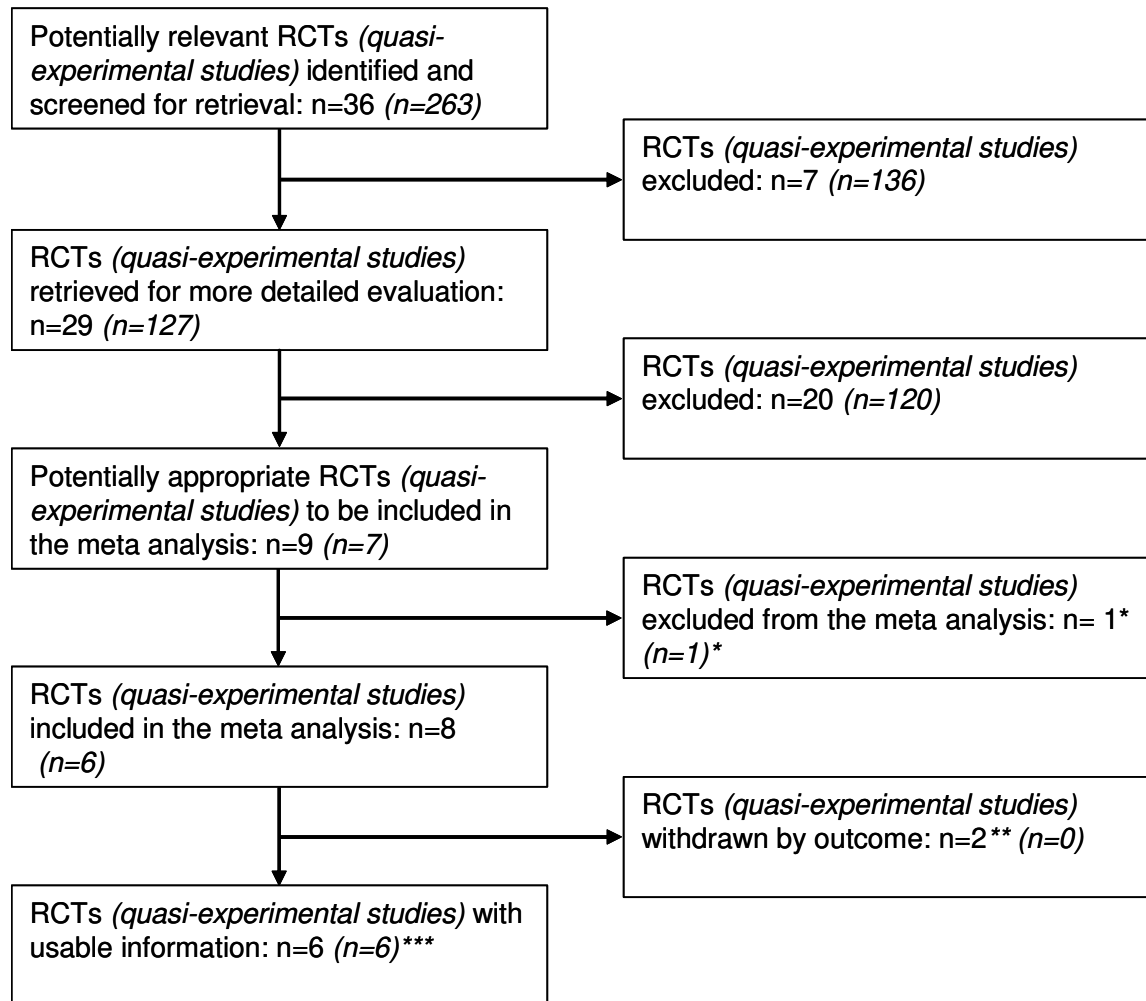
Table 2: Overview of populations for study included in the review

Type of respite	No. studies	No. participants (range)	Study duration (range, months)	Caregivers		Care receivers ('older people')	
				%male (range)	mean age (range)	%male (range)	mean age (range)
Day care	8	96 to 826	2 to 12	16% to 42%	54 to 72	25% to 96%	72 to 80
Host family respite	2	6 to 25	<12	14%	unclear	17%	82
In-home respite	5	24 to 306	0.3 to 12	12% to 38%	58 to 73	20% to 50%	66 to 82
Institutional respite	1	26	3	unclear	unclear	unclear	unclear
Multidimensional packages: ^a	1						
<i>Audit data</i>		624	12	unclear	41% aged over 60	43%	73% aged over 60 20% aged over 80
<i>Survey data</i>		121	12	23%	58% aged over 60	NA	NA
Respite packages	4	15 to 632	2 to 12	17% to 26%	38 to 89	33% to 48%	76 to 82
Video respite	1	31	1	32%	66	45%	78

^a the study reported two sets of findings (from a referrals audit and a postal survey of carers) which are presented separately

NA: not applicable

Figure 1: Flow diagram for meta-analysis of RCTs (and quasi-experimental studies)



KEY

* no useable data reported

** single trial reports each outcome, so pooling not possible

*** 5 RCTs and 4 quasi-experimental studies reported carer outcomes

Figure 2: Forest plot for respite studies reporting caregiver burden (N=8)

Comparison: Respite vs. usual care
 Outcome: Burden (caregiver)

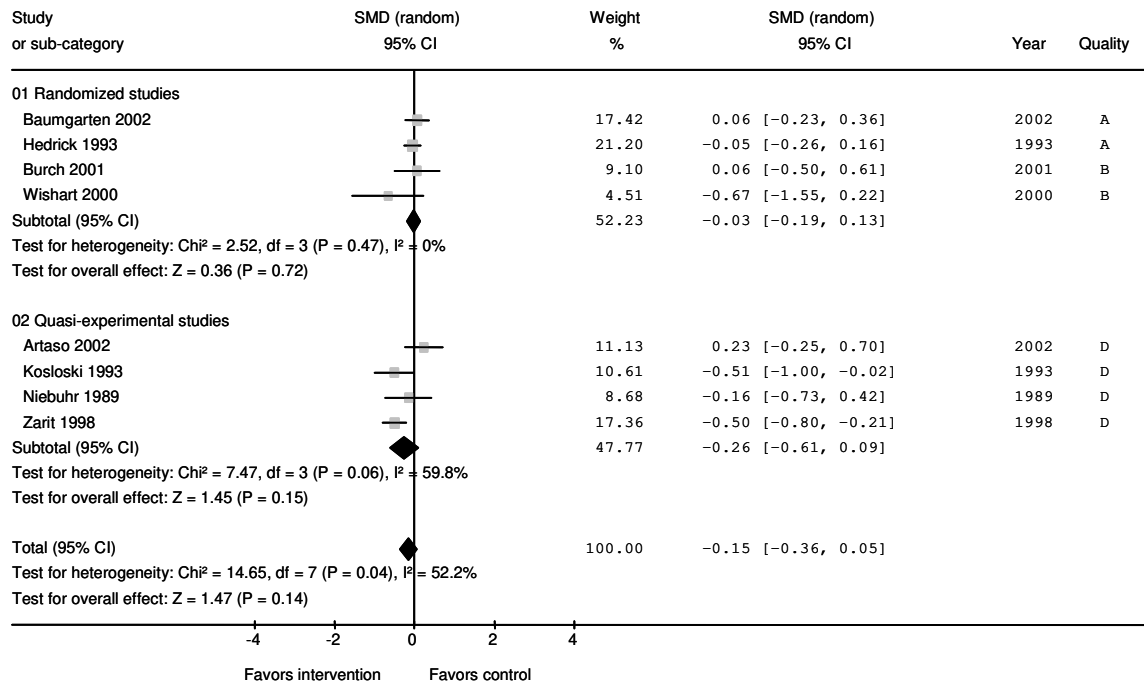


Figure 3: Forest plot for respite studies reporting caregiver depression (N=3)

